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Stakeholder perspectives on Relationships and Sex Education outcomes for students with intellectual disability to inform the development of a Core Outcome Set: a qualitative study

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Little is known about how to deliver Relationships and Sex Education to students with intellectual disability and what outcomes to measure. UNESCO defines Relationships and Sex Education as a part of the curriculum that aims to provide students with comprehensive knowledge, skills and attitudes about their sexuality. Evaluations of Relationships and Sex Education for people with intellectual disability indicate inconsistent outcome measurement and a lack of stakeholder involvement in outcome selection. Development of a Core Outcome Set could address this limitation as it involves identifying a stakeholder consensus-based minimum set of outcomes to be used in research evaluations. This qualitative study explored student and adult stakeholders' views on important Relationships and Sex Education outcomes for students with intellectual disability to inform a development of a Core Outcome Set. A total of 53 adult stakeholders (students' parents, teachers, researchers and policy makers) took part in online interviews and workshops. Nineteen students with intellectual disability took part in visual data collection sessions. A list of 31 outcome domains was identified as important by stakeholders. These were grouped into 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. Stakeholders' rationale for outcome importance involved unique needs and difficulties experienced by this population. The list of outcomes will be used to establish consensus across stakeholders on the most important outcomes to be included in the Core Outcome Set. The findings provide stakeholder identified strategies for enabling students to achieve the outcomes.

This study highlights the importance of including key stakeholders in the initial stages of a Core Outcome Set development and provides methodological insights on how to engage a diverse group of stakeholders.

KEYWORDS

Core Outcome Set, intellectual disability, outcomes, Relationships and Sex Education, students

Introduction

Sexuality is an essential part of being a human for all people including those with intellectual disability, a neurodevelopmental condition defined by significant limitations in intellectual functioning and adaptive skills present during the developmental period (Schalock et al., 2021). Sexuality as defined by the World Health Organization (WHO) comprises “sex, gender identity and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” (World Health Organization [WHO], 2006, p.5). The development of human sexuality starts from birth and continues through childhood and adulthood till death (Kar et al., 2015; Greydanus and Pratt, 2016; Sharpe, 2003). Healthy sexual development in childhood and adolescence is important for achieving optimal life as an adult (Sharpe, 2003; Kar et al., 2015; Greydanus and Pratt, 2016; Kågesten and van Reeuwijk, 2021).

Children and young people with intellectual disability experience sexual development just like their peers without intellectual disability (Burke et al., 2010; Wilson et al., 2011; Quint and O’Brien, 2016; O’Neill et al., 2016). Young people with intellectual disability also question their gender identity and sexual orientation and are interested in exploring their sexuality e.g., they masturbate, watch pornography, and engage in sexual behaviors (Wilson et al., 2011; Frawley and Wilson, 2016; McCann et al., 2016; Pryde and Jahoda, 2018; Baines et al., 2018; Strnadová et al., 2021; Schmidt et al., 2022; Gil-Llario et al., 2022). Similar to 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 and Crane, 2016).

Research indicates that young people with intellectual disability have very limited knowledge and skills regarding sexuality and relationships (Jahoda and Pownall, 2014; Borawska-Charko et al., 2017; Baines et al., 2018). They are more likely to experience sexually transmitted diseases, unintended pregnancy and sexual abuse than young people from the general population (Jones et al., 2012; Jahoda and Pownall, 2014; Borawska-Charko et al., 2017; Wissink et al., 2015; Baines et al., 2018). Delivery of effective Relationships and Sex Education (RSE) curriculum to students with intellectual disability could address these risks and improve their knowledge and skills. As the United Nations Educational Scientific and Cultural Organization (UNESCO) indicates, RSE aims to equip all students with knowledge, attitudes, and skills about “the cognitive, emotional, physical and social aspects of sexuality” (United Nations Educational Scientific and Cultural Organization [UNESCO], 2018, p.16). 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” (United Nations Educational Scientific and Cultural Organization [UNESCO], 2018, p.16). However, very little is known about how to deliver RSE to this population effectively and what outcomes to measure to evaluate its effectiveness. However, very little is known about how to deliver RSE to this population effectively and what outcomes to measure to evaluate its effectiveness.

Existing systematic reviews have examined RSE content, design, and effectiveness for people with intellectual disability of any age and have only included peer-reviewed papers written in English (Schaafsma et al., 2015; Sala et al., 2019; McCann et al., 2019; Brown et al., 2020). RSE evaluations to date have failed to reach definitive conclusions regarding the effectiveness of existing RSE models, partly because the evaluations tend to lack specific outcome goals, and outcomes measured tend to be heterogeneous (Schaafsma et al., 2015; Sala et al., 2019; McCann et al., 2019; Brown et al., 2020). 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 useful comparison of RSE programmes across studies and impacts understanding of the effectiveness of existing RSE models and development of new effective RSE programmes that could inform practice and policy for this population.

