

The development of a Core Outcome  
Set for evaluating the impact of  
Relationships and Sex Education with  
students with intellectual disability

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PhD thesis

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Thesis submitted for the degree of Doctor of  
Philosophy (PhD)

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## **Declaration**

I, Laura Paulauskaite, confirm that the work presented in my thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Date: 26.06.24

## **Abstract**

People with intellectual disability have limited knowledge and skills regarding relationships, sexuality, and experience poor sexual health. Despite this, very little is known about how to deliver Relationships and Sex Education (RSE) effectively to this vulnerable population, how to measure the impact of its delivery in schools, and what stakeholders perceive as important outcomes. To address these issues, this PhD project aimed to develop a stakeholder consensus-based Core Outcome Set (COS) of RSE for and with students with intellectual disability aged 5-25 years. This was a two-stage mixed methods project. The first stage involved a systematic review of RSE outcomes reported in the international literature and qualitative exploration with students with intellectual disability, their parents, teachers, researchers, and policy makers on meaningful RSE outcomes. The second stage used findings from stage one in a Delphi survey with adult stakeholders to develop consensus on the most important outcomes included in the COS. A total of 171 participants (N=19 students and N=152 adults) took part in this project. Outcomes included in the COS of RSE for students with intellectual disability in primary and secondary education related to: the human body and development; emotions and feelings; healthy relationships and associated social skills; keeping safe; consent; self-esteem; and human rights. Outcomes related to sex and sexuality were identified for inclusion in secondary education only. Stakeholders justified their selection of outcomes based on the unique needs and difficulties of this group of students. RSE delivery, the physical environment, and adults in students' lives were perceived as important factors impacting outcome attainment by students. The findings provide a significant first step to assist the implementation, delivery, evaluation, and sustainability of RSE for students with intellectual disability. Key audiences are teachers, researchers, policy makers, and decision makers.

## **Impact statement**

Little is known about how to evaluate Relationships and Sex Education (RSE) delivered to students with intellectual disability and what stakeholders perceive are important outcomes. This PhD project addressed this gap in knowledge by developing the first stakeholder-consensus based a Core Outcome Set of RSE for and with students with intellectual disability.

The findings provide a significant first step in the successful implementation, delivery, evaluation, and sustainability of RSE for students with intellectual disability. For educational practice, the findings provide insights to RSE content, delivery, and evaluation with this population. Such findings are in high need in practice considering the ambivalence of RSE delivery for students with intellectual disability that the new RSE policy in England brought, a lack of research evidence and support from different stakeholders regarding RSE delivery to this population. For the policy makers, the findings provide insights how to support the roll-out of the compulsory RSE for students with intellectual disability in England. The findings should also inform policy around supporting people with intellectual disability in all settings to reduce their risks of sexual abuse and engagement in behaviours that challenge.

In the long term, the findings will address the current gaps in the literature regarding a lack of standardisation of outcome measurement in RSE evaluation studies, development of effective RSE for this population and research utility. The views of students with intellectual disability on important RSE outcomes were explored and incorporated for the first-time in a COS development making sure it reflects their needs and wishes. Thus, the application of the COS in educational practice will improve the knowledge and skills of students with intellectual disability regarding RSE and in the long term, will lead to better quality of life. My project also makes methodological contributions towards seeking direct views of students with intellectual disability with communication difficulties in research and practice. The findings challenge stigma towards abilities of students with intellectual disability to



participate in research and current definitions of participatory research with or by this population.

I published modified versions of two chapters of this thesis in peer-reviewed academic journals. My systematic review is one of the top cited papers in the Journal of Intellectual Disability Research. I disseminated the findings of two chapters of this thesis in two international conferences and two seminars to researchers working in the field of intellectual disability. The findings of the systematic review were also disseminated to teachers working at special and mainstream schools. I am planning to publish other studies of this thesis in academic journals and disseminate the findings to schools, so that the findings reach the academic community and educational practice. Through these dissemination events, I will encourage schools to adopt the COS to evaluate their current RSE delivery. I will publish a policy briefing on the final COS, so the findings reach a wider policy maker audience. I will publish the COS in the open-access COMET database so that the COS is easily accessible to researchers, journal editors, and funding bodies.

## **Acknowledgements**

I am extremely grateful to my supervisors, Professor Carol Rivas and Professor Vaso Totsika, for their consistent support and mentorship throughout the years. Thank you for your help with my studentship application, your valuable suggestions, discussions, and encouragement to take up opportunities that enabled me to develop as a researcher.

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Thanks to my fiancé, Marius, and my mother, Tatjana, for support and always believing in me when at times I struggled to believe in myself.

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LP designed and carried out the systematic review, extracted data, wrote the manuscript and made all final decisions with review and discussion from CR and VT. AP screened 20% of studies on title/abstract and full-text and extracted 10% of data as a second reviewer to check the consistency of the screening and data extraction process.

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## **Introduction**

This PhD research project developed a stakeholder consensus-based Core Outcome Set of Relationships and Sex Education for and with students with intellectual disability. The stakeholders involved were students with intellectual disability, parents, teachers, researchers, and policy makers/people from third sector organisations. The research comprised a systematic review to collate a long list of published outcomes, followed by workshops and interviews with stakeholders to refine and further develop the long list of outcomes that were then subjected to a Delphi style survey to reach agreement on the most important ones.

In this introductory section, I first provide definitions of key terms used throughout the thesis. I then discuss my personal motivation for carrying out this research project. I finish this introductory section by presenting the structure of this thesis.

## **Definitions**

### **Intellectual Disability**

Intellectual disability is a neurodevelopmental condition defined by significant limitations in intellectual functioning and adaptive skills present from the developmental period (0-18 years) (Schalock et al., 2021). Intellectual functioning involves activities such as learning and problem-solving. Adaptive skills refer to conceptual, social, and practical skills used in everyday activities such as socialising and managing money. Intellectual disability is diagnosed by a score of two standard deviations (SDs) below the general population mean on standardised tests of cognitive skills such as intelligence quotient (IQ) and adaptive skills (Schalock et al., 2021). To diagnose intellectual disability the scores of both tests need to be lower than 70 (Schalock et al., 2021).

Intellectual disability can be classified into four levels depending on severity: mild, moderate, severe, and profound. Children with mild intellectual disability may have subtle developmental delays (Schalock et al., 2021; Patel et al.,



2020). For example, they may have school learning problems and delays in communication abilities (Schalock et al., 2021; Patel et al., 2020). Children with severe or profound intellectual disability will have severe developmental delays (Schalock et al., 2021; Patel et al., 2020). For example, they may have limited or no speech and require significant support with basic needs such as using a toilet or eating (Schalock et al., 2021; Patel et al., 2020). Intellectual disability can be caused by genetic and chromosomal abnormalities (Schalock et al., 2021; Patel et al., 2020; Boat & Wu et al., 2015). Examples involve conditions such as Down syndrome and Fragile X syndrome (Schalock et al., 2021; Patel et al., 2020; Boat & Wu et al., 2015). Intellectual disability can also be caused by problems during pregnancy and birth such as infection or maternal substance abuse (Schalock et al., 2021; Patel et al., 2020; Boat & Wu et al., 2015).

Many children and adults with intellectual disability have diverse difficulties with communication (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Communication is a broad term that refers to receiving and transferring information in spoken, written, symbol or another format (Beukelman & Mirenda, 2013; Bunning, 2009). Communication is a complex process that involves cognitive skills (e.g. expressive and receptive language, memory, reasoning), non-vocal behaviours (e.g. body language, facial expressions) and social pragmatics (rules about how language is used in different social contexts) (Beukelman & Mirenda, 2013).

Some children and young people with intellectual disability might use vocal communication such as speech and vocalisations (Sigafoos et al., 2016; Marrus & Hall, 2017; Remington, 1997; Bunning et al., 2013). Speech is referred throughout the thesis as involving the use of vocal articulate sounds (e.g. oral spoken words) for expressing one's needs and views (Sigafoos et al., 2016). Vocalisations are referred as the act or process of producing sounds with the voice (e.g. screaming, grunts) (Bunning et al., 2013). Some such vocalisations may be used to communicate relatively nuanced needs and views, such as assent, querying and surprise (Sigafoos et al., 2016; Marrus & Hall, 2017).

Some children with intellectual disability might use non-vocal communication instead of or in addition to vocal communication (Sigafoos et al., 2016; Marrus & Hall, 2017). Non-vocal communication is referred through the thesis as signals that are not uttered by voice such as “manual sign (standard and idiosyncratic), body movement, hand arm gesture, facial expression, eye gaze, prompted operation of speech generating device/voice output communication aid and object manipulation” (Bunning et al., 2013, p.44). Throughout the thesis, I use a term “use speech to communicate” to refer to people who are able to express their thoughts and needs by using oral speech and the term “does not use speech to communicate” to refer to people who physically cannot speak. I also use a term “vocal communication” to refer to all spoken communication such as speech and vocalisations.

Some children with intellectual disability who use speech to communicate might have difficulties with their speech and language production and/or comprehension (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Language is referred through the thesis as involving words and rules (e.g. grammar and syntax) to convey information by speaking, writing, or symbols (Sigafoos et al., 2016). Language involves vocal (e.g. words said orally) and non-vocal communication (e.g. gestures, eye contact) (Sigafoos et al., 2016). For example, some children with intellectual disability who use speech to communicate might struggle to understand spoken, written or signed language (receptive language) and might have difficulties with semantic skills (understanding what words mean) (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Some children who use speech to communicate might have difficulties with sharing their thoughts, needs and views (expressive language), might have difficulties with syntactic skills (how to combine words into sentences or phrases) and might have limited vocabulary amongst other difficulties (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Some children with intellectual disability might have poor speech intelligibility and fluency (e.g. difficulties with pronouncing certain sounds or difficulties with vocal cords) which might make it difficult for them to vocalise certain sounds and for communication partners to understand what

they are saying (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Some children with intellectual disability might also struggle with social pragmatics that impact communication and language development (e.g. turn taking or staying on a topic) (Diken, 2019; Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Some children with intellectual disability who use speech to communicate might also have difficulties with non-vocal communication (e.g. understanding other people's facial expressions and body language) (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021). Thus, some children with intellectual disability who are physically able to speak to some degree might have a range of communication difficulties and might use Augmentative and Alternative Communication (AAC) to help them to communicate and help communication partners to understand them (for more details on AAC see below) (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021).

In the UK, the term "learning disability" is used in services to refer to intellectual disability. The term should not be confused with specific learning disabilities that refer to a different set of specific learning difficulties e.g. dyslexia. I use the international term "intellectual disability" throughout the thesis. However, some stakeholders in this project, used terms such as "learning disability" and "moderate to severe learning difficulties" to refer to intellectual disability. I have left such terms in their quotes to keep the language that stakeholders used.

According to the UK Department for Education, there are approximately 228,315 school registered children with intellectual disability in England (Department for Education [DfE], 2021). However, it is likely that the total number of children with intellectual disability is higher as the current data do not include children with intellectual disability educated at home or in private schools. Many children with intellectual disability have co-occurring conditions such as autism, sensory difficulties (e.g. issues with hearing and visual impairment), mental and physical health problems and require significant support in daily functioning (Buckley et al., 2020; Oeseburg et al., 2011).

## **Special Educational Needs and Disabilities**

Special Educational Needs and Disabilities (SEND) is a term used in English educational settings to refer broadly to all children with any learning difficulty or/and disability that require additional support in school (DfE, 2015).

## **Education Health and Care Plans**

Education Health and Care Plans (EHCPs) are personalised statutory support plans in England that describe students' special educational needs, learning outcomes, and support needed across education, health, and social care (DfE, 2015). Terms "moderate learning difficulties" and "severe learning difficulties" used in EHCPs and educational settings are synonymous with moderate and severe levels of intellectual disability (DfE, 2015).

## **Augmentative and Alternative Communication**

Some children with intellectual disability have complex communication needs and use Augmentative and Alternative Communication (AAC) to communicate (Crowe et al., 2022; Beukelman & Light, 2020). AAC is a term used to refer to a range of communication methods other than oral speech (Beukelman & Light, 2020; Beukelman & Mirenda, 2013; Beukelman & Light, 2020). AAC methods can help people with communication disorders of "speech-language production and/or comprehension, including spoken and written modes of communication" to communicate (American Speech-Language-Hearing Association, 2024). AAC methods can be used by children with intellectual disability in addition to their speech as well as instead of their speech (Crowe et al., 2022; Beukelman & Light, 2020). For example, AAC methods can help children who are vocal but have difficulty comprehending speech, have difficulties with semantic (understanding what words mean) and syntactic (how to combine words into sentences or phrases) skills or have difficulty using speech (e.g. able to say only few words or difficulties using speech in certain situations) (Crowe et al., 2022; Beukelman & Light, 2020). AAC methods can

help communication partners to understand what children with intellectual disability are communicating (Crowe et al., 2022; Beukelman & Light, 2020).

AAC methods can be classified into two categories: aided and unaided (Beukelman & Mirenda, 2013; Crowe et al., 2022; Beukelman & Light, 2020). Unaided AAC methods do not require any aided tools outside a children's body for communication and examples of such methods include gestures, manual signs, eye gaze, facial expressions, body movements (Beukelman & Mirenda, 2013; Crowe et al., 2022; Beukelman & Light, 2020). However, some unaided AAC methods may require children with intellectual disability to have gross and fine motor skills, for example, for being able to sign or provide gestures as well as communication partners who are familiar with these gestures and signs (Crowe et al., 2022). Aided AAC methods include an external tool, or a device used for communication such communication boards, pictures, symbols, (e.g. "Makaton", "Picture Exchange Systems") and technology-based tools such as speech-generating devices and eye-tracking devices that can produce a visual and a speech output (Beukelman & Mirenda, 2013; Crowe et al., 2022; Beukelman & Light, 2020).

## **Relationships and Sex Education**

I use the term "Relationships and Sex Education" (RSE) to refer to a sex education curriculum that is taught directly to students in educational settings. Different terms across countries are used to refer to RSE (e.g. "sexuality education" or "reproductive health education") (Ketting & Ivanova, 2018). I use this term as it is the preferred term in England, the setting of my project.

## **Sexuality**

I use the term "sexuality" as defined by the World Health Organization to involve "sex, gender identify and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (World Health Organization [WHO], 2006, p.5).

## **Outcomes**

Outcomes of RSE are knowledge, skills, and attitudes that students are expected to attain or develop after receiving RSE. These outcomes might include understanding what friendships are, development of social skills and improvement in attitudes towards sexuality topics (e.g. homosexuality). When evaluating RSE programmes in research, these outcomes can be considered as “what” was measured after RSE delivery to assess the effect this education had on students.

Throughout this thesis, I am using the term “outcomes” to refer to constructs being measured after RSE delivery. In Chapters 3-6, the term “outcomes” is used to also refer to RSE topic areas. The conceptualisation of “outcomes” as constructs to be taught and measured following RSE was made before data collection. Some stakeholders might not understand what a term “outcome” means. For example, during data collection with stakeholders such as students with intellectual disability, the term “outcome” was replaced with the term “topic” to aid comprehension following suggestions by familiar adults. By including stakeholders’ views on RSE topics in outcome identification, I was able to include a wide range of views on possible outcomes extracted from the systematic review and data collection with key stakeholders for developing consensus on the most important outcomes.

According to the UK Medical Research Council (MRC) guidance (Skivington et al., 2021) on development and evaluation of complex interventions, the intended outcomes of an intervention should inform the development of the intervention. For example, if an RSE outcome is development of friendships then the content delivered should involve teaching students how to develop friendships.

## **Stakeholders**

I use the term “stakeholders” to refer to a diverse group of participants that took part in this project. Stakeholders are defined as individuals, organisations,

or communities that have a direct interest in research, can affect research (e.g. outputs produced or future research) or be affected by decisions that are informed in research evidence (Concannon et al., 2019; Deverka et al., 2012; Skivington et al, 2021). Stakeholders in this project were students with intellectual disability, their parents, teachers, researchers, and policy makers/people from third sector organisations. I use the term “stakeholders” in this thesis to highlight that the views of different groups of people (e.g. researchers’ and students’) equally affected the research output i.e. their views were treated equally in this PhD project that will affect future research and practice. The term “participants” is associated with a passive participation, unequal opportunities to influence future research and powerlessness (e.g. researchers’ views have more power than participants’) (Ritchie & Rigano, 2001; Northway, 2010) which was not the case in this project.

### **Adult stakeholders**

I use the term “adult stakeholders” to refer to parents, teachers, researchers, policy makers/people from third sector organisations who took part in this project. Students with intellectual disability who also took part in this project and were adults (i.e. above 16 years) are referred as “students with intellectual disability” to avoid confusion and to highlight their views on RSE. I use those two terms throughout the thesis because students with intellectual disability did not take part in all studies of this project. Also, I use those two terms when presenting differences in views between students and adults.

### **Knowledge versus understanding**

Throughout the thesis, I use the term “knowledge” to refer to theoretical and practical information on a subject acquired through an experience or education, which involves skills and understanding of concepts (Trevethan, 2017). I use the term “understanding” throughout the thesis to refer to the ability to comprehend concepts (Trevethan, 2017). I use the term “knowledge”, “skills” and “understanding” separately in this thesis to emphasise the importance of these different terms (that involve different cognitive skills) for

this population e.g. the importance of development of skills for people with intellectual disability.

In Chapter 4 on the systematic review, outcomes were extracted verbatim from the identified papers and some outcomes were reported as “knowledge”. Authors did not provide the definition of “knowledge” that they used. In the findings of the systematic review, Chapter 4, when presenting information what outcomes RSE evaluation instruments were measuring I use the term “knowledge” because this is how the outcomes were reported in the papers by the authors. I extracted outcomes verbatim from the papers as explained in the 4.2.6 section.

### **Personal motivation**

My motivation to carry out this research project comes from my past work experiences. Through my work as an Assistant Psychologist in an inpatient forensic mental health service for young men with intellectual disability, I became aware that sexuality and relationships are ignored for this population. I learned that this ignorance could have devastating consequences to the young people with intellectual disability and those who support them. For example, I saw that in some cases the lack of RSE was a contributing factor for young people with intellectual disability facing criminal charges or being abused. I struggled to accept that RSE was never provided to some people with intellectual disability and the impact it had on their lives.

As a Research Assistant on studies for people with intellectual disability, I learned about significant disparities in education, health, and social care that this population is experiencing. I have come to appreciate the impact research can have on improving the quality of life of people with intellectual disability. Working with children with intellectual disability and vocal communication difficulties in research settings, I have come to realise that their voice has been overlooked in research and practice despite each child having unique strengths to express it.



These experiences have influenced my motivation to carry out a research project at a doctoral level. When thinking about potential topics for this research project, the DfE announced that RSE will be statutory for all students in England. This new law caused debates as depicted in media (e.g. <https://www.bbc.co.uk/news/education-49497837>). I started looking more deeply into this topic and reviewed the literature on RSE and sexuality of people with intellectual disability. As I discuss in the next chapter, I realised that only a small number of studies explored this topic. However, the message from the literature was very clear. The literature indicated that people with intellectual disability are marginalised when it comes to access RSE. Most of the literature was also describing the problem rather than aiming to change it.

Considering my previous work experiences, the ambivalence that the new RSE policy brought in England, and a lack of research in this area, I decided to carry out a research project on this topic to contribute to the evidence base on RSE delivery for people with intellectual disability and try to improve their situation. Thus, I decided to gather opinions of different stakeholders on RSE outcomes for this population, and most importantly to ask students with intellectual disability what they want to achieve in this education.

### **Structure of the thesis**

This thesis is structured as follows. **Chapter 1** is a literature review on RSE for people with intellectual disability. It explains why this education is important for this population and societal attitudes, resources, historical and policy contexts that have been a barrier to people with intellectual disability receiving RSE. I then critically review the current existing research on RSE delivery to people with intellectual disability and its limitations. **Chapter 2** is a separate literature review on participation in research by people with intellectual disability. I explain what participation in research means, discussing degrees of participation and factors that impact it. I then present the current evidence on research participation by people with intellectual disability and potential barriers reported in the literature. Research methods used to enable people with intellectual disability and diverse needs to participate are discussed as

well. I finish this chapter providing a rationale for this PhD project and its aims and objectives.

**Chapter 3** presents the methodology and methods selected to achieve the project's aims and objectives. I discuss my ontological and epistemological position and theoretical underpinnings of this project. I then provide justifications for the methodology selected. An overview of methods is also discussed including the design of the project, recruitment approaches and ethical considerations. Due to the variety of methods used in this project, I only provide a brief overview about how each method was applied and how data was analysed. Detailed data collection and analysis methods are discussed in corresponding empirical chapters (Chapters 4-7).

**Chapter 4** is the first study of this project. I report a systematic review carried out in two stages. The first stage aimed to identify RSE outcomes for students with intellectual disability reported in the international literature. The second stage aimed to identify RSE outcome measurement instruments used in the literature and to evaluate their measurement properties. I discuss the aims of the review, its procedures, results and provide a discussion of the findings.

**Chapter 5** is a second study of this project. This is a qualitative study that explored the views of adult stakeholders on important RSE outcomes for students with intellectual disability. The aim of this study was to supplement the outcomes identified in the literature and to understand why stakeholders perceived RSE outcomes as important. Differences in views on important RSE outcomes between subgroups of stakeholders (e.g. parents compared to teachers) are presented as well.

**Chapter 6** is a third study of this PhD. This is a qualitative study that explored the views on RSE outcomes of students with intellectual disability with a range of abilities using visual data collection methods. The study aimed to understand what RSE outcomes students with intellectual disability perceive as important and to supplement the list of outcomes identified in the previous stages of the project (Chapters 4-5). Differences in views on important RSE

outcomes between adult stakeholders and students with intellectual disability are presented as well.

**Chapter 7** is the fourth study of this PhD. This study aimed to establish consensus on important RSE outcomes across adult stakeholders. I discuss how data collected from the previous studies (Chapters 4-6) were integrated and presented to adult stakeholders for consideration and a methodological approach used to achieve consensus. This study provides RSE outcomes that different groups of stakeholders perceived as important for students with intellectual disability to achieve at primary and secondary education. **Chapter 8** is the general discussion chapter. I bring together the findings of all four studies of this project. I discuss the strengths and limitations of the studies of this project and provide implications of the findings. Future research directions are discussed as well.

## **Chapter 1 - Relationships and Sex Education for people with intellectual disability**

*“Persons with disabilities have the same sexual and reproductive health needs as other people. Yet they often face barriers to information and services. The ignorance and attitudes of society and individuals, including health-care providers, raise most of these barriers – not the disabilities themselves.” (WHO, 2009, p.1)*

### **Introduction**

This chapter begins by describing the current state of research on sexuality, relationships, and sexual health of people with intellectual disability. I then provide findings on RSE provision to people with intellectual disability. Potential barriers and facilitators of RSE provision for this population are discussed next. This chapter finishes by critically discussing existing research on this topic and its limitations.

RSE for people with intellectual disability has received attention only in recent years. Thus, there is a paucity of research on this topic. However, the message emerging from the limited literature is very clear - people with intellectual disability are marginalised when it comes to accessing RSE. There is a paucity of research on RSE delivery particularly to children and young people with intellectual disability, the target population of this PhD project. Thus, throughout this chapter, I present findings reported in the existing literature on RSE delivery to both young people and adults with intellectual disability to illustrate the current situation. Due to the paucity of research, I also present evidence from the international literature including the UK to provide a better understanding of the situation. The UK context (e.g. history and policy) is discussed to provide additional details about the setting of this study.

## **1.1 Importance of Relationships and Sex Education**

### **1.1.1 Human sexuality and its development**

Sexuality is an essential part of being a human for all people including those with intellectual disability. Sexuality as defined by the World Health Organisation (WHO) comprises “sex, gender identity and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” (WHO, 2006, p.5). Sexuality has many dimensions such as thoughts, desires, values, attitudes, and behaviours (WHO, 2006). Sexuality is influenced by a combination of biological, psychological, and cultural factors (WHO, 2006). It contributes to one’s identity, sexual health, relationships, well-being, and quality of life.

The development of human sexuality starts from birth and continues through childhood and adulthood till death (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Healthy sexual development in childhood and adolescence is generally important for achieving optimal life as an adult (Kågesten & van Reeuwijk, 2021; Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). All children go through stages of sexual development that are influenced by biological and psychosocial factors (e.g. children’s cultural and religious background, family, peers, school, past experiences and trauma, media, social norms, and policies) (Kågesten & van Reeuwijk, 2021; Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Thus, which behaviours, feelings, attitudes, and physical body changes children exhibit at each stage will vary between children (Kågesten & van Reeuwijk, 2021; Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). I now discuss some of the behaviours and physiological body functions reported in the literature that some children may experience during different sexual development stages.

During infancy (8-10 months), children may become aware of their genitals (vagina and penis) and may experience genital pleasure e.g. erections (Kar et al., 2015; Greydanus & Pratt, 2016). During toddler years (2-3 years), some children may learn the names of body parts and expected social norms for boys and girls (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). By the age of three years, some children will acknowledge their own gender

identity (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Some children may begin masturbating between the ages of 2-6 years (Greydanus & Pratt, 2016).

During preadolescence (before the age of 11 years), children may form same gender friendships and will continue collecting information about sexuality (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Some children during this time may be curious about pregnancy, birth, reproductive human body parts, sexual behaviour (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Children might question their sexual orientation and gender identity (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016) and some may develop romantic crushes towards the same or opposite sex (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Towards the end of this stage, children start experiencing puberty with physical, psychological, and hormonal changes (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). These may involve: organ growth (e.g. breasts, testicles, and penis), pubic hair growth, increase in height, menstruation, wet dreams, mood swings, sexual feelings and erections (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016).

During early and middle adolescence (11-16 years), most children will experience puberty which marks the transition from childhood to adulthood and ability to reproduce (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Adolescents may express a desire to be more independent and autonomous from their parents or carers (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Some adolescents may masturbate to orgasm and may begin experimenting with homosexual and heterosexual behaviours (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Towards the end of this stage, adolescents may start dating which may lead to their first sexual intercourse and at times a pregnancy or a sexually transmitted disease (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Some adolescents may experience no sexual attraction to other people or desire for sexual attraction (known as being asexual) (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016).

At this stage, adolescents will form their identity, continue developing social skills and forming relationships with their peers (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Masculinity and femininity ideas may be tested with their peers (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Peer pressure becomes apparent (as at the previous stage) which might lead to engagement in inappropriate behaviours (e.g. sending naked images) or sexual activities (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). During late adolescence (17-25 years), young people will reach full physical and sexual maturity (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016). Some young people will transition into adult roles and responsibilities which might involve development of long-term romantic and sexual relationships, living independently, becoming parents, being able to take risks without negative consequences and enjoying adult life (Kar et al., 2015; Sharpe, 2003; Greydanus & Pratt, 2016).

### **1.1.2 Sexuality and relationships of people with intellectual disability**

Children with intellectual disability also experience sexual development. Children with intellectual disability will undergo puberty just like their peers without intellectual disability (Burke et al., 2010; Quint & O'Brien, 2016; Wilson et al., 2011; O'Neill et al., 2016). Young people with intellectual disability also question their gender identity and sexual orientation (Schmidt et al., 2022; Strnadová et al., 2021; McCann et al., 2016) and are interested in exploring their body and sexuality (Wilson et al., 2011; Frawley & Wilson, 2016). Children and young people with intellectual disability masturbate, watch pornography, and engage in sexual behaviours (Frawley & Wilson, 2016; Pryde & Jahoda, 2018; Baines et al., 2018; Gil-Llario et al., 2022). Young people with mild to moderate intellectual disability engage in sexual activities at similar rates to young people without intellectual disability (Baines et al., 2018). Findings from the UK national survey indicate that about 75% of young people with mild to moderate intellectual disability engaged in sexual intercourse before the age of 19 years (Baines et al., 2018). In comparison, about 89% of young people without intellectual disability engaged in sexual intercourse before this age (Baines et al., 2018). Another study conducted in Spain (Gil-Llario et al., 2022),

found that young people with intellectual disability (aged 20-30 years) during the COVID-19 pandemic engaged in masturbation, used sexual toys, engaged in online sex, watched pornography, and sent naked images of themselves to other people.

Like their peers without intellectual disability, young people with intellectual disability also use the Internet and social media to search for romantic partners and to fall in love (Löfgren-Mårtenson, 2008; Turner & Crane, 2016). Many young people with intellectual disability want independence and autonomy from their parents and carers (Sandjojo et al., 2019, 2020; Bond & Hurst, 2010; Haigh et al., 2013). As I discuss in this chapter, many children and young people with intellectual disability experience barriers towards their sexual development such as stigma from others and a lack of education provision. These barriers impact their sexual development, relationships, sexual health, and quality of life.

Research indicates that people with intellectual disability have very limited knowledge and skills regarding sexuality and relationships (Baines et al., 2018; Jahoda & Pownall, 2014; Borawska-Charko et al., 2017; Galea et al., 2004). They are two times more likely to practise unsafe sex, have sexually transmitted diseases and experience unwanted pregnancies than people without intellectual disability (Baines et al., 2018; Van Schrojenstein Lantman-De Valk et al., 2000). Women with intellectual disability also experience repeated pregnancies that occur within 12 months of giving birth which in many cases results in a new-born being removed from their parents (Brown, Ray et al., 2018; Brown, Potvin, et al., 2018; Baines et al., 2018).

People with intellectual disability lack understanding of abusive relationships and have very little understanding of the law in terms of sexual relationships (O'Callaghan & Murphy, 2007; Murphy & O'Callaghan, 2004). This lack of knowledge possibly explains the high rate of sexual abuse reported in this population. Studies indicate that 6%-34% of adults with intellectual disability experienced sexual abuse in their lives (Tomsa et al., 2021; Gil-Llario et al., 2019). Children with intellectual disability have between 4-6 times higher risk



of sexual abuse than children without intellectual disability (Wissink et al., 2015; Spencer et al., 2005; Jones et al., 2012). These sexual abuse rates differ between studies because of different data collection methods used (e.g. self-report or informant-report), countries the studies were carried out in (differences in legal aspects of reporting abuse) and how sexual abuse and intellectual disability were defined. However, it is likely that the rates of sexual abuse might be higher than the studies indicate as people with intellectual disability lack knowledge identifying such behaviours and might struggle to report them.

Many people with intellectual disability do not know their sexual rights that, amongst others, involve rights to privacy, pursuing satisfying sexual lives, having a romantic partner, getting married and having children (WHO, 2006; McCarthy, 2009, 2010; Ledger et al., 2016; Murphy & O'Callaghan, 2004; O'Callaghan and Murphy, 2007). Studies indicate that many women with intellectual disability are prescribed long-term contraception even after childbearing age to avoid pregnancies and to manage menstruation (McCarthy, 2009, 2010; Ledger et al., 2016). This decision is usually made by people involved in their care rather than the women with intellectual disability themselves (McCarthy, 2009, 2010; Ledger et al., 2016). People with intellectual disability also feel uncertain whether they are allowed to engage in sex and get married (Murphy & O'Callaghan, 2004; O'Callaghan and Murphy, 2007). For example, in O'Callaghan and Murphy's (2007) study, half of the people with intellectual disability thought that by law they were not allowed to engage in sex, get married and make decisions regarding abortions. These findings suggest that people with intellectual disability are not perceived as having sexual rights, they are not taught about them, and they do not have opportunities to understand and exercise their rights.

A significant proportion of people with intellectual disability feel lonely and wish to have close friends and romantic partners (Black & Kammes, 2019; Schaafsma et al., 2017; Bates et al., 2017). However, many people with intellectual disability lack social skills and opportunities to develop such relationships (Black & Kammes, 2019; Schaafsma et al., 2017; Bates et al.,

2017). Evidence suggests that the lack of opportunities to develop romantic relationships and express their sexual needs for some people with intellectual disability is associated with engagement in inappropriate sexual behaviours (e.g. masturbation in public places) (Lockhart et al., 2010). This might have devastating consequences for people with intellectual disability and those who support them (e.g. social exclusion and/or facing criminal charges) (Lockhart et al., 2009).

### **1.1.3 Relationships and Sex Education provision**

The delivery of an RSE curriculum to students with intellectual disability may help to tackle their poor knowledge and skills and improve their sexual health and quality of life. RSE aims to equip all students, whether or not they have intellectual disability, with knowledge, attitudes, and skills about “the emotional, social and physical aspects of growing up, relationships, sex, human sexuality and sexual health” (Sex Education Forum, 2020). As the United Nations Educational Scientific and Cultural Organization (UNESCO) describes, RSE will empower students to “realize their health, well-being and dignity; develop respectful social and sexual relationships; consider how their choices affect their own well-being and that of others; and understand and ensure the protection of their rights throughout their lives” (UNESCO, 2018, p.16).

The RSE curriculum in Europe usually starts in primary schools (when students are aged 5 years) and continues through secondary education (when students are usually aged up to 18 years) (Ketting & Ivanova, 2018). Therefore, RSE is provided proactively in the early years before students start engaging in sexual activities so that they have the necessary knowledge and skills to deal with these situations when they occur (Ketting & Ivanova, 2018). RSE can be delivered as a stand-alone subject or integrated into other subjects (Ketting & Ivanova, 2018). For example, in England, RSE usually is delivered within the wider curriculum of Personal, Social, Health and Economic (PSHE) (Department for Education and Employment, 2000). RSE can be delivered to a whole classroom by teachers, school-based nurses, or external specialists

(Ketting & Ivanova, 2018). For students with intellectual disability, RSE can be delivered in small groups or on a one-to-one basis (Lafferty et al., 2012; Sala et al., 2019).

Young people in the general population receive RSE in schools as well as gain information from informal sources e.g. friends (Jahoda & Pownall, 2014). However, as people with intellectual disability have fewer opportunities to socialise and learn from their friends, they must rely instead on parents, and support workers, as well as teachers, for RSE (Jahoda & Pownall, 2014; Frawley & Wilson, 2016). Therefore, when RSE programmes for people with intellectual disability are provided, they tend to not only involve schools, but may also be given in social care settings by support workers and in students' homes by their parents (Lafferty et al., 2012; Sala et al., 2019).

However, international studies indicate that a significant proportion of young people with intellectual disability do not receive RSE in schools or community settings and that this subject is not discussed with their parents at home (Nelson et al., 2020; Wos et al., 2020; Barnard-Brak et al., 2014; Schaafsma et al., 2014; Rurangirwa et al., 2006). For example, findings from a USA based national survey indicate that young people with intellectual disability were 6 to 10 times less likely to receive RSE in schools and at home than people in the general population (Rurangirwa et al., 2006). Another survey carried out in the USA revealed that special school students with severe intellectual disability were the least likely to receive RSE (Barnard-Brak et al., 2014). The findings of the survey revealed that 16% of students with severe intellectual disability received RSE compared to 44% of students with mild intellectual disability (Barnard-Brak et al., 2014). Studies carried out in the UK also reported that mothers discuss fewer RSE topics and start these conversations later with their children with intellectual disability when compared to their children without intellectual disability (Pownall et al., 2011, 2012).

People with intellectual disability tend to receive RSE reactively (e.g. after behaving inappropriately in public) rather than proactively (Schaafsma et al., 2014; Isler et al., 2009; Aderemi, 2014; Pryde & Jahoda, 2018). For example,

Schaafsma et al. (2014) found that only 39% of staff provided RSE to people with intellectual disability in an adult intellectual disability service in the Netherlands. The main reasons for delivering RSE were that a person with intellectual disability engaged in inappropriate sexual behaviours or had questions about their sexuality (Schaafsma et al., 2014). Staff carers who work in intellectual disability services in the UK also reported that RSE is delivered reactively rather than proactively (Lafferty et al., 2012).

There are no recent studies that explored RSE delivery to people with intellectual disability. It is unlikely that RSE delivery has changed internationally since the studies presented above as such a change would likely have been reflected in publications. The literature presented above indicates that people with intellectual disability are marginalised when it comes to access to RSE. People with severe intellectual disability are the least likely to receive this education.

## **1.2 Barriers and facilitators to provision**

There are several possible explanations as to why people with intellectual disability do not receive RSE. The most likely are societal attitudes towards the sexuality of people with intellectual disability and a lack of resources available (Lafferty et al., 2012; Evans et al., 2009). As more research has been carried out on societal attitudes, they are discussed in greater detail than a lack of resources. After this, I discuss facilitators of RSE delivery to people with intellectual disability reported in the literature.

### **1.2.1 Barriers**

#### *Attitudes*

Research indicates that there are mixed attitudes towards the sexuality of young people with intellectual disability which impact whether RSE is provided to them or not. One common misconception is that people with intellectual disability are “asexual” meaning that they are not interested in sex and/or do not have capacity to understand the complexities of their sexuality and thus,

RSE would not be beneficial to them (Dupras & Dionne, 2014; Sinclair et al., 2015; Gürol et al., 2014). For example, in studies carried out in Turkey and India, mothers believed that RSE will not be beneficial to their children with intellectual disability as they do not have sexual desires and will not get married (Gürol et al., 2014; Gokgoz et al., 2021; Menon & Sivakami, 2019).

Another common misconception is that people with intellectual disability cannot control their sexual desires and therefore, the provision of RSE would exacerbate these which would lead to inappropriate sexual behaviours or being sexually abused by others (Dupras & Dionne, 2014; Aderemi, 2014; Goli et al., 2020; Phasha & Runo, 2017). For example, Nigerian teachers reported that students with intellectual disability are “hypersexual” and therefore, when delivering RSE, teachers provide false information (such as that every time people engage in sex that leads to a pregnancy) so that students are scared to act on their sexual “urges” (Aderemi, 2014). In a study carried out in the UK, mothers of sons with intellectual disability reported feeling worried about providing RSE to their children because it could potentially lead to engagement in sexually inappropriate behaviours (Pryde & Jahoda, 2018).

These attitudes towards the sexuality of people with intellectual disability are also influenced by people’s cultural and religious backgrounds (Ionescu et al., 2019; Helleve et al., 2009; Lafferty et al., 2012). In some non-Western countries it is shameful to talk about the sexuality of people with disabilities (Jeyachandran et al., 2022; Gürol et al., 2014; Phasha & Runo, 2017; Helleve et al., 2009; Menon & Sivakami, 2019; Gokgoz et al., 2021). In some studies, carried out in non-Western countries, parents reported feeling ashamed that their children with intellectual disability started going through puberty and have sexual interests (Gürol et al., 2014; Phasha & Runo, 2017; Helleve et al., 2009; Menon & Sivakami, 2019; Gokgoz et al., 2021).

Research also indicates that some teachers feel uncomfortable delivering RSE to students with intellectual disability due to their religious and cultural backgrounds (Phasha & Runo, 2017; Helleve et al., 2009; Strnadová et al., 2022). As discussed above, in some cultures, it is considered not appropriate

to talk about sexuality topics with people with disability (Jeyachandran et al., 2022; Gürol et al., 2014; Phasha & Runo, 2017; Helleve et al., 2009; Menon & Sivakami, 2019; Gokgoz et al., 2021). In some studies, teachers reported that they cannot discuss specific topics with students with intellectual disability as such discussions are against their religious values (Phasha & Runo, 2017; Helleve et al., 2009). For example, South African teachers in Helleve's et al. (2009) study reported that due to their religion they cannot say anatomically correct names of the human reproductive organs (e.g. penis) to students with intellectual disability (Helleve et al., 2009). In this study, teachers reported delivering RSE to students with intellectual disability without using these words or saying them in the English language rather than their native language. In Western countries, there might be more liberal attitudes towards the sexuality of people with intellectual disability (Correa et al., 2022; Sankhla & Theodore, 2015); however, that does not translate into providing RSE to people with intellectual disability.

Findings from these studies need to be considered with caution. This is a sensitive topic that some people might find uncomfortable to talk about. Some researchers also mentioned struggling to recruit people in the studies because of this topic (Pryde & Jahoda, 2018; Menon & Sivakami, 2019). Thus, participants who took part in the studies and expressed their views might have more liberal attitudes towards the sexuality of people with intellectual disability or perhaps experienced greater difficulties supporting the sexuality of people with intellectual disability. People who do not feel comfortable taking part in such studies might hold different views than the ones represented in the literature.

### *Resources*

Another significant barrier that impacts RSE provision to people with intellectual disability is a lack of resources available to support parents, teachers, and staff members to deliver this curriculum effectively. Many parents across different countries reported having a lack of confidence to provide RSE to their children with intellectual disability (Strnadová et al., 2022;

Kürtüncü & Kurt, 2020; Pryde & Jahoda, 2018; Gokgoz et al., 202; Lafferty et al., 2012; Pownall et al., 2012). Parents in previous studies discussed that they need to be provided with training and support from professionals on how to discuss complex topics related to RSE with their children with vocal communication difficulties and cognitive impairments (Colarossi et al., 2023; Kürtüncü & Kurt, 2020; Pryde & Jahoda, 2018; Gokgoz et al., 2021; Lafferty et al., 2012; Pownall et al., 2012).

Teachers at schools and support staff in community intellectual disability services reported feeling unprepared and unsupported to deliver RSE to students with intellectual disability (Lafferty et al., 2012; Evans et al., 2009). Many of them had never been trained on how to deliver RSE for students with intellectual disability and wished to receive more guidance (Lafferty et al., 2012; Evans et al., 2009). There is also a paucity of RSE teaching materials developed specifically for students with intellectual disability; material that considers the heterogeneity of needs (e.g. different levels of intellectual disability and vocal communication abilities) (Sinclair et al., 2015). Therefore, teachers reported having to develop their own materials when providing RSE and often lacking support and funding for such activities (Lafferty et al., 2012). Teachers and staff members are also worried about what they can discuss in RSE with students with intellectual disability without upsetting their parents (Lafferty et al., 2012; Evans et al., 2009).

As previously discussed in the introduction section, many people with intellectual disability have communication difficulties (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021) which can impact their understanding of concepts related to sexuality and relationships. For example, some people with intellectual disability struggle to understand receptive language (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021), have issues with understanding abstract language such privacy or trust and long complex sentences (Finlay et al., 2015). Learning about pregnancy and sexual health involves learning about complex biological information of human reproduction system which may be difficult for students with intellectual disability to

comprehend (Finlay et al., 2015). Learning about consent in sexual activities and how to obtain consent involves learning that other people have different views than one has which is also an area that some people with intellectual disability struggle with i.e. “theory of mind” (Finlay et al., 2015). Some people with intellectual disability might not understand information related to sexual activities (e.g. what it involves, its consequences) and might not be able to retain or weight such information and communicate their decision and thus, might be deemed as not having capacity to consent. However, research indicates that delivery of RSE can improve the capacity of young people with intellectual disability to provide consent in sexual activities (Dukes & McGuire, 2009). In other words, people with intellectual disability might lack capacity to understand information or have difficulties to communicate their decisions; however, provision of education can improve such aspects for some people with intellectual disability. Some people with intellectual disability also struggle to express themselves using speech (Sigafoos et al., 2016; Marrus & Hall, 2017; Barton-Hulsey et al., 2022; Hofmann & Müller, 2021) which might impact assessments on their understanding of such concepts carried out in research and educational settings.

There is also evidence that content and materials used in RSE delivery for people with intellectual disability involve complex language and lack appropriate visual stimuli e.g. pictures or symbols (Wolforda & Jansen, 2023; Finlay et al., 2015). This perspective on poor knowledge and skills regarding sexuality and relationships experienced by students with intellectual disability (i.e. having speech and communication difficulties and some lacking capacity to understand complex information) reflects a medical model of disability (Oliver, 2018). However, as I argued so far in this thesis, reflecting from a social model of disability (Oliver, 2018) and evidence available in the literature on barriers of RSE delivery for this population, students with intellectual disability lack knowledge and skills regarding relationships and sexuality due to environmental barriers (e.g. stigma towards their sexuality, a lack of RSE provision and appropriate resources for teaching RSE to this population) rather than solely because of their cognitive and communication difficulties.



### **1.2.2 Facilitators**

There is a paucity of research on facilitators of RSE delivery to people with intellectual disability. However, some authors report strategies that have potential to improve or facilitate RSE provision to this population. First, some authors report that RSE needs to be integrated into the curriculum and provided to students with intellectual disability in schools so that students receive this education proactively (Borawska-Charko et al., 2023; Wilkenfeld & Ballan, 2011; Swango-Wilson, 2009). Second, a whole school approach that involves training all teachers to deliver RSE was reported as another potential facilitator of RSE delivery to students with intellectual disability (Hanass-Hancock et al. 2018). Training all teachers to deliver RSE might ensure consistency of RSE information and provision and would also provide teachers with opportunities to reflect on their own attitudes towards students with intellectual disability (Lafferty et al., 2012; Hanass-Hancock et al. 2018). Third, a collaborative approach to RSE delivery that involves teachers and parents was also reported as a potential facilitator (Borawska-Charko et al., 2023; Hanass-Hancock et al. 2018; Pryde & Jahoda, 2018). As discussed previously, parents might believe that RSE is not beneficial to their children with intellectual disability. Thus, parents might not discuss topics related to RSE at home or might withdraw their children from RSE lessons. Involving parents in RSE delivery and lesson planning at schools might help to change their attitudes as well as ensure that consistent RSE information is provided across school and home (Borawska-Charko et al., 2023; Hanass-Hancock et al. 2018; Pryde & Jahoda, 2018). Fourth, having RSE resources that are developmentally appropriate and adapted to the needs and abilities of people with intellectual disability was also reported as a possible facilitator of RSE (Pryde & Jahoda, 2018).

### **1.3 Historical and policy context**

The historical and policy context has also influenced RSE delivery to people with intellectual disability (Kempton & Kahn, 1991). In this paragraph, I summarise how historical events in the UK impacted this and the new RSE policy in England.

### **1.3.1 Recent history**

#### *Eugenics*

Historically, the sexuality of people with intellectual disability was considered problematic and has been oppressed for several centuries. In the early 20<sup>th</sup> century, the eugenics movement impacted societal views and policies towards people with intellectual disability in many Western countries including the UK (Kempton & Kahn, 1991; Tilley et al., 2012; Taylor Gomez, 2012). The ideology of the eugenics movement considered some people's genetic backgrounds (e.g. individuals with disabilities) as inferior to others (Kempton & Kahn, 1991). The goal of this movement was to stop a reproduction of such "inferior" genes to improve the human race (Kempton & Kahn, 1991). This led to the segregation of people with intellectual disability from society into institutions (Kempton & Kahn, 1991).

At that time, there were also many misconceptions regarding the sexuality of people with intellectual disability (Kempton & Kahn, 1991). They were viewed as "child-like" that is, not interested in having sexual relationships and thus, incapable of raising children (Block, 2000; Kempton & Kahn, 1991). People with intellectual disability were also perceived as "hypersexual," in particularly men with intellectual disability, and thus, unable to control their sexual desires (Block, 2000; Kempton & Kahn, 1991).

In the institutions, people with intellectual disability were sterilised against their will and expressions of sexuality (e.g. engagement in masturbation or homosexual activities) were severely punished (Kempton & Kahn, 1991; Tilley et al., 2012). This movement did not stop the reproduction of disabled genes as children with intellectual disability were born to parents without intellectual disability (Kempton & Kahn, 1991; Tilley et al., 2012). However, compulsory sterilisation and the institutionalisation of people with intellectual disability continued till at least the 1970s in many Western Countries. In the UK, compulsory sterilisation was not legal (Tilley et al., 2012). However, many

parents preferred their female children with intellectual disability to be sterilised to control menstruation (Tilley et al., 2012).

Between 1950s-1970s, young people in the general population received very little RSE in schools (discussed in more detail below) (Pilcher, 2005; Iyer & Aggleton, 2015). However, they were able to receive information about it from informal sources e.g. friends, books, or movies (Kempton & Kahn, 1991; Tilley et al., 2012). People with intellectual disability were kept in institutions and they never had a chance to learn (or even observe) about sexuality and relationships through formal and informal sources (Kempton & Kahn, 1991; Tilley et al., 2012).

In the 1970s, deinstitutionalisation began and people with intellectual disability were moved from institutions to community settings (Tilley et al., 2012). Since this time, many human rights activists have urged society to accept that people with intellectual disability are sexual, have sexual rights and need to receive appropriate sex education (Kempton & Kahn, 1991). In 1975, the United Nations (UN) developed the Declaration on the Rights of Disabled Persons (UN, 1975). This declaration specified that people with disability including those with intellectual disability have the same human rights as people without disability that, amongst others, include rights to being provided education, living with their families, and being protected against exploitation (UN, 1975). These rights were nonbinding to UN member states (countries worldwide that were part of the UN). However, these rights encouraged different countries to recognise, accept and protect the rights of people with disability and become signatories to the declaration.

However, some researchers argue that eugenics-based ideas still affect to some extent how society views the sexuality of people with intellectual disability (Taylor Gomez, 2012; Tilley et al., 2012). As discussed previously, there are still negative attitudes towards people with intellectual disability which impact RSE provision.

### *History of RSE in the UK*

In this paragraph, I provide a summary of recent history of RSE delivery in the UK schools. This summary illustrates how British society perceived the delivery of this education to the general population which could possibly have contributed to suboptimal RSE provision to people with intellectual disability.

What we now call Relationships and Sex Education (RSE) in the UK, has been referred to using different names in the past e.g. Sex and Relationships Education (SRE) or sex education. The change of terminology reflects changes that RSE provision and policy has undergone throughout the years. Overall, the delivery of RSE in the British educational system was greatly influenced by national politics and sexual health problems (Lewis & Knijn, 2002).

During the first half of the 20<sup>th</sup> century, the common discourse in British society was that sex is an inappropriate topic to discuss with children in schools (Beier, 2003). This view started changing in the 1950s as sexually transmitted diseases (STDs) and unplanned pregnancies were rising (Pilcher, 2004). Some schools started delivering lessons on sex education within the health education curriculum that were vague, basic, and medical (Pilcher, 2004). However, whether sex education was delivered or not depended on head teachers' preferences (Pilcher, 2005). Girls were more likely to receive RSE lessons that mainly focused on menstruation (Pilcher, 2005).

In the 1970s-80s, the delivery and content of sex education still greatly varied within schools and students received little information on this topic, typically delivered in biology lessons (Pilcher, 2005; Iyer & Aggleton, 2015). The HIV pandemic in the 1980s also impacted the sex education content delivered in the UK (Iyer & Aggleton, 2015). At that time, homosexual people in the UK were the most likely to get infected with the sexually transmitted virus HIV and die from it. However, the inclusion of HIV and homosexuality topics in sex education lessons was widely debated in the UK (Lewis & Knijn, 2002; Pilcher, 2005). In 1988, the Local Government Act was passed under Section 28 that

forbade local authorities to promote homosexuality as an acceptable family relationship (Lewis & Knijn, 2002; Pilcher, 2005). This caused confusion and anxieties to teachers as to whether and how this topic should be discussed in schools (Pilcher, 2005).

In the early 1990s, the UK experienced one of the highest numbers of teenage pregnancies in Europe (Green, 1994; McEwan et al., 1994). To reduce the rates of teenage pregnancies, sex education became compulsory in secondary schools (Lewis & Knijn, 2002; DfE, 1994). This new law stated that delivery of sex education in schools was only supplementary to the primary responsibility of parents to provide this education to children (DfE, 1994). The content delivered to students in schools should also be approved by parents (DfE, 1994). Additionally, parents had a right to withdraw their children aged over 16 years from sex education lessons (DfE, 1994). Parents could exercise this right despite children's wishes and the fact that the legal age of sexual intercourse in the UK was 16 years (Pilcher, 2005). Teachers were informed that they were not allowed to give advice to students under 16 years about contraception or other aspects of sexual behaviour without parents' consent (DfE, 1994).

In the 2000s, the Department for Education published guidance on Sex and Relationships (SRE) education (Department for Education and Employment, 2000). This guidance stated that all schools must have a policy on delivering SRE, this education should be delivered within the PSHE framework and that parents' wishes on the content should be incorporated (Department for Education and Employment, 2000). This is also the time when topics on relationships were integrated into sex education and become known as "Sex and Relationships Education" (Department for Education and Employment, 2000). Parents had the right to withdraw their children from SRE in primary and secondary schools except from information on the reproductive system delivered in the National Science Curriculum.

Despite the government providing some guidance on SRE, the provision of SRE varied between schools (Strange et al., 2006; Buston et al., 2001). The Office for Standards in Education, Children's Services and Skills (Ofsted)

national inspection on SRE delivery in mainstream schools in 2013 indicated that about 40% of students were not receiving comprehensive SRE (Ofsted, 2013). Some schools only covered biology without delivering the relationship aspects of SRE (Ofsted, 2013). Teachers reported feeling unprepared and unsupported, which resulted in a suboptimal SRE provision in some schools (Ofsted, 2013).

Throughout the last 100 years, young people have received very little comprehensive sex education in the UK. Parents, who over the years were the key people to provide such education to their children, themselves never received adequate RSE in schools and therefore might have had educational needs too. Teachers were not allowed to discuss topics outside the biological aspects of sex education and many worried that they might be blamed for teaching something that parents or senior staff did not agree with. Thus, RSE delivery in the British schools were perceived as a “taboo” topic. These views in society impacted its delivery to students in the general population that do not experience stigma like students with intellectual disability (discussed in the barriers section above).

### **1.3.2 Statutory Relationships and Sex Education**

In 2015, an investigation by British Broadcasting Corporation (BBC) revealed that over 5,500 sexual offences including 600 rapes were carried out in UK schools over three years (BBC, 2015). A fifth of the offenses were performed by another student (BBC, 2015). These shocking statistics led the government to reform the national guidance on SRE. As part of this, the Children and Social Work Act (2017) renamed SRE to “Relationships and Sex Education” (RSE), stating that relationships topics should be taught before sex education (Children and Social Work Act, 2017).

In 2019, the Department for Education published a new statutory guidance on RSE delivery (DfE, 2019). The new guidance indicated that from September 2020, RSE became compulsory in schools in England for all students including those with intellectual disability (DfE, 2019). The guidance indicates that

Relationships Education must be delivered to all students in primary schools (when students are aged 5 to 11 years) (DfE, 2019). Relationships Education should focus on developing students' knowledge of positive relationships and how to recognise and report unhealthy relationships, covering topics such as appropriate and inappropriate physical contact, personal space, and bullying (DfE, 2019).

RSE must also be delivered in secondary schools (when students are aged 11 to 16 years) (DfE, 2019). RSE should cover broader topics on relationships including intimate and sexual relationships, sexuality, and safeguarding (DfE, 2019). These topics should involve: the law related to sex, reproductive health, contraception, abortion, STDs, consent, sexual orientation including Lesbian, Gay, Bisexual and Transgender (LGBT), sexual exploitation, domestic abuse, and female genital mutilation (DfE, 2019).

This is the first government published guidance on RSE delivery which mentions that schools might consider teaching students about LGBT (DfE, 2019). The guidance specifies that schools can adapt the content especially when delivering to students with SEND to meet their individual needs and developmental levels (DfE, 2019). Thus, some students may be taught a different content based on their abilities. RSE frequency, duration, and mode of delivery is not specified in the guidance (DfE, 2019).

The guidance also indicates that schools must have a policy on delivering RSE that includes:

- 1) Definition of Relationships Education and RSE;
- 2) Definition of the content, how it is taught, who is delivering it, including how the content is adapted for students with intellectual disability;
- 3) Definition of how RSE is monitored and evaluated;
- 4) Information about parents' rights in relation to withdrawing their children from this education.

The new statutory guidance indicates that parents do not have a right to withdraw their children from Relationships Education delivered in primary schools (DfE, 2019). However, parents have a right to withdraw their children for up to three terms from RSE lessons if their children are aged below 16 years (DfE, 2019). When children are 16 years old, parents no longer have a right to withdraw their children from RSE irrespective of children's cultural backgrounds and levels of cognitive ability (DfE, 2019).

Across the UK, there is a lack of standardisation of RSE delivery and content (Lafferty et al., 2012). For example, RSE is not compulsory in Scotland (Scottish Government, 2014). In Northern Ireland, this education is compulsory (Council for the Curriculum, Examinations and Assessments, 2019). However, parents have a right to withdraw their children from parts of this education in primary schools and schools can develop their own content of RSE to match schools' ethos (Council for the Curriculum, Examinations and Assessments, 2019). From 2022 RSE became compulsory in Wales (Welsh Government, 2021).

## **1.4 Current research and limitations**

### **1.4.1 Effectiveness of Relationships and Sex Education**

There are only a few studies that have evaluated the effectiveness of RSE delivery to people with intellectual disability. These evaluation studies indicate that RSE can improve knowledge and skills of people with intellectual disability. For example, studies have shown that after RSE delivery, people with intellectual disability improved their knowledge of different RSE topics such as: understanding of private and public places, how to keep safe from potential abuse, different types of relationships, sexual activities, and contraception (Sheppard, 2006; Stankova & Trajkovski, 2021; Graff et al., 2018; Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000; van den Toren et al., 2021; Hui, 2023). Studies also indicate that after RSE delivery people with intellectual disability improved their social skills, hygiene skills, attitudes towards sexuality (e.g. homosexuality) and enriched their vocabulary (e.g. improved their understanding of different emotional



terms) (Sheppard, 2006; Stankova & Trajkovski, 2021; Graff et al., 2018; Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000).

### *Quality of evidence*

However, the quality of these RSE evaluation studies makes them of limited value in improving our understanding of RSE effectiveness. Most of the studies (Sheppard, 2006; Stankova & Trajkovski, 2021; Graff et al., 2018; Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000; van den Toren et al., 2021; Hui, 2023) relied on small sample sizes and performed the evaluations using non- or quasi-experimental research designs (e.g. pre-post evaluations) or employed qualitative methods (e.g. observations or interviews). It is difficult to determine the impact of RSE in such studies. For example, whether the changes in scores seen after RSE delivery were due to the intervention or other factors such as differences in how pre-post assessments were performed.

Moreover, results are not generalisable to a wider intellectual disability population as mainly adults with mild to moderate intellectual disability who use speech were involved in existing evaluation studies (Sheppard, 2006; Stankova & Trajkovski, 2021; Graff et al., 2018; Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000). Therefore, it is unclear if results are applicable to younger people with intellectual disability. There are no randomised controlled trials to establish more clearly the effectiveness of RSE and its long-term impacts for this population. Although existing studies lack scientific rigour, they have value in showing that people with intellectual disability can improve their knowledge and skills. These studies also provide methods of delivery (e.g. role-plays) that could potentially be adapted in future RSE evaluation studies.

Existing systematic reviews on RSE have focused on RSE content, design, and effectiveness for people with intellectual disability of any age and have only included peer-reviewed papers written in English (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). These

reviews found that existing RSE programmes delivered to people with intellectual disability lack specific outcome goals, and outcomes measured were heterogeneous. For example, some studies measured knowledge of different sexuality topics while others self-protection skills. This inconsistent reporting of RSE outcomes in the literature hinders the comparison of RSE approaches across studies which in turn could affect the development of appropriate and effective RSE for this vulnerable population.

In addition, researchers highlight that people with intellectual disability are not involved in RSE programme development (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). Thus, their needs and concerns are not considered (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). Instead, researchers decide what outcomes to select in their evaluation studies to assess the effectiveness of RSE for people with intellectual disability. This is a significant limitation of the existing RSE programmes empirically evaluated in the literature. First, it is difficult to understand how effective a programme is without having clearly specified outcomes that the programme aims to achieve. Second, a lack of involvement of people with intellectual disability in the outcome selection, can lead to ineffective RSE programmes being provided in practice. People with intellectual disability might perceive different outcomes as important compared to researchers without intellectual disability.

Family members and other stakeholders involved in RSE delivery to students with intellectual disability also need to be included in outcome selection when developing RSE programmes. As discussed previously, the views of adults who support people with intellectual disability can impact whether RSE is delivered in practice and what topics are perceived as appropriate to discuss with students with intellectual disability. Thus, various stakeholders need to be involved in RSE outcome selection to make sure their views are reflected in this sensitive topic. Such involvement could lead to effective RSE development and delivery to students with intellectual disability that is supported by diverse stakeholders.

### **1.4.2 Content and methods of delivery**

The literature indicates that the content delivered in RSE evaluations studies to people with intellectual disability mainly focused on biology (e.g. puberty, hygiene, and anatomy of the human body) and how to keep safe (e.g. private and public behaviours, consent) (Strnadová et al., 2022; Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020; Hole et al., 2022). Topics on sexuality (e.g. masturbation) and development of relationships (e.g. dating skills) are rarely taught to people with intellectual disability in RSE (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). Researchers also reported that details were lacking in RSE evaluation studies about what exactly is covered in RSE lessons delivered to people with intellectual disability (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020).

Whilst biology and risks are important topics, this does not reflect a comprehensive RSE delivery that should involve aspects on relationships, communication, and positive sexuality (WHO, 2010). Some researchers argue that a lack of information provided on positive aspects of sexuality in RSE (e.g. pleasure, romantic relationships) can influence attitudes of people with intellectual disability (de Wit et al., 2023). For example, some people with intellectual disability might have negative attitudes towards having a sexual relationship or their own sexuality (de Wit et al., 2023). The content delivered in RSE programmes should reflect its intended outcomes. For example, if a RSE programme aims to improve people's understanding of sexual health, the content delivered to them might involve teaching what sexually transmitted diseases are and how to maintain one's sexual health.

Research indicates that various methods have been used to deliver RSE to people with intellectual disability to improve their knowledge and skills (Strnadová et al., 2022; Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). These methods included: didactic presentations, pictures, drawings, anatomically correct dolls, videos, books, role-plays, modelling, discussions using simplified language and social stories, rehearsal,

and practise of skills (Strnadová et al., 2022; Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). However, many studies lack details specifying what each method actually involved (Sala et al., 2019; McCann et al., 2019; Schaafsma et al., 2015; Brown et al., 2020). This lack of information in the studies makes it difficult to understand the effectiveness of methods to deliver this education for this vulnerable population. However, it is likely that the method of RSE delivery to each student with intellectual disability will depend on their unique needs and abilities and will differ between students and topics taught (Colarossi et al., 2023). Additionally, methods of delivery should reflect the outcomes of RSE programmes. For example, if an outcome of a RSE programme is an improvement of students' dating skills, then the teaching might involve role-plays, modelling, and practise-based activities.

#### **1.4.3 The views of people with intellectual disability**

There is a paucity of research that directly examines the views of young people with intellectual disability about RSE (Strnadová et al., 2022). In some RSE evaluation studies, adults with intellectual disability reported finding RSE programmes beneficial and particularly valued improvement in self-esteem and knowledge that were gained after receiving RSE (Dukes & McGuire, 2009; Garwood & McCabe, 2000; McCann et al., 2019).

In recent studies carried out in Australia and the USA, students with intellectual disability identified important topics that were not provided in their lessons (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022). These topics involved: lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual (LGBTQIA+) relationships, masturbation, development of relationships, dating, marriage, reproduction, different types of contraception and parenting. These findings indicate that the topics involved in RSE evaluation studies in the literature do not always reflect the views of students with intellectual disability. However, only young people with mild to moderate intellectual disability with good vocal communication abilities were included in these studies that used interviews and focus groups. Thus, the current evidence on the perspectives of people with intellectual disability on

RSE is limited. The views of younger students with intellectual disability with vocal communication difficulties have not been explored. There are no studies to my knowledge that aimed to explore the views of students with intellectual disability on RSE outcomes.

In previous studies, students with intellectual disability also provided suggestions on how RSE needs to be delivered (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022). First, students with intellectual disability discussed that RSE delivery needs to start early in their education especially topics on puberty (Schmidt et al., 2022). Second, methods of delivery should include videos, social media, real-life examples, and simple language to describe complex and abstract RSE topics (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022). Some students reported that complex language used in their RSE lessons made it difficult for them to understand what is being taught (Strnadová et al., 2021).

In another recent study carried out in Canada that explored the views of adults with intellectual disability on RSE delivery, participants reported that RSE teaching materials should represent people with different needs and abilities (Hole et al., 2022). Adults with intellectual disability reported that when this education was provided to them, it did not include representations of people with disabilities which made them feel discriminated against (Hole et al., 2022). Adults with intellectual disability also wished that RSE delivery would continue after school education (Hole et al., 2022). Adults with intellectual disability discussed that a refresher of RSE provided in the community would have been helpful because many of them forgot the information taught in schools. Besides, adults with intellectual disability felt that at this time i.e. after school education this information is the most relevant as they start having relationships (Hole et al., 2022).

Regarding a person that should be delivering RSE in schools, people with intellectual disability had mixed views in previous studies (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022; Hole et al., 2022). Some young people with people with intellectual disability reported that a teacher

whom they know well and feel comfortable with should deliver RSE (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022; Hole et al., 2022). Some young people with intellectual disability reported that a professional outside school should be delivering RSE, so they can provide comprehensive information (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022; Hole et al., 2022). Adults with intellectual disability reported that people with intellectual disability should be involved in RSE delivery as co-teachers (Hole et al., 2022). Learning from experiences of other people with intellectual disability might help students with intellectual disability to learn the information provided and might help to reduce negative attitudes that some of them have towards their own sexuality (Hole et al., 2022). There are examples in the literature where people with intellectual disability were involved successfully as co-teachers of RSE (Frawley & Bigby, 2014; Löfgren-Mårtenson et al., 2012). However, more research is needed to evaluate such RSE delivery e.g. the effectiveness on outcomes.

## **Conclusions**

In this chapter, I presented available evidence on RSE delivery to people with intellectual disability. This literature review illustrated the importance of this education for this population. It also highlighted that people with intellectual disability are marginalised when it comes to accessing RSE. I discussed potential barriers to its provision reported in the literature including attitudes, resources, historical and political background. The evidence presented in this chapter also suggested that there is a paucity of research that aims to change RSE provision for people with intellectual disability. The small number of existing studies on RSE delivery for this population indicate that people with intellectual disability are not involved in RSE programme development and outcome selection. Thus, these programmes do not reflect the needs and wishes of people with intellectual disability and may be less effective. In the next chapter, I discuss the current state of research on directly involving people with intellectual disability in research and reasons for the current state.

## **Chapter 2 - Participation of people with intellectual disability in research**

*“We need to believe in ourselves and challenge negative opinions by showing how able we are.” (Lansdown, 2003)*

### **Introduction**

In the previous chapter, I provided evidence that people with intellectual disability are marginalised when it comes to accessing RSE and that their views are not involved in RSE programme development and outcome selection in research. In this chapter, I provide another literature review carried out to illustrate the current situation of research participation by people with intellectual disability. In this chapter, I first explain what participation in research means, discussing degrees of participation and factors that impact it. I then provide the current state of participation in research by people with intellectual disability. Barriers to participation experienced by people with intellectual disability as well as participatory research methods carried out with this population are discussed next. I finish this chapter by providing a rationale for this PhD project and its aims and objectives.

### **2.1 Definition of participation**

Participation in research is defined as voluntarily taking part in a research project to provide data as a participant (e.g. share one's views or experiences) or to participate in a new intervention or a treatment being evaluated (Cornwall & Jewkes, 1995; Northway, 2010). Individuals, organisations, or communities (thereafter “communities”) who participate in research (e.g. patients, people with disability) have lived experience of a condition or a service or are affected by research-informed decisions (e.g. teachers, healthcare professionals or policy makers) and are outside the research team that the project is being carried out. Communities do not initiate or control a research project as researchers do in “traditional research” (e.g. decide what to research and how) (Northway, 2010; Higginbottom & Liamputtong, 2015; Cornwall & Jewkes, 1995).

Participatory research is different from participation in research. Participatory research is defined as research carried out “by” and “with” communities rather than “for” or “on” communities (Norway, 2010; Cargo & Mercer, 2008; Higginbottom & Liamputtong, 2015). The defining feature of participatory research is that it engages communities that have historically been silenced in research and the wider society such as people with disability or children (Northway, 2010; Higginbottom & Liamputtong, 2015). In participatory research, communities work as co-researchers to at least some level, or in the best cases initiate and control a research project (Northway, 2010; Higginbottom & Liamputtong, 2015; Schubotz, 2020). The power to make decisions in best practice participatory research (e.g. what to research and how) is shared between researchers and communities (Northway, 2010; Higginbottom & Liamputtong, 2015; Schubotz, 2020). Participatory research is considered to be more effective than “traditional research” because the former will produce outputs that more authentically reflect the needs of communities involved and thus, are more likely to change their day-to-day lives (Northway, 2010; Higginbottom & Liamputtong, 2015; Bigby & Frawley, 2017; Greenhalgh et al., 2019). However, such benefits are rarely reported in the literature and the effectiveness of participatory research compared to “traditional research” is seldom evaluated empirically (Walmsley et al., 2018; Lewis-Dagnell et al., 2023). In the next section, I discuss how participation in research is perceived in different models and frameworks and how application of some models in research can silence the voices of certain communities.

### **2.1.1 Degrees of participation**

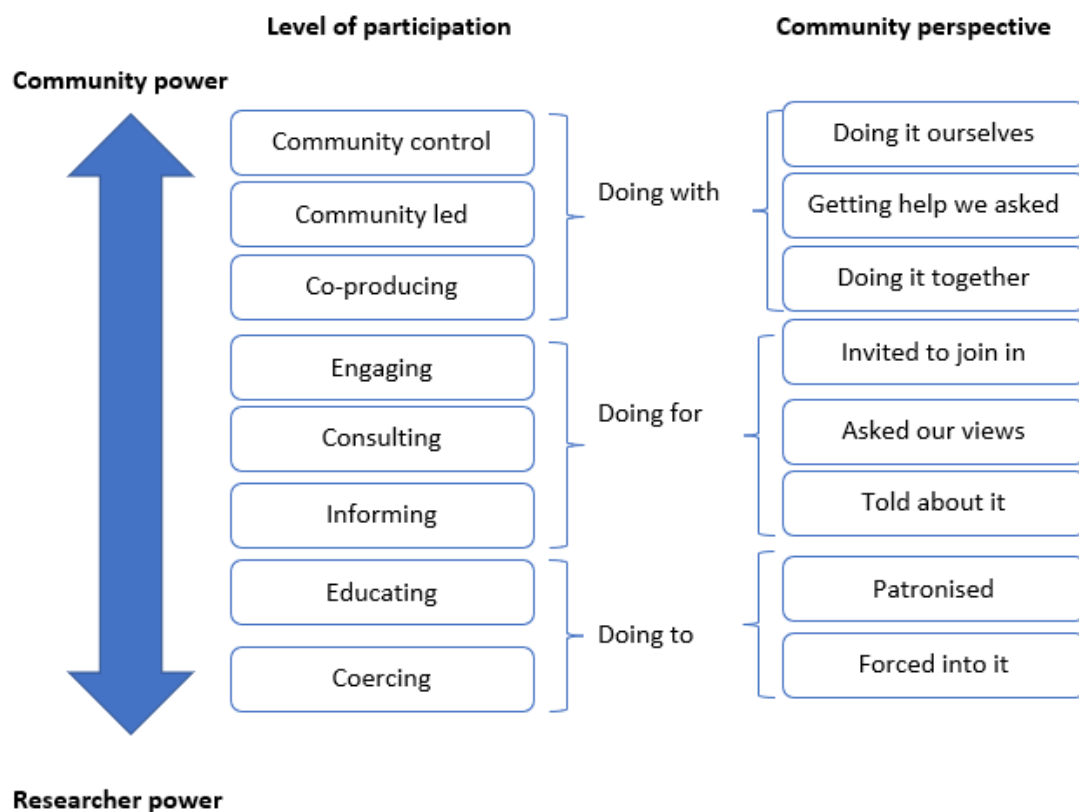
There are many different models and frameworks that define participants’ involvement in research (Greenhalgh et al., 2019; Aldridge, 2015). The degree of participants’ participation in research varies between the models and depends on the population involved and an overall aim of research.



## *Hierarchical models*

The influential Arnstein's (1969) eight rung ladder of participation (Figure 2.1) describes a hierarchical model of participation that contains eight distinct degrees of participation. This model has also been used to define children's participation in research (Hart, 1992; Shier, 2001). In Arnstein's (1969) model, different rungs of the ladder indicate the different degrees of power communities have to make decisions in research processes (Figure 2.1). The lower rungs of the ladder represent no community participation as community members do not have power to make decisions in research (Arnstein, 1969). The middle rungs of the ladder, represent tokenistic community participation as community members are provided opportunities to share their views in research processes, but they do not have power to make all decisions in research (Arnstein, 1969). The top rungs of the ladder, represent research that is community led and controlled as community members have all the power to make decisions in research (Arnstein, 1969).

Figure 2.1 Representation of Arnstein's (1969) ladder of community participation in research



Another influential model that has been widely used in health and social research in England proposed by the INVOLVE group funded by the National Institute for Health Research (NIHR) (Hanley et al., 2004) defines participation as containing three stages similar to the top three levels of participation in Arestin's (1969) model. Those three stages involve: 1) consultation, 2) collaboration and 3) consumer control (Hanley et al., 2004). Consultation is defined as asking community members to share their views on research priorities or decisions about research process e.g. advising researchers about design of a project, recruitment, data analysis (Hanley et al., 2004). Researchers do not necessarily have to implement the ideas of community members, but these ideas can influence a research project (Hanley et al., 2004). Collaboration is defined as on-going partnerships between community and researchers where community members collaborate with researchers to design, undertake and disseminate a research project (Hanley et al., 2004). Consumer controlled research is defined as research where communities lead and control a research project from inception to dissemination (Hanley et al., 2004). In such research, academic researchers can be involved if the community wishes (Hanley et al., 2004).

### *Critique of hierarchical models*

Hierarchical models of participation in research have been criticised (Tritter & McCallum, 2006; Morrison & Dearden, 2013; Aldridge, 2015). First, these models fail to address that not all community members will be able to participate at the higher levels of the rungs where they are provided power to make decisions i.e. control a project (Tritter & McCallum, 2006; Aldridge, 2015). Research that is led and controlled by people with intellectual disability is very rare as is research where people with intellectual disability work as co-researchers (Walmsley et al., 2018; Rix et al., 2020; Jones et al., 2020; Stick & McDonald, 2014). People with intellectual disability do not have finances to fund research projects, complex academic skills and abilities needed to carry out research projects, and some are unaware of issues that impact their lives (Walmsley, 2004; McCarthy & Millard, 2003; Aldridge, 2015). Some people with intellectual disability such as children and adults with severe or profound

intellectual disability due to limitations in intellectual functioning are unable to participate at the higher levels of the participation ladder (Aldridge, 2015; de Haas et al., 2022; Milner & Frawley, 2018). Thus, their views remain silenced in research when such models are applied in practice or when “true” participation in research is defined working as an academic researcher. The application of such models in research is also likely to produce outputs that do not reflect the needs of the wider intellectual disability population (e.g. those with more severe difficulties).

However, the views of children and adults with intellectual disability could be obtained about a research topic and included in decision making (Tritter & McCallum, 2006). By focusing on the top levels of participation where power is provided to make decisions, hierarchical participation models are excluding certain communities such as children and adults with intellectual disability and disempowering them (Tritter & McCallum, 2006). These models also provide very little understanding of how to involve people with intellectual disability in research or what “participatory research” might look like for this population.

Hierarchical models also do not consider the wishes and interests of community members involved (Tritter & McCallum, 2006; Morrison & Dearden, 2013). For example, some communities such as children with disability might not want to lead a research project, but they might be interested in contributing to a research project e.g. share their views on important research topics (Tritter & McCallum, 2006). Thus, community members’ views can be included in decision-making activities in research without having to lead a research project (Tritter & McCallum, 2006). Further, the quality of involvement is not considered as important in these hierarchical models (Tritter & McCallum, 2006). For example, community members might be involved at a collaboration level in a research project, meaning they are working as co-researchers. However, they might feel that their views are not valued and not included in decision making. Thus, this type of research, when poorly done, is less likely to have a meaningful impact on the lives of community members compared to research where people are involved at the lower levels of the rungs, but their views are incorporated in decision making (Tritter & McCallum, 2006). Some

researchers argue that is more important to provide equal opportunities for diverse community members to participate in research (e.g. people who do not use speech for communication or have vocal communication difficulties) rather than insisting on the top levels of involvement (Tritter & McCallum, 2006; Nind, 2014; Aldridge, 2015).

### *Priority-setting frameworks*

There are participatory frameworks where communities are provided with power to make decisions in research without them having to lead a research project (Greenhalgh et al., 2019). For example, the UK-based James Lindt Alliance (JLA) Priority Setting Partnership (PSP) is a framework developed for involving patients, carers, and clinicians in selecting research topics for a health area (JLA, 2021). The PSP is a structured consensus-based approach that involves mixed stakeholder groups (e.g. patients, carers, clinicians, and researchers) working together to produce a list of unanswered research questions (JLA, 2021). This framework was developed to address imbalances of views represented in health research agendas (JLA, 2021). Historically, researchers had all the power to decide what to research (Northway, 2003). However, research indicates that this practice still exists despite such frameworks (Crowe et al., 2015; Chalmers & Glasziou, 2009). There is evidence of a mismatch between topics that are addressed in research and what patients consider as important topics to research (Crowe et al., 2015; Chalmers & Glasziou, 2009). Studies that do not use frameworks such as the PSP can produce outputs of little relevance to the needs of patients and those who support them that result in a waste of funding. The PSP aims to change what research topics are being funded and carried out by identifying research priorities that have direct relevance to patients and those who support them (JLA, 2021).

The PSP principles consist of balanced inclusivity of different stakeholders in the process (e.g. people affected by the health condition, their carers and health care professionals), treatment of different stakeholders' views of equal value, transparency of process and commitment to an evidence base (JLA,

2021). Patients and carers can be involved in managing the PSP e.g. by inviting patients and carers to participate as well as providing their views on the most important areas to research (JLA, 2021). Non-clinical researchers are excluded from topic rating activities to address the imbalances discussed above (JLA, 2021).

Another initiative that aims to incorporate the views of community members in research decisions is the Core Outcome Measures in Effectiveness Trials (COMET) initiative (Williamson et al., 2017). The COMET initiative promotes the inclusion of the views of community members such as patients, carers, health care providers and academic researchers (hereinafter abbreviated to “stakeholders”) in selecting outcomes to measure in evaluation studies (Williamson et al., 2017). The COMET initiative was developed to address selective outcome measurement in evaluation studies such as clinical trials. There is evidence that outcomes measured in evaluation studies do not necessarily reflect the needs of service users as well as being very varied (Chalmers & Glasziou, 2009). Thus, treatments or interventions evaluated in such studies tend to have little relevance to service users’ needs and priorities (Chalmers & Glasziou, 2009). This is important because such studies could lead to ineffective treatments being provided to service users (Chalmers & Glasziou, 2009; Williamson et al., 2017).

To address the problem of selective outcome measurement in evaluation studies, the COMET initiative promotes the development of a Core Outcome Set (COS) (Williamson et al., 2017). The development of a COS involves identifying “what” to measure and includes stakeholders’ opinions on what constitutes meaningful outcomes (Williamson et al., 2017). In the development of a COS, stakeholders such as people with a health condition, their carers, and researchers are involved as participants (Williamson et al., 2017). COMET recognises the expertise and the importance of involving patients as well as other stakeholders such as researchers and health care professionals when selecting outcomes. In the development of a COS, diverse stakeholders are asked to work together to achieve consensus on the most important outcomes (Williamson et al., 2017). Everyone’s views regarding meaningful outcomes

are treated as having equal value (Williamson et al., 2017). The final COS provides a minimum standard of outcomes that stakeholders perceive as important and that should be used in evaluation studies and practice-based audits within a specific health or social care area (Williamson et al., 2017).

Similar to hierarchical models, activities involved in priority-setting frameworks (e.g. indicating important research areas or outcomes to measure) might not be accessible to all communities. For example, children and adults with intellectual disability and vocal communication difficulties might not be able to participate in such complex tasks without appropriate adaptations to accommodate their needs for participation. Thus, their voices might be left unexplored leading to imbalances of views represented in research that such frameworks aim to change.

### *Children's participation*

Children's participation in research is complex, defined by different degrees of participation and methods (Sinclair, 2004; Aldridge, 2015; Kirby et al., 2013; Stafford, 2017; Conrad, 2015). For example, not all children will have skills and interests to carry out all research activities such as initiate or control a project as adults (Sinclair, 2004; Aldridge, 2015; Kirby et al., 2013). Children might also lack confidence to share their views due to not being used to expressing their voice and taken seriously by adults (Sinclair, 2004; Aldridge, 2015; Kirby et al., 2013). This is particularly the case for children with disability who are more dependent on their caregivers and have fewer opportunities to share their views (Nowak et al., 2020; Griffin et al., 2014). Therefore, Sinclair (2004) argues that adults need to consider four factors for enabling successful children's participation in research or decision-making activities in practice:

- 1) The level of children's participation will depend on children's interests, abilities, and the aim of a project.
- 2) The purpose of the decision-making activity will impact the degree of children's participation. For example, a decision-making activity can aim

to change children's services, inform policy, or can involve research or service evaluation. Based on the purpose of a decision-making activity children can be involved as participants, consultants, or collaborators.

- 3) The nature of children's participation can take many different forms e.g. one-off consultation or on-going involvement.
- 4) The appropriate method for participation will depend on children's needs and abilities.

The United Nations Convention on the Rights of the Child (UNCRC) (1989) Articles 12 and 13 indicate that all children with disability, despite their vocal communication abilities, must be given opportunities to express their views in decisions that affect their lives using appropriate methods (UN General Assembly, 1989). The UNCRC define children's participation as being provided opportunities to share their views. Lundy (2007) critiqued the UNCRP children's rights by saying that children cannot obtain their participation rights by only being provided with opportunities to express their voice. Children's voices must be listened to and acted upon. Lundy (2007) developed a framework for planning and evaluating children's participation. This framework involves four inter-related elements that when applied in practice allow children to achieve their rights for participation. The four elements involve:

- 1) *Space*: children must be given the opportunity to express their views safely. Children's participation cannot be forced. Children should feel free to decide whether they wish to share their views in a safe and comfortable space where adults are attuned to their needs.
- 2) *Voice*: children must be facilitated to express their views. Children should have agency and freedom to share their views and they must be supported to form and express their views using any "media of the child's choice" (Lundy, 2007, p. 935).
- 3) *Audience*: children's views must be listened to and given equal weight e.g. involved in decision-making.

- 4) *Influence*: children's views must be acted upon and lead to changes.

## **2.2 Barriers to participation**

Despite recognition of the rights of adults and children with intellectual disability to participate in research over 30 years ago (UN General Assembly, 1989; UN 2006), they are still not involved in research. People with intellectual disability are often not included in research even as participants (Feldman et al., 2014; Martino & Schormans 2018; Crook et al., 2016; McDonald et al., 2013). There is a paucity of research that seeks to gather views of people with intellectual disability directly rather than through "proxy respondents" (e.g. their carers) (Jones et al., 2020; McDonald et al., 2013). People with intellectual disability want to be included in research directly, perceive their involvement beneficial (such as increase in confidence) and value opportunities for participation (Conroy et al., 2021; Bishop et al., 2023; McDonald et al., 2013; 2016).

Children with intellectual disability and vocal communication difficulties are especially invisible in research (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). The views of family members and carers are still gathered on behalf of children with intellectual disability (Brady & Franklin, 2019; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). I now discuss barriers for participating in research that children and young people with intellectual disability are experiencing as they are one of the target populations of my project. These barriers have also been reported as preventing adults with intellectual disability to participate in research (Rix et al., 2020; Nind, 2008; Lennox et al., 2005; Bishop et al., 2023; Crook et al., 2016).

### **2.2.1 Difficulties reaching**

One of the barriers reported in the literature for involving children and young people with intellectual disability in research is difficulties reaching them (Gjertsen, 2019; Adams et al., 2017; Williams, 2020; Collings et al., 2016). Children and young people with intellectual disability form a vulnerable population and are protected by their family members and carers (Collings et



al., 2016). To involve children with intellectual disability in research under the age of 16 years, their carers first need to approve their participation and provide informed consent (Nind, 2008). Carers, teachers, and service providers can act as “gatekeepers” and restrict children with intellectual disability from participating in research (Gjertsen, 2019; Williams, 2020; Collings et al., 2016). For example, carers might not see the value of their family member taking part in research projects or might not believe that children with intellectual disability are able to participate (Gjertsen, 2019; Collings et al., 2016; Williams, 2020). Schools might restrict participation of students with intellectual disability due to fears that a research project might identify negative things about a school (Williams, 2020; Dentith et al., 2012; Collings et al., 2016).

### **2.2.2 Lack of accessible research methods**

A lack of appropriate research methods available has also been reported as a potential reason for exclusion of this population from research (Rabiee et al., 2005; Bloom et al., 2020; Tesfaye et al., 2019; Nicholas et al., 2019; Lewis-Dagnell et al., 2023). This is especially the case for exploring the views of children with intellectual disability that have vocal communication difficulties (Bloom et al., 2020; Tesfaye et al., 2019; Nicholas et al., 2019; Lewis-Dagnell et al., 2023). Research that aims to explore direct experiences of children with intellectual disability is in its infancy and only a few studies aimed to do this (Tesfaye et al., 2019; Nicholas et al., 2019; Lewis-Dagnell et al., 2023; Bloom et al., 2020). Systematic reviews that explored methods for seeking direct views of children with complex needs, indicate that children and young people with mild intellectual disability of older age and good vocal communication abilities were predominantly included in research using interviews or focus groups (Tesfaye et al., 2019; Nicholas et al., 2019; Lewis-Dagnell et al., 2023). This is a limitation of current research as not all children and young people with intellectual disability are able to express themselves using speech. Thus, the methods for enabling children with intellectual and vocal communication difficulties to express their views remain to be explored as their voices.

### 2.2.3 Attitudes

Children with intellectual disability face double discrimination in research due to being children and having disability (Lundty, 2007; Stafford, 2017; Greenaway-Clarke & Franklin, 2023; Lewis-Dagnell et al., 2023). Prior to the 1990s, children were perceived as lacking the ability to share their views and were not involved in research as informants (James & Prout, 2015; Nind, 2014; Aldridge, 2015). In the 1990s, sociologists argued that childhood is socially constructed and that there are diversities in childhood experiences (James & Prout, 2015; Aldridge, 2015). Children are not passive recipients of information, but they actively engage and construct their lives (James & Prout, 2015). Sociologists argued that children's views are "worthy" of being studied independent of adults' perspectives (James & Prout, 2015).

However, there is still an assumption in research and society that children are incapable of providing accurate views of their experiences due to their age (Stafford, 2017; Sinclair, 2004). This belief is influenced by "adultism" that is defined as: "behaviors and attitudes based on the assumption that adults are better than young people, and entitled to act upon young people without their agreement" (Bell, 2010, p.1). Such thinking views children as immature, incapable of making decisions and sharing their views and needing adults' control and supervision (Stafford, 2017).

Children with disability are also perceived as incapable to share their views due to having a disability (Greenaway-Clarke & Franklin, 2023; Stafford, 2017; Lewis-Dagnell et al., 2023; Rouvali & Riga, 2021). Children with intellectual disability many of whom have vocal communication difficulties are perceived as unable to communicate and thus, not having a "voice" (Greenaway-Clarke & Franklin, 2023; Bloom et al., 2020). Such thinking reflects "ableist" ideas that perceive people without disability ("ablebodiness") as perfect and "true" humans (Campbell, 2001). Ableism sees people with disability as "others" that do not have value because they only represent "a diminished state of being humans" (Campbell, 2001, p. 44). To challenge these adultism and ableism assumptions that marginalise the voices of children with intellectual disability

in research and practice can be a challenging task (Lewis-Dagnell et al., 2023; Stafford, 2017). Development of research methods that are based on children's strengths and diverse ways that children with intellectual disability communicate (e.g. using pictures, symbols) could challenge these assumptions.

## **2.3 Participatory research methods**

In this paragraph, I discuss research methods used to seek direct views of children and young people with intellectual disability.

### **2.3.1 Methods used**

Interviews and focus groups that were predominantly used in the literature to find out the views of children with intellectual disability have been criticised for only allowing children who use speech as the main mode of communication to participate (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Ethnographic approaches such as observations and videos of children's with intellectual disability behaviour were also employed in research settings to infer their experiences (Sapiets et al., 2021; Hart, 2022; Hill et al., 2016; Lewis-Dagnell et al., 2023; Nind et al., 2010). Behavioural observations were used with children with intellectual disability who do not use words or symbols to communicate such as young children or those with severe or profound intellectual disability (Greathead et al., 2016; Hill et al., 2016; Lewis-Dagnell et al., 2023; Ware, 2004).

However, behavioural observations for exploring direct views of children and young people with intellectual disability have also been critiqued. Such method was reported as being too passive and unreliable for exploring direct views of children with intellectual disability (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Richards & Crane, 2020). Children with intellectual disability vary in how they express themselves (Richards & Crane, 2020; Sapiets et al., 2021). For example, some children with intellectual disability might laugh when they are happy and some when they are anxious (Richards & Crane, 2020; Sapiets et al., 2021). Thus, researchers who are unfamiliar

with children with intellectual disability and analyse their behaviour can misinterpret their behaviour and potentially produce unreliable data (Ware, 2004; Sapiets et al., 2021; Greathead et al., 2016; Nind et al., 2008). A small literature indicates that other visual and creative research methods can be used to explore direct experiences of children and young people with intellectual disability (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019).

### *Picture sorting activities*

Picture sorting activities such as “Talking Mats”, “Diamond Ranking”, “School Preferences Cards” were used to gather first person experiences of children and young people with intellectual disability in research (Hill et al., 2016; Gore et al., 2020; Bradshaw et al., 2018; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Bloom et al., 2020). In these picture sorting activities, children with intellectual disability are asked to use pictures or symbols to indicate their views (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Bloom et al., 2020). Thus, children with vocal communication difficulties are enabled to participate and express their views. For example, in one study children with intellectual disability completed the Talking Mats activity that involved sorting pictures into “like” and “do not like” piles to indicate their views on factors impacting their challenging behaviour (Bradshaw et al., 2018). Children reported factors that were influencing their challenging behaviour (e.g. not having access to riding bikes) which were not known by their carers. Discussions with carers can be carried out after such activities to provide supplementary information to what has been expressed by children with intellectual disability.

However, picture sorting activities have been criticised in that only children with intellectual disability who can make a choice (e.g. place pictures into “like” and “do not like” piles) and understand symbols or pictures can express themselves using this method (Richards & Crane, 2020; Doak, 2019). Thus, children with more severe intellectual disability might not be able to participate in such activities. Some studies report that this method is impacted by a limited

number of symbols/pictures available for children with intellectual disability to express their views (Lewis-Dagnell et al., 2023; Richards & Crane, 2020). Also, it is unclear whether children with intellectual disability understand the symbols and pictures selected which can impact the validity of their views obtained (Ware, 2004; Lewis-Dagnell et al., 2023).

### *Art-based methods*

Art-based methods such as art, photography and drama were also employed to seek the views of children and young people with intellectual disability in previous studies (Vega & Saavedra, 2018; Welsby & Horsfall, 2011; Goodall, 2018). In these methods, children and young people with intellectual disability produce drawings, collages, plays or photographs to express their views and feelings (Joosa et al., 2012; Chinn & Balota, 2023; Lewis-Dagnell et al., 2023). The advantages of these methods to standard interviews are that they are flexible, creative and give opportunities for children that use different modes of communication to participate (Stafford, 2017; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Thus, these methods might be more suited for children with more severe needs.

In a study on sex and relationships, drama sessions were used to understand the views of young people with intellectual disability about this topic (Garbutt et al., 2010). In drama sessions, young people with intellectual disability acted different characters to express what they thought about this topic (Garbutt et al., 2010). Then, young people with intellectual disability created a play based on the information provided in the sessions (Garbutt et al., 2010). The play was performed by young people with intellectual disability to the public to raise awareness about the negative attitudes that they experience towards their sexuality (Garbutt et al., 2010).

Photovoice is another example of an art-based method that does not rely on speech as the main mode of communication. Photovoice has been used with young people with intellectual disability with limited vocal communication abilities (Krisson et al., 2021; Chinn & Balota, 2023; Lewis-Dagnell et al., 2023;

Tesfaye et al., 2019; Nicholas et al., 2019). Using this method, people with intellectual disability are asked to share their experiences through pictures taken by them using a camera (Krisson et al., 2021; Chinn & Balota, 2023). Usually, pictures produced by young people with intellectual disability are discussed with them or with their carers to provide additional information of what has been produced (Chinn & Balota, 2023).

However, art-based methods have limitations. First, not all children and young people with intellectual disability have skills such as fine motor skills needed to use a camera or participate in drama sessions if they have not used such methods before (Garbutt et al., 2010; Chinn & Balota, 2023). Thus, teaching children with intellectual disability how to participate in such activities will add extra time and resources for carrying out research projects (Garbutt et al., 2010). Similar to picture sorting activities, interviews with carers might need to be carried out to supplement information provided by children with intellectual disability in art-based activities (Chinn & Balota, 2023). This poses risks that the data produced by children with intellectual disability might be misinterpreted by adults (Chinn & Balota, 2023).

### *Mosaic approach*

Mosaic approaches have also been used to investigate experiences of children and young people with intellectual disability (Rouvali & Riga, 2019; Bradly & Male, 2017; Richard & Crane, 2022; Carroll & Sixsmith, 2016; Oulton et al., 2018; Nind, 2008; Paige-Smith & Rix, 2011). This approach involves a combination of methods such as interviews, observations and art-based methods carried out with children with intellectual disability and carers (Clark & Moss, 2017; Carroll & Sixsmith, 2016; Oulton et al., 2018; Nind, 2008). Multiple data are collected from different sources on several occasions to find out the experiences of children with more severe communication difficulties or those of younger age who might not be able to take part in other activities discussed above (Rouvali & Riga, 2019; Bradly & Male, 2017; Richard & Crane, 2022).

For example, in Richard's and Crane's (2022) study, young people with autism, limited vocal communication abilities and co-occurring conditions such as intellectual disability created a multimodal "Talking Wall". In this study, a combination of different methods was undertaken to find out young people's views of their experiences at a residential school (Richard & Crane, 2022). Interviews and focus groups were carried out with staff members, aspects of the Talking Mats were completed with young people to develop the Talking Walls followed by observations of young people's behaviour (Richard & Crane, 2022). Young people created Talking Walls to express their experiences by sticking pictures on a wall with staff members' help e.g. staff members selected symbols for young people to stick and prompted them when to stick the symbols on the wall (Richard & Crane, 2022). The results of this study indicate that young people with complex needs and limited vocal communication abilities were able to identify aspects of their life in a residential school that they enjoy (Richard & Crane, 2022). The study also raised awareness amongst staff members about the importance of seeking direct views of students at the school (Richard & Crane, 2022).

However, mosaic approaches have been criticised for ambiguity regarding authenticity of children's voices represented in the findings (Lewis-Dagnell et al., 2023). Collection of data with carers and children with intellectual disability raises questions how multiple data are analysed and interpreted when there are disagreements between the two sources (Sun et al., 2023; Pearlman & Michaels, 2019). Further, using this approach carers and researchers can be actively involved in co-construction of knowledge e.g. researchers by analysing children's behaviour and carers by providing information on a behalf of a child with intellectual disability (Stafford, 2017; Rouvali & Riga, 2019; Bradly & Male, 2017; Richard & Crane, 2022). Thus, there is a possibility that the knowledge produced using this approach might reflect the views of adults without intellectual disability.

### **2.3.2 Other considerations**

The literature discussed above indicates there is no one method that could be applied in research to explore direct experiences of this heterogeneous population (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Bloom et al., 2020). The literature also shows that a range of different methods are needed to enable children and young people with intellectual disability to participate in research (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Bloom et al., 2020). The selection of methods needs to be person-centred and based on children's strengths and interests (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Indeed, most studies that explored direct views of this population employed at least two different methods to enable children with intellectual disability to share their views (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Carroll & Sixsmith, 2016). Literature also indicates that involving the expertise of family members and carers (e.g. for suggesting the best method to use with a particular child) can enable children and young people with intellectual disability to participate in research (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Carroll & Sixsmith, 2016).

Research discussed above illustrates that children and young people with intellectual disability and vocal communication difficulties can express their views and have differing insights to share (Bradshaw et al., 2020; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Thus, students with intellectual disability might have different views towards RSE outcomes compared to researchers who decide what to measure in RSE evaluation studies (as discussed in Chapter 1).

Despite the range of methods discussed above, all studies concluded that more research is needed on methods for enabling children and young people with vocal communication difficulties to express their voice (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Some researchers also argue that it is important to consider whether children's views gathered in research have been acted upon e.g. incorporated into decision-making within



research process or had changed their day-to-day lives (Lewis-Dagnell et al., 2023). Usually, studies benefit from children's participation e.g. by producing inclusive outputs rather than it leading to changes in children's lives (Lewis-Dagnell et al., 2023). Studies that aimed to incorporate the views of children and young people with intellectual disability to change services or practice such as education are rare (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019).

However, some researchers argue that documentation of successful processes for involving people with intellectual disability in research particularly those of younger age and with vocal communication difficulties is an important benefit of such research (Walmsley et al., 2018; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Sharing these successful processes with the wider research community can lead to more research being carried out involving this population (Walmsley et al., 2018; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). Such research could also provide methods for exploring the voices of people with intellectual disability that could be applied in everyday practice and could address negative attitudes that people with intellectual disability are incapable of sharing their views (Northway, 2013; Walmsley et al., 2018; Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019). The importance of including children's views in educational practice is also emphasised in legally binding documents in England such as the Special Educational needs and Disability (SEND) code of practice (Department for Education and Department of Health, 2015) and the Children and Families Act (DfE, 2014). Such research could also provide important insights what genuine participation in research might mean for children and adults with intellectual disability and vocal communication difficulties. As discussed previously, perceiving "true" participation in research as being able to work as a co-researcher continues to marginalise the voices of people with intellectual disability.

## **Conclusions**

In this chapter, I provided evidence that people with intellectual disability are not involved in research even as participants despite having rights for participation and having important insights to share. Children with intellectual disability with vocal communication difficulties are particularly invisible in research. The literature indicates this population is facing barriers for participating in research. Such barriers include: difficulties reaching this population, stigma towards their abilities and capacity to participate and a lack of research methods to support their participation in research. The literature review highlights that more research is needed on methods that enable children with intellectual disability of varied abilities to express their voice that could challenge negative attitudes that this population is experiencing in research and society. In the next chapter, building on the findings of the literature review, I discuss the methodology and methods selected to achieve the projects' aims and objectives (reported below).

## **Rationale for the current PhD**

In Chapter 1, I presented evidence on the importance of RSE delivery to people with intellectual disability and that their views are not involved in the RSE programme development and outcome selection. In Chapter 2, I presented evidence that despite its importance, the views of people with intellectual disability are rarely sought in research due to several barriers.

Based on the evidence provided in these two literature reviews, this project aims to develop a Core Outcome Set of RSE for and with students with intellectual disability. Considering the limitations in the current evidence on the effectiveness of RSE (Chapter 1), there is an urgent need to clearly map RSE outcomes for school students with intellectual disability. Based on the evidence presented in Chapters 1 and 2, it is also important to achieve engagement of all stakeholder groups (students with intellectual disability, parents, teachers, policy makers, and researchers) in this process. The development of a Core Outcome Set (COS) involves identifying "what" to measure and includes stakeholders' opinions on what constitutes meaningful outcomes (Williamson

et al., 2012). The COS provides a minimum standard of outcomes that all evaluation studies and practice-based audits should measure and report within a specific health or social care area (Williamson et al., 2012).

The Core Outcome Measures in Effectiveness Trials (COMET) Initiative aims to promote COS development and emphasises the importance of including different stakeholders in the process (Williamson et al., 2017). To do this, COMET has proposed a standardised approach for developing a COS that has been successfully used to develop COS across a range of health and social care areas. COMET produced a handbook for researchers to follow when developing a COS (Williamson et al., 2017). This initiative also developed an open-access database (<https://www.comet-initiative.org/Studies>) where all COS projects are registered, making COS easily accessible for researchers, funders, service providers and journal publishers.

In Chapter 2, I discussed benefits of having a COS in relation to findings of previous literature on stakeholder involvement in research. In this paragraph, I provide benefits of having a COS of RSE for students with intellectual disability. First, having a standardised outcome set for RSE would reduce the inconsistency of outcomes currently measured. This in turn would allow researchers to develop good quality evaluation studies that would help to determine the effectiveness of RSE for this population and that could be pooled usefully in systematic reviews. Second, it would reduce reporting bias (when only significant outcomes are reported instead of all outcomes assessed) as researchers would have a list of outcomes that should be measured as a minimum. This is important because evaluation studies inform policy and practice, and reporting bias could possibly lead to ineffective RSE programmes being applied in schools. Third, this COS would improve research utility and would help to develop consensus in this sensitive area as key stakeholders' perspectives would be incorporated. The engagement of students with intellectual disability in the development of COS would provide useful methodological developments how to enable students with intellectual disability to participate in such studies and how to seek their direct views in practice. Fourth, a COS of RSE would allow researchers to develop an

effective RSE curriculum for this vulnerable population and standardised outcome measurement instruments that teachers could use in schools to assess how effective RSE delivery was to a particular student/group of students and what additional educational needs might be. Fifth, a COS of RSE in the long-term could potentially improve sexual health of this population by supporting improvements in educational practice. Despite these potential benefits, there is no published COS of RSE for students with intellectual disability.

### **Aims and objectives of this project**

#### **Aim**

To develop a stakeholder consensus-based COS of RSE for students with intellectual disability for use in English educational and research settings.

#### **Objectives**

1) to develop a comprehensive list of potential outcomes based on a) findings from a systematic review of RSE outcomes reported in the international literature for students with intellectual disability and b) qualitative data collected from stakeholders.

2) to finalise a COS using a consensus-based approach through an electronic Delphi survey.

A modified version of this chapter has been published in the Journal of Medical Internet Research (JMIR) Research Protocols:

Paulauskaite, Laura, Totsika, V., & Rivas, C. (2022). Relationships and Sex Education Outcomes for Students With Intellectual Disability: Protocol for the Development of a Core Outcome Set. *JMIR Research Protocols*, 11(11). <https://doi.org/10.2196/39921>

## **Chapter 3 – Methodology and general methods**

*“It’s hard battling with your sexuality, you know what I mean? I won’t have people telling me it’s wrong. There’s not enough people telling me it’s right. Hard enough if you have a disability, but sexuality too . . . We are people, not animals, people with a voice.” (Abbott, 2013, p. 1082)*

### **Introduction**

In this chapter, I discuss the methodology and methods selected to address the aims and objectives of this project. The chapter begins with discussing my ontological and epistemological positions and providing justification for the methodology selected, which I then discuss. General methods developed from the methodological principles are discussed next. I finish this chapter by providing a brief overview of how each data collection method and data analysis was performed in this project.

### **3.1 Philosophical stance**

#### **3.1.1 Ontology and epistemology**

In the social sciences, there are several philosophical positions which impact the type of research researchers undertake and how it is undertaken (Grix, 2002; Creswell & Poth, 2018). Each philosophical position has unique beliefs about the nature of social reality (known as ontology) and the creation of knowledge (known as epistemology) (Grix, 2002; Creswell & Poth, 2018). These philosophical positions will impact the methodology selected to answer

a research question (Grix, 2002; Creswell & Poth, 2018). For example, researchers adopting a positivist ontology would argue that social reality and its meanings are objective and exist independent of interpretations of the human mind (Grix, 2002; Creswell & Poth, 2018). Positivist epistemology asserts that the knowledge about this world is developed through observations and measurements of the objective reality “out there” (Grix, 2002; Creswell & Poth, 2018). Researchers adopting such ontological and epistemological positions would primarily select quantitative methodology to control and measure the social world and produce objective knowledge (Grix, 2002; Creswell & Poth, 2018).

In contrast, researchers using an interpretivist or constructivist ontological perspective would argue that the social reality is subjective. Regarding epistemology, the social constructivist position asserts that humans do not discover knowledge, rather each person is creating their own version of a subjective reality through human interaction and the social, cultural, and historical context they live in (Schwandt, 2000; Lincoln & Guba, 2000; Crotty, 1998). Therefore, there are multiple realities that are socially and culturally constructed. For example, concepts such as “disability” and “sexuality” can mean different things to different people from different social and cultural backgrounds at a different time in history. This epistemology is in contrast to a positivist epistemology which would argue that the objective knowledge “out there” can be discovered by applying scientific research methods (Grix, 2002; Creswell & Poth, 2018).

Researchers adopting such an ontological and epistemological position would primarily select qualitative methodology to understand meanings and interpretations people provide in relation to behaviours, events, and contexts (Schwandt, 2000; Lincoln & Guba, 2000; Crotty, 1998). This research is carried out inductively to allow participants’ own voices and realities to emerge from the data (Schwandt, 2000). Researchers also understand that they play an active role in constructing the knowledge and position themselves in the research to provide understandings of how their own background and

experiences might influence interpretation of the data collected (Schwandt, 2000).

I am adopting a social constructivist position considering the evidence (discussed in the literature review Chapter 1) that people from different cultural backgrounds hold different attitudes towards RSE for students with intellectual disability and the aim of this research to explore different stakeholders' opinions on RSE outcomes.

### **3.1.2 My positionality**

There is a debate in qualitative research regarding the outsider and insider positioning and the effect of each on the ability to produce credible and trustworthy findings (Holmes, 2020; Mullings, 1999; Dwyer & Buckle, 2009). Trustworthy and credible findings in qualitative research are considered to be findings that are congruent with social reality and accurately represent participants' experiences (Delamont, 2018; Holmes, 2020; Lincoln & Guba, 1985; Stahl & King, 2020) "Insiders" are researchers who study a group/community they belong to (Holmes, 2020; Dwyer & Buckle, 2009). Some researchers argue that insiders can produce more authentic and insightful research because they are able to use their insider knowledge (Holmes, 2020; Dwyer & Buckle, 2009). Some participants might also trust an insider-researcher and thus, might share more information (Holmes, 2020; Dwyer & Buckle, 2009). However, the insider positionality might lead to biased research or the interpretation of data that reflects researchers' experiences (Holmes, 2020; Dwyer & Buckle, 2009). In contrast, "outsiders" are researchers who study a group they do not belong to (Holmes, 2020; Dwyer & Buckle, 2009). Some researchers argue that outsider-researchers might be more neutral towards a research topic, might elicit information that is not shared to insiders, and might be able to produce unbiased interpretation of data (Holmes, 2020; Dwyer & Buckle, 2009). However, outsider researchers might be less informed about the group experiences and might have a less trusted relationship with them and, thus, might gather less genuine participants' responses (Holmes, 2020; Dwyer & Buckle, 2009).

However, I consider that “true neutrality” in qualitative research is impossible and to some degree all research is biased regardless of the insider or outsider position of a researcher. I believe that researchers’ values, beliefs, past experiences, educational and professional background, gender, race, religious affiliation amongst other factors impact a research topic selection, a choice of methodology (e.g. who is involved in research and why), data collection (e.g. which participants’ views were explored further in interviews), interpretation of findings and their presentation (e.g. which participants’ quotes were presented in findings). For example, Mehra (2002) points out that the knowledge produced in qualitative research will reflect the interaction between a researcher and participants because a researcher cannot separate themselves from a research topic and participants. Brown (1996) discusses that people and their interactions in qualitative research do not produce objective facts but reflect a researcher’s subjective reality which impacts how a researcher interprets the interaction, what meaning is attributed to it and what is considered as important and irrelevant.

I believe that being a reflective researcher who acknowledges their own biases through the research process is important for assessing the trustworthiness of qualitative research and whether research reflects participants’ views rather than a researcher’s. Being transparent about research decisions I also believe is important as it helps a reader to decide how researchers’ subjective reality and an outsider/insider position impacted the data collected.

### *My position*

I am not a student with intellectual disability, a teacher, a parent of a child with intellectual disability nor a policy maker or a person working in the third sector organisation that support people with intellectual disability. Therefore, my position could be considered as an “outsider”. The closest identity that I share with is of researchers who took part in this study based on my past work experiences and being a doctoral researcher in the same field as participating researchers.



I have discussed in the introductory section of this thesis how my educational background and work experiences influenced my decision to explore RSE outcomes for students with intellectual disability. My past experiences also influenced my views towards RSE delivery for this population. As discussed previously, working in a forensic setting with people with intellectual disability opened my eyes to the importance of effective RSE provision to this population. I saw that the lack of RSE delivery to young people with intellectual disability in some cases was a contributing factor for people with intellectual disability being sexually abused or committing sexual crimes. Working with children with intellectual disability in research settings, I became aware of the importance of healthy friendships for this population and the development of social skills as many children I worked with were bullied or stigmatised at schools. Thus, I believe that students with intellectual disability should be provided RSE proactively to learn how to protect themselves and how to enjoy their sexuality. I believe RSE needs to be provided in the early years to all students with intellectual disability despite their level of intellectual disability. I am aware that people from different cultural backgrounds might hold different beliefs.

#### *Impact of researcher's positionality*

Being an outsider, in my view, both positively and negatively influenced how participants in this project perceived me and possibly what information they chose to share. This is illustrated by the following examples. Considering negative impact, one parent in the interview commented: *"It is very easy as an outsider and you know, kind of researcher to look at that [RSE delivery for students with intellectual disability] and think "God, why haven't they [parents] thought about that [the importance of RSE]?"*. One participant researcher encouraging commented: *"you are very brave to take this topic [...] it is like a minefield that needs desperately clearing"*. These narratives suggest that my position as an outsider left people with the viewpoint that I might not understand parents' reasons for not discussing topics related to RSE to their children with intellectual disability at home. On the other hand, a positive impact might have been felt by some participants, with my outsider position

being perceived as appropriate for approaching this sensitive topic and asking questions that perhaps insiders were reluctant or uncomfortable to ask.

Also with a positive impact, my outsider positionality might have also provided a neutral space for some participants to share their views. In the interviews and workshops, teachers commented about the role that parents play in RSE delivery to students with intellectual disability and that at times they can be a barrier. Similarly, parents discussed the importance of RSE delivery by teachers at schools and provided suggestions for improvements. In other words, participants were critiquing other participant groups, and they might have been more reluctant to share these views if I was a teacher or a parent of a student with intellectual disability. During the interviews with students, my outsider positionality might have allowed students to share their opinions openly because I was not familiar to students. However, in many of the interviews, the student's teacher was present. Thus, I am not sure whether my outsider position increased students' willingness to share their views openly or whether alternatively students shared less because their teachers were present in the interviews. In other words, I am not sure where the balance lay. However, rich data involving multiple perspectives were collected in this project with adult and student stakeholders suggesting that participants possibly shared their views openly.

My identity and positionality also probably impacted the interpretation of data collected in this study. As a non-religious person, who also grew up in a different country than the setting of this study (Lithuania), I was extremely cautious not to over/underestimate participants' views regarding RSE outcomes especially people from different cultural backgrounds when collecting and analysing data. I reflected on my own biases in supervision throughout the project. For example, when carrying out a systematic review, I came across studies where parents and teachers from non-Western cultural backgrounds reported that outcomes related to masturbation and menstruation should not be included in RSE for students with intellectual disability. I was not sure if I should report this information as I did not want to produce research that, in my view, stigmatises people with intellectual disability.

However, I reflected on this bias in supervision and ended up reporting this information in the systematic review and its publication. This reflection early in the project helped me to be extremely cautious of my own bias and not letting it influence the interpretation of data collected. When analysing the data collected with adult and student stakeholders, I shared my interpretations with the supervisory team for discussions that helped to address my bias and misinterpretations. To assess the validity of coding qualitative data collected in this project, inter-rater reliability assessments were performed with colleague researchers not involved in this project. My supervisors and colleagues involved in the inter-rater reliability assessments and reviewing my interpretations of findings had a range of work experiences with people with intellectual disability and different cultural backgrounds. Thus, each of the researchers involved in this project had different perspectives that enhanced the validity and credibility of the data interpretation.

### **3.1.3 Theoretical underpinnings**

My views towards the rights of people with intellectual disability, assumptions about the origin of disability and sociology of childhood also influenced this research project and methodology selected. As discussed in the literature review chapter (Chapter 2), children with intellectual disability have a legal right to be involved in decision-making activities such as research projects aiming to improve their education provision as specified in the UNCRC Articles 12 and 13 (UN General Assembly, 1989). Thus, aligned with these rights, I selected methodology that seeks to encompass the views of children and young people with intellectual disability on important RSE outcomes. Additionally, the sociology of childhood influenced my views towards the capabilities of students with intellectual disability. Sociology of childhood as discussed in Chapter 2 acknowledges that children are active social agents capable of constructing their own experiences and sharing them in research settings (James & Prout, 2015). Thus, based on this theoretical approach, I viewed children with intellectual disability as capable of providing their views on RSE outcomes and decided to involve them directly in this project rather than asking their parents to provide information on their behalf.

My assumptions about the origin of disability influenced strategies used to involve children and young people with intellectual disability in this project. I view disability as socially constructed. Thus, I used the social model of disability when planning students' involvement in this project (Oliver, 2018). According to the social model of disability, people with disability are disabled not because of their medical "deficiencies" but due to environmental and social barriers that they experience (Oliver, 2018). Based on this model, the biological "deficiencies" of children and young people with intellectual disability do not exclude them from research participation (Beresford, 2002). Environmental barriers such as stigma towards their capabilities and a lack of appropriate research environments prevent their participation. Thus, based on this model, I selected methodology that aims to address these barriers and enable their participation.

