

**Understanding the views of children with
complex learning and communication
needs for person-centred planning**

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D. Ed. Psy. Thesis (Volume 1, 2022)

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ABSTRACT

Background

Children with special educational needs and disability (SEND) have the right to express their views about matters affecting them. This includes children severely affected by disability who are required to entrust adults to speak on their behalf. The literature exploring the participation of children with complex learning and communication needs (CLCN) in decision-making using person-centred planning (PCP) is limited.

Aims

This study explores how adults understand the views of children with CLCN and how this understanding can inform PCP.

Sample

Three children with CLCN aged 4-11 years attending one special school, their mothers and two professionals working with each child. Other professionals and one father also took part in the PCP meetings.

Method

Social constructivist grounded theory methodology was employed, emphasising researcher reflexivity and co-construction of research with participants. Individual interviews with adult participants took place followed

by observations of the children in school, observations of their PCP meetings, and discussion of data analysis with participants.

Results

Research findings relate to three psychological concepts: agency and self-efficacy, social construction, and an ecological perspective upon human development.

Conclusions

Understanding the views of children with CLCN takes place over time in relational and social contexts. Different interpretations of a child's communication are considered when adults collaborate, leading to shared understandings of a child's views being socially constructed. Adults infer the meaning of a child's views about what is important to them for the future from their understanding of the child's views about their immediate contexts, which informs PCP.

THESIS IMPACT STATEMENT

Local level

I have disseminated the knowledge, understanding and expertise on PCP developed through my research to a PCP special interest group for professionals and parents. My findings have contributed to the redevelopment of local authority guidance for education settings on exploring the views of children with SEND. I have also presented my findings to the local Special Educational Needs Coordinator forums and led discussion groups on legislation and practice principles for exploring children's views. These forums were attended by education professionals working with children and young people aged 3-25 years, and feedback suggests the potential benefit of my research to children and young people with CLCN of all ages.

Regional level

My research findings may be disseminated via presentations and seminars at regional forums to other special schools catering for children with CLCN and to other professional groups who seek to understand children's views through their work, such as social care professionals and children's advocacy services, assisting them to fulfil the rights of children with CLCN to express their views on matters affecting them.

National level

The impact of my thesis at a national level may be realised through conference presentations to professional groups and charitable organisations who work with children with CLCN and their families. I aim to publish my research in relevant academic journals and write practice guidance for understanding the views of children with CLCN for person-centred planning.

The knowledge, understanding, and expertise that I have developed in grounded theory methodology would be beneficial to trainees and doctoral researchers within the educational psychology profession and other social science fields. This could be disseminated through workshops, seminars, and publications. I intend to publish the critical appraisal tool for grounded theory (CAT-GT) developed during my thesis work for use by other researchers to appraise the quality of published research and to guide their own grounded theory studies, offering a distinct contribution to the field of qualitative research methods.

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Glossary

CAT-GT	Critical Appraisal Tool – Grounded Theory A tool developed during the thesis work to provide guidance for researchers when designing and appraising grounded theory studies
CLCN	Complex Learning and Communication Needs

The term used in the context where the study is located to describe children and young people with the most severe communication and learning needs

CPD	<p>Continuing Professional Development</p> <p>Learning undertaken post-qualification to enhance knowledge, understanding, and expertise in relation to a professional practice role</p>
CT	<p>Class Teacher</p> <p>A teacher who teaches and is responsible for the education and care of a particular group of students in a school</p>
EHCP	<p>Education, Health, and Care Plan</p> <p>A plan that identifies a child or young person's education, health, and care needs and the support they will require in addition to what would be typically available in a school</p>
EP	<p>Educational Psychologist</p> <p>A psychologist who applies psychological theory, research, and techniques to support children, young people, their families, and schools to overcome children and young people's barriers to learning and promote their emotional and social well-being.</p>
FAST	<p>Feeding and Swallowing Team</p> <p>A team comprising speech and language therapists and occupational therapists, existing in the local context where the research takes place, and offering treatment and advice for children who are experiencing difficulties eating, drinking, and swallowing.</p>
GT	<p>Grounded Theory</p> <p>A qualitative methodology employed for the current research</p>
LA	<p>Local Authority</p> <p>An organisation in local government that is responsible for public services and facilities in a particular area of the UK</p>
OT	<p>Occupational Therapist</p> <p>A professional who provides advice and treatment to overcome barriers that are preventing a person from doing practical and purposeful activities independently in their everyday life</p>

PCP	<p>Person-centred Planning</p> <p>A set of approaches for helping an individual and the significant people in their life to plan for the future</p>
PMLD	<p>Profound and Multiple Learning Difficulties</p> <p>A term used to describe when a person has a severe learning difficulty and other disabilities that significantly affect their communication and independence.</p>
PW	<p>Play Worker</p> <p>A person employed to organise and take part in play and leisure activities for children and young people with special educational needs and disabilities outside of school</p>
REC	<p>Research Ethics Committee</p> <p>A group of people appointed to review research proposals to assess formally if the research is ethical before granting permission for the research to take place</p>
RQ	<p>Research Question</p> <p>A question that a researcher sets out to answer through their empirical work</p>
SALT	<p>Speech and Language Therapist</p> <p>A professional who provides advice and treatment for people who experience difficulties communicating</p>
SEND	<p>Special Educational Needs and Disabilities</p> <p>A term used to refer to a child or young person who experiences difficulties and/or a disability that affects their ability to learn</p>
TA	<p>Teaching Assistant</p> <p>A person employed to support the work of a teacher in a school</p>

Acknowledgements

First, my sincere thanks go to my tutor, Dr Phil Stringer, for his guidance, support, and encouragement throughout my doctoral studies.

Thank you to my participants and to all of the children and staff at the school where my research took place. I would like to thank Sue and Gwyneth, in particular, for their help and support.

Thank you to my colleagues for their interest in my research, and especially to Malcolm and Barbara for encouraging me begin my doctoral studies.

Thank you to my fellow course members for the encouragement, laughter, and fun. It has been a pleasure to be part of such a talented and supportive group or people.

Finally, I would like to say thank you to my children, Josh and Emma, for your love and understanding. I am so proud of you both. And to my husband, Martyn, thank you for always believing in me and for taking care of everything when I was busy typing.

PART 1 – INTRODUCTION

1.1 The person-centred planning context for children with special educational needs and disabilities (SEND)

Children have the right to express their views about matters affecting them (United Nations, 1989) and participate in decision-making for their future

(Children and Families Act 2014). The SEND Code of Practice (DfE & DoH, 2015) recommends a person-centred planning (PCP) approach is taken to facilitate the participation of children and young people with SEND in decision-making. Person-centred planning¹ came to prominence in the UK in 2001 following the publication of the government White Paper *Valuing People* (DoH, 2001), which established a requirement of local areas to develop a framework for using PCP to support the transition of young people with learning disabilities to adult services. The Department of Health published advice in 2010 on the use of PCP to plan transition from school to employment for young people with disabilities (DoH, 2010). The use of PCP more broadly in schools for children and young people with SEND of all ages is a relatively new practice.

Person-centred planning is not a prescriptive technique but a term used to describe a range of approaches sharing common characteristics (Ratti et al., 2016). Commonality among descriptions of PCP lies within the consideration given to the views of the child or young person, how these views inform planning for their future, and the involvement of significant adults in the child's life in the planning process. Person-centred approaches emphasise the self-determination, choice, and autonomy of both the child or young person and the adults contributing to their plan (Ratti et al., 2016).

White and Rae (2016) propose that person-centred approaches should be adapted to meet individual needs, ensuring all children and young people can

¹ Person-centred approaches originated in the USA and Canada over 30 years ago to promote participation and inclusion of adults with learning disabilities (Corrigan, 2014).

participate in the process. The Department of Health guidance for schools (DoH, 2010) offers examples of questions to facilitate PCP, which include thinking about how a child or young person communicates if they are not able to use spoken words. The Council for Disabled Children suggests that young people with communication and learning difficulties may encounter significant barriers to participation. Children and young people experiencing profound and multiple learning difficulties (PMLD) can be considered to have the most complex learning and communication needs, often using alternative forms of communication to speech and being dependent upon others to interpret their communicative intent (Bellamy et al., 2010). This raises the question of how PCP should be adapted to ensure these children and young people can fulfil their right to express their views.

MacKay (2009) reports that PMLD is one of many terms used to describe learning difficulties, although there is not an agreed definition for PMLD. He suggests that terminology used to describe a person's learning difficulties should convey the important characteristics of the people being described and have meaning to all involved. The term 'complex learning and communication needs' (CLCN) will be used to describe the needs of the children participating in the current research, as this term recognises the children's communication needs and is consistent with the language used in the context where the research is located.

1.2 The researcher's interest in the topic

My interest in PCP for children with CLCN arose from my professional practice experience as an Educational Psychologist (EP) working with a special school catering for this area of need. I am employed by an LA as a Senior EP with a specialism for early years. My specialist role involves contributing to the strategic planning of LA early years SEND services and supervising the local Early Support and Portage team, which provides an educational service for children aged 0-5 years with SEND and their families. In my view, there are strong similarities between PCP approaches and Portage principles which value the uniqueness of every child and promote communication and partnership working between professionals, children, and families (NPA, 2016). This sparked my interest in PCP when recommendation came for the approach to be used for all children and young people with SEND (DfE & DoH, 2015).

My professional role also involves assessing the needs of children and young people in mainstream early years, primary, and secondary school settings, and a special school for children with CLCN. Exploring the child or young person's views forms part of my assessment practice. I reflected upon how the right to express their views about matters affecting them applies to all children and young people regardless of their age or the nature of their special educational needs, requiring different practice approaches to be taken when gathering individual views. My practice with secondary aged pupils in mainstream schools, for example, often involves using psychology tools and techniques while engaging a young person directly in conversation about their views. In contrast, my practice with children with CLCN typically involves combining information gathered through conversations with their parents and setting staff

with observations and play-based assessment of the child in their education setting.

My professional role with a special school for children with CLCN often involves assessing the needs of new pupils to the school, which can include early years children joining the school's nursery class as well as children and young people moving into the LA from inside and outside of the UK, for example as asylum seekers. I also support the school in meeting local and statutory requirements in relation to the SEND Code of Practice (DfE & DoH, 2015) and I participate in meetings to contribute to children and young people's EHCPs. The school uses an established PCP approach for these meetings. I observed how attempts to ensure the views of children with CLCN are considered when planning for their future can position adults in the role of proxy for the child. I reflected upon how adults can ensure the child's views are captured authentically during a PCP process.

I undertook a systematic review of the literature relating to exploring the views of children and young people with CLCN in January 2018, a full account of which is submitted in Volume 2 of the thesis. I wrote a professional practice doctoral assignment on the topic and proposed a practice framework (appendix 1), which can be considered as a theoretical proposal based upon critical review of existing literature. I recommended that approaches to exploring the views of children and young people with CLCN should be evaluated in terms of how the information gathered leads to meaningful participation by the child or young person in decision-making for their future.

Person-centred planning provides a context in which the proposed practice framework can be evaluated.

1.3 Person-centred planning for children with complex learning and communication needs

This section will detail a scoping literature review² undertaken in March 2018 and repeated in March 2021 to explore the literature available relating to PCP for children with CLCN in a SEND context. Thornberg (2012) asserts that exploring literature prior to empirical work helps a researcher to plan how their research will make a unique contribution to the current knowledge and understanding in the field of study.

The search term 'person-centred planning' was used in various combinations with terms 'children', 'special educational needs', 'communication', 'learning difficulties' and 'learning disabilities'. A total of 158 citations including duplicates were found using the electronic databases PsycInfo, ERIC, and Web of Science. Titles and abstracts were screened for relevance to the topic of PCP for children with CLCN in a SEND context. There were no studies found relating to this specific field, although three empirical studies and one systematic review were identified that provide insight into aspects of the field. The strengths and limitations of this literature in relation to the scoping review topic will now be discussed.

² A scoping review aims to identify the nature and extent of the empirical evidence that exists in relation to a topic rather than answer a particular question (Armstrong et al., 2011).

Ratti et al. (2016) provide a systematic review of the effectiveness of PCP for people with learning disabilities. Three out of the sixteen studies they selected involve children under the age of sixteen with only one of these studies taking place in an education setting (see Kaehne & Beyer, 2014). Ratti et al. do not give details of the communication needs of participants in their selected studies nor the nature of their participation in PCP. They report finding evidence to suggest participants' everyday choice making improves after PCP, although they conclude that this does not translate into improved self-determination for people with learning disabilities and that there is insufficient evidence to suggest PCP affords people with learning disabilities greater involvement in decision-making about their lives.

Kaehne and Beyer (2014) explore the effectiveness of PCP for young people with learning difficulties when preparing to leave a special school. They undertook a thematic analysis of the written records of forty-four PCP meetings and triangulated this data with interviews of family members. Kaehne and Beyer consider accessibility of PCP meetings to be key to ensuring the meaningful participation of young people in decision-making. They define accessibility in relation to use of language and visual cues during the meeting. However, they do not report upon the communication needs of the young people in their study and whether the general strategies they associate with accessibility can lead to improved participation for all. Kaehne and Beyer state that families were asked during interviews whether their child's views were considered during the PCP process, however their responses are not reported.

Pearlman and Michaels (2019) report there to be limited guidance on how to elicit the views, wishes and feelings of children and young people with PMLD for their Education, Health and Care Plan (EHCP). Although they do not refer to PCP specifically, the context for their research is provided by the SEND Code of Practice (DfE & DoH, 2015) requirement for children and young people to participate in decision-making. Their research takes place in a special school and includes seven children with PMLD as well as children with learning difficulties ranging from moderate to severe. A structured interview was undertaken with each child to elicit their views using alternative communication approaches such as pictures, symbols, or sign language. Interviews were recorded and watched by parents and professionals who were asked to rate the child's level of understanding and engagement during the interview.

Pearlman and Michaels (2019) report that the children participating in their study found responding to questions about their future more challenging relative to questions about their current school experience. Statistical analysis using a repeated measures ANOVA showed a significant difference between the ratings assigned by parents and professionals of the children's understanding and engagement during interviews ($F(1.43, 25.74) = 7.025, p = 0.007, \text{partial eta squared} = 0.281$), with parents rating their child's understanding higher relative to teachers and speech and language therapists. Pearlman and Michaels suggest further consideration should be given to criteria used by parents and professionals to interpret a child's communication. They conclude that when interpreting a child's views, a range of evidence needs to be gathered from a variety of sources so as to achieve a consensus. They caution that interpretations should not be made from a single

observation, as this may reflect the child's response in the moment and not represent a reliable view over time.

Taylor (2007) undertook three case studies to explore approaches to eliciting the views of children with multi-sensory impairment about their school experience. One of the children can be considered as having CLCN with limited intentional communication. Taylor's approach to exploring this child's views was to devise a questionnaire to be completed by school staff from the child's perspective. She cautions that proxy reporting of a child's views in this way should be seen as reflecting the adults' opinions unless triangulation takes place through observation and use of other school records, similar to Pearlman and Michaels' (2019) conclusion. Taylor acknowledges that her research findings are reported from her personal perspective and that data analysis is not undertaken. She considers a weakness of her study to be the considerable variation among her participants' learning and communications needs and the implications for the generalisability of her findings to a larger population group. In my view, this variability is as a strength that demonstrates the need for highly individualised approaches to be taken to exploring the views of children with CLCN.

Pearlman and Michaels (2019) and Taylor (2007) focus their research upon approaches to eliciting a child's views. Kaehne and Beyer (2014) give some consideration to a young person's participation in a PCP meeting. However, these studies do not report on how consideration of a child or young person's views can lead to improved participation in decision-making, which Ratti et al.'s

(2016) systematic review draws into question. The scoping review has revealed that the published literature exploring the use of person-centred approaches for children and young people with CLCN is limited, highlighting a gap in the literature that the current research will aim to address.

1.4 Theoretical perspectives and values informing the research

The systematic literature review (see Volume 2) indicates that exploring the views of children and young people with CLCN should be viewed as a social process. Language, communication, and social interaction provide the context within which PCP takes place and the child's expression of views is understood. Concepts pertaining to PCP require consideration, for example adults may have different conceptual understandings of a 'view' in relation to children with CLCN (see Ware, 2004; Harding, 2009). Definitions of PMLD (see Bellamy et al., 2010) highlight the significance of the relationship between child and adult as communicative partners when adults are required to infer meaning and interpret the communicative intent of a child who cannot speak for themselves. Consideration needs to be given to the frameworks adults bring to constructing the meaning of a child's views (Ingram, 2013) and how this process is influenced by the interactions between adults in the child's life and the ethos and values of the organisational context.

The relational context within which the views of children with CLCN are understood raises ethical issues. There is acknowledgement within the literature of the emotional involvement and 'power relationships' that may exist between a child and the adults in their everyday lives (see Porter, 2009; Ware,

2004; Wright, 2008), which must be considered when a child with CLCN is required to entrust others to speak on their behalf. Ingram (2013) suggests a child should have the opportunity for the construction of their views to be challenged, which implies a need for adults to reflect upon alternative interpretations of the child's views. The current research is underpinned by a fundamental ethical position regarding the need to consider the adult role when children severely affected by disability are dependent upon their relationship with adults to communicate their views and affect decision-making for their future.

1.5 Selecting a research methodology

The theoretical perspective and values informing the current research suggest a methodology is required that promotes reflexivity throughout the empirical process and allows exploration of the use of language and the relational context within which meaning is constructed. A qualitative methodology is chosen, as qualitative approaches enable researchers to explore language, thoughts and how meaning is created in social and cultural contexts (Corbin and Strauss, 2008). Grounded theory (GT) is a qualitative approach complementary to the proposed practice framework (appendix 1) providing the basis for the current research. Grounded theory research enables complex social processes to be explored (Miller, 1995) and aims to understand participants' experiences, the meanings they give to their experiences, and the wider context within which those experiences are located (Corbin and Strauss, 2008). Grounded theory methods allow a researcher to gather 'rich data' from multiple sources, with the aim of developing a theory that explains actions and

events found within the data (Charmaz, 2014). This approach mirrors the proposed practice framework that recommends drawing upon multiple sources of information to construct the meaning of a child's views.

There have been several developments in GT methodology since the original method was described by Glaser and Strauss (1967). Charmaz's (2014) constructivist version of GT informs the current research. Charmaz considers reflexivity to distinguish her approach from earlier versions of GT. She is concerned with the relationships and interactions between participants and researcher. She views research as constructed within a social context and encourages researchers to consider the personal perspective they bring to understanding their participants' lived experiences during their empirical work. This stance reflects the ethical position underpinning the current research and the consideration given to relationships and interactions between a child and the adults in their life when the child's views are constructed.

Original descriptions of GT methodology advise researchers to delay their literature search until the later stages of their research. Glaser and Strauss (1967) believe this approach ensures researchers remain open to generating new theories from data by avoiding pre-existing literature that may tend them towards fitting their data to extant theories. Thornberg (2012) considers this approach to be problematic, as researchers are prevented from undertaking GT studies in their field of expertise due to the knowledge and understanding they will already hold of pre-existing theories and literature relevant to their research topic. Thornberg proposes a variation on Charmaz's approach called

informed grounded theory. He offers seven 'data sensitising principles' (appendix 2) for researchers to follow, which guide them to scrutinise the prior knowledge, preconceptions and beliefs they may hold about their field of study from their professional practice experience and engagement with pre-existing literature.

Thornberg's (2012) approach is highly relevant to the current research given my professional role includes working with a school for children and young people with CLCN, my prior knowledge and practice experience of PCP, and the systematic literature review that I have undertaken already on exploring the views of children and young people with CLCN. Thornberg's data sensitising principles will be drawn upon to guide researcher reflexivity during my empirical work, promoting open and honest reflection upon the prior knowledge, preconceptions and beliefs that are likely to have informed and shaped my research design.

1.6 Overview of the thesis

This thesis is concerned with the empirical evaluation of a practice framework (appendix 1) created by the researcher from critical review of the literature on exploring the views of children and young people with CLCN. The literature review undertaken in part 2 will inform the research design by evaluating the use of GT methodology in the field of educational psychology, with a specific focus upon researcher reflexivity and how researchers engage with extant literature relevant to their research topic. The empirical report presented in part 3 will describe how GT methodology is used to explore and elaborate upon

existing theories and concepts underpinning the proposed practice framework and identify new theoretical perspectives to inform practice development. A critical appraisal tool devised from the literature review in part 2 will be used to guide the critical review of the research presented in part 4.

PART 2 – LITERATURE REVIEW

2.1 An introduction to grounded theory

The literature review is concerned with the application of GT methodology in professional educational psychology, with a specific focus upon researcher reflexivity and how researchers engage with extant literature relevant to their research topic. I will begin by describing the development of GT methodology. A summary of the origins of GT is provided in appendix 3.

Glaser and Strauss' (1967) original version of GT recommends researchers allow concepts and hypotheses to emerge from their data *before* exploring whether extant theories may be relevant to their field of study. They consider this to be an objective approach, allowing researchers to be open to generating new theories by ignoring the pre-existing literature that may be pertinent to their research topic and, therefore, avoiding a tendency towards making their data fit extant theories. Furthermore, they recommend researchers focus upon new areas of study where novel theories can emerge from data free from contamination by previous research findings.

Glaser and Strauss (1967) use terms such as “*predictions, explanations, interpretations and applications*” (p. 1) to justify the worth of a GT developed from data which, in my view, are positivist. However, aspects of their work do suggest an awareness of the social context for theory development and how a researcher may be an active agent in the process. Glaser and Strauss state a belief that construing theory development as an ever-evolving process rather than a final product reflects the reality of social interaction. Their concept of ‘theoretical sensitivity’ shows a recognition of how the theoretical insight developed by a researcher in their field may be helpfully combined with concepts and hypotheses emerging from the data to progress theory development. Although advocating for review of the extant literature coming later in the research process, Glaser and Strauss appear to recognise how researchers will inevitably bring knowledge of their field to the research process and that this may inform theory development provided that the researcher’s thinking does not become wedded to a preconceived theoretical position.

Charmaz (2014) suggests that it was Strauss who contributed pragmatism and references to human agency and interactionism to Glaser and Strauss’ (1967) version of GT. This philosophical position is clear in Strauss’ collaboration with Corbin in *Basics of Qualitative Research* (Strauss and Corbin, 1990). Strauss and Corbin consider a researcher’s knowledge and experience to be inextricably part of their thought processes leading to theory development, describing how a researcher’s perspective “*enters silently*” (p. 4) into the

conclusion they draw. They refute claims of objectivity being achieved by disregarding personal experience, stating that this undervalues the importance of reflexivity in theory development. Their stance towards the pre-existing literature in a field of study is similar to Glaser and Strauss (1967) in that they endorse delaying the literature review until concepts have begun to emerge from the data to ensure extant theories relevant to the research topic do not constrain a researcher. They accept that researchers are likely to have knowledge of the literature pertinent to their research arising from their professional and academic background and suggest that, as well as enhancing theoretical sensitivity, this may stimulate observation and interview questions in the initial stages of research enquiry. My interpretation of their position is that a deeper analysis of the extant literature should not be embarked upon once a researcher has determined a research proposal.

Strauss and Corbin (1990) reflect frequently upon the effects of a researcher's knowledge, experiences, and beliefs upon their research process. They believe that a researcher's attitudes and beliefs about the world they wish to study influence their research from the earliest stage when methodological choices are made that will advance theory development. They detail sixteen assumptions underpinning their construction of methodology, which include statements of how individual perspectives and interpretations of events may differ and how shared perspectives may be created when differences are debated and explored through social interaction. They also refer to the need to consider broader social, political, and cultural influences upon the context within which social interaction is located. They consider the actions and events forming the focus for a research enquiry to have arisen from a complex

interaction of multiple factors, and they seek a methodology that enables these complexities to be captured.

In a revised third edition of the *Basics of Qualitative Research*, Corbin offers a personal reflection upon how her own thinking about methodology has evolved over time. She talks of having selected her ideas about methodology “*based upon who and what I am*” (p. 9, 2008)³. Corbin notes that she has been influenced by postmodernist and constructivist paradigms while continuing to draw upon pragmatist and interactionist traditions, acknowledging the possibility that researchers may ascribe to more than one approach. She also states that multiple interpretations and reconstructions of research do not detract from research findings but add value by enabling shared understandings to be achieved. She writes of her concerns for ethics: the responsibility of a researcher to sensitively reflect participants’ perspectives and the emotional response of a researcher when listening to participants’ stories. She constructs researcher reflexivity as being “*self-reflective about how we influence the research and, in turn, how it influences us*” (p. 11, 2008).

Corbin (2008) cites Charmaz’s work as influential upon her approach to qualitative research. Both Corbin and Charmaz are concerned with the relationship between a researcher and their research, considering a researcher’s perspective to be an intrinsic part of the research process.

³ Corbin’s (2008) personal motivations and world view are suggested in her statement “I want to bring about social change and make persons’ lives better” (p. 11). She refers to her professional nursing background when discussing the importance of knowledge-based practice and an agreed conceptual language that enables researchers and practitioners to understand and talk about research findings.

Charmaz (2017a) states that a researcher's values and worldview define the meaning and relevance of the research questions posed. She shows particular concern for researcher position, privilege, and power, considering these to be constructions within the research process and an integral part of the complex interactions surrounding theory development. Charmaz encourages researchers to take a reflexive approach to their backgrounds and values and to the relationship between themselves and their participants. She believes that a researcher's knowledge and understanding of a participant's stories and actions is always interpretive. Charmaz recounts criticism of GT as a research approach that positions a researcher as an "*authoritative voice*" who "*fragments the respondent's (research participant's) story*" (p. 13, 2014). She proposes that a constructivist approach responds to this criticism by offering a method to transform otherwise invisible influences upon the research, such as the historical, situation and social contexts and the self, into explorable thoughts, actions, and processes.

Charmaz (2017b) considers her reflexive stance to be one of the fundamental differences between constructivist GT and earlier versions. Charmaz (2017a) introduces a concept of 'methodological self-consciousness' as assisting a researcher to identify and analyse their worldview, use of language and the meanings they create as well as the privileges and power that accompany their position. She also suggests that researchers make a conscious attempt to view their research from their participants' perspectives. She proposes that reflexivity can change how a researcher views their research aims, participants and themselves, which necessitates a flexible and evolving research process as originally described by Glaser and Strauss (1967). The fundamental

difference between Charmaz (2014, 2017a, 2017b) and Glaser and Strauss is that Charmaz considers a grounded theory as *constructed* rather than discovered.

Thornberg's (2012) re-interpretation of GT focuses upon a researcher's engagement with the literature in their field of study. He describes his version as *informed grounded theory* with its origins in Charmaz's (2014, 2017a, 2017b) constructivist approach and the pragmatist tradition. Thornberg believes that delaying the literature review until the later stages of a GT study is problematic for several reasons. He states that this approach prevents researchers from undertaking GT research in their areas of expertise due to the knowledge and understanding they will already hold of existing theories and literature relevant to their research topic. He discusses the practical need for researchers to write research proposals in order to gain funding and ethical approval, which require an overview of the related literature to be provided to assist members of organisations and committees in understanding why the research is required and how it will contribute to the current knowledge and understanding in the field of study. He warns that ignorance of the literature may cause a researcher to repeat the mistakes of previous researchers and "*reinvent the wheel*" (p. 245) without offering new perspectives or interpretations for consideration or debate to advance theory development.

Thornberg (2012) suggests that avoiding pre-existing literature prior to undertaking empirical work underestimates a researcher's ability to be reflexive and consciously aware of how their knowledge and understanding of the literature influences their research. My interpretation of Thornberg's

concerns for delaying the literature review is that this raises ethical concerns by leading a researcher into dishonesty and denial of the prior knowledge and preconceptions they will inevitably bring to the theory development process. Macfarlane (2009) warns researchers against *exaggeration* or *concealment* of their findings in order to confirm a preconceived idea (see appendix 4).

While Glaser and Strauss (1967) aimed to provide practical guidance for undertaking a GT study, Thornberg (2012) offers strategies for developing a theory grounded in data that has been informed by existing literature, theories, and concepts. He suggests that by following his proposed 'data sensitising principles' (appendix 2), researchers can take a critical view of the pre-existing literature in terms of "*relevance, fit and utility*" (p. 255) in relation to their data and, therefore, avoid forcing their data to fit pre-existing theories and concepts. Thornberg contrasts the inductive and abductive approaches to data analysis. The former describes the emergence of theories and concepts based purely upon the data while the latter allows a researcher to use their prior knowledge to generate a hypothesis that may explain aspects of the data. Thornberg is careful to note that he is not suggesting a hypothesis is 'tested' in a deductive sense. Instead, a hypothesis should be viewed as a "*source of inspiration*" (p. 247). He describes abduction as an innovative and creative process that draws a researcher towards noticing the surprises and exceptions in their data that cannot be accounted for fully by pre-existing theories and then to modify and elaborate upon their original hypothesis until all variations in the data can be explained. In practical terms, Thornberg describes how a researcher will move back and forth between their data and the literature, making comparisons that may offer new perspectives upon existing theories.

In my view, Thornberg's (2012) approach guides a researcher to apply the processes of analysis and reflexivity detailed by Glaser and Strauss (1967) and by Strauss and Corbin (1990) to their data *and* the literature. Thornberg suggests that researcher engagement with the literature should be guided by the codes, concepts and questions arising during data gathering and analysis. He encourages researchers to write down their thoughts and ideas while reading the literature as well as while analysing their data. It is through this process that Thornberg suggests a researcher can reveal the personal analytical lens through which they view their data and the pre-existing literature that informs theory development.

Summary

Grounded theory approaches offer practical guidance for exploring the theory development process. Elaborations of GT methodology have been influenced by social constructivist and pragmatist traditions with greater emphasis upon the influence of a researcher's perspective and worldview upon their research. Researcher reflexivity has become an integral part of the research process with researchers encouraged to consider the personal attitudes and beliefs shaping their research question and design, the privileges and power accompanying their position, their relationship with participants and how their research may be viewed from a participant's perspective. Open and honest reflection upon researcher engagement with the extant literature, theories and concepts related to their field of study is recommended for increasing theoretical sensitivity in order to advance theory development and for capturing

and analysing the influences upon the personal analytical lens through which a researcher views their data. Social interaction provides the context within which individual perspectives and interpretations of research findings can be considered, aiming towards a shared understanding of the value and significance of a study in its relevant field. The next section will consider GT research in professional educational psychology.

2.2 Grounded theory research in educational psychology

This section will explore how GT approaches have been used to inform theory development in the fields of educational psychology and support for children and young people with SEND. Consideration will be given to the suitability of GT methodology to educational psychology research and how EPs can undertake GT research in their professional practice field.

Miller (1995) applies GT methods to research behavioural interventions in primary schools. He presents a well-reasoned argument for the use of qualitative approaches in educational psychology, referring to the socially complex contexts within which EP practice takes place and the rich data generated as a result. However, after gaining first-hand experience of applying GT methodology, he concludes that GT is *“unlikely to become the research technique most widely used by practitioner EPs”* (p. 13). He considers the time-consuming nature of the method to be problematic for EPs practicing in LAs. He also suggests that a high level of supervision is required, potentially placing time demands upon others within an EP service.

Miller's (1995) study is the first example of GT research to appear in the UK educational psychology literature. Fourteen years pass until the next GT study undertaken in the UK is published. Butterworth (2009) uses social constructivist GT methodology alongside action research to explore ways in which reading attainment and enjoyment can be raised in one primary school in Jersey. Her reflections on the time consuming nature of the method echo Miller, although she concludes that the demand upon EP time is outweighed by the benefits of her research as reported by her participants. A consistent publication of grounded theory research in the UK educational psychology field is then seen from the late-2000s to present day.

Miller (1995) retains his view that qualitative approaches are relevant to educational psychology despite his reservations about the practical application of GT methods. His justifications reflect a social constructivist epistemology. He shows concern for the relationship between a researcher and their research, making a distinction between research undertaken by academics and that which is undertaken by practitioners in their field. He suggests that it is challenging for academic researchers to reflect the complexity of practice contexts in their theories. Furthermore, he proposes that practitioner-researchers are better positioned to form relationships with policy makers in their fields to construct a context for discussion and debate about their research findings, leading towards the creation of shared understandings between policy makers and practitioners that can influence future practice. This extends Charmaz's (2014) thinking about researcher position, privilege, and power beyond the researcher-participant relationship to the relationship between a researcher and those external to the research process yet

influential upon the research findings becoming a force for change. Macfarlane (2009) cautions that a researcher's relationship with influential others, such as sponsors or employers, requires ethical consideration when potential exists for organisational or political agendas to influence presentation of research findings.

My interpretation of Miller's (1995) position is that GT methodology is relevant to the complex social contexts where EP practice takes place yet may be better undertaken by researchers other than practising EPs. McKay et al. (2016) suggest that at the time of Miller's research, LAs and education settings were at an early stage of considering research activity to be a worthwhile use of EP time. They report that in the mid-1990s recognition of the importance of evidence-based practice within the educational psychology profession was beginning to grow with increasing opportunities available by the late-1990s for practising EPs to undertake doctoral research. This was followed by a significant redesign of the initial training for EPs, with doctoral level qualification becoming the single route for entry into the profession by the mid-2000s. MackKay et al. suggest that this change in initial training has increased the number of practising EPs who are skilled in undertaking research and who are able to offer research supervision to others.

Another change for the EP profession came in 2009 when a statutory requirement was introduced for all practising EPs to meet the standards of the Health and Care Professions Council. These standards require registrants to

undertake continuing professional development (CPD)⁴ to contribute to the quality of their practice and to benefit service users. The statutory requirement to undertake CPD means that practitioner EPs are likely to approach a research topic of interest with some prior knowledge of the pre-existing theories and concepts in their field of study acquired through CPD activities. This is congruent to Thornberg's (2012) view that practitioner-researchers undertaking research in their practice field will already have knowledge and understanding of the existing theories and literature relevant to their research.

MacKay et al. (2016) report that qualitative approaches are now well established within psychological research. There are recent examples within the educational psychology literature⁵ of GT methodology informing EP practice in several domains, despite Miller's (1995) doubts about the method. This raises the question of how practitioner-researcher EPs have been able to manage the prior knowledge and preconceptions they have acquired through CPD activities and professional practice experience when using GT to study a topic relevant to EP practice. A response to this question may come from inspection of procedural accounts given by researchers of how they have applied different elements of GT methodology in their research design. The social constructivist versions of GT described by Charmaz (2014) and Thornberg (2012) propose a reflexive stance practitioner-researchers can take towards evaluating how contextual factors affect theory development,

⁴ A mixture of different types of learning must be included in CPD activities, for example reading professional journals, attending conferences, or undertaking research. HCPC registrants are required to evidence their reflections upon how each activity has informed their practice.

⁵ Peer reviewed journals 'Educational Psychology in Practice' and 'Educational and Child Psychology' in the UK and 'Journal of Educational Psychology' in the USA.

including the influence of their prior knowledge, preconceptions, and beliefs upon their research activities. This leads to consideration of whether these versions of GT have influenced GT research undertaken within professional educational psychology.

Summary

Qualitative approaches afford educational psychology researchers the opportunity to explore the complex social interactions providing the context within which EP practice takes place. Miller's (1995) argument in favour of qualitative approaches and the relevance of GT methodology to educational psychology research shares similarities with Charmaz's (2014) social constructivist approach. Changes in the initial training of EPs has increased research activity within the profession and examples of the use of GT methodology can be found within educational psychology literature. However, EPs are unlikely to be able to approach research in their practice field without prior knowledge of the theories and concepts related to their research topic, conflicting with the GT approach described by Glaser and Strauss (1967).

The versions of GT described by Charmaz (2014) and Thornberg (2012) offer a reflexive approach that EPs can take to considering how their knowledge of pre-existing literature, theories, and concepts relevant to their field of study influences their empirical work. In the next section, the empirical literature relating to the use of GT in educational psychology will be systematically reviewed with the aim of exploring the procedural accounts given by

researchers of how they have applied GT methodology and whether Thornberg's data sensitising principles have influenced research design.

2.3 The systematic literature review

2.3.1 The purpose and rationale for the literature review

My prior knowledge and professional practice experience are pertinent to the current research for two reasons. First, I have an ongoing professional role working with a school that caters for children with CLCN where the research is located. Second, I have written a professional practice doctoral assignment on the topic of exploring the views of children and young people with CLCN and so I have knowledge of the existing literature relevant to the research topic. These experiences will inevitably cause me to bring preconceptions, attitudes and beliefs to the research process that will need to be managed within a GT research paradigm.

The broad aim of the systematic literature review, therefore, is to explore the empirical literature relating to the use of GT in educational psychology to inform the current research design. The specific focus is upon how researchers engage with the extant literature in their field of study and whether Thornberg's (2012) data sensitising principles are evident within their empirical process. Four review questions are presented in table 1

Table 1. Systematic literature review questions

Review question 1	What approaches have been taken to gathering and analysing data within a grounded theory research paradigm?
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Review question 2	How have researchers engaged with the pre-existing literature in their field of study when using a grounded theory approach?
Review question 3	How have differing and competing theoretical perspectives been identified and considered by researchers when developing a grounded theory?
Review question 4	How have researchers described and reflected upon their own thinking and theorising during the research process?

2.3.2 The systematic literature review process

The literature search began by locating citations of Thornberg’s (2012) *informed grounded theory* approach using the electronic databases ERIC and PsycInfo. Eighty-seven papers were identified. The titles and abstracts were screened using the inclusion and exclusion criteria shown in table 2. Seven empirical studies were identified that met the inclusion criteria, three of which were by Thornberg. A decision was made to include only one of Thornberg’s studies in order to seek a broad and balanced perspective on the use of GT by different researchers. The chosen study was considered to be most relevant to EP practice. An overview of the final five empirical studies identified for systematic review is presented in appendix 5.

Table 2. Inclusion and exclusion criteria for grounded theory studies*

	Participants	Context	Research topic	Study design
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<i>Inclusion criteria</i>	Study includes participants who are education professionals, parents, children or young people.	Education setting relevant to EP practice e.g. school, home.	Topic relevant to EP practice e.g. bullying, emotional well-being, school ethos, home education, reading development.	<u>Must</u> use a grounded theory approach to data gathering and analysis.
<i>Exclusion criteria</i>	Participants from other professional groups e.g. counsellors, psychologists; Participants not typically the focus for EP practice in the UK e.g. medical students, student athletes.	Other education setting e.g. higher education establishment without explicit link to SEND; Context unrelated to education.	Topic not typically the focus for EP practice in the UK e.g. development of spiritual and philosophical meaning, corporal punishment.	Other qualitative approaches e.g. thematic analysis or phenomenological analysis.

* Date parameters for the search are set from the publication of Thornberg's paper in 2012-present day. An additional inclusion criterion was applied to select only those studies published in peer reviewed journals.

The first phase literature search yielded a small number of empirical papers that met the inclusion criteria. Only one of the five studies found was undertaken by a practitioner-researcher EP. Sutcliffe's (2016) use of GT to explore a model of person-centred reviewing featured within a journal edition on research methods for educational psychology. As well as outlining his research, Sutcliffe described the history and development of GT and conducted a literature review of GT research undertaken by psychologists in education. This review focussed upon research elements such as topics and aims, data collection and participant sampling. Sutcliffe's literature review is considered complementary to the current research aims and offers scope to be extended.

A second phase literature search was, therefore, initiated to increase the number of empirical studies identified for systematic review by using the search terms 'educational psychology' and 'grounded theory' provided by Sutcliffe (2016). Seventy-five citations were found using the electronic databases ERIC and PsycInfo including three duplications and two studies already identified during the first phase literature search. The titles and abstracts were screened using the inclusion and exclusion criteria in table 2. Seventeen studies were identified from peer reviewed journals that met the inclusion criteria. Studies published prior to Thornberg's (2012) paper were excluded in keeping with the date parameters of the first phase literature search. This resulted in nine empirical studies satisfying all inclusion criteria and an overview of these studies is presented in appendix 6.

2.3.3 Critical review and synthesis of the literature

Thomas et al. (2017) detail several approaches to synthesising textual information obtained through a literature review process with relevance to the current literature review. They emphasise that although such a review may be described as qualitative, this does not necessarily reflect the methodology of the studies selected for review but instead refers to *how* the information provided by these studies has been analysed. They present a continuum upon which different approaches to synthesis can be located, ranging from approaches that aim to describe and summarise themes and concepts presented in the literature to those that aim to expand upon existing themes and promote conceptual development in order to create a deeper or new way of understanding a topic that may not be present within the current literature.

Thomas et al. (2017) place 'framework synthesis' at the midpoint on their synthesis continuum. They describe the distinguishing feature of this approach as being that it begins with either the selection of an initial conceptual framework from the background literature relevant to the review topic or by a researcher constructing an initial framework from their prior knowledge. The initial framework is used to help a researcher to understand the literature and employ an iterative process to expand upon the themes and concepts within the initial framework as the literature review progresses. The aim of framework synthesis is to develop a revised or entirely new framework that reflects the enhanced understanding that a researcher has developed by undertaking the literature review.

Framework synthesis has relevance to the current literature review as Thornberg's (2012) data sensitising principles have been used to create an initial framework through which to view the use of GT methodology in research relevant to EP practice. An intended outcome of the literature review is to create a new framework that translates Thornberg's principles into practical guidance that a researcher can use to guide and appraise their use of GT methodology. The sections that follow will describe how, guided by the four review questions, Thornberg's principles are used to understand the research design and methods described in the fourteen studies identified through the systematic review process. Selected studies are referred to in the following discussion to illustrate the response to each of the review questions.

2.3.3.1 Approaches to data gathering and analysis

This section will consider the first review question relating to how data is gathered and analysed within a GT research paradigm. Thornberg's (2012) principles of 'theoretical playfulness' and 'staying grounded' will provide the initial framework through which the empirical studies will be viewed to formulate a response to the review question. Thornberg describes 'theoretical playfulness' as a critical and creative way of thinking that enables a researcher to move from analysing data to generating new questions to ask of the data that stimulate theory development. Thornberg suggests that by combining this way of thinking with the principle of 'staying grounded', which requires the main research activity to remain focussed upon the data rather than the literature, a researcher may extend their thinking beyond pre-existing theories and concepts to create new possibilities.

Data gathering

Wong et al (2013) is the only study selected for critical review to use a questionnaire for data gathering. Their study explores multiple perspectives on school bullying with a sample size of over fifteen hundred participants, which is much larger than the other selected studies. Notably, Wong et al. are the only researchers among the selected studies not to interact with their participants during data gathering. They acknowledge that their questionnaire approach means that participant perspectives cannot be explored in depth. Their approach to data gathering generates large volumes of data but limits the richness and complexity of the data and the subsequent opportunities for

creativity and new ways of thinking to be stimulated to advance the research process akin to the 'theoretical playfulness' principle.

Semi-structured interviews with individual participants are the most commonly used method for data gathering among the selected studies. Seven studies use semi-structured interviews alone while two studies combine semi-structured interviews with other methods such as narrative approaches (see Fitzgerald et al., 2015) and focus groups (see Salter-Jones, 2012). Wolfe (2014) conducts semi-structured interviews with parents to explore their perceptions of a school-based programme aiming to build resilience in children aged 11 to 13 years. She describes a flexible interview style that follows a schedule of conversation topics rather than using pre-worded interview questions. Wolfe believes that allowing the line of enquiry to evolve during the interview process helps build rapport and increases the depth of understanding gained by the researcher of each participant's story, suggestive of Charmaz's (2014) thinking about the researcher participant relationship. However, Wolfe does not seek feedback from participants on how they experienced her interview style and whether her approach fostered the openness intended.