Existing evidence points to the lack of involvement of people with intellectual disability in outcome selection (Schaafsma et al., 2015; Sala et al., 2019; McCann et al., 2019; Brown et al., 2020). Thus, their needs and concerns are not considered (Schaafsma et al., 2015; Sala et al., 2019; McCann et al., 2019; 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. A lack of involvement of people with intellectual disability in outcome selection could result in ineffective or even harmful RSE programmes being provided in practice.

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. Research indicates that the views of adults (e.g., parents and teachers) who support students with intellectual disability can impact whether RSE is delivered in practice and what topics are perceived as appropriate to include in the curriculum (Gürol et al., 2014; Sankhla and Theodore, 2015; Menon and Sivakami, 2019; Gokgoz et al., 2021; Correa et al., 2022). It is important for all stakeholders, including the young people themselves, to be involved in RSE outcome selection to make sure all relevant views are

included and buy-in from all stakeholder groups is facilitated in RSE evaluations.

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). A COS provides a minimum standard of outcomes that all evaluation studies 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 proposed a standardized approach for developing a COS that has been successfully used to develop COSs across a range of health and social care areas (Williamson et al., 2017). There are two key steps in a COS development: (1) identification of a comprehensive list of potential outcomes and (2) achievement of consensus across stakeholders on the most important outcomes to be included in evaluations (Williamson et al., 2017).

The present study aimed to explore the views of student and adult stakeholders on important RSE outcomes so as to develop a comprehensive list of potential outcomes, building on findings of a systematic review of the international literature (Paulauskaite et al., 2022a). This study is a part of a COS development project registered with COMET¹ and its protocol is published (Paulauskaite et al., 2022b).

Materials and methods

Study design

This was a qualitative study adopting a social constructivist position which 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 Crotty (1998), Schwandt (2000), and Lincoln and Guba (2000). The social constructivist position was selected based on the aim of this study - i.e., to explore different stakeholders’ opinions on RSE outcomes by giving a free voice to stakeholders and exploring their realities and what emerges from this.

Procedure

Ethical approval was provided by the Institute of Education, University College London Research Ethics Committee (REC 1565). To be eligible to take part, parents had to have a child with intellectual disability aged 5–25 years living in England. Teachers and school staff members living in England with any years of experience working with students with intellectual disability aged 5–25 years were also included. Researchers who specialized in research on RSE, education, sexuality, and relationships of people with intellectual disability were included whether based in the UK or abroad. Policy makers in England (such as people from government agencies, parliamentary committees, third sector organizations, and charities) and people from third sector

organizations who were involved in developing or campaigning for policies for people with intellectual disability were eligible to take part in the study. Students with intellectual disability aged 5–25 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 also eligible.

Adult stakeholders took part either in an online workshop or an interview based on their preference between February and September 2022. Adult stakeholders were recruited via internet searches, authors identified through the systematic review (Paulauskaite et al., 2022a), the list of organizations involved in the statutory RSE policy in England, charities and third sector organizations that support families of children with intellectual disability, a special school network and social media posts. Informed consents were obtained from adult stakeholders prior to participation. Then, demographic information (e.g., age, gender, ethnicity, and religious affiliation) about adult stakeholders was collected.

Students with intellectual disability were recruited to face-to-face interviews between March 2022 - January 2023 by approaching special schools in England (identified through internet searches and contacts), parent carer forums, and using social media posts and snowball recruitment. Students’ parents provided consents for students to take part in the interviews. Students’ assent was obtained prior to participation and continuously monitored throughout the study (e.g., by observing students’ behavior, telling a student to touch a red card placed next to them if they wished to stop an interview or say “stop”). Students’ parents and teachers provided demographic information about participating students.

Workshops and interviews with adult stakeholders

To explore adult stakeholders’ views on important RSE outcomes for students with intellectual disability, we conducted one mixed stakeholder online workshop (containing all four adult stakeholder groups), three additional smaller online workshops (each comprising a single stakeholder group) and online semi-structured interviews. The smaller online single stakeholder group workshops and online interviews were conducted based on stakeholders’ requests and difficulties in recruiting many people to one online mixed stakeholder workshop. Workshops lasted 1 h and 30 min and interviews between 20 and 45 min. They were carried out using Zoom™ version 5.15.7 (Zoom Video Communications Inc.).

The workshops were carried out using an adapted process of a Priority Setting Partnership (PSP) based on the James Lind Alliance principles (JLA) (James Lindt Alliance [JLA], 2021). PSP is a structured consensus-based approach that involves mixed stakeholder groups working together to produce a prioritized list of outcomes (James Lindt Alliance [JLA], 2021). Questions (the schedules) used in the workshops and interviews were developed based on the aims of the study and were informed by the findings of the systematic review (Paulauskaite et al., 2022a) (i.e., no outcomes were extracted for students with intellectual disability in primary education). In the workshops, adult stakeholders were

¹ <https://www.comet-initiative.org/Studies/Details/1787>

asked to work in small groups to select the top three RSE outcomes for students with intellectual disability in primary, secondary and further education and then to share their selection to all participants for a discussion. The mixed stakeholder workshop was facilitated by the lead researcher (LP) and three other facilitators who were trained by the lead researcher. The smaller workshops comprising a single stakeholder group were facilitated by the lead researcher (LP). In the interviews, adult 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 the workshops and interviews were piloted with a small number of parents and teachers who did not take part in the study, prior to being used with study participants.