### **3.2 Methodology**

The methodological implications based on the social constructivist position for my project were:

- 1) Multiple opinions on RSE outcomes were gathered from different stakeholders.
- 2) Multiple data collection methods were used to facilitate the collection of diverse perspectives.
- 3) Information on participants' cultural and religious backgrounds were collected that provided information on the context in which this new knowledge is situated.
- 4) The aim of the study was to give free voice to stakeholders and explore their realities and what emerges from this.
- 5) Qualitative data were analysed using the framework approach for the same reason as above.

The methodological implications based on the theoretical underpinnings discussed above were:

- 1) Children and young people with intellectual disability were perceived as having a right to participate in this research project, like their parents, teachers and other professionals involved in RSE delivery to this population.
- 2) Children and young people with intellectual disability of varied levels of intellectual and vocal communication ability were perceived as capable of sharing their views.
- 3) A creative, visual methodology was selected to address barriers for participation and enable students with diverse abilities to share their views.

I discuss each of these implications and methodological decisions in detail in the next section.

### **3.2.1 Methodological decisions**

#### **3.2.1.1 COMET**

I have chosen to develop this COS using the COMET proposed approach (Williamson et al., 2017) for several reasons. First, COMET emphasises the importance of including different stakeholder groups in a COS development because each stakeholder brings different views on what are important outcomes (Williamson et al., 2017). Second, COMET's standardised approach for developing a COS involves multiple methods: a literature review, stakeholder consultations, and a consensus meeting (Williamson et al., 2017). These varied methods allowed me to gather diverse perspectives on important outcomes. These methods also exposed participants to other people's ideas providing opportunities to reconsider their positions and develop agreement on RSE outcomes. This is the way that true consensus is achieved, through a process of deliberation, rather than compromise (Williamson et al., 2017; Solomon, 2006). Therefore, the new knowledge of RSE outcomes using the COMET's proposed approach was produced collaboratively through structured social interactions with others.

### **3.2.1.2 Systematic review**

A first step in COS development, according to COMET, involves identification of outcomes reported in the literature (Williamson et al., 2017). These outcomes will then form an inclusive “long list” of potential outcomes for later parts of the process (Williamson et al., 2017). An important aspect of such review is also to identify all outcome measurement instruments used to measure the outcomes and evaluate their psychometric properties (Prinsen et al., 2016). The COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) Initiative has developed criteria for evaluating instruments’ measurement properties (reliability, validity, and responsiveness) that help to select the most reliable instruments to measure outcomes (Mokkink et al., 2018).

In this study, a systematic review was carried out to identify all RSE outcomes for students with intellectual disability and to evaluate measurement properties of identified outcome measurement instruments using COSMIN criteria. A systematic review was selected rather than other types of reviews (e.g. literature, scoping, and rapid reviews) because a systematic review involves tracing all available evidence on a specific research question using pre-specified inclusion criteria for studies to be reviewed, evaluating the quality of evidence, systematic data extraction and combining the evidence from all studies (Higgins et al., 2019). Thus, a systematic review is a comprehensive and replicable search of the literature that avoids subjectivity, missing significant evidence, and involves transparency of methods (Higgins et al., 2019). Literature, rapid or scoping reviews involve less sophisticated searches (e.g. do not involve searching all possible sources). Therefore, these reviews would not have identified all RSE outcomes reported in the literature and could potentially have presented biased evidence since they are likely to have been biased because of non-systematisation (Grant & Booth, 2009).

### **3.2.1.3 Workshops and interviews with adult stakeholders**

Workshops and interviews with stakeholders (parents, teachers, researchers, policy makers/people from third sector organisations) were carried out to

supplement the identification of outcomes from the systematic review and their importance. Outcomes measured by researchers in the studies might not necessarily match to what stakeholders perceive as important outcomes and/or views of a particular stakeholder's group might not be represented in the literature (Williamson et al., 2017). Further, in the workshops and interviews, appropriate language to refer to outcomes can be identified making sure that the final COS is understandable and accessible to all stakeholders (Williamson et al., 2017).

I chose to carry out a workshop using the adapted process of a Priority Setting Partnership (PSP) based on the James Lind Alliance principles (JLA) (JLA, 2021). As discussed in the 2.1.1 section, the PSP is a structured consensus-based approach that involves mixed stakeholder groups working together to produce a prioritised list of outcomes. This approach has been used successfully to identify priorities across health and social care research (JLA, 2021). Using this approach stakeholders are asked to discuss RSE outcomes within their groups (e.g. within a parents' group, teachers' group etc.) before sharing outcomes to everyone in the group. Not mixing stakeholders within groups during initial discussions might reduce possibilities of people perceived as having an authority (e.g. researchers or policy makers) dominating the discussion or predisposing to certain outcomes. Therefore, this type of workshop is more advantageous than individual interviews as the workshop allows to explore differences between subgroups (e.g. what outcomes parents perceive as the most important compared to teachers) while unpacking their different understandings together, thus reducing the demand and burden on participants.

#### **3.2.1.4 Interviews with students**

The views of students with intellectual disability on RSE outcomes were explored using individual face-to-face interviews. It is uncommon to seek views of children in COS development studies even though the importance of their inclusion is widely recognised (Sherratt et al., 2020; Gargon et al., 2021). For example, the most recent systematic review of all COS studies published until

2019 indicated that out of 68 COS developed for children only 11 studies (16%) included children directly in their process (Gargon et al., 2021). The review also showed that many of studies used methods developed for adults (e.g. Delphi surveys discussed below) for eliciting children's voices. It is unclear how well these methods enabled children to express their views and whether only older children were able to participate due to complex skills required in such tasks (Gargon et al., 2021). Therefore, the quality of these COS is questionable in terms of the representation of the child stakeholders.

There is only one COS study carried out that included a total of three young people with neurodevelopmental conditions who had communication difficulties but did not have intellectual disability (one person had autism and two people had neuromuscular conditions) (Morris et al., 2015). This study is also noteworthy because it used a data collection method tailored to the young population - an outcome rating activity using pictures to aid communication (Morris et al., 2015). However, the views of children and young people with intellectual disability in a COS development have never been explored before as there is no COS on any topic developed for people with ID yet. This COS of RSE is therefore the first COS developed for this population and the first that also involves children and young people with different levels of intellectual disability and vocal communication abilities as participants.

Interviews were selected as opposed to a focus group because many students with intellectual disability have complex needs and differences in their communication profiles. This would mean a focus group would have been unable to cater for them all. As the interviews were carried out in March 2022 just after the final restrictions of the COVID-19 pandemic were lifted in England (February 2022), I considered whether to carry out face-to-face or remote interviews. However, face-to-face interviews were chosen as research conducted remotely with children with intellectual disability during the pandemic indicated that children found it very challenging (Skipp et al., 2021). Moreover, teachers in special schools reported that about 30% of families of children with intellectual disability had no access to a computer or internet



during the pandemic (Skipp et al., 2021). Thus, a remote approach would have excluded many voices.

The interviews were based on one of three promising visual qualitative data collection methods discussed in the literature review chapter (Chapter 2). These three data collection methods were: 1) a picture sorting activity based on the Talking Mats framework; 2) an art-based discussion or 3) a diamond ranking activity. The choice of one method for a specific student was made by parents and teachers based on the student's interests and experience. I was offering three data collection methods because of the evidence presented in the literature review (Chapter 2) that a "one size-fits-all" method for exploring views of this heterogeneous population does not exist (Tesfaye et al., 2019; Nicholas et al., 2019).

#### *1) Picture sorting activity using Talking Mats*

Talking Mats have been shown to be effective in enabling people with different levels of intellectual disability and vocal communication abilities to express their views (Bradshaw et al., 2018; Murphy & Cameron, 2008; Gore et al., 2021). Talking Mats is a visual, structured, symbol-based communication framework that allows a person with vocal difficulties to express their views by using symbols (Murphy & Cameron, 2008) (see Appendix 3.1 for more details). In this project, I chose to explore students' views of RSE outcomes using Talking Mats instead of standard interviews for several reasons. For example, using Talking Mats no vocal abilities are needed for students with intellectual disability to express their views and the process can be adapted to meet individual needs (Murphy & Cameron, 2008). However, this data collection method might be more suitable for students who understand "like" and "do not like" phrases and can make a choice.

It is also important that the symbols to represent the topics are selected well and are not confusing for students with intellectual disability, so it does not lead to misinterpretations (Ware, 2004). Therefore, in this study I consulted with students with intellectual disability who did not take part in this project

regarding pictorial RSE outcomes (identified in the review and the workshop). This involved asking them to select the most accurate pictures to represent RSE outcomes using Talking Mats. The consultation of people with intellectual disability using Talking Mats about interview material has been successfully done before as well (Bunning et al., 2017).

## *2) Art-based discussion*

Art-based methods (e.g. drawings and posters) have been used in educational and therapeutic settings to explore the views of people with intellectual disability who struggle to express themselves using speech (Vega & Saavedra, 2018; Welsby & Horsfall, 2011; Goodall, 2018). This method of exploring the views of students with intellectual disability on RSE outcomes was selected because students do not need to have good expressive language, nor they need to understand a visual scale (e.g. “OK” or “Do not know”) to take part. Thus, this data collection method might be more suitable for students with severe intellectual disability. However, it might be difficult to interpret drawings of students who do not use speech for communication (Chinn & Balota, 2023). In such situations, a researcher might need to supplement the information provided from students by carrying out interviews with students’ carers (Chinn & Balota, 2023).

## *3) Diamond ranking activity*

A diamond ranking activity involves ranking items from the most important to the least important in a diamond shape (O’Kane, 2008). This activity has been used successfully with young people with intellectual disability and complex communication profiles (Hill et al., 2016; Robinson et al., 2020; Bloom et al., 2020). This activity was selected for this study as it might be particularly suitable for students with intellectual disability and autism who do not like direct questioning (Hill et al., 2016). The emphasis of this activity is sorting items in the diamond shape and questions could be asked while students complete the task (Hill et al., 2016). However, this activity might be more suitable for students with better reasoning and vocal communication abilities as they need

to describe their rating choices and less suitable for students with more severe difficulties (Hill et al., 2016; Bloom et al., 2020).

### **3.2.1.5 Delphi survey**

The final step of a COS development involves reaching consensus amongst stakeholders on outcomes from the long list to be included in the final COS. There are several possible methods to use e.g. the nominal group technique, semi-structured discussions, a consensus development conference, or the Delphi method to reach consensus on a COS (Williamson et al., 2017; Gargon et al., 2014; Gargon et al., 2019). The nominal group technique (NGT) is usually carried out face-to-face as a group discussion (Delbecq & Van de Ven, 1971; McMillan et al., 2014; Murphy et al., 1998). Using the NGT, participants are first asked to generate ideas for a question/problem on their own (McMillan et al., 2014; Murphy et al., 1998). Then, each participant shares their ideas to everyone in the group (McMillan et al., 2014; Murphy et al., 1998). After this, participants discuss the ideas suggested by others, group similar ideas together, and generate an agreed list of ideas (McMillan et al., 2014; Murphy et al., 1998). Then, participants rank or vote the suggested ideas from the list individually (e.g. identify top five important ideas and rank them) (McMillan et al., 2014). Individual ratings are aggregated statistically to identify group response e.g. ideas that scored the highest points (McMillan et al., 2014; Murphy et al., 1998).

Similarly, semi-structured discussions and consensus development conferences are also carried out face-to-face, in a group format and involve discussions of outcomes and individual ranking (Murphy et al., 1998; Williamson et al., 2017; Gargon et al., 2014). In all these methods, participants are not provided formal feedback on group ratings of outcomes as in the Delphi method (discussed below) (Murphy et al., 1998; McMillan et al., 2014). However, using these methods participants have a chance to hear other people's perspectives during a group discussion before a ranking exercise.

The Delphi method involves groups of participants completing rounds of questionnaires anonymously (McMillan et al., 2016; Hsu & Sandford, 2007; Keeney et al., 2011; Holloway, 2012). The first round of the survey can involve identification of ideas related to a problem which in the subsequent rounds of the survey are anonymously rated by participants (McMillan et al., 2016; Hsu & Sandford, 2007; Keeney et al., 2011; Holloway, 2012). Feedback between rounds on the group opinion (showing how other participants on average answered the same questions alongside their previous answers) is provided to participants (McMillan et al., 2016; Hsu & Sandford, 2007; Keeney et al., 2011; Holloway, 2012). Participants are asked to re-consider their original answers (keep their original answers or change them after seeing how other people answered questionnaires) in subsequent rounds (McMillan et al., 2016; Hsu & Sandford, 2007; Keeney et al., 2011; Holloway, 2012). Individual responses are statistically aggregated to determine group responses of the final round (Rowe & Wright, 1999). Consensus is calculated by measuring the variance of group responses across participants (Rowe & Wright, 1999). Little variance between participants indicates greater consensus (Rowe & Wright, 1999).

The Delphi online survey has been chosen for this study for use with adult stakeholders (parents, teachers, researchers, and policy makers/people from third sector organisations) because of advantages compared to the other methods (Keeney et al., 2011; Hsu & Sandford, 2007; Rowe & Wright, 1999), derived from key features as follows:

1. Anonymity: The Delphi style survey is a structured consensus method during which participants are invited to rate the outcomes anonymously to other participants via online questionnaires (Keeney et al., 2011; Holloway, 2012; Hsu & Sandford, 2007; Rowe & Wright, 1999). Anonymity of the responses allows participants to rate the outcomes without peer pressure or dominant people influencing outcome ratings observed in face-to-face group discussions (Nasa et al., 2021).
2. Controlled feedback: The feedback provided on the group opinion allows participants to reconsider their own individual ratings and

provides opportunities to change their responses which is missing in other group discussion methods earlier discussed (Keeney et al., 2011; Holloway, 2012; Hsu & Sandford, 2007; Rowe & Wright, 1999). Thus, consensus in Delphi online surveys is developed through deliberation and a structured group interaction (Keeney et al., 2011; Holloway, 2012; Hsu & Sandford, 2007; Rowe & Wright, 1999). The feedback also contains anonymous group ratings of all participants rather than a dominant or more vocal people's views as in group discussions (Keeney et al., 2011; Holloway, 2012; Hsu & Sandford, 2007; Rowe & Wright, 1999). Being provided with controlled feedback also exploits the tendency of people to group to a social norm (Rowe & Wright, 1999) which I argue is important for COS development studies. The COS needs to be small enough to be practical as well as suitable across typical future studies and yet incorporate diverse views (Williamson et al., 2017).

3. Ability to complete it online: Delphi surveys are suited to being done online and this reduces participant burden as people do not need to travel to complete the survey (Keeney et al., 2011; Holloway, 2012; Hsu & Sandford, 2007). This was an important feature because of the timing of this study (just after the final restrictions were lifted of the COVID-19 pandemic in England).

As discussed, stakeholders rate the outcomes in a face-to-face meeting during the nominal group technique or semi-structured group discussions (Nair et al., 2011). Therefore, these methods involve smaller sample sizes (impacting the representation of diversity of opinions and the reliability of consensus achieved) and possibilities of dominant individuals influencing the ranking of outcomes (Nair et al., 2011).

Students with intellectual disability were not involved in the Delphi survey because this method is not adapted for children and young people with cognitive difficulties (Gargon et al., 2021). Students' views regarding the outcomes were incorporated in the list of outcomes presented in the Delphi

survey and the feedback that was used in the consensus development stage of the survey (for more details see Chapter 7).

### **3.2.1.6 Framework approach**

The framework approach was performed to analyse qualitative data collected (Ritchie & Spencer, 1994; Ritchie, 2013). The framework approach involves a systematic categorisation of a large amount of data into a more meaningful and manageable format and is widely used in social policy research (Ritchie & Spencer, 1994; Ritchie, 2013). A key advantage of this approach to other similar data analysis approaches such as reflective thematic analysis (Braun & Clarke, 2019), is it enables a cross-sectional analysis of data descriptions within each participant and across participants by developing “charts” (Ritchie & Spencer, 1994; Ritchie, 2013). This cross-sectional comparison enables the recognition of patterns in the data such as those that are characteristic of particular subsets of participants (known as typologies) (Ritchie & Spencer, 1994; Ritchie, 2013). Thus, this data analysis method allows more easily to explore differences in views between different groups compared to other forms of thematic analysis. This is because using the framework approach charts developed to summarise participants’ views allow for visual comparison between and across participants. Thus, this data analysis method allowed me more easily to explore the differences in the views between different stakeholder groups (e.g. students compared to adults) on RSE outcomes.

The framework approach is often deductive at the beginning of data analysis. The development of a framework used for coding data is based on prior knowledge (e.g. research questions, literature, theoretical frameworks) and key themes inductively developed after reading transcriptions of participants’ narratives (Ritchie & Spencer, 1994; Ritchie, 2013). In this study, the findings of systematic review were used to inform the development of the framework as well as participants’ narratives.

This approach also acknowledges that a researcher plays an active role in interpreting the data and therefore contributes to the construction of the

knowledge (Ritchie & Spencer, 1994; Ritchie, 2013). Other methods of analysing qualitative data (e.g. Interpretative Phenomenological Analysis, Narrative Analysis, Grounded theory, or language-based approaches) were not suitable for this project because I was not focusing on subjective experiences of RSE (but rather subjective perspectives on what outcomes to measure); not looking at identity construction; not exploring the role of language in social life nor I was developing a theory.

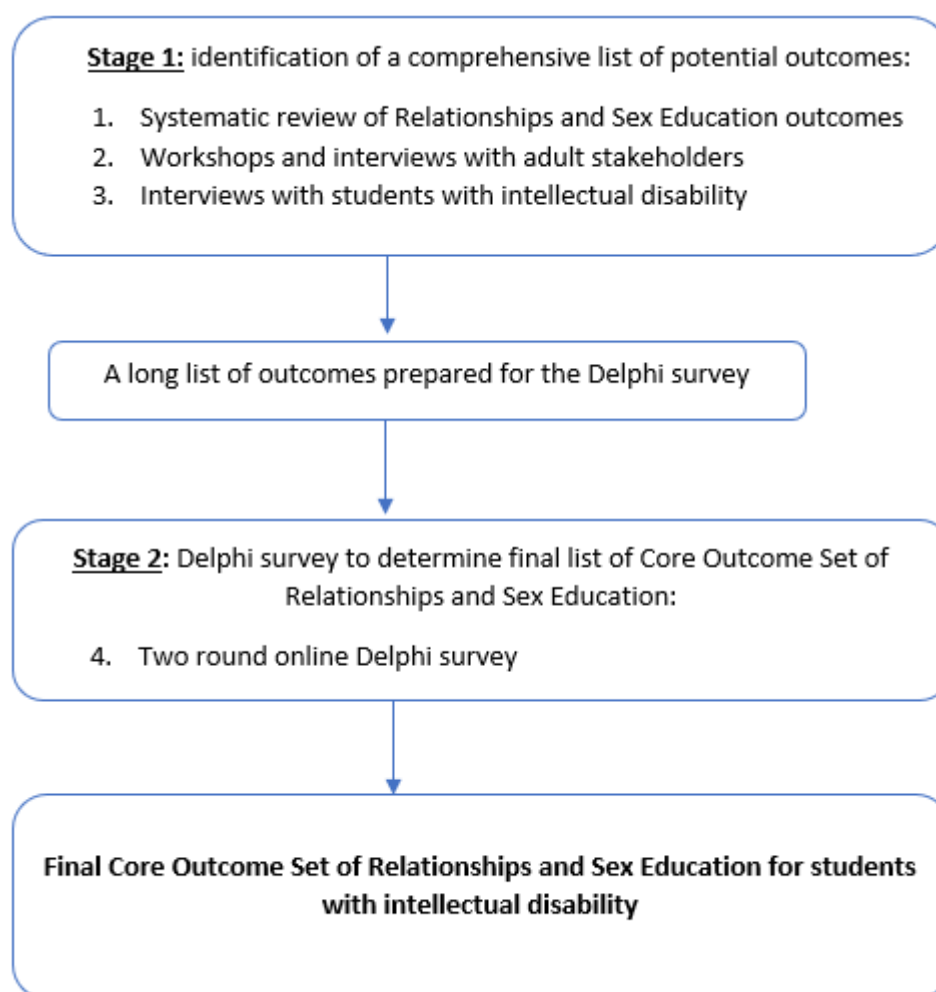
### **3.3 General methods developed from the methodological principles**

So far in this chapter, I have discussed the methodological underpinnings of this PhD project. In this section, I provide an overview of the methods employed to address the aims and objectives of this research project. I explain the design of this research project and recruitment approaches used. Considering the variety of methods used in this project, I only provide a brief discussion of how each data collection method was applied and how data was analysed. Detailed data collection and analysis methods are discussed in corresponding empirical chapters (Chapters 4-7).

#### **3.3.1 Overall research design**

This was a two-stage mixed-methods project that involved four studies (see Figure 3.1). In the first stage of this project, I aimed to identify a comprehensive list of potential RSE outcomes through a systematic review. The second study was qualitative and involved workshops and interviews with adult stakeholders. The third study was also qualitative and involved interviews with students with intellectual disability. Outcomes identified through those three studies were used in the second stage of this project. This second stage of the project involved consensus development on the most important outcomes across adult stakeholders. To do so, I carried out a fourth study that was quantitative and involved an online Delphi style survey with adult stakeholders.

Figure 3.1 Project Design



### 3.3.2 Stakeholders and setting

#### 3.3.2.1 Eligibility criteria

##### *Students with intellectual disability*

Students aged 5 to 25 years with any level of intellectual disability (mild, moderate, severe, or profound) and vocal communication ability (speaks in sentences; speaks a few words; makes some sounds; no speech) living in England were eligible to take part in the project. This age range was selected to include all school students with intellectual disability who are receiving RSE in English schools. Although RSE delivery for students without intellectual disability continues until students are aged 16 years (DfE, 2019), the upper age limit of 25 years was selected because some students with intellectual



disability in England remain in education until the age of 25 years (DfE, 2015). Students with a formal intellectual disability diagnosis were eligible to take part as well as students who had their intellectual disability defined as a primary or a secondary educational need of “moderate to severe learning difficulties” in their support plans.

Many children with intellectual disability have co-occurring conditions and disabilities (Patel et al., 2019; Buckley et al., 2020). Thus, students with intellectual disability and any co-occurring neurodevelopmental conditions and disabilities (e.g. specific learning disabilities or autism) were included in the study making sure the COS developed in this project is applicable across the intellectual disability spectrum.

#### *Parents and carers*

Parents or unpaid carers of children aged 5-25 years with intellectual disability living in England were included in the project. Carers (e.g. grandparents) were eligible to take part because they might be providing care to students with intellectual disability instead of parents. Parents and carers needed to have a level of English comprehension that allowed participation in the study, with support if needed.

#### *Teachers and school staff members*

Teachers and school staff members working with students with intellectual disability aged 5-25 years and/or involved in RSE delivery for this population in special and mainstream schools were eligible to take part. School staff members such as special educational needs coordinators, teaching assistants, speech and language therapists working with students with intellectual disability were included in the project. Teachers and school staff members with any years of experience spent working with students with intellectual disability were eligible to take part.

### *Researchers*

Researchers who specialised in research on RSE, education, sexuality, and relationships of people with intellectual disability or authored key papers on RSE for this population were eligible to take part in the study. Researchers could be based in the UK or abroad.

### *Policy makers/people from third sector organisations*

Policy makers (such as people from government agencies, parliamentary committees, third sector organizations, and charities) who were involved in developing or campaigning for policies for people with intellectual disability or special education in England were eligible to take part in the project. There were no exclusion criteria based on policy makers' professional background or seniority. People from third sector organisations and charities that support families of children with intellectual disability and were involved in policies for this population in England were also eligible to take part.

### *Sampling*

I used purposive sampling and prospective snowballing to recruit participants in the study. There is no "gold standard" number of stakeholders to involve in the COS development and the Delphi surveys (Williamson et al., 2017). In previous COS development studies, the number of stakeholders included in the process ranged from 12 to 838 participants (Gargon et al., 2021). The number of participants to include in COS development depends on the scope the COS is developed. Some studies that developed a COS for an international audience involved large numbers of stakeholders to achieve representation of the sample (Gargon et al., 2021). However, many stakeholders in previous COS studies were involved only in the final consensus stages (e.g. a Delphi survey) rather than the initial stages of the COS development (e.g. workshops or interviews to understand why outcomes are important) (Gargon et al., 2021). The samples of previous COS studies were also numerically dominated by

clinicians rather than service users that the COS is developed for (Gargon et al., 2021).

In this project, I aimed to recruit 10-15 participants in each of the four stakeholder groups (parents, teachers, researchers, and policy makers) for the workshops and interviews with adult stakeholders, 10-15 students with intellectual disability for the interviews, and 10-15 of participants in each of the four adult stakeholder groups for the Delphi online survey. The following considerations influenced the sample size in this project that were re-evaluated during the data collection:

- 1) The aim of the study was to explore different stakeholders' perspectives on RSE outcomes and to agree on the most important outcomes. Thus, including 10-15 people in each of five stakeholder groups was expected to allow me to explore different perspectives without overburdening participants. Consensus approaches with 15 participants are considered to be effective (Rosas & Kane, 2011).
- 2) In terms of specificity of experiences within the sample, the inclusion criteria for this study were wide for all stakeholder groups. This was done to explore a wide variety of stakeholders' views on important RSE outcomes. Thus, it needed a sufficient sample to enable this. A target sample of 10-15 participants in each of the 5 stakeholder groups (a total N=50-75) in the stage 2 of the project (workshops and interviews with student and adult stakeholders) was considered sufficient for allowing me to explore stakeholders' views on important RSE outcomes (Rosas & Kane, 2011). I initially planned to carry out one workshop with adult stakeholders with 6-8 participants in each 4 stakeholder groups. However, as recruitment unfolded changes to the study design were implemented to recruit more stakeholders to this stage of the project as I could not recruit the target sample (see the section 3.3.2.3 for more details). Thus, two data collection methods were used (interviews and workshops) and the sample size was increased to 10-15 participants in each four groups. Offering stakeholders to take part either to a workshop or an interview was

expected to allow me to reach more participants (Heath et al., 2018). I have also over-recruited students with intellectual disability to include the views of female students with intellectual disability. This decision was made during data collection because I initially could not recruit female students with intellectual disability.

### **3.3.2.2 Recruitment**

Recruitment to this project was carried out between February 2022 to July 2023. I first provide information on how stakeholders were recruited to each study of this project. After it, I discuss challenges experienced when initially recruiting stakeholders to this project and approaches used to solve them.

#### *Study 2 - Workshops and interviews with adult stakeholders*

Adult stakeholders (parents, teachers, researchers, policy makers/people from third sector organisations) were recruited to workshops and interviews between February and September 2022. Several recruitment approaches were employed to successfully recruit stakeholders (see Appendix 3.2 for more details). Stakeholders were identified through: internet searches, the findings of the systematic review (Chapter 4), the list of organisations involved in the statutory RSE policy in England (shared with me by DfE), charities and third sector organisations that support families of children with intellectual disability. Stakeholders who had their email addresses publicly available (i.e. researchers, policy makers/ people from third sector organisations) were approached by individual emails.

I also approached a London-based network of special schools that serve students with intellectual disability asking their help to recruit parents and teachers. I presented the study face-to-face at this network's meeting and four schools offered their help. A recruitment approach used in a school was determined by a school and possibly depended on time availability that staff members had to recruit parents to research studies. The schools also differed in the recruitment approaches carried out. For example, one school offered to

share the study information to parents by post via a school newsletter. Another school offered me to present the study at a parent coffee morning and recruit parents face-to-face. This face-to-face recruitment approach proved to be the most effective and two parents were recruited. No other parents from the special school network were recruited.

Other special and mainstream schools outside the London-based special school network were also approached (see Appendix 3.2). However, only one mainstream school in the Southeast of England that serves students with intellectual disability offered their help with parent recruitment. A research lead from the school identified eight parents who met the inclusion criteria and called parents directly to obtain their permission to share their contact details with me. Two parents were interested in taking part in the study and shared their contact details. However, only one parent was recruited because the other parent changed their mind.

Social media posts on Twitter and Facebook and snowball recruitment were also used to recruit stakeholders. The study poster was shared in the posts that contained a link to the study website with the information about the study and free text boxes to express interest in taking part (please see Appendix 3.3 for the study poster and the study website).

### *Study 3 - Interviews with students with intellectual disability*

Students with intellectual disability were recruited to the interviews between March 2022 - January 2023. A total of 25 schools identified through internet searchers and a special school network in London were approached to help with student recruitment. Out of those, 23 were special schools and 2 were mainstream schools that had Special Educational Needs and Disabilities (SEND) provision located in and outside London. I emailed headteachers with a short study summary and help needed. Out of 25 schools approached, five (20%) schools helped with student recruitment in this study. Out of five schools, two schools were identified from the special school network in London, two schools were referred by parents who took part in the workshops

and interviews, and one school was identified through the supervisory team's network. I also approached parent carer forums and shared the study poster on Twitter and Facebook to parent forums to ask parents' help with recruitment (see Appendix 3.4 for the poster).

Many of the schools approached declined their participation because teachers felt that students would not be able to participate in the interviews due to their cognitive limitations or lack of RSE knowledge. These two characteristics were not a part of inclusion criteria for my study. Some schools also refused participation because teachers felt that parents of students with intellectual disability, especially those from diverse cultural and religious backgrounds, would object to their children participating in the study. One college for students with intellectual disability pulled out from the study due to staff shortages following the COVID-19 pandemic. One special school withdrew from the study (i.e. stopped replying to emails and calls) without providing a reason. I had parents' consents for carrying out interviews with three students at this special school, but the interviews were not carried out.

Five schools that helped with student recruitment employed different recruitment approaches, though I had no control which parents of students with intellectual disability were approached about their child taking part in the study. In one mainstream school with SEND provision, a research lead identified students who met the inclusion criteria and called parents to inform them about the study. In another mainstream school with SEND provision, I approached a SEND lead and a headteacher to ask if I could interview a child of a parent who took part in this project and provided consent for their child's participation. This mainstream school agreed for the interview to take place at the student's school but were not interested to help with student recruitment. The interview had to take place at the student's school due to ethical approval obtained for the interviews to take place at student's school rather than students' home.

In two special schools, RSE teachers identified students who met the inclusion criteria and approached their parents about the study. In the third special school, teachers inserted short information sheets about the study and

expression of interest forms in all students' backpacks that attended that school. Expression of interest forms completed by parents were passed to me. I then liaised with parents to provide more information about the study and obtain an informed consent if they wished their child to take part in the study. A total of six parents filled in the expression of interest form from this school. Out of those, three parents changed their mind about their child participating in the study at the time when they were provided information sheets in preparation for the consent process. These parents thought that I will be providing their children RSE lessons rather than asking their children to take part in the interview. A total of three students were recruited from this special school.

#### *Study 4 - Delphi survey with adult stakeholders*

Adult stakeholders were recruited to the electronic Delphi survey between May-July 2023. The same recruitment approach as recruiting stakeholders to the workshops and interviews were used to recruit adult stakeholders to this study. This involved re-approaching the government agencies, charities and third sector organisations, the special school network and sharing the study poster via social media as discussed above (see Appendix 3.2). Additionally, adult stakeholders who took part in the workshops and interviews and provided consents for being approached about future studies related to this project were contacted to take part in the survey. I also asked stakeholders to share the study poster with their colleagues who might be interested to take part (see Appendix 3.5 for study poster). The study poster had the survey link.

#### **3.3.2.3 Challenges experienced recruiting stakeholders**

In this section, I discuss challenges experienced with initial recruitment of stakeholders to this project and approaches used to solve them.

##### *COVID-19 impact*

The recruitment to this project commenced in February 2022 just after the final COVID-19 restrictions were lifted in England. However, the pandemic

impacted the recruitment. First, I experienced severe delays with the ethical application and ethics review for this project. I initially prepared an ethics application to be submitted to the NHS Social Care Research Ethics Committee (REC) because the project could potentially involve adults who may lack capacity to consent i.e. students with intellectual disability aged above 16 years. As part of this process, I first needed the study sponsor's approval. I submitted the project documentation in August 2021 to be reviewed by the University College London (UCL) Joint Research Office (JRO) for granting sponsorship. However, my documentation had not been checked after three months due to pandemic-induced staff shortages and a large number of COVID-19 related studies being reviewed by the JRO. To avoid further delays, the project documentation was revised and resubmitted to the Institute of Education, University College London Research Ethics Committee. Ethical approval for this study was received on the 24<sup>th</sup> of January 2022 (REC 1565). For an ethics application for all studies in this PhD project please see Appendix 3.6. Thus, the start of the recruitment to this project was delayed by five months. Second, during this time schools were also struggling with pandemic induced staff shortages. This impacted the availability of schools to help with recruitment of parents, teachers, and students to this project.

#### *Recruitment of adult stakeholders to workshops and interviews*

I initially planned to carry out one mixed stakeholder workshop either online or face-to-face depending on participants' preferences and the COVID-19 restrictions at that time. I aimed to recruit a total of 24-32 participants (six to eight participants in each of four stakeholder break-out groups). This number of participants would have allowed me to explore the views in one workshop and thus, reduce participant burden. However, I could not recruit the target number of participants to one online workshop (selected instead of a face-to-face workshop by stakeholders). Some stakeholders declined their participation because they were unavailable at the suggested times. Therefore, after completing the mixed stakeholder workshop with available stakeholders, I decided to carry out additional online workshops consisting of about two to three stakeholders in the workshop. Recruitment to smaller



workshops turned out to be more successful than recruitment to a large mixed stakeholder workshop because it was easier for the smaller groups of stakeholders to agree on a collectively convenient time to take part.

Additionally, some stakeholders wanted to take part in the study but could not commit for 1 hour and 30 minutes (the length of the mixed stakeholder workshop). Some stakeholders also preferred to take part in an individual interview instead of a group workshop because of not feeling confident to share their views in a group format. Thus, following stakeholder requests, an additional data collection method – individual interviews of 20 minutes were offered to stakeholders. Offering stakeholders to choose either to take part in a group online workshop or an individual interview helped to recruit more stakeholders and to include more voices in the project.

#### *Additional recruitment approaches employed*

The initial recruitment approach via the special schools' network in London was not successful. As discussed previously, four schools from the network offered their help. However, only a few parents were recruited from those schools. Thus, to recruit more parents, I applied for an ethics amendment. The amendment included an additional parent recruitment method via social media e.g. posting a study poster on Twitter and Facebook which proved to be successful. Recruitment of students with intellectual disability to the interviews was also challenging as discussed above. Approaching parents who took part in workshops and interviews and asking them to share the study poster with schools that their children attended helped to reach the target number of students in this project.

### **3.3.3 Data collection methods**

In this section, I discuss briefly how each data collection method was applied in this project for more details please see Chapters 4-7.

### **3.3.3.1 Systematic review**

The search strategy consisted of two stages. The first stage of the search was carried out in March 2021 to identify all RSE outcomes and their measurement instruments using nine electronic databases e.g. MEDLINE (Ovid provider), Embase (Ovid provider) and grey sources such as Research gate and Google scholar. The search included a combination of controlled and free-text terms related to intellectual disability, the age of the population and RSE, which were combined using the Boolean operator “AND” and adapted for each database. The second stage of the search was carried out in August 2021 to retrieve studies on identified instruments’ measurement properties using the same databases and grey sources as in the first stage. The search included the name of the instrument and terms on intellectual disability which were combined with the Boolean operator “AND” and adapted for each database.

In the first stage of the review, studies were included only if the sample included at least 75% of people with intellectual disability aged 5-25 years or their parents and teachers. The studies also had to provide information on outcomes measured after RSE delivery or stakeholders’ views on RSE content to be included in the review. In the second stage of the review, at least 75% of sample had to include students with intellectual disability aged 5-25 years and the study had to provide information on instruments’ development, reliability, validity, or interpretability of scores to be included in the review.

Screening of studies on title/abstract and full text was performed by me and 20% of records were screened independently by a second reviewer for avoiding subjective selection of studies and missing relevant data. Data extraction was also conducted by me with an independent check of 10% by a second reviewer.

### **3.3.3.2 Workshops and interviews with adult stakeholders**

Adult stakeholders took part to either an online workshop or an online interview based on their preference. Prior to the workshops and interviews, I collected demographic information from participants such as their age, gender, ethnicity,

and religious affiliation. The workshops consisted of smaller group discussions to select the top three RSE outcomes for students with intellectual disability in primary, secondary and further education. Then, stakeholders were asked to share their selection of outcomes from smaller groups and reasons for outcome selection to all participants in the workshop. In the interviews, stakeholders were asked to share what they perceived as important RSE outcomes for students with intellectual disability in primary, secondary and further education. Questions used in workshops and interviews were piloted with a small number of parents and teachers who did not take part in the study. Workshops and interviews were audio recorded.

### **3.3.3.3 Interviews with students**

The interviews were piloted with a small group of students (N=3) who did not take part in the study. A consultation with students who did not take part in this study was carried out to select pictures and symbols used to represent RSE outcomes. All interviews with study participants were audio recorded and pictures were taken of finished activities e.g. posters. I conducted preparatory sessions with the participating students' parents and/or teachers prior to the interviews to discuss which method out of three to choose and how to adapt the interview to each students' needs. After the interviews with students, I also had discussions with students' teachers to check if the finished activity represented students' views.

- 1) In a picture sorting activity using Talking Mats, students were introduced to the RSE topic (e.g. "We are going to talk about what you learn at school. Tell me which topic you like") and asked to place pictorial RSE outcomes under categories of the visual scale (e.g. "Like" or "Do not like") adapted for each student. The placement of outcomes started with practice rounds of sorting neutral topics making sure students understand the task and building up towards RSE outcomes. I asked simple questions to find out why certain outcomes were placed into "like" and "do not like" piles.

- 2) In an art-based discussion, students were asked to make a poster with an example and help provided. Students were presented with pictorial RSE outcomes and were asked to select interesting pictures or pictures that they want to learn more about. The selected pictures and other material (e.g. water paint, sticky notes, stickers) were used to decorate posters. While students were decorating their posters, I asked simple questions to find out their views about selected RSE outcomes.
- 3) In a diamond ranking activity, students are presented with pictorial RSE outcomes and asked to sort them in a diamond shape. Students are told to place RSE outcomes that they like on the top, the outcomes that they are unsure about in the middle row, the outcomes that they do not like on the bottom. Students are asked questions about their outcome placements. However, none of students completed this activity. The other two methods were selected as more appropriate methods for eliciting students' views.

#### **3.3.3.4 Delphi survey**

Adult stakeholders participated in two rounds of the online Delphi survey. Before starting to rate the outcomes, participants were asked to answer demographic questions embedded in the survey. In round 1, participants were presented with a list of outcomes identified through the review, workshops and interviews with students and adult stakeholders. Participants were asked to score on a 9-point Likert scale how important they think it is that students with intellectual disability have knowledge related to each outcome. Participants were also asked to provide comments and to suggest any missing outcomes not presented in the survey in free text boxes. In round 2, stakeholders were presented the feedback on how other stakeholder groups on average rated the outcomes. Stakeholders were asked to re-rate the outcomes and if they wished to change their responses. The survey was first piloted with a small number of parents, teachers who did not take part in the study to assess clarity and readability before being sent to Delphi participants.

### **3.3.4 Data analysis**

#### **3.3.4.1 Outcome categorisation**

The COMET Handbook (Williamson et al., 2017) was used for categorising outcomes retrieved through the systematic review. Outcomes were extracted verbatim from the text and grouped into three separate lists based on students' age. The thematic framework discussed below were used to categorise the outcomes collected with stakeholders in this project.

#### **3.3.4.2 Framework approach**

Five data analysis stages were carried out that involved: familiarising with the data by reading and re-reading the transcripts and making notes for potential codes on RSE outcomes; development of a thematic framework based on the participants' suggested outcomes; assessing the validity of the framework by performing an inter-reliability assessment; application of the framework to code all the data; creation of "charts" to summarise stakeholders' views on outcomes and differences between stakeholder groups; mapping and interpreting perspectives on RSE outcomes and comparing it between stakeholder groups.

#### *Trustworthiness*

Several strategies were implemented to ensure trustworthiness of the qualitative data collected in this project. Trustworthiness of qualitative research refers to whether researcher ensured that the interpretation of the data and conclusions made are trustworthy (Lincoln & Guba, 1985; Giddings & Grant, 2009; Shenton, 2004). Lincoln and Guba (1985) proposed criteria for trustworthy qualitative research that involves credibility, transferability, dependability, and confirmability.

#### *Credibility*

Credibility refers to the extent that the narratives provided by participants and my interpretation of those narratives resulted in accurate and credible findings

that reflect the social reality (Giddings & Grant, 2009; Stahl & King, 2020; Lincoln & Guba, 1985). I carried out several strategies to establish credibility of qualitative findings. First, I provided above a reflection on how my identity and position impacted the data collection and interpretation. I also discussed procedures used throughout the project to reflect on my own bias. Second, my supervisors and colleague researchers were involved in data interpretation that promoted reflexivity and dialogue for alternative interpretations of the data. Third, data triangulation was used in this project that also address the researcher bias. I used four studies on the same topic to establish the findings i.e. stakeholders' perspectives on important RSE outcomes. Fourth, a wide range of views towards RSE outcomes were collected from different stakeholder groups making sure it represents multiple realities. Fifth, throughout the thesis, I present participants quotes to illustrate the findings and that the findings reflect their views rather than mine.

### *Transferability*

Transferability refers the degree to which the findings can be generalised to other situations or contexts (Giddings & Grant, 2009; Stahl & King, 2020; Lincoln & Guba, 1985). Qualitative research does not aim for replicability of findings as in quantitative research (Giddings & Grant, 2009; Stahl & King, 2020). However, in qualitative research, some findings e.g. patterns and descriptions might be applicable to other contexts (Giddings & Grant, 2009; Stahl & King, 2020). To assess whether the findings of qualitative research can be applied in different settings, detailed contextual factors are needed to understand the settings the findings were generated. Detailed contextual factors (e.g. participants' characteristics, the setting, methods used for data collection and timeframes) were provided in this thesis to assess the transferability of findings.

### *Dependability*

Dependability refers to whether the methods used in this study are reliable and the research process is traceable (Giddings & Grant, 2009; Stahl & King, 2020;

Lincoln & Guba, 1985). To collect qualitative data in this project, I used well-established methods such as semi-structured interviews and workshops. To develop this COS, I also used a systematic and rigorous approach that was successfully applied in other COS developed studies (Williamson et al., 2017). I explained the study design, methods and decisions made in detail in this thesis. Besides, the project protocol (Paulauskaite et al., 2022) and the systematic review protocol (PROSPERO registration number: 1787) were published prospectively for transparency, sharing research methods, and controlling possible bias. In addition, inter-reliability assessments were performed on qualitative data collected in this project to assess the consistency of a coding scheme developed to analyse the qualitative data.

### *Confirmability*

Confirmability is concerned with establishing that the research process and findings are not biased by a researcher (Giddings & Grant, 2009; Stahl & King, 2020; Lincoln & Guba, 1985). According to Lincoln and Guba (1985), confirmability can only be achieved when credibility, transferability, dependability are attained. I discussed above steps taken in this study to achieve these elements and strategies to mitigate my bias.

### **3.3.4.3 Quantitative analysis**

Quantitative data collected in the survey were analysed using descriptive statistics such as median and percentages. The ratings of outcomes collected in the survey produced ordinal data. Thus, the summary statistic calculated was the median as this is the preferred measure of central tendency for ordinal data (Holcomb, 2016). Consensus to keep the outcome in the final list of COS was defined as 70% or more of respondents assigning a score between 7 and 9 points and fewer than 15% of respondents assigning a score for the same outcome between 1 and 3 points. The outcomes which were scored by 70% of respondents as 1 to 3 points and fewer than 15% of respondents scored as 7 to 9 points were not included in the final list of COS. The criteria to determine consensus were selected based on the recommendations by the COMET

initiative (Williamson et al., 2017). The criteria are stringent (i.e. the majority of participants (70%) need to rate an outcome as the most important, while only a small minority (<15%) rate it as important). The stringent criteria ensure that not all outcomes from the long lists are rated as the most important and are included in a COS which needs to represent the minimum set of outcomes (Williamson et al., 2017).

To explore whether the feedback provided in round 2 impacted stakeholder ratings, statistical differences on outcome ratings between two rounds were explored by applying the Wilcoxon signed-rank test (Wilcoxon, 1945). The non-parametric Wilcoxon signed-rank test was selected because it allows comparisons on two sets of scores (i.e. the outcome ratings between two rounds) when the data are not normally distributed (one of the criteria for the parametric tests) (Field, 2017). In this study, outcome ratings were not normally distributed and thus, the Wilcoxon signed-rank test was applied.

Statistical differences on outcome ratings in round 2 between four stakeholder groups were explored by applying the Kruskal–Wallis test (Kruskal & Wallis, 1952). The non-parametric Kruskal–Wallis test was selected because it allows comparison of more than two groups of independent scores (i.e. outcome rating scores of four stakeholder groups) when the data are not normally distributed (i.e. as in this study) (Field, 2017). When the Kruskal–Wallis test indicated significant differences on the outcome rating scores between stakeholder groups, pairwise comparisons were performed. Pairwise comparisons with adjusted p-values (to not inflate Type I error, false positive results, by performing several tests on the same data) were performed to explore which groups differed on outcome ratings (Field, 2017).

## **Conclusions**

In this chapter, I described the methodology selected to address the aims and objectives of this PhD project. I discussed how my social constructivist position and my views towards the rights of people with intellectual disability, the origins of disability and sociology of childhood impacted this research project. I then



discussed methodology selected to develop this COS of RSE for and with students with intellectual disability. The development of this COS involved a two-stage mixed-methods project consisting of four studies: a systematic review, workshops and interviews with adult stakeholders, interviews with student stakeholders and a Delphi style survey with adult stakeholders. A brief overview of how each data collection method was applied in each study and how data was analysed was discussed as well. In the next chapter, I present the first study of this PhD project - a systematic review of RSE outcomes for students with intellectual disability reported in the international literature.

A modified version of this chapter has been published in the Journal of Intellectual Disability Research:

Paulauskaite, L., Rivas, C., Paris, A., & Totsika, V. (2022). A systematic review of relationships and sex education outcomes for students with intellectual disability reported in the international literature. *Journal of Intellectual Disability Research*, 66(7), 577-616. <https://doi.org/10.1111/jir.12952>

## **Chapter 4 - Systematic review of Relationships and Sex Education outcomes for students with intellectual disability**

*“It is not our learners who are disabled. It is our systems, our curriculum.” (Novak, 2021)*

### **Introduction**

In this chapter, I present a systematic review carried out as a first study in this COS development. The systematic review aimed to identify a compressive list of Relationships and Sex Education (RSE) outcomes to be used with stakeholders in the following stages of this COS development. This chapter begins by describing the aims and objectives of the review. I then discuss methods employed and present results of the review. I finish this chapter by providing a discussion of the findings.

### **4.1 Aims**

The primary aim of the review was to identify a comprehensive list of RSE outcomes for students with intellectual disability aged 5-25 years.

Secondary aims were:

- 1) to identify all validated outcome measurement instruments used to measure the extracted outcomes;
- 2) to assess instruments' measurement properties (validity, reliability, and responsiveness) using the Consensus-based Standards for the

selection of health Measurement Instrument (COSMIN) criteria (Mokkink et al., 2018);

- 3) to conduct a risk of bias assessment using the COSMIN Risk of Bias checklist (Mokkink, 2017) for the included studies on measurement properties of instruments.

## 4.2 Methods

The systematic review was registered with PROSPERO (registration number: 1787) before starting the searches for transparency and controlling possible bias. The systematic review was carried out following PRISMA guidelines (Liberati et al., 2009).

### 4.2.1 Search Strategy

The search consisted of two stages. To address objectives (1) and (2), the first stage of the search was carried out in March 2021 to identify all RSE outcomes and instruments used to measure the outcomes. Nine electronic databases were searched, and grey sources listed in Table 4.1. Cochrane Library was also searched for any related systematic reviews and the Clinicaltrials.gov website for any studies. Additional search strategies were also performed which included backwards (scanning reference lists) and forwards (checking where the eligible studies are cited) reference searching of articles that met the inclusion criteria. The search included a combination of controlled and free-text terms related to intellectual disability, the age of the population, RSE which were combined using the Boolean operator “AND” and adapted for each database (see Appendix 4.1 for an example of a search).

Table 4.1 Sources used to search in systematic review

| Sources                     |                                                                                                                                                                                                                                                                                              |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Electronic databases</b> | MEDLINE (Ovid provider), Embase (Ovid provider), PsychINFO (Ovid provider), Social Science Citation Index in the Web of Science database, ERIC (EBSCO provider), BEI (British Education Index; EBSCO provider), ASSIA (Applied Social Sciences Index and Abstracts; ProQuest provider), IBSS |

|                      |                                                                                                                                                      |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
|                      | (International Bibliography of the Social Sciences; ProQuest provider) and SCOPUS.                                                                   |
| <b>Grey sources</b>  | Research gate, Google Scholar (first 10 pages), Google (first 10 pages), NICE Evidence Search, The King's Fund, Zetoc, WorldCat, OpenGrey and EThoS. |
| <b>Other sources</b> | Cochrane Library and Clinicaltrials.gov websites.                                                                                                    |

To address objective (3), the second stage of the search was carried out in August 2021 to retrieve studies on identified instruments' measurement properties. For each instrument the search was carried out separately. The search strategy included searching the same electronic databases and the grey literature as in the first stage (Table 4.1). The search strings included the name of the instrument and terms on intellectual disability which were combined with the Boolean operator 'AND' and adapted for each database (see Appendix 4.2 for an example of a search)

The search strings were also piloted in preliminary searches. I intended to use a search filter developed by COSMIN (Terwee et al., 2009) to identify studies on measurement properties as specified in my review protocol registered in PROSPERO. The COSMIN search filter was specifically developed for identifying studies on instruments' measurement properties and contains terms such as "psychometr\* OR "cronbach\* alpha\*" OR "replicab\* measure\*". The search filter has a sensitivity of 97.4% and a precision of 4.4% for selecting studies on instruments' measurement properties (Terwee et al., 2009). Therefore, it is considered a reliable filter to use in such searches (Terwee et al., 2009). However, when I added this filter to the search strings described above, no studies were retrieved. This might have occurred due to the poor indexing of instruments' measurement properties in the abstracts or a genuine lack of relevant studies. Thus, this filter was not used in the final search.

#### 4.2.2 Inclusion and exclusion criteria

In the first stage of the review, articles were eligible for inclusion only if they met the following criteria:

- 1) **Participants/population:** at least 75% of samples consisted of students with intellectual disability aged 5-25 years (e.g. upper quartile or 75th percentile) or parents, teachers, and school staff members of students with intellectual disability aged 5-25 years. Studies were included when intellectual disability was administratively defined (e.g. students received education or other statutory services because of intellectual disability). Studies were also included when intellectual disability was defined using standardised assessments of intelligence quotient (IQ) and adaptive functioning (e.g. IQ below 70 and adaptive scores below 70). Students with intellectual disability that had additional conditions e.g. autism were eligible for inclusion;
- 2) **Intervention:** focused on any type of RSE delivered in schools, home, and social care services. Studies that reported clinical interventions aimed to treat clinical problems related to sexuality were excluded;
- 3) **Comparison:** was not applicable as the aim of the review was to identify RSE outcomes for students with intellectual disability and not to evaluate RSE effectiveness;
- 4) **Outcomes:** provided information about outcomes measured after RSE delivery or contained the views of stakeholders (e.g. students with intellectual disability, parents, and teachers) on RSE content. This decision was made to identify all possible outcome constructs to inform the later stages of this study (consensus development).
- 5) **Study Design:** used any qualitative, quantitative, observational, and mixed-methods study designs. Systematic reviews were excluded;
- 6) **Publication:** published in any language from 1999. Most of the development of RSE policies and practice in Europe took place from 1999 (Ketting and Ivanova, 2018). At this time topics on relationships were integrated into the Sex Education curriculum in England and

become known as “Sex and Relationships Education” (Department for Education and Employment, 2000).

In the second stage of the review, articles were eligible for inclusion only if they met the following criteria:

- 1) **Participants/population:** at least 75% of participants consisted of students with intellectual disability aged 5-25 years. Studies that defined intellectual disability administratively as well as using standardised assessments described above were eligible for inclusion. Studies that included students with intellectual disability and additional conditions, e.g. autism, were also included;
- 2) **Intervention:** not applicable as the aim of this stage of the review was to evaluate measurement properties of the identified instruments.
- 3) **Comparison:** not applicable as explained above.
- 4) **Outcomes:** provided information on the identified instrument’s development or measurement properties (e.g. reliability and validity) or evaluated the interpretability of scores (e.g. distribution of scores or floor and ceiling effects);
- 5) **Study Design:** Any study design (qualitative, quantitative and mixed methods).
- 6) **Publication:** no studies were excluded based on the language and the date of publication as the aim of this stage of the review was to find all studies on instruments’ measurement properties.

#### 4.2.3 Study selection

In both stages of the review, retrieved studies were stored in the information management tool, EPPI-Reviewer 4 (Thomas et al., 2020) and checked for duplicates. Screening of titles/abstracts, and full text articles against the inclusion criteria was performed by me. Twenty percent of titles/abstracts and full text articles were discerned independently by a colleague researcher to check the consistency of the screening process. Numbers of excluded studies were recorded as well as their reasons. Any disagreements or discrepancies

about included studies were resolved by consensus and discussions with my supervisory team.

Studies written in non-English languages that had an abstract written in English were screened against the inclusion criteria. However, I did not exclude any studies based on whether they had an English abstract or not. The full text of articles written in a non-English language where the abstract appeared to meet the criteria or where there was no abstract were screened by me and my supervisory team who were proficient or native-level fluent in the relevant language. Other researchers and PhD students helped to screen studies written in a language that me and the supervisory team was not fluent in. I also used professional translation services for some studies that I or the colleagues were unable to translate.

#### **4.2.4 Data extraction**

During the first stage of the review, I extracted data from the studies into standardised study selection forms developed for this study. Ten percent of data was extracted independently by a colleague researcher to check the consistency of data extraction process. Data were extracted on characteristics on the included studies, sample, data collection method, RSE, outcomes and outcome measurement instruments. Studies that provided qualitative data on RSE outcomes (e.g. contained information on the views of students, parents, and teachers of RSE outcomes or content) were extracted as well.

In the second stage of the review, I planned to extract data into standardised tables provided by the COSMIN Initiative (available from: <https://www.cosmin.nl/tools/guideline-conducting-systematic-review-outcome-measures/?portfolioCats=19>) that included:

- 1) characteristics of the studies on measurement properties;
- 2) results on the instruments' measurement properties (validity, reliability, and responsiveness);

3) information on the interpretability of scores (such as the distribution of scores and floor and ceiling effects) and instruments' feasibility characteristics (e.g. cost of the instrument, required equipment or training, ease of score calculation, availability).

However, the data extraction of the studies retrieved in the second stage of the review was not performed as no studies met the inclusion criteria.

#### **4.2.5 Risk of bias**

A risk of bias assessment for the included studies was not performed. The aim of the first stage of the review was to summarise RSE outcomes reported in the studies and as such a risk of bias assessment of these studies is not relevant and, for this, was not planned. However, in the second stage of the review, I planned to apply the COSMIN Risk of Bias checklist (Mokkink et al., 2018) to each study independently with a second reviewer to see if there is a risk of bias in how the evaluation of measurement properties or development of an instrument was performed and whether the results are trustworthy. I also planned to use the Excel spreadsheet developed by the COSMIN Initiative to record the ratings of the risk of bias assessment (the spreadsheet is available online: <https://www.cosmin.nl/tools/guideline-conducting-systematic-review-outcome-measures/?portfolioCats=19>). However, this was not performed as no study retrieved in the second stage of the review met the inclusion criteria.

#### **4.2.6 Outcome categorisation**

The COMET Handbook (Williamson et al., 2017) was followed for categorising outcomes extracted from the studies. However, I did not follow any outcome classification systems of grouping outcomes into specific domains as there are no such typologies developed for RSE outcomes to my knowledge. Thus, outcomes were extracted verbatim from the papers with their definitions (when available) and compiled into a long list. Then, I grouped the verbatim outcomes by educational stage into three separate lists. RSE outcomes reported for/by students aged 5-11 years were grouped into a list of outcomes for primary education, outcomes reported for/by students aged 12 -16 years were grouped



into a list of outcomes for secondary education and outcomes reported for/by students aged 17- 25 years were grouped in a list of outcomes for further education.

Then, the outcomes that were overlapping or had the same definitions in those three lists were merged under the same outcome name. I also recorded the frequency the same outcome was reported across the studies and who reported the outcome (e.g. students with intellectual disability, parents, teachers and/or whether it was measured by researchers). The outcomes that I considered semantically related were presented to the supervisory team for evaluation. After discussion with supervisory team, I grouped semantically related smaller outcomes into outcome domains. My supervisory team reviewed the final list of outcomes and outcome categorisation. The feasibility and measurability of identified outcomes was reviewed independently by me and my two supervisors (see Table 4.2 for the criteria). Any disagreements or discrepancies about outcomes were resolved by consensus and discussions.

Table 4.2 Criteria used for assessing feasibility and measurability of identified outcomes

|                                                                                                                                                                                                                                                           |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Outcomes rated by two reviewers independently as one of the following options were not included in the lists:</b>                                                                                                                                      |
| 1) This outcome does not have a definition, we cannot provide one, and it is unclear what this outcome is referring to.                                                                                                                                   |
| 2) This outcome is not a directly relevant outcome of RSE (meaning that the identified outcome is not related to the RSE topic e.g. a clinical outcome such as incidence of hyperactivity during RSE teaching).                                           |
| 3) This outcome is not student centred (meaning the identified outcome does not refer to aspects associated with students' attitudes, knowledge or skills development but relates to other aspects e.g. school environment or teacher's characteristics). |
| 4) This outcome is not a feasible outcome to be used in educational settings (meaning that there are contextually insurmountable logistic barriers to implementation e.g. follow-up period does not allow it to be measured in educational settings).     |

#### **4.2.7 Evaluation of measurement properties of identified instruments**

In the second stage of the review, I planned to apply the COSMIN criteria for content validity (Terwee et al., 2018) to appraise studies on the development of an instrument and content validity evaluations. I also planned to apply the COSMIN criteria for good measurement properties (Mokkink et al., 2018) to rate the other measurement properties of identified instruments. However, this was not performed as no studies retrieved met the inclusion criteria.

### **4.3 Results**

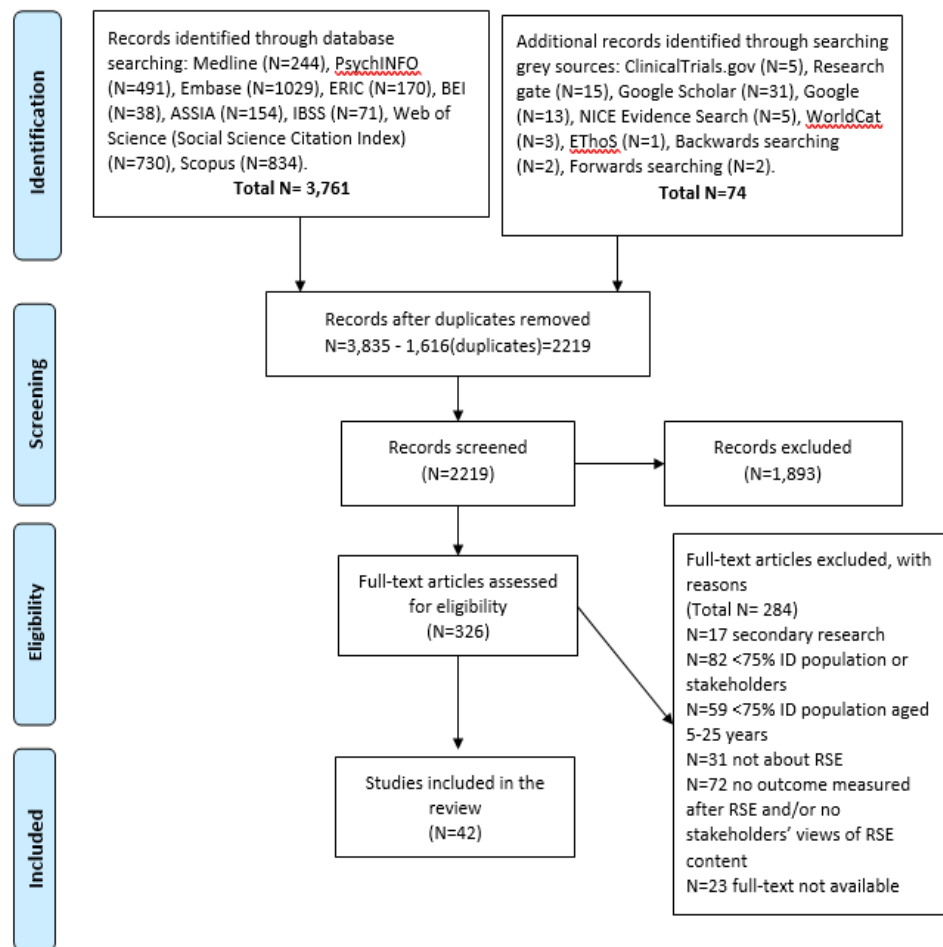
In this paragraph, I first present the results of the first stage of the review on RSE outcomes and outcome measurement instruments. I then present the results of the second stage of the review on measurement properties of identified instruments.

#### **4.3.1 First stage of the review**

##### **4.3.1.1 Results of the search**

The search retrieved 3835 articles. Please see Figure 4.1 for the PRISMA flow diagram. After removing duplicates, 2219 articles were screened on title and abstract for inclusion in the full text review. This resulted in 1893 articles being omitted as not meeting the inclusion criteria and 326 articles were screened on full text. Of these, 284 were excluded after reading full text as not meeting the inclusion criteria. In total, 42 articles were included in the review.

Figure 4.1 PRISMA Flow Diagram



#### 4.3.1.2 Study characteristics

Table 4.3 provides a description of the 42 studies included in the review. Out of these, 27 studies provided qualitative data, six quantitative data and nine mixed-methods data. The studies were published between 2000 and 2021 and carried out in the UK, USA, Africa, Turkey, Australia, Sweden, Ireland, Spain, Greece, Cyprus, Lithuania, Iran, India, Israel, Japan, and Republic of North Macedonia. Articles were written in the English, Lithuanian and Spanish languages.

Table 4.3 Characteristics of the included studies grouped by type of data provided

| Study reference         | Study location, language of report                        | Aim                                                                                             | Data collection method                                      | Sample                                                                                                                                                                               | Setting                                     |
|-------------------------|-----------------------------------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------|
| <b>Qualitative data</b> |                                                           |                                                                                                 |                                                             |                                                                                                                                                                                      |                                             |
| Aderemi (2014)          | Location: Nigeria (South Africa)<br><br>Language: English | Explore educators' opinions of sexuality and sexuality education for learners with ID.          | Semi-structured interviews                                  | 12 <u>teachers</u> (3 male and 9 female) aged 29-55 years of students with ID.<br><br><u>ID</u> : age, gender, level of ID not reported.                                             | Special schools                             |
| Finlay et al., (2015)   | Location: UK<br><br>Language: English                     | Examine how Sexual Health Education is delivered to people with ID.                             | Semi-structured interviews and observations of SHE sessions | 4 <u>teachers</u> (age and gender not reported) of students with ID.<br><br><u>ID</u> : students aged 16-19 years with mild-moderate ID, gender not reported.                        | Youth club and special school               |
| Frawley & Wilson (2016) | Location: Australia<br><br>Language: English              | Explore views of people with ID of sex education.                                               | Focus groups                                                | 25 <u>individuals with ID</u> (14 male and 11 female), aged 17-20 years (Mean age=18.6 years).<br><br><u>ID</u> : level of ID not reported.                                          | Community transition programme              |
| Gokgoz et al., (2021)   | Location: Turkey<br><br>Language: English                 | Explore experiences of mothers providing sexual education to their children with Down syndrome. | Semi-structured interviews                                  | 7 <u>mothers</u> of children with Down syndrome.<br><br><u>ID</u> : 3 male and 5 female children with Down syndrome aged 16-30 years (Mean age=23.7 years) with mild to moderate ID. | Special education and rehabilitation centre |
| Garwood & McCabe (2000) | Location: Australia<br><br>Language: English              | Evaluate the effectiveness of 2 different sex education                                         | Questionnaires                                              | 6 <u>males with ID</u> : 3 in Co-Care program aged 12-25 years (Mean age=19 years, SD=6.5) and 3 in Family Planning                                                                  | Community service                           |

|                                      |                                                 | programs delivered to people with ID.                                                                                                  |                                              | Victoria program aged 28-32 (Mean age=31.6 years, SD=3.2).<br><u>ID</u> : mild ID.                                                                                                                                   |                                              |
|--------------------------------------|-------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|
| Study reference                      | Study location, language of report              | Aim                                                                                                                                    | Data collection method                       | Sample                                                                                                                                                                                                               | Setting                                      |
| Girgin-Büyükbayraktar et al., (2017) | Location: Turkey<br><br>Language: English       | Explore teachers' opinions of providing sex education for mentally handicapped students.                                               | Semi-structured interviews                   | 25 <u>teachers</u> (18 female and 7 male) aged 25-40 years of students with ID.<br><br><u>ID</u> : age and level of ID not reported.                                                                                 | Special education and rehabilitation centres |
| Goli et al., (2020)                  | Location: Iran<br><br>Language: English         | Explore experiences of girls with ID, parents, teachers, and service providers of the sexual and reproductive health of girls with ID. | Semi-structured interviews and a focus group | 52 participants: 4 <u>girls with ID</u> , 23 <u>parents</u> , 7 <u>teachers</u> , 16 <u>healthcare providers</u> and 2 <u>school managers</u> .<br><br><u>ID</u> : Girls aged 14-18 years, level of ID not reported. | Special schools                              |
| Hanass-Hancock et al., (2018)        | Location: South Africa<br><br>Language: English | Explore experiences of teachers of implementing sex education for learners with ID.                                                    | Interviews (type of interviews not reported) | 8 <u>teachers</u> (age and gender not reported) of students with ID.<br><br><u>ID</u> : age, gender and level of ID not reported.                                                                                    | Special schools                              |
| Karellou (2017)                      | Location: Greece<br><br>Language: English       | Explore attitudes of individuals with ID towards sexuality.                                                                            | Structured interviews                        | 66 <u>people with ID</u> (48 male and 18 female), 78.8% aged 15-25 years and 21.2% aged 26-30 years.<br><br><u>ID</u> : 36 (54.5%) moderate ID, 19 (28.8%) mild and 11 (16.6%) borderline ID.                        | Vocational training facility                 |

| Kostigen (2021)         | Location: USA<br>Language: English                   | Explore policies and teaching practices of sexuality education for students with ASD and ID.                                                  | Participant observations, semi-structured interviews, and document reviews of policies at school | 11 special <u>school staff</u> (2 male and 9 female): 7 behaviour therapists, 3 administrators and 1 clinician (works in special school). Participants' age not reported.<br><br><u>ID</u> : school staff serve 45 students with ASD and ID, 7 girls (15%) and 38 (85%) boys, aged 7-21 years (75% aged 14-21 years). ID level is reported as "low cognitive functioning". | Special school                      |
|-------------------------|------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|
| Study reference         | Study location, language of report                   | Aim                                                                                                                                           | Data collection method                                                                           | Sample                                                                                                                                                                                                                                                                                                                                                                     | Setting                             |
| Kürtüncü & Kurt (2020)  | Location: Turkey<br>Language: English                | Examine the opinions of mothers of sexual education of children with ID.                                                                      | Semi-structured interviews and a questionnaire                                                   | 14 <u>mothers</u> (Mean age= 39.2 years) of children with ID.<br><br><u>ID</u> : children (71.4% males and 28.6% females) aged 10-15 years (Mean age=12.3 years). 42.9% had Down Syndrome, 57.1% had ID, ASD, speech, hearing and physical disabilities.                                                                                                                   | Education and rehabilitation centre |
| Lafferty et al., (2012) | Location: Northern Ireland (UK)<br>Language: English | Examine the attitudes of family carers, direct care staff and trained professionals of the provision of RSE for teenagers and adults with ID. | Focus groups and semi-structured interviews                                                      | Focus groups: 26 <u>carers</u> (fathers, sisters, brothers, and sisters-in-law) and 24 <u>staff members</u> (23 female and 1 male) from day centres and supported accommodation services. Interviews: 22 <u>carers</u> and 24 <u>staff members</u> (15 female and 9 male).<br><br><u>ID</u> : teenagers and young adults with ID, gender and level of ID not reported.     | Community service                   |

|                          |                                           |                                                                                                                    |                                              |                                                                                                                                                                                                                                                                                                                    |                 |
|--------------------------|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------|----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|
| Löfgren-Mårtenson (2012) | Location: Sweden<br>Language: English     | Explore experiences of adolescents with ID receiving of sex education.                                             | Interviews (type of interviews not reported) | 16 <u>students with ID</u> (7 male and 9 female) aged 16-21 years.<br><br><u>ID</u> : level of ID reported as “varying degrees of ID”.                                                                                                                                                                             | Special schools |
| Menon & Sivakami (2019)  | Location: India<br>Language: English      | Explore parents' perceptions and concerns about the sexuality and reproductive health of their child with IDD.     | Semi-structured interviews                   | 14 <u>primary caregivers</u> (9 mothers and 1 guardian) of individuals with IDD.<br><br><u>ID</u> : 4 children had ASD, 2 had ASD and ID, 5 had ID and mutism and 2 had Down Syndrome. 1 child was aged <10 years, 7 aged 10-20 years and 5 aged 21-30 years.                                                      | Special schools |
| <b>Study reference</b>   | <b>Study location, language of report</b> | <b>Aim</b>                                                                                                         | <b>Data collection method</b>                | <b>Sample</b>                                                                                                                                                                                                                                                                                                      | <b>Setting</b>  |
| Nelson et al., (2020)    | Location: Sweden<br>Language: English     | Explore teachers' experiences of teaching Sexual and Reproductive Health and Rights Education to students with ID. | Semi-structured interviews                   | 10 <u>teachers</u> (6 female and 4 male) aged 24-55 years (Mean age=39 years) of students with ID.<br><br><u>ID</u> : students aged 16-20 years with mild-severe ID.                                                                                                                                               | Special schools |
| Peters (2007)            | Location: USA<br>Language: English        | Explore attitudes of teachers towards the teaching of sexuality education to students with mental retardation.     | Survey                                       | 90 special education <u>teachers</u> (73 female and 7 male) of students with mental retardation.<br><br><u>ID</u> : Teachers taught students aged 5-19 years. Students had mild-severe ID and other disabilities: autism, speech and language impairments, visual impairments, and specific learning disabilities. | Special school  |

| Phasha & Runo (2017)   | Location: Kenya (Africa)<br><br>Language: English | Explore sexuality education offered to learners with ID.                                     | Semi-structured interviews and focus groups                                                                        | 56 <u>students with ID</u> (32 male and 24 female) aged 16-22 years and 15 <u>school staff</u> : 5 head teachers and 10 teachers (gender not reported).<br><br><u>ID</u> : mild ID.                                                                                                                                         | Special school     |
|------------------------|---------------------------------------------------|----------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------|
| Pownall et al., (2011) | Location: Scotland (UK)<br><br>Language: English  | Explore mothers' experiences of dealing with the sexuality of offspring with and without ID. | Semi-structured interviews                                                                                         | 8 <u>mothers</u> aged 46-53 years (Mean age=48 years, SD=2.4) of children with ID and without ID.<br><br><u>ID</u> : 4 males and 4 females with ID aged 17-19 years (Mean age=18 years, SD=0.8); 1 had Cerebral palsy, 2 Down syndrome; 1 Visual-perceptual and spatial disability; 3 Global developmental delay and 1 ASD. | Participants' home |
| Pryde & Jahoda (2018)  | Location: Scotland (UK)<br><br>Language: English  | Explore views of mothers on sexuality and sexual development of their sons with ASD and ID.  | Semi-structured interviews                                                                                         | 5 <u>mothers</u> of children with ID and ASD.<br><br><u>ID</u> : 5 males with moderate-severe ID and ASD aged 16-24 years.                                                                                                                                                                                                  | Not specified      |
| Study reference        | Study location, language of report                | Aim                                                                                          | Data collection method                                                                                             | Sample                                                                                                                                                                                                                                                                                                                      | Setting            |
| Todd (2009)            | Location: UK<br><br>Language: English             | Observe the delivery of sex education in a special school.                                   | Observations of a classroom (type of observation is not reported) and interviews (type of interviews not reported) | Observations: <u>a class of children with ID</u> aged 15-16 years in a special school for students with severe ID, physical disabilities, and sensory impairments. Level of ID varied in the class and not all had severe ID.<br><br>Interviews- <u>teachers</u> (no other information provided).                           | Special school     |



|                                  |                                                  |                                                                                                           |                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                          |
|----------------------------------|--------------------------------------------------|-----------------------------------------------------------------------------------------------------------|---------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| Ustilaitė & Petrauskienė, (2018) | Location: Lithuania<br><br>Language: Lithuanian  | Explore parents' experiences and needs when providing sex education to their children with ID.            | Focus group                                 | 8 <u>mothers</u> aged 36-58 years of children with ID.<br><br><u>ID</u> : moderate level of ID, aged 12-21 years (5 male and 3 female).                                                                                                                                                                                                                                                                                                                                                                                     | Community service                                        |
| Wilkenfeld & Ballan (2011)       | Location: USA<br><br>Language: English           | Explore educators' attitudes and beliefs of the sexuality of individuals with developmental disabilities. | Semi-structured interviews                  | 5 <u>teachers</u> (1 male and 4 female) aged 42-57 years (Mean age=50.2 years) from special schools, 5 <u>instructors</u> (1 male and 4 females) aged 30-50 years, Mean age=37 years) from adult day services.<br><br><u>ID</u> : teachers of middle-high school aged students with ID, with ID level ranging from <12 months (i.e. sensory level of function) to IQs <70. All students had multiple physical disabilities in addition to ID e.g. Cerebral Palsy and "various genetic disorders" (which are not specified). | Special schools and adult day services                   |
| <b>Study reference</b>           | <b>Study location, language of report</b>        | <b>Aim</b>                                                                                                | <b>Data collection method</b>               | <b>Sample</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | <b>Setting</b>                                           |
| Williams et al., (2014)          | Location: Scotland (UK)<br><br>Language: English | Identify experiences of people with ID about sexual health services.                                      | Structured interviews                       | 34 <u>people with ID</u> (17 male and 17 female) aged 16-35 years (64% aged 16-17 years).<br><br><u>ID</u> : level of ID not reported.                                                                                                                                                                                                                                                                                                                                                                                      | Special schools, colleges, day, and residential services |
| Williamson (2018)                | Location: USA<br><br>Language: English           | Explore experiences of women with ID about                                                                | Semi-structured interviews and focus groups | 6 <u>women with ID</u> and ASD aged 19-21 years.<br><br><u>ID</u> : mild to moderate ID (IQ=54-70).                                                                                                                                                                                                                                                                                                                                                                                                                         | Special school                                           |

|                                        |                                                  | sexuality and sex education.                                                                           |                                                                        |                                                                                                                                                                                                                                                       |                                                    |
|----------------------------------------|--------------------------------------------------|--------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------|
| Wiseman & Ferrie (2020)                | Location: Scotland (UK)<br><br>Language: English | Explore experiences of women with ID of receiving Relationship Sexual Health and Parenthood Education. | Focus groups and a questionnaire                                       | 21 <u>women with ID</u> completed the questionnaire and 12 <u>women with ID</u> in focus groups, aged 18-25 years (the sample involved older women; however, results for this age group were extracted).<br><br><u>ID</u> : level of ID not reported. | Questionnaire-online; focus groups- not specified. |
| Wright (2011)                          | Location: UK<br><br>Language: English            | Explore whether young people with ID receive sex education.                                            | Semi-structured interviews and focus groups                            | 7 <u>people with ID</u> aged 11-16 years (gender not reported) without physical impairments or ASD, 7 <u>parents</u> , 12 <u>teachers</u> and 2 <u>nurses</u> from a special school.<br><br><u>ID</u> : level of ID not reported.                     | Special school                                     |
| Yektaoglu-Tomgüsehan & Akçamete (2018) | Location: Cyprus<br><br>Language: English        | Examine the opinions of teachers of sex education for students with mental deficiencies.               | Semi-structured interviews                                             | 6 <u>teachers</u> (5 female and 1 male) aged 26-30 years of students with ID.<br><br><u>ID</u> : level of ID and students' age not reported.                                                                                                          | Special school                                     |
| <b>Quantitative data</b>               |                                                  |                                                                                                        |                                                                        |                                                                                                                                                                                                                                                       |                                                    |
| Study reference                        | Study location, language of report               | Aim                                                                                                    | Data collection method                                                 | Sample                                                                                                                                                                                                                                                | Setting                                            |
| Dukes & McGuire (2009)                 | Location: Ireland<br><br>Language: English       | Evaluate a sex education intervention for people with ID.                                              | Design: Single subject multiple baseline<br><br>Method: Questionnaires | 4 <u>adults with ID</u> (2 male and 2 female) aged between 22-23 years.<br><br><u>ID</u> : moderate level of ID (IQ=41-45; Adaptive behaviour composite=37-54). Diagnostic tools used: Vineland                                                       | Community group homes                              |

|                       |                                           |                                                                                                                                                                       |                                                                        |                                                                                                                                                                                                                                                                                                                        |                                  |
|-----------------------|-------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|
|                       |                                           |                                                                                                                                                                       |                                                                        | Adaptive Behaviour Scales and the Stanford-Binet Intelligence Scale.                                                                                                                                                                                                                                                   |                                  |
| Holmes & Himle (2014) | Location: USA<br><br>Language: English    | Understand what topics were the most frequently discussed by parents when providing sex education to children with ASD based on the level of the child's functioning. | Design: Cross-sectional<br><br>Method: Survey                          | 36 <u>parents</u> of children with ID and ASD (that meet the inclusion criteria in terms of child having ID).<br><br><u>ID</u> : children aged 12-18 years (Mean age=15.5 years, SD=1.9) with mild-profound ID and ASD.                                                                                                | Online                           |
| Howard-Barr (2005)    | Location: USA<br><br>Language: English    | Explore teachers' opinions of what are the most and least important RSE topics to provide to students with ID.                                                        | Design: Cross-sectional<br><br>Method: Questionnaires                  | 26 <u>teachers</u> of students with ID. 49% of teachers taught elementary school, 32% middle school and 19% high school.<br><br><u>ID</u> : level of ID not reported.                                                                                                                                                  | Special school                   |
| Luque & Lugo (2015)   | Location: Spain<br><br>Language: Spanish  | Evaluate Emotional-Sexual Education for students with ID.                                                                                                             | Pre-post evaluation<br><br>Method: Questionnaires                      | 8 <u>students with ID</u> (5 male and 3 female) aged 16-22 years from a special school (that meet the inclusion criteria).<br><br><u>ID</u> : level is not reported.                                                                                                                                                   | Special Education Centre         |
| Plaks et al., (2010)  | Location: Israel<br><br>Language: English | Evaluate Social Sexual Group Education Program delivered to adolescents with ID and their parents.                                                                    | Design: Single group pre-post evaluation<br><br>Method: Questionnaires | 10 <u>adolescents with neurogenetic conditions</u> (5 male and 5 female) aged 15-24 years (Mean age=19.5 years, SD=2.6) and 14 <u>parents</u> (age, gender not reported).<br><br><u>ID</u> : level of ID not reported; 5 had Williams Syndrome, 3 Velocardiofacial syndrome, 1 neurofibromatosis, and 1 idiopathic ID. | Behavioural Neurogenetics Centre |

| Tsutsumi (2009)           | Location: Japan<br><br>Language: English                       | Explore teachers' and parents' opinions about sex education for mentally retarded pupils.                                             | Design: Cross-sectional<br><br>Method: Survey                                                        | 235 <u>teachers</u> (149 female and 86 male) and 312 <u>parents</u> (166 female and 43 male) of mentally retarded pupils. <u>ID</u> : level of ID not reported, students were aged 7-16 years.                                                                                                                                                          | Special classes in mainstream schools                        |
|---------------------------|----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|
| Study reference           | Study location, language of report                             | Aim                                                                                                                                   | Data collection method                                                                               | Sample                                                                                                                                                                                                                                                                                                                                                  | Setting                                                      |
| <b>Mixed methods data</b> |                                                                |                                                                                                                                       |                                                                                                      |                                                                                                                                                                                                                                                                                                                                                         |                                                              |
| Bleazard (2010)           | Location: Western Cape (South Africa)<br><br>Language: English | Explore attitudes of women with ID, teachers, and mothers towards the sexuality of women with ID.                                     | Semi-structured interviews, focus group and questionnaire (quantitative questions)                   | 21 <u>women with ID</u> aged 16-25 years with visual, motor, speech, and growth difficulties in the interviews; 10 out of 21 women with ID also took part in a focus group, <u>10 parents</u> in separate interviews and <u>12 teachers</u> completed a questionnaire.<br><br><u>ID</u> : level of ID is not reported.                                  | Special schools                                              |
| Box & Shawe (2014)        | Location: UK<br><br>Language: English                          | Evaluate a sexuality and relationship programme delivered to adults with ID and explore their experiences of attending the programme. | Semi-structured interviews, participant observations, and pre-post evaluation using a questionnaire. | 2 male <u>adults with ID</u> (that meet the inclusion criteria) aged 20-24 years.<br><br><u>ID</u> : mild to moderate ID. 1 participant had mild ID, Asperger's syndrome, and ADHD. The other participant had moderate ID and ASD.                                                                                                                      | Community ID Service                                         |
| Graff et al., (2018)      | Location: USA<br><br>Language: English                         | Evaluate sex education curriculum delivered to students with ID.                                                                      | Questionnaires and open-ended questions                                                              | 53 <u>students</u> with IDD aged 18-27 years (Mean age= 20.7 years). 1 <sup>st</sup> intervention group: 13 students (46.2% males and 53.8% female), Mean age= 20.7 years, SD= 1.4, 76.9% had ID and 23.1% had ASD. 2 <sup>nd</sup> intervention group: 12 students (66% males and 33% females), Mean age= 20.8 years, SD= 1.7, 50% had ID and 50% ASD. | Post-secondary program for students with IDD at a university |

|                         |                                                  |                                                                                                                    |                                                         | 4th intervention group: 16 participants (43% males and 56% females), Mean age= 19.3 years, SD 4.6, 71% had ID and 29% ASD. The control group: 12 students with IDD (33.3% males and 66.6% females), Mean age= 22.1 years, SD= 21.9. 83.3% had ID and 16.7% other disabilities. <u>ID</u> : level of ID not reported.                                                                 |                                            |
|-------------------------|--------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|
| Study reference         | Study location, language of report               | Aim                                                                                                                | Data collection method                                  | Sample                                                                                                                                                                                                                                                                                                                                                                               | Setting                                    |
| Kammes (2019)           | Location: USA<br><br>Language: English           | Examine how parental attitudes and experiences towards sexuality differ for their children with ID and without ID. | Semi-structured interviews and survey (quant questions) | 50 <u>parents</u> (46 mothers, 4 fathers) of children with and without ID in the survey and 20 of <u>parents</u> (1 father and 17 mothers) in the interview.<br><br><u>ID</u> : 50 adult children with ID (30 male and 20 female) aged 18-33 years, Mean age= 23.9 years, SD= 3.7 with other comorbidities e.g. Down syndrome, ASD, WS, physical, mental health and speech problems. | Online survey and phone or video interview |
| Pownall et al., (2012)  | Location: Scotland (UK)<br><br>Language: English | Explore mothers' experiences of providing sex education to children with ID and without ID.                        | Questionnaire with quant and qual questions             | 30 <u>mothers</u> (Mean age=48.8 years, SD=6.5) of young people (15 males and 15 female) with ID (Mean age=18.8 years, SD=1.9).<br><br>ID: children were aged 16-24 years (Mean age=18.8 years, SD=1.9) and had mild ID. 4 children had physical disability (not specified) in addition to ID.                                                                                       | Participants' homes                        |
| Rohleder et al., (2012) | Location: Western Cape (South Africa)            | Explore the extent to which safe sex education is being                                                            | Survey (quant questions), semi-                         | 55 <u>teachers</u> of students with various disabilities                                                                                                                                                                                                                                                                                                                             | Special schools                            |

|                                                    | Language: English                                              | provided to young people with disabilities.                                                                                               | structured interviews, and a focus group                                               | <u>ID</u> : 76.5% of teachers served students with ID, level of ID not reported.                                                                                                                                                                                   |                                                                       |
|----------------------------------------------------|----------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
| <b>Study reference</b>                             | <b>Study location, language of report</b>                      | <b>Aim</b>                                                                                                                                | <b>Data collection method</b>                                                          | <b>Sample</b>                                                                                                                                                                                                                                                      | <b>Setting</b>                                                        |
| Scottish Commission for Learning Disability (2018) | Location: Scotland (UK)<br><br>Language: English               | Gather information about RSHPE provision in secondary schools for students with ID.                                                       | Survey (quant and qual questions)                                                      | 130 <u>school staff</u> members that serve students with ID: 71.8% worked in mainstream school with additional support need unit, 25.2% worked in additional support need school, 1.9% worked in residential schools.<br><br><u>ID</u> : ID level is not reported. | Secondary mainstream schools and special schools for students with ID |
| Sheppard (2006)                                    | Location: Australia<br><br>Language: English                   | Evaluate the effectiveness of "Growing Pains" program for students with ID and to explore parents' and teachers' views about the program. | Pre-post evaluation using a checklist and questionnaires with quant and qual questions | 68 <u>students with ID</u> (48 male and 20 female), 12 <u>teachers</u> and 13 <u>parents</u> .<br><br><u>ID</u> : mild to moderate ID, aged 11-15 years.                                                                                                           | Special school                                                        |
| Stankova & Trajkovski (2021)                       | Location: Republic of North Macedonia<br><br>Language: English | Assess the effects of the use of Social Stories to implement sexuality education with participants with ASD and cognitive difficulties.   | Pre-post evaluation and semi-structured interviews                                     | 1 <u>boy with ID</u> , ASD and speech delay (that meets the inclusion criteria and results reported separately) aged 11 years.<br><br><u>ID</u> : level is reported as "low".                                                                                      | Special school                                                        |

Note: ID=Intellectual Disability, ASD=Autism Spectrum Disorder, IDD=Intellectual and Developmental Disability, RSHPE= Relationships, Sexual Health and Parenting Education, SHE=Sexual Health Education.

#### **4.3.1.3 Participants**

A total of 1767 participants took part across all included studies. Out of which, 38% (678) were teachers and school staff members, 34% (612) were parents and carers, 23% (413) were students with intellectual disability and 3% (64) were staff members from community intellectual disability services. Out of 413 students with intellectual disability, 211 were male and 202 were female, aged 5-25 years (73% were aged 16-25 years), 51% had mild to moderate intellectual disability. Two studies involved students with genetic conditions such as Down syndrome, Williams Syndrome, Velocardiofacial syndrome and neurofibromatosis (Gokgoz et al., 2021; Plaks et al., 2010). Four studies involved students with intellectual disability and co-occurring conditions such as autism, Attention Deficit and Hyperactivity Disorder (ADHD), speech delay and physical disabilities (Bleazard, 2010; Box & Shawe, 2014; Stankova & Trajkovski, 2021; Williamson, 2018).

#### **4.3.1.4 RSE characteristics**

Out of 42 included studies, 12 studies reported some RSE characteristics and content delivered to students with intellectual disability (see Appendix 4.3) (Box & Shawe, 2014; Garwood & McCabe, 2000; Dukes & McGuire, 2009; Plaks et al., 2010; Graff et al., 2018; Sheppard, 2006; Stankova & Trajkovski, 2021; Finlay et al., 2015; Kostigen, 2021; Todd, 2009; Williamson, 2018; Luque & Lugo, 2015). The aim of RSE programme was only specified in four studies (Sheppard 2006; Todd, 2009; Plaks et al., 2010; Graff et al., 2018). Only four studies reported that RSE was delivered using materials developed specifically for people with intellectual disability e.g. using books or programme manuals (Dukes & McGuire, 2009; Sheppard, 2006; Williamson, 2018; Box & Shawe, 2014).

Across the studies, the content mainly focused on protection and risks that involved: private body parts for males and females, puberty, hygiene, sexual activities and its consequences, contraception, different types of relationships, appropriate and inappropriate behaviours, information on abuse and how to keep safe. The length and type of RSE sessions varied between the studies

as well as its frequency and settings where it was delivered. Some studies reported delivering RSE in small groups whilst other studies delivered it on an individual basis over 10 weeks to 6 months period. RSE was delivered in special schools, group homes, students' homes, and community services (such as day centres for people with intellectual disability, youth clubs, health services and a neurogenetics centre) by teachers, parents, youth service workers, community intellectual disability nurses and researchers. None of the studies reported that parents were involved in the content delivery of RSE in schools (e.g. asked to deliver after-school activities to their children at home).

#### **4.3.1.5 Outcomes**

A total of 135 individual outcomes were extracted from the retrieved studies which were grouped by educational stage (e.g. secondary education and further education). Seven studies reported RSE outcomes for students with intellectual disability but did not specify their age (Aderemi, 2014; Girgin-Büyükbayraktar et al., 2017; Hanass-Hancock et al., 2018; Howard-Barr, 2005; Rohleder et al., 2012; Scottish Commission for Learning Disability, 2018; Yektaoglu-Tomgösehan & Akçamete, 2018). These outcomes were not included in the tables presented here but were incorporated in the later stages of this COS development, Chapter 7 (see Appendix 4.5 for these outcomes)

##### *Primary education*

There were no outcomes reported specifically for students with intellectual disability in primary education (aged 5-11 years). However, three studies reported outcomes for students aged 5-25 years and the lower age of participants was in the primary education age range (see Appendix 4.5). (Tsutsumi, 2009; Peters, 2007; Menon & Sivakami, 2019). These outcomes were: understanding of hygiene, human body (e.g. what menstruation and wet dreams are), relationships (e.g. what dating, love and marriage is), human sexuality (heterosexuality, homosexuality, and bisexuality), sex and its consequences (e.g. sexual intercourse and sexually transmitted diseases), appropriate social behaviour and ability to protect yourself from sexual abuse.



## *Secondary education*

Table 4.4 provides 43 individual outcomes extracted from 15 studies for students with intellectual disability in secondary education (aged 12- 16 years). The extracted outcomes were grouped under 11 outcome domains: understanding of human life cycle, human body, hygiene, relationships, keeping safe, appropriate and inappropriate behaviours, human sexuality, sex and its consequences, rights and responsibilities, emotional vocabulary, and positive self-esteem.

The most frequently reported outcomes of RSE for students aged 12-16 years were: understanding of private body parts for females and males, understanding of areas of a body that should not be touched by others and understanding of what pregnancy is, all mentioned in five of the 15 studies. Out of 43 extracted outcomes, 85% (36) of outcomes were knowledge-based (e.g. understanding of what contraception is), 4% (2) of outcomes were skills based (e.g. hygiene skills), 9% (4) of outcomes were behaviour-based (e.g. protective behaviour) and 2% (1) of outcomes were attitudes-based (e.g. positive self-esteem).

Only two studies provided information about how some of the extracted outcomes were measured (Sheppard, 2006; Stankova & Trajkovski, 2021). For example, in Stankova and Trajkovski (2021), students' understanding of body areas that should not be touched by others was assessed before and after RSE delivery. Students were presented illustrations of people touching each other and were asked to indicate if this is appropriate touch or inappropriate touch based on people's facial expressions in the pictures. In Sheppard (2006), outcomes were measured based on teachers' reports of students' behaviour before and after RSE delivery. Teachers were asked to rate the frequency (always, regularly, occasionally, seldom, or never) students demonstrated friendship skills, understanding of what sexual relationships are, ability to identify elements of peer pressure, understanding of rights and responsibilities, understanding of different emotions and feelings, and ability to identify positive self-attributes. However, what teachers were considering

when evaluating these outcomes was not reported (e.g. what rights of self and rights of others actually involve). In the paper, it was also not reported how these evaluations were conducted (e.g. whether teachers asked students to describe positive self-attributes using speech or point to pictures).

Table 4.4 RSE outcomes reported for students in secondary education (12-16 years)

| Outcome domain                    | Outcome                                                                                                                                   | Frequency of reporting and study reference                                                                               | Who reported/<br>measured                             |
|-----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------|
| Understanding of human life cycle | Able to identify the stages of the human life cycle (e.g. birth, baby, child, teenager, adult, elderly, death)                            | 2 studies: Sheppard (2006); Stankova & Trajkovski (2021)                                                                 | Measured by researchers                               |
| Understanding of human body       | Understanding of private body parts for females and males                                                                                 | 5 studies: Kürtüncü & Kurt (2020); Stankova & Trajkovski (2021); Sheppard (2006); Holmes & Himle (2014); Koskinen (2021) | Parents, school staff and measured by researchers     |
|                                   | Understanding of puberty related body changes for males and females                                                                       | 2 studies: Stankova & Trajkovski (2021); Karellou (2017)                                                                 | Students with ID and measured by researchers          |
|                                   | Understanding of what wet dreams are                                                                                                      | 2 studies: Stankova & Trajkovski (2021); Peters (2007)                                                                   | Teachers and measured by researchers                  |
|                                   | Understanding of what erection is                                                                                                         | 1 study: Stankova & Trajkovski (2021)                                                                                    | Measured by researchers                               |
|                                   | Understanding of what menstruation is*                                                                                                    | 1 study: Peters (2007)                                                                                                   | Teachers                                              |
| Understanding of hygiene          | Understanding of what personal hygiene is                                                                                                 | 2 studies: Tsutsumi (2009); Holmes & Himle (2014)                                                                        | Parents, teachers                                     |
|                                   | Hygiene skills (able to: dress self, undress self, wash hands and face, menstrual care, showering, toileting, grooming, e.g. hair, teeth) | 2 studies: Koskinen (2021); Sheppard (2006);                                                                             | School staff and measured by researchers              |
| Understanding of relationships    | Understanding of different type of relationships                                                                                          | 3 studies: Wright (2011); Ustilaitė & Petrauskienė (2018); Stankova & Trajkovski (2021)                                  | Students with ID and parents, measured by researchers |

|                                |                                                                                                   |                                                                                                                                   |                                                             |
|--------------------------------|---------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|
|                                | Appropriate greeting patterns                                                                     | 1 study: Todd (2009)                                                                                                              | Content of RSE                                              |
|                                | Friendship skills                                                                                 | 1 study: Sheppard (2006)                                                                                                          | Measured by researchers                                     |
|                                | Understanding of how to make close friends                                                        | 1 study: Wright (2011)                                                                                                            | Students with ID                                            |
|                                | Understanding of how to socialise with girls/boys                                                 | 1 study: Ustilaitė & Petrauskienė (2018)                                                                                          | Parents                                                     |
|                                | Understanding of what dating is                                                                   | 1 study: Tsutsumi (2009)                                                                                                          | Teachers                                                    |
|                                | Understanding as to why people kiss                                                               | 1 study: Ustilaitė & Petrauskienė (2018)                                                                                          | Parents                                                     |
|                                | Understanding of what love is                                                                     | 2 studies: Peters (2007); Ustilaitė & Petrauskienė (2018)                                                                         | Teachers, parents                                           |
|                                | Understanding of what marriage is                                                                 | 2 studies: Tsutsumi (2009); Peters (2007)                                                                                         | Teachers                                                    |
|                                | Understanding of what parenting is                                                                | 1 study: Peters (2007)                                                                                                            | Teachers                                                    |
|                                | Understanding of what sexual relationships are                                                    | 1 study: Sheppard (2006)                                                                                                          | Measured by researchers                                     |
|                                | Ability to identify elements of peer pressure                                                     | 1 study: Sheppard (2006)                                                                                                          | Measured by researchers                                     |
|                                | Ability to distinguish appropriate and inappropriate behaviour in different type of relationships | 1 study: Stankova & Trajkovski (2021)                                                                                             | Measured by researchers                                     |
|                                | Respecting yourself in romantic relationships (not sleeping with everyone)                        | 1 study: Ustilaitė & Petrauskienė (2018)                                                                                          | Parents                                                     |
| <b>Outcome domain</b>          | <b>Outcome</b>                                                                                    | <b>Frequency of reporting and study reference</b>                                                                                 | <b>Who reported/ measured</b>                               |
| Understanding how to keep safe | Understanding a concept of privacy                                                                | 1 study: Koskinen (2021)                                                                                                          | School staff                                                |
|                                | Understanding of areas of a body that should not be touched by others                             | 5 studies: Kürtüncü & Kurt (2020); Holmes & Himle (2014); Lafferty et al., (2012); Koskinen (2021); Stankova & Trajkovski (2021); | Parents, teachers, school staff and measured by researchers |

|                                                          |                                                                                                                                                                                                                                              |                                                                                                          |                                                  |
|----------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|--------------------------------------------------|
|                                                          | Understanding of what abuse is                                                                                                                                                                                                               | 1 study: Kürtüncü & Kurt (2020)                                                                          | Parents                                          |
|                                                          | Understanding of how to protect yourself from sexual abuse                                                                                                                                                                                   | 2 studies: Peters (2007); Menon & Sivakami (2019)                                                        | Parents, teachers                                |
|                                                          | Protective behaviours (recognises safe/unsafe situations/environments, avoids of unsafe situations such as isolation, dark places, recognises threatening behaviour of others and knows what to do when someone shows threatening behaviour) | 1 study: Sheppard (2006)                                                                                 | Measured by researchers                          |
|                                                          | Ability to request another to stop an aversive activity                                                                                                                                                                                      | 1 study: Koskinen (2021)                                                                                 | School staff                                     |
| <b>Outcome domain</b>                                    | <b>Outcome</b>                                                                                                                                                                                                                               | <b>Frequency of reporting and study reference</b>                                                        | <b>Who reported/<br/>measured</b>                |
| Understanding of appropriate and inappropriate behaviour | Understanding public and private places                                                                                                                                                                                                      | 4 studies: Stankova & Trajkovski (2021); Holmes & Himle (2014); Lafferty et al., (2012); Sheppard (2006) | Parents and teachers and measured by researchers |
|                                                          | Ability to recognise public and private behaviour                                                                                                                                                                                            | 1 stud: Sheppard (2006)                                                                                  | Measured by researchers                          |
|                                                          | Understanding as to why people wear clothes                                                                                                                                                                                                  | 1 study: Stankova & Trajkovski (2021)                                                                    | Measured by researchers                          |
|                                                          | Understanding of appropriate sexual behaviour                                                                                                                                                                                                | 1 study: Karellou (2017)                                                                                 | Students with ID                                 |
|                                                          | Understanding of appropriate social behaviour                                                                                                                                                                                                | 2 studies: Menon & Sivakami (2019); Wilkenfeld & Ballan (2011)                                           | Parents, teachers                                |
| Understanding of human sexuality                         | Understanding of different sexualities (what heterosexuality, homosexuality, and bisexuality is)                                                                                                                                             | 1 study: Peters (2007)                                                                                   | Teachers                                         |
|                                                          | Understanding of what masturbation is*                                                                                                                                                                                                       | 3 studies: Stankova & Trajkovski (2021); Holmes & Himle (2014); Lafferty et al., (2012)                  | Parents, teachers                                |

|                                              |                                                                                                                                             |                                                                                                                  |                                         |
|----------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-----------------------------------------|
| Understanding of sex and its consequences    | Understanding of what pregnancy is                                                                                                          | 5 studies: Tsutsumi (2009); Lafferty et al., (2012); Ustilaite & Petrauskienė (2018); Wilkenfeld & Ballan (2011) | Teachers, parents.                      |
|                                              | Understanding of what contraception is                                                                                                      | 4 studies: Tsutsumi (2009); Karellou (2017); Lafferty et al., (2012); Peters (2007)                              | Teachers, parents, and students with ID |
|                                              | Understanding of what sexual intercourse is*                                                                                                | 4 studies: Tsutsumi (2009); Karellou (2017); Peters (2007); Ustilaite & Petrauskienė (2018)                      | Teachers, parents, students with ID     |
|                                              | Understanding of what STDs are                                                                                                              | 3 studies: Tsutsumi (2009); Lafferty et al., (2012); Wilkenfeld & Ballan (2011)                                  | Teachers, parents                       |
|                                              | Understanding of consequences of sexual activities                                                                                          | 2 studies: Ustilaite & Petrauskienė (2018); Wilkenfeld & Ballan (2011)                                           | Parents, teachers                       |
| <b>Outcome domain</b>                        | <b>Outcome</b>                                                                                                                              | <b>Frequency of reporting and study reference</b>                                                                | <b>Who reported/ measured</b>           |
| Understanding of rights and responsibilities | Understanding of rights and responsibilities (demonstrates understanding of rights of self, demonstrates understanding of rights or others) | 1 study: Sheppard (2006)                                                                                         | Measured by researchers                 |
| Emotional vocabulary                         | Understanding of different feelings and emotions (identifies feelings and emotions)                                                         | 2 studies: Sheppard (2006); Lafferty et al., (2012)                                                              | Teachers and measured by researchers    |
| Positive self-esteem                         | Able to identify positive self-attributes                                                                                                   | 1 study: Sheppard (2006)                                                                                         | Measured by researchers                 |

Note: STDs=Sexually Transmitted Diseases, ID= intellectual disability. Understanding of what menstruation is\*= 1 study contradict that this should be an outcome of RSE (Goli et al., 2020). Understanding of what masturbation is\*= 2 studies contradict that this should be an outcome of RSE (Todd, 2009; Menon & Sivakami, 2019). Understanding of what sexual intercourse is\*= 1 study contradicts that this should be an outcome of RSE (Menon & Sivakami, 2019).

### *Outcomes reported by parents, teachers, and students in secondary education*

There was an overlap between 13 (46%) out of 28 RSE outcomes reported by parents and teachers for students with intellectual disability in secondary education: understanding of personal hygiene, appropriate and inappropriate social and sexual behaviour, consequences of sexual activities, contraception, and protection from sexual abuse. Outcomes reported by only parents and only teachers closely correspond. However, in three retrieved studies (Todd, 2009; Menon & Sivakami, 2019; Goli et al., 2020) parents and teachers did not agree that understanding of menstruation, masturbation, and sexual intercourse should be outcomes of RSE for students with intellectual disability.

Students with intellectual disability in secondary education aged (12-16 years) reported six RSE outcomes: understanding of puberty related body changes for males and females, understanding of relationships (e.g. how to make close friends), and understanding of sexual intercourse (e.g. understanding of appropriate sexual behaviour and contraception).

### *Outcomes for students in further education*

A total of 92 individual outcomes were extracted for students in further education (17-25 years) from 37 studies and grouped under 13 domains: human body, hygiene, menstruation, human sexuality, sex and its consequences, appropriate and inappropriate behaviours, relationships, keeping safe, assertiveness skills, social skills, positive self-esteem, emotional vocabulary, and improvement in attitudes towards sexuality topics (see Table 4.5). The most frequently reported outcomes across the studies were understanding of private body parts and understanding of what contraception is, both reported in 13 studies. Out of 92 outcomes, 78.2% (72) of outcomes were knowledge based (e.g. understanding of what sexual intercourse is), 8.6% (8) of outcomes were skills based (e.g. social skills), 9.7% (9) of outcomes were attitudes based (e.g. positive self-esteem) and 3.5% (3) of outcomes were behaviour based (e.g. engagement in inappropriate sexual behaviour).

Only one study (Graff et al., 2018) reported how some of the extracted outcomes were measured. For example, students' understanding of consent, public and private places, terms such as 'self-esteem' and 'empathy' were assessed by asking students to match a word (e.g. consent) with a correct definition out of several possible definitions on a paper questionnaire developed for the study. Five studies (Garwood & McCabe, 2000; Dukes & McGuire, 2009; Plaks et al., 2010; Box & Shawe, 2014) only mentioned the names of the instruments used to measure the outcomes. For example, in the Dukes and McGuire (2009) study, researchers used the Sexual Consent and Education Assessment (SCEA) (Kennedy 1993), an interview schedule, to measure students' understanding of sexuality topics (e.g. private body parts, ability to identify own gender). Students' engagement in inappropriate sexual behaviour and understanding of safety practices was assessed by asking students' carers to complete the SCEA instrument. However, authors did not report specific questions that carers were asked. In Luque and Lugo's (2015) study, students' understanding of private body parts, how to express affection in different relationships, and ability to listen and respect peers was assessed through students' reports (e.g. whether they think they are able respect their peers), teacher's and parents' reports of student's behaviour. However, what specific behaviours teachers and parents were considering when evaluating these outcomes nor how students' understanding of private body parts was assessed (e.g. not showing private body parts in public or asking students to describe it using speech) were not specified in the paper.