Harcohen (2012) does seek participant views of their interview experience when exploring teacher perceptions of the effect of high student turnover in international schools in the UK. Her semi-structured interview schedule begins with 'warm-up' questions to build rapport and concludes with debriefing questions to check whether participants felt comfortable to share their thoughts openly and to ascertain whether participants viewed the questions asked as

significant to their experience. Harcohen considers these checks important for increasing the validity of a researcher's interpretation of interview data. In my view, these debriefing questions also serve an ethical purpose to ensure, as far as possible, that each participant's story is told authentically by a researcher, responding to the criticism of GT noted by Charmaz (2014) regarding the risk of the participants' experience becoming fragmented when recounted through a researcher's "*authoritative voice*" (p. 13).

Wolfe (2014) acknowledges that a limitation of an open-ended interview style is that a researcher may "*lose sight of the direction of the interview*" (p. 61) for the research purpose intended. Other researchers refer to methods they have used to create a schedule for their interviews. Sheffield and Morgan (2017) adapt an interview framework from a similar study when exploring the perceptions and school experiences of young people with a behavioural, social, emotional, or mental health 'label' of SEN. They pilot their interview framework and subsequently introduced visual prompts, although the reason for this adjustment is not stated. Purcell (2012) conducted pilot interviews to develop an interview guide prior to her study of child, teacher, and parent perceptions of bullying in primary schools. The children involved in the pilot phase were not participants in Purcell's study and attended school in a different country to where the research and participants were located. In my view, this piloting approach limits the opportunity for participants to play an active role in co-constructing their interview experience and shifts the balance of power towards the researcher. Harcohen (2012) describes drawing upon "*relevant literature*" (p. 116) to develop a pilot interview schedule that aims to explore potential misunderstandings, use of language and "*power issues*" (p. 116)

between researcher and participant prior to data gathering. It seems to me that Harcohen's data gathering approach reflects the creativity of 'theoretical playfulness' while also demonstrating the 'methodological self-consciousness' described by Charmaz (2017a) by viewing the research from the participants' perspectives.

Three studies report using narrative approaches to gather data. Levy et al. (2018) and Fitzgerald et al. (2015) both used semi-structured interview schedules with the aim of eliciting participant stories about their lived experiences in their respective fields of study (see appendix 5 for details), although the extent to which these narrative approaches are distinguishable from other interview methods is unclear. Jones (2013) describes a different approach to gathering data for her narrative study of children's experiences of home education. She details a method involving children taking photographs of their everyday experiences and then providing a written or verbal narrative to accompany their photographs. Jones considers a strength of her approach to be the control afforded to participants over the data gathering process, which she considers addresses the power relationship between researcher and participants, echoing Charmaz's (2017a) social constructivist perspective.

Fitzgerald et al. (2015) also afford power to their participants by providing a choice of how they would like to provide their data, by individual interview or by taking part in a focus group discussion. In total, four of the studies selected for critical review refer to using focus groups for data gathering. Salter-Jones (2012) uses a series of focus groups followed by individual semi-structured

interviews with selected participants to explore teachers' and children's views on the implementation of emotional well-being initiatives in school. Migliaccio (2015) conducts a series of focus groups over a two-year period to explore teachers' definitions and perceptions of bullying. He requests participants respond to one another during focus group discussions to enable participant reactions to differing viewpoints to be observed by the researcher. Migliaccio considers the data gathered to reflect the sense of self and identity that participants wish to present to other group members, suggesting that he views his data as socially constructed within the focus group context. I consider this to extend Charmaz's (2014) thinking about the relationship between researcher and participant to also consider the relationships between participants and how their interactions influence the data gathered.

Sharp (2014) also encourages participants to respond to one another's ideas during focus group discussions when exploring the role of agency in young people's lives. His focus groups are located within community organisations where participants are established group members. He reports feedback from participants on their focus group experience, stating that they viewed the focus group as positive and enjoyed the opportunity to talk about themselves. Sharp supplements data generated from focus group discussions with observations of group interactions, conversations with adults involved in the community organisations where the research is located, and consideration of tangible items produced by the community groups' activities such as posters and news reports. He believes that these additional data sources enable constructs to be identified during data analysis that may have been harder for participants to articulate during focus group discussions. In my view, the breadth of data

gathered by Sharp enables the 'theoretical playfulness' principle to be realised by increasing the opportunities for new possibilities to be discovered and for new lines of research enquiry to be followed.

The range of opportunities for data gathering described by Sharp (2014) share similarities with the ethnographic fieldwork approaches of Thornberg (2018) and Murray (2013). Thornberg describes a longitudinal study that involves "*making observations of everyday interactions*" (p. 146) between teachers and children in the classroom, engaging in "*informal conversations*" (p. 146) and conducting interviews with participants to explore interpretations of school bullying. Murray aims to explore factors affecting children's ability to find solutions to problems in their home and education settings. She describes a "*jigsaw methodology*" (p. 1151) of combining multiple sources of data, including observations, fieldnotes, informal conversations and school documents in order to create "*a multi-layered case study series*" (p. 1151) that reveals contextual factors and affords opportunity for the research to be co-constructed with participants.

Murray (2013) gathers and analyses her data simultaneously, enabling decisions to be made about further data gathering to advance the empirical process, for example children are identified to undertake empirical work with their parents at home from the analysis of data gathered in the classroom context. This reflects Glaser and Strauss' (1967) description of GT as an evolving method that allows empirical decisions to be made during the research process to advance theory development. Murray implies that

empirical decisions are made through a process of comparing data gathered in the classroom context to a framework developed from the analysis of interview data gathered at the start of the research. However, this is not stated explicitly and a description of the researcher's thinking during the decision-making process would add credibility to the method.

The relationship between researcher and participants is of concern to Thornberg (2018) when gathering data and particularly with regards to the children participating in his study. He describes how he explained to the children his presence in their classroom as a visitor rather than an authoritative figure, giving particular attention to adult-child power relationships specific to the context where the research is located. Murray (2013) is also concerned by power imbalances between children and adults in relation to her own study and also in relation to empirical research in general. She believes that children should be considered to have potential to undertake research activity in addition to adults and she construes young children's problem-solving as a form of research behaviour. The method Murray describes implies that she positions the adults and children taking part in her study as 'research partners' who undertake research activity and data gathering independent of the researcher in their naturalistic setting. She considers her data analysis to be co-construction between researcher and participants. The next section will turn to the approaches to data analysis described by researchers.

Data analysis

All of the studies selected for review report using a constant comparison process for data analysis to generate theory from data akin to Glaser and Strauss' (1967) description of GT. Corbin and Strauss define constant comparison as *"the analytic process for comparing different pieces of data for similarities and differences"* (p. 65, 2008). They describe a process for comparing incident with incident within the data in order to group those incidents thought to be conceptually similar and identify the distinctive properties and dimensions of a code. Charmaz describes coding as a process of *"naming segments of data with a label that simultaneously categorises, summarises, and accounts for each piece of data"* (p. 111, 2014).

Some variation is seen between studies in the terms used to refer to different stages of the constant comparison process, for example both 'open coding' and 'initial coding' are used to describe the first stage of analysing segments of data. Jones (2013) refers to taking a 'line-by-line' approach to the initial coding of her data followed by asking questions about her codes to reveal her participants' actions, their purpose, and the reasoning for these actions. These questions move the analysis towards developing focussed codes that group the data into themes and formulate a response to the research question. Thornberg (2018) also refers to using questions after initial coding to consider his participants' concerns in each event within the data and what these might suggest. The use of questioning by Thornberg (2018) and Jones (2013) ensures a researcher's thinking remains focussed upon their data, demonstrating the 'staying grounded' principle. The questions they propose direct a researcher's attention to their participants' actions. I would expect the questions posed by a researcher to become more nuanced as the analysis

progresses and new associations, comparisons and possibilities are identified within data that stimulate further questioning, akin to the ‘theoretical playfulness’ principle.

Thornberg (2018) and Harcohen (2012) begin coding data early in their empirical work. Their early analysis guides the kind of data they plan to gather as their research progresses. Harcohen describes a process of naming ideas and events within her data during open coding of her first three interviews. She then plans further questions to ask during subsequent interviews to explore these events in more detail with other participants. As well as affording opportunity for deeper exploration of the ideas within her data, Harcohen’s simultaneous data gathering and analysis allows her to check whether her open codes have arisen from a “*subjective interpretation*” (p. 118) rather than the actual meaning of her participants’ words. This approach reflects the ‘staying grounded’ principle but also demonstrates the ‘constant reflexivity’ principle that Thornberg (2012) suggests ensures a researcher remains consciously aware of how their preconceptions may influence their analysis.

There are differences in terminology used by researchers to describe their approach to moving from ‘initial’ or ‘open’ coding to the later stages of data analysis and theory development. The terms ‘focussed coding’, ‘selective coding’ and ‘axial coding’ are all found to precede a final ‘theoretical coding’ stage. Purcell (2012) and Thornberg (2018) refer to using focussed coding to explain larger data segments by emphasising the most commonly occurring initial codes within their data. While Thornberg proceeds to theoretical coding,

Purcell describes an axial coding stage used to make comparisons between codes and identify similarities and differences that link codes into categories. Harcohen (2012) and Sutcliffe (2016) describes a similar process of axial coding followed by selective coding whereby axial codes are refined and the relationships between them are explored. Fitzgerald et al. (2015) use the terms selective coding and axial coding differently, with the former coming first in their analysis to develop themes and subthemes within initial codes and the latter being used to explain how concepts within the data are related. Migliaccio (2015) and Sheffield and Morgan (2017) use the term focussed coding to describe the overall process of identifying key concepts among the initial codes, refining these codes, and developing connections to form categories. These examples of terminology being used in different ways demonstrate the importance of researchers providing clear descriptions of their approach to data analysis and how the language associated with GT methodology has meaning to them and their study.

Four studies actively sought inconsistencies and exceptions within the data during analysis. Wong et al. (2013) refer briefly to identifying inconsistencies and exceptional cases during axial coding to modify their developing theory, although details are not given of how this was achieved. Wolfe (2014) refers to using 'negative case analysis' to add credibility to her findings by considering exceptions to her developing theory. She reports that exploring exceptions revealed to her the significance of context when developing a theory and understanding each participant's story. Sharp (2014) refers to looking for exceptions within his data during initial coding. When presenting his findings, he reports specifically upon constructs occurring less frequently within data

gathered during focus groups. He suggests that these exceptions may represent constructs that participants found harder to articulate during a focus group discussion, which are then explored by Sharp using other data sources. In my view, this approach demonstrates commitment by Sharp to ensuring the voices of the young people participating in his research are heard and that all of their contributions are considered equally valuable to the theory development process.

Sutcliffe (2016) adopted a different use of inconsistencies and exceptions to aid theory development. He refers to sampling one additional participant as a “*possible negative case example*” (p. 51) to test the credibility of his final analysis. He describes taking a purposive approach to sampling, with each participant selected specifically to facilitate exploration of concepts and themes emerging during data analysis. However, details are not given of the characteristics of each participant and Sutcliffe’s reasoning for why their selection enabled particular themes to be explored. Sutcliffe relies upon peer auditing to determine that he has reached the point of ‘theoretical saturation’ after his final interview, a term that Corbin and Strauss (2008) define as the point at which no data emerges and all concepts and themes can be explained in depth for the purpose of the study. Although Corbin and Strauss note that theoretical saturation is not easily attained and probably never achieved fully, Sutcliffe’s sample size of five participants is the smallest of all the studies selected for review and raises the question of whether new themes would have emerged had the sample size been increased.

Three studies used peer support to compare intercoder agreement with the aim of increasing the credibility and reliability of their analysis. Sutcliffe's (2016) analysis was checked by an experienced researcher during the early stages of axial coding and after selective coding. He then presented his theory to a professional with practice experience relevant to the research topic who gave feedback on open and axial codes and confirmed the logic and relevance of the theory to the field. Levy et al. (2018) and Wong et al. (2013) took a different approach to checking the reliability of their coding by working as a research team. Wong et al. describe a "*collaborative coding*" (p. 282) approach whereby a team aims to reach agreement on their use of coding to avoid a single researcher imposing their personal viewpoint upon the data. However, I would argue from a social constructionist perspective that a team of researchers working together must remain mindful of how their shared understanding of the data has been constructed within the social context of their research team and may still be susceptible to the influence of individual perceptions and beliefs that each team member wants to present to the group. Sutcliffe does not state his relationship to the peers who checked his analysis, but they are independent to his research and may be more likely, therefore, to provide an objective view.

Three studies sought participants' views of the GT developed during the empirical process. Miller (1995) presents a summary of his developing theory to participants whose interviews took place later in his research. This enabled feedback to be sought and the theory amended and clarified accordingly, however, the views of those participants whose interviews took place early in the research were excluded from this process. Sutcliffe (2016) refers to

presenting a “*brief summary of the final theory*” (p. 52) to his participants for feedback to check respondent validity and ensure key themes had not been missed from the analysis. Sheffield and Morgan’s (2017) approach to seeking participants feedback on their developing theory can be considered to be the more comprehensive of the three studies taking this approach. They present their theory in a focus group setting to all participants taking part in their study, although they acknowledge that some participants were unable to attend due to circumstances beyond their control. The focus group discussion was audio recorded and transcribed for coding, allowing new themes arising from participants’ feedback to be included within the developing theory.

Summary

The first review question is concern with approaches to data gathering and analysis within a GT study. The majority of studies selected for review adopt a data gathering method that affords direct interaction between researcher and participants. Studies vary in terms of the context within which interaction takes place with some researchers opting for one-to-one engagement with participants using semi-structured interviewing, others creating focus groups of participants interacting with one another and some researchers choosing to interact with their participants in naturalistic settings. Several researchers are concerned by their relationship with their participants. Some seek feedback on their participants’ research experience while others request the perspective of their participants upon their developing theory. Active involvement of participants in the research design and theory development process extends Thornberg’s (2012) ‘staying grounded’ principle beyond a researcher remaining focussed upon their data to ensuring researchers also maintain attention to the well-being and lived experience of their participants.

All studies use the constant comparative method of data analysis. Thornberg's (2012) 'theoretical playfulness' principle can be realised when researchers ask questions of their data to stimulate their thinking and generate new lines of enquiry. These opportunities can be increased when researchers begin data gathering and analysis simultaneously and at an early stage in their research process so as to guide their empirical work and deepen their understanding of the concepts and themes within their data. New possibilities may be discovered to advance theory development when several different data sources are drawn upon for comparison and when new perspectives upon the data are sought by sharing the developing theory with professionals with practice experience relevant to the research field.

2.3.3.2 Researcher engagement with pre-existing literature

This section will consider the second review question relating to how researchers engage with the pre-existing literature in their field of study when using GT approaches. A response to this review question will be considered by drawing upon Thornberg's (2012) principle of 'theoretical sampling of the literature' to provide an initial framework for evaluation of the empirical studies. This principle enhances a researcher's theoretical sensitivity by allowing them to search for concepts and theories within the extant literature and discover potential codes for consideration during their analysis. Furthermore, engaging with the extant literature can enable a researcher to locate the relevance and value of their work within a pre-existing body of research.

The most common use of literature among the studies selected for review is to justify research aims and methods, define concepts and key terms relevant to the research and outline the political, legislative and policy context within which a study is located. Levy et al. (2018) provide a detailed discussion of the pre-existing literature on shared reading between parents and children, justifying a need for qualitative research to explore factors affecting this practice. They return briefly to the literature when discussing the implications of their findings, contrary to traditional GT approaches that advise delaying the literature search until empirical work is complete (see Glaser and Strauss, 1967). Fitzgerald et al. (2015) discuss the benefits of undertaking an early literature review in terms of enhancing theoretical sensitivity, modifying existing theories and avoiding methodological errors made by previous researchers. They suggest the potential value of their study to the existing body of research by identifying a gap in the literature regarding parents' perceptions of early intervention services for children with disabilities. However, a critique of research methods employed by previous researchers is not offered to support their decision to take a qualitative approach.

Miller (1995) undertakes his literature review after data analysis, stating the purpose as being to support the theory that has been discovered. Wolfe (2014) and Salter-Jones (2012) focus their discussion of the literature prior to their empirical work upon the political, legislative and policy context within which their research is located. Their review of the literature pertinent to their research topic takes place after data analysis to support the concepts and themes within their data in line with Miller's approach.

Wong et al. (2013) and Purcell (2012) draw upon the pre-existing literature prior to their empirical work to define concepts relevant to their research on bullying. Wong et al. provide a definition of bullying and the roles that may be taken within a bullying dynamic. These terms are key to their research aim, which seeks to discover and compare the perspectives of bullying taken by different individuals within the dynamic. Purcell highlights the many definitions of bullying debated within the literature and the need, therefore, to specify which definition provides the frame of reference for her research findings. Both Wong et al. and Purcell offer critique by comparing differing perspectives within the pre-existing literature and comparing their research findings to extant theories and concepts.

Jones (2013) draws upon pre-existing literature to describe the context in which her research is located. She outlines the reasons why parents choose to home educate their children and the different forms home education can take before exploring children's perceptions of their home education experience through her empirical work. Jones conducts a further literature review at the focussed coding stage of her analysis to expand upon each of the three themes found within her data, for example she highlights relevant research to deepen understanding of children's identity and development of self with relevance to her research findings. Sheffield and Morgan (2017) draw upon pre-existing literature prior to their empirical work to define psychological concepts, such as attribution theory, relevant to their research on young people's perception of having special educational needs. They return to the

literature after their empirical work to consider how this and other psychological concepts, such as resilience theory, aid the understanding of their findings and implications for practice.

Harcohen (2012) states explicitly that GT methodologies open the possibility for theories and concepts to be discovered within the data that were not considered by a researcher when engaging with the literature prior to their empirical work. Sharp (2014) notes that there is a range of psychological research that supports the constructs found within his data and he acknowledges that the research he cites should not be considered exhaustive. This suggests that other psychological theories could frame the discussion of Sharp's findings and emphasises the need for Thornberg's (2012) principle of 'theoretical pluralism' to be applied when evaluating the pre-existing theoretical perspectives that may be used to understand a GT, which will be discussed in the next section.

Four of the studies identified for review undertook their literature review and data analysis simultaneously. All of these studies cite Thornberg (2012) and demonstrate the principle of 'theoretical sampling of the literature'. In his own study of bullying in schools, Thornberg (2018) describes bullying as a complex interaction that requires a researcher to draw upon a wide literature base to explore fully the theoretical concepts that may be associated with its occurrence. He maintains that theoretical concepts derived from the pre-existing literature can focus a researcher's attention to particular aspects and nuances in the data as considered relevant to the analysis. Sutcliffe (2016)

discusses Thornberg's belief that a researcher should acknowledge and reflect upon the literature relevant to their field of study rather than deny its influence upon the research process. Sutcliffe states that his research design is informed by Thornberg's thinking with regards to conducting a brief literature review to support application for ethical approval followed by a staged approach to a substantive literature review during data analysis.

Murray (2013) provides a clear rationale for her literature review with regards to defining key terms relevant to her research, establishing the context for her empirical work, and exploring differing perspectives within the pre-existing literature relevant to her research topic. With reference to Thornberg (2012), she states that her approach to GT methodology aims to combine existing theories and concepts with new empirical data to create an enhanced theoretical framework through which the phenomenon studied may be better understood. Migliaccio (2015) outlines a theoretical framework within which his study of teacher engagement with bullying may be understood prior to gathering data. Central to Migliaccio's study is the potential for disconnect to exist between academic understanding and lived experience. He details how his teacher participants' definitions of bullying reflect the definitions found within the academic literature yet their accounts of bullying taking place in their school and their perceptions and attitudes towards bullying are different to the literature definitions. Understanding of the pre-existing literature is, therefore, needed to draw comparisons with the data and explore this phenomenon.

Summary

The second research question considers the approaches researchers take to engaging with the pre-existing literature relating to their research topic when conducting a GT study. A range of approaches to literature review can be found within the studies identified for systematic review. Commonality exists between them in terms of their use of literature to define key concepts relevant to their study, consistent with Thornberg's (2012) 'theoretical sampling of the literature' principle. Typically, researchers draw upon the pre-existing literature after their empirical work to describe the concepts and themes they have identified within their data. However, some research topics require terminology and context to be defined clearly before embarking upon empirical work to ensure the ensuing findings are located and understood within the existing body of knowledge. Those researchers conducting their literature review alongside their data gathering and analysis use the pre-existing literature to compare, contrast and combine their data with existing theories and concepts to create an enhanced theoretical framework within which the phenomena being studied may be better understood. The comparing and contrasting of theoretical perspectives during a GT study will be explored in the next section.

2.3.3.3 Comparing and contrasting theoretical perspectives

This section will consider the third review question of how researchers identify, compare and contrast differing and competing theoretical perspectives during their theory development process. Thornberg's (2012) principles of 'theoretical agnosticism' and 'theoretical pluralism' will provide the initial framework through which the empirical studies will be considered to provide a response

to this review question. 'Theoretical agnosticism' is defined by Thornberg as taking a critical stance towards pre-existing theories and concepts, treating all as proposals that can be modified or disputed whether they have arisen from a researcher's professional practice experience or from the findings of other researchers. 'Theoretical pluralism' is conceptualised as the comparing, contrasting, and combining of a range of theoretical perspectives, sometimes from different epistemological positions, so that a researcher may achieve a fuller understanding of their data and guard against forcing data to fit a particular theory that match their pre-conceptions about the research topic.

Five studies selected for review refer to identifying theoretical perspectives from pre-existing literature to enhance the 'theoretical sensitivity' of the researcher (see Miller, 1995; Sharp, 2014; Fitzgerald et al., 2015; Sutcliffe, 2016; Thornberg, 2018). Miller draws upon a wide range of literature to deepen his existing understanding of theories, models, and concepts that he anticipates may be used as codes during data analysis. His approach is in keeping with Glaser and Strauss' (1967) description of how a researcher should develop their theoretical sensitivity by engaging with a broad literature base. Sutcliffe and Thornberg refer to theoretical perspectives within pre-existing literature as 'tools' that can focus a researcher's attention upon certain aspects of their data. Sharp (2014) uses meta-ethnography to combine meanings derived from pre-existing literature and propose factors that may promote the development of young people's sense of self and agency ahead of his analysis. He cautions that a researcher should remain consciously aware of allowing their analysis to be driven by the knowledge and understanding they have gained from the literature while developing the

theoretical sensitivity required to identify concepts and themes within their data. In my view, 'theoretical agnosticism' could facilitate the conscious awareness that Sharp recommends by reminding a researcher to view the pre-existing literature as a theoretical proposal.

Fitzgerald et al. (2015) suggest that engaging with pre-existing literature at an early stage facilitates constant comparison by allowing a researcher to compare their data with existing theories and concepts during analysis. They compare their findings to models of multi-agency working to support children with disabilities. Purcell (2012) and Wong et al. (2014) also compare their findings to pre-existing literature to identify agreement and inconsistencies. This approach leads Wong et al. to integrate their findings about multiple perspectives on the targets and causes of school bullying into one theoretical model, while Purcell compares participant constructs of bullying and friendship to findings by other researchers and selects Bronfenbrenner's (1979) ecological model to frame her own findings.

Migliaccio (2015) elaborates upon Bronfenbrenner's (1979) model to frame the discussion of his research findings and explain the disconnect between teacher education and their engagement with bullying in schools. He proposes a circular relationship exists whereby human agency, social interaction, and the wider social context influence one another. He demonstrates 'theoretical agnosticism' by treating an existing theoretical model as modifiable and 'theoretical pluralism' when combining theoretical perspectives. A sociological perspective is the dominant discourse within Migliaccio's writing and is

congruent with the description of his research interests and his overarching aim to address bullying as a social problem.

Sharp (2014) also demonstrates 'theoretical pluralism' when integrating theoretical perspectives from different psychological domains. He describes taking a social-cognitive perspective on human agency to explore factors that enable young people to perceive themselves as active agents in their lives. He generates a schema from his research findings which he compares to his initial literature review to identify emerging constructs not evident within the pre-existing literature. Sharp integrates existing theories on efficacy, attribution, and self-determination into one model as well as drawing upon Vygotskian theory and theoretical perspectives from occupational and developmental psychology to explain constructs for a young person's perceptions of themselves as agents in their lives.

Murray (2013), Jones (2013), and Thornberg (2018) use contrasting theoretical perspectives to provide alternative lenses through which their findings can be viewed, demonstrating 'theoretical pluralism' by offering insight into how their research can be understood in different ways. Jones acknowledges that different theoretical perspectives upon child development, pedagogy, community, and citizenship are likely to influence individual perceptions of what constitutes 'education' in her study of children's experiences of home education. Murray discusses differing theoretical perspectives on children's learning and development in her study of children's problem-solving behaviour. She references Piaget when describing cognitive

skill development as a series of problem-solving episodes but rejects this theory as a framework for understanding her research findings. Instead, Murray draws upon Vygotskian thinking to consider how children make meaning when they actively engage in posing and resolving problems and how socio-emotional factors such as attention, self-regulation, and planning affect children's problem-solving behaviour.

Thornberg (2018) details the theoretical perspectives taken by previous researchers when exploring bullying in schools and discusses how each perspective alters how bullying is viewed. He is critical of perspectives from developmental and educational psychology, suggesting that these offer a deficit view of individual and family factors leading to the occurrence of bullying (although I would contest his representation of educational psychology). He argues the need for socio-ecological and symbolic interactionist perspectives to be taken to bullying in schools to explore the influence of factors such as school ethos, cultural norms, social interaction, diversity, and power. Thornberg's justification for his methodology is routed in the theoretical perspectives he has chosen for his research. He demonstrates 'theoretical pluralism' by acknowledging the value of both individual and socio-ecological perspectives when discussing his research findings, concluding that individual factors alone cannot explain the occurrence of bullying in schools but should be considered within a socio-ecological framework.

Summary

The third research question explores how researchers identify and consider differing and competing theoretical perspectives when developing a GT. Several researchers identify extant theories within pre-existing literature to enhance their theoretical sensitivity for noticing concepts and themes within their data. Thornberg's (2012) 'theoretical agnosticism' principle reminds a researcher to treat concepts and themes arising from the findings of other researchers as proposals that can be challenged or revised. This principle guards a researcher against allowing their analysis to be shaped by a particular pre-existing theoretical perspective, requiring a researcher to take reflexive approach towards the thought processes underpinning data analysis which will be considered in the next section.

Thornberg's (2012) 'theoretical pluralism' principle guides a researcher to view their research through the different lenses provided by competing and contrasting theoretical perspectives to explore how their findings may be understood in different ways. By considering a range of theoretical viewpoints and by integrating theories into one model, a researcher is afforded opportunity to consider how their findings may be located within an existing body of knowledge and how they can make a distinct contribution to their field of study.

2.3.3.4 The reflexive researcher

This section will consider the fourth review question relating to how researchers describe and reflect upon their thought processes during their empirical work. Thornberg's (2012) principles of 'memoing extant knowledge associations' and 'constant reflexivity' will be drawn upon to formulate a

response to this review question. The studies selected for review will be scrutinised to consider how researchers acknowledge and reflect upon their preconceptions, attitudes and beliefs towards their research topic as well as considering whether researchers demonstrate a conscious awareness of their epistemological position and how this is manifested in their research design and theory development process. First, I will consider how memoing is described within each version of GT and then turn to its use by researchers.

The practice of memo writing is found consistently within descriptions of GT methodology and is defined by Glaser and Strauss (1967) as a tool for illustrating ideas and integrating codes when comparing data during analysis. They describe the comparison of data as “*dependent on the skills and sensitivities of the analyst*” (1967, p. 103), suggesting awareness of how researchers may engage with data differently with the potential for individual researchers to conduct different analyses and arrive at different conclusions from the same data set. However, they see memo writing only as an aid to coding that supports theory development rather than an opportunity to reveal the researcher’s thinking during the analytic process.

Strauss and Corbin (1990) consider memo writing to be more than just a representation of the ideas within a code but a method to “*stimulate and document the analytic thought processes and provide direction for further theoretical sampling*” (p. 140), implying that empirical decisions may be made as a result of thoughts occurring during the writing process. They refer to different kinds of memos as “*coding notes, theoretical notes, and operational*

notes” (p. 118) but caution that memoing should be a fluid process and researchers should not be constrained by attempts to make their thinking fit into a category.

Charmaz’s (2014) description of memo writing expands the notion of documenting a researcher’s thinking to consider how the preconceptions, attitudes, and beliefs that a researcher may bring to their research may be revealed and become part of the analysis. She states that through the act of memoing “*your (a researcher’s) standpoints and assumptions can become visible*” (P. 162). Charmaz makes a distinction between memo writing that facilitates the development and refinement of codes and their meaning and methodological journal writing that documents the “*methodological dilemmas, directions and decisions*” (p. 165) presented to a researcher that result in action that shapes their empirical work. She considers these forms of writing to afford a researcher opportunity to explore participants’ actions and the meanings they have created from their experiences as well as exploring the actions of a researcher and the meanings they have created through their active engagement in research activity.

Thornberg (2012) extends further the application of memo writing to reveal how a researcher’s engagement with the extant literature relevant to their research field may influence how they view their data. His principles of ‘theoretical agnosticism’ and ‘memoing extant knowledge associations’ guide a researcher to treat their knowledge of pre-existing theories and concepts, obtained from the extant literature or from their prior experience in the research

field, as proposals that are flexible and modifiable during the research process. He suggests that memos are written while a researcher engages with the literature as well as with their data. In my view, this approach offers practical action a researcher can take towards making explicit the prior knowledge and preconceptions they will inevitably bring to the theory development process.

There are different examples of memoing found in the studies identified for systematic review. Levy et al. (2018) and Purcell (2012) make no reference to memo writing during their analysis. They state that their data analysis was informed by GT principles, but they do not discuss the different versions of the method nor their epistemological position. Fitzgerald et al. (2015) also do not refer to writing memos. However, they are clear on their epistemological position and approach to GT, selecting a constructivist approach within a pragmatist and relativist research paradigm. They affirm their belief that new theories are constructed by a researcher through their interactions with the research topic and participants. The credibility of this position could be strengthened by providing examples of the researchers' thinking during the empirical process in the form of memos to make explicit how their thought processes contributed to theory development.

Some studies use memo writing during one part of their analysis only. Migliaccio (2015) writes memos but not until the theoretical coding phase of data analysis. He states that the purpose for using memos at this stage is to develop the researcher's theoretical perspective. However, no explanation is given of *how* this was achieved. Migliaccio (2015) is the only study selected

for review to describe his analysis as “*lean(ing) towards an (Thornberg’s) informed grounded theory approach*” (p. 89) by drawing upon past research in his field of study. He states his epistemological position as constructionist, suggesting that his participants’ descriptions of their experiences and behaviours should not be taken as accounts of actual events but rather as social constructions developed within a group context. Application of Thornberg’s (2012) principle of ‘memoing extant knowledge associations’ while engaging with the data *and* past research could have illustrated, from Migliaccio’s perspective, the value added to the theory development process by choosing Thornberg’s variation of GT over other versions of the method.

Sheffield and Morgan (2017) refer to using memos during focussed coding to explain “*emergent categories*” (p. 53). They opt for a constructionist GT approach, although their reasoning relates to pragmatic issues such as flexibility and adaptability of the approach for effective data gathering rather than a stated epistemological position. Jones (2013) also refers to writing memos at the focussed coding stage for developing themes and for guiding her literature review. She does not state explicitly whether a particular GT approach has influenced her methodology nor does she give her epistemological position. Sharp (2014) refers to using an “*abbreviated version of grounded theory*” (p.351). He explains which aspects he has chosen for his research design with a focus upon the need for a researcher to remain consciously aware of the potential for their perceptions and subconscious biases to influence coding during data analysis. He describes taking a critical realist perspective, accepting the existence of a reality about which different

people hold different perceptions, including researchers. However, Sharp does not use memoing or another form of reflexive writing during his research.

Wolfe (2014) does not commit to a specific GT approach and suggestion of an epistemological position is only made in her discussion of eco-systemic psychological theory. However, she does provide an example of her memo writing during open coding alongside the data segments accompanying the memo. This provides an insight into her thinking and affords the reader opportunity to consider whether alternative interpretations of the data may be possible. Without examples of a researcher's reflexive writing, the links between the data, the researcher's thinking and the next steps in the empirical process are implied rather than explicit.

Harcohen (2012), Miller (1995) and Wong et al. (2013) describe writing both a reflective diary and memos at the start of their empirical work to record their knowledge and assumptions about their research topic. Although these researchers do not state an epistemological position, their awareness of the potential for a researcher's preconceptions, attitudes, and beliefs to affect the empirical process and their aim of curtailing these effects upon their data is embedded within their method. In my view, this reflects a critical realist perspective. Salter-Jones' (2017) social constructionist position within a critical realist research paradigm accepts the reality of the school systems that provide the context for her study while acknowledging that individual perspectives upon these systems will have been socially constructed. Salter-Jones is concerned for her role as a researcher in constructing her participants'

stories within the social interaction created to gather data. She does not use memo writing until the final stage of her analysis as a tool for clarifying and integrating key themes within her data and exploring the psychosocial processes underpinning these themes. Reflexive writing at an earlier stage in the process could have offered insight into the researcher-participant relationship and how, from Salter-Jones' perspective, this affected theory development.

Sutcliffe (2016) refers to writing memos throughout his empirical work to record his thoughts during data analysis and theory development as well as during literature review. He suggests that this approach increases the "*transparency and trustworthiness*" (p. 51) of his analysis, reflecting Thornberg's (2012) 'memoing extant knowledge association' principle. Sutcliffe (2016) states clearly how his methodology is informed by Strauss and Corbin's (1990) GT approach. He justifies his research design by stating how their critical realist epistemology matches his own theoretical position and also his research aims, which seek to explore changes in school processes and explain how these changes have occurred.

Murray (2013) also uses memos at more than one stage in her research. She refers to writing memos when developing initial codes and when moving to the theoretical coding stage of her analysis. She acknowledges that the scope of her paper limits the exemplification and depth of discussion of her data. Therefore, few data extracts are provided for scrutiny and examples are not given of Murray's memo writing. However, she states her theoretical and

ethical position clearly. The overarching aim of her study is to address what she considers to be the social injustice of denying young children the opportunity to undertake research activity. She describes how her methodology is based upon constructivist GT with participants' descriptions of how they understand their experiences viewed as constructions between researcher and participant.

The references Murray (2013) makes to her preconceptions, beliefs and stance as a researcher illustrate Thornberg's (2012) 'constant reflexivity' principle. Thornberg considers a researcher to be "*a main instrument in data collection and analysis*" (p. 254) when undertaking qualitative research. It is, therefore, essential in Thornberg's view for a researcher to reflect openly upon their preconceptions and theoretical influences that create a frame through which their data and analysis is viewed. I would add that of equal importance is a researcher's reflection upon their ethical position, the worldview that underpins their research aims, and their motivation to embark upon their particular field of study, as illustrated by Murray.

Summary

The fourth review question considers how researchers reflect upon their thought processes during theory development with a specific focus upon researchers' preconceptions, attitudes and beliefs and the epistemological position underpinning their empirical work. There is significant variation among the studies identified for systematic review in their reflexive writing practices and in their discussion of their epistemological position. In my view,

Thornberg's (2012) 'memoing extant knowledge associations' and 'constant reflexivity' principles can be realised by combining the reflexive practice examples offered by individual studies. Wolfe's (2014) examples of memo writing accompanied by extracts from her data gives the reader opportunity to reflect upon how her thinking shaped her theory development, demonstrating the open and honest reflection recommended by Thornberg. Salter-Jones (2017) and Sutcliffe (2016) not only state their epistemological position but provide an explanation of how the perspective they have taken matches their research aims and the context within which their research is located. The reflexivity demonstrated by Murray (2013) extends Thornberg's thinking to consider a researcher's ethical position and motivations for embarking upon their particular research journey.

2.4 Conclusions and implications for grounded theory research

The discussion of GT methodology has focussed upon two main themes. First, consideration has been given to how a researcher engages with the extant literature relevant to their research topic when undertaking a GT study. Second, the relationship between a researcher's prior knowledge, beliefs, and preconceptions about their field of study and the theory development process has been explored.

There have been several evolutions of GT methodology since the mid-twentieth century. The influence of social constructivist and pragmatist traditions can be seen in later versions of GT. Researcher reflexivity is integral to Charmaz's (2014, 2017a, 2017b) approach, which encourages researchers to consider the personal attitudes and beliefs shaping their research question

and design, the privileges and power accompanying their position, their relationship with participants and how their research may be viewed from a participant's perspective. Thornberg (2012) extends Charmaz's ideas about researcher reflexivity, recommending open and honest reflection upon researcher engagement with the extant literature, theories and concepts related to their field of study. He proposes researchers take an abductive approach to data analysis by comparing and contrasting their data with existing theories and concepts, which may then be modified and expanded upon to create new theoretical perspectives.

Thornberg (2012) proposes that delaying the literature review until the later stages of a GT study will prevent practitioner-researchers from undertaking GT research in their professional field due to their existing knowledge and understanding of theories and concepts relevant to their research topic. This is pertinent to EPs who are likely to have acquired prior knowledge and understanding in their research field through their professional practice activities. My own professional practice experience as an EP working with children with CLCN stimulated my curiosity and interest in wanting to learn more about how the adults working with this group of children understand their views (see section 1.3). I believe that exploring the meaning of the views of children with CLCN is a social process requiring an interactionist research approach. Hence, I consider Charmaz's (2014) social constructivist version of GT to be appropriate to my research topic (see section 1.6).

The broad aim of the systematic literature review was to see how other researchers have drawn upon Thornberg's (2012) data sensitising principles when undertaking a GT study with professional practice experience and knowledge of the literature pertinent to their research topic. Thornberg's principles were used to create an initial framework by which the empirical studies could be evaluated and a response to the review questions could be formulated. An intended outcome of the literature review was to create a new framework that translates Thornberg's principles into practical guidance that a researcher can use to appraise their application of GT methods. This new framework – the 'critical appraisal tool for grounded theory' (CAT-GT) – is presented in appendix 7.

The commonality among all of the studies selected for critical review, including those citing Thornberg (2012), is that none provide a detailed account of how his data sensitising principles are realised in their research designs and translated into actions that can be evidenced during their empirical process. I will employ the CAT-GT in part 4 to appraise my application of Thornberg's principles and to critically review the empirical work detailed part 3.

PART 3 – EMPIRICAL REPORT

3.1 Introduction

This section will provide a critical summary of the literature relating to exploring the views of children with CLCN. The systematic literature review was

undertaken between January 2018 and March 2018 for the purpose of writing a professional practice doctoral assignment⁶. This assignment discusses my prior knowledge, understanding and beliefs about the current research topic. The literature review in part 2 identified researcher reflexivity to be an integral part of GT research (see Thornberg, 2012; Charmaz, 2014). I have applied a process informed by Thomas et al.'s (2017) continuum for analysing textual information (see appendix 8) to facilitate reflection prior to my empirical work and to create the critical summary that follows.

3.1.1 Critical summary of the literature relating to exploring the views of children and young people with CLCN.

The critical summary has three aims. First, the personal analytical lens through which I will view my research will be described. Second, the methodological and ethical issues identified within the literature that are pertinent to my research and may inform my research design will be considered. Thornberg (2012) suggests that research engagement with extant literature should provide opportunity for methods employed by previous researchers to be critiqued, ensuring mistakes are not repeated that may hinder theory development. Third, the concepts and themes that will provide my frame of reference for data gathering and analysis will be identified.

My knowledge, understanding, and beliefs about the research topic

⁶ A full account of the systematic review and methodological critique of the literature relating to exploring the views of children with CLCN is submitted in Volume 2 of the thesis.

Exploring the views of children with CLCN is an under-researched area with limited literature available to guide EPs working in this field. Greathead et al. (2016) note that there has been little research undertaken specifically to explore the views of children with CLCN communicating at a pre-verbal stage. The systematic literature review identified 10 studies relevant to understanding the views of children and young people with CLCN (see appendix 9). Seven of these studies are empirically based and three present a theoretical discussion.

The conceptual meaning of a 'view' is discussed within the literature. Wright (2008) considers all children to be authorities on their lived experiences while Ware (2004) and Harding (2009) question whether the concept of a having a 'view' can be attributed to children with CLCN. They conceptualise a viewpoint as different to a reaction or emotional response, with the former requiring the cognitive skills of memory, comparison, reasoning, and hypothetical thinking that children with CLCN may not possess. While acknowledging the legitimacy of the debates within the literature about the conceptual meaning of a 'view' in relation to children with CLCN, I believe that the enabling and strengths-based definitions of PMLD described by Bellamy et al. (2010) move the discussion about the conceptual meaning of 'view' towards a realistic appraisal of the information gathered and how this information will be used by others to benefit the child or young person. In my view, ensuring the rights established in law of children with CLCN to express their views about matters affecting them (see section 1.1) requires a pragmatic approach.

Bellamy et al. (2010) identify commonality among definitions of PMLD with regards to the need for those familiar with a child or young person to interpret communicative intent. Porter (2009) describes ways in which adult behaviour may shape children's responses in her study of how teachers can support communication process when ascertaining children's views. Greathead et al. (2016) observed both the child's communicative acts and adult behaviours that may affect the child's communication in their study of how to support children with CLCN to express their views. Wright (2008) compared several sources of data to demonstrate a potential for bias when adults familiar to a child infer meaning from their communication to interpret a child's views. Ingram (2013) describes the different psychological frameworks that may be applied when adults infer meaning from a child's communication.

Engagement with the literature has led me to consider from an ethical perspective the adult role as a communicative partner when exploring and interpreting the views of children with CLCN. I believe that exploration of how to understand these children's views should extend beyond debating the conceptual meaning of a 'view' or considering the practical application of a communication tool, for example Talking Mats (Murphey & Cameron, 2008) or the Mosaic Approach (Clark & Moss, 2001), to explore how adults construct meaning from the information gathered.

Methodological issues identified in the literature

Qualitative approaches and case study design are typical among the empirical studies (see Ware, 2004; Brewster, 2004; Wright, 2008; Greathead et al.,

2016). Harding (2004) suggests that case study design is appropriate when exploring the views of children with CLCN, as a small sample size can yield rich data for analysis while allowing the individualistic and diverse needs of children with CLCN to be planned for within the research design. Empirical studies mostly involve children and young people from secondary school age to adulthood. Greathead et al. (2016) provide the only study to include one participant with CLCN of primary school age.

Empirical studies do not explore the thought processes of the adults involved in gathering the views of a child or young person with CLCN. Ware (2004), for example, does not question whether her participants' conceptualisation of a 'view' in relation to the young person central to her study was different to her own and whether her own beliefs may have influenced her participants' responses and how they experienced the research process. Greathead et al. (2016) are the only researchers to acknowledge a limitation of their study being that the adult's experience of supporting the child's communication was not explored. The adult role in understanding the views of children with CLCN will, therefore, be the focus of the current research. I will return to the methodological issues noted above when describing my method in section 3.2.