Interviews with student stakeholders

Interviews with students with intellectual disability were based on one of two visual qualitative data collection methods to enable students with diverse needs and abilities to participate: (1) a picture sorting activity using Talking Mats (Murphy and Cameron, 2008) and (2) an art-based discussion (Welsby and Horsfall, 2011; Vega and Saavedra, 2018). Interviews were carried out by the lead researcher (LP) at students' schools, lasting between 10 and 30 min. The student's RSE teacher was present during interviews but was asked not to contribute to the discussion.

In the picture sorting activity, students were presented with pictorial RSE outcomes (extracted by the lead researcher from the systematic review and data collected with adult stakeholders) and were asked to sort these pictures to represent their views using the Talking Mats procedure (Murphy and Cameron, 2008). RSE outcomes were referred to as "topics" to aid students' comprehension (see [Supplementary Material 1](#) for outcomes presented to students in the interviews). 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") and the visual scale to place the outcomes under (e.g., "Topics that you like"; "Topics you are not sure about"; and "Topics you do not like"). Then, students were handed with one pictorial RSE outcome and explained what the picture depicted (e.g., "This is learning about making friends"). After this, a student was handed each pictorial RSE outcome to place it on the mat under the visual scale to indicate what a student thinks about this topic until all outcomes were sorted.

When the interview included an art-based discussion, students were presented with pictorial RSE outcomes and were asked to make a poster on interesting RSE topics. Students were introduced to the pictorial RSE outcomes one-by-one by the researcher explaining what each picture depicts and asked to select RSE topics that they find interesting to be used in their posters. Once students finished selecting RSE topics for their poster, they were asked to stick the pictures onto their poster with paper glue and to decorate their posters (see [Supplementary Material 2](#) of pictures of activities completed by students).

Both activities involved a clear structure, a practice round and almost identical instructions with the language adapted when needed for each student. Throughout the interviews, students

were asked about their views on RSE outcomes (e.g., "Why did you place this topic on this side of the mat?"), to identify any additional outcomes that were not presented to them and to indicate the most interesting RSE outcome. This final question enabled the exploration of any differences between perspectives of student and adult stakeholders on the most important outcomes. Not all students were able to answer all questions and at times students' teachers helped to explain what students with vocal communication difficulties were expressing. At the end of the interview, the lead researcher took a picture of finished activities (e.g., a poster) and asked a RSE teacher to review if the finished activity depicted students' views. Teachers also suggested possible explanations regarding selection of pictures for students with limited or no speech (e.g., "We discussed hygiene last year and he really liked this topic").

Interviews were piloted with a small group of students ($N = 3$) who did not take part in the study. The same group of students also took part in three consultation sessions to select pictures and symbols used to represent RSE outcomes to participating students making sure they are meaningful and accurate. Preparatory sessions were carried out with each student's parents and RSE teachers separately before carrying out interviews with participating students. Parents and teachers were asked to select the visual data collection method to be used at the interview, complete with each student based on each student's prior experience and preferences. Parents and teachers also reviewed the list of pictorial RSE outcomes and language to be used in the interviews to make sure that the interviews did not lead to anxiety or distress to students (e.g., if an unfamiliar or an upsetting outcome was presented). Interviews with students followed data collection from adult stakeholders and data from adult stakeholders' interviews informed the interview schedule for students' interviews.

Data analysis

Workshops and interviews were audio recorded and transcribed verbatim using the transcription feature in Zoom and OneDrive™ (Microsoft 365) version 2308. The transcriptions were checked 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 and Spencer, 1994; Ritchie, 2013) was performed using NVivo 2020 version 1.0 (Lumivero) on the qualitative data to identify important RSE outcomes by stakeholders. Data collected with adults were analyzed separately to data collected from students with intellectual disability.

Five data analysis stages were carried out: familiarizing 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 plus the outcomes extracted from the systematic review (three new themes were added during the development of the framework based on the stakeholder suggested outcomes to ensure that there were no overlaps between codes and all outcome categories suggested by stakeholders were captured in the framework); an inter-rater reliability assessment of the coding framework (Cohen's Kappa statistic was 0.85); application of the framework to code all the

data; creation of “charts” to summarize stakeholders’ views on outcomes and differences between stakeholder groups; mapping and interpreting perspectives on RSE outcomes and comparing it between stakeholder groups (see [Supplementary Material 3](#) for more details).