Table 4.5 RSE outcomes reported for students in further education (17- 25 years)

| Outcome Domain                | Outcome                                                                                                                       | Frequency of reporting and study reference                                                                                                                                                                                                                                                          | Who reported/ measured                                                        |
|-------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|
| Understanding of human body   | Understanding of private body parts for males and females                                                                     | 13 studies: Finlay et al., (2015); Gokgoz et al., (2021); Kammes (2019); Pownall et al., (2012); Williamson (2018); Löfgren-Mårtenson (2012); Dukes & McGuire (2009); Graff et al., (2018); Garwood & McCabe (2000); Plaks et al., (2010); Box & Shawe (2014); Kostigen (2021); Luque & Lugo (2015) | Teachers and school staff, parents, students with ID, measured by researchers |
|                               | Understanding of puberty related body changes                                                                                 | 4 studies: Pownall et al., (2012); Box & Shawe (2014); Karellou (2017); Luque & Lugo (2015)                                                                                                                                                                                                         | Parents, students with ID and content of RSE                                  |
|                               | Understanding of what wet dreams are                                                                                          | 3 studies: Frawley & Wilson (2016); Box & Shawe (2014); Peters (2007)                                                                                                                                                                                                                               | Students with ID, teachers                                                    |
|                               | Understanding of what self-examination is for cancer screening (includes checking private body parts for cancer e.g. breasts) | 1 study: Box & Shawe (2014)                                                                                                                                                                                                                                                                         | Content of RSE                                                                |
| Understanding of hygiene      | Understanding of personal hygiene for males and females                                                                       | 4 studies: Nelson et al., (2020); Phasha & Runo (2017); Wiseman & Ferrie (2020); Graff et al., (2018)                                                                                                                                                                                               | Teachers, students with ID                                                    |
|                               | Hygiene skills                                                                                                                | 1 study: Kostigen (2021)                                                                                                                                                                                                                                                                            | School staff                                                                  |
|                               | Understanding of sexual hygiene (e.g. knowing to clean yourself after masturbation)                                           | 1 study; Kammes (2019)                                                                                                                                                                                                                                                                              | Parents                                                                       |
| Understanding of menstruation | Understanding of what menstruation is*                                                                                        | 6 studies: Gokgoz et al., (2021); Graff et al., (2018); Box & Shawe (2014); Wiseman & Ferrie (2020); Garwood & McCabe (2000); Peters (2007)                                                                                                                                                         | Parents, teachers, students with ID, and measured by researchers              |
|                               | Understanding physiology of menstruation                                                                                      | 1 study: Bleazard (2010)                                                                                                                                                                                                                                                                            | Students with ID                                                              |
|                               | Understanding of how to manage menstruation pain                                                                              | 1 study: Wiseman & Ferrie (2020)                                                                                                                                                                                                                                                                    | Students with ID                                                              |

|                                        |                                                                                                             |                                                                                                                                                                  |                                                                 |
|----------------------------------------|-------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|
|                                        | Understanding of how to identify problems with menstruation                                                 | 1 study: Wiseman & Ferrie (2020)                                                                                                                                 | Students with ID                                                |
|                                        | Understanding of how menstruation cycle is linked to pregnancy                                              | 1 study: Wiseman & Ferrie (2020)                                                                                                                                 | Students with ID                                                |
|                                        | Understanding of how long the menstruation last over the life course and what the end of menstruation means | 2 studies: Wiseman & Ferrie (2020); Box & Shawe (2014)                                                                                                           | Students with ID and content of RSE                             |
|                                        | Understanding of how to choose, use menstrual products and the right times to change them                   | 2 studies: Phasha & Runo (2017); Wiseman & Ferrie (2020)                                                                                                         | Teachers, students with ID                                      |
|                                        | Knowing how to identify changes in menstruation and possible issues that warrant medical attention          | 1 study: Wiseman & Ferrie (2020)                                                                                                                                 | Students with ID                                                |
| <b>Outcome domain</b>                  | <b>Outcome</b>                                                                                              | <b>Frequency of reporting and study reference</b>                                                                                                                | <b>Who reported/ measured</b>                                   |
| Understanding of human sexuality       | Able to identify own gender                                                                                 | 1 study: Dukes & McGuire (2009)                                                                                                                                  | Measured by researchers                                         |
|                                        | Understanding of what different sexualities are (homosexuality, bisexuality, and heterosexuality)           | 3 studies: Pownall et al., (2012); Garwood & McCabe (2000); Peters (2007)                                                                                        | Parents, teachers and measured by researchers                   |
| Understanding sex and its consequences | Understanding of what sexual intercourse is*                                                                | 7 studies: Nelson et al., (2020); Bleazard (2010); Garwood & McCabe (2000); Karellou (2017); Peters (2007); Ustilaitė & Petrauskienė (2018); Luque & Lugo (2015) | Teachers, parents, students with ID and measured by researchers |
|                                        | Knowledge of sexual behaviour (includes things you do by yourself and things you do with others)            | 2 studies: Plaks et al., (2010); Box & Shawe (2014)                                                                                                              | Measured by researchers                                         |
|                                        | Understanding of what homosexual sexual experiences are                                                     | 2 studies: Löfgren-Mårtenson (2012); Box & Shawe (2014)                                                                                                          | Students with ID and measured by researchers                    |
|                                        | Understanding of what happens when men and women have an orgasm                                             | 1 study: Garwood & McCabe (2000)                                                                                                                                 | Measured by researchers                                         |
|                                        | Understanding of how to have sex                                                                            | 2 studies: Phasha & Runo (2017); Frawley & Wilson (2016)                                                                                                         | Students with ID                                                |

|  |                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                      |                                                                 |
|--|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|
|  | Understanding of how to enjoy sex                                                                                                                                                                                                                | 1 study: Phasha & Runo (2017)                                                                                                                                                                                                                                                                        | Students with ID                                                |
|  | <b>Outcome</b>                                                                                                                                                                                                                                   | <b>Frequency of reporting and study reference</b>                                                                                                                                                                                                                                                    | <b>Who reported/ measured</b>                                   |
|  | Understanding of what contraception is (including different options of contraception, its side effects, that sometimes contraception does not work e.g. condoms can break, how to use it and how it fits in with family planning for the future) | 13 studies: Phasha & Runo (2017); Kammes (2019); Pownall et al., (2012); Löfgren-Mårtenson (2012); Wiseman & Ferrie (2020); Graff et al., (2018); Frawley & Wilson (2016); Box & Shawe (2014); Garwood & McCabe (2000); Karellou (2017); Lafferty et al., (2012); Peters (2007); Luque & Lugo (2015) | Students with ID, parents, teachers and measured by researchers |
|  | Understanding what STDs are                                                                                                                                                                                                                      | 8 studies: Nelson et al., (2020); Phasha & Runo (2017); Pownall et al., (2012); Löfgren-Mårtenson (2012); Williams et al., (2014); Wiseman & Ferrie (2020); Lafferty et al., (2012); Wilkenfeld & Ballan (2011)                                                                                      | Teachers, parents, students with ID                             |
|  | Understanding consequences of sexual activity                                                                                                                                                                                                    | 4 studies: Williamson (2018); Plaks et al., (2010); Ustilaitė & Petrauskienė (2018); Wilkenfeld & Ballan (2011)                                                                                                                                                                                      | Students with ID, parents and measured by researchers           |
|  | Understanding consequences of having multiple sexual partners or “one-night stand” (e.g. STDs)                                                                                                                                                   | 2 studies: Phasha & Runo (2017); Williamson (2018)                                                                                                                                                                                                                                                   | Teachers, students with ID                                      |
|  | Understanding of what pregnancy is                                                                                                                                                                                                               | 8 studies: Nelson et al., (2020); Phasha & Runo (2017); Löfgren-Mårtenson (2012); Pownall et al., (2011); Garwood & McCabe (2000); Lafferty et al., (2012); Ustilaitė & Petrauskienė (2018); Wilkenfeld & Ballan (2011)                                                                              | Teachers, students with ID, parents and measured by researchers |
|  | Understanding that is hard to be a parent when you are young                                                                                                                                                                                     | 1 study: Löfgren-Mårtenson (2012)                                                                                                                                                                                                                                                                    | Students with ID                                                |
|  | Understanding of how to take care of baby                                                                                                                                                                                                        | 2 studies: Graff et al., (2018); Box & Shawe (2014)                                                                                                                                                                                                                                                  | Students with ID and measured by researchers                    |
|  | Understanding of how child develops                                                                                                                                                                                                              | 1 study: Williamson (2018)                                                                                                                                                                                                                                                                           | Students with ID                                                |
|  | Understanding what abortion is                                                                                                                                                                                                                   | 1 study: Garwood & McCabe (2000)                                                                                                                                                                                                                                                                     | Measured by researchers                                         |

|                                                        |                                                                                                                                                            |                                                                                                                                                                       |                                                        |
|--------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
|                                                        | Understanding what masturbation is*                                                                                                                        | 5 studies: Pownall et al., (2012); Box & Shawe (2014); Garwood & McCabe (2000); Lafferty et al., (2012); Luque & Lugo (2015)                                          | Parents, teachers and measured by researchers          |
|                                                        | Understanding what kiss is and why people kiss                                                                                                             | 2 studies: Box & Shawe (2014); Ustilaite & Petrauskienė (2018)                                                                                                        | Parents and measured by researchers                    |
| <b>Outcome domain</b>                                  | <b>Outcome</b>                                                                                                                                             | <b>Frequency of reporting and study reference</b>                                                                                                                     | <b>Who reported/ measured</b>                          |
| Understanding appropriate and inappropriate behaviours | Understanding of appropriate and inappropriate sexual behaviours                                                                                           | 5 studies: Finlay et al., (2015); Pownall et al., (2011); Pownall et al., (2012); Pryde & Jahoda (2018); Karellou (2017)                                              | Teachers, parents, students with ID                    |
|                                                        | Understanding of appropriate ways to express sexual needs and desires                                                                                      | 1 study: Phasha & Runo (2017)                                                                                                                                         | Teachers                                               |
|                                                        | Understanding the differences between public and private places (e.g. where you can be naked and where you cannot be naked)                                | 4 studies: Pryde & Jahoda (2018); Graff et al., (2018); Box & Shawe (2014); Luque & Lugo (2015)                                                                       | Parents, measured by researchers, and content of RSE   |
|                                                        | Understanding of appropriate and inappropriate places for sexual activity (e.g. appropriate places to masturbate and not appropriate places to masturbate) | 1 study: Pryde & Jahoda (2018)                                                                                                                                        | Parents                                                |
|                                                        | Not engaging in inappropriate sexual behaviour (actual behaviour was measured)                                                                             | 1 study: Dukes & McGuire (2009); Plaks et al., (2010)                                                                                                                 | Measured by researchers and content of RSE             |
|                                                        | Understanding a concept of privacy                                                                                                                         | 1 study: Kostigen (2021)                                                                                                                                              | School staff                                           |
|                                                        | Understanding of appropriate social behaviour                                                                                                              | 2 studies: Menon & Sivakami (2019); Wilkenfeld & Ballan (2011)                                                                                                        | Parents, teachers                                      |
| Understanding of relationships                         | Understanding of different relationships (e.g. friends, family, romantic relationships)                                                                    | 7 studies: Nelson et al., (2020); Phasha & Runo (2017); Löfgren-Mårtenson (2012); Graff et al., (2018); Box & Shawe (2014); Graff et al., (2018); Luque & Lugo (2015) | Teachers, students with ID and measured by researchers |

|  |                                                                                                                          |                                                                                          |                                                        |
|--|--------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|--------------------------------------------------------|
|  | Understanding of a concept of a friend                                                                                   | 2 studies: Plaks et al., (2010); Garwood & McCabe (2000)                                 | Measured by researchers                                |
|  | <b>Outcome</b>                                                                                                           | <b>Frequency of reporting and study reference</b>                                        | <b>Who reported/ measured</b>                          |
|  | Understanding of what marriage is                                                                                        | 4 studies: Williamson (2018); Box & Shawe (2014); Garwood & McCabe (2000); Peters (2007) | Students with ID, teachers and measured by researchers |
|  | Understanding of what is like being with someone in romantic relationship (including what is like living with a partner) | 2 studies: Löfgren-Mårtenson (2012); Nelson et al., (2020)                               | Students with ID, teachers                             |
|  | Knowing how to flirt                                                                                                     | 1 study: Löfgren-Mårtenson (2012)                                                        | Students with ID                                       |
|  | Understanding of how to express affection in different relationships and contexts                                        | 1 study: Luque & Lugo (2015)                                                             | Measured by researchers                                |
|  | Able to identify abusive and healthy relationships                                                                       | 2 studies: Phasha & Runo (2017); Williamson (2018)                                       | Teachers, students with ID                             |
|  | Understanding of what dating is                                                                                          | 2 studies: Pownall et al., (2012); Garwood & McCabe (2000)                               | Parents and measured by researchers                    |
|  | Understanding of what attraction is                                                                                      | 2 studies: Pownall et al., (2012); Box & Shawe (2014)                                    | Parents, measured by researchers                       |
|  | Understanding of what love is                                                                                            | 3 studies: Löfgren-Mårtenson (2012); Peters (2007); Ustilaite & Petrauskienė (2018)      | Students with ID, teachers, parents                    |
|  | Understanding of what sexual relationships are                                                                           | 1 study: Phasha & Runo (2017)                                                            | Teachers                                               |
|  | Understanding how to have a relationship with a girlfriend/boyfriend                                                     | 1 study: Frawley & Wilson (2016)                                                         | Students with ID                                       |
|  | Ability to make choices in relationships                                                                                 | 1 study: Williams et al., (2014)                                                         | Students with ID                                       |
|  | Understanding of what girls/boys want in relationships                                                                   | 1 study: Frawley & Wilson (2016)                                                         | Students with ID                                       |
|  | Understanding of how to keep romantic relationships long-term                                                            | 1 study: Frawley & Wilson (2016)                                                         | Students with ID                                       |

|                                   |                                                                                                                                              |                                                                                                                                                                                      |                                                                 |
|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|
|                                   | Understanding of how to break up in romantic relationships                                                                                   | 1 study: Löfgren-Mårtenson (2012)                                                                                                                                                    | Students with ID                                                |
|                                   | Understanding of what commitment in relationships means                                                                                      | 1 study: Williamson (2018)                                                                                                                                                           | Students with ID                                                |
|                                   | Understanding of boundaries in relationships                                                                                                 | 1 study: Williamson (2018)                                                                                                                                                           | Students with ID                                                |
|                                   | Understanding what consent is                                                                                                                | 2 studies: Graff et al., (2018); Box & Shawe (2014)                                                                                                                                  | Measured by researchers                                         |
|                                   | Understanding of consent in relationships (including how it is related to their current relationships)                                       | 1 study: Williamson (2018)                                                                                                                                                           | Students with ID                                                |
|                                   | Understanding of what peer pressure is                                                                                                       | 1 study: Pownall et al., (2012)                                                                                                                                                      | Parents                                                         |
|                                   | Respecting yourself in romantic relationships (not sleeping with everyone)                                                                   | 1 study: Ustilaitė & Petrauskienė (2018)                                                                                                                                             | Parents                                                         |
| <b>Outcome domain</b>             | <b>Outcome</b>                                                                                                                               | <b>Frequency of reporting and study reference</b>                                                                                                                                    | <b>Who reported/ measured</b>                                   |
| Understanding of how to keep safe | Safety skills (keeping distance with strangers, not accepting gifts, money, or car rides from strangers, reporting when strangers call them) | 8 studies: Finlay et al., (2015); Gokgoz et al., (2021); Kammes (2019); Pownall et al., (2012); Pryde & Jahoda (2018); Dukes & McGuire (2009); Plaks et al., (2010); Karellou (2017) | Teachers, parents, students with ID and measured by researchers |
|                                   | Understanding of appropriate and inappropriate touch                                                                                         | 3 studies: Pryde & Jahoda (2018); Box & Shawe (2014); Luque & Lugo (2015)                                                                                                            | Parents, and content of RSE                                     |
|                                   | Understanding of what people are allowed to see you naked                                                                                    | 2 studies: Graff et al., (2018); Kostigen (2021)                                                                                                                                     | School staff and measured by researchers                        |
|                                   | Understanding of what rape is                                                                                                                | 1 study: Phasha & Runo (2017)                                                                                                                                                        | Students with ID                                                |
|                                   | Understanding what to do in case of abuse                                                                                                    | 2 studies: Phasha & Runo (2017); Luque & Lugo (2015)                                                                                                                                 | Students with ID, content of RSE                                |
|                                   | Understanding of what sexual abuse is                                                                                                        | 3 studies: Bleazard (2010); Pownall et al., (2011); Box & Shawe (2014)                                                                                                               | Parents and content of RSE                                      |

|                       |                                                                                                                                                                  |                                                                                                                         |                                               |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------|
|                       | Understanding of how to protect yourself from sexual abuse                                                                                                       | 1 study: Peters (2007)                                                                                                  | Teachers                                      |
|                       | Understanding of different types of abuse                                                                                                                        | 2 studies: Graff et al., (2018); Box & Shawe (2014)                                                                     | Students with ID and content of RSE           |
|                       | Knowing the risks of being on the internet                                                                                                                       | 1 study: Löfgren-Mårtenson (2012)                                                                                       | Students with ID                              |
| <b>Outcome domain</b> | <b>Outcome</b>                                                                                                                                                   | <b>Frequency of reporting and study reference</b>                                                                       | <b>Who reported/ measured</b>                 |
| Assertiveness skills  | Able to communicate (with behaviour e.g. pushing) or say “no” to people if they (students) do not agree with something or do not want to participate in activity | 5 studies: Box & Shawe (2014); Finlay et al., (2015); Dukes & McGuire (2009); Plaks et al., (2010); Luque & Lugo (2015) | Teachers, students with ID and content of RSE |
| Social skills         | Social skills                                                                                                                                                    | 3 studies: Nelson et al., (2020); Pownall et al., (2012); Plaks et al., (2010)                                          | Teachers, parents, and content of RSE         |
|                       | Listening to and respecting your peers                                                                                                                           | 1 study: Luque & Lugo (2015)                                                                                            | Measured by researchers                       |
|                       | Respecting other peoples’ private space                                                                                                                          | 1 study: Luque & Lugo (2015), Kostigen (2021)                                                                           | School staff, measured by researchers         |
|                       | Understanding of what a term “empathy” means                                                                                                                     | 1 study: Graff et al., (2018)                                                                                           | Measured by researchers                       |
|                       | How to communicate, socialise with opposite sex (e.g. what is appropriate for boys to say to girls and what is not appropriate)                                  | 1 study: Frawley & Wilson (2016); Ustilaitė & Petrauskienė (2018)                                                       | Students with ID, parents                     |
|                       | How to deal with other people (e.g. people you like or do not like)                                                                                              | 1 study: Williamson (2018)                                                                                              | Students with ID                              |
|                       | Respecting people’s differences and different opinions                                                                                                           | 1 study: Williamson (2018)                                                                                              | Students with ID                              |
| Positive self-esteem  | Understanding of what is like being a woman or a man with disability                                                                                             | 1 study: Williamson (2018)                                                                                              | Students with ID                              |

|                                                   |                                                      |                                                       |                                     |
|---------------------------------------------------|------------------------------------------------------|-------------------------------------------------------|-------------------------------------|
|                                                   | Loving and accepting yourself                        | 2 studies: Williamson (2018); Plaks et al., (2010)    | Students with ID and content of RSE |
|                                                   | Being comfortable and confident in yourself          | 2 studies: Williamson (2018); Luque & Lugo (2015)     | Students with ID, content of RSE    |
|                                                   | Understanding of what a term "self-esteem" means     | 1 study: Graff et al., (2018)                         | Measured by researchers             |
| <b>Outcome domain</b>                             | <b>Outcome</b>                                       | <b>Frequency of reporting and study reference</b>     | <b>Who reported/ measured</b>       |
| Emotional vocabulary                              | Ability to recognise and express emotions            | 1 study: Luque & Lugo (2015); Lafferty et al., (2012) | Teachers and content of RSE         |
| Improvement in attitudes towards sexuality topics | Improvement in attitudes towards friendships         | 1 study: Garwood & McCabe (2000)                      | Measured by researchers             |
|                                                   | Improvement in attitudes towards dating and intimacy | 1 study: Garwood & McCabe (2000)                      | Measured by researchers             |
|                                                   | Improvement in attitudes towards sexual interaction  | 1 study: Garwood & McCabe (2000)                      | Measured by researchers             |
|                                                   | Improvement in attitudes towards masturbation        | 1 study: Garwood & McCabe (2000)                      | Measured by researchers             |
|                                                   | Improvement in attitudes towards homosexuality       | 1 study: Garwood & McCabe (2000)                      | Measured by researchers             |

Note: understanding of what menstruation is\*= 1 study contradict that this should be an outcome of RSE (Goli et al., 2020); understanding of what masturbation is\*= 1 study contradict that this should be an outcome of RSE (Menon & Sivakami, 2019); understanding of what sexual intercourse is\*= 1 study contradicts that this should be an outcome of RSE (Menon & Sivakami, 2019).



### *Outcomes reported by parents, teachers, and students in further education*

There was an overlap between 14 (31%) out of 44 RSE outcomes reported by parents and teachers for students with intellectual disability in further education. These outcomes relate to private body parts, understanding of sex and its consequences, relationships, different sexualities, appropriate and inappropriate behaviours, social skills and how to keep safe.

Outcomes reported by only parents and only teachers closely correspond. For example, parents reported an outcome of RSE “understanding of what menstruation is”, whereas teachers reported an outcome of RSE “understanding of how to choose and use menstrual products”. It is likely that when parents discuss what menstruation is with their children, parents also discuss how to choose and use menstrual products, but this information was not specified in the papers. However, in two studies (Menon & Sivakami, 2019; Goli et al., 2020) parents and teachers did not agree that understanding of menstruation, masturbation, and sexual intercourse should be an outcome of RSE for students with intellectual disability.

Students with intellectual disability reported 52 individual RSE outcomes that they perceived as important. The most frequently reported outcomes of RSE by students with intellectual disability were understanding of contraception and STDs, both reported in four studies (Phasha & Runo, 2017; Löfgren-Mårtenson, 2012; Wiseman & Ferrie, 2020; Williams et al., (2014). However, students with intellectual disability reported different outcomes as meaningful compared to parents and teachers. Students reported that they would like to learn how to identify problems with menstruation, how to have sex and enjoy it, how to use contraception (e.g. how to apply condoms), how to take care of a baby, what are homosexual sexual experiences, what is like living with a partner, how to flirt, how to break up in relationships, how to love and accept yourself, and what to do in the case of abuse. On the other hand, outcomes reported by parents and teachers were about how to protect yourself and appropriate and inappropriate behaviours.

#### **4.3.1.6 Characteristics of outcome measurement instruments**

In the retrieved studies, five instruments were used to measure RSE outcomes (see Table 4.6). One of the instruments retrieved was Not a Child Anymore (Fraser, 1987) used in Box and Shawe's (2014) study. In this study, the instrument was administered to people with intellectual disability aged 20–24 years to assess their knowledge of sexual behaviour (e.g. kissing and sexual assault) and knowledge of sexual topics (e.g. masturbation and contraception). The authors reported that this is a self-report questionnaire that contains 111 questions, and no other information about the instrument was provided (e.g. whether it was developed for people with intellectual disability and its measurement properties).

The Sexual Consent and Education Assessment (SCEA) (Kennedy, 1993) is an interview schedule developed to assess individuals' with cognitive impairment (e.g. intellectual disability or traumatic brain injury) capacity to consent to sexual activities and identify areas where individuals need further education. This instrument was administered in Dukes and McGuire's (2009) study before RSE delivery, at the end of each session and at a 6 months' follow-up to students with intellectual disability aged 22–23 years. It contained 35 questions distributed over three scales: Knowledge of Human Sexuality (only the first four items of the scale were used with students in an interview lasting 20–50 min), Safety Practices, and Inappropriate Sexual Behaviour (the former two scales delivered in a separate interview to students' carers). Dukes and McGuire (2009) reported that the instrument 'has high internal stability and inter-rater reliability and satisfactory test–retest reliability' without providing data to support these statements.

The Sexuality Knowledge, Experience, Feelings and Needs Scale for people with Intellectual Disability (Sex Ken-ID) (McCabe, 1994) is an interview schedule developed for people with mild intellectual disability to assess their knowledge, experiences, feelings and needs over 12 sexuality topics: Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy,

Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. The instrument contains 248 questions administered in three separate interviews each lasting 1–1.5 hours. This instrument was administered in two studies (Garwood & McCabe, 2000; Plaks et al., 2010) to students with intellectual disability aged 12–25 years before and after RSE delivery. In Garwood and McCabe (2000) only the Knowledge and Feelings scales were administered. Authors reported that the instrument has ‘moderate to high’ internal consistency within each of 12 sexuality topics. In their paper, authors provided Cronbach’s alpha for selected scales: 0.47 for Knowledge of Dating and Intimacy; 0.79 for the Feelings of Dating and Intimacy scale; 0.79 for Knowledge of Sexual Interaction scale and 0.46 for Feelings of Sexual Interaction scale. The authors reported that the feelings scale was less reliable as it has only 2–3 questions within each of 12 sexuality topics.

The Skills and Independent Activities Questionnaire (Argaman, 2003), a parent-report scale, was used in Plaks et al., (2010) to assess social skills and engagement in independent activities at home before and after RSE delivery for students with intellectual disability aged 15–25 years. The assessment of the understanding of the concept of a friend (Argaman, 2003), a self-report questionnaire, was also administered in Plaks et al., (2010) to students with intellectual disability. No other information about these two instruments was provided in the paper (e.g. whether the instruments were developed for people with intellectual disability and instruments’ measurement properties).

Table 4.6 Characteristics of outcome measurement instruments

| Where located                     | Instrument                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Box &amp; Shawe (2014)</b>     | <p><b>Name:</b> “Not a Child Anymore” (Fraser, 1987).</p> <p><b>Constructs:</b> Knowledge of social behaviour: kissing, sexual assault, marriage and caring for children. Knowledge of sexual topics: masturbation, menstruation, and contraception.</p> <p><b>Target population:</b> not reported.</p> <p><b>Intended contexts of use:</b> not reported.</p> <p><b>Mode of administration:</b> self-report questionnaire administered to people with ID.</p> <p><b>When administered:</b> before and after program (specific timings not reported).</p> <p><b>No. of items and subscales:</b> 111 questions over 16 sections (which are not specified).</p> <p><b>Response options:</b> not reported.</p> <p><b>Original language:</b> not reported.</p> <p><b>Available translations:</b> not reported</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Dukes &amp; McGuire (2009)</b> | <p><b>Name:</b> The Sexual Consent and Education Assessment (SCEA) (Kennedy, 1993)</p> <p><b>Constructs:</b> knowledge of safety practices; knowledge of human sexuality that contained: knowledge of the physical self, knowledge of sexual functioning, knowledge of choices and consequences in sexual activities; inappropriate sexual behaviour.</p> <p><b>Target population:</b> cognitively impaired individuals (ID and traumatic brain damage).</p> <p><b>Intended contexts of use:</b> not reported.</p> <p><b>Mode of administration:</b> interview based. The knowledge of human sexuality scale delivered in 1 interview (of 20-60 min) with the person with cognitive impairment and the knowledge of safety practices and inappropriate behaviour scales delivered in separate interviews (of 15-25 min each) with a caregiver.</p> <p><b>When administered:</b> pre intervention, after each session and at 6 months follow-up.</p> <p><b>No. of items and subscales:</b> 35-item instrument with three scales: Knowledge of Human Sexuality (K-Scale) (only first 4 questions were administered), Safety Practices (S-Scale) and Inappropriate Sexual Behaviour Scale.</p> <p><b>Response options:</b> Questions in the Knowledge and Safety Practices scale are scored as 0 (fail) and 1 (pass). Questions in the Inappropriate Sexual Behaviour scale are scored on 5-point Likert scale (ranging from 1-5) with responses “never, rarely, occasionally, frequently, almost always”.</p> |

|                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-----------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                 | <p><b>Original language:</b> English.</p> <p><b>Available translations:</b> not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <p><b>Garwood &amp; McCabe (2000); Plaks et al., (2010)</b></p> | <p><b>Name:</b> The Sexuality Knowledge, Experience, Feelings and Needs Scale for people with Intellectual Disability (Sex Ken-ID) (McCabe, 1994).</p> <p><b>Constructs:</b> Knowledge of sexual topics: friendship, dating and intimacy, marriage, body part identification, sex education, menstruation, sexual interaction, contraception, pregnancy, abortion and childbirth, STDs, masturbation, and homosexuality. Feelings towards sexuality topics: friendship, dating and intimacy, marriage, body part identification, sex education, menstruation, sexual interaction, contraception, pregnancy, abortion and childbirth, STDs, masturbation, and homosexuality.</p> <p><b>Target population:</b> people with mild ID.</p> <p><b>Intended contexts of use:</b> not reported.</p> <p><b>Mode of administration:</b> interviews with people with ID (3 separate interviews lasting of 1-1.5 hours).</p> <p><b>When administered:</b> before and after program (specific timings not reported).</p> <p><b>No. of items and subscales:</b> 248 item interview schedule classified into Knowledge, Experience, Feelings and Needs areas (only knowledge and feelings scales used in the study).</p> <p><b>Response options:</b> The knowledge questions are open-ended questions, with responses scored as 0, 1 or 2. The feelings questions are the yes-no type (responses scored as 1 to 2) or scored on a 5-point Likert scale (ranging from 1 to 5): "very bad, bad, neutral, good, very good". 2. A total score is obtained for each of the sub-areas (knowledge or feelings) within each subscale (e.g, friendship, STDs).</p> <p><b>Original language:</b> English.</p> <p><b>Available translations:</b> not reported.</p> |
| <p><b>Plaks et al., (2010)</b></p>                              | <p><b>Name:</b> The Skills and Independent Activities Questionnaire (Argaman, 2003).</p> <p><b>Constructs:</b> social skills and engagement in independent activities at home.</p> <p><b>Target population:</b> not reported.</p> <p><b>Intended contexts of use:</b> not reported.</p> <p><b>Mode of administration:</b> parent-report questionnaire.</p> <p><b>When administered:</b> pre-post education.</p> <p><b>No. of items and subscales:</b> 19 items "Social Entertainment" (9 items) and "Independent Activities" (10 items).</p> <p><b>Response options:</b> not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |

|                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                    | <p><b>Original language:</b> not reported.</p> <p><b>Available translations:</b> not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <p><b>Plaks et al., (2010)</b></p> | <p><b>Name:</b> The assessment of the understanding of the concept of a friend (Argaman, 2003).</p> <p><b>Constructs:</b> not reported.</p> <p><b>Target population:</b> not reported.</p> <p><b>Intended contexts of use:</b> not reported.</p> <p><b>Mode of administration:</b> self-report questionnaire administered to people with ID.</p> <p><b>When administered:</b> pre-post education.</p> <p><b>No. of items and subscales:</b> not reported.</p> <p><b>Response options:</b> not reported.</p> <p><b>Original language:</b> not reported.</p> <p><b>Available translations:</b> not reported.</p> |

Note: ID=intellectual disability.

### **4.3.2 Second stage of the review**

A separate systematic search was carried out for the five instruments: the Not a Child Anymore (Fraser, 1987); the SCEA (Kennedy, 1993); the Sex Ken-ID (McCabe, 1994); the Skills and Independent Activities Questionnaire (Argaman, 2003) and the assessment of the understanding of the concept of a friend (Argaman, 2003). For three instruments - the Not a Child Anymore (Fraser, 1987), the SCEA (Kennedy, 1993) and the Sex Ken-ID (McCabe, 1994) - the searches retrieved studies additional to the ones retrieved in the first stage of the review (see Appendix 4.6 for PRISMA flow diagrams).

The search of studies on the SCEA (Kennedy, 1993) retrieved eight individual articles which were screened on title and abstract. Four papers were screened on full text, but they did not meet the inclusion criteria: one did not evaluate measurement properties of the instrument; one was a duplicate and two provided information on the instrument's development, internal consistency, criterion validity and construct validity, but evaluations were carried out involving people with intellectual disability aged above 25 years.

The search on the Sex Ken-ID (McCabe, 1994) retrieved six individual studies which were screened on title and abstract. Three studies were screened on full-text, but they did not meet the inclusion criteria: two did not evaluate the instrument and one provided information on the instrument's development, internal consistency, and test-retest reliability, but evaluations were carried out with people with intellectual disability aged above 25 years.

The search on the Not a Child Anymore (Fraser, 1987) retrieved two individual articles which were screened but one did not evaluate the instrument and one full-text was not available.

## **4.4 Discussion**

This review identified 135 outcomes for students with intellectual disability aged 5-25 years reported as important in the international literature by stakeholders and measured in RSE evaluation studies. The majority of the outcomes (92) related to students with intellectual disability in further education

(aged 17- 25 years) and 43 outcomes were extracted for students in secondary education (aged 12-16 years). In the literature, there were no outcomes reported specifically for students with intellectual disability in primary education (aged 5-11 years).

Outcomes were predominantly knowledge based and focused on improving understanding of the human body, hygiene, relationships, sexual intercourse and its consequences, how to protect from potential abuse, and appropriate and inappropriate behaviours rather than pertaining to skills and attitudes. However, many students with intellectual disability have difficulties understanding abstract and complex sexuality concepts (e.g. consent in relationships) and applying new knowledge in practice (Finlay et al., 2014; Bundock & Hewitt, 2017). This also possibly explains why students with intellectual disability reported that they want to develop skills (e.g. how to apply condoms) to learn how to have romantic relationships and enjoy their sexuality. In contrast, outcomes reported by parents and teachers focused on developing knowledge of appropriate and inappropriate behaviours and how to keep safe. Differences between the views of students and parents and teachers on RSE outcomes indicate the importance of including students with intellectual disability in the development of RSE programmes.

Most of the outcomes were extracted from qualitative data and only eight studies reported outcomes measured following RSE delivery. However, RSE evaluation studies included in the present review were reported in ways that suggest they were not developed systematically. The aim of RSE programmes was rarely specified, none of the studies mentioned theoretical underpinnings of their programmes, and only two studies delivered RSE based on materials developed for people with intellectual disability. Studies also lacked detail on what specific outcomes were measured, why these outcomes were selected, and how the measurement was performed.

These represent some significant limitations as RSE programmes without clearly specified aims and theoretically linked outcomes cannot be robustly evaluated to determine the effects of their implementation (Fernandez et al., 2019). Without a theory of change, an understanding of what “active ingredients” may bring about change is also hindered (O’Cathain et al., 2019).



Conclusions drawn from such studies are of limited value and it is very challenging to replicate the findings in different settings without additional information.

RSE programme aims should be developed based on needs assessment and stakeholders' views (Fernandez et al., 2019; Skivington et al., 2021). However, I found that none of the studies reported including the views of students with intellectual disability in the development of RSE programmes. This is a significant limitation as learner-centred teaching that incorporates students' interests and individual needs is associated with higher students' motivation, achievement, and skills development (Meece et al., 2003; Dano-Hinosolango & Vedula-Dinagsao, 2014; Alfassi, 2004). Thus, these RSE programmes are likely to be less relevant and effective for students with intellectual disability.

RSE content delivered to students with intellectual disability was only briefly mentioned in the papers and focused mainly on protection and managing risks. Compared to the suggested topics of comprehensive sexuality education by the World Health Organisation (WHO, 2010), the content of RSE in the studies did not seem to include topics on sexual identity, sexual pleasure, how to seek help and information on sexuality topics (e.g. how to access sexual health services), how to express needs and wishes within relationships and information on their sexual rights (including the right to marriage and choosing romantic partners). This gap also contrasts with the RSE statutory guidance for English schools (DfE, 2019).

This review identified five instruments that were administered in RSE evaluation studies to measure outcomes. These instruments were self-report questionnaires administered to students with intellectual disability. Two of the subscales of the Sexual Consent and Education Assessment (SCEA) (Kennedy, 1993) - Safety Practices, and Inappropriate Sexual Behaviour - were administered to carers. Constructs that the instruments were measuring included: "knowledge of social behaviour" (such as kissing and caring for children, social skills), "knowledge of sexuality topics" (such as friendships, dating, sexual interaction, masturbation and homosexuality) and "knowledge of safety practices" and "feelings towards sexuality topics" (such as homosexuality). Limited information was provided in the papers regarding what

the constructs measured actually included (e.g. what knowledge of masturbation included) and how it was measured. Some of the constructs (e.g. knowledge of masturbation, kissing, inappropriate sexual behaviour, social skills) that some instruments were measuring are not included as learning targets in RSE statutory guidance for English schools. This discrepancy suggests that the current statutory guidance does not include outcomes considered as important by researchers for students with intellectual disability.

Most importantly, the review also indicates that no instruments have been validated to measure RSE outcomes for students with intellectual disability aged 5-25 years. Searches carried out on measurement properties of the five identified instruments revealed that only two instruments (the Sex Ken-ID and SCEA) had been evaluated at all. However, the evaluations had not been performed involving students with intellectual disability aged 5-25 years. For example, the Sex Ken-ID instrument was administered in two studies (Plaks et al., 2010; Garwood & McCabe, 2000) to students with intellectual disability aged 12-25 years, but the piloting of the instrument was performed with adults with intellectual disability aged above 27 years (McCabe et al., 1999). Further, the measure's reported internal reliability was low (e.g. Cronbach's alpha values for Knowledge of Dating and Intimacy and Feelings of Sexual Interaction scales are below 0.60) (Garwood & McCabe, 2000) and no studies on its content validity were found.

Neither instrument was designed to be used across the intellectual disability spectrum, and their content is likely outdated (both developed in the 1990s). The SCEA instrument was designed for people with cognitive impairments such as people with traumatic brain injury and people with intellectual disability. However, those two populations are not the same and the instrument might fail to capture relevant aspects for people with intellectual disability. The administration of the Sex Ken-ID requires three individual interviews of one to one and a half hours. Thus, administration of this instrument is possibly not feasible with students with intellectual disability and vocal communication difficulties. Therefore, additional studies are needed to evaluate these instruments' validity, reliability, and feasibility with students with intellectual

disability. There is also a need to develop validated instruments to assess the effectiveness of RSE with students with different levels of intellectual disability and vocal communication abilities in school settings.

#### **4.4.1 Strengths and limitations**

To my knowledge, this is the first systematic review on RSE outcomes for students with intellectual disability. This is also the first systematic review with the aim of evaluating RSE outcome measurement instruments' measurement properties. I used a comprehensive search strategy that involved searching nine electronic databases and grey literature and including studies published in any language. Thus, I was able to capture a range of stakeholders' perspectives of meaningful outcomes reported in the literature.

Although the review included studies from several countries, the majority of studies were carried out in Western countries. Therefore, the identified list of outcomes might be less generalisable to non-Western countries.

Outcomes identified this review also do not represent RSE outcomes for all students with intellectual disability. This review identified that there were no RSE outcomes reported specifically for students with intellectual disability in primary education (5-11 years). It is likely that RSE outcomes for younger students would differ from the outcomes extracted for older students with intellectual disability. Further, outcomes reported by students with intellectual disability were extracted from studies that carried out interviews with students who use speech for communication. There were no studies that had included the views of students with more severe intellectual disability and vocal communication difficulties. I was also not able to retrieve full texts of 23 papers (7%) to see if they would meet the inclusion criteria. Thus, there is the possibility that I missed some RSE outcomes.

#### **Conclusions**

In this study, I carried out a systematic review to identify RSE outcomes for students with intellectual disability reported in the international literature to inform development of this COS. 135 RSE outcomes were extracted for

students in secondary and further education that related to the human life cycle, the human body, hygiene, relationships, keeping safe, appropriate and inappropriate behaviours, human sexuality, sex and its consequences, rights and responsibilities, emotional vocabulary, and positive self-esteem. Most of the outcomes were knowledge based rather than pertaining to development of skills and attitudes. Students with intellectual disability perceived different outcomes as important compared to parents and teaches. None of the outcomes were measured using validated instruments for this population. RSE evaluation programmes lacked clear aims, information on theoretical underpinnings and a wide range of RSE topics delivered to students with intellectual disability. In the next chapter, I present a second study in this project that explored the views of adult stakeholders on RSE outcomes and their rationale for outcome importance.

## Chapter 5 - Perspectives of adult stakeholders

*“...you cannot just educate the person with the learning disability you have to educate everybody around them.” (Participant researcher\_07)*

### Introduction

In this chapter, I present the second study. This study explored adult stakeholders' views on RSE outcomes to inform consensus stages of this COS development. The chapter begins by describing the aims of this study and methods employed. I then provide participants' demographic characteristics. Findings on the outcomes perceived as important by stakeholders are presented next followed by the environmental adaptations needed for outcome attainment. The associations between outcomes are discussed as well as frequencies of outcome reporting between and across stakeholder groups. I finish this chapter by providing a discussion of the findings.

### 5.1 Aims

The main aim of this study was to find out what key adult stakeholders i.e. parents, teachers and school staff members, researchers, and policy makers/ people from third sector organisations perceive as important RSE outcomes.

Secondary aims were:

- 1) to understand why the outcomes are perceived as important by stakeholders;
- 2) to explore whether different stakeholder groups (e.g. parents compared to teachers) perceive different outcomes as important;
- 3) to supplement the list of outcomes identified in the first stage of the project (the systematic review) that later in the project were presented in the Delphi survey to reach consensus on the most important outcomes that were included in the COS (Chapter 7).

## **5.2 Methods**

### **5.2.1 Study Design**

This was a qualitative study that involved a mixed stakeholder online workshop, online workshops comprising of a single stakeholder group, and semi-structured online interviews.

### **5.2.2 Development of questions**

Questions used in the workshops and interviews were developed based on the aims of the study and were also informed by the findings of the systematic review (Chapter 4).

In the workshops, adult stakeholders were first asked to share their views on RSE outcomes for students with intellectual disability and their reasons for outcome importance (see Appendix 5.1 for questions). Stakeholders were provided with an explanation what “outcome” means (e.g. what skills, understanding and attitudes students should achieve in RSE). After that, stakeholders were asked to discuss and agree as a group on the most important three outcomes for each educational stage (e.g. primary, secondary, and further). Findings of my systematic review revealed that there were no outcomes reported in the literature specifically for students with intellectual disability in primary education (aged 5-11 years). Thus, in the workshops, stakeholders were asked to share their views of RSE outcomes for students with intellectual disability in primary, secondary, and further education.

The task of selecting of top three outcomes was used to find out which outcomes different stakeholder groups perceived as the most important. Some stakeholders might perceive all outcomes as the most important and having a limit (e.g. asking to select top three outcomes) might have helped stakeholders to prioritise. This number (i.e. top three outcomes rather than top eight outcomes) was selected considering the length of the workshops, the number of stakeholders that took part in the workshops and the subsequent task that

this activity involves (sharing with everyone in the workshop the selection of top three outcomes).

The interview schedule involved the same questions as in the workshops (see Appendix 5.2). The only difference between the questions asked in the interviews and workshops was that the former did not involve the question on selecting the top three outcomes as a group due to the format of the interviews.

### **5.2.3 Piloting**

Questions used in the workshops, interviews, and associated demographic survey were piloted with three teachers from mainstream and special schools who did not take part in the study. One teacher was also a parent of a student with intellectual disability. See Appendix 5.3 for demographic questions. Overall, the feedback on the questions was positive (i.e. that the questions were appropriate, clear, and not misleading). However, there were a few suggestions for the clarity of language. Teachers suggested to change the phrase “teaching RSE” to “RSE delivery” and change the term “intellectual disability” to “learning disability”. Teachers explained that these terms are used in schools and thus, are more familiar to parents and teachers.

### **5.2.4 Format and procedure**

In the workshops and interviews, informed consents were obtained from participants prior to participation. After it, participants were asked to complete an anonymous demographic questionnaire embedded in Qualtrics™ software version 2023 (Qualtrics International Inc.). Participants were informed that they could skip questions in the questionnaire if they wished. Participants did not receive compensation for taking part in workshops and interviews (e.g. shopping vouchers) because I did not have funding allocated for such expenses.

#### **5.2.4.1 Mixed stakeholder workshop**

The mixed stakeholder online workshop was carried using the adapted process of a Priority Setting Partnership (PSP) based on the James Lind Alliance principles (JLA) (JLA, 2021). I also followed the JLA guidebook for designing the mixed stakeholder workshop (JLA, 2021).

The online workshop was carried out in May 2022 based on the majority of participants' preferences for a workshop to take place online. The workshop was conducted using Zoom™ version 5.15.7 (Zoom Video Communications Inc.) and was audio recorded. I chaired the workshop and facilitated discussions with other three facilitators (PhD students). One facilitator oversaw running the workshop online using Zoom software (e.g. allocating people to breakout rooms). The other two facilitators were facilitating discussions in other two small groups. Facilitators were trained before the workshop by me on how to run the workshop and provided tips for troubleshooting (e.g. what to do when a participant is dominating a discussion).

The workshop started with introductions from the facilitators and participants. Then, the aim of the workshop was explained emphasising the importance of confidentiality and respecting everyone's views in the workshop. After it, participants were split into three mixed stakeholder small groups using Zoom's breakout function. In the small breakout groups, participants were asked to share their views on the outcomes and to agree on the top three outcomes as a group. These top three outcomes were written by facilitators on a digital whiteboard for everyone in the small group to see (see Figure 5.1 for a completed whiteboard by one of the small groups). After the small group discussion, a whole group discussion began where each small group shared their top three outcomes and why they were selected. Participants also had a chance to ask questions and to provide comments on what was presented by other participants. The workshop lasted one hour and 30 minutes and finished after presenting the next steps of the project.



Figure 5.1 Top three outcomes selected by participants in a small group

### Top 3 RSE outcomes

#### Group 1

Outcomes for students in primary education (5-11 years):

1. Knowing the body parts for boys and girls, being positive with your body, emotional regulation
2. Understanding of different relationships and what it involves, the consent, the implications towards the sexual abuse
3. Reproduction, life cycles

Outcomes for students in secondary education (12-16 years):

1. Puberty changes
2. Risk prevention and pleasure of sexual behaviours (with yourself and others)
3. Knowing the public and private places and behaviour and the body

Outcomes for students in further education (17-25 years):

1. Relationships: developing and maintaining the relationships (as well for other ages), how to cope with rejection, how to behave in these situations, dealing with loss, what I want in the future, how to deal with things you cannot have, understanding different point views that other people might not like you, help to divert them
2. Online safety
3. Clear understanding of crime, abuse, consent, respect other people, potentially harming other people



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### Challenges experienced

I experienced challenges when running this online mixed stakeholder workshop. First, only three small breakout groups were formed containing mixed stakeholder groups. I initially planned four stakeholder groups that consisted of a single type in each (e.g. parents' group, teachers' group etc). However, I could not recruit equal numbers of stakeholders to form four single type stakeholder groups (see Chapter 3 for more details on recruitment). Only two parents were recruited for this workshop and thus, a parents' group could not be formed. This also meant that I was not able to find out group norms (e.g. what parents perceive as important outcomes compared to teachers) after this workshop. Second, a few participants did not attend the workshop resulting in unequal numbers of people in the small groups. The first group had six participants, the second group had four participants, and the third group had only two participants. Smaller groups with fewer participants had more time for a discussion compared to a larger group consisting of six participants. Third, in one of the small groups, the facilitation of the discussion on RSE outcomes was not carried out effectively. In that small group, a participant researcher

was dominating a discussion by trying to recruit stakeholders (i.e. teachers) to their own research study.

#### **5.2.4.2 Workshops comprising a single stakeholder group**

Based on the challenges experienced recruiting to and carrying out the mixed stakeholder workshop, three additional smaller online workshops were carried out between June - July 2022. These workshops comprised a single stakeholder group in each e.g. one workshop was with parents only and two workshops were with teachers only. Researchers and policy makers preferred to take part in the semi-structured interviews (discussed below). Thus, no smaller workshops with only these two stakeholder groups were conducted.

These smaller workshops followed the same format and procedure as the mixed stakeholder workshop described above (e.g. lasted one hour and 30 minutes, were carried out using Zoom, audio recorded and involved the same tasks). However, the consequences of being smaller (two to three participants) and comprising a single stakeholder group in each (i.e. parents or teachers) made these workshops easier to run and facilitate the discussion. For example, the power imbalances experienced in the large mixed stakeholder workshop were reduced in the smaller workshops. I also did not need another facilitator helping me. Thus, I was able to bring the conversation back onto the topic when needed in a way that was not possible with the large mixed stakeholder workshop where I was not present in two of the small breakout groups.

#### **5.2.4.3 Semi-structured interviews**

Following stakeholder requests (as discussed in Chapter 3), participants could choose to take part in an online semi-structured interview instead of an online workshop. The interviews were carried out between June - September 2022 using Zoom. The interviews were audio recorded in Zoom and lasted between 20 - 45 minutes. One participant completed interview questions via email due to not having time to take part in an online interview. The follow-up questions to clarify this stakeholders' views were answered via email as well. One

interview was carried out online with a teacher who translated the interview questions, and the data collected with a parent participant who did not speak the English language. This teacher was a native speaker of the Chinese language (the language that the parent spoke). The teacher and I met on several occasions before the interview to discuss the aim of the interview, the interview schedule, and the process of carrying out the interview (e.g. no leading questions when clarifying the parent's views).

### *Stakeholders' feedback*

After the workshops and interviews, I sent emails to participants asking them to provide feedback on their participation in the workshops and interviews. Only one feedback was received from a teacher who participated in the mixed stakeholder online workshop saying that she found a participant researcher's behaviour that was dominating the discussion intimidating, but overall, the teacher enjoyed participating in the workshop.

### **5.2.5 Data analysis and inter-rater reliability**

Participants' demographic information was analysed using descriptive statistics using STATA™ version 17 (StataCorp). The qualitative data collected in the online workshops and interviews were transcribed verbatim using a transcription feature in Zoom. I then reviewed transcriptions for clarity and readability by listening to the audio recordings, reading, and editing the automatic transcriptions and removing identifiable information from the transcripts.

The framework approach (Ritchie & Spencer, 1994; Ritchie, 2013) was performed using NVivo 2020 version 1.0 (Lumivero) on the qualitative data. The analysis aimed to find out what RSE outcomes stakeholders perceived as important, their reasons for importance, and to explore the differences on outcome importance between stakeholder groups (e.g. parents, teachers, researchers, and policy makers). This data analysis method enabled me to explore typologies i.e. patterns in the data that are characteristics of particular

groups of participants. This was useful for exploring differences between stakeholders' perspectives on RSE outcomes.

The framework approach involves the following five stages: 1) familiarisation; 2) identifying a thematic framework; 3) indexing the framework against the data; 4) charting; 5) mapping and interpretation (Ritchie & Spencer, 1994; Ritchie, 2013). I now discuss how each of these stages were applied in this study.

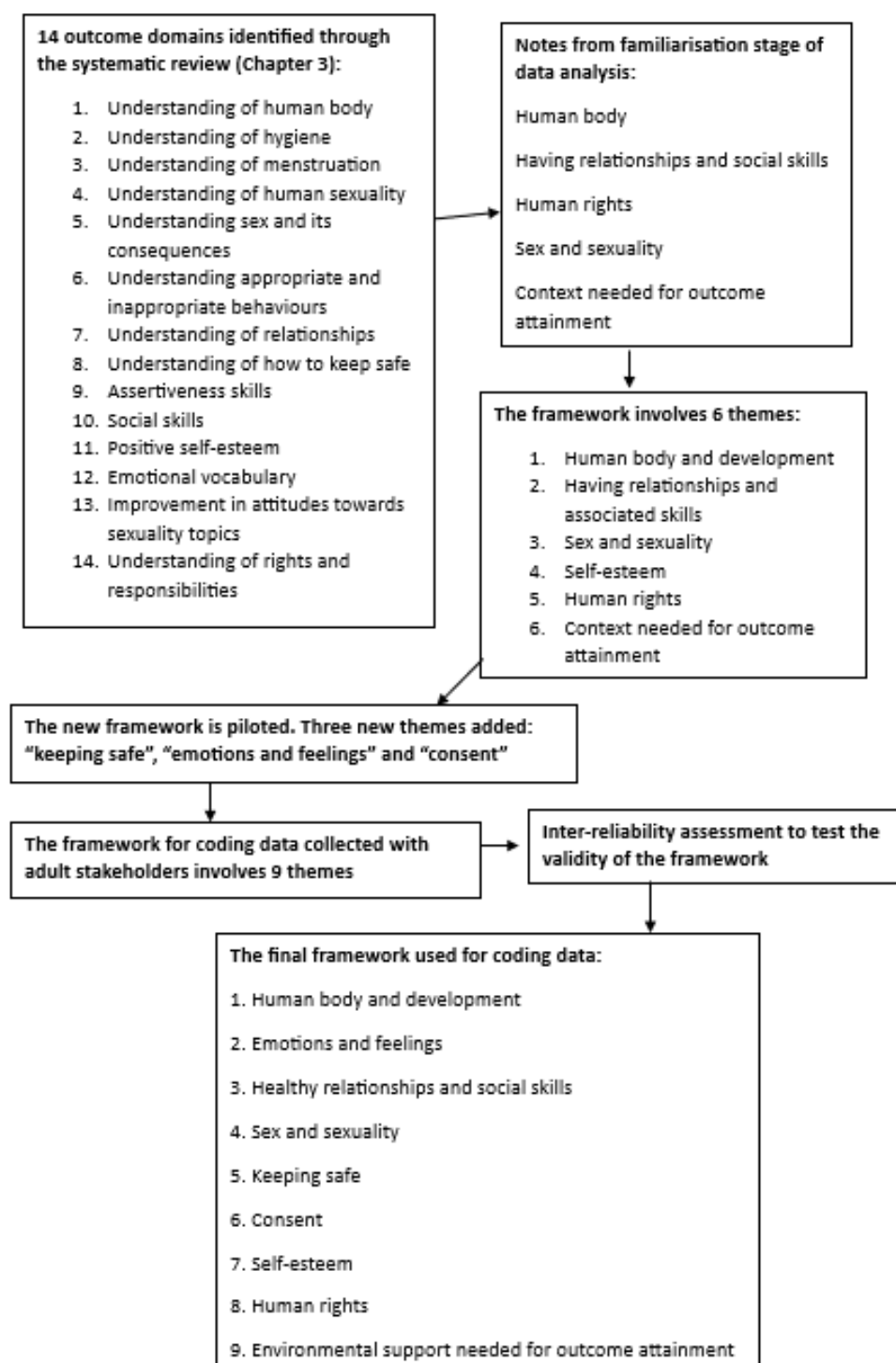
Data collected from the workshops and interviews were analysed together due to the same aims of identifying outcomes that stakeholders perceived as important. An outcome was regarded as knowledge, skills, or attitudes that students with intellectual disability should achieve or develop in RSE or what RSE topics should be taught to them as suggested by stakeholders. The first stage, familiarisation, involved reading and re-reading ten richest data sets (interviews and workshops) selected from each stakeholder group to get the overview of the data. At this stage I was writing notes and ideas for possible codes on RSE outcomes suggested.

After this, an initial thematic framework was developed which was informed by outcome domains extracted from the systematic review and stakeholder suggested outcomes identified in the ten richest data sets (see Figure 5. 2 for the process of developing thematic framework in this study). When developing this initial framework, I merged semantically related outcomes suggested by stakeholders and outcome domains extracted from the review into broader outcome themes.

Then, I piloted this initial framework by applying it to four new data sets across stakeholder groups to see if additional codes were needed in the framework. Three additional themes were added to the framework to capture all outcomes suggested by stakeholders. I performed several amendments (regrouping outcome themes) and pilots to the thematic framework because there seemed to be an overlap between "keeping safe" and "healthy relationships and social skills" themes. Several discussions with the supervisory team were also

carried out on the initial framework that helped to refine it. I carried out amendments on the framework until no overlaps between codes were apparent and no new codes were needed in the framework. Please see Appendix 5.4 for an extract of the final framework.

Figure 5.2 Development of thematic framework



After that, an inter-rater reliability assessment was carried out between two raters (a colleague PhD student and me) who independently coded 20% of the data randomly selected from all four stakeholder groups. Cohen's Kappa statistic was 0.85 indicating a very good agreement between two raters based on parameters suggested by Landis and Koch (1977). After that, I applied the thematic framework to the rest of the data (known as indexing, the third stage).

The fourth stage, charting, involved creation of a "chart" that summarised the data on outcomes and its importance between stakeholder groups. The chart involved a matrix diagram where the rows were themes (components of the framework), and the columns were stakeholder groups. The unit of analysis was the stakeholder group rather than individual participant because not every single participant contributed to the themes specified in the thematic framework and I was not looking for differences between individuals. The charting was performed in NVivo using the "crosstabulations" function that contained one chart per theme per stakeholder group. In each chart, I was able to read each participant's narratives from a specific stakeholder group on a specific outcome theme.

I then read the data coded in each chart for each participant and wrote summaries on stakeholders' views for each group on each outcome and their rationale in a table in a word document. This table allowed me to articulate the typologies indicated in the chart (see Appendix 5.5 for an extract of the table). The frequency of how many stakeholders reported each outcome subtheme (i.e. to how many stakeholders a code was assigned to) between and across stakeholder groups was calculated using NVivo. The frequencies of outcome reporting were calculated to explore which outcome subthemes were most frequently reported between and across stakeholder groups.

The final stages of data analysis (mapping and interpretation) involved exploration of stakeholders' perspectives on RSE outcomes and differences between stakeholder groups. I first reviewed the table created in the charting stage to understand stakeholders' perspectives on RSE outcomes and their rationale for outcome importance. I was also making notes on outcome

associations by reviewing the table and reading participants' narratives. I then mapped stakeholders' perspectives on RSE outcomes on to the thematic map to visually represent the outcomes and associations between them. After this, I reviewed the table again (created at charting stage) and wrote notes on differences between stakeholder groups on outcomes and its importance. I used this table and my notes to report the differences between stakeholder groups on outcomes and rationale for their importance.

### **5.3 Results**

The results are presented as follows: first, I provide participants' demographic characteristics. Second, I present outcomes perceived as important by stakeholders and their reasons for outcome importance. Where there were differences in stakeholders' views regarding the outcomes and their rationale for the importance, this is reported as well. Environmental adaptations needed for outcome attainment suggested by stakeholders are presented next. I then discuss the associations between outcomes and present frequencies of outcome reporting between and across stakeholder groups.

#### **5.3.1 Participants' demographics characteristics**

A total of 53 participants (N=17 parents; N=16 teachers and school staff members; N=12 researchers and N=8 policy makers/people from third sector organisations) took part in the study (please see Tables 5.1 and 5.2 for more details). Twelve participants took part in the mixed stakeholder online workshop, 9 participants took part in the three smaller workshops comprising a single stakeholder group and 32 participants took part in the semi-structured interviews. Most participants (75.5%) were female, aged between 36-44 years (30.8%), from White ethnic background (90.5%), having no religious affiliation (54.9%) and living in England (90.6%).

Most parents had a son with intellectual disability (76.5%), aged a mean of 14.9 years (SD=4.3, range=6-24 years), having a moderate intellectual disability (58.8%), and autism (64.7%) as a co-occurring condition in addition to intellectual disability. Most participants in the teachers' and school staff

members' group, were class teachers (68.8%) working in a special school (81.3%) a mean of 8.1 years (SD=3.5, range=2-17 years) supporting students with intellectual disability and currently delivering RSE (93.8%). Participants in the policy making/third sector group were: policy advisers from educational and third sector organisations that support families of children with intellectual disability; RSE and special education needs and disabilities (SEND) consultants who had been involved in policies for people with intellectual disability in England.

It is important to note, participants were placed in the stakeholder groups (e.g. parents, teachers, researchers, and policy makers/people from third sector) based on how they identified themselves in the demographic questionnaire (i.e. which stakeholder group they told me that they belong to). However, after carrying out workshops and interviews it became apparent that some stakeholders had multiple roles/backgrounds that they drew on to talk about the outcomes. For example, there were some parents who were working with students with intellectual disability in clinical or educational settings. Some researchers were involved in RSE delivery to this population. Some participants from the policy makers/third sector group had also been involved in RSE delivery in the past or advised schools on RSE delivery.



Table 5.1 Participants' demographic characteristics

| Characteristics              | Total sample | Stakeholder group |                                               |                      |                                           |
|------------------------------|--------------|-------------------|-----------------------------------------------|----------------------|-------------------------------------------|
|                              |              | Parents<br>N (%)  | Teachers/<br>school staff<br>members<br>N (%) | Researchers<br>N (%) | Policy<br>makers/third<br>sector<br>N (%) |
| <b>Participated</b>          | <b>N=53</b>  | <b>17 (32.1%)</b> | <b>16 (30.2%)</b>                             | <b>12 (22.6%)</b>    | <b>8 (15.1%)</b>                          |
| Workshops                    | 21 (39.6%)   | 4 (19%)           | 14 (66.7%)                                    | 3 (14.3%)            | -                                         |
| Interviews                   | 32 (60.4%)   | 13 (40.6%)        | 2 (6.3%)                                      | 9 (28.1%)            | 8 (25%)                                   |
| <b>Age</b>                   |              |                   |                                               |                      |                                           |
| Under 25 years               | 1 (1.9%)     | -                 | -                                             | 1 (9.1%)             | -                                         |
| 25-35 years                  | 9 (17.3%)    | 1 (5.88%)         | 8 (50%)                                       | -                    | -                                         |
| 36-45 years                  | 16 (30.8%)   | 4 (23.5%)         | 5 (31.3%)                                     | 3 (27.3%)            | 4 (50%)                                   |
| 46-55 years                  | 15 (28.9%)   | 9 (52.9%)         | 1 (6.2%)                                      | 2 (18.2%)            | 3 (37.5%)                                 |
| 56-65 years                  | 11 (21.1%)   | 3 (17.7%)         | 2 (12.5%)                                     | 5 (45.4%)            | 1 (12.5%)                                 |
| <b>Gender</b>                |              |                   |                                               |                      |                                           |
| Female                       | 40 (75.5%)   | 14 (82.3%)        | 13 (81.2%)                                    | 6 (50%)              | 7 (87.5%)                                 |
| Male                         | 12 (22.6%)   | 2 (11.8%)         | 3 (18.8%)                                     | 6 (50%)              | 1 (12.5%)                                 |
| <b>Country of residence</b>  |              |                   |                                               |                      |                                           |
| England                      | 48 (90.6%)   | 17 (100%)         | 15 (93.8%)                                    | 8 (66.7%)            | 8 (100%)                                  |
| Outside the UK (Europe)      | 3 (5.6%)     | -                 | -                                             | 3 (25%)              | -                                         |
| <b>Ethnicity</b>             |              |                   |                                               |                      |                                           |
| White                        | 48 (90.5%)   | 15 (88.2%)        | 15 (93.8%)                                    | 10 (83.4%)           | 8 (100%)                                  |
| <b>Religious affiliation</b> |              |                   |                                               |                      |                                           |
| No religion                  | 28 (54.9%)   | 6 (35.3%)         | 8 (53.3%)                                     | 11 (91.7%)           | 3 (42.9%)                                 |
| Christianity                 | 17 (33.3%)   | 8 (47.1%)         | 5 (33.3%)                                     | 1 (8.3%)             | 3 (42.9%)                                 |
| Other                        | 6 (11.3%)    | 3 (17.6%)         | 2 (6.7%)                                      | -                    | 1 (14.2%)                                 |

Table 5.2 Additional participants' demographic characteristics

| Characteristics                                    | Total N (%)       |
|----------------------------------------------------|-------------------|
| <b>Parents (N=17)</b>                              |                   |
| Child's age (years)- Mean (SD) (range)             | 14.9 (4.3) (6-24) |
| Child is a boy                                     | 13 (76.5%)        |
| <b>Child's level of ID</b>                         |                   |
| Mild                                               | 2 (11.8%)         |
| Moderate                                           | 10 (58.8%)        |
| Severe                                             | 5 (29.4%)         |
| Child speaks in sentences                          | 14 (87.5%)        |
| <b>Child has additional conditions</b>             |                   |
| Autism                                             | 11 (64.7%)        |
| ADHD                                               | 6 (35.3%)         |
| Speech delay                                       | 7 (41.2%)         |
| Hearing or visual impairment                       | 2 (11.8%)         |
| Sensory difficulties                               | 1 (5.9%)          |
| Mental health problems                             | 2 (11.8%)         |
| Physical health problems                           | 1 (5.9%)          |
| <b>Teachers/school staff members (N=16)</b>        |                   |
| <b>Professional role</b>                           |                   |
| Class Teacher                                      | 11 (68.8%)        |
| RSE Teacher                                        | 3 (18.8%)         |
| Assistant Head Teacher                             | 1 (6.2%)          |
| Occupational Therapist                             | 1 (6.2%)          |
| Works in a special school                          | 13 (81.3%)        |
| Years teaching students with ID- Mean (SD) (range) | 8.1 (3.5) (2-17)  |
| Currently delivers RSE                             | 15 (93.8%)        |
| Years spent delivering RSE- Mean (SD) (range)      | 3.4 (1.7) (1-6)   |
| <b>Policy makers/third sector (N=8)</b>            |                   |

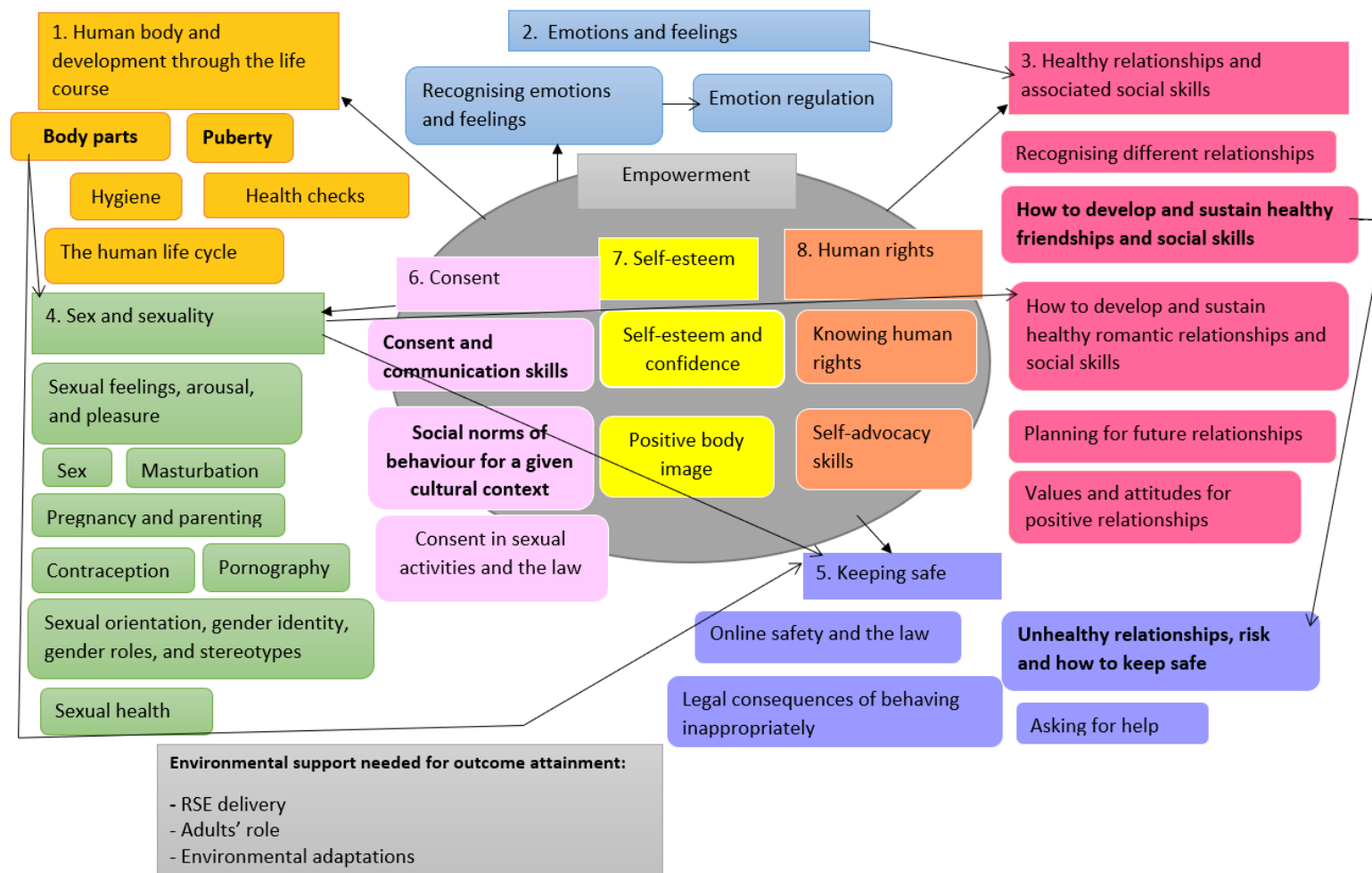
| <b>Professional role</b>                                      |           |
|---------------------------------------------------------------|-----------|
| Senior policy adviser in an education service                 | 1 (12.5%) |
| Policy adviser from third sector/charities for people with ID | 2 (25%)   |
| RSE specialist/consultant                                     | 2 (25%)   |
| SEND specialist/consultant                                    | 2 (25%)   |
| SEND education officer                                        | 1 (12.5%) |

Note: ID= intellectual disability; ADHD= attention deficit hyperactivity disorder;  
RSE=Relationships and Sex Education; SEND= special education needs and disabilities.

### **5.3.2 Outcome themes**

The thematic map (Figure 5.3) represents outcomes perceived as important by stakeholders which related to eight themes: the human body and development through the life course; emotions and feelings; healthy relationships and associated social skills; sex and sexuality; keeping safe; consent and communication skills; self-esteem; and the human rights. Additional participants' quotes are presented in Appendix 5.6.

Figure 5.3 Thematic map of RSE outcomes



Note: Lines are associations between outcome themes (in unrounded rectangles) and subthemes (in rectangles with rounded corners) suggested by adult stakeholders. The most frequently reported outcomes across stakeholder groups (mentioned by  $\geq 50\%$  of participants) are highlighted in bold.

## Theme 1 – Human body and development through the life course

This theme involves outcomes related to the human body and development through the life course grouped into five subthemes:

- *Human body parts*

This subtheme involves the following outcomes: understanding what public and private body parts for each sex are and how to communicate (using speech or a communication aid) about body parts using scientifically correct names (e.g. a penis and a vagina).

Participants' explanations for the importance of these outcomes related to safeguarding reasons. Students with intellectual disability were reported having an increased risk to sexual abuse due to receiving support with their intimate care from adults e.g. when using a toilet. Thus, all students despite their vocal communication skills were reported as needing to achieve these outcomes in RSE, so students can communicate which body parts have been touched or are in pain:

*"They [students] have to have practical knowledge about their own bodies and they have to be given the language [...] my children were assaulted age 6 and 7. [Child's name] was nonverbal and you cannot make a disclosure to the police, if you cannot tell them what happened [...] my children use PECS to pick up new vocabulary but you cannot get PECS for genitals [...]. So, we were left with a nonverbal 7-year-old, who could not make a disclosure to the police [...]. There was a doll "but that is a doll the man did not touch the doll; the man touched me". So, if you do not have those tools in place around empowering language, whether that is spoken language, the correct words, or the correct symbol available, then you cannot put children in a position where they are empowered to say "no". (Parent\_04)*

Teachers discussed that the knowledge of human body parts is a core knowledge needed to understand other RSE outcomes such as hygiene, appropriate and inappropriate touch, sexual pleasure, and abuse.

- *Puberty*

This subtheme involves the following outcomes: understanding the emotional, hormonal, and physical changes for each sex (e.g. periods, erections) and what the changes mean in terms of growing up (e.g. being able to reproduce), how to ask for help when dealing with puberty changes and understanding that puberty changes are normal/natural.

Participants reported that students with intellectual disability need to achieve these outcomes at an early age e.g. in primary school before puberty changes happen. This is because some students start experiencing puberty changes while they are in primary school and changes can be perceived as scary if students do not understand them.

- *Hygiene*

This subtheme involves outcomes related to understanding of how to maintain personal hygiene (e.g. how to wash hands, private body parts, menstruation care). Participants reported students should learn how to look after their own body to be clean and healthy. Parents emphasised that teaching these outcomes should be non-stigmatising and considerate of students' abilities. Students should understand that it is normal to manage hygiene in ways that are different to other people (e.g. needing help when having a shower).

- *Health checks*

This subtheme involves the following outcomes: understanding what health checks are (e.g. cervical screenings, examining testicles), why they are done, what normal private body parts should look and feel like (e.g. testicles, breasts, vaginal discharges), what changes will need to be checked by a doctor (e.g. discharge from a nipple) and what to do if these changes happen (e.g. ask for help). Participants explained that students should have the knowledge related to these outcomes so they could seek help when experiencing bodily changes.

- *Human life cycle*

This subtheme involved outcomes on understanding that people grow and the life cycle e.g. baby, child, teenager, adults, and elderly. Teachers explained that for some young students and those with severe intellectual disability understanding that people grow, and change is a stepping stone to understanding more complex RSE topics.

## **Theme 2 - Emotions and feelings**

This theme contains outcomes on emotions and feelings grouped into two subthemes:

- *Recognising emotions and feelings*

This subtheme involves the following outcomes: understanding what different emotions and feelings are and what they mean (e.g. happy, scared), how to communicate (using speech or a communication aid) about different emotions/feelings, and how to empathise with other people (e.g. identify other people's emotions/feelings and put themselves in their situation).

Participants reported that students with intellectual disability struggle to understand their own and other people's different emotions and feelings due to a lack of social skills. Being able to understand one's own emotions was considered critical to understanding oneself and other RSE outcomes e.g. consent, ability to regulate emotions, being empathetic and developing relationships.

*"They [students] need to understand feelings, they need to understand themselves. And that can be quite a challenge, because they may not have that vocabulary [...] and for them what they are feeling might not match with some of the emotional words we use." (Education officer\_01)*

- *Emotion regulation*

This subtheme involves the following outcomes: being able to manage different emotions/feelings and understanding that it is okay to feel different feelings/emotions but that there are risks if not managing emotions/feelings effectively (e.g. mental health problems or hurting other people).

Participants discussed that students should achieve these outcomes because they underpin students' own mental well-being and ability to sustain healthy relationships. Many students with intellectual disability were reported struggling to regulate and manage their emotions which at times can lead to mental health problems or hurting other people. Some students were reported as being shielded from experiencing negative emotions particularly in relationships (e.g. feeling rejected) and thus, lacking skills to cope with such emotions.

### **Theme 3 - Healthy relationships and social skills**

This theme involves outcomes related to healthy relationships and social skills needed for having such relationships grouped into five subthemes:

- *Recognising different types of relationships*

This subtheme involves the following outcomes: ability to recognise different types of relationships (e.g. friendships, romantic relationships), different family types (e.g. same sex families, single parent families) and what is involved in different relationships (e.g. what is different in a relationship between friends and romantic partners).

Participants explained that students with intellectual disability should learn about different family set-ups and relationships so that students understand that it is okay to be different (e.g. is it okay to have intellectual disability or same sex parents). This understanding was reported as needed for developing tolerant attitudes towards people who might be "different". Teachers' reasons

for achieving these outcomes involved that students learn how to behave appropriately.

- *How to develop and sustain healthy friendships and social skills*

This subtheme involves the following outcomes: understanding the qualities of good friends, boundaries in friendships (e.g. what is appropriate and not appropriate behaviour), and social skills needed to have healthy friendships (e.g. communication skills, negotiation skills, conflict resolution).

Participants explained that students should develop these outcomes so that they are able to develop and sustain friendships. Students with intellectual disability were reported as struggling to develop social skills through experience:

*“They are very concrete learners, people with learning disabilities, because at some level they are working like a toddler, like a young child. So, it is about hands on learning, in a sense [...] you know we absorb so much just by being with other people, those of us who did not have learning difficulties [...] But our children, they are concrete learners they need to be shown how to do it [develop friendships].” (Teacher\_15)*

- *How to develop and sustain healthy romantic relationships and social skills*

This subtheme involves the following outcomes: understanding what healthy romantic and sexual relationships are, boundaries in such relationships, attraction, love, commitment, marriage, and social skills needed to have such relationships (e.g. communication skills, dating skills, and negotiation skills).

Participants explained that students with intellectual disability should achieve these outcomes so they can develop healthy romantic relationships without



being abused or abusing other people. Development of social skills needed for having such relationships was emphasised as important:

*“We need to also address the social skills, how to flirt, how to date, how to kiss, how to start this kind of social behaviour, social etiquette that nondisabled people acquire from friends and social platforms. [...] Persons with intellectual disability do not have the opportunity to acquire these skills.” (Researcher\_02)*

- *Planning for future relationships*

This subtheme involves the following outcomes: being able to identify what students want in their future relationships, what their adult life might look like, and what realistic options in life and alternatives for students would be.

Participants explained that some students with intellectual disability due to having a disability may not be able to have the same things in their personal life (e.g. children or living with a partner) that other people without intellectual disability might have. Therefore, participants suggested that students should learn what unique realistic options are available in their future relationships and possible alternatives to their wishes (e.g. if they cannot have children the alternative option may be working with children).

- *Values and attitudes for having positive relationships*

This subtheme involves the following outcomes: understanding the importance of trust, respect, honesty, and kindness for relationship development, how to be respectful to people who identify differently regarding sexuality and gender identity, that having any type of healthy relationship is important, enjoyable and has benefits and that misogynistic attitudes and language (e.g. that women are not equal to men) negatively impact relationships.

Participants explained that some students with intellectual disability due to feeling a pressure to fit in and being accepted by people without intellectual disability can copy other people's behaviours or misogynistic language. Thus, students should develop these outcomes, so they are respectful and tolerant

towards other people. Understanding that having any relationship is enjoyable and has benefits was also reported as an important outcome for students with intellectual disability to achieve. Researchers explained that some students with intellectual disability might be dissuaded from having relationships due to their carers' fears of the "risks" associated with having relationships e.g. pregnancy.

#### **Theme 4 - Sex and sexuality**

This theme involves outcomes related to sex and sexuality that were grouped into eight subthemes:

- *Sexual feelings, sexual arousal, and pleasure*

This subtheme involves the following outcomes: understanding what sexual feelings, sexual arousal, sexual pleasure, and orgasm are, that they are natural/normal physiological reactions, what is appropriate and inappropriate to feel when sexually aroused for both sexes and in different sexualities (e.g. erection, heat in genitals, producing fluids) and understanding which organs bring sexual pleasure (e.g. clitoris).

Participants reported that these outcomes are important to achieve because the feelings and sensations involved in sexual arousal can be scary to students if they do not understand them. Outcomes on sexual pleasure were discussed as important for prevention of sexual abuse:

*"...talking about arousal is important particularly men with learning disability. If you are not showing people how to tell if their partner is aroused, and you have women who are perhaps not able to say "no", and we are not talking about rolling consent, and knowing what that looks like, you risk people being sexually traumatised quite early and learning some unhelpful sexual behaviours." (Participant from third sector\_02)*

- Sex

This subtheme involves the following outcomes: understanding what sex is, why people engage in sex (e.g. pleasure), which body parts are involved in sex, what activities counts as sex (e.g. anal and oral sex), with whom students can and cannot have sex (e.g. not with teachers) and what is appropriate and inappropriate sexual activity.

Participants' rationale for the importance of these outcomes included safeguarding reasons e.g. being able to report when sexual abuse happens and preventing students from committing a sexual abuse:

*"[Child's name] came to me after he had his year five or six sex education. He knew that he was a sperm producer, and they knew that girls produced eggs and when you get eggs and sperm together, you get babies. Several weeks after the sex education he took me to one side and said: "Mummy, how does the sperm get to the egg?" And it is like right, so you have had sex education, but nobody has explained to you what sex is. And when I explained to him and unfortunately, he has got previous sexual experiences that have come out of time and are wrong. He was then confused because: "I have not got eggs so why did that [sexual abuse] happened?" Because of course we never ever teach that sex might be about other things other than making babies [...] So, he could not understand [...] what the other party has been up to because he realised that: "I do not have eggs. So why was he trying to put sperm inside me?" (Parent\_04)*

Outcomes related to sex were discussed as particularly important for students with intellectual disability to achieve because they are used to adults cleaning them and touching their private areas (e.g. when providing help with their intimate care). Thus, sexual abuse might be unreported if students do not understand what sex is. However, the "sex" topic was discussed as being omitted from RSE delivery to students with intellectual disability due to teachers' fears and attitudes:

*"Children should be able to know what sex is, but in a lot of schools where I have seen sex education delivered to children with learning disabilities very little is talked about sex. There is a real fear from teachers that you might get it wrong. In some schools, I have seen it is almost better not to teach it to its full*

*extent than teach it and get it wrong for children. [...] I also think there are challenges about conceptual views of children with learning disabilities that they are childlike and therefore you do not need to teach them adult content, because they will never be interested in sex.” (Participant from third sector\_01)*

- *Masturbation*

This subtheme involves the following outcomes: understanding what masturbation is for both sexes, where it is appropriate and inappropriate to masturbate, how to masturbate safely (e.g. what are the movements) and that it is natural/normal to masturbate.

Participants reported that these outcomes are important to achieve for students with intellectual disability because some students are masturbating in public places and are also hurting themselves while masturbating. This lack of understanding where it is appropriate to masturbate can put students at risk of being exploited or breaking the law. Some students were also reported as having negative attitudes towards masturbation e.g. that it is inappropriate to do and thus, students should achieve understanding that is normal for both sexes to masturbate.

*“I know this is not particularly in the guidance [RSE guidance] but I think there is a necessity for young people with learning disabilities to learn more about masturbation about how to do it successfully and not in front of others [...]. For some young people, that [masturbation] might be their only form of sexual pleasure. So, it is key to consider that.” (RSE consultant\_01)*

- *Pregnancy and parenting*

This subtheme involves the following outcomes: understanding what pregnancy and parenting is, what are the signs of a female being pregnant (e.g. period stops), that all females including those with intellectual disability can get pregnant, what support and help is available when pregnant or raising a child and understanding the responsibility that comes with having a child.

Participants reported that students with intellectual disability should achieve these outcomes because they lack understanding related to them. Topics related to these outcomes are not being taught to students with intellectual disability due to their parents' fears that students will want to have children. Understanding the responsibilities of having a child was also discussed as particularly important outcome for students with intellectual disability to achieve because many parents with intellectual disability lose custody of their children.

- *Contraception*

This subtheme involves the following outcomes: understanding what contraception for both sexes is (e.g. internal condoms, pills), why people use them, where and how to get contraception (e.g. pharmacy), how to use contraception and that people may choose what contraception they use (e.g. long-term contraception or condoms).

Participants reported that students should achieve these outcomes because they might be engaging in sexual activities and thus, need to understand how to do so safely. Students with intellectual disability were reported as not learning this information from other sources e.g. their parents or friends because they too lack this information. Thus, students with intellectual disability need to receive this information in RSE. Understanding that people can choose what contraception they use was discussed as particularly important outcome for young women with intellectual disability to achieve. Women with intellectual disability have been reported forced to take long-term contraception without their consent due to caregivers' fears that they will get pregnant.

- *Pornography*

This subtheme involves the following outcomes: understanding what pornography is, why people watch it, that pornography is not an accurate representation of what respectful sexual relationships are, that watching

pornography at a young age can impact sexual arousal later in life (e.g. cannot get aroused in the future), that it is a sexual abuse to show pornography to someone below the age of 18 years and to talk with a trusted adult if it happens.

Participants reported that some students with intellectual disability watch pornography to educate themselves about sex. Participants explained that pornography can potentially negatively influence students' attitudes towards sex if they do not understand that pornography involves actors. Thus, participants' rationale for the importance of these outcomes involved safeguarding reasons (e.g. from sexual abuse and committing sexual crimes):

*"I had a safeguarding thing pass my desk that was quite traumatising there was about a young man [with intellectual disability] who had not accessed sex and relationship education. He was getting married and was a virgin but had accessed porn and on his wedding night he without asking for consent, because this is what he thought was normal attempted to choke his bride. She left and went back to her family, and he tried to kill himself because he had absolutely no idea what was normal, or what was acceptable, or how consent works in a real relationship because porn does not talk about consent."  
(Participant from third sector organisation\_02)*

- *Sexual orientation, gender identity, gender roles and stereotypes*

This subtheme involves the following outcomes: understanding what different sexual orientations (e.g. bisexual, homosexual) are, gender identities (e.g. non-binary and transgender), that students' own sexuality and gender identity is normal, what it is like to be a man and a woman (e.g. what masculinity and femininity mean), the negative impact of gender stereotypes (e.g. that boys are stronger than girls) and how sexuality is viewed in different religions or cultural contexts.

Participants reported that achieving these outcomes is important for developing tolerant attitudes towards other people who identify differently and for students accepting their own sexuality and gender identity. Participants across stakeholder groups, except teachers, reported that students with intellectual disability should achieve this outcome at the early years. They

explained that many students with intellectual disability (particularly those who have autism as an additional condition to intellectual disability) are questioning their gender and sexuality. Development of positive attitudes towards one's own sexual and gender identity was also perceived as impacting students' self-esteem and resilience.

- *Sexual health*

This subtheme involves the following outcomes: understanding how to maintain sexual health, what sexually transmitted diseases are, what sexual health clinics are, how they can help (e.g. pregnancy, contraception), and skills on how to request an appointment at a sexual health clinic.

Participants reported that students should develop these outcomes in RSE because they might be engaging in sexual activities and need to learn how to avoid infections, unplanned pregnancies, and keep themselves safe. Some students have been reported having serious sexual health problems or being not aware of the consequences of engaging in unprotected sex. Having school trips to sexual health clinics were suggested as a potential way to learn about these outcomes.

## **Theme 5 - Keeping safe**

This theme involves outcomes related to keeping safe from potentially being abused or committing a crime that were grouped into five subthemes:

- *Online safety and the law*

This subtheme involves the following outcomes: understanding the rules and boundaries of using the Internet and social media (e.g. scams, cyber bullying, sexting, sharing naked images, risks of online dating), how the rules and boundaries of using the Internet are related to the law (e.g. sharing naked images of a person under the age of 18 is illegal) and how to ask for help when feeling pressured online.

Participants' rationale for the importance of these outcomes related to safeguarding reasons such as prevention of being abused and committing crimes. Many students with intellectual disability have been reported being groomed, bullied, and abused online. Some young people with intellectual disability have also been reported using the Internet to find romantic partners and committing crimes due to the lack of understanding related to these outcomes. Some students with intellectual disability were described as lacking impulse control for not engaging in inappropriate activities online when asked.

- *Unhealthy relationships, risk, and how to keep safe*

This subtheme involves the following outcomes: understanding unhealthy relationships, bullying, harassment, power imbalances, grooming, different types of abuse (e.g. sexual, emotional, and physical abuse), coercion, what to do in these situations, that people with intellectual disability are vulnerable to being abused and taken advantage of, and skills how to keep safe (e.g. not keeping secrets).

Participants' rationale for the importance of these outcomes related to students' increased risk for abuse and exploitation. Participants discussed that students with intellectual disability do not understand what unhealthy relationships are and lack social skills to recognise such relationships. Some students have also been reported having fixed views that every person must be kind to them and well intentioned which puts students at risk of being manipulated by others. Some students with intellectual disability also been reported feeling pressure to fit in amongst people without disability which also opens them to being exploited by others.

- *Legal consequences of behaving inappropriately*

This subtheme involves the following outcomes: what illegal behaviours are (e.g. stalking, harassment, touching people's private parts, sex offending, shouting personal insults) and what happens when people break the law and how it impacts people's future negatively.



Participants' rationale for the importance of these outcomes related to prevention of students from hurting other people or committing crimes. Participants explained that students can engage in inappropriate behaviours towards other people e.g. touch a stranger's private body parts without having understanding what criminal behaviours are and what the legal consequences can be e.g. going to prison. Thus, students need to understand that they are accountable for their behaviours and that there are legal consequences of their behaviours.

- *Asking for help*

This subtheme involves the following outcomes: skills on how to ask for help in any situation (e.g. when there is a risk for safeguarding, when pregnant or having issues in relationships), understanding who can help (e.g. teachers, parents, doctors, police), that asking for help is a good thing and if something bad is happening to students they will not be in trouble if they ask for help.

Participants' rationale related to students' difficulties with communication and increase risk to abuse:

*"I think that skills around asking for help, who is a safe person because they [students] are targeted. So, people who are sexual predators are looking at the lowest possible risk of being able to fulfil their sexual needs without getting caught. So, we know that people can choose to work with people with learning disabilities, because they will have access to them. And they [students] are less likely to know the boundaries, and they are less likely to be believed if they say anything." (Participant from third sector organisation\_01)*

## **Theme 6 - Consent**

This theme involves outcomes related to understanding consent in different settings which were grouped into three subthemes:

- *Consent and communication skills*

This subtheme involves the following outcomes: understanding what consent is in different situations (e.g. consensual and non-consensual touch, consent

in relationships), that it is okay to say “no”, that people will show their “no” in different ways (e.g. vocal and non-vocal consent) and students need to respect it, and teaching communication skills related to providing consent and seeking consent (e.g. what to say, understanding people’s responses).

Participants’ rationale for the outcome’s importance related to safeguarding reasons such as prevention from abuse and committing crimes. Participants reported that students with intellectual disability are taught to comply and follow adults’ rules throughout their lives due to having additional needs and needing adults’ help to attain those needs. Because students are taught to comply, they struggle to understand consent and to say “no”. Thus, achieving outcomes related to consent was perceived as important for students to learn how to protect themselves from abuse. Students with intellectual disability were also described as having a lack of social skills needed to provide consent and to recognise when other people are being uncomfortable with students’ behaviour or showing their “no”. This lack of social skills can lead to students harming other people and thus, achieving these outcomes in RSE were discussed as important.

- *Social norms of behaviour for a given cultural context*

This subtheme involves the following outcomes: understanding what acceptable and unacceptable behaviours are and how they vary by cultural context (e.g. it is okay to hug your parents but not strangers), what is appropriate and inappropriate touching (e.g. who can touch students’ private parts and in what situations), personal space and private and public social behaviours (e.g. inappropriate to be naked in outside).

Similarly, as in the previous subtheme, participants’ explanations for the outcome importance related to safeguarding reasons. Participants reported that students with intellectual disability have an increased risk to sexual abuse due to adults providing help with their intimate care. Thus, it is important for students to understand what appropriate and inappropriate touching is so that students can report sexual abuse. Additionally, some students with intellectual

disability have been reported behaving inappropriately e.g. touching strangers' private body parts or being naked in public. Thus, achieving these outcomes (e.g. understanding of unacceptable behaviours) was discussed as important so that students do not make themselves vulnerable by behaving inappropriately and do not commit crimes.

- *Consent in sexual activities and the law*

This subtheme involves the following outcomes: understanding what consent in sexual activities is, why it is important (e.g. sexual abuse), the legal framework for providing consent in sexual activities (e.g. the legal age of consent, that people consent because they are sexually aroused and want to engage in sex without any conditions attached) and how consent in sexual activities may be linked to sexual abuse (e.g. understanding on-going consent).

Participants' explanations for the importance of these outcomes included safeguarding reasons (prevention from sexual abuse and committing sexual offences) and ability to determine if students' have capacity to consent to sexual activities. Participants discussed that many young people with intellectual disability are being sexually exploited, trafficked, and abused because they do not understand consent in sexual activities. This lack of understanding related to consent in sexual activities was also discussed by participants as a reason for some young people with intellectual disability committing sexual crimes. Some stakeholders also discussed that students should receive information on these outcomes so they can provide consent to sexual activities or people working with students could assess if students' have capacity to consent to sexual activities.

*“There have been many incidents where a person with intellectual disability has engaged with persons below the age of consent or non-consensually due to not having been taught about the legal change once they move past the age of 16 or if their partner (who may be of a similar intellectual level) is below the age of consent. The law does not often respect the impact of intellectual disability in reasonable adjustment to sentencing, not*

*that it should, but young people have not been given the same information as their peers, so this is an area that needs addressing.” (Education officer\_01)*

## **Theme 7 - Self-esteem**

This theme involves outcomes related to development of positive self-esteem grouped into two subthemes:

- *Self-esteem and confidence*

This subtheme involves the following outcomes: how to love and accept yourself, be confident in your abilities (e.g. to say “no” or ask for help), understanding that having a disability does not make someone a “bad” person, and that students are worthy and deserve respect from others.

The importance of these outcomes related to students’ lack of confidence and self-esteem. Participants reported that some students with intellectual perceive themselves as “different” due to having a disability and do not value themselves. Development of students’ confidence in RSE was discussed as important because it underpins attainment of other RSE outcomes such as being able to raise concerns, say “no” or disagree with people:

*“...much more about building up their self-esteem. Until a young person sees themselves as worthy, doing this sort of how to say “no” to something is not much of use. If they practiced how to say “no”, they also need to have the confidence to be able to do that. So, it is kind of building that confidence.” (RSE consultant\_01)*

- *Positive body image*

This subtheme involves the following outcomes: understanding what positive body image is, that there is no “normal” body type, and that social media may negatively impact people’s body image and confidence.

Participants explained that these outcomes are important for students to achieve because they impact development of students’ self-esteem and development of tolerant attitudes towards other people.

## Theme 8 - Human rights

This theme involves outcomes related to the human rights grouped into 2 subthemes:

- *Knowing human rights*

This subtheme involves the following outcomes: understanding that all people, including people with intellectual disability, have human rights to privacy, body autonomy, sexual relationships, having children and getting married.

Participants' reasons for the importance of these outcomes related to students having an autonomy over their lives. Participants reported that students with intellectual disability do not understand that they have human rights. Some young people with intellectual disability were reported as having negative internal views regarding their personal life (e.g. that they are not allowed to have a romantic partner) which impact their quality of life. Other people's negative attitudes towards students' sexuality were discussed as reasons for students lacking opportunities to exercise their rights:

*"They have an entitlement to a sex life and to relationships. [...] Sadly, that is something that we need to teach in addition to the standard [RSE] curriculum, because a lot of people presume that because you have a learning disability that you would not be interested in that, or you get this "babyfication" of people with learning disabilities. We find them acceptable, as long as we consider them as children." (SEND consultant\_01)*

- *Self-advocacy skills*

This subtheme involves the following outcomes: having skills how to challenge people or raise concerns when students' rights are being ignored (e.g. rights to privacy, body autonomy, sexual relationships, having children and getting married) and understanding how history, society and cultural attitudes impact these rights for people with intellectual disability (e.g. some people might have negative attitudes towards people with intellectual disability having relationships and enjoying their sexuality).

Participants' reasons for the importance of these outcomes related to students being able to exercise and defend their human rights. Participants explained that people in students' environment e.g. carers might not perceive students having the same human rights and might prevent them from exercising their rights. Thus, achieving self-advocacy skills was discussed as an important outcome for students to have autonomy over their lives.

### **5.3.3 Environmental support needed for outcome attainment**

This theme involves stakeholder suggestions on environmental support needed for students to achieve the outcomes grouped into three subthemes:

#### **RSE delivery**

Participants discussed that for students with intellectual disability to achieve the outcomes, the format of RSE delivery needs to be detailed, consistent throughout their education, skills-based and adapted to student's abilities and needs e.g. using visual materials, social role models, and accessible language to understand complex and abstract topics taught. To ensure consistent RSE delivery, participants suggested to include RSE outcomes in students' Education, Health, and Care plans (EHCPs).

Appropriate resources on the "sex", "gender and sexual identity" topics were also suggested as needed for students to achieve outcomes related to these topics:

*"...finding appropriate resources is just a complete bone of contention for when you are teaching special needs across the board [...]. There is nothing out there that is explicit and simple enough for many children to understand [...]. There are no good materials where you are teaching these children, what is sex? [...] How does the sperm get to the egg is a minefield and trying to teach that in a safe and appropriate way with the right resources it is really challenging." (Teacher\_04)*

Participants' views towards the timing of RSE delivery to this population diverged. Some participants discussed that because students' chronological

age will be different to their developmental age some students might not have cognitive skills or emotional maturity to understand some of RSE topics taught. Therefore, the timing of RSE delivery and what outcomes students with intellectual disability should achieve will depend on their individual abilities.

In contrast, other participants emphasised that tailoring the content and timing of RSE delivery based on students' abilities have risks of not delivering that content at all. Participants discussed that all students regardless of the level of intellectual disability should achieve the same outcomes. Participants emphasised that students' intellectual disability describes their cognitive abilities (e.g. their academic abilities) but not their sexual maturity and needs. The format of RSE delivery was suggested as needing to be tailored (e.g. using images or communication tools) to students' needs. A "ladder" approach was suggested for teaching complex topics to students with severe intellectual disability:

*"...create a ladder in the subject so that you can work out which step your learner is on that ladder. It might be that they are on the very bottom rung and maybe getting from there to the next rung is extremely lengthy process [...] but at least we know we are on that ladder [...]. Take something like pornography [...], teaching about pornography would be extremely difficult because it would involve things like teaching firstly about sex for pleasure, why somebody might want to watch pornography [...], the fact that the people are actors. [...] But where I can start is an understanding about whether it is okay or not to take pictures of people with no clothes [...]. Whilst that is not really a pornography lesson obviously it is a step one on a journey [...]. So, that is how I would encourage teachers to work with that bit in the guidance [RSE guidance in England] about tailoring the contents and not chopping up a whole topic out." (RSE consultant\_02)*

Participants highlighted the need to start RSE in the early years e.g. primary schools because it takes time for students with intellectual disability to understand the concepts taught and acquire skills:

*"I have found in my practice teaching people with complex intellectual disabilities because learning takes a lot longer [...] you need to teach from the start, what you want to be known at the end. So, for example, I worked with a young lady who had Down syndrome and from when she was six years old, we*

*taught her that she was not supposed to sit on the laps of people, she did not now [...]. We understood that, if we taught her at six that that was acceptable behaviour, she would still think that that was acceptable behaviour at 18.” (SEND consultant\_01)*

## **Adults’ role**

Participants reported that adults in students’ environment (e.g. parents, teachers, and support staff members) impact students’ learning. Participants reported that all adults in the students’ environment need to achieve specific outcomes first so that students can achieve the outcomes. I now present these adult-centred outcomes in turn.

First, adults should actively seek students’ consent (e.g. when assisting with personal care) and respect students’ consent withdrawal for students to develop knowledge related to consent. Participants explained that learning how to provide or seek for consent is impacted by people in students’ environment:

*“When we talk about the outcomes being for students with intellectual disabilities, we are placing in some regards those outcomes within those students. [...] What I want as outcomes for those children is more outcomes regarding the people around them. I would want them to be existing in places where those outcomes were happening around them, both within the home and at school. And so that is things like seeking their consent to change them, stopping when they say “stop”.” (SEND consultant\_02)*

Second, adults should be following consistent boundaries with students with intellectual disability. Some adults (e.g. parents, support staff members) were reported as setting different boundaries with students with intellectual disability than they do with students without intellectual disability. For example, allowing students with intellectual disability to masturbate in public places by thinking that these behaviours are part of their disability. Therefore, students with intellectual disability were reported as struggling to learn social norms of behaviour and are behaving inappropriately.



Third, adults should create opportunities for students to consolidate the knowledge learned. Participants reported that is not enough to teach students with intellectual disability skills on how to develop relationships in RSE lessons. For students to achieve the outcomes on relationships, adults should create opportunities for students to experience relationships (e.g. build classes in schools around friendships) and practise the skills learned.

Fourth, all adults who support students with intellectual disability should receive RSE themselves to provide consistent information to students. Adults should also receive RSE from the perspective of what RSE topics and outcomes mean to students (e.g. what it means to students if they have skills to develop relationships). Educating adults in students' environment was discussed as important for the development of positive attitudes towards the sexuality of students with intellectual disability:

*“...you cannot just educate the person with the learning disability; you have to educate everybody around them. And that can help because it changes attitudes [...] So, the outcome should be that everybody has a really positive attitude towards people with learning disability developing relationships [...]. I think we make the mistake often when we are looking at this issue is that we only think it is about educating the person with learning disability, but it should be about educating everybody around that individual. And not just educating them from the perspective of here is a book about sexual relationships [...] but this is what that means when we apply it to this person.” (Participant researcher\_07)*

Fifth, parents of students with intellectual disability should be supported to understand the importance of RSE delivery to their children and empowered to discuss RSE topics at home. Participants reported that informing parents what their children will learn in RSE and having them on board with RSE delivery can be helpful for students to attain the outcomes (e.g. by having consisted messages taught in both settings) and to consolidate the knowledge learned (e.g. by helping students to apply the knowledge in different settings). Some parents reported lacking confidence to discuss RSE topics with their children at home and needing support for having such discussions. Teachers discussed that parents can be a barrier of RSE delivery to students with

intellectual disability. Some parents were reported as perceiving their children younger than they are or believing that children will not experience puberty due to their disability. Thus, parents can object a certain topic delivery to their children:

*“We have a strong barrier for us, parents, because we are a very diverse population in [the location of a school]. When informing the parents about what exactly their children are going to be taught, we have to word it in specific way and focus more [..] about being healthy rather than talking about sex. And sex seems to be like a forbidden area.” (Teacher\_05)*

### **Physical environment adaptations**

The physical environment in schools and residential places was reported as needing to align with RSE content so that students could achieve RSE outcomes. Participants reported that some special schools do not have doors in the toilets which makes it difficult for students to understand concepts related to private and public behaviours. The physical environment was also discussed as contributing to students' engagement in inappropriate behaviours. In some residential schools, students with intellectual disability have been reported masturbating and having sex in public toilets because they are not provided privacy in their bedrooms (e.g. people walking in and out of students' bedrooms). Thus, participants discussed that the physical environment should align to RSE outcomes and adults in students' environment should respect students' rights to privacy and provide opportunities for privacy (e.g. knock on the door and wait before going into students' bedrooms).

#### **5.3.4 Associations between themes and subthemes**

Participants perceived RSE outcomes as inter-related or underpinning the attainment of other outcomes. I presented these associations between outcome themes and subthemes as lines in the thematic map (please see Figure 3 above). A super theme called “Empowerment” was created that contains outcome themes on consent, self-esteem, and the human rights. Participants viewed these three outcome themes as related to or impacting the

attainment of all other outcome themes. For example, understanding private body parts (an outcome in theme 1) was discussed as needed to understand consensual and nonconsensual touch and appropriate and inappropriate touching (outcomes in theme 6). Outcomes on understanding emotions and feelings (theme 2) were linked to understanding consent e.g. when to say “yes” or “no” according to how one is feeling. Understanding consent was also discussed as being a critical outcome for being able to develop healthy relationships (theme 3) and keeping safe (theme 5):

*“...understanding of how to have a relationship. Some of the very fundamental boundaries around consent and asking: “would it be okay, if I hold your hand?” as opposed to grabbing someone’s hand.” (Participant researcher\_04)*

Outcomes under “self-esteem and confidence” (theme 7) were discussed as needed for: facing puberty changes (theme 1); developing and sustaining healthy relationships (theme 3); accepting one’s sexuality, seeking medical help when experiencing sexual health problems (theme 4); asking for help in any situation in particular when there is a risk for safeguarding (theme 5); saying “no” (theme 6); and developing self-advocacy skills (theme 8):

Outcomes under “human rights” (theme 8) were discussed as underpinning attainment of outcomes related to developing romantic relationships (theme 3). Participants discussed that students need to understand that they have a right to develop romantic relationships and, in some cases, defend these rights to have such relationships. Outcomes on human rights (e.g. understanding that they have rights to have sex) were discussed as impacting attainment of outcomes on experiencing sexual pleasure, having children, and choosing what contraception they use (theme 4). Understanding body autonomy was also discussed as needed to understand appropriate and inappropriate touching (theme 6):

*“They should learn about bodily autonomy and boundaries that they have a say over what happens to their bodies.” (Parent\_09)*

Some outcomes not included in the “empowerment” super theme were also discussed by participants as underpinning attainment of other outcomes. For

example, understanding private body parts (theme 1) was discussed as needed to understand sexual abuse (theme 5) and sexual pleasure (theme 4). Outcomes on emotions and feelings (theme 2) were discussed as needed for being able to develop and sustain relationships (theme 3) and understanding illegal behaviours (theme 5). Understanding sexual arousal and pleasure (theme 3) was discussed as needed for developing healthy romantic relationships (theme 3) and understanding sexual abuse (theme 5). Understanding what healthy relationships is (theme 3) was discussed as needed to understand unhealthy relationships (theme 5). Understanding where is appropriate to masturbate was reported as underpinning students' understanding on how to keep safe (theme 5). Outcomes on pornography were also discussed impacting students' understanding on how to develop healthy relationships (theme 6).

### **5.3.5 Similarities and differences between stakeholder groups**

Differences between stakeholder groups regarding the rationale for outcome importance has been presented above (in the 5.3.2 section). In this paragraph, I present which outcomes were reported by stakeholder groups the most frequently.

Across stakeholder groups, the most frequently reported outcome subthemes were (mentioned above 50% of participants from each stakeholder group): human body parts; puberty; how to develop and sustain friendships; unhealthy relationships, risk and how to keep safe; consent and communication skills; social norms of behaviour for a given cultural context.

There were differences between stakeholder groups regarding which outcome subthemes they reported most frequently (see Table 5.3). Parents reported the following outcome subthemes most frequently (presented in order of frequency): sex (reported by 76.5% of parents from the perspective of keeping safe from sexual abuse or committing crimes as well as needing to know because some students may be sexually active); unhealthy relationships, risk and how to keep safe (64.7%); consent and communication skills (64.7%);

social norms of behaviour for given cultural context (58.8%); and how to develop romantic relationships and social skills (58.8%).

Teachers' views differed from the other stakeholder groups. The most frequently reported outcomes by teachers were: human body parts (68.8%); social norms of behaviour for a given cultural context (68.8%); and unhealthy relationships, risk, and how to keep safe (62.5%) (also one of the most frequently discussed outcomes by parents). However, teachers did not report any outcomes in the following subthemes: health checks, planning for future relationships, pornography, the human rights, and self-advocacy skills.

Only a few of teachers (2 or fewer) reported outcomes in the following subthemes: the human life cycle; values and attitudes for positive relationships; sexual feelings, sexual arousal, and pleasure; sex; sexual orientation, gender identity, gender roles, and stereotypes; legal consequences of behaving inappropriately; consent in sexual activities, self-esteem and confidence; and positive body image. Subtheme on the human life cycle was the only subtheme of outcomes that was only mentioned by teachers but were not reported by other stakeholder groups.

Researchers' views on the outcomes also differed to other stakeholder groups. Researchers mentioned the following subthemes of outcomes most frequently: how to develop and sustain romantic relationships and having social skills (reported by 83.3% of researchers who emphasised the development of social skills needed to have such relationships); sexual orientation, gender identity, gender roles and stereotypes (75%); and contraception (66.7%)

The most frequently reported outcomes by policy makers/third sector were: sex (reported by 87.5% of participants from the perspective that students might become sexually active, and it is their right to know how to do it safely), masturbation (87.5% of participants emphasised the importance of knowing how to masturbate safely); social norms of behaviour (87.5%) and puberty (87.5%).

Table 5.3 Frequencies of outcome reporting between stakeholder groups

| Subthemes                                                                       | Parents (N=17)     | Teachers or school staff members (N=16) | Researchers (N=12) | policymaker/third sector (N=8) |
|---------------------------------------------------------------------------------|--------------------|-----------------------------------------|--------------------|--------------------------------|
| <b>1.1. Human body parts*</b>                                                   | 9 (52.9%)          | <b>11 (68.8%)</b>                       | 7(58.3%)           | 6 (75%)                        |
| <b>1.2 Puberty*</b>                                                             | 9 (52.9%)          | 9 (56.3%)                               | 6 (50%)            | <b>7 (87.5%)</b>               |
| 1.3 Health checks                                                               | 2 (11.8%)          | -                                       | -                  | 1 (12.5%)                      |
| 1.4 Human life cycle                                                            | -                  | 2 (12.5%)                               | -                  | -                              |
| 1.5 Hygiene                                                                     | 2 (11.8%)          | 5 (31.3%)                               | -                  | 1 (12.5%)                      |
| 2.1 Recognising emotions and feelings                                           | 2 (17.7%)          | 4 (25%)                                 | 4 (33.3%)          | 3 (37.5%)                      |
| 2.2 Emotion regulation                                                          | 3 (29.4%)          | 6 (37.5%)                               | 2 (16.7%)          | 1 (12.5%)                      |
| 3.1 Recognising different relationships                                         | 3 (35.3%)          | 4 (25%)                                 | 5 (41.7%)          | 3 (37.5%)                      |
| <b>3.2 How to develop and sustain healthy friendships and social skills*</b>    | 9 (52.9%)          | 9 (56.3%)                               | 7 (58.3%)          | 4 (50%)                        |
| 3.3 How to develop and sustain healthy romantic relationships and social skills | <b>10 (58.82%)</b> | 4 (25%)                                 | <b>10 (83.3%)</b>  | 6 (75%)                        |
| 3.4 Planning for future relationships                                           | 2 (11.8%)          | -                                       | 1 (8.3%)           | -                              |
| 3.5 Values and attitudes for positive relationships                             | 7 (41.2%)          | 2 (12.5%)                               | 5 (41.7%)          | 2 (25%)                        |
| 4.1 Sexual feelings, sexual arousal, and pleasure                               | 4 (23.5%)          | 2 (12.5%)                               | 6 (50%)            | 4 (50%)                        |
| 4.2 Sex                                                                         | <b>13 (76.47%)</b> | 1 (6.25%)                               | 4 (33.3%)          | <b>7 (87.5%)</b>               |
| 4.3 Masturbation                                                                | 4 (23.5%)          | 8 (50%)                                 | 5 (41.7%)          | <b>7 (87.5%)</b>               |
| 4.4 Pregnancy and parenting                                                     | 7 (41.2%)          | 4 (25%)                                 | 5 (41.7%)          | 2 (25%)                        |
| 4.5 Contraception                                                               | 9 (52.9%)          | 3 (18.8%)                               | <b>8 (66.7%)</b>   | 5 (62.5%)                      |
| 4.6 Pornography                                                                 | 5 (29.4%)          | -                                       | 2 (16.7%)          | 3 (37.5%)                      |
| 4.7 Sexual orientation, gender identity, gender roles and stereotypes           | 4 (23.5%)          | 1 (6.3%)                                | <b>9 (75%)</b>     | 1 (12.5%)                      |
| 4.8 Sexual health                                                               | 8 (47%)            | 6 (37.5%)                               | 4 (33.3%)          | 4 (50%)                        |
| 5.1 Online safety and the law                                                   | 8 (47%)            | 6 (37.5%)                               | 5 (41.7%)          | 3 (37.5%)                      |
| 5.2 Legal consequences of behaving inappropriately                              | 3 (17.7%)          | 1 (6.25%)                               | 1 (8.3%)           | 1 (12.5%)                      |
| <b>5.3 Unhealthy relationships, risk and how to keep safe*</b>                  | <b>11 (64.7%)</b>  | <b>10 (62.5%)</b>                       | 5 (41.7%)          | 6 (75%)                        |
| 5.4 Asking for help                                                             | 4 (23.5%)          | 8 (50%)                                 | 2 (16.7%)          | 4 (50%)                        |
| <b>6.1 Consent and communication skills*</b>                                    | <b>11 (64.7%)</b>  | 8 (50%)                                 | 6 (50%)            | 6 (75%)                        |
| <b>6.2 Social norms of behaviour for a given cultural context*</b>              | <b>10 (58.82%)</b> | <b>11 (68.8%)</b>                       | 6 (50%)            | <b>7 (87.5%)</b>               |
| 6.3 Consent in sexual activities and the law                                    | 7 (41.2%)          | 1 (6.3%)                                | 3 (25%)            | 4 (50%)                        |
| 7.1 Self-esteem and confidence                                                  | 4 (23.5%)          | 1 (6.3%)                                | 3 (25%)            | 3 (37.5%)                      |
| 7.2 Positive body image                                                         | 2 (11.5%)          | 2 (12.5%)                               | 1 (8.3%)           | 2 (25%)                        |

|                          |           |   |           |         |
|--------------------------|-----------|---|-----------|---------|
| 8.1 Knowing human rights | 5 (29.4%) | - | 4 (33.3%) | 4 (50%) |
| 8.2 Self-advocacy skills | 1 (5.9%)  | - | 2 (16.7%) | 2 (25%) |

*Note:* \* indicates outcome subthemes reported by ≥50% of participants across stakeholder groups

## 5.4 Discussion

In this study, I explored the perspectives of parents, teachers, researchers, and policy makers/people from third sector on important RSE outcomes. Their views informed the development of the COS (discussed in Chapter 7). The outcomes perceived as important by stakeholders related to eight themes: the human body and development; emotions and feelings; healthy relationships and social skills; sex and sexuality; keeping safe; consent; self-esteem and human rights.

This study identified additional important RSE outcomes for students with intellectual disability that were not reported in the international literature (Paulauskaite et al., 2022). These were: consent in sexual activities; positive body image; emotion regulation; planning for future relationships; sexual feelings arousal, and pleasure; pornography; gender roles and stereotypes; asking for help; legal consequences of behaving inappropriately; the human rights and self-advocacy skills.

The differences between the outcomes extracted in the review (Paulauskaite et al., 2022) and the outcomes reported in this study could be due to methodological differences between the studies. This study was carried out with the aim of identifying stakeholders' views on RSE outcomes to inform development of the COS of RSE which is the first study of such type. The studies included in the systematic review were on RSE effectiveness, methods of delivery and content and therefore, had different aims than this study.

Some outcomes identified here are not included in the statutory guidance (DfE, 2019) for RSE delivery in all English schools: the human body and development throughout the life course; emotions and feelings; emotion regulation; how to develop and sustain romantic relationships and social skills; planning for future relationships, sexual feelings and arousal; masturbation;

social norms of behaviour for a given cultural context; self-esteem and confidence; and self-advocacy skills.

The discrepancy between outcomes identified in the RSE statutory guidance for English schools (DfE, 2019) and this study could be because the guidance was not developed specifically for students with intellectual disability. The development of RSE statutory guidance did not involve key stakeholders of this population in the development (e.g. students with intellectual disability, their parents, teachers).

#### **5.4.1 Rationale for outcome importance**

Overall, stakeholders' reasons for outcome importance related to students with intellectual disability being able to: keep safe and healthy, including physically and mentally; develop and sustain healthy relationships, including friendships and romantic sexual relationships; accept their sexuality, gender, and identity and have autonomy over their lives (e.g. being in charge of what happens to them).

Stakeholders' rationale for outcome importance involved unique needs and difficulties experienced by this population e.g. a lack of social skills, communication difficulties, low self-esteem, and confidence. Research indicates that many young people with intellectual disability lack social skills, struggle with communication, and have low self-esteem which can impact their ability to develop relationships and keep safe (Tipton et al., 2013; Black & Kammes, 2019; Schaafsma et al., 2017; Bates et al., 2017).

Extrinsic factors such as the environment and practices involved in supporting students with intellectual disability were also reasons for outcome importance. Students with intellectual disability due to having additional needs and needing adults to attain those needs were reported as being taught to comply to adults' requests. Some students with intellectual disability also receive help from adults with their intimate care (e.g. when using a toilet). These extrinsic factors were reported as impacting students' understanding of consent and putting them at risk for sexual abuse. The increased risk of sexual abuse amongst



people with intellectual disability is well established in the intellectual disability literature (Curtiss & Kammes, 2019; Tomsa et al., 2021; Gil-Llario et al., 2019) and the importance of RSE for its prevention (Curtiss & Kammes, 2019; Schaafsma et al., 2015; Brown et al., 2020). The increased risk in the literature had been attributed to a lack of RSE provision, difficulties with communication and social skills, overprotection, disempowerment (e.g. not being listened to or included in decision-making activities), social isolation, reliance on others for day-to-day functioning, and emphasis on compliance (e.g. taught to follow adults' rules) (Tomsa et al., 2021; Gil-Llario et al., 2019; Wissink et al., 2018; Jojo et al., 2023).

Stigma towards sexuality of people with intellectual disability was also a reason for outcome importance. Stakeholders in this study discussed that adults in student's environment can perceive that having relationships and sexual activities are not important for this population. These views can impact what information is provided in RSE to students with intellectual disability and can prevent students from experiencing such things in life. These findings are in line with previous research (discussed in Chapter 1) where parents believed that students with intellectual disability are not interested in having sexual relationships and thus, there is no need to deliver this information in RSE (Gürol's et al., 2014; Gokgoz et al., 2021; Menon & Sivakami, 2019).

#### **5.4.2 Differences between stakeholder groups**

Across stakeholder groups, participants in this study placed more value on outcomes related to learning how to keep safe and what is appropriate behaviour. These findings are in line with previous research (Paulauskaite et al., 2022). However, stakeholders in this study also perceived knowing how to develop and sustain friendships as an important outcome subtheme which was not reported in the existing literature (Paulauskaite et al., 2022).

There were differences between stakeholder groups on some outcome subthemes that they perceived as important that may reflect stakeholders' different experiences of supporting students with intellectual disability and

different social roles that each group contains. The most frequently reported outcomes amongst parents were about sex and development on romantic relationships. Parents reflected on their experiences of raising a child with intellectual disability (some of whom were sexually abused) and reported that these outcomes are important for safeguarding reasons and understanding that some students want and should be able to have sexual or romantic relationships.

These findings on parents' perspectives on RSE outcomes contrast parents' views reported in the literature. In previous studies, parents reported that the "sex" topic should not be taught to their children with intellectual disability (Pryde & Jahoda, 2018; Dupras & Dionne, 2014; Sinclair et al., 2015; Gürol et al., 2014). In previous studies, parents explained that their children with intellectual disability might start behaving inappropriately after receiving information on sex or that students with intellectual disability are not interested in having sex and thus, it is irrelevant to teach them about it (Pryde & Jahoda, 2018; Dupras & Dionne, 2014; Sinclair et al., 2015; Gürol et al., 2014). In previous studies, parents also did not mention that they value their children with intellectual disability learning how to develop romantic relationships (Paulauskaite et al., 2022).

Teachers' views on important RSE outcomes were different to the other stakeholder groups. Teachers placed more emphasis on outcomes related to keeping safe and understanding social norms of behaviour rather than outcomes related to human rights, and sex and sexuality (not mentioned at all or rarely mentioned by teachers). Teachers were also the only group of stakeholders that mentioned outcomes related to the human life cycle. Teachers' views on RSE outcomes reported in this study were in line with findings reported in the systematic review (Paulauskaite et al., 2022) which suggests that teachers perceive outcomes related to keeping safe and managing risks as important.

The selection of outcomes as important by teachers might reflect the current RSE delivery to students with intellectual disability in English schools which

might have been impacted by several factors. As stakeholders in this study explained, some teachers do not deliver these topics to students with intellectual disability due to fears that students might misunderstand them. Some teachers were also reported as believing that these topics are not relevant for students with intellectual disability. Parents' objections towards a "sex" topic delivery to their children was discussed as a barrier to its provision by teachers in this study. Additionally, a lack of appropriate resources related to sex and sexuality were reported by teachers in this study as making difficult to deliver such topics to students with intellectual disability.

Besides, the statutory guidance on RSE delivery in English schools (DfE, 2019) barely mentions topics on sex and sexuality in particular pornography or sexual pleasure. Therefore, this might be a reason why teachers did not mention these outcomes as important in this study because they are not a part of statutory RSE learning outcomes. The human life cycle is mentioned in the statutory guidance as a topic that teachers might want to draw upon when preparing students for discussions around puberty. Thus, this might be a possible reason why teachers were the only group of stakeholders that reported these outcomes as important in this study. Besides, many teachers (66.7%) took part in the workshops and perhaps did not have enough time to discuss all possible outcomes that they perceived as important. Research on carrying out focus groups for COS development indicates that each participant in such groups has about 10-15 minutes to share their views which might impact the scope of outcomes reported (Keeley et al., 2019).

Outcomes on sexual orientation, gender identity, gender roles and stereotypes, and contraception were the most frequently reported outcome subthemes by researchers. Researchers reflected on their experiences working with people with intellectual disability and reported that people with intellectual disability (particularly those who had autism as a comorbid condition) are questioning their sexual and gender identity. Young female students were discussed by researchers as being forced to take long-term contraception against their will. Participants from the policy makers/third sector group reported masturbation as one of the most frequently reported outcome

subthemes. Participants in this subgroup reported that these outcomes are important for understanding that students have a right for a sexual pleasure and prevention from behaving inappropriately or hurting themselves while masturbating.

There are no studies (to my knowledge) that aimed to explore such stakeholders' views on RSE outcomes to compare these findings with. However, research indicates that young people with intellectual disability question their gender and sexual identity and wished that these topics were delivered to them in RSE (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022). Forced contraception experienced by this population has been reported before as well (McCarthy, 2009, 2010; Ledger et al., 2016). In previous studies, students with intellectual disability reported that topics on masturbation and contraception are missing from their RSE (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022).

#### **5.4.3 Environmental support needed for outcome attainment**

In this study, stakeholders provided suggestions on enabling students to achieve the outcomes which included detailed, consistent, and skills based RSE delivery. These findings are in line with previous research which indicated that the format of delivery and inclusion of RSE in students' support plans are important strategies for improving RSE delivery to this population (Strnadová et al., 2021). In previous studies, students with intellectual disability also reported that the format of RSE should involve simple language and visuals to support their learning (Strnadová et al., 2021; Colarossi et al., 2023; Schmidt et al., 2022)

Stakeholders in this study discussed that adults (e.g. parents, teachers, support staff members) in students' environment can impact RSE outcome attainment for students with intellectual disability. Some of the adult-centred outcomes reported in this study (e.g. seeking students' consent; creation of opportunities for knowledge consolidation; supporting parents to understand the importance of RSE; and working on adults' attitudes) have been reported

in the literature before as strategies needed for improving RSE delivery to this population (Strnadová et al., 2021; Paulauskaite et al., 2022). However, some of adult-centred outcomes (consistent boundaries and educating adults on RSE) and findings on the physical environment (e.g. no doors in toilets) identified in this study have not been reported in the literature before. These findings provide valuable insights towards facilitators of RSE delivery for this population.