Concepts and themes providing a frame of reference for data gathering and analysis

The concepts and themes identified in my professional practice doctoral assignment by applying a process informed by Thomas et al. (2017) (see appendix 8) are summarised in table 3. These will be kept in mind throughout

my empirical work to enhance my theoretical sensitivity and provide potential avenues to explore. Further discussion of these themes will take place alongside consideration of the research findings in part 3.4.

Table 3. Summary description of themes identified in the extant literature

<i>Theme</i>	<i>Frequency</i>	<i>Description</i>
Cognition and development	8	The cognitive skills of the child and the cognitive demands placed upon the child when seeking their views.
Communication approaches	18	The methods the child uses and the context in which the child communicates their views.
Conceptual meaning of a 'view'	9	The ways in which adults define the term 'views' and what the adults consider constitutes a view
Empirical approaches	19	The methods used by other researchers that are relevant to the current research.

Ethics and principles	23	A sense of moral principles guiding exploration of the child's views.
Interpreting and creating meaning	19	How the adults understand and make meaning from the child's communication.
Organisational context	4	The organisational context within exploration of the child's views is located.
Participation	11	Children's views are sought in a way that promotes their active engagement in decision making and planning for their future.
Relationships	29	The relationship between the adult and the child that supports communication and the relationship between the adults around the child.
Researcher beliefs	12	The researcher's attitudes, beliefs, preconceptions and epistemological position regarding the current research and the researcher's attitudes and beliefs about EP practice.
Statutory duties	5	Awareness of the legislation that states that children have a right to express their views when decisions are made that affect them.

3.1.2 Research aims and questions

The research has two main aims. First, approaches to gathering the views of children with CLCN will be explored and consideration will be given to how this can inform person-centred planning. Second, the application of Thornberg's (2012) data sensitising principles to a GT study will be evaluated. Three research questions have been devised to address the research aims, as shown in table 4.

Table 4. Research questions

Research question 1 (RQ1)	How do parents and professionals describe their experience of understanding the views of a child with complex learning and communication needs?
Research question 2 (RQ2)	How can parents' and professionals' understanding of the views of a child with complex learning and communication needs inform person-centred planning?
Research question 3 (RQ3)	How can Thornberg's data sensitising principles (see appendix 2) be applied when developing a grounded theory that has been informed by existing literature, theories, and concepts?

The research will focus upon exploring how adults construct meaning when ascertaining the views of children with CLCN, as literature review identified that existing empirical studies have not explored the experiences of adults during this process. The research is located within a PCP context in order to explore how the process of engaging adults in thinking about a child's views can facilitate a child's participation in decision-making. A proposed practice framework for gathering the views of children and young people with CLCN (see appendix 1) will be applied in order to achieve the research aims. The research will provide opportunity for the framework to be developed in response to research findings and for the validity of the framework to be increased through empirical investigation.

The first and second research questions will be addressed from the findings of the empirical study described in part 3. The third research question will be addressed in part 4 by using the critical appraisal tool for grounded theory (CAT-GT) (see appendix 7) developed from the literature review in part 2 to critically review the empirical study.

3.1.3 Epistemological position

The study is underpinned by a social constructionist epistemology. The literature review submitted in Volume 2 of the thesis indicated that exploring the views of children and young people with CLCN should be seen as a social process with consideration given to contextual factors such as the intended purpose of the adults seeking the child or young person's views, how adults construct the meaning of a 'view' in relation to the child or young person and how adults interact with one another when interpretations of the child or young person's views are constructed. Social interaction also provides the context for person-centred approaches to ensuring a child's views inform decision-making about matters affecting them. Person-centred planning requires collaboration between the significant adults in a child's life (Corrigan, 2014). The child, their family, and the professionals involved are viewed as equal partners in the planning process and power imbalances are addressed (Sanderson, 2000). Person-centred planning does not intend to identify one 'objective truth' about what is best for a child. Instead, a range of perspectives are considered equally through the discourses and social interactions taking place between the people involved with the aim of co-constructing a shared plan.

A social constructionist epistemology considers knowledge and meaning as created collectively within a group. This position accepts that each group member holds a subjective viewpoint that has been influenced by their individual experiences, leading to multiple realities influencing the creation of shared meanings by the group. The current study aims to explore the

individual subjective viewpoints that contribute to understanding the views of a child with CLCN when decision-making for their future takes place in a PCP context. In the context of the current research, participants' descriptions of their experiences and inferences when making sense of the views of a child with CLCN will be thought of as constructions of reality created through the discourses and social interaction taking place between researcher and participants.

A social constructionist epistemology accepts that a researcher's attitudes and beliefs about the field she wishes to study are likely to have influenced her empirical work. A conscious attempt is made to make explicit my thinking throughout the research process from the earliest stage. A reflexive approach is also taken towards the social context in which the research is located, considering potential issues of privilege and power and how these may be manifested within the researcher-participant relationships. The research design actively seeks to engage participants in the process of shaping and elaborating upon themes and concepts within the data so that the developing theory is co-constructed by researcher and participants.

3.2 Method

3.2.1 Research design

The literature review identified qualitative approaches and case studies to be dominant methodologies among research aiming to explore the views of children and young people with CLCN (see section 3.1.1). Simons (2009)

defines case study as the study of a phenomenon in its 'real life' context, exploring its complexity and uniqueness in-depth and from multiple perspectives. She notes a strength of case study design being the opportunity afforded to a researcher to explore the influence of individuals and the interactions between them upon a particular situation. Furthermore, Simons states that case studies can address imbalances of power over who controls the creation of new knowledge derived from research activity by actively engaging participants in the process of co-constructing shared meanings with the researcher. This complements the social constructionist epistemology of the current research and reflects Charmaz's (2014) thinking about researcher power and the researcher-participant relationship.

The current research is informed by Charmaz (2014) and Thornberg's (2012) versions of GT and uses a multiple case study design. Language, communication, and social interaction provide the context and tools for exploration of individual perspectives and co-construction of shared meanings between researcher and participants. Three case studies are undertaken, each comprising one child with CLCN and three adults significant to the child's school experience. Data is analysed collectively to formulate a response to the research questions.

3.2.2 Ethical considerations

This section will detail the ethical considerations made when designing the study. A review of the ethical matters arising during the empirical process and how these were addressed will be provided in section 4.2.

Ethical approval for the study was granted by the UCL Research Ethics Committee (REC) (see appendix 10). The committee scrutinised how consent would be obtained from the children participating in the study, noting that they would be unable to make an informed decision about their participation due to their cognitive impairment. MacIntyre's (1999) thinking about disability was drawn upon to formulate a response to the committee. MacIntyre asserts that people with the most severe forms of disability and dependence upon others should not be seen as 'passive objects' from whom we have nothing to learn. He suggests that caring for someone with a severe disability offers the opportunity to learn what it means to be answerable for another person's well-being. In my view, preventing children with severe cognitive impairment from participating in research because they are unable to give informed consent disenfranchises these children from research activity and the opportunity to make a difference through empirical pursuit; an opportunity which is afforded to other population groups.

The British Psychological Society's (BPS) Code of Human Ethics Research (BPS, 2014) states that appropriate methods must be used, when possible, to enhance the ability of vulnerable people, such as children with CLCN, to "*understand the nature, purpose and anticipated outcomes of any research participation*" (p. 31). The children participating in the current study have severe cognitive impairment and do not use a formal communication system. It is accepted that information about the study cannot be presented in a way that would enhance their understanding. When informed consent cannot be

obtained, the BPS Code of Human Ethics Research states that the person legally responsible for the child must give consent and the principle of monitoring *assent* should be applied throughout the research. This principle is employed by Greathead et al. (2016) in their study of approaches to supporting children with severe-to-profound learning difficulties and complex communication needs to make their views known. They refer to monitoring the children's assent during research activities by observing their behaviour and responses towards the researcher. A similar approach was adopted for the current research. Assent was monitored by asking the adult participants to describe how each child would usually communicate that they do not want to do something or that they do not want an activity to continue. These descriptions were kept in mind throughout the observation phase of data gathering and observation ceased if a child showed behaviours suggesting they wished to withdraw from an activity.

The research design includes consideration of the children's views to enable the process for exploring their views to be evaluated and the research aims fulfilled. I was mindful that the children do not use formal communication systems and cannot communicate their views directly. Attempts to understand their views are seen as a social construction made by the researcher and adult participants. The proposed practice framework (appendix 1) developed for exploring the views of children and young people with CLCN recommends that alternative interpretations of the child views should be constructed for comparison. This is an important ethical consideration when there is potential for an adult's own views, wishes and feelings to influence their interpretation of a child's views. The research design, therefore, includes data gathering

from multiple sources to enable comparisons to be made. The children's views are explored with a range of adults who have different relationships with each child as well as observing the children's reactions and responses in the school context so that adults' interpretations of the children's views can be contrasted with the children's communication about their school activities.

The potential vulnerability of the parent participants is considered within the research design. I am aware through my professional practice experience that parents of children with SEND can be at different stages in understanding and accepting their child's needs. The process for recruiting parent participants, therefore, aimed to identify parents who are considered likely to feel comfortable answering questions about their child's needs so as to guard against exposing parents to threat of undue emotional distress from being asked to talk about their child. I was also mindful of the level of commitment asked of participants and how research activities might impinge upon their lives. The children participating in the study were observed without disruption to their usual school activities. However, I was conscious of placing time demands upon parents who are caring for a child with complex needs alongside the usual challenges of daily living. A flexible approach was taken to making practical arrangements for parent interviews and individual circumstances were considered⁷.

⁷ One parent, for example, asked for her interview to take place at home rather than in school due to family commitments.

I remained mindful of the need to manage my dual role with the school as a local authority (LA) EP and researcher throughout the study. The inclusion criteria for participant selection (see table 4) aimed to reduce the potential for conflicts of interest occurring by ensuring parents and children participating in the study were not known to me in my LA role. A reflexive research diary was kept throughout the research process to facilitate reflection upon issues that could require me to give a view in my LA role on matters affecting the school (see appendix 11). Issues arising were explored through the usual supervision arrangements within the LA, ensuring alternative viewpoints were considered to reduce potential for bias.

When granting ethical approval, the REC stipulated a condition that I must work with the children, parents, and relevant professionals during the course of the study with a view to establishing alternative ways of enhancing the children's communication approaches. The research design, therefore, included collaboration with the school speech and language therapist (SALT) to consider the information gathered about the children's communication and views and evaluate each child's communication approaches accordingly.

3.2.3 Participants

The research is located in one special school for pupils aged 2-19 years who have severe and complex learning difficulties. The school's ethos and existing practice were considered to complement the research aims and offer opportunity for best practice approaches in the field of working with children and young people with CLCN to be explored (see appendix 12). The headteacher welcomed the opportunity for the school to host the study.

Selection of potential participants began through discussion with the headteacher and the school SALT, focussing first upon the children and their parents. The purpose for this discussion was to apply the inclusion and exclusion criteria for participant selection (see table 5) to identify three children and their parents to approach to take part in the study.

Table 5. Inclusion and exclusion criteria for child and parent participants

	<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
1.	Children attending the special school who are aged between 3 and 11 years at the start of the study.	Children or young people attending the special school who are over 12 years of age at the start of the study.
2.	Children who have been identified by professionals as having severe or profound learning difficulties <i>and</i> complex communication needs.	Children who have complex communication needs without cognitive impairment, e.g. children with a physical disability affecting their communication.
3.	Children who are not yet using a formal communication system such as such as speech, sign, symbols, pictures or other augmentative communication aids.	Children who are using a formal communication system effectively to express their wants and needs so that they can be understood by other people.
4.	Children and their parents who have not met the researcher in her professional role but may have been involved previously with another educational psychologist, e.g. from the local service, from another LA service or privately.	Children and their parents who have had previous involvement with the researcher in her professional role as a LA educational psychologist.
5.	Parents who are considered by school staff to appear comfortable and at ease when answering questions about their child's needs.	Parents who have appeared distressed when talking to school staff about their child's needs or who are known at the start of the research to be in dispute with professionals regarding their child's needs or provision.

Inclusion criteria one to three were developed from review of the literature relating to exploring the views of children and young people with CLCN (see section 3.1.1). With regards to criterion one, existing research has focussed predominantly on exploring the views of children and young people with CLCN of UK secondary school age through to adulthood. Hence, the children participating in this research were selected from the early years and UK primary school age phases of 3 to 11 years. With regards to criteria two and three, children with severe cognitive impairment who are not able to use a formal communication system are considered to be the most dependent upon adults to infer meaning when their views are gathered. This population group was, therefore, considered most relevant to the first research question of exploring adults' experiences of understanding the views of a child with CLCN. Criteria four and five relate to the ethical considerations regarding participant vulnerability and the researcher's dual role.

Six children and their parents were identified initially by applying the inclusion and exclusion criteria to the school's total cohort. Further discussion took place to consider in more depth which of the parents were most likely to feel comfortable talking about their child's needs and whether there were any known circumstances that may present a challenge to parents participating in the study. Three children and their parents were identified from this discussion.

Once the children and parent participants were recruited, discussion took place with the headteacher and the school SALT to identify members of school

staff to approach to take part in the study. The purpose for this discussion was to determine which staff had experience of working with the children and would be able to talk about their communication and views. The aim was to recruit two members of staff per child with each pair comprising two different professional roles within the school, for example a class teacher (CT) and a teaching assistant (TA). This approach was intended to increase the breadth and depth of the data gathered by exploring perspectives from different professional backgrounds. One professional was recruited from outside of the school due to the availability of staff who know the children well (see appendix 13). The potential to recruit a participant outside of the school context was seen as an opportunity to further increase the breadth and depth of data gathered.

The method for recruiting participants, and the written information provided for participants and consent forms are detailed in appendix 13. A summary of the relevant background information of the three children and the professionals participating in the study is presented in tables 6 and 7.

Table 6. Summary of background information for participating children and parents

<i>Parent and child participants</i>	<i>Child's age at start of research</i>	<i>Family context⁸</i>	<i>Child's special educational needs and medical diagnoses⁹</i>	<i>Child's educational history</i>	<i>Parental experience of EHCP review.</i>
Child_1 and mother	4 years	Child living at home with mother, father, and baby brother (aged under 1 year).	Chromosomal deletion 1p36 syndrome Epilepsy Visual impairment Low muscle tone (unable to walk unaided) Gastrostomy fed	Joined school this academic year due to family moving into the LA. Attended childminder previously but had not attended a school.	First annual review.
Child_2 and mother	11 years	Child living at home with mother, father, and twin brother (aged 11 years). Regular contact with four cousins of a similar age.	White Sutton syndrome Epilepsy Visual impairment (affecting distance vision) Mild hearing impairment Structural talipes and low muscle tone (began walking unaided recently) Abdominal migraines (controlled by medication)	Joined school this academic year after parental request for change of school placement from special school in home LA.	Annual reviews have taken place in previous school. First annual review to take place in current school.

⁸ None of the children's siblings were reported to have special educational needs or a disability

⁹ Special educational needs in addition to the severe or profound learning difficulties and communication needs specified within the inclusion criteria.

Child_3 and mother	11 years	Child living at home with mother, father, brother (aged 9 years) and sister (aged 7 years).	Angelman syndrome Epilepsy Coordination difficulties (unable to walk unaided) Feeding difficulties	Joined school three years ago after parental request for change of school placement from special school in home LA.	Annual reviews have taken place in previous school and current school.
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Table 7. Summary of background information for participating professionals

<i>Child known to professional</i>	<i>Current professional role</i>	<i>Professional experience</i>
Child_1	Class Teacher (CT_1)	12 years of experience working in a school for children with severe and complex learning difficulties, working as a teacher and lead in the primary and early years phases. 18 months of experience as a teacher in a mainstream school prior to current role.
	Teaching Assistant (TA_1)	25 years of experience working in a school for children with severe and complex learning difficulties. The past 15 years have been as a higher level TA in the early years phase.
Child_2	Speech and Language Therapist (SALT_2)	3 years of experience as a SALT in a school for children with severe and complex learning difficulties, with prior experience of working as a SALT assistant in mainstream and special schools.
	Play Worker (PW_2)	11 years of experience working for a local charity providing support to families and short break activities for children and young people with learning and physical disabilities, working as a play worker and session supervisor.
Child_3	Class Teacher (CT_3)	4 years of experience working in school for children with severe and complex learning difficulties, currently teaching the more able cohort. Previously a teacher in a mainstream school prior to current role.
	Teaching Assistant (TA_3)	19 years of experience working in a school for children with severe and complex learning difficulties.

Additional participants were present for phase 3 of data gathering and details are provided in appendix 14.

3.2.4 Data gathering

An overview of the timeline for the empirical work is presented in appendix 15. Data gathering was undertaken in three phases.

3.2.4.1 Phase 1 – Semi structured interviews

The first phase of data gathering involved a semi-structured interview being conducted individually with the adult participants. All of the interviews shared three aims. First, the interview process aimed to explore the kinds of approaches that participants may take to understanding the views of a child with CLCN and how they describe their experience of attempting to make sense of the child's perspective. It is intended that analysis of this data will address RQ1. Second, the interview process aimed to explore participants' experiences of planning for the child's future and their thoughts about how a child with CLCN might be involved in decision-making. It is intended that analysis of this data will contribute towards addressing RQ2. Third, each interview aimed to explore the participants' views of how the child communicates and their understanding of the child's views of their experiences and activities. This data was analysed with the data gathered through observations during phase two and presented during each child's PCP meeting in phase three to contribute towards addressing RQ2.

Semi-structured interviews are the most common form of data gathering among the GT studies selected for review in part 2. Wolfe (2014) uses a schedule of conversation topics as an interview guide rather than planning pre-worded questions, however, she warns that an interview style that is too open-ended may lose direction and not address the intended purpose of the

research. An interview schedule was, therefore, created using questions to structure the conversation between researcher and participant to ensure data gathered addresses the research aims. Corbin and Strauss (2008) suggest a researcher's prior knowledge can inform interview questions and Harcohen (2012) draws upon relevant literature to develop her interview schedule. The interview schedule for the current study is informed by themes within the proposed practice framework (appendix 1).

Charmaz's (2014) approach to conducting an interview for a GT study was drawn upon when planning the interview schedule. She advises researchers begin by developing broad open-ended questions followed by focussed questions that delve into conversation topics. The structure of the interview schedule, therefore, comprises a series of open-ended questions each of which is accompanied by focussed questions that may be used as prompts to further the line of enquiry. The interview schedules for parents and professionals (see appendices 16 and 17 respectively) were broadly similar with some minor differences. Parents were asked to provide demographic data regarding their child's educational history, special educational needs, and disability. Professionals were asked to reflect more broadly upon their experience of PCP and understanding the views of children with CLCN beyond the case study, increasing the breadth of data gathered to address RQ1. The current research employed methods for data gathering and analysis simultaneously (see section 3.2.6) to reveal new lines of enquiry to explore during the empirical process. This gave rise to new interview questions being developed during data gathering and explored in later interviews (see appendix 18).

Charmaz (2014) suggests that an interview schedule should be treated as a flexible tool that may be revised during the empirical process. A decision was made, therefore, not to pilot the interview schedule with the aim of co-constructing the interview process with participants. I aimed throughout the interviews to strike a balance between pursuing conversation topics arising from my knowledge, experiences, and beliefs, and exploring stories participants brought to mind during the interview process. Questions could be rephrased, and follow-up questions could be posed later in the interview to pursue an alternative line of enquiry or to encourage a participant to elaborate upon their first response. An example transcript is provided in appendix 19.

Harcohen (2012) and Wolfe (2014) note the importance of researchers building rapport with participants to create a context in which participants feel comfortable to tell their stories. Rapport was developed with participants during the contacts made by the researcher at the recruitment stage (see appendix 13). Charmaz (2014) suggests that rapport should be monitored during an interview by a researcher paying attention to their participant's non-verbal cues and being sensitive to the participant's interview experience. She also advises researchers consider their own responses during an interview and how their comments validate the participant's perspective and convey appreciation for their contribution to the research. Active listening skills used in my professional EP role were drawn upon during interviews. Non-verbal cues such as nodding and brief verbal affirmations such as "*yes, that makes sense*" were used to validate participant responses. Paraphrasing was used

to show my understanding of the participant. Illustrative example transcripts are provided in appendices 20 and 21.

All interviews were conducted in a location convenient for participants, which typically was the school. The length of interviews ranged from 30 minutes to one hour. The interviews with the TAs were noticeably shorter. This was attributed to them not previously taking part in a PCP process and, therefore, interview questions relating to their experience of the process were not relevant. Interviews were audio-recorded. I transcribed the audio recordings rather than using third party transcription in order to increase my familiarity with the words used by the participants before beginning data analysis. Transcription focussed upon the spoken word rather than non-verbal communication.

3.2.4.2 Phase 2 – School-based observations

The second phase of data gathering involved observing the children in school. The aim of the observations was to check the validity of the information gathered during the interviews in relation to how each child communicates and the child's views of their experiences and activities. This phase of data gathering ensured analysis of data that would contribute towards addressing RQ2 was as close to representative of the child's views as possible.

Murray (2013), Sharp (2014) and Thornberg's (2018) methodologies were drawn upon when designing phase two. These researchers use observations

and fieldnotes as sources of data combined with formal approaches to data gathering such as focus groups and interviews. Thornberg describes his method for researching school bullying as “*ethnographic fieldwork*” (p. 146) involving observations of everyday interactions between adults and children in the classroom as well as informal conversations and interviews with participants. My location within the children’s everyday school context for data gathering purposes is informed by Thornberg’s method.

Activities to be observed were planned after analysis of interview data, ensuring relevant lines of enquiry discovered during phase one were pursued. Some pragmatic considerations were made when planning observations such as my availability alongside my professional commitments. Child_1 was in the school’s nursery class and discussion with the CT indicated that the pattern of activities for each nursery session was fairly consistent. This led to the decision to undertake an extended observation of child_1 during one nursery session. Child_2 and child_3 were in the primary phase of the school and followed a structured timetable with different activities taking place across the week. A series of observations was, therefore, considered appropriate to capture a range of activities. Child_2 was observed on three occasions and child_3 was observed on two occasions due to her being absent from school.

Observations included activities described by adults during their interviews as eliciting a response from the child and indicating a possible preference. The observations of child_2 and child_3 also included an activity suggested by

SALT_2 called 'Lis'n Tell'¹⁰. This activity was considered by SALT_2 to be relevant to the current research. Murray (2013) afforded her participants autonomy when making decisions about data gathering. Observing an activity suggested by a participant was considered to offer opportunity to reveal a new lens through which to view the research findings.

Observations ranged in length from 30 to 70 minutes depending upon the activity and the child's engagement and assent. My professional practice skills were drawn upon when making observations, paying attention to the nature of the activity and how the child was responding to the activity and to the people around them. Focussed codes developed during analysis of interview data were used to guide observations. I also remained open to the possibility of new concepts and themes being discovered. I was present in the room where the activity was taking place but remained on the periphery of the group so as not to intrude. Adults and children were present in addition to those who had consented to take part in the study. All adults were aware of the research activity taking place. I did not seek to engage with the adults or children during observation but responded to them positively if they initiated interaction or conversation. Handwritten fieldnotes were used to record observations and informal conversations considered relevant to the research. These were typed after the observation in a style that would be used in EP professional practice, recording the observations made and my thinking about what had been observed (see appendix 22).

¹⁰ Lis'n Tell is an interactive storytelling approach for children with speech, language and communication needs that enables the children's spontaneous participation in the story to develop the narrative (website accessed 27 December 2020).

3.2.4.3 Phase 3 – The person-centred planning meetings

The third phase of data gathering involved a PCP meeting for each child. The school uses a person-centred format for all EHCP annual review meetings developed in-house and well-known to school staff and professionals working in the school (see appendix 23). This format reflects the principles of a person-centred approach described by the SEND Code of Practice (DfE & DoH, 2015) and was considered appropriate to use for the current research. The PCP process was observed for each child with the aim of addressing RQ2 by exploring how discussion about the child's views during the meeting informed decision-making and planning for the child's future.

Information gathered from the interviews and observations about the child's views were shared with the children's CTs one week prior to the PCP meetings (see appendix 24). Discussion took place with each CT about video clips, photographs, and captions they could use to create a presentation to illustrate the child's views, in keeping with the school's usual practice. Presentations were watched by participants at the beginning of the PCP meetings and parents were asked whether they thought the presentation reflected their child's views. All parents agreed with the representation of their child's views.

The PCP meetings were facilitated by the headteacher and lasted approximately 90 minutes. Introductions were made at the start of the meetings, which provided opportunity for participants to be reminded that I was

attending the meeting in a research capacity rather than in my professional role typically associated with an EHCP annual review. The discussion taking place during the meeting was observed and handwritten fieldnotes were made. Focussed codes developed during the preceding phases of data gathering (see section 3.2.6.3) were used to guide observations with careful attention paid to how the child's views informed decision-making.

The PCP meetings also provided opportunity for a summary of the analysis from the preceding phases of data gathering to be presented to participants for their feedback. This aspect of the empirical process had two aims. First, participant agreement with the interpretation of their interview responses could be checked to increase the validity of the research findings. Second, the act of inviting feedback was intended to address potential power imbalances between researcher and participants by actively involving participants in the theory development process, reflecting a social constructionist epistemology.

Written information (appendix 25), was prepared and sent to participants a week before their meeting, providing a summary of concepts and codes developed during initial and focussed coding stages of data analysis that would form the basis for the developing theory. Selection of codes to discuss with participants focussed upon codes occurring frequently within the data and codes that suggested an unexpected research finding when compared to the pre-existing literature (see section 3.1.1). I asked for feedback, for example, on the 'concept of future and time' and 'meaning of a view' as the former was prominent within the data but not present within the pre-existing literature while

the latter was prominent within the pre-existing literature but discussed by only one participant during phase one.

The written information was proofread by a layperson¹¹ to ensure terminology used would be accessible to participants. Some changes were made in response to the feedback received. The term 'code', for example, was changed to 'theme' to reflect everyday use of language. The codes 'agency of the child' and 'affective factors' were changed to 'children's emotions and preferences', which was in keeping with the language used by participants during their interviews rather than the language I had used during focussed coding to create concepts or ideas to synthesise initial codes and explain larger segments of data.

The start of the meetings was chosen as the time to seek feedback from participants as they would be present in school for the meeting and so the additional demand upon their time would be minimised. All parent participants attended the meeting for their child, however, not all professionals participating in the study were able to attend due to circumstances beyond my control. One such circumstance was due to the delay in the meetings taking place caused by the coronavirus pandemic, which meant that the children had entered a new school year since the research began and the adults working with them in school had changed. The written information about the research findings was made available to these participants.

¹¹ A personal friend with knowledge of my research topic and who was a parent but not a professional working in a field related to my study.

A focus group format was used to gather feedback from participants. The written information was given to participants at the start of the meeting with reading time allowed. The purpose for seeking participant feedback was then reiterated and three questions were posed for participants to consider, as shown on the information sheet (appendix 25). I facilitated the discussion by guiding participants to consider each question in turn and ensuring quieter members of the group had the opportunity to contribute. All three focus group discussions lasted approximately 20 minutes followed by the 90 minute PCP meeting. Handwritten fieldnotes were made during the discussion to record participant responses.

3.2.5 Data analysis

3.2.5.1 The constant comparison process

The empirical process for developing a GT from data is underpinned by constant comparison, as seen in the first description of the method by Glaser and Strauss (1967) and the later versions developed by Charmaz (2014) and Thornberg (2012). Thornberg's data sensitising principles (appendix 2) guide a researcher to make a conscious shift between comparing data with data, data with codes and codes with codes to make comparisons between the data and a researcher's prior knowledge of the extant literature in the field of study.

The current research used constant comparison throughout the empirical process. The literature review undertaken in part 2 identified several studies whereby data gathering and analysis are undertaken simultaneously (see Harcohen, 2012; Murray, 2013; Thornberg, 2018). A similar approach was taken for the current research of moving back and forth between gathering data and making comparisons within the data to inform decision-making about lines of enquiry to pursue and subsequent data to gather.

3.2.5.2 Initial coding

The first stage of data analysis, initial coding, was informed by Charmaz's (2014) guidance on beginning data analysis (see appendix 26). Analysis began after the first interview. The interview transcript was uploaded to the NVivo computer software program. I read through the transcript, highlighting segments of text containing incidents¹² and assigning a word or phrase to represent the meaning of each incident and create a code. Text segments were compared with previous text segments to consider whether their meanings shared similarities that meant they could be assigned the same code. New codes were generated when words and phrases used by participants carried meaning that was different in comparison to previous codes. Concepts and themes noted in table 3 provided a frame of reference when embarking upon coding while I also remained open to discovering new possibilities that could be contrary to my beliefs or something that I had not considered previously. Memos were written when codes were created (see

¹² Charmaz (2014) defines an 'incident' within the data as an event, action, thought or feeling described by the participant.

section 3.2.6.4) to capture my thoughts about the meaning of the code. Memos were refined and expanded upon as new text segments were added.

The initial coding process was applied to each interview transcript throughout phase one of data gathering. Text segments assigned to each code were compared after coding each transcript to check for similarities and differences between the meanings of the words used by participants. Text segments were recoded as required. Codes were then compared with codes to check for distinctiveness. Codes were combined if they shared a similar meaning. Next, the words and phrases used to name each code were compared, checking they were representative of the meanings within the text segments assigned to the code and amended when necessary. Finally, codes were compared with the concepts and themes noted in table 3 to identify any interesting or unexpected lines of enquiry to pursue in subsequent interviews.

The coding of a transcript sample was peer reviewed by an EP¹³ to check inter-rater agreement. Fieldnotes written during phases two and three of data gathering were also compared to the initial codes. Fieldnote segments were assigned to codes if the events and ideas they described shared a similar meaning. Appendix 27 provides an example of how the initial code 'types of conversations with others' evolved during the constant comparison process.

¹³ A fellow doctoral candidate who was familiar with my study and was using grounded methodology research for her own research.

3.2.5.3 Focussed and theoretical coding

The literature review identified different approaches to moving from initial coding to the next stage of analysis. Charmaz (2014) refers to focussed coding as the second stage of data analysis, describing this process as a comparison and synthesis of initial codes to create concepts or ideas that explain events within larger segments of data. Migliaccio (2015) and Sheffield and Morgan (2017) also refer to focussed coding when describing the process of developing connections between initial codes to form categories. A similar approach was taken for the current research.

Charmaz (2014) describes the move from initial to focussed coding as a fluid process not necessarily taking place in a linear fashion. Focussed codes may be developed as a researcher makes connections while continuing to gather data and create initial codes. Focused coding began after initial coding of the first three interviews. Codes were compared and arranged into groups of codes sharing a similar concept or theme. Arranging and rearranging¹⁴ of codes continued until I was satisfied that the groupings reflected the potential connections that could be made between the codes. Some initial codes were placed in more than one group if they reflected more than one concept or idea. Words or phrases representing the meaning of the connections between the initial codes were assigned to each group to create the focussed codes. These codes aimed to reflect a higher order concept relative to the words and phrases used to name the initial codes. Memos were written to capture my thoughts

¹⁴ Initial codes were displayed on individual pieces of paper to be arranged and rearranged by visual inspection.

about the meaning of each focussed code, drawing upon the memos written to describe the initial codes earlier in the analytic process.

Focussed codes were revisited after initial coding of subsequent interview transcripts and after phases two and three of data gathering. Focussed codes were adjusted and developed as new initial codes were discovered and included within the analysis and as existing initial codes were shaped through the constant comparison process. At this stage, Thornberg's (2012) 'theoretical playfulness' principle (appendix 2) was applied to compare and contrast the focussed codes with my knowledge and understanding of concepts and themes within the pre-existing literature (see table 3).

I was not selective over the initial codes to include in the next stage of the analysis, as Charmaz (2014) indicates a researcher might be when focussed coding. Sharp (2014) suggests that a researcher should report upon rather than discount concepts occurring less frequently within their data to ensure the voices of all participants contribute to the analysis. Inconsistencies and exceptions within the data were actively sought and 'negative case examples' were identified in the form of initial codes that present an opposing idea and offer challenge to the meaning of a focussed code. Wong et al. (2013), Wolfe (2014) and Sharp all identify negative case examples. Wolfe proposes that a researcher can add credibility to their findings by considering exceptions to their developing theory.

The final stage of analysis was theoretical coding and was undertaken once initial and focussed coding were complete and following feedback from participants to check the credibility of my analysis (see section 3.3.2). Charmaz (2014) describes theoretical coding as a way of showing how focussed codes are related, progressing the analysis towards developing a theory to explain the events within the data. My approach to theoretical coding involved drawing upon my existing knowledge of psychological concepts and theories as a practising EP and enlisting peer support. I discussed the focussed codes and my thoughts about the psychological concepts they may represent with my research supervisor and also during a team meeting with my EP colleagues in the LA where I am employed. Memos were written to capture my thoughts and ideas following peer feedback before deciding upon theoretical codes to complete the analysis.

3.2.5.4 Memo writing and the reflexive research diary

Memoing is a constant feature of GT methodology. The studies selected for review in part 2 use memoing for different purposes and at different stages of the research process. Sutcliffe (2016) is the only researcher to write memos throughout his empirical work, providing insight into his thinking during data analysis and theory development and when engaging with the literature relevant to his research. Sutcliffe's approach informs the use of memoing for the current research. I began writing memos before empirical work began to aid the reflexive process detailed in section 3.1.1. Two forms of reflexive writing were then undertaken during data gathering and analysis. First, a research diary was written to record my thoughts about methodological and

ethical issues encountered during the research process (see appendix 11). Second, memos were written to document my thoughts about the meaning of the initial and focussed codes. Memos were revised and became increasingly detailed as analysis moved beyond initial coding to consider the relationships between the codes and the theories and concepts that may explain the data (see appendix 27). The final version of memos accompanying the initial and focussed codes are shown in appendices 28 and 29, respectively.

Memos were also written to consciously mark the shift in focus between the data and the extant literature during empirical work (see appendix 11). This involved documenting my thinking about how pre-existing concepts and themes proposed by other researchers could be elaborated upon or challenged as a result of new ideas discovered within the data. Thornberg (2012) considers the process of 'memoing extant knowledge associations' to be essential when developing a GT in a field in which a researcher has prior knowledge and experience, enabling his principles of 'staying grounded' and 'theoretical playfulness' to be realised.

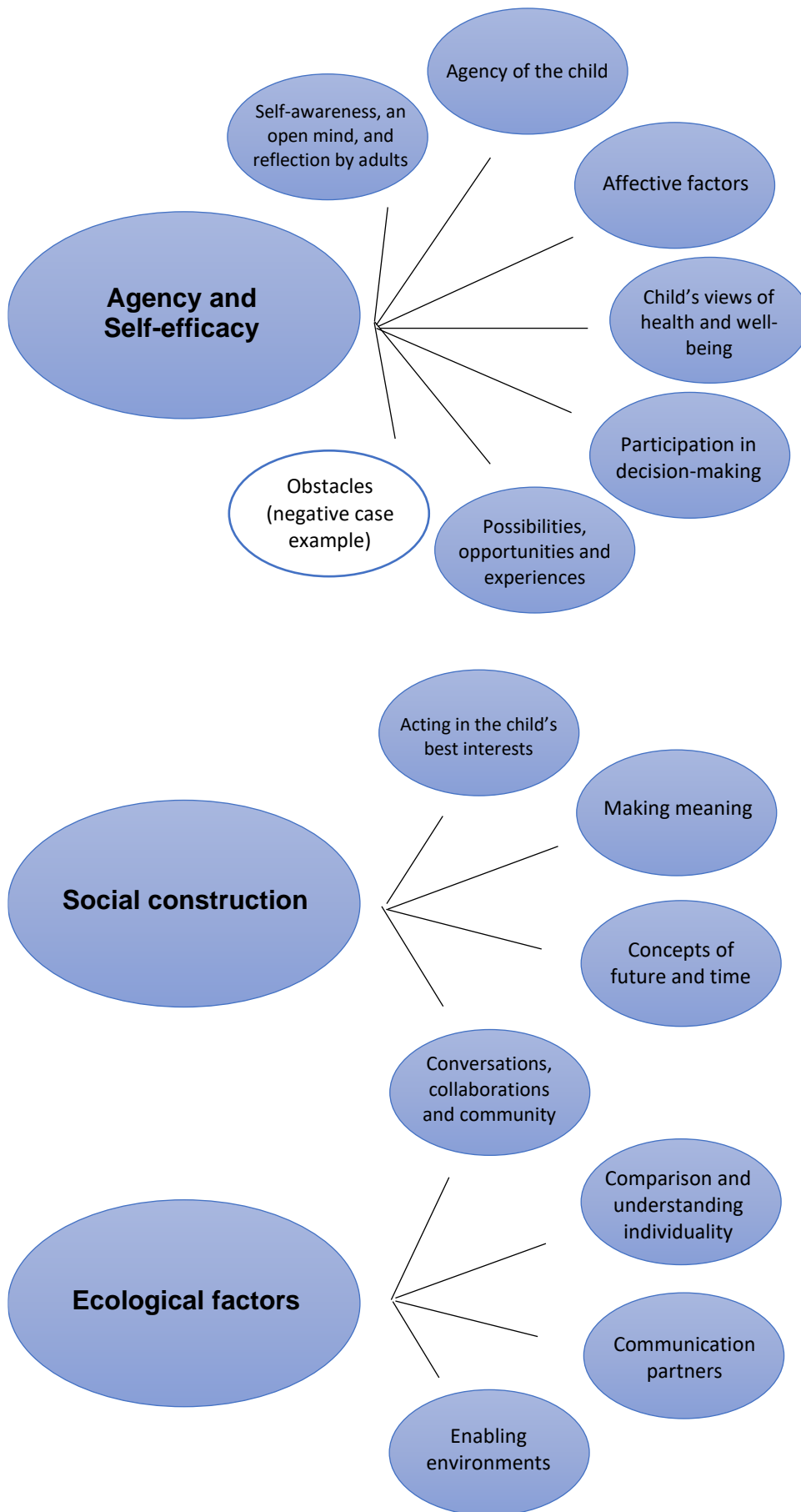
3.3 Results

3.3.1 Introduction

This section will present the combined analysis of data across the three data gathering phases. Fifty-eight initial codes were identified and grouped into 14 focussed codes. The initial and focussed codes and their accompanying memos are presented in appendices 27 and 28 respectively. The focussed

codes were then grouped into three theoretical codes. A visual representation of the final analysis is presented in figure 1.

Figure 1. Visual representation of theoretical coding



The theoretical and focussed codes will be used to structure the reporting of the research findings with reference to three psychological concepts:

- Bronfenbrenner's (1979) ecological model of human development
- Charmaz's (2014) writing on social construction
- Bandura's (1982) theories of self-efficacy and human agency

Each focused code will be presented in turn, accompanied by illustrative examples of transcripts and references to fieldnotes. Initial codes considered pertinent to the research findings will be drawn upon to explore the meaning ascribed to each focussed code. Discussion of the relevance of each focussed code to the research questions will be presented in section 3.4.

3.3.2 Validity of the research findings

Corbin and Strauss (2008) propose that the validity of qualitative research be judged by the extent to which a credible interpretation of the data is offered that reflects participants' experiences. The credibility of data analysis during the current research was enhanced by checking during phase three of data gathering participants' agreement with the interpretation of data gathered during phases one and two (see section 3.2.4.3). Parents and professionals reported their agreement with the concepts and codes I developed during data analysis and highlighted no aspects with which they disagreed. This will be discussed further in section 4.3. Some concepts and codes sparked discussion and appeared of greater interest to participants and a summary of this discussion is presented in table 8.

Table 8. Summary of participant feedback on data analysis

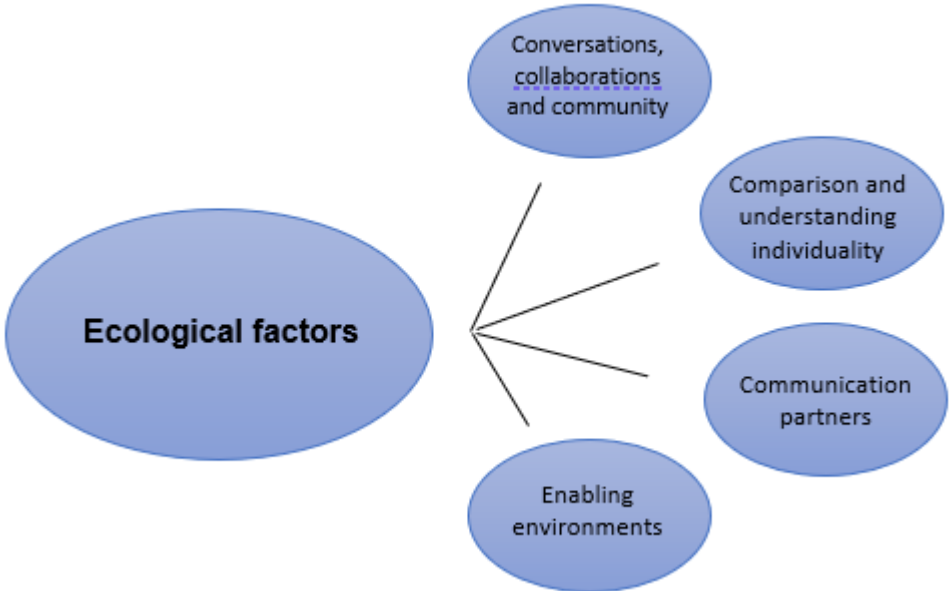
<i>Concept or code within the data</i>	<i>Participant feedback</i>
What do we mean by the 'future'?	<p>Parents spoke about how they believe their concept of 'future' is different to their child's concept of 'future', with the child's view being about the here and now. Parents commented that they tend not to think too far into the future.</p> <p>Professionals spoke about using children's views to inform planning in the here and now.</p> <p>All agreed about the need for flexibility when planning for the future to allow opportunity for a child to change their mind.</p> <p>One parent spoke about the importance of using videos and photographs to celebrate a child's achievements through life story that also conveys a sense of time for the child.</p>
Careful watching	<p>All agreed about the need for careful observation by everyone in the child's life so as to understand a child's communication and views.</p> <p>One parent spoke about how her child has different ways of communicating in different contexts depending upon what is available to her, therefore, adults need to watch careful to see how she is communicating (links to 'enabling environments')</p>
Children's views about their health and well-being	<p>Parents and professionals agreed that the child's view of their health is hard for adults to understand.</p> <p>One parent spoke about her child's awareness of her disability when she is unable to join in and do what she sees other people doing.</p>
Building up a picture over time	<p>Professionals talked about the importance of allowing a child time to experience an activity, as their first response to trying something new may not reflect their view.</p> <p>One parent spoke about the importance repetition and allowing a child processing time so that their views of an activity can develop.</p>
Enabling environments	<p>Participants discussed this theme in relation to a child's relationships and responses to people.</p> <p>Siblings and peers were spoken about in particular, with participants recognising a child's relationship with other children as different to their relationship with adults.</p>
Conversations with other adults	<p>One professional suggested siblings should also be asked to contribute to conversations about what the child's views might be.</p>

The PCP meetings providing the context for checking participant agreement with data analysis were attended by professionals in addition to the those had

been interviewed in phase one. Their feedback adds to the credibility of the research findings by suggesting that the interpretation of the data not only makes sense to those who participated in the study but also to professionals for whom the research findings would have relevance to their practice.