The inter-rater reliability assessment was carried out between two raters (a colleague Ph.D. student and the lead researcher) who independently coded 20% of the data randomly selected from all five stakeholder groups. The raters used the themes/codes specified in the framework (alongside descriptions of themes) to code the data, and agreement was assessed on the codes assigned to the data in NVivo using Cohen’s Kappa statistic.

During the charting stage of the students’ data analysis, in addition to narratives of vocal students, we also analyzed photographs of completed activities (e.g., posters). To identify student preferences regarding the importance of outcomes, we analyzed each students’ outcome placement and added numbers in Excel spreadsheet version 2401 (Microsoft Corporation). For example, outcomes placed in the “like” side of a 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. We also wrote short summaries of students’ narratives on RSE outcomes by reviewing the coded transcriptions and outcome placements recorded in Excel.

An additional three students with severe intellectual disability and limited vocal communication abilities took part in the study. To enhance the accessibility of the interview for these students, several preparation sessions with the students’ RSE teacher were carried out to discuss adaptations e.g., using symbols for RSE outcomes that were familiar from their communication aids; simple and familiar two-three word phrases; a small number (up to 10) of concrete outcomes presented; a picture sorting activity using the Talking Mats containing a visual scale with only two options (“like” and “don’t like”) was selected; two paper sheets containing hearts developed by the schools’ speech and language therapist were used for students to sort RSE outcomes that were more familiar than a door mat used in the Talking Mats; students’ communication aids were used to explain the task. However, during the interview it emerged that these adaptations were still not working well. For example, these students said “like” when presented with RSE outcomes but placed those outcomes in the “do not like” side of the mat. Following the interviews, teachers reported that it appeared that these students randomly sorted RSE pictures. Therefore, information collected from these three students was not analyzed further.

Results

Participants

A total of 72 participants ($N = 53$ adult stakeholders and $N = 19$ students with intellectual disability) were included in the study. Out of 53 adult stakeholders, 17 were parents, 16 were teachers and school staff members, 12 were researchers and 8 were policy

makers/people from third sector organizations. Out of 19 students with intellectual disability, 12 were male and 7 were female with a mean age of 15.2 years ($SD = 2.7$, range 12–24 years). One student (5.3%) did not use speech to communicate and used their eye gaze to communicate in the interview. [Tables 1, 2](#) report participants’ demographic characteristics (see [Supplementary Material 4](#) for additional adult stakeholders’ demographic characteristics).

Outcomes

A list of 31 outcome domains were identified as important by stakeholders. These were grouped into 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 human rights (see [Figure 1](#) of the thematic map). For more detailed description of each subtheme, reasons for outcome importance and additional stakeholders’ quotes see [Supplementary Material 4](#).

Participants perceived RSE outcomes as inter-related or underpinning the attainment of other outcomes. Associations between outcome themes and subthemes are presented as lines in the thematic map ([Figure 1](#)). 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 necessary to understand consensual and non-consensual touch and appropriate and inappropriate touching (outcomes in consent theme 6). Understanding consent was also discussed as being a critical outcome for developing 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)

Differences between stakeholder groups

Parents reported the following outcome subthemes most frequently (presented in order of frequency): sex (reported by 76.5% of parents); unhealthy relationships, risk and how to keep safe (64.7%); consent and communication skills (64.7%); social norms of behavior for given cultural context (58.8%); and how to develop romantic relationships and social skills (58.8%). Parents reflected on their experiences of raising a child with intellectual disability (some of whom had been 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:

TABLE 1 Adult stakeholders' demographic characteristics.

Characteristics	Total adult sample	Adult stakeholder group			
	N (%) N = 53	Parents N (%)	Teachers/school staff members N (%)	Researchers N (%)	Policy makers/third sector N (%)
Participated		17 (32.1%)	16 (30.2%)	12 (22.6%)	8 (15.1%)
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%)
Age					
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%)
Gender					
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%)
Country of residence					
England	48 (90.6%)	17 (100%)	15 (93.8%)	8 (66.7%)	8 (100%)
Outside the UK (Europe)	3 (5.6%)	–	–	3 (25%)	–
Ethnicity					
White	48 (90.5%)	15 (88.2%)	15 (93.8%)	10 (83.4%)	8 (100%)
Religious affiliation					
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%)

“[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 things other than making babies [...] So, he could not understand [...] what the other party has been up to because he realized that: “I do not have eggs. So why was he trying to put sperm inside me?” (Parent_04)

Teachers’ views differed to other stakeholder groups. Teachers placed more emphasis on outcomes related to keeping safe and understanding social norms of behavior rather than outcomes related to human rights, sex and sexuality (rarely mentioned by teachers). Teachers were also the only group of

stakeholders that mentioned outcomes related to the human life cycle:

“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)

Researchers’ views on the outcomes also differed to other stakeholder groups. Researchers mentioned the following outcome subthemes most frequently: how to develop and sustain romantic relationships and having social skills (reported by 83.3% of researchers who emphasized the development of social skills needed to have such relationships); sexual orientation, gender identity, gender roles and stereotypes (75%); and contraception (66.7%). Researchers reflected on their experiences working with people with intellectual disability and reported that people with intellectual disability (particularly those who are also autistic)

TABLE 2 Students' demographic characteristics.