#### **5.4.4 Strengths and limitations**

To my knowledge, this is the first study that explored key adult stakeholder views on RSE outcomes for students with intellectual disability with the aim to inform a COS. I was able to engage with different stakeholder groups (e.g. policy makers, parents, teachers, and research) to capture their views on important RSE outcomes. Stakeholders that took part in this study had a range of experiences of supporting students with intellectual disability in educational and social care settings of different ages, abilities, and levels of intellectual disability. Offering stakeholders to take part either in workshops or interviews, enabled me to reach vulnerable people such as parents of children with intellectual disability that were sexually abused and include their perspectives on RSE outcomes in this study. Therefore, the methodological approach used in this study allowed me to explore a variety of different perspectives on RSE outcomes and include them in the development of this COS.

However, the findings need to be interpreted considering the study's limitations. First, recruitment to the study was carried out using convenience sampling (i.e. stakeholders volunteered to take part in this study) and thus, it is possible that sampling bias might have impacted the results. Stakeholders who took part in the study might have had more liberal attitudes towards sexuality of students with intellectual disability or perhaps experienced greater difficulties supporting their sexuality than people who did not take part in the study. The pandemic impacted the availability of participants to take part in the study. Teachers reported struggling with staff shortages due to covid sickness and finding a colleague to cover teaching while they took part in online

workshops or interviews. Parents reported feeling overloaded with taking part in research related to the COVID-19 pandemic. Therefore, stakeholders that took part in the study probably had more time and resources to join online workshops and interviews than people who did not take part.

Despite being able to engage with different groups of stakeholders, many stakeholders who took part were from White ethnic background and identified as being non-religious. Research indicates that people from non-Western cultural backgrounds have more conservative attitudes towards RSE topic delivery to students with intellectual disability (Correa et al., 2022; Sankhla & Theodore, 2015). Therefore, it is possible that RSE outcomes identified in this study does not reflect the views of all key stakeholders from culturally and religiously diverse backgrounds.

Additionally, three researchers (25%) who took part in this study were from other countries in Western Europe rather than England where the majority of participants were from. This decision to include international expert researchers was made before the study commenced as specified in the study protocol published prospectively to reach a target sample of researchers (N=10-15 researchers) (Paulauskaite et al., 2022). The literature review (Chapter 1) indicated that there are very few English researchers in the field of sexuality of people with intellectual disability. Thus, to reach the target sample I included international researchers. The COMET initiative (Williamson et al., 2017) encourages an inclusion of international stakeholders in a COS development to ensure that a COS is applicable across countries and thus, applied in research settings. Several other COS developed primarily for use within the UK have also included international stakeholders in the development (e.g. Powell et al., 2022; Ram et al., 2022). Thus, inclusion of international researchers in COS development is considered a strength.

However, one could argue that data provided by the three international researchers reflected their cultural or religious contexts and may not be applicable to students with intellectual disability living in England. Research evidence discussed above indicates that people from Non-Western countries

(e.g. Turkey and Iran) hold more conservative attitudes towards RSE delivery for people with intellectual disability compared to people from Western countries (Correa et al., 2022; Sankhla & Theodore, 2015). Thus, if some stakeholders were from non-Western countries, it is possible that they suggested more conservative outcomes as important. In this study, international researchers were from Western Europe, and they did not suggest different outcomes as important compared to researchers from England. All researchers (including three researchers from outside England), reported outcomes related to romantic relationships, sexual orientation, gender identity, gender roles and stereotypes and contraception.

The divergence of views between stakeholder groups evident in this study could have also been impacted by differences in data collection methods employed. In this study, the majority of teachers took part in the workshops (one teacher also completed the questions initially via email and then attend an online interview) whilst the majority of participants from other stakeholder groups (e.g. parents) took part in interviews. As discussed above, research indicates people have about 10-15 minutes to contribute to the discussion in workshops carried out in a COS development due to the number of participants involved (Keeley et al., 2019). Discussion in one of several small breakout groups (in the mixed stakeholder workshop) was also not facilitated efficiently as one researcher was dominating a discussion. Thus, stakeholders who participated in semi-structured interviews had more time to share their views as the interviews were carried out individually. In the interviews, stakeholders were not exposed to other people's views and some of the challenges experienced with the mixed stakeholder workshop (domination of discussion) was avoided. Thus, the semi-structured interviews potentially allowed me to elicit more personal reflections on the outcomes compared to the workshops. Therefore, it is possible that teachers' views on important RSE outcomes in this study were not explored in more depth to allow for comparisons between stakeholder groups (i.e. to explore divergence).

On the other hand, the workshops allowed me to collect a large amount of data from different stakeholder groups in one session and thus, reduce participant

burden which was an important factor for teachers when deciding to take part. The mixed stakeholder workshop allowed participants to hear people's perspectives from different stakeholder groups on the outcomes and to reconsider their position. The smaller homogeneous workshops also revealed what outcomes subgroups of participants perceived as important (e.g. what parents perceived as important compared to teachers), that is, more collective as opposed to more individual views. Even though the workshops were small, any method that involves at least two non-connected people is likely to reveal a more normative perspective for that group, a feature that is well recognised for focus groups (Nyumba et al., 2018). This feature was important for my study as I wanted to explore whether different stakeholder groups (e.g. parents compared to teachers) perceived different outcomes as important. The task of selecting the top three outcomes as a group in the small group discussions helped to keep the conversation on the topic and to explore outcome priorities for each educational stage.

As mentioned previously, two data collection methods employed in this study was a strength rather than a limitation in this study (e.g. impacting generalisability of the findings). First, qualitative research does not aim for generalisability as in quantitative research (I provided a discussion on trustworthiness of qualitative research in section 3.3.4.2). Second, employment of two data collection methods were in response to stakeholders' requests and reflects ethical research that allows participants to choose how they share their views on a sensitive topic (e.g. in a group or an individual format) (Liamputtong, 2006). Third, offering stakeholder to choose to take part in either workshops or an interview, allowed me to reach more stakeholders and include their views in the development of this COS.

## **Conclusions**

In this study, I explored adult stakeholders' perspectives regarding important RSE outcomes for students with intellectual disability to inform the development of the COS. Outcomes perceived as important related to eight themes. Stakeholders' rationale for outcome importance involved



consideration of the unique needs and difficulties experienced by this population, a physical environment that students live in, practices involved supporting students and other people's attitudes towards them. Stakeholders also suggested strategies for enabling students to achieve the outcomes, which included: the format of RSE delivery, the adults' role, and the physical environment. In the next chapter, I will present the views of students with intellectual disability on important RSE outcomes.

## **Chapter 6 - Perspectives of students with intellectual disability**

*“If our parents are not in this world, you need to know this stuff.”  
(Student17, female, 16 years)*

### **Introduction**

In this chapter, I present the third study. This study explored the views of students with intellectual disability on RSE outcomes to inform the development of the COS. It begins by describing the aims of this study and methods employed. I then provide participants' demographic characteristics. Findings on students' views on RSE outcomes are presented next. After it, I discuss the differences between the perspectives of students and adult stakeholders on RSE outcomes (carried out in this project and reported in Chapter 5). I finish this chapter by providing a discussion of the findings.

### **6.1 Aims**

The main aim of this study was to investigate the views of students with intellectual disability about RSE outcomes.

Secondary aims were:

- 1) to understand why the outcomes were perceived as important by students with intellectual disability;
- 2) to explore whether students with intellectual disability perceive different outcomes as important than adult stakeholders (presented in Chapter 5);
- 3) to supplement the list of outcomes identified in the previous stages of the project (Chapters 4 and 5) that were presented in the consensus development stages of this COS (Chapter 7).

## **6.2 Methods**

### **6.2.1 Study design**

This was a qualitative study that involved semi-structured interviews which were facilitated using visual data collection methods.

### **6.2.2 Interviews**

I described these methods briefly in Chapter 3. In this section, I provide more information on how the methods were applied in this study.

#### **1) Picture sorting activity using Talking Mats**

This visual data collection method involved a picture sorting activity. Students were presented with pictorial RSE outcomes and were asked to sort these pictures to represent their views using the Talking Mats procedure (Murphy & Cameron, 2008). I have completed foundation and advanced trainings in the Talking Mats procedure provided by its developers prior to carrying out interviews with students.

In this activity, students were introduced to the topic of conversation (e.g. “We are going to do this mat to find out what you think about Relationships and Sex Education lessons”). I explained the visual scale to students (e.g. “topics that you like”; “topics you are not sure about”; and “topics you do not like” the language adapted to each student’s understanding). Then, I presented a picture that represented one RSE topic and explained what the picture depicted (e.g. “This is learning about making friends”). After this, I asked the student to indicate what they think about this topic (e.g. “What do you think about this topic?”) and handed the picture to the student to place it on the mat under the visual scale.

I also asked simple follow-up questions to find out why certain pictures were placed under the options of the visual scale (e.g. “What you like about this topic? What you want to learn about this topic?”). Once all the pictures were sorted on the mat, I read out loud the picture placement to students (e.g. “Let

me check I understood this, you told me you do not like learning about x and y). This was done to check whether the placement of pictures on the mat represented students' views and to give an opportunity to students to change their mind (e.g. move pictures to the other side of the mat). Please see Appendix 6.1 for pictures of Talking Mats completed by students.

## 2) Art-based discussion

This visual data collection method involved a poster making activity. Students were presented with pictorial RSE outcomes and were asked to make a poster on interesting RSE topics.

In this activity, students were presented with a piece of paper and explained that this will be their base for the poster. Then, students were introduced to the pictures of RSE topics one-by-one by explaining what each picture depicts. After that, I asked students to select RSE topics that they find interesting or topics that they would like to learn more about in their RSE lessons language adapted for their understanding. Students were explained that the pictures of RSE topics they selected will be used in their poster. Once students finished selecting RSE topics for their poster, they were asked to stick the pictures onto their poster with a paper glue and help provided when needed.

While students were sticking the pictures onto their poster, I was asking simple questions to find out their views on RSE topics (e.g. "Why you chose this topic? What you want to learn about this?"). Then, students were presented with art-and-crafts based material (e.g. play dough, water paint, crayons, markers, stickers, and stamps) to decorate their posters. While they were decorating their posters, I was asking simple questions (e.g. "What students in your class need to learn in RSE lessons?" or "What is missing from your RSE lessons?" language adapted to students' understanding). Please see Appendix 6.1 for pictures of posters completed by students.

### 3) Diamond ranking activity

In this activity, students are asked to sort pictures that represent RSE outcomes into a diamond shape to indicate their views. Students are told to place RSE outcomes that they like on the top, the outcomes that they are unsure about in the middle row, the outcomes that they do not like on the bottom (see Appendix 6.1 for an example). However, this activity was not used in this study. Parents and teachers indicated that this activity is too complex and abstract for students to understand, and the other two activities were selected instead.

#### **6.2.2.1 Overlaps and differences between methods employed**

As discussed above, only two visual data collection methods (i.e. a picture sorting activity using Talking Mats and a poster making activity) were employed with study participants. In this section, I provide an overlap and differences between these two methods.

Both activities involved a clear structure and instructions with the language adapted when needed for each student. RSE teachers reviewed the interview scripts developed for this study and suggested adaptations of the language (for more information on scripts please see the 6.2.3 section below). Both activities involved almost identical instructions for completion which involved: a practice round of sorting pictures or discussing an example of a poster; introduction of a RSE topic as a topic of a discussion and RSE outcomes one by one; placement of outcomes to a different sides of the mat or selection of outcomes for a poster to find out students' views on outcomes; checking if a student understood what a picture depicted; asking follow-up questions to find out students views on outcome placement or selection; checking if any outcomes were missing; finding out the most interesting outcome; and a debrief. Both activities required students to be able to: make a choice (e.g. to select outcomes they want to learn more about), recognise pictures and understand simple questions or two phrase words to participate.

The main differences between the tasks centred around the point that the arts-based discussion involved slightly more tasks to complete because students were asked to decorate their posters. While they were decorating them, I was also able to ask some students additional follow-up questions. Follow-up questions were carried out after a placement of each outcome on the mat in the picture selection activity using Talking Mats. Additional follow-up questions were asked in the picture sorting activity at the “reflect and review” step which was not completed in the arts-based discussion. In other words, in both activities, students were asked additional follow-up questions but at a slightly different time during the activity. In the arts-based discussion, additional outcomes were drawn on the poster by some students rather than articulated using speech as in the picture sorting activity by a student making the arts-based discussion possibly more suitable for students who struggle to express themselves using speech. In terms of skills needed to participate in both activities, in the arts-based discussion, students did not need to understand categories of a visual scale (e.g. “topic I like learning about” and “topics I do not like learning about”) to participate.

### **6.2.3 Procedure**

Semi-structured interviews with students with intellectual disability were carried out face-to-face between July 2022 - January 2023 at students’ schools. The interviews lasted between 10-30 minutes and were audio recorded. The student’s RSE teacher was present during the interview but was asked not to contribute to the discussion. In the interviews, students with intellectual disability were presented with RSE outcomes extracted from the previous stages of this project (the systematic review Chapter 4 and data collected with adult stakeholders Chapter 5). RSE outcomes were referred to as “topics” to aid students’ comprehension (see the “outcomes presented” section for more details.)

In the interviews, I followed an “interview script” developed for this study (see Appendix 6.2 for an example). The script contained step-by-step instructions written for me on how to carry out the activities and the language to use with

students which was reviewed by a RSE teacher for each student to aid comprehension. Interview scripts helped me to follow a standard procedure across the interviews with some flexibility to accommodate students' needs (e.g. the language and RSE outcomes presented). Having scripts ensured that I followed a consistent data collection procedure across the interviews. Besides, it helped me to carry out the interviews using activities that involved many steps for completion.

The interviews started by presenting an easy read information sheet to students and obtaining their assent for participation (see Appendix 6.3 for information sheets). Students were informed that they can say "stop" or touch a red card placed next to them to stop the interview (see Picture 1 below). After that, a practice round was completed. In the picture sorting activity, students practised sorting pictures on a neutral concrete topic (e.g. "Things I like to do at school" with reading, drawing, and counting as options). In art-based discussions, a poster example was presented to students. Students were then introduced to RSE outcomes and began an activity. Throughout the interviews, students were asked simple questions to find out their views on RSE outcomes and to indicate the most interesting RSE outcome. This question to indicate the most interesting outcome was added to find out which outcome students perceive as the most important as some students might have indicated that they like all RSE outcomes. Students were asked to indicate one outcome that they perceived as the most interesting rather than several outcomes (e.g. top three outcomes) not to overload students with complex tasks. This question enabled the exploration of any differences between what adult stakeholders perceived as the most important outcomes compared to students. Students were also asked to indicate interesting RSE outcomes that were not presented to them. These additional RSE outcomes suggested by students were written on sticky notes and incorporated in the activities. Regular breaks were offered to students (e.g. having a snack) as well as re-checking assent.

To control acquiescence bias throughout the interviews (e.g. for students saying "yes" to all questions or "like" to all outcomes) several strategies were employed. Before starting the activities, I explained to students that is okay to

say “I do not like” in the interviews. Some parents and teachers reported that students need encouragement to indicate what they do not like. A RSE teacher present in the interview also explained to students that she will not be upset if students indicated that they do not like some of RSE outcomes. Open ended questions were also used in the interviews (e.g. “How you feel learning about this topic? What you think about this topic?”). Students’ indication of RSE topics that they do not like or feel not sure about was praised (e.g. by saying “thank you” or “good”). This was done to reassure students that they do not have to say they like all RSE outcomes.

After students finished the activities, I asked students how they found the interview, whether they have any questions, and what activities they are going to do next. After the interview, I took pictures of finished activities (e.g. of a poster or a mat). Teachers and parents were able to request the pictures that could be used as a guide for RSE teaching (e.g. contained students’ views on RSE topics that they would like to learn) if students did not object. This was communicated before obtaining informed consents from parents and before data collection to teachers. At the end of the interview, I asked students if I could share the pictures of finished activities with their teachers and parents if they ask. Some teachers had requested the pictures of finished activities for planning RSE lessons for students that provided assents to share their pictures. Students were not offered the option to request pictures of their finished mats or posters because I thought this task might be too difficult for students to request. Instead, their parents and teachers were told that they could request the pictures and use them to inform students’ learning. However, students took the finished posters with them after the interview. This was not possible to carry out in the picture sorting activity using Talking Mats due to the nature of the activity (e.g. one mat is used for data collection with all students). At the end of the activity, I checked what students said and confirmed their placement and selection of pictures e.g. “I want to check I understand, you told me x and y. Do you want to change the placement of the pictures?”. I also asked students’ views on how the interviews went at the end of each session.



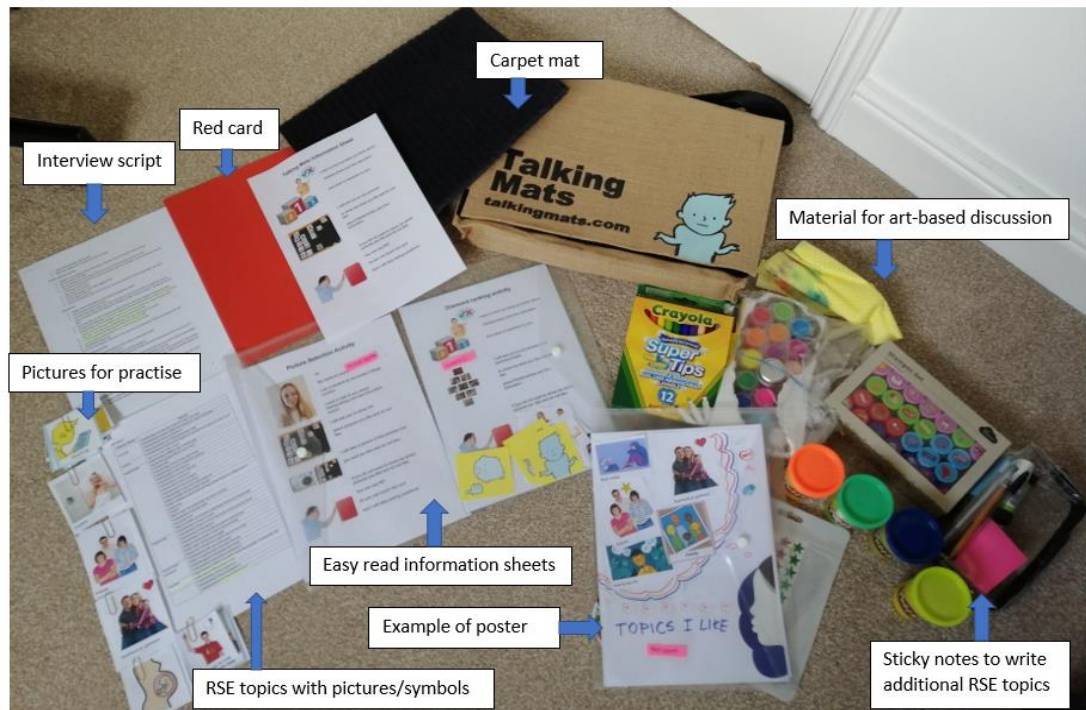
The interviews were not videotaped and the effectiveness of communication between students and myself was not assessed in this study. Murphy and Cameron have developed several effectiveness frameworks for evaluating the effectiveness of communication between two people, one of whom has communication difficulties, when using the Talking Mats procedure (Murphy & Cameron, 2008; Murphy et al., 2010). I decided not to use this effectiveness framework or any other frameworks to evaluate the effectiveness of communication between students and myself by evaluating observations of students' behaviour for several reasons. First, as explained in Chapter 3 (section 3.3.2.2), recruitment of students to the interviews was very challenging. Asking parents to provide their consents for allowing me to video record interviews with their children, would, I felt, have added an additional barrier to the recruitment. Second, the validity of the effectiveness framework for evaluating communication during the Talking Mats activity developed by Murphy and Cameron has been questioned by other researchers as no studies on its content and construct validity are available (Stans et al., 2019).

Therefore, I used a different approach to evaluate whether students were engaged in the activity and understood the topic of the conversation. For example, I used the step in the Talking Mats - "reflect and check" where I read the placement of pictures back to students and gave them an opportunity to reflect on what has been discussed and change their responses. Only RSE outcomes previously discussed with students were presented to them in the interviews. Besides, when presenting each outcome to students I also asked if they know what the outcome means (e.g. "Do you know what it is? Can you explain it to me?"). This step was done to make sure that students understood the topic of conversation. I was also asking simple questions throughout both activities (a picture sorting activity and a poster making activity) to find out why certain pictures were selected (e.g. "Why you selected this picture? Why you draw x and y?"). Students' explanations to these simple questions provided an understanding whether students were engaged in the activity, understood the topic being discussed and provided additional information regarding their views on outcomes.

Besides, at the end of each interview, I had discussions with students' teachers who knew students well to check whether finished activities depicted students' views. I showed the pictures of final activities and asked teachers to provide additional information as to why a certain student placed each picture in a certain side of the mat or selected certain pictures for a poster making activity. Teachers reported that all study participants expressed their views on RSE outcomes rather than sorted/selected pictures randomly. Teachers also suggested possible explanations regarding selection of pictures for students that had limited or no speech (e.g. "We discussed hygiene last year and he really liked this topic").

In the interviews, all students were engaged in the activities. Students were asking questions related to the topic and/or were interested to see a next pictorial RSE outcome e.g. sometimes taking pictures from my hands without waiting till I gave pictures to them. Some students asked their RSE teacher when they can learn more about some of the outcomes. RSE teachers took notes on these outcomes. Students with severe intellectual disability that appeared unable to express their views on the outcomes were also engaged throughout the interviews. They were following the steps involved in the activities till the end of the interview. Most students reported that they found interviews: "amazing"; "fun"; "easy"; "very good". Some students asked if I would come back to speak with them again. After the interviews, some teachers reported that students felt "special" that a researcher wanted to find out their views on their lessons (possibly indicating lack of opportunities to be involved in research). Most students did not appear to be distressed or uncomfortable when talking about sensitive topics e.g. sex or abuse. However, four male students touched a red card next to them wishing to stop the interview when these sensitive outcomes were presented indicating that the procedure for carrying out interviews on this sensitive topic employed in this study was effective. Some students explained that they feel uncomfortable talking about this. Please see Figure 6.1 for the interview material used in this study.

Figure 6.1 Material used in the interviews with students



Note: Images reproduced with permission of the rights holder, Photosymbols limited (<https://www.photosymbols.com>), Widgit Symbols © Widgit Software Ltd 2002-2024 (<http://www.widgit.com>), Unplash (Getty Images), and Talking Mats Ltd. ([www.talkingmats.com](http://www.talkingmats.com)). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.

### 6.2.3.1 Outcomes presented

The perspectives of students with intellectual disability were explored on RSE outcomes extracted from the systematic review (reported in Chapter 4) and outcomes suggested by adult stakeholders (reported in Chapter 5). I extracted all the outcomes and added them into a long list of RSE outcomes. Table 6.1 represents the total list of RSE outcomes to be used in student interviews. However, not all RSE outcomes (identified in the previous studies of this project) were presented to students with intellectual disability. Students' parents and RSE teachers reviewed the list of RSE outcomes. They indicated which outcomes they considered sensitive because of cultural, religious, or historical safeguarding reasons. Teachers also indicated which RSE outcomes had yet to be discussed in lessons. These outcomes were not presented to

students. Most parents did not identify outcomes that should be avoided during their child's interview. There was only one parent who indicated that outcomes on "sexual orientation" and "gender diversity" should not be discussed with their child in the interview due to cultural and religious reasons.

The removal of outcomes from the discussion in the interviews was done to make sure that interviews do not lead to anxiety or distress to students (e.g. if an unfamiliar or an upsetting outcome was presented). As a secondary consideration, unfamiliar RSE outcomes could have resulted in unreliable data (e.g. if students indicated that they do not like a particular RSE outcome without understanding what the outcome means).

Table 6.1 RSE outcomes discussed during student interviews

| RSE outcome themes                      | RSE outcomes presented                                                                | Number of students outcome discussed with<br>Total N=19 |
|-----------------------------------------|---------------------------------------------------------------------------------------|---------------------------------------------------------|
| Human body and development              | Human life cycle                                                                      | N=19 (100%)                                             |
|                                         | Human body parts                                                                      | N=19 (100%)                                             |
|                                         | Puberty for boys                                                                      | N=19 (100%)                                             |
|                                         | Puberty for girls                                                                     | N=16 (84.2%)                                            |
|                                         | Hygiene                                                                               | N=19 (100%)                                             |
| Emotions and feelings                   | Recognising emotions and feelings                                                     | N=16 (84.2%)                                            |
|                                         | Emotion regulation                                                                    | N=16 (84.2%)                                            |
| Healthy relationships and social skills | Recognising different types of relationships                                          | N=19 (100%)                                             |
|                                         | How to make friends                                                                   | N=19 (100%)                                             |
|                                         | Healthy romantic relationships and social skills which included:                      |                                                         |
|                                         | - Boyfriends and girlfriends                                                          | N=17 (89.5%)                                            |
|                                         | - Dating                                                                              | N=16 (84.2%)                                            |
|                                         | - Love                                                                                | N=16 (84.2%)                                            |
|                                         | - Marriage                                                                            | N=10 (52.6%)                                            |
|                                         | - Hugs and kisses                                                                     | N=16 (84.2%)                                            |
|                                         | Values and attitudes for positive relationships (e.g. what language is inappropriate) | N=18 (94.7%)                                            |
| Sex and sexuality                       | Sex*                                                                                  | N=4 (21.1%)                                             |
|                                         | Contraception*                                                                        | N=4 (21.1%)                                             |
|                                         | Sexual health*                                                                        | N=2 (10.5%)                                             |
|                                         | Pregnancy                                                                             | N=6 (31.6%)                                             |
|                                         | Parenting                                                                             | N=3 (15.8%)                                             |
|                                         | Sexual orientation                                                                    | N=10 (52.6%)                                            |
|                                         | Gender identity                                                                       | N=2 (10.5%)                                             |
|                                         | Pornography                                                                           | N=3 (15.8%)                                             |
| How to keep safe                        | Online safety which included:                                                         |                                                         |

|                           |                                                                     |                                                                 |
|---------------------------|---------------------------------------------------------------------|-----------------------------------------------------------------|
|                           | - Online safety                                                     | N=7 (36.8%)                                                     |
|                           | - Online bullying                                                   | N=7 (36.8%)                                                     |
|                           | - Sexting and sending naked images*                                 | N=2 (10.5%)                                                     |
|                           | Unhealthy relationships, risk, and how to keep safe which included: |                                                                 |
|                           | - How to keep safe                                                  | N=14 (73.7%)                                                    |
|                           | - Good and bad relationships                                        | N=17 (89.5%)                                                    |
|                           | - Bullying                                                          | N=15 (78.9%)                                                    |
|                           | - Abuse                                                             | N=9 (47.4%)                                                     |
|                           | - Harassment                                                        | N=2 (10.5%)                                                     |
|                           | Legal consequences of behaving inappropriately                      | N=4 (21.1%)                                                     |
|                           | How to ask for help                                                 | N=19 (100%)                                                     |
| <b>RSE outcome themes</b> | <b>RSE outcomes presented</b>                                       | <b>Number of students outcome discussed with<br/>Total N=19</b> |
| Consent                   | Consent                                                             | N=17 (89.5%)                                                    |
|                           | How to say "no"                                                     | N=17 (89.5%)                                                    |
|                           | Social norms of behaviour which included:                           |                                                                 |
|                           | Public and private places                                           | N=17 (89.5%)                                                    |
|                           | Public and private behaviours                                       | N=15 (78.9%)                                                    |
|                           | Personal space                                                      | N=17 (89.5%)                                                    |
|                           | Private body parts that should not be touched by other people       | N=16 (84.2%)                                                    |
|                           | Good and bad touch                                                  | N=16 (84.2%)                                                    |
| Human rights              | Human rights                                                        | N=3 (15.8%)                                                     |
| Self-esteem               | Confidence                                                          | N=12 (63.2%)                                                    |
|                           | Positive Body image                                                 | N=12 (62.2%)                                                    |

*Note:* \*outcomes discussed only with students attending Special Educational Needs and Disabilities units within mainstream schools.

Semantically related RSE outcomes were presented in groups. For example, outcomes on human body parts and development were presented together. This was done to facilitate students' understanding and reduce overload. I presented concrete outcomes on the human body first, moving onto more complex and abstract outcomes (e.g. outcomes on relationships). I also spent more time explaining abstract outcomes using specific examples anchored in students' life wherever possible (see Appendix 6.4 for language used to refer to outcomes). In the interviews, I asked students if they understand the outcomes presented to them e.g. "Do you know what this means? Can you tell me what it is?". Outcomes that students did not know were excluded from the activities.

The range of outcomes presented to students differed between the type of school (i.e. special vs mainstream) that students attended. I was able to present a wider range of outcomes to students attending SEND units within mainstream schools than students attending special schools (see Table 6.1). Some outcomes (e.g. sex, sexual health, contraception) were only presented to students from the SEND units. These outcomes were omitted from discussions with students from special schools as not delivered yet. However, an outcome on sexual orientation was presented to students that attended special schools where staff members were open about their diverse sexual orientation (as reported by teachers). Online safety was rarely discussed with students attending special schools because teachers indicated that students do not use the Internet unsupervised in schools and rarely use the Internet at home. For example, students can only access specific websites that have security controls in place and blocks inappropriate content.

#### **6.2.3.2 Consultation**

Three students with intellectual disability (2 girls and 1 boy) aged between 13-14 years participated in three consultation sessions carried out in June 2022. The aim of the consultation sessions was to ask students' help to select the most accurate and meaningful pictures to represent RSE outcomes for use during the interviews. The sessions were carried out face-to-face, individually with each student at their school, lasting about 20 minutes. Students were attending a SEND unit within a mainstream school. They were able to communicate using speech about a wide variety of topics. These students did not take part in the interviews.

I used the Talking Mats framework (Murphy & Cameron, 2008) to consult students about the material to be used in the interviews. Similar processes to consult people with intellectual disability about the most meaningful pictures have been used before (Bunning et al., 2017). First, I collected a variety of pictures and symbols to represent RSE outcomes from symbol/picture databases designed for people with communication difficulties (e.g. Widgit™, Photosymbols™) and the Internet (pictures that had public copyright licence).

I also asked students' RSE teachers to share their visual teaching material (e.g. pictures that they use to deliver RSE) that would have been incorporated in this session. However, RSE teachers from this school did not have any visual RSE material to share.

In the sessions, students were told that I am looking for pictures to represent topics they learn at school. I presented to students the mat and a visual scale on top of the mat (e.g. "like/easy", "not sure" and "do not like/difficult"). Then, students were introduced to a picture that represented a RSE outcome which was placed at the bottom of the mat. Students were told that I am looking for good pictures to represent this outcome. After it, I handed pictures, that could be used to represent this outcome, one-by-one to students. While handing the pictures, I asked: "What about this picture?" for students to place it on the mat under the visual scale. I asked simple questions to find out why students placed a specific picture on one side of a mat (e.g. "Why did you put this picture in the like side?"). I took pictures of each mat that represented the selection of pictures for each RSE outcome and wrote notes after the session (please see Appendix 6.1 for an example of a finished mat).

On average, pictures that were placed by students under the "do not like/difficult" or "not sure" category were not used in the study. Pictures placed on average under the "like/easy" category were used with the study participants. I used an Excel version 2401 (Microsoft Corporation) spreadsheet to calculate median scores of picture placement across students. In the spreadsheet, rows contained pictures presented to students and the columns were students' placement on the mat (e.g. 3="like", 2="not sure", 1="do not like").

However, at times it was difficult to identify one picture that students selected as the most accurate. This is because only three students took part in the session and there were individual differences. For example, one student did not like any of the pictures that featured people with intellectual disability (selected from the Photosymbols<sup>TM</sup> database). Teachers explained that students at this SEND unit feel pressure to fit in amongst students without



intellectual disability. This could be a reason as to why this student perceived pictures featuring people with intellectual disability as misleading. When it was difficult to select one best picture to represent a RSE topic, I selected two pictures indicated by students as accurate. I then checked with students' teachers which picture would be the best to show to a particular student in the interview.

This consultation session revealed RSE pictures that were perceived as misleading by students with intellectual disability. For example, students indicated that the picture on "private and public places" was a misleading picture (see Figure 6.2 below). Students explained that the sign on the door shown in the picture in their school means "do not enter" rather than a "private place". Thus, this picture was not used with study participants. This session also revealed that on average students perceived pictures that represented humans or real-life objects as more accurate pictures than symbols that contained cartoon like characters. However, some of the symbols were used in this study to represent RSE outcomes for students with intellectual disability who had more severe communication difficulties and used a symbol system to communicate.

Figure 6.2 The picture (middle of the mat) perceived as misleading by students



Note: Images reproduced with permission of the rights holder, Photosymbols limited (<https://www.photosymbols.com>), Widgit Symbols © Widgit Software Ltd 2002-2024 (<http://www.widgit.com>), Sexuality, Education, Counselling and Consultancy Agency (SECCA) (<https://www.secca.org.au/>), and Talking Mats Ltd ([www.talkingmats.com](http://www.talkingmats.com)). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.



### **6.2.3.3 Pilot**

Interviews based on three visual data collection methods were piloted with three students with intellectual disability who were involved in the co-production sessions. These methods were: a picture sorting activity using Talking Mats; an art-based discussion; and a diamond ranking activity. Each student took part in an interview based on a different method. Teachers indicated which method would be the best to complete with each student based on their prior experience of using a similar method and preferences. The aim of piloting was to check whether students understand the process of the interview (e.g. the activities involved), they are able to express their views, and what amendments to the procedure were needed.

The piloting revealed that students were able to express their views on RSE outcomes in the interviews based all three visual data collection methods. Students were engaged throughout the interviews and asked questions related to RSE outcomes. Students also reported that they enjoyed completing the activities. The piloting exercise provided practical information needed for improving the interview procedure. For example, it revealed that duplicate RSE pictures were needed for carrying out the interviews successfully. During the pilot, a couple of RSE pictures were glued on a poster in an art-based discussion which meant they were not available to students who completed other activities.

### **6.2.4 Preparation**

Preparation sessions either face-to-face or over a phone were carried out with each student's parents and RSE teachers separately before carrying out interviews with students. The aim of the sessions was to discuss how to adapt the interview to each student's needs and abilities. In those sessions, I discussed: the list of pictorial RSE topics; the language that I intended to use in the interviews; the length and time of an interview; and a practise round to check if students understand an activity. Parents were also asked to answered demographic questions about students (Appendix 6.5). Parents and teachers reported which one visual data collection method to complete with each

student based on students' prior experiences and preferences. A simple guide of what each method involved and what skills students may need to have to take part were given to parents and teachers (see Appendix 3.1 in Chapter 3). I also attended schools to demonstrate in person to teachers what each activity involves.

For students with more severe cognitive and communication difficulties attending a residential special school several preparatory sessions were carried. Symbols from students' communication aid and selected by other students in the consultation sessions were used in the interviews to represent RSE outcomes and to explain the activities (Appendix 6.6). Simple language was used in the interviews (e.g. "This is hygiene. Like or don't like?"). A small number of concrete outcomes (about 10) were presented to students. A picture sorting activity using the Talking Mats, contained visual scale with only two options ("like" and "don't like"). Two paper sheets containing hearts developed by schools' speech and language therapist were used for students to sort RSE outcomes (Appendix 6.7). Teachers reported that students were more familiar using a heart symbol to indicate things they like, and that the door mat used in the Talking Mats will confuse students.

#### **6.2.5 Data analysis and inter-rater reliability**

Students' demographic information was analysed using descriptive statistics using STATA<sup>TM</sup> (Stata Corp) version 17. The qualitative data collected in the interviews were transcribed verbatim using a transcription feature in a OneDrive<sup>TM</sup> (Microsoft 365) version 2308 (accessed via [www.office.com](http://www.office.com)). I then reviewed transcriptions for clarity and readability by listening to the audio recordings. This involved reading and editing the automatic transcriptions and removing identifiable information from the transcripts.

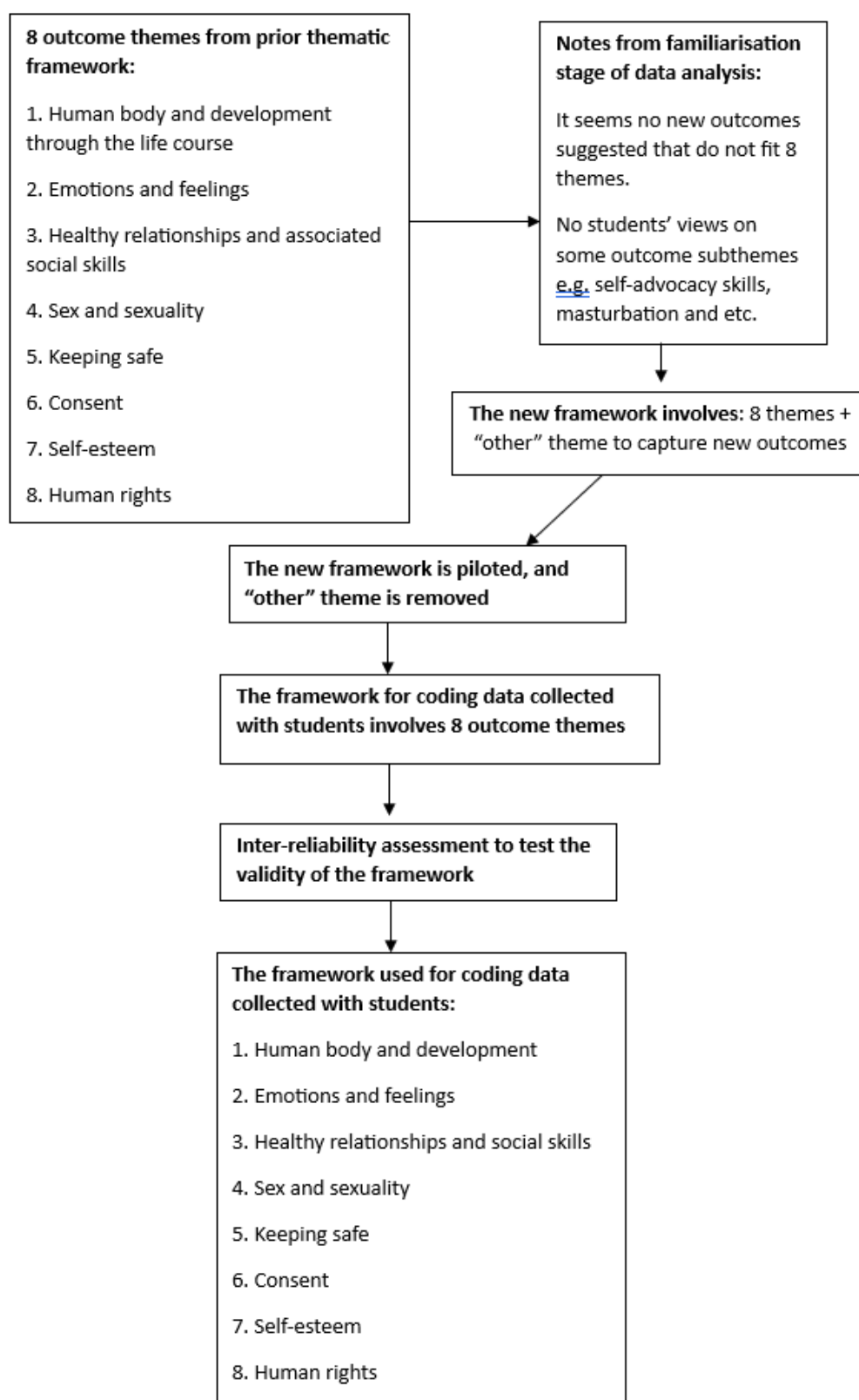
The framework approach (Ritchie & Spencer, 1994; Ritchie, 2013) was performed using NVivo 2020 (Lumivero) version 1.0 on the qualitative data collected with students i.e. students' narratives on RSE outcomes. The aim of the analysis was to find out students' views on RSE outcomes, their reasons

for its importance, and to explore the differences on outcome importance between students and adult stakeholders. This data analysis method enabled me to explore typologies i.e. patterns in the data that are characteristics of particular groups of participants. This was useful for exploring differences between students' and adults' perspectives on RSE outcomes. Five data analysis stages were carried out as it was discussed in Chapter 5. I now explain how each stage was carried out in this study.

The first stage, familiarisation, involved immersion in the data collected with all students with intellectual disability to get an overview of the data. In this stage, I also aimed to note new outcome themes suggested by students that were not extracted in the previous stages of this project (see below). This involved re-reading all interviews carried out with students, reviewing pictures of finished activities, and writing notes. Then, a thematic framework was developed informed by outcome themes of the previous thematic framework developed for analysing data collected with adult stakeholders (Chapter 5). In this study, students with intellectual disability were presented outcomes suggested by adult stakeholders and extracted from the systematic review that informed the development of the prior framework. Thus, data collected in this study had students' narratives on outcome themes developed in the prior framework.

However, I was also mindful that students with intellectual disability might have suggested additional RSE outcomes that semantically did not fit the themes or subthemes involved in the prior framework. This would have involved the amendment of the prior framework. For this reason, a theme called "other" was added to the framework to capture students' narratives on additional RSE outcomes. I then tested this framework (contained outcome themes identified previously and a new outcome theme "other") by applying it to five richest interviews carried out with students with intellectual disability. This pilot of the framework revealed that no new outcome themes were suggested by students and the "other" outcome theme was removed from the framework. Please see Figure 6.3 on the development of the thematic framework in this study.

Figure 6.3 Thematic framework development for coding data collected with students



Then, the validity of this framework that only contained outcome themes identified previously was tested by performing an inter-reliability assessment in Excel. Two raters (a colleague and me) coded independently 20% of the data collected with students with intellectual disability that was randomly selected. The Cohen's Kappa statistic was 0.87 indicating a very good level of agreement between two raters (Landis and Koch, 1977). After this, this thematic framework was used to code all data collected with students with intellectual disability (known as indexing a third stage).

The fourth stage, charting, involved creation of summaries of students' perspectives on RSE outcomes and reasons for its importance. To do this, I developed a matrix table in Excel. In this table, rows contained a summary of each student's views and columns were RSE outcomes (see Appendix 6.8 for an extract of the table). Excel was used instead of NVivo because interview transcriptions and photographs of completed activities (e.g. posters) were used to create summaries. Interview transcriptions did not capture the views on RSE outcomes amongst students who do not use speech as the main mode of communication. I analysed each student's outcome placement and added numbers in Excel to represent students' views on outcomes. For example, outcomes placed in the "like" side of mat were assigned a number 3, outcomes in the "not sure" side of the mat were assigned 2, and outcomes in the "do not like" pile were assigned 1. In art-based discussions, outcomes selected as the most interesting to be featured on posters were assigned a 3. I also wrote short summaries of students' narratives on RSE outcomes by reviewing the coded transcriptions.

This matrix table in Excel was used to create summaries of students' views on RSE outcomes which were grouped in outcome subthemes developed in the previous study on adult stakeholders' perspectives (Chapter 5). The summaries of students' views as a group on RSE outcome subthemes were written in a Word table next to summaries of adult stakeholders' views on RSE outcome subthemes. This Word table was created to compare students' and adults' views (see Appendix 6.9 for an extract of the table).

The final stages of data analysis (mapping and interpretation) involved exploration of perspectives of students with intellectual disability on RSE outcomes which were then compared to perspectives of adult stakeholders. I first reviewed the tables created on students' views to compare their views on outcome subthemes within and across students. I noted similarities and differences amongst students' views on RSE outcome subthemes and their explanations for outcome importance or unimportance. After it, I compared and contrasted students' views to adults' views by reviewing the table created for this purpose. I noted additional smaller outcomes that students suggested as important that were not suggested by adults. These smaller outcomes semantically related to outcome subthemes suggested by adults. I also noted similarities and differences between students' and adults' explanations on outcome importance. I mapped students' views on important RSE outcomes on to the thematic map (developed on adults' views) to visually represent the similarities and differences between students' and adults' perspectives.

### **6.3 Results**

The results are presented as follows: first, I present participants' demographic characteristics and the setting this study took place. I then provide the perspectives of students with intellectual disability on RSE outcomes including their rationale for outcome importance (whenever possible). Where there were differences in the perspectives of students with intellectual disability on RSE outcomes, this is reported as well. Second, I present the differences between the perspectives of students and adult stakeholders (reported in Chapter 5) on RSE outcomes.

#### **6.3.1 Participants and setting**

Participants were 19 students with intellectual disability (N=12 male and N=7 female) with a mean age of 15.2 years (SD=2.7, range 12-24 years). The majority of students (68.4%) selected Christianity as a religious affiliation and 42.1% of students were from a White British ethnic background (see Table 6.2 for more details). Most students were attending a special school (78.9%) and had moderate intellectual disability (78.9%) identified as "moderate learning

difficulties” as the primary need in their Education, Health, and Care Plans (EHCPs). Three students (15.8%) had “cognition and learning” identified as a primary learning need in their EHCPs. “Cognition and learning” is a broad category used in EHCPs to refer to students who have any type of learning difficulties (e.g. intellectual disability or dyslexia) (DfE, 2015). However, parents of those three students reported that students had a mild intellectual disability.

Students had varied communication abilities and additional needs: 47.4% of students had autism and 42.1% of students had speech delay as additional conditions to intellectual disability. About half of students (52.6%) who participate in this study were able to communicate (using speech or a communication aid) about a limited number of topics and 42.1% of students were able to understand most routine everyday language. One student (5.3%) did not use speech to communicate (used eye gaze to indicate picture placement on the mat). Five students (26.3%) used aided augmentative and alternative communication methods to communicate such as Picture Exchange Communication System (PECS) in addition to using speech.

Most students (84.2%) participated in the study through a picture sorting activity using Talking Mats, and three students (15.8%) took part in art-based discussions. An additional three students with severe intellectual disability and limited vocal communication abilities took part in the study. However, these students were unable to express their views on RSE outcomes in the interviews. Several preparation sessions with the students’ RSE teacher were carried out to discuss adaptations for enabling these students to take part (discussed in the “preparation section” above). However, these students with severe intellectual disability did not appear to understand pictures presented to them nor the activity selected as the best method to enable their participation. For example, these students said “like” when presented with RSE outcomes but placed those outcomes in the “do not like” side of the mat. After the interviews, teachers reported that it appeared that these students randomly sorted RSE pictures. Therefore, these three students were not included in the

total number of study participants. Data collected with these three students were not included in the data analysis.

### *Setting*

Participants attended five diverse schools that served students with intellectual disability with a range of co-occurring conditions and abilities located in London and South East England. Out of five schools, three were special schools, and two were mainstream schools that had Special Educational Needs and Disability (SEND) provision.

Out of three special schools, one school was for students with a primary learning need identified as moderate to severe learning difficulties (synonymous to moderate to severe intellectual disability) and physical health needs located in London. The other school was a residential school for students with diagnosis of autism and moderate to severe learning difficulties (synonymous to moderate to severe intellectual disability) that also had complex needs including minimal speech and behaviours that challenge located in South East England. The third special school was for students with a diagnosis of autism who were working academically below age-related expectations and was located in London.

Out of two mainstream schools with SEND provision, one was a catholic secondary school located in London. The second mainstream school was a secondary and a sixth form school located in South East of England. Students at these SEND units were taught in small student groups together with other students who receive SEND provision by trained SEND teachers. Some students, depending on their needs and abilities, received part of their education in mainstream classes.



Table 6.2 Students' demographic characteristics

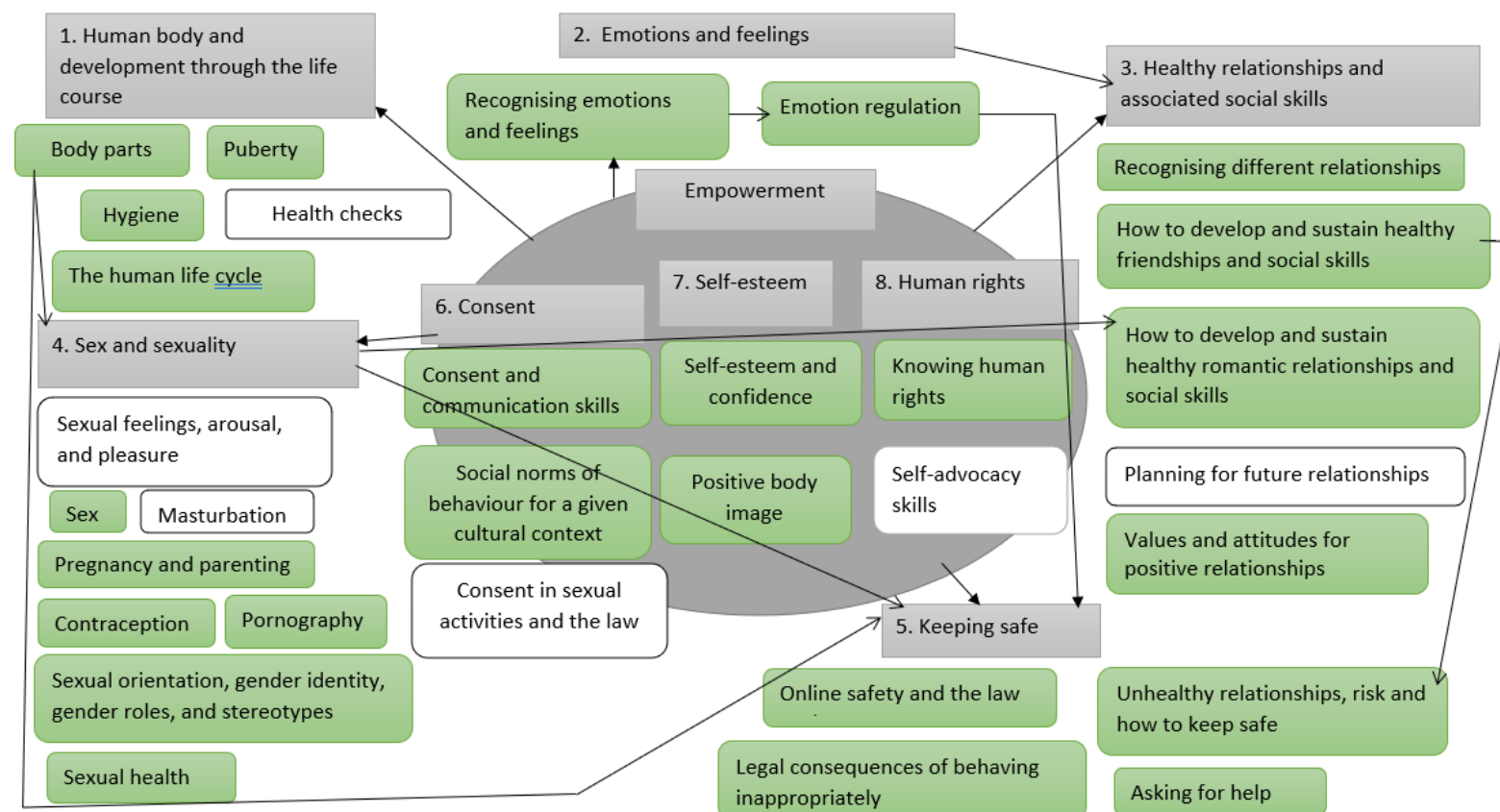
| Characteristics                                                                           | Total sample N=19<br>N (%) |
|-------------------------------------------------------------------------------------------|----------------------------|
| <b>Interview method</b>                                                                   |                            |
| Picture sorting activity using Talking Mats                                               | 16 (84.2%)                 |
| Art-based discussion                                                                      | 3 (15.8%)                  |
| <b>Age (years)- Mean (SD) (range)</b>                                                     | 15.2 (2.7) (12-24)         |
| <b>Gender</b>                                                                             |                            |
| Female                                                                                    | 7 (36.8%)                  |
| Male                                                                                      | 12 (63.2%)                 |
| <b>Ethnicity</b>                                                                          |                            |
| White                                                                                     | 8 (42.1%)                  |
| Other                                                                                     | 11 (57.9%)                 |
| <b>Religious affiliation</b>                                                              |                            |
| Christianity                                                                              | 13 (68.4%)                 |
| Hinduism                                                                                  | 3 (15.8%)                  |
| Other                                                                                     | 1 (5.3%)                   |
| No religion                                                                               | 2 (10.5%)                  |
| <b>Type of school attended</b>                                                            |                            |
| Special school                                                                            | 15 (78.9%)                 |
| SEND unit within mainstream school provision                                              | 4 (21.1%)                  |
| <b>Primary learning need in EHCPs</b>                                                     |                            |
| Cognition and learning*                                                                   | 3 (15.8%)                  |
| Moderate learning difficulties (synonymous to moderate intellectual disability)           | 15 (78.9%)                 |
| Severe learning difficulties (synonymous to severe intellectual disability)               | 1 (5.3%)                   |
| <b>Level of ID*</b>                                                                       |                            |
| Mild                                                                                      | 3 (15.8%)                  |
| Moderate                                                                                  | 15 (78.9%)                 |
| Severe                                                                                    | 1 (5.3%)                   |
| <b>Receptive language abilities</b>                                                       |                            |
| Understands complex language                                                              | 6 (31.6%)                  |
| Understands most routine everyday language                                                | 8 (42.1%)                  |
| Understands most basic instructions and questions                                         | 3 (15.8%)                  |
| Understands some basic language and simple instructions in familiar context e.g. sit down | 2 (10.5%)                  |
| <b>Expressive language abilities</b>                                                      |                            |
| Able to communicate about a wide variety of topics                                        | 4 (21.1%)                  |
| Able to communicate about a limited number of topics                                      | 10 (52.6%)                 |
| Able to communicate needs and wants                                                       | 2 (10.5%)                  |
| Able to communicate basic needs and wants                                                 | 2 (10.5%)                  |
| Did not use speech for communication                                                      | 1 (5.3%)                   |
| <b>Uses augmentative and alternative methods of communication (e.g. PECS)</b>             | 5 (26.3%)                  |
| <b>Additional conditions</b>                                                              |                            |
| Autism                                                                                    | 9 (47.4%)                  |
| ADHD                                                                                      | 5 (26.3%)                  |
| Speech delay                                                                              | 8 (42.1%)                  |
| Hearing or visual impairment                                                              | 2 (10.5%)                  |
| Down syndrome                                                                             | 1 (5.3%)                   |
| Other genetic condition                                                                   | 2 (10.5%)                  |
| Epilepsy                                                                                  | 4 (21.1%)                  |
| Cerebral palsy                                                                            | 4 (21.1%)                  |

Note: ID= Intellectual Disability; ADHD= Attention Deficit Hyperactivity Disorder; SEND= Special Education Needs and Disabilities, PECS=Picture Exchange Communication System; EHCP= Education, Health, and Care Plan; Cognition and Learning= broad category of learning needs that includes different levels of learning difficulties; however, level of learning difficulties not specified; Level of ID\*= reported by parents.

### **6.3.2 Outcome themes**

On average, students indicated that they like all of the outcomes presented to them. The thematic map (Figure 6.4) indicates RSE outcome subthemes (in green) perceived as important by the majority by students with intellectual disability. Outcome subthemes in a white colour suggested by adult stakeholders were not presented to students. Therefore, students' views on these outcomes were not explored in this study. These outcome subthemes were: health checks; planning for future relationships; sexual feelings, sexual arousal, and pleasure; masturbation; consent in sexual activities and the law; self-advocacy skills. These outcome subthemes were not presented to students because adults indicated that these topics should not be discussed with students (due to reasons mentioned previously in the "preparation" section).

Figure 6.4 Thematic map of RSE outcomes perceived as important (in green) by students



Note: Lines are associations between outcome themes (in a grey colour) and subthemes (in green and white colours) suggested by adult stakeholders. Outcome subthemes in a white colour were not presented to students.

## Theme 1 – Human body and development through the life course

This theme involves the perspectives of students with intellectual disability on outcomes related to the human body and development through the life course grouped into four subthemes:

- *Human Body Parts*

Overall, students indicated that they like this outcome and wanted to learn more about it. Students reported that it is important to learn scientifically correct language of private body parts for being able to communicate effectively when having a medical issue:

*“It is good to know because it might be useful in the future because when you go to doctors and they ask what is wrong and if it involves your body parts you have to do that right name otherwise, they will not know what.” (Student12, female, 15 years)*

However, five students (26.3%) indicated that they do not like learning about private body parts or placed this outcome in the “not sure” side of the mat as to whether they want to learn about it in RSE. Students explained that this outcome is uncomfortable to learn because it involves a discussion of private body parts of the opposite sex:

*“I do not like this one, because it makes me uncomfortable learning about body parts of different types of women.” (Student14, male, 12 years)*

- *Puberty*

Students reported that it is important to learn in RSE how to deal with puberty changes by themselves e.g. how to use menstruation products. Some students reported that they do not know what happens during puberty and thus, would like to learn more about it in RSE:

*“Well, I like how I learn how to do it [use menstruation products] by myself and I get used to it.” (Student08, female, 13 years)*

*“[I want to learn more about puberty] because actually I do not know what it is. [...] I do not know why girls have different body changes to the boys.” (Student16, male, 15 years)*

However, three boys (15.8%) reported that they do not like learning about puberty changes that happen to girls:

*“Not sure about this one. Well, it is one thing learning about guys puberty, but when you are learning of girls’ different types of puberty it is kind of uncomfortable. [...] probably for many girls it may be uncomfortable especially if guys are hearing this.” (Student14, male, 12 years)*

- *Hygiene*

Students indicated that they like learning about hygiene in RSE because they want to be clean and healthy. Students discussed that they are able to do some of hygiene activities by themselves e.g. they can have independent showers. Therefore, they would like to learn in RSE how to take care of their body by themselves:

*“I like hygiene [topic] because I really like taking good care of my body and my hair [...]. Well, I like it [the topic] because I take independent showers.” (Student08, female, 13 years)*

*“[I want to learn more] because sometimes I actually I do not know how they [points to hygiene products] work.” (Student16, male, 15 years)*

- *Human life cycle*

All students indicated that that they like this outcome because they wanted to find out how their life is going to change in the future:

*“I feel happy about it [learning about this topic] because it tells me if I grow up, I get a job and stuff.” (Student11, male, 16 years)*

## Theme 2 – Emotions and feelings

This theme contains the perspectives of students with intellectual disability on outcomes related to emotions and feelings grouped into two subthemes:

- *Recognising emotions and feelings*

Students reported that they find difficult to understand other people's emotions and feelings. They are also struggling to recognise and express their own emotions (e.g. to show a correct facial expression that matches how they are feeling). Thus, they would like to learn more about it in RSE:

*"I want to know more, because sometimes it is confusing to read some people when they are angry or upset. [I want to learn] like how to know if someone is upset by the mood or the face expressions and stuff like that." (Student03, male, 14 years)*

*"Well, sometimes I can make the wrong facial expressions, so sometimes I could cry for no apparent reason and instantly stop in the next 10 seconds. Sometimes I could be angry for no reason [...] and it is something I am trying to learn how to control." (Student14, male, 12 years)*

Two students (10.5%) from the same school reported that learning about different feelings and emotions in RSE is "boring". After interviews, a teacher explained that students discuss their feelings and emotions every morning in their school. This could be a reason as to why these students felt that learning about emotions and feelings in RSE is boring.

- *Emotion regulation*

Students reported that they would like to learn how to manage their emotions when they are feeling angry, anxious about new transitions in their lives, and when in grief:

*"I need to learn more about that [emotion regulation] because I get quite angry sometimes. [I want to learn] how to like to do the right thing when you are angry." (Student03, male, 14 years)*

*“Yeah, I want to learn more of this [...] just to help me get ready for college [...] like I am just going to be sad not seeing these friends [I] usually do.” (Student11, female, 16 years)*

### **Theme 3 – Healthy relationships and associated social skills**

This theme involves the perspectives of students with intellectual disability on outcomes related to development of healthy relationships and social skills needed for such relationships. Findings are grouped into four subthemes:

- *Recognising different types of relationships*

Students reported that learning about different relationships gives them good, positive emotions. The reasons for these emotions varied. For example, one student said it made her more confident about having such relationships in real-life, while another liked the variety of relationships; learning about this topic may allow the student to acknowledge what relationships he has in life:

*“I feel good [about this topic] because when they [teachers] teach me, I feel more like confident... I need to get used to it and been taught in my lessons.” (Student08, female, 13 years)*

*“That [topic] makes me happy because we have everyone, teachers, family, friends, and boyfriends, girlfriends.” (Student10, male, 14 years)*

- *How to develop and sustain healthy friendships and social skills*

Students reported that in RSE they want to develop social skills needed to have friends such as how to talk and play with new friends, how to be a good friend, and how to resolve conflicts. Across students, this outcome was reported the most frequently as the most interesting topic to learn in RSE. Students explained the issues they had in making friends and that they do not want to be alone. Having friends was perceived as positive.

*“Oh yeah, definitely yeah [I want to learn more] it is harder to make friends if you have a disability. [I want to learn about] how to make more friends.” (Student03, male, 14 years)*

*“Well, I would like to learn about friends. [...] so last week, I do not have any friends [...] I was lonely, I was so sad because [...] I do not have friends.” (Student13, male, 13 years)*

*“I like this topic because [...] you get to learn how to make more friends, [...] learn about how to talk to different people, how to be more social [...]. And it is really nice [...] because if you are lucky like me, you could have like a lot of fun, you could have like a lot of friends learning about this.” (Student 14, male, 12 years)*

- *How to develop and sustain healthy romantic relationships and social skills*

Students reported that they would like to learn: what are expectations of being in romantic relationships; how to kiss and hug with a romantic partner; what happens during dates; what love is and how it feels; what marriage is; and the responsibilities and commitments that come with marriage. Students explained that they would like to learn this because they want to go on dates, have boyfriends and girlfriends and get married in the future. Students explained that it is important to learn this in RSE to be prepared for the future relationships and to avoid making mistakes or hurting people:

*“What are the expectations of being in [romantic] relationships. Do you know? [...] [I want to learn] what happens when you get in a relationship, what to expect and what to [be] prepared for.” (Student02, male, 14 years)*

*“I would like to learn how to kiss and hug with boyfriend because I never been taught about this lesson and like it is quite different.” (Student08, female, 13 years)*

*“I like this one [topic] because you get to know the feeling of love and you also get to know [how] to actually feel it. [...] So, learning about love is a good thing because you know who you love [and] you do not actually end up hurting someone.” (Student14, male, 12 years)*

However, three students did not know what outcomes in this outcome subtheme means (e.g. what a boyfriend is) and indicated that they are unsure



if they like learning about this in RSE. Two boys reported that they do not like learning about romantic relationships due to a lack of success in the past:

*“Sketchy [...] what happens girls just dates you randomly because they want your money.” (Student01, male, 14 years)*

*“Well, I think I do not like this [...] I asked a girl on a date, and she said “no”, so I do not really care.” (Student13, male, 14 years)*

- *Values and attitudes for having positive relationships*

Students reported that they want to learn in RSE: what inappropriate language is (e.g. misogynistic language), the values of a good friend, and how to be respectful to people who identify differently in terms of their sexuality. Students explained that achieving these outcomes is important for being able to make friends, and to avoid hurting other people:

*“Because, like you may say some things that a girl might not like, you may be [...] abusing the girl, but you may have not known. So, it is best if you know what to say to her or not to say to a girl, because if you know what to say to a girl then you could make more friends and more girls can be more comfortable around you.” (Student14, male, 12 years).*

*“[Students in my class need] to learn how to behave [...] how to respect [...] if someone comes out [gay], they have to be respectful [...] because people in our class not like all of them but they are not very sensible with that [...] because they do not actually know what people go through when they come out [gay].” (Student12, female, 15 years)*

#### **Theme 4 – Sex and Sexuality**

This theme contains the perspectives of students with intellectual disability on outcomes related to sex and sexuality grouped into six subthemes:

- *Sex*

An outcome “understanding what sex is” was only presented to four boys (21.1%) attending SEND units within mainstream schools. Out of four

students, two boys indicated that they like this outcome and reported that they want to learn more about sex in RSE. Students explained that they might be engaging in sexual activities in the future. However, some students reported that teaching on sex needs to be gradual because this topic is uncomfortable to learn:

*“Yeah [I want to learn more about it] and also, I do not know that much about what happens during sex, but I do remember saying to use condoms, yeah?” (Student02, male, 14 years)*

*“I do not know. It is like you get to do [engage in sex] at some point, but [...] when you get told this it is like do this more slowly you know what I am saying?” (Student03, male, 14 years)*

The other two boys indicated that they do not like this outcome because:

*“It is bad for you [to have sex] because you can get... I do not know what is called but I know it is really bad for you to have sex.” (Student01, male, 14 years)*

*“It is too uncomfortable to speak about it.” (Student04, male, 14 years)*

- *Pregnancy and parenting*

This outcome was presented to only five students (26.3%). All five students indicated that they would like to learn more about pregnancy and parenting because they might become parents in the future:

*“It is good to know [about parenting] just in case if I or like your brother or sister has a baby and they ask [to] look after it you know what to do.” (Student03, male, 14 years)*

Additionally, two female students from a special school reported that they would like to learn about pregnancy and how babies are made. This outcome was not presented to these two students in the interviews. Students explained that they need to learn about pregnancy and how babies are made in RSE because they are not children anymore and they themselves might have children in the future. They also reported that they need to know this

information themselves because they parents will not be around forever to answer their questions:

*"[I want to learn about] babies! [...] we learn a little bit, but I want to learn more [because] you are older, they need to tell you how you do it [have a baby] because when a girl is older that [pregnancy] does happen [...]. If our parents are not in this world, you need to know this stuff." (Student17, female, 16 years)*

- *Contraception*

This outcome was presented to only five students (26.3%). Out of five students, three students indicated that they would like to learn more about contraception because this is an important information to know if students decide to engage in sexual activities. Some students only remembered being taught about condoms (and no other contraception options). However, students did not know as to why people use contraception in sexual activities. The other two students were unsure if they want to learn about this in RSE and were unable to provide reasons as to why.

*"I think it [contraception] is more vital [to know] you know what I am saying? If you do it [sex] and you do not know like about [...] condoms and stuff like that, they [teachers] should have told you before you do it [engage in sex]." (Student03, male, 14 years)*

*"Yeah [I want to learn more about contraception] I remember I could get [...] I think it is during that [points to picture on sex] always use protection in case something happens." (Student02, male, 14 years)*

- *Pornography*

This outcome was presented to only three students (15.8%). Two students reported that it is important to learn the legal age to view the pornography (i.e. 18 years old) because some students might not know this:

*"Does not have to be 18 [to view pornography]? That one [pornography] to learn more some people do not know [about it]." (Student04, male, 14 years)*

However, one student said that he does not want to learn about pornography because: *“I do not like this. It is weird.”* (Student01, male, 14 year)

- *Sexual orientation and gender identity*

Outcome on sexual orientation was presented to ten students (52.6%). Out of which, five students indicated that they like this outcome and wanted to learn more about it in RSE. Students explained that they need to learn about different sexualities because they are going to meet people who are sexually diverse in real life e.g. their family members might be gay. The other five students were unsure if they want to learn about it in RSE and were unable to explain as to why.

*“I'm OK with it [learning about different sexualities] because my auntie got married [to a woman] and I was not sure before, but she is happy. I was like: “okay, I understand you”. [I want to learn] like when I get old, girl can marry girl and boy and boy.”* (Student11, female, 16 years)

Outcome on gender identity was presented to only two students (10.5%). One student did not understand this outcome. The other student reported that it is important to learn about gender diversity in RSE to understand that is normal to be different:

*“[I like gender identity topic] because it is okay to be like if you want to change your mind of who you are even and who like your identity is [...]. It is important [to learn about this] because other people can know it is okay to be what you want.”* (Student12, female, 15 years)

- *Sexual health*

Outcome on sexually transmitted diseases was presented to only two students (10.5%). One student indicated that he does not want to learn about it and was unable to explain as to why. The other student indicated that she wants to learn about it and selected this topic as one of the most interesting RSE topic for a poster making activity:

*“Yeah, I want to do this [learn more about sexually transmitted diseases].” (Student12, female, 15 years)*

## **Theme 5 – Keeping safe**

This theme contains the perspectives of students with intellectual disability on outcomes related to keeping safe grouped into four subthemes:

- *Online safety and the law*

This outcome was presented to only seven students (36.8%). Teachers indicated that this topic was not delivered yet or that students do not use the Internet unsupervised. The majority of students perceived this outcome as important to achieve in RSE. Students discussed that they use social media, and they need to learn how to protect themselves from people who might want to harm them online. Students also reported that they are being bullied online. Some students due to being bullying are not attending schools and feeling depressed. Thus, students wanted to learn in RSE: how to keep their accounts private, how to block people online, and what to do when experiencing cyberbullying. However, some students indicated that they do not like learning about online safety because it involves a discussion about negative things e.g. cyberbullying.

*“[I want to learn more about] Social media [...] because I do not want to get people bullying me [...] I get these a lot [...] I get people bullying me [online].” (Student01, male, 14 years)*

*“I like it [the topic] because you learn how to stay safe from the Internet, and you learn how to avoid cyberbullying [...] because cyberbullying has been happening to this day and a lot of people are suffering depression [...] and stopped going to school and learning.” (Student14, male, 12 years)*

*“[Students in my class need to learn] about social media [...] because nowadays everything is on social media. [...] When to block someone, when not to trust no one because they [strangers online] lie [...] because they are dangerous, and they want something.” (Student 12, female, 15 years)*

Outcomes on sexting, sending or forwarding naked pictures online was only presented to two students (10.5%) from SEND units within mainstream schools. One student reported that he wants to learn more about this: *“because I do not know what it is.”* (Student03, male, 14 years). The other student reported that he does not want to learn about sexting and sending naked images because: *“You can just ignore it, just block them [strangers online]. Everyone knows what to do.”* (Student04, male, 14 years).

- *Unhealthy relationships, risk, and how to keep safe*

Students reported that they would like to learn in RSE about: good and bad relationships including forced marriages, abuse, and what to do in such situations. Students reported that it is important to achieve these outcomes because they need to know how to protect themselves. Students explained that because of their disability or additional conditions (e.g. autism) some students might not know the difference between good and bad relationships and how to leave a bad relationship:

*“Because for me, I like this lesson [good and bad relationships], but [...] I have a feeling if somebody with a lot of autism did not really get this [...] they would try the bad relationship.”*  
(Student14, male, 12 years)

*“[I like this topic] because some people do not know that stuff [how to keep safe] like other people like me. [I want to learn] like how to protect yourself from people doing it.”* (Student03, male, 14 years)

Many students reported that they would like to learn about bullying in RSE. This involved: what classifies as bullying, what to do when being bullied or witnessing students' friends being bullied, and the impact bullying has on mental wellbeing. Students reported that they have been bullied by their peers and other students without intellectual disability:

*“I would like to talk about truly sad things [in RSE]. So yesterday a boy called [name] he is autistic, and a year seven boy called [name] he is from mainstream, and he is bullying the boy autistic, because he is autistic. He pushes him and says rude words [...].”*

*[Student's name that is being bullied] did not cry, he was so brave, but I prayed for him." (Student13, male, 13 years)*

*"I would like to learn how to stop bullying [...] I would like to learn how to make stepping and say: "Hey, stop bullying that person" and then after that I would say: "How about if you stop bullying [...] you can bully me instead?" Because I have been bullied before and if I get bullied at least the person who was getting bullied does not have to go for that anymore." (Student14, male, 12 years)*

However, three students (15.8%) did not like this outcome because learning about this outcome involves discussions about negative things e.g. abuse or bullying.

- *Legal consequences of behaving inappropriately*

This outcome was presented to only four students (21.1%). All students indicated that it is important to learn what classifies as illegal behaviours so that students do not engage in such behaviours and get in trouble with the law:

*"I want to know more [about illegal behaviours] because I might be doing something... like someone might be doing something illegal, but they do not know what is illegal." (Student03, male, 14 years)*

- *Asking for help*

Students reported that it is important to achieve this outcome in RSE because they struggle to ask for help and do not know what to do when needing help. Students discussed that they would like to learn: how to ask for help, when to ask for help (e.g. when feeling unsure), and that there are different people that can help (e.g. parents and teachers):

*"I like this topic because it tells us how this can help you. Friends can help you; parents can help you. [I want to learn] like how to ask people for help if you are not sure to say something, to tell them." (Student10, male, 14 years)*

## Theme 6 – Consent

This theme involves the perspectives of students with intellectual disability on outcomes related to consent grouped into two subthemes:

- *Consent and communication skills*

Students reported that they would like to learn in RSE: why consent is important, what would happen if people touched other people without their consent, how to say “no” when feeling pressured by their peers, and how to have confidence to say “no”. Students reported that is important to learn about consent and how to say “no” to be able to make choices by themselves and resist peer pressure for engage in inappropriate behaviours:

*“I like this one [topic], because people who probably have a lot of autism they probably do not know how to say “no” like I used to [...]. So, it is good that they learn how to do the subject, because if they learn how to say “no”, they will start to [...] learn how to make choices by themselves, they will start to learn how to ignore people like I did [...]. There is just one time in primary [...] someone told me to kiss someone [...]. I sat alone thinking should I do this? But then something inside me just told me no [...]. I felt bad about it because I do not like saying “no” to people [...] because I really love helping people. And like sometimes to this day, I most likely say “yes”.” (Student14, male, 12 years)*

*“[I want to learn] how people say “no” and like build up the confidence [...] because if you like shy and if you do not feel confident saying “no”, just ask a friend or an adult to help you saying the word “no”.” (Student08, female, 13 years)*

However, two students reported that they do not want to learn about consent and how to say “no” in RSE. One student explained that: *“I already learned this topic.” (Student04, male, 14 years)*. The other student did not want to learn about this because teachers at the end of the interview explained that the student does not like saying “no” to people.



- *Social norms of behaviour for a given cultural context*

Students reported that in RSE they would like to learn: what appropriate and inappropriate touch is and why it is important; why some people want to touch other people's private body parts; and what public and private places and behaviours are. Students reported that learning about this e.g. appropriate and inappropriate touch is important for learning how to behave appropriately and to protect themselves from abuse:

*"I want to learn more [about public and private behaviours] because it might be doing embarrassing stuff." (Student04, male, 14 years)*

*"That is very important [learning about appropriate and inappropriate touch] because [...] it is like very bad for you [...]. because you have to say "stop" otherwise there is no stop." (Student12, female, 15 years)*

However, some students indicated that they do not like learning about appropriate and inappropriate touch because these topics involves learning about negative things (e.g. people touching private body parts). Some students also reported that having conversations about these topics makes them feel uncomfortable: *"It is just [a] weird conversation." (Student03, male, 14 years)*

## **Theme 7 – Self-esteem**

This theme involves the views of students with intellectual disability on outcomes related to developing positive self-esteem and confidence grouped into two subthemes:

- *Self-esteem and confidence*

Students reported that they are not feeling confident. Thus, they would like to learn how to be more confident especially when approaching new transitions in life (e.g. going to a new school). Students also wanted to learn how to have confidence to say "no" to people especially when they are in abusive situations:

*“Yes [I want to learn more] because I am not sure how to stay strong yet. [I want to learn about] like if someone is doing something to you really bad you stay strong, you say “no” to their face.” (Student10, male, 14 years)*

*“I would [like to] learn to be confident to go to a new school and do my exams.” (Student01, male, 14 years)*

Students with mobility problems and those who used wheelchairs or mobility devices perceived “confidence” as a prerequisite outcome for being independent in life. These students discussed that they would like to learn in RSE how to be confident to go to community places on their own and ask for help (e.g. when needing help to move up the stairs):

*“Like [this topic] because I want to know like when I am walking home by myself, and my mother and aunt is not there as well. How would you say to them [strangers]: “May I go upstairs by myself?” (Student11, female, 16 years)*

*“I like [this topic] because if you did not feel strong inside you need to build up your confidence and be more independent.” (Student08, female, 13 years)*

*“Confident go to the shop and ask for things, yes [I want to learn more].” (Student17, female, 16 years)*

- *Positive body image*

Students reported that it is important to achieve this outcome in RSE to be more confident in oneself and accept oneself:

*“I like learning about that all bodies are beautiful because [...] you get to feel safer, happier to know that your body is not disgusting, and you get to learn how to love yourself [...] to care about yourself.” (Student14, male, 12 years)*

However, three boys (15.8) placed this outcome into “not sure” side of the mat whether they want to learn about it in RSE and were unable to explain why.

## **Theme 8 – Human rights**

The outcome on knowing human rights was the only outcome presented in this outcome theme to three students (15.8%). All three students indicated that it is important to achieve this outcome in RSE (i.e. understanding that they have

human rights). Students explained that they need to learn about human rights in RSE so that they understand that they have autonomy in their lives (e.g. they can speak up and share their opinions) and they should be treated like all people:

*"[Student selected this outcome as interesting and was asked why] because you should have rights to... if you do not have rights then you feel like you cannot do anything. So, it is good to have rights." (Student12, female, 15 years)*

*"I like this one [human rights] because in case if you are like a person who you feel like you have no rights [...] you have no authority to give your own opinion, this is the perfect lesson because you get to like say to people: "you do have rights, you are a human being, and you deserve to be treated like the rest". (Student14, male, 12 years)*

### **6.3.3 Comparison to adult stakeholders' perspectives**

There were no new outcome themes and subthemes suggested by students in this study. However, students provided additional information on aspects of outcomes already existing; this information had not emerged through the adult stakeholder interviews and served to enrich the description of existing outcomes. Students wanted to learn more on understanding why people want to touch other people's private body parts; what would happen if people touched other people without their consent; why girls have different body changes than boys during puberty; how to express emotions (e.g. to show a correct facial expression that matches how students feel); what to do when students are experiencing cyberbullying; what to do when witnessing students' friends being bullied; and the impact bullying has on mental well-being.

Students' reasons for outcome importance related to some of adult stakeholders' reasons. For example, students wanted to achieve outcomes related to developing healthy romantic relationships (e.g. how to kiss and hug with a romantic partner) so they can develop such relationships in the future as discussed by adults. Outcomes on the social norms of behaviour for a given cultural context were reported as important by students and adults for learning how to behave appropriately and protect themselves. Knowing human rights

was also perceived by students as an important outcome for achieving autonomy in life as suggested also by adults. Achieving outcomes on the sexual orientation and gender identity were reported by students and adults as important for developing tolerant attitudes towards people who identify differently.

Students also agreed with adult stakeholders' views that their unique needs and difficulties were reasons for perceiving some RSE outcomes as important. For example, students discussed that they struggle with recognising their own and other people's different emotions and feelings. Thus, students reported that they want to learn more about this in RSE. Students also discussed that they struggle to say "no" and lack confidence to say "no". Therefore, students wanted to achieve outcomes on consent and confidence which was also discussed by adults as a reason for achieving these outcomes. Students like adults also reported that due to students' difficulties (e.g. with social skills) students struggle to understand unhealthy relationships and how to protect themselves from people who might want to harm them. This was a reason discussed by students and adults for achieving outcomes on unhealthy relationships, risk, and how to keep safe.

However, students provided different reasons than adults as to why some of RSE outcomes were important. Students discussed that they want to achieve outcomes on how to develop and sustain healthy friendships because they do not have friends and feel lonely. Students explained that their disability can be a barrier for finding and making new friends. Adults discussed that students' disability makes it difficult for students to learn how to make friends from informal sources (e.g. by observing other people) rather than that their disability impacts finding and maintaining friends. Learning about different types of relationships in RSE was perceived by students as an important step for developing their confidence of having such relationships in real life. This perspective that learning about relationships is important for developing confidence for having relationships was not mentioned by adult stakeholders. Students also discussed that they want to achieve outcomes on consent to

resist peer pressure for engaging in inappropriate behaviours which was not mentioned as a reason by adult stakeholders.

Students reported that they are bullied online and in person. Many students witnessed their peers being bullied at schools. These students' experiences were reasons for achieving outcomes on online safety and unhealthy relationships. Outcomes on online safety discussed by adult stakeholders had more emphasis on what is inappropriate in the online context so that students do not commit crimes or are abused. Outcomes on unhealthy relationships suggested by adults placed emphasis on students' lack of social skills to recognise such relationships and increased vulnerability to abuse. However, none of adult stakeholders reported that students should achieve these outcomes because they are bullied online and in person.

Students perceived being independent as a reason for achieving outcomes on consent, confidence, pregnancy, and parenting which was not reported as a reason by adults. Students reported that it is important to achieve outcomes on consent to be able to make choices by themselves and be independent in life. Adult stakeholders emphasised the importance of being able to protect themselves and other people as reasons for achieving outcomes on consent. Achieving outcomes on confidence were perceived by students as a prerequisite for being independent in life especially amongst students with mobility difficulties. Students who used wheelchairs and mobility devices reported that they need to develop confidence to be able to go to community places on their own or to ask strangers' help. Adults perceived confidence as impacting attainment of other outcomes e.g. being able to raise concerns and asking for help. However, adults did not mention students' development of independence as a reason for achieving outcomes on confidence in RSE.

Students also discussed that they need to be taught about pregnancy and parenting in RSE because they are not children anymore and they might have children in the future. Students also explained that they will not be able to rely on their parents forever to receive information about these topics. This perspective of wanting to be seen as adults and not depending on their parents

for information was not mentioned by adult stakeholders as reasons for achieving outcomes on pregnancy and parenting. Adults discussed that students should achieve outcomes on pregnancy because they lack understanding related to this topic and they can lose custody of their children.

Students also perceived development of their independence in managing their intimate self-care as an important focus on the outcomes related to puberty and hygiene. Students discussed that learning how to carry out hygiene activities on their own as well as how to deal with puberty changes by themselves in RSE is important. Students explained that they can do some of the hygiene activities by themselves and thus, they would like to learn more how to be independent in their intimate self-care. Development of intimate self-care skills was mentioned by some adult stakeholders when discussing outcomes on hygiene. However, adult suggested outcomes on puberty focused more on understanding what puberty is rather than development of self-care skills.

## **6.4 Discussion**

In this study, I explored the perspectives of students with intellectual disability on RSE outcomes to inform the development of the COS (discussed in Chapter 7). The most important RSE outcome across students with intellectual disability was how to develop and sustain friendships and associated social skills. Consistent with previous studies, students with intellectual disability reported feeling lonely because they do not have friends (Black & Kammes, 2019; Schaafsma et al., 2017; Bates et al., 2017). In the international literature, students with intellectual disability also valued the development of skills in RSE particularly for having friendships (Paulauskaite et al., 2022). Development of social skills needed to develop and maintain friendships is not included as a learning outcome in the statutory RSE guidance (DfE, 2019).

Outcomes on online safety were also perceived by students with intellectual disability as important. This contrasts with teachers' views who in this study reported that students with intellectual disability do not use the Internet

unsupervised. Therefore, topics on online safety were not delivered to some students in RSE. However, students in this study reported that they use social media, and that they experience cyberbullying. Outcomes on unhealthy relationships, risk, and how to keep safe were also perceived as important by students. They mentioned being bullied in person and witnessed their peers being bullied at school. Some students reported not attending school because of bullying.

Previous research also shown that people with intellectual disability are excluded from the online world due to caregivers' fears (Chadwick et al., 2019; Löfgren-Mårtenson et al., 2015; Alfredsson Ågren et al., 2020). A significant proportion of children with intellectual disability have been reported in previous studies as experiencing bullying which can be a reason for school refusal (Llauradó & Estévez 2024; Martínez-Cao et al., 2021; Adams et al., 2022). Outcomes on cyberbullying and unhealthy relationships were perceived as important by students with intellectual disability in the international literature (Paulauskaite et al., 2022). These outcomes are included in the statutory RSE guidance (DfE, 2019).

Development of confidence was another valued RSE outcome by students with intellectual disability. Students perceived outcomes on confidence as a prerequisite for: being independent in life, particularly for students with mobility issues; being able to apply skills in practice (e.g. being able to say “no”); and development of relationships. Outcomes on confidence were also perceived as important by students with intellectual disability in the international literature (Paulauskaite et al., 2022). However, these outcomes were not measured in RSE evaluation studies by researchers (Paulauskaite et al., 2022). The statutory RSE guidance mentions that comprehensive RSE will contribute to development of students' confidence (DfE, 2019). However, “confidence” is not a learning outcome in the guidance (DfE, 2019).

While no new RSE outcomes were identified through the student interviews, students with intellectual disability provided additional information about some of the outcomes that had not been reported by adult stakeholders (Chapter 5).

Most additional aspects of RSE outcomes (e.g. understanding why people want to touch other people's private body parts) are not specified in the statutory RSE guidance (DfE, 2019). Thus, this study identified additional dimensions of RSE outcomes perceived as important by students with intellectual disability that could be used to inform the content of RSE curriculum and the development of the COS of RSE for students with intellectual disability (see Chapter 7 for more details).

#### **6.4.1 Students' reasons for outcome importance**

Students with intellectual disability reported the development of their independence as reasons for achieving some outcomes that was not mentioned as reasons by adults. Students perceived the development of their independence in RSE as involving: being provided with information (e.g. on how to take care of their body); having skills (e.g. self-care and social skills to develop relationships); ability to make choices; go out to community places on their own; and ask for help when needed.

These findings are in line with previous research that indicates that many people with intellectual disability wish to become more independent (Sandjojo et al., 2019, 2020; Bond & Hurst, 2010; Haigh et al., 2013). In previous studies, people with intellectual disability reported that being independent is important because it increases their confidence, self-worth, and autonomy (Sandjojo et al., 2019, 2020; Bond & Hurst, 2010; Haigh et al., 2013). Research indicates that more interventions and programmes for this population should be targeting independence because it is a valuable outcome for people with intellectual disability (Sandjojo et al., 2019, 2020).

Development of students' independence (alongside paid employment, independent living, and community participation) is also one of the aims of special educational needs provision in England (DfE, 2014). A legally binding Special Educational needs and Disability (SEND) code of practice (DfE, 2014) indicates that information and skills needed for development of students' with SEND independence must start early in students' education. When students



with SEND reach 14 years, their education must focus on students' goals for their future and preparation for adult life e.g. employment and living independently (DfE, 2015).

However, research indicates that many people with intellectual disability lack self-determination skills, independence, opportunities for community participation (e.g. opportunities for social activities and friendships), paid employment, and living independently (Bouck et al., 2017; Vicente et al., 2023). For example, in the UK, only 4.8% of people with intellectual disability aged 18-64 years were in paid employment in 2022 (Department for Work and Pensions, 2023). About 65.9% of adults with intellectual disability were living with their parents in 2021 (Office for National Statistics, 2022). In 2019, a survey conducted by a charity "Mencap" in the UK found that 24% of people with intellectual disability reported feeling lonely "a lot" compared to 3.4% of people without intellectual disability (Mencap, 2019). Thus, the aims of special education provision are not being met by young people with intellectual disability.

#### **6.4.2 Students' views on outcomes they do not like**

All students identified some RSE outcomes that they did not like learning about. Some students reported that they do not like learning about private body parts, puberty changes of opposite sex, and sexual activities because learning about these outcomes is 'uncomfortable'. Some students also did not like outcomes on abuse, bullying, appropriate and inappropriate touch because these outcomes involve learning about negative experiences (e.g. people being bullied or touched by strangers). Four students stopped the interviews when these outcomes were presented to them. Many students who took part in the study reported being bullied and some students had historical safeguarding concerns. Therefore, the reason as to why these students perceived these outcomes as uncomfortable could possibly be due to students' negative past experiences. However, learning about these outcomes could possibly involve sensitive and uncomfortable conversations regardless of past negative experiences. Students' perceptions towards learning about sex which

included being uncomfortable, “weird” or a “bad” activity could possibly be impacted by some of adults’ (e.g. parents’ or teachers’) attitudes. For example, some adults in students’ environment might perceive sex as a “bad” or a “weird” activity which then impacts students’ views regarding learning about these outcomes.

#### **6.4.3 RSE content delivered to students**

In this study, RSE content delivered to students with intellectual disability differed depending on the type of school that students attended. This was indicated by the range of outcomes presented to students in the interviews. Students attending SEND units within mainstream schools were taught a wider range of RSE topics compared to students attending special schools. Students at SEND units within mainstream schools also had mild intellectual disability compared to students attending special schools that had moderate to severe intellectual disability. Schools’ ethos and culture (i.e. staff members being open about their sexual diversity) also impacted the range of RSE topics being delivered to students. Teachers’ attitudes towards the “relevance” of delivering a specific topic to students (e.g. online safety) also influenced what students received in RSE.

These findings are consistent with the previous literature which indicates that students with severe intellectual disability are less likely to receive RSE compared to students with mild intellectual disability (Barnard-Brak et al., 2014). Possible explanations reported in the literature include: negative attitudes towards the sexuality of students with severe intellectual disability; believing that teaching RSE topics is not relevant for them; fear that students with severe intellectual disability will misunderstand information; lack of resources and training available to deliver RSE to students with more severe cognitive difficulties (Lafferty et al., 2012; Evans et al., 2009; Kürtüncü & Kurt, 2020; Pryde & Jahoda, 2018; Pownall et al., 2012).

Across students with intellectual disability, outcomes on human rights, sex and sexuality, and the legal consequences of behaving inappropriately were the

least frequently presented outcomes during the interviews as these topics have not been taught yet. Some outcome subthemes suggested by adult stakeholders (Chapter 5) were not presented to students with intellectual disability because they were yet to be taught to the students. These outcomes were: health checks; planning for future relationships; sexual feelings, sexual arousal, and pleasure; masturbation; consent in sexual activities and the law; self-advocacy skills. These outcome subthemes are also not included in the statutory RSE guidance for English schools (DfE, 2019).

However, it seems that students with intellectual disability wanted to learn about these outcomes that were not presented to them in the interviews. Additional information about RSE outcomes provided by students in this study suggests this. For example, students reported that they wanted to learn in RSE why people want to touch other people's private body parts. Learning about this outcome could involve learning about sexual feelings and pleasure. Students also reported that they wanted to learn in RSE what would happen if people touched other people without their consent. Learning about this outcome could involve discussions about the legal consequences of behaving inappropriately and sexual activities and the law.

#### **6.4.4 Strengths and limitations**

To my knowledge, this is the first study to explore the views of students with intellectual disability on RSE outcomes. This is also the first study that has included stakeholders with lived experience of intellectual disability in the development of a COS, making sure that outcomes reflect their needs and concerns. This study is also one of only a few studies that has involved voices of children and young people on meaningful outcomes to develop a COS (Sherratt et al., 2020; Gargon et al., 2021). Besides, this study is also one of a few studies that explored direct views of children and young people with intellectual disability with vocal communication difficulties (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019).

In this study, the methodological approach used for exploring the views of students with intellectual disability is a clear strength. Three visual data collection methods were offered to accommodate varied students' needs and abilities for participation (although only two methods were employed with students). Consultation with students with intellectual disability who did not take part in this study on the visual material used in the interviews was carried out to facilitate comprehension on this complex topic. Talking Mats and art-based discussions proved to be useful methods to explore the perspectives of students with intellectual disability. I was able to engage with male and female students with intellectual disability that had different abilities, ages (12-24 years), ethnicities (e.g. only 42% of students identified as White), attending mainstream and special schools. Thus, a range of perspectives of students with intellectual disability on RSE outcomes were explored and informed the consensus stages of the COS.

Collaboration with students' teachers and parents to adapt the interview procedure was an essential part for successful data collection with students with intellectual disability. Parents and teachers helped to select one out of three possible data collection methods since they knew the students well and knew which method students were familiar with. Students' assent was obtained prior to data collection and re-evaluated throughout the study despite familiar adults providing information regarding which activity students would prefer to take part in. The involvement of familiar adults' views for selection of a suitable data collection method with children with intellectual disability was mentioned in the literature before as an essential step for allowing the views of children with diverse abilities to be explored in research settings (discussed in Chapter 2) (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019; Carroll & Sixsmith, 2016). In previous studies, parents of children with intellectual disability reported that they wished researchers presented to them a couple of possible data collection methods so that parents could guide researchers which one method would be suitable for their child (Teskaye et al., 2019; Nicholas et al., 2019).

The presence of familiar staff i.e. RSE teachers in the interviews, helped some students to feel more comfortable in the interview. Some students at times were seeking reassurance from their teachers e.g. by looking at them when placing RSE outcomes on the mat or asking how they would answer questions. RSE teachers also helped to monitor students' signs of distress and anxiety that would require termination of the interviews. None of the interviews were terminated because students appeared distressed. RSE teachers also helped me at times to understand what students with vocal communication difficulties were saying and to explain some of RSE outcomes to students. Thus, this study showcases the importance of involving familiar adults in the data collection procedure as facilitators for enabling children and young people to participate in research.

However, this study has some limitations. First, convenience sampling was used to recruit students in this study. I struggled to find schools that could help with recruitment (as discussed in Chapter 3). Many of the schools approached declined to participate because they felt that students would not be able to participate due to their lack of RSE knowledge or cognitive abilities. Schools also often declined participation because they thought that students' parents from cultural and religious diverse backgrounds would object students' participation. Therefore, it is possible that findings are subject to sampling bias. The COVID-19 pandemic also impacted the availability of school staff to help with student recruitment. One school pulled out from the study due to pandemic induced staff shortages. Thus, it is possible that students who took part in the study were attending schools that had: more resources (e.g. time and school staff); more comprehensive RSE delivery; and more liberal attitudes towards students' abilities to participate than schools that declined participation.

Second, the views on RSE outcomes reported in this study do not necessarily reflect the views of all students with intellectual disability. I was not able to recruit students in primary education or aged 5-11 years. Schools reported that younger students with intellectual disability would not be able to participate in this study due to a lack of knowledge on this topic. Most students with

intellectual disability (68.4%) reported Christianity as their religious affiliation. Only one student who took part in the study had severe intellectual disability. Thus, the findings in this study do not reflect the views of younger students with intellectual disability (i.e. aged 5-11 years), those with severe intellectual disability, and diverse religious backgrounds. Additionally, nine (47.4%) students had autism as an additional condition to intellectual disability. Young autistic people with or without intellectual disability struggle with social interactions and have difficulties with social skills (Hughes et al., 2012; Bellini et al., 2007). This could be another possible reason in addition to reasons provided by students as to why one of the most important outcomes across students in this study was understanding how to develop and sustain friendships and associated social skills. It is also possible that outcomes perceived as important by students with intellectual disability in this study do not reflect outcomes that all students with intellectual disability perceive as important e.g. (students that have Down syndrome, Williams syndrome).

Third, the methodological approach while generally useful had some limitations. Three students with severe intellectual disability were not able to express their views on RSE outcomes in this study. A picture sorting activity using Talking Mats selected as the best method out of three possible was not effective. However, one student with severe intellectual disability was able to express his views using this method. This finding possibly reflects differences in students' cognitive abilities or the quality of RSE delivered to them. However, this study echoes the findings of previous studies that reliable methods for seeking the direct views of children and young people with severe communication difficulties are needed (Richards & Crane, 2020; Gore et al., 2021; Tesfaye et al., 2019; Nicholas et al., 2019).

Additionally, I have not carried out any effectiveness frameworks for evaluating the effectiveness of communication in the poster making activity and the picture sorting activity using Talking Mats for reasons previously explained in this chapter. Thus, there is a possibility that I over- or under- estimated the engagement of some students in the activities, their comprehension of the

topic being discussed and their views on outcomes. In other words, there is possibility that my own bias has impacted the interpretation of data collected with students which as I argued in Chapter 3 (section 3.1.2) is unavoidable in all research. For this reason, it is always important to understand the positionality of the researcher, which I have described in the 3.1.2 section.

Three students (15.8%) took part in arts-based discussions rather than a picture sorting activity using Talking Mats that was completed by most participants (84.2%). It is possible that slight differences between these two methods such as different times when additional follow-up questions were asked and the way that students indicated their preferences towards the outcomes (e.g. by placing on sides of the mat or selecting to be feature on their poster) impacted students' views gathered in this study. For example, it is possible that more information was collected during a picture sorting activity that involves follow-up questions asked for each placement of a picture on either side of the mat (e.g. why you placed this outcome on the do not like side?). Adaptations to the language made in this study to accommodate students' different abilities for participation, might have also impacted what information was shared by a student in this study. For example, in an arts-based activity some students were asked to select interesting RSE topics, and some students were asked to select topics that they like learning about. Language used in both activities aimed at finding out students' views towards RSE outcomes as well as follow-up questions; however, it is possible that these adaptations might have produced different responses. Importantly though, these differences enabled the input of students who could not otherwise have taken part at all, and given that the purpose of the exercises was to develop a diverse range of outcomes for the survey (Chapter 7), this should be seen as a strength, not a weakness, so long as it is acknowledged (Clark & Moss, 2017).

I was also unable to explore students' views on all outcomes collected in this project (e.g. masturbation). Familiar adults e.g. teachers and parents decided what topics should not be discussed with students due to the fact that such

topics were not delivered yet to students or are sensitive (relate to historical safeguarding concerns). Thus, student's views on more sensitive RSE outcomes have not been explored in this study and were not involved in the COS development.

## **Conclusions**

In this study, I explored the perspectives of students with intellectual disability on RSE outcomes using an approach that enabled students with different abilities to take part. The most important RSE outcomes across students were: how to develop and sustain friendships and associated social skills; online safety; unhealthy relationships, risk, and how to keep safe; and development of confidence. Students' explanations for the importance of these outcomes related to difficulties developing friendships, bullying, and a lack of confidence. Outcomes on private body parts, puberty changes of opposite sex, sexual activities, abuse, bullying, appropriate and inappropriate touch were perceived by students as 'uncomfortable' due to involving learning about negative experiences. Students' reasons for some of the outcome importance related to development of independence that was not reported as reasons by adult stakeholders. Adult explanations for the importance of these outcomes related to managing risks and keeping safe. Students also provided additional information about some of the outcomes that had not been reported by adult stakeholders. In the next chapter, I will discuss how students' views were incorporated with the data collected in this project to inform the development of consensus of this COS.



## Chapter 7 – Consensus on important outcomes

*“I think [RSE] concepts need to be age appropriate but more work with parents needs to be done on the why we teach these topics.”  
(Teacher\_26, round 2)*

### Introduction

In this chapter, I present the fourth study. This study aimed to establish stakeholder consensus on the importance of RSE outcomes to be included in the COS for RSE evaluations. Stakeholders for this study were parents, teachers/school staff members, researchers, and policy makers/people from third sector organisations. This chapter begins by describing the aims of this study and methods employed to reach consensus. I then present participants' demographic characteristics and findings on outcomes that reached consensus to be included in the final COS. The differences between stakeholder groups are also discussed. I finish this chapter by providing a discussion of the findings.

### 7.1 Aims

The main aim of this study was to establish consensus across adult stakeholders on important RSE outcomes to be included in the COS of RSE for students with intellectual disability.

Secondary aims were:

- 4) to establish consensus across adult stakeholders on the most important RSE outcomes for students with intellectual disability in primary and secondary education;
- 5) to explore whether different stakeholder groups (e.g. parents compared to teachers) perceive different outcomes as important.

## **7.2 Methods**

### **7.2.1 Study design**

This was a quantitative study that involved an electronic survey.

### **7.2.2 Delphi survey**

A two round electronic Delphi survey was used to reach consensus across adult stakeholders on the most important outcomes to be included in the final COS. Students with intellectual disability did not take part in the Delphi survey, as explained in Chapter 3. The Delphi survey was hosted in Qualtrics™ software version 2023 (Qualtrics International Inc.). In the survey, stakeholders were presented with RSE outcomes extracted from previous phases of this PhD (the systematic review and data collection with adults and students Chapters 4-6) and grouped into 31 outcome subthemes (presented previously in Figure 5.3 in the 5.3.2 section). Please see the “7.2.3 outcome generation for inclusion in the Delphi study” section on how the outcomes were extracted and categorised in this study. Outcomes related to eight RSE themes: the human body and development; emotions and feelings; healthy relationships and associated social skills; sex and sexuality; keeping safe; consent; self-esteem; and human rights.

#### *Round 1 of the survey*

In this round, stakeholders were presented with 31 outcomes, each accompanied by a brief and accessible description (see Figure 7.1 below for an outcome rating question and Appendix 7.1 for round 1 of the survey). The order of outcome theme presentation was random to control for presentation order effects. Subthemes were grouped within their relevant themes. For example, all outcomes in the “human rights” theme were presented together to make the order of survey questions easier to follow.

Participants were asked to rate how important it is that students with intellectual disability have knowledge related to each outcome. Participants

rated outcomes separately for younger and older children anchored at the end of primary education and at the end of secondary education. These two time points were selected based on feedback received from the survey pilot (see the “7.2.4 Pilot” section). Terms relating to COS were not used in the survey such as “How important is it to include x outcome in the COS?”. The population involved in this study e.g. parents might not have had prior knowledge of the “COS” term. To avoid confusion and participant burden this term was avoided and simple language was used throughout the survey.

A 9-point Likert scale was used to rate each outcome. The anchor points were as follows: 1 - extremely unimportant; 2 - very unimportant; 3 - unimportant; 4 - maybe unimportant; 5 - unsure whether it is important/unimportant; 6 - maybe important; 7 - important; 8 - very important; 9 - extremely important. The wording of the scale options was based on the wording used in another COS development study on a psychosocial intervention (Powell et al., 2022). The piloting indicated that this wording of response options was clearer to stakeholders than the wording used in the scoring framework recommended by the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) that I initially planned to use (Guyatt et al., 2011). Stakeholders were also provided with a response option for “unable to score” (scored as missing data) for outcomes that they were unable to rate.

A free text box was provided at the end of outcome rating questions for stakeholders to leave comments or suggest any missing outcomes that were not presented in the survey. After the outcome rating questions, stakeholders were asked to indicate which stakeholder group they belonged and to provide demographic information (see Appendix 7.1). Stakeholders who belonged to two or more stakeholder groups, e.g. they were parents and also teachers, were asked to select the perspective that they used more frequently to rate the outcomes.

### *Round 2 of the survey*

In this round, stakeholders received feedback on how they rated the outcomes in round 1 alongside how other stakeholder groups (four adult groups and students) rated the same outcomes. Students' views on RSE outcomes were presented based upon the findings of the previous study (Chapter 6). Outcomes that students liked and wanted to learn more about was reported alongside some of their quotes. Stakeholders were presented with their own ratings from round 1 so they could see how they rated the outcomes compared to other stakeholders. The average score of each of the four adult stakeholder groups was presented in a bar chart (see Figure 7.2 below and Appendix 7.2 for round 2 of the survey). Stakeholders were asked to re-rate the 31 outcomes using the same 9-point scale as in round 1. Stakeholders were told that they could select their original rating (from round 1) or change to another rating. Towards the end of the survey, stakeholders were asked to provide comments about the outcomes, their ratings, and the survey.

Figure 7.1 Outcome rating question in round 1

### Consent and communication skills

Teaching about consent may include, but is not limited to, teaching what consent is in different situations (e.g. consensual and non-consensual touch), why consent is important (e.g. what will happen if students touch someone without their consent), that it is okay to say “no”, that people will show their “no” in different ways (e.g. verbal and non-verbal consent) and students need to respect it, and teaching communication skills related to providing consent and seeking consent (e.g. what to say, understanding people’s responses).

Please rate how important it is that students with learning disability have knowledge related to **consent** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

Figure 7.2 Outcome rating question in round 2

**Recognising emotions and feelings**

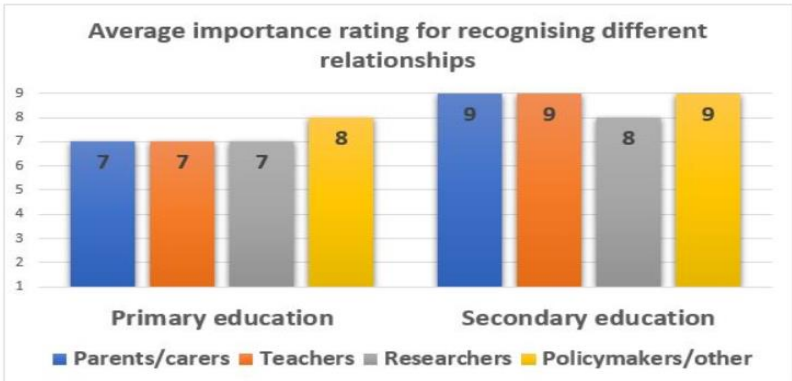
Teaching about different emotions and feelings **may** include, but is not limited to, teaching what different feelings/emotions are and what they mean (e.g. happy, scared), how to communicate (verbally or using a communication aid) about different feelings/emotions, how to empathise with other people (e.g. identify other people's emotions/feelings and put themselves in their situation).

**Summary of scores:**

You rated this outcome as: **7** for the primary educational stage and **9** for the secondary educational stage.

**Students** liked this outcome or/and wanted to learn more about it. Some students' quotes: "I want to know more, because sometimes it is confusing to read some people when they are angry or upset. [I want to learn] like how to know if someone is upset by the mood or the face expressions and stuff like that" (Student03, male, 14 years); "[I want to learn more about] different feelings, if people are rude or something" (Student17, female, 16 years)

Other groups of people rated this outcome as:



Please rate how important it is that students with learning disability have knowledge related to **recognising different emotions/feelings** after RSE? Please select one option below for each educational stage. You can select your original rating (from round 1 presented above) or change to another rating.

|                                           | 1-<br>Extremely<br>Unimportant | 2- Very<br>Unimportant | 3-<br>Unimportant     | 4- Maybe<br>unimportant | 5- Unsure<br>whether it is<br>important/<br>unimportant | 6- Maybe<br>important | 7-<br>Important       | 8- Very<br>Important  | 9-<br>Extremely<br>important | Unable to<br>score    |
|-------------------------------------------|--------------------------------|------------------------|-----------------------|-------------------------|---------------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------------|-----------------------|
| By the end of <b>primary</b> education?   | <input type="radio"/>          | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>        | <input type="radio"/> |
| By the end of <b>secondary</b> education? | <input type="radio"/>          | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>        | <input type="radio"/> |

### **7.2.3 Outcome generation for inclusion in the Delphi study**

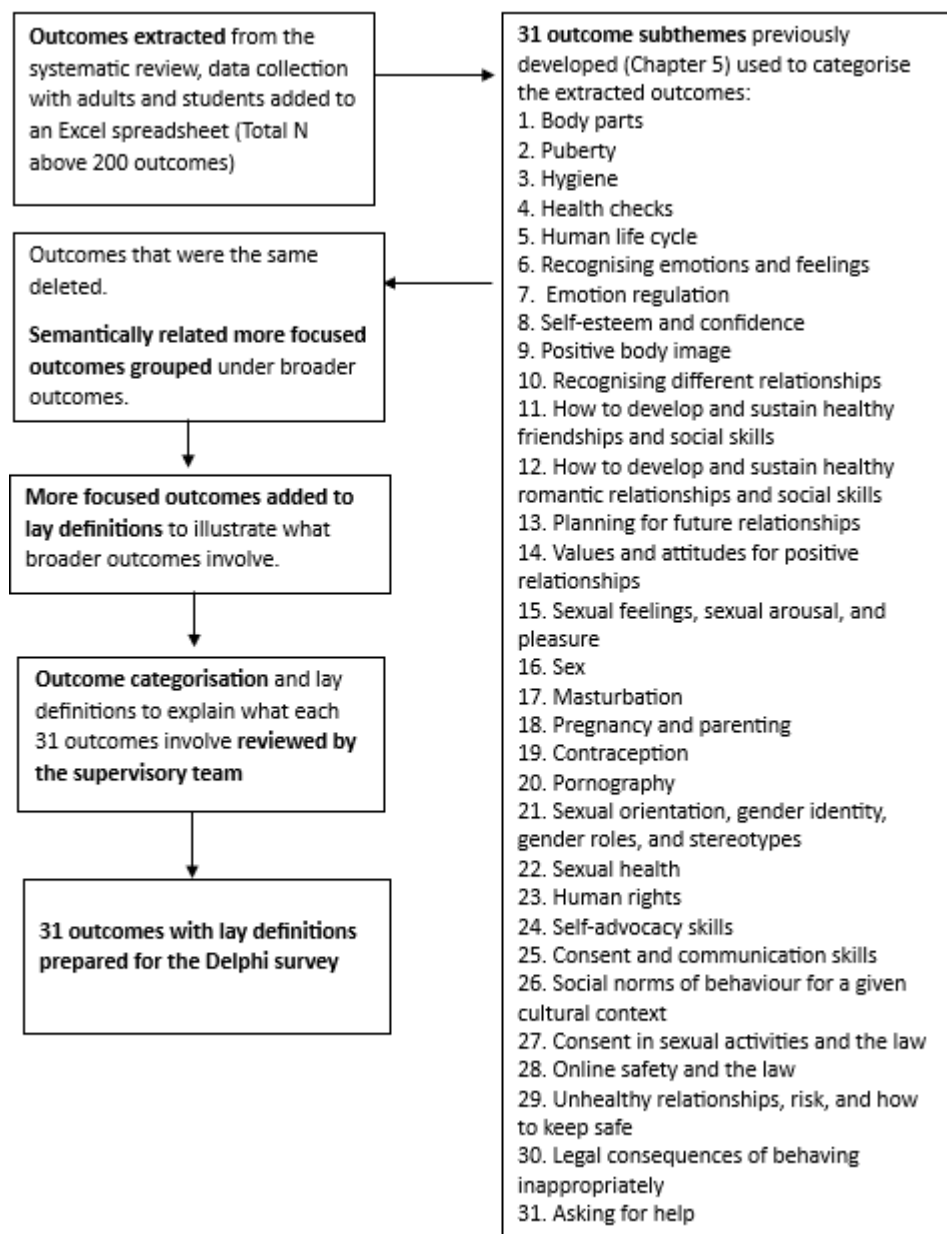
Outcome subthemes developed from the framework analysis on adult stakeholders' perspectives (Chapter 5) were used as a "taxonomy" to categorise extracted outcomes from the previous studies of this project. The categorisation of extracted outcomes to the subthemes involved an iterative process (presented in Figure 7.3). First, I extracted outcomes identified in the previous stages and added them to semantically related outcome subthemes in an Excel spreadsheet. For example, outcomes extracted on the human body were added to the outcome subtheme on body parts. Then, the outcomes that were the same were deduplicated (deleted).

Semantically related more focused outcomes were grouped under broader outcomes. For example, the outcome "understanding what is like being a man or a woman with disability" extracted from the systematic review was grouped under the "self-esteem and confidence" broad outcome. I have added more focused outcomes to lay definitions to illustrate what broader outcomes involve. For example, an outcome on "understanding why some people want to touch other people's private body parts" suggested by students (Chapter 6) was added to describe what the "social norms of behaviour for a given cultural context" outcome involves. The supervisory team has reviewed the categorisation of outcomes and definitions of outcomes that helped to refine them.

Extracted outcomes were not categorised to three outcome lists based on educational stages or students' age as a deviation from the project protocol (Paulauskaite et al., 2022), for two reasons. First, there was an overlap between outcomes for different educational stages extracted from the systematic review and suggested by adult stakeholders. Second, outcome subthemes were used to reduce the long list of outcomes (for reasons previously explained). Presenting the same outcomes separately for three

educational stages might have resulted in higher participant burden and likely higher levels of attrition.

Figure 7.3 Outcome categorisation process



#### 7.2.4 Pilot

Both rounds of the survey were piloted separately with a small group of parents of students with intellectual disability and RSE teachers who did not take part in this study. Parents had children with different levels of intellectual disability and teachers were from two special schools. I sent both rounds of the survey



on two separate occasions to parents and teachers to review. Then, I had discussions over the phone with parents and teachers separately. Findings from the pilot phase indicated that parents and teachers did not find the survey too long and enjoyed reading it. However, parents and teachers provided some suggestions to improve the readability and clarity.

The pilot of round 1 revealed that the wording of the 9-point scale used in another COS study (Powell et al., 2022) was perceived clearer than the wording used in the GRADE approach (Guyatt et al., 2011). In the GRADE scoring framework, outcomes scored 1 to 3 are worded as “unimportant outcomes”, outcomes scored 4 to 6 are worded as “important but not critical” and outcomes scored 7 to 9 are worded as “critical outcomes”. It was not clear to stakeholders what is the difference between outcomes rated as 1-3 as they are worded the same e.g. “unimportant”. The outcome rating question was also changed from “how important is it that students *demonstrate knowledge* related to the outcome” to “*have knowledge*”. The term “demonstrate knowledge” was perceived as misleading by parents and the term “have knowledge” was suggested as alternative. An explanation of what the term “have knowledge” means was also added to the information on how to rate the outcomes in the survey.