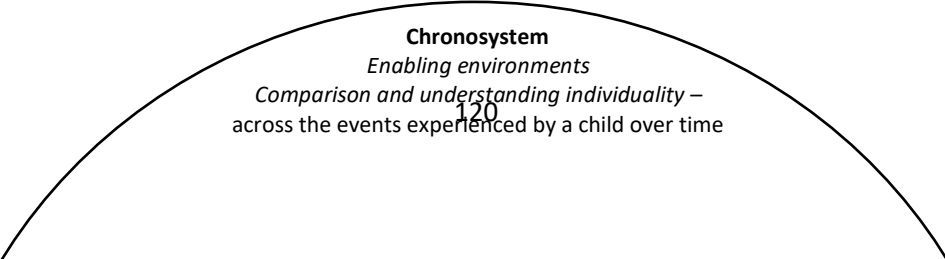
3.3.3 Ecological factors

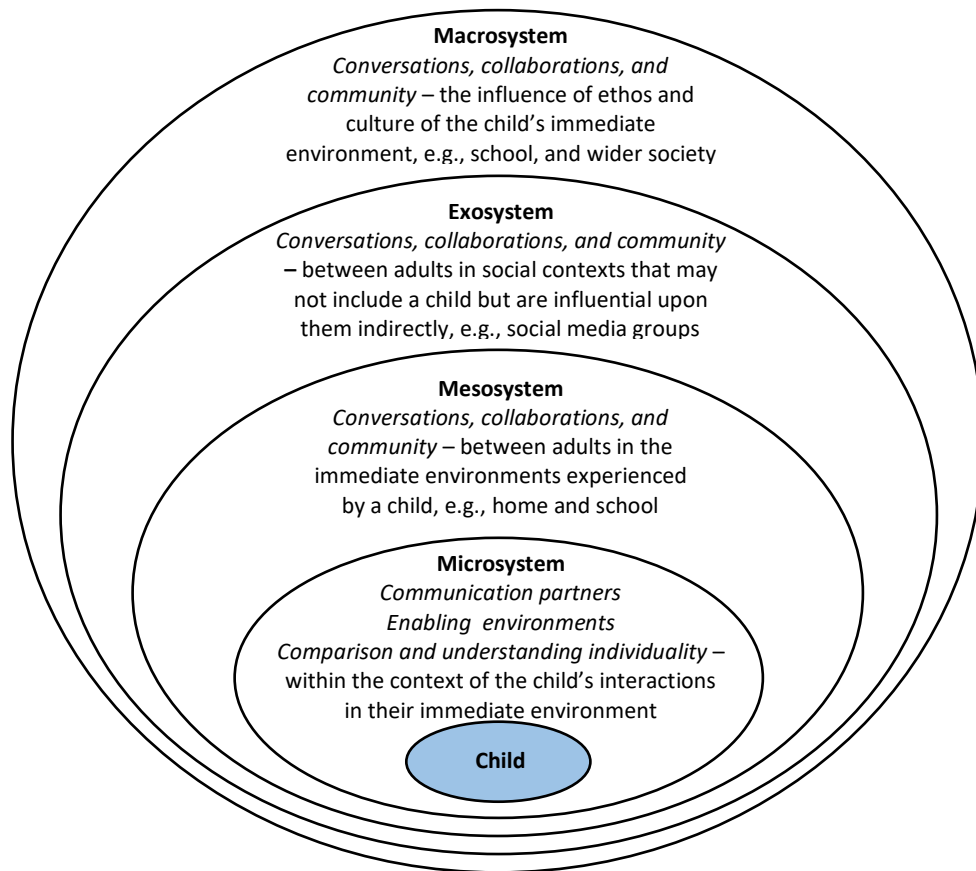
Figure 2. Focussed codes associated with ‘ecological factors’



Bronfenbrenner’s (1979) ecological model of human development provides the theoretical basis for the discussion of the research findings relating to the theoretical code ‘ecological factors’. Figure 3 shows how focussed codes have been related to the systems in Bronfenbrenner’s model.

Figure 3. Focussed codes associated with Bronfenbrenner’s (1979) ecological model of human development





3.3.3.1 Communication partners

The adult-child communicative relationship is detailed within participants' interview responses. This relationship is positioned within the microsystem of Bronfenbrenner's (1979) model, which describes the interaction between the child and the people in their immediate environment. Participants describe a range of observable actions made by a child to which adults give meaning in order to interpret the child's communication. Listening to the child's vocalisations and observing the child's movements is referred to most often by participants as well as noticing the child's eye gaze and facial expression and observing the child's interaction with objects in their environment. Some

participants also interpret the child withdrawing from activities as communication.

The initial code 'every little response' represents an adult-child communicative relationship described by participants that facilitates the child's communication of their views. Participants spoke about noticing small responses from a child that we may not attend to typically during communication, as illustrated by the extracts in table 9.

Table 9. Text extracts for focussed code 'communication partners'

<i>Initial Code</i>	<i>Participant</i>	<i>Text extract</i>
Every little response	SALT_2	We've got one young lady who uses her little finger like that <demonstrates action> to say 'yes' and it wasn't until her dad mentioned it a few years ago that everyone was like 'oh wow, ok we realise that now' and now you know to look for that ... I think human nature doesn't tell you to look at someone's hands necessarily, particularly if they're not moving very much, to give you communication clues.
	Parent_1	Sometimes you don't really pay attention, if you're not really paying attention you might miss a lot of things.
	PW_2	If they <child> don't want to be there, they'll kind of like squirm back ... those are the things that you a really looking for and if a child is like fiddling with their jumper, stuff like that.

3.3.3.2 Enabling environments

A child's response to their immediate environment is described by participants when talking about the child's communication and views. This includes how

the child responds to different people such as parents, siblings, or teachers, and how the child responds to different environmental stimuli and events. The initial code 'relationships and responding to people' is one of the most frequently occurring codes within the data. The extracts in table 10 show how parent participants observe and interpret their child's actions as indicating the child's awareness of their different relationships with different people.

Table 10. Text extracts for focussed code 'enabling environments' (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Relationships and responding to people	Parent_2	When he has his carer come round ... he knows that she's gonna do more with him ... and play with him <more> than I would ... so he'll make all these happy sounds that she's here and sometimes he'll lead her by the hand because he wants to go into his bedroom and play with his toys or he'll want to sit on the settee with her, so he knows exactly what she'll do with him.
Responding to siblings	Parent_1	Every morning when we wake up, I take <sibling> to <child_1>'s room, I bring him close to her bed and I say, 'good morning <child_1>' ... and she will reach out and hold his hand and they will just be there in silence. I know there is some sort of communication going on between them because she's not one to sit quietly either but for some reason they just hold hands and they stare.

Variation is seen in participant responses regarding whether a child's relationship with an adult affects the child's expression of views. Participant responses suggest that it is not the relationship per se but the *actions* a person takes to create stimuli and events in the child's immediate environment that supports the child in developing *and* communicating their views, as illustrated by the extracts in table 11.

Table 11. Text extracts for focussed code ‘enabling environments’ (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Choices, experiences, and informed decisions	PW_2	Sometimes he will kind of give more of a response to one than the other <option> so we think it’s that one, but there have been times where he’s led you somewhere and you get him there and ... it’s kind of in his head <that> it sounds like a good idea but then when he gets there it might be too busy.
	TA_3	<i>Do you find, as you’ve known her a while now, do you find that her likes and dislikes have been quite consistent over that time?</i> TA_3: They’ve changed ... when she first come in, she didn’t really like messy play, she’d touch things and was like ‘I’m not quite sure’ and then we started mucking about and, you know, we all muck about and <over> the years ... she’s just like ‘that’s it’ and gets caked in shaving foam.
Anticipating, repeating, and remembering	Parent_2	<i>What might you see him doing that would show you that he had recognition?</i> Parent_2: ... with the swing he will grab my hand and turn around because he knows I put him in the swing backwards.
	CT_1	She has like a snack ... like these cheesy puff crisp things every day ... and she obviously knows them like, she hears the bag rustling, she looks, so I think ... that sort of thing she remembers and that’s probably very repetitive because she has it every day.
	CT_3	She does anticipate those things and she will remember, like in my classroom ... toys she liked were away in the cupboard so you couldn’t see them, but if she wanted them ... she would like pull you towards the cupboard, like she knew that that’s where the things she likes were, she remembered that that’s where they’re kept.

Participants talk about providing a broad range of experiences and opportunities for a child to explore what their preferences might be so that they can make informed decisions having experienced the options available. Parent_3, for example, spoke during the PCP meeting about the importance

of positioning objects at a height her child can access while walking so that she can reach out to what she wants from a range of available options.

Some participants suggest that repeating activities over time can help a child to anticipate and remember, which informs their decision-making. Participants also talk about children's preferences changing in the moment and over time once they have experienced an activity. This finding can be positioned within the *chronosystem* of Bronfenbrenner's (1979) model, which comprises all of the events a person experiences during their lifetime. Opportunity for a child to experience an activity that changes their views and affects planning for their future can be considered as a significant life event.

3.3.3.3 Comparison and understanding individuality

Examples of adults making within-child and between-child comparisons when developing an understanding of a child's communication and views are seen within participant interview responses and in the observations of the PCP meetings. Participants talk about making within-child comparisons when observing how a child might respond differently to different activities and in different environments as well as noticing when a child responds differently to the same activity or environment but at different times. Adults in child_2's PCP meeting compared the different responses he makes when changing his clothes. Initially, they wondered whether he resists changing his clothes because he dislikes the physical sensation. However, drawing comparisons to changing child_2's clothes for swimming led adults to consider his

responses as a communication of his views about the activity happening next rather than a reflection of his overall views about changing his clothes.

Participants made between-child comparisons to other children with SEND when developing bespoke communication approaches for a child, as shown in the extracts for the initial code 'different for each child' in table 12.

Table 12. Text extracts for focussed code 'comparison and understanding individuality'

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Different for each child	Parent_1	She can hear and she can sometimes not want to <hear> and I don't think that's different from any other child to be honest ... obviously every child is different but I'm sure they'll be some cross over and perhaps we should think about that as well.
Like any other child	SALT_2	It's just like us isn't it ... a simple way of putting it, you can eat the same dinner once a week for five weeks and all of a sudden think I can't face jacket potato and beans again ... because like everybody, your tastes change, your experiences change ... there are various points in your life when you think 'I know I don't like it but I'm going to try it again just in case'.

The initial code 'like any other child' shows participants making comparisons to typically developing children when thinking about how a child's views are understood. The comparison made in the extract from SALT_2 provides an example of how participants consider children with CLCN to have the same agency and autonomy afforded to their typically developing peers with regards to their views changing over time.

3.3.3.4 Conversations, collaborations, and community

The significance of the interactions and relationships between the adults supporting a child when understanding their communication and views is evident within participant interview responses and in the observations of the PCP meetings. This shifts consideration of the research findings into the *mesosystem* of Bronfenbrenner's (1979) model, which describes how the different immediate environments experienced by a child, such as home and school, are interlinked and may influence one another.

'Types of conversations with others' is one of the most frequently occurring initial codes within the data. Participants talk about different ways in which they may communicate with other people about a child's communication and views. The initial code 'interesting to see other people's views' reflects a desire by participants to develop their understanding of a child through their interactions with others. Participants' interview responses suggest that engaging with other professionals from different fields can enable a child's communication to be understood in different ways.

The extract from CT_3 in table 13 shows how her thoughts on what child_3 might be communicating about eating changed after engaging with the feeding and swallowing team (FAST). A similar observation was made during the PCP meeting for child_1 when an Occupational Therapist (OT) explained how adults' observations of child_1 putting her hands in her mouth may reflect her sensory need for mouthing rather than being a communication of her disinterest in an activity, as first thought by parents and school staff.

Table 13. Text extracts for focussed code ‘conversations, collaborations and community’ (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Interesting to see other people’s views	CT_3	The change in routine we had noticed at school ... there’d been a holiday and then she’d come back and she wasn’t eating ... but the tiring ... when she’s chewing, we thought ‘oh yeah that’s true’, we didn’t really think of that and obviously the Feeding and Swallowing Team that’s their expertise and sometimes things you don’t really think ... and then <you> think ‘oh that’s quite obvious’ ... that’s why it is helpful that we have multidisciplinary ... because we’re all experts in different things so we kind of all need each other.
Inclusion and community	Parent_2	It’s <online community> really good because it’s hard when you’ve got a child with special needs to really understand what’s going on but ... meeting all these people, they’ve got a really good understanding of him.

The extract from parent_2 in table 13 shows how she values conversations with other parents of children with the same medical condition as her child. These parents are members of a wider online community and are not part of child_2’s life directly. Although not reflected across participant interviews, this finding is of interest as it suggests consideration be given to the *exosystem* of Bronfenbrenner’s (1979) model which incorporates other social contexts that may not include the child but are influential upon them indirectly.

Some participants spoke about a need for understanding in the community of how a child communicates and expresses their views, for example when meeting new people in public places, acknowledging that this can be

challenging. Their responses reflect the *macrosystem* of Bronfenbrenner's (1979) model and the influence of society and culture upon a child. The ethos and culture of a child's immediate environments is referred to by participants when talking about how the organisational context can foster collaborative working relationships between adults, as shown by the extracts in table 14. Although the initial code 'feel like you've failed' was only reflected in PW_2's responses, this code demonstrates the empathy PW_2 has for her co-workers and speaks to the ethos of the environment where she works and the supportive approach taken to responding to staff feelings when they are finding their work challenging.

Table 14. Text extracts for focussed code 'conversations, collaborations and community' (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Types of conversations with others	Parent_2	I've been into school quite a few times ... the parents evening was brilliant, I managed to see absolutely everyone, even some of the dinner ladies were there as well.
	CT_3	<The SALTs> are really supportive ... if we have a question or whatever they'll support us.
	SALT_2	I think that's because of the way that the <person-centred planning> meeting's structured ... its really positive here and I think it really does keep the child at the heart of ... what they need and what's important for them.

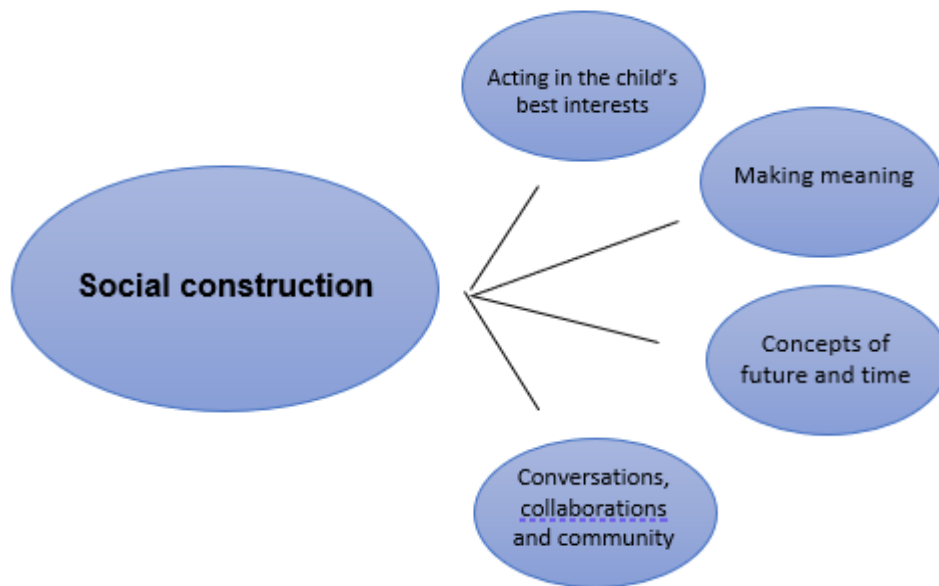
	PW_2	I think that's probably one of the biggest positives that we are quite fluid with our communication, we try and make sure everybody feels involved.
Feel like you've failed	PW_2	I think that it is always difficult when a child doesn't speak to communicate with them and a lot of support workers struggle ... and I think that they feel that they've failed if they don't get a positive response ... I can imagine that would be quite sad for the support worker.

The initial code 'difficulty or disagreement with other adults' provides a negative case example. Participant responses assigned to this code are mostly from parent_1 and parent_2 and describe their experience of talking to adults in their children's previous education settings. This indicates a potential difference in ethos and culture between organisations and adds significance to the finding that factors within the *exosystem* and *macrosystem* of Bronfenbrenner's (1979) model should be considered when developing approaches to support a child's communication of their views.

The focussed code 'conversations, collaborations, and community' is associated with the theoretical codes 'ecological factors' and 'social construction' to represent the range of social contexts influential upon how a child's views are understood. In the next section, consideration will be given to how meaning is created in a social context.

3.3.4. Social Construction

Figure 4. Focussed codes associated with 'social construction'



3.3.4.1 Making meaning

Language, communication, and social interaction provide the context and tools to create the relationships between adults located within Bronfenbrenner's (1979) ecological model (see figure 3) and represented by the focussed code 'conversations, collaboration and community'. Within a social context, adults consider what a child's communication might mean by reflecting upon what the child might be thinking and what they might want to communicate.

The initial code 'interpreting and modelling' is one of the most frequently occurring codes within the data. Participants describe using their own words to model what they think the child is trying to communicate. Some participants used words during their interviews such as "comical", "cheeky" and "daredevil" to extend their thinking about what a child's communication might mean to making inferences about a child's personality and character. The use of interpretation and modelling was also seen during observation of the Lis'n Tell activity (see appendix 22 observation child_2 (3)).

A sense of empathy and an appreciation of a child's lived experience is conveyed in the extract from PW_2 in table 15 in which she draws upon her own emotional responses to make sense of what child_2 is communicating about his experience of having seizures.

Table 15. Text extracts for focussed code 'making meaning' (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Interpreting and modelling	Parent_2	Sometimes he'll be sitting in his chair and he's head-banging and I go "do you want to get out?" and he'll stop and his arm will come up and I'll go "come on, we'll come out now" and that's what he'll do.
	TA_3	She'll be watching them <peers> out of the corner of her eye as if to say, "you're not supposed to be doing that".
Empathy for child's perspective	PW_2	He's still young and it must be scary to not necessarily know what's happening, but the feeling of not feeling right must be quite scary and I <would think> 'I'd like it if my mum was here'

The initial code 'led by adults' offers a negative case example. Participant responses assigned to this code are provided mostly by CT_3. Notably, this participant has the fewest years of experience working with children with CLCN relative to other participants. The extract in table 16 shows her questioning whether her experience of adults discussing what a child enjoys or finds challenging is an authentic representation of the child's views.

Table 16. Text extracts for focussed code 'making meaning' (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>

Led by adults	CT_3	A lot of it is adults' interpretation or what adults want for that child, what they want for their future, what they want for them to be happy and healthy and safe ... there's difficulty in accurately finding out exactly what the child wants ... things they enjoy, things they find more challenging, the things they've made progress with but obviously that's not necessarily always the child's views, that's kind of what they've done at school ... the <person-centred planning> meetings are very much 'this is what we're doing for your child so your child can do this' ... rather than this is what you're child thinks, this is what you're child's views are.
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Charmaz's (2014) social constructivist perspective acknowledges subjectivity when individuals construct meaning in a social context. This is consistent with individual participants seeking to make sense of a child's communication and views within a frame of reference provided by their social worlds. When participants make meaning within the context of a community and through their interactions with others, as suggested by the focussed code 'conversations, collaborations and community', they are implicitly influenced by the culture and values of the various organisations and groups, including the family, to which an individual belongs.

3.3.4.2 Concepts of future and time

The concepts of future and time are spoken about by participants in relation to affording a child opportunity to develop their views over time and with respect to planning for a child's future. Opportunities for a child to develop their views as a result of actions taken by adults were considered in section 3.3.3.2 as events located within the *chronosystem* of Bronfenbrenner's (1979) model.

This section will consider the findings relating to the period of time taken by adults to develop their understanding of a child's views and how the concept of 'future' is socially constructed by adults for a child.

The initial code 'building up a picture over time' occurred frequently within the data and across participant interviews. There was agreement among participants that their understanding of how a child with CLCN communicates and what their views might be needs to develop over time, as illustrated by the extracts in table 17.

Table 17. Text extracts for focussed code 'concepts of future and time' (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Building up a picture over time	Parent_2	I think they've <school staff> got a very good understanding of him now, but ... when you've got a child that's complex, it takes a while to actually get to know them.
	PW_2	The longer you've known the children the easier it is, obviously when they first start and you're seeing how they develop and stuff like that, it's quite difficult to work out their little triggers and ticks but once, say with <child_2>, we've known him for a long time now, it's quite easy to kind of work out ... where you are with him.
	TA_1	I think it's <understanding a child's views> just sort of like a gradual thing, I mean don't go like a bull in a china shop but just try to go with things they might like or take an interest in and then you can build from there.

	CT_3	We're kind of doing that <gathering their views> all the time, so particularly the likes and the dislikes, things that engage them, things that they don't enjoy, things that they find challenging, that's like all the time ... I would say it's more kind of a day to day picture of the child.
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Participants suggest that gathering a child's views should not be undertaken as a 'one-off' activity. CT_3, who has experience working with more able children, thought this to be true particularly for children who are not yet using a formal communication system. Some participants talk about reflecting upon a child's communication and views as part of their everyday practice, enabling them to develop their understanding over time.

The initial code 'really easily and quickly' provides a negative case example. Responses assigned to this code are from two participants and refer to their experience of being able to understand a child's communication quicker when the child's responses to their environment are more visible and noticeable (see table 26 for text extract example).

Participants' thoughts about future and time also relate to the PCP process. Participants talk about planning for the future being 'day-by-day' for children with CLCN, however different reasons are given by professionals and parents, as shown in the extracts in table 18. Professionals speak positively about shorter term planning creating opportunity for a child to change their mind about what they want to do, affording the child agency and autonomy. Parents'

responses reflect uncertainty on the part of the adult as to whether a child will be able to express a view about what they want to do in the future. This finding is significant when PCP takes place in a group context involving parents and professionals who may hold different beliefs about concepts relevant to the process, such as future, and what this means for the child.

Table 18. Text extracts for focussed code ‘concepts of future and time’ (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Future is in the moment or day-by-day	CT_1	We don't tend to go too far into the future ... someone could come in at the start and be completely different three months down the line ... so we tend not to go too far ... they change so much at this age don't they, very quickly.
	Parent_1	I don't think so ...I don't see how ... it's day by day to me, so when it comes to communicating with us about what she wants to do in the future ... even as a baby she liked being in water ... and even now she still enjoys it, you know, going for the hydrotherapy ... so we think that's something that she will carry on with ... what else does she want to do in the future, to be honest, I don't know.
	Parent_2	We're just on a day-to-day basis ... I couldn't say to him 'what do you want to do tomorrow' ... I can't imagine how he would tell me that he wants to go to <play centre> today, that kind of thing, or that he wants to go

		trampolining ... I don't know how he would be able to communicate that.
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3.3.4.3 Acting in the child's best interests

When participants talk about making decisions on behalf of a child, this is mostly in relation to keeping them healthy and safe. A plausible link could be made to the initial code 'like any other child' in this respect (see appendix 28), as all parents are required to make judgements and take actions deemed necessary to keep their child healthy and safe. This kind of decision-making may be socially constructed in the context of a parent's interactions with others. Participant responses suggest that adults' understanding of how to keep a child with CLCN healthy and safe is likely to be socially constructed within a group of adults that includes a range of specialist professionals, as shown in the extract from CT_3 in table 19. This was seen during child_2's PCP meeting when adults talked about the importance of ongoing physiotherapy sessions, even though they think physiotherapy is something he does not enjoy, because child_2 is prone to weight gain due to his medical condition.

Table 19. Text extracts for focussed code 'acting in the child's best interests'

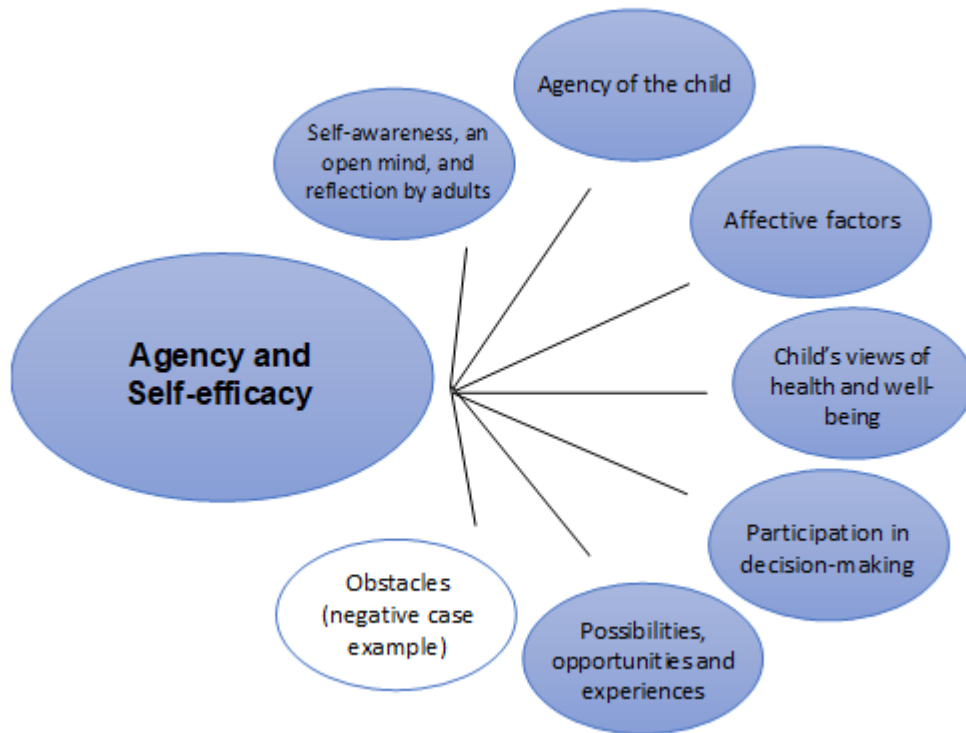
<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Making a judgement for the child	CT_3	There'll be discussions with ... nurses and physiotherapists ... and quite often after those <person-centred planning> meetings things change in importance so things that might have not really been high priority ... they'll move up to a higher priority for that child.
	Parent_1	Some music students ... were going to start some music therapy sessions with the kids

		and they asked whether I was happy for O to join in ... my first gut instinct was to say no ... obviously I don't want her going and ruining it for the other kids, so I said let her have one session, if you think she's ok then we can carry on.
	Parent_2	I can't envisage how he would be able to decide, like once he finishes at 19, where he wants to go from there ... it will be choices that I will have to make for him, but just knowing him, knowing his likes and dislikes ... what we tend to do with him is everything that he likes, I wouldn't send him somewhere <he doesn't like> ... if he wasn't happy they would let me know, so at the moment the decision is totally down to myself and my husband.

Other perspectives on decision-making on behalf of a child are offered in the extracts from parent_1 and parent_2. The extract from parent_1 suggests social norms may inform decision-making, with parent_1 acting on behalf of her child to ensure that her child's needs do not impact negatively upon other children in the group. The extract from parent_2 reflects her doubts over her child's ability to make decisions about the future for himself, yet she considers her child's views even when making decisions on his behalf.

3.3.5 Agency and Self-efficacy

Figure 5. Focussed codes associated with 'agency and self-efficacy'



3.3.5.1 Agency of the child

All participants convey certainty about the children's ability to express their likes, dislikes and what they want, as illustrated by the extracts in table 20. The children are seen as having agency and ability to affect the world around them.

Table 20. Text extracts for focussed code 'agency of the child'

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
What the child wants	PW_1	When he wants to do something, he's much more cooperative, he wanted to go on that rollercoaster so he climbed the stairs properly, he listened and did what I asked him to do ... he got in the rollercoaster and out of the rollercoaster, well he didn't want to get out <laughs> but he got in.
	TA_3	She will let you know what she wants ... if she doesn't want to do something, she'll definitely let you know ... if she really, really doesn't wasn't want to do it, she will not do it and if there's other things going on, she'll be more interested in what's going on over there than what we're doing here.

	Parent_1	<Child_1> is the kinda person that if she doesn't like something you will know ... she's not one just to go along with things for the sake of it.
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3.3.5.2 Affective factors

All participants talk about the children's emotions. They suggest the children are able to communicate a range of different emotions including happiness, anger, frustration, excitement, fear, and boredom, as shown in table 21.

The initial code 'depending upon mood' reflects participants thoughts on how a child's mood may affect their engagement with the world around them. A similar point was noted during observations of child_2 (see appendix 22). A difference was seen in his engagement in activities between the first and second observations. The classroom staff explained that child_2 had been trampolining immediately before the second observation. They considered his lack of engagement to indicate his want to withdraw from activities due to feeling tired after trampolining rather than construing his actions as a communication of his views about the activities. The meaning the adults ascribe to child_2's actions reflect their view of him as an autonomous person with agency over his engagement with the world around him.

Table 21. Text extracts for focussed code 'affective factors'

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Emotions and mood	CT_3	Frustration I think she can show ... if she wants something she can't have ... if it's not

		time for something she wants, if she's finding something challenging.
	Parent_2	He knows when he's going to go to school because once he's dressed ... and transport knock at the door, he's screeching, he's really happy ... If he's afraid I can see, sometimes if he's going backwards and he can't see where he is ... you'll get a look of fear come across his face and I recognise the expression.
	Parent_1	If she's upset, there's a distinct sound and if she's happy there's a different sound, she laughs a lot, she's really happy, I don't think she's capable of hiding her emotions in any way.
	PW_2	<Child_2> doesn't like to be in one place for too long, he gets quite bored ... his boredom is like, slumped down in his chair and he just looks bored, if he's tired, he is sitting upright and he'll just sort or nod ... his head will be on his shoulder and he'll be more cuddly but he'll still be smiling.
Depending upon mood	Parent_1	It's more dependent on her mood really ... if she's not happy she does not engage with it, or she will just cry or she will throw.
	PW_2	<Child_2> bum shuffles on the floor or he'll walk holding one hand or two hands depending upon what mood he's in, sometimes it can be just not for him.

3.3.5.3 Child's views of their health and well-being

Some participants consider it challenging for a child to communicate their views in relation to their health and medical needs, suggesting a child may have less agency in this aspect of their life. The extracts in table 22 illustrate participants' uncertainty about a child being able to communicate their experience of feeling unwell. The extract from parent_2 also reflects her thoughts about her child's ability to communicate his experience of being visually impaired, suggesting that it may be difficult for a child to communicate their views about their disability.

The initial code 'child's views of provision' suggests participants believe a child can be afforded agency by communicating their views of using equipment intended to help them overcome a barrier presented by their disability. This is illustrated by the extract from SALT_2 describing a child's views of using an augmentative communication aid. A similar observation was made during child_1's PCP when the physiotherapist spoke about observing child_1's response to a range of walkers to explore her views of which assists her best.

Table 22. Text extracts for focussed code 'child's views of their health and well-being'

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
What the child can't communicate	TA_1	Some of the children that are able to, not necessarily tell you vocally ... it's really hard for them, if they've got a pain and your just thinking have you got a pain, you know are you just uncomfortable ... it is really difficult to fathom that out.
	Parent_1	Occasionally you're not really sure what's going on and I think particularly more difficult when she's ill and she's about to fall ... she might be giving us some clues and we just don't get it ... we don't understand ... if your blood sugar levels are low and you might feel dizzy, but she's not able to communicate that and she has no way of communicating that.
	Parent_2	It's hard ... when he's unwell, so unless he's got a temperature or he's sneezing its quite difficult, sometimes if he goes quiet it might be

		because a seizure's coming ... but all the time you're trying to second guess ... he has squints in both eyes, which means he has a problem with depth perception ... his visual impairment is more that he can't see distance ... he probably sees someone across the room, it's quite hard to work out how far he can see ... I think the vision really is the thing that is a question mark because you can't really measure it.
Child's views of provision	SALT_2	He did like using the eye gaze to call his friends over, so that was something that was quite powerful for him ... if he had not been engaged with the newer equipment ... that would have shown us that's something that he's not interested in anymore and we need to explore other things.

3.3.5.4 Possibilities, opportunities, and experiences

Participant responses suggest that, as well as seeing the children as having agency and autonomy, adults consider the children as efficacious and believe development and change is possible. Bandura (1982) states a person's efficacy is not dependent only upon their knowledge and skill performance but is influenced by how their capabilities are judged. Use of language by participants during interviews suggests optimism and positivity when talking about children's ability and potential, as illustrated in table 23.

Table 23. Text extracts for focussed code 'possibilities, opportunities and experiences'

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Let's try it	Parent_1	She knows a lot of things, so we just have to not assume ... so we try and integrate her into whatever we're doing as much as possible, even though she's not talking, she still gets it ... so there was a time that when my husband came home from work ... he'd say "how is <child_1>?" and I would say why don't you ask her ... he's like "but she doesn't speak"

		and I'd say let's try it and when he comes home now, he says "hello <child_1>", gives her a cuddle and she really smiles.
	TA_1	Sometimes they might need a bit of extra time, say if they'd never done messy play before, sometimes they might be 'not sure about this' but obviously the more you do it the more they like it or don't like it ... or you might do it in a different way, say instead of starting off with wet materials do dry materials.
Choices, opportunities, and informed decisions	Parent_2	We do music therapy twice a month ... he's getting better and better with it, so the other week the music therapist said choose your instruments and <child_2> got up and rummaged through the box and he was looking for a specific one, because I know that's his favourite, because he gets a lot back from it ... so it just shows that sometimes I think some things go over his head but, no, that was amazing.
At the moment	TA_3	It's going to take time, one day she'll just do it and we'll think 'oh god it's taken years to get that and we've got it' ... some people are like 'how can you do that over and over and over?' but you do and it could take years and then all of a sudden it just clicks.

This focussed code shares similarity with the focussed code 'enabling environments' in terms of how adults may create opportunities to facilitate a child's communication and development of views. Participants talk about being careful not to interpret a child's initial response to an activity as a reflection of their views. The extract from TA_1 shows how adults may make adaptations to an activity to encourage engagement and allow the child's views to develop over time.

Bandura (1982) suggests that judgements of self-efficacy will determine how long someone persists with activities in the face of obstacles, as those who judge themselves to be less efficacious are more likely to take a negative view of setbacks and perceived challenges. Considering a child as having efficacy

may explain why adults are optimistic about trying new ways of engaging or communicating with them and show perseverance even when a child's initial response suggests a lack of engagement or interest. It is possible that this explanation also speaks to the adults' self-efficacy, which will be explored further in next section.

3.3.5.5 Self-awareness, an open mind and reflection by adults

This focussed code relates to the agency of the adults when seeking to understand a child's communication and views. Observation is referred to often by participants as an action they can take to help them to understand what a child's communication might mean. The importance of continuing to observe a child even when a formal communication system is being introduced was spoken about by adults during the child_3's PCP meeting.

Table 24. Text extracts for focussed code 'self-awareness, an open mind and reflection by adults' (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Observing and paying attention	CT_3	Observing them ... getting to know the child and how they communicate is really important and using observations in different situations ... observe her communication when its more adult led and when ... she's more free in child led situations.
	CT_1	I'd say like watch for the cues and see what she does ... I think you just watch their responses to things and I think you can pick up quite a lot really.
	Parent_1	We've kind of observed her ... in terms of understanding the child's communication, I'd say pay attention or you're not going to understand everything ... because sometimes you don't really pay attention, if you're not really paying attention you might miss a lot of things.

Opportunities to communicate	SALT_2	Staff are really good at interpreting the children's needs ... so we can sometimes be going along the lines or 'you're so good at interpreting the needs that you need to give them more opportunities for them to be able to communicate' ... rather than ... just automatically doing things all the time ... people don't realise they're doing it ... it's just they're so good at working with our children.
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The extract from SALT_2 in table 24 suggests adults should observe their own actions as the child's communication partner as well as observing the child, considering how they may facilitate or hinder the child's expression of views. SALT_2 commented during observation of the List'n Tell activity (see appendix 25) that she chose for child_2 to remain out of his chair during the activity to afford him the opportunity to move around the room as one of the ways he expresses his views. This suggests awareness of how the decisions adults make may impact upon the child's opportunities to communicate their views.

With the exception of SALT_2, self-reflection by participants relates mostly to their thinking about different interpretations of a child's communication, as illustrated by the extracts in table 25. A link can be suggested between these findings and the focussed codes 'comparisons and understanding individuality' when adults use comparison to consider different possible interpretations of a child's communication, and 'conversations, collaborations and community' when adults draw upon the knowledge and expertise of others to consider alternative explanations for a child's actions.

Participant responses suggest that they openly acknowledge their uncertainty when interpreting a child's views and are willing to question their judgement. Bandura (1982) suggests that a degree of uncertainty can benefit task performance by encouraging a person to take preparatory action ahead of a task, such as observing a child carefully over time. He proposes that a highly self-efficacious person may invest less effort in preparing for a task while those who judge themselves as inefficacious may find it hard to tolerate feelings of uncertainty and doubt, focussing upon their emotional response to the task rather than considering potential ways forward. Bandura's thinking when applied to the task of understanding the views of a child with CLCN suggests a degree of self-efficacy is required by adults that enables them to tolerate feelings of uncertainty and doubt while promoting self-reflection and consideration of new possibilities.

Table 25. Text extracts for focussed code 'self-awareness, an open mind and reflection by adults' (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Unsure what child's communication means	CT_1	I don't know why she does that <laughs> I don't know what it is ... it's almost she's laughing too much she has to cry <laughs> I don't know what it is.
	Parent_2	There are sometimes I can't work out what's wrong, it's like on Monday my other son had made waffle mixture, so I gave H waffles instead of his pancakes and he kicked off, so that's all I could <think of>, because he was really headbanging, and he was eating them but he was quite angry that I hadn't given him <pancakes> that's all I could work out that was wrong.
Maybe communication means different things	CT_3	Like sausages, she use to spit the sausage out so we thought maybe she doesn't like sausages ... but then the FAST team said take the skin off and then she ate it because she couldn't chew the skin, so ... it was a physical element to it rather than a dislike of that thing.

	SALT_2	One of our sensory TAs worked out that in order to be able to use a switch ... he would put his head down, bring his arms up and then like activate the switch, but it was over a period of time ... watching him and realising that, whereas I think ... the fact that he'd put his head down in his arms, you could perceive that as disengaging in that activity and so reading the body language I think is hugely important.
Learning by experience	Parent_1	I think it was difficult initially, we didn't have any experience of having a special needs child ... but as time's gone on ... I think it's gotten easier ... I think we've learnt by experience to kind of just observe and see what it is that she just <wants>, all of this be experience.
	Parent_2	It does open your eyes what you're saying ... because sometimes I think I just blindly go ahead and think oh we'll do this for H ... because he is so happy, <I wonder> whether I'm just bombarding him.

The extract from parent_1 in table 25 suggests experience over time has had a mediating effect upon initial feelings of uncertainty, with self-efficacy potentially increasing as she sees herself becoming more adept at understanding her child's communication and views.

Two negative case examples were identified in relation to this focussed code, as shown in table 26. The initial code 'I just know' offers another perspective upon self-reflection, suggesting some participants may perceive themselves as efficacious when understanding a child's communication and views but are unable to identify or articulate the reasons for their success. The extract from SALT_2 suggests a potential expansion of the focused code 'conversations, collaboration and communities' to include adults noticing and reflecting upon one other's strengths and skills when collaborating to explore a child's communication and views. This is akin to Bandura's (1982) description of

'verbal persuasion' whereby social influence is used to raise a person's awareness of the capabilities they possess to achieve a task.

Table 26. Text extracts for focussed code 'self-awareness, an open mind and reflection by adults' (3)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Really easy and quickly	TA_1	I think it's been really easy getting to know her, because ... she'd let you know if she didn't like something ... if a new person was coming in, they would get to know her quite quickly ... I think anybody would be able to see whether <she's> quite happy and enjoying something.
I just know	SALT_2	We're really lucky to have lots of skilled staff here ... I think without even realising <they> are picking up on things ... and noticing things ... and will share that information with you without even realising that they've picked up on really important information.
	TA_3	I don't know, you just go with it, it's hard to explain really, I think where I've worked with her for so many years I've just got to 'oh I know what you want' ... It came really quick with <child_3>, it really did, and I don't know, there was something that just sort of clicked, I don't know what it was.

3.3.5.6 Participation in decision-making

This focussed code represents how adults use their understanding of a child’s views to inform decision-making for the child. Interview extracts relating to this focussed code are provided by professionals only, as shown in table 27. One explanation for this difference could be that the parents had less experience of PCP at the time of their interview relative to the professionals. A link can also be made to the extracts in table 20, which show parents questioning the extent to which their child can be involved in decision-making about their future.

Table 27. Text extracts for focussed code ‘participation in decision-making’

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Planning activities and provision	CT_3	It would be things that engage ... when you learn about their views, what they like, what makes them tired, what they find more challenging, what’s too easy for them ... when you’ve learnt all those things ... you’d plan activities around those things.
	CT_1	If there’s like a piece of equipment they’re not really keen on using and we’re doing it with something that they really like then they can use it a little bit longer or like it a little bit more ... I think if we can distract with something we know they really like, I think it makes that a little bit easier ... the provision, I suppose you’d use their views more for that rather than the outcomes themselves.
	PW_2	I would say that we take a person centred approach ... the service we provide is very structured ... obviously there are certain children that will follow a structure and there are certain children who wont and we ... decide on that when they come for their initial needs assessment, if their parent says they have a very short attention span they would be the sort of children who wouldn’t follow the structure so ... <child_2> likes to wander, so <child_2> and other children like him are in red group so there’s no pressure for him to follow a structure, if

		he's willing to follow a structure then we will but if he doesn't want to then we won't and it's not because he's got behaviours, it's because he likes to wander.
	SALT_2	If somebody really likes something that will continue to happen, if they don't like something so much ... that will be withdrawn ... it might be well yes, they've been doing it a long time but actually they still really enjoy those things so we can keep them going ... I think the outcomes are decided with the children in mind because there have been conversations of this child has been set this target for the last three years ... is it relevant to keep going and I think you'd gauge that by their response to the activities.

The initial code 'planning activities and provision' relates to how the professionals consider a child's views when making decisions about the child's day-to-day activities. They talk about drawing upon their understanding of what the child likes and dislikes to plan activities that they anticipate the child will enjoy. The extract from CT_1 illustrates how adults may plan activities that the child does not enjoy but are considered to be in their best interests, such as using equipment to promote physical skill development. An adult's understanding of a child's views can enable changes to be made to these kind of activities to increase the child's enjoyment and engagement.

All PCP meetings provided examples of how participants' understanding of the child's views can affect decision-making for the child, as shown in table 28. Parents and professionals discussed as a group what they consider to be important to the child, which informed their thinking about what the child might want to do in the future. This finding suggests that in the context of the PCP meetings observed, the child was seen by adults as autonomous and was

afforded agency in decision-making about matters affecting them. A link can be made to the focussed code ‘possibilities, opportunities and experiences’ in terms of the child being seen as efficacious and with potential to achieve their future goals.