Characteristics	Total sample N = 19 N (%)
Interview method	
Picture sorting activity using Talking Mats	16 (84.2%)
Art-based discussion	3 (15.8%)
Age (years)- Mean (SD) (range)	15.2 (2.7) (12–24)
Gender	
Female	7 (36.8%)
Male	12 (63.2%)
Ethnicity	
White	8 (42.1%)
Other	11 (57.9%)
Religious affiliation	
Christianity	13 (68.4%)
Hinduism	3 (15.8%)
Other	1 (5.3%)
No religion	2 (10.5%)
Type of school attended	
Special school	15 (78.9%)
SEND unit within mainstream school provision	4 (21.1%)
Level of ID*	
Mild	3 (15.8%)
Moderate	15 (78.9%)
Severe	1 (5.3%)
Receptive language abilities	
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%)
Expressive language abilities	
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%)
Used augmentative and alternative methods of communication (e.g., PECS) in addition to speech	5 (26.3%)
Additional conditions	
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%)

ID, intellectual disability; ADHD, attention deficit hyperactivity disorder; SEND, special education needs and disabilities; PECS, Picture Exchange Communication System; Level of ID*, reported by parents.

are questioning their sexual and gender identity at an early age. Participants mentioned that young female students were being forced to take long-term contraception against their will.

“Looking at different sexualities I think that is important [...] Research shown 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)

The most frequently reported outcomes by policy makers/people working in the 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 engage in sex safely), masturbation (87.5%); social norms of behavior (87.5%) and puberty (87.5%). Participants in this subgroup reported that these outcomes are important for understanding that students have a right to sexual pleasure and with that comes the need to prevent inappropriate behavior or their hurting themselves while masturbating:

“I know this is not particularly in the guidance [RSE statutory 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)

Students' views on important RSE outcomes differed from adults' views. The most important RSE outcomes for 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 discussed that they want to achieve such outcomes because they lack confidence to develop relationships in real life and their disability can be a barrier for finding and making new friends. Some students also reported experiencing bullying in person and online and not attending school because of it:

“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)

“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)

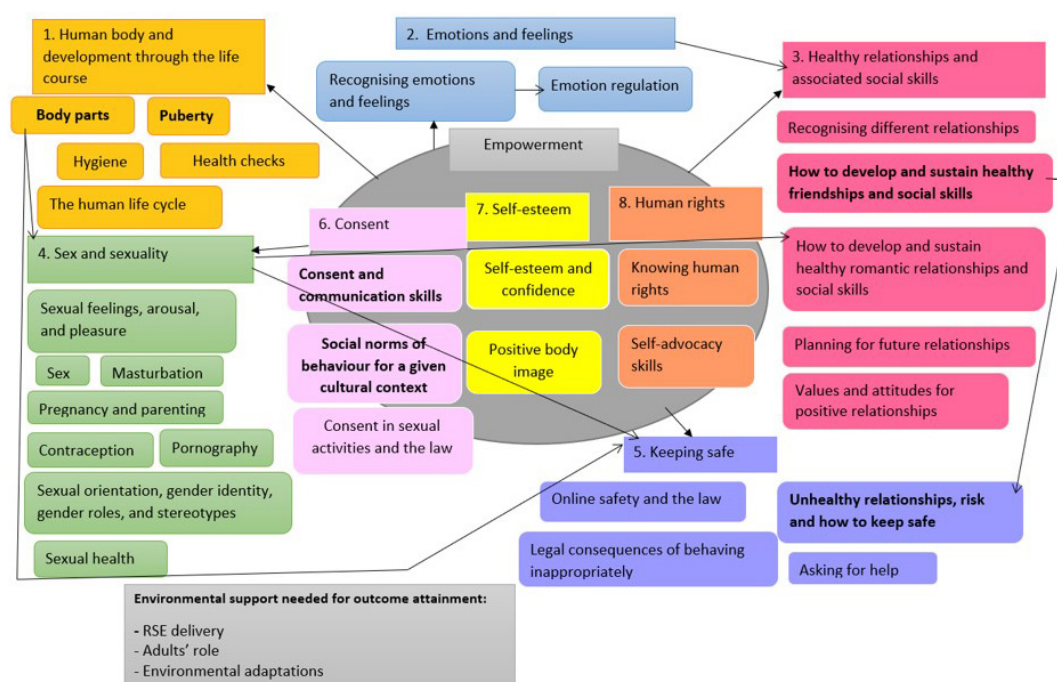


FIGURE 1

Thematic map of RSE outcomes perceived as important by stakeholders. 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 adult stakeholder groups (mentioned by $\geq 50\%$ of participants) are highlighted in bold.