Asking participants to rate RSE outcomes at two educational stages (i.e. the end of primary education and the end of secondary education) was selected as the most appropriate way to differentiate developmental or chronological age differences. In English schools, RSE is delivered to students with intellectual disability over a period of 10 years e.g. when students are aged 5-25 years (DfE, 2019). Rating outcomes for two educational stages was discussed as important considering the length of RSE delivery and the population concerned. Different RSE outcomes might be important to achieve for students with intellectual disability at different educational stages as they grow and develop. However, some parents felt that rating outcomes by educational stages is not appropriate because of differences between students’ developmental age and chronological age. Parents explained that some students with intellectual disability will not be “ready” to learn some of

the topics due to their developmental delays. Thus, some students with intellectual disability will not receive RSE till they are older e.g. 16 years old and in further education. However, teachers disagreed with this view. They reported that rating outcomes for two educational stages is important. Teachers discussed that they need guidance on what should be taught at the earlier stages of students' education i.e. during primary school. Teachers explained that RSE is currently delivered reactively to students with intellectual disability (e.g. after puberty or a problem) and not proactively (e.g. before puberty).

I asked parents and teachers whether a third educational stage (i.e. by the end of further education) should be added. However, both groups suggested that this third educational stage should be incorporated into the secondary educational stage. Parents and teachers reported that students in further education might be learning what they have not learned in secondary education. The distinction between important outcomes to achieve by the end of primary education and the end of secondary education was perceived as more meaningful than between secondary and further education. Thus, two educational stages were used as anchors for rating important RSE outcomes.

In the pilot of the round 2 of the survey, bar charts were perceived by parents and teachers as a clear way to represent the summary of scores from round 1. Parents and teachers also provided suggestions on how to improve the clarity of language used to share students' feedback on RSE outcomes.

### **7.2.5 Procedure**

Participants took part in the study from May to July 2023. Round 1 of the survey was open for about 3 weeks from 17<sup>th</sup> May to 11<sup>th</sup> June 2023. Round 1 of the survey was administered via an anonymous survey link using the Qualtrics survey tool to facilitate recruitment. Stakeholders did not need to provide their emails first to receive round 1 of the survey. The landing page of the survey contained information about the study and a participant information sheet. The importance of completing two rounds of the survey was explained in the

landing page. Participants were informed that they have one week to complete round 1 of the survey once they have started it.

Stakeholders were asked to provide informed consent; the form for indicating consent was embedded in the survey. Only participants who provided informed consents were able to access the survey questions. Participants were asked to provide their full name and email address to enable invitation to round 2 of the survey. These data were used to link round 1 to round 2 so that participants could see their ratings from round 1 in round 2 of the survey (see Appendix 7.3 for instructions on how this Delphi survey was programmed in Qualtrics). After this, participants were presented with information on how to rate the outcomes. Participants were informed that outcomes presented in the survey were extracted from the previous stages of this project i.e. suggested by adult and student stakeholders. Participants were informed that the aim of the survey is to identify the most important RSE outcomes for students with intellectual disability regardless of whether they think they are feasible to measure. Participants were told that deciding on how these outcomes should be measured is not the aim of this study. Then, participants were presented with outcome rating questions; these were mandatory, and participants were unable to skip the questions. Once participants finished rating all outcomes, they were asked to provide comments and answer demographic questions.

Round 2 of the survey was open for about 3 weeks from 15<sup>th</sup> June to 11<sup>th</sup> July 2023. To access round 2 of the survey, participants were asked to type in the email address they had provided in round 1. Then, participants were presented with information about this round of the survey and how to re-rate the outcomes. The outcome rating questions had a summary of scores presented as bar charts for adult stakeholder groups and students' views on outcomes presented in writing alongside some of their quotes. All 31 outcomes were retained in round 2. Once participants finished re-rating the outcomes, they were asked to provide comments. The end of survey message had a list of national resources (charities that support families of students with intellectual disability and RSE teaching resources developed for this population) that participants could refer to if interested (see Appendix 7.4).

In both rounds of the survey, two reminders to complete the survey were sent to participants who had not declined participation but had not completed the survey. Each round of the survey took approximately 30 minutes to complete and support for accessing and completing the survey was provided when needed.

#### **7.2.6 Data analysis**

The data collected in Qualtrics were extracted in an Excel version 2401 (Microsoft Corporation) spreadsheet and anonymised. I removed participants' identifiable information from the spreadsheet. Participants' demographic information and outcome ratings were analysed using descriptive statistics such as medians and percentages in Excel. Consensus to retain an outcome in the final COS was determined following criteria suggested by the COMET (Williamson et al., 2017) and decided a priori as specified in the project protocol (Paulauskaite et al., 2022). In this study, consensus to retain an outcome in the final COS ("consensus in") was determined when  $\geq 70\%$  of the participants gave the outcome a score between 7 and 9 while also  $< 15\%$  of the participants scored the outcome as 1 to 3 points in round 2 of the survey. Outcomes were not included in the final COS ("consensus out") when  $\geq 70\%$  of the participants scored the outcome as 1 to 3 points and  $< 15\%$  of the participants scored the outcome as 7 to 9 points in round 2 of the survey.

Attrition bias was also assessed in this study. Participants who completed only round 1 of the survey might have had different views than participants who completed both rounds of the survey. If participants who only completed round 1 also completed round 2 their scores might have impacted the final COS list. Attrition bias was assessed by comparing an average outcome rating (median) across all outcomes between round 1 of participants who completed both rounds and an average outcome rating (median) across all outcomes of participants who completed only round 1. These average scores were compared in parents' and teachers' stakeholder groups because these were the groups where attrition happened in round 2. The calculations were performed in Excel using "Pivot Tables" function.

I also compared outcomes that reached “consensus in” and “consensus out” in round 1 and round 2 to see whether the feedback provided in round 2 impacted participants’ ratings and the final COS. The comparison was performed on outcome ratings provided by 90 participants who fully completed both rounds. Statistical differences on outcome ratings between two rounds were explored using the Wilcoxon signed-rank test (Wilcoxon, 1945) in SPSS version 28.0.0.0 (190) (IBM).

Differences between stakeholder groups (e.g. parents and teachers) on outcomes that reached “consensus in” and “consensus out” were also assessed. I applied the consensus criteria (discussed above) to outcome ratings in round 2 to each stakeholder group separately. Statistical differences on outcome ratings in round 2 between four stakeholder groups were explored by applying the Kruskal–Wallis test (Kruskal & Wallis, 1952) in SPSS. When the Kruskal–Wallis test indicated significant differences on the outcome rating scores between stakeholder groups, pairwise comparisons were performed in SPSS. The pairwise comparisons with adjusted p-values (to not inflate the Type I error, false positive results, by performing several tests on the same data) was performed to explore which groups differed on outcome ratings (Field, 2017).

Stakeholders’ comments provided in the free text boxes were reviewed to identify new outcomes. Stakeholders’ suggestions for outcomes and their definitions from round 1 were brought to the supervisory team for discussion ensuring credibility of my decisions. A summary of stakeholders’ comments from round 1 and 2 (presented in the results section) was completed by me. I read the comments in both rounds and presented a summary of main points mentioned by stakeholders. I did not perform a qualitative data analysis on the stakeholders’ comments because I did not aim to collect qualitative data (e.g. on participants’ reasons for outcome ratings) at this stage of the project. The aim of the free text boxes was for stakeholders to suggest additional outcomes that were not presented in the survey.

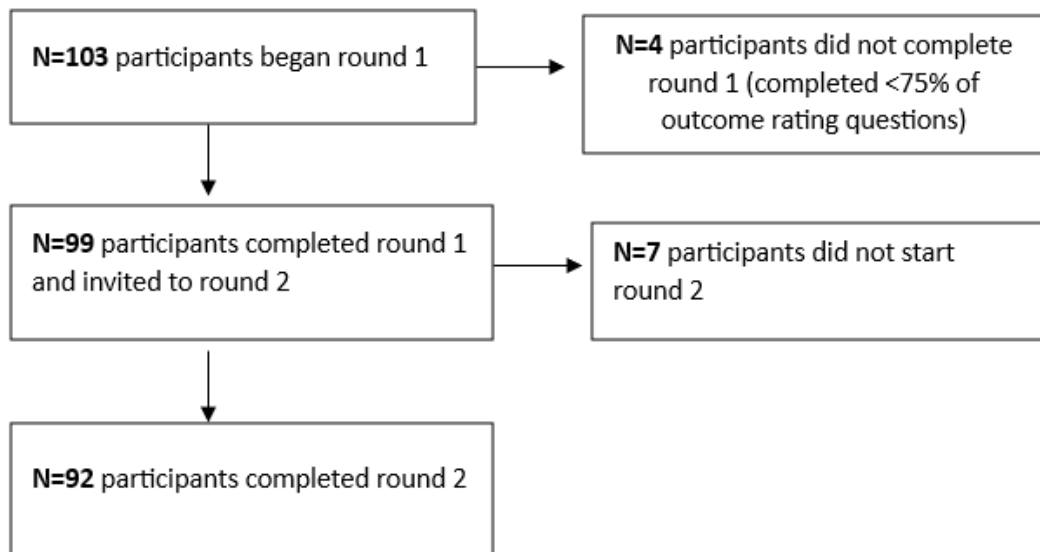
## **7.3 Results**

The results are presented as follows: first, I present participants' demographic characteristics. Second, outcomes that reached consensus as the most important across participants and were included in the COS are presented alongside findings of the attrition bias assessment. Where there were differences regarding outcomes that reached consensus as the most important between different stakeholder groups, this is reported as well. I then provide a summary of participants' comments reported in round 1 and round 2 of the survey.

### **7.3.1 Participants**

Figure 7.4 represents a flow chart of study participants in round 1 and 2 of the survey. A total of 103 participants took part in the study. Of those, 99 completed round 1 of the survey and rated all outcomes. Four participants (3.9%) completed less than 75% of round 1 (i.e. only rated a few outcomes). Thus, these four participants were not invited to participate in round 2. Their scores were not included in the data analysis. Out of 99 participants who completed round 1, 92 (92.3%) participants completed both rounds of the survey. Seven participants (7%; 2 parents and 5 teachers) did not complete round 2 of the survey. Out of 92 participants who completed round 2 of the survey, 90 participants answered all outcome rating questions, and 2 participants did not rate all the outcomes. Thus, a total of 90 participants rated all outcomes in round 1 and round 2. However, all 92 participants' outcome ratings from round 2 were included in the data analysis. I purposively overrecruited participants in round 1 (the target number was 10-15 participants in each adult stakeholder group) to account for possible attrition in round 2. Participant retention in round 2 was 92.9%.

Figure 7.4 Flow chart of study participants



Participants' demographic characteristics who completed only round 1 or both rounds of the survey were similar (Tables 7.1-7.3). I discuss here participants' demographic characteristics who completed both rounds of the survey as they determined the final COS. In round 2, the four adult stakeholder groups consisted of: 33 (33.7%) parents, 30 (32.6%) teachers/school staff, 13 researchers (14.1%) and 18 (19.6%) policy makers/people from third sector organisations. Most participants were female (80.4%) and reported having White ethnicity (90.2%), no religious affiliation (57.8%) and living in England (86.8%). About a third of participants were aged between 36-45 years (34.8%). Most parents who took part in this study had a boy (57.6%) aged a mean of 14 years (SD=4.7, range 7-24 years) with moderate intellectual disability (45.5%) and autism as an additional condition (72.7%). The majority of teachers and school staff were currently delivering RSE to students with intellectual disability (76.7%). Most participants in the policy makers/third sector group were policy advisers from third sector organisations and charities for people with intellectual disability (61.1%).

Table 7.1 Participants' demographic characteristics in round 1 and 2

| Characteristics                                          | Round 1<br>N=99<br>N (%) | Round 2<br>N=92<br>N (%) |
|----------------------------------------------------------|--------------------------|--------------------------|
| <b>Stakeholder group</b>                                 |                          |                          |
| Parents                                                  | 33 (33.3%)               | 31 (33.7%)               |
| Teachers/school staff members                            | 35 (35.4%)               | 30 (32.6%)               |
| Researchers                                              | 13 (13.1%)               | 13 (14.1%)               |
| Policy makers/people from third sector organisations     | 18 (18.2%)               | 18 (19.6%)               |
| <b>Age</b>                                               |                          |                          |
| 25-35 years                                              | 20 (20.2%)               | 19 (20.7%)               |
| 36-45 years                                              | 36 (36.4%)               | 32 (34.8%)               |
| 46-55 years                                              | 31 (31.3%)               | 29 (31.5%)               |
| 56-65 years                                              | 10 (10.1%)               | 10 (10.9%)               |
| <b>Gender</b>                                            |                          |                          |
| Female                                                   | 80 (80.8%)               | 74 (80.4%)               |
| Male                                                     | 17 (17.2%)               | 16 (17.4%)               |
| <b>Country of residence</b>                              |                          |                          |
| England                                                  | 86 (87.8%)               | 79 (86.8%)               |
| Other country in the UK                                  | 4 (4%)                   | 4 (4.4%)                 |
| Outside the UK (Europe, USA, Australia, and New Zealand) | 8 (8.2%)                 | 8 (8.8%)                 |
| <b>Ethnicity</b>                                         |                          |                          |
| White                                                    | 88 (88.9%)               | 83 (90.2%)               |
| Other                                                    | 11 (11.1%)               | 9 (9.8%)                 |
| <b>Religious affiliation</b>                             |                          |                          |
| No religion                                              | 57 (58.8%)               | 52 (57.8%)               |
| Christianity                                             | 33 (34%)                 | 32 (35.5%)               |
| Islam                                                    | 4 (4.2%)                 | 3 (3.3%)                 |
| Other                                                    | 3 (3%)                   | 3 (3.3%)                 |



Table 7.2 Participants' child with intellectual disability characteristics

| Characteristics                              | Round 1<br>N (%)    | Round 2<br>N (%)    |
|----------------------------------------------|---------------------|---------------------|
| <b>Parents</b>                               | <b>N=36* (100%)</b> | <b>N=33* (100%)</b> |
| Child's age (years)- Mean (SD) (range)       | 14.2 (4.6) (7-24)   | 14 (4.7) (7-24)     |
| Child's gender- male                         | 20 (57.2%)          | 19 (57.6%)          |
| <b>Child's level of ID</b>                   |                     |                     |
| Mild                                         | 4 (11.4%)           | 4 (12.1)            |
| Moderate                                     | 15 (42.9%)          | 15 (45.5%)          |
| Severe                                       | 14 (40%)            | 13 (39.4%)          |
| Profound                                     | 2 (5.7%)            | 1 (2%)              |
| <b>Child's vocal communication abilities</b> |                     |                     |
| Speaks in sentences                          | 23 (65.7%)          | 23 (69.7%)          |
| Speaks a few words                           | 6 (17.1%)           | 5 (15.2%)           |
| Makes some sounds                            | 3 (8.6%)            | 2 (6%)              |
| No speech                                    | 3 (8.6%)            | 3 (9.1%)            |
| <b>Child has additional conditions</b>       |                     |                     |
| Autism                                       | 25 (69.4%)          | 24 (72.7%)          |
| ADHD                                         | 13 (36.1%)          | 12 (36.4%)          |
| Speech delay                                 | 12 (33.3%)          | 10 (30.3%)          |
| Hearing or visual impairment                 | 4 (11.1%)           | 2 (6%)              |
| Sensory difficulties                         | 2 (5.5%)            | 2 (6%)              |
| Mental health problems                       | 2 (5.5%)            | 2 (6%)              |
| Physical health problems                     | 1 (2.7%)            | 1 (2%)              |
| Epilepsy                                     | 2 (5.5%)            | 2 (6%)              |
| Down Syndrome                                | 1 (2.7%)            | 1 (2%)              |
| Cerebral palsy                               | 1 (2.7%)            | 1 (2%)              |

*Note:* The total number of parents in this table is higher than the number of parents in the stakeholder group because some teachers and policy makers/ people from third sector organisations also had children with intellectual disability; ID=intellectual disability; ADHD=attention deficit hyperactivity disorder.

Table 7.3 Additional stakeholders' characteristics

| Characteristics                                               | Round 1<br>N (%)   | Round 2<br>N (%)   |
|---------------------------------------------------------------|--------------------|--------------------|
| <b>Teachers/school staff members</b>                          | <b>N=35 (100%)</b> | <b>N=30 (100%)</b> |
| <b>Professional role</b>                                      |                    |                    |
| Class Teacher                                                 | 12 (34.3%)         | 12 (40%)           |
| RSE Teacher                                                   | 11 (31.4%)         | 10 (33.3%)         |
| Headteacher                                                   | 2 (5.7%)           | 2 (6.7%)           |
| Assistant Headteacher                                         | 2 (5.7%)           | 1 (3.3%)           |
| Speech and language therapist                                 | 2 (5.7%)           | 1 (3.3%)           |
| Teaching assistant                                            | 1 (2.9%)           | 1 (3.3%)           |
| Pastoral                                                      | 1 (2.9%)           | -                  |
| Years spent teaching students with ID- Mean (SD) (range)      | 12 (6.8) (1-25)    | 11.3 (6.2) (1-25)  |
| Currently delivers RSE                                        | 26 (74.3%)         | 23 (76.7%)         |
| Years spent delivering RSE- Mean (SD) (range)                 | 7.9 (7.2) (1-25)   | 6.8 (6.6%) (1-25)  |
| <b>Policy makers/people from third sector</b>                 | <b>N=18 (100%)</b> | <b>N=18 (100%)</b> |
| <b>Professional role</b>                                      |                    |                    |
| Policy adviser from third sector/charities for people with ID | 11 (61.1%)         | 11 (61.1%)         |
| RSE specialist/consultant                                     | 2 (11.1%)          | 2 (11.1%)          |
| SEND specialist/consultant                                    | 2 (11.1%)          | 2 (11.1%)          |
| SEND education officer/adviser                                | 2 (11.1%)          | 2 (11.1%)          |
| Community intellectual disability nurse                       | 1 (5.5%)           | 1 (5.5%)           |

Note: ID=intellectual disability; RSE=Relationships and Sex Education; SEND=Special Education Needs and Disabilities.

### 7.3.2 Consensus

Table 7.4 represents outcomes that reached consensus as the most important for students with intellectual disability to achieve by the end of primary and secondary education (see Appendix 7.5 for outcome definitions).

### *Primary education*

Out of 31 presented outcomes, participants reached consensus on 18 RSE outcomes as the most important for students with intellectual disability to achieve by the end of primary education (see Table 7.4 below). Thirteen outcomes did not reach consensus as the most important outcomes for students to achieve by the end of primary education.

### *Secondary education*

All 31 RSE outcomes reached consensus (were rated by  $\geq 70\%$  of the participants as 7-9 points and by  $<15\%$  of the participants as 1 to 3 points) across participants for students with intellectual disability to achieve by the end of secondary education (see Table 4 below).

Table 7.4 Outcome ratings in round 2 across participants

| Outcome theme                                      | Outcomes                                                                    | Primary education |              |              | Secondary education |              |              |
|----------------------------------------------------|-----------------------------------------------------------------------------|-------------------|--------------|--------------|---------------------|--------------|--------------|
|                                                    |                                                                             | Median (IQR)      | % scored 1-3 | % scored 7-9 | Median (IQR)        | % scored 1-3 | % scored 7-9 |
| Human body and development                         | Body parts                                                                  | 8 (8-9)           | 3%           | 93%          | 9 (9-9)             | 3%           | 97%          |
|                                                    | Puberty                                                                     | 8 (7-9)           | 1%           | 90%          | 9 (8-9)             | 0%           |              |
|                                                    | Hygiene                                                                     | 8 (8-9)           | 2%           | 96%          | 9 (9-9)             | 3%           | 97%          |
|                                                    | Health checks                                                               | 6 (6-7)           | 9%           | <b>34%</b>   | 9 (8-9)             | 1%           | 95%          |
|                                                    | Human life cycle                                                            | 7 (7-8)           | 2%           | 80%          | 9 (9-9)             | 3%           | 95%          |
| Emotions and feelings                              | Recognising emotions and feelings                                           | 8 (7-9)           | 1%           | 96%          | 9 (8-9)             | 1%           | 99%          |
|                                                    | Emotion regulation                                                          | 9 (8-9)           | 1%           | 96%          | 9 (9-9)             | 1%           | 99%          |
| Self-esteem                                        | Self-esteem and confidence                                                  | 9 (8-9)           | 0%           | 97%          | 9 (9-9)             | 0%           | 99%          |
|                                                    | Positive body image                                                         | 8 (7-9)           | 0%           | 95%          | 9 (8-9)             | 0%           | 99%          |
| Healthy relationships and associated social skills | Recognising different relationships                                         | 7 (7-8)           | 0%           | 92%          | 9 (8-9)             | 0%           | 99%          |
|                                                    | How to develop and sustain healthy friendships and social skills            | 8 (8-9)           | 0%           | 97%          | 9 (8-9)             | 0%           | 99%          |
|                                                    | How to develop and sustain healthy romantic relationships and social skills | 6 (6-7)           | 7%           | <b>41%</b>   | 9 (9-9)             | 0%           | 98%          |
|                                                    | Planning for future relationships                                           | 6 (5-7)           | 9%           | <b>35%</b>   | 9 (8-9)             | 0%           | 98%          |
|                                                    | Values and attitudes for positive relationships                             | 8 (7-8)           | 2%           | 95%          | 9 (8-9)             | 0%           | 99%          |
| Sex and sexuality                                  | Sexual feelings, sexual arousal, and pleasure                               | 6 (5-6)           | 14%          | <b>24%</b>   | 9 (8-9)             | 1%           | 97%          |
|                                                    | Sex                                                                         | 6 (5-7)           | 9%           | <b>32%</b>   | 9 (8-9)             | 0%           | 98%          |
|                                                    | Masturbation                                                                | 6 (5-7)           | 13%          | <b>31%</b>   | 9 (8-9)             | 1%           | 94%          |
|                                                    | Pregnancy and parenting                                                     | 6 (5-7)           | 4%           | <b>42%</b>   | 9 (8-9)             | 0%           | 97%          |
|                                                    | Contraception                                                               | 5 (4-6)           | 13%          | <b>21%</b>   | 9 (9-9)             | 1%           | 97%          |
|                                                    | Pornography                                                                 | 6 (4-7)           | 12%          | <b>26%</b>   | 9 (8-9)             | 0%           | 92%          |
|                                                    | Sexual orientation, gender identity, gender roles and stereotypes           | 7 (6-8)           | 6%           | <b>61%</b>   | 9 (8-9)             | 1%           | 93%          |
|                                                    | Sexual health                                                               | 5 (4-6)           | 18%          | <b>19%</b>   | 9 (8-9)             | 0%           | 99%          |
|                                                    |                                                                             |                   |              |              |                     |              |              |
| Human rights                                       | Human rights                                                                | 7 (7-9)           | 1%           | 80%          | 9 (8-9)             | 0%           | 98%          |
|                                                    | Self-advocacy skills                                                        | 7 (7-9)           | 0%           | 78%          | 9 (8-9)             | 0%           | 100%         |

| Outcome theme                        | Outcomes                                               | Primary education |    |            | Secondary education |    |      |
|--------------------------------------|--------------------------------------------------------|-------------------|----|------------|---------------------|----|------|
| Consent and associated social skills | Consent and communication skills                       | 9 (8-9)           | 1% | 94%        | 9 (9-9)             | 0% | 99%  |
|                                      | Social norms of behaviour for a given cultural context | 9 (7-9)           | 0% | 89%        | 9 (8-9)             | 0% | 99%  |
|                                      | Consent in sexual activities and the law               | 6 (6-7)           | 6% | <b>46%</b> | 9 (9-9)             | 0% | 97%  |
| Keeping safe                         | Online safety and the law                              | 7 (7-9)           | 1% | 87%        | 9 (9-9)             | 0% | 100% |
|                                      | Unhealthy relationships, risk and how to keep safe     | 8 (7-9)           | 2% | 89%        | 9 (8-9)             | 1% | 99%  |
|                                      | Legal consequences of behaving inappropriately         | 7 (6-7)           | 6% | <b>51%</b> | 9 (8-9)             | 0% | 99%  |
|                                      | Asking for help                                        | 9 (8-9)           | 0% | 97%        | 9 (9-9)             | 0% | 100% |

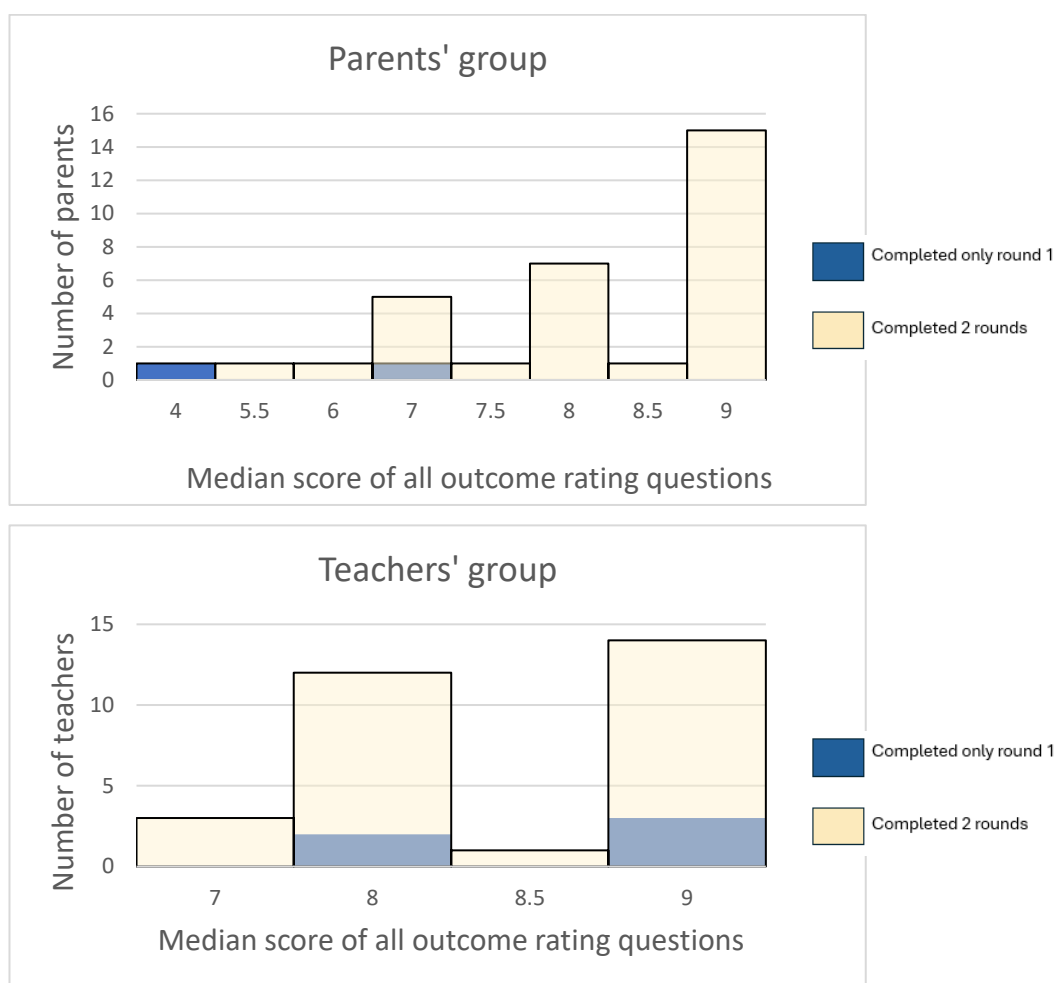
Note: IQR= interquartile range; outcomes highlighted in an orange colour indicate items where consensus was not reached; Consensus criteria= ≥70% of participants gave a score of 7-9 points and <15% participants scored the same outcome as 1 to 3 points; % scored 1-3= percentage of participants that rated an outcome as 1-3 points (“extremely unimportant” – “unimportant”); % scored 7-9= percentage of participants that rated an outcome as 7-9 points (“important” – “extremely important”).

### 7.3.3 Attrition bias

The attrition rate across participants between round 1 and round 2 was 7%. Attrition rates between round 1 and round 2 were 6% for parents (N=2 parents did not complete round 2) and 14% for teachers (N=5 teachers did not complete round 2). Figure 7.5 represents medians of scores across all outcomes of participants who completed both rounds of the survey and participants who completed only round 1 of the survey in parents' and teachers' groups (attrition groups). This figure indicates that median scores of teachers who completed only round 1 of the survey (blue bars) are contained within the median scores of teachers who completed both rounds (yellow bars). On average, teachers who completed both rounds scored the outcomes similarly to teachers who only completed round 1. This finding suggests that attrition bias was unlikely to have impacted the results in the teachers' group in round 2.

The figure also indicates that one parent's median score is lower and not contained with the median scores of parents who completed both rounds. This suggests that if this parent took part in round 2, their median scores on outcome ratings might have been equally low. However, it is unlikely that one participant's rating would have changed the overall conclusion regarding consensus given the high overall number of parents in the survey (N=31). These findings on the attrition bias assessment in parents' and teachers' groups indicate that it is unlikely that bias had been introduced in round 2 through participant attrition.

Figure 7.5 Median scores in round 1 across all outcomes in parents' and teachers' groups



*Note:* Yellow bars represent participants that completed 2 rounds of the survey. Blue bars represent participants that completed only round 1 of the survey.

### 7.3.4 Comparisons

#### *Round 1 and Round 2*

The same outcomes reached consensus as the most important in round 1 and round 2 across participants (see Table 7.5 for more details). Wilcoxon signed-rank tests revealed that there were no statistically significant differences between stakeholders' ratings of outcomes in round 1 and round 2 (for all comparisons  $p > 0.05$ ).

Table 7.5 Outcome rating in round 1 and round 2

| Outcomes                                                                           | Round 1      |              |              | Round 2      |              |              | P value |
|------------------------------------------------------------------------------------|--------------|--------------|--------------|--------------|--------------|--------------|---------|
|                                                                                    | Median (IQR) | % scored 1-3 | % scored 7-9 | Median (IQR) | % scored 1-3 | % scored 7-9 |         |
| <b>Body parts</b>                                                                  |              |              |              |              |              |              |         |
| Primary                                                                            | 8 (8-9)      | 1%           | 93%          | 8 (8-9)      | 3%           | 93%          | 0.64    |
| Secondary                                                                          | 9 (9-9)      | 0%           | 98%          | 9 (9-9)      | 3%           | 97%          | 0.79    |
| <b>Puberty</b>                                                                     |              |              |              |              |              |              |         |
| Primary                                                                            | 8 (7-9)      | 3%           | 80%          | 8 (7-9)      | 1%           | 90%          | 0.17    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 99%          | 9 (8-9)      | 2%           | 98%          | 0.75    |
| <b>Hygiene</b>                                                                     |              |              |              |              |              |              |         |
| Primary                                                                            | 8.5 (7-9)    | 0%           | 96%          | 8 (8-9)      | 2%           | 96%          | 0.89    |
| Secondary                                                                          | 9 (9-9)      | 0%           | 100%         | 9 (9-9)      | 3%           | 97%          | 0.83    |
| <b>Health checks</b>                                                               |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (5-7)      | 9%           | <b>37%</b>   | 6 (6-7)      | 9%           | <b>34%</b>   | 0.75    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 98%          | 9 (9-9)      | 1%           | 95%          | 0.57    |
| <b>Human life cycle</b>                                                            |              |              |              |              |              |              |         |
| Primary                                                                            | 7 (6-8)      | 2%           | 71%          | 7 (7-8)      | 2%           | 80%          | 0.65    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 96%          | 9 (9-9)      | 3%           | 94%          | 0.65    |
| <b>Recognising emotions and feelings</b>                                           |              |              |              |              |              |              |         |
| Primary                                                                            | 9 (7-9)      | 0%           | 99%          | 8 (7-9)      | 1%           | 96%          | 0.07    |
| Secondary                                                                          | 9 (9-9)      | 0%           | 100%         | 9 (8-9)      | 1%           | 99%          | 0.65    |
| <b>Emotion regulation</b>                                                          |              |              |              |              |              |              |         |
| Primary                                                                            | 9 (7-9)      | 0%           | 96%          | 9 (8-9)      | 1%           | 96%          | 0.67    |
| Secondary                                                                          | 9 (9-9)      | 0%           | 100%         | 9 (9-9)      | 1%           | 99%          | 0.46    |
| <b>Self-esteem and confidence</b>                                                  |              |              |              |              |              |              |         |
| Primary                                                                            | 9 (8-9)      | 0%           | 93%          | 9 (8-9)      | 0%           | 97%          | 0.34    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 98%          | 9 (9-9)      | 0%           | 99%          | 0.14    |
| <b>Positive body image</b>                                                         |              |              |              |              |              |              |         |
| Primary                                                                            | 8 (7-9)      | 0%           | 86%          | 8 (7-9)      | 0%           | 94%          | 0.45    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 99%          | 9 (8-9)      | 0%           | 99%          | 0.29    |
| <b>Recognising different relationships</b>                                         |              |              |              |              |              |              |         |
| Primary                                                                            | 7 (7-9)      | 2%           | 82%          | 7 (7-8)      | 0%           | 92%          | 0.85    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 97%          | 9 (8-9)      | 0%           | 99%          | 0.09    |
| <b>How to develop and sustain healthy friendships and social skills</b>            |              |              |              |              |              |              |         |
| Primary                                                                            | 8 (7-9)      | 0%           | 96%          | 8 (8-9)      | 0%           | 98%          | 0.94    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 99%          | 9 (8-9)      | 0%           | 99%          | 0.17    |
| <b>How to develop and sustain healthy romantic relationships and social skills</b> |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (5-7)      | 11%          | <b>43%</b>   | 6 (6-7)      | 7%           | <b>41%</b>   | 0.68    |
| Secondary                                                                          | 9 (8-9)      | 1%           | 97%          | 9 (9-9)      | 0%           | 98%          | 0.24    |
| <b>Planning for future relationships</b>                                           |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (5-7)      | 12%          | <b>32%</b>   | 6 (5-7)      | 8%           | <b>36%</b>   | 0.28    |
| Secondary                                                                          | 9 (7-9)      | 0%           | 91%          | 9 (8-9)      | 0%           | 98%          | 0.06    |
| <b>Values and attitudes for positive relationships</b>                             |              |              |              |              |              |              |         |
| Primary                                                                            | 8 (7-9)      | 1%           | 89%          | 8 (7-8)      | 2%           | 94%          | 0.93    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 98%          | 9 (8-9)      | 0%           | 99%          | 0.08    |
| <b>Sexual feelings, sexual arousal, and pleasure</b>                               |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (4-7)      | 24%          | <b>27%</b>   | 6 (5-6)      | 14%          | <b>24%</b>   | 0.19    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 97%          | 9 (8-9)      | 1%           | 97%          | 0.58    |
| <b>Sex</b>                                                                         |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (4-7)      | 17%          | <b>36%</b>   | 6 (5-7)      | 9%           | <b>32%</b>   | 0.58    |
| Secondary                                                                          | 9 (8-9)      | 0%           | 97%          | 9 (8-9)      | 0%           | 98%          | 0.68    |
| <b>Masturbation</b>                                                                |              |              |              |              |              |              |         |
| Primary                                                                            | 6 (4-7)      | 13%          | <b>39%</b>   | 6 (5-7)      | 13%          | <b>31%</b>   | 0.30    |
| Secondary                                                                          | 8 (7-9)      | 0%           | 96%          | 9 (8-9)      | 1%           | 94%          | 0.42    |



|                                                                          |                |              |              |                |              |              |      |
|--------------------------------------------------------------------------|----------------|--------------|--------------|----------------|--------------|--------------|------|
| <b>Pregnancy and parenting</b>                                           |                |              |              |                |              |              |      |
| Primary                                                                  | 5 (3-7)        | 30%          | <b>26%</b>   | 6 (5-7)        | 4%           | <b>42%</b>   | 0.41 |
| Secondary                                                                | 9 (8-9)        | 0%           | 96%          | 9 (8-9)        | 0%           | 97%          | 0.09 |
| <b>Contraception</b>                                                     |                |              |              |                |              |              |      |
| Primary                                                                  | 6 (4-7)        | 19%          | <b>28%</b>   | 5 (4-6)        | 13%          | <b>21%</b>   | 0.42 |
| Secondary                                                                | 9 (8-9)        | 0%           | 91%          | 9 (9-9)        | 1%           | 97%          | 0.39 |
|                                                                          | <b>Round 1</b> |              |              | <b>Round 2</b> |              |              |      |
| <b>Outcomes</b>                                                          | Median (IQR)   | % scored 1-3 | % scored 7-9 | Median (IQR)   | % scored 1-3 | % scored 7-9 |      |
| <b>Pornography</b>                                                       |                |              |              |                |              |              |      |
| Primary                                                                  | 7 (6-8)        | 18%          | <b>55%</b>   | 6 (4-7)        | 12%          | <b>26%</b>   | 0.50 |
| Secondary                                                                | 9 (8-9)        | 0%           | 91%          | 9 (8-9)        | 0%           | 92%          | 0.79 |
| <b>Sexual orientation, gender identity, gender roles and stereotypes</b> |                |              |              |                |              |              |      |
| Primary                                                                  | 7 (6-8)        | 6%           | <b>55%</b>   | 7 (6-8)        | 6%           | <b>61%</b>   | 0.42 |
| Secondary                                                                | 9 (8-9)        | 1%           | 91%          | 9 (8-9)        | 1%           | 93%          | 0.55 |
| <b>Sexual health</b>                                                     |                |              |              |                |              |              |      |
| Primary                                                                  | 4 (3-6)        | 28%          | <b>19%</b>   | 5 (4-6)        | 18%          | <b>19%</b>   | 0.42 |
| Secondary                                                                | 9 (8-9)        | 0%           | 96%          | 9 (8-9)        | 0%           | 99%          | 0.88 |
| <b>Human rights</b>                                                      |                |              |              |                |              |              |      |
| Primary                                                                  | 7 (6-9)        | 4%           | 73%          | 7 (7-9)        | 1%           | 80%          | 0.45 |
| Secondary                                                                | 9 (8-9)        | 0%           | 99%          | 9 (8-9)        | 0%           | 98%          | 0.20 |
| <b>Self-advocacy skills</b>                                              |                |              |              |                |              |              |      |
| Primary                                                                  | 7 (6-9)        | 4%           | 71%          | 7 (7-9)        | 0%           | 78%          | 0.26 |
| Secondary                                                                | 9 (8-9)        | 0%           | 97%          | 9 (8-9)        | 0%           | 100%         | 0.07 |
| <b>Consent and communication skills</b>                                  |                |              |              |                |              |              |      |
| Primary                                                                  | 9 (7-9)        | 1%           | 90%          | 9 (8-9)        | 1%           | 94%          | 0.22 |
| Secondary                                                                | 9 (9-9)        | 0%           | 100%         | 9 (9-9)        | 0%           | 99%          | 0.62 |
| <b>Social norms of behaviour for a given cultural context</b>            |                |              |              |                |              |              |      |
| Primary                                                                  | 8 (7-9)        | 1%           | 87%          | 9 (7-9)        | 0%           | 89%          | 0.38 |
| Secondary                                                                | 9 (9-9)        | 0%           | 98%          | 9 (8-9)        | 0%           | 99%          | 0.40 |
| <b>Consent in sexual activities and the law</b>                          |                |              |              |                |              |              |      |
| Primary                                                                  | 6 (4-8)        | 13%          | <b>44%</b>   | 6 (6-7)        | 6%           | <b>46%</b>   | 0.38 |
| Secondary                                                                | 9 (8-9)        | 0%           | 96%          | 9 (9-9)        | 0%           | 97%          | 0.17 |
| <b>Online safety and the law 28</b>                                      |                |              |              |                |              |              |      |
| Primary                                                                  | 7 (7-9)        | 2%           | 78%          | 7 (7-9)        | 1%           | 87%          | 0.43 |
| Secondary                                                                | 9 (8-9)        | 0%           | 100%         | 9 (9-9)        | 0%           | 100%         | 0.08 |
| <b>Unhealthy relationships, risk and how to keep safe</b>                |                |              |              |                |              |              |      |
| Primary                                                                  | 8 (7-9)        | 2%           | 82%          | 8 (7-9)        | 2%           | 89%          | 0.59 |
| Secondary                                                                | 9 (8-9)        | 0%           | 99%          | 9 (8-9)        | 1%           | 99%          | 0.78 |
| <b>Legal consequences of behaving inappropriately</b>                    |                |              |              |                |              |              |      |
| Primary                                                                  | 6 (5-7)        | 12%          | <b>48%</b>   | 7 (6-7)        | 6%           | <b>51%</b>   | 0.26 |
| Secondary                                                                | 9 (8-9)        | 0%           | 98%          | 9 (8-9)        | 0%           | 99%          | 0.11 |
| <b>Asking for help</b>                                                   |                |              |              |                |              |              |      |
| Primary                                                                  | 9 (8-9)        | 1%           | 97%          | 9 (8-9)        | 0%           | 97%          | 0.90 |
| Secondary                                                                | 9 (9-9)        | 0%           | 100%         | 9 (9-9)        | 0%           | 100%         | 0.35 |

Note: IQR=interquartile range; Primary=by the end of primary education; Secondary=by the end of secondary education; Outcomes highlighted in an orange colour did not reach consensus in round 1 and round 2 as the most important for primary education. Calculations performed on outcome ratings of participants that completed both rounds (N=90).

### *Unable to score*

In round 1, the “unable to score” option was selected by three participants (3%) for five outcomes: sexual orientation for primary education; sex for primary education, sexual health for primary education; recognising emotions for primary and secondary education. One participant explained that they were not able to rate outcomes about recognising emotions and feelings because information provided to explain what these outcomes involved was “too neurotypical”.

In round 2 of the survey, two participants (2.2%; the same participants from round 1) rated 9 outcomes as “unable to score”. These were: sexual feelings for primary and secondary education; masturbation for primary and secondary education; sexual orientation for primary and secondary education; unhealthy relationships for primary and secondary education and contraception for secondary education.

### *Stakeholder groups*

Overall, four stakeholder groups (parents, teachers/school staff, researchers, and policy makers/people from third sector organisations) achieved consensus on the same outcomes. However, there were some differences between outcomes that reached consensus for primary education between four stakeholder groups (see Appendix 7.6). Outcomes on the human life cycle and human rights did not reach consensus amongst parents as the most important for primary education. However, these outcomes reached consensus across participants and were included in the COS of RSE for primary education. The Kruskal–Wallis test revealed that there were no statistically significant differences on the “human life cycle” outcome rating for primary education between the four stakeholder groups ( $H(3)=7.57$ ,  $p=0.06$ ). There were also no statistically significant differences on the “human rights” outcome rating for primary education between stakeholder groups ( $H(3)=3.76$ ,  $p=0.29$ ).

An outcome on sexual orientation, gender identity, gender roles and stereotypes did not reach consensus as the most important for primary education across participants and thus, was not included in the COS. However, this outcome reached consensus as the most important for primary education in researchers' and policy makers' groups. There were statistically significant differences on this outcome rating for primary education between stakeholder groups ( $H(3)=15$ ,  $p=0.002$ ) (see Appendix 7.7). Pairwise comparisons with adjusted p-values showed that there was a statistically significant difference on the "sexual orientation, gender identity, gender roles and stereotypes" outcome rating for primary education between the parents' group (Median score=5; interquartile range=6-7) and policy makers' group (Median score=8; interquartile range=7-9) ( $p=0.005$ ;  $r=-3.26$ ). There was also a statistically significant difference on this outcome rating for primary education between teachers' group (Median score=6.5; interquartile range=6-7) and policy makers' group (Median score=8; interquartile range=7-9) ( $p=0.007$ ,  $r=3.32$ ). There were no significant differences on this outcome rating for primary education between other stakeholder groups ( $p>0.05$ ).

The teachers' group rated outcomes in the "sex and sexuality" theme the least frequently as important for primary education (7-9 points) compared to other stakeholder groups. The Kruskal–Wallis test revealed that there were statistically significant differences only on the pregnancy and parenting outcome rating for primary education in the "sex and sexuality" theme between stakeholder groups ( $H(3)=11.87$ ,  $p=0.008$ ). Pairwise comparisons with adjusted p-values showed that there was a statistically significant difference on the "pregnancy and parenting" outcome rating for primary education between the teachers' group (Median score=5; interquartile range=4-6) and policy makers' group (Median score=7; interquartile range=6-7) ( $p=0.014$ ;  $r=-3.04$ ). All other comparisons on the outcome ratings in the "sex and sexuality" theme (e.g. masturbation, sex) for primary education were non-significant between stakeholder groups ( $p>0.05$ ).

Some outcomes that reached consensus across all participants as the most important align with the views of students with intellectual disability. The most

important RSE outcomes for students with intellectual disability reported in the previous study of this project (Chapter 6) were: how to develop and sustain healthy friendships and social skills; online safety and the law; unhealthy relationships, risk and how to keep safe; self-esteem and confidence. Following the Delphi survey, these outcomes reached consensus and are included in the COS for primary and secondary education.

### **7.3.5 Participants' comments**

In round 1, 34 of 99 participants (34%) provided comments in the free text box at the end of outcome rating questions. No additional outcomes were suggested by stakeholders. However, two participants from the researchers' group suggested amending the descriptions of two outcomes. One participant reported that the description of the pornography outcome was negatively formulated (e.g. only the risks associated with viewing pornography were presented). The participant suggested including a more balanced view about pornography (e.g. that pornography can be used for sexual arousal and pleasure). Another participant suggested adding an understanding that sex toys can be used for pleasure in the definition of the outcome on sexual feelings, sexual arousal, and pleasure. These suggestions were taken forward in the definition of outcomes in round 2.

Nine participants (9%) from the parents' and teachers' groups reported that it is difficult to rate the outcomes by educational stages for students with intellectual disability due to heterogeneity of abilities experienced by this population. Participants reported that students' severity of intellectual disability will impact the timing of RSE delivery and when they are able to achieve these outcomes. Participants discussed that the delivery of RSE needs to be adapted to students' level of intellectual disability, their abilities, and needs.

However, another nine participants (9%) from parents' and policy makers' groups disagreed with this view. Participants reported that RSE delivery on all outcomes presented in the survey needs to start from the early years. Participants explained that in primary education, students should be

introduced to all outcomes in an age-appropriate way. This would ensure that students are prepared to have more in depth discussions on the outcomes in secondary education.

*“These are all ongoing conversations. The earlier they are started, the more they can be revisited before the children become teenagers and only believe or listen to their peers. It also means when inappropriate things come along (pornography, abuse) they are at least partially prepared, and have some idea where to go for help. Especially with it not being unusual for 7–8-year-olds to see porn. It does not have to go into detail but answering their questions honestly and preparing them.”*  
(Parent\_01, round 1)

Two participants (2%) reported that the information provided in the description of what the outcome involves would have prompted a different outcome rating for primary education. These two participants reported that some information presented in the description of the outcomes was not appropriate for primary education.

Based on the comments provided in round 1, additional information was provided on how to rate the outcomes in round 2 of the survey. Participants were told that the description of the outcomes include information that would not be applicable to each student with intellectual disability at a specific point in time. Participants were told that teaching about relationship and sex needs to be adapted to each student, their abilities, developmental level, and cultural background. Participants were asked, when rating an outcome, to consider how important it is that students have knowledge related to that outcome at that age rather than the specific examples presented in descriptions of the outcomes.

In round 2, 30 out of 92 participants (32.6%) provided comments at the end of the survey. In most of the comments, participants reported that they found the feedback provided on how other people rated the outcomes interesting and helpful. Participants also reported that receiving students' views on the outcomes made them reconsider their position and change their outcome ratings. Two participants (2.2%) mentioned that students with severe

intellectual disability will not be able to achieve all outcomes presented in the survey because they will not be able to understand abstract concepts involved in the outcomes e.g. commitments of romantic relationships. Thus, differentiation of outcomes for students with severe intellectual disability was suggested as needed:

*“It will be important to consider what any element of RSE looks like according to the level of understanding of the learners concerned. The student comments given as examples indicate learners with moderate learning difficulties. None of my primary age pupils, who all have severe learning difficulties, would be able to engage at this level of understanding. So, the question of what may be or may not be important looks different for them. For instance, ideally, they need to learn to say "no" to anything they do not like, but they will not have the conceptual understanding to grasp detail around context relating to consent.”*  
(Teacher\_12, round 2)

Four participants (4.3%) mentioned that resources for RSE delivery are needed for students with intellectual disability to achieve the outcomes. Participants discussed that teachers need support from parents and policies to deliver RSE to this population. Teachers were reported as feeling afraid to deliver RSE to students with intellectual disability due to parents' objections. Students with intellectual disability have also been reported as needing opportunities to be involved in RSE delivery:

*“There needs to be some way of ensuring young people with disabilities get to co-develop learning opportunities and materials/resources and have the opportunity to be involved in the teaching as peer educators and through their own stories.”*  
(Participant researcher\_07, round 2)

*“I think concepts need to be age appropriate but more work with parents needs to be done on the why we teach these topics.”*  
(Teacher\_26, round 2)

One participant reported that teaching regarding outcomes on emotions and feelings for students with intellectual disability and autism should include information about interoception and alexithymia for those students to achieve these outcomes:

*“Regarding emotions teaching, I struggle to answer this fully because of the lack of reference to neurodiversity teaching, e.g. interoception and alexithymia. If either included then, yes, so 100% think it is extremely important at both primary and secondary. However, if we are talking about teachers holding up images of people looking a certain emotion and attributing meaning to this for say, autistic learners, then that would make it harder for me to base a rating on considering what we know about autistic people being more likely to experience sexual abuse and violence.” (School staff\_01, round 2)*

## **7.4 Discussion**

In this study, I employed the Delphi methodology to establish consensus across adult stakeholders on the COS of RSE for students with intellectual disability. Eighteen outcomes reached consensus as the most important and were included in the final COS of RSE for primary school students with intellectual disability. Thirty-one outcomes reached consensus as the most important and were included in the final COS of RSE for secondary school students with intellectual disability. Outcomes across both educational stages related to: the human body and development; emotions and feelings; healthy relationships and associated social skills; keeping safe; consent; self-esteem; and human rights. Outcomes related to sex and sexuality are additional outcomes included in the COS for secondary education only.

There was an overlap between outcomes included in the COS for primary and secondary education. All 18 outcomes that reached consensus as the most important for primary education also reached consensus for secondary education. This finding reflects the type of “programme” and the population this COS was developed for. This COS was developed for RSE that is a curriculum taught in schools to developing individuals over a 10-year period (DfE, 2019). RSE delivery in English schools as specified in the statutory RSE guidance and the literature on effective RSE should reflect a “spiral curriculum” (DfE, 2019; Pound et al., 2017; Schaafsma et al., 2015). As a spiral curriculum, RSE delivery should involve iteratively revisiting topics throughout educational stages that matches students’ developmental stages (Pound et al., 2017; DfE, 2019). The initial RSE delivery stages should involve development of

knowledge related to basic concepts which is deepened in the later educational stages and built on the knowledge previously developed (Pound et al., 2017; DfE, 2019). This COS was developed for students with intellectual disability many of whom have difficulties understanding complex and abstract RSE concepts and require information delivered repeatedly in different contexts in an accessible format throughout their education (Schaafsma et al., 2015; Finlay et al., 2015; Bundock & Hewitt, 2017).

Indeed, some stakeholders in this study reported that delivery on RSE outcomes presented in this study should start in the early years and the knowledge on RSE outcomes should be deepened in secondary education. In the previous study of this project (Chapter 5), adult stakeholders had similar views. Stakeholders reported that RSE delivery for students with intellectual disability should start in the early years and should be delivered consistently throughout students' education. Stakeholders explained that it takes time for students with intellectual disability to acquire complex knowledge on RSE outcomes. There was also an overlap on RSE outcomes for students with intellectual disability reported as important to achieve in different educational stages in the international literature (Paulauskaite et al., 2022).

Some outcomes that reached consensus in this study are not reported as important in the international literature (Paulauskaite et al., 2022): consent in sexual activities; positive body image; emotion regulation; planning for future relationships; sexual feelings, arousal, and pleasure; pornography; asking for help; legal consequences of behaving inappropriately; human rights and self-advocacy skills. Some outcomes that reached consensus in this study are also not included in the statutory guidance of RSE delivery in English schools (DfE, 2019): the human body and development throughout the life course; recognising emotions and feelings; emotion regulation; how to develop and sustain romantic relationships and social skills; planning for future relationships, sexual feelings and arousal; masturbation; social norms of behaviour for a given cultural context; self-esteem and confidence; and self-advocacy skills.



As it was discussed in the previous chapters (Chapters 5-6), statutory guidance was not developed for students with intellectual disability only. Thus, this could be a reason as to why these outcomes are not included in the guidance. Methodological differences between studies included in the review (Paulauskaite et al., 2022) and this study could be a possible reason for the differences seen between outcomes reported in the literature and this study. This is the first study that aimed to establish consensus on important RSE outcomes for students with intellectual disability across key stakeholders. Rigorous methodology that explored key stakeholders' views (e.g. students' with intellectual disability, their parents' etc.) on RSE outcomes was employed to identify the list of outcomes presented in this study. Studies included in the review did not have the same aim as this study and were on RSE evaluation, delivery, and format for people with intellectual disability (Paulauskaite et al., 2022).

#### **7.4.1 Comparisons between stakeholder groups**

Overall, different adult stakeholder groups (parents, teachers, researchers, and policy makers/people from third sector) perceived the same RSE outcomes as important. This finding indicates that there are many shared RSE outcome priorities across adult stakeholders. This finding is also in line with the previous literature which indicates that parents' and teachers' views on important RSE outcomes for students with intellectual disability converge (Paulauskaite et al., 2022).

Previous COS development studies on health conditions and domestic abuse also found little variation between stakeholder groups regarding outcome ratings in round 2 of Delphi surveys (Powell et al., 2022; Almoajil et al., 2023; Srikantharajah et al., 2020; Davies et al., 2022). There is some evidence that the type of feedback provided in round 2 Delphi survey used in COS development can impact the number of outcomes that reach consensus and variability of scores between stakeholder groups (Brookes et al., 2016). In one study, stakeholders that were randomised to receive feedback containing average ratings of each stakeholder groups separately rated significantly more

outcomes as important and had significantly lower variation on outcome ratings between stakeholder groups in round 2 compared to stakeholders randomised to receive feedback containing only their group's responses (Brookes et al., 2016). However, another study found no significant differences between two types of feedback presented (stakeholder groups separately versus peer feedback) on the number of outcomes that reached consensus and variability of ratings (MacLennan et al., 2019). In MacLennan's et al. (2019) study there was a high agreement between stakeholder groups in round 1 and this could be a reason why no significant differences were observed compared to Brookes' et al. (2016) study.

These findings indicate that the type of feedback presented in round 2 can impact consensus and variability of scores between stakeholder groups when there is a low initial agreement. Being presented with feedback on outcome ratings of each stakeholder groups separately was reported as making stakeholders to reconsider the outcomes from other people's positions and rate them as more important in round 2 (Fish et al., 2020). In this study, there was a high agreement in round 1 between stakeholder groups on many outcomes. However, there was a disagreement regarding eight outcomes between stakeholder groups in round 1. Some stakeholders in this study also reported that being presented feedback in round 2 on how other stakeholder groups including students rated the outcomes made them reconsider their ratings. Thus, the feedback presented in this study might had an impact on the high agreement between stakeholder groups. Nonetheless, deliberation/reconsideration is a key feature of consensus development (Williamson et al., 2017; Solomon, 2006).

In this study, there were some differences between stakeholder groups on outcomes that reached consensus as the most important in round 2 and were included in the COS. Outcome on sexual orientation, gender identity, gender roles and stereotypes reached consensus as the most important for primary education only between researchers and policy makers/people from third sector organisations but is not included in the final COS for primary education. This outcome was also one of the most frequently reported outcomes in the

researchers' group in the previous study of this project (Chapter 5). In the previous study, participants across stakeholder groups except teachers' group reported that students with intellectual disability should achieve this outcome at the early years. Stakeholders in the previous study explained that this outcome is important because many students with intellectual disability especially those that also have autism as an additional condition question their sexuality and gender identity at a young age. This outcome was not measured in RSE evaluation studies for students with intellectual disability at primary education in the literature (Paulauskaite et al., 2022). The systematic review (Chapter 4; Paulauskaite et al., 2022) did not retrieve any RSE evaluation studies for students with intellectual disability at primary education nor outcomes specifically for students with intellectual disability at primary education reported as important by stakeholders.

In this study, teachers rarely rated outcomes on sex and sexuality as important for primary education compared to other stakeholder groups. In the previous study (Chapter 5), teachers also rarely reported outcomes on sex and sexuality as important for students with intellectual disability to achieve in RSE at any educational stage. As discussed in Chapter 5, many teachers have reported feeling afraid to deliver topics on sex and sexuality to students with intellectual disability due to parents' objections. In this study, participants also reported that teachers need support from parents and policies to deliver RSE to students with intellectual disability. The statutory RSE guidance in English schools (DfE, 2019) does not involve outcomes on sex and sexuality as learning outcomes for students at primary education. This could also be a possible reason as to why many teachers in this study did not perceive outcomes on sex and sexuality as important for students to achieve at primary education.

In previous studies as discussed in Chapter 1, some parents of students with intellectual disability did not think that the "sex" topic should be delivered to their children in RSE (Gürol's et al., 2014; Gokgoz et al., 2021; Menon & Sivakami, 2019). Parents believed that students with intellectual disability are not interested in having sex and thus, there is no need to teach this topic in

RSE (Gürol's et al., 2014; Gokgoz et al., 2021; Menon & Sivakami, 2019). In another study, parents of children with intellectual disability were concerned that learning about the “sex” topic will lead to children engaging in sexually inappropriate behaviours and thus, parents were unsure if this topic should be taught in RSE (Pryde & Jahoda, 2018). Parents from non-Western countries (e.g. India and Turkey) also reported that talking about sexuality of people with disability is not acceptable and “shameful” in their culture (Gürol et al., 2014; Menon & Sivakami, 2019; Gokgoz et al., 2021). These culturally acceptable norms were influenced by religious beliefs and cultural values (Gürol et al., 2014; Menon & Sivakami, 2019; Gokgoz et al., 2021). This might be another reason as to why some parents from different cultural and religious backgrounds might have objections towards the “sex” topic delivery to students with intellectual disability.

However, in previous study of this project (Chapter 5), parents reported the most frequently outcomes on sex compared to other outcomes and other stakeholder groups. Parents’ reasons for the importance of outcomes on the “sex” topic involved safeguarding reasons (e.g. prevention from sexual abuse and committing crimes) and understanding that some students want and should be able to have sexual relationships.

Outcomes on human rights and the human life cycle did not reach consensus as the most important outcomes for primary education in the parents’ group. However, these outcomes reached consensus across stakeholders and were included in the COS for primary education. Parents did not provide reasons for their ratings in this study. In the previous study of this project (Chapter 5), outcomes on the human life cycle were not reported by parents and outcomes on human rights were reported by only a few parents. During the pilot of this study, some parents who did not take part in this study mentioned that they do not want their children to learn outcomes on human rights in RSE. Parents explained that students with intellectual disability might be perceived as “challenging” if adults in the students’ environment do not know that the students have these rights and students start questioning adults’ behaviour.

Parents also reported that questioning adults' behaviour might put children with intellectual disability at risk of being harmed by adults.

Previous studies indicate that parents' wishes to protect their children with intellectual disability can impact students' independence, development of self-determination skills and opportunities to use their human rights e.g. development of romantic relationships (Callus et al., 2019; Curryer et al., 2015; Hemm et al., 2017; Meral et al., 2023; Pérez-Curiel et al., 2023; Correa et al., 2022). For example, some parents of young people with intellectual disability make decisions on a behalf of their children and restrict young peoples' access to activities to protect them from a possible harm (Hemm et al., 2017; Callus et al., 2019). Overprotection of people with intellectual disability is linked to perceiving them as incapable of learning and having increased vulnerabilities to abuse and exploitation (Callus et al., 2019). However, some researchers argue that understanding human rights and having self-determination skills (ability to make decisions) allows people with intellectual disability to be less dependent on their parents and carers and allows to develop self-protection skills which reduce the risks of being exploited or abused by others (Callus et al., 2019; Buhagiar & Azzopardi Lane, 2020).

Some outcomes that reached consensus across adult stakeholders as the most important for primary and secondary education also reflect the priorities of students with intellectual disability explored in the previous study (Chapter 6). This finding indicates that students with intellectual disability shared some RSE outcome priorities with adult stakeholders. However, in the previous study it was not possible to explore students' views on all RSE outcomes (extracted from the previous studies of this project and presented in this study) as they are yet to be delivered to students. Thus, students' views on some outcomes were not presented in round 2 of the survey and this might have influenced the final COS. All outcomes that did not have students' views presented in the survey (except one outcome on self-advocacy skills) did not reach "consensus in" for primary education. These outcomes that did not have students' views presented in round 2 and that did not reach "consensus in" were: health checks; planning for future relationships; sexual feelings, sexual arousal, and

pleasure; masturbation; consent in sexual activities and the law; self-advocacy skills.

#### **7.4.2 Ceiling effect**

In this study, a very high agreement across stakeholder groups on outcomes included in the COS indicates shared priorities across stakeholders and a possible ceiling effect. Thirty-one outcomes that reached consensus as the most important for secondary education were rated by more than 90% of stakeholders as important. Eighteen outcomes that reached consensus as the most important for primary education were rated by more than 78% of stakeholders as important. Thus, it is possible that the consensus criteria and the rating scale used in this study were unable to provide the differentiation in participants' responses and a ceiling effect occurred.

There is no agreement on the most appropriate consensus criteria and the scale to use in COS development studies (Williamson et al., 2017). However, in this study, a 9-point scale was used and stringent consensus criteria. For example, consensus was calculated when at least 70% of participants scored 7-9 and less than 15% of participants scored the same outcome as 1-3. Some COS development studies determine consensus when 50% of participants rate the outcomes between 7-9 points (Williamson et al., 2017). Thus, the criteria used in this study were more stringent. The 9-point scale used in this study provides a wider range of rating options than a 5-point scale used in other COS development studies (Williamson et al., 2017). Thus, using the 9-point scale participants in this study had more options to select a response that could have resulted in wider diversity of ratings and agreements or disagreements.

However, the number of outcomes included in the final COS for primary (N=18) and secondary education (N=31) indicates that an additional round of the survey or a consensus workshop might have been needed. In this additional part of the study, participants could have been asked to rank the outcomes that reached consensus (e.g. from the most important outcomes to the least important outcomes) that could possibly reduced the final COS. I planned to

carry out the consensus workshop after the survey as indicated in the study protocol (Paulauskaite et al., 2022). However, I was unable to carry out the consensus workshop due to time constraints. The two round Delphi survey finished just before school summer holidays (July 2023). Recruitment to the workshop would not have been possible till schools opened at the beginning of September 2023. This project's funding finished in September 2023.

In the comments received in this study, many stakeholders reported that all outcomes are important for students with intellectual disability to achieve in RSE. Outcomes presented in the survey were suggested by adults and students with intellectual disability who provided unique needs and difficulties experienced by this population as reasons for its importance. Therefore, it is possible that stakeholders rated all these outcomes as the most important due to the significance of these outcomes for students with intellectual disability.

There is some evidence that RSE is not delivered proactively to this group of students (Barnard-Brak et al., 2014; Schaafsma et al., 2014; Rurangirwa et al., 2006). Thus, it is possible that all outcomes were rated as important for secondary education because stakeholders wanted to see improved RSE delivery to students with intellectual disability. It is also unclear whether all RSE outcomes perceived as important in this study would be sustained in the future e.g. if RSE delivery improves to students with intellectual disability. It is also possible that changes in societal attitudes towards RSE, sexuality of people with intellectual disability, and improved RSE delivery to students with intellectual disability might impact the outcomes included in this COS in the future.

As discussed previously, this COS was developed for RSE that is a curriculum, delivered to students with intellectual disability over a 10-year period. RSE has a wide focus. Thus, the number of outcomes included in this COS is bigger than in the "traditional" COS development studies on medical interventions that include about 5-10 outcomes in the COS (Williamson et al., 2017). The number of outcomes included in this COS also raises questions how the COS can be

applied in research settings which is discussed in the general discussion (Chapter 8) with implications of this study findings.

### **7.4.3 Operationalisation of outcomes**

Outcomes included in the COS of RSE for students with intellectual disability are broad. Outcome definitions involved smaller outcomes suggested by stakeholders for students with intellectual disability at any educational stages. Several adult stakeholders mentioned in the comments received in this study, that outcome definitions need to be adapted for students with intellectual disability at primary education to involve age-appropriate information. Thus, further consensus work involving the views of key stakeholders (e.g. students with intellectual disability and their parents) is needed to refine definitions of outcomes in the COS of RSE for students with intellectual disability for primary education and for secondary education. Methodological approaches used in this project (Chapters 5-7) provide suggestions on how to involve different stakeholders successfully in such collaborations. Further consensus work is also needed on how to measure outcomes included in this COS for students with intellectual disability. The systematic review (Chapter 4) indicates that there are no validated instruments to measure RSE outcomes for students with intellectual disability aged 5-25 years. Thus, future work should focus on development of validated stakeholder consensus-based instruments to measure the COS of RSE for this population.

A small number (N=2) of stakeholders who took part in this study reported that outcomes presented in this study were not applicable to students with severe intellectual disability because they are too complex and abstract. A few stakeholders (N=2) withdrew from the study because they could not see how these outcomes were “relevant” to students with profound intellectual disability and multiple disabilities. This COS was not intended to be restrictive to a specific subgroup of students but rather inclusive considering the heterogeneity of abilities and co-representing problems experienced by this population. This study sample also reflects students with intellectual disability being educated in English schools. As discussed in Chapters 1 and 6, literature



indicates that students with severe intellectual disability are less likely to receive RSE due to a fear that they might misunderstand information or believing that RSE is not relevant for them (Lafferty et al., 2012; Evans et al., 2009; Kürtüncü & Kurt, 2020; Pryde & Jahoda, 2018; Pownall et al., 2012).

#### **7.4.4 Strengths and limitations**

To my knowledge, this is the first study that established consensus on important RSE outcomes amongst adult stakeholders that were included in the COS of RSE for students with intellectual disability in primary and secondary education. This is also the first COS developed for and with an intellectual disability population. This is also the first study that provides important RSE outcomes for students with intellectual disability in primary education addressing a gap in the literature (Paulauskaite et al., 2022).

The Delphi methodology used in this study enabled development of consensus on important RSE outcomes across adult stakeholders. This methodology also enabled exploration of differences between adult stakeholder groups on outcome priorities. Outcomes included in the COS were strongly agreed across adult stakeholder groups as important. Adult stakeholders rated outcomes anonymously to other adult stakeholders via the online survey. Thus, outcomes included in the COS represent adult stakeholders' own priorities rather than outcomes impacted by social desirability bias or dominant stakeholders' views. Even though students with intellectual disability did not take part in this study, their views were incorporated in the survey. Student suggested outcomes (Chapter 6) were incorporated in the list of outcomes presented in the survey and their views were presented in feedback in round 2 which made some adult stakeholders to reconsider their ratings.

A broad range of outcomes that considers the unique needs and difficulties experienced by people with intellectual disability suggested by adult and student stakeholders are included in this COS. Rigorous and comprehensive methodology (Chapters 4-6) was used to develop the list of outcomes presented in the survey. Participants who took part in this study represented

key adult stakeholder groups and had a wide range of experiences supporting students with intellectual disability with range of abilities in education, clinical, and research settings. Low attrition of participants in round 2 and findings of the attrition bias assessment suggest that attrition bias have not impacted the final COS.

However, this study has some limitations. First, a convenience sample was used to recruit participants. Therefore, it is likely that sampling bias has impacted the results. Participants who volunteered to take part in the study might had more liberal attitudes towards sexuality of people with intellectual disability or experienced greater difficulties supporting the sexuality of people with intellectual disability than people who did not take part in the survey.

Previous research that examined the impact of sampling bias on self-report data in sexuality research provide mixed evidence. Some studies indicate that people who volunteer to participate in such research have younger age, higher educational attainment, less conservative attitudes towards sexuality and sexual pleasure, lower church attendances, earlier engagement in sexual behaviours and higher rates of sexual abuse compared to people who refuse to participate (Strassberg & Lowe, 1995; Dunne et al., 1997; Bouchard et al., 2019; Dawson et al., 2019). However, another study did not find difference on these variables, except higher incidence of sexual abuse, between people who participate in sexuality research compared to those who refuse (Roath et al., 2023). This mixed evidence could possibly be attributed to methodological differences between the studies such as the format of participation (online surveys versus postal surveys; hypothetical willingness to participate versus actual participation in sexuality research) and the time studies were carried out (the last five years versus 19 years as people's attitudes towards sensitive sexuality topic might change over time as societal norms change). Besides, it is unclear if these findings are applicable beyond research providing self-report data e.g. research exploring carers' attitudes towards sexuality of people with disability.

Second, most adult stakeholders who took part in this study reported having White ethnicity and no religious affiliation. Thus, the findings of this study do not reflect the views of adult stakeholders from diverse religious and cultural backgrounds. Research indicates that people from non-Western cultural backgrounds hold more conservative attitudes towards sexuality of people with intellectual disability than people from Western cultural backgrounds (Correa et al., 2022; Sankhla & Theodore, 2015).

Out of 13 researchers, 11 (84.6%) were from outside England (from other UK and non-UK countries). As explained previously in Chapter 5, inclusion of international researchers in this study was deliberate and planned before data collection (Paulauskaite et al., 2022). Twelve participants (11 international researchers and 1 teacher from the UK) that were from outside England and that took part in the round 2 of the survey (the round that achieved consensus) represent 13% of the sample in this study. Thus, the majority of participants (87%) were from England, the context in which this new knowledge on RSE outcomes was generated. Thus, as explained above, this COS is limited in terms of possibly not being applicable across different cultural and religious contexts (e.g. non-Western countries). In Chapter 5, stakeholders across stakeholder groups reported unique needs and difficulties experienced by people with intellectual disability as reasons for the outcome importance rather than reflecting on their cultural or religious characteristics of each country.

Third, outcomes presented in the survey and the feedback in round 2 did not reflect the views of students with intellectual disability in primary education e.g. aged 5-11 years or those with severe intellectual disability. As discussed in Chapter 6, I was not able to recruit students with intellectual disability in primary education and only one student with severe intellectual disability shared their views on the outcomes. Thus, this COS does not reflect the priorities of students with intellectual disability in primary education and students with severe intellectual disability. Besides, some sensitive outcomes, e.g. masturbation, that reached consensus as the most important for the secondary education also do not reflect the views of students with intellectual disability. In the previous study, I was unable to explore the perspectives of

students with intellectual disability on some RSE outcomes because they have not been delivered yet. Thus, it is unclear if students' value these more sensitive outcomes and whether their views presented in round 2 would have impacted the final COS for primary and secondary education.

Fourth, most of the sample in this study consisted of parents and teachers (66.3%). Thus, consensus in this study numerically was dominated by those two stakeholder groups. However, exploration of outcome ratings between stakeholder groups in round 2 revealed that the same outcomes, except one, reached consensus between stakeholder groups. Outcome on sexual orientation, gender identity, gender roles and stereotypes reached consensus as the most important for primary education between researchers and policy makers/people from third sector. However, this outcome did not reach consensus as the most important across stakeholders for primary education and was not included in the final COS. On the other hand, many stakeholders who took part in the study had dual roles. For example, participants who reported belonging to policy makers'/ third sector group were also parents of students with intellectual disability or involved in RSE delivery in educational settings. Thus, the divergence of opinions between stakeholder groups on this one outcome might be less significant than observed.

## **Conclusions**

In this study, I aimed to establish consensus on RSE outcomes for students with intellectual disability across adult stakeholders. Eighteen outcomes reached consensus as the most important for primary education and were included in the COS of RSE for students with intellectual disability at primary education. Thirty-one outcomes reached consensus the most important for secondary education and were included in the COS of RSE for students with intellectual disability at secondary education. Outcomes included in the COS for both educational stages related to: the human body and development; emotions and feelings; healthy relationships and associated social skills; keeping safe; consent; self-esteem; and human rights. Outcomes related to sex and sexuality are additional outcomes included in the COS for secondary

education only. Overall, outcomes that reached consensus shared priorities between adult stakeholder groups. Only one outcome on sexual orientation, gender identity, gender roles and stereotypes reached consensus as the most important for primary education between researchers and policy makers/people from third sector but is not included in the final COS for primary education. Some outcomes included in the COS also reflect students' priorities. In the next chapter (Chapter 8), I will discuss implications of these findings together with a discussion of findings of this project.

## Chapter 8 - General discussion

*"Education is in a state of crisis. It has failed to respond to changing social needs—lagging behind rather than leading." (Bruner, 1974)*

### Introduction

In this final chapter, I provide a general discussion of the findings. I first provide a summary of the objectives of my PhD project and findings. Strengths and limitations of the overall project are discussed next. I finish this chapter by discussing implications and future directions.

### 8.1 Summary of objectives and findings

This PhD project aimed to develop a stakeholder consensus-based COS of RSE for and with students with intellectual disability aged 5-25 years for use in English educational and Western research settings. Objectives of this PhD project were:

- 1) to develop a comprehensive list of potential outcomes;
- 2) to develop a COS using a consensus-based approach.

Objective one was achieved by carrying out three studies. The first study, the systematic review (Chapter 4), identified 135 RSE outcomes for students with intellectual disability reported in the international literature. The second study (Chapter 5) supplemented the outcomes extracted from the review by providing adult stakeholders' views on important RSE outcomes for students with intellectual disability. Outcomes perceived as important by adult stakeholders related to: the human body and development; emotions and feelings; healthy relationships and social skills; sex and sexuality; keeping safe; consent; self-esteem; and human rights. Adult stakeholders' rationale for the importance of outcomes identified rested on the unique needs and difficulties experienced by this group of people, stigma towards the sexuality of people with intellectual disability, and the environment that students with

intellectual disability live in. RSE delivery, the physical environment, and adults in students' lives were perceived as important factors impacting outcome attainment by students. The third study (Chapter 6) contributed the perspective of students with intellectual disability on important RSE outcomes. Findings from this study supplemented the outcomes identified in previous studies. The most important RSE outcomes identified by students related to the development of friendships and associated social skills; online safety; unhealthy relationships, risk, and how to keep safe; and development of confidence. Outcomes identified through these studies were analysed using the framework approach (Ritchie, 2013) and grouped into 31 outcome subthemes.

Objective two was achieved in this project. Eighteen outcomes reached consensus across adult stakeholders as being the most important outcomes for primary education. Thirty-one outcomes reached consensus as being the most important outcomes for secondary education.

## **8.2 Strengths and limitations**

### **8.2.1 Strengths**

This PhD project developed the first COS of RSE for and with students with intellectual disability and this has implications for research, policy, and practice. This is the first study that examined consensus across key stakeholders on important RSE outcomes for students with intellectual disability at primary and secondary education. This is the first study, to my knowledge, that explored the views of students with intellectual disability on RSE outcomes. This is one of very few studies that included children and young people in the development of a COS (Sherratt et al., 2020; Gargon et al., 2021). This is also one of few studies that explored direct views of children and young people with communication difficulties aiming to improve educational practice using creative visual data collection methods (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019; Nicholas et al., 2019).

A key strength of my PhD project is the extent of engagement of stakeholders in this COS development. In this project, all stakeholder groups were engaged from the early stages of the COS development (e.g. identification of possible outcomes) as consultants and participants. As discussed in empirical chapters, adult stakeholders had a range of experiences supporting students with intellectual disability with varied abilities in educational and clinical settings. Male and female students with varied intellectual and different vocal communication abilities participated in this COS development making sure it reflects their needs and wishes. Thus, a range of perspectives on important RSE outcomes for students with intellectual disability were included and informed the development of the COS.

Another key strength of this project is the methodology selected to develop this COS. I used rigorous, well established, and comprehensive methodology (i.e. a systematic review, interviews, a Delphi survey) suggested by the COMET Initiative (Williamson et al., 2017). Adaptations to the COMET methodology employed in this project (discussed in the 8.3.1.3 section below) allowed me to successfully involve all key stakeholders. Visual data collection methods used with students with intellectual disability enabled me to include their views in the COS. The consensus development stage, the Delphi survey, had a large sample size (N=92 participants in both rounds) and a low attrition rate (7%).

A systematic review of Delphi surveys published till 2016 used for COS development suggested an average response rate of 80% (range 45% to 100%) and sample size of 110 participants (range 9 to 678 participants) (Gargon et al., 2019). These Delphi surveys were used to develop a COS for health conditions or interventions to be used in international settings involving stakeholder groups such as clinicians and patients (Gargon et al., 2019). A COS developed for an international audience requires a large sample size to ensure representation of stakeholders from different countries and its applicability to different cultural settings (Williamson et al., 2017). In another Delphi study used to develop a COS for international physical activity interventions in primary schools that involved a group of stakeholders similar to this project (e.g. teachers and parents), a total of 65 participants completed



both rounds of the survey and the attrition rate was 27% (Ram et al., 2022). Thus, the attrition rate in my study was lower compared to similar studies (Ram et al., 2022; Gargon et al., 2019) and the sample size was relatively high considering that this COS was not developed for an international audience.

## **8.2.2 Limitations**

However, this COS development project has some limitations. The same limitations discussed in each empirical chapter (e.g. the impact of the COVID-19 pandemic, possible sampling bias) apply to the overall project. In this section, I discuss broad limitations of this overall project in relation to the COS applicability to evaluation studies, stakeholder representation and methodological limitations.

### **8.2.2.1 Applicability to evaluation studies**

The key limitation of this project is the large number of outcomes (N=18 for primary and N=31 for secondary education) identified for inclusion in the COS which impacts its immediate application in evaluation studies. The large number of outcomes that reached consensus and a very high agreement across stakeholders was unexpected considering the literature on attitudes towards the sexuality of people with intellectual disability presented in the literature review chapter (Chapter 1). However, several methodological decisions made in my project might have impacted this finding.

First, to facilitate stakeholders' participation in a complex COS development, several adaptations to the COMET methodology (Williamson et al., 2017) were implemented in my project (for more details see the 8.3.1.3 section). For example, no "homework" that involves information to read about a COS or select important outcomes individually prior to data collection was used in my project. I also did not use COS terminology (e.g. asking stakeholders to select the minimum set of outcomes for a COS) throughout the data collection. Stakeholders were informed that the aim of the project was to identify *the most important* RSE outcomes for RSE evaluations with students with intellectual disability.

Such adaptations might have made it difficult for stakeholders to differentiate important outcomes for research, as they were not explicitly asked to select the “minimum” set of outcomes to be measured in all studies. For example, in the Delphi survey, stakeholders might have rated the outcomes for informing the content of RSE delivery rather than important outcomes for an evaluation study. On the other hand, using COS terminology in the project and asking stakeholders to complete “homework” would have resulted in attrition as indicated during consultation stages with stakeholders and would have excluded many voices. Asking stakeholders in the Delphi survey to rate the importance of including outcomes in the COS (as in “traditional” COS studies) could possibly have made it more difficult for stakeholders to prioritise the outcomes in this project due to needing knowledge on a COS terminology for participation.

Research indicates that patients and health care professionals differ in their understanding of the information about COS studies distributed before participation, the terminology used in such studies, and the purpose of Delphi surveys (Biggane et al., 2019). Participants who participated for the first time in COS development studies reported struggling to understand the purpose of a COS and the Delphi surveys which impacted their contributions (Biggane et al., 2019). Thus, more guidance is needed from the COMET about how to explain complex terminology and a purpose of COS studies to populations beyond patients and health care professionals (e.g. teachers or parents who might be less familiar with outcomes and evaluation studies) without overburdening them with lengthy preparation sessions and ensuring their meaningful participation.

Second, this COS was developed intentionally for a broad target “intervention” (i.e. RSE curriculum) delivered to students having a wide age range (i.e. students with intellectual disability aged 5-25 years). A long list of outcomes presented in the Delphi survey, contained outcomes reported for and by students with intellectual disability of a broad age (5-25 years). In the Delphi survey, stakeholders were asked to rate the same outcomes for two educational stages (i.e. primary and secondary education) to differentiate the

outcomes important for different ages as children develop. Thus, rating the same outcomes for two educational stages might have made it difficult for stakeholders to prioritise outcomes specifically for each educational stage that might have resulted in many outcomes included in the COS. Having a narrower scope of the COS (e.g. only for secondary education) might have resulted in a smaller number of outcomes included in the final COS.

Third, a final consensus workshop after the Delphi survey was planned to be carried out in this project as reported in the protocol (Paulauskaite et al., 2022) but due to time constraints it did not go ahead (discussed in Chapter 7). The final workshop would have involved strategies aiming to identify the “minimum” set of outcomes to be used in all studies. Previous Delphi surveys used to develop a COS for health conditions, child abuse, physical activity interventions in primary schools also resulted in numerous outcomes (range 13 to 39 outcomes) (Cooper et al., 2023; Powell et al., 2022; Tyler et al., 2020; Demidova et al., 2023; Ram et al., 2022; Crudgington et al., 2019). In some of these studies, a final consensus workshop was carried out with the aim of reducing the number of outcomes and finalising the COS (Cooper et al., 2023; Powell et al., 2022; Tyler et al., 2022; Demidova et al., 2023). In other COS studies, authors reported that a further consensus work is needed to reduce and finalise the COS (Ram et al., 2022; Crudgington et al., 2019). COMET suggests that the final consensus workshop should be carried out in COS development studies so that stakeholders have opportunities to discuss the findings of Delphi surveys, undertake additional voting if needed, and finalise a COS (Williamson et al., 2017). Thus, further consensus work might be necessary to reduce the number of outcomes for evaluation studies.

However, it is possible that further consensus work might not reduce the number of outcomes included in the COS due to several reasons. As discussed in Chapter 7, many stakeholders in the Delphi survey reported that all outcomes are the most important for students with intellectual disability to achieve in RSE. Stakeholders’ reasons provided for outcome importance (Chapters 5 and 6) such as unique needs and difficulties experienced by this group of students (e.g. increased risk for sexual abuse, lack of social skills,

opportunities to socialise, low self-esteem) suggest that attainment of such outcomes might have a significant impact on students' quality of life and their abilities to keep safe. Thus, it is possible that many outcomes might be rated as the most important in further workshops due to the significance of these outcomes for this population reported by stakeholders in my project.

Additionally, this COS was not developed for a clearly defined health condition or intervention and thus, the number of outcomes included in the COS is likely higher than in other COS (Williamson et al., 2017). The number of outcomes included in the COS reflects the type of intervention that this COS was developed for – RSE curriculum. Many outcomes included in the COS underpin attainment of other outcomes. This reflects the type of intervention the COS was developed for (i.e. curriculum where more complex knowledge is built on pre-existing knowledge) and might explain the number of outcomes included in the COS. For suggestions on how this COS can be applied in research settings please see the 8.3.1.1 section below.

#### **8.2.2.2 Representation of stakeholders**

Data collection with adult stakeholders was carried out online based on their preference (i.e. workshops and interviews) and benefits of reaching more participants and reducing participation burden in the Delphi survey. However, it is possible that I was unable to reach the most marginalised adult stakeholders who did not have access to the Internet. Many adult stakeholders who took part in this project identified as having White ethnicity and being non-religious. Thus, any future development of this COS (e.g. operationalisation of the COS discussed in the 8.3.1.1 section) should address this limitation and include adult stakeholders from diverse cultural and religious backgrounds. This COS was developed for use in English educational practice and Western research evaluations and thus, might be less applicable to an international audience. However, this COS can be used as a guide when adapting its application to other contexts and cultural backgrounds e.g. Non-Western countries.

While the methodological approach for exploring students' views was generally successful, I could not recruit younger students with intellectual disability (e.g. aged 5-11 years) and meaningfully include students with severe and profound intellectual disability. Thus, the views of these two groups of students are not represented in the COS and should be addressed in any future development of this COS.

Researchers interested in exploring the perspectives of students with severe or profound intellectual disability on this topic could carry out multiple case studies using ethnographic approaches, visual creative methods and involving carers in data collection. For example, researchers could observe students' behaviour in RSE lessons in contrast to other lessons to find out their views on RSE topics taught to them. Carers (e.g. parents or teachers) who know students well should be consulted to learn about students' communication or asked to interpret their behaviour. Previous studies that employed ethnographic approaches were able to explore the meaning of behaviours that people with profound intellectual disability exhibit in relation to their social context by carrying out observations over extensive period (1-3 years) and consultations with carers (Mietola et al., 2017; Simmons & Watson, 2015; Skarsaune et al., 2021; Grace et al., 2024). Researchers working with people with profound intellectual disability argue that inclusion of carers in knowledge co-construction with people with profound intellectual disability is a necessity rather than a limitation of research (Gjermestad et al., 2023; Skarsaune et al., 2021; Grace et al., 2024; de Haas et al., 2022; Mietola et al., 2017; Simmons & Watson, 2015; Cluley, 2017). Researchers emphasise that all people including people with profound intellectual disability live mediated lives and rely on others to interpret their communication (Cluley, 2017; de Haas et al., 2022; Gjermestad et al., 2023). Thus, multiple voices explored in research add additional details regarding the lives of people with profound intellectual disability rather than pose threats to validity of such information (Cluley, 2017; de Haas et al., 2022; Gjermestad et al., 2023).

Photovoice methodology could also be used to include the views of students with severe or profound intellectual disability on RSE outcomes. For example,

students with carers' help could be asked to create picture albums of RSE teaching materials used in schools. Pictures included in the albums could be used to find out students' preferences on RSE topics/outcomes (e.g. which pictures students like to look or point at). Such data could be supplemented by data collected through observations and consultations with carers to ensure that multiple perspectives were captured on the same topic. In previous studies, visual creative methods (photovoice, pictures, video, storytelling) enabled people with profound intellectual disability to illustrate or tell their experiences (Boxall & Ralph, 2011; Cluley, 2016; Whitehurst, 2007). In such studies, carers were asked to take pictures or create a video on a behalf of people with profound intellectual disability to represent their experiences by paying close attention to their preferences expressed through behaviour (Boxall & Ralph, 2010; Cluley, 2016; Whitehurst, 2007). Data triangulation has also been used to ensure validity of data collected (Boxall & Ralph, 2011; Cluley, 2016; Whitehurst, 2007).

It is also unclear if the outcomes identified as the most important in my project reflect the views of students with intellectual disability who identify as lesbian, gay, bisexual, and transgender (LGBT). Some of the students who took part in the study might have identified as LGBT; however, I did not collect data to measure sexual orientation. Research indicates that the needs of students with intellectual disability who identify as LGBT are not reflected in RSE (McCann et al., 2016; Drew et al., 2023). Thus, future work should include such students to make sure their views are reflected in the COS.

#### **8.2.2.3 Methodological limitations**

Further to methodological limitations mentioned in the paragraph above, this COS development study has potential additional limitations. As discussed in Chapters 5 and 7, some research stakeholders who took part in the study were not from England, especially the consensus development stage, that involved more than half of all researchers (84.6%) (Chapter 7) from other Western countries than England. It could be argued that data provided by international participants represented their cultural and religious backgrounds that may not

be applicable to students with intellectual disability being educated in English schools and RSE evaluations with this population in Western research settings (the setting this COS was developed for). However, as explained in previous chapters, researchers from Western countries outside England had similar views towards outcomes as researchers from England and both groups reported unique needs and difficulties experienced by students with intellectual disability as reasons for outcomes rather than reflecting on cultural or religious characteristics dominant in their countries. Crucially, consensus was achieved across stakeholders, where parents and teachers were more numerous (comprised 66.3% of the sample). Thus, it is unlikely that the views of international researchers had a substantial impact on the final COS or produced a COS that is not applicable for the setting of this COS. The obverse of this is that the COS does not include nuance on cultural and religious needs, which were not a focus of this work.

Another possible limitation of this COS is that the majority of parents who took part in the initial development stages (Chapter 5) and consensus development stages (Chapter 7) had children with autism as a co-occurring condition in addition to intellectual disability. One could argue that outcomes that were suggested by such parents for students with intellectual disability and autism might have not been applicable or as important if a different subgroup of students with intellectual disability were considered (e.g. students with Down syndrome without autism). Other stakeholders who took part in initial stages and consensus development supported students with intellectual disability with a range of co-occurring conditions in different settings e.g. education, clinical and research. Thus, such a diverse group of stakeholders have suggested a range of outcomes considering supporting students with intellectual with different abilities and were involved in the development of consensus.

As mentioned in Chapter 6, not all outcomes were presented to students with intellectual disability, some outcomes related to sex and sexuality were not presented following requests from parents or teachers. Thus, it is questionable whether student-reported outcomes represent the views of students with

intellectual disability in their entirety, and in the section above I provided suggestions how their views could be explored in the refinement of this COS.

### **8.3 Implications and future directions**

In this section, I discuss the implications of the findings and areas for further work that emerged from the findings that I have not mentioned in this chapter already.

#### **8.3.1 Research**

The findings provide valuable insights to researchers interested in the development of RSE evaluation studies, outcome measurement tools and a comprehensive RSE curriculum for students with intellectual disability.

##### **8.3.1.1 Outcome measurement**

The findings represent a significant first step towards harmonising outcome measurement in RSE evaluation studies and improving research utility.

First, the findings of this project indicate that outcomes included in the COS (i.e. N=18 outcomes for primary and N=31 outcomes for secondary education) need to be measured by researchers when evaluating comprehensive RSE. For researchers who cannot use the full set of proposed outcomes (e.g. due to a lack of resources) one suggestion is to select one outcome from each theme included in the COS that matches their programme's logic model. However, it is important that researchers specify why certain outcomes were not selected in their publications and what are the mechanisms of RSE programme that will bring the change on the selected outcomes. This information will allow better to understand the effects of RSE programme on the outcomes.

Second, the findings of this project indicate that a balance of knowledge, skills and attitudes need to be assessed when evaluating comprehensive RSE delivery. Outcomes included in the COS involve knowledge-based outcomes (e.g. pregnancy and parenting), skills-based outcomes (e.g. self-advocacy



skills) and attitudes based-outcomes (e.g. values and attitudes for positive relationships). However, further stakeholder consensus work is needed to establish outcome definitions (e.g. whether outcomes contain skills or knowledge-based information) for primary and secondary education and the best way to measure each outcome (e.g. using a questionnaire or a performance-based test and what time points). In the COS development, once “what” to measure is identified, the identification of “how” to measure a COS is the next step (Williamson et al., 2017). Different definitions of the same outcomes and applications of instruments with poor measurement properties (e.g. validity and reliability) can result in inconsistent outcome measurement, unreliable findings, and research waste (Williamson et al., 2017).

A joint initiative between COMET and COSMIN developed a guideline for researchers on how to select outcome measurement instruments for outcomes included in a COS (Mokkink et al., 2018). When developing consensus on the measurement of a COS, a systematic or a literature review is carried out to identify instruments used to measure the outcomes in the COS and studies on instruments’ measurement properties (i.e. validity, reliability, and responsiveness) (Mokkink et al., 2018). Identified instruments are then presented alongside their measurement properties for stakeholder consideration.

Previous studies on consensus development of outcome measurement used Delphi surveys and consensus workshops with stakeholders such as patients and carers (Gorst et al., 2020; 2023; Davies et al., 2022). For example, in Gorst et al. (2023) study that developed consensus on outcome measurement for a long COVID-19 condition, stakeholders including patients and carers were presented with instruments extracted from a literature review and were asked to rate each instrument from “not important” to “critically important” to measure outcomes included in a COS. Stakeholders were also provided information to facilitate their ratings such as “instrument cards” that contained descriptions about each instrument (e.g. which outcomes included in the COS the instrument is measuring) and instruments’ measurement properties (e.g. validity, reliability and responsiveness).

However, a recent systematic review of methods used to establish consensus on how to measure outcomes included in a COS indicate that predominantly clinicians and researchers were involved (Gorst et al., 2020). Patients and carers might struggle to understand purposes of such studies which might explain their lack of participation. Stakeholder groups beyond clinicians and researchers (e.g. teachers, parents and students with intellectual disability) might struggle to participate meaningfully in such complex tasks (e.g. considering instruments' measurement properties). Thus, more guidance is needed from the COMET/COSMIN initiative on how to involve diverse stakeholders when developing consensus on outcome measurement. For example, stakeholders such as parents and teachers might be asked to evaluate an instruments' content validity (e.g. relevance, comprehensibility, comprehensiveness) (Terwee et al., 2017) rather than asking to evaluate instrument's psychometric properties which might be a difficult task to complete.

Third, the findings of this project provide insights to researchers interested in developing validated outcome measurement instruments that in the long term is going to standardise outcome measurement. My systematic review (Chapter 4) revealed that there are no validated instruments for this population that had been used to assess the outcomes. Thus, researchers need to develop validated instruments that measure all outcomes included in the COS with students with intellectual disability. Some outcomes included in this COS (e.g. emotion regulation, human rights and self-advocacy skills) were not measured in any RSE evaluation studies with this population. The findings on associations between outcomes (Chapter 5) provide useful insights to researchers interested in the development of such instruments. For example, to assess whether students after RSE delivery understand what sexual abuse is, researchers might want to first assess whether students understand private body parts, sex, and consent (as reported in this project underpinning the understanding of sexual abuse).

Methods used for data collection with students with intellectual disability in this project (e.g. the picture selection activity using Talking Mats) provide examples

of possible ways to measure some of the outcomes. Previous research has shown that the application of Talking Mats was successful for facilitating an assessment of sexual knowledge and attitudes of an adult with severe intellectual disability and severe vocal communication difficulties (Bell & Cameron, 2003). In Bell's and Cameron's (2003) study, the Talking Mats approach was employed to facilitate the use of the "Not the Child Anymore" instrument (Fraser, 1987). The authors used pictures to represent complex terms used by the instrument and asked a participant to sort the pictures to into two piles to assess their knowledge on different sexuality topics e.g. asked to sort pictures into two sides of the mat to indicate public and private behaviours. This project was a case study and no formal evaluation of "effectiveness" of this method for assessing sexual knowledge was carried. Thus, it is difficult to understand how effective the method is across the intellectual disability population for assessing sexual knowledge. The effectiveness of Talking Mats for exploring direct views of people with intellectual disability has been investigated in a previous study (Murphy & Cameron, 2008).

There are other practice-based examples reported in the literature (not evaluated in research) that demonstrate how to use Talking Mats to assess sexual knowledge and vocabulary of students with intellectual disability aged 16-25 years in educational settings (Homes, 2021a; 2021b). Such examples and empirical findings discussed above illustrate the potential of using Talking Mats for facilitating outcome measurement with students with intellectual disability who have vocal communication difficulties. However, more research is needed that evaluates the application of aided augmentative and alternative communication (AAC) methods such as Talking Mats for such purpose as the empirical evidence is limited in this area. Such research should involve evaluations of psychometric properties e.g. validity and reliability of an instrument that uses AAC methods to facilitate outcome assessment.

### **8.3.1.2 Development of comprehensive RSE curriculum**

Findings of my project, i.e. the number of outcomes included in the COS, support the need to develop a comprehensive RSE curriculum for students with intellectual disability. Findings on associations between outcome themes and subthemes (Chapter 5), provide insights to the sequence of the content needed to be delivered in RSE for students to achieve the outcomes (i.e. content on the outcomes that are prerequisite knowledge needs to be taught first for students to achieve more complex outcomes). Findings on the format of RSE delivery and environmental support needed for outcome attainment (Chapter 5) provide insights to how a RSE curriculum needs to be delivered and that parental involvement is important for the effectiveness of such programmes.

Thus, researchers should consider designing a RSE curriculum for this population that involves a separate RSE delivery to students' parents. The parents' version of RSE should focus on reasons for outcome importance for this population because as the findings of this project indicate (Chapters 5 and 7) parents' objections to RSE delivery can be a barrier to RSE provision to this population. The parent version of RSE should also include practical steps on how to enable students to achieve the outcomes (e.g. by providing privacy, opportunities to apply the knowledge in real-life situations) and development of parents' confidence for having RSE related conversations with their children at home.

The importance of training parents on RSE for delivery of a comprehensive RSE to children with intellectual disability has been emphasised in the literature before (Donnelly et al., 2023; Kurt & Kürtüncü, 2024; Frank & Sandman, 2021; Kok & Akyuz, 2015; Rooks-Ellis et al., 2020). In some countries (e.g. Turkey and different states in the USA), RSE is not compulsory in schools and thus, parents are the main source of RSE information for their children with intellectual disability (Kurt & Kürtüncü, 2024; Frank & Sandman, 2021). Research indicates that RSE training provided to parents of children with intellectual disability: improved parents' knowledge related to different

sexuality topics and their children's sexual development; increased parents' confidence in having discussions related to RSE topics with their children; reduced parents' negative attitudes towards their children's sexuality (which some parents were not aware of having before the training) (Donnelly et al., 2023; Kurt & Kürtüncü, 2024; Kok & Akyuz, 2015; Rooks-Ellis et al., 2020) and led to parents having discussions with their children on wider RSE related topics after the training (Frank & Sandman, 2021). Parents reported particularly valuing social networks developed in such trainings and learning from experiences of other parents that helped to address negative attitudes towards their children's sexuality (Donnelly et al., 2023; Kurt & Kürtüncü, 2024; Frank & Sandman, 2021).

Such parent training should be co-led by students with intellectual disability so students could explain to parents why it is important for them to achieve RSE outcomes that might help parents to change their negative attitudes towards RSE delivery or attitudes towards students' sexuality. Findings of meta-analyses and reviews of systematic reviews indicate that interventions aimed at reducing stigma are more effective when people who are stigmatised involved indirectly (e.g. co-develop the content) and directly in its delivery (Waqas et al., 2020; Mehta et al., 2015; Thornicroft et al., 2016; 2022; Corrigan et al., 2012). Research has also shown that inclusion of people with intellectual disability indirectly (e.g. by presenting a video of them) and directly in trainings can reduce negative attitudes towards them held by support staff, students without intellectual disability, teachers, and public (Seewooruttun & Scior, 2014; Hastings et al., 2018; Jansen-van Vuuren & Aldersey, 2020).

Fourth, the findings of this project (i.e. the COS, stakeholders' rationale for outcome importance, and environmental support needed for outcome attainment) could guide the development of a logic model of a RSE curriculum that will help to develop, implement, and evaluate this curriculum. Findings of the systematic review (Chapter 4) indicate that RSE programmes evaluated in research settings were not developed systematically (i.e. did not have clear outcome goals, theoretical underpinnings, or logic models) which impact understanding of its effectiveness. The development of a logic model for a

complex intervention such as RSE, that has multiple outcomes and a heterogeneous target population, will help to understand how to deliver this curriculum to achieve the outcomes and weak links that need improvements. The development of a logic model involves collaborations with stakeholders to identify desired outcomes and specification of inputs, processes, and contexts needed to achieve the outcomes (Fernandez et al, 2019; Skivington et al, 2021). The development of a logic model is also based on theories that provide insights on how and why interventions will produce the impact on the outcomes i.e. contexts and methods needed for it (Fernandez et al, 2019; Skivington et al, 2021).

The findings of this project provide information on outcomes perceived as important by stakeholders, inputs (e.g. adults receive training, RSE teaching materials for students with intellectual disability are available) and processes (RSE is delivered detailed, skills-based, and consistently) needed to produce the desirable outcomes. The findings also provide insights to multilevel factors (i.e. unique needs and difficulties experienced by intellectual disability population, the environmental factors such as practices and other people's attitudes) that influence outcome attainment by students that should inform the development of a logic model of a RSE curriculum.

Once a comprehensive RSE curriculum has been developed, research is needed to evaluate its effectiveness. Findings of my systematic review (Chapter 4) indicate that there is a lack of randomised controlled trials of RSE for students with intellectual disability especially in primary education (aged 5-11 years). Thus, future research should focus on development of good quality RSE evaluation studies for this population to understand its effectiveness (i.e. what works, for whom, why, and in what situations). Longitudinal studies are also needed to establish a long-term impact of effective RSE delivery to students with intellectual disability.

### **8.3.1.3 Application of COS methodology beyond health conditions and interventions**

This project provides insights to researchers interested in applying the COMET suggested methodology beyond health conditions, interventions, and populations other than clinicians and researchers (e.g. children and young people). In this project, several adaptations were made to enable successful application of the methodology and stakeholder engagement. First, the systematic review in this project included not only RSE evaluation studies, as suggested by the COMET (Williamson et al., 2017), but also qualitative studies and grey literature sources published in the international literature that most of the outcomes were extracted from. This inclusion of qualitative and grey sources written in any language enabled to extract a wide range of outcomes that were important for stakeholders such as students with intellectual disability from different cultural and religious backgrounds. The translation of the papers in this project did not require a significant additional time or resources for completion (the wider network of researchers, native in required languages, helped with this task). Thus, future researchers should consider reviewing qualitative and quantitative studies written in any language in the COS development to capture a range of outcomes especially the views of the target population which are likely to be reported in qualitative studies.

Second, data collection with adult stakeholders was carried out considering burden associated with such participation and population involved (i.e. parents of students with intellectual disability). As discussed in Chapter 5, adult stakeholders were able to choose to take part in either an online workshop or an interview based on their preference that enabled me to reach more voices on RSE outcomes and inform the development of the COS. In this project, the length of workshops based on the JLA principles was also shorter (1 hour and 30 minutes) than in “traditional” JLA workshops (one to two days) (JLA, 2021). Research indicates that parents of children with intellectual disability have significantly less free time than parents of typically developing children (Luijkx et al., 2017). This is because children with intellectual disability have significant care needs that require parents’ help to attend to those needs (Luijkx et al.,

2017). Besides, in this project, some teachers needed to find a colleague who could cover them and deliver teaching while teachers were taking part in workshops and interviews. Data collection with teachers and other stakeholders was carried out after the COVID-19 pandemic finished in England and when schools were struggling with staff shortages. Therefore, it is likely that carrying out a longer workshop (e.g. lasting a day) would have excluded many voices.

Third, the project provides insights towards involvement of children and young people directly in the process of COS development which is uncommon in COS development studies (Sherratt et al., 2020; Gargon et al., 2021). Visual data collection methods used with students with intellectual disability with a range of abilities provide examples of how to seek direct views of children and young people on RSE outcomes. The inclusion of students' views in round 2 of the Delphi survey shows one of the ways their views could be included in consensus development. However, more guidance and resources are needed from COMET about how to apply their suggested methodology beyond health conditions and interventions. Methodological approaches used in this project can be used as example when developing such guidance.

More research is needed to determine the best way to present feedback in consensus development stages of a COS and rating scales to use in such activities. As discussed in Chapter 7, the type of feedback provided (e.g. feedback containing ratings of each stakeholder groups versus feedback containing only peers' scores) seem to impact the variability of scores between stakeholder groups and consensus (Brookes et al., 2016; MacLennan et al., 2019). More research is also needed to determine the best rating scale to use to rate the outcomes (e.g. 5-point or 9-point Likert scales) and its impact on the variability of scores and consensus. Besides, the language used in the 9-point Likert scale developed by the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) (Guyatt et al., 2011) and recommended by COMET is not easily understood by all stakeholders as my project indicates and needs improvement (discussed in Chapter 7).



#### **8.3.1.4 Involvement of students with intellectual disability in research**

##### ***A paradigm shift***

My project provides examples to researchers of how to involve children and young people in decision-making activities in research settings without them having to lead a research project or work as co-researchers. Such methodological insights could inform participatory research projects with this population.

Based on the hierarchical models of participant involvement in research, such as Arnstein's (1969) ladder of participation, my project reflects the lower rungs of the ladder i.e. research carried out "to" or "for" rather than "true" participatory research. In my project, stakeholders did not have the power to make decisions (e.g. what to research and how) nor did they work as co-researchers (e.g. were responsible for collecting and analysing data and writing the findings). However, I argue that my PhD project was "quasi-participatory" research because marginalised communities, namely children and young people with intellectual disability, were engaged directly and their views were treated as equal to adults' views e.g. incorporated in consensus development. To engage students in this project successfully, students' parents and teachers have selected which data collection method out of three possible would be the best to carry out with students based on what students have used in the past and students' preference (e.g. enjoying arts activities). Such involvement of adults to select a method of participation for children is not traditionally considered "true" participatory research. However, I argue that involvement of familiar adults in facilitation of data collection with children or young people with intellectual disability is a necessity for increasing their involvement in research rather than a "risk" for producing unreliable data or blurring the lines between participatory research and research "on" people (for more details on adults' role in facilitating children's participation in research please see below).

In this project, consultations have also been carried out with some stakeholders who did not take part in this project, which in some models (e.g.

suggested by the INVOLVE group Hanley et al., 2004), represent lower levels of participatory research. For example, parents and teachers were consulted about the need and relevance of this project by my supervisors prior to me drafting an application for my PhD funding. Parents and teachers also reviewed the project material used for data collection with adults and provided suggestions for reducing participant burden. Students with intellectual disability were consulted for selecting the best pictures to represent RSE outcomes that helped to facilitate data collection with participating students. However, such involvement is not traditionally considered as participatory research. Besides, I argue that much research, including a PhD project, is rarely “truly” participatory in the sense of power balance in decision-making, since a PhD student needs to show independent decision-making (albeit that decisions can involve participatory activities). PhD projects can also be driven by funders who decide what topics to fund and how they should be undertaken to reduce funding risk, as in this project.

The movement from “traditional research”, where children with intellectual disability are seen as objects of research, to participatory research “with” children with intellectual disability as informants of their lives is important for improving research outputs and reducing stigma towards their abilities (Norway, 2010; Higginbottom & Liamputtong, 2015; Greenaway-Clarke & Franklin, 2023; Stafford, 2017; Rouvali & Riga, 2021). However, I argue that more “fluid” participatory research models are needed to understand what “true” participatory research might mean “with” or “by” children with a range of intellectual and vocal and non-vocal communication abilities and how to carry out such research. The current taken for granted definition of participatory research that might make research more fundable is not applicable for children with a range of intellectual and vocal and non-vocal communication abilities. The assumption that only “true” participatory research (i.e. lead with children or them working as co-researchers) can change children’s lives or that it produces better outputs than other forms of involvement, continues excluding this population from research and prevents development of research methods enabling their participation.

Other researchers have also questioned the application of a current definition of participatory research as research carried out “by” or “with” communities such as people with profound and multiple intellectual disabilities (de Haas et al., 2022; Walmsley et al., 2018; Gjermestad et al., 2023). Authors suggested that a paradigm shift is needed in how participatory research with this population is perceived which currently relies on having cognitive abilities and speech as a necessary condition for participation and working as equals in research (de Haas et al., 2022; Walmsley et al., 2018; Gjermestad et al., 2023). Other authors emphasised that development of data collection methods that do not rely on words for accessing experiences of people with profound and multiple intellectual disabilities are needed for this paradigm shift (de Haas et al., 2022; Walmsley et al., 2018; Gjermestad et al., 2023). Other authors argue that once researchers find ways to enable people with profound intellectual disability to participate in data collection, researchers will be able to figure out how to involve this population in other research roles (de Haas et al., 2022).

When theorising what such participatory models might look like, Lundy’s (2007) model developed for defining children’s participation in decision-making activities could be used as a starting point. As discussed in Chapter 2, Lundy’s (2007) model emphasises that children should be provided opportunities to participate in decision making activities using appropriate modes of communication and that their voice should influence a change in practice or perceptions. Thus, a defining feature of “fluid” participatory research “by” or “with” children with intellectual disability and vocal communication difficulties might be that their voice is explored and given an equal value in research. In this “fluid” participatory research with this population, researchers should not strive for working with children with intellectual disability as co-researchers but aim for enabling children with diverse abilities to share their views and treat them as equal. It is important that this “fluid” participatory research with children with intellectual disability is acknowledged and accepted by the wider research community including funders that have potential for increasing research carried out with this population and addressing stigma towards their abilities in society.

### ***Changes needed***

Based on the findings of this project, I propose several additional suggestions for increasing involvement of students with intellectual disability in research. First, I suggest that systems such as schools that students with intellectual disability exist in need to see the value of exploring their direct views. Methods developed by researchers for seeking students' direct experiences are needed to be available in services and staff members should be trained to apply such methods in practice. In this project, many teachers volunteered to help with student interviews because teachers wanted to learn more about the methods used to explore students' views. When approaching schools for their help with student recruitment to interviews, several schools mentioned that they have not considered asking students' views regarding their RSE lessons and were intrigued that I aimed to do so. Exploring children's direct views is not just important for research outputs, but also for the development of children's self-determination skills, independence, and is also a requirement by law to include children's views in English educational practice (Department for Education and Department of Health, 2015; DfE, 2014).

Once exploring students' voice in their everyday settings becomes a "norm", it will help to change adults' attitudes towards their abilities to participate in research. As discussed in Chapter 6, I struggled to recruit students with intellectual disability to this project due to teachers' perceptions that students will not be able to participate because of their cognitive difficulties or lack of RSE knowledge. I also could not recruit any students with intellectual disability of younger age (i.e. aged 5-11 years). Once the first interviews with students were completed, I used pictures of finished activities to show to teachers that such involvement is possible that helped to recruit more students. These findings regarding attitudes towards students' abilities to participate are in line with previous research on the barriers to research participation by children with intellectual disability discussed in Chapter 2 (Gjertsen, 2019; Williams, 2020; Collings et al., 2016; Stafford, 2017; Sinclair, 2004).

Second, services such as schools need more resources in terms of funding and staff to support researchers interested in involving children with intellectual disability in research. In this project, schools varied in how much time and resources they had to support me with this project. For example, some schools had a research lead that helped me with setting up recruitment to this project and student interviews, while in other schools, RSE teachers volunteered with such tasks on top of their normal workloads. As mentioned previously, one school pulled out from the project without a reason being given after extensive engagement with the school and having parents' consents for students' participation. Having worked previously with this population in research settings that involved mental health services, I felt that schools were less resourced and prepared to have such collaborations with researchers. Thus, schools need resources to support researchers interested in conducting research with children with intellectual disability and see the value of such collaborations to increase their participation in research.

### **8.3.2 Policy and practice**

The findings of this project also provide valuable information for policy makers and RSE teachers that in the long term will improve RSE delivery and sustainability to students with intellectual disability.

#### **8.3.2.1 Relationships and Sex Education content**

Findings of this project indicate that the current statutory guidance on RSE delivery in English schools does not contain outcomes included in the COS and does not reflect the unique needs and difficulties experienced by the intellectual disability population. This is important because the statutory RSE guidance not only impacts RSE delivery to students with intellectual disability, but also students' knowledge, ability to keep safe, their sexual health, and quality of life. Therefore, findings of this project should inform consultations on updating the current RSE policy in England especially the current brief section on RSE delivery to students with Special Educational Needs and Disabilities (SEND) that include students with intellectual disability. The findings of this study provide the content of a comprehensive RSE curriculum that key

stakeholders perceive as important for students with intellectual disability. Such content after evaluations of its effectiveness could inform a statutory RSE curriculum for students with intellectual disability.

Specification of RSE content in the statutory guidance for students with intellectual disability is important to make sure students with intellectual disability receive consistent and comprehensive RSE. Currently, the guidance specifies that RSE content (developed for all students) can be tailored to students with SEND (DfE, 2019), meaning that some students with SEND might receive different RSE content based on their developmental levels. However, in this project, adult stakeholders disagreed with this view and reported that tailoring RSE content to students' developmental levels often leads, in their experience, to not providing the content at all to students with intellectual disability, thus leading to the inadvertent exclusion of students with intellectual disability from the curriculum. The specification of RSE content for students with intellectual disability in the statutory guidance would provide clarity to teachers and support from the government to deliver it.

Until the updated statutory RSE guidance, the COS could be used by teachers as a guide for developing the content of a compressive RSE curriculum for students with intellectual disability. Findings on associations between outcome themes (reported in Chapter 5) provide insights to teachers on the possible sequence of RSE content delivery (i.e. students need to achieve outcomes first that are a prerequisite for other outcomes). Besides, after cultural adaptations, this COS could also be used by teachers internationally as a guide of RSE content for this population.

#### **8.3.2.2 Delivery and evaluation**

The findings (Chapter 5) on the timing of RSE delivery for this population (i.e. in the earlier years) should also be reflected in the updated RSE guidance and delivery in schools. In this project, adult stakeholders reported that RSE delivery to students with intellectual disability need to start in the early years e.g. primary schools because due to students' additional needs it takes time

for them to learn new information and acquire skills. This means that delivery of information, for example, on outcomes included in the COS for secondary education should start in the early years by providing age-appropriate information to students and revisiting the topics and deepening their knowledge in later years. Other researchers have also emphasised the importance of proactive RSE delivery to people with intellectual disability for development of their knowledge and skills and ability to keep safe (Schaafsma et al., 2014; Wilkinson et al., 2015; Schmidt et al., 2022). In contrast, early RSE delivery for this population is not reported in the current statutory guidance (DfE, 2019). Sex education is also not a compulsory part of a RSE curriculum for primary education (DfE, 2019), meaning that in some schools such information will not be provided till students are in secondary education.

To improve RSE delivery, the findings of this project should be used by the Office for Standards in Education, Children's Services and Skills (Ofsted) who are appointed to review RSE delivery in English schools to all students including those with intellectual disability. The COS can be used by Ofsted to evaluate if schools provide comprehensive RSE to students with intellectual disability (e.g. by reviewing the content of curriculum taught in schools and outcomes included in the COS) and for informing their evaluations of its effectiveness (i.e. whether students achieved the outcomes included in the COS). Since the publication of the statutory guidance in 2019 on RSE delivery in English schools (DfE, 2019), to my knowledge, there is no single published review by Ofsted on RSE delivery to students with intellectual disability. Thus, the updated statutory RSE guidance should also include a section on how RSE delivery to students with intellectual disability will be evaluated in schools (for suggestions for school evaluations please see below) and by the government.