Table 28. Examples of adults’ understanding of a child’s views affecting decision-making

<i>Child</i>	<i>Adults’ understanding of the child’s view</i>	<i>Associated decision-making for the child</i>
Child_1	Parents talked about child_1’s sociability and how they think it is important to her to develop her social skills so that she can have more opportunities for social interaction. They also spoke about her interest in food and how they think it is important to her to develop her independence at mealtimes.	Discussion took place about how child_1 can have more opportunities to eat with her peers so that she can be part of the social aspect of mealtimes and develop her independence alongside her friends.
Child_2	Parent_2 and professionals talked about how making food choices is important to child_2.	A discussion followed about how child_2’s interest in exploring tactile objects could be used to develop a communication system for choice-making at mealtimes.
	Parent_2 and professionals talked about child_2’s enjoyment of movement	A discussion followed about how an adapted bicycle could be provided to increase child_2’s opportunity for movement and travel in his local area.
Child_3	Parent_3 spoke about child_3’s friendships and how they appear more important to child_3 than her relationships with adults at present.	A discussion followed about this being age appropriate and planning took place for ways in which child_3 could be given greater opportunity to spend time independently and safely with her

		peers, as would be expected for a child entering their pre-teen years.
	Parent_3 and professionals talked about how child_3 is increasingly 'letting go' when walking and how they consider independent walking to be important to child_3.	A discussion followed about increasing opportunities for child_3 to practice her physical skills to help her to achieve her goal.

3.3.5.7 Obstacles to developing child's views

This focussed code offers a negative case example reflecting participants thoughts about the barriers to a child developing *and* communicating their views. The initial code 'communication needs to develop' reflects some participants' thoughts about how barriers to a child communicating their views could be overcome by the child developing a functional communication system, such as verbal communication or sign. In these participant responses shown in table 29, emphasis is placed upon increasing the child's efficacy and developing their communication skills rather than focussing upon the strengths and skills of the adult as the child's communication partner.

Table 29. Text extracts for focussed code 'obstacles to developing child's views' (1)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
Communication needs to develop	CT_1	I suppose it would be like trying to give them those skills to show their responses ... to allow them to communicate to a range of people what they like, what they don't like, what they don't want to do and what they do want to do, so it's ... equipping them with those skills to let them have an influence.

	SALT_2	If he had something more formal then other people might be able to communicate with him better ... in terms of carers and other family members.
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Participants talk about how a child’s medical needs or disability may affect their access to activities, limiting the breadth of their experiences and their opportunities to develop their views about the world around them. The extract from PW_2 in table 30 shows her thoughts about how child_2’s physical disability limited his access to activities previously and his communication of what he wanted to do. Child_1 and child_2’s visual needs were discussed during their PCP meetings in relation how their actions may reflect needs arising from their visual impairment rather than suggesting their view of an activity. Child_1’s use of her hands to explore an object, for example, is thought to reflect her use of touch to find out about the object rather than her preference for engaging with the object in the first instance.

Table 30. Text extracts for focussed code ‘obstacles to developing child’s views’ (2)

<i>Initial code</i>	<i>Participant</i>	<i>Text extract</i>
What the child can’t do	PW_2	<Child_2> has got a lot more confident on his feet and now he’s a lot more confident with moving himself ... he will take you to where he wants to go ... when he was a bit younger and he wasn’t so strong on his feet ... he used to spend a bit more time in the chair.
Medical and developmental needs	SALT_2	In terms of communication, we’ve had families where they’ve got so much going on in their family life ... the children have got so many medical needs that the aid for communication or that extra thing to think about is just too much.

Meeting a need	CT_3	If they're not happy, in that they're not safe, they're not healthy, their views are going to be skewed ... you wouldn't pick a time when the child was crying ... you're not going to try and ask a child their views about the future while they're crying or while they're in pain, so it's kind of meeting those physical, emotional needs first.
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The extracts from SALT_2 and CT_3 suggest a child's health and medical needs may take priority over developing their communication in some instances, yet their reasoning is different. SALT_2 considers the needs of a child's family when caring for a child with complex needs, suggesting the influence of Bronfenbrenner's (1979) mesosystem upon a child when parents and professionals collaborate to agree priorities. CT_3 reflects upon a child's need for physical comfort and safety being met first and foremost, alluding to Maslow's (1943) hierarchy of needs by reflecting upon whether a child's communication is indicative of an unmet need rather than being an expression of their views.

3.4 Discussion

3.4.1 Introduction

In this section, a response to RQ1 and RQ2 will be formulated by, first, comparing the research findings to my prior knowledge and understanding of the concepts and themes relevant to the current research (see sections 1.4 and 3.1.1). I will aim for open and honest reflection upon the research findings that are congruent with the frame of reference I brought to understanding the data. Agreement and inconsistencies between the research findings and the extant literature in the field of study will be highlighted. The research findings

will be used to elaborate upon existing concepts and themes and I will highlight new theoretical perspectives identified during data analysis that offer an alternative framework within which the research findings can be understood. The limitations of the current study will be discussed and recommendations for future research will be made. Finally, I will return to the proposed practice framework (appendix 1) for exploring the views of children and young people with CLCN and elaborate upon the framework in light of the research findings.

3.4.2 Reconsideration of Research Question 1

How do parents and professionals describe their experience of understanding the views of a child with complex learning and communication needs?

3.4.2.1 The conceptual meaning of ‘a view’

The social constructionist perspective of the current research emphasises use of language and co-construction of shared meaning within a social context. One language concept relevant to the current research is the meaning of ‘a view’ and there are differing opinions presented within the literature in relation to children with CLCN (see Ware, 2004; Wright, 2008; & Harding, 2009). Participants in the current study expressed certainty about the children’s ability to communicate their likes, dislikes, wants, and feelings during their everyday activities. The children are seen by the adults as having agency and autonomy. They are considered able to affect the world around them. Harding (2009) suggests that a child’s emotional response should not be confused with a viewpoint, as the latter requires reasoned thought. Participants in the current study described a range of emotions that they consider the children to be able to convey. They talked about how a child’s emotional state should not necessarily be construed as their view of an activity. This suggests a

distinction is made by participants between a child's emotional response and viewpoint, as Harding recommends.

Several references are made within the literature to the cognitive skills a child is thought to need, such as anticipation, comparison, and evaluation, in order to have a viewpoint about their future (Ware, 2004; Porter, 2009; Harding, 2009). Participant responses included suggestion of how repeating activities over time and using visual cues may improve a child's ability to anticipate and remember. This shifts consideration of the cognitive skills required to formulate a view away from within-child deficits and towards actions adults can take to support a child's development of skills associated with informed decision-making, akin to Vygotsky's (1978) social constructivist theories of learning which associate children's functioning with adult actions. Kaniel and Feuerstein (1989) propose a *Mediated Learning Experience (MLE)* model of learning for children with learning difficulties that considers cognitive skills as modifiable within a relational context between adult and child. This position is supported by participants' perception of the children in the study as efficacious and their belief that development and change is possible despite the children's significant learning difficulties. Barriers to exploring a child's views are seen by participants when they focus upon the child's communication skills rather than considering the adult-child communicative relationship and the efficacy of the adult to *mediate* the child's expression of their views.

The meaning of 'a view' in relation to children with CLCN was raised by one participant during her interview. She questioned whether her experience of

adults discussing what a child enjoys or finds challenging during a PCP meeting is an authentic representation of the child's views. The reference she makes to adult interpretations of what the child wants for the future echoes the proxy reporting of a child's views referred to by Taylor (2007) as requiring triangulation with other data sources. I was conscious during my empirical work that the reflections offered by this participant challenged the conceptualisation of a view presented by other participants and my own beliefs about the meaning of a view in relation to children with CLCN (see section 3.1.1). I decided to include 'the meaning of a view' as a potential discussion topic during focus groups (see section 3.2.4.4) to invite further consideration by participants. However, this concept was not chosen by participants as one they wished to discuss in the focus groups context. Instead, participants were interested to discuss the conceptual meaning of 'future' in relation to a child's views. This will be explored further in section 3.4.3 in response to RQ2.

A social constructionist perspective leads to consideration of how social desirability may affect participant responses in a focus group context. Sharp (2014) suggests that the participants in his study may have found some constructs harder to articulate in a focus group. Brown (1988) writes of how an individual may deny their own viewpoint to conform with the majority view and maintain group membership. The school where the research is located is recognised for its commitment to ensuring all pupils are able to express their likes, dislikes, and opinions (see appendix 12). Participants in the current study would, therefore, have to express an opinion that could be seen as contrary to the values of the group in order to question how 'a view' is construed for children with CLCN. This offers one possible explanation for why

the conceptual meaning of a view was not explored by participants during focus groups.

The findings suggest there may be differing views held by members of an organisation regarding the meaning of 'a view' in relation to children with CLCN, as evident in the literature. The Communication Trust (2016) suggests that organisational values can counter perceptions of children as unable to express a view. However, social desirability may risk there being a difference between espoused beliefs and practice for some group members. Organisational values should, therefore, encourage open and honest reflection by its members on the attitudes, assumptions and beliefs affecting how the concept of 'a view' is construed in relation to a child with CLCN.

3.4.2.2 The relational context for exploring a child's views

Relationships are a prominent theme within the literature (see section 3.1.1), in terms of the adult-child communicative relationship (see Greathead et al., 2016; Porter, 2009) and the collaborative relationship between the adults supporting the child (see Harding, 2009). Bronfenbrenner's (1979) ecological model provides a framework within which the different kinds of relationships referred to by participants in the current study can be understood in order to elaborate upon existing themes within the literature (see figure 3). I will begin by exploring the findings relating to the *microsystem*, which describes the interaction between a child and the people in their everyday environment.

Participants in the current study were adept at describing a range of observable actions to which they give meaning in order to interpret a child's views, some of which may not be attended to typically during communication. This is congruent with the finding of Greathead et al. (2016) who observed school staff to recognise most of the communicative attempts of children with CLCN during their everyday school activities. Greathead et al. propose that adults may modify activities to increase opportunities for a child to communicate, which speaks to the efficacy of the adult in the adult-child communicative relationship. The findings of the current study support and elaborate upon this position. Participants talked about providing a broad range of experiences, observing a child's responses carefully and allowing time for a child to explore different options so that they can develop an informed view. Participants were mindful of how a child's medical needs or disability may affect their access to activities and limit the breadth of their experiences. The perspective offered by one participant suggests an adult's role as communicative partner may be to ensure a child's needs are met in order to minimise barriers, so far as possible, to the child accessing opportunities to develop their views.

Consideration is given in the literature to the nature of the relationship between adult and child when exploring a child's views. Several studies raise ethical concerns in relation to how an adult's thoughts and actions could influence a child's communication and views (see Taylor, 2007; Porter, 2009) and the potential for bias when a child's views are interpreted by an adult who is emotionally involved with the child (see Ware, 2004; Wright, 2008). Participants in the current study offer a different perspective upon a child's

relationship with significant others in their life. Participants talked about a child's awareness of the different nature of their relationships with different people. Although there was not a consensus among participants as to whether a child's relationships with different adults affects their expression of views, children's relationships with their siblings and friends featured during focus group discussions and during all of the PCP meetings. Participants talked about how a child's relationships with other children are different to their relationships with adults, with one participant suggesting that siblings may be able to offer a valuable perspective upon the interpretation of a child's views. This finding is similar to the work of Brewster (2004) who considered the role of peers in creating communication systems that ensure a child with CLCN has opportunity to express their views about matters considered relevant by their peer group. Brewster acknowledges that conclusions could not be drawn about the effectiveness of peer involvement from her small-scale study. Nevertheless, the findings of the current study support further investigation of the role siblings and peers could play in exploring the views of a child with CLCN. Careful consideration of the ethical issues raised within the literature would be required, given the emotional nature of sibling relationships.

The findings of the current study expand upon the idea that organisational ethos and culture can affect a child's expression of views (see Porter, 2009; Ware, 2004; Wright, 2008). While the literature focusses upon the value an organisation places upon seeking a child's views, participants in the current study talked about how the organisational context can foster collaborative relationships between the adults to help them to understand a child's views. The perspective offered by one participant suggests these relationships may

also support reflection by adults upon their role as a child's communicative partner, recognising an adult's strengths and promoting their efficacy in facilitating a child's expression of views. The empathy shown by another participant when talking about staff who are finding their work with children with CLCN challenging speaks to an ethos and culture that promotes reflexive practice by fostering supportive and non-judgemental interactions between adults. These findings relate to the *mesosystem* of Bronfenbrenner's (1979) model when adults from the child's different immediate environments, such as home and school, collaborate and influence one another. The findings also suggest that social groupings which do not include a child directly, such as social media networks and parent support groups, may be influential upon the way in which adults come to understand a child's views, extending consideration of the relational context for exploring a child's views to Bronfenbrenner's *exosystem*. I will now turn to the social context in which a child's views are understood, with reference to influences within the *macrosystem* comprising the ethos, culture, and values of a child's social contexts.

3.4.2.3 Making meaning in a social context

A social constructionist approach to understanding the views of children with CLCN is found in the literature. The Communication Trust (2016) proposes a 'support circle' is established of key people close to a child with CLCN to reflect upon and consider all possible interpretations when seeking to understand the child's views. Ingram (2013) suggests that socially constructing the meaning of a child's views may be problematic when members of a group are unable to

empathise with other perspectives and achieve a consensus. This perspective will be explored further in section 4.3 when reconsidering the epistemological position for the current research.

Reaching agreement about the meaning of a child's views was not found to be difficult for participants. Conversations taking place during PCP meetings were collaborative and supportive, which may reflect the skills of the headteacher as the meeting facilitator and the meeting structure (see appendix 25) that ensures everyone's contribution is valued equally. This finding is supported by Corrigan (2014) who reported that participants in her study of the use of PCP for children excluded from school recognised the importance of the meeting facilitator's skills in empowering others and co-constructing different perspectives. Participants in the current study spoke positively about developing their understanding of a child through their interactions with others. The findings demonstrated the value of drawing upon perspectives from different professional fields to enable a child's communication to be understood in different ways, an approach that could be realised within the Communication Trust's (2016) 'support circle'.

Parent participants referred to conflict with others when describing their experience of talking to adults in their child's previous education setting, suggesting a potential difference in ethos and culture between schools. Corrigan (2014) identified a potential difference in ethos between schools, with staff from one of six educational settings in which her research was located giving consistently negative responses about their experience of PCP relative

to participants from the other schools. The current study is located in one school, which prevents further consideration of the influence of organisational ethos and values upon the construction of a child's views and how this process is experienced by adults.

Participant responses highlight use of language as significant when making inferences about a child's views, with participants describing how they use their own words to model what they think a child is trying to communicate. This use of language also serves to communicate to others the inferences an adult is making from the child's actions. Wright (2008) demonstrates the potential for mismatch between the views of children with CLCN about their school activities and inferences made by adults about the child's views. Participants in the current study openly acknowledged their uncertainty about their interpretation of a child's views and showed willingness to question their judgement. They talked about making comparisons between a child's responses to different activities and in different contexts when considering a range of possible interpretations of the child's views. Different interpretations were discussed during PCP meetings, with a shared understanding of a child's views being socially constructed during the conversation between the adults.

3.4.3 Reconsideration of Research Question 2

How can parents' and professionals' understanding of the views of a child with complex learning and communication needs inform person-centred planning?

3.4.3.1 The conceptual meaning of 'future'

The importance of co-constructing shared meanings of language concepts when understanding the views of a child with CLCN is evident within the literature and the research findings. While discussion within the literature focusses upon the conceptual meaning of 'a view', participants in the current study spoke about the meaning of 'future' in relation to children with CLCN during their interviews and selected this language concept as a theme for further discussion during focus groups. Participants talked about planning for the future as being 'day-by-day' for children with CLCN. They acknowledged a difference between an adult's conceptualisation of 'future' and how a child with CLCN is thought to experience time in the 'here and now'. This finding supports the research of Pearlman and Michael (2019) who found children with learning difficulties ranging from moderate to severe were more able to respond to questions about their current school experience rather than their future.

Harding (2009) warns that suggestions in the literature that children with CLCN may not have 'a view' could deter professionals from attempting to engage with a child and explore what may be possible. The findings of the current study shift consideration of whether a child with CLCN is able to have 'a view' towards thinking about the timeframe associated with the view expressed and how this may be socially constructed by adults. Parents were uncertain whether their child would be able to have a view about what they want to do in the future. They also spoke about focussing upon the immediate future

themselves when planning for their child rather than thinking longer term. This finding arose during focus group discussions and the reasons for the parents' timeframe were not explored but could be an avenue for future research. Parents agreed with professionals during focus group discussions that focussing upon the 'here and now' for children with CLCN can be beneficial in terms of ensuring plans are flexible and opportunity is provided for a child to change their mind about what they want to do.

Observations made during the PCP meetings suggest that adults' understanding of a child's views in the 'here and now' can inform decision-making for the child's future. Participants were found to infer the meaning of a child's views about what is important to them for the future from their understanding of the child's views about their immediate context. This approach shows regard for the views a child has been able to express in the 'here and now' and ensures adults learn from a child's views, as far as possible, when making decisions for their future. This finding is consistent with MacIntyre's (1999) thinking about those with the most severe forms of disability being people from whom we *do* have something to learn and who can inform our thinking. This approach to understanding the views of a child with CLCN for PCP still requires adults to act as a proxy for the child and, therefore, raises ethical considerations when there remains potential for an adult's own views, wishes and feelings to influence their representation of a child's views.

3.4.3.2 Developing children's views over time

There is agreement within the literature that approaches to exploring the views of children with CLCN should draw upon multiple sources of information to

increase the validity of the views obtained (Harding, 2009; Porter, 2009; Taylor, 2007; Ware, 2004). The potential for a child's views to be biased by an adult's wishes and feelings may be reduced when triangulation of the information gathered takes place. The findings of the current study expand upon this idea by also considering the timeframe for gathering information, suggesting there should be triangulation of different sources of information and also comparison of how a child responds to an activity at different times.

Participants agreed that their understanding of how a child with CLCN communicates and what the child's views might be should develop over time, locating the process for understanding the views of children with CLCN within the *chronosystem* of Bronfenbrenner's (1979) model which comprises a timeline of events experienced by a child (see figure 3). The findings suggest that gathering a child's views should not be a 'one-off' activity undertaken for the purpose of a PCP meeting for two reasons. First, a child's response to an activity on one occasion could reflect their mood or an unmet need at a given time, such as hunger or tiredness, rather than reflecting their view of the activity. Second, a child with CLCN requires opportunity and time to explore different options available to them so that they can develop an informed view. This finding is supported by reference within the literature to the concept of time in relation to the cognitive skills associated with having a view about the future. Harding (2009) states that a child with CLCN is unlikely to be able to undertake the hypothetical thinking required when options for the future are presented to them. Affording the child opportunity to experience these options enables the adults to observe the child's responses carefully to inform their decision-making for the child's future.

Participants suggested that exploring the views of a child with CLCN over time provides opportunity for the child to change their mind and revise their view once they have new experiences and greater exposure to an activity in the same way as their typically developing peers. Comparison made within the literature between children with CLCN and typically developing children tends to focus upon deficits that may prevent a child with CLCN from developing and expressing a view. The findings of the current study suggest that comparison should also prompt consideration of whether children with CLCN are being afforded agency and autonomy in the same way as typically developing children.

3.4.3.3 Children's participation in decision-making

The literature on the use of PCP for children and young people with CLCN does not report on how consideration of a child's views can lead to improved participation in decision-making (see section 1.4). The findings of the current study suggest that understanding a child's views about their immediate context and experiences can lead to informed decision-making by adults for the child's future. That said, participants acknowledged that sometimes decision-making for a child with CLCN is led by adults acting in a child's best interests. The examples given by participants related typically to keeping a child healthy and safe and were often informed by professional assessment and advice, for example by a physiotherapist advising upon activities to improve a child's strength. In these instances, participants talked about using their understanding of a child's views to make changes to the activity with the aim

of increasing a child's engagement and enjoyment. This finding expands upon the notion that adults should have regard for a child's views in their decision-making by considering not only a child's aspirations for their future but also the provisions that can be made to enable them to develop the skills needed to achieve their goals.

There was recognition by participants that a child's ability to communicate their views about their health, medical needs and how they experience their disability may be limited relative to their ability to express their likes, dislikes, and wants in relation to their everyday activities. This finding suggests that children with CLCN may experience less agency in this aspect of their life. Participant responses indicated that adults could have regard for a child's views when selecting activities and equipment to support and promote the child's health and development. Ratti et al.'s (2016) systematic review of the effectiveness of PCP for people with intellectual disabilities identified only two studies that described health outcomes of PCP (see Truesdale-Kennedy et al. 2006; Robertson et al. 2006). Data gathered for both studies was reported by parents and professionals and the extent to which the views of people with intellectual disabilities about their health were included in the PCP process is unclear. The findings of the current study highlight health and medical needs as an area for future research with respect to how children with CLCN can express their views and experience agency in this aspect of their life. The next section will highlight other areas for future research in the context of the limitations of the study.

3.4.4 Limitations of the current study

Limitations explored in this section will focus upon the relationship between the research methods and exploration of the research questions. Consideration will be given to the characteristics of the adult participants and the organisational context within which the research is located. Recommendations will be made for future research, taking account of the limitations discussed. Evaluation of the use of GT methodology will take place in part 4.

3.4.4.1 Characteristics of the parents

Selection of participants focussed primarily upon the characteristics of the children and their parents and was underpinned by two ethical considerations. First, the selection strategy aimed to minimise potential conflicts of interest arising from my dual practitioner-researcher role within the school by ensuring I had not worked with the parents previously in my LA role. Second, the parents selected were considered by school staff to appear comfortable talking about their child's needs to guard against exposing them to undue emotional distress while participating in the study. These two factors led to the recruitment of parents with shared characteristics considered pertinent to the interpretation of the research findings.

Two of the three children lived in a neighbouring LA to the school, which meant they met the criteria of not being known to me as they accessed EP services in their home LA. Their parents had requested a change of school placement

from their local special school provision. This process requires parents to be strong advocates for their child when making the case for why their child's needs are not being met in their current school. Both parents experienced success in achieving a change of school placement. Bandura (1982) notes that perceived performance success influences self-efficacy and people are likely to continue to perform tasks that give rise to an efficacious self-percept. It is possible that the agency and self-efficacy these parents experienced as advocates for their child may lead to increased efficacy in relation to understanding their child's communication and views. Furthermore, this brings into question whether a relationship exists between a parent's self-efficacy and the agency and efficacy they attribute to their child.

The current case study design gave rise to a small sample size of three parents, with one parent unable to participate in phase one of data gathering. The approach taken to recruiting participants led to the children's mothers participating in the research in all three cases, although one father took part in phase three of data gathering. A parent's role in understanding the views of a child with CLCN could be a focus for future research, using a larger sample size of parents, engaging with all adults with parental responsibility for a child, and exploring factors such as parental perception of agency and self-efficacy in relation to their child's special educational needs. Demographic data such as parents' age, education, and socio-economic status was not gathered during the current research and may also offer avenues to explore when considering a potential relationship between parental self-efficacy and the agency of the child.

3.4.4.2 Characteristics of the professionals

Recruitment of professionals focussed upon their experience of working with the children. While the intention was to recruit participants from a range of professional backgrounds to increase the breadth and depth of data gathered, the case study design meant that the number of participants belonging to each professional group was small. The insights provided by the SALT were sometimes unique and could be attributed to her professional perspective, for example with regards to observing the actions of a child's communication partner (see section 3.3.5.5). Similarly, the explanation offered by the OT during the PCP meeting relating to how a child's actions may indicate a sensory need rather than an expression of views about an activity (see section 3.3.3.4) could be attributed to knowledge associated with her professional domain. The research findings do suggest a benefit of seeking perspectives from different professional groups and indicate value in a multi-agency approach when exploring the views of children with CLCN. Future research could include larger sample sizes from different professional groups to explore the understanding that different professions, rather than individual professionals, may bring to interpreting a child's views, strengthening the argument for multi-agency practice approaches.

The majority of professionals participating in the study had been working with children with CLCN for over ten years with the exception of two participants (see table 7). The participant with the fewest years of experience in her current role relative to other classroom-based participants and who was teaching a

relatively more able cohort within the school was also the only participant who questioned the conceptual meaning of how a 'view' is understood in relation to children with CLCN (see section 3.3.4.1). It is possible that her perspective could be attributed to her different professional practice experience relative to the other participants. Future research could include participants with varying professional practice experiences to explore how this may shape the way in which the concept of a 'view' is understood in relation to children with CLCN.

3.4.4.3 School context within which research is located

The current research is located in one school. I had an established relationship with the school in my professional role prior to the research. This meant that I had an existing relationship with some school staff participating in the study, which would be expected to continue beyond the research. A social constructionist perspective considers research findings as co-constructed by researcher and participants. The multifaceted nature of my relationship with some participants should, therefore, be acknowledged when considering the research findings and how social desirability could have influenced data gathered.

The school where the research is located is recognised for its commitment to ensuring all pupils are able to express their views (see appendix 12). The perspectives shared by the parent participants alluded to potential differences in ethos and practice between schools (see section 3.3.3.4). Charmaz (2014) writes that locating a GT study in one context should not be considered problematic, as a single location allows for in-depth exploration of the

historical, social, local, and interactional contexts to strengthen understanding of the developing theory. Corbin and Strauss (2008) assert that the aim of qualitative research is not to create a theory that can be generalised across contexts. Instead, a GT study can illuminate concepts and ideas that pose questions to be asked by other researchers and practitioners to gain insight and understanding of the phenomena being studied within their own context. In my view, the location of the current study in a single school is not a limitation but a factor to be acknowledged when considering how the findings can inform future research and practice.

3.4.5 Conclusions from the empirical study

Children with CLCN participating in the current study are viewed by the adult participants as having agency, autonomy, and ability to affect the world around them. Adults' understanding of their experience of exploring the views of a child with CLCN can be positioned within a relational and social context. Adults reflect upon their communicative relationship with a child and how they can best support a child to develop and express their views. Offering a broad range of experiences, observing a child's responses carefully and allowing time for a child to explore different options are considered by participants as important when developing an understanding of a child's views.

An organisational context that promotes collaboration between adults when inferring the meaning of a child's views was also recognised as important. Participants spoke positively about developing their knowledge and understanding of a child through their interactions with others. The research

findings demonstrate the value of drawing upon perspectives from different professional fields to enable a child's communication to be understood in different ways. Participants openly acknowledge their uncertainty when interpreting a child's views and are willing to question their judgement. A variety of possible interpretations of a child's communication are considered and a process of comparison and triangulation takes place in order to socially construct a shared understanding of the child's views.

Participants suggest that a child's ability to communicate their views about their health, medical needs and how they experience their disability may be limited relative to their ability to express their likes, dislikes, and wants in relation to their everyday activities. Participants spoke about decision-making being adult-led when the primary aim is to keep a child healthy and safe. Nevertheless, suggestion is made that adults may afford a child some agency by having regard for the child's views when selecting activities and equipment to support and promote the child's health and development

A social constructionist perspective recognises use of language and co-construction of shared meanings as important. While discussion within the literature focusses upon the conceptual meaning of 'a view', participants in the current study consider the meaning of 'future' when planning for children with CLCN. A difference between an adult's conceptualisation of 'future' and how a child with CLCN is thought to experience time in the 'here and now' is suggested by participants. Adults infer the meaning of a child's views about what is important to them for the future from their understanding of the child's

views about their immediate contexts. This approach shows regard for the views a child has been able to express in the 'here and now' and ensures adults are informed by a child's views, as far as possible, when making decisions. An ethical perspective is vital when adults take an '*informed proxy*' role as potential remains for the adult's own views, wishes and feelings to influence their representation of the child's views.

3.4.6 Implications for future practice

An intended outcome of the current research was to develop a proposed framework for gathering the views of children and young people with CLCN (appendix 1) in response to the research findings. A revised framework is presented in appendix 30.

Some aspects of the framework remain unchanged, such as the suggestion that multiple sources of information and alternative interpretations are considered when adults seek to understand a child's communication and views. Other aspects of the framework have been elaborated upon in response to the research findings. The guidance on identifying a child's method of communication, for example, now includes details of *how* adults can develop their understanding of a child's communicative approach by carefully observing the child and their interactional and situational context. The guidance relating to 'school ethos' now considers the professional development of school staff and emphasises the importance of reflexive practice. The section on gaining a child's consent to seek their views has been replaced with ethical considerations now embedded throughout the new

framework, as the research findings demonstrate the importance of an ethical perspective being taken *throughout* the process of seeking a child's views.

The proposed framework suggested that consideration be given to the 'kind of view' adults are seeking from a child and the cognitive skills associated with developing this view. This guidance has now been replaced in response to the research findings by reference to how the school ethos can encourage adults to take actions during a child's everyday activities to support the child's development of skills associated with informed decision-making. There is also new guidance within the framework on building a picture of a child's views over time, which replaces suggestion in the proposed framework that consideration is given to the kind of 'one-off' practical activities that may be undertaken to explore a child's views.

The current research had two main aims. The implications for practice highlighted in this section focussed upon the first aim of exploring approaches to gathering the views of children with CLCN for person-centred planning. In the next part of the thesis, a critical appraisal of the current research will address the second aim of exploring the application of Thornberg's (2012) 'data sensitising principles' to the empirical process and the implications for GT research.

PART 4 – CRITICAL APPRAISAL

4.1 Introduction

The final part of the thesis will provide a critical review of the use of GT methodology for the current research by using the CAT-GT (appendix 7) developed from the literature review in part 2. A response to RQ3 will also be provided by considering how Thornberg's (2012) data sensitising principles were applied during the empirical process.

The current research has been underpinned by researcher reflexivity and I have aimed for open and honest reflection upon my prior knowledge, understanding and preconceptions about the research topic that provided a lens through which data was viewed. I believe researcher reflexivity should also include consideration of the ethical position and worldview that underpins a researcher's empirical pursuit. This critical review will, therefore, begin with reflection upon my ethical position and the ethical dilemmas that arose during my research. I will then reconsider my epistemological position and the theoretical perspectives underpinning my analysis. I will go on to provide a critique of my approaches to data gathering and analysis. I will conclude by providing a response to RQ3 and evaluating my application of Thornberg's (2012) data sensitising principles to the current research.

4.2 Ethical matters arising during the empirical process

In this section, I will reflect upon two challenges that I encountered during data gathering. I will draw upon Macfarlane's (2009) *respectfulness* and *resoluteness* character virtue continuums (see appendix 4) to explore the values that underpinned my thinking and decision-making when presented with these ethical dilemmas. I will also refer to the *researcher reflexivity*

section of the CAT-GT to evaluate approaches to monitoring ethical decision-making during my research.

The potential vulnerability of participants was considered at the research design stage with regards to placing time demands upon parents who are caring for a child with complex needs alongside the usual challenges of daily living. A flexible approach was taken when making practical arrangements for interviews and alternative times and venues were offered to accommodate individual needs. The practicalities of participating in the study were particularly challenging for one parent. She asked twice to postpone her interview due to family circumstances, although she told me that she remained keen for her child to be involved in the research and was happy for other research activities relating to her child to continue. We agreed for her interview to take place at a later stage and a provisional date was set, but data gathering was then interrupted by the coronavirus pandemic. I invited the parent to contact me if she wanted to reschedule her interview, leaving the opportunity for an interview open for her to choose whether or not to pursue.

We eventually met during phase three of data gathering when the parent attended her child's EHCP review meeting, a time when she would be present in school ordinarily as opposed to a research specific activity. She spoke during the meeting about her family circumstances and the challenge of caring for a child with complex needs during the pandemic. It became apparent why she had found it difficult to commit the time to being interviewed for research purposes and I was pleased that I had not tried to pursue this with her further.

I was conscious of feeling anxious that the timeline for data gathering would be different for one of my three case studies, as interviews with professionals and observations would take place before my opportunity to speak with the parent and, potentially, the interview with the parent may not take place. I recognised that further attempts to reschedule the interview could be seen as persistent or intrusive by the parent, tending me towards *inflexibility* and *manipulation* in pursuit of data (see appendix 4). I considered whether to alter my multiple-case study research design from three case studies to two. However, I remained mindful of my ethical position with regards to ensuring children with severe cognitive impairment are not disenfranchised from research activity and have the opportunity to make a difference through empirical pursuit. I did not want to prevent the parent and child from being included in the study due to their individual circumstances and a change in the research design could have tended me towards *laziness* (see appendix 4). I chose, therefore, to reframe the challenge I was facing as an opportunity to reflect upon whether differences in data gathering between case studies might affect the process of exploring a child's views. When the children's PCP meetings began, I reflected upon how I had a sense of knowing more about the views of the two children whose mothers I had already met in comparison to the child whose mother I was yet to meet, as I had been able to learn about the child's response in a range of contexts experienced during their home life in addition to school.

I faced a second ethical dilemma when my empirical work was interrupted by the coronavirus pandemic with phase three of data gathering still to take place. I considered whether the PCP meetings could happen virtually to comply with the pandemic restrictions at that time. The school community where the research is located comprises vulnerable children and families, many of whom have complex medical needs. School staff had to adjust quickly to an unprecedented and rapidly changing context when the pandemic began, focussing all of their efforts on responding to government guidance and supporting children and families. I decided that it would not be ethical at the start of a global pandemic to pursue gathering data for the purpose of my research and I agreed with the headteacher that data gathering would pause. All participants were kept informed of the change to the expected timeline for their participation in the study and a request to extend the timeframe for data gathering was approved by UCL's research ethics committee (REC).

The *researcher reflexivity* section of the CAT-GT developed from the literature review in part 2 recommends a researcher reflects upon their relationship with their participants and their thought processes during data analysis, which is consistent with Charmaz's (2014) social constructivist perspective. The reflexive writing approach I took to documenting my thinking during my research (see section 3.2.5.4) enabled me to reflect upon how the decisions I made during my empirical work would be experienced by my participants. I also believe that writing a research diary enabled me to become consciously aware of my potential to shift along Macfarlane's (2009) virtue continuums. Therefore, I have developed the *researcher reflexivity* section of the CAT-GT as a result of empirical work to refer specifically to a researcher's reflexive

writing about the ethical issues arising during their research in order to reveal the thought processes underpinning their decision-making.

4.3 Reconsideration of my epistemological position

In this section, I will draw upon the *researcher reflexivity* section of the CAT-GT when reconsidering my epistemological position. I will reflect upon the epistemological approaches that EPs may take when considering a child's views as described by Ingram (2013): social constructionist, positivist, and critical realist (see appendix 31). I will then reconsider how a social constructionist perspective requires a researcher to examine how their research may be shaped by the researcher-participant relationship and by a researcher's preconceptions, attitudes, and beliefs about their field of study.

Ingram's (2013) context for exploring children's views relates to problem-solving in EP casework, which is different to the current research. She does not consider whether differences in children's communication and learning needs affect how their views are expressed and understood. Nevertheless, her discussion of different epistemological positions provides a framework within which the epistemology of the current research can be reconsidered. I will begin by addressing her criticism of the social constructionist perspective.

Ingram's (2013) concern for adults being unable to reach a consensus when socially constructing the meaning of a child's views was not realised during the current research. Group discussions about each child's views were observed

to be collaborative and supportive, and a range of alternative interpretations of the child's views were explored. When discussing the research findings in section 3.4.2.3, I considered how organisational ethos and values can create a context in which everyone's contribution is valued equally and adults are able to explore different perspectives. The current study was located in one school and parent participants alluded to differences in ethos and practice between schools, which may give rise to the potential for disagreement and conflict referred to by Ingram. However, a social constructionist perspective would accept the existence of different viewpoints, as each individual viewpoint would be recognised as influenced by cultural, social, and relational factors that may be unique to the individual. The research findings highlight the importance of adults remaining open to considering a range of possible interpretations of a child's views, particularly when children severely affected by disability are dependent upon adults to speak on their behalf. Adults aim for a socially constructed consensus about what the child's views might be when an 'objective truth' may not be possible to achieve.

The epistemology of the current research accepts that understanding the views of children with CLCN is a social process. Language, communication, and social interaction are considered to provide the context and tools for PCP and for the co-construction of shared meanings of a child's views. Viewing my empirical work through a social constructionist lens led me to explore two language concepts relevant to the process of understanding the views of children with CLCN – the conceptual meaning of 'a view' and the conceptual meaning of 'future'. I did not consider these concepts to be objective truths but social constructions, the meanings of which are embedded within

situational, interactional, and social contexts. The conceptual meaning of 'a problem' is pertinent to the context for exploring children's views that Ingram (2013) describes. However, she does not consider how language concepts are understood when critiquing social constructionism. A social constructionist perspective would not construe 'a problem' as an objective truth but would allow for exploration of how actions and events are understood by the people involved and whether the perception of 'a problem' is shared by all.

The focus upon language, communication, and social interaction requires the relationship between researcher and participants to be examined. Charmaz (2017a) considers researcher-participant interactions to be influenced by the social constructs of position, privilege, and power, which she locates within the research context. In my view, when a researcher-participant relationship exists prior to research activity, the situational and social contexts for this relationship should also be examined.

I had an existing relationship with several participants in the context of my professional practice role as an EP and this relationship would be expected by participants to continue beyond my research. The nature of this relationship meant that I had observed participants' work and engaged in consultation with them to develop their understanding of children's needs. Nolan and Moreland (2014) discuss the social dynamics of consultation between EPs and teachers. They refer to consultation as a collaborative process which aims to co-construct an agreed plan between those involved. They acknowledge the potential imbalance of power during consultation when a consultee seeks help

to solve a problem, which may elevate the status of the consultant. My strategic role within the LA where I am employed meant that, in addition to a consultant-consultee relationship, several participants had a relationship with me as chairperson of decision-making groups of which they are members, creating a context in which I could be perceived as a helpful facilitator or an authority figure.

The process of reflecting upon the multifaceted nature of my existing relationship with some participants has reaffirmed my agreement with Charmaz's (2014) social constructionist perspective upon the researcher-participant relationship. When I consider my own experience of position, privilege, and power in my relationship with participants prior to my research, I acknowledge that my LA strategic role may well have created a power imbalance in my favour. However, my experience of the consultant-consultee relationship in the school where my research is located is somewhat different to Nolan and Moreland's (2014) perspective. My perception of the school staff is that they are experienced and capable of meeting the needs of children with CLCN – a role which I have known them to perform throughout the many years I have worked with the school. This contrasts with my own limited experience of working directly with children with CLCN. When I enter a consultant-consultee relationship with a member of school staff, I perceive the balance of power to lie with the staff who hold knowledge and understanding of how to cater for children with CLCN. I construe my role in terms of reflecting, reframing, and asking questions that may challenge and develop their thinking while the staff hold the power to affect change through their daily practice. Nevertheless, a social constructionist perspective accepts that the school staff

may view their relationship with me differently, which may in turn affect how issues of position, privilege, and power are manifested within the current research. I will return to power relationships in section 4.5 when reflecting upon the approach taken to co-constructing my research with participants.

There were some participants with whom I did not have a relationship prior to the research. Although these participants did not know me personally, they are likely to have interacted with other EPs given their role in supporting a child with CLCN. The parent participants, for example, would have experienced an EP undertaking assessment of their child's special educational needs during their EHC needs assessment. I saw the parent participants as having agency and self-efficacy due to their previous experience of advocating for their child (see section 3.4.5.1). However, a social constructionist perspective accepts the possibility that these participants held pre-conceptions about the EP role which led them to have a different perspective upon their relationship with me, leading to constructs of position and power in the researcher-participant relationship being manifested differently to my expectation. An interesting line of inquiry would have been to explore participants' experiences, attitudes, and beliefs about the EP role prior to their engagement in research activities, although it is also acknowledged that they may not have felt able to explore this with me openly given their awareness of my profession.

A social constructionist epistemology also requires a reflexive approach to be taken by researchers towards their preconceptions, attitudes, and beliefs about a research topic and how these shape their empirical work. Thornberg's

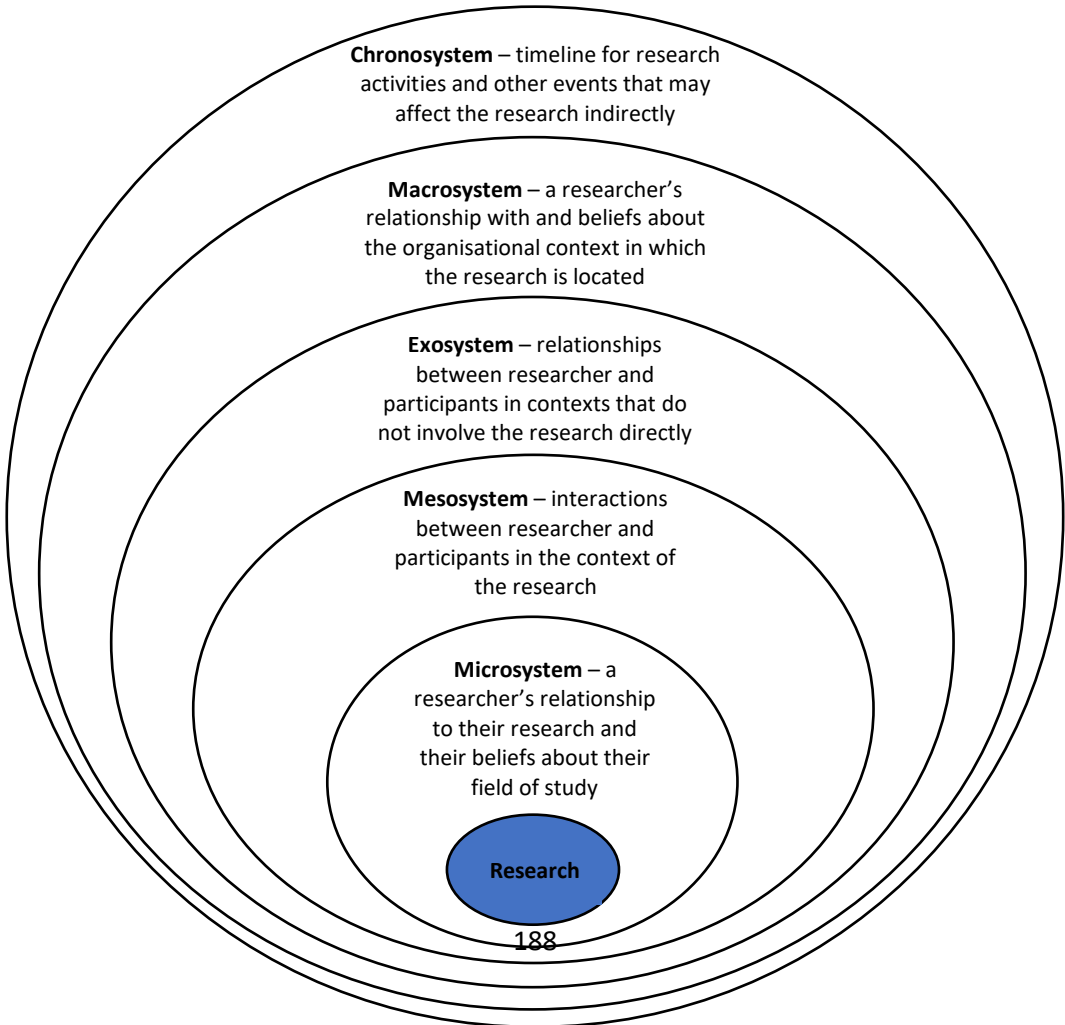
(2012) variation of GT informed the current research design, as this approach guides a researcher to scrutinise their prior knowledge and preconceptions about the field they wish to study. I will reflect upon my application of Thornberg's principles (appendix 2) in section 4.6. The reflexive approach I took to the current research focussed upon my knowledge and understanding of concepts and themes related to the research topic that I had developed through my professional practice and engagement with the pre-existing literature in my field of study. Reconsideration of my epistemological position and the implications for how my research is viewed has led me to consider the value of also taking a reflexive approach towards the preconceptions, attitudes, and beliefs I held about the context where my research is located.