Students' rationale for several of the reported outcomes (e.g., outcomes on consent, confidence, pregnancy, and parenting, hygiene) involved a wish to become more independent in life. For example, students reported that they wanted to achieve outcomes on consent in RSE to be able to make choices by themselves and be independent; these was not discussed by adult stakeholders. Achieving outcomes on confidence was perceived by students as a prerequisite to being independent in life (e.g., being able to go to community places on their own or ask someone for help). When discussing outcomes on puberty and hygiene, students in RSE wanted to develop self-care skills to be able to look after their body by themselves. 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:

"[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)

Environmental support needed for outcome attainment

This theme involves adult stakeholders' suggestions on environmental support needed for students to achieve the outcomes.

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 a student's abilities (e.g., using visual materials, social role models, and an accessible language). To ensure consistent RSE delivery, participants suggested including RSE outcomes in students' Education, Health, and Care plans (EHCPs) which are statutory support plans in England. 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 toward 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 will depend on students' individual abilities. However, other participants emphasized that RSE delivery

should start in the early years (e.g., in primary schools) because it takes time for students with intellectual disability to understand complex concepts and acquire skills. Participants reported that tailoring the content and timing of RSE delivery based on students' cognitive abilities increases the risk of not delivering that content at all. Participants emphasized that students' intellectual disability describes their cognitive abilities (e.g., their academic abilities) but not their sexual maturity and needs. It was suggested that the format of RSE delivery needs to be tailored (e.g., using images or communication tools) to students' needs rather than curtailing topics delivered. 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)

"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 6 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 behavior, she would still think that that was acceptable behavior at 18." (SEND consultant_01)

Adults' role

Participants reported that all adults (e.g., parents, teachers, and support staff members) in the students' environment need to achieve specific outcomes first so that students can achieve the outcomes. First, for students to develop knowledge related to consent, adults should actively seek students' consent (e.g., when assisting with personal care) and respect students' consent withdrawal. 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_01)

Second, adults should be setting consistent boundaries with students with intellectual disability. Participants reported that parents and support staff set different boundaries with students with intellectual disability compared to students without intellectual disability (e.g., allowing students with intellectual disability to masturbate in public by thinking that these behaviors are part of their disability). This, participants suggested, leads to students with intellectual disability struggling to learn social norms and contributes to inappropriate behavior.

Third, adults should create opportunities for students to consolidate the knowledge learned. Participants reported that 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 practice the skills learned in RSE.

Fourth, all adults who support students with intellectual disability should receive RSE themselves to help them provide consistent information to students and develop positive attitudes toward their sexuality:

"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 toward 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 for their children and should be empowered to discuss RSE topics at home. Teachers reported that informing parents what their children will learn in RSE and having them on board with RSE delivery can help students attain the outcomes (e.g., by having consistent messages across both settings) and 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. Teachers also discussed that parents can be a barrier to 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 behaviors. The physical environment was also discussed as contributing to students' engagement in inappropriate behaviors and needing to align to RSE outcomes. 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) and thus, struggling to learn what privacy is.

Discussion

To our knowledge, this was the first study that explored perspectives of student and adult stakeholders on RSE outcomes for students with intellectual disability to inform the development of the COS.

Findings from the study identified outcomes that have so far not been reported in the international literature (Paulauskaite et al., 2022a): 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. Compared with the UNESCO suggested guide for comprehensive RSE (United Nations Educational Scientific and Cultural Organization [UNESCO], 2018), the majority of stakeholders suggested outcomes are included in the guide as learning objectives. However, the following outcomes are not included in the guide: planning for future relationships and the human life cycle. Most of the suggested stakeholder outcomes also have a slightly different focus to the learning outcomes included in the UNESCO guide. For example, the health checks outcome suggested by stakeholders in this study focus on any sexual health concern rather only HIV and STIS (the focus in the guide).

The difference between outcomes reported in this study and outcomes reported in previous studies and the UNESCO guide could be due to methodological differences between studies and the guide: e.g., previous studies were on effectiveness of RSE, and, thus, had different aims than the present study (Paulauskaite et al., 2022a). The guide was not developed specifically for students with intellectual disability including key stakeholders in the development. This finding showcases the importance of including key stakeholders in identification of the long list of outcomes in a COS development to make sure the final COS is grounded in stakeholders' perspectives. The list of outcomes has been used in

the next stage of this COS development project to establishment consensus on the most important outcomes to be included in the COS.

Stakeholders' rationale for outcome importance involved unique needs and difficulties experienced by this population (e.g., a lack of social skills and confidence); the environment and practices involved in supporting students with intellectual disability (e.g., being taught to comply and needing adults help with intimate care that puts students at risk of sexual abuse) and stigma toward sexuality of people with intellectual disability (e.g., for having romantic relationships). Having autonomy of their lives was particularly important for students with intellectual disability who mentioned development of their independence as reasons for achieving many outcomes in this study.