The findings of this project also provide insights to teachers on how to apply the COS when assessing the effectiveness of RSE delivery to students with intellectual disability in schools (i.e. whether the students have achieved the outcomes). Findings of the systematic review (as discussed in the research implications section above) indicate that teachers would need to decide on and create methods to assess outcomes included in the COS with students with

intellectual disability. Teachers could use data collection methods used in this project (i.e. art-based discussions and a picture sorting activity using Talking Mats), students' communication aids, pictures, videos, vignettes, TV shows, social media, and role-plays to assess the outcomes. For example, students could be presented videos depicting situations where people are manipulated or abused and asked to describe using speech or a communication aid what videos depicts and what to do in such situations before and after delivery of such topics in RSE.

Skills-based outcomes (e.g. how to develop and sustain healthy friendships and social skills; how to develop and sustain healthy romantic relationships and social skills; self-advocacy skills; consent and communication skills; asking for help) could be assessed observing students' skills in classrooms (e.g. using role plays or reviewing if students' have close friends at schools). Parents should also be consulted about students' behaviour to assess if students achieved skills-based outcomes (e.g. asked if students are able to ask for help). Collecting information from several sources would provide a more comprehensive understanding of skill attainment and its generalisability to different contexts that many students with intellectual disability are struggling with (e.g. students might be able to ask for help during role-plays in schools but might struggle to apply this skill in real life situations) (Domitrovich et al., 2007; Boorom et al., 2023; Finlay et al., 2014; Bundock & Hewitt, 2017).

An updated statutory RSE guidance based on the findings of this project (e.g. early RSE delivery) and outcomes included in the COS (that focused on protection and development of students' autonomy) might enable a paradigm shift of negatively viewing the sexuality of people with intellectual disability and perceiving them as eternal children which may also lead to consistent and effective RSE provision in schools.



### **8.3.2.3 Environmental support needed**

#### *Training*

Findings on the role of adults in outcome attainment (Chapters 5 and 7) indicate that training is needed by all adults in the student's environment (e.g. parents, teachers, and support staff members) to support students to achieve RSE outcomes. Such findings should be reflected in the updated statutory guidance and implemented in schools. First, training is needed to make sure that students receive consistent RSE information between home and school. Second, adults should receive training so that they are aware of how their behaviour can influence not only outcome attainment, but also students' engagement in inappropriate behaviours (e.g. if adults let students masturbate in public places thinking that this behaviour is a part of intellectual disability). Third, training is needed for all adults who support students with intellectual disability to explore their attitudes towards sexuality of students with intellectual disability. Adults' attitudes can impact the selection of outcomes, the timing of RSE delivery, and creation of opportunities for students to develop relationships and enjoy their sexuality (i.e. apply knowledge in practice).

More work is needed from schools to support parents to see the value of comprehensive RSE delivery to this population. As discussed, parents have been reported to act as a barrier to RSE delivery (Chapters 5 and 7). Therefore, schools could use the rationale on outcome importance identified in this project to provide explanations to parents why their children with intellectual disability need to achieve the outcomes. This information could be distributed to parents via a post or emails as some parents might feel uncomfortable to have such discussions in group settings as this project indicates. Parents should also receive training to address their attitudes towards RSE delivery to their children. Such training should be co-led by students with intellectual disability. As discussed in research implications section, such RSE training can improve parents' negative attitudes towards their children's sexuality and parents' confidence for discussing RSE topics at

home (Donnelly et al., 2023; Kurt & Kürtüncü, 2024; Kok & Akyuz, 2015; Rooks-Ellis et al., 2020).

### *Resources*

The English government should provide resources for schools to deliver effective and comprehensive RSE to students with intellectual disability. The government has allocated six million pounds to support RSE delivery in schools since the statutory guidance published in 2019 (Long, 2023). However, it is unclear how much of this funding is allocated to support RSE delivery to students with intellectual disability. Resources are needed to train and support all school staff members on RSE delivery to this population and students' parents. Resources are also needed to develop RSE teaching materials that consider the heterogeneity of abilities and needs. Findings of this project indicate that many teachers struggle to deliver complex and abstract RSE topics to students with intellectual disability due to a lack of appropriate resources available, aligning with similar evidence from previous studies (Strnadová et al., 2022; Kürtüncü & Kurt, 2020; Pryde & Jahoda, 2018; Gokgoz et al., 202; Lafferty et al., 2012; Pownall et al., 2012). Thus, the government should provide funding for stakeholders interested to co-develop such teaching materials. The COS can be used to identify what the teaching materials should be about.

### *Physical environment*

Findings on the adults' role and the physical environment (Chapter 5) should inform all policies in England around supporting people with intellectual disability in all settings. Practices reported in this project involved in supporting students with intellectual disability (e.g. toilets without doors, no privacy given in residential schools, adults not following consistent boundaries with students with intellectual disability) may impact their increased vulnerability to sexual abuse and exploitation, engagement in inappropriate behaviours such as masturbation in public and deny their human rights.

In previous studies, young people with intellectual disability also reported that they experience a lack of privacy in their residential bedrooms (e.g. people enter their bedrooms without knocking or while they are engaging in sexual activities) (Healy et al., 2009; Lockhart et al., 2010). Research has also shown that a lack of privacy given to people with intellectual disability to engage in sexual activities is associated with engagement in inappropriate sexual behaviours (e.g. masturbation in public places) (Lockhart et al., 2010; Hollomotz, 2009; Cambridge et al., 2003). Other authors have also emphasised how a lack of privacy given to people with intellectual disability to fulfil their sexual needs and opportunities to express their views is associated with an increased risk of sexual abuse experienced by this population (Tomsa et al., 2021; Gil-Llario et al., 2019; Wissink et al., 2018; Jojo et al., 2023).

The school physical environment needs to align to RSE content (e.g. doors in toilets) to facilitate students' learning and outcome attainment. Previous research has also shown that adaptations made to schools' physical environment to match curriculum content can facilitate students' learning, motivation, attendance and lead to cultural changes within a school (Woolner & Tiplady, 2016; Woolner et al., 2018; Woolner et al., 2012; French et al., 2020). For example, in Woolner's and Tiplady's (2016) case study, several areas in a primary English school were adjusted to support the delivery of additional topics, such as gardening and cooking, added to the curriculum. Unused areas in the school were reorganised to match the content of additional learning topics e.g. a mobile classroom was reorganised as a cooking space and gardens for growing vegetables were created on the school's grounds (Woolner & Tiplady, 2016). Even though the effectiveness of such physical adaptations on students' skill development were not evaluated in the study, students reported that they had developed and improved their cooking and gardening skills (Woolner & Tiplady, 2016). Teachers reported that physical adaptations made in the school increased students' attendance and motivation to learn (Woolner & Tiplady, 2016). A two-year follow-up revealed that the additional learning topics and the physical spaces were incorporated in other subjects and were embedded within the wider curriculum (Woolner et al., 2018).

## **Conclusions**

In this PhD project, I developed the first stakeholder-consensus based COS of Relationships and Sex Education for and with students with intellectual disability. The findings provide important insights to education providers, policy makers, and researchers that will contribute to effective RSE delivery, development, evaluation, and sustainability for this population. My project also provides theoretical and methodological developments for increasing stakeholder involvement in research. The findings demonstrate changes needed for increasing involvement of students with intellectual disability in decision-making activities in research and practice. Several areas for further work emerged from the findings of my PhD project that involve further stakeholder work to operationalise the COS and its measurement, development of comprehensive RSE programmes, evaluation studies, and validated outcome measurement instruments.

**Word count: 99,282.**

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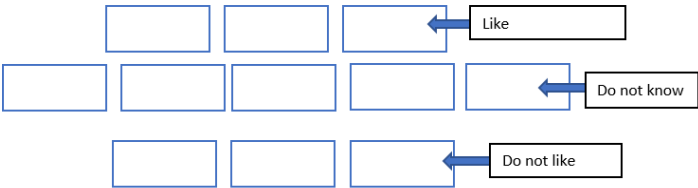
## Appendices

### Appendices - Chapter 3

#### Appendix 3.1 Summary of data collection methods

| Method                                                | What involves                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Suitability                                                                                                                                                                                                                                                                                                                                                       | Advantages                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Disadvantages                                                                                                                                                                                            |
|-------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1. Picture sorting activity using Talking Mats</b> | <p>Placing pictorial outcomes of RSE under “ok” and “I do not know” categories or other visual scale that a student is familiar with e.g. “need” and “do not need”.</p>  <p><i>Note: Images reproduced with permission of the rights holder, Photosymbols limited (<a href="https://www.photosymbols.com">https://www.photosymbols.com</a>), Widgit Symbols © Widgit Software Ltd 2002-2024 (<a href="http://www.widgit.com">http://www.widgit.com</a>), and Talking Mats Ltd (<a href="http://www.talkingmats.com">www.talkingmats.com</a>). The Symbols are designed and © to Adam Murphy</i></p> | <ul style="list-style-type: none"> <li>-used picture exchange systems before or likes using pictures when communicating</li> <li>- able to recognise pictures</li> <li>-able to make a choice</li> <li>- has good receptive language (e.g. understands simple questions or 2-word phrases) but no need of having expressive language (ability to talk)</li> </ul> | <ul style="list-style-type: none"> <li>-flexible (students can go on their own pace and take breaks and go back and change their mind)</li> <li>- does not need to be completed sitting at the table and could be completed hanging the mat on the wall so the student could move in the room (this might be suitable for students with ID and ADHD)</li> <li>-provides views of students who might not be able to express themselves using speech</li> <li>-if used before, might be familiar or similar activity</li> <li>-hands-on approach</li> </ul> | <ul style="list-style-type: none"> <li>- Students who never used Talking Mats might find difficult to take part</li> <li>-Students who cannot make a choice might find difficult to take part</li> </ul> |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                          |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                          |
| <b>Method</b>                  | <b>What involves</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | <b>Suitability</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | <b>Advantages</b>                                                                                                                                                                                              | <b>Disadvantages</b>                                                                                                                                                                                                                                                                                                                                     |
| <b>2. Art-based discussion</b> | <p>Using what a student likes e.g. pictures, drawings, sticky notes or “Play Dough” to produce a “topics I like learning about in Relationships and Sex Education” poster or collage or just individual images. Simple questions during this session are asked to guide the expression of views on RSE topics.</p>  <p>Note: Images reproduced with permission of the rights holder, Photosymbols limited (<a href="https://www.photosymbols.com">https://www.photosymbols.com</a>), Widgit Symbols © Widgit Software Ltd 2002-2024 (<a href="http://www.widgit.com">http://www.widgit.com</a>), Unplash (Getty Images), Autism Services, Education, Resources and Training (ASERT) (<a href="https://paautism.org/resources/">https://paautism.org/resources/</a>), and Talking Mats Ltd (<a href="http://www.talkingmats.com">www.talkingmats.com</a>). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.</p> | <ul style="list-style-type: none"> <li>- no need to have expressive language but a minimal receptive language (2-word phrases)</li> <li>- no need to be able to understand a visual scale e.g. “like” and “do not like”.</li> <li>- ability to recognise pictures if pictures are selected for the task</li> <li>- good fine motor abilities for picking up the pictures and placing on a poster if pictures selected for this activity and for drawings if drawings are used</li> </ul> | <ul style="list-style-type: none"> <li>- fun, creative, sensory, hands-on activity</li> <li>-flexible</li> <li>-provides views of students who might not be able to express themselves using speech</li> </ul> | <ul style="list-style-type: none"> <li>- if a student does use speech it might be difficult to understand what has been produced or whether this is about RSE thus the reliability of data might be questionable.</li> <li>- might need help from a student’s carers to help facilitate the communication for students that do not use speech</li> </ul> |

| Method                             | What involves                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | Suitability                                                                                                                                                                                                                                                                                                          | Advantages                                                                                                                                                                                                                                                                                                                                                                                                                 | Disadvantages                                                                                                                                                                        |
|------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>3. Diamond ranking activity</b> | <p>Students are asked to sort pictures that represent RSE outcomes into a diamond shape to express their views. For example, they are asked to place outcomes of RSE that they like on the top (row 1), the outcomes that they are unsure about in the middle row (row 2), the outcomes that they “do not like” to place on the bottom (row 3) and will be asked about their ranking choices (e.g. “Why this picture was placed on top of the diamond?”)</p>  | <ul style="list-style-type: none"> <li>- good expressive and receptive language</li> <li>-ability to understand simple questions</li> <li>-good reasoning abilities</li> <li>-for students who do not like direct questioning (e.g. standard interviews) but can answer questions while doing an activity</li> </ul> | <ul style="list-style-type: none"> <li>- instead of asking direct questions in an interview format, this is a hands-on approach</li> <li>-might be more suitable for students with ID and autism who do not like direct questioning</li> <li>- would provide students with ID views of RSE and ranking of the outcomes</li> <li>-for students who do not like using Talking Mats and prefer answering questions</li> </ul> | <ul style="list-style-type: none"> <li>- students with no expressive language and reasoning abilities will not be able to take part but there are other methods suggested</li> </ul> |

Note: ID=intellectual disability; ADHD=attention deficit hyperactivity disorder.

### Appendix 3.2 Approaches used to recruit adult stakeholders to workshops and interviews

| Stakeholder group                                            | Recruitment approaches employed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|--------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Parents</b>                                               | <ul style="list-style-type: none"> <li>- 1 special school network in London was approached</li> <li>- 4 special schools from the network offered their help with recruitment (i.e. 1 school invited me to present the study to parents at a school, 1 school shared study information via a school's newsletter, 1 school posted information on their website and 1 school shared information to the parents at a school's RSE event)</li> <li>- 3 schools (special and mainstream) outside the network were approached and 1 mainstream school offered their help with recruitment (i.e. made individual calls to the parents)</li> <li>- 22 parent carer forums in England were approached</li> <li>- 12 charities and third sector organisations that support families of children with ID were approached (e.g. Mencap, Contact a Family, Challenging Behaviour Foundation)</li> <li>- Social media (posts on Twitter and Facebook e.g. SEND parent groups)</li> <li>- Snowball recruitment</li> </ul> |
| <b>Teachers and school staff members</b>                     | <ul style="list-style-type: none"> <li>- 1 special school network in London was approached</li> <li>- 4 special schools from the network offered their help (i.e. invited teachers from schools to take part)</li> <li>- 3 schools (special and mainstream) outside the network were approached and 1 mainstream school offered their help with recruitment (i.e. invited teachers from the school to take part)</li> <li>- 6 educational organisations and charities in England were approached (e.g. PSHE association, NASEN, FLSE, Association of Muslim schools, Catholic Education Service)</li> <li>- Social media (posts on Twitter and SEND teaching forums)</li> <li>- Snowball recruitment</li> </ul>                                                                                                                                                                                                                                                                                            |
| <b>Researchers</b>                                           | <ul style="list-style-type: none"> <li>- 28 researchers identified from the systematic review and internet searchers were approached</li> <li>- Study poster distributed via research in ID mailing list (ID-RESEARCH-UK@JISCMail.AC.UK)</li> <li>- Social media (posts on Twitter)</li> <li>- Snowball recruitment</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Policy makers/ people from third sector organisations</b> | <ul style="list-style-type: none"> <li>- 2 government agencies specialising in education in England were approached (i.e. Department for Education: RSE department and Ofsted)</li> <li>- Parliamentary Education Committee in England was approached</li> <li>- The Children's Commissioner for England</li> <li>- 32 third sector organisations and charities that support families of children with ID or specialise in special education policy in England or were involved in RSE policy in England (e.g. Sex Education Forum, Council for Disabled Children, National</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                     |



|  |                                                                                                                                                                                                                         |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  | Autistic Society, Ambitious about Autism, NASEN, Brook, Big Talk Education, Family Planning Association, CHANGE, Disabled Children's Partnership, NSPCC)<br>- Social media (posts on Twitter)<br>- Snowball recruitment |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

*Note:* SEND=Special Educational Needs and Disabilities; ID= intellectual disability; PSHE= Personal, Social, Health and Economic; NASEN=National Association for Special Educational Needs; FLSE=Federation of Leaders in Special Education; Ofsted=Office for Standards in Education, RSE=Relationships and Sex Education; Children's Services and Skills; NSPCC=National Society for the Prevention of Cruelty to Children.

### Appendix 3.3 Study poster used for recruitment to workshops and interviews



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Photo Symbols

**What Relationships and Sex Education (RSE) should provide for students with learning disability?**

We are looking for **parents** of students with learning disability aged 5-25 years, **teachers, researchers, policymakers and other experts** to share their views on RSE outcomes.

To find out more about the study and express your interest follow this link:  
[https://uclioe.eu.qualtrics.com/jfe/form/SV\\_0HebK8u9v1o09L0](https://uclioe.eu.qualtrics.com/jfe/form/SV_0HebK8u9v1o09L0)  
or email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

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## Appendix 3.4 Study poster used for recruitment of students

### Relationships and Sex Education (RSE) outcomes for students with intellectual (learning) disability



This study aims to identify important RSE outcomes for students with intellectual disability as agreed by students, caregivers, teachers and other experts. These outcomes will be useful to teachers and researchers interested in evaluating their practice.

### We are looking for schools/colleges in England to take part

- What the study involves?

**Interviews with students with intellectual disability aged 5-25 years** to find out their views on RSE. We are asking them to use pictures, drawings and symbols to share what they think about RSE. Examples:



**Please help to develop effective RSE that involves students' views!**

**To find out more please email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)**

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### Appendix 3.5 Study poster used for recruitment to Delphi survey

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**Please take part in a survey to identify important Relationships and Sex Education (RSE) outcomes for students with learning (intellectual) disability!**

We are looking for **parents/carers of students with learning disability** aged 5-25 years, **teachers, researchers** and **policymakers/people working in third sector organisations**.

To find out more please scan this code:  
or email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)



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## Appendix 3.6 Ethics application for all studies in this project

### Doctoral Student Ethics Application Form

Anyone conducting research under the auspices of the Institute of Education (staff, students or visitors) where the research involves human participants or the use of data collected from human participants, is required to gain ethical approval before starting. This includes preliminary and pilot studies. Please answer all relevant questions in simple terms that can be understood by a lay person and note that your form may be returned if incomplete.

#### **Registering your study with the UCL Data Protection Officer as part of the UCL Research Ethics Review Process**

If you are proposing to collect personal data i.e. data from which a living individual can be identified **you must be registered with the UCL Data Protection Office before you submit your ethics application for review.** To do this, email the complete ethics form to the UCL Data Protection Office. Once your registration number is received, add it to the form\* and submit it to your supervisor for approval. If the Data Protection Office advises you to make changes to the way in which you propose to collect and store the data this should be reflected in your ethics application form.

***Please note that the completion of the UCL GDPR online training is mandatory for all PhD students.***

#### Section 1 – Project details

- a. Project title: The development of a Core Outcome Set for evaluating the impact of Relationships and Sex Education with students with intellectual disability.
- b. Student name and ID number (e.g. ABC12345678): Laura Paulauskaite; 12054636.
- c. **\*UCL Data Protection Registration Number:** Z6364106/2021/08/63 social research

- a. Date Issued: 20/08/2021.
- d. Supervisor/Personal Tutor: Primary Supervisor-Professor Carol Rivas.  
Secondary supervisor- Dr Vaso Totsika.
- e. Department: Social Research Institute.
- f. Course category (Tick one):
- PhD ☒
- EdD ☐
- DEdPsy ☐
- g. **If applicable**, state who the funder is and if funding has been confirmed. This work is supported by the Economic and Social Research Council PhD studentship awarded to Laura Paulauskaite: ES/P000592/1.
- h. Intended research start date: 07/01/2022.
- i. Intended research end date: 31/10/2023
- j. Country fieldwork will be conducted in: England.
- k. If research to be conducted abroad please check the Foreign and Commonwealth Office (FCO) and submit a completed travel risk assessment form (see guidelines). If the FCO advice is against travel this will be required before ethical approval can be granted: UCL travel advice webpage
- l. Has this project been considered by another (external) Research Ethics Committee?

Yes ☐

External Committee Name: Enter text

Date of Approval: Enter text

No ☒ **go to Section 2**

**If yes:**

- Submit a copy of the approval letter with this application.
- Proceed to Section 10 Attachments.

**Note:** Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES) or Social Care Research Ethics Committee (SCREC). In addition, if your research is based in another institution then you may be required to apply to their research ethics committee.

## **Section 2 - Research methods summary (tick all that apply)**

☒ Interviews

☒ Focus Groups

☒ Questionnaires

☐ Action Research

☐ Observation

☐ Literature Review

☐ Controlled trial/other intervention study

☐ Use of personal records

☐ Systematic review – **if only method used go to Section 5**

☐ Secondary data analysis – **if secondary analysis used go to Section 6**

☐ Advisory/consultation/collaborative groups

☐ Other, give details:      Enter text

Please provide an overview of the project, focusing on your methodology. This should include some or all of the following: purpose of the research, aims, main research questions, research design, participants, sampling, data collection (including justifications for methods chosen and description of topics/questions to be asked), reporting and dissemination. Please focus on your methodology; the theory, policy, or literary background of your work can be provided in an attached document (i.e. a full research proposal or case for support document). *Minimum 150 words required.*

**The aim** of this PhD project is to develop a stakeholder consensus-based Core Outcome set of Relationships and Sex Education (RSE) for students with intellectual disability aged 5-25 years. Core Outcome Set (COS) involves identifying “what” to measure and includes stakeholders’ opinions (students with intellectual disability, parents, teachers, school staff, researchers, and policy makers) on what constitutes meaningful outcomes.

The research question:

What stakeholders (students with intellectual disability, parents, teachers, school staff, policymakers, and expert researchers) perceive as important outcomes of RSE for students with intellectual disability?

**Objectives:**

- 1) to develop a comprehensive list of potential outcomes based on a) findings from a systematic review of RSE outcomes reported in the literature for students with intellectual disability and b) qualitative data from key stakeholders: students with intellectual disability, parents, teachers, school staff, policymakers, and expert researchers.
- 2) to finalise a COS using a consensus-based approach through an electronic Delphi survey and if needed a subsequent workshop with key stakeholders.

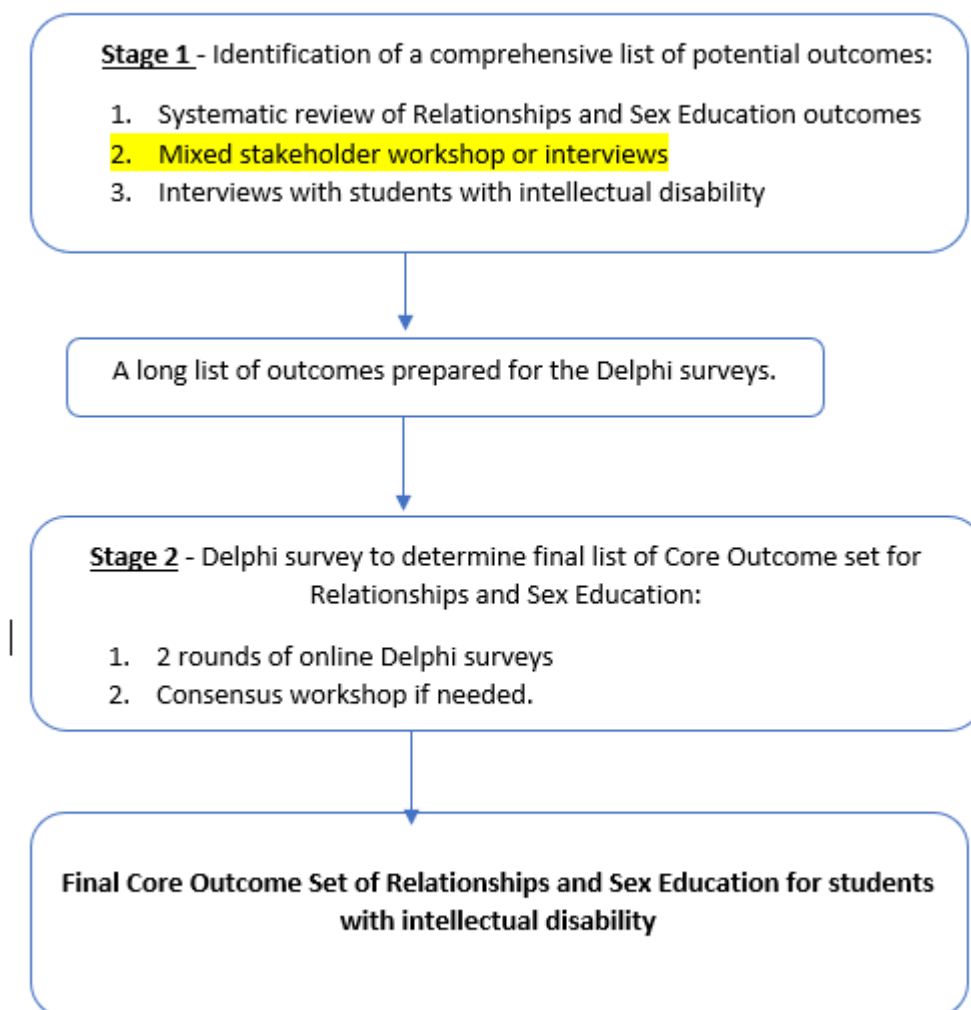


## **Study design and methods of data collection and analysis**

This is a two-stage mixed-methods study (please see study flow chart) that involves a systematic review, a stakeholder workshop, interviews with students with intellectual disability and an online Delphi style survey. The systematic review of RSE outcomes for students with intellectual disability that will form a part of objective (1) is completed. The systematic review protocol was registered in the International Prospective Register of Systematic Reviews (PROSPERO) (registration number: 1787). This PhD study is registered prospectively in the Core Outcome Measures in Effectiveness Trials database (registration number: CRD42021243176).

I am seeking ethical approval for the mixed stakeholder workshop, interviews with adult stakeholders, interviews with students with intellectual disability and an online Delphi style survey. The COMET handbook for COS development [22] will guide the methodology of this study. I (the PhD student) will be a primary researcher who will be leading all three studies, data collection and analysis as I am carrying out these 3 studies for my PhD research project. CR and VT will be supervising my work.

Figure 1 Study Design



### Stage 1: identifying a comprehensive list of potential outcomes

The mixed stakeholder workshop: to gather information on what outcomes stakeholders perceive as necessary for RSE a mixed stakeholder workshop will be carried out with parents, teachers, policy makers and researchers (N=6-8 in each group). The workshop will be carried out either face-to-face (at the University College London) or remotely (e.g. using the Microsoft Teams or Zoom software) depending on the current COVID-19 regulations and

participants' preferences. Prior to the workshop when obtaining informed consents, I will ask demographic information from stakeholders (please see Appendix 1 for the questions). I will collect data on ethnicity and religious affiliation as research indicates that people from different backgrounds hold different beliefs about what topics are appropriate to deliver in RSE [25-27]. Participants will have an option to not to answer these questions if they wish.

The process of a Priority Setting Partnership (PSP) based on the James Lind Alliance principles [27] will be adapted to carry out this workshop. The PSP is a structured consensus-based approach that involves mixed stakeholder groups working together to produce a prioritised list of outcomes [28]. In the workshop, I will explain the aims of the workshop emphasising the confidentiality and anonymity and will answer any questions. Then, stakeholders will be split into smaller groups (e.g. there will be a parents' group, teachers' group and etc.). If participants will prefer to have a remote workshop, they will be split into breakout rooms using the Microsoft teams or Zoom software. Each group will be asked to discuss a list of possible outcomes of RSE and come up with the top three outcomes of RSE which will be written down on a board or on a PowerPoint slide (in a remote workshop) for everyone to see (please see Appendix 2 for the workshop guide). When presenting their top three outcomes each group will be asked as to why they have chosen these outcomes and how important they are to the group. After that, all stakeholders will be asked to work together and prioritise the outcomes from the board or the PowerPoint slide which might be renamed or refined. Outcomes from the systematic review will be discussed if it is unclear how they should be presented in the Delphi Survey, e.g. if there are outcomes that are similar but not identical or where multiple follow-up time points are used. The outcomes list from the review will also be available for participants to see (in the face-to-face workshop the outcomes from the review will be presented on printed sheets handed to each participant and in the online workshop on a PowerPoint slide). The workshop will be audio recorded (in the face-to-face workshop using audio recorders and in the remote workshop using an audio record option in the chosen software). The recording of the group discussions might provide additional outcomes that were discussed in the smaller groups but

were not presented for the discussion. This workshop will allow us to explore differences between subgroups (e.g. what outcomes parents perceive as the most important) while unpacking their different understandings together and also achieving consensus-based list of outcomes in one workshop, thus reducing the demand and burden on participants.

**Interviews with adult stakeholders:** Stakeholders (parents, teachers and school staff, researchers and policy makers) who expressed an interest to take part in the study but cannot attend the workshop due to time commitments or the format (i.e. group discussion) will be offered to express their views on RSE outcomes through taking part in one individual interview with me (the PhD student). The same data collection process as in the workshop (described above) will be used for carrying out these individual interviews. That is, the interview will be carried out either face-to-face (at the University College London) or remotely (e.g. using the Microsoft Teams or Zoom software) depending on the current COVID-19 regulations and participants' preferences. Prior to the interview when obtaining informed consents, I will ask the same demographic information as in the workshop. In the interview participants will be asked to tell what they think the outcomes of RSE should be and to select the most important three outcomes (please see the interview schedule in Appendix 3). The interview will be audio recorded for the same reason as above. The only difference between the workshop and the interviews will be that the interviews will last shorter time (20 minutes) and will be carried individually and do not lead to the development within the one session of social norms. Thus, this data collection method might allow participants who cannot take part in the workshop (due to time commitment or not feeling comfortable with the group format) to express their views. This option for participants to choose either to take part in the workshop or an interview was added because after carrying out participant recruitment for the workshop, there were people who wanted to take part in the study but could not commit for 1 h and 30 (the length of the workshop) or/and preferred to take part in the interview. Thus, this is a direct response to participant requests. The number of participants who will take part in the interview will depend on how many took part in the

workshop. The total N for data collection from adult stakeholders using the workshop and interviews will be 10-15 in each 4 stakeholder groups.

### **Data analysis of the workshop and interviews**

Data collected through the workshop and interviews will be analysed using the inductive method of thematic analysis described by Braun and Clarke [29]. I will transcribe the data in full and analyse in the NVivo qualitative data analysis software. The inductive method of thematic analysis is a data driven approach and involves coding data into themes which emerge from the text and are not predefined by a specific theoretical framework or previous research [29]. This approach to analysing qualitative data has been chosen because the aim of the stakeholder workshop is to find out stakeholders' views of RSE outcomes while keeping the language it has been said rather than conceptualising the data in relation to theoretical framework or previous research. Data will be analysed at a semantic level meaning that the themes will be identified from what has been explicitly said in stakeholders' descriptions [29]. The process of data analysis will involve (not in a linear fashion): reading and re-reading the transcripts, coding the data, sorting the topics on outcomes of RSE into potential themes and subthemes, reviewing these potential themes and subthemes in relation to individual themes and the whole data making sure that they are meaningful and coherent and naming, defining and reporting the themes. Twenty percent of the data will be second-coded by another researcher for dependability and confirmability. Inter-rater reliability will be measured using Cohen's Kappa coefficient and based on the parameters proposed by Landis and Koch [30] to assess the validity of the analysis.

### **Interviews with students with intellectual disability**

The views of students with intellectual disability (N=10-15) on outcomes of RSE identified in previous stages (the mixed stakeholder workshop and the systematic review) will be explored using individual interviews based on one of three qualitative data collection methods: 1) a picture sorting activity based on the Talking Mats framework; 2) a visual arts-based session or 3) a diamond ranking activity. These three methods will be piloted with a small number of

students (N=3-5) with intellectual disability who are not taking part in the study before interviews with the study participants.

### **General procedure**

The choice of one data collection method out of three possible (e.g. whether this will be a picture sorting activity or a visual arts-based session) for a specific student will be decided based on this student's preferences and information discussed in preparation sessions with the student's parents and/or teachers. The preparation sessions (either over a phone or face-to-face depending on extant pandemic restrictions and teacher' and parents' preferences) will be conducted before the interviews with students by me to discuss the following: 1) a student's reasoning and communication abilities; 2) students' experiences of any of these methods; 3) a student's interests; 4) adaptations of the selected method; 5) a student's current RSE knowledge and sensitive topics that could lead to distress; 6) an appropriate length of the interview and a place at student's school and 7) a parent's or a teacher's presence in the interview.

In the preparation session, a simple guide of what each method involves and what skills students may need to have to take part will be given to parents and teachers (see Appendix 3). Additionally, parents and/or teachers will be given an easy read social story of what will happen in each data collection method produced for students with intellectual disability to explain the data collection methods to their children and find out which method they would prefer. The social stories might also help to reduce uncertainty and anxiety for students with intellectual disability about what will happen in the interviews (see an example of a social story in Appendix 5). Students' with intellectual disability current knowledge of RSE topics as well as upsetting topics and their cultural and religious backgrounds will be discussed with parents and/or teachers making sure that interviews do not upset students. Unfamiliar topics of RSE will not be discussed with students in the interviews because this could lead to anxiety or distress for students if they do not understand what this outcome of RSE means. As a secondary consideration it could also result in unreliable data (e.g. if students placed an outcome of RSE on the Talking Mat not understanding what this outcome means). The most suitable place at the

student's school for interviews and whether the interview will be completed sitting at a table or hanging materials on a wall (so students could move around the room if needed) will be discussed as well. The length of the interview will be also discussed so that the interview does not overload the student. However, no interview will be longer than 30 minutes and a couple of visits for some students might be needed to finish an activity. Students' interests will be discussed as well and I will try to incorporate this information in the activities whenever possible (e.g. if a student likes a specific TV show or a cartoon, pictures of characters from this show will be produced for a student to use in the interview; or the interview could start by talking briefly about the interests and then building up towards the activity of the interview).

I will also discuss if a parent or a teacher should be present in the interview considering what is best for each student and if I need assistance given the particular student's needs, on a case-by-case basis. Parents/teachers will be asked not to engage in the discussion during the interview.

All interviews with students will be audio recorded as students who use speech to communicate might provide their views of RSE outcomes or might suggested additional outcomes. In the interviews, outcomes presented to students will be age-appropriate and matched to students' comprehension and developmental level. The interviews will start with simpler RSE outcomes first and moving towards more complex and abstract outcomes. At the end of an interview, a student will be debriefed e.g. by asking how a student found the interview, whether they have any questions about what happened and lastly talking about activities that the student will have for the day.

I understand that there will be students who cannot complete the tasks or answer all questions. I will offer regular breaks or visits and I will be particularly vigilant to students' signs of distress, anxiety, or engagement in challenging behaviours. If this happens, the interviews will be terminated immediately.

## **Material**

I will ask students with mild intellectual disability (N=5) who are not taking part in the interviews to help to co-produce the material for the interviews. This will involve asking them to select the most accurate pictures to represent RSE outcomes identified in previous stages (the systematic review and the mixed stakeholder workshop). This will ensure that the symbols selected to represent the outcomes are unambiguous and clear for students with intellectual disability. Additionally, I might not be able to select symbols to represent all outcomes using the symbols that students currently use in their symbol-communication tools (e.g. Talking Mats or Picture Exchange Communication system). Seeking the views of people with intellectual disability views on the best symbols to illustrate specific topics have been successfully achieved in research settings before [31] and I will follow the same process.

I will collect a variety of different pictures and symbols to represent the outcomes which will either be selected from: the Widget.com website (which is a symbol database designed to be used with people with communication difficulties and contains symbols for the RSE topic), the Photosymbols.com website (which is a picture database widely used in educational and clinical settings to produce easy read material for people with intellectual disability and contains pictures on the RSE topic); photographs taken by LP of RSE material that teachers use to teach the RSE topic (this might produce pictures that students are familiar with) or/and pictures taken from the internet that will have public copyright licence and magazines. I will collect the pictures instead of students with intellectual disability to reduce the burden on the students, but they will then decide which ones to use with different RSE outcomes (there will be many more pictures than are needed).

The selection of pictures to be used in the interviews, will be carried out in an individual face-to-face session. A student with intellectual disability will be presented with a mat, a visual scale on top of the mat (e.g. “yes/easy” and “no/difficult” the wording will be adapted based on students’ preferences and abilities). The visual scale will be explained to the student and a couple of practise runs of sorting familiar pictures under this scale will be performed before moving to the RSE outcomes making sure that a student understands



what to do. Then, a student will be introduced to a picture that represents an RSE outcome (e.g. understanding of intimate relationships) and explained that we are looking for pictures to represent this outcome (see picture 1 for an example of a picture). Then, a student will be presented with a couple of pictures that could be used to represent this topic by asking “what about this picture?” and asked to place it in one of the groups (“yes/easy” and “no/difficult”). The picture selection will start with simpler outcomes first and building towards more abstract and difficult outcomes. Pictures that were placed by students on average under the “no/difficult” category will not be used in the study and pictures placed on average under the “yes/easy” category will be used in the interviews with students with intellectual disability.

Picture 1: An example of picture to represent intimate relationships



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### **1) Picture sorting activity based on the Talking Mats framework**

In this study, the Talking Mats framework [32] will be used to find students' preferences of RSE outcomes. The interview will start first by explaining the visual scale (e.g. “OK” or “Do not know” options will be based on the student's understanding) and asking a student to complete couple of practise runs of sorting pictures on neutral topics e.g. activities or weather (see picture 2 for an example of Talking Mats). Then, the student will be introduced to the RSE topic (e.g. “We are going to talk about what you learn at school. Tell me which topic

you like”). The sorting of RSE outcomes will start by sorting more simple outcomes first and moving towards more complex and abstract outcomes. A student will be asked a question (e.g. “What about friendships?”) depending on a student’s comprehension level to guide the sorting of outcomes and asked to place a picture that represents friendships under e.g. “OK” or “Do not know” categories which will be based on students’ understanding. If a student uses speech to communicate, I will ask if any topics are missing that she or he would like to know more about in RSE classes (this topic will be written down on sticky note and placed on the mat under “OK” category). Additionally, students that use speech to communicate might be asked why they placed a certain picture under a particular category. At the end of the sorted RSE mat, I will double check that the sorted pictures correspond to student’s views by discussing the placements of pictures (e.g. “I want to check I understand, you told me you want to know more about how to say no to strangers”) making sure that the sorted outcomes represent the student’s preferences and are not sorted randomly or to make a specific pattern. A picture will be taken of the final mat of sorted RSE outcomes. A copy of the picture of the sorted RSE outcomes will be available to the student’s parents or teachers to request from me that might be used as a guide when discussing RSE with the student. The interview will end by sorting neutral topics or discussing neutral topics (e.g. activities that students will be doing today).

Picture 2: An example of Taking Mats



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This picture sorting activity was designed for enabling students with different levels of intellectual disability and having limited or no speech take part in the study. A similar outcome sorting activity using symbols with young people with neurodevelopmental disability (e.g. autism, epilepsy) has been used before in a COS development [33].

## **2) Visual arts-based session**

In this session, students will be presented with visual art material of different textures e.g. pictures of RSE outcomes co-produced with students with intellectual disability, sticky notes, water paint, crayons, colouring pencils, magazines or other material that students like (e.g. play dough) and a large piece of paper to make a poster. Students will be told by me and/or a caregiver present in the session that the student is asked to make a “What I want to learn in RSE” poster (adapted to each student’s comprehension and RSE level). All material will be placed on a table and students will be asked to draw, write or stick (using paper glue with support provided if needed) the pictures on the poster. An example of how to do this activity will be presented and students will be guided through the process whenever needed. Students who use speech to communicate will be asked simple questions about what they selected and why and might indicate additional outcomes of RSE. Teachers and parents of students that have with limited or no speech will be asked to comment what they think the student selected and why. A picture will be taken of a final poster and the final poster will be given to students to keep. A similar activity has been used with young people with ASD and complex needs (ID, sensory processing difficulties and limited or no speech) before [34, 35]. In these studies, young people were asked to make a “graffiti” wall by placing sticky notes on like and do not like sides of the wall with full support provided by caregivers [34, 35].

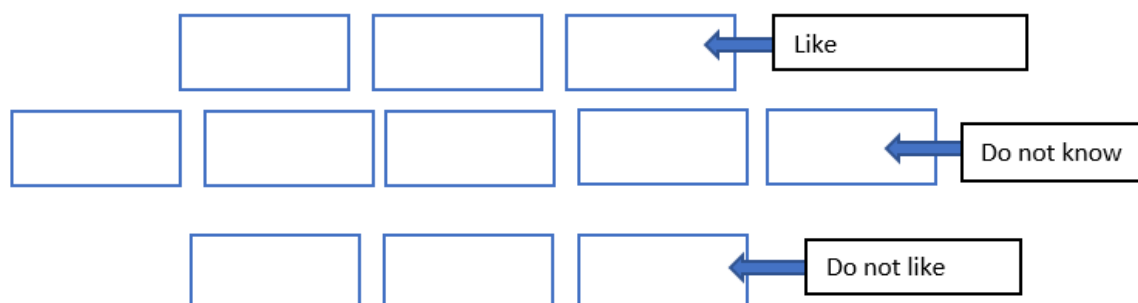
To take part in this session, students do not need to have good expressive language abilities, nor they need to understand a visual scale (e.g. “OK” or “Do not know”) (see Appendix 3 for details on suitability of this session). This might make this approach more suitable for students with severe intellectual disability. Additionally, to compete this activity students do not need to sit at a

table and the poster could be hung on a wall so students could move from the table to the wall based on what works best for each student.

### 3) A diamond ranking activity

In this activity, I will use an adaptation of the original diamond ranking activity [35]. The adaptation will involve one-to-one sessions instead of group sessions as students with intellectual disability and complex needs might find group sessions difficult to cope with. Additionally, instead of showing only nine items I will be showing all pictures of RSE outcomes. In this adapted activity, each line in the diamond shape might have more pictures than in the original activity, the language used to represent each row will be adapted to meet each student's understanding. The diamond will also have 3 rows instead of 5 rows to reduce the complexity of the task for students with intellectual disability (see picture 3 for an example).

Picture 3: An example of an adapted diamond shape



Students with intellectual disability will be presented with the pictures of RSE outcomes co-produced with students with intellectual disability that will have short descriptions written at the bottom of each picture. They will be given time to explore the pictures and ask questions. Then, students will be asked to sort the pictures of RSE outcomes by placing pictures on a piece of paper in a diamond shape with examples provided as needed. They will be told to place outcomes of RSE that they like on the top (row 1), the outcomes that they are

unsure about in the middle row (row 2), the outcomes that they “do not like” to place on the bottom (row 3). During this activity students might indicate additional outcomes that were not identified in the previous stages, and these will be written on the same size paper as the pictures and incorporated in the sorting activity. Students with intellectual disability will be asked questions about their rating choices (e.g. “Why did you put this picture at the top?”) and their views of these outcomes (e.g. “What do you like about this outcome/picture?”). A picture will be taken of the final sorted diamond which could also be shared with students with intellectual disability, their parents and/or teachers. This activity might be more suitable for students with mild intellectual disability and good expressive and receptive language (see Appendix 3 for suitability of this activity) who do not like using Talking Mats or arts-based activities. Students with more severe difficulties could take part in other two activities discussed above.

### **Data analysis of the interviews**

I will use the same data analysis method as described previously in the data analysis section (for the workshop and interviews with adult stakeholders) for analysing the data from the interviews with students with intellectual disability. The ratings of outcomes (e.g. from the sorting activity based on the Talking Mats method and a diamond ranking activity) will be grouped together, analysed using descriptive statistics and presented in the final round of the online Delphi survey alongside additional outcomes suggested by students.

### **Stage 2: Delphi survey to determine final list of COS for RSE**

**The online Delphi survey:** The Delphi process will be used to reach a consensus on the COS. The process involves completion of questionnaires answered anonymously by a panel of stakeholders (parents, teachers, school staff, policymakers, and expert researchers N=10-15 in each group). In this study, the Qualtrics online survey tool [37] will be used to send individual invitations via email to the online survey which could be completed using a mobile phone, laptop, or desktop. The Qualtrics survey tool also has a function to pull participants responses from round 1 to round 2 automatically without

needing to manually prepare surveys for each participant in round 2 and possibly minimising typing errors. In both rounds, participants will have 2 weeks to complete the survey and participants who have not completed the survey and have not declined to participate will receive 2 email reminders. The list of outcomes identified from the systematic review and workshops will be incorporated in the online survey. The online survey will be first piloted with a small number of parents, teachers and other professionals who are not taking part in the project to assess clarity and readability before being sent to Delphi participants.

Prior to taking part in the survey, participants will receive information about the study, explaining how to rate the outcomes and the importance of completing surveys in both rounds. Participants will also be offered support from the research team if they have difficulties completing the survey. When participants will click on the survey link, they will be asked to provide consent to take part in the survey and participants who do not provide consent will not be able to access the survey. Before starting to rate the outcomes, participants will be asked to answer the same demographic questions as in the mixed stakeholder workshop which will be embedded in the survey (see Appendix 1 for the demographic questions). I will be also collecting information on stakeholder's ethnicity and religious backgrounds for the same reasons as explained in the workshop section. Participants will have an option to skip these questions if they wish.

In round 1, stakeholders will be asked to score anonymously the importance of including a particular outcome in a COS on a 9-point Likert scale using a scoring framework recommended by the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group for evaluating the importance of evidence [38]. Based on this framework, outcomes scored 1 to 3 will indicate "not important" outcomes, 4 to 6 will indicate "important but not critical" outcomes and items scored 7 to 9 "critical" outcomes. Participants will also have an option to choose "unable to score" option for the items that they feel unable to score (see Appendix 5 for an example of rating questions). Responses to the rating outcomes will be

compulsory (meaning that they will not be able to proceed to the next question if they do not provide a response for a current rating question). However, participants will be able to go back to previous questions and change their responses if they wish before proceeding to the next rating question. Participants will also have an option to provide comments and feedback in free text boxes for each rating question. All outcomes from round 1 will be retained to round 2 for allowing stakeholders to see each stakeholder groups' ratings and then make a final decision regarding the importance of including this outcome in the COS.

However, I will consider dropping outcomes after round 1 to reduce participant burden and attrition rates in round 2 if the piloting of the survey will indicate that the initial list of potential outcomes is considered too long by stakeholders. In this case, the outcomes from round 1 will be retained into round 2 if 50% or more of participants rated this outcome as 7 to 9 points and fewer than 15% of participants rated these outcomes as 1 to 3 points. Outcomes will be dropped if 50% or more of participants rated this outcome as 1 to 3 points and fewer than 15% of participants rated these outcomes as 7 to 9 points. New outcomes suggested by participants in comments sections will be included in round 2.

Participants who completed at least 75% of the survey in round 1 will be invited in round 2. In round 2, stakeholders will be able to see a summary of scores of each stakeholder groups' separately presented as a median score. Each person will be asked to think about the groups' results and decide if they want to change their responses. Outcomes will be analysed using descriptive statistics in Excel. Consensus to keep the outcome in the final list of COS will be determined if 70% or more of respondents scored the outcome as 7 to 9 points and fewer than 15% of respondents scored the same outcome as 1 to 3 points. The outcomes which were scored by 70% of respondents as 1 to 3 points and fewer than 15% of respondents scored as 7 to 9 points will not be included in the final list of COS. Attrition bias will be assessed by comparing the average scores of each outcome ratings of participants who completed only round 1 and participants who completed both rounds in each stakeholder groups to see if this had impacted the final list of COS.

**Optional final workshop:** Stakeholders from the Delphi survey will be invited to a final workshop (which will either be face-to-face or online depending on participants' preferences) if all outcomes identified as critical by a specific stakeholder group (e.g. students with intellectual disability or parents) did not end up included in the final list of COS or if there will be a lot of outcomes that participants were unable to reach consensus on. In this final workshop, stakeholders will be presented with these omitted outcomes and asked to work together and discuss these outcomes and re-evaluate whether they should be placed in the core COS (or even in a subset that is recommended for specific groups). If all of the outcomes identified by a specific stakeholder group as critical even after the final workshop do not end up being included in the final list of COS, we will report these and recommend that users of COS for RSE add at least one outcome from the parallel list.

### **Sample: eligibility criteria**

Five groups of stakeholders will be involved in the study:

#### **1) Students with intellectual disability:**

I am aiming to include students aged 5-25 years old with any level of intellectual disability (mild, moderate, severe, and profound) and vocal communication ability (speaks in sentences; speaks a few words; makes some sounds; no speech) and they may also have additional neurodevelopmental conditions or disabilities (e.g. specific learning disabilities or autism). Intellectual disability is a neurodevelopmental condition defined by significant limitations in cognitive and adaptive skills assessed by standardised tests or diagnostic criteria e.g. IQ below 70 or/and adaptive scores below 70. In the UK, the term intellectual disability is synonymous to learning disability/difficulty. In younger ages, intellectual disability may be identified by a different term (e.g. developmental delay, or global developmental delay). Identification in the UK is focused on need (rather than label/diagnosis of the individual). Students might receive additional support in mainstream schools or may be eligible for intellectual disability services (e.g. attend special school for children with intellectual disability). Our target population will include students that have a



formal intellectual disability diagnosis as well as young students that have intellectual disability administratively defined (e.g. receive special education or other services because of their intellectual disability).

Students with intellectual disability and other neurodevelopmental conditions e.g. autism will be included in the study because intellectual disability is a heterogeneous condition that involves other co-occurring conditions such as autism, learning disabilities or sensory processing difficulties and by including people with diverse needs and abilities we will make sure that this COS is applicable across the range of intellectual disability and co-occurring conditions.

Students with intellectual disability aged 5-25 years will be included because literature indicates that RSE for students in the general population begins in primary schools (when students are 5-11 years old) and continues through to the secondary schools (when students are 11-18 years old) [39, 40]. Special schools typically provide education to students from age 2 to 19 years. However, some students with intellectual disability in the UK remain in education until the age of 25 [41].

## **2) Parents or carers of students with intellectual disability**

Parents or carers of students with (any level) intellectual disability, aged 5-25 years and any other co-occurring conditions will be approached to take part.

## **3) Teachers**

Teachers and school staff (e.g. special educational needs coordinators, teaching assistants, speech and language therapists, psychologists and etc.) of students with intellectual disability and/or who are involved in the delivery of RSE for this population will be also asked to take part. Teachers and school staff with any years of experience spent working with students with intellectual disability will be eligible to take part in the study.

## **4) Policy makers**

Policy makers who are involved in formulating the RSE or/and special education policies in England will be approached to take part in the study. There will be no exclusion criteria based on policy makers professional background or seniority.

### **5) Researchers**

Researchers who specialise in education for people with intellectual disability in England and /or who authored key papers on RSE for people with intellectual disability will be approached to take part.

Teachers and school staff, researchers and policy makers must be able to speak, read and understand the English language in order to take part in the study. Parents who do not speak English, but a school has a capacity to translate the interview or has a translator will be eligible to take part. Students with intellectual disability do not need to be able to speak and read the English language to take part.

### **Sampling**

In the mixed stakeholder workshop, interviews and the online Delphi survey I will be using a purposive sampling and prospective snowballing recruitment. The target number for the adult qualitative data collection (i.e. for both the workshop and interviews combined) is 10-15 participants. However, in the workshop I will aim to have no more than 6-8 participants from each of the 4 stakeholder groups (parents, teachers and school staff, policy makers and researchers), due to practical reasons of running the workshop (particularly if remotely).

In the Delphi survey 10-15 participants in each of 4 groups. The prospective snowball technique (asking participants to send our study details to their colleagues who might be interested in taking part in our study before starting the data collection) will be carried out as well. The target number for interviews with students with intellectual disability is between 10-15 participants.

There is no “gold standard” number of stakeholders to involve in the COS development and the Delphi surveys [22]. I will aim to have 6-8 people per stakeholder group in the workshop as this is a suggested number for the focus groups that allows to explore different perspectives without overburdening participants. I will aim to have 10-15 people in the interviews and the Delphi online survey as it is proposed that qualitative data saturation is reached in homogeneous groups when 12 people are interviewed [42-44]. The total number of participants we are aiming to recruit in all 3 studies (the workshop, interviews with students and the survey) is 74 participants and we will try to recruit over this number (maximum 107 participants in all 3 studies) to cover dropouts and attrition rates.

## **Recruitment**

### **Recruitment for the mixed stakeholder workshop, interviews with adult stakeholders and interviews with students with intellectual disability:**

Students with intellectual disability, their parents, teachers, and school staff will be recruited from the special schools in England via established contacts with special school networks. I will aim to recruit approximately 3-4 schools to reach our target sample (2-3 teachers and school staff per school involved in RSE delivery). However, the exact number of schools that we will recruit will depend on how many teachers and school staff are involved in RSE delivery in a specific school. For example, if only one teacher is involved in RSE delivery, then we will need to recruit more than 4 schools. I will approach approximately 8 schools to see if they would be interested in the project allowing for a 50% drop out/decline rate. However, if the first 4 schools will indicate that they are interested in the project, I will not approach other schools.

The initial contact will be made by me with head teachers via emails to see if they would be interested in the study. Any head teachers' questions will be answered via email or phone conversations. Headteachers who will agree for their school to be involved in the project will be asked to pass the information sheets about the workshop and interviews with students with intellectual disability to teachers and parents. I will also present the study to teachers and parents at special schools (either online or face-to-face depending on

participants' preferences) and that might help to recruit parents and teachers and answer any questions that they might have.

The screening process will involve asking teachers if they are involved in the delivery of RSE and for the parents asking if they have a child with intellectual disability aged 5-25 years, what additional co-occurring conditions the child has and whether parents are able to read, speak and understand the English language. The screening process for students with intellectual disability will involve asking parents and/or teachers about the student's age.

Expert researchers will be approached via research networks in England (e.g. Intellectual Disability Research JISCmail mailing list; Sharland Foundation Developmental Disabilities Research Network) as well as from relevant publications identified through the systematic review and internet searches. Policy makers will be identified through special education charity and policy networks in England (e.g. Nasen), internet searches and snowball sampling and approached about the study via individual emails.

In addition to this, participants (parents, teachers, researchers and policy makers) will be recruited to the workshop and adult interviews using study advertisement material (e.g. a study poster see Appendix 7) distributed via social media posts (such as Twitter and Facebook).

### **Recruitment for the online Delphi survey:**

Stakeholders who took part in the mixed stakeholder workshop and interviews and provided their consent to be contacted in further studies related to this project, will be approached to take part in the survey. If needed, other stakeholders will be recruited using the same approach described above which will involve approaching the same schools and special schools and research networks and snowball recruitment.

### **Dissemination**

I will aim to publish the study protocol in an academic journal (e.g. the Trials journal) for transparency, controlling bias and avoiding duplication once I have ethical approval for the study. Findings of the study will be published in academic journals (such as the Sex Education Journal or the Journal of Research in Special Educational Needs), the open-access Core Outcome Measures in Effectiveness Trials (COMET) database, presented at special schools using links with special schools and research networks and presented at conferences. An easy read summary of findings will be disseminated to stakeholder groups involved. Through these dissemination events, I will encourage special schools to adopt the COS to evaluate their current delivery, or to work with researchers to achieve this. With my supervisors' help, I will publish a policy briefing on the final COS, so the findings reach a wider policy maker audience. We will contact relevant journals and funding bodies so they may include the COS in their guidelines for researchers and authors.

### **Section 3 – Research Participants (tick all that apply)**

- ☐ Early years/pre-school
- ☒ Ages 5-11
- ☒ Ages 12-16
- ☒ Young people aged 17-18
- ☒ Adults please specify below
- ☐ Unknown – specify below
- ☐ No participants

Participants in this study will be: students with intellectual disability aged 5-25 years, parents, teachers and school staff, researchers and policy makers.

**Note:** Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the [National Research Ethics Service](#) (NRES) or [Social Care Research Ethics Committee](#) (SCREC).

#### Section 4 - Security-sensitive material (only complete if applicable)

Security sensitive research includes: commissioned by the military; commissioned under an EU security call; involves the acquisition of security clearances; concerns terrorist or extreme groups.

- a. Will your project consider or encounter security-sensitive material?  
Yes\* ☐ No ☐
- b. Will you be visiting websites associated with extreme or terrorist organisations?  
Yes\* ☐ No ☐
- c. Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?  
Yes\* ☐ No ☐

*\* Give further details in **Section 8 Ethical Issues***

#### Section 5 – Systematic reviews of research (only complete if applicable)

- a. Will you be collecting any new data from participants?  
Yes\* ☐ No ☐
- b. Will you be analysing any secondary data?  
Yes\* ☐ No ☐

*\* Give further details in **Section 8 Ethical Issues***

*If your methods do not involve engagement with participants (e.g. systematic review, literature review) **and** if you have answered **No** to both questions, please go to **Section 8 Attachments**.*

#### Section 6 - Secondary data analysis (only complete if applicable)

- a. Name of dataset/s: Enter text
- b. Owner of dataset/s: Enter text
- c. Are the data in the public domain?  
Yes ☐ No ☐

***If no, do you have the owner's permission/license?***

Yes ☐ No\* ☐

- d. Are the data special category personal data (i.e. personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation)?

Yes\* ☐ No ☐

- e. Will you be conducting analysis within the remit it was originally collected for?

Yes ☐ No\* ☐

- f. **If no**, was consent gained from participants for subsequent/future analysis?

Yes ☐ No\* ☐

- g. **If no**, was data collected prior to ethics approval process?

Yes ☐ No\* ☐

\* Give further details in **Section 8 Ethical Issues**

*If secondary analysis is only method used **and** no answers with asterisks are ticked, go to **Section 9 Attachments**.*

## **Section 7 – Data Storage and Security**

**Please ensure that you include all hard and electronic data when completing this section.**

- a. Data subjects - Who will the data be collected from?

I will collect data from students with intellectual disability, parents, teachers and school staff, researchers, and policy makers.

- b. What data will be collected? Please provide details of the type of personal data to be collected

I will be collecting (in the workshop, interviews and survey) basic demographic information such as participants' age, sex, their geographical location (where they live) to report how representative the sample was. Following the General Data Protection Regulation (GDPR) definitions on personal data, I will also be collecting *special category personal information*- participants' ethnicity and religious affiliations (in the workshop and survey) as research indicates that people from different cultural and religious backgrounds hold different beliefs what topics are appropriate to deliver in Relationships and Sex Education. Participants will have an option not to answer these questions if they wish. I will be collecting this special category personal information because it will affect what outcomes participants indicate as important and we will consider this in our data analysis. Additionally, in the Delphi online survey, in order to produce individual links to the survey in round 2 so that participants are able to see how people in their group rated the outcomes and how they rated themselves, I will need to collect participants' email addresses so I could pull the data from round 1 to the round 2. Thus, I will be collecting participants' emails for research administration purposes as identified in the GDPR guidelines.

**Is the data anonymised?** Yes ☒ No\* ☐

Do you plan to anonymise the data? Yes\* ☒ No ☐

Do you plan to use individual level data? Yes\* ☐ No ☒

Do you plan to pseudonymise the data? Yes\* ☐ No ☒

\* Give further details in **Section 8 Ethical Issues**

c. **Disclosure** – Who will the results of your project be disclosed to?

No one.

**Disclosure** – Will personal data be disclosed as part of your project?

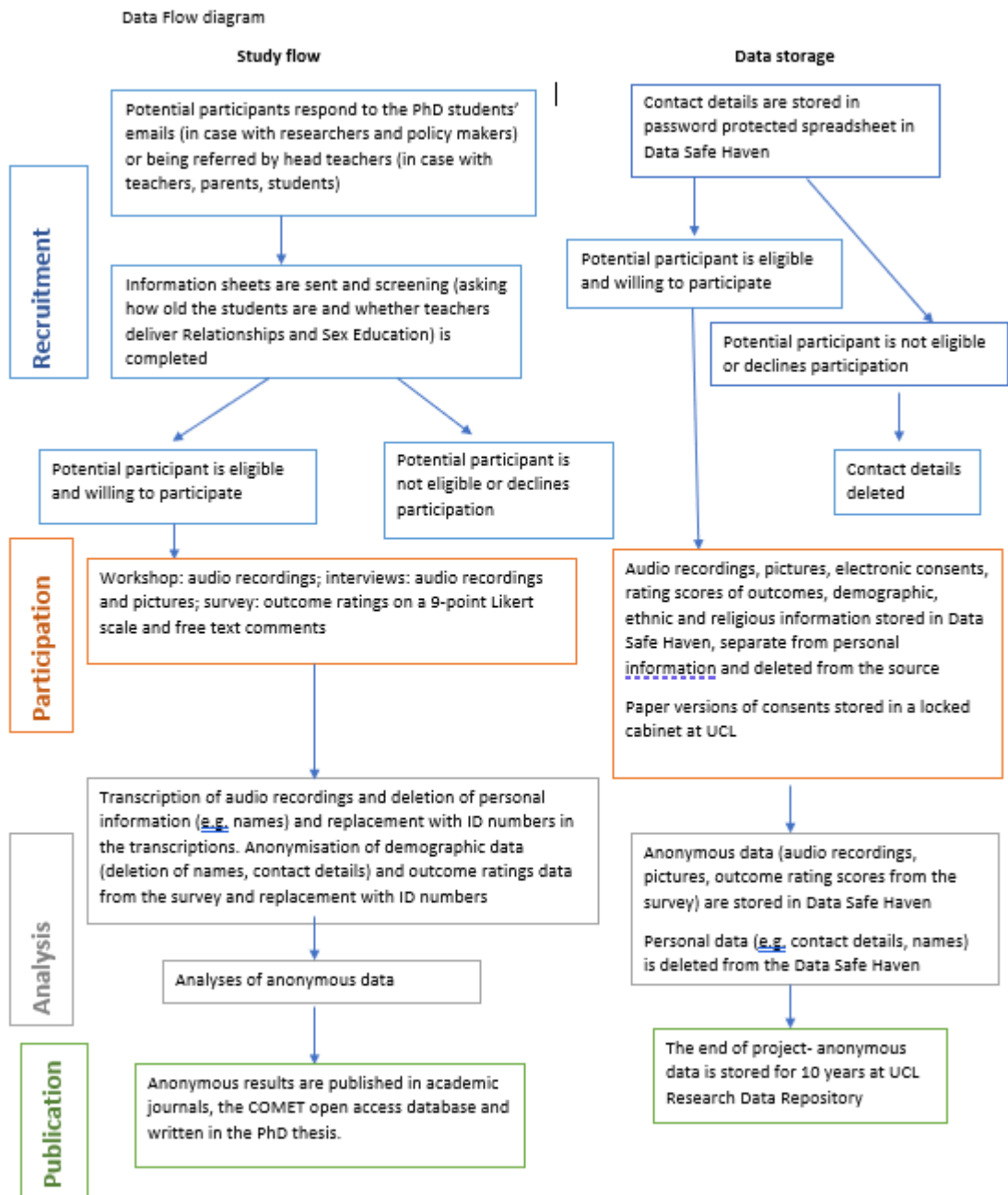
No, it will not be disclosed to anyone.

d. **Data storage** – Please provide details on how and where the data will be stored i.e. UCL network, encrypted USB stick\*\*, encrypted laptop\*\* etc.



*\*\* Advanced Encryption Standard 256 bit encryption which has been made a security standard within the NHS*

Please see the data flow diagram below that specifies where the data will be stored at different stages of the project. Potential participants' contact details (e.g.) emails will be stored in Data Safe Haven and only the PhD student will have access to it. Participants' contact details who will not be interested in the study or will not meet the inclusion criteria will be deleted from the Data Safe Haven. Audio recordings, pictures, electronic consents, rating scores of outcomes, demographic, ethnics and religious information will be stored in Data Safe Haven (collected data will be stored separately from personal information) and deleted from the source (e.g. audio recorder). Paper consents will be stored in a locked cabinet at UCL. After the data collection finishes, the anonymised data (without participants' names and contact details) will be moved from Data Safe Haven to the UCL Research Data Storage Service for analysis and retention. Only 2 researchers will have access to the data stored in the UCL Research Data Storage (me, the PhD student, and a secondary researcher involved in the double coding of the data). When the project finishes (end of October 2023), personal data will be deleted from the Data Safe Haven. After the reports are written and published, the anonymised data (without special category personal information- participants' ethic and religious backgrounds) from the UCL Research Data Storage Service will be moved to the UCL Research Data Repository where it will be kept at UCL for 10 years which is in line with the Data Protection 2018 and GDPR guidelines, then disposed of securely by shredding paper documents and erasing computer storage.



- e. **Data Safe Haven (Identifiable Data Handling Solution)** – Will the personal identifiable data collected and processed as part of this research be stored in the UCL Data Safe Haven (mainly used by SLMS divisions, institutes and departments)?

Yes ☒ No ☐

- f. How long will the data and records be kept for and in what format?

When the project finishes (end of October 2023), personal data will be deleted from the Data Safe Haven. After the reports are written and published, the anonymous data (without special category personal information- participants' ethic and religious backgrounds) from the UCL Research Data Storage Service will be moved to the UCL Research Data Repository where it will be kept at UCL for 10 years which is in line with the Data Protection 2018 and GDPR guidelines, then disposed of securely by shredding paper documents and erasing computer storage.

Will personal data be processed or be sent outside the European Economic Area? (If yes, please confirm that there are adequate levels of protections in compliance with GDPR and state what these arrangements are)

Enter text

Will data be archived for use by other researchers? (If yes, please provide details.)

Enter text

- g. If personal data is used as part of your project, describe what measures you have in place to ensure that the data is only used for the research purpose e.g. pseudonymisation and short retention period of data'.

Enter text

*\* Give further details in **Section 8 Ethical Issues***

## **Section 8 – Ethical Issues**

Please state clearly the ethical issues which may arise in the course of this research and how they will be addressed.

**All** issues that may apply should be addressed. Some examples are given below, further information can be found in the guidelines. *Minimum 150 words required.*

- Methods
- Sampling
- Recruitment
- Gatekeepers
- Informed consent
- Potentially vulnerable participants
- Safeguarding/child protection
- Sensitive topics
- International research
- Risks to participants and/or researchers
- Confidentiality/Anonymity
- Disclosures/limits to confidentiality
- Data storage and security both during and after the research (including transfer, sharing, encryption, protection)
- Reporting
- Dissemination and use of findings

## **Design**

I have chosen to carry out interviews with students with intellectual disability as opposed to focus group because many students with intellectual disability have complex needs (e.g. autism, sensory processing difficulties, mental and physical health problems) and might have difficulties in taking turns, concentrating and engaging in a group discussion and thus might find group sessions extremely difficult to cope with. Additionally, face-to-face sessions have been chosen as research conducted on remote sessions with children with intellectual disability during the pandemic indicates that children found it very challenging or impossible to engage in online sessions and cope with looking excessively at a screen (Skipp, Smith and Wall, 2021). Teachers in special schools that serve students with intellectual disability reported that about 30% of families of children with intellectual disability had no access to a computer or internet during the pandemic (Skipp, Smith and Wall, 2021). Besides, I have chosen to carry out interviews based on one out of three visual qualitative data collection methods as they have been shown in previous studies as promising tools for eliciting the views of people with intellectual

disability (Tesfaye et al 2019; Nicholas et al 2019). These methods are visual, hands-on approaches, involve different students' interests, cognitive and communication abilities and might also be similar to activities and games students regularly do. Thus, the selection of these methods will enable students with different vocal communication abilities to take part in the study and express their views. The methods will be piloted with students with intellectual disability who are not taking part in the study before being used with the study participants. In the interviews students will be presented with age and developmentally appropriate Relationships and Sex education outcomes and any topics indicated as upsetting will not be discussed.

### **Informed Consent**

Written informed consent for participating in the mixed stakeholder workshop and interviews will be obtained from participants before taking part in the workshop. Participants will receive information sheets and will be given time to think about the study and ask questions. When all questions will be answered and participants will indicate that they wish to take part in the study, written informed consent will be obtained which may be handwritten or electronically signed.

Electronic consent for taking part in the Delphi survey will be obtained before participants take part in the survey. First, they will receive an information sheet, and time will be given to consider it and ask questions. Then, participants who will indicate that they are interested in taking part in the survey, will receive a link to the survey and before they proceed to the survey, they will be asked to provide informed consent which will be embedded in the survey. Participants will not be able to proceed to the rating questions if they do not provide their consent for participation.

### **Informed consent and people who might lack capacity to consent**

Written or verbal informed assent/consent for interviews with students with intellectual disability will be obtained in line with the Mental Capacity Act 2005

before the interviews as well. For students with intellectual disability below 16 years old, written consent will be obtained from students' parents or caregivers making sure that students' assent for participation is also secured prior to any data collection. Students' parents/caregivers will have option to provide written or electronic consent (as described above) depending on their preferences and current COVID-19 regulations. Before the interview, I will double check that the child is happy to take part in the interview by asking questions (e.g. "Do you know what we will be taking about? Is it OK?") that will be adapted to meet the student's level of understanding and vocal communication abilities.

For students with intellectual disability aged 16 years or over that will have capacity to consent (able to understand the information, retain the information, weight the information, and communicate decisions) informed consent (written or verbal using audio recorder) will be obtained directly from them. I will obtain assent from the parent for their child aged 16 years or over for taking part in the study. For the students aged 16 years and over who will be deemed not to have capacity to give consent independently, consent will be obtained from the student's parents following a process similar to that for participants aged 16 years or less.

To assess the capacity to consent for taking part in the study for students with intellectual disability I will follow an approach used in previous studies conducted with people with intellectual disability [45, 46]. First of all, students will be presented with easy read information sheets about the study and will be given time to consider it and ask questions. Then, students will be asked the following 6 questions:

- 1) What will we be talking about today?
- 2) How long will it take?
- 3) Can you tell me why you want to take part?
- 4) If you do not want to do activities, what do you do?
- 5) When would I need to tell other people what you told me?
- 6) Do you want to take part in the study?

Questions 1, 4 and 5 must be answered correctly to deem the capacity and questions 2 and 3 can be incorrect [45]. I will explain these two questions and what correct answers are.

### **RSE topic, vulnerable population, and confidentiality limits**

Relationships and Sex Education as a topic might be perceived as sensitive or uncomfortable. Participants will be told explicitly about the aim of this study and that this topic will be discussed so that they are aware about it when making informed decisions whether to participate or not. Participants will also be told that there will be no personal questions, and they will be asked to think about outcomes of this curriculum. Potential participants will be informed that they can refuse to answer any questions that they find uncomfortable, and they can stop their participation at any point without providing a reason. I will be extremely vigilant to any signs of participants' (parents, teachers, school staff, policy makers and expert researchers) signs of anxiety or distress during the workshops. This might involve terminating workshops, offering frequent breaks throughout the process or rescheduling workshops for another time or place.

Participants at the end of data collection sessions (at the end of the mixed stakeholder workshop, interviews and the survey) will be given a list of resources that contains information on online RSE teaching materials, charities and support groups that provide support for people with intellectual disability and those who support them (please see Appendix 6 for a list of resources). If participants will disclose during the study sessions that they (or they children) are in immediate danger or being maltreated, I will report this information to headteachers who will follow their safeguarding procedures.

Teachers or school staff might feel blamed or questioned about their current delivery of RSE. To tackle these feelings before they happen, it will be clearly explained from the initial contact with schools/teachers that the aim of the study is to find out their views of RSE outcomes so it could be improved in the future and not to evaluate their current provision so that teachers are not afraid to take part in the study and share their views.

During the interviews with students with intellectual disability, the leading researcher (LP) will be particularly sensitive to potential activity overload. The interviews will be adapted based on the discussion with the students' parents and/or teachers as explained before. RSE topics that will be indicated as sensitive for a particular student will not be discussed in the interview, so it does not upset the student. Regular breaks will be scheduled and couple of visits might be carried out to finish the interview whenever needed. If a student starts showing any sign of distress, anxiety or engagement in challenging behaviours (e.g. shouting, spitting or kicking) the interview will be terminated immediately. For the following sessions, the student's parents or teachers will be asked to join.

Some students with intellectual disability might find the RSE topic embarrassing or uncomfortable to talk about. This will be addressed by explaining at the initial contact with students what the study is about and what they say in the interview will be not shared to other people. Research conducted on evaluating some young people's with intellectual disability experiences of taking part in sexuality research and talking about sensitive topics [44,45] indicate that young people with intellectual disability enjoy talking with a researcher about their experiences and do not appear anxious or distressed after participation. However, students will be told that they can stop the interviews by saying using speech that they wish to stop and for students that will have limited or no speech by touching a red card which will be placed in proximity to the student and its meaning explained before the interview. Also, I will be vigilant to any signs of anxiety during the interviews and would stop the interview without waiting for the student to indicate this. At the end of each interview, students will be debriefed by asking if they have any questions or by talking about neutral topics or playing short games. If there will be any specific questions about RSE topic that students wish to discuss with the researcher, students will be encouraged to speak about it with their teachers or parents. If students will indicate that they are hurting themselves or other people are hurting them this will be passed to headteachers and parents depending on what is appropriate on a case-by-case basis. I also have a DBS check completed for this project (certificate number:001745877971).



There should not be any disadvantages or risks for the researcher who is conducting the sessions (me). I will be following the UCL's lone working policy when traveling to collect the data in the schools. Additionally, in the schools I will be in a close proximity to school staff in case I will need their assistance. In case I hear anything distressing, I will be debriefed by my supervisors.

### **Rapport building**

I will spend time building a rapport with students and their families prior to the data collection. This will involve presenting the study to the parents at school e.g. during "coffee mornings" (or virtual coffee mornings). Prior to meeting with parents, I will discuss with the school's lead for research on potential cultural and religious barriers for participation in this study. This will inform my conversations with parents. During those conversations, when parents are deciding whether to take part in the study or not, parents will be informed that their cultural and religious backgrounds will be considered during data collection with them, and their children. They will be reassured that if there is anything that they wish not to discuss with their children will be listened to, respected, and not discussed. Parents will be told that the aim of the workshop is to find RSE outcomes that are meaningful to different people from different cultural and religious backgrounds and that it would be very valuable to hear their perspective. Everyone in the workshop will be told to be considerate and sensitive to other peoples' backgrounds and be mindful that not everyone will be able to engage in all conversations. Parents will be told that they can refrain from engaging in conversation during the workshop if they feel uncomfortable and that they have the right to stop participating at any time without providing a reason why. Prior to interviewing students with intellectual disability, I will carry out preparation sessions with parents and/or teachers to identify what topics should not be discussed considering students' cultural and religious backgrounds. I will also come to the school before interviews with students with intellectual disability to build rapport with students by meeting them and spending time at school to increase familiarity.

**The steps that will be taken to mitigate the COVID-19 related hazards and risks for the face-to-face data collection sessions:**

I will follow the current England's government guidance, UCL's guidance and local school policies in respect of mitigating the COVID-19 related risks. Even though most of the restrictions are currently removed in England such as social distancing, wearing a face mask, and not mixing with people outside your "bubble", I will follow the government's suggestions how to stay safe and prevent the spread of the virus: <https://www.gov.uk/guidance/covid-19-coronavirus-restrictions-what-you-can-and-cannot-do> and also the guidance on protecting clinically vulnerable people: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19> as the sample will involve students with intellectual disability.

Before travelling to the data collection sessions (either for the interviews with students with intellectual disability or mixed stakeholder workshop or interviews with adult stakeholders if participants will prefer to have it face to face), I will take a lateral flow test to make sure that I do not have the COVID-19. When travelling to the venue using public transport, I will be following the government's recommendations on safe travel - the Coronavirus (COVID-19): safer travel guidance for passengers: <https://www.gov.uk/guidance/coronavirus-covid-19-safer-travel-guidance-for-passengers>. I will be avoiding peak hours when travelling to the sessions, covering her face, maintaining social distancing, and using a hand sanitiser. Once at the venue for the data collection sessions, I will be maintaining social distancing, wearing a face cover and washing hands regularly. Besides, I am vaccinated and will not be travelling to the sessions if I will have symptoms of COVID-19 and if this happens the session will be rescheduled.

If participants will prefer to have the mixed stakeholder workshop and interviews face-to-face, and if this is possible with extant UCL pandemic policy, I will select a spacious room at UCL so social distancing could be maintained and windows could be opened regularly to let fresh air in the room. Before traveling to the session, participants will be asked if they have any COVID-19

related symptoms to stay at home and not to attend the workshop. In the room, participants will be asked to wear a face mask, maintain social distancing, and wash their hands or use a hand sanitiser (which will be provided) regularly throughout the session. Even though this is not the requirements by law to wear a face mask and maintain social distancing, participants will be advised to do so to mitigate the risks of the spread of the virus as the workshop will involve mixing people from different households. I will be following a revised guidance if the guidance described here changes.

Interviews with students with intellectual disability most likely to start in November 2021 and continue till April 2022. I will also be following the UK's government guidance for schools due to COVID-19: <https://www.gov.uk/government/publications/actions-for-schools-during-the-coronavirus-outbreak/schools-covid-19-operational-guidance> when planning interviews and I will work closely with schools on their policies for visitors. I will follow the same rules that will be in use at that time for controlling transmission of COVID-19 virus that teachers are following when coming to school. It might involve the following: before travelling to the interview, I will call a school to check if there is no recent confirmed case of Covid-19 at the school and it is safe to come. I will not travel to the school if I have any symptoms similar to the Covid-19 symptoms. Upon arrival to the school, my temperature might be taken before entering the school and I will be asked to wash my hands or use hand-sanitiser regularly throughout my visit. During the interviews with students with intellectual disability, I will be wearing a transparent face covering so students will be able to see my face that might aid communication. After the interview, students will be asked to wash their hands and the material used will be cleaned with antibacterial wipes.

### **Data protection and confidentiality**

All the data collected in this study will be completely confidential and anonymised. Participants will be given random ID numbers, and the data will not contain any identifiable information e.g. such as participants' names or contact details. Identifiable information (e.g. emails) is collected only for the

purposes of administering the research and will be kept separately from the collected data and stored securely online on the UCL's data security system – "Data Safe Haven" only for the duration of the project and deleted when the project finishes (at the end of October 2023). The Data Safe Haven is a secure system for storing sensitive information and complies with the NHS Data Security and Protection Toolkit. Only the researcher (LP) will have access to the participants' identifiable information (e.g. emails and names) and special category data as she will be recruiting participants.

All recordings and study materials (e.g. consent forms) will be stored according to the UCL's data handling policy encrypted and only with a study number. If there will be any paper versions of the consent forms, they will be stored in a locked cupboard at UCL, and electronic consents will be stored in the Data Safe Haven. The audio recordings and pictures taken in this study will be also stored securely in the Data Safe Haven and immediately erased from the recorder and LP's UCL Zoom or Microsoft Teams account (if the data is recorded using online software in the mixed stakeholder workshop or interviews with adult stakeholders). To record conversations in the online mixed stakeholder workshop or interviews with adult stakeholders we will be either using the Microsoft Teams or Zoom software because both have end to end encryption meaning that third parties cannot access it while it is transferred from the device to a secure place. The recordings will only be used for analysing the data and no one outside the research team will have the access to it. The data collected in the survey will be held in Qualtrics survey tool where all the data collected is encrypted and only accessed by the researcher (LP). At the end of each survey round, the data will be downloaded and stored in the UCL's Data Safe Haven.

When all data collection finishes, the anonymised data will be moved from the Data Safe Haven to UCL Research Data Storage Service for analysis and retention. Only two researchers will have access to the anonymised data stored in UCL Research Data Storage Service (the PhD student and a secondary researcher involved in the double coding of the data).

When the project finishes (end of October 2023), personal data will be deleted from the Data Safe Haven. After the reports are written and published, the anonymised data (without special category personal information- participants' ethic and religious backgrounds) from the UCL Research Data Storage Service will be moved to the UCL Research Data Repository where it will be kept at UCL for 10 years which is in line with the Data Protection 2018 and GDPR guidelines, then disposed of securely by shredding paper documents and erasing computer storage.

Personal data breaches (that have affected the confidentiality, integrity, or availability of personal data) will be immediately reported to the UCL Information Security Group (ISG) and the UCL Data Protection Officer (Alexandra Potts [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)), (as per form and guidance: <https://www.ucl.ac.uk/legal-services/guidance/reporting-loss-personal-data>), and to the Sponsor via the UCL REDCAP incident reporting form (<https://redcap.slms.ucl.ac.uk/surveys/?s=NE5dypTdFo>). The following information will be provided: full details as to the nature of the breach, an indication as to the volume of material involved, and the sensitivity of the breach (and any timeframes that apply).

Please confirm that the processing of the data is not likely to cause substantial damage or distress to an individual

Yes ☒

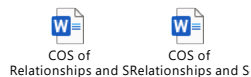
## **Section 9 – Attachments.**

*Please attach your information sheets and consent forms to your ethics application before requesting a Data Protection number from the UCL Data Protection office. Note that they will be unable to issue you the Data Protection number until all such documentation is received*

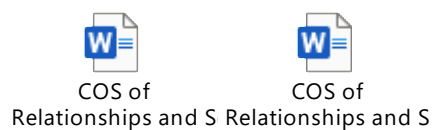
- a. Information sheets, consent forms and other materials to be used to inform potential participants about the research (List attachments below)

Yes ☒ No ☐

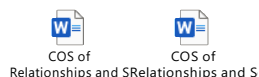
## Participant Information Sheet and Consent form for the **Workshop**



## Participant Information Sheet and Consent form for the **Interviews**



## Parent of Caregiver Information Sheet and Consent form for the **Student Interview**



## Student Information Sheet, Consent Form and Assent Form for Interview: **Talking Mats**



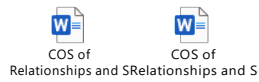
## Student Information Sheet, Consent Form and Assent Form for Interview: **Arts**



## Student Information Sheet, Consent Form and Assent Form for Interview: **Diamond**



## Participant Information Sheet and Consent Form for the **Survey**



## Other documentation being used to invite/inform participants about the research:

### Head Teacher Initial Contact email



### Stakeholder Initial Contact Email Workshop



### Stakeholder Initial Contact Delphi Survey



- b. Approval letter from external Research Ethics Committee Yes ☐
- c. The proposal ('case for support') for the project Yes ☒
- d. Full risk assessment Yes ☒



The proposal ('case for support') for the



ioe\_fieldwork\_risk\_ assessment.docx



ioe-staff-ethics-star ting-fieldwork-prof

## **Section 10 – Declaration**

I confirm that to the best of my knowledge the information in this form is correct and that this is a full description of the ethical issues that may arise in the course of this project.

I have discussed the ethical issues relating to my research with my supervisor.

Yes ☒ No ☐

I have attended the appropriate ethics training provided by my course.

Yes ☒ No ☐

**I confirm that to the best of my knowledge:**

The above information is correct and that this is a full description of the ethics issues that may arise in the course of this project.

Name            Laura Paulauskaite

Date            24/05/22

**Please submit your completed ethics forms to your supervisor for review.**



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## APPENDICIES

### Appendix 1 - Demographic questions

#### Demographics

So that we better understand who took part in this workshop could you please **tick or circle one response to each question.** If you do not want to answer these questions, **please feel free to leave them empty.**

##### 1. What is your role?

- ☐ I am a parent or caregiver of a student with intellectual disability
- ☐ I am a teacher or school staff
- ☐ I am a researcher
- ☐ I am a policy maker

If you ticked a **teacher or school staff**, please answer the following questions:

##### 1.1. What is your professional role in school?

- ☐ Class teacher
- ☐ Teaching assistant
- ☐ PSHE teacher
- ☐ Speech and language therapist
- ☐ Psychologist
- ☐ Headteacher
- ☐ Other, please specify:

##### 1.2 How many years you have been working with children with intellectual disability?

- ☐ Please specify:

##### 1.3 Do you currently teach Relationships and Sex Education for students with intellectual disability?

- ☐ Yes
- ☐ No

If no, please answer the following question:

##### 1.4 Have you taught Relationships and Sex Education for students with intellectual disability in the past?

☐ Yes

☐ No

**1.5 How many years you have been involved in the delivery of Relationships and Sex Education for students with intellectual disability?**

☐ Please specify:

**If you ticked a “Researcher” or a “Policy Maker”, please answer:**

**1.6 What is your professional role (e.g. educational psychologist, researcher and ect.)?**

☐ Please specify:

**Pease answer the following questions regardless of what you ticked in the question 1:**

**2 What is your gender?**

☐ Female

☐ Male

☐ Other (please specify):

**3 What is your age?**

☐ Under 25

☐ 25-34

☐ 35-44

☐ 45-54

☐ 55-64

☐ 65 or over

**4 What is your ethnicity?**

• **White:**

☐ English, Welsh, Scottish, Northern Irish or British

☐ Irish

☐ Gypsy or Irish Traveller

☐ Any other White background (please specify):

- **Mixed or Multiple ethnic groups:**

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other Mixed or Multiple ethnic background (please specify):

- **Asian or Asian British**

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background (please specify)

- **Black, African, Caribbean or Black British**

☐ African

☐ Caribbean

☐ Any other Black, African or Caribbean background (please specify):

- **Other ethnic group (please specify):**

☐ Please specify:

## **5 What is your religion?**

☐ No religion

☐ Christianity

☐ Islam

☐ Hinduism

☐ Judaism

☐ Sikhism

☐ Buddhism

☐ Any other religion (please specify):

## **6 Where in the UK do you live? If you live outside the UK, please specify.**

☐ England

☐ Scotland

☐ Wales

- ☐ Northern Ireland
- ☐ Outside the UK (please specify):

**7 Do you have children with intellectual disability (also known as learning disability)?**

- ☐ Yes
- ☐ No

**If yes, please answer the questions below:**

**7.5 How old is your child?**

Please specify:

**7.6 What is your child's gender?**

- ☐ Female
- ☐ Male
- ☐ Other (please specify):

**7.7 How would you describe your child's level of intellectual disability (also known as learning disability)?**

- ☐ Mild
- ☐ Moderate
- ☐ Severe

**7.8 Does your child have any of the following conditions (please tick all that apply) in addition to intellectual disability?**

- ☐ Autism
- ☐ Attention Deficit Hyperactivity Disorder (ADHD)
- ☐ Speech delay
- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ Other (please specify):

**7.9 What your child's expressive vocal communication abilities are?**

- ☐ No speech
- ☐ Makes some sounds
- ☐ Speaks a few words
- ☐ Speaks in sentences

**7.10 Do you have more than one child with intellectual disability?**

☐ Yes (please specify how many in total):

☐ No

## Appendix 2 - Mixed Stakeholder Workshop Guide

### Mixed Stakeholder Workshop Guide

An introductory question (asked to a whole group):

1. In an ideal world, if teachers had all of the resources, time, training, and support to deliver Relationships and Sex Education in schools, what do you think this education should achieve for students with intellectual disability?

*Prompts:*

- What type of knowledge this education should provide for students with intellectual disability and why?
- What type of skills students should develop after receiving this education and why?

Questions asked in small groups:

1. What top three targets of Relationships and Sex Education for students with intellectual disability should be and why?
2. What top three things Relationships and Sex Education should provide for students with intellectual disability in primary education, secondary, and further education and why?
3. What would be the most inappropriate or unhelpful things that Relationships and Sex Education could provide for students with intellectual disability and why?



### **Appendix 3 – Interview Schedule for the adult interview**

Interview schedule for a 20-minute interview

*An introductory question:*

1. What do you think the outcomes/targets of Relationships and Sex Education should be for students with intellectual disability? and why?

Probing questions:

-What skills it should provide? and why?

-What knowledge it should provide? and why?

-What attitudes students should develop? and why?

2. Thinking about different age groups of students with intellectual disability, what do you think this education should provide for young students in primary education (aged 5-11 years) and why?

Probing questions:

-What skills it should provide? and why?

-What knowledge it should provide? and why?

-What attitudes students should develop? and why?

3. What RSE outcomes should be for students with intellectual disability in secondary education (aged 12-16 years), so this is for teenagers with intellectual disability and why?

*Probing question:*

-What skills it should provide? and why?

-What knowledge it should provide? and why?

-What attitudes students should develop? and why?

4. What outcomes of Relationships and Sex Education should be for older students with intellectual disability in further education/post 16-education (when students are 17-25 years) and why?

*Probing question:*

-What skills it should provide? and why?

-What knowledge it should provide? and why?

-What attitudes students should develop? and why?

6. Is there anything that you wished I asked about this topic?

## Appendix 4 - Summary of data collection activities with students with intellectual disability

| Activity                                                     | What involves                                                                                                                                                    | Suitability                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Advantages                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Disadvantages                                                                                                                                                                                            |
|--------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Picture sorting activity using the Talking Mats framework | Placing pictorial outcomes of RSE under “ok” and “I do not know” categories or other visual scale that a student is familiar with e.g. “need” and “do not need”. | <ul style="list-style-type: none"> <li>-used picture exchange systems before or likes using pictures when communicating</li> <li>- able to recognise pictures</li> <li>-able to make a choice</li> <li>- good eye hand coordination for moving the pictures and fine motor abilities for picking up the pictures from the mat or pointing to the pictures</li> <li>- has good receptive language (e.g. understands simple questions or 2 word phrases) but no need of having expressive language (ability to talk).</li> </ul> | <ul style="list-style-type: none"> <li>-flexible (students can go on their own pace and take breaks and go back and change their minds)</li> <li>- does not need to be completed sitting at the table and could be completed hanging the mat on the wall so the student could move in the room (this might be suitable for students with intellectual disability and ADHD)</li> <li>-provides views of students who might not be able to express themselves using speech</li> <li>-if used before, might be familiar or similar activity</li> </ul> | <ul style="list-style-type: none"> <li>- Students who never used Talking Mats might find difficult to take part</li> <li>-Students who cannot make a choice might find difficult to take part</li> </ul> |

|                               |                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                   |
|-------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                               |                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | -hands on approach                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                   |
| 2. Visual arts-based session  | Using what a student likes e.g. pictures or drawings or writings or sticky notes or "Play Dough" to produce a "what I want to learn about growing up" poster or collage or just individual images. Simple questions during this session will be asked to guide the expression of views on RSE topics. | <ul style="list-style-type: none"> <li>- no need to have expressive language but a minimal receptive language (2-word phrases)</li> <li>- no need to be able to understand a visual scale e.g. "like" and "do not like"</li> <li>- ability to recognise pictures if pictures board are selected for the task</li> <li>- good fine motor abilities for picking up the pictures and placing on a board if pictures selected for this activity and for drawings if drawings are used</li> <li>- could be completed sitting on a table or hanging the board on a wall</li> </ul> | <ul style="list-style-type: none"> <li>- fun, creative, sensory, hands-on activity</li> <li>-flexible</li> <li>-provides views of students who might not be able to express themselves using speech</li> </ul> | <ul style="list-style-type: none"> <li>- if a student does use speech to communicate, it might be difficult to understand what has been produced or whether this is about RSE thus the reliability of data might be questionable.</li> <li>- might need help from a student's support worker to help facilitate the communication for students that does not use speech to communicate</li> </ul> |
| 3. A diamond ranking activity | Students will be asked to sort pictures                                                                                                                                                                                                                                                               | -expressive and receptive language                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | - instead of asking direct questions in an                                                                                                                                                                     | - students with no expressive language and                                                                                                                                                                                                                                                                                                                                                        |

|  |                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                 |
|--|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
|  | <p>that represent RSE outcomes into a diamond shape to express their preferences of the outcomes and will be asked about their ranking choices (e.g. "Why this picture was placed on top of the diamond?")</p> | <p>-ability to understand simple questions</p> <p>-good reasoning abilities</p> <p>- for students who can engage in one-to-one discussions.</p> <p>-for students who do not like direct questioning (e.g. standard interviews) but can answer questions while doing an activity.</p> | <p>interview format, this is a hands-on approach</p> <p>-might be more suitable for students with intellectual disability and Autism who do not like direct questioning</p> <p>- would provide students with intellectual disability views of RSE and ranking of the outcomes.</p> <p>-for students who do not like using Talking Mats and prefer answering questions.</p> | <p>reasoning abilities will not be able to take part but there are other methods suggested.</p> |
|--|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|

**Appendix 5 - An example of a social story used with students with intellectual disability**

## **Student Laura comes to school**



1. Laura comes to school



2. Laura wants to know what I think about Relationships and Sex Education



3. I will be choosing pictures or drawing to tell what I think about Relationships and Sex Education

*Note: Images reproduced with permission of the rights holder, Photosymbols limited (<https://www.photosymbols.com>), Widgit Symbols © Widgit Software Ltd 2002-2024 (<http://www.widgit.com>), and Talking Mats Ltd (<http://www.talkingmats.com>). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.*

## Appendix 6 - An example of questions in the Delphi style survey

1. Please rate how important do you think is to include **knowledge of contraception** in the Core Outcome Set of Relationships and Sex Education for students with intellectual disability in secondary education?

**Contraception** is a method of preventing unwanted pregnancies.

**Knowledge of contraception** involves students knowing what contraception methods exist (e.g. oral contraception, condoms, injections, implants and ect) and why to use them.

|                                | Not Important<br>1    | Not Important<br>2    | Not Important<br>3    | Important<br>but not<br>critical<br>4 | Important<br>but not<br>critical<br>5 | Important<br>but not<br>critical<br>6 | Important<br>7        | Important<br>8        | Important<br>9        | Unable<br>to<br>score |
|--------------------------------|-----------------------|-----------------------|-----------------------|---------------------------------------|---------------------------------------|---------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Knowledge of<br>contraceptions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                 | <input type="radio"/>                 | <input type="radio"/>                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

2. Please rate how important do you think is to include **knowledge of private body parts** in the Core Outcome Set of Relationships and Sex Education for students with intellectual disability in primary education?

**Private body parts** are private body areas that are covered by a swimming suit for both females and males.

**Knowledge of private body parts** involves students being able to correctly identify the areas by pointing or naming them.

|                                       | Not Important<br>1    | Not Important<br>2    | Not Important<br>3    | Important<br>but not<br>critical<br>4 | Important<br>but not<br>critical<br>5 | Important<br>but not<br>critical<br>6 | Important<br>7        | Important<br>8        | Important<br>9        | Unable<br>to<br>score |
|---------------------------------------|-----------------------|-----------------------|-----------------------|---------------------------------------|---------------------------------------|---------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Knowledge of<br>private body<br>parts | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                 | <input type="radio"/>                 | <input type="radio"/>                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

## Appendix 7 - List of resources

### **Resources**

#### **Resources about Relationships and Sex Education:**

Growing up, sex and relationships: a booklet to support parents of young disabled people:

- [https://contact.org.uk/wp-content/uploads/2021/03/growing\\_up\\_parents\\_new\\_logo.pdf](https://contact.org.uk/wp-content/uploads/2021/03/growing_up_parents_new_logo.pdf)

Growing up, sex and relationships: a booklet for young disabled people:

- [https://contact.org.uk/wp-content/uploads/2021/03/growing\\_up\\_young\\_people.pdf](https://contact.org.uk/wp-content/uploads/2021/03/growing_up_young_people.pdf)

Sex and sexual awareness information for disabled young people:

- <https://contact.org.uk/help-for-families/information-advice-services/preparing-for-adult-life/growing-up-sex-and-relationships/sex-and-sexual-awareness/>

Sex education - a guide for parents:

- <https://www.autism.org.uk/advice-and-guidance/topics/family-life-and-relationships/sex-education/parents-and-carers>

Relationship and sex resources:

- <https://www.mencap.org.uk/advice-and-support/relationships-and-sex/relationships-and-sex-resources>

Love Life: resources for young people with learning disabilities:

- <https://learning.nspcc.org.uk/research-resources/schools/love-life>

Sexual Health, Relationships and Parenthood a workbook resource for one-to-one support:

- <https://www.centralexualhealth.org/media/7591/ASN-workbook.pdf>

Easy read health resources for people with learning disability:

- <https://www.easyhealth.org.uk/>

Collection of articles and links written by a mother of an ASD child around Puberty:

- <http://www.tacanow.org/family-resources/teens-with-asd-puberty>

An accessible website designed to be used by people with intellectual disability that has information about relationships and sex education:



- <https://www.ckuk.org.uk/index.php/about-ckuk/>

### **Charities that offer support for families of children with learning disability:**

**Contact a Family** is a national charity for families with disabled children. For information and advice on any aspect of caring for a disabled child:

- **Freephone helpline: 0808 808 3555**  
9.30am-5pm, Monday-Friday; free from UK landlines and UK mobiles
- **Facebook:** [facebook.com/contactafamily](https://www.facebook.com/contactafamily)
- **Twitter:** [@contactafamily](https://twitter.com/contactafamily)
- **Email:** [helpline@cafamilly.org.uk](mailto:helpline@cafamilly.org.uk)
- **Website:** <https://www.cafamily.org.uk/>

**Cerebra Charity** is a UK charity dedicated to helping the parents of children with brain related neurological conditions.

- Helpline (freephone): 0800 328 1159
- Telephone: +44 (0) 1267 244200
- Email: [enquiries@cerebra.org.uk](mailto:enquiries@cerebra.org.uk)

**Family Fund** is a UK based registered charity for disabled children and their families.

- **Website:** <https://www.familyfund.org.uk/>

**Kids Charity** for families of disabled children.

- **Website:** <https://www.kids.org.uk/>

**The Challenging Behaviour Foundation (CBF)** was founded in 1997 by Vivien Cooper OBE, the parent of a child with severe learning disabilities and behaviour described as challenging:

- **Website:** <http://www.challengingbehaviour.org.uk/>

**Mencap** offer help support to people with a learning disability, and their families and carers. Advisors can offer advice and information about learning disability and help you find the right support and Mencap services in your area:

- **Freephone Helpline:** 0808 808 1111 (from 8am to 6pm, Monday to Friday)
- **Email:** [helpline@mencap.org.uk](mailto:helpline@mencap.org.uk)

**Scope About disability** provides support, information and advice to disabled people and their families every year.

- **Freephone helpline:** 0808 800 3333
- Website: <https://www.scope.org.uk/support/families/diagnosis/learning-difficulty>

**The National Autistic Society (NAS)** are a UK charity for autistic people (including those with Asperger syndrome) and their families:

- **Helpline:** 0808 800 4104 (open 10am-4pm, Monday-Thursday, 9am-3pm on Fridays)
- Website: [www.autism.org.uk](http://www.autism.org.uk)
- NAS Parent to Parent (P2P) is a UK-wide confidential telephone service providing emotional support to parents and carers of children or adults with autism. Call 0808 800 4106 (Free from landlines and most mobiles)

## Appendices - Chapter 4

### Appendix 4.1 Example of search strategy used in the first stage of the review

| Medline (Ovid) searched on 31/04/2021 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |         |
|---------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|
| Set                                   | Search Terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Results |
| 1                                     | Intellectual Disability/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | 55535   |
| 2                                     | Autistic Disorder/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | 20890   |
| 3                                     | Down Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 24701   |
| 4                                     | Smith-Magenis Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | 202     |
| 5                                     | Rett Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 2645    |
| 6                                     | Lesch-Nyhan Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | 1213    |
| 7                                     | Prader-Willi Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | 2950    |
| 8                                     | Angelman Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | 1219    |
| 9                                     | Fragile X Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 5164    |
| 10                                    | Cri-du-Chat Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | 677     |
| 11                                    | De Lange Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | 834     |
| 12                                    | Rubinstein-Taybi Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | 512     |
| 13                                    | Developmental Disabilities/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | 20665   |
| 14                                    | Education, Special/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 8870    |
| 15                                    | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | 134213  |
| 16                                    | ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual* impair*" or "intellectual dysfunction" or "development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or IQ or "subaverage intelligence" or "cognitive impair*" or autis* or ASD or Asperg* or "Autism Spectrum Disorders" or "Down* Syndrome" or "trisomy 21" or "Smith-Magenis" or Rett* or "Lesch-Nyhan" or "Prader-Willi" or Angelman or "fragile X" or "Cri-du-chat" or "Cornelia de Lange" or "de Lange" or "Rubinstein-Taybi" or "special education* need*" or SEN or "special education* need* and disab*" or SEND or "special need*" or "additional support need*" or ASN).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 410172  |
| 17                                    | 15 or 16                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | 415360  |
| 18                                    | Sex Education/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 8901    |
| 19                                    | Sexual Health/ed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | 128     |
| 20                                    | Psychosexual Development/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | 3564    |
| 21                                    | Sexuality/px                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | 2111    |
| 22                                    | Sexual Behavior/ed, px                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | 11773   |
| 23                                    | ("sex* education" or "sex* curricul*" or "sex* and relationship* education" or "sex* and relationship* curricul*" or "relationship* and sex* education" or "relationship* and sex* curricul*" or "relationship* education" or "relationship* curricul*" or "sex* health education" or "sex* health curricul*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | 14591   |

|    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |            |
|----|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| 24 | ("reproductive health education" or "reproductive health curricul*" or "life skills education" or "life skills curricul*" or "personal social health and economic education" or "personal social and health education" or PSHE or PSHEE or "social personal health education" or SPHE or "personal social health and citizenship education" or PSHCE or "personal social and emotional development" or PSED).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 493        |
| 25 | 18 or 19 or 20 or 21 or 22 or 23 or 24                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | 30907      |
| 26 | (child* or youth* or pupil* or adolesc* or pre-adolesc* or pubert* or pediatric* or paediatric* or boy* or girl* or teen* or juvenil* or minor* or school* or student* or learner* or "young people*" or "young person*" or "young adult*" or "young women" or "young woman" or "young men" or "young man" or "early adult*" or "emerging adult*").mp.                                                                                                                                                                                                                                                                                                                                               | 4861166    |
| 27 | 17 and 25 and 26                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 501        |
| 28 | limit 27 to humans                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | 465        |
| 29 | limit 28 to yr="1999 -Current"                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | <b>244</b> |

## Appendix 4.2 Example of search strategy used in the second stage of the review

| Medline (Ovid) searched on 13/08/21. |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |         |
|--------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|
| Set                                  | Search Terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Results |
| 1                                    | Intellectual Disability/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | 56334   |
| 2                                    | Autistic Disorder/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 21687   |
| 3                                    | Down Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | 25000   |
| 4                                    | Smith-Magenis Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 209     |
| 5                                    | Rett Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | 2708    |
| 6                                    | Lesch-Nyhan Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | 1219    |
| 7                                    | Prader-Willi Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | 3032    |
| 8                                    | Angelman Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 1256    |
| 9                                    | Fragile X Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | 5262    |
| 10                                   | Cri-du-Chat Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | 684     |
| 11                                   | De Lange Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | 853     |
| 12                                   | Rubinstein-Taybi Syndrome/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | 526     |
| 13                                   | Developmental Disabilities/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | 21096   |
| 14                                   | Education, Special/                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | 8926    |
| 15                                   | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 136681  |
| 16                                   | ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual* impair*" or "intellectual dysfunction" or "development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or IQ or "subaverage intelligence" or "cognitive impair*" or "autis*" or ASD or Asperg*" or "Autism Spectrum Disorders" or "Down* Syndrome" or "trisomy 21" or "Smith-Magenis" or Rett*" or "Lesch-Nyhan" or "Prader-Willi" or Angelman or "fragile X" or "Cri-du-chat" or "Cornelia de Lange" or "de Lange" or "Rubinstein-Taybi" or "special education* need*" or SEN or "special education* need* and disab*" or SEND or "special need*" or "additional support need*" or ASN).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 420307  |
| 17                                   | 15 or 16                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | 425510  |
| 18                                   | SCEA.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | 31      |
| 19                                   | "Sexual Consent and Education Assessment".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | 1       |
| 20                                   | 19 or 20                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | 31      |
| 21                                   | 17 and 20                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | 2       |

| Set | Search Terms                                                                                                                                                                                                                                                                                         | Results |
|-----|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|
| 1   | "Sex KEN-ID".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] | 1       |
| 2   | "Sexuality Knowledge Experience Feelings and Needs Scale for people with Intellectual Disability".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word,                                                            | 0       |

|  |                                                                                                                                                    |          |
|--|----------------------------------------------------------------------------------------------------------------------------------------------------|----------|
|  | organism supplementary concept word, protocol supplementary concept word,<br>rare disease supplementary concept word, unique identifier, synonyms] |          |
|  | 1 OR 2                                                                                                                                             | <b>1</b> |

### Appendix 4.3 RSE characteristics reported in the studies

| Reference                         | RSE characteristics                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Box &amp; Shawe (2014)</b>     | <p><b>Name:</b> Sexuality and Relationships group based on programmes developed for people with ID (McCarthy, 1998; Craft, 2003; Kerr-Edwards &amp; Scott, 2003)</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> Adult males with mild-moderate ID and ASD and ADHD aged 20-24 years.</p> <p><b>Content:</b> Basic anatomy and body differences, puberty, hygiene, menstruation, menopause, sexual activities including same-sex relationships, conception, contraception, safe sex including abstinence, masturbation, wet dreams, self-examination, attractions, different types of relationships, forming and managing relationships, emotions, attitudes including stereotyping, good and bad touch, consent, public and private places, abuse, and assertiveness.</p> <p><b>Delivery:</b> 10 group sessions of 2 hours session once per week.</p> <p><b>Setting:</b> Day centre for adults with ID.</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> 1 male and 1 female community ID nurse.</p> |
| <b>Dukes &amp; McGuire (2009)</b> | <p><b>Name:</b> Sex Education based on the “Living Your Life – The Sex Education and Personal Development Resource for Special Education Needs” (Bustard 2003) book.</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> Adults (male and female) with moderate ID aged 22-23 years.</p> <p><b>Content:</b> Sexual safety practices, physical self, sexual functioning, choices, and consequences in sexual matters.</p> <p><b>Delivery:</b> Individual sessions of 45 minutes per session delivered twice per week.</p> <p><b>Setting:</b> Group homes for adults with ID</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> Researchers.</p>                                                                                                                                                                                                                                                                                                                                                              |
| <b>Finlay et al., (2015)</b>      | <p><b>Name:</b> Sex and Health Education.</p> <p><b>Aim:</b> Not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

|                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                    | <p><b>Population:</b> Adolescents (males and females) with mild-moderate ID aged 16-19 years.</p> <p><b>Content:</b> Sexual behaviour, contraception, norms, and relationships.</p> <p><b>Delivery:</b> Weekly group sessions (4-8 people) of 1 hour per session (total number of sessions not reported).</p> <p><b>Setting:</b> Youth club and special schools</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> 4 (male and female) youth service workers</p>                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Garwood &amp; McCabe (2000)</b> | <p><b>Name:</b> Co-Care.</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> Males with mild ID aged 12-25 years (Mean age=19 years, SD=6.5).</p> <p><b>Content:</b> Feelings, body language, social skills, the human life cycle, puberty, body awareness "private" and "public" behaviour, sexual relationships, conception, pregnancy, childbirth, contraception (including safe sex, STDs), menstruation and protective behaviours.</p> <p><b>Delivery:</b> Total number of sessions not reported. Sessions were delivered twice per week for 45 min per session.</p> <p><b>Setting:</b> Community health service</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> 2 (male and female) educators.</p>                                                                                                                     |
| <b>Graff et al., (2018)</b>        | <p><b>Name:</b> Relationships and Sexuality Education.</p> <p><b>Aim:</b> Teach skills and increase judgment about healthy relationships, sexuality, and safe boundaries.</p> <p><b>Population:</b> Adults (male and female) with IDD (some had ID, and some had ASD) aged 18-27 years (Mean age=20.7 years, SD= 1.4). Level of ID not reported.</p> <p><b>Content:</b> Relationships and self-awareness, maturation, the life cycle, sexual health, being strong, staying safe and hygiene.</p> <p><b>Delivery:</b> Group sessions (total number of sessions and length of the session not reported).</p> <p><b>Setting:</b> Inclusive postsecondary program for students with IDD at a university.</p> <p><b>Parent involvement:</b> The curriculum was developed with guidance from parents.</p> <p><b>Providers:</b> Teachers (gender not reported).</p> |
| <b>Kostigen (2021)</b>             | <p><b>Name:</b> Health and Sexuality Education.</p> <p><b>Aim:</b> Not provided.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |



|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | <p><b>Population:</b> Students with ID and ASD aged 7-21 years (75% 14-21 years). Level of ID not reported.</p> <p><b>Content:</b> Concepts of privacy, body part identification, hygiene skills, respecting personal space, and requesting another to stop an aversive activity.</p> <p><b>Delivery:</b> Group sessions (total number of sessions and length of the session not reported).</p> <p><b>Setting:</b> Special school.</p> <p><b>Parent involvement:</b> Not provided.</p> <p><b>Providers:</b> Teachers.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Luque &amp; Lugo (2015)</b> | <p><b>Name:</b> Emotional-Sexual Education based on Affective Sex Education materials (Bolaños, González, Jiménez, Ramos-Rodríguez y Rodríguez, 1994; Colectivo Harimaguada, 2007). Not specified if these materials were developed for people with ID.</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> Students with ID (5 male and 3 female) aged 16-22 years (level of ID not reported).</p> <p><b>Content:</b> the education contained 6 parts: 1) "Body" which involved private body parts, understanding the anatomy and physiology of the genitals, body changes during adolescence, body differences between males and females; 2) "Social skills" which involved active listening, assertiveness, empathy, respect for other people and their desires; 3) "emotional" which included work on relational skills and abilities such as recognition and expression of emotions, self-esteem; 4) "affective-sexual" which focused on learning about different ways people express affection and feelings, understanding of contraceptive methods and masturbation; 5) "private/public context" which includes awareness of the difference between public and private spaces; 6) "abuse or sexual abuse" which included information on appropriate and inappropriate physical contact, learning to say "no" and what to do in case of abuse.</p> <p><b>Delivery:</b> Group sessions of 1h per session, two sessions per week delivered over 4 months.</p> <p><b>Setting:</b> Special Education Centre.</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> Teachers.</p> |
| <b>Plaks et al., (2010)</b>    | <p><b>Name:</b> Social Sexual Education</p> <p><b>Aim:</b> Adolescents' self-identification, acceptance of the developmental disability, independence in social life, establishment of friendship and intimate relationship, sexual knowledge and sexual development, safety skills and assertiveness skills.</p> <p><b>Population:</b> Adolescents (male and female) with genetic conditions (WS, VCFS, ID) aged 15-24 years (Mean age=19.5 years, SD=2.6). Level of ID not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |

|                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-----------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                         | <p><b>Content:</b> Anatomic parts of the sexual system, differences between males' and females' sexual organs, sexual development, changes occurring in the body during adolescence, appropriate sexual behaviour (e.g. masturbation is something one does in private).</p> <p><b>Delivery:</b> 10 group sessions (length per session not reported).</p> <p><b>Setting:</b> Behavioural Neurogenetics Centre.</p> <p><b>Parent involvement:</b> Parents participated in a separate Social Sexual Education group.</p> <p><b>Providers:</b> Not reported.</p>                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Sheppard (2006)</b>                  | <p><b>Name:</b> Growing Pains Program (based on variety of resources).</p> <p><b>Aim:</b> Skills and knowledge acquisition in these areas: socialisation, personal hygiene, protective behaviours, sexuality, assertiveness, and substance abuse.</p> <p><b>Population:</b> Adolescents with mild-moderate ID, aged 11-15 years.</p> <p><b>Content:</b> Social skills: self-esteem, anger, conflict management, peer interaction, rights and responsibilities, decision-making; drug education; relationships and sexuality; protective behaviours: safe behaviours, public/private, body parts; grieving and loss; human life cycle; personal hygiene.</p> <p><b>Delivery:</b> Group sessions delivered over 20 weeks (45-65 minutes per session).</p> <p><b>Setting:</b> Special school</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> Teachers (gender not reported).</p>                                                                |
| <b>Stankova &amp; Trajkovski (2021)</b> | <p><b>Name:</b> Sex Education curriculum using Social Stories.</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> An adolescent male with ASD and low level of intellectual functioning aged 11 years with speech and developmental delay. ID level not reported.</p> <p><b>Content:</b> 14 Social Stories: My body; Private and Public Space; My intimate parts of the body; Why do I wear clothes; Where can I be naked; How do I grow and change; Wet dreams; Masturbation; What is pleasant; What is unpleasant; Pleasant touches; Unpleasant touches; Types of relationships. Content was personalised based on individual needs and cognitive level.</p> <p><b>Delivery:</b> Individual sessions of 45 minutes over 6 months (total number of sessions not reported).</p> <p><b>Setting:</b> Special school.</p> <p><b>Parent involvement:</b> Parents were asked about the perceived benefits in their children after they received the education.</p> |

|                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                          | <b>Providers:</b> Teacher (gender not reported).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Todd (2009)</b>       | <p><b>Name:</b> Personal Relationships and Health Education.</p> <p><b>Aim:</b> Develop respect for self and others, build up a positive self-concept, encourage the concept of loving relationships within the context of the family and encourage socially acceptable behaviour.</p> <p><b>Population:</b> Class of adolescents aged 15-16 years in a special school for children with severe ID. Level of ID varied in the class.</p> <p><b>Content:</b> "Range of topics, from health to appropriate greeting patterns, and a brief biological tour of the body and sex education".</p> <p><b>Delivery:</b> Group sessions of 90 min delivered over 13 weeks.</p> <p><b>Setting:</b> Special School.</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> Teachers.</p> |
| <b>Williamson (2018)</b> | <p><b>Name:</b> Sex Education curriculum based on "positive choices programme for people with ID" (Duguay, 2009)</p> <p><b>Aim:</b> Not reported.</p> <p><b>Population:</b> Women with ID and ASD aged 19-21 years with mild-moderate ID (IQ=54-70).</p> <p><b>Content:</b> Not reported.</p> <p><b>Delivery:</b> Group sessions of 1.5 h per session delivered over 32 weeks (one per week).</p> <p><b>Setting:</b> Special school.</p> <p><b>Parent involvement:</b> Not reported.</p> <p><b>Providers:</b> Teachers</p>                                                                                                                                                                                                                                                                      |

Note: ID= intellectual disability; ASD= autism spectrum disorder; ADHD=attention deficit hyperactivity disorder.