My existing relationship with the school where the research took place and the potential for this relationship to affect data gathering was acknowledged when considering the limitations of the study (see section 3.4.5.4). I was aware at the research design stage that the school was recognised by Ofsted for its commitment to ensuring all pupils are able to express their views. I considered the school's ethos and existing practice to complement my research aims and the written information given to participants (see appendix 13) stated that the school was chosen to host my research due to its commitment to PCP. My knowledge of the school's Ofsted status coupled with my professional practice relationship with the school meant that I expected the research context to yield findings that reveal examples of best practice approaches in my field of study. This belief is likely to have influenced the personal analytical lens through which I viewed my data. Subsequently, I have developed further the *researcher reflexivity* section of the CAT-GT to include conscious reflection by

a researcher on their knowledge, ideas, and preconceptions about their field of study *and* about the context in which their research is located.

Bronfenbrenner’s (1979) ecological model provided a theoretical framework within which I came to understand some of my research findings (see figure 3). I have returned to Bronfenbrenner’s model in figure 6 below to illustrate the different kinds of social influences upon a research process that a social constructionist epistemology reveals. In the next section, I will explore further the theoretical perspectives that have influenced my understanding of the research process and my research findings.

Figure 6. A social constructionist perspective on factors influential upon the current research



4.4. Reconsideration of my theoretical perspective

In this section, I will reconsider the theoretical perspectives underpinning my analysis and conceptualisation of the research process. I will draw upon two sections of the CAT-GT to describe how my personal analytical lens has shaped and been shaped by the current research: *engaging with the extant literature in the field of study* and *comparing and contrasting competing theoretical perspectives*.

Thornberg's (2012) principle of 'theoretical pluralism' guides a researcher to compare, contrast, and combine different theoretical perspectives so that a fuller understanding of their data can be achieved. Three theoretical perspectives inform the conceptual understanding of current research findings: Bronfenbrenner's (1979) ecological model of human development, Charmaz's (2014) writing on social constructionism, and Bandura's (1982) theories of self-efficacy and human agency. These perspectives may appear disparate at first with each arising from different fields of psychology: Bronfenbrenner's work is located within developmental psychology while Bandura's theories relate to socio-cognitive learning. While each theoretical perspective enables different aspects of the data to be understood, the combination of these perspectives allows a deeper understanding to be achieved and the conceptual quality of the study to be realised.

Bronfenbrenner's (1979) ecological model describes the various social and relational contexts that influence how an adult interprets and constructs the meaning of a child's views. Social constructionism is located across all systems of Bronfenbrenner's model, with each system describing a different level of social influence upon the individual subjective realities that come together when shared understandings of a child's views are co-constructed in a PCP context. Only when thought is given to the social and relational contexts located within each system, such as the communication between parents and school staff, the perspectives offered by different professional groups, the influence of social media networks, and the ethos and culture of the different organisations to which group members belong, can a fuller understanding of the multiple realities influencing the creation of shared meanings of a child's views by the group be achieved.

The different levels within Bronfenbrenner's (1979) model also represent the contexts for socio-cognitive learning affecting self-efficacy. Organisational and cultural influences located in the *macrosystem*, for example, can create an ethos that values a person's strengths and provides feedback about their capabilities to promote an efficacious self-percept, as Bandura (1982) suggests. Social relationships within the *mesosystem* and *exosystem* can provide the 'verbal persuasion' that Bandura proposes will increase self-efficacy, for example when adults notice and reflect upon one another's skills in facilitating a child's communication and expression of views. Social contexts also provide opportunities for adults to model reflective thinking about different interpretations of a child's views and how to regulate feelings of uncertainty, which Bandura indicates will encourage adults to invest in activities to enhance

their understanding of a child's views, such as observing a child carefully over time.

Thornberg's (2012) principles of 'theoretical playfulness' and 'theoretical agnosticism' guide a researcher to compare and contrast their developing theory with pre-existing theories, all of which should be treated as theoretical proposals that may explain the research findings. I, therefore, accept the possibility that my research findings could be viewed from other theoretical perspectives. I referred briefly to Vygotsky's (1978) social constructivist theories of learning, for example, when discussing my findings in relation to the efficacy of an adult to mediate a child's expression of views (see section 3.4.2.1). There are three influences upon the theoretical perspectives I have chosen of which I am consciously aware and which persuade me that these perspectives offer the completest explanation of my research findings: my engagement with the extant literature relating to my field of study, the theoretical perspectives informing my professional EP practice, and my conversations about my research with EP colleagues in the LA where I am employed and with my research supervisor. I will discuss each of these in turn, beginning with reflections upon my engagement with the pre-existing literature.

In part 2, I discussed Glaser and Strauss' (1967) belief that grounded theorists should undertake a literature review after their empirical work. They assert that delaying the literature review ensures researchers remain open to generating new theories from their data and avoid making their data fit extant theories. Conversely, their conceptualisation of 'theoretical sensitivity' implies

that practitioner-researchers will bring knowledge of their field to their research and that this may inform theory development provided that their thinking does not become wedded to a preconceived theoretical position. Glaser and Strauss define 'theoretical sensitivity' in terms of how theoretical insights developed by a researcher over time in their field may be combined with concepts and hypotheses emerging from their data to progress theory development. Thornberg (2012) describes this as an abductive approach, which calls upon a researcher to take a reflexive stance towards how their prior knowledge and understanding influences their research.

My engagement with the literature relating to my field of study combined with a reflexive approach towards my prior knowledge and preconceptions arising from my professional practice served to advance my analysis by providing a range of 'lenses' through which my data could be viewed. The conceptual meaning of a 'view' is discussed widely within the literature and offered one such lens. I was aware prior to my empirical work of the differing and competing perspectives presented within the literature on this concept in relation to children with CLCN. The belief I held when embarking upon my research was that a pragmatic approach should be taken to move the debate about the conceptual meaning of 'view' towards a realistic appraisal of the information gathered and how this information will be used to benefit a child or young person (see section 3.1.1). Sutcliffe (2016) and Thornberg (2018) suggest that theoretical perspectives within the pre-existing literature can focus a researcher's attention upon certain aspects of their data. Conscious reflection upon my knowledge and understanding of the debates surrounding the conceptual meaning of a 'view' increased my sensitivity to this concept

within my data and to viewpoints offered by participants that both supported and challenged my belief (see section 3.4.2.1).

Furthermore, debate within the literature about the conceptual meaning of a 'view' heightened my sensitivity for noticing other language concepts within the data pertinent to my research aims, namely the conceptual meaning of 'future'. This concept had not featured for discussion within the pre-existing literature yet was referred to frequently by participants during individual interviews and during focus group discussions when feedback was sought from them on the research findings (see section 3.3.2). In my view, my engagement with the pre-existing literature did not narrow my focus upon one concept but widened my lens to identify another concept, enabling my research to make a distinct contribution to my field of study by inviting further debate to advance theory development.

The literature review highlighted the value in researchers combining theoretical perspectives to create new insights in their research field (see Sharp, 2014; Thornberg, 2018). My engagement with pre-existing literature prior to my research enabled me to combine 'lenses' through which to view my data and reveal something new. Two prominent themes within the pre-existing literature were the relationships between the adults supporting a child and the ways in which adults infer meaning about a child's views (see table 3). Combining these two themes focused my attention towards exploring in my data the perspectives that adults from different professional fields can bring to enable a child's communication to be understood in different ways, which in turn

allowed me to elaborate upon the 'support circle' approach proposed by the Communication Trust (2016) (see section 3.4.2.3)

My prior engagement with the literature relating to my research topic focussed upon identifying concepts and themes to stimulate my thinking, critiquing methodological and ethical issues to inform my research design, and establishing how my research will contribute to knowledge and understanding within my field of study. Miller (1995) took a somewhat different approach to engaging with literature prior to his analysis. He focussed broadly upon fields in psychology, such as social psychology and organisational psychology, which he hypothesised could progress his developing theory on behavioural approaches in schools, rather than exploring the literature relating specifically to his research topic. The theoretical perspectives I have drawn upon during my research relate to the fields of social psychology and developmental psychology. I referred to social processes when introducing the theoretical perspectives underpinning my research (see section 1.4). Two specific psychological concepts were then considered during the theoretical coding stage of my analysis to explain the theory I was developing from my data: Bronfenbrenner's (1979) ecological model of human development and Bandura's (1982) theories of self-efficacy and human agency.

Bronfenbrenner's model has informed my practice throughout my EP career. I came to consider Bandura's (1982) theories when discussing my focussed codes with my research supervisor and EP colleagues in the LA where I am employed. Sutcliffe (2016) was the only researcher identified during the

literature review who sought feedback on his analysis from a professional independent to his research but with practice experience relevant to his research topic. My research supervisor and EP colleagues had practice experience relevant to my research topic and discussing my analysis with them revealed insights from their individual perspectives which broadened the conceptual understanding of my research findings. While I was aware of self-efficacy and human agency as conceptual proposals prior to my research, I did not consider these concepts to have shaped my professional practice in the same way as Bronfenbrenner's (1979) model. The process of inviting others to view my research through their personal 'lenses' and engaging in conversations with them about what they saw ensured I heeded Glaser and Strauss' (1967) warning to guard against fitting my data to match my worldview. A further development I would now make to the *comparing and contrasting theoretical perspectives* section of the CAT-GT is to recommend researchers make explicit prior to their empirical work the theoretical perspectives underpinning their professional practice that may also influence their thinking when undertaking research within their professional field.

4.5 Reflections upon using grounded theory methods

The rationale for my research design and chosen methods was explained in section 3.2 with reference to the literature review undertaken in part 2. In this section, I will discuss the strengths and weaknesses of the methods I chose

by using the *data gathering* and *data analysis* sections of the CAT-GT to critically evaluate the approaches taken.

The literature review in part 2 highlighted that most approaches taken to gathering data for a GT study involve direct interaction between researcher and participant, although the context for the interaction may vary (see section 2.3.2.1). The current research drew upon a range of participant perspectives and contexts for gathering data by using a combination of in-depth interviews, observations, and focus group discussions within a multiple case study design. I consider this to be a strength of the research design and also an important ethical consideration when exploring the views of children who are dependent upon adults to speak on their behalf, as this method ensured data gathered about the children's views could be triangulated (see section 3.2.2).

I consider the co-construction of data analysis between researcher and participants to be a strength and an important part of my research design given my social constructionist perspective. The focus group discussions in phase three of data gathering aimed to check participant agreement with my interpretation of their interview responses and gather feedback from participants on the proposed research findings (see section 3.2.4.3). I took the decision to use focus groups for this aspect of my research for ethical reasons (see section 3.2.2). However, seeking feedback in a group setting presents another ethical dilemma with regards to how able participants are in this context to challenge a researcher's interpretation.

Migliaccio (2015) highlights the importance of considering how participants respond to one another when gathering data in a group context. He suggests that data gathered in a group reflects the sense of self and identity that participants wish to present to other group members. The focus groups were attended by a range of professionals (see appendix 14) who were present for the child's EHCP review meeting in addition to participants who took part in the interview phase of data gathering. The nature of the relationships between professionals varied, with some professionals being visitors to the school and others having long established relationships with one another as colleagues albeit occupying different positions and status within their respective organisations. In response to RQ1, I considered how social desirability may have prevented participants from discussing the conceptual meaning of 'a view' in a group context (see section 3.4.2.1), although one participant did discuss this with me during her individual interview. Social desirability may also explain why, in a focus group context, participants did not challenge my interpretation and analysis due to their concern for how this may be perceived by the group.

Migliaccio (2015) observed his participants' responses to one another during focus group discussions. The current research used different methods of recording data in phases two and three compared to phase one. The method used during phase one can be considered to be the most rigorous approach, with use of audio-recording and transcription ensuring participants' language was captured fully. The use of fieldnotes during phase two enabled the informality of social interaction in a classroom context to be captured, with spontaneous conversations and structured activities often occurring

simultaneously. In contrast, the PCP meetings observed in phase three followed a structured format which would have been appropriate for audio-recording and transcription. A pragmatic decision was made to use handwritten fieldnotes during phase three due to the time-consuming nature of transcription considered alongside the time available when research activities are undertaken by a single researcher. However, the use of audio-recording and transcription to record focus group discussions could have enabled me to observe the social processes occurring in the group context rather than focussing my attention on the spoken word. Observing whether some group members were more likely to lead the conversation and how different group members responded to one another could have revealed power dynamics within the group and allowed me to consider how these affected theory development. These kind of observations may reveal social and situational influences upon data gathered, which Charmaz (2014) refers to as invisible influences upon research that a social constructivist perspective can reveal.

Furthermore, the different approaches taken to data recording meant that data gathered during phase three was less detailed in comparison to data gathered in phase one. This limitation is particularly relevant to RQ2, as data gathered during phase three contributed mostly to addressing this research question. Future research could focus specifically upon exploring the PCP process for children with CLCN with a similar approach to data gathering and analysis employed during phase one to enable use of language, communication and social interaction underpinning the process to be explored.

An alternative to seeking participant feedback in a focus group context would be to seek participants' views on my interpretation and analysis of their interview responses on an individual basis. The coronavirus pandemic occurred during my research and I have observed in my professional practice how the way in which professionals and parents communicate with one another is evolving. The use of video call technologies has become more prevalent and offers an alternative to face-to-face meetings that places less time demand upon those involved who are not required to travel to a physical meeting place. The literature review highlighted the importance of involving participants in choosing data gathering methods when co-constructing theory and I offered participants the opportunity to choose the venue and timing for their interview. The activities observed in phase two were also guided by participants' interview responses. Greater autonomy could have been given to participants by also seeking their views about the context and method by which they would like to give their feedback on my interpretation and analysis of their interviews and allowing them to choose the amount of time they want to give to research activities rather than making this decision on their behalf.

The literature review also highlighted the importance of seeking feedback from participants on their experience of taking part in research (see Harcohen, 2012). Use of paraphrasing (see appendix 20) and attention to participants' non-verbal cues during interviews enabled me to check that I had understood participants' stories correctly and that they felt comfortable during the interview process. The final question of the interview schedules (appendices 15 and 16) invited participants to comment and ask questions about the research. I also asked how they had found their interview experience. The transcript extracts

in appendix 32 illustrate two kinds of responses received. The extract from PW_2 shows her views about the method of data gathering and how she preferred the informal conversational style taken to an approach such as video recording that may appear formal and intrusive. The extract from parent_2 suggests that our conversation during the interview offered a different perspective upon her child's communication and promoted her to reflect upon how he expresses his views.

Charmaz (2017a) encourages researchers to make a conscious attempt to view their research from their participants' perspectives. She suggests that reflexivity can change how a researcher views their research aims, participants, and themselves. A social constructivist perspective also suggests that a participant's attitudes and beliefs may be changed by their participation in research activity. The process for seeking feedback from participants on their interview experience could, therefore, also explore participants' views of the interview questions they were asked and whether their thoughts or actions have changed since participating in the research.

Four of the studies selected for review in part 2 actively sought inconsistencies and exceptions within the data during analysis (see Wong et al., 2013; Wolfe, 2014; Sharp, 2014; Sutcliffe, 2016). I took this approach during initial coding and identified five 'negative case examples' that each opposed the meaning of a focussed code, enabling me to achieve a deeper understanding of these codes in the context of my participants' lived experiences. The negative case example discussed in section 3.3.3.4, for example, revealed the organisational

ethos and cultural influences upon how the focussed code 'conversations, collaborations, and community' is experienced by participants. Sutcliffe (2016) took a somewhat different approach to identifying negative case examples (see section 2.3.2.1). He sampled one additional participant as a "*possible negative case example*" (p. 51) to explore particular themes within his analysis. This approach could be taken to explore further the perspective given by CT_3 on how the conceptual meaning of a 'view' is understood in relation to children with CLCN. I attributed the different perspective offered by CT_3 to her professional practice experience, which was different to the other participants (see section 3.4.5.2). A purposive approach to sampling one more participant who shared CT_3's characteristics would have allowed me to test the way in which I understood this difference in my data.

4.5.1 Recommendations for future research

Recommendations for future research are based upon the limitations of the current research discussed in section 3.4.4 and my reflections upon using grounded theory methods in section 4.5. Recommendations focus upon the selection of participants, methods of data gathering, and potential avenues to explore further suggested by the research findings. The role of parents in understanding the views of a child with CLCN and the relationship between parental self-efficacy and the agency of the child could be explored using a larger sample size of parents and including fathers. The contribution made by different professional groups to understanding the views of a child with CLCN could also be explored to ascertain whether different professional backgrounds and experiences offer different perspectives upon how a child's views are construed. Future research is also recommended to focus specifically upon the social processes underpinning how shared meanings of a child's views are

created by a group in a PCP context, employing audio-recording and transcription methods for gathering rich data while affording a researcher opportunity to also observe the non-verbal communications and interactions occurring within the group.

4.6 Reconsideration of Research Question 3

How can Thornberg's seven 'data sensitising principles' (see appendix 2) be applied when developing a grounded theory that has been informed by existing literature, theories and concepts?

The current research was informed by Thornberg's (2012) version of GT with the aim of promoting honest and open reflection upon the knowledge, preconceptions, and beliefs I have developed through my professional practice experience and engagement with pre-existing literature relating to my field of study that are likely to have influence my research. In this section, I will formulate a response to RQ3 by reflecting upon my experience of applying Thornberg's 'data sensitising principles'. I will begin by considering Thornberg's principle of 'theoretical sampling of the literature'.

In my view, Thornberg's (2012) 'theoretical sampling of the literature' principle guides a researcher to apply a coding process to the literature as well as to their data so as to identify concepts and questions posed by the literature that may be explored further in the empirical field. The starting point for the current research was the professional practice doctoral assignment I had written on exploring the views of children and young people with CLCN (see Volume 2). Writing this assignment meant that I had already undertaken a systematic review of the literature in my field of study prior to my research. Thornberg

describes an iterative process in which a researcher moves back and forth between the literature and their data to explore what each can reveal about the codes and concepts under development. However, my engagement with the literature had taken place before data gathering and analysis began. If I was to follow Thornberg's 'theoretical sampling of the literature' principle, I would need to apply a coding process retrospectively to the literature to reveal conceptual proposals to guide my empirical work.

Thomas et al.'s (2017) continuum for analysing textual information suggested a process that could be applied to my written assignment to identify the concepts and themes that I had found within the literature *and* my thoughts and interpretations of the literature about which I was writing (see appendix 8). These concepts and themes were summarised in table 3 and were treated as conceptual proposals and tentative codes to explore when data analysis began. This approach enhanced my 'theoretical sensitivity' and advanced my developing theory, as described in section 4.4. Thornberg considers this to be a desirable outcome of applying his 'theoretical sampling of the literature' principle along with enabling researchers to understand how their research will contribute to the current knowledge and understanding in their field of study, which the scoping review of literature relating to PCP for children with CLCN detailed in section 1.4 helped me to achieve.

It was at the stage of identifying concepts and codes within the literature that I began applying Thornberg's (2012) 'memoing extant knowledge associations' principle by writing my thoughts and ideas about the concepts and themes I

found within the literature (see appendix 11). I then moved on to writing memos to describe each initial code I identified during the first stage of data analysis (see appendix 28) while simultaneously writing my thoughts about methodological and ethical issues as they arose (see appendix 11). I became increasingly aware as my empirical work progressed of the amount of written data I was generating in the form of memos, research diary entries, interview transcripts and field notes. The initial and focussed coding process created a structure within which I could organise written data gathered through research activities. The literature review in part 2 suggested that my reflexive writing could be categorised into two groups – ‘coding memos’ and ‘research diary entries’. However, I found this approach still created large volumes of unorganised data and I considered a more nuanced system to be required. I began a process of assigning codes to my reflective writing, as follows: ‘pre-engagement with the extant literature’, ‘methodological issues’, ‘ethical issues’, ‘initial coding memos’, ‘focussed coding memos’, ‘possibilities arising from the data’, and ‘returning to the literature’. I found that using language in this way to describe my reflexive writing revealed a link between my thoughts and my actions during research activities, and that making this link explicit supported my application of Thornberg’s (2012) principles of ‘staying grounded’ and ‘theoretical playfulness’.

The principle of ‘staying grounded’ reminds a researcher that the main focus for their research activity should be upon their data rather than the literature. Charmaz (2014) encourages researchers to ask questions about what is happening in their data and create codes that delineate actions within the data. Asking these questions of my reflexive writing increased my sensitivity for

noticing whether my thinking and theorising was primarily about my data or the literature. The code 'possibilities arising from the data', for example, described the thoughts and ideas that occurred to me during initial and focussed coding when my attention was upon my data. The code 'returning to the literature', in contrast, marked a shift in my thinking as I compared and contrasted my theorising from my data with the concepts and themes suggested within the literature. While I acknowledge that a binary classification that distinguishes between my thinking about the data and my thinking about the literature is unlikely, I found that coding my reflexive thinking in this way enabled me to monitor whether my participants' stories were my main focus. Furthermore, monitoring the timeline for my reflexive writing practices also allowed me to ensure Thornberg's principle of 'constant reflexivity' was applied throughout all stages of my empirical work.

Thornberg (2012) encourages researchers to take a critical and creative stance towards pre-existing literature in their field of study. He asserts that his 'theoretical playfulness' principal guides researchers to compare and contrast the theory they are developing from their data with extant literature in order to reveal new insights by elaborating upon or challenging theories and concepts presented by other researchers. My reconsideration of the extant literature in my field of study began during the focussed coding stage of my analysis (see section 3.2.5.3). I compared and contrasted the codes I was developing with my knowledge and understanding of the concepts and themes I had identified through my 'theoretical sampling of the literature' (see table 3) and using the code 'returning to the literature' in my reflexive writing delineated my shift in thinking between literature and data.

My response to RQ3 has so far focussed upon my thoughts and actions as an individual researcher and how a metacognitive approach to memoing enabled me to translate Thornberg's (2012) principles into practice. I will now take a social constructivist position to consider Thornberg's remaining two principles: 'theoretical agnosticism' and 'theoretical pluralism'. The former guides researchers to treat all pre-existing theories and concepts as proposals that can be modified or disputed whether they have arisen from a researcher's professional practice experience or from the literature. The latter relates to the comparing, contrasting, and combining of different theoretical perspectives so that a researcher may achieve a fuller understanding of their data and guard against forcing data to fit a particular theory that matches their pre-conceptions about their field of study.

My reflections upon my epistemology and the theoretical perspectives I have taken during my research (see sections 4.3 and 4.4) led me to consider the different kinds of social influences upon my empirical work. I intended for my research to be co-constructed with participants from the onset (see section 3.1.3). A different social context influential upon my research was revealed when I shared my focussed codes with my research supervisor and EP colleagues in the LA where I am employed. Thornberg's (2012) 'theoretical agnosticism' principle guided me to view my focussed codes as conceptual proposals at this stage and I was open to changing my developing theory in response to the feedback I received from the perspectives taken by others towards my research. Thornberg's (2012) 'theoretical pluralism' principle was

then realised in this context as alternative theoretical perspectives upon my data were offered, which simultaneously extended my thinking and made me consciously aware of the pre-conceptions I had brought to my analysis.

4.7 Conclusion

Research question 3 is concerned with *how* Thornberg's (2012) 'data sensitising principles' can be applied to a GT study. In my view, writing memos from the earliest stage of my research enabled me to translate Thornberg's principles into practice and I consider the principle of 'memoing extant knowledge associations' to be fundamental to the application of Thornberg's version of GT. Thornberg considers the process of writing memos to facilitate a researcher's thinking and theorising about the literature and their data. Critical appraisal of my research has highlighted other factors for consideration by a researcher when taking a reflexive approach towards their ideas and beliefs about their field of study which underpin their thinking and decision-making and influence their research: the theoretical perspectives informing a practitioner-researcher's professional practice, a researcher's relationship with and beliefs about the context in which their research is located, the researcher-participant relationship in contexts external to the research as well as during research activities, and ethical issues encountered during the empirical process.

Application of Thornberg's (2012) version of GT requires a metacognitive approach to be taken by researchers so that they may become consciously aware of how their thought process influence their research. Furthermore, by

locating theory development in a social context and by actively engaging with participants and practitioners related to the field of study during the empirical process, new perspectives and interpretations may be revealed to a researcher that advance theory development.

REFERENCES

Armstrong, R., Hall, B. J., Doyle, J. et al. (2011). Cochrane Update: 'Scoping the scope' of a Cochrane review. *Journal of Public Health, 33 (1)*, 147-150.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist, 37 (2)*, 122-147.

Bellamy, G., Croot, L., Bush, A. et al. (2010). A study to define: profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities, 14 (3)*, 221-235.

Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities, 32 (4)*, 166-169.

British Psychological Society (BPS) (2014). *Code of human research ethics*. Leicester: BPS.

Bronfenbrenner, U. (1979) *The ecology of human development: experiments by nature and design*. Cambridge, Mass.: Harvard University Press

Brown, R. (1988). *Group processes*. Oxford: Blackwell Publishers Ltd.

Butterfield, J. (2009). Using grounded theory and action research to raise attainment in, and enjoyment of, reading. *Educational Psychology in Practice*, 25:4, 315-326.

Charmaz, K. (2017a). The power of constructivist grounded theory for critical inquiry. *Qualitative Inquiry*, 23 (1), 35-45.

Charmaz, K. (2017b). Constructivist grounded theory. *The Journal of Positive Psychology*, 12 (3), 299-300.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). London: Sage.

Clark, A. & Moss, P. (2001). *Listening to young children: The Mosaic Approach* (2nd ed.). London: Jessica Kingsley Publishers.

Communication Trust (2016). *Involving children and young people with SLCN. A toolkit for education settings*. Available at www.thecommunicationtrust.org.uk

Corbin, J. & Strauss, A. L. (2008). *Basics of Qualitative Research* (3rd ed.). London: Sage.

Corrigan, E. (2014). Person centred planning 'in action': exploring the use of person centred planning in supporting young people's transition and re-integration to mainstream education. *British Journal of Special Education*, 41:3, 268-288.

Council for Disabled Children (n.d.). *Participation*. Retrieved 13 January 2018 from <https://councilfordisabledchildren.org.uk/our-work/participation>

Department for Education (1994). *The Code of Practice on the Identification and Assessment of Special Educational Needs*. London: DfE.

Department for Education and Skills (2001). *Special Educational Needs Code of Practice: 0 to 25 years*. London: DfES.

Department for Education and Department of Health (DfE & DoH) (2015). *The Special Educational Needs and Disability Code of Practice*. London: DfE & DoH.

Department of Health (2001). *Valuing People: a new strategy for learning disability for the 21st century*. London: DoH.

Department of Health (2010). *Person-centred planning: advice for using person-centred thinking, planning, and reviews in school and transition*. London: DoH.

Fitzgerald, N., Ryan, P. & Fitzgerald, A. (2015). Team-based approaches in early intervention services for children with disabilities: Irish parents' experiences. *Journal of Policy and Practice in Intellectual Disabilities*, 12 (3), 199-209.

Glaser, B. G. & Stauss, A. L. (1967). *The Discovery of Grounded Theory*. Chicago, IL: Aldine.

Greathead, S., Yates, R., Hill, V. et al. (2016). Supporting children with severe-to-profound learning difficulties and complex communication needs to make their views known. *Topics in Language Disorder*, 36 (3), 217-244.

Harcohen, C. (2012). "The norm is a flux of change": teachers' experiences in international schools. *Educational Psychology in Practice*, 28 (2), 113-126.

Harding, E. (2004). Obtaining the views of children with profound and multiple learning difficulties. *Educational and Child Psychology*, 26 (4), 117-128.

Ingram, R. (2013). Interpretation of children's views by educational psychologists: dilemmas and solutions. *Educational Psychology in Practice*, 29 (4), 335-346.

Kaehne, A. & Beyer, S. (2014). Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disabilities. *Journal of Intellectual Disability Research*, 58 (7), 603-613.

Kaniel, S. & Feuerstein, R. (1989). Special needs of children with learning difficulties. *Oxford Review of Education*, 15 (2), 165-179.

Levy, R., Hall, M. & Preece, J. (2018). Examining the links between parents' relationships with reading and shared reading with their pre-school children. *International Journal of Educational Psychology*, 7 (2), 123-150.

Macfarlane, B. (2009). *Researching with Integrity: the ethics of academic inquiry*. Oxford: Routledge.

MacIntyre, A. (1999). *Dependent Rational Animals*. London: Duckworth Publishers.

MacKay, T. (2009). Severe and complex learning difficulties: issues of definition, classification, and prevalence. *Educational and Child Psychology*, 26 (4), 9-18.

MacKay, T., Boyle, J. & Cole, R. (2016). Guest editorial: Methods for research in professional educational psychology. *Educational and Child Psychology*, 33 (3), 6-10.

Maslow, A. H. (1943). *A theory of human motivation*. New Dehli: General Press.

Migliaccio, T. (2015). Teacher engagement with bullying: Managing an identity within a school. *Sociological Spectrum*, 35 (1), 84-108.

Miller, A. (1995). Building grounded theory in educational psychology practice. *Educational and Child Psychology*, 12 (2), 5-14.

Murphey J. & Cameron, L. (2008). The effectiveness of Talking Mats with people with intellectual disability. *British Journal of Learning disabilities*, 36, 232-241.

Murray, J. M. (2013). Young children's research behaviour? Children aged four to eight years finding solutions at home and at school. *Early Child Development and Care*, 183 (8), 1147-1165.

National Portage Association (NPA) (2016). *Portage Workshop. A Small Steps Approach to Learning for Children with Special Educational Needs and Disabilities (SEND). Participant Handbook*. Birmingham: National Portage Association.

Nolan, A. & Moreland, N. (2014). The process of psychological consultation. *Educational Psychology in Practice*, 30 (1), 63-77.

Pearlman, S. & Michaels, D. (2019). Hearing the voice of children and young people with a learning disability during Educational Health Care Plan (EHCP). *Support for Learning*, 34 (2), 148-161.

Porter, J. (2009). Missing out? Challenges in hearing the views of all children on barriers and supports to learning. *Education 3-13*, 37 (4), 349-360.

Purcell, A. (2012). A qualitative study of perceptions of bullying in Irish primary schools. *Educational Psychology in Practice*, 28 (3), 273-285.

Ratti, V., Hassiotis, A., Crabtree, J. et al. (2016). The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities, 57*, 63-84.

Robertson, J., Emerson, E., Hatton, C. et al. (2006). Longitudinal analysis of the impact and cost of person-centred planning for people with intellectual disabilities in England. *American Journal on Mental Retardation, 111*, 400-416.

Salter-Jones, E. (2012). Promoting the emotional well-being of teaching staff in secondary schools. *Educational and Child Psychology, 29 (4)*, 18-31.

Sanderson, H. (2000). Person Centred Planning: Key Features and Approaches. Retrieved 12 February 2022 from <http://www.familiesleadingplanning.co.uk/Documents/PCP%20Key%20Features%20and%20Styles.pdf>

Sharp, R. (2014). Ready, steady, action: what enables young people to perceive themselves as active agents in their lives? *Educational Psychology in Practice, 30 (4)*, 347-364.

Sheffield, E. L. & Morgan, G. (2017). The perceptions and experiences of young people with a BESD/SEMH classification. *Educational Psychology in Practice*, 33 (1), 50-64.

Simons, H. (2009). *Case Study Research in Practice*. London: Sage.

Strauss, A. L. & Corbin, J. (1990). *Basics of Qualitative Research* (1st ed.). London: Sage.

Sutcliffe, A. (2016). Grounded theory: a method for practitioner research by educational psychologists. *Educational and Child Psychology*, 33 (3), 44-54.

Taylor, K. (2007). The participation of children with multi-sensory impairment in person-centred planning. *British Journal of Special Education*, 34 (4), 204-221.

Thomas, J., Gough, D., & Oliver, S. (2017). *An Introduction to Systematic Reviews*. London: Sage.

Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research*, 56 (3), 243-259.

Thornberg, R. (2018). School bullying and fitting into the peer landscape: a grounded theory field study. *British Journal of Sociology of Education*, 39 (1), 144-158.

Truesdale-Kennedy, M., McConkey, R., Ferguson, P. et al. (2006). An evaluation of a family-centred support service for children with a significant learning disability. *Child Care in Practice*, 12, 377-390.

UNESCO (1994). *The Salamanca Statement and Framework for Action on Special Needs Education*. New York: UNESCO.

United Nations (1989). *Convention on the Rights of the Child*. New York: United Nations General Assembly.

Vygotsky, L. S. (1978). *Mind in society: the development of higher psychological processes*. London: Harvard University Press.

Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32, 175-179.

White, K. & Rae, T. (2016). Person-centred reviews and transition: an exploration of the views of students and their parents/carers. *Educational Psychology in Practice*, 32 (1), 38-53.

Wolfe, V. (2014). The Voice of the parent: perceptions of the United Kingdom resilience programme. *Educational and Child Psychology, 31 (4)*, 58-71.

Wong, C., Cheng, Y. & Chen, L. (2013). Multiple perspectives on the targets and causes of school bullying. *Educational Psychology in Practice, 29 (3)*, 278-292.

Wright, K (2008). Researching the views of pupils with multiple and complex needs: Is it worth doing and who's interests are served by it? *Support for Learning, 23 (1)*, 32-40.

Appendix 1. Proposed framework for exploring the views of children and young people with CLCN

The framework below was created by the researcher prior to the empirical study from critical review of the literature on exploring the views of children and young people with CLCN. The framework has been developed in response to the research findings (see appendix 30).

School ethos

Are children's views gathered as a regular school activity?

Is there direct teaching of approaches to enable children to express their views?

What is the child's previous experience of expressing their views?

The child's usual communication method

At what stage on the communication continuum is the child currently?

- Pre-intentional communication
- Intentional non-symbolic communication
- Symbolic communication

How does the child usually communicate?

Which adults are usually involved in the child's communication?

In what ways do these adults support the child's communication?

The purpose for seeking the child's views

What kind of view is the adult seeking?

- A preference in relation to a past activity
- An immediate choice
- A choice for a future activity

What methods of communication are suitable for achieving the intended purpose?

How do these methods of communication compare to the child's usual way of communicating?

N.B. Consideration may also be given at this stage to information gathered about the child's cognitive skills and how this relates to the kind of view being sought e.g. memory, recognition of similarities and differences, comparison and evaluation, representational and symbolic understanding, understanding of time, hypothetical thinking and abstract decision-making.

Gaining the child's consent

How has the purpose for seeking views been communicated to the child?

How have the choices available been selected and communicated to the child?

How can the child communicate their consent and how can the child communicate that they wish to withdraw consent during the activity?

The practical activity for seeking the child's views

Is the context within which the views are sought familiar or unfamiliar to the child?
 What is the relationship between the child and the adult in the role of communicative partner?
 What is the quality of the interaction between the child and the adult and how does this compare to the child's usual communication?
 Are there multiple sources of information about the child's views that can be drawn upon to increase validity?

Interpreting the meaning of the child's views

Has a 'support circle' been established to consider the child's communication and the meaning of their views?
 Does the 'support circle' include adults close to the child and adults who do not have a direct relationship with the child?
 Have alternative interpretations of the child's views been considered and how has agreement been reached?
 How can the child communicate their agreement or disagreement with the interpretation of their views?
 Has the meaning of the views been presented to an advocate to offer challenge on behalf of the child and, if so, how was this advocate selected?

Evaluation

How will the child's views influence planning for the child's future?
 How will the benefit to the child be evaluated?
 How will the process for seeking the child's views be reviewed and adapted as required?
 When will the child's views be gathered again?

Appendix 2. Summary of Thornberg's (2012) data sensitizing principles.

Theoretical agnosticism	<p>A critical stance is taken towards pre-existing theories and research findings.</p> <p>All pre-existing theories and concepts, derived from literature review or from the researcher's existing knowledge, are treated as conceptual proposals, which can be disputed and modified.</p> <p>An 'open conversation' between the researcher and the pre-existing literature takes place to identify emerging ideas and concepts.</p>
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Theoretical pluralism	<p>Differing and competing theoretical perspectives are identified for comparison within the pre-existing literature from the substantive field as well as from other associated and relevant fields.</p> <p>Limitations of pre-existing theories are explored, and revisions are made.</p> <p>A conversation takes place between multiple perspectives so that a fuller understanding can be achieved.</p>
Theoretical sampling of the literature	<p>Prior knowledge in the substantive field is explored to enhance the researcher's <i>theoretical sensitivity</i> and to establish how the research will contribute to pre-existing knowledge.</p> <p>The literature search is guided by codes, concepts and questions and 'emerging' codes and concepts are compared. Literature search continues until no new codes, categories or theoretical concepts are generated from the literature and <i>theoretical saturation</i> is reached.</p>
Staying grounded	<p>The main focus for research activity remains upon the data rather than the literature.</p> <p>An active and conscious shift is made between exploring the data and exploring the research's prior knowledge and the pre-existing literature.</p>
Theoretical playfulness	<p>Critical thinking and creative thinking are combined to move beyond coding and categorising to generate new possibilities. Free associations are made to generate stimulating questions to ask of the data and new comparisons to be made.</p> <p>Theoretical codes and models used by other researchers in the pre-existing literature are identified and then elaborated upon and challenged through the constant comparison process.</p>
Memoing extant knowledge associations	<p>The researcher's thinking process and theorizing from the data is documented.</p> <p>Pre-existing knowledge and concepts are treated as flexible, modifiable and a stimulus for making creative associations.</p>
Constant reflexivity	<p>A process of constant reflexivity acknowledges prior knowledge and ideas rather than denying the researcher's preconceptions that may influence data analysis.</p> <p>Personal writing, in the form of memos or a research diary, enable the personal analytical lens through which the data and pre-existing literature are viewed to be described and documented.</p>

Appendix 3. History of grounded theory

Charmaz (2014) details the history of grounded theory in the context of social science in the US. She describes how qualitative research in sociology undertaken in the early twentieth century took the form of field research, ethnographic studies, and participant observation, although the actual methods undertaken by researchers were often unclear. Charmaz recounts a shift in US sociology research in the mid-twentieth century towards the positivist paradigm with emphasis upon hypothesis testing, replication of research and generalisability of findings. Positivism assumes the existence of an external world with researchers considered to be “*passive observers(s) who collect facts but (do) not participate in creating them*” (Charmaz, 2014, p. 6).

Glaser and Strauss’ collaboration in the mid-1960s is described by Charmaz (2014) as a merging of the positivist and pragmatist traditions. In their seminal text *The Discovery of Grounded theory*, Glaser and Strauss (1967) suggest that sociology research had been concerned primarily with testing and verifying existing theories without consideration of the concepts and hypotheses underlying theory generation. They present practical guidance for exploring the process of theory development using comparative analysis. They describe an evolving research process using methods for data collection, coding, and analysis simultaneously while making empirical decisions that aim to advance theory development.

Appendix 4. Macfarlane (2009) character virtues for ethical research

Macfarlane (2009) draws upon the work of Aristotle to detail six character virtues required of a researcher at different stages of their empirical work to ensure ethical research practice. Each virtue is presented as the mid-point on a continuum with a vice at each extreme. The virtues of *sincerity*, *respectfulness*, and *resoluteness* are used to frame the discussion of ethical dilemmas raised during the current research.

The virtue of *sincerity* is thought by Macfarlane (2009) to be needed for the analysis and interpretation research phase, ensuring a researcher presents a truthful account of how they have arrived at their research findings. A researcher may move along the continuum towards the vices of *concealment* or *exaggeration* if results are emphasised or masked in order to confirm a preconceived idea held by the researcher.

The virtue of *resoluteness* requires adaptability by a researcher so as to continue with their empirical pursuit when circumstances are not as expected. A researcher may move along the *resoluteness* continuum, for example, towards *laziness* if frustration or disappointment arising from lack of progress causes a researcher to compromise their research goals or towards *inflexibility* if a dogmatic approach is taken by a researcher in pursuit of their original research design.

The virtue of *respectfulness* calls upon researchers to remain mindful that participants are people and not a resource to exploit. A researcher may shift on the *respectfulness* continuum towards the vices of *manipulation* if proceeding with data gathering without due care towards participants or towards *partiality* if they are over-responsive to the needs of people in positions of power who have a vested interest in their research.

Appendix 5. Mapping table of grounded theory studies citing Thornberg (2012)

Study	Journal	Theme	Participants	Grounded theory approach	Data gathering	Data analysis	Engagement with the literature
Thornberg, R. (2018)	British Journal of Sociology of Education	Bullying in schools	144 pupils and 7 teachers across 3 primary schools.	Constructivist – symbolic interactionist perspective within a modified ecological model.	Field observations of everyday interactions, informal conversations and qualitative interviews 1-3 days per week over a 4-6 month period.	Constant comparison process – moving between data collection and analysis throughout empirical work – memo writing and sorting – initial and focussed coding used to guide further data gathering.	Differing theoretical perspectives identified in pre-existing literature – existing theoretical concepts seen as ‘tools’ for data analysis – literature discussed alongside data analysis.
Sutcliffe, A. (2016)	Educational and Child Psychology	Person-centred reviewing	5 primary school SENCOs – purposeful sampling of participants to explore emerging themes.	Strauss & Corbin’s grounded theory – within a critical realism research paradigm.	One semi-structured interview with each participant – brief summary of final theory shared with participants to check validity and credibility.	Constant comparison process – open, axial and selective coding – Max QDA 11 computer application used to record memos from axial coding – coding checked by experienced researcher with peer audit of final coding system – test codes against possible negative case.	‘Brief’ initial literature review to justify research and support ethical approval – existing theoretical concepts seen as ‘tools’ for data analysis – ‘staged approach’ to literature review alongside data analysis – memos used to record researcher thoughts during literature review.

Fitzgerald, N. et al. (2015)	Journal of policy and practice in intellectual disabilities	Team bases approaches in early intervention services for children with disabilities	15 mothers and 4 fathers from 18 families with a child with disability and/or developmental delay attending two early intervention services.	Constructivist – pragmatist and relativist epistemology – viewing data and theories as constructed by researcher through the interaction with the subject and participants.	Narrative and semi structured interviews with each participant and focus groups – participants given the choice of how their data would be collected – interview guide developed to explore experience of both team based models.	Initial coding also identifying frequency of codes occurring within data – coding manual created – selective coding to develop themes and subthemes – axial coding to explore relationships between concepts and categories – visual representation of model presented for both team based approaches.	Discussion of pre-existing literature focusses on prevalence and policy context, defining key theoretical models and identifying gaps to justify current research – benefits of early literature reviewed discussed in terms of constant comparison process although not clear how this fitted with data gathering – agreements and inconsistencies between data and pre-existing literature discussed.
Migliaccio, T. (2015)	Sociological Spectrum	Teacher response to bullying	96 elementary school teachers.	Constructionist approach – reference to Charmaz but also stating a “lean” towards informed grounded theory by relying upon past research.	Focus groups to explore how individual perspectives explained within a social context – data gathered over a 2 years period.	Initial, focussed and theoretical coding – analytical questions posed to generate initial codes from the data – memos used during theoretical coding.	Pre-existing literature used to support and justify research aims – literature discussed alongside data analysis to identify disconnect between academic understanding and lived experience – psychological processes used to explain participant responses – findings used to

							support and elaborate upon existing model within the literature.
Murray, J. (2013)	Early Child Development and Care	Young children's problem solving	138 children and 15 practitioners initially across 3 early years settings – 5 children and their families were then selected from each setting for case studies.	Constructivist – synergising extant theories with new empirical data – participant's experiences and meanings viewed as constructs of reality.	'Jigsaw' methodology – ethnographic approach with practical elements of mosaic approach and descriptive case study – observation, fieldnotes, conversations and documents – data viewed as co-constructed by researchers and participants.	Interview conversations with early years researchers to identify behaviours against which data was constantly compared – initial, focussed, axial and theoretical coding – memos used for initial and theoretical coding – aspects of analysis from other methodologies also used at the initial coding stage e.g. mosaic approach.	Comprehensive discussion of pre-existing literature – clear rationale stated for literature review – differing theoretical perspectives compared and treated as modifiable proposals – literature discussed alongside data analysis.