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; Schaafsma et al., 2017; Bates et al., 2017; Black and Kammes, 2019). The increased risk of sexual abuse amongst people with intellectual disability is well established in the literature and the importance of RSE for its prevention (Schaafsma et al., 2015; Gil-Llario et al., 2019; Curtiss and Kammes, 2020; Brown et al., 2020; Tomsa et al., 2021). In previous studies, people with intellectual disability also reported wanting to be more independent because it increases their confidence, self-worth, and autonomy (Bond and Hurst, 2010; Haigh et al., 2013; Sandjojo et al., 2019, 2020).

Differences between stakeholder groups

Across student and adult stakeholders, participants in this study placed more value on outcomes related to development of friendships and keeping safe. However, there were some differences between stakeholder groups on some outcomes that may reflect different social roles that each group contains and different experiences of supporting students with intellectual disability. Such findings indicate the importance of including key stakeholder groups in the development of the COS for sustainable RSE delivery and evaluation for this population.

Parents emphasized outcomes on sex and development on romantic relationships as important for safeguarding reasons and students having a right to explore such relationships. In contrast, in previous studies, parents reported that the “sex” topic should not be taught to their children with intellectual disability because children might start behaving inappropriately after receiving information on sex or such topic is irrelevant to students who are not interested in having sex (Gürol et al., 2014; Dupras and Dionne, 2014; Sinclair et al., 2015; Pryde and Jahoda, 2018). 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., 2022a).

Teachers placed more emphasis on outcomes related to keeping safe and managing risks rather than outcomes related to human rights, sex and sexuality. This finding is in line with previous literature (Paulauskaite et al., 2022a). 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: learning outcomes specified in the statutory RSE guidance (Department for Education, 2019) where sex and sexuality are barely mentioned, parents' objections toward teaching about "sex" and a lack of appropriate teaching resources on sex and sexuality as mentioned in this study.

Researchers emphasized outcomes on sexual orientation, gender identity, and contraception as important whilst people from the policy makers/third sector group outcomes on masturbation. 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; Schmidt et al., 2022; Colarossi et al., 2023). 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; Schmidt et al., 2022; Colarossi et al., 2023).

Students with intellectual disability prioritized outcomes on development of friendships, their confidence and cyberbullying. Consistent with previous studies, students with intellectual disability reported feeling lonely because they do not have friends (Schaafsma et al., 2017; Bates et al., 2017; Black and Kammes, 2019). Outcomes on cyberbullying, development of relationships, and confidence were also perceived as important by students with intellectual disability in the previous literature (Paulauskaite et al., 2022a).

Environmental support

In this study, adult stakeholders identified environmental strategies for facilitating RSE delivery and outcome attainment by this population. Adult stakeholders reported that RSE delivery needs to be detailed, consistent, and skills based which was also reported in previous studies as important strategies for improving RSE delivery to this population (Strnadová et al., 2021; Schmidt et al., 2022; Colarossi et al., 2023). Some of the adult-centered 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 also been reported in the literature before as strategies needed for improving RSE delivery to this population (Strnadová et al., 2021; Paulauskaite et al., 2022a).

However, unique findings include some of adult-centered outcomes (i.e., consistent boundaries and educating adults on RSE) and findings about the physical environment (e.g., no doors in toilets). These findings could inform all policies around supporting people with intellectual disability as practices discussed in this study may impact students' increased vulnerability to sexual abuse, engagement in inappropriate behaviors (e.g., masturbation in public) and deny their human rights. Practices similar to the ones discussed in this study for supporting people with intellectual disability have been reported before (Cambridge et al., 2003; Lockhart et al., 2009; Hollomotz, 2009). Findings highlighted the need for development of RSE teaching materials on sensitive topics to suit a variety of ability levels (Lafferty et al., 2012; Pownall et al., 2012; Pryde and Jahoda, 2018; Kürtüncü and Kurt, 2020; Strnadová et al., 2022; Gokgoz et al., 2021).

The findings of this study highlighted the need to train school staff and students' parents to ensure consistent RSE information is provided at home and school and adults are aware how their behavior can impact students' learning and engagement in inappropriate behaviors. There are well documented positive impacts from RSE training for parents of children with intellectual disability: improved parental knowledge related to different sexuality topics and their children's sexual development; increased confidence in having discussions related to RSE topics with their children; reduced negative attitudes toward their children's sexuality (which some parents were not aware of having before the training) (Kok and Akyuz, 2015; Rooks-Ellis et al., 2020; Donnelly et al., 2023; Kurt and Kürtüncü, 2024) and led to parents having discussions with their children on wider RSE related topics after the training (Frank and Sandman, 2021). Such training should be co-led by students with intellectual disability to address attitudes toward students' sexuality, as research indicates that interventions aimed at reducing stigma are more effective when people who are stigmatized involved in its delivery (Corrigan et al., 2012; Mehta et al., 2015; Thornicroft et al., 2016, 2022; Waqas et al., 2020).