#### Appendix 4.4 RSE outcomes for students with intellectual disability that age was not specified

| Outcome domain                                   | Outcomes                                              | Frequency of reporting and study reference                   | Who reported |
|--------------------------------------------------|-------------------------------------------------------|--------------------------------------------------------------|--------------|
| <b>Understanding of the human body</b>           | Understanding of physical changes in adolescence      | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers     |
|                                                  | Able to name private body parts for males and females | 1 study; Hanass-Hancock et al., (2018)                       | Teachers     |
|                                                  | Understanding of reproductive anatomy and physiology  | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding of reproduction                         | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding what puberty is                         | 1 study; Howard-Barr (2005)                                  | Teachers     |
| <b>Understanding of sex and its consequences</b> | Understanding of what sexual experiences are          | 2 studies; Hanass-Hancock et al., (2018); Howard-Barr (2005) | Teachers     |
|                                                  | Understanding that sex can lead to pregnancy          | 1 study; Aderemi (2014)                                      | Teachers     |
|                                                  | Understanding what contraception is                   | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding what abortion is                        | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding of what STDs are                        | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding what HIV is                             | 1 study; Aderemi (2014)                                      | Teachers     |
|                                                  | Satisfying sexual needs in an appropriate environment | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers     |
|                                                  | Understanding what masturbation is                    | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Masturbation in an appropriate environment            | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers     |
|                                                  | Understanding of what ejaculation is                  | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding of what sexual dysfunction is           | 1 study; Howard-Barr (2005)                                  | Teachers     |
| <b>Understanding of the human sexuality</b>      | Understanding gender roles                            | 1 study; Howard-Barr (2005)                                  | Teachers     |
|                                                  | Understanding concept of illegal sexual activity      | 1 study; Howard-Barr (2005)                                  | Teachers     |

|                                                                 |                                                                                                                           |                                                              |          |
|-----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|----------|
|                                                                 | Understanding of different types of sexual orientations (e.g. bisexual, homosexual, heterosexual)                         | 1 study; Howard-Barr (2005)                                  | Teachers |
| <b>Understanding of appropriate and inappropriate behaviour</b> | Understanding of appropriate and inappropriate touch (e.g. which regions they (students) must not touch of other people)  | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers |
| <b>Understanding of hygiene</b>                                 | Understanding how to clean genital regions on their own                                                                   | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers |
| <b>Understanding of how to stay safe</b>                        | Understanding what body parts other people can touch and body parts other people cannot touch                             | 1 study; Girgin-Büyükbayraktar et al., (2017)                | Teachers |
|                                                                 | Understanding of consensual or non-consensual touch                                                                       | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
|                                                                 | Understanding of sexual abuse                                                                                             | 1 study; Howard-Barr (2005)                                  | Teachers |
| <b>Assertiveness skills</b>                                     | Able to say “no” if they don’t agree with something                                                                       | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
|                                                                 | Able to show with their facial expressions if they do not agree with something                                            | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
| <b>Emotional vocabulary</b>                                     | Able to recognise and name different feelings                                                                             | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
| <b>Social skills</b>                                            | Social skills (no description provided)                                                                                   | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
|                                                                 | Social boundaries                                                                                                         | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
| <b>Understanding of relationships</b>                           | Understanding of different types of relationships (e.g families, friendships, dating, marriage, and lifetime commitments) | 2 studies; Hanass-Hancock et al., (2018); Howard-Barr (2005) | Teachers |
|                                                                 | Understanding difference in ‘relationships’ between adults and learners or between girls and boys at school               | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
|                                                                 | Understanding of appropriate relationships                                                                                | 1 study; Hanass-Hancock et al., (2018)                       | Teachers |
|                                                                 | Understanding what love means                                                                                             | 2 studies; Hanass-Hancock et al., (2018)                     | Teachers |

|                                            |                                                                                  |                                        |          |
|--------------------------------------------|----------------------------------------------------------------------------------|----------------------------------------|----------|
| <b>Tolerance towards other sexualities</b> | Knowledge of different opinions with regards to sexuality and sexual orientation | 1 study; Hanass-Hancock et al., (2018) | Teachers |
|                                            | Knowledge of different opinions with regards to sexuality and religion           | 1 study; Howard-Barr (2005)            | Teachers |
|                                            | Tolerance of different opinions with regards to sexuality and sexual orientation | 1 study; Hanass-Hancock et al., (2018) | Teachers |

### Appendix 4.5 RSE outcomes where the lower age of the sample involves students in primary education (5-11 years)

| Outcome domain                                   | Outcome                                                                                          | Age range   | Reference                      | Who reported         |
|--------------------------------------------------|--------------------------------------------------------------------------------------------------|-------------|--------------------------------|----------------------|
| <b>Understanding of hygiene</b>                  | Understanding of what personal hygiene is                                                        | 7-16 years  | Tsutsumi (2009)                | Teachers and parents |
| <b>Understanding of human body</b>               | Understanding of what menstruation is                                                            | 5-19 years  | Peters (2007)                  | Teachers             |
|                                                  | Understanding of what wet dreams are                                                             | 5-19 years  | Peters (2007)                  | Teachers             |
| <b>Understanding of relationships</b>            | Understanding of what dating is                                                                  | 7-16 years  | Tsutsumi (2009)                | Teachers and parents |
|                                                  | Understanding of what marriage is                                                                | 5-19 years  | Tsutsumi (2009); Peters (2007) | Teachers and parents |
|                                                  | Understanding of love is                                                                         | 5-19 years  | Peters (2007)                  | Teachers             |
|                                                  | Understanding of what parenting is                                                               | 5-19 years  | Peters (2007)                  | Teachers             |
| <b>Understanding of human sexuality</b>          | Understanding of different sexualities (what heterosexuality, homosexuality, and bisexuality is) | 5-19 years  | Peters (2007)                  | Teachers             |
| <b>Understanding of sex and its consequences</b> | Understanding of what pregnancy is                                                               | 7-16 years  | Tsutsumi (2009)                | Teachers and parents |
|                                                  | Understanding of what contraception is                                                           | 5-19 years  | Tsutsumi (2009); Peters (2007) | Teachers and parents |
|                                                  | Understanding of what sexual intercourse is*                                                     | 5-19 years  | Tsutsumi (2009); Peters (2007) | Teachers and parents |
|                                                  | Understanding of what STDs are                                                                   | 7-16 years  | Tsutsumi (2009)                | Teachers and parents |
| <b>Understanding of appropriate behaviour</b>    | Understanding of socially acceptable public behaviour                                            | 10-25 years | Menon & Sivakami (2019)        | Parents              |
| <b>Understanding of sexual abuse</b>             | Ability to protect yourself from sexual abuse                                                    | 5-19 years  | Peters (2007)                  | Teachers             |

Note: STDs=Sexually Transmitted Diseases.

## Appendix 4.6 PRISMA flow diagrams of study selection process in the second stage of review

**Figure 1 Study selection process on the Sexual Consent and Education Assessment (SCEA)**

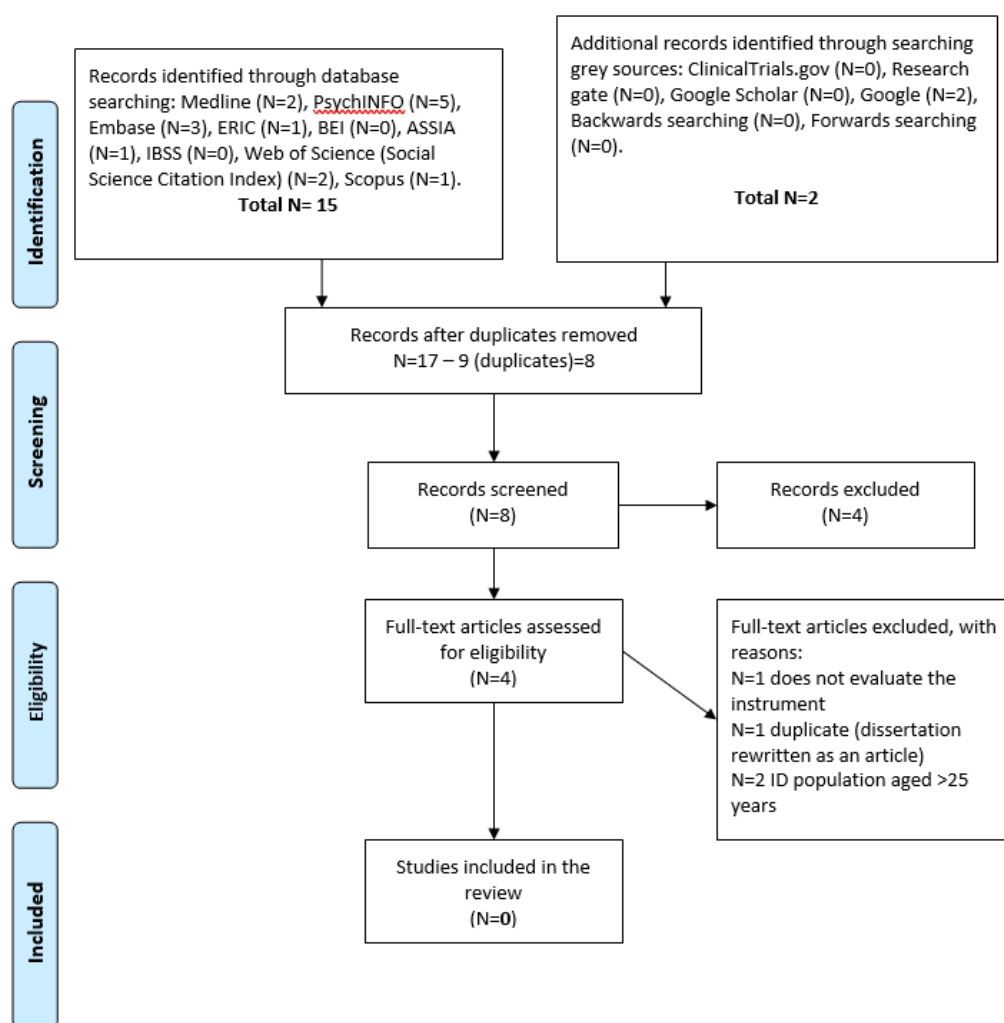
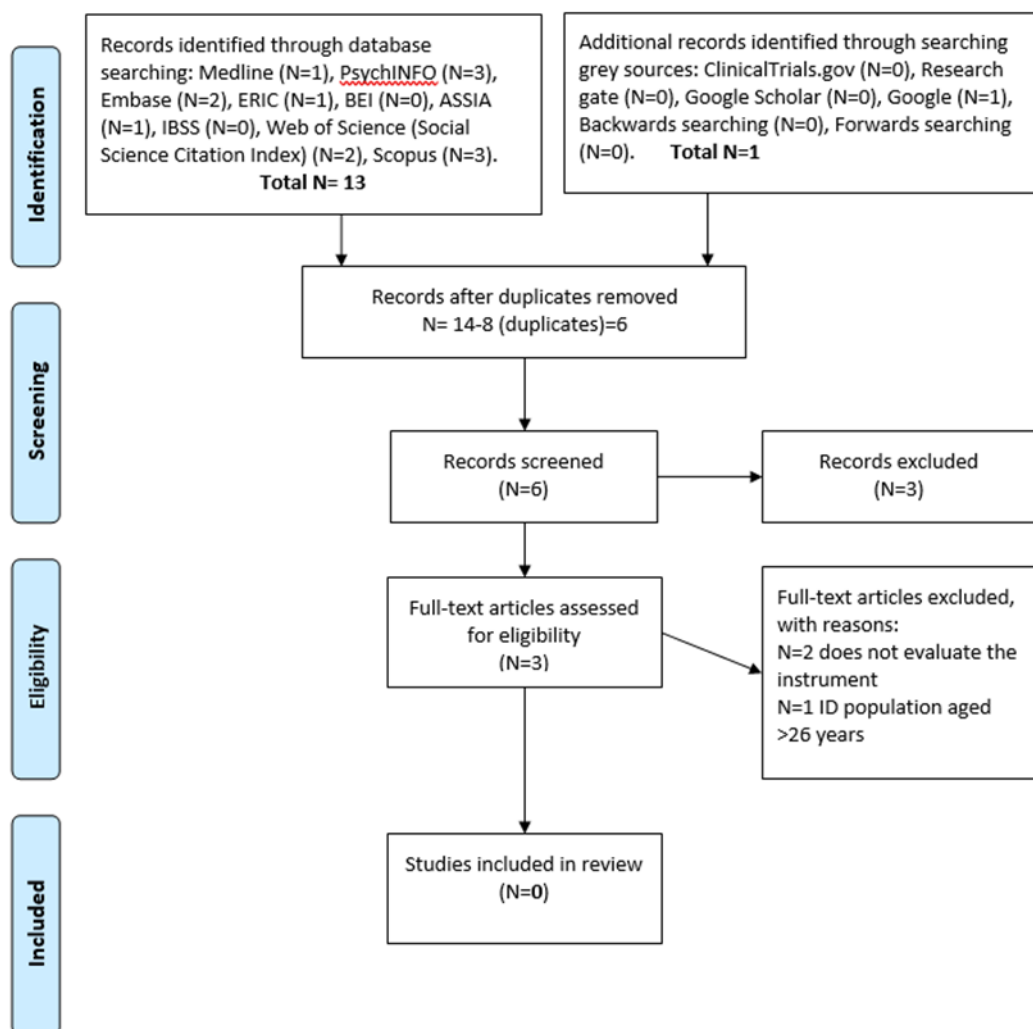




**Figure 2 Study selection process on the Sexuality Knowledge, Experience, Feelings and Needs Scale for people with Intellectual Disability (Sex Ken-ID)**



## **Appendices - Chapter 5**

### **Appendix 5.1 Questions asked workshops**

1. What do you think the outcomes of Relationships and Sex Education should be for students with learning disability in primary, secondary and further education? Why?

Please consider the outcomes in terms of knowledge, skills, and attitudes that this education should provide.

2. What you as a group think are the top three outcomes of Relationships and Sex Education for students in primary, secondary and further education? Why?

## **Appendix 5.2 Interview schedule for adult interview**

*An introductory question:*

1. What do you think the outcomes/targets of Relationships and Sex Education should be for students with learning disability? and why?

Probing questions:

- What skills it should provide? and why?
- What knowledge it should provide? and why?
- What attitudes students should develop? and why?

2. Thinking about different age groups of students with learning disability, what do you think this education should provide for young students in primary education (aged 5- 11 years) and why?

Probing questions:

- What skills it should provide? and why?
- What knowledge it should provide? and why?
- What attitudes students should develop? and why?

3. What RSE outcomes should be for students with learning disability in secondary education (aged 12-16 years), so this is for teenagers with learning disability and why?

*Probing question:*

- What skills it should provide? and why?
- What knowledge it should provide? and why?
- What attitudes students should develop? and why?

4. What outcomes of Relationships and Sex Education should be for older students with learning disability in further education/post 16-education (aged 17-25 years) and why?

*Probing question:*

- What skills it should provide? and why?
- What knowledge it should provide? and why?
- What attitudes students should develop? and why?

# Demographic questions

---

**Study name: The development of a Core Outcome Set for evaluating the impact of Relationships and Sex Education with students with intellectual disability**

Dear workshop participant,

Thank you for agreeing to take part in the workshop to discuss Relationships and Sex Education outcomes for students with learning disability (also known as intellectual disability).

So that we better understand who is taking part in the workshop could you please complete the questions below. If you do not want to answer some of the questions, please feel free to leave them empty.

If you have any questions, please get in touch: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

Thank you very much for your help and time!

Best wishes,  
Laura Paulauskaite

**1. How do you identify yourself?** If you belong to 2 or more groups (e.g. you are a parent and a teacher), please select one perspective that you would like to use:

- ☐ I am a parent/carer of a child with learning disability
- ☐ I am a teacher or school staff member involved in RSE delivery
- ☐ I am a researcher
- ☐ I am a policymaker/ working in a third sector organisation/other

If clicked "I am a policymaker/working in a third sector organisation/other":

**1.1 What is your professional role?** (e.g. RSE consultant, SEND consultant, policy maker, educational psychologist, working in third sector organisation)

**Please provide more information about your professional role:**

If clicked "I am a teacher or school staff member involved in RSE delivery":

**1.1 What is your professional role in school?**

- ☐ Class teacher
- ☐ Teaching assistant
- ☐ PSHE/ RSE teacher
- ☐ Speech and language therapist
- ☐ Psychologist
- ☐ Headteacher
- ☐ Other, please specify:

**1.2 How many years have you been working with students with learning disability?**

**Please specify:**

**1.3 Do you currently deliver Relationships and Sex Education to students with learning disability?**

- ☐ Yes
- ☐ No

**1.4 How many years have you been involved in the delivery of Relationships and Sex Education to students with learning disability?**  
**Please specify:**

**All together:**

**2. What is your gender?**

- ☐ Female
- ☐ Male
- ☐ Another gender
- ☐ Prefer not to say

**3. What is your age?**

- ☐ Under 25 years
- ☐ 25 to 35 years
- ☐ 36 to 45 years
- ☐ 46 to 55 years
- ☐ 56 to 65 years
- ☐ 66+ years

**4. What is your ethnic background?**

Please select an option that best describes your ethnic group or background.

• **White:**

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background (please specify):

- **Mixed/ Multiple ethnic groups:**

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/ Multiple ethnic background (please specify):

- **Asian or Asian British**

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background (please specify)

- **Black/African/Caribbean/Black British**

- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/ Caribbean background (please specify):

- **Other ethnic group (please specify):**

- ☐ Arab
- ☐ Please specify:

**5. What is your religion?**

- ☐ No religion
- ☐ Christianity
- ☐ Islam
- ☐ Hinduism
- ☐ Judaism
- ☐ Sikhism
- ☐ Buddhism
- ☐ Any other religion (please specify):

**6. Where do you live? If you live outside the UK, please specify.**

- ☐ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

☐ **Outside the UK (please specify):**

**7. Do you have a child with learning disability aged 5-25 years?**

- ☐ Yes
- ☐ No

**If yes, please answer some questions about your child. If you have more than one child with learning disability select one child that is aged 5-25 years that you would like to answer the questions about.**

**7.1 How old is your child with learning disability?**

Please specify:

**7.2 What is your child's gender?**

- ☐ Female
- ☐ Male
- ☐ Another gender
- ☐ Prefer not to say

**7.3 How would you describe your child's level of learning disability?**

- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Profound

**7.4 Does your child have any of the following conditions in addition to learning disability? Please tick all that apply:**

- ☐ Autism
- ☐ Attention Deficit Hyperactivity Disorder (ADHD)
- ☐ Speech delay
- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ Other (please specify):

**7.5 What your child's expressive vocal communication abilities are?**

- ☐ No speech
- ☐ Makes some sounds
- ☐ Speaks a few words
- ☐ Speaks in sentences

## Appendix 5.4 Example of thematic framework

| Theme                                                                    | Description and subthemes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Illustrative quotations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1. Knowing the human body and development through the life course</b> | <p>Stakeholders describe outcomes related to the human body and development throughout the life course. This theme also includes stakeholders' explanations why these outcomes are important.</p> <p>Subthemes:</p> <ul style="list-style-type: none"> <li>- Understanding body parts</li> <li>- Understanding hygiene</li> <li>- Understanding puberty and having skills to manage the changes</li> <li>- Understanding health checks</li> </ul> <p>This theme <b>does not</b> include outcomes on emotions and feelings, private and public <u>places</u> and behaviours and how the human body feels when sexually aroused.</p> | <p><b>Understanding body parts:</b><br/>           "...Actually, I was going to say it's also very important for our students to know the names of their body parts, to learn which parts of their body are private, to know the proper names for them and that probably pretty starts quite early. We then do a lot of work about what is private what is public, which parts of your body do you show?" (Teacher_01)</p> <p>"I think it's really <u>critical</u> that they're also taught the scientific names of the parts of their body, so that if there is any safeguarding concerns that they can report that effectively. We've had an awful case in in [the name of location], where a vagina was referred to as a "cookie". It was an uncle that she was complaining was regularly eating her cookie. Nobody took it seriously because of course they thought she was just sharing a biscuit with her uncle because she didn't have the vocabulary to be able to effectively share what was really happening..." (Teacher_04)</p> <p><b>Understanding hygiene:</b><br/>           "...children of that age should understand things [...] about [...] personal hygiene and looking after themselves in that regard, which it's not directly relationships education, but that sort of feeds in that. You're now getting to an age where some of this will become more your responsibility and your choice, do you know what I mean? There's an element, isn't there, of making choices around the way that you look and when you use deodorant, all those kinds of things..." (Policy maker_01)</p> <p>"I keep telling him that you need to have a shower, because you know when they become adults if they don't have a shower they will smell [...] that is why it is important to you know I don't know how to explain to you, but really, we need to communicate to them, despite they do not talk too much [...] they should learn, it is about hygiene, there is a part, you know the sex education is a part of hygiene because when you are clean you are healthy as well" (Parent_16)</p> <p><b>Understanding puberty and having skills to manage the changes:</b><br/>           "...and then very important as well to learn about body changes and puberty, how our body works, how it will change and what happens with those changes" (Teacher_06)</p> |



## Appendix 5.5 Example of table involved in charting

| Themes and subthemes                                               | Total (N=53)   | Parents/carers (N=17)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Teachers/school staff members (N=16)                                                                                                                                                                                                                                                                                                                                                                                                                 | Researchers (N=12)                                                                                                                                                                                                                                                  | Policymakers/third sector (N=8)                                                                                                                                                                                                                                                                             |
|--------------------------------------------------------------------|----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1: Human body and development through the life course</b> |                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                             |
| <b>1.1 Body parts</b>                                              | N=33 (62.26%)  | <p><b>Frequency of reporting:</b> N=9 (52.94%) parents/carers reported this outcome as important</p> <p><b>What this outcome should involve:</b> understanding private and public body parts for males and females and being able to communicate verbally or using communication aid about their private body parts using scientifically correct names.</p> <p><b>Why this outcome is important:</b> All students including non-verbal students should be able to communicate about their private body parts for safety and safeguarding reasons (e.g. in case of medical issues or sexual abuse).</p> | <p><b>Frequency of reporting:</b> 68.75% teachers/school staff reported this outcome as important</p> <p><b>What this outcome should involve:</b> the same views as described by parents/carers.</p> <p><b>Why this outcome is important:</b> due to safeguarding reasons as well as this is a core outcome that underpins understanding of other outcomes e.g. its knowledge is needed to understand hygiene, inappropriate touch and pleasure.</p> | <p><b>Frequency of reporting:</b> 58.33% researchers reported this outcome as important</p> <p><b>What this outcome should involve:</b> the same views as described by parents/cares.</p> <p><b>Why this outcome is important:</b> due to safeguarding reasons.</p> | <p><b>Frequency of reporting:</b> 75%</p> <p><b>What this outcome should involve:</b> the same views as described by parents/carers.</p> <p><b>Why this outcome is important:</b> due to safeguarding reasons and also related to understanding social norms of behaviour e.g. where you can touch them</p> |
| <b>1.2 Puberty</b>                                                 | N= 31 (58.49%) | <p><b>Frequency of reporting:</b> 52.94%</p> <p><b>What this outcome should involve:</b> understanding the puberty changes for each sex and that they are normal/natural.</p> <p><b>Why this outcome is important:</b> Can be scary if changes happen and students cannot verbalise or understand them; parents struggle</p>                                                                                                                                                                                                                                                                           | <p><b>Frequency of reporting:</b> 56.25%</p> <p><b>What this outcome should involve:</b> understanding the physical and emotional puberty changes, why the changes happen, how to deal with changes.</p> <p><b>Why this outcome is important:</b> It is a confusing time and difficult to understand the changes for any</p>                                                                                                                         | <p><b>Frequency of reporting:</b> 50%</p> <p><b>What this outcome should involve:</b> understanding the physical and emotional puberty changes and what they mean.</p> <p><b>Why this outcome is important:</b> Every student</p>                                   | <p><b>Frequency of reporting:</b> 87.5%</p> <p><b>What this outcome should involve:</b> understanding hormonal, physical and emotional changes that comes with puberty for each sex and having skills to request for help.</p>                                                                              |

## Appendix 5.6 Additional participants' quotes

| Theme                                                 | Subthemes                                                                                                                                                       | Participants' quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Human body and development through the life course | <ul style="list-style-type: none"> <li>• Human body parts</li> <li>• Puberty</li> <li>• Hygiene</li> <li>• Health checks</li> <li>• Human life cycle</li> </ul> | <ul style="list-style-type: none"> <li>• <b>Human body parts</b><br/> <p>“One of my children use iPad to communicate, and there were no intimate body parts on it. So, he [the son] had a medical issue that involved his testicles. There was no word for testicles, and he needs to be able to say that: “I have a problem with my body parts, or somebody has touched my body parts” [...] he needs to be able to communicate that to be safe. I have heard stories of kids going and saying: “somebody has touched my cookies”. And then what does that mean? And do you take that child seriously? And we teach our disabled kids, I think, to comply a lot: “you need to sit in this chair, you need to go in the toilet now” much more than we teach non-disabled kids that open them up for abuse that they have taught all their lives that they need to comply. My daughter has physical disabilities, so she needs help with intimate care, and she has to let the teachers help her with her intimate care, but she also needs to be able to say “When the teacher was helping me to change my nappy the teacher touched my vulva” right? She needs that word so she can tell us that is not the safe thing that happened. So that's why I care about that.” (Parent_12)</p> <p>“We thought that the first topic for primary [education] was going to be body parts. Not only naming them but being aware that they are there. Because we know that some people with learning disabilities have problems with that. Then, we thought it was important not only in terms of safety and safeguarding, but also in terms of pleasure because if you [...] do not know [your] body, you cannot identify what you like yourself.” (Teacher_06)</p> <p>“I want them to know as much as they can about their own body. Can they you know name body parts? if I am talking about their body say when I am changing them [...] do they know that they can respond effectively to that? Are they able to communicate to me about their bodies, are they poorly or are they well? Where does it hurt? So that is really the foundational knowledge that they need before they can even begin to sort of be brought along in terms of RSE. [...] If you do not know about your body you</p> </li> </ul> |

|  |  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|--|--|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  |  | <p>cannot then talk about hygiene and good touch and bad touch and [...] it becomes relevant to romantic and sexual implications of the body.” (Teacher_15)</p> <ul style="list-style-type: none"> <li> <b>Puberty</b> <p>““Understanding what those [puberty] changes mean in terms of how they may affect their body, their minds, their feelings because [...] knowing some of our primary boys you know we were talking about [...] masturbation, and all these things were happening in year four, five and the parents were shocked. I think that they thought: “this is not going to happen, because he has an intellectual disability”. Yes, it did not stop any of the physical things they all still happen in a similar trajectory. So, I think there is a little bit of helping children to understand that these things are okay and what it means in terms of growing up, for example, able to reproduce and what these changes might do.”” (Education officer_01)</p> <p>“He [the son] needs [...] to understand what is happening to his body and why it is happening, and he needs to understand that it is perfectly normal. He also needs to understand what is happening in relation to girls as well. He has got friends that are girls, and he does not understand, for example, why they might be off for a day in the month because they have period pains. He needs to understand the things are also changing and happening to young ladies as well that affect them in a different way and that is perfectly normal.” (Parent_03)</p> <p>“We need to recognise that puberty is starting at 9 [years] these days, which is a lot younger than they used to be. And they [students] need to understand the body changes, I mean we had people who have gone through puberty by the age of 11 but physically they are a teenager, emotionally and mentally they are still a primary school child.” (Researcher_05)</p> <p>“I think as well as at that age they do need to understand what is going to happen to their body. It is a very scary thing if puberty hits you in the face and you are not aware of it, you do not know what is happening that is really terrifying.” (Teacher_04)</p> <ul style="list-style-type: none"> <li> <b>Hygiene</b> <p>“I mean obviously there is the self-care aspects of RSE you know, can they look after their own body? do they understand that because of puberty because of the changes,</p> </li> </ul> </li> </ul> |
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|  |  | <p>as the body turns into an adult body you know, you need to be thinking about some different things about washing and self-care and shaving if you are a bloke, periods if you are a female you know. So, there's those sort of self-care aspects as skills that they need to know.” (Teacher_15)</p> <p>“I keep telling him [the son] that you need to have a shower, because you know when they become adults if they do not have a shower they will smell. [...] That is why it is important to know. [...] We need to communicate to them; despite they do not talk too much [...]. They should learn hygiene [...]. Hygiene is a part of sex education. Because when you are clean you are healthy as well.” (Parent_16)</p> <p>“I am fine with if they want to find ways of discreetly managing their self-care in ways that are different than other children because they might need more help. My children wash each other's hair because nobody can manage to wash the shampoo out. My social worker is appalled, but my children wear swimsuits [...]. This is learning to manage your self-care in the way that you can manage your self-care because I cannot teach [a child's name] to use the shampoo first, then the conditioner, because he cannot read, and he is 15. The best way to do is have a friend's help, but that is not what we teach. We teach you should be doing this on your own by now. So, then it is a stigma.” (Parent_04)</p> <ul style="list-style-type: none"> <li>• <b>Health checks</b></li> </ul> <p>“People should understand how their bodies work and not just in terms of at this age and you start to have periods but some of the problems that go around that and things like endometriosis and that your body will continue to change you do not just go through puberty at whatever age 12 and then nothing happens so you are 50.” (Policy maker_01)</p> <p>““Regular health checks [...] things like cervical screening, examining testicles, examining your breasts and [...] being aware of any bodily changes that you need to think about [...]. You can say: “Testicles should feel like this, they should have been a roughly spherical, always going to be one that is a bit bigger. If you feel that your testicles change shape, if it is sore, you need to get help” Do they understand that? [...] For girls there always going to have some kind of discharge. If your discharge changes or smelly or something like that, then you need to get medical help [...]. The difficulty I am finding is that whereas I am quite open my girls are private, and they</p> |
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|                                       |                                                                                                                                   | <p>do not want me talking about [...] having cervical screenings or discharges, but they need to know that.” (Parent_10)</p> <ul style="list-style-type: none"> <li>• <b>Human life cycle</b></li> </ul> <p>“For children and learners with severe learning disability it is very difficult to grasp these topics because do they know a concept of time and change? With 8- and 10-year-olds we do a lot of work with them around growth and change looking at growth cycles and you know babies, children, teenagers, grownups, old people. So, I do a lot of work with them around that before you are even thinking about RSE specifically.” (Teacher_14)</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
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| 2.Understanding emotions and feelings | <ul style="list-style-type: none"> <li>• <b>Recognising emotions and feelings</b></li> <li>• <b>Emotion regulation</b></li> </ul> | <ul style="list-style-type: none"> <li>• <b>Recognising emotions and feelings</b></li> </ul> <p>“They [students] need to understand feelings, they need to understand themselves and that can be quite a challenge, because they may not have that vocabulary[...] and for them what they are feeling might not match with some of the emotional words we use, you know we say: “Oh, you’re happy”, and they are like: “Oh, is that what it is?” And we do not link it to their interception. So, we do not say: “when you are happy, what happens inside? You know? My tummy gurgles my face muscles move. I feel I feel bouncy” [...] So I think really getting them to understand their own way they experience feelings and validating that with linking it to those feelings inside our bodies.” (Education Officer_01)</p> <p>“...because if you do not know how you are feeling you are not going to be able to say what you want and what you do not want and you are not going to be empathetic, and to know what other people might want or not. And then if you know your feelings and you know how you are feeling, you can regulate yourself and you can help yourself.” (Teacher_06)</p> <p>“...knowledge about people’s feelings is really critical so not just thinking about consent, but also thinking about you know how you might empathise with that person, how you might think in a way that that takes into account their feelings and what is happening in that situation, so I think definitely that should be part of outcomes [...] being able to understand the human being is a really critical point of knowledge that is the bit that tends to go wrong for people I think they get that wrong and then the rest of it just falls apart.”(Participant researcher_07)</p> <ul style="list-style-type: none"> <li>• <b>Emotion regulation</b></li> </ul> |

|                                                              |                                                                                                                                                                                                                                                          | <p>“... how to cope with those emotions and showing them that it's OK to feel all these different kinds of things there are ways that we can help you. And then once they've got that basic understanding, it's then about you know if you're feeling sad and you do this, this is how it can make another person feel and then that's when it would come into, you know, the relationships and friends' side of things. But I think for them to understand their emotions and how to regulate are like the basis of all of it really.” (Teacher_08)</p> <p>“I think they [students] need to tolerate rejection because it happens to all does not it? Relationships break down and they [students] need to understand that that is okay [...] So, he [the son] needs to actually be able to take and accept maybe rejection or accept rejecting somebody without them developing feelings of guilt or effect on his own mental well-being because he then worries about it always anxious [...] these are the feelings this group do not always understand why they feel that way and sometimes they do not have great strategies for coping with it. So, you do not want the fact that you have finished chatting to a young lady and they have rejected you to cause a huge mental health problem or a meltdown at home that means that they smash up your house.” (Parent_03)</p> <p>“...there is some risk around engaging in relationships like break up from feeling upset [...] around the whole managing your emotions and a lot of people from my experience are shielded from experiencing negative emotions [...] I imagine that the negative emotions that would come around a breakup which can often be quite traumatic are also not very well addressed and supported so I guess building up some understanding around that as well and the risks from that sort of emotional side would be really important.” (Participant researcher_04)</p> |
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| <b>3. Healthy relationships and associated social skills</b> | <ul style="list-style-type: none"> <li>• <b>Recognising different types of relationships</b></li> <li>• <b>How to develop and sustain healthy friendships and social skills</b></li> <li>• <b>How to develop and sustain healthy romantic</b></li> </ul> | <ul style="list-style-type: none"> <li>• <b>Recognising different types of relationships</b></li> </ul> <p>“I would have no problem as a mother and with my son learning about different family setups [...] him learning about same sex couples because I think young children, whether they have an intellectual disability or not, just tend to accept what they are told. If you go in it with an attitude, then they think there is a problem. [...] I think attitudes are really important in life and I think when you have got someone with an intellectual disability, they know they are different and we want them to be able to say: “I am different because of such and such”, and to accept that other people are different and that includes family relationships. And you know it, it's really trying to culture a way of thinking about, you know there is difference [...] I think those</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |

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|  | <p><b>relationships and social skills</b></p> <ul style="list-style-type: none"> <li>• <b>Planning for future relationships</b></li> <li>• <b>Values and attitudes for positive relationships</b></li> </ul> | <p>differences are important to acknowledge and to not make them you know you're different because you've got an intellectual disability, but you know, sort of put it in their context of there are lots of differences in the world. Your difference is this and there are lots of different family differences [...] who have two moms or two dads or [...] single parents who will overwhelmingly be mothers and so that is a certainly a family type that people will come across a lot and so they need to understand that you know that there may not be a mum and dad together." (Parent_06)</p> <p>"...understanding the differences in relationships and what you do about that, because it's like you know and yes, you like Miss [name], she's your teacher and she helps you but that's not the same as you know, if you have a girlfriend or a boyfriend, there are different kinds of feelings and we don't kiss like Miss [name] well, we don't have to do but we might want to kiss our girlfriend or a boyfriend and helping them to understand all of that stuff." (Teacher_07)</p> <ul style="list-style-type: none"> <li>• <b>How to develop and sustain healthy friendships and social skills</b></li> </ul> <p>"OK so I think one of the one of the fundamentals is understanding relationships and looking at in terms of the qualities of friendship. So, understanding what a friend is and how one can behave to attain friends. So, understanding and managing your behaviour, being able to interact, communicate and sustain some sort of socialisation with somebody else and then recognising in return what a friend is and whether he or she is actually giving that back [...] I think that is a good starting point it is understanding friends what makes a good friend." (Teacher_09)</p> <p>"So you need to know about friendships before you can even begin to understand romantic relationships and sexual relationships, because they are if you like a very specialised form of friendship that sort of their sort of technically, you know more complex versions of normal relationships between friends between strangers, you know how do you get on with a stranger what's appropriate, how do you get on with friend what's appropriate, how do you know those sorts of things and that's where you begin to get into those realms of appropriate touch at appropriate ways of relating to people, and you know learning just about platonic friendships. It is the start of that it's the building block it's the foundation, which you can then move on to other things. (Teacher_14)</p> <ul style="list-style-type: none"> <li>• <b>How to develop and sustain healthy romantic relationships and social skills</b></li> </ul> |
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|  |  | <p>“I do think it's important with children like [child's name] for them to be encouraged and educated on you know healthy sexual relationships and what that looks like and so they are not used or manipulated and so that they can recognise when they truly might be ready for that type of activity.” (Parent_09)”</p> <p>“The children should be able to have their own girlfriend or boyfriend. I will be very pleased if my son could have a girlfriend at this stage.” (Parent_13)</p> <p>“...dating and developing long-term relationships, and marriage and becoming life partners and how that works [...] I think we kind of close your eyes to the fact that our kids want the same thing as other kids. They want boyfriends and girlfriends, and they want intimate relationships.” (Parent_12)</p> <p>“If you are having a third or fourth date with somebody does that mean that you are going to kiss them or maybe you are not ready to kiss them and all that kind of stuff that we need support and learn as well, and so this kind of relationship skills for me in my classroom is about breaking down stuff that my learners might need to be taught on a more granular level.” (RSE consultant_02)</p> <ul style="list-style-type: none"> <li> <b>Planning for future relationships</b> <p>“...how your future what it looks like with or without children is also part [...] of sex education and it is also a topic that is especially in [the name of the country] is mainly omitted. While they [students] grow up seeing families, wanting families wanting to be normal, so I think that is a very important part of the conversation [...] what is it like to have a family or not? What does it require? Is this something for you? And what are the alternatives? I do not know what your experiences are, but I think the default is having a family. But there are other options nowadays as well [...] is it maybe a theme like that you discuss a future in which you know there will be loss. So also dealing with loss [...] also with for example family like [...] will you be able to have children, or no? [...] and then dealing with the things you cannot have because of your disability.” (Participant researcher_10)</p> <p>“They [students] need to know that their life might not involve having a partner or it might involve living with friends or it might involve a whole host of things that are not the things that are traditionally presented because not everybody with learning disabilities can find a partner, where they can live as a couple. So, I think that just presenting that as the ideal outcome is</p> </li> </ul> |
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|                             |                                                                                                                                                               | <p>quite limiting if that is potentially something that is not in your future [...] It would be overlaying the options over their reality as opposed to providing them with a whole host of information about which they are not going to be able to interact safely [...] they should be having an idea by the age of 20-21 what their life might look like.” (Parent_04)</p> <ul style="list-style-type: none"> <li>• <b>Values and attitudes for positive relationships</b></li> </ul> <p>“It is very important to understand positivity around and the benefits of having a relationship even a sexually active relationship as well [...] people [with ID] are shielded from that because people question their understanding and capabilities to do that in a safe way [...] I think there is a risk of people being persuaded from not engaging in such an activity because of risks that might be apparent. So, sort of shifting that dialogue away from it being like: “uhu sex and relationships you are not capable of this” and having a more positive attitude for people with learning disabilities is really important.” (Participant researcher_04)</p> <p>“I mean there are skills that were lacking in the boys that I worked with and that that kind of [...] basic skills around you know what to say and what not to say to people and it is a bit of a skill, I think, is you know they can often be persuaded into developing a bit of a misogynistic kind of ideology around relationship development and they have got quite a bit of encouragement for that, I think. So they get encouragement from you know the boys and men in their lives, but they’re also get encouragement from some of the women in their lives as well, they would say: “well you know men should behave like that you know men need to do this, you know that’s how a man should behave” and I think that needs to be addressed in in almost kind of a skill development kind of way with young men with learning disability and women with learning disability about thinking how men behave and what skills you require to be able to again cope and deal with that so there’s a bit of knowledge in there, but it’s also kind of a skill to I think [...] and that kind of idea of how men and women behave and being able to cope with that.” (Participant researcher_07)</p> |
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| <b>4. Sex and sexuality</b> | <ul style="list-style-type: none"> <li>• <b>Sexual feelings, sexual arousal, and pleasure</b></li> <li>• <b>Sex</b></li> <li>• <b>Masturbation</b></li> </ul> | <ul style="list-style-type: none"> <li>• <b>Sexual feelings, sexual arousal, and pleasure</b></li> </ul> <p>“...I think children need to be taught about actually how their body’s going to feel because I think definitely people with sensory difficulties it will be a set of feelings that they have not had before and [...] you feel heat in your genitals [...] but actually nobody ever talks about that and</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

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|  | <ul style="list-style-type: none"> <li>• <b>Pregnancy and parenting</b></li> <li>• <b>Contraception</b></li> <li>• <b>Pornography</b></li> <li>• <b>Sexual orientation, gender identity, gender roles and stereotypes</b></li> <li>• <b>Sexual health</b></li> </ul> | <p>our kids will not know that either that is normal or it is not normal you know they will not necessarily recognise what sexual arousal is they will not know that it increases their heart rate that they might look flushed because actually a lot of those things, I think that that are sexual arousal are also associated with panic attacks [...] we spend a lot of time helping our children manage those heightened emotions, those panic emotions, those stress emotions and give them all the tools to how they can calm down how they can regulate themselves but actually that you want is heightened emotions and you want that body reactions when you are about to have sexual intercourse with somebody.” (Parent_10)</p> <p>“...because I have met lots of students who have had erections and just don't know what's going on, you like suddenly at some part of your body is sticking out and you don't know why that's quite disconcerting, or if parts of your body are producing fluid or becoming lubricated you don't know why it's just worrying because there's been this change, and you don't know what's causing this change and that increased sensitivity that comes with arousal is only pleasurable if you're not frightened of it [...] so knowing clearly what happens when a person becomes aroused and that that can be a pleasant feeling and that it is a normal thing.” (SEND consultant_01)</p> <p>“... sex education that people had [...] not really [...] pleasure focused and I think that is a really important thing [...] I always teach people when we are doing sex education I always say that if it, you know it hurts, it feels uncomfortable, not nice, you are not doing it right because it should feel nice [...] you should feel happy about what is happening, and if you do not then, then it is not right. I think we need to change the narrative [...] there is a lot of research around showing that women with learning disabilities have really unpleasant experiences during sex [...] and women with learning disabilities whilst engaging in the sex with men in terms of sexual activity that was all focused around men pleasure, so a lot about anal sex, oral sex for men, but not for women.” (Participant researcher_03)</p> <p>“...parts of the female anatomy like for both women and men, where is the clitoris? like that is actually quite an important thing that women get told early and lots of women head into their second decade of sexual life not really knowing what' is happening like “why is not he blowing my mind?” and not really being able to direct to the men that they are with to how to make that happen and actually we can be really squeamish about talking to people with a learning disability around orgasm but people with disability have just as much a right to an orgasm as everybody else, ” (Participant from third sector_01)</p> |
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|  |  | <ul style="list-style-type: none"> <li>• <b>Sex</b></li> </ul> <p>“...it needs a much clearer teaching for people with intellectual disabilities around safe sex and sex is a part of conception and, quite literally, how you do sex because I have known people [...] trying to have sex with each other's belly buttons. I think within mainstream education we pretty much assume they know which bit goes where and those sorts of incidental learnings and understandings that you might have acquired through watching TV or just listening to other people are not necessarily going to be available to people with intellectual disabilities, and so I think it should be taught [...] how to have sex. I do not need the whole Kama sutra, but I probably need a recognition that sex is not always between partners of the same gender and all of this safely.” (SEND consultant_01)</p> <p>“...the whole mechanics of having sex needs to be understood. And I think, unfortunately these guys, it needs to be very, very graphic and detailed and very blunt and presented in a very matter of fact way because they will not pick up the stuff that you might teach mainstream children that they will ultimately figure out for themselves, these guys will not figure it out [...]. Person, delivering it, needs to be very frank about it, why do people do it, what do people get out of it, what is normal in that context, what is not normal but okay or unusual, and what is just not okay.” (Parent_03)</p> <p>“...we should be looking at what sex is because that is important from the point of view of being able to report if sex happens. I mean, there are certainly cases where people had no idea that sex had happened and because they were not told what it was, and because quite often, especially with intellectual disability, you may have someone who is quite uncomfortable with something that is being done to them [...] like being washed and [...]or needs cleaning and therefore they may not completely understand that what has happened is sex if sexual abuse takes place. So, what is sex? Who can you have sex with? So, it's not your teacher, it's not your mum. It's not your sister. It's not your dad, so you know they're drawing the boundaries around, who you can have sex with.” (Parent_06)</p> <ul style="list-style-type: none"> <li>• <b>Masturbation</b></li> </ul> <p>“Some children touch themselves as in they touch their genitals which you need to kind of an early age teaching that this is not okay to that group not five necessarily but certainly by the time, they were 11 years and [...] they need to understand the rules and safety around it. That is not okay to do that in Sainsbury's on Saturday afternoon. We were very clear with my son</p> |
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|  |  | <p>that it is okay to do that, but you must do that only it in your own bedroom with the doors shut and that is the only place you do it." (Parent_03)</p> <p>"Quite frequently colleges and schools come to me to ask for support because learners are masturbating in college or school and it is a very, very difficult thing to manage and it is something that the guidance [RSE guidance in England] and mainstream schools do not reflect at all, because it just simply does not happen in those places. And even if it did happen in there the young person would be able to have it discussed with them and have it explained why it is inappropriate and then it would not happen again, but some of my learners it is such a sensory response that actually it's not something that you can even just say "look no, this is the rule". You have got this constant process of reiterating the rule, making sure that the young person understands, not just that it is not okay, but why it is not okay." (RSE consultant_01)</p> <p>"...this is so important because, if a school or a college takes their kind of: "oh well it [masturbation] happens, the learner does not understand" sort of approach to it is not setting them up for independent adult life. Because not being understanding the nuances of privacy, where you are and are not allowed to do things like that highlights your vulnerability as well as it being something other people do not want to see and [...] makes somebody very vulnerable to exploitation." (RSE consultant_02)</p> <p>"I was not expecting to learn it in [the name of an organisation] about the importance of teaching young men about masturbating safely [...]. We realised that there was quite a high incidence of young men harming themselves masturbating because they did not know what was an acceptable amount of pressure to put on their member and they did not know about lubricants because what young men were being told was it is either it is not okay to masturbate or do not do that it is dirty, which is obviously really unhelpful because people need to know that their own urges are natural [...]. So, you do need support them to understand what are risky for you and around your sensitivity and how to have a good time with yourself in a safe way and I do not see that appearing on curriculums." (Participant from third sector_02)</p> <p>"...include how to masturbate on a general level for boys and for girls [...]. The difference in here imagine if you banned the average 16-year-old boy from masturbating what pent up ball of frustration and rage you would have. If you do not know from messing around with mates and from like incidental contact with pornography, or watching films, and wherever it is that you get your information from, you literally physically do not know what the movements are</p> |
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|  |  | <p>[...]. So, I think I would want practical information about how to masturbate for both types of genitals.” (SEND consultant_01)</p> <p>“...It is about masturbation [...] as parents as far as we can go to explain him or even to show him to be independent or so in this because he [the son] is 16 so while he is touching himself, but it [penis] is not going up. So, we have a bit maybe the word it is a shock, he is touching himself, but it is not masturbation really but maybe he needs that, or can we explain him? And as I said even is it possible to show him or how to do it?” (Parent_15)</p> <ul style="list-style-type: none"> <li> <b>Pregnancy and parenting</b> <p>“Understanding what it means to be a good parent, what parenting looks like, and the responsibility that comes with having a baby, the financial costs that comes with having a baby [...] The sad reality is that many of our ex-pupils have gone on to have children. One of them has had two [...] so they were pregnant in year 11 and these children are no longer with them because they have not been deemed to be fit parents or able to care and provide for the child, say and, and that is all a lack of understanding of what it really means to be a parent.” (Teacher_04)</p> <p>“...I do not want us to live in a society where we are telling people with learning disabilities that they cannot have children because besides anything else I know some really excellent parents who have learning disabilities who care for their children beautifully and with great love and they have got a system working around them [...] and that there is an additional risk to losing your child having a child taken into care if you have a learning disability [...] and additional thinking you need to do in planning, you need to do in order to ensure that you and your child can be safe and happy. I do think that it is important talking through if you decide, you want to have a child, what does parenting involve and where are you going to need to ask for help.” (Participant from third sector_01)</p> <p>“I mean the amount times I have spoken to lot of adults who have an intellectual disability who are going through menopause now who did not know they could ever get pregnant [...]. That discussion does not happen because parents are terrified that their young person will want a baby [...]. In the past there been a tendency for parents to want contraception that will prevent any form of pregnancy [...] because of their periods [...] or if they are sexually abused, they are just not going to get pregnant [...]. So, I think we should talk about pregnancy as something that people with intellectual disability can do despite all the fears of their parents</p> </li> </ul> |
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|  |  | <p>[...] that they can get early support from maternity services and understand that is what all women should have.” (Parent_06)</p> <ul style="list-style-type: none"> <li> <b>Contraception</b> </li> </ul> <p>“Similarly, to the same as the younger group the 11-16 group I think this the skills for that group go further in the ones that are most likely to be engaging in sexual relationships, so you I think you need to be teaching them about contraception.” (Parent_03)</p> <p>“...understanding contraception [...] But unless people are told what to do in terms of contraception how can anyone be expected to have safe sex? so some skills around that would be really important.” (Participant researcher_04)</p> <p>“...they do have a right to know how to use contraception, how to access free contraception. We sign all our children up to this. If they possibly get it competency and that they do need to understand about sexually transmitted infections because this really will be the last time that they get it. And the reality of many of our children is that they come they are second or third generation that we've seen at the school. So, the education hasn't always been there for parents, so if they don't get it from us, they're often not getting it at all, and I think that's terrible.” (Teacher_04)</p> <p>“...I would like both sexes to learn both of those things and that's not necessarily something that happens in mainstream, but I think it would be useful, that it did. Because it's a shared activity, a lot of the time and if you know if I was with a partner, and I was on the pill, they would be checking if I was taking my pills, because they have an awareness that that's something that I would do. If I was with a partner and they put their condom on wrong I would know because I know how to put a condom or how to check, so these aren't you know these aren't things that belong to one gender or another they're just done by you know one person has to do with one person's body or the other but it's a shared thing, and so I think it's useful for both groups to know and it. Especially within the learning disabled world if you are in a relationship, you might have a relationship where you both have some kind of impairment, but it is not necessarily the same one so like if you're a woman who's learning disabled and has dreadful executive functioning but you are dating an autistic boy who is you know socially compromised, but not intellectually disabled he will remember to take the pill far better than you will, so it makes sense for him to have them to have learned it too.” (SEND consultant_01)</p> |
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|  |  | <p>“...We have a problem with forced contraception in young women with intellectual disability, so I think unless we also teach self-determination, self-advocacy and we teach what bodily autonomy is, we will not equip them with that voice to be able to protect themselves against people who want them to have forced contraception, I mean if they want to take contraception it is their choice of course and this will be an informed choice, though not forced [...] but it is not even mentioned as part of sex education, I feel there is contraception as in this is the pill, and this is the condom, and this is what does what, but the phenomena of forced contraception on women is not discussed enough.” (Participant researcher_02)</p> <ul style="list-style-type: none"> <li>• <b>Pornography</b></li> </ul> <p>“I think we need to understand our kids are not being educated in schools, but they have been educated by porn [...] in my experience of knowing [it] it is very wrong [...] and that actually very unreal element of pornography. Because I think all teenagers are trying to educate themselves using pornography, we must admit it is out there, they have all seen it, but obviously it is staged, it is unreal, this is not what real life is going to be like.” (Parent_10)</p> <p>“I think, particularly now in in more recent years with the way the pornography has become so easily accessible to young people [...] what they see in pornography is not women experiencing sexual pleasure and actually women being degraded and harmed and abused and if that is what you think sex is [...] then that is a recipe for giving very kind of confused, mixed and unhelpful messages to both men and women.” (Participant researcher_06)</p> <p>“...I think, as soon as it gets to secondary school age you absolutely need to be talking in quite a lot of depth about how arousal works and how you protect your ability to actually be able to enjoy sex by managing your own exposure to different types of arousing material because what we're seeing a lot right now with teenage boys, is that they're watching porn on a daily basis, but they're not having sex with their girlfriends because they can't get aroused in real situations because they've been watching things that is incredibly extreme from a young age and that's a pretty miserable place to be actually to be a teenager and already to have kind of backed yourself into a corner that you're probably going to need therapeutic support to back yourself back out.” (participant from third sector organisation_02)</p> <ul style="list-style-type: none"> <li>• <b>Sexual orientation, gender identity, gender roles and stereotypes</b></li> </ul> |
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|  |  | <p>“...people understand that they are different in a sexual way early on I think there needs to be as we were talking about families being different, and I think there needs to be a thread that talks about just relationships being different so when you start to talk about sex itself at that point there needs to be and everybody needs to understand that there can be [...] same-sex relationships.” (Parent_06)</p> <p>“...looking at different sexualities I think that is important [...] research show that a lot of people on the autistic spectrum are more likely to identify as gender diverse and sexually diverse and so I think it is really important to start giving people that language quite early as we have worked with people who have not had that language, and I think primary school is a good time to introduce that to people they watch TV, they see it.” (Participant researcher_03)</p> <p>“...it is about normalising everything really and creating the knowledge to be embedded in them that boys and girls are just people yeah none of the gender stereotypes anymore get rid of all and understanding the negative side as well [...] I always correct my boys I think I am doing my bit to the future here [...] and I say: “there are no boys’ jobs, there are no girls’ jobs, there are no stronger boys or the boys are not stronger than girls” [...] it is all about making sure that the next generation is really tolerant of each other and more understanding.” (Parent_01)</p> <p>“... I suppose gender diversity has become a sort of more relevant topic these days and cultural issues as well [...] different ethnicities, different religions and what that might mean in terms of how people conduct close relationships [...] so that people can behave in respectful way in relationships, but also in commenting on engaging friendships with other people and their relationships.” (Participant researcher_08)</p> <p>“...they need to be taught about that it is okay to be attracted to different groups of people there is not necessarily a man to woman relationship, it might be girl to girl or man to man and that is acceptable as well [...] but I think a lot of what they’re told in school puts a boundary on what is acceptable [...] if you have got a child who is got learning disabilities and is a concrete learner then they learn very early that what they like, or who they are is wrong and then you have to do a huge amount of extra work to restore [...] the self-esteem, the resilience and all of that you have just destroyed it all by telling them that they are not normal.” (Parent_04)</p> <ul style="list-style-type: none"> <li>• <b>Sexual health</b></li> </ul> |
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|  |  | <p>“...just keeping them safe so that that they understand that if you do not practice safe sex or, if you have unprotected sex, you know the outcome can be that you will end up either being pregnant or you know maybe getting an STI.” (Parent_11)</p> <p>“...the second one [outcome] is safe sexuality. So how to have sex safely and how to avoid conception and how to avoid infections and STI's” (Teacher_06)</p> <p>“...sexually transmitted infections [...] there is a whole set of things that potentially could happen, and people need to know about those and how to try to avoid those.” (Participant researcher_06)</p> <p>“...I have got an awareness to clients my colleagues deal with or work with where they [people with ID] have now got sexual health problems [...] quite promiscuous [...] and you have to question if something earlier on in their life lead them to believe I am worthless this is what happens to me I do not know.” (Parent_07)</p> <p>“...I mean I have got a friend who is got a son just a little bit younger than yours [parent's name] and they went to London and his mate also has learning difficulties and then my friend's son found himself standing outside a brothel while this guy went in to go and pay for a prostitute and he had no knowing whether prostitute had taking any precautions [...] I suppose, what I am trying to say is that actually sex is out there [...] there are prostitutes and there is pornography and actually [...] our kids have as much access to it as anybody else [...] but those with learning difficulties have less ability to manage it and so I think that being really explicit you know if you go to a prostitute you have to understand this.” (Parent_10)</p> <p>“...in terms of skills, I think that young people need to know what local services are available to them and have had the experience of going to those local services. So you know, very often with young people with intellectual disabilities they will go on various trips, so I really believe that every school should have close relationships with sexual health clinics so they meet the people who are there so that it is an experience not just for the young people themselves, but also for staff who very often have had no experience at all of people with intellectual disabilities until they present with something and then it is very difficult to in terms of communication it can be very difficult for staff to sort of work out how to communicate effectively, so I think those things would be useful on a practical basis.” (Parent_06)</p> |
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| Theme                                    | Subthemes                                                                                                                                                                                                                 | Participants' quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
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| 5.Keeping yourself and other people safe | <ul style="list-style-type: none"> <li>Online safety and the law</li> <li>Unhealthy relationships, risk, and how to keep safe</li> <li>Legal consequences of behaving inappropriately</li> <li>Asking for help</li> </ul> | <ul style="list-style-type: none"> <li>Online safety and the law</li> </ul> <p>“...because even whether you know something happens and they got additional needs they can find themselves in that situation, you know, the whole thing about here now with you know with youngsters that if they exchanged photos that could be seen as pornography. This other thing sexting [...] so I mean it is such a worry for parents I think really, the whole thing about education [...] it does have to be you know at a relatively young age because of the way society has evolved.” (Parent_11)</p> <p>“...the other thing to remember is that our kids just do not have a filter and they have no impulse control and if somebody says: “send me a picture”, somebody upsets them or whatever it is back there before they even realise what they are doing.” (Parent_10)</p> <p>“...we get a lot of issues around the Internet and lots of issues, particularly around people befriend them [people with ID] and then people are grooming them online. So men often being particularly vulnerable because they will get messages from girls images of beautiful women and they will believe that they are their girlfriend that people are really lonely and they will believe or wanting a partner and they will believe these people are their friends and [...] there is a lot of issues in learning disabilities where people struggle with ages so they will be talking to young girls online not really understanding they are like 15 but not really understanding the legal implications of that and quite a number have ended up on the Internet caught by vigilantes. That was something I had never heard of until about three-four years ago, and now it is quite a common thing and always people with learning disabilities get lots of hate and always we get people getting financially abused where they have been asked to send money...so I think like there should be a real focus on like online safety and understanding the Internet and how people are not who they say they are and understanding how to use the Internet safely, because I think that that has not been given to people with learning disability in school.” (Participant researcher_03)</p> <p>“...overall goals for any of them [students with ID] are the Internet and the online world, because that is now a big part, especially after covid that there is been a lot of individuals that are now searching for partners on the Internet and getting into trouble because of the conversations that happen on that [...] I mean they need to learn then again about the law</p> |

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|  |  | <p>because there is a law linked to the Internet, then there needs to be understanding about sort of Internet etiquette concerning how you are talking with people [...] recognising safety concerning meeting up with people, recognising that there are people in online world that that will lie to you that will do things to try and obtain images to contain information from you [...] I have worked with people that are the older end from an emotional level they are still quite young so you have then got 24 year olds talking to a 14 year old and [...] they talk about being boyfriend and girlfriend nothing sexual is happening, but you know [...] it is opening up the 24 year old to being abused or being an abuser.” (Participant researcher_05)</p> <p>• <b>Unhealthy relationships, risk, and how to keep safe</b></p> <p>“students do not necessarily understand social cues they are being manipulated and used in an unhealthy relationship so teaching them what that manipulation might look like, so that they can then apply that elsewhere in their life too [...] I think there is more peer pressure or that anxiety about fitting in might be more for those vulnerable children that they get manipulated, because they want to fit in so they do not always make good choices.” (Teacher_11)</p> <p>“...some young people with intellectual disability, they go: “You're my friend. You're my friend”, and that's a fixed thing “You're now my friend”. And they can get into they are quite vulnerable in terms of being manipulated, and so helping them to understand when a friend is being nice to them, and then a friend is taking a fancy to them it's quite a key thing. It's very subtle, you know: “If you're my friend, then you, you are bound to be good to me, because that's what a friend does”, and so they can't sometimes rationalise that is still not okay that relationship might at times they may be being horrible to you just because they're your friend that doesn't mean you should put up with it, and I think that you know some of the vulnerability comes from the fixed view of what friends are and “Now you're my friend, [...] I will give you money, I will...”. But you know, there are examples of adults [...] with intellectual disability, who'd be massively taken advantage of because “Oh, but he's my friend”. Yes, but he's taking money off you. “Yeah, I give him my money because he asks, and I give him” [...] We do not teach our children about “friend danger”, and the people we love and the people around us might actually also be doing us damage, and how to work with that as well” (Education officer_01)</p> <p>“Things like power imbalances and ever looked at in a lot of detail with children with learning disabilities [...] Children with learning disabilities are way more vulnerable to an institutionalised power difference, so your carer or the person who helps you go to football or</p> |
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|  |  | <p>the person who's paying you the extra attention at a club that you have finally managed to access, because your accessibility is different and so you're susceptibility to an inappropriate relationship that starts off as pricing where you're groomed as opposed to a coercive relationship, but a groomed relationship is much more vulnerable than a typical child same age with the same social options, so I think that recognising your boundaries around what it is appropriate for other people to be approaching you about is important as well [...] I don't mean that they have to be scared of everybody, and everything, but they just need to be a lot more aware of it, and it needs to be much more explicitly explained as to why and where that might be a problem with those things. Because we will assume that children will sort of pick it up and, in my experience, they don't, and it can be problematic." (Parent_04)</p> <p>"...a real skill would be how to deal with being approached or groomed [...] people asking you to share sexual images that sort of thing" (Teacher_12)</p> <p>"...not keeping secrets even if people ask them [students] to keep secrets [...] perpetrators of sexual abuse will almost always tell younger people [...]: "do not tell your mom, do not tell your teacher, this is our secret" that is a common strategy of you know people who want to harm children." (Participant researcher_06)"</p> <p>"...a real skill is working out how a not OK friendship or not OK relationship feels so you feel scared but for a lot of young people with an intellectual disability just saying oh you feel scared, doesn't do it you have to have some level of quite often a physical something physical that will show them how their stomach might feel upset so you know you can use physical things like toys that sort of show them and they can put against their stomach and feel their stomach moving." (Parent_06)</p> <p>"...about vulnerability and risk [...] we ought to be educating or growing knowledge in individuals about their own vulnerability and the vulnerability of others [...] we are not just talking about people with learning disability and their desires were talking about and their own vulnerability we are also talking about how they can put people at risk sometimes because of their lack of knowledge, because of their lack of skills [...] a reason for it is to make sure that they have a good understanding of their own vulnerability, but also the vulnerability of others and kind of what risk is about." (Participant researcher_07)</p> <ul style="list-style-type: none"> <li>• <b>Legal consequences of behaving inappropriately</b></li> </ul> |
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|  |  | <p>“...people [with ID] do not realise what can and cannot class as a sexual offense or an ordinary offense and things like the texting side [...] we need to be having more open discussions about those because people do need to know [...] I have had people [with ID] that have not had the full information and they have gone off and ignorance is not a defence in court [...] we might be able to reduce your sentence but you are going to be sentenced and you are going to be a sex offender.” (Participant researcher_05)</p> <p>“...have a clear understanding of where the crime becomes you know where if you push that limit, then you are in into crime situations or into abuse situations or potentially you know harming people [...] we always said with [parent’s name] until the age of 10, you know 10, 12, 13 he [the son] is still a child. So OK, he might do something inappropriate, but people will say: “well OK, I understand he is disabled, and he is a child. OK, fine.” At the age of 16 or 17 or 20 he is no longer a child and people will react very differently and you know what you could do before you know touching people on the trains, for example, you travel, you go around and you touch people on the trains where OK, 13 years old people say “oh, keep your child of my breast” but you know at 20 years old that’s a very different story.” (Parent14)</p> <p>“As well the fact that the whole thing about managing their emotions and that they can get in trouble as well in either sort of like the harassment or stalking them either online or in person. And then trying to explain that sense typically where they’re at an older adult age that’s it doesn’t matter what we’ve got a learning disability or autism once you are an adult you can be either you can get a criminal record and [...] can involve a custodial sentence and yes there are people in prison with autism and learning disabilities [...] we do not put the fear in them but at the same time, you know they have to take responsibility for their actions and to be aware of the consequences”. (Parent_11)</p> <p>“...understanding of what actually does constitute sexual harassment that I think is really important for secondary aged students because they do not understand that what they are doing actually does often constitute as sexual harassment and [...] but it is only through lack of knowledge and that often these things are taking place.” (Teacher_04)</p> <ul style="list-style-type: none"> <li>• <b>Asking for help</b></li> </ul> <p>“...but if you know if they [students] are feeling some you know some kind of emotion or if something has happened even if they cannot communicate directly at least they know that they can go to someone that can help them to communicate this or that can then</p> |
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|            |                                                                                    | <p>pass it on to somebody that can help them further and they struggled just in class to ask for help for the most basic things like to open a bag of crisps, or to put on their coat and so I think understanding how to ask for help and who you know they can ask for help it is really important". (Teacher_07)</p> <p>"Yeah, how to how to get to the right people to give the right and the right It's almost you know if something bad is happening to you, who do you talk to? Who do you go to and establishing those clear pathways that you know what we know from abuse is that they will say, "If you tell anyone, I will kill you, or I will do", you know. So, it's breaking those barriers and going you know: "If bad things are happening to you, you're not going to be at fault. You're not you're not to blame for this you need to tell a trusted adult". And developing those the kind of no blame approach to it, and really enabling those conversations to happen. And with the additional vulnerability, I think, highlighting that the other people around that can help and support with that as well." (Education officer_01)</p> <p>"We need to equip our children to know that if somebody tries to do that [sex], and you don't want them to do that, you can say no and then you can scream very loudly and adults are not going to be cross with you for having tiptoed into that realm of sexual experience." (Parent_04)</p> <p>"...I think locating that individual is such a scale, and I think we've seen for a long time that ability to be able to locate the right person can be catastrophic for you, if you've got a mild disability or living independently in the community, you just choose the wrong person and, and you don't really recognise that they're going to be the wrong person and you know we're about started a project in [the name of a location] looking at exploitation and people with learning disability and I think some of that is about just that inability to find the right people who are going to help you and the consequence of that is often is that person is exploited and just because they didn't have the skill to be able to check out whether this was the right person for them or not." (Participant researcher_07)</p> |
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| Theme      | Subthemes                                                                          | Participants' quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| 6. Consent | <ul style="list-style-type: none"> <li>Consent and communication skills</li> </ul> | <ul style="list-style-type: none"> <li>Consent and communication skills</li> </ul> <p>"... in primary it is important that they learn and which things they can say "no" to. So I think with children with learning disabilities as adults, we quite often ride roughshod over</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

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|  | <ul style="list-style-type: none"> <li>• <b>Social norms of behaviour for a given cultural context</b></li> <li>• <b>Consent in sexual activities and the law</b></li> </ul> | <p>their consent, because we need to get them to do something whether that's personal hygiene or self-care or things like that, and I think that, unfortunately, that teaches them that adults can ride roughshod over all the decisions, so I think that they need to have the language and the knowledge to be able to say no, if an adult puts them in a position that makes them uncomfortable. (Parent_04)</p> <p>“...sometimes these are very basic skills [...] but I see it on my day to day where I work that is not that easy and because [...] we teach them sometimes do what adults want all the time you know? And somebody is going to be happy if you do what they are telling you to do, and you know in education this is what we do. But for them it's difficult to then be able to say no. It's important to for them to know when to say no and how to.” (Teacher_06)</p> <p>“...And they you know someone who has had your body or personal care taken care all the time [...] and lots of people seeing you naked [...] I think people [with ID] get desensitised to that and I think there's a real need to get people to understand about consent and it's their body, and they have the right to say no” (Participant researcher_03)</p> <p>“about consent even if they are nonverbal, we need to be able to allow them to have the understanding that there is good touch bad touch because often they are going to be the ones that require 24 hour care, seven days a week they are the ones that could potentially be more discreetly open to abuse and it is actually their right to be able to at least understand on whatever level we provide to them with the way somebody is touching is not the right way” (Participant researcher_05)”</p> <p>“How to gain consent and what that conversation is. Knowing what it is, but then actually you know, knowing how to ask if it is okay to give someone a hug or that is it okay to enter their own personal space” (Teacher_12)</p> <p>“They need to be taught how to consent, and how to refuse it. Understanding that only “yes” means “yes”. Silence and “mhmm” does not mean “yes” and it needs to be that explicit for our kids.” (Parent_10)</p> |
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|  |  | <p>“...there is all about consent [...] and specifically different ways that people might show you their "No" when they're not saying it. I think that sort of thing is really important, because children are quite literal and so there'll be like: “yeah I took that person's train and they did not tell me I could not” you know they didn't tell you they couldn't but they didn't go and cry or let it hold it behind their back or they did do something else, and I think supporting children of that age to understand when approaching other people's boundaries is really important [...] So that people understand how to tell when other people are uncomfortable and it's not it's not other people's responsibility to keep themselves safe from you, because you have a learning disability.” (Participant from a third sector_01)</p> <ul style="list-style-type: none"> <li>• <b>Social norms of behaviour for a given cultural context</b></li> </ul> <p>“...they do not necessarily understand that perhaps growing up and grabbing someone's arm is not an acceptable behaviour but then in primary school whilst that is not usually a massive deal in secondary school that can be handled differently depending on who it is perhaps that they are engaging with at the time. So having that knowledge before they come to secondary school, I think is important.” (Teacher_09)</p> <p>“...It is okay to hug your mother, but it is not okay to hug your teacher, and it is okay to give a kiss to your sister, but maybe not okay to give a kiss to the girls next to you. But that is also very cultural, isn't it? My children were born in France, and in France it would be totally normal to give a kiss to your friends when you see them in the morning. I mean not, you know, a romantic kiss, but a kiss on the cheek [...] I feel like there needs to be some cultural sensitivity taught about you know, in some cultures It would be okay to hug your friends and in some cultures it would not be okay to hug your friends, and that's complicated and hard, I think, for our kids with learning disabilities but it's important.” (Parent_12)</p> <p>“A practical understanding so with regards to safety, I think it's in addition to the ordinary curriculum to the sort of standard curriculum that people get taught students with learning disabilities lead supported lives, and that makes them more at risk of sexual assault and sexual abuse and it's a very tricky boundary to teach when you're sort of telling people, you know that the message that we would give to typically developing children is nobody is allowed to touch parts of you that are in in your underwear. But if you're somebody who is supporting toileting and your intimate care people are allowed to touch those parts so it's actually a much</p> |
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|  |  | <p>harder message that we have to teach the students than it is to a mainstream audience. And we are teaching to students who have less intellectual capacity to understand that message, so I would want to see within an RSE curriculum certainly in addressing of that topic and an acknowledgement that this is an extra part of the curriculum that's required in addition to what is taught in mainstream I would want to see them taught." (SEND consultant_01)</p> <p>"...to understand that even at an early age to as much they can do to their ability it's not okay for adults unnecessarily to touch in certain places without you know again it's back to you know if they are a three-year-old, who needs a nappy changed, you need to explain to them and let them understand why an adult is touching them because they are changing your nappy and the same even if you're fifteen in you are still in a nappy that still the case." (Parent_03)</p> <ul style="list-style-type: none"> <li>• <b>Consent in sexual activities and the law</b></li> </ul> <p>"I think probably in terms of tangible outcomes one of the things that would be useful would be to pin those on the sort of capacity assessment that is made with young people with intellectual disabilities. So that would be things like looking at their knowledge around things around with the consequences of sex and so STI's, pregnancy and around things like how to prevent pregnancy, how to prevent STIs so those kinds of very practical things. And that when you're looking at and you know kind of capacity there's an assumption that people have capacity, unless they're shown to not have capacity, and therefore to try and structure something so that we can work out if someone has the capacity to consent to sexual activity." (Parent_06)</p> <p>"...I really want the very basics so if we look at the legal framework of the basic understanding someone must have in order to consent to a sexual relationship that understanding of the mechanics of sex, the potential outcomes of sex, whether it's pregnancy or STI and the understanding that you can say no and you can say no at any point. So that kind of real basic knowledge, so they are, they have enough knowledge to legally be able to consent to a sexual relationship will be my ideal outcome for some of my young people in the school..." (School staff member_01)</p> <p>"...consent and partly that is how to know whether or not you can consent and it is whether or not the person, that is your prospective partner can consent and [...] one of the pieces of work we did at the [the name of an organisation] was around how to know whether or not you want</p> |
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|                |                                                                                                               | <p>to have sex with someone so there is a huge thing that like we talked about all the time [...] around the amount of times that people say that they've lose that lost their virginity or consented to sex when they actually didn't want to because they were told of things or when they thought they wanted to, but they weren't sure, so they were told that: "if you really like me this is something you want to do". "Well, I do really like you, but I don't necessarily fancy you and I'm not necessarily aroused" [...] how to support people to understand how to interpret the signals their body is giving them, as well as the signals their mind is too giving them, because actually it's a complex thing deciding whether or not you consent to something. Because you can like somebody and be friends with them and not fancy them at all and if you don't have to them at all, and if you're not aroused you shouldn't consent, because actually what you're allowing yourself to do is essentially be exploited for the sake of your affection for somebody[...] we see a lot of sexual exploitation of people with learning disabilities almost most often with either young gay man or young women being essentially often sex trafficked and or pimped by people they believe to be their partners." (Participant from third sector_02)</p> <p>"...key priority is a whole kind of set of concerns around consent around choice around autonomy that [...] people need to know that they should only be doing what they want to do and what they are comfortable with doing and it's absolutely fine to set your own boundaries and to expect other people to respect those boundaries [...] in terms of sexual activity with other people that is absolutely fine [...] that you should not be being persuaded against your will you should not be forced into doing anything, it should be something that you are engaging in of your own free will. And sadly, a lot of people, even in my experience, a lot of a woman with learning disabilities either do not know that or do not have the boundaries respected by other people and their boundaries are constantly being kind of eroded and pushed by other people." (Participant researcher_06)</p> |
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| Theme          | Subthemes                                                                                                     | Participants' quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 7. Self-esteem | <ul style="list-style-type: none"> <li>• Self-esteem and confidence</li> <li>• Positive body image</li> </ul> | <ul style="list-style-type: none"> <li>• Self-esteem and confidence</li> </ul> <p>"So I think one of the first outcomes, is that they need to they need to be taught I was going to say self-validation that's not the right term it's that kind of that self-esteem in a way, so I think, because I think that underpins everything and the first thing you've got to do before you can move on, is love yourself isn't it?." (Parent_10)</p> <p>"I think skill to be able to communicate their concerns I think that's something that children can find really, really difficult and if there is a concern and installing that confidence in them, I think,</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

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|  |  | <p>confidence can be a skill and that that needs to be developed and also can, to a degree be taught.” (Parent_02)</p> <p>“...the assertiveness stuff is a real issue and particularly for young women with learning disability [...] I really do find that some of the young women that I work with are incredibly passive and very...the learning disability adds that level that kind of extra level of vulnerability in there which is I do I find quite concerning in with some of the groups that I work with, so I will very often do young women's work sort of post 16 level, which is much more about building up their self-esteem and thinking about all of the things that sort of come along with that, but actually until a young person that you know kind of sees themselves as worthy of something you know doing this sort of how to say no to something isn't much use if they're if they've got the skill of half actually how to say no, if they practiced how to say no they also need to have the confidence to be able to do that so it's kind of building that confidence that sort of stuff definitely.” (RSE consultant_01)</p> <p>“For most of the students I have taught with intellectual disability this was not an issue, but for some who were more aware of their difference that was hard. They knew they were different, and they really needed that acceptance and celebration of the fact that that was great. “You are different that's fine”, and they needed that boost in self-esteem, because they were just very aware that they were not like the other children they were not, and they looked at the deficits rather than their strengths. So, I think, in a way, we've got to be really celebrating the strengths that they have, and enhancing that rather than they were doing that themselves “oh I can't do that, I am rubbish at that” rather than: “oh but you're really good at...you're really good at...” you know building their self-esteem is massively important task I think.” (Education Officer_01)</p> <ul style="list-style-type: none"> <li>• <b>Positive body image</b></li> </ul> <p>“I think having an understanding just how many body types there are I think that's a big thing you know [...] it's very, very, very normal for women to grow beards, it's very, very normal for men not to be able to grow a beard, it's very, very normal to have a pear shaped silhouette or an apple silhouette [...] that there are so many different variations, that there is no normal in the same way, I would say, for healthy relationships when we're talking about contraception and stuff that there isn't such a thing as a normal relationship, contraception, and STIs and a healthy relationship is looks different across a variety of sexualities same thing goes for body</p> |
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|                 |                                                                                                          | image it's not a one size fits all with body hair and with weight or with you know things are hormone conditions that cause things like cystic acne..." (Teacher_12)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
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| 8. Human rights | <ul style="list-style-type: none"> <li>• Knowing human rights</li> <li>• Self-advocacy skills</li> </ul> | <ul style="list-style-type: none"> <li>• <b>Knowing human rights</b><br/> <p>"...that they have the right to control their own bodies and their own relationships [...] because we need them to sit in their chairs all day at school and listen and be compliant, to eat lunch when it is lunch time, and not necessarily when they are hungry, and to go to the toilet when it is a break time not necessarily when they need to go. And I understand all of that. But I think with our disabled kids that last longer than with my non-disabled kids [...] I mean, my daughter is in a wheelchair, and sometimes a teacher says: "You must sit up straight. You must put your feet down". They would not say that to a thirteen-year-old who is able they would not tell her how she must hold her body in that kind of way, and they do it because well you know she is in a wheelchair, and so we need to take care of her. That is okay. But she also is a teenager, and sometimes she is going to slump, you know. So, she needs to be able to say: "No, actually right now I need to put my head down", or "right now I need to stretch my legs" and it is not respectful when you are constantly controlling other people's bodies." (Parent_12)</p> <p>"...my research has found that people do not know what their rights are, and they do not understand that they have the same rights as some people without a learning disability. So, I work with people who are adults, and some do not understand that they have autonomy [...] have a right to a relationship, and they have a right to a sex life, and they have a right to enjoy all the parts of life that that we enjoy. And just sort of challenges like [...] come from a young age and [...] instilling the messaging people that they have these rights, and they are the same as everybody else [...] and raising expectations to people and [...] we work with people, and they have bad internalised views around their life [...] they do not expect to have a partner not that everyone must have a partner, but you know, to have a life that would resemble a life most of us have, living with somebody, sharing lives." (Participant researcher_03)</p> </li> <li>• <b>Self-advocacy skills</b><br/> <p>"Sex is a wonderful part of life, and they should know that they're entitled to it and there is almost an advocacy thing that needs to be taught there because sadly as provision stands currently it could well be something that they need to self-advocate for and against care providers their parents, whoever it might be (SEND consultant_01)"</p> </li> </ul> |

|                                                        |                                                                                                                                            | <p>“... about some of the attitudes and values that exist in society and not just around sex and although obviously that would be included, but also around someone with a learning disability in a relationship, and what that might mean and what that might look like and that is quite tough and difficult, but I think that is important”. (RSE consultant_01)</p> <p>“The thing that I always talk as well as is whether within the education to develop knowledge, we ought to be talking about the history of learning disability and introducing ideas of [...] how the past sometimes cast a shadow over what is permissible for people with learning disability and that definitely includes relationship development, sexuality and sexual orientation [...] growing some knowledge of the past, I think, is useful, and I think in where there have been other projects where you know, certainly people learning disability had been taught about history about segregation, it helps them to form a view that, then they can use to defend where they want to be now. And I think that should be the same with issues around sexuality and you know developing relationships is that they should have some of that information so they can defend their decisions in this modern world” (Participant researcher_07)</p> |
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| Theme                                                  | Subthemes                                                                                                                                  | Participants’ quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 9. Environmental support needed for outcome attainment | <ul style="list-style-type: none"> <li>• RSE delivery</li> <li>• The role of adults</li> <li>• Physical environment adaptations</li> </ul> | <ul style="list-style-type: none"> <li>• RSE delivery</li> </ul> <p>“We need to make sure that it [RSE] is covered in statutory EHCPs, that is not the lesson that they always skip to catch up on reading. So, just making sure that is comprehensively and consistently taught and not seen as an addition, or something that will be caught up later. Even schools where they know it is important, they are only interested when you have the safeguarding need in play.” (Parent_04)</p> <p>“For our children some things that we would naturally learn without even trying, they have to catch up, so they are already behind. So, for me, if you are going to tell them something you it has to be very black and white and do not willy-nilly it.” (Parent_05)</p> <p>“...repetition is essential across all of the areas [...] especially with some young people with learning disabilities because it might be that they learn a skill, but they do not use it and then they forget it.” (Teacher_06)</p> <p>“They need to be provided with role models and visual examples (multimedia – videos, cartoons, live pictures) to fully grasp the concept that is being explained. They require everything to be in language that is accessible and with terminology that is easily understood</p>                               |

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|  |  | <p>or explained. They require additional time to support their understanding and, where appropriate, discussion in different contexts.” (Education officer_01)</p> <p>“... we do not necessarily explore how they [students with ID] can put that knowledge into practical skills. We talked about do you understand what the age of consent is, what does consent mean, but actually we do not spend time how can you show us that you understand consent in practice without it actually being in practice [... things like scenarios.” (Participant researcher_05)</p> <p>“...we should be looking at the skills and part of our skill as a teacher needs to be to look at the guidance [RSE DfE 2019 guidance] look at what it is asking of us and look for the skills, because yes in mainstream classes you might ask them to draw a list of STIs and explaining which are bacterial and viral. That is not going to work in my classroom. In my classroom, we need to be thinking about the skills, knowing that chlamydia can be cured with antibiotics is great, but how do you know if you are at risk of chlamydia? Have you ever made a formal phone call phone to ask for an appointment? Have you ever you ever been to a clinic by yourself? Because that list of bacterial does not give you that.” (RSE consultant_02)</p> <p>“...with mainstream young people, you would teach something before it happens and you use a preventing kind of approach, but with people with learning disabilities most of the time we cannot do that because they do not have the ability to understand before something has happened [...] it is difficult to teach about masturbation before they have already started to masturbate because you know the mental level might be lower than what is happening to the body. (Teacher_06)</p> <p>“My son at a very early age at the age of 11 he become attracted to people, and I think he needs to start there. All his sex education at the moment is starting when he is 17 and that is far too late. They needed to have had all of that to drip fed to him throughout school, while he was 11.” (Parent_03)</p> <p>“The earlier we are teaching this stuff the better because for our students learning a new concept or understanding his concept takes time. So, it is not good [...] waiting until they are like 14-15 and then saying: “oh, by the way, this is this and this is that”. I think that the earlier we start introducing these things, they start to learn this is okay [...] and things like that then God forbid if anything did happen, they already have some understanding there. You know</p> |
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|  |  | <p>one of my worst fears would be if anything happened, and then it was like, well, I haven't taught them that because he is only eight or I haven't taught her that because she's only five and she you know she won't understand it." (Teacher_08)</p> <p>"And I think one of the difficulties is if you do not get the education in there quickly enough and you do not draw the public and private when they are little, then as they are getting older I mean, the biggest thing that I am asked to go and give advice on is on young people who are usually teenagers behaving sexually in public or behaving sexually towards teachers." (Parent_06)</p> <p>"I would like an environment that recognises the idea of measuring functioning according to a chronological age is flawed across the board, not just with regards to sex education but with all sorts, so we quite often have these setups where because somebody has a sort of literacy function of a two-year-old we say that they are intellectually impaired, and they are equivalent to a two year old. They might be equivalent to a two-year-old in terms of their literacy functioning but they will not be equivalent to a two year old in terms of their emotional maturity, more often than not emotional maturity tracks chronological age and neither will they be equivalent in terms of their sexual maturity and their creative abilities [...] and the viewing of people with intellectual disabilities as a kind of forever children [...] it is a form of cruelty and prejudice." (SEND_02)</p> <p>"We are infantilising our disabled kids, and we assume that they are emotionally younger than they are. People often talk about cognitive age [...] but it drives me crazy when a child is ten or thirteen with all the lived experience of a ten or a thirteen-year-old, and just because maybe they cannot read or they cannot speak does not mean that they have not lived those thirteen years with all the things that entail you know friendships and relationships and puberty, and they go through all of that just like the rest of our able kids but we treat them like they are much younger. My daughter's class, she is thirteen and they are reading the very hungry caterpillar. And I said: "Really?" I mean that might be where her reading skills are pegged, but that is not where her emotional maturity is pegged. So, you have got to consider these are thirteen-year-old kids and thirteen-year-olds want to have boyfriends and girlfriends." (Parent_12)</p> <p>"...standard outcomes regardless of intellectual disability because [...] I think there is a tendency for people to look at someone who perhaps has greater communication difficulties or</p> |
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|  |  | <p>looks more disabled to be given less information and the firm assumptions being that they are not going to need the skills and, that is a real problem. So, I think that whatever outcomes you have should be standard right across the board.” (Parent_06)</p> <ul style="list-style-type: none"> <li> <b>Adults’ role</b> </li> </ul> <p>“...we will teach people [with ID] about consent, but for a lot of young people with learning disabilities, we need to model it, we need to show them what consent looks like we need to, we need to be working in an environment where the whole school appreciates that. If we're going to ask [...] to touch somebody or ask for permission [...] we need to be modelling that too to make sure that things aren't being done without young people's consent. So, there's a lot [...] around that approach, I think, around how schools actually treat their young people within the different settings.” (RSE consultant_01)</p> <p>“...I certainly believe that staff and even parents should be saying, you know: “right we're going into the toilet now. This is our private area. Do you mind I'm going to clean your, you know vulva or whatever it is your penis now?” So that there's an introduction there isn't just an assumption that you're going to start cleaning because that's It's all about you, you know, kind of boundaries, and ensuring that children even from a young age understand that there are boundaries and if they feel uncomfortable with something that's happening, they are more able to report it.” (Parent_06)</p> <p>“...before [the name of an organisation] most of my career was working with people with learning disabilities and was a pattern of people coming to work with people with learning disabilities with something of a saviour complex like “oh they are so lovely” and then displaying different boundaries as a as an adult female with an adult male with a learning disability, then you would with an adult male without a learning disability and therefore, teaching people different boundaries are acceptable, as a result of their disability. We said this of course puts that person [with ID] at risk of acting inappropriately with somebody who has not set boundaries in those ways. So, I think [...] that is around educating everybody about the importance of having consistent boundaries.” (Participant from third sector_02)</p> <p>“...opportunity to meet people because lots of my learners get picked up from their parents’ house in a minibus taking to college where they spend the whole day with maybe five other people who have the same kind of needs to them in their class back on the minibus straight</p> |
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|  |  | <p>back home. Were we supposed to meet your girlfriend or your boyfriend? That is a fantasy life and part of this role is to support these places like education basis or day centres to create these opportunities for people to meet because you are not going to meet your “the one” on your mom’s sofa.” (RSE consultant)</p> <p>“It is about giving them that opportunity [...] often what we do is we do a lot of teaching. And, especially in the word of learning disabilities they don't have the opportunity, because services when you turn into an adult tend to be relying upon staff, relying upon people consciously putting things together, so you can interact with others. So, I think it is an important outcome is creating the opportunity to practice the skills.” (Participant Researcher_05)</p> <p>“...young people with intellectual disabilities very often are at special schools so they live miles away from their friends that they have in school [...] that is exactly what happened with my son and it takes a huge amount of effort to build up those friends and I think that should be actively encouraged by parents and also by the school and which often is not because the school [...] fill their classroom in a very sort of practical way rather than thinking these are friendships let's keep these friends together, which I think that is what they should be doing. (Parent_06)</p> <p>“...for every person who had regular contact with people with learning disabilities we did a GCSE in sex and relationships education, so we had GCSE level qualification, so that we all had the correct language us we using it consistently, and then we did with all of the adults in order to kind of ensure that we all got the same base level of understanding about what was appropriate rather than as a staff having an understanding that was never shared except to tell off people with a learning disability when they broke boundaries that no one had ever told them existed kind of that thing. And I think that's important at every age actually to kind of be saying, not this is what your expectation our expectations as a view, but this is what everyone's expectation should be everybody else stuff around kindness stuff around how to know whether or not people are consenting.” (Participant from third sector_02)</p> <p>“..if he [the sone] comes back with a question or he says something I will reinforce what he has just told me and make it something that the school is doing some of the job, but as a parent, I still need to do some of that job, but they are actually supporting me as well as him because I do not know how to explain it and get him to understand it and school have taken that role on but then I feel as his mum is then my responsibility or our responsibility to then reinforce what</p> |
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|--|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  |  | <p>has been said and try and model or try and show him in different ways that is what he has got to do.” (Parent_05)</p> <p>“Parents should be much more comfortable with having these conversations and again, you know, the more that we can talk about it, the more our children learn at home is a good thing. Culturally, it is difficult, and I do think that that has to be considered [...] culturally it was not something that was normal in my household I had to learn these things myself [...] as a mom I am not perfect.” (Parent_17)</p> <p>“...I mean ideally in schools you are sharing that information with them [with parents] on a terminal basis, because children are going to come home and talk about it, and as parents, it is good to be informed [...] they have got that information of what exactly being told to them, so they [parents] can kind of debunk some of [...] misconstrued elements if the child comes back and says: “Oh, this happened” and they are like:” Did it? No, I don't think so. Let's talk a little bit more about that “and kind of empowering parents, who would maybe feel a little bit awkward talking about some of these situations with their children. This is what we're saying so if you just back it up at home that would be great so we're all saying the same thing”.” (Education Officer_01)</p> <p>“...we need in the parenting groups [...] to be empowering the parents to support proper sex education and to see the value of proper sex education for the developmentally disabled children because the infantilisation is real and will make the children more vulnerable.” (Parent_04)</p> <p>“I think with parents I've had a lot of you know: “But he is a baby, she is a baby they should not be doing that” and I completely understand where they're coming from 100%. I think I have to be very mindful that yes, you know academically and socially, they are functioning you know way below their expected years, I guess, but they are still having these changes that a normal teenager would have. So, for me, I find it difficult to have that balance [...] of like making sure that it's attainable but also allowing them to grow up and it's helping them to understand all those things that come with becoming a teenager. (Teacher_07)</p> <p>“...when they [students with ID] go home parents are just so used to infantilise [...] and I have said you know “child B has done X, Y and Z” and then their [parent's] mouth just hits the floor</p> |
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|--|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  |  | <p>and then they say: “well, I have still wipe his bum” and I said: “well he is 13 years old he is making a recipe by himself following step by step instructions” [...] they [parents] cannot believe it so we could do so much for them at school to support them to be independent learners but as soon as they go home you have got the family cutting their food, feeding them.” (Teacher_08)</p> <p>“I think it is important that parents are really included in this [...] because puberty does hit our parents quite hard because they kind of think it's not going to happen, and because they [students with ID] may experience the rest of the world in a different way. So because of their intellectual disability they are still watching “Bluey” for example, even though they're thirteen that does not mean they're not still experiencing the hormones and the feelings of your typical thirteen year olds, and that that kind of difference can be quite shocking for parents, as they get older as well in the late teens and early twenties, it can come quite a shock to parents that they actually want to have a sexual relationship with people, because I think they think “Oh, that's not going to. It's just not going to happen”. Lots of things they've been told weren't going to happen for their child, but they don't kind of see that this is going to be part of their normal development.” (Education officer_01)</p> <ul style="list-style-type: none"> <li>• <b>Physical environment adaptations</b></li> </ul> <p>“I would teach them that your bedroom with the door shut is a private location, and the bathroom is a private location. That is a much harder thing to teach, not just because of the intellectual disability, but because of the environment that these children exist in. The bathroom that we had for use at school was completely open plan. There were toilets that were witnessed to all the other toilets. So how on earth, am I supposed to teach that you should do these things in private, when your day-to-day practice in school is completely on display?” (SEND consultant_02)</p> <p>“...I have had situations before where schools or colleges were reporting that learners were either having sex or masturbating in inappropriate places. And then actually when we probed into what's going on it's because the bedrooms weren't private because people just breeze in and out of the bedroom so if they wanted some time alone but the reason they were locking themselves in a toilet was because actually there nobody could breeze in so whilst that still an inappropriate place to do that it did kind of makes sense as to why they'd pick that place and if</p> |
|--|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|  |  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|--|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  |  | <p>our message in the classroom is your bedroom is a private place is the person supporting you in your home setting understanding that?" (RSE consultant_02)</p> <p>"...kind of privacy in terms of closing the bedroom door and having to knock on it and wait to go in. I will often do sessions with parents and people come up at the at the end and say: "Do you know what? I didn't think about closing doors and knocking and waiting to go in my son's room or my daughters' room" [...] because quite often, especially with intellectual disability, parents do just walk in because they have had to do that all this child life and they have not instilled any sense of privacy for the child." (Parent_06)</p> |
|--|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Note: ID=intellectual disability.

## Appendices - Chapter 6

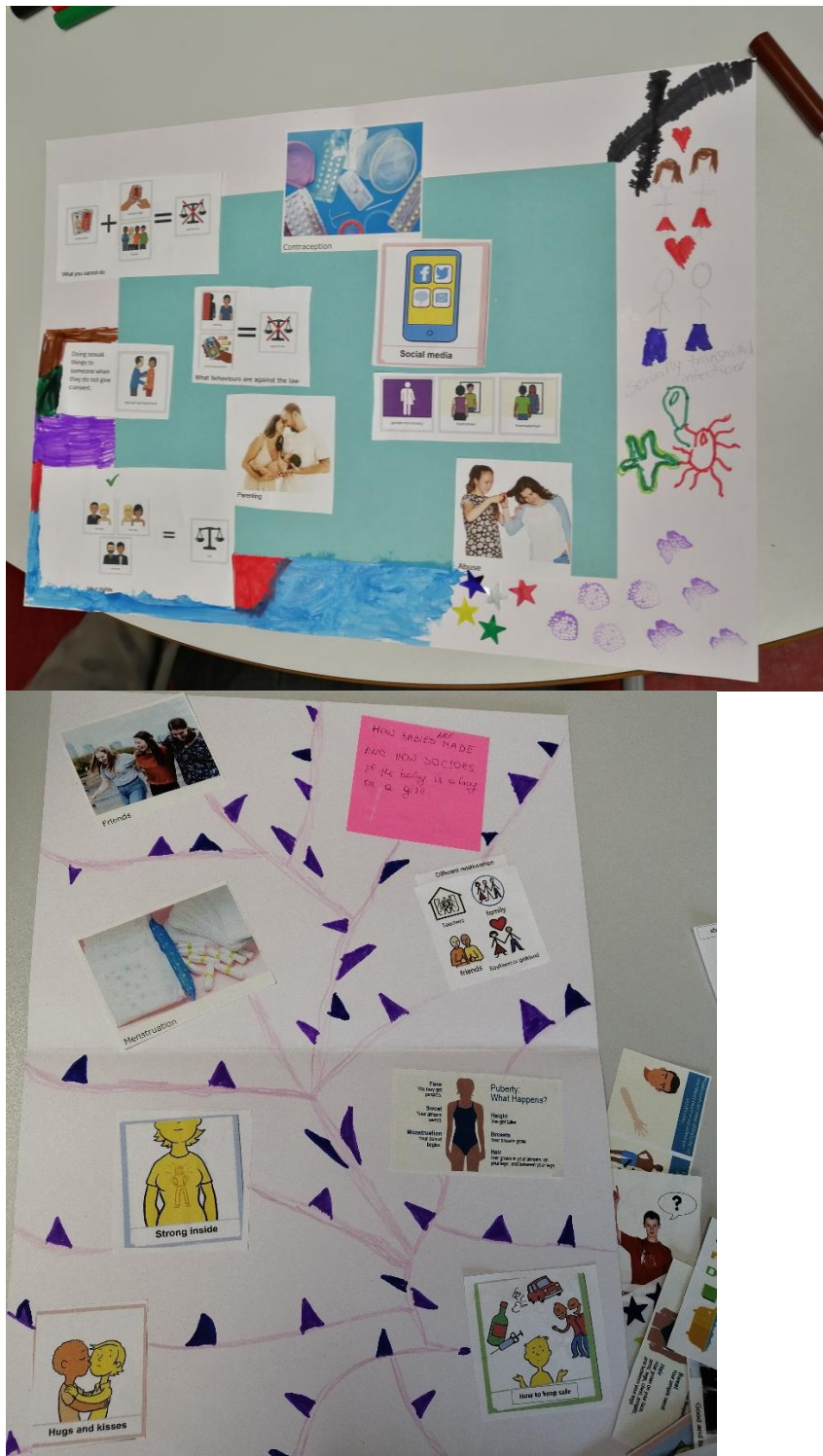
### Appendix 6.1 Pictures of activities completed by students

Figure 1 Picture sorting activities using Talking Mats completed by students



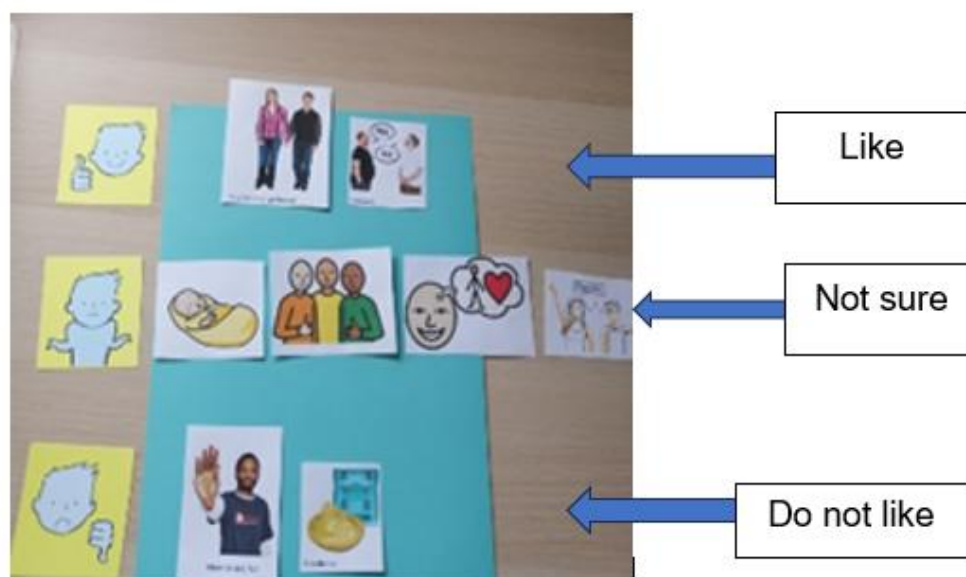
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Figure 2 Posters completed by students



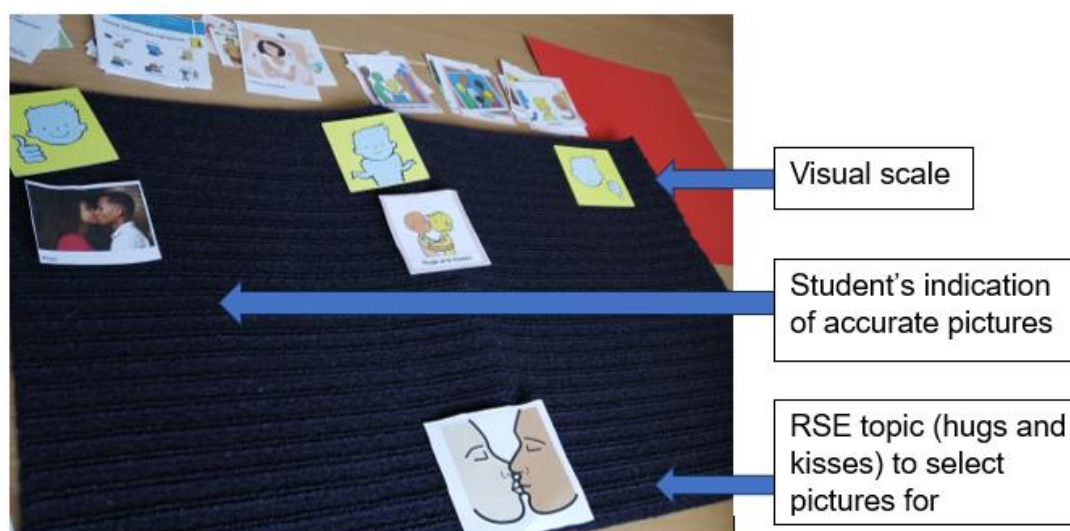
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Figure 3 An example of a finished diamond ranking activity



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Figure 4 A finished mat of pictures selected to represent a RSE topic



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## **Appendix 6.2 Interview scripts**

### **A picture selection activity using Talking Mats:**

1. Explain what will happen to a student using an easy read sheet.
2. Ask if a student wants to do the activity.
3. Ask if I can record and take a picture of the finished mat.
4. Introduce the topic of the mat. For example: "We are going to do this mat to find out what you like to do at school" with the visual scale "things you like" "not sure about" "things you do not like".
5. Reassure that it is okay to say: "do not like".
6. Teacher reassures a student too.
7. Run a practise round with 3 neutral symbols/options were e.g. reading, writing and maths.
8. Introduce the RSE topic: "Now we are going to do this mat to find out what you think about Relationships and Sex Education lessons" with the visual scale e.g. "topics that you like learning about" "topics you are not sure learning about" "topics you do not like learning" or "topics that are interesting", "topics that you are not sure", "topics that are not interesting" or "like", "not sure", "do not like".
9. Lead in phrase to introduce each RSE outcome: "This one is learning about relationships. How you feel about this topic? What do you think about this topic?"
10. Check if student understands the topic: "Do you know what it means? Can you tell me what it is?"
11. Follow-up questions on outcome placement on the mat. "What do you like about this topic? What you want to learn about this topic? Why do you not like this topic?"
12. Give time for a student to think and only ask one question at the time. Do not ask multiple questions.
13. Is there anything missing that you want to learn? Any topics to add?
14. Check the sorted pictures with a student: "Let me check I understood this, you told me you do not like learning about... Do you want to move the pictures?"
15. Find out the most interesting topic: "Which topic is the most interesting? Which topic you like the most?"
16. Can I share the picture with teachers and parents if they ask?
17. Debrief the student: "How was it? How did you find the activity? Do you have any questions? What are you going to do next?"
18. Tell the student that the interview finished and thank for their help.
19. Check with a teacher what has been sorted by the student.



### **Art-based discussion to make a poster:**

1. Explain what will happen to a student using an easy read sheet.
2. Show an example of a poster.
3. Ask if a student wants to do the activity.
4. Ask if I can record and take a picture of the finished poster.
5. Introduce the poster making activity: Let's make a poster of topics you like to learn at school.
6. Ask student to select a base for their poster: "Let's select a big or small paper sheet. Do you want to make your poster on this paper sheet or this? This will be the base for your poster."
7. Introduce RSE outcomes: "Now let's look at the topics that you can learn at school. Tell me which topics you like learning or topics that are interesting. We will put these topics on your poster."
8. Reassure that it is okay to say: "do not like" some of RSE topics.
9. Teacher reassures a student too.
10. Show each RSE outcome one-by-one: "This one is learning about... What do you think about this topic? Do you want to put it on your poster?"
11. Check if a student understands the outcome: "Do you know what this means? Can you tell me what it is?"
12. Check missing RSE outcomes not presented to a student: "Are there any topics missing that you want to learn?". Write down additional topics on the sticky notes and incorporate in the activity.
13. Tell the student to put the pictures on the poster and offer help: "Now put the topics you like learning on the poster with a glue". While student does this find out why these topics were selected: "What you like about this topic? Why you like this topic? What do you want to learn about this topic?"
14. Tell the student that he/she can add drawings and use material brought e.g. water colours, stamps, stickers to decorate their poster.
15. Find out the most interesting topic: "Which topic is the most interesting? Which topic you like the most?"
16. Can I share the picture with teachers and parents if they ask?
17. Debrief the student: "How was it? How did you find the activity? Do you have any questions? What are you going to do next?"
18. Tell the student that the interview finished and thank for their help.
19. Check with a teacher what has been sorted by the student.

Some of the following questions were asked while a student decorated a poster:

1. What do you think about your RSE lessons?
2. What lessons you like learning about? and why?

3. What lessons you do not like and why?
4. Which lesson is the most interesting and why?
5. Which lesson is not interesting and why?
6. What is missing from your RSE lessons?
7. What students in your class need to learn in RSE lessons? And why?
8. Is there anything that you would like to learn in RSE that we have not discussed today?
9. Do you have any questions about this topic?

## Appendix 6.3 Example of an easy read information sheet

### Student Laura comes to school



Hi.

My name is Laura.

I am a student at University College London.



I want to find out what you think about

Relationships and Sex Education lessons



I will ask you to use pictures

to show me what you like and do not like

about Relationships and Sex Education.



I will record what you tell me  
so I can listen to what you like and do  
not like  
about Relationships and Sex  
Education.



I will take a picture of the pictures you  
said you like and do not like



If you do not want to talk to me  
You can say NO  
Or you can touch red card  
And I will stop asking questions.

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## Appendix 6.4 Example of language used to explain RSE outcomes to students

| RSE outcome themes                      | RSE outcomes presented                       | Language used to explain RSE outcomes                                                                                                                                        |
|-----------------------------------------|----------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Human body and development              | Human life cycle                             | This topic is learning that people grow and change. People grow from a small baby to a child to a teenager and an adult.                                                     |
|                                         | Human body parts                             | This topic is learning about private body parts for boys and girls. Private body parts for girls are breasts, vagina, and bottom.                                            |
|                                         | Puberty for boys                             | This topic is learning about puberty and body changes that happen to boys. Boys might become tall, have spots on their face and grow hair in armpits and private body areas. |
|                                         | Puberty for girls                            | This topic is learning about puberty and body changes that happen to girls. Girls might become tall, have spots on their face, have a period, and grow breasts.              |
|                                         | Hygiene                                      | This topic is learning about hygiene. For example, how to wash your body, hair, and brush your teeth.                                                                        |
| Emotions and feelings                   | Recognising emotions and feelings            | This topic is learning about different feelings and emotions. For example, what feeling sad means, what feeling angry means.                                                 |
|                                         | Emotion regulation                           | This topic is learning about how to manage your emotions. What to do when you are worried, or angry.                                                                         |
| Healthy relationships and social skills | Recognising different types of relationships | This topic is learning about different relationships. For example, learning about relationships with teachers, friends, boyfriend, and girlfriend.                           |
|                                         | Different family set ups                     | This topic is learning about different families. For example, learning that some families have mum and dad. Some families have mum and grandmom, and some have mum and mum.  |
|                                         | How to make friends                          | This topic is learning about how to make friends. Learning what to say to them and how to find them.                                                                         |

|                   |                                                                                       |                                                                                                                                                                                                                                   |
|-------------------|---------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                   | Boyfriends and girlfriends                                                            | This topic is learning what boyfriend and girlfriend is.                                                                                                                                                                          |
|                   | Dating                                                                                | This topic is learning what dating is.                                                                                                                                                                                            |
|                   | Love                                                                                  | This topic is learning what love is.                                                                                                                                                                                              |
|                   | Marriage                                                                              | This topic is learning what marriage is.                                                                                                                                                                                          |
|                   | Hugs and kisses                                                                       | This topic is learning about hugs and kisses. For example, learning why people kiss and hug.                                                                                                                                      |
|                   | Values and attitudes for positive relationships (e.g. what language is inappropriate) | This topic is learning about good and bad language. For example, how to talk to boys and girls, what is good and bad to say to them.                                                                                              |
| Sex and sexuality | Sex                                                                                   | This topic is learning what sex is.                                                                                                                                                                                               |
|                   | Contraception                                                                         | This topic is learning about contraception.                                                                                                                                                                                       |
|                   | Sexual health                                                                         | This topic is learning what sexually transmitted diseases are.                                                                                                                                                                    |
|                   | Pregnancy                                                                             | This topic is learning what pregnancy is.                                                                                                                                                                                         |
|                   | Parenting                                                                             | This topic is learning what parenting is.                                                                                                                                                                                         |
|                   | Sexual orientation                                                                    | This topic is learning about different sexualities. For example, what heterosexuality, homosexuality, and bisexuality are. Another example, when a boy loves a boy, or when a girl loves a boy and a girl.                        |
|                   | Gender identity                                                                       | This topic is learning about different genders. Learning about if I am a boy or a girl or none of them or in between. For example, this boy looks in the mirror and sees himself as a girl (describing what the picture depicts). |
| How to keep safe  | Pornography                                                                           | This topic is learning what pornography is.                                                                                                                                                                                       |
|                   | Online safety                                                                         | This topic is learning about internet safety. For example, how to stay safe while using computer or your phone online.                                                                                                            |
|                   | Online bullying                                                                       | This topic is learning about online bullying.                                                                                                                                                                                     |
|                   | Sexting and sending naked images                                                      | This topic is learning about “sexting” and sharing naked images.                                                                                                                                                                  |
|                   | How to keep safe                                                                      | This topic is learning how to keep safe. For example, learning what to do when a stranger asks to take a ride in their car (describing what the picture depicts).                                                                 |
|                   | Good and bad relationships                                                            | This topic is learning about good and bad relationships. For example, this girl pushes another girl and that is a bad relationship (describing what the picture depicts).                                                         |
|                   | Bullying                                                                              | This topic is learning about bullying. For example, this girl is pushing another girl (describing what the picture depicts)                                                                                                       |
|                   | Abuse                                                                                 | This topic is learning about abuse.                                                                                                                                                                                               |

|              |                                                               |                                                                                                                                                                            |
|--------------|---------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|              | Harassment                                                    | This topic is learning about sexual harassment.                                                                                                                            |
|              | Legal consequences of behaving inappropriately                | This topic is learning about what behaviours that are illegal (e.g. stalking, forwarding naked pictures to your friends).                                                  |
|              | How to ask for help                                           | This topic is learning how to ask for help. For example, learning about how to ask for help.                                                                               |
| Consent      | Consent                                                       | This topic is learning about asking for permission. People should ask my permission before they hug me, and I can say “yes” or “no” (describing what the picture depicts). |
|              | How to say “no”                                               | This topic is learning how to say “No”.                                                                                                                                    |
|              | Public and private places                                     | This topic is learning about public and private behaviours.                                                                                                                |
|              | Public and private behaviours                                 | This topic is learning about public and private places.                                                                                                                    |
|              | Personal space                                                | This topic is learning about personal space.                                                                                                                               |
|              | Private body parts that should not be touched by other people | This topic is learning about private body parts that should not be touched by other people.                                                                                |
|              | Good and bad touch                                            | This topic is learning about good and bad touch. For example, a handshake is a good touch. Touching someone’s legs is a bad touch.                                         |
| Human rights | Human rights                                                  | This topic is learning that you have the same rights as other people. For example, to get married or to have children when you are older.                                  |
| Self-esteem  | Confidence                                                    | This topic is learning how to feel confident e.g. strong inside.                                                                                                           |
|              | Positive Body image                                           | This topic is learning how to love your body.                                                                                                                              |

Note: The table represents examples of language used to explain RSE outcomes to students. However, the language was adapted to each student’s understanding.

## Appendix 6.5 Demographic questions

**Study name: The development of a Core Outcome Set for evaluating the impact of Relationships and Sex Education with students with intellectual disability**

Dear Parent,

Thank you for providing a consent for your child to take part in the study.

Could you please answer couple of questions about your child? This information will help me to adapt the interview to your child's individual needs.

Thank you very much!

Best wishes,

Laura Paulauskaite

Email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

Q1. How old is your child?

---

Q2. What is your child's gender?

- ☐ Male
- ☐ Female
- ☐ Another gender

Q15 3. What is your child's ethnic background?

*Please select an option that best describes your child's ethnic group or background.*

- ☐ Bangladeshi
- ☐ Pakistani



- ☐ Chinese
- ☐ Any other Asian background. Please describe:  
\_\_\_\_\_
- ☐ African
- ☐ Caribbean
- ☐ Any other Black, African or Caribbean background. Please describe:  
\_\_\_\_\_
- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Another white background. Please describe:  
\_\_\_\_\_
- ☐ White and Black African
- ☐ White and Black Caribbean
- ☐ White and Asian
- ☐ Another Mixed/ multiple ethnic background. Please describe:  
\_\_\_\_\_
- ☐ Please describe:  
\_\_\_\_\_

Q4. What is your child's religion?

- ☐ No religion
- ☐ Christianity
- ☐ Islam
- ☐ Hinduism
- ☐ Judaism

- ☐ Sikhism
  - ☐ Buddhism
  - ☐ Any other religion (please specify):
- 

**Q5. What Relationships and Sex Education topics you do not want me to discuss with your child? For example, because of cultural or religious reasons.**

---

Q6. Which activity your child would like to complete? These activities will help to understand what your child thinks about this education.

- ☐ Picture sorting activity: this activity involves asking a student to sort pictures under two categories e.g. "Like" and "Do not like" to indicate which RSE topics they like.
- ☐ Art-based discussion: This activity involves different textures of arts-based material (e.g. water colours, crayons, pictures or play dough) and asking a student to make a poster or images of RSE topics they like.
- ☐ Diamond ranking activity: this activity involves sorting pictures in a diamond shape from the most interesting RSE topics to the least interesting topics and if possible, to tell why particular topics are interesting or not interesting.

Q7. How would you describe your child's level of learning disability?