Appendix 6. Mapping table of grounded theory studies relevant to educational psychology

Study	Journal	Theme	Participants	Grounded theory approach	Data gathering	Data analysis	Engagement with the literature
Miller, A. (1995)	Educational and Child Psychology	EP use of behavioural approaches	24 primary school teachers across 8 local authorities – purposeful sampling of participants with successful experience of using behavioural intervention after EP consultation.	Not stated explicitly – reference made to Glaser and to Stauss & Corbin.	One interview with each participant – early data analysis guides later interview questions – precis of emerging theory presented to participants in later interviews.	Constant comparison process – researcher lists possible areas for analysis prior to data gathering to be aware of potential biases when coding – open, categorical and theoretical coding – memo writing – schematic diagram drawn to clarify emerging theory.	Pre-reading of general “theories, models and concepts” that maybe relevant to the research – literature used to generate ‘names’ for codes – literature review after analysis to support the emerging theory.
Levy, R. et al. (2018)	International Journal of Educational Psychology	Parents’ relationships with reading and shared reading with pre-school children.	29 families with at least one pre-school child – recruited from disadvantaged inner city areas.	‘Principles’ of grounded theory analysis – reference made to Braun & Clarke – no discussion of grounded theory approaches.	‘Narrative inquiry’ used to construct semi-structured interview with each participant.	NVivo software used for initial analysis – open, categorical and theoretical coding – three researchers coded independently and compared to agree emergent core themes – participants categorised by themes to identify those with strongest link to	Detailed discussion of pre-existing literature to justify research relevance and need for qualitative approach – brief return to literature when discussing implications of research findings.

						research question for in-depth analysis.	
Sheffield, E. & Morgan G. (2017)	Educational Psychology in Practice	Perceptions of young people with BESD/SEMH classification.	9 secondary school pupils with a statement of SEN for BESD – purposeful sampling.	Constructionist grounded theory – reference made to Charmaz.	Semi-structured interviews – adapting a common interview framework from a previous similar study – visual prompts included after pilot – emergent grounded theory shared with participants during debrief.	Constant comparison process – initial, focussed and theoretical coding – memo writing – Atlas Ti software used for analysis – conditional relationship guide used to arrange emergent codes into framework – reflective coding matrix tool used to find core category.	Discussion of pre-existing literature includes legislation and policy, justification of research and existing psychological concepts relevant to the research – return to literature when discussing findings with new psychological concepts discussed in relation to emergent themes.
Sharp, R. (2014)	Educational Psychology in Practice	Agency in secondary age pupils	11 secondary age pupils – purposeful sampling of young people involved in community projects.	‘Abbreviated version’ of grounded theory – reference made to Strauss & Corbin – critical realist perspective	Focus groups using open-ended questions as primary data source – combined with observations of group interactions, conversations with key adults, group products e.g. posters.	Researcher attempt to maintain awareness of applying existing knowledge during coding – search for data that ‘does not fit’ – moving between open and axial coding to generate a schema – additional data sources used to identify constructs that maybe harder for participants to articulate.	Systematic literature review to identify themes to guide data collection – reference made to legislative context – generated schema compared to initial literature review – new literature drawn upon to support emergent constructs in resultant schema.

Wolfe, V. (2014)	Educational and Child Psychology	Parents' perceptions of the UK resilience programme	Opportunistic sample of 8 parents.	Not stated explicitly – described as 'in-depth' with Strauss & Corbin mostly referenced.	One interview with each participant following a flexible outline of topics and questions.	Constant comparison process – personal diary and memo writing – negative case analysis – peer supervision to validate researcher's thoughts and interpretations – open, axial, selective coding.	Discussion of pre-existing literature focusses upon political and legislative context and background to intervention – literature review takes place after data analysis.
Wong, C. et al. (2013)	Educational Psychology in Practice	Bullying in schools	Large sample size – 1558 participants including children and adults across 77 secondary schools.	Strauss & Corbin's grounded theory – chosen to enable comparison of multiple perspectives	Qualitative questionnaire with 10 questions administered by school rep – researchers acknowledge that in-depth perspectives could not be explored.	Researchers explored own knowledge and beliefs prior to coding – open coding using constant comparison – inconsistencies and exceptions identified during axial coding to develop theoretical framework – memo writing used during selective coding to develop narrative – intercoder reliability calculated.	Detailed discussion of pre-existing literature to define concept and critique research methods – findings compared to pre-existing literature to identify agreement and inconsistency.
Jones, T. (2013)	Educational Psychology in Practice	Children's perceptions of home education.	9 children from 6 families – recruited from a 'snowball' sample of home	Not stated explicitly – reference made to Charmaz.	Photovoice research tool used to develop narratives – some variation by	Initial 'line by line' coding, focussed coding using NVivo software, questions posed to guide	Discussion of pre-existing literature to describe research context, to consider differing and

			educators – considered able to give informed consent.		participant in type of data gathered e.g. dictated narrative, use of PowerPoint – further sampling with group of school children with additional needs but method not described.	focussed coding – memo writing began as themes developed – researcher influence on data analysis considered in discussion only.	competing perspectives within the literature and to define and critique key terms – literature used to support choice of research tool – further literature search combined with memo writing at final stage of analysis to deepen understanding of emerging themes.
Purcell, A. (2012)	Educational Psychology in Practice	Bullying in schools	8 children, 8 parents and 2 teachers.	Strauss & Corbin's grounded theory – chosen to enable comparison of multiple perspectives – reference also made to Charmaz	Semi structured interviews – pilot study to develop interview topic guide – separate topic guides for parents and for teachers.	Constant comparison process – initial coding to categorise segments of data, focussed coding to explain larger data segments, axial coding to elicit similarities and differences between emerging categories – categories collated into four themes.	Pre-existing literature used to discuss policy and prevalence, to define concept and justify the need for qualitative approach – findings compared to pre-existing literature to extend discussion on a theme, one finding contrary to pre-existing literature identified.
Harcohen, C. (2012)	Educational Psychology in Practice	Student 'turnover' in international schools in the UK.	8 teachers in 4 international schools in the UK.	Description given of a range of grounded theory approaches –	Individual semi-structured interviews – pilots conducted to refine research	Iterative process of analysis – open coding of the first three interviews followed by axial	Brief discussion of pre-existing literature to define concept, explain relevance and

				Strauss & Corbin's constant iterative process referenced.	questions, process and address ethical issues – 7 open-ended questions with planned probes – questions to check participants' experience of interview.	coding to connect codes and final stage 'selective coding' – 'sensitising' memos written as cues to codes in following interviews – reflective diary records researcher's possible assumptions and biases.	identify gap in past research – new literature drawn upon to support emerging constructs.
Salter-Jones, E. (2012)	Educational and Child Psychology	Emotional well-being of teaching staff	Case study – staff and pupils in one secondary school chosen as an example of 'best practice'.	Social constructionist – within a critical realism research paradigm.	Focus groups and semi-structured interviews in 3 cycles over a 7 month period.	Constant comparison process– initial, focussed and then final stage coding to categories – memo writing at the final stage of analysis	Discussion of pre-existing literature focussed upon political, legislative and policy context – literature review takes place after data analysis.

Appendix 7. Critical Appraisal Tool for Grounded Theory – CAT-GT

Engaging with the extant literature in the field of study

- The literature is used to justify why new research is required and how it will contribute to current knowledge and understanding
- The literature provides a stimulus for proposing codes and concepts and for generating questions to ask of the data
- An active and conscious shift is made between exploring the literature and exploring the data
- New literature is introduced to support the development of emerging themes

Data gathering

- Participants are selected to provide multiple perspectives for comparison.
- Data gathering methods are open-ended to promote breadth and depth to the data, e.g. semi-structured interview or narrative approach.
- Multiple sources of data are drawn upon to enhance the richness of the data gathered, e.g. observation, interview, non-technical literature relevant to context.
- Participants are involved in choosing appropriate methods for data gathering, e.g. individual interviews, focus groups, suggesting contexts for observations
- Participants' views are sought on their experience of providing data, e.g. feelings during interview, opportunity to provide additional information.

Data analysis

- Constant comparison process is used for data analysis, which progresses through a series of stages from initial to theoretical coding. Terms used to define each stage of analysis are clearly defined.

- Data analysis begins at the earliest stage so that emerging themes can inform data gathering.
- Inconsistencies and exceptions in the data are actively sought, e.g. negative case analysis is used to test codes
- A process is in place for checking the reliability of codes, e.g. peer support to compare intercoder agreement
- Participants' views are sought on the emerging codes and concepts with theory development being co-constructed by the researcher and participants.

Comparing and contrasting theoretical perspectives

- The researcher makes explicit the theoretical perspectives underpinning their professional practice that may also inform their research when undertaking research within their professional field*
- Differing and competing theoretical perspectives are identified in the pre-existing literature for comparison and consideration as modifiable proposals
- Definitions of key terms given within the pre-existing literature are critiqued
- Research methods used by other researchers in the field of study are critiqued, which informs the research design
- Research findings are compared to pre-existing literature to identify areas of agreement and inconsistencies
- Research findings are used to elaborate upon existing theories and to develop new models when emerging concepts are not evident within the literature.

Research reflexivity

- The researcher's epistemological position is stated clearly
- The researcher consciously explores their knowledge, ideas, and preconceptions about the field of study prior to the research

- The researcher considers their relationship with the research context and their preconceptions, attitudes, and beliefs and the context that may influence analysis*
- A reflective diary or memoing is used to record and make explicit the researcher's thought processes, interpretations and theorizing from their prior knowledge, engagement with literature *and* during data analysis
- The researcher considers their relationship with their participants and how issues of privilege, position and power may have affected the research process
- The researcher's reflexive writing documents ethical issues arising during the research process and the thought processes underpinning the researcher's decision-making*

* Additions made to the CAT-GT following critical review of the empirical work undertaken for the current research.

Appendix 8. Thomas et al.'s (2017) continuum for analysing textual information

Thomas et al. (2017) offer two approaches for analysing textual information positioned at either end of a continuum. The 'thematic summaries' approach organises information presented within texts into pre-determined themes, aiming to summarise the themes while leaving concepts identified within the text unchanged. The 'thematic synthesis' approach begins with identification of themes, which may be predetermined or discovered within the text, but goes beyond providing a summary to explore the meaning of the themes within the context of the review. It is possible within this process that concepts may be elaborated upon or modified as new conceptualisations and explanations of the text are constructed by a researcher, which I believe reflects Thornberg's (2012) 'theoretical pluralism' principle (see appendix 2).

Aspects of both approaches were applied to my professional practice doctoral assignment (see Volume 2) to create a critical summary of the literature relating to exploring the views of children and young people with CLCN. My professional practice doctoral assignment was uploaded to the NVivo qualitative data analysis computer software program and text segments containing an underlying concept or idea were coded. Constant comparison (Thornberg, 2012; Charmaz, 2014) was employed, comparing segments and codes to refine and define the concepts and themes contained within the text.

Concepts and themes identified within my writing were not intended to be developed or changed at this stage, as the aim was to clarify the themes that

characterise my thinking and provide the basis from which theory development will proceed over the course of the research. Some themes were predetermined and derived from Charmaz's (2014) and Thornberg's (2012) thinking, such as 'empirical approaches', 'ethics and principles' and 'researcher beliefs', while other themes were discovered within the text through a process of coding and constant comparison. Thomas et al. (2017) distinguish between thematic synthesis approaches that focus solely upon coding empirical findings presented in a text and those that also code text that reflects the author's thoughts and interpretations of the research about which they are writing. Both types of textual information were coded to achieve the aims of the critical summary.

Appendix 9. Mapping table of studies relating to understanding the views of children and young people with CLCN

Study	Journal	Theme	Method	Context	N	Participants' age range	Participants' learning needs
Porter, J. (2009)	Education 3-13	Practical approaches to exploring children's views	Qualitative review of teacher responses to exploring children's views	Mainstream and special schools	11 schools – exact number of participants not stated	Children – reception to year seven – potential age range 4-12 years but not stated	Mixed – with and without disability – not stated specifically.
Murphy, J. & Cameron, L. (2008)	British Journal of Learning Disabilities	Talking Mats as a communication tool for people with intellectual disability	Qualitative and quantitative analysis of participant use of the Talking Mats tool	Speech and language therapist casework	48	Adults – mean age range 24-27 years	Intellectual disability – participants with a profound learning difficulty responding at a sensory level were excluded
Ingram, R. (2013)	Educational Psychology in Practice	Interpretation of children's views by educational psychologists	Discussion of theoretical approaches to interpreting children's views	Educational psychology practice	n/a	n/a	n/a
Bellamy, G. et al (2010)	Journal of Intellectual Disabilities	Defining the term 'profound and multiple learning difficulties' (PMLD)	Qualitative review of literature definitions, focus group and interview responses	Healthcare services and family	23	Adults – age range not stated	n/a
Ware, J. (2004)	British Journal of Learning Disabilities	Exploring the views of people with profound and multiple learning disabilities	Qualitative review of an approach to exploring the views of one young man with PMLD.	School and family	1	Age not stated	Profound level of learning disability
MacKay, T (2009)	Educational and Child Psychology	Defining severe and complex learning difficulties	Discussion of the issues of definition, classification	Educational psychology practice	n/a	n/a	n/a

			and prevalence of learning difficulties				
Harding, E (2009)	Educational and Child Psychology	The educational psychologist's role in ascertaining the views of children with PMLD.	Discussion of the ethical considerations, conceptual issues and methodological approaches to ascertaining children's views.	Educational psychology practice	n/a	n/a	n/a
Greathead, S et al (2016)	Topics in Language Disorder	The communicative behaviours of children with complex communication needs and the responses by their communication partners.	Qualitative and quantitative analysis using ethnographic methods and structured observations.	Residential special schools	3	Ages 8, 11 and 13 years	One participant had a diagnosis of autism and severe learning difficulties. Two participants had profound learning difficulties.
Brewster, S (2004)	British Journal of Learning Disabilities	Selecting the vocabulary to be available when using Talking Mats as a communication tool.	Qualitative review of vocabulary selection for Talking Mats by two adults with learning disability	Speech and language therapist casework	2	Adults – age not stated	Diagnosis of cerebral palsy and learning disability.
Wright, K. (2008)	Support for Learning	Involving children with multiple and complex needs in research to explore the use of the Talking Mats communication tool.	Qualitative review using practitioner research to explore the comparison between satisfaction expressed by children using Talking Mats and observations of satisfaction made by school staff.	Support unit in a Scottish mainstream secondary school.	3	Children – 1 st and 3 rd year of Scottish secondary school system – age not stated	Participants had motor disability and speech delay in common but to varying degrees.

Appendix 10. Ethical approval

Dear Dr Stringer

Notification of Ethics Approval with Prerequisites

Project ID/Title: 15873/001: 'Understanding the views of children with complex learning and communication needs for person-centred planning'

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until 23rd July 2020.

Approval is granted on condition that you:

- work with the child, parents and school staff including the relevant therapists to support the children during the course of the study with a view to identifying and establishing alternative ways of enhancing different communication approaches wherever possible, as you indicated in your response to the Committee's comments.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix 11. Reflexive research diary extract examples

Thoughts and ideas from pre-engagement with the extant literature

'Relationships' is the most frequently occurring theme within my writing about the research topic prior to empirical work. I mostly describe the communicative relationship between adult and child with reference to the literature. I also discuss the relationships between adults supporting the child and how their interactions can shape the way in which a child's communication and views are understood.

The themes 'communication approaches' and 'interpreting and creating meaning' are also found frequently within my writing. I have considered the potential for bias when adults who are emotionally involved with a child infer meaning from their communication to interpret the child's views. I suggest that bias may be reduced by considering a range of possible interpretations and by triangulating the information gathered.

The themes of 'ethics and principles' and 'empirical approaches' are found often within my writing, which can be expected given the requirements of a doctoral assignment and purpose for which the text was created. Text segments relating to 'ethics and principles' detail how researchers have described the principles and beliefs underpinning their research and the process of exploring a child or young person's views.

The themes 'cognitive development' and 'conceptual meaning of a view' occur less frequently within my writing but are also evident within text segments relating to 'researcher beliefs'. These themes are likely, therefore, to have influenced my thinking prior to empirical work.

The themes 'organisational context', 'participation' and 'statutory duties' occur less frequently in my writing. Thornberg's (2014) description of an abductive approach to data analysis suggests that a researcher may notice exceptions and less frequently occurring events within their data in order to lead them towards new lines of enquiry during their empirical work, hence it is important for me to keep these themes in mind when beginning my analysis.

Reflections upon methodology issues

Recruiting parent participants: I'm pleased with the positive interest shown in my research by the parents. Parent H commented that she is looking forward to talking about her child's views. Parent E commented that her child's views have so far not been included in plans.

Interview skills: Transcribing the interviews myself has enabled me to reflect upon and monitor my interview style and responses to participants. I have noticed that I often use summaries during interviews to reflect and check my understanding of what participants are saying, sometimes adding my own thinking to check participants' responses to my thinking about their ideas.

Interview duration: I have noticed that the interviews vary in duration from thirty minutes to an hour. The teaching assistant interviews were shorter – both of these participants had not had previous experience of taking part in PCP meetings and being involved in planned discussions about a child's views, therefore, having different background experience relative to the other professional participants prior to interview.

Differences between the case studies: I had a sense of knowing H's views better than the other two children. I wonder if this is because H is older (relative to O) and adults have had longer to get to know what his views might be. I also wonder if this is because I was able to speak to his parent (not the case for E) and also play worker H who knows H in a context different to school. This links to the code 'building up a picture over time' and 'relationships and responding to people'.

Reflections upon ethical issues

Managing the dual roles of researcher and practicing EP: A potential area of disagreement has arisen between the SEN service where I am employed and the school where my research is located. An EP view may be requested. I wonder whether it may be more appropriate to ask a colleague to respond, given my current relationship with the school as a researcher. I will use my next supervision session at work to reflect upon the view I would give and seek my supervisor's view on the matter.

Change to planned timeline for data collection and analysis: Parent E requested her interview be postponed until the new year due to a family matter. She expressed that she remains keen to participate in the research as she wants her daughter to "have a voice". We agreed that I will continue with the staff interviews as planned and reschedule her interview for a better time. This will mean that the staff will be interviewed before the parent, which is a different approach to data collection for child O and child H. I will need to reflect upon whether this might affect the co-construction of data for child E.

Remaining mindful of my emotional response to participants: I had a sense when interviewing class teacher E that she did not necessarily believe it to be possible to explore the views of children with CLCN. This is opposed to the view that I hold. I need to be mindful of my thoughts and feelings about this participant's view so as remain open to hearing her story. This links to Corbin's

(2008) writing on the emotional response of a researcher when listening to the participants' stories and Charmaz's (2017a) concept of 'methodological self-consciousness', which she describes as assisting a researcher to identify and analyse their world view.

Thoughts and ideas during data analysis about possibilities arising from the data

The initial code '*what the child wants*' suggests that the child is perceived as having a strong will, being active rather than passive and being able to be definite about what they want and do not want to do. The code suggests that the child has agency.

The initial code '*what the child can't communicate*' suggests that it may be more challenging for the child to communicate about their wellness, medical needs or to give their views of their disability relative to communicating their wants and preferences etc.

The initial code '*offering choices*' developed into the code '*choices, experiences, and informed decisions*' to reflect how choice making develops from making choices between objects and toys in the early years to making decisions that are informed by experience of the options available for the future. This code suggests that teaching skills such as choice making in the early years supports young people to develop the skills needed to take an active role in making plans for adulthood. There would appear to a link to the focusses code '*the child's agency and autonomy*' in terms of skills development. There may also be a link to the literature on preparing for adulthood.

Play worker H offers a different perspective to other professionals on communication with others, as the only professional participant not based in a school. There is a sense of relying upon parents or one key professional to share information and of not being fully involved in plans for the child, which are seen as 'led by the school', but also a sense of feeling valued and included when opportunities arise to be more involved. In terms of creating a shared understanding of the child's communication and views, I wonder if professionals supporting the child in the community may be an 'untapped resource'.

When new codes emerge towards in the later stages of data analysis, such as "*empathy for child's perspective*", this raises the question of whether this code can be found in the data that had been analysed previously but had been missed. I need to ensure I check for this code when reviewing transcripts analysed earlier in the process.

Returning to the literature during data analysis

Conceptual meaning of a 'view' (Ware and Harding): Participants talk about preferences, likes and dislikes and extend the concept of a view beyond what a child or young person would like to do to their experience and views of their health, well-being, and disability.

Cognition and development (Ware): Ware's position on the advanced cognitive skills needed to give a view can be challenged if the concept of 'future' is construed differently, e.g., moment-by-moment or day-by-day.

Communication approaches (Bellamy et al.): The data supports Bellamy et al.'s description of other forms of communication used by people with PMLD.

Enabling environments (Brewster): This focussed code develops Brewster's ideas about ensuring the right options are made available to the child so they can both develop *and* communicate their view.

Appendix 12. School context in which the research is located

Characteristics of the pupils attending the school

The school had approximately 70 pupils on role at the time of the research. All pupils have an Education, Health and Care plan (EHCP) or are in the process

of an Education, Health and Care needs assessment. The majority of pupils live within the local authority where the school is located with some pupils admitted from neighbouring authorities. The school specialises in catering for pupils with sensory and physical needs in addition to their severe learning difficulties. The school does not admit pupils with a diagnosis of autism spectrum condition as their primary need. Those children and young people living in the local authority who have a diagnosis of autism in addition to severe learning difficulties attend another specialist provision catering specifically for their needs.

Pupils attending the school require a highly personalised curriculum tailored to meet their individual needs, which corresponds to five areas of learning and development: communication and interaction, well-being and independence, physical development, creative and sensory learning, and exploring and understanding the world. There is a focus upon developing pupil's functional life skills and preparing for adulthood. The pupils in Key Stage 4 and post-16 are given the opportunity to take part in a work preparation programme before choosing a work experience placement, supporting them to make a more informed decision about their future.

Characteristics of the school relevant to the research

The school was inspected by the Office for Standards in Education, Children's Services and Skills (Ofsted)¹⁵ while the research was taking place and judged as 'outstanding' for the fourth time in a row. The inspectors reported that school staff are highly skilled in ensuring pupils' needs do not become a barrier to their attainment. The inspectors commented that staff are skilled in finding ways to enable pupils to communicate, which ensures all pupils have a 'voice' and are able to express their likes, dislikes, and opinions.

The school has a communication and sensory team including two speech and language therapists (SALTs). One of the roles of this team is to facilitate the school council and seek the pupils' views and ideas about matters affecting the school community. The SALTs also provide training and support for school staff to develop each pupil's communication and interaction skills across all curriculum activities. The school has developed a person-centred review process, which ensures the child or young person, their family and all other adults supporting them are involved in gaining individual pupil's views. The school was cited as a case study in the SEND reforms green paper (DfE, 2011) for their approach to participation for young people with severe learning difficulties and PMLD in planning for their future.

¹⁵ Ofsted is a non-ministerial UK government department responsible for inspecting a range of educational settings, children care, adoption and fostering agencies, initial teaching training providers and local authority children's services (2019).

Appendix 13. Recruitment and written information for participants

Recruitment of parents and children

The initial approach to parents and professionals was made the school SALT.

The SALT was considered to have a 'neutral' role in school in terms of authority and position relative to the headteacher or class teachers, therefore, reducing

the potential for potential participants to feel coerced into participating by a perceived authority figure.

A telephone call was made to the parent who was the main contact between home and school, which was the child's mother in all three cases. Brief details were given of the study aims and what participation would involve. Parents who expressed interest in taking part in the study were sent the participant information sheet for parents and consent form (see below). I made a follow-up telephone call one week later to allow time for parents to consider the information provided and to offer opportunity for them to ask questions before consenting to take part. The parents were also offered the opportunity to meet me before giving their consent.

All three parents approached to take part in the study agreed to participate. Parent_2 accepted the invitation to meet me prior to the research. Parent_1 did not want to meet, stating that she thought the participant information sheet explained the research well and she did not have further questions. Parent_3 also declined the opportunity to meet, stating that her child had been a research participant previously and they were familiar with the process. Due to unforeseen circumstances, parent_3 was eventually unable to give her time to be interviewed for phase one of data gathering, however she continued to

consent to her child participating in the study and all other research activities associated with this case study were undertaken.

Participant Information Sheet for Parents and Carers

UCL Research Ethics Committee Approval ID Number: 15873/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study:

Understanding the views of children with complex learning and communication needs for person-centred planning

Department:

Research Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s):

Kate Farmer and Dr Phil Stringer
Educational Psychology Group,
Research Department of Clinical, Educational and Health Psychology,
University College London,
26 Bedford Way,
London WC1H 0AP

Name and Contact Details of the Principal Researcher:

Dr Phil Stringer – contact details as above

1. Invitation to take part in the research project

My name is Kate Farmer. I am a Senior Educational Psychologist for XXXX Council and I have worked with XXXX Academy for the past eight years. I am inviting you and your child to take part in a research project taking place at XXXX Academy as part of my doctoral studies at University College London (UCL).

To help you decide if you and your child would like to take part, it is important for you to understand why my research is taking place and what participation will involve. Please take time to read the following information carefully. You are welcome to contact me, or you may like to speak to XXXX, Principal of XXXX, if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part.

2. What is the purpose of the project?

Recent changes in legislation and policy have strengthened the rights of children to express their views in all matters affecting them. The special educational needs and disability (SEND) Code of Practice (2015) states that local authorities must have regard for the views, wishes and feelings of children and young people with SEND when making decisions about their provision. This means that children's views must be sought in a way that enables them to participate as fully as possible in planning for their future. This includes children with complex learning and communication needs.

My research aims to explore how parents and professionals describe their experience of understanding the views of children with complex learning and communication needs. The research will also aim to explore the views of each child participating in the project and evaluate the process.

The research will take place during the academic year 2019/20.

3. Why have I been chosen?

XXXX Academy has been chosen to host the research project as an outstanding school (OFSTED, 2016) that is recognised for their person-centred approach to involving young people in preparing for adulthood.

Research so far has explored the views of young people and adults with complex learning and communication needs. My research at XXXX Academy will explore the views of younger children. You and your child have been chosen to take part as your child is in the nursery or primary phase of their education. You have also been chosen due to your child's learning needs and that your child is not yet effectively using spoken language or a formal communication system.

There will be three children and their parents participating in the research.

4. Do I have to take part?

Taking part in the research is your decision. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form on behalf of you and your child. You can withdraw from the research at any time without giving a reason and without affecting benefits that you or your child are entitled to such as requesting to meet with a member of school staff to talk about your child's progress and needs. If you decide to withdraw, you will be asked what you would like to happen to the information you and your child have provided up to that point.

5. What will happen to me if I take part?

If you decide to take part, you will be asked to meet with me at XXXX Academy for an interview lasting between 30 minutes and one hour. The interview will be informal and more like a conversation. I will ask you some questions to begin and may then ask some follow up questions to explore the points you raise.

If you agree to take part in the research, you will also be agreeing for me to talk to other adults who work with your child about your child's views. This will include adults working with your child in school and other adults who visit your child, for example a speech and language therapist and other health professionals. You may like to suggest adults that you would like me to talk to, but it will be their decision whether they wish to participate.

After I have met with the adults, I will observe your child taking part in their everyday school activities. The activities that will be observed maybe guided by information shared by the adults during the interviews.

The interview and observation stage of the research is planned to take place over one school term. During the next school term, you will be invited to come into school to take part in a person-centred planning meeting for your child. The meeting will be led by a member of school staff, most likely to be the principal, and will follow the format that the school typically uses for these meetings. There will be opportunity during the meeting to share and discuss the information gathered about your child's views from the interviews and observations. I will observe the meeting and will ask all adults attending to complete a short, written feedback questionnaire at the end of the meeting.

6. Will I be recorded and how will the recorded media be used?

My interview with you will be audio-recorded, which I will transcribe and analyse. I will make written notes of my observations of your child in school and of the person-centred planning meeting.

7. What are the possible disadvantages and risks of taking part?

It is understood that talking about your child's needs can sometimes be an emotional time for parents. If you would like to talk to someone further after taking part in any stage of the research, this can be arranged by contacting the school.

8. What are the possible benefits of taking part?

Whilst there are no immediate benefits for participants in the research, one aim is that the project will help adults working with your child to get to know your child better.

9. What if something goes wrong?

Should you wish to raise a complaint about the research during the research project, you can contact the Principal Researcher, Dr Phil Stringer XXXX. Should you think your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

10. Will my taking part in this project be kept confidential?

The staff at XXXX Academy and other adult participants will be aware that you and your child are taking part in the research. Your participation will not be shared with anyone else outside of the research project.

All the information collected about you and your child during the research will be kept strictly confidential. Data gathered will be stored securely on a USB drive and password protected. Only the researcher and principal researcher will have access to the original data. A coding system will be used to identify data in place of using participants' names, e.g. *child's initials parent interview, child's initials classroom observation*.

Some extracts from transcripts maybe used for illustration purposes, for example within my thesis and subsequent publications, and these will be anonymised fully. You and your child will not be able to be identified in any reports or publications about the research.

11. Limits to confidentiality

Please be aware that confidentiality will be maintained as far as possible, unless information is shared during the research that raises concern that someone might be at risk of harm. In this case, I will inform the school's designated safeguarding officer or may speak to another relevant professional if the concern does not relate to a pupil at the school.

12. What will happen to the results of the research project?

The results of the research project will be presented in my doctoral thesis, which will be made available by the UCL library. The results are also likely to be shared during

presentations made by me to adults involved with children and young people with complex learning and communication needs. I will write articles for publication in relevant professional journals. You and your child will not be able to be identified in any reports, presentations or publications.

13. Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice.

The legal basis that would be used to process your personal data will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project.

If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

16. Contact for further information

You are welcome to contact me at XXXX Council Civic Offices if you would like more information. My telephone number is XXXX. You will be given a copy of this information sheet and a signed consent form to keep if you agree to taking part in this research.

CONSENT FORM FOR PARENTS AND CARERS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Understanding the views of children with complex learning and communication needs for person-centred planning

Department: Research Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s): Kate Farmer and Dr Phil Stringer, Educational Psychology Group, Research Department of Clinical, Educational and Health Psychology, University College London, 26 Bedford Way, London WC1H 0AP

Name and Contact Details of the Principal Researcher: Dr Phil Stringer – contact details as above

Name and Contact Details of the UCL Data Protection Officer: data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee: Project ID number:

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialing each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	<p>"I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I consent to the following (please tick):</p> <ul style="list-style-type: none"> - Taking part in an individual interview with the researcher - The researcher interviewing other adults who work with my child - Observation of my child in school by the researcher - Taking part in a person-centred planning meeting for my child 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

2.	"I consent to me and my child participating in the study. I understand that my responses to interview questions, my contributions to the person-centred planning meeting and the researcher's observations of my child in school will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	<input type="checkbox"/>
3.	"I understand that all personal information will remain confidential and that all efforts will be made to ensure that me and my child cannot be identified unless information is shared during the research that raises concern that someone might be at risk of harm. In this case, I understand that the researcher will inform the school's designated safeguarding officer or may speak to another relevant professional if the concern does not relate to a pupil at the school.	<input type="checkbox"/>
	"I understand that data gathered in this study will be pseudonymised e.g. child's initials/parent interview; child's initials classroom observation , and stored securely. It will not be possible to identify me or my child in any reports, presentations or publications.	<input type="checkbox"/>
	"I understand that my comments may be presented for illustration purposes and I agree to (you only need to tick ONE option):	
	(a) my role/affiliation (i.e. parent or carer) being mentioned with my comments (b) my comments being presented anonymously with no mention of my role/affiliation.	<input type="checkbox"/> <input type="checkbox"/>
4.	"I understand that the information provided by me and my child may be subject to review by responsible individuals from the University for monitoring and audit purposes.	<input type="checkbox"/>
5.	"I understand the potential risks of participating and the support that will be available to me should I become distressed during the research.	<input type="checkbox"/>
6.	"I understand the indirect benefits of participating and that there is no promise or guarantee that me or my child will benefit from participation in the research.	<input type="checkbox"/>
7.	"I understand that the data provided by me and my child will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	<input type="checkbox"/>
8.	"I understand that the results of this study will be presented in the researcher's doctoral thesis and may be published and shared during presentations by the researcher.	<input type="checkbox"/>
9.	"I consent to my interview with the researcher being audio recorded and understand that the recording will be destroyed immediately following transcription.	<input type="checkbox"/>
10.	"I hereby confirm that I understand why my child and I have been invited to participate, as detailed in the Information Sheet and explained to me by the researcher.	<input type="checkbox"/>
11.	"I am aware of who I should contact if I wish to lodge a complaint.	<input type="checkbox"/>

Name of parent/carer participant

Date

Signature

Name of child participant

Date

Signature of parent/carer on behalf of child

Recruitment of professionals

Professionals were approached to take part in the study once the parents and children had been recruited. The CT and TA were considered appropriate in relation to child_1. The recruitment of staff was more problematic for child_2 and child_3, as both were being taught by a temporary CT who did not know them well. A decision was made to approach child_3's CT from the previous academic year and the TAs working with child_3. Child_2 joined the school during the current academic year, which meant that approaching school staff who had worked with him previously was not an option. A member of the SALT team was working with him and was considered able to offer a perspective on his communication and views. Parent_2 was then asked if she could suggest a professional who knows her child well. She suggested a member of staff from an independent charity where child_2 attends regularly for short break activities.

All professionals were told that the children's participation would not be affected should they choose not to take part. The participant information sheet for professionals and consent form (see below) were shared and opportunity was provided for professionals to meet me to ask questions before giving consent. One member of staff declined to take part. The potential participant from the independent charity was approached by parent_2 and the participant information sheet and consent form were shared. A follow-up telephone call

was made one week later to reduce the potential for this person to feel pressured to participate due to the approach being made by a parent.

Participant Information Sheet for Professionals

UCL Research Ethics Committee Approval ID Number: 15873/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study:

Understanding the views of children with complex learning and communication needs for person-centred planning

Department:

Research Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s):

Kate Farmer and Dr Phil Stringer
Educational Psychology Group,
Research Department of Clinical, Educational and Health Psychology,
University College London,
26 Bedford Way,
London WC1H 0AP

Name and Contact Details of the Principal Researcher:

Dr Phil Stringer – contact details as above

14. Invitation to take part in the research project

My name is Kate Farmer. I am a Senior Educational Psychologist for XXXX Council and I have worked with XXXX Academy for the past eight years. I am inviting you to take part in a research project taking place at Beacon Hill Academy as part of my doctoral studies at University College London (UCL).

To help you decide if you would like to take part, it is important for you to understand why my research is taking place and what participation will involve. Please take time to read the following information carefully. You are welcome to contact me, or you may like to speak to XXXX, Principal of XXXX Academy, if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part.

15. What is the purpose of the project?

Recent changes in legislation and policy have strengthened the rights of children to express their views in all matters affecting them. The special educational needs and disability (SEND) Code of Practice (2015) states that local authorities must have regard for the views, wishes and feelings of children and young people with SEND when making

decisions about their provision. This means that children's views must be sought in a way that enables them to participate as fully as possible in planning for their future. This includes children with complex learning and communication needs.

My research aims to explore how parents and professionals describe their experience of understanding the views of children with complex learning and communication needs. The research will also aim to explore the views of each child participating in the project and evaluate the process.

The research will take place during the academic year 2019/20.

16. Why have I been chosen?

XXXX Academy has been chosen to host the research project as an outstanding school (OFSTED, 2016) that is recognised for their person-centred approach to involving young people in preparing for adulthood.

Research so far has explored the views of young people and adults with complex learning and communication needs. My research will explore the views of younger children who are not yet effectively using spoken language or a formal communication system. You have been chosen to take part because you work with at least one of the three children who will be participating in the research with their parents. Other adults working with the children in school and professionals who visit the children in school have also been asked to take part.

17. Do I have to take part?

Taking part in the research is your decision. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. You can withdraw from the research at any time without giving a reason and without affecting benefits that you or other participants are entitled to such as requesting to meet with a member of school staff to talk about a child's progress and needs. If you decide to withdraw, you will be asked what you would like to happen to the information you have provided up to that point.

18. What will happen to me if I take part?

If you decide to take part, you will be asked to meet with me at XXXX Academy for an interview lasting between 30 minutes and one hour. The interview will be informal and more like a conversation. I will ask you some questions to begin and may then ask some follow up questions to explore the points you raise.

After I have met with the adults, I will observe the three children taking part in their everyday school activities. The activities that will be observed maybe guided by information shared by the adults during the interviews.

The interview and observation stage of the research is planned to take place over one school term. During the next school term, you will be invited to take part in a person-centred planning meeting for each child you work with who is taking part in the research.

The meetings will take place in school. Each meeting will be led by a member of school staff, most likely to be the principal, and will follow the format that the school typically uses for these meetings. There will be opportunity during the meetings to share and discuss the information gathered about the child's views from the interviews and observations. I will observe the meetings and will ask all adults attending to complete a short, written feedback questionnaire at the end of each meeting.

19. Will I be recorded and how will the recorded media be used?

My interview with you will be audio-recorded, which I will transcribe and analyse. I will make written notes of my observations of the person-centred planning meetings.

20. What are the possible disadvantages and risks of taking part?

It is understood that talking about a child's needs can sometimes be an emotional time for professionals when they work closely with a child. If you would like to talk to someone further after taking part in any stage of the research, this can be arranged by contacting the school.

21. What are the possible benefits of taking part?

Whilst there are no immediate benefits for participants in the research, one aim is that the project will help adults working with the children to get to know them better.

22. What if something goes wrong?

Should you wish to raise a complaint about the research during the research project, you can contact the Principal Researcher, Dr Phil Stringer XXXX. Should you think your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

23. Will my taking part in this project be kept confidential?

The children's parents, the staff at XXXX Academy and the other adult participants will be aware that you are taking part in the research. Your participation will not be shared with anyone else outside of the research project.

All the information collected during the research will be kept strictly confidential. Data gathered will be stored securely on a USB drive and password protected. Only the researcher and principal researcher will have access to the original data. A coding system will be used to identify data in place of using participants' names, e.g. *child's initials teacher interview, child's initials classroom observation*.

Some extracts from transcripts maybe used for illustration purposes, for example within my thesis and subsequent publications, and these will be anonymised fully. You will not be able to be identified in any reports or publications about the research.

24. Limits to confidentiality

Please be aware that confidentiality will be maintained as far as possible, unless information is shared during the research that raises concern that someone might be at risk of harm. In this case, I will inform the school's designated safeguarding officer or

may speak to another relevant professional if the concern does not relate to a pupil at the school.

25. What will happen to the results of the research project?

The results of the research project will be presented in my doctoral thesis, which will be made available by the UCL library. The results are also likely to be shared during presentations made by me to adults involved with children and young people with complex learning and communication needs. I will write articles for publication in relevant professional journals. You will not be able to be identified in any reports, presentations or publications.

26. Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice.

The legal basis that would be used to process your personal data will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project.

If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

16. Contact for further information

You are welcome to contact me at XXXX Council Civic Offices if you would like more information. My telephone number is XXXX.

You will be given a copy of this information sheet and a signed consent form to keep if you agree to taking part in this research.

CONSENT FORM FOR PROFESSIONALS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Understanding the views of children with complex learning and communication needs for person-centred planning

Department: Research Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s): Kate Farmer and Dr Phil Stringer, Educational Psychology Group, Research Department of Clinical, Educational and Health Psychology, University College London, 26 Bedford Way, London WC1H 0AP

Name and Contact Details of the Principal Researcher: Dr Phil Stringer – contact details as above

Name and Contact Details of the UCL Data Protection Officer: data-privacy@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee: Project ID number:

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/unticking each box below I am consenting to this element of the study. I understand that if will be assumed that unticked/unfilled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	<p>"I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I consent to the following (please tick):</p> <ul style="list-style-type: none"> - Taking part in an individual interview with the researcher - Taking part in a person-centred planning meeting for each child I work with who is participating in the research 	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
2.	<p>"I consent to my participation in the study. I understand that my responses to interview questions and my contributions to the person-centred planning meetings will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.</p>	<p><input type="checkbox"/></p>

Appendix 14. Additional participants for PCP meetings

The third phase of data gathering (see section 3.2.4.3) took place during an annual review meeting for each child’s education, health, and care plan (EHCP) where a PCP process is followed. Meetings were not taking place exclusively as a research activity and were attended, therefore, by adults in addition to those who had consented to take part in the study. I had an ethical responsibility to ensure everyone present understood the research activity taking place. The research aims were explained at the start of the meeting with a description of the intended purpose of the observations to be made, how these would be recorded and the right of each person to decide whether they wished to take part in the discussion. All adults attending the meetings chose to take part. Contributions to this phase of data gathering came from a range of professional backgrounds, increasing further the breadth and depth of the data gathered. The adults participating in the meetings are noted in table 1.

Table 1. Adults participating in person-centred planning meetings

<i>Adults participating in the person-centred planning meeting</i>									
	Mother	Father	Head Teacher	Class Teacher	SALT	School Nurse	Physio-therapist	Occupational therapist	Social Worker
1	✓	✓	✓	✓	✓	-	✓	✓	-
2	✓	-	✓	✓	✓	✓	-	-	-
3	✓	-	✓	✓	✓	✓	-	-	✓

Appendix 15. Timeline for empirical work

The empirical process was intended to take place over an eight-month period, as shown in table 2. The planned timeline for the empirical process was interrupted by the coronavirus pandemic. The school closed fully to all visitors, pupils and staff in mid-March 2020 and did not re-open again until August 2020. The school's leadership team took the decision to cancel all annual review meetings during the school closure period due to the redeployment of health professionals and the pressures upon parents and school staff to care for vulnerable children with complex needs during a global pandemic. This meant that phase 3 of data gathering did not take place until September – October 2020 when the annual review meetings were rescheduled.

Table 2. Summary and planned timeline for the empirical process

September 2019	Initial discussion with Head Teacher and school SALT to select participants and draft timeline for data gathering.
October 2019	Participants recruited and introductions made between researcher and participants.
November 2019	Phase 1a – Semi-structured interviews with parents.
December 2019	Phase 1b – Semi-structured interviews with first professional for each case study.
January 2020	Phase 1c – Semi-structured interviews with second professional for each case study.
February – March 2020	Phase 2 – Observations of the children in school.
March – May 2020	Phase 3 – Annual review meetings take place for each child to seek feedback from participants on the themes identified within phase one and two of data gathering, to share information gathered about the child's views and to observe how the child's views contribute to the person-centred planning process.

Appendix 16. Interview schedule for parents

1. Please can you tell me about <child's name>'s special educational needs?

Prompt questions –

What have you been told by professionals about <child's name>'s needs? What do you think this means for their learning and development?