Strengths and limitations

The methodological approach used in this study is a clear strength. Offering stakeholders to take part either in workshops or interviews, enabled us to reach all key adult stakeholder groups targeted as well as vulnerable people such as parents of children with intellectual disability that were sexually abused. Offering two visual data collection methods with students with intellectual disability we were able to engage with male and female students with intellectual disability that had different cognitive and vocal communication abilities, ages (12–24 years), ethnicities (e.g., only 42% of students identified as White). Thus, a range of perspectives were explored and informed this COS development.

This study provides methodological insights to researchers interested in engaging populations other than clinicians and researchers (e.g., children and young people) in the development of a COS who are rarely involved in such developments (Sherratt et al., 2020; Gargon et al., 2021). Collaborations with students' parents and teachers as facilitators were essential for enabling students with intellectual disability to participate which was mentioned before as a necessity for involving such population in research (Carroll and Sixsmith, 2016; Tesfaye et al., 2019; Nicholas et al., 2019; Lewis-Dagnell et al., 2023).

However, 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 had more liberal attitudes toward the sexuality of students with intellectual disability or may have experienced greater difficulties supporting their sexuality compared to people who did not take part in the study.

The COVID-19 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, adult stakeholders who took part in the study probably had more time and resources to join online workshops and interviews than people who did not take part.

Many schools approached to help with student recruitment declined to participate because they felt that students would not be able to participate due to their lack of RSE knowledge, cognitive abilities or parents from cultural and religious diverse backgrounds objecting students' participation. Students who took part in the study probably were attending schools that had: more resources (e.g., time and school staff); more comprehensive RSE delivery; and more liberal attitudes toward students' abilities to participate than schools that declined participation.

Despite being able to engage key stakeholders, the study findings do not represent the views of people from diverse cultural and religious backgrounds nor younger students (e.g., in primary education) and those with severe and profound intellectual disability as we were unable to and meaningfully engage such subgroups and future research should address this limitation. Data from three students with severe intellectual disability had to be excluded because of low reliability, despite adaptations to the interview process which were guided by teachers, parents and the school's speech and language therapist who knew the students well. This 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 (Tesfaye et al., 2019; Nicholas et al., 2019; Richards and Crane, 2020; Gore et al., 2021).

We were also not able to explore students' views on all outcomes collected in this COS development project (e.g., masturbation). Teachers and parents decided what topics should not be discussed with students because such topics were not delivered yet or were sensitive. Thus, students' views on more sensitive RSE outcomes have not been explored in this study and were not involved in the COS development.

We have not used any effectiveness frameworks for evaluating the effectiveness of communication in the activities carried out with students due to challenges experienced with student recruitment (asking parents' consents for making videos of student interviews to evaluate its effectiveness would potentially added an additional recruitment barrier) and no validated effectiveness frameworks available for such tasks (Stans et al., 2019). Thus, there is the possibility that we over- or under-estimated the engagement of some students in the activities, their views on outcomes and thus, our own bias could have impacted the interpretation of the findings. However, "true neutrality" in qualitative research is impossible (Dwyer and Buckle, 2009; Holmes, 2020). Slight differences between two activities carried out with students and individual adaptations made to data collection procedures to enable students with a range of abilities to participate might have impacted what information was shared by students in this study.

The divergence of views between adult stakeholder groups evident in this study might be less significant than observed due to the dual roles that adults have and differences in data collection methods employed. For example, some people with a policy making background were also parents of students with intellectual disability or involved in RSE delivery in educational settings. Most teachers took part in workshops and perhaps had less time to share their views compared to other stakeholders who took part in interviews.

Conclusion

This study identified RSE outcomes for students with intellectual disability perceived as important to student and adult stakeholders to inform the development of the COS. Outcomes perceived as important 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. Outcomes were multi-dimensional and findings indicated how certain outcomes overlap between them to build cumulative knowledge in the area. Novel outcomes such as consent in sexual activities; planning for future relationships; self-advocacy skills were identified, not previously reported in the research literature. Stakeholders' rationale for outcome importance involved consideration of the unique needs and difficulties experienced by this population, the physical environment that students live in, practices involved in supporting students and other people's attitudes toward 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. These findings provide insights toward improving delivery, sustainability and evaluation of RSE for this population.

Data availability statement

The data sharing is not available because this study considers sensitive information. It was not a requirement by the funder to deposit data in a publicly available repository for studies undertaken by PhD students, and participants' consents for data sharing were not obtained in this study.

Ethics statement

The studies involving humans were approved by the Institute of Education, University College London Research Ethics Committee (REC 1565). The studies were conducted in accordance with the local legislation and institutional requirements. Adults provided written informed consents to participate in the study. Written informed consents for young people participation in this study was provided by the participants' parents or legal guardians/next of kin.

Author contributions

LP: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. VT: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. CR: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/feduc.2025.1704150/full#supplementary-material>

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