- ☐ Mild
- ☐ Moderate
- ☐ Severe

Q8. Does your child have any of the following conditions in addition to learning disability? Please tick **all** that apply:

- ☐ Autism
- ☐ Attention Deficit Hyperactivity Disorder (ADHD)

- ☐ Speech delay
- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ **Other (please specify):**
- 

Q7. How much does your child understand spoken language? Please select **one**:

- ☐ Able to understand very little spoken language
- ☐ Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down)
- ☐ Able to understand most basic instructions and questions
- ☐ Able to understand most routine everyday language
- ☐ Able to understand complex language about a wide range of topics

Q8. How much does your child use spoken language to communicate? Please select **one**:

- ☐ Able to use very little meaningful speech
- ☐ Able to communicate basic needs and wants
- ☐ Able to communicate needs, wants and some ideas
- ☐ Able to communicate about a limited number of topics in a meaningful way
- ☐ Able to communicate about a wide variety of topics in a meaningful way

Q9. How much does your child use alternative methods of communication (e.g. signing, Makaton, symbol systems, PECS) to

communicate? Please select one:

- ☐ Does not use alternative means of communication
- ☐ Able to communicate very little by using alternative means of communication
- ☐ Able to communicate needs, wants and some ideas by using alternative means of communication
- ☐ Able to communicate about a limited range of topics in a meaningful way by using alternative means of communication
- ☐ Able to communicate about a wide variety of topics in a meaningful way by using alternative means of communication

Q12. Please add any other comments:

---

Thank you for completing the survey!

If you have any questions, please get in touch:

[laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

Best wishes,  
Laura Paulauskaite

## Appendix 6.6 Students' communication aid used to explain interviews

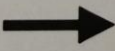


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1.  Look at  symbol

2.  Choose  like or  don't like

3.  Place on  like or  don't like

4.   Next symbol

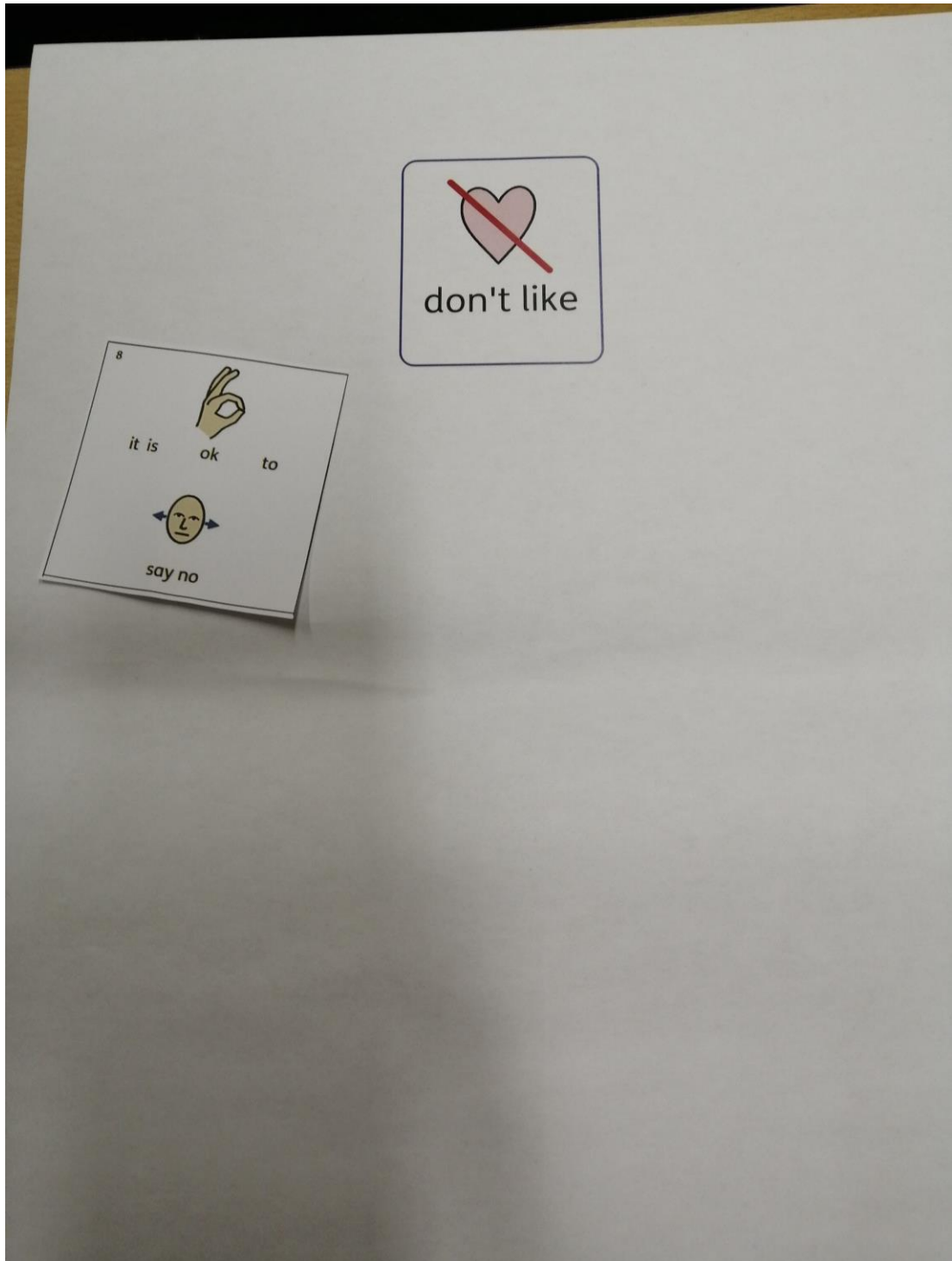
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## Appendix 6.7 Paper sheets used for a picture selection activity



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## Appendix 6.8 Extract of table to create summaries of students' views

| Theme     | Human body and development |                        |                    |                            |                   |                | feelings and emotions |                                 |                               |
|-----------|----------------------------|------------------------|--------------------|----------------------------|-------------------|----------------|-----------------------|---------------------------------|-------------------------------|
| Outcomes  | human life cycle           | body parts             | puberty for boys   | puberty for girls          | menstruation      | hygiene        | feelings and emotions | what to do when you are worried | what to do when you are angry |
| Student01 | 3                          | 1                      | 3                  | 1 (weird)                  |                   | 3              | 3                     | 3                               | 3                             |
| Student02 |                            |                        |                    |                            |                   |                |                       |                                 |                               |
| Student03 |                            | 2                      | 2 (already knows   | 2 (weird)                  |                   | 2 (weird)      | 3                     | 2 (already kn                   | 3                             |
| Student04 | 2                          | 1 (it's embarrassing)  | 1 (Embarrassing)   | 1                          |                   | 3              | 2                     |                                 | 3                             |
| Student05 | 3                          | 1                      | 1                  |                            |                   | 1 (doesn't lik | 3                     |                                 |                               |
| Student06 | 3                          | 3                      | 3                  |                            |                   | 3              | 3                     |                                 | 3                             |
| Student07 | 3                          | 3                      | 3                  |                            |                   | 3              | 3                     |                                 |                               |
| Student08 | 3                          | 3                      |                    | 1 (did not know v          | 3                 | 3              | 3                     | 3                               | 2                             |
| Student09 | 3                          | 3 (because I can't see | 1 (Because I can't | 2                          | 3                 | 3              | 2                     | 2                               | 2                             |
| Student10 | 3                          | 3                      | 3                  | 3                          | 2                 | 3              | 3                     | 3                               | 3(wants to le                 |
| Student11 | 3                          | 2 (do not like talk ab | 2 (strange to talk | 2 (don't want to t         | 1 (do not like th | 3              | 3                     | 3                               | 3                             |
| Student12 |                            | 3                      |                    | 3                          |                   |                |                       |                                 |                               |
| Student13 | 3                          | 1                      | 3                  | 1                          |                   | 3              |                       |                                 |                               |
| Student14 | 2 (too much resp           | 1 (we should know th   | 3                  | 2 (uncomfortable to learn) |                   | 3              | 3                     | 3                               | 3                             |
| Student15 | 3                          | 3                      | 1                  | 1                          |                   | 3              |                       |                                 |                               |
| Student16 | 3                          | 3                      | 3 (not sure becau  | 3 (does not abou           | 1(does not wan    | 2              |                       |                                 |                               |
| Student17 |                            |                        |                    | 3                          | 3                 |                |                       |                                 |                               |
| Student18 | 3                          | 3                      | 2 (don't like body | 2 (don't like body         | 3                 | 3              | 2(boring we t         | 2                               | 2                             |
| Student19 | 3                          | 3                      | 1 (boring)         | 3                          | 2(in wheelchail   | 2 (does not li | 2(boring)             | 3                               | 3                             |

## Appendix 6.9 Extract of table to compare students' and adults' views

| Themes and subthemes                                               | Adults                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Students                                                                                                                                                                                         |
|--------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1: Human body and development through the life course</b> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                  |
| <b>1.1 Body parts</b>                                              | <p><b>What this outcome should involve:</b> understanding private and public body parts for males and females and being able to communicate verbally or using communication aid about their private body parts using scientifically correct names.</p> <p><b>Why this outcome is important:</b> due to safeguarding reasons as well as this is a core outcome that underpins understanding of other outcomes <u>e.g.</u> its knowledge is needed to understand hygiene, inappropriate touch and pleasure.</p> | <p><b>Additional outcomes:</b> Not suggested.</p> <p><b>Why this outcome is important:</b> for communicating effectively when having medical issues.</p>                                         |
| <b>1.2 Puberty</b>                                                 | <p><b>What this outcome should involve:</b> understanding the puberty changes for each sex and that they are normal/natural.</p> <p><b>Why this outcome is important:</b><br/>Can be scary if changes happen and students cannot verbalise or understand them.</p>                                                                                                                                                                                                                                            | <p><b>Additional outcomes:</b> why girls have different body changes during puberty to boys</p> <p><b>Why this outcome is important:</b> to be able to manage puberty changes by themselves.</p> |
| <b>1.3 Hygiene</b>                                                 | <p><b>What this outcome should involve:</b> understanding that taking showers is important to be clean and healthy and also that it is okay to manage your hygiene discretely than other people (<u>e.g.</u> needing help when using shower)</p> <p><b>Why this outcome is important:</b> <u>so</u> students are able to look after their own body and to be clean and healthy.</p>                                                                                                                           | <p><b>Additional outcomes:</b> understanding how different hygiene products work.</p> <p><b>Why this outcome is important:</b> the same as reported by adults.</p>                               |
| <b>1.5 The human life cycle</b>                                    | <p><b>What this outcome should involve:</b> understanding that people grow and change and the growth cycle <u>e.g.</u> a baby, child, teenager, adult and an elderly.</p> <p><b>Why this outcome is important:</b> it is important to understand that people grow and change so that students <u>are able to</u> understand other RSE outcomes.</p>                                                                                                                                                           | <p><b>Additional outcomes:</b> Not suggested.</p> <p><b>Why this outcome is important:</b> to learn how their life will change in the future.</p>                                                |
| <b>Theme 2: Emotions and feelings</b>                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                  |
| <b>2.1 Recognising emotions and feelings</b>                       | <p><b>What students should achieve:</b> understanding their own and other people's feelings and emotions; understanding that they can share feelings with other people</p> <p><b>Why this outcome is important:</b> It is important for developing relationships; for providing consent, to be able to regulate own feelings, understand what students want and do not want and for being empathetic understanding what other people want to do and do not want to do</p>                                     | <p><b>Additional outcomes:</b> being able to express emotions</p> <p><b>Why this outcome is important:</b> students struggle with this.</p>                                                      |

Note: Areas highlighted in a green colour represents differences between students' and adults' views.

## Appendices - Chapter 7

### Appendix 7.1 Survey round 1

#### Landing page

Welcome to the study: **The development of a Core Outcome Set for evaluating the impact of Relationships and Sex Education with students with intellectual disability.**

You are being invited to take part in this survey to share your views on what should be assessed when schools teach Relationships and Sex Education (RSE) to students with learning disability (also known as intellectual disability).

Before you decide to take part, please take time to read this information sheet: [Information Sheet for the Survey](#)

Please note, there are two rounds to this survey. If you decide to complete this round, round 1, you will receive the second round a couple of weeks later. **It is very important that you complete both rounds of the survey.** The survey will help to determine what are the most important outcomes to assess after RSE teaching. The questions in the survey were developed following interviews with students with learning disability, parents, teachers, researchers, and policymakers.

If you have any questions, please contact me: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

To take part you will need to give consent for participation. In the next page (click “next” button), you can provide your consent. You will then enter the survey. If you do not complete it in one go, you can stop the survey and finish it later. The survey takes about 30 minutes to complete. You have 1 week to complete the survey once you start it.

Thank you for your time and valuable contribution!  
Best wishes,  
Laura Paulauskaite  
PhD researcher  
email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

## Consent

### **This is your consent form**

Please complete this form after you have read the [Information Sheet for the Survey](#)

**Title of Study:** The development of a Core Outcome Set for evaluating the impact of Relationships and Sex Education with students with intellectual disability.

**Department:** The Social Research Institute, Institute of Education.

**Name and Contact Details of the Researcher(s):** Laura Paulauskaite [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk), supervisory team: Prof Carol Rivas [c.rivas@ucl.ac.uk](mailto:c.rivas@ucl.ac.uk) and Dr Vaso Totsika [v.totsika@ucl.ac.uk](mailto:v.totsika@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Prof Carol Rivas [c.rivas@ucl.ac.uk](mailto:c.rivas@ucl.ac.uk)

**Name and Contact Details of the UCL Data Protection Officer:** Alexandra Potts [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

**This study has been approved by the UCL IOE Research Ethics Committee: REC 1565.**

If you wish to take part, please click the “YES” boxes next to each statement. Please note, statement 6 can be left empty and you can still take part in the survey.

I confirm that I understand that by clicking in each “yes” section I am consenting to this element of the study.

|                                                                                                                                                                                                                                                                                                                                                                                        |            |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| 1. I confirm that I have read and understood the information sheet and any questions that I had were adequately answered.                                                                                                                                                                                                                                                              | <b>YES</b> |
| 2. I agree to take part in the study and complete <b>two rounds</b> of the survey.                                                                                                                                                                                                                                                                                                     |            |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that I will be able to withdraw my data up to 2 weeks after I finish the survey.                                                                                                                                                                |            |
| 4. I understand that my email address will be only used to send the survey links and to link my responses between the two survey rounds and deleted at the end of the study. I understand that according to data protection legislation, ‘public task’ will be the lawful basis for processing, and ‘research purposes’ will be the lawful basis for processing special category data. |            |

|                                                                                                                                                               |  |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| 5. I understand that all data collected in this study will be anonymous and securely stored under the terms of the General Data Protection Regulation (GDPR). |  |
| 6. I would like to be contacted at a later stage by the research team to see if I would like to take part in another study related to this project.           |  |

### **Contact details**

**Please provide your name and your email address.** We need this information so we could invite you to the second round of the survey.

☐ \* **First name**

---

☐ \* **Last name**

---

☐ \* **Your email**

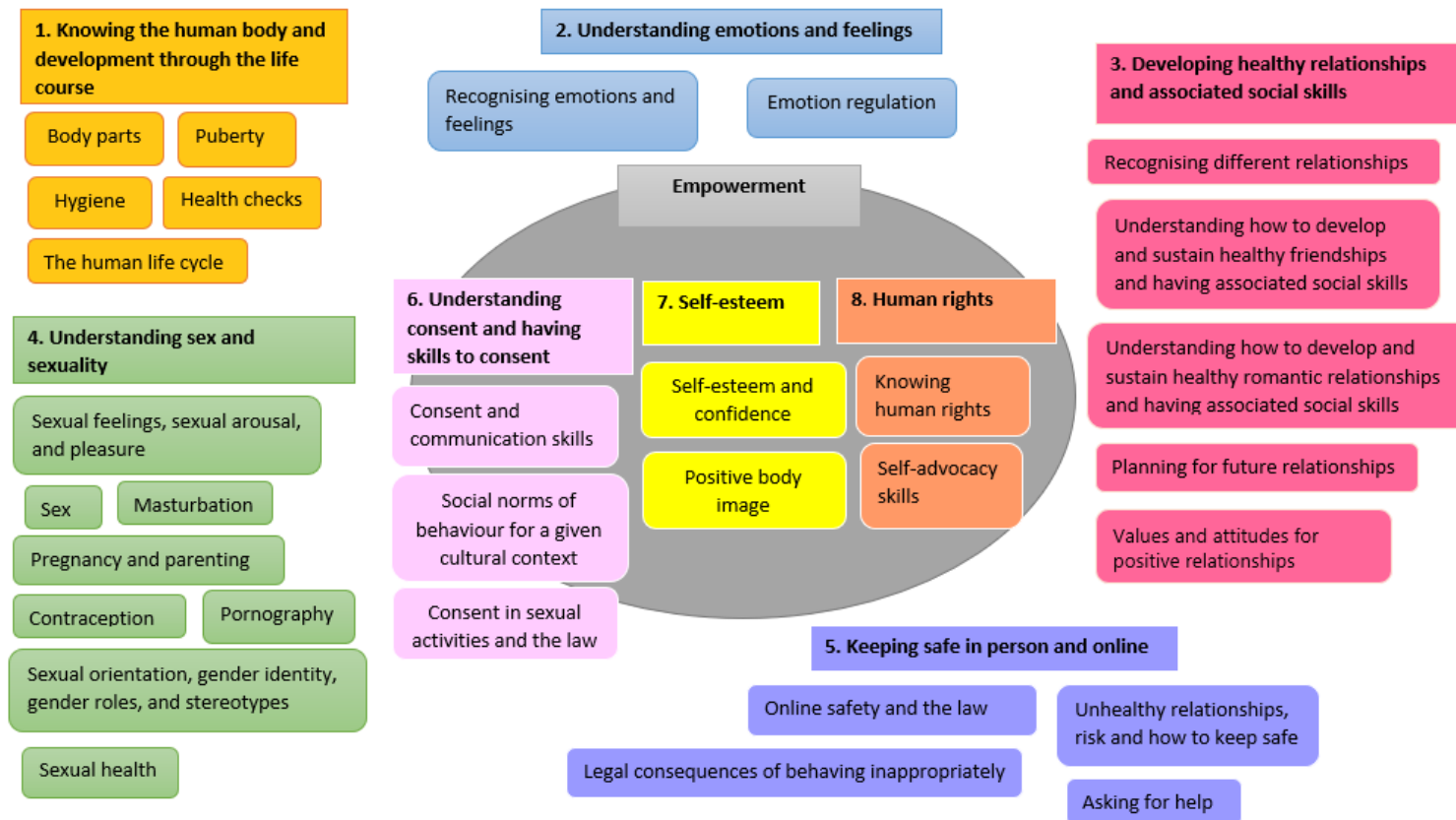
---

Please **re-enter** your email address (this is to make sure it is correct):

---

## The survey

In a previous study, we asked students with learning disability, parents, teachers, researchers, and policy makers what RSE outcomes they think are important. Below, you see all RSE outcomes that students, parents, teachers, researchers, and policy makers suggested as important. The description of outcomes involves their words.



We will now ask you to rate **how** important each of these suggested outcomes is when we assess RSE for students with learning disability. The suggested RSE outcomes will be presented to you in no particular order. You are asked to provide a rating on how important it is for students to achieve these outcomes **by the end of primary education** and a separate rating **by the end of secondary education**. RSE teaching content differs by educational stage. Different outcomes may be important for students to achieve at different educational stages as they develop. The aim of the survey is to identify the most important learning outcomes for students **working** at these two educational stages.

***Please note:***

- You are being asked to rate **how** important, in your view, is that students “have knowledge” related to each of these outcomes. This means that students have understanding related to the concepts. An example, if students are taught about the human body, then at the end of RSE they understand different body parts, what hygiene is, what puberty is and etc (see figure above).
- Each student with learning disability is unique. Every student has their own strengths in relation to communication, understanding and behaviour. You may think that an outcome cannot be measured for a student who, for example, has severe learning disability. We are **not** asking you to decide how this knowledge should or will be measured – this is not part of our study. For this project, we want to know is: **In your view, how important it is that students know x or y after RSE?**
- At the end of this project (after the next survey), we want to identify the outcomes that students, parents, teachers, researchers, and policy makers think are the most important to know after RSE.
- You can choose an “unable to score” option in the rating scale (please move the grey bar to the right) if you feel you cannot rate a specific outcome.
- You can provide comments or suggest any missing outcomes that were not presented in the survey in the “please add any comments” section towards the end of the survey.
- At the end of the survey, we will ask you to answer some questions about yourself.

Thank you for your time and valuable contribution!

## Survey questions

### Body parts

Teaching about body parts **may** include, but is not limited to, teaching what are public and private body parts for each sex, how to communicate (using speech or a communication aid) about body parts using scientifically correct names (e.g. a penis, breasts).

Please rate how important it is that students with learning disability have knowledge related to **body parts** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Puberty

Teaching about puberty may include, but is not limited to, teaching the emotional, hormonal and physical changes for each sex (e.g. periods, wet dreams, pubic hair growth), why males and females have different changes, what changes mean in terms of growing up (e.g. being able to reproduce), how to ask for help when dealing with puberty changes (e.g. when having tummy pain during menstruation) and understanding that puberty changes are normal/natural.



Please rate how important it is that students with learning disability have knowledge related to **puberty** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Hygiene

Teaching about hygiene may include, but is not limited to, teaching how to maintain personal hygiene (e.g. how to wash hands, private body parts, menstruation care), why it is important, how different hygiene products work and that it is okay/normal to manage hygiene in ways that are different to other people (e.g. needing help when using a toilet).

Please rate how important it is that students with learning disability have knowledge related to **hygiene** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Health checks

Teaching about health checks may include, but is not limited to, teaching what health checks are (e.g. cervical screenings, examining testicles), why they are done, what normal private body parts should look and feel like (e.g. testicles, breasts, vaginal discharges), what changes will need to be checked by a doctor (e.g. discharge from a nipple) and what to do if these changes happen (e.g. ask for help).

Please rate how important it is that students with learning disability have knowledge related to **health checks** after RSE teaching? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## The human life cycle

Teaching about the human life cycle may include, but it not limited to, teaching that people grow and change over time, and the cycle of life (e.g. birth, baby, child, teenager, adult, elderly, death).

Please rate how important it is that students with learning disability have knowledge related to **the human life cycle** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Recognising emotions and feelings

Teaching about different emotions and feelings may include, but is not limited to, teaching what different feelings/emotions are and what they mean (e.g. happy, scared), how to communicate (using speech or a communication aid) about different feelings/emotions, how to empathise with other people e.g. identify other people's emotions/feelings and put themselves in their situation.

Please rate how important it is that students with learning disability have knowledge related to **recognising different emotions/feelings** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Emotion regulation

Teaching about emotion regulation may include, but is not limited to, teaching how to manage different emotions/feelings (e.g. feeling rejected, jealous, anxious about starting a new school or when in grief), teaching that it is okay to feel different feelings/emotions but that there are risks if not managing emotions/feelings effectively (e.g. mental health problems or hurting other people).

Please rate how important it is that students with learning disability have knowledge related to **emotion regulation** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Self-esteem and confidence

Teaching about self-esteem and confidence may include, but is not limited to, teaching how to love and accept yourself, be confident in your abilities (e.g. to say no, ask for help), how to identify positive things about yourself, what is like being a man or a woman with disability, that having a disability does not make someone a “bad” person, and that students are worthy and deserve respect from others.

Please rate how important it is that students with learning disability have knowledge related to **self-esteem and confidence** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Positive body image

Teaching about positive body image may include, but is not limited to, teaching what positive body image is, that there is no “normal” body type, and that social media may negatively impact people’s body image and confidence.

Please rate how important it is that students with learning disability have knowledge related to **positive body image** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Recognising different relationships

Teaching students to recognise different types of relationships may include, but is not limited to, teaching different types of personal

relationships (e.g. friendships, romantic relationships), different family types (e.g. same sex families, single parent families), what is involved in different relationships (e.g. what is different in a relationship between friends and romantic partners).

Please rate how important it is that students with learning disability have knowledge related to **recognising different relationships** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## How to develop and sustain healthy friendships and social skills

Teaching how to develop and sustain healthy friendships may include, but is not limited to, teaching the qualities of good friends, how to be a good friend, boundaries in friendships (e.g. what is appropriate and not appropriate behaviour), and social skills needed to have healthy friendships (e.g. communication skills, negotiation skills, conflict resolution).

Please rate how important it is that students with learning disability have knowledge related to **healthy friendships** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## How to develop and sustain healthy romantic relationships and social skills

Teaching how to develop and sustain healthy romantic relationships may include, but is not limited to, teaching, what healthy romantic and sexual relationships are, boundaries in such relationships, attraction, love, commitment, types of marriages (e.g. same sex), and social skills needed to have such relationships (e.g. communication skills, dating skills, how to kiss and hug a partner, negotiation skills).

Please rate how important it is that students with learning disability have knowledge related to **healthy romantic relationships** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Planning for future relationships

Teaching about planning for future relationships may include, but is not limited to, teaching students how to identify what they want in their future relationships, what their adult life might look like, the realistic options in life and alternatives. For example, discussing if they want to have children in the future, is this something for them and what the options would be: having children or working with children.

Please rate how important it is that students with learning disability have knowledge related to **planning for the future relationships** after RSE? Please select one option below for each educational stage.

[illegible]

## Values and attitudes for positive relationships

Teaching about values and attitudes for having positive relationships may include, but is not limited to, teaching the importance of trust, respect, honesty and kindness for relationship development, how to be respectful to people who identify differently regarding sexuality and gender identity, that having any type of healthy relationship is important, enjoyable and has benefits and that misogynistic attitudes and language (e.g. that women are not equal to men) negatively impact relationships.

Please rate how important it is that students with learning disability have knowledge related to **values and attitudes for positive relationships** after RSE? Please select one option below for each educational stage.

[illegible]



## Sexual feelings, sexual arousal, and pleasure

Teaching about sexual feelings, sexual arousal and pleasure may include, but is not limited to, teaching what sexual feelings, sexual arousal, sexual pleasure and orgasm are, that they are natural/normal physiological reactions, what is appropriate and inappropriate to feel when sexually aroused for both sexes and in different sexualities (e.g. erection, heat in genitals, producing fluids) and understanding which organs bring sexual pleasure (e.g. clitoris).

Please rate how important it is that students with learning disability have knowledge related to **sexual feelings, arousal, and pleasure** after RSE? Please select one option below for each educational stage.

[illegible]

Sex

Teaching about sex may include, but is not limited to, what sex is, why people engage in sex (e.g. pleasure), what happens during sex, which body parts are involved in sex, what activities counts as sex (e.g. anal and oral sex), with whom students can and cannot have sex (e.g. not with teachers) and what is appropriate and inappropriate sexual activity.

Please rate how important it is that students with learning disability have knowledge related to **sex** after RSE? Please select one option below for each educational stage.

[illegible]

## Masturbation

Teaching about masturbation may include, but is not limited to, teaching what masturbation is for both sexes, where is appropriate and inappropriate to masturbate, how to masturbate safely (e.g. what are the movements) and that it is natural/normal to masturbate.

Please rate how important it is that students with learning disability have knowledge related to **masturbation** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Pregnancy and parenting

Teaching about pregnancy and parenting may include, but is not limited to, teaching what pregnancy and parenting is, how babies are made (e.g. that sex can sometimes lead to pregnancy), what are the signs of a female being pregnant (e.g. period stops), that all females including those with learning disability can get pregnant, what support and help is available when pregnant or raising a child, the responsibility that comes with having a child and when a child is taken away from their parents.

Please rate how important it is that students with learning disability have knowledge related to **pregnancy and parenting** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Contraception

Teaching about contraception may include, but is not limited to, teaching what contraception for both sexes is (e.g. internal condoms, pills), why people use them, where and how to get contraception (e.g. pharmacy), how to use contraception and that people may choose what contraception they use (e.g. long-term contraception or condoms).

Please rate how important it is that students with learning disability have knowledge related to **contraception** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Pornography

Teaching about pornography may include, but is not limited to, teaching what pornography is, why people watch it, that pornography is not an accurate representation of what respectful sexual relationships are, that watching pornography at a young age can impact sexual arousal later in life (e.g. cannot get aroused in the future), that it is a sexual abuse to show pornography to someone below the age of 18 years and to talk with a trusted adult if it happens.

Please rate how important is that students with learning disability have knowledge related to **pornography** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Sexual orientation, gender identity, gender roles and stereotypes

Teaching about sexual orientation, gender identity, gender roles and stereotypes may include, but is not limited to, teaching about different sexual orientations (e.g. bisexual, homosexual), gender identities (e.g. non-binary and transgender), that students' own sexuality and gender identity is normal, what it is like to be a man and a woman (e.g. what masculinity and femininity mean), the

negative impact of gender stereotypes (e.g. that boys are stronger than girls) and how sexuality is viewed in different religions or cultural contexts.

Please rate how important it is that students with learning disability have knowledge related to **sexual orientation, gender identity, gender roles and stereotypes** after RSE? Please select one option below for each educational stage.

[illegible]

## Sexual health

Teaching about sexual health may include, but it not limited to, teaching how to maintain sexual health, what sexually transmitted diseases are, what sexual health clinics are, how they can help (e.g. pregnancy, contraception), and skills on how to request an appointment at a sexual health clinic.

Please rate how important it is that students with learning disability have knowledge related to **sexual health** after RSE? Please select one option below for each educational stage.

[illegible]

## Human rights

Teaching about human rights may include, but is not limited to, teaching that all people, including people with learning disability, have the human rights (e.g. right to privacy, body autonomy, sexual relationships, being in love with the same sex person, having children and getting married).

Please rate how important it is that students with learning disability have knowledge related to **human rights** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

## Self-advocacy skills

Teaching self-advocacy skills may include, but is not limited to, teaching students how to challenge people or raise concerns when students' rights are being ignored (e.g. rights to privacy, body autonomy, sexual relationships, having children and getting married), how history, society and cultural attitudes impact these rights for people with learning disability (e.g. some people might have negative attitudes towards people with learning disability having relationships and enjoying their sexuality).

Please rate how important it is that students with learning disability have knowledge related to **self-advocacy skills** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Consent and communication skills

Teaching about consent may include, but is not limited to, teaching what consent is in different situations (e.g. consensual and non-consensual touch), why consent is important (e.g. what will happen if students touch someone without their consent), that it is okay to say “no”, that people will show their “no” in different ways (e.g. vocal and non-vocal consent) and students need to respect it, and teaching communication skills related to providing consent and seeking consent (e.g. what to say, understanding people’s responses).

Please rate how important it is that students with learning disability have knowledge related to **consent** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Social norms of behaviour for a given cultural context

Teaching about social norms of behaviour may include, but is not limited to, teaching what acceptable and unacceptable behaviours are and how they vary by cultural context (e.g. it is okay to hug your parents but not strangers), what is appropriate and inappropriate touching (e.g. why private body parts should not be touched and why some people want to touch them), personal space, private and public social behaviours (e.g. inappropriate to be naked in class) and who can see students naked and in what situations.

Please rate how important it is that students with learning disability have knowledge related to **social norms of behaviour** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Consent in sexual activities and the law

Teaching about consent in sexual activities and the law may include, but is not limited to, teaching what consent in sexual activities is, why it is important (e.g. sexual abuse), the legal framework for providing consent in sexual activities (e.g. the legal age of



consent, that people consent because they are sexually aroused and want to engage in sex without any conditions attached) and how consent in sexual activities may be linked to sexual abuse (e.g. understanding on-going consent).

Please rate how important it is that students with learning disability have knowledge related to **consent in sexual activities and the law** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely<br>Unimportant | 2- Very<br>Unimportant | 3-<br>Unimportant     | 4- Maybe<br>unimportant | 5- Unsure<br>whether it is<br>important/<br>unimportant | 6- Maybe<br>important | 7- Important          | 8- Very<br>Important  | 9- Extremely<br>important | Unable to<br>score    |
|-------------------------------------------|-----------------------------|------------------------|-----------------------|-------------------------|---------------------------------------------------------|-----------------------|-----------------------|-----------------------|---------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>       | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>       | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>   | <input type="radio"/>                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> |

### Online safety and the law

Teaching about online safety and the law may include, but is not limited to, teaching the rules and boundaries of using the Internet and social media (e.g. scams, cyber bullying, sexting, sharing naked images, risks of online dating), how the rules and boundaries of using the Internet are related to the law (e.g. sharing naked images of a person under the age of 18 is illegal) and how to ask for help when feeling pressured online.

Please rate how important it is that students with learning disability have knowledge related to **online safety and the law** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Unhealthy relationships, risk and how to keep safe

Teaching about unhealthy relationships, risk, and how to keep safe may include, but is not limited to, teaching about unhealthy relationships, bullying, harassment, power imbalances, grooming, different types of abuse (e.g. sexual, emotional and physical abuse), coercion, what to do in these situations, that people with learning disability are vulnerable to being abused and taken advantage of, and skills how to keep safe (e.g. not keeping secrets, not accepting car rides from strangers).

Please rate how important it is that students with learning disability have knowledge related to **unhealthy relationships, risk and how to keep safe** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Legal consequences of behaving inappropriately

Teaching about legal consequences of behaving inappropriately may include, but is not limited to, teaching what illegal behaviours are (e.g. stalking, harassment, touching people's private parts, sex offending, shouting personal insults), what happens when people break the law, how it negatively impacts people's future, that the world outside school is different and students might get in trouble if they behave inappropriately.

Please rate how important it is that students with learning disability have knowledge related to the **law consequences of behaving inappropriately** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

### Asking for help

Teaching about asking for help may include, but is not limited to, teaching skills on how to ask for help in any situation (e.g. when there is a risk for safeguarding, when pregnant or having issues in relationships), who can help (e.g. teachers, parents, doctors, police), that asking for help is a good thing and if something bad is happening to students they will not be in trouble if they ask for help.

Please rate how important it is that students with learning disability have knowledge related to **asking for help** after RSE? Please select one option below for each educational stage.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/ unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important | Unable to score       |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|------------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|-----------------------|
| By the end of <u>primary</u> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |
| By the end of <u>secondary</u> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> |

**Please add any comments about the survey here or suggest any missing outcomes that were not presented in the survey:**

### **Some questions about you**

**2. How do you identify yourself?** If you belong to 2 or more groups (e.g. you are a parent and a teacher), please select one perspective that you used most frequently to answer the survey:

- ☐ I am a parent/carer of a child with learning disability
- ☐ I am a teacher or school staff member involved in RSE delivery
- ☐ I am a researcher
- ☐ I am a policymaker/ working in a third sector organisation/other

If clicked "I am a policymaker/working in a third sector organisation/other":

**3.1** What is your professional role (e.g. RSE consultant, SEND consultant, policy maker, educational psychologist, working in third sector organisation)?

**Please provide more information about your professional role:**

If clicked "I am a teacher or school staff member involved in RSE delivery":

**1.5** What is your professional role in school?

- ☐ Class teacher
- ☐ Teaching assistant
- ☐ PSHE/ RSE teacher
- ☐ Speech and language therapist
- ☐ Psychologist
- ☐ Headteacher
- ☐ Other, please specify:

**1.6** How many years have you been working with students with learning disability?

**Please specify:**

**1.7** Do you currently deliver Relationships and Sex Education to students with learning disability?

- ☐ Yes
- ☐ No

**1.8** How many years have you been involved in the delivery of Relationships and Sex Education to students with learning disability?

**Please specify:**

### **All together:**

**4. What is your gender?**

- ☐ Female
- ☐ Male
- ☐ Another gender

- ☐ Prefer not to say

**5. What is your age?**

- ☐ Under 25 years
- ☐ 25 to 35 years
- ☐ 36 to 45 years
- ☐ 46 to 55 years
- ☐ 56 to 65 years
- ☐ 66+ years

**4. What is your ethnic background?**

Please select an option that best describes your ethnic group or background.

- **White:**

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background (please specify):

- **Mixed/ Multiple ethnic groups:**

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/ Multiple ethnic background (please specify):

- **Asian or Asian British**

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background (please specify)

- **Black/African/Caribbean/Black British**

- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/ Caribbean background (please specify):

- **Other ethnic group (please specify):**

- ☐ Arab
- ☐ Please specify:

**8. What is your religion?**

- ☐ No religion

- ☐ Christianity
- ☐ Islam
- ☐ Hinduism
- ☐ Judaism
- ☐ Sikhism
- ☐ Buddhism
- ☐ Any other religion (please specify):

**9. Where do you live? If you live outside the UK, please specify.**

- ☐ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland
- ☐ Outside the UK (please specify):

**10. Do you have a child with learning disability aged 5-25 years?**

- ☐ Yes
- ☐ No

**If yes, please answer some questions about your child. If you have more than one child with learning disability, select one child that is aged 5-25 years that you would like to answer the questions about.**

**7.2 How old is your child with learning disability?**

Please specify:

**7.2 What is your child's gender?**

- ☐ Female
- ☐ Male
- ☐ Another gender
- ☐ Prefer not to say

**7.3 How would you describe your child's level of learning disability?**

- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Profound

**7.6 Does your child have any of the following conditions in addition to learning disability? Please tick all that apply:**

- ☐ Autism
- ☐ Attention Deficit Hyperactivity Disorder (ADHD)

- ☐ Speech delay
- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ Other (please specify):

**7.7 What your child's expressive vocal communication abilities are?**

- ☐ No speech
- ☐ Makes some sounds
- ☐ Speaks a few words
- ☐ Speaks in sentences

**End of survey message**

Thank you for your time completing the first round of the survey! We really appreciate your contribution.

You will receive a link to the second round of the survey shortly.

Best wishes,

Laura Paulauskaite

Email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)



## Appendix 7.2 Survey round 2

Please note, only an extract of outcome rating questions is presented in here due to the large number of questions.



Please log in.

Please type in your email



Welcome to the second round of the survey!

The aim of this study is to identify what outcomes should be measured after Relationships and Sex Education (RSE) for students with learning disability.

In this round, you will be able to see the average importance rating that different groups of people (e.g. parents, teachers, researchers, policymakers, and students) assigned to each outcome. You will see this alongside your own rating from round 1 of the survey so you can see how you rated the outcomes compared to others.

**Now that you can see the group rating, please re-rate the outcomes. You can select your original rating (from round 1 presented below) or change to another rating.**

Please note:

- At the end of this survey, we want to identify the outcomes that students, parents, teachers, researchers, and policymakers think are the most important to know after RSE.
- The examples presented on what each outcome may include are suggested by students, their parents, teachers, researchers, and policymakers. However, it does not mean that all information in the examples will be applicable to each student with learning disability at a specific point in time. RSE teaching will need to be adapted to each student, their abilities, developmental level, and cultural background. When rating an outcome, please consider **how important it is that students have knowledge related to that outcome** rather than the specific examples presented.
- You can choose an "unable to score" option in the rating scale (please move the grey bar to the right) if you feel you cannot rate a specific outcome.
- If you do not complete this survey in one go, you can stop the survey and finish it later. The survey takes about 30 minutes to complete. You have 1 week to complete the survey once you start it.
- Any questions or problems, please get in touch: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

Thank you for your time and valuable contribution!

### The survey questions:

#### Body parts

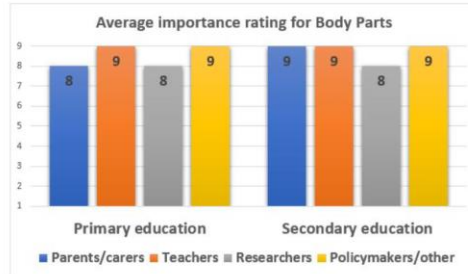
Teaching about body parts **may** include, but is not limited to, teaching what are public and private body parts for each sex, how to communicate (verbally or using a communication aid) about body parts using scientifically correct names (e.g. a penis, breasts).

#### Summary of scores:

You rated this outcome as:  $\$(e://Field/Q1\_1E)$  for the primary educational stage and  $\$(e://Field/Q1\_2E)$  for the secondary educational stage.

Students liked this outcome or/and wanted to learn more about it. Some students' quotes: "[I want to learn] the body parts [...]" which is public versus private" (Student06, male, 24 years); "Yeah [I want to learn more] I actually do not understand everything about body parts" (Student14, male, 14 years).

Other groups of people rated this outcome as:



Please rate how important it is that students with learning disability have knowledge related to **body parts** after RSE? Please select one option below for each educational stage. You can select your original rating (from round 1 presented above) or change to another rating.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|
| By the end of <b>primary</b> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| By the end of <b>secondary</b> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |

#### Sexual feelings, sexual arousal and pleasure

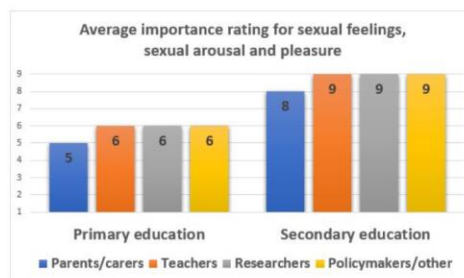
Teaching about sexual feelings, sexual arousal and pleasure **may** include, but is not limited to, teaching what sexual feelings, sexual arousal, sexual pleasure and orgasm are, that they are natural/normal bodily reactions, what is appropriate and inappropriate to feel when sexually aroused for both sexes and in different sexualities (e.g. erection, heat in genitals, producing fluids), understanding which organs bring sexual pleasure (e.g. clitoris) and understanding that sex toys can be used for pleasure.

#### Summary of scores:

You rated this outcome as:  $\$(e://Field/Q15\_1E)$  for the primary educational stage and  $\$(e://Field/Q15\_2E)$  for the secondary educational stage.

We do not have students' views on this outcome.

Other groups of people rated this outcome as:



Please rate how important it is that students with learning disability have knowledge related to **sexual feelings, arousal, and pleasure** after RSE? Please select one option below for each educational stage. You can select your original rating (from round 1 presented above) or change to another rating.

|                                           | 1- Extremely Unimportant | 2- Very Unimportant   | 3- Unimportant        | 4- Maybe unimportant  | 5- Unsure whether it is important/unimportant | 6- Maybe important    | 7- Important          | 8- Very Important     | 9- Extremely important |
|-------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------------------------------|-----------------------|-----------------------|-----------------------|------------------------|
| By the end of <b>primary</b> education?   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| By the end of <b>secondary</b> education? | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |

**Please leave any comments on the outcomes, your ratings and the survey here:**

Thank you for completing the second round of the survey! I greatly appreciate your time and valuable contribution!

Please see the list of national resources on RSE and charities that support people with learning disability: [Resources](#)

I will be analysing the results soon. If you have any questions or would like to provide feedback on your participation, please get in touch:

[laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

Best wishes,

Laura Paulauskaite

Email: [laura.paulauskaite.16@ucl.ac.uk](mailto:laura.paulauskaite.16@ucl.ac.uk)

## **Appendix 7.3 Instructions on how Delphi survey was programmed**

### **Round 1:**

1. A survey was created with all the questions that was round 1 of the Delphi survey.
2. The survey was distributed via an anonymous survey link to maximise recruitment. An anonymous survey link was added to the study's poster and participants could take part in the survey by following the link on the poster or distributed by me via emails (for participants that took part in previous stages of the project and provided consents for being approached about other studies of this project). Stakeholders did not need to send their emails first to me so I could then send the survey link. Instead, all participants took part via one anonymous survey link. Participants also could share the same survey link that they completed with their colleagues who may be interested to take part. Because the survey was distributed via an anonymous link, I needed to collect people's emails in round 1 to send round 2 of the survey.
3. I created a contact details question in the survey that asked participants to provide their name, surname, and their email address (see Figure 1 below). This question was added as a "form field" question type in the survey. I followed this Qualtrics guide to set up this question: <https://www.qualtrics.com/support/survey-platform/survey-module/editing-questions/question-types-guide/standard-content/form-field-question/>

This contact details question was added after a consent form in the survey. In the consent form, participants were asked to consent for providing their contact details with explanation as to why this information was collected (to send round 2 of the survey). This survey question was used to link two surveys discussed below.

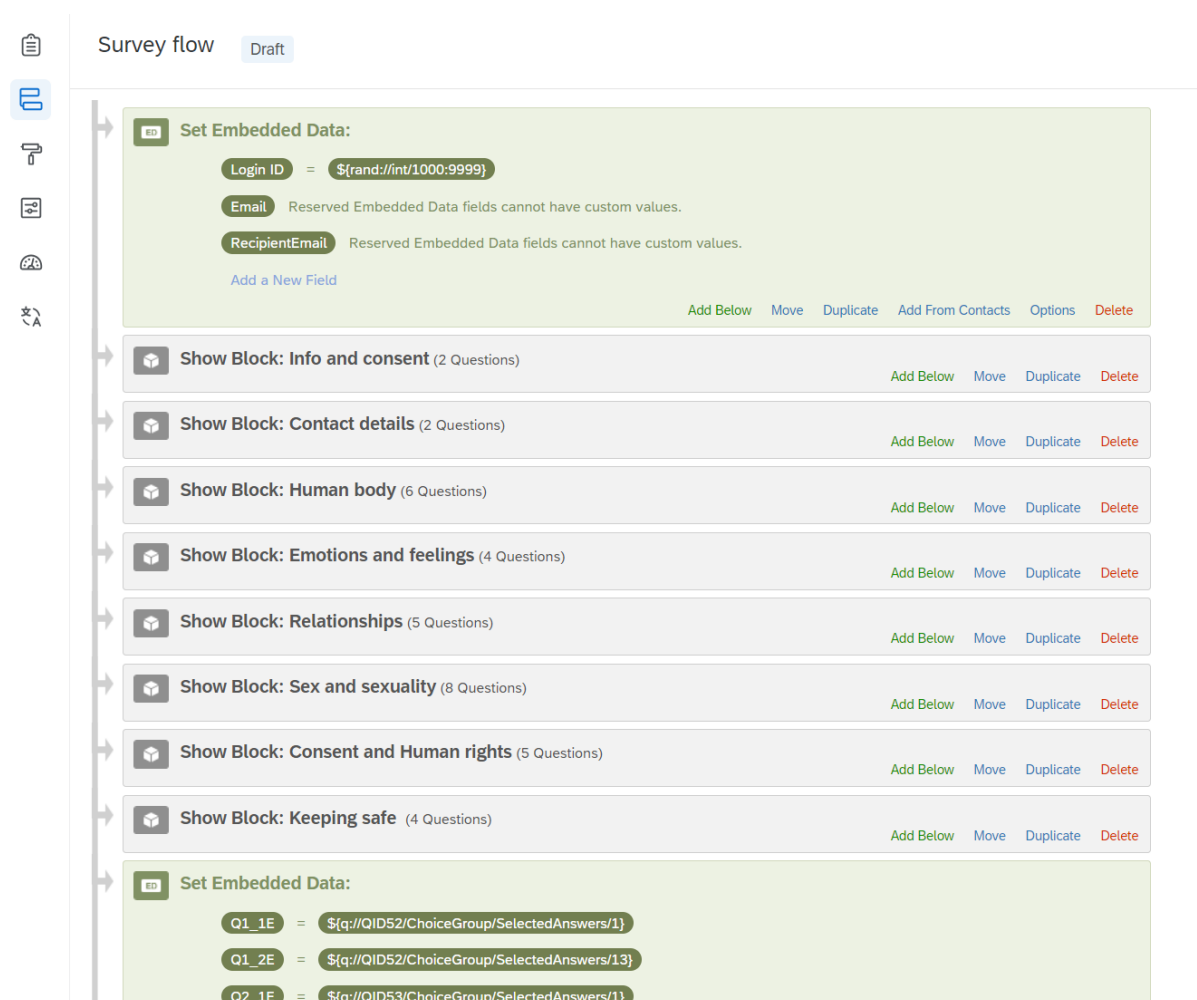
Figure 1: Contact details question in round 1

The screenshot displays the Qualtrics survey editor interface. On the left, the 'Question type' dropdown is set to 'Form field', which is circled in red. Below this, the 'Form fields' section shows 'Number of fields' set to 3. The 'Response requirements' section has 'Force response' selected. The 'Question behavior' section includes options for 'Display logic', 'Skip logic', 'Carry forward form fields', and 'Form field randomization'. The main preview area shows a 'Contact details' question (Q94) with the text: 'Please provide your name and your email address. We need this information so we could invite you to the second round of the survey.' Below this text are three input fields labeled 'First name', 'Last name', and 'Your email'. A second question (Q95) is partially visible below, with the text: 'Please re-enter your email address (this is to make sure it is correct):' and a single input field.

4. Participants' email addresses were used to pull participants' responses from round 1 to round 2 so they can see their scores from round 1 in round 2. To do this, "embedded data" in the survey flow was created. I followed the Qualtrics guide on longitudinal surveys to create the embedded data: <https://www.qualtrics.com/support/survey-platform/common-use-cases-rc/pulling-data-into-a-second-survey-longitudinal-surveys/>
5. In the survey flow (please see Figure 2 below), embedded data was created for "Login ID", "email" and "recipient email". The last two embedded data fields (email and recipient email) enabled participants to access round 2 of the survey by entering their emails. However, I still needed to set up "Login ID" embedded data together with two other embedded data for this to work. In round 2, I asked participants to type their email addresses instead of random login numbers that "Login ID" embedded data provides. I have chosen to ask participants to enter their emails in round 2 rather than random numbers to reduce participant burden and possible typing errors. I thought that participants will be more likely to remember their emails and type in them without mistakes rather than a random number. Besides, if random ID numbers were used to link two surveys, I would have needed to distribute the unique random numbers via emails to 103

participants. This might have also induced typing errors. Thus, participants' emails were used to link two surveys (round 1 and round 2).

Figure 2: Round 1 survey flow



6. Embedded data for each outcome rating for the primary and secondary education was created in the survey flow (represented at the bottom of Figure 2 as Q1\_1E, Q1\_2E etc.). The embedded data of each outcome rating was placed after all the outcome rating questions. This embedded data was pulled from round 1 to round 2 so that participants could see their responses from round 1 in round 2.
7. In the survey workflow (Figure 3 below), I created a new event to record when a participant provides their consent and contact details (i.e. when completes round 1). This information was saved in a new

contact list in Qualtrics. I followed steps 11-35 in the Qualtrics guide for this part: <https://www.qualtrics.com/support/survey-platform/common-use-cases-rc/pulling-data-into-a-second-survey-longitudinal-surveys/>. In this workflow, I specified that participants' first and last names and email addresses will be saved in this new contact list from the contact details question (point 3 above). I have also specified that external reference ID (used to link two surveys) will be embedded data of participants' emails. The Qualtrics guide specifies to use "Login ID" for the external reference but as discussed above I used participants' emails instead.

Figure 3: Round 1 survey workflow

Add to XM Directory

---

Select a contact list and set XM Directory fields

Contact List

Test for pulling data De... ▾

|                                                                |                                                                |                                                                |
|----------------------------------------------------------------|----------------------------------------------------------------|----------------------------------------------------------------|
| First name                                                     | Last name                                                      | Email address                                                  |
| <input type="text" value="\$q://QID95/ChoiceTextEntry"/> {a} ▾ | <input type="text" value="\$q://QID95/ChoiceTextEntry"/> {a} ▾ | <input type="text" value="\$q://QID95/ChoiceTextEntry"/> {a} ▾ |
| Phone number (optional)                                        | Language (optional)                                            | External reference ID (optional)                               |
| <input type="text" value="Select phone number"/> {a} ▾         | <input type="text" value="Select language"/> {a} ▾             | <input type="text" value="\$e://Field/Email"/> {a} ▾           |

[Add or remove embedded data fields](#)

Contact update options

Select how you want to save or update info. [Learn more](#)

☒ Save or update it as embedded data to your XM directory contacts

☒ Update recipient from survey response

☐ Unsubscribe the contact

☐ Add it as a new transaction to your XM directory contacts

## Round 2:

1. After round 1 of the survey was created, I then created a second survey that was round 2.
2. In Round 2 survey flow, I first added embedded data for "Login ID", "Email" and "Recipient Email" as shown in Figure 4 below.

- I then added an authenticator specifying that the contact list created in round 1 (point 7) will be used to pull participants' emails. This was an important step that allowed participants to access round 2 and see their responses from round 1. In the authentication fields, I selected embedded data "Email" and did not tick the "pre-fill" option. In the field next to email, I typed an instruction for participants which appeared in the landing page of round 2 of the survey (see Figure 5 below).

Figure 4: Round 2 survey flow

Survey flow Draft

---

Set Embedded Data:

Login ID

Value will be set from Panel or URL. [Set a Value Now](#)

Email

Reserved Embedded Data fields cannot have custom values.

RecipientEmail

Reserved Embedded Data fields cannot have custom values.

[Add a New Field](#)

[Add Below](#) [Move](#) [Duplicate](#) [Add From Contacts](#) [Options](#) [Delete](#)

Branch on Successful Authentication

Authentication Type:

Contact

Authenticate Using Contact

My Library: Laura Paulauskaite

Test for pulling data Delphi

Authentication Fields

Email

Please type in your email

☐ Password

☐ Pre-fill

[Move](#) [Duplicate](#) [Options](#) [Collapse](#) [Delete](#)

Set Embedded Data:

Q1\_1E

Value will be set from Panel or URL. [Set a Value Now](#)

Q1\_2E

Value will be set from Panel or URL. [Set a Value Now](#)

Q2\_1E

Value will be set from Panel or URL. [Set a Value Now](#)

Q2\_2E

Value will be set from Panel or URL. [Set a Value Now](#)

Q3\_1E

Value will be set from Panel or URL. [Set a Value Now](#)

Q3\_2E

Value will be set from Panel or URL. [Set a Value Now](#)

Figure 5: Landing page of round 2

The logo for the University College London (UCL) Institute of Education (IOE) Faculty of Education and Society. It features the UCL crest and the text "UCL IOE - FACULTY OF EDUCATION AND SOCIETY".

Please log in.

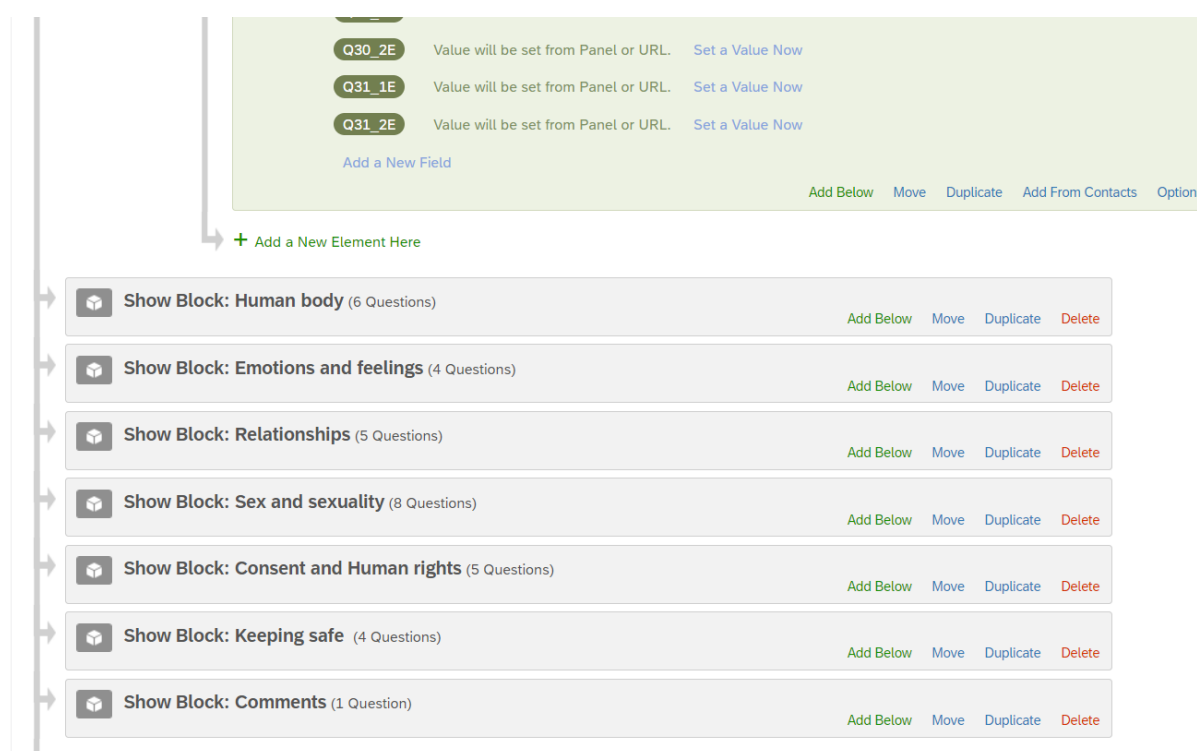
Please type in your email

588



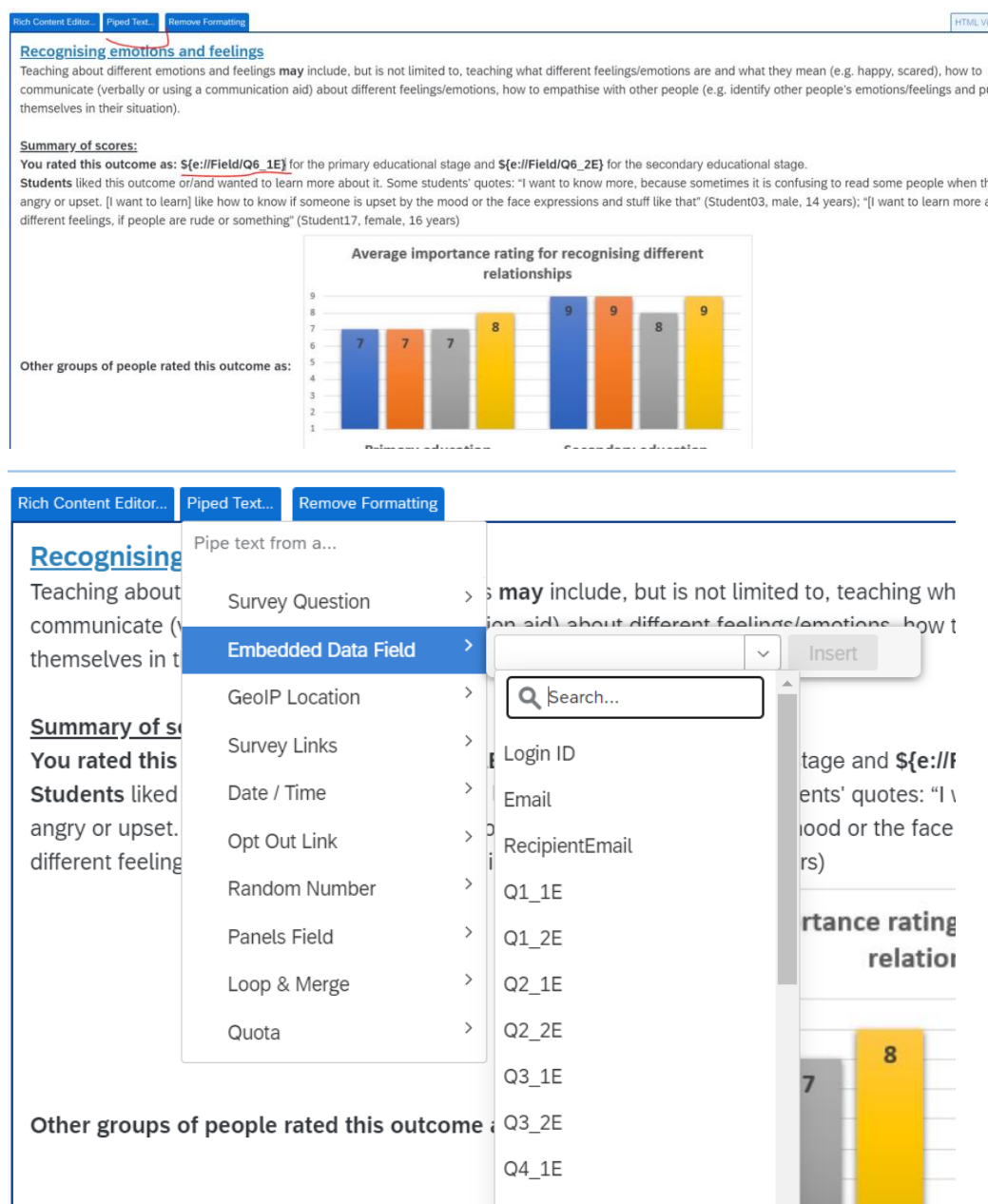
4. After this, I added all embedded data from round 1 in the survey flow (the bottom of Figure 4).
5. Then all questions in round 2 were added in this survey flow as shown in Figure 6 below. It was important to set up the embedded data and authentication part (steps 4-5) in this order in the survey flow for the pulling of the data from round 1 to round 2 to work.

Figure 6: Round 2 survey flow additional information



6. Then, I added embedded data of participants' responses from round 1 in the survey questions. I clicked on the outcome rating question specified where I want to add the embedded data and clicked on "piped text" and selected the embedded data field and then the embedded outcome rating from round 1 (please see Figure 7). I repeated this step for all outcome rating questions for primary and secondary stages (saved as separate embedded data e.g. Q1\_1E and Q1\_2E).

Figure 7: Embedded data of participants' ratings from round 1 added to round 2



- To distribute round 2 of the survey I needed to create a "special" survey link. I followed the steps 1-6 in the Qualtrics guide on longitudinal surveys to create this:

<https://www.qualtrics.com/support/survey-platform/common-use-cases-rc/pulling-data-into-a-second-survey-longitudinal-surveys/>

However, I did not add the following ending to the survey link as specified in the guide: **?Login%20ID=\${e://Field/Login%20ID}** because I did not use “Login ID” to link to surveys. Instead, I added this ending to the survey link of round 2:

**?Email=\${m://Email}&Login=\${e://Field/LoginID}**. This was an important step to complete to make sure all programming performed for linking two surveys had worked.

8. I tested both surveys many times to make sure the pulling of the data from round 1 to round 2 works correctly.

## Appendix 7.4 List of national resources

### Resources

#### **Resources about Relationships and Sex Education:**

Growing up, sex and relationships: a booklet to support parents of young disabled people:

- [https://contact.org.uk/wp-content/uploads/2021/03/growing\\_up\\_parents\\_new\\_logo.pdf](https://contact.org.uk/wp-content/uploads/2021/03/growing_up_parents_new_logo.pdf)

Growing up, sex and relationships: a booklet for young disabled people:

- [https://contact.org.uk/wp-content/uploads/2021/03/growing\\_up\\_young\\_people.pdf](https://contact.org.uk/wp-content/uploads/2021/03/growing_up_young_people.pdf)

Sex and sexual awareness information for disabled young people:

- <https://contact.org.uk/help-for-families/information-advice-services/preparing-for-adult-life/growing-up-sex-and-relationships/sex-and-sexual-awareness/>

Sex education - a guide for parents:

- <https://www.autism.org.uk/advice-and-guidance/topics/family-life-and-relationships/sex-education/parents-and-carers>

Relationship and sex resources:

- <https://www.mencap.org.uk/advice-and-support/relationships-and-sex/relationships-and-sex-resources>

Love Life: resources for young people with learning disabilities:

- <https://learning.nspcc.org.uk/research-resources/schools/love-life>

Sexual Health, Relationships and Parenthood a workbook resource for one-to-one support:

- <https://centralsexualhealth.org/wp-content/uploads/sites/15/2022/12/ASN-Workbook.pdf>

Easy read health resources for people with learning disability:

- <https://www.easyhealth.org.uk/>

**Supported Loving** is network that supports people with learning disability to find relationships. Their website has a list of RSE training organisations, dating agencies for people with learning disability and LGBTQ+ social groups.

- Website: <https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving>
- Twitter: @SupportedLoving

### **Charities that offer support to families of children with learning disability:**

**Contact a Family** is a national charity for families with disabled children. For information and advice on any aspect of caring for a disabled child:

- **Freephone helpline: 0808 808 3555**  
9.30am-5pm, Monday-Friday; free from UK landlines and UK mobiles
- **Facebook:** [facebook.com/contactafamily](https://www.facebook.com/contactafamily)
- **Twitter:** [@contactafamily](https://twitter.com/contactafamily)
- **Email:** [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)
- **Website:** <https://www.cafamily.org.uk/>

**Cerebra Charity** is a UK charity dedicated to helping the parents of children with brain related neurological conditions.

- Helpline (freephone): 0800 328 1159
- Telephone: +44 (0) 1267 244200
- Email: [enquiries@cerebra.org.uk](mailto:enquiries@cerebra.org.uk)

**Family Fund** is a UK based registered charity for disabled children and their families.

- Website: <https://www.familyfund.org.uk/>

**Kids Charity** for families of disabled children

- <https://www.kids.org.uk/>

**The Challenging Behaviour Foundation (CBF)** was founded in 1997 by Vivien Cooper OBE, the parent of a child with severe learning disabilities and behaviour described as challenging:

- Website: <http://www.challengingbehaviour.org.uk/>

**Mencap** offers help support to people with a learning disability, and their families and carers. Advisors can offer advice and information about learning disability and help you find the right support and Mencap services in your area:

- **Freephone Helpline:** 0808 808 1111 (from 8am to 6pm, Monday to Friday)
- Email: [helpline@mencap.org.uk](mailto:helpline@mencap.org.uk)

**Scope About disability** provides support, information and advice to disabled people and their families every year.

- **Freephone helpline:** 0808 800 3333
- Website: <https://www.scope.org.uk/support/families/diagnosis/learning-difficulty>

**The National Autistic Society (NAS) are a UK charity for autistic people and their families:**

- **Helpline:** 0808 800 4104 (open 10am-4pm, Monday-Thursday, 9am-3pm on Fridays)
- Website: [www.autism.org.uk](http://www.autism.org.uk)
- NAS Parent to Parent (P2P) is a UK-wide confidential telephone service providing emotional support to parents and carers of children or adults with autism. Call 0808 800 4106 (Free from landlines and most mobiles).

**Resources for reporting sexual abuse of people with learning disability:**

If a person with learning disability is in immediate danger call police on 999 or in the non-immediate situation call 101 in England.

**The Ann Craft Trust** is a national association dedicated to the protection from abuse of adults and children with learning disabilities.

- Telephone: 0115 951 5400
- Email: [ann-craft-trust@nottingham.ac.uk](mailto:ann-craft-trust@nottingham.ac.uk)
- Website: <https://www.anncrafttrust.org/>

**Respond** is a national charity providing therapy and specialist support services to people with learning disabilities, autism or both who have experienced abuse, violence or trauma.

- Email: [admin@respond.org.uk](mailto:admin@respond.org.uk)
- Telephone: 020 7383 0700
- Website: <https://respond.org.uk/>

## Appendix 7.5 COS of RSE for students with intellectual disability for primary and secondary education

| Outcomes                          | Outcome definition                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Body parts                        | Teaching about body parts may include, but is not limited to, teaching what are public and private body parts for each sex, how to communicate (using speech or a communication aid) about body parts using scientifically correct names (e.g. a penis, breasts).                                                                                                                                                                                                      |
| Puberty                           | Teaching about puberty may include, but is not limited to, teaching the emotional, hormonal and physical changes for each sex (e.g. periods, wet dreams, pubic hair growth), why males and females have different changes, what changes mean in terms of growing up (e.g. being able to reproduce), how to ask for help when dealing with puberty changes (e.g. when having tummy pain during menstruation) and understanding that puberty changes are normal/natural. |
| Hygiene                           | Teaching about hygiene may include, but is not limited to, teaching how to maintain personal hygiene (e.g. how to wash hands, private body parts, menstruation care), why it is important, how different hygiene products work and that it is okay/normal to manage hygiene in ways that are different to other people (e.g. needing help when using a toilet).                                                                                                        |
| Health checks                     | Teaching about health checks may include, but is not limited to, teaching what health checks are (e.g. cervical screenings, examining testicles), why they are done, what normal private body parts should look and feel like (e.g. testicles, breasts, vaginal discharges), what changes will need to be checked by a doctor (e.g. discharge from a nipple) and what to do if these changes happen (e.g. ask for help).                                               |
| Human life cycle                  | Teaching about the human life cycle may include, but it not limited to, teaching that people grow and change over time, and the cycle of life (e.g. birth, baby, child, teenager, adult, elderly, death).                                                                                                                                                                                                                                                              |
| Recognising emotions and feelings | Teaching about different emotions and feelings may include, but is not limited to, teaching what different feelings/emotions are and what they mean (e.g. happy, scared), how to communicate (using speech or a communication aid) about different feelings/emotions, how to empathise with other people e.g. identify other people's emotions/feelings and put themselves in their situation.                                                                         |

| Outcomes                                                                    | Outcome definition                                                                                                                                                                                                                                                                                                                                                                                                          |
|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Emotion regulation                                                          | Teaching about emotion regulation may include, but is not limited to, teaching how to manage different emotions/feelings (e.g. feeling rejected, jealous, anxious about starting a new school or when in grief), teaching that it is okay to feel different feelings/emotions but that there are risks if not managing emotions/feelings effectively (e.g. mental health problems or hurting other people).                 |
| Self-esteem and confidence                                                  | Teaching about self-esteem and confidence may include, but is not limited to, teaching how to love and accept yourself, be confident in your abilities (e.g. to say no, ask for help), how to identify positive things about yourself, what is like being a man or a woman with disability, that having a disability does not make someone a “bad” person, and that students are worthy and deserve respect from others.    |
| Positive body image                                                         | Teaching about positive body image may include, but is not limited to, teaching what positive body image is, that there is no “normal” body type, and that social media may negatively impact people’s body image and confidence.                                                                                                                                                                                           |
| Recognising different relationships                                         | Teaching students to recognise different types of relationships may include, but is not limited to, teaching different types of personal relationships (e.g. friendships, romantic relationships), different family types (e.g. same sex families, single parent families), what is involved in different relationships (e.g. what is different in a relationship between friends and romantic partners).                   |
| How to develop and sustain healthy friendships and social skills            | Teaching how to develop and sustain healthy friendships may include, but is not limited to, teaching the qualities of good friends, how to be a good friend, boundaries in friendships (e.g. what is appropriate and not appropriate behaviour), and social skills needed to have healthy friendships (e.g. communication skills, negotiation skills, conflict resolution).                                                 |
| How to develop and sustain healthy romantic relationships and social skills | Teaching how to develop and sustain healthy romantic relationships may include, but is not limited to, teaching, what healthy romantic and sexual relationships are, boundaries in such relationships, attraction, love, commitment, types of marriages (e.g. same sex), and social skills needed to have such relationships (e.g. communication skills, dating skills, how to kiss and hug a partner, negotiation skills). |
| Planning for future relationships                                           | Teaching about planning for future relationships may include, but is not limited to, teaching students how to identify what they want in their future relationships, what their adult life might look like, the realistic options in life and alternatives. For                                                                                                                                                             |



|                                                 | example, discussing if they want to have children in the future, is this something for them and what the options would be: having children or working with children.                                                                                                                                                                                                                                                                                                                                                          |
|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Outcomes                                        | Outcome definition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Values and attitudes for positive relationships | Teaching about values and attitudes for having positive relationships may include, but is not limited to, teaching the importance of trust, respect, honesty and kindness for relationship development, how to be respectful to people who identify differently regarding sexuality and gender identity, that having any type of healthy relationship is important, enjoyable and has benefits and that misogynistic attitudes and language (e.g. that women are not equal to men) negatively impact relationships.           |
| Sexual feelings, sexual arousal, and pleasure   | Teaching about sexual feelings, sexual arousal and pleasure may include, but is not limited to, teaching what sexual feelings, sexual arousal, sexual pleasure and orgasm are, that they are natural/normal bodily reactions, what is appropriate and inappropriate to feel when sexually aroused for both sexes and in different sexualities (e.g. erection, heat in genitals, producing fluids), understanding which organs bring sexual pleasure (e.g. clitoris) and understanding that sex toys can be used for pleasure. |
| Sex                                             | Teaching about sex may include, but is not limited to, what sex is, why people engage in sex (e.g. pleasure), what happens during sex, which body parts are involved in sex, what activities counts as sex (e.g. anal and oral sex), with whom students can and cannot have sex (e.g. not with teachers) and what is appropriate and inappropriate sexual activity.                                                                                                                                                           |
| Masturbation                                    | Teaching about masturbation may include, but is not limited to, teaching what masturbation is for both sexes, where is appropriate and inappropriate to masturbate, how to masturbate safely (e.g. what are the movements) and that it is natural/normal to masturbate.                                                                                                                                                                                                                                                       |
| Pregnancy and parenting                         | Teaching about pregnancy and parenting may include, but is not limited to, teaching what pregnancy and parenting is, how babies are made (e.g. that sex can sometimes lead to pregnancy), what are the signs of a female being pregnant (e.g. period stops), that all females including those with learning disability can get pregnant, what support and help is                                                                                                                                                             |

|                                                                   | available when pregnant or raising a child, the responsibility that comes with having a child and when a child is taken away from their parents.                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Outcomes                                                          | Outcome definition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Contraception                                                     | Teaching about contraception may include, but is not limited to, teaching what contraception for both sexes is (e.g. internal condoms, pills), why people use them, where and how to get contraception (e.g. pharmacy), how to use contraception and that people may choose what contraception they use (e.g. long-term contraception or condoms).                                                                                                                                                                                                               |
| Pornography                                                       | Teaching about pornography may include, but is not limited to, teaching what pornography is, why people watch it (e.g. some people watch it for sexual arousal and pleasure), that pornography is not a real life (e.g. it is a film that involves actors and a fantasy), that it is a sexual abuse to show pornography to someone below the age of 18 years and to talk with a trusted adult if it happens.                                                                                                                                                     |
| Sexual orientation, gender identity, gender roles and stereotypes | Teaching about sexual orientation, gender identity, gender roles and stereotypes may include, but is not limited to, teaching about different sexual orientations (e.g. bisexual, homosexual), gender identities (e.g. non-binary and transgender), that students' own sexuality and gender identity is normal, what it is like to be a man and a woman (e.g. what masculinity and femininity mean), the negative impact of gender stereotypes (e.g. that boys are stronger than girls) and how sexuality is viewed in different religions or cultural contexts. |
| Sexual health                                                     | Teaching about sexual health may include, but it not limited to, teaching how to maintain sexual health, what sexually transmitted diseases are, what sexual health clinics are, how they can help (e.g. pregnancy, contraception), and skills on how to request an appointment at a sexual health clinic.                                                                                                                                                                                                                                                       |
| Human rights                                                      | Teaching about human rights may include, but is not limited to, teaching that all people, including people with learning disability, have the human rights (e.g. right to privacy, body autonomy, sexual relationships, being in love with the same sex person, having children and getting married).                                                                                                                                                                                                                                                            |
| Self-advocacy skills                                              | Teaching self-advocacy skills may include, but is not limited to, teaching students how to challenge people or raise concerns when students' rights are being ignored (e.g. rights to privacy, body autonomy, sexual relationships, having                                                                                                                                                                                                                                                                                                                       |

|                                                        | children and getting married), how history, society and cultural attitudes impact these rights for people with learning disability (e.g. some people might have negative attitudes towards people with learning disability having relationships and enjoying their sexuality).                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Outcomes                                               | Outcome definition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Consent and communication skills                       | Teaching about consent may include, but is not limited to, teaching what consent is in different situations (e.g. consensual and non-consensual touch), why consent is important (e.g. what will happen if students touch someone without their consent), that it is okay to say “no”, that people will show their “no” in different ways (e.g. vocal and non-vocal consent) and students need to respect it, and teaching communication skills related to providing consent and seeking consent (e.g. what to say, understanding people’s responses). |
| Social norms of behaviour for a given cultural context | Teaching about social norms of behaviour may include, but is not limited to, teaching what acceptable and unacceptable behaviours are and how they vary by cultural context (e.g. it is okay to hug your parents but not strangers), what is appropriate and inappropriate touching (e.g. why private body parts should not be touched and why some people want to touch them), personal space, private and public social behaviours (e.g. inappropriate to be naked in class) and who can see students naked and in what situations.                  |
| Consent in sexual activities and the law               | Teaching about consent in sexual activities and the law may include, but is not limited to, teaching what consent in sexual activities is, why it is important (e.g. sexual abuse), the legal framework for providing consent in sexual activities (e.g. the legal age of consent, that people consent because they are sexually aroused and want to engage in sex without any conditions attached) and how consent in sexual activities may be linked to sexual abuse (e.g. understanding on-going consent).                                          |
| Online safety and the law                              | Teaching about online safety and the law may include, but is not limited to, teaching the rules and boundaries of using the Internet and social media (e.g. scams, cyber bullying, sexting, sharing naked images, risks of online dating), how the rules and boundaries of using the Internet are related to the law (e.g. sharing naked images of a person under the age of 18 is illegal) and how to ask for help when feeling pressured online.                                                                                                     |

|                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|----------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Unhealthy relationships, risk and how to keep safe | Teaching about unhealthy relationships, risk, and how to keep safe may include, but is not limited to, teaching about unhealthy relationships, bullying, harassment, power imbalances, grooming, different types of abuse (e.g. sexual, emotional and physical abuse), coercion, what to do in these situations, that people with learning disability are vulnerable to being abused and taken advantage of, and skills how to keep safe (e.g. not keeping secrets, not accepting car rides from strangers). |
| <b>Outcomes</b>                                    | <b>Outcome definition</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Legal consequences of behaving inappropriately     | Teaching about legal consequences of behaving inappropriately may include, but is not limited to, teaching what illegal behaviours are (e.g. stalking, harassment, touching people's private parts, sex offending, shouting personal insults), what happens when people break the law, how it negatively impacts people's future, that the world outside school is different and students might get in trouble if they behave inappropriately.                                                               |
| Asking for help                                    | Teaching about asking for help may include, but is not limited to, teaching skills on how to ask for help in any situation (e.g. when there is a risk for safeguarding, when pregnant or having issues in relationships), who can help (e.g. teachers, parents, doctors, police), that asking for help is a good thing and if something bad is happening to students they will not be in trouble if they ask for help.                                                                                       |

*Note:* outcomes in a green colour are included in the COS for primary education and secondary education. Information in the outcome definition will need to be adapted to reflect age-appropriate concepts for primary education. Outcomes in an orange colour are additional outcomes included in the COS for secondary education only.

## Appendix 7.6 Outcome ratings between stakeholder groups

Table 1 Outcome ratings in round 2 between stakeholder groups

| Outcomes                                 | Parents |     |              |              | Teachers/school staff |     |              |              | Researchers |     |              |              | Policy makers/people form third sector |     |              |              |
|------------------------------------------|---------|-----|--------------|--------------|-----------------------|-----|--------------|--------------|-------------|-----|--------------|--------------|----------------------------------------|-----|--------------|--------------|
|                                          | M       | IQR | % scored=1-3 | % scored=7-9 | M                     | IQR | % scored=1-3 | % scored=7-9 | M           | IQR | % scored=1-3 | % scored=7-9 | M                                      | IQR | % scored=1-3 | % scored=7-9 |
| <b>Body parts</b>                        |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 8       | 7-9 | 6%           | 87%          | 8                     | 8-9 | 3%           | 97%          | 8           | 8-9 | 0%           | 92%          | 9                                      | 8-9 | 0%           | 100%         |
| Secondary                                | 9       | 9-9 | 6%           | 94%          | 9                     | 9-9 | 0%           | 100%         | 9           | 8-9 | 0%           | 100%         | 9                                      | 9-9 | 6%           | 94%          |
| <b>Puberty</b>                           |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 8       | 7-9 | 3%           | 81%          | 8                     | 7-9 | 0%           | 90%          | 8           | 8-8 | 0%           | 100%         | 9                                      | 8-9 | 0%           | 100%         |
| Secondary                                | 9       | 9-9 | 6%           | 94%          | 9                     | 8-9 | 0%           | 100%         | 9           | 8-9 | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| <b>Hygiene</b>                           |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 8       | 8-9 | 6%           | 87%          | 8                     | 8-9 | 0%           | 100%         | 8           | 7-9 | 0%           | 100%         | 9                                      | 8-9 | 0%           | 100%         |
| Secondary                                | 9       | 9-9 | 6%           | 94%          | 9                     | 9-9 | 0%           | 100%         | 9           | 9-9 | 0%           | 100%         | 9                                      | 9-9 | 6%           | 94%          |
| <b>Health checks</b>                     |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 6       | 6-7 | 10%          | 32%          | 6                     | 6-7 | 3%           | 40%          | 6           | 4-6 | 23%          | 23%          | 6                                      | 6-8 | 6%           | 33%          |
| Secondary                                | 9       | 8-9 | 3%           | 94%          | 9                     | 8-9 | 0%           | 97%          | 8           | 7-9 | 0%           | 85%          | 9                                      | 9-9 | 0%           | 100%         |
| <b>Human life cycle</b>                  |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 7       | 6-8 | 6%           | 65%          | 7                     | 7-7 | 0%           | 87%          | 7           | 7-8 | 0%           | 77%          | 7.5                                    | 7-9 | 0%           | 100%         |
| Secondary                                | 9       | 8-9 | 6%           | 94%          | 9                     | 8-9 | 0%           | 97%          | 8           | 7-8 | 0%           | 92%          | 9                                      | 8-9 | 6%           | 94%          |
| <b>Recognising emotions and feelings</b> |         |     |              |              |                       |     |              |              |             |     |              |              |                                        |     |              |              |
| Primary                                  | 8       | 7-9 | 3%           | 87%          | 8                     | 8-9 | 0%           | 100%         | 8           | 7-8 | 0%           | 100%         | 9                                      | 8-9 | 0%           | 100%         |
| Secondary                                | 9       | 8-9 | 0%           | 97%          | 9                     | 8-9 | 0%           | 100%         | 9           | 8-9 | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |

| Emotion regulation                                                          |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
|-----------------------------------------------------------------------------|---------|---------|---------------------|---------------------|-----------------------|---------|---------------------|---------------------|-------------|---------|---------------------|---------------------|----------------------------------------|-----|---------------------|---------------------|
| Primary                                                                     | 8       | 7-9     | 3%                  | 87%                 | 9                     | 8-9     | 0%                  | 100%                | 8           | 8-9     | 0%                  | 100%                | 9                                      | 8-9 | 0%                  | 100%                |
| Secondary                                                                   | 9       | 9-9     | 3%                  | 97%                 | 9                     | 9-9     | 0%                  | 100%                | 9           | 9-9     | 0%                  | 100%                | 9                                      | 9-9 | 0%                  | 100%                |
|                                                                             | Parents |         |                     |                     | Teachers/school staff |         |                     |                     | Researchers |         |                     |                     | Policy makers/people form third sector |     |                     |                     |
| Outcomes                                                                    | M       | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 | M                     | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 | M           | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 | M                                      | IQR | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 |
| Self-esteem and confidence                                                  |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 9       | 8-9     | 0%                  | 93%                 | 9                     | 8-9     | 0%                  | 97%                 | 8           | 7-9     | 0%                  | 100%                | 9                                      | 8-9 | 0%                  | 100%                |
| Secondary                                                                   | 9       | 9-9     | 0%                  | 97%                 | 9                     | 9-9     | 0%                  | 100%                | 9           | 9-9     | 0%                  | 100%                | 9                                      | 8-9 | 0%                  | 100%                |
| Positive body image                                                         |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 8       | 7-9     | 0%                  | 93%                 | 8                     | 7-9     | 0%                  | 93%                 | 8           | 7-9     | 0%                  | 92%                 | 8                                      | 8-9 | 0%                  | 100%                |
| Secondary                                                                   | 9       | 8-9     | 0%                  | 97%                 | 9                     | 8-9     | 0%                  | 100%                | 9           | 9-9     | 0%                  | 100%                | 9                                      | 9-9 | 0%                  | 100%                |
| Recognising different relationships                                         |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 7       | 7-8     | 0%                  | 87%                 | 7                     | 7-9     | 0%                  | 93%                 | 7           | 7-7     | 0%                  | 92%                 | 8.5                                    | 7-9 | 0%                  | 100%                |
| Secondary                                                                   | 9       | 8-9     | 0%                  | 97%                 | 9                     | 8-9     | 0%                  | 100%                | 9           | 8-9     | 0%                  | 100%                | 9                                      | 9-9 | 0%                  | 100%                |
| How to develop and sustain healthy friendships and social skills            |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 8       | 7-9     | 0%                  | 90%                 | 8                     | 7-9     | 0%                  | 100%                | 8           | 7-9     | 0%                  | 100%                | 9                                      | 8-9 | 0%                  | 100%                |
| Secondary                                                                   | 9       | 8-9     | 0%                  | 97%                 | 9                     | 8-9     | 0%                  | 100%                | 9           | 8-9     | 0%                  | 100%                | 9                                      | 9-9 | 0%                  | 100%                |
| How to develop and sustain healthy romantic relationships and social skills |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 6       | 5-7     | 7%                  | 33%                 | 6                     | 5-7     | 3%                  | 37%                 | 6           | 6-7     | 8%                  | 46%                 | 7                                      | 6-8 | 11%                 | 56%                 |
| Secondary                                                                   | 9       | 9-9     | 0%                  | 93%                 | 9                     | 8-9     | 0%                  | 100%                | 9           | 9-9     | 0%                  | 100%                | 9                                      | 9-9 | 0%                  | 100%                |
| Planning for future relationships                                           |         |         |                     |                     |                       |         |                     |                     |             |         |                     |                     |                                        |     |                     |                     |
| Primary                                                                     | 6       | 5-7     | 13%                 | 27%                 | 6                     | 5-7     | 7%                  | 40%                 | 6           | 6-7     | 8%                  | 31%                 | 6                                      | 6-8 | 6%                  | 44%                 |

|                                                        |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
|--------------------------------------------------------|-----|---------|---------------------|------------------------------|---|---------|---------------------|---------------------|---|---------|---------------------|-----------------------------------------------|-----|-----|---------------------|---------------------|
| Secondary                                              | 8.5 | 7-9     | 0%                  | 97%                          | 9 | 8-9     | 0%                  | 97%                 | 9 | 8-9     | 0%                  | 100%                                          | 9   | 8-9 | 0%                  | 100%                |
| <b>Values and attitudes for positive relationships</b> |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary                                                | 7   | 7-8     | 3%                  | 90%                          | 8 | 7-8     | 0%                  | 100%                | 7 | 7-8     | 8%                  | 85%                                           | 8.5 | 7-9 | 0%                  | 100%                |
| Secondary                                              | 9   | 8-9     | 0%                  | 97%                          | 9 | 8-9     | 0%                  | 100%                | 9 | 8-9     | 0%                  | 100%                                          | 9   | 9-9 | 0%                  | 100%                |
| <b>Parents</b>                                         |     |         |                     | <b>Teachers/school staff</b> |   |         |                     | <b>Researchers</b>  |   |         |                     | <b>Policy makers/people form third sector</b> |     |     |                     |                     |
| <b>Outcomes</b>                                        | M   | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9          | M | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 | M | IQ<br>R | %<br>scored=1-<br>3 | %<br>scored=7-<br>9                           | M   | IQR | %<br>scored=1-<br>3 | %<br>scored=7-<br>9 |
| <b>Sexual feelings, sexual arousal, and pleasure</b>   |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary                                                | 5   | 3-7     | 28%                 | 28%                          | 6 | 5-6     | 7%                  | 17%                 | 6 | 6-6     | 8%                  | 23%                                           | 6   | 5-8 | 11%                 | 33%                 |
| Secondary                                              | 8   | 7-9     | 3%                  | 90%                          | 9 | 8-9     | 0%                  | 100%                | 9 | 9-9     | 0%                  | 100%                                          | 9   | 8-9 | 0%                  | 100%                |
| <b>Sex</b>                                             |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary                                                | 5   | 4-7     | 17%                 | 28%                          | 6 | 4-6     | 10%                 | 23%                 | 6 | 6-7     | 0%                  | 46%                                           | 6   | 6-7 | 0%                  | 44%                 |
| Secondary                                              | 9   | 8-9     | 0%                  | 97%                          | 9 | 9-9     | 0%                  | 97%                 | 9 | 9-9     | 0%                  | 100%                                          | 9   | 9-9 | 0%                  | 100%                |
| <b>Masturbation</b>                                    |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary                                                | 5   | 4-7     | 24%                 | 28%                          | 6 | 5-6     | 10%                 | 23%                 | 6 | 6-7     | 0%                  | 38%                                           | 6   | 5-8 | 11%                 | 44%                 |
| Secondary                                              | 8   | 7-9     | 3%                  | 86%                          | 9 | 8-9     | 0%                  | 100%                | 9 | 8-9     | 0%                  | 92%                                           | 9   | 9-9 | 0%                  | 100%                |
| <b>Pregnancy and parenting</b>                         |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary*                                               | 6   | 5-7     | 3%                  | 45%                          | 5 | 4-6     | 3%                  | 20%                 | 7 | 6-7     | 8%                  | 62%                                           | 7   | 6-7 | 6%                  | 61%                 |
| Secondary                                              | 9   | 8-9     | 0%                  | 97%                          | 9 | 8-9     | 0%                  | 93%                 | 9 | 8-9     | 0%                  | 100%                                          | 9   | 9-9 | 0%                  | 100%                |
| <b>Contraception</b>                                   |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |
| Primary                                                | 5   | 4-7     | 10%                 | 28%                          | 5 | 4-6     | 17%                 | 10%                 | 6 | 5-6     | 15%                 | 23%                                           | 6   | 5-7 | 11%                 | 28%                 |
| Secondary                                              | 9   | 8-9     | 0%                  | 97%                          | 9 | 9-9     | 0%                  | 97%                 | 9 | 9-9     | 0%                  | 100%                                          | 9   | 9-9 | 6%                  | 94%                 |
| <b>Pornography</b>                                     |     |         |                     |                              |   |         |                     |                     |   |         |                     |                                               |     |     |                     |                     |

|                                                                   |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
|-------------------------------------------------------------------|---------|------|--------------|--------------|-----------------------|------|--------------|--------------|-------------|------|--------------|--------------|----------------------------------------|-----|--------------|--------------|
| Primary                                                           | 5       | 4-7  | 21%          | 28%          | 5.5                   | 4-6  | 13%          | 17%          | 6           | 4-6  | 8%           | 23%          | 6                                      | 6-7 | 0%           | 39%          |
| Secondary                                                         | 9       | 8-9  | 0%           | 79%          | 9                     | 8-9  | 0%           | 97%          | 9           | 8-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
|                                                                   | Parents |      |              |              | Teachers/school staff |      |              |              | Researchers |      |              |              | Policy makers/people form third sector |     |              |              |
| Outcomes                                                          | M       | IQ R | % scored=1-3 | % scored=7-9 | M                     | IQ R | % scored=1-3 | % scored=7-9 | M           | IQ R | % scored=1-3 | % scored=7-9 | M                                      | IQR | % scored=1-3 | % scored=7-9 |
| Sexual orientation, gender identity, gender roles and stereotypes |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary*                                                          | 5       | 6-7  | 14%          | 48%          | 6.5                   | 6-7  | 0%           | 50%          | 7           | 7-8  | 8%           | 77%          | 8                                      | 7-9 | 0%           | 89%          |
| Secondary                                                         | 8       | 7-9  | 3%           | 83%          | 9                     | 8-9  | 0%           | 100%         | 8           | 8-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 94%          |
| Sexual health                                                     |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary                                                           | 5       | 4-6  | 21%          | 17%          | 5                     | 4-6  | 17%          | 10%          | 5           | 4-6  | 23%          | 23%          | 5                                      | 4-7 | 11%          | 33%          |
| Secondary                                                         | 9       | 8-9  | 0%           | 97%          | 9                     | 8-9  | 0%           | 100%         | 9           | 8-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| Human rights                                                      |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary                                                           | 7       | 6-9  | 0%           | 69%          | 7                     | 7-8  | 0%           | 80%          | 7           | 7-9  | 8%           | 77%          | 8                                      | 7-9 | 0%           | 100%         |
| Secondary                                                         | 9       | 8-9  | 0%           | 93%          | 9                     | 8-9  | 0%           | 100%         | 9           | 8-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| Self-advocacy skills                                              |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary                                                           | 7       | 6-9  | 0%           | 72%          | 7                     | 7-9  | 0%           | 77%          | 7           | 7-8  | 0%           | 77%          | 9                                      | 7-9 | 0%           | 89%          |
| Secondary                                                         | 9       | 8-9  | 0%           | 100%         | 9                     | 8-9  | 0%           | 100%         | 9           | 9-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| Consent and communication skills                                  |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary                                                           | 8       | 7-9  | 3%           | 93%          | 9                     | 8-9  | 0%           | 90%          | 9           | 9-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| Secondary                                                         | 9       | 9-9  | 0%           | 100%         | 9                     | 9-9  | 0%           | 97%          | 9           | 9-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |
| Social norms of behaviour for a given cultural context            |         |      |              |              |                       |      |              |              |             |      |              |              |                                        |     |              |              |
| Primary                                                           | 8       | 7-9  | 0%           | 83%          | 8.5                   | 7-9  | 0%           | 90%          | 9           | 8-9  | 0%           | 92%          | 9                                      | 9-9 | 0%           | 94%          |
| Secondary                                                         | 9       | 8-9  | 0%           | 97%          | 9                     | 8-9  | 0%           | 100%         | 9           | 9-9  | 0%           | 100%         | 9                                      | 9-9 | 0%           | 100%         |



|                                                           |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
|-----------------------------------------------------------|---|-----|--------------|--------------|------------------------------|-----|--------------|--------------|--------------------|-----|--------------|--------------|-----------------------------------------------|-----|--------------|--------------|
| <b>Consent in sexual activities and the law</b>           |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
| Primary                                                   | 6 | 5-7 | 7%           | 41%          | 6                            | 6-7 | 3%           | 40%          | 6                  | 6-8 | 8%           | 46%          | 7                                             | 6-8 | 6%           | 61%          |
| Secondary                                                 | 9 | 8-9 | 0%           | 90%          | 9                            | 9-9 | 0%           | 100%         | 9                  | 9-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |
| <b>Parents</b>                                            |   |     |              |              | <b>Teachers/school staff</b> |     |              |              | <b>Researchers</b> |     |              |              | <b>Policy makers/people form third sector</b> |     |              |              |
| <b>Outcomes</b>                                           | M | IQR | % scored=1-3 | % scored=7-9 | M                            | IQR | % scored=1-3 | % scored=7-9 | M                  | IQR | % scored=1-3 | % scored=7-9 | M                                             | IQR | % scored=1-3 | % scored=7-9 |
| <b>Online safety and the law</b>                          |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
| Primary                                                   | 7 | 7-9 | 0%           | 90%          | 7                            | 7-9 | 0%           | 83%          | 7                  | 7-7 | 8%           | 77%          | 9                                             | 7-9 | 0%           | 94%          |
| Secondary                                                 | 9 | 8-9 | 0%           | 100%         | 9                            | 9-9 | 0%           | 100%         | 9                  | 9-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |
| <b>Unhealthy relationships, risk and how to keep safe</b> |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
| Primary                                                   | 7 | 7-8 | 3%           | 86%          | 7.5                          | 7-8 | 0%           | 87%          | 8                  | 7-9 | 8%           | 92%          | 9                                             | 8-9 | 0%           | 94%          |
| Secondary                                                 | 9 | 8-9 | 3%           | 97%          | 9                            | 9-9 | 0%           | 100%         | 9                  | 9-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |
| <b>Legal consequences of behaving inappropriately</b>     |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
| Primary                                                   | 6 | 6-8 | 0%           | 48%          | 7                            | 6-7 | 7%           | 57%          | 6                  | 5-7 | 8%           | 38%          | 7                                             | 6-9 | 11%          | 56%          |
| Secondary                                                 | 9 | 8-9 | 0%           | 97%          | 9                            | 8-9 | 0%           | 100%         | 9                  | 8-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |
| <b>Asking for help</b>                                    |   |     |              |              |                              |     |              |              |                    |     |              |              |                                               |     |              |              |
| Primary                                                   | 9 | 8-9 | 0%           | 93%          | 9                            | 8-9 | 0%           | 97%          | 9                  | 8-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |
| Secondary                                                 | 9 | 9-9 | 0%           | 100%         | 9                            | 9-9 | 0%           | 100%         | 9                  | 9-9 | 0%           | 100%         | 9                                             | 9-9 | 0%           | 100%         |

Note: M=median; outcomes in a blue colour represent differences on outcomes that reached consensus between stakeholder groups; outcomes in an orange colour represent outcomes that did not reach consensus across stakeholder groups; \*= significant differences between stakeholder groups.

Table 2 Outcome ratings in round 1 between stakeholder groups

| Outcomes                                 | Parents |     |               |               | Teachers/school staff |     |               |               | Researchers |     |               |               | Policy makers/people form third sector |     |               |               |
|------------------------------------------|---------|-----|---------------|---------------|-----------------------|-----|---------------|---------------|-------------|-----|---------------|---------------|----------------------------------------|-----|---------------|---------------|
|                                          | M       | IQR | % scored= 1-3 | % scored= 7-9 | M                     | IQR | % scored= 1-3 | % scored= 7-9 | M           | IQR | % scored= 1-3 | % scored= 7-9 | M                                      | IQR | % scored= 1-3 | % scored= 7-9 |
| <b>Body parts</b>                        |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 8       | 7 9 | 6%            | 82%           | 9                     | 8 9 | 0%            | 83%           | 8           | 7 8 | 0%            | 77%           | 9                                      | 8 9 | 0%            | 94%           |
| Secondary                                | 9       | 8 9 | 3%            | 88%           | 9                     | 9 9 | 0%            | 86%           | 8           | 8 9 | 0%            | 85%           | 9                                      | 9 9 | 0%            | 94%           |
| <b>Puberty</b>                           |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 8       | 7 9 | 6%            | 70%           | 8                     | 6 9 | 3%            | 63%           | 8           | 7 8 | 0%            | 85%           | 9                                      | 8 9 | 0%            | 89%           |
| Secondary                                | 9       | 8 9 | 3%            | 88%           | 9                     | 8 9 | 0%            | 86%           | 9           | 8 9 | 0%            | 92%           | 9                                      | 9 9 | 0%            | 94%           |
| <b>Hygiene</b>                           |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 8       | 7 9 | 3%            | 82%           | 9                     | 7 9 | 0%            | 86%           | 8           | 7 9 | 0%            | 92%           | 9                                      | 8 9 | 0%            | 89%           |
| Secondary                                | 9       | 8 9 | 3%            | 91%           | 9                     | 9 9 | 0%            | 86%           | 9           | 9 9 | 0%            | 92%           | 9                                      | 9 9 | 0%            | 94%           |
| <b>Health checks</b>                     |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 6       | 4 8 | 15%           | 36%           | 6                     | 5 7 | 6%            | 31%           | 5           | 4 7 | 23%           | 31%           | 6                                      | 6 7 | 0%            | 33%           |
| Secondary                                | 9       | 7 9 | 3%            | 88%           | 9                     | 8 9 | 0%            | 83%           | 8           | 7 9 | 0%            | 85%           | 9                                      | 9 9 | 0%            | 94%           |
| <b>Human life cycle</b>                  |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 7       | 6 8 | 9%            | 64%           | 7                     | 7 9 | 3%            | 66%           | 8           | 6 8 | 0%            | 62%           | 7                                      | 7 9 | 0%            | 72%           |
| Secondary                                | 9       | 8 9 | 3%            | 85%           | 9                     | 8 9 | 0%            | 86%           | 8           | 7 8 | 0%            | 85%           | 9                                      | 8 9 | 0%            | 89%           |
| <b>Recognising emotions and feelings</b> |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 8       | 7 9 | 3%            | 88%           | 9                     | 8 9 | 0%            | 86%           | 8           | 7 8 | 0%            | 92%           | 9                                      | 8 9 | 0%            | 94%           |
| Secondary                                | 9       | 8 9 | 3%            | 91%           | 9                     | 9 9 | 0%            | 86%           | 9           | 8 9 | 0%            | 92%           | 9                                      | 9 9 | 0%            | 94%           |
| <b>Emotion regulation</b>                |         |     |               |               |                       |     |               |               |             |     |               |               |                                        |     |               |               |
| Primary                                  | 8       | 7 9 | 3%            | 82%           | 9                     | 8 9 | 0%            | 86%           | 8           | 7 8 | 0%            | 92%           | 9                                      | 7 9 | 0%            | 94%           |
| Secondary                                | 9       | 8 9 | 3%            | 91%           | 9                     | 9 9 | 0%            | 86%           | 9           | 9 9 | 0%            | 92%           | 9                                      | 9 9 | 0%            | 94%           |

|                                                                                    |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
|------------------------------------------------------------------------------------|---|---|---|-----|-----|---|---|---|-----|-----|---|---|---|-----|-----|
| <b>Self-esteem and confidence</b>                                                  |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 9 | 8 | 9 | 3%  | 82% | 9 | 8 | 9 | 0%  | 86% | 8 | 7 | 9 | 0%  | 83% |
| Secondary                                                                          | 9 | 8 | 9 | 3%  | 88% | 9 | 8 | 9 | 0%  | 86% | 9 | 9 | 9 | 0%  | 89% |
| <b>Positive body image</b>                                                         |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 8 | 6 | 9 | 3%  | 67% | 8 | 7 | 9 | 0%  | 80% | 8 | 7 | 9 | 0%  | 83% |
| Secondary                                                                          | 9 | 7 | 9 | 3%  | 88% | 9 | 8 | 9 | 0%  | 86% | 9 | 9 | 9 | 0%  | 94% |
| <b>Recognising different relationships</b>                                         |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 7 | 7 | 9 | 3%  | 73% | 8 | 7 | 9 | 3%  | 71% | 7 | 7 | 7 | 0%  | 77% |
| Secondary                                                                          | 9 | 8 | 9 | 0%  | 82% | 9 | 8 | 9 | 0%  | 86% | 8 | 8 | 9 | 0%  | 92% |
| <b>How to develop and sustain healthy friendships and social skills</b>            |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 8 | 7 | 9 | 0%  | 79% | 8 | 7 | 9 | 0%  | 86% | 8 | 7 | 8 | 0%  | 85% |
| Secondary                                                                          | 9 | 8 | 9 | 0%  | 88% | 9 | 8 | 9 | 0%  | 86% | 8 | 8 | 9 | 0%  | 92% |
| <b>How to develop and sustain healthy romantic relationships and social skills</b> |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 6 | 5 | 7 | 12% | 42% | 6 | 4 | 7 | 6%  | 37% | 6 | 5 | 7 | 15% | 38% |
| Secondary                                                                          | 9 | 8 | 9 | 3%  | 88% | 9 | 8 | 9 | 0%  | 80% | 9 | 8 | 9 | 0%  | 92% |
| <b>Planning for future relationships</b>                                           |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 6 | 5 | 7 | 9%  | 30% | 6 | 6 | 7 | 9%  | 26% | 6 | 5 | 7 | 15% | 31% |
| Secondary                                                                          | 8 | 7 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 77% | 9 | 7 | 9 | 0%  | 85% |
| <b>Values and attitudes for positive relationships</b>                             |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 7 | 7 | 8 | 3%  | 76% | 8 | 7 | 9 | 0%  | 83% | 7 | 7 | 7 | 8%  | 69% |
| Secondary                                                                          | 9 | 8 | 9 | 3%  | 85% | 9 | 8 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 92% |
| <b>Sexual feelings, sexual arousal, and pleasure</b>                               |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 5 | 3 | 6 | 36% | 15% | 6 | 4 | 7 | 14% | 29% | 6 | 5 | 7 | 15% | 31% |
| Secondary                                                                          | 8 | 7 | 9 | 0%  | 82% | 9 | 8 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 92% |
| <b>Sex</b>                                                                         |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                            | 5 | 3 | 7 | 27% | 27% | 6 | 4 | 7 | 14% | 26% | 7 | 6 | 7 | 8%  | 46% |

|                                                                          |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
|--------------------------------------------------------------------------|---|---|---|-----|-----|---|---|---|-----|-----|---|---|---|-----|-----|---|---|---|-----|-----|
| Secondary                                                                | 8 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 83% | 9 | 8 | 9 | 0%  | 85% | 9 | 9 | 9 | 0%  | 94% |
| <b>Masturbation</b>                                                      |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 5 | 3 | 6 | 33% | 15% | 6 | 5 | 7 | 9%  | 26% | 7 | 6 | 8 | 8%  | 46% | 6 | 5 | 7 | 11% | 44% |
| Secondary                                                                | 8 | 6 | 9 | 0%  | 67% | 8 | 8 | 9 | 0%  | 77% | 8 | 7 | 9 | 0%  | 92% | 9 | 8 | 9 | 0%  | 94% |
| <b>Pregnancy and parenting</b>                                           |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 6 | 4 | 7 | 12% | 30% | 6 | 4 | 6 | 11% | 20% | 7 | 6 | 7 | 15% | 54% | 6 | 6 | 7 | 11% | 39% |
| Secondary                                                                | 9 | 8 | 9 | 0%  | 88% | 9 | 8 | 9 | 0%  | 80% | 9 | 8 | 9 | 0%  | 85% | 9 | 9 | 9 | 0%  | 94% |
| <b>Contraception</b>                                                     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 5 | 3 | 6 | 30% | 21% | 5 | 3 | 6 | 23% | 20% | 6 | 5 | 7 | 23% | 31% | 6 | 4 | 7 | 22% | 33% |
| Secondary                                                                | 9 | 8 | 9 | 0%  | 82% | 9 | 8 | 9 | 0%  | 83% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0%  | 94% |
| <b>Pornography</b>                                                       |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 5 | 3 | 7 | 30% | 33% | 5 | 4 | 6 | 14% | 14% | 6 | 4 | 6 | 15% | 23% | 6 | 6 | 7 | 0%  | 33% |
| Secondary                                                                | 9 | 8 | 9 | 0%  | 76% | 9 | 8 | 9 | 0%  | 80% | 8 | 7 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 94% |
| <b>Sexual orientation, gender identity, gender roles and stereotypes</b> |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 6 | 5 | 7 | 16% | 41% | 7 | 5 | 8 | 0%  | 46% | 7 | 6 | 8 | 8%  | 54% | 7 | 7 | 9 | 0%  | 72% |
| Secondary                                                                | 8 | 7 | 9 | 6%  | 82% | 9 | 8 | 9 | 0%  | 77% | 8 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 89% |
| <b>Sexual health</b>                                                     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 5 | 3 | 6 | 36% | 18% | 4 | 4 | 6 | 20% | 6%  | 5 | 4 | 7 | 23% | 31% | 5 | 4 | 7 | 11% | 28% |
| Secondary                                                                | 9 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 80% | 8 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0%  | 94% |
| <b>Human rights</b>                                                      |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 7 | 5 | 8 | 6%  | 48% | 7 | 7 | 9 | 3%  | 69% | 7 | 6 | 9 | 8%  | 62% | 8 | 7 | 9 | 0%  | 94% |
| Secondary                                                                | 8 | 8 | 9 | 0%  | 88% | 9 | 8 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0%  | 94% |
| <b>Self-advocacy skills</b>                                              |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |
| Primary                                                                  | 7 | 5 | 9 | 9%  | 55% | 7 | 6 | 9 | 3%  | 60% | 7 | 7 | 8 | 0%  | 69% | 9 | 7 | 9 | 0%  | 83% |
| Secondary                                                                | 9 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0%  | 83% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0%  | 94% |
| <b>Consent and communication skills</b>                                  |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |     |     |

|                                                               |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
|---------------------------------------------------------------|---|---|----|-----|-----|---|---|---|-----|-----|---|---|---|-----|-----|---|---|---|----|-----|
| Primary                                                       | 8 | 7 | 9  | 3%  | 82% | 8 | 7 | 9 | 0%  | 71% | 9 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0% | 94% |
| Secondary                                                     | 9 | 9 | 9  | 0%  | 94% | 9 | 9 | 9 | 0%  | 86% | 9 | 9 | 9 | 0%  | 92% | 9 | 9 | 9 | 0% | 94% |
| <b>Social norms of behaviour for a given cultural context</b> |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 7 | 7 | 9  | 3%  | 70% | 9 | 7 | 9 | 0%  | 80% | 9 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0% | 78% |
| Secondary                                                     | 9 | 8 | 9  | 0%  | 94% | 9 | 8 | 9 | 0%  | 83% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0% | 89% |
| <b>Consent in sexual activities and the law</b>               |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 6 | 4 | 7  | 18% | 30% | 6 | 4 | 7 | 9%  | 37% | 6 | 6 | 8 | 8%  | 38% | 7 | 5 | 9 | 6% | 61% |
| Secondary                                                     | 9 | 8 | 9  | 0%  | 85% | 9 | 8 | 9 | 0%  | 80% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0% | 94% |
| <b>Online safety and the law</b>                              |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 7 | 7 | 8  | 0%  | 70% | 7 | 6 | 9 | 3%  | 63% | 7 | 7 | 7 | 8%  | 69% | 8 | 7 | 9 | 0% | 83% |
| Secondary                                                     | 8 | 8 | 9  | 0%  | 91% | 9 | 9 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 92% | 9 | 8 | 9 | 0% | 94% |
| <b>Unhealthy relationships, risk and how to keep safe</b>     |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 7 | 6 | 8. | 3%  | 67% | 7 | 7 | 9 | 3%  | 69% | 8 | 7 | 9 | 8%  | 77% | 9 | 8 | 9 | 0% | 89% |
| Secondary                                                     | 9 | 9 | 9  | 0%  | 91% | 9 | 8 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 85% | 9 | 9 | 9 | 0% | 94% |
| <b>Legal consequences of behaving inappropriately</b>         |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 6 | 6 | 7. | 9%  | 42% | 6 | 5 | 7 | 11% | 37% | 7 | 5 | 7 | 15% | 46% | 7 | 6 | 7 | 6% | 50% |
| Secondary                                                     | 9 | 8 | 9  | 0%  | 88% | 9 | 8 | 9 | 0%  | 86% | 9 | 8 | 9 | 0%  | 85% | 9 | 8 | 9 | 0% | 94% |
| <b>Asking for help</b>                                        |   |   |    |     |     |   |   |   |     |     |   |   |   |     |     |   |   |   |    |     |
| Primary                                                       | 8 | 8 | 9  | 3%  | 88% | 9 | 8 | 9 | 0%  | 83% | 9 | 8 | 9 | 0%  | 92% | 9 | 9 | 9 | 0% | 94% |
| Secondary                                                     | 9 | 8 | 9  | 0%  | 94% | 9 | 9 | 9 | 0%  | 86% | 9 | 9 | 9 | 0%  | 92% | 9 | 9 | 9 | 0% | 94% |

Note: M=median; outcomes in a blue colour represent differences on outcomes that reached consensus between stakeholder groups; outcomes in an orange colour represent outcomes that did not reach consensus across stakeholder groups.

## Appendix 7.7 Findings of comparisons between stakeholder groups on outcome ratings in round 2

Table 1 Findings of the Kruskal–Wallis test for outcomes that appeared<sup>a</sup> to be rated differently by stakeholder groups

| Outcome                                                                                 | Kruskal–Wallis test statistic (H) and p value |
|-----------------------------------------------------------------------------------------|-----------------------------------------------|
| Human life cycle for primary education                                                  | $H(3)=7.57, p=0.06$                           |
| Sexual feelings, sexual arousal, and pleasure for primary education                     | $H(3)=4.38, p=0.22$                           |
| Sex for primary education                                                               | $H(3)=11.5, p=0.09$                           |
| Masturbation for primary education                                                      | $H(3)=6.86, p=0.77$                           |
| Pregnancy and parenting for primary education                                           | $H(3)=11.87, p=0.008^*$                       |
| Contraception for primary education                                                     | $H(3)=4.22, p=0.24$                           |
| Pornography for primary education                                                       | $H(3)=7.33, p=0.06$                           |
| Sexual orientation, gender identity, gender roles and stereotypes for primary education | $H(3)=15, p=0.002^*$                          |
| Sexual health for primary education                                                     | $H(3)=0.96, p=0.81$                           |
| Human rights for primary education                                                      | $H(3)=3.76, p=0.29$                           |

Note: <sup>a</sup>= appeared to be rated differently between stakeholder groups when applying consensus criteria on outcome ratings in round 2 between stakeholder groups; \*=significant results.

Table 2 Findings of Pairwise comparisons on outcomes that had significant differences between stakeholder groups

| Outcome                                                                                 | Pairwise comparisons statistic (R) and adjusted p values |
|-----------------------------------------------------------------------------------------|----------------------------------------------------------|
| Pregnancy and parenting for primary education                                           |                                                          |
| 2-1                                                                                     | $R=1.80, p=0.43$                                         |
| 2-3                                                                                     | $R=-2.55, p=0.07$                                        |
| 2-4                                                                                     | $R=-3.04, p=0.014^*$                                     |
| 1-3                                                                                     | $R=-1.13, p=1.00$                                        |
| 1-4                                                                                     | $R=-1.46, p=0.89$                                        |
| 3-4                                                                                     | $R=-0.17, p=1.00$                                        |
| Sexual orientation, gender identity, gender roles and stereotypes for primary education |                                                          |
| 2-1                                                                                     | $R=-0.09, p=1.00$                                        |
| 2-3                                                                                     | $R=-1.89, p=0.36$                                        |
| 2-4                                                                                     | $R=-3.32, p=0.005^*$                                     |
| 1-3                                                                                     | $R=-1.82, p=0.41$                                        |
| 1-4                                                                                     | $R=-3.26, p=0.007^*$                                     |
| 3-4                                                                                     | $R=-1.01, p=1.00$                                        |

Note: 1=Parents' group; 2=Teachers' group; 3=Researchers' group; 4=Policy makers'/people from third sector group; \*=significant results.