Does <child's name> have a medical diagnosis? How does this affect their learning and development?

2. Please can you tell me about <child's name>'s communication skills?

Prompt questions –

How would you know if <child's name> is enjoying an activity or not? What changes would you notice in them at these times?

Do you think <child's name> lets you know what they are thinking and feeling? Are you able to tell if <child's name> is feeling happy or sad? How? Are there other emotions that they show you? What do you notice?

Are there some people who <child's name> appears to communicate with better than others? What do you notice? Is there anything that these people do that helps <child's name> to communicate?

What advice would you give to other people to help them to understand <child's name>'s communication?

3. What has it been like for you to try to understand <child's name>'s views and how they experience the world around them?

Prompt questions –

Is this something that you have found easy or difficult? What has been helpful? What has been hard?

Have other people talked to you about what they think <child's name>'s views are? Was this helpful? How or Why not?

Have there been times when your thoughts about <child's name>'s views have changed? What caused you to change your mind?

4. Please can you tell me about <child's name> views of their experience of coming to school?

Prompt questions –

Are there particular activities that <child's name> likes and dislikes?

Do you think that <child's name> remembers activities from the past that they like or dislike? How do they respond when presented with this activity again?

Do you think it is possible for <child's name> to give their views about what they would like for their future? What, if anything, do you think would need to happen to make this more possible?

5. Do you have experience of <child's name>'s views being talked about during review meetings in school?

Prompt questions –

What was this experience like for you? What happened during the meeting? Was it helpful?

Do you think that talking about <child's name>'s views influenced planning for their support and their future? How? What, if anything, do you think would need to happen to make this more possible?

6. What advice, if any, would you give to a parent of a child with similar needs to <child's name> to help them to understand their own child's views?
7. Is there anything else that you would like to tell me about <child's name>'s communication or views?
8. Is there anything that you would like to ask me?

Participants will be thanked at the end of the interview for their time and for the valued contribution they have made to the research.

Appendix 17. Interview schedule for professionals

1. Please can you tell me about your experience of exploring the views of children with complex learning and communication needs?

Prompt questions –

Are children's views gathered as a regular school activity or a regular part of your own practice? What has your experience been like?

Has thinking about the children's views made a difference to what happens in school or to your own practice? In what way?

2. Please can you tell me about your experience of person-centred planning approaches for children with complex learning and communication needs?

Prompt questions –

Have you been part of review meetings in school where children's views have been discussed? What was this like? What happened during the meeting?

Do you think that talking about the children's views has influenced planning for their support and their future? How? What, if anything, do you think would need to happen to make this more possible?

3. Please can you tell me about <child's name>'s communication skills?

Prompt questions –

How would you know if <child's name> is enjoying an activity or not? What changes would you notice in them at these times?

Do you think <child's name> lets you know what they are thinking and feeling? Are you able to tell if <child's name> is feeling happy or sad? How? Are there other emotions that they show you? What do you notice?

Are there some people who <child's name> appears to communicate with better than others? What do you notice? Is there anything that these people do that helps <child's name> to communicate?

What advice, if any, would you give to other people to help them to understand <child's name>'s communication?

4. What has it been like for you to try to understand <child's name>'s views and how they experience the world around them?

Prompt questions –

Is this something that you have found easy or difficult? What has been helpful? What has been hard?

Have other people talked to you about what they think <child's name>'s views are? Was this helpful? How or Why not?

Have there been times when your thoughts about <child's name>'s views have changed? What caused you to change your mind?

5. Please can you tell me about <child's name> views of their experience of coming to school?

Prompt questions –

Are there particular activities that <child's name> likes and dislikes?

Do you think that <child's name> remembers activities from the past that they like or dislike? How do they respond when presented with this activity again?

Do you think it is possible for <child's name> to give their views about what they would like for their future? What, if anything, do you think would need to happen to make this more possible?

6. What advice, if any, would you give to professionals working with a child with similar needs to <child's name> to help them to understand the child's views?
7. Is there anything else that you would like to tell me about <child's name>'s communication or views?
8. Is there anything that you would like to ask me?

Participants will be thanked at the end of the interview for their time and for the valued contribution they have made to the research.

Appendix 18. Additional interview prompt questions

Do you think it is easier to tell what <child's name> wants or how they are feeling? What do you notice? What is it like for you?

Have there been times when <child's name> responded in a way that was not typical for them or that surprise you? What did you notice? Was there anything that was different at those times?

How do you think <child's name> thinks about the future? Do you think it is possible for <child's name> to give you their views about what they want to do next / later today / tomorrow / next week?

Appendix 19. Transcript extract (1)

The breadth and depth of data gathered was increased by remaining open-minded and allowing the interview process to be constructed with participants.

The transcript extract below shows parent_2's train of thought on inclusion, community and attitudes towards disability when asked about her experience of talking to other people about their interpretation of her son's views. The stories she recounts may not appear relevant to the research aims at first and suggest she may have misunderstood the question asked. However, these stories have potential to reveal insights that had not been visible previously and offer a different lens through which to view the research questions and, in this instance, the social and cultural influences upon the research.

So, if you can tell me a bit about what your experience is like of when, say, you take him to places like school or to his activities and other people have talked to you about what they think his views are, what's that been like?

Parent_2: Erm, well, I mean, we got to church, which is a challenge in itself, and they're very good there, erm, but he's got no understanding of when he needs to pipe down a bit, like when the brownies are saying prayers and I've literally got him cuddled up to me and he's screeching and then the music starts and I say you can let go now and he's happy and he's calm because of the music, I think, I've always taken him wherever I can, erm, because I think it's good for people to see that children are different.

Of course

Parent_2: His twin's friends accept him, and I explain stuff to him, erm, you get a lot of stares, last year we went to Dubai, erm, and I don't think, they hide their disabled away, so there was an awful lot of stares and I think you just have to rise above it don't you?

Yeah, absolutely

Parent_2: But, no, we'll be on the train and then all of a sudden he's grabbed hold of some woman because he wants to touch her and I think people want to talk to him and I say oh he doesn't talk he just wants to listen to you that's all, so he'll go up to anyone, no fear at all, he'll walk off with anyone, erm, be quite happy, he seems to like to have strangers coming, so he, if erm, sometimes they say when they have visitors come to the class he is one of the first to greet them and maybe it's just him being nosey, or just have a little bit of variety in his life.

Appendix 20. Transcript extract (2)

The transcript extract below shows how active listening was used to reassure a participant and validate her response that could be considered contrary to current SEND practice.

How about thinking about planning what we now call outcomes, so the next steps, what we want the child to work towards, how much do you feel their <the child's> views influence that part of planning for them?

CT_1: I suppose it's probably more a little bit what we think is important to them and what will help them with their day-to-day living really probably comes into it a bit more than their views

Yeah

CT_1: It sounds really bad doesn't it?

No, it doesn't at all

CT_1: But I think whatever the outcomes are we use their views to do that

Yes, so it's more <like> using the views to plan the environment around them?

CT_1: The provision, I suppose you'd use their views more for that rather than the outcomes themselves, I think

Yes, that does make sense

Appendix 21. Transcript extract (3)

The transcript extract below shows how paraphrasing was used to show understanding of the story a participant was telling and to illustrate the value of her contribution to the research, which encouraged the participant to provide further detail.

SALT_2: ... I think, guiding the young people to options that are suitable for them that will keep them safe, I'm thinking of a young man in particular who left a couple of years ago and he was adamant that he wanted to do his driving test and he wanted to go to college ... so, for him in particular it was supporting him to go to college because that was something he was really passionate ... it's making sure that he has enough context to be able to make an informed decision so the things like, erm, his driving test, his family ... they had brought him books and CDs and set him up so he could practise a theory test online ... he was positively putting his energy into something that he wanted to do, he hadn't just been told no you're not going to be able to do that, ... I think he needed to experience that to be able to know ... I think it does link back to engagement again, it's what they're <children and young people> engaged in and what we know they enjoy.

I think you make a really good point about experience because, and thinking about the youngest children in the school as well and getting that picture of what their views are going to be, it's making sure they <the children> have the opportunity to experience a broad range of things and then gauging their responses to those things.

SALT_2: Yes

Because without that experience it's hard for our children with complex needs to be able to give a view, they need to have those experiences first?

SALT_2: Absolutely, yes

It's a bit like your young man with the driving test example, he had that experience of working through those theory things he was doing at home so he was able to give a bit more of a view about whether that

was something that he wanted to do for the future rather than the adult coming in first and saying whether he will do that or not

SALT_2: Absolutely

Does that make sense of what you're saying?

SALT_2: Yes, one hundred percent, ... in the very lower end of the school I've done some sessions recently and I think it was around fireworks and with party poppers and one of the children didn't like the noise of the party poppers ... I just acknowledged, I said "oh I'm sorry you don't like this but we have got two more to pop and your friends are enjoying it so we're going to pop them" and I explain afterwards ... this young man has a carer, I said, you know, unfortunately there are loud noises in the world so if we can support him to, you know, to become use to them in a safe environment he might begin to realise that sometimes they're not as scary because we all, I think, we all experience things that we don't like experiencing and although we try to avoid them ... it's also important to be able to give enough experience to be able to say "oh, ok you really don't like this so we won't do that anymore" ... because sometimes children aren't as keen to begin with but then end up really liking something or in a couple of years down the line end up really liking that thing again.

So, it's almost as though keeping in mind what we think their views might be but still providing that broad range of experience, so they have the opportunity to potentially change their mind but also for us as adults keeping in mind what we think is in their best interests as well

SALT_2: Absolutely

Appendix 22. Fieldnotes from classroom observations

Observation of Child_1

Context: Afternoon session in the nursery classroom – independent free play, time in her standing frame and a structured ‘messy play’ activity with an adult.

Duration: 70 minutes

Child_1 presents as sociable and interested in people. She noticed when the taxi escort said goodbye to her and moved her head to look towards them. She vocalised, sometimes loudly, and looked when the nursery staff approached her during the session. She did not take her eyes off the adult taking her out of her buggy, making lots of vocalisations and then becoming quiet when the adult walked away. Interest in peers was less so, although she was noticed to look towards a peer who was taking their turn during circle time.

Child_1 was observed to engage in social interaction and play with adults. She looked towards the adult during a ‘ready, steady, go’ game, appearing to anticipate ‘go’. She vocalised and appeared to join in when an adult said “ooo” to express excitement for the next activity. On one occasion, she appeared to move an adult’s hand to request they continue splashing during water play. She smiled and made eye contact with adults during tickling games, during a sensory ‘brushing’ activity and when an adult wiggled her legs playfully. Child_1 often reached her arms out towards adults during play. A different response was noted when adults sang to Child_1. She became quiet and still but still looking towards the adult as if she were listening carefully.

There was a noticeable change in Child_1’s presentation and vocalisations when using her standing frame. It seemed apparent that she did not enjoy this activity and the adult commented *“I know you don’t like this position”*. The tone of her vocalisations changed, and her smiles returned when the adult began to take her out of her standing frame. This change in her presentation was seen only on one other occasion when Child_1 cast a toy away with which she had been playing, seeming to communicate that she had finished play.

Child_1 was observed to demonstrate clear preferences for toys. She reached out to make a choice when presented with two toys and showed preference for the mirror carousel and chain toy. She appeared quick to grasp and explore new objects and toys presented to her by an adult, for example putting her hands into the rice and bubbly water straight away during ‘messy play’. She made lots of vocalisations and movement when the adult poured water onto her hands, seeming to enjoy this activity. Later, she pushed the water away, showing preference for exploring the taste of the

icing sugar. She also reached out to explore a toy torch offered to her by an adult during circle time, showing greater interest in the torch when the light was switched on.

There were times during observation when Child_1 mouthed her hands. This was sometimes during play with a preferred toy, such as the mirror carousal, and also when not engaging with an adult or activity. It is unclear whether this behaviour is a communication of preference or in fact demonstrates a sensory need that overrides Child_1's engagement in her activities.

Observation of Child_2 (1)

Context: Cooking followed by snack time – Child_2 was in his chair throughout cooking but able to walk around the classroom at snack time

Duration: 60 minutes

Child_2 showed interest in new objects shown to him individually and to the group at the beginning of the cooking activity. He looked when an adult showed him a picture and object from his visual timetable and looked when cooking ingredients and equipment were shown, seeming to still at these times as if to pay attention. He also watched nearby peers using a food mixer. Child_2 stopped looking towards objects towards the end of the activity, suggesting he no longer wanted to engage. Instead, he looked and reached out towards the adult showing the object to him.

There were some occasions during the activity when Child_2 turned away from an object, suggesting he did not want to engage. These activities involved tactile experiences through the hands, for example when an adult wiped Child_2's hands and when he was encouraged to feel the butter packet. He also turned away from an adult using hand-over-hand to guide him to press a switch. In contrast, Child_2 was observed to reach out to explore the feel of the butter, changing the tone of his vocalisations and seeming excited and actively engaged. When he was offered to smell a banana, he lent forward to lick the banana and explore the taste as well. When hand-over-hand was used to help Child_2 to mash a banana with a fork, he stilled and looked initially but then turned away, suggesting he had made a choice about whether he wanted to engage once he had experienced the activity.

Child_2's vocalisations and movement in his chair increased towards the end of the activity. The adults interpreted this as Child_2 showing excitement. Another possibility is that Child_2 was communicating that he wanted to finish the activity and move on.

Child_2 shows good understanding of his familiar routine. He walked towards the snack table when told it was snack time and climbed into his chair independently when shown his snack. Child_2 cast his food and drinks bottle to show when he had finished.

Child_2 appears keen to interact with both familiar and unfamiliar adults. He reached out frequently towards adults in the room and this included familiar adults and new adults that he had not met before. He noticed when adults came entered the room, looking away from activities to watch the adult walk in. When a familiar adult approached Child_2 to talk to him, he responded by looking at the adult and reaching out to hug her arm. Child_2 also approached me and initiated a hug while making lots of vocalisations. In contrast, Child_2 was not seen to approach his peers to initiate interaction although he did show interest in watching the other children's activities.

Observation of Child_2 (2)

Context: Group parachute games followed by an individual task – Child_2 had returned to the classroom from trampolining prior to the observation

Duration: 30 minutes

Child_2 did not show the same level of engagement in activities relative to the previous observation. The classroom staff commented that he seemed tired after his trampolining session.

Child_2 attempted to lead an adult away from the parachute activity. When the adult did not follow, he got down onto the floor and crawled away while increasing his vocalisations. He then sat down in his chair at the parachute. He watched his peers taking part in the activity but did not actively engage.

The next activity involved Child_2 sitting in his chair stacking building bricks to practise his fine motor skills. He was seen to yawn and turn his head away from the activity. He accepted hand-over-hand support from an adult to stack the bricks and, gradually, he began exploring the feel of the bricks with his hands and fingers. The adult commented "*you just don't want to be with us today*" to interpret his non-engagement. Child_2 was shown his visual timetable by the adult at the end of the activity and he responded by turning away and putting his head down on his tray, which contrasted with the previous observation.

Observation of Child_2 (3)

Context: Weekly 'List'n Tell' group activity in the classroom led by the Speech and Language Therapist

Duration: 30 minutes

Child_2's health and medical needs affected the extent to which he was able to communicate his preferences for classroom activities during this observation. Child_2 had a seizure yesterday and again while travelling on the bus to school. Adults acknowledged that Child_2 did not appear to be himself and wondered whether he may still be feeling unwell after the seizures. There was a noticeable difference in Child_2's vocalisations when approached by an adult today compared to previous observations. He seemed to be seeking comfort rather than pleasure through social interaction. He was also noticed to be using his chew buddy more often, possibly also for comfort.

Child_2 laid under a nearby table when the adult began the activity. He sat up and vocalised when the adult started singing the 'hello' song, which the adult interpreted as him communicating "*remember I'm here*".

When an adult modelled actions for Child_2 to encourage him to join in, he turned away, lowered his head, and moved further away from the group. When the adult moved away from him, he rocked briefly and then lifted his head again. He then stood up and allowed the adult to hold his hands and rock with him to the music. He began to smile and appeared to enjoy this social interaction. Allowing time for him to join in at his own pace appeared to work well today.

Child_2 continued to take part in the activity one-to-one with an adult, but he resisted being led to join the group by withdrawing and cuddling up to the adult. The adult copied his vocalisations and he responded by turning his whole body towards her and holding on to her arm.

The Speech and Language Therapist reported after the activity that she thought it was important for Child_2 to be out of his chair today so that he had opportunity to move around the room, as this is one of the main ways in which he communicates.

Observation of Child_3 (1)

Context: Snack time followed by free choice of activities in the classroom

Duration: 30 minutes

Child_3's choices and preferences as expressed through her actions and gestures were clearly observable. She was seen to turn her head away and raise her arm to indicate 'no' when offered more juice. She reached out towards objects on a shelf across the room, which the adult interpreted as "*I want toys*". Child_3 confirmed this interpretation by reaching out again. The adult offered her a book and a puzzle, and she reached out to the puzzle to make a clear choice. Later, Child_3 gave a big smile and looked when an adult showed her a picture choosing board.

Child_3 appeared to enjoy engaging in activities with an adult. She looked at objects and then to the adult to share her interest. She smiled when watching adults join in with her activities, for example when an adult signed to accompany the pictures in a story book. She repeated the actions of smiling and lifting up her arms each time an adult stamped their feet on the sound board. She copied the adult's stamping action too and this enabled a turn-taking exchange to develop. When the adult shifted their attention to another child, Child_3 stamped her feet and smiled while looking at the adult as if she were trying to regain their attention. It seemed unclear, on some occasions, whether Child_3 was gaining more enjoyment from the activity or from the interaction with the adult.

Child_3 presents as sociable and interested in people. Typically, she did not seek interaction with adults, and she waited to be approached. She sat still when adults were not nearby but gave eye contact and a beaming smile when they came to her and often wiggled her body as if to express excitement. She was seen to track adults with her eyes as they moved around the classroom and to watch their activities, but she did not attempt to try to gain their attention.

Child_3 showed her sense of humour in the classroom when a peer threw a toy and she responded with laughter and smiles.

Observation of Child_3 (2)

Context: Weekly 'List'n Tell' group activity in the classroom led by the Speech and Language Therapist

Duration: 30 minutes

Child_3 showed excitement and enjoyment throughout and appeared to thoroughly enjoy this activity, which involved a mixture of songs, actions, and storytelling. She did not take her eyes off the adult leading the group throughout the activity. Child_3 wiggled her body and gave a big smile when the adult approached her and sang the 'hello' song. She joined in when the adult danced for the group and copied the adult's hand actions for 'boing' and 'splat'. Child_3 gave a big smile and looked to the adult nearest to her when the group began shaking the parachute, as if to share her excitement.

Child_3 appeared to particularly enjoy adults and peers copying her actions. She introduced new actions to the group on several occasions and then wiggled her body and giggled when everyone copied. After the List'n Tell session ended, Child_3 repeated some of the actions from the activity. This enabled her to regain attention from adults but maybe also communicated how much she had enjoyed the activity and that she would like the activity to continue or be repeated another time.

It was time for Child_3 to take her medication after the List'n Tell session and there was a definite change in her presentation when an adult approached with her medicines. She stopped smiling, her vocalisations changed and she covered her face with her hands, which appeared to be a clear communication that she did not want to take her medicine.

Appendix 23. PCP meeting process

Meetings begin with a presentation compiled by the child's class teacher comprising video clips and photographs thought to reflect the child's views and achievements in school, ensuring listening to the child provides the foundation for the discussion that follows. A series of questions are then posed, which create the agenda for the meeting and guide the person-centred process. The

person facilitating the meeting ensures everyone has the opportunity to contribute a response to each question. These questions are shared before the meeting in the form of a 'My Thoughts About...' template, which parents, school staff and professionals are encouraged to complete in preparation for the meeting. This template may also be completed by people who are unable to attend the meeting, such as wider family members, and shared during the meeting to ensure as many people in the child's life as possible contribute to the person-centred process.

'My Thoughts About ...' person-centred planning tool	
	<ul style="list-style-type: none"> • What do you like and admire about ...? • What is ... good at doing? • What does ... find difficult? • What is important for ... in the future? • What support does ... need to stay safe and healthy? • What is working well in ...'s life? • What is not working well for ...? • What would you like more help with in your role supporting ...?

Appendix 24. Summary of information gathered about the children's communication and views

<i>Child_1</i>	
Communication approach	Big smiles and lots of laughter Can't hide how she's feeling Making different sounds when happy, sad, excited, or frustrated Making a different sound when uncomfortable in her standing frame Making sounds for attention

	<p>Making loud sounds and looking away when finished play Following adults with her eyes Shuffling towards adults Reaching out to people Reaching out quickly to explore new toys Making a choice between toys and reaching or moving towards her preference</p> <p>Pushing away the toy she does not choose Animated when exploring Quiet and still when listening to singing Withdrawing from an activity and people when feeling overwhelmed Hands in her mouth when not busy and also during play Crying when hearing her brother or friends cry</p>
Views	<p><i>Relationships</i> Happy, sociable, and interested in all people Likes being tickled, picked up and having physical contact with people Likes involving other people in her play Content to play by herself as well as being sociable</p> <p><i>Activities and play</i> Enjoys music groups, hearing people sing and musical toys that give a response Enjoys hydrotherapy and swimming ever since she was a baby Keen to explore different toys and happy to explore most things The mirror carousel, lollipop jungle, chain toys, bead toys, bells and space blanket are favourites Likes toys that she can touch with her hands and spin Likes time to explore messy play</p> <p><i>Physical activity</i> Happy when taken out of her standing frame</p> <p><i>Independence and self-feeding</i> Interested in her feeding tube Prefers to feed herself</p> <p><i>Dislikes</i> Overwhelmed and restless if there's too much sound Upset by sudden noise Does not like to hear her brother or her friends cry Does not like physical activities and having to exert herself physically Not keen on her standing frame Needs opportunity to rest and sleep sometimes</p>

Child_2	
Communication approach	<p>H communicates his views differently when sitting in his chair compared to when he is able to move around a room independently.</p> <p>Making a screeching sound and giving a beaming smile when he likes what is happening Face lighting up with a big smile when enjoying an activity Walking towards what he wants Sitting down by the activity he wants to do Moving his body to show what he wants to do, e.g. turning around to go on his swing backwards Tapping an object to make a choice Looking or glancing towards what he wants Grabbing an adult to gain their attention Leading adults by the hand to show them what he wants to do with them Cooperating with adults during preferred activities Not wanting preferred activities to end Pushing the boundaries with someone new</p> <p>Laughing and smiles stop when not enjoying an activity Looking away when doing an activity to show that it's not something he wants to do Turning away when sitting in his chair and unable to walk away Going rigid and sitting on the floor when doesn't want to do something Walking away from an activity when done Dropping to the floor and crawling away when he does not want to engage Head banging when unhappy Making a growling sound when unhappy Slumping in his chair and chewing on his chewy if bored or seeking comfort Giving less eye contact, cuddles, and smiles if bored or feeling unwell Might lead an adult to an activity and then change his mind when he's there, e.g. if it's too busy Casting or turning his head away when does not want food Something is not right if H does not eat his lunch</p>
Views	<p><i>The sensation of movement</i> 'A bit of a daredevil' and likes to be active Likes being able to wander and be on the move a lot Loves the sensation of moving Loves going to theme parks and going on the rollercoasters on the BOSP farm trip</p>

	<p>Enjoys going on the swing and slide in the park Lives ride-along toys at BOSP Loved experiencing a speedboat ride on holiday Loves riding on the duet bike at Centre Parcs Lives trampolining and the bouncy castle Lives the waterbed in the sensory room at BOSP Lives movement in his chair when feeling tired and wanting to relax Lives bath time and swimming Loves the sensation of moving around the water in the swimming pool and floating on a noodle</p> <p><i>The sensation of being enclosed</i> Lives being under the parachute Loves being enclosed in his cuddle swing Lives being enclosed in his dark cube and tunnel Interested in window and door frames Standing and sitting in doorways</p> <p><i>Other sensory experiences</i> Explores tactile feedback from scratchy material Enjoys music therapy and the sensory room</p> <p><i>Relationships</i> Sociable and enjoys the company of whoever is in the room with him at the time Lives attention and cuddles Loves dancing in TicToc videos with his cousin</p> <p><i>Independence and leisure time</i> Lives making choices about his food Happy and laughing when attending BOSP</p> <p><i>Dislikes</i> Does not like to be in his chair or in one place for too long Art and creative activities are not favourite activities Watching films is not a preferred activity</p>
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<i>Child_3</i>	
Communication approach	Facial expression Laughter Eyes open wide when enjoying an activity Eye contact when wants to engage in an activity Tracking adults when interested in an activity Pointing and making sounds to show what she wants Repeating an action to confirm what she wants, e.g. pointing again Vocalising for attention

	<p>Shuffle to what she wants when sitting on the floor Gets the wiggles and laughs when enjoying an activity Reach out to what she wants Looking at an object and then at an adult to share enjoyment of an activity</p> <p>Stiffen up and turn her head away when doesn't want to do something Facial expression drops when doesn't want to do something Whinges/vocalisations change when unhappy Hands under the table or over her face when doesn't want to do something Looking away or out of the window when disinterested Push things away that she does not want</p>
Views	<p><i>Independence</i> Independent and knows what she wants Would like to be able to do more things independently, for example walking Points when using her walker, as if to say she would like to get there a bit quicker</p> <p><i>Activities and leisure time</i> Likes horse riding Likes toys with buttons that make sounds Loves swimming Loves music and songs including the List'n Tell sessions Enjoys messy play</p> <p><i>Sociability and sense of humour</i> Loves anything funny that's going on around her, for example if someone is doing something they shouldn't be doing, she has a good sense of humour Thinks the water spray is funny during sensory stories Likes working with people Likes to share her excitement for an activity with an adult Interested in what other people are doing Enjoys other people copying her actions</p> <p><i>Physical activities</i> Physio is not a favourite activity Fine motor tasks can be frustrating</p>

Appendix 25. Summary of codes and concepts for participants

Title of Study: *Understanding the views of children with complex learning and communication needs for person-centred planning*

Thank-you very much for taking part in the study. Below you will find some themes from the interviews with participants. These themes have been identified by the researcher and so it is important that participants are able to give feedback on whether they think the themes make sense and are relevant to understanding a child's views.

Some of the themes might be familiar to you while others might be something you had not thought of before. Please take a moment to consider the themes and the following questions. We can talk about these questions when we meet for your child's annual review.

- Which of these themes, if any, do you think are most important when considering a child's views?
- Are there themes with which you disagree?

- Which themes interest you the most and which would you like to know more about?

Careful watching

Adults pay careful attention to changes in children's facial expression, gaze, vocalisations, and movements. The potential meaning of every little response the child makes to their surroundings is considered carefully when thinking about what the child's views might be.

Enabling environments

Children's responses may depend upon the people, places and activities in which they are engaging. The time and the place for exploring a child's views may need to be chosen carefully to ensure other factors, such as tiredness or pain, are not affecting the child's responses and could be misinterpreted by adults.

Building up a picture over time

Adults reflect upon the child's views every day as an integral part of what they do. The child's responses to their typical day-to-day activities are thought about as well as thinking about the child's achievements. A picture of the child's views and an understanding of how the child communicates develops over time.

Children's experiences and informed decision-making

Adults provide a range of opportunities for children to explore what their views might be. This helps children to make an informed decision once they have experienced the options available to them. Children's views might change once they have had greater experience of an activity.

Self-reflection and making meaning

Adults are aware of the need to observe carefully, reflect, and remain open to different possibilities. Adults reflect upon how their own behaviour may enable or inhibit a child's communication, e.g. being too quick to interpret or pre-empt the child. Adults take time to reflect upon different possible interpretations of the child's communication, and sometimes express uncertainty or question the judgement they are making about the child's views.

Conversations with other adults

Adults work together to build an understanding of how a child communicates and what their views might be. This may take the form of informal conversations as well as formal meetings such as annual reviews. Adults may think that more

opportunity to discuss the child's communication and views with one another is needed.

Children's emotions and preference

Adults are confident that the child is able to communicate their feelings, likes, dislikes and what they want.

Children's views about their health and well-being

Although adults are confident the child can communicate their feelings, likes and dislikes, adults may suggest that it can be hard for a child to express their views about their health, medical needs and how they experience their disability.

Acting in the child's best interests

The child's views are used to plan activities that the child enjoys, increasing their access to opportunities to develop their skills and achieve outcomes that may have been planned by the adults acting in the child's interests.

Developing communication skills

Adults may talk about the child developing their communication skills to help them to express their views and the need for other people in the child's life to develop a greater understanding of how the child communicates so that their views can be understood

What do we mean by a 'view'?

Adults may think about whether 'likes and dislikes' in the here and now can be interpreted as the child's 'view' of what they would like to do in the future.

What do we mean by the 'future'?

Adults may talk about the child giving their views 'in the moment'. The child's future is considered 'day by day' and there is appreciation that the child's views might change over time. Adults may feel uncertain about knowing the child's views for the long-term future.

Appendix 26. Charmaz's (2014) approach to initial coding

Charmaz (2014) describes coding as a process of “*naming segments of data with a label that simultaneously categorises, summarises, and accounts for each piece of data*” (p. 111). Grounded theory codes are defined by Charmaz as delineating actions within the data, describing people’s responses to events and the meanings they have created from their experiences. She advises researchers to create codes using language that describes actions, suggesting that this approach prevents a researcher from generating concepts and theories too soon in the analytical process without thorough inspection of what is happening in the data. She also recommends that codes are created using participants’ words when possible, rather than using professional or technical language. She suggests that this approach ensures analysis takes place from

the participants' perspective and guards against retelling participants' lived experiences through a researcher's voice.

Charmaz (2014) compares two approaches to initial coding. The line-by-line approach requires a researcher to name each line of written data even when some lines may contain sentences or ideas that are incomplete. The incident-with-incident approach, in contrast, enables a researcher to assign names to larger segments of data, therefore retaining the context for the action or idea being coded. This approach means that some segments of data may be given more than one code when they contain more than one action or idea. Charmaz suggests that incident-with-incident coding may be more helpful for analysing data when context is needed to give meaning to behavioural observations. This coding approach was, therefore, chosen for the current research as the interview transcripts often contained observations made by participants of children's behaviour and context was required to explore the possible meanings of these actions within the data.

Appendix 27. Constant comparison process example

initial code: ‘Types of conversations with others’

One transcript coded	
<p>Code name: Feedback to and from others</p>	<p>Text extract examples:</p> <p>Parent_1 – <i>“Usually, we get feedback from the nursery, erm, sometimes, erm, from family members if she’s gone with them for a couple of hours, they might mention observations of, especially if they haven’t seen her for a long time and they see her they’re like “we think this is different”, they might say she’s been more attentive <for example>”</i></p> <p>Parent_1 – <i>“It was good to get feedback on what was working and what we can replicate at home, erm, so it was good to have that feedback, and also we can feedback to them what we think is working really well and what we think maybe not”</i></p>
<p>Memo: Feedback to and from others has been a two-way interaction and considered helpful to understanding the child’s communication and views</p>	

Four transcripts coded	
<p>Code name: Types of conversation with others</p>	<p>Text extract examples:</p> <p>CT_1 – <i>“We get like one afternoon every half term where the sensory team have the children for an hour and then we get that time to sit and go through the children but it’s probably not enough”</i></p> <p>SALT_2 – <i>“We’re <SALTs> kind of present in the school so we’ll casually catch teachers in the corridor and say how are things going, how is so and so, and they come to you and say oh guess what H did today or guess what this person did today so I think it’s quite flexible but it works”</i></p> <p>SALT_2 – <i>“I think that’s because of the way that the meeting’s structured that it allows that <person-centred planning> to happen and, you know, quite often you can say things that I’ve noticed X is doing this in my sessions and then the teacher will say oh yes they’re doing that at school and parents will say oh actually I’ve noticed that at home but I didn’t really connect why they were doing it, so I think the way that its <person-centred meeting> happening is really positive here and I think it really does keep the child at the heart of, you know, what they need and what’s important for them”</i></p>
<p>Memo: Adults talk about feedback to and from others being helpful in understanding the child's communication and views. Adults also mention difficulties in finding opportunities and time to communicate. Some adults suggest that informal opportunities for feedback in the context of ongoing relationships between adults works well, ensuring all of the child's communicative partners have a good understanding of how the child communicates. The way that conversations are structured keeps the child at the centre.</p>	
Eight transcripts coded	
<p>Code name: Types of conversation with others</p>	<p>Text extract examples:</p> <p>PW_2 – <i>“I think that’s probably one of the biggest positives that we are quite fluid with our communication, we try and make sure everybody feels involved so, like, we’ve got a senior team of support workers and we meet quarterly, like every three months, to discuss any problems or talk about new things that are happening or any new children starting and that cascades down to the support workers, but at session myself or my family liaison worker are</i></p>
<p>Memo: Adults talk about feedback to and from others being helpful in understanding the child's communication and views. Adults also mention difficulties in finding opportunities and time to communicate. Some adults suggest that informal opportunities for feedback in the context of ongoing relationships between adults</p>	

<p>works well, ensuring all of the child's communicative partners have a good understanding of how the child communicates. The way that conversations are structured keeps the child at the centre.</p> <p>The organisational culture impacts upon the types of conversations taking place between adults, e.g., reflective, open, and supportive (see PW_2). Communication may be face to face or written. Sometimes the focus for conversations is on other aspects affecting the child, e.g., personal budget, and does not include reflection upon their needs. Adults may offer different interpretations of a child's communication from their professional viewpoint and this is valued - links to code 'maybe communication means different things?')</p>	<p><i>always on hand so we're there, we know <the> children, if they have any problems or worries they can just off load basically, which I think helps them and the kids have a better day really"</i></p> <p><i>CT_3 – "The change in routine we had noticed at school, because obviously there'd been a holiday and then she'd come back and she wasn't eating as well, but the tiring, like tiring when she's chewing, we thought oh yeah that's true, we didn't really think of that and obviously the FAST team that's their expertise and sometimes things you don't really think of and then think oh that's quite obvious ... that's why it is helpful that we have multidisciplinary here ... because we're all experts in different things so we kind of all need each other"</i></p>
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Appendix 28. Initial codes and coding memos

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
Advocacy for children and families	2	2	The adult refers to acting on the child's behalf to support other people to understand the child's communication or needs, e.g., presenting the child's views during a PCP meeting
Anticipating, repeating, and remembering	15	7	The adult interprets the child's responses as anticipation or recognition of a familiar activity. Some adults believe this to occur particularly when an activity is motivating and repeated frequently as part of the child's daily routine. Other adults believe an activity may be remembered over time when the child is presented with the activity again.

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
At the moment	13	2	A reference to the child's current functioning and an implied suggestion of change being possible in the future. The adult does not want to place limits upon what the child may be able to achieve.
Being more aware	1	1	The adult behaves in a way that consciously raises their awareness of the child's communicative attempts, helping them to become more sensitive to the child's communication in the future.
Building up a picture over time	27	7	The adult refers to time as an important factor in building an understanding of the child's communication and views, especially for children without a formal communication system. Understanding communication may be more difficult in the early stages of getting to know the child and for those adults who are less familiar with the child. Suggestion is made that time needs to be allowed for the child to experience a communication approach before determining if this is useful to the child, e.g. core board.
Child's view of provision	5	4	The adult interprets the child's view of the provision, equipment or resources made available to them. This may include whether the child finds a task too easy or too challenging. This may also refer to the child's view of resources designed to meet a need arising from their disability, e.g. communication aid.
Choices, experiences, and informed decisions	22	7	The adult interprets the child's communication as making a choice or showing a preference. Adults provide a range of options which gives the child opportunity to explore what their

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			preferences might be, ensuring the child is able to make an informed decision having experienced the options available to them. The child's preference may change once they had experienced an activity (links to autonomy and changing your mind) This may also include exploring different ways of communicating and seeking their view.
Communication needs to develop	4	4	The adult's view of what needs to happen so that the child can give a view about their future. Verbal communication is mentioned but also the child's understanding and having communication skills that will enable them to express their views so that they can be understood by a range of people so that they can have influence on the world around them (possible link to child's agency?)
Day-to-day thinking	6	2	The adult is thinking about the child's views every day, continually and as an integral part of what they do rather than thinking about the child's views as a specific activity at a specific point in time. A negative case example is offered by playworker H who sees the child less frequently.
Depending upon mood	8	7	The adult suggests that the child's communication, engagement with people and the world around them is dependent upon their mood. The adult suggests that the time at which to explore the child's views needs to be chosen carefully to ensure other factors, such as tiredness or pain, are not affecting the child's responses, which may then be misinterpreted by the adult as a

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			preference (links to building up a picture over time?)
Different for each child	14	6	Adults show an awareness of how there may be different ways of interacting and communicating that are appropriate to each child. Adults are thinking about the child as an individual and there is a strong sense of individual differences being acknowledged even among children with the same medical condition.
Difficulty or disagreement with other adults	21	5	The adult disagrees with other adults about the child's communication or has a sense of 'knowing more' about the child than other adults, which seems to be a particular experience for parents, and of needing to help others to understand the child's needs (links to child being unable to communicate how they experience their disability?). Professionals can express an awareness of needing to acknowledge the parent's view when there is disagreement and of needing to advocate for the child's view and challenge.
Emotions and mood	38	8	The adults are certain about the child being able to show and communicate different emotions and moods.
Empathy for child's perspective	2	1	The adult expresses a sense of appreciation and understanding of the child's feelings and their lived experience.
Every little response	10	7	The adult considers small responses from the child as important in understanding their communication and views, similar to the total communication approach. This may include responses that we would not typically look for when reading someone's

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			communication cues e.g. finger movements.
Facial expression	11	5	The adult talks about being able to understand the child's communication by observing their facial expression.
Feel like you've failed	5	1	The adult's emotional response to finding it hard to interact with and form a relationship with the child. This links to relationships and responding to people but from the adult's perspective.
Finding it difficult	1	1	The adult acknowledges that understanding the views of children with complex needs is a difficult thing to do.
Future is in-the-moment day-by-day	9	5	The adult talks about the child giving their views 'in the moment', construing 'future' for the child as 'day by day'. The adults suggest an awareness of the child changing over time, possibly as they develop their skills, have new experiences that shape their views and also with the possibility of them changing their mind.
Getting attention from adults	5	3	The adult interprets the child's actions as an attempt to gain the adult's attention, suggesting motivation to interact with others and communicative intent to convey a message to the adult
I just know	5	3	The adult expresses a sense of acting almost intuitively when communicating with and understanding the child or possibly the adult is unaware of the approaches they take and finds it hard to describe.

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
Inclusion and community	13	4	The way in which other people in the wider community, not within the child's immediate social/family circle, respond to and communicate with the child. Adults also talk about the way in which they are able to explain how their child communicates to new people in their community. Suggestion is made that people may not understand how a child's communication can be supported if they are not using speech. The community created for the child by being part of the school is also valued.
Interesting to see other people's views	19	7	The adult actively expresses a want to ask questions and engage with other people, e.g. support groups and on line forums, to learn from others, particularly outside of their usual social circle/community for parents, in order to develop their understanding of child's communication and needs. Professionals express a keenness to share information and engage with others.
Interpreting and modelling	72	8	The adult suggests what the child's communication might mean and may model this for the child or for other people using words, pictures, or objects. The adult may make a judgement about what the child's communication suggests of their personality and character, e.g. sociable or happy demeanour (links to advocacy for the child?) and also about what the child might be thinking as well as what they might want to say.
Learning by experience	4	3	The adult talks about learning from their own experience or from the experience of others (links to I just know, how aware the

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			adult is of the approaches they are developing?)
Learning, developing and understanding	6	4	The adult refers to how the child learns, e.g. as a sensory learner, or talks about the child developing their understanding, e.g. when progressing to a formal communication system, or developing their skills over time.
Led by adults	8	3	The adult talks about the expression of the child's views being led by the adult with limited communication by the child (or parent). This is different to the adult making judgements in the child's best interests where the child's views can be acknowledged. The adult may create their own narrative for the child, which they may believe to be in the child's interest, e.g. to access a provision. The adult interprets the child's likes and dislikes as their view, raising the meaning of 'views'.
Let's try it	16	7	The adult tries a new way of engaging or communicating with the child or offers the child a new experience to see how the child will respond. The adults' responses suggest the importance of not limiting the possibilities of what the child might experience and respond to and also making sure a child's initial reaction is not interpreted as their view (links to offering choices and also to learning from experience?)
Like any other child	13	5	The adult compares the child to other children, both typically developing and with special educational needs, in order to understand the child's needs. There is

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			also suggestion of the child having agency and autonomy just like all children.
Looking	11	5	The adult notices the child's gaze and interprets this as communication
Loves, likes and dislikes	47	7	The adult's views of what they think the child likes and dislikes. Adults seem certain about the child's ability to express likes and dislikes.
Making a judgement for the child	30	7	The adult makes a decision acting in the child's interests, including ensuring the child accesses activities, develops their skills, keeps healthy and safe and whether or not to intervene. The adult's decision may be informed by the child's views. This seems different to the adult misinterpreting or disregarding the child's views (I wonder if children with disabilities experience adults making a judgement for them more so than typically developing children in order to keep them safe and meet their needs?)
Maybe communication means different things	10	4	The adult discusses different explanations for what the child's communication might mean, reflecting openness in relation to interpreting the child's communication
Medical and developmental needs	27	5	The child's medical diagnosis and their developmental and health needs. How this is communicated to others, how these needs may change and how the child's medical needs, developmental needs or disability might affect their communication and engagement e.g. use of communication aids, use of speech.

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			Meeting medical and health needs takes priority.
Meeting a need	7	3	The adult shows awareness of how the child's actions may not be communicating a preference but may arise from them needing to meet a need, e.g. sensory seeking behaviours or health needs. A need and a preference should be seen as different and not confused (links to interpreting and modelling, links to communication maybe meaning different things?).
Movements and body language	52	8	The child's movements, e.g. reaching, throwing, moving are noticed by the adult and interpreted as communication. These may be actions, gestures or interpreted by the adult as body language. (Does the child may show communicative intent through these actions or is communicative intent interpreted by the adult?)
Noticing what's different or not typical	14	5	The adult observes responses from the child that are new or not typical or compares the child's responses to different experiences and uses this information to develop their understanding of the child's communication and views. Differences in responses may also be an indication of the child feeling unwell.
Objects and visual cues	12	4	The adult talks about how objects or visual cues are being used to support the child's understanding or communication, e.g. when offering choices. A distinction needs to be made between using objects to communicate to the child, e.g. now and next board, and using objects to facilitate

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			the child's communication and expression of views.
Observing and paying attention	18	6	Adults observe closely and pay attention to help them to understand the child's communication and views. Comparison may be made between the child's communication in different contexts.
Opportunities to communicate	6	4	Adults need to be mindful of creating opportunities that enable the child to communicate. This may involve creating an environment that facilitates the child's communication approach and avoiding anticipating and over-interpreting the child's communication, which may prevent the child from being able to communicate their views.
Planning activities and provision	22	6	Adults plan activities that the child enjoys so as to help them towards achieving their outcomes, which may have been determined by the adult in the child's best interests. The adults consider how the curriculum can be delivered through the child's interests and value 'curriculum' in the broadest sense.
Really easy and quickly	5	2	The adult talks about how getting to know the child's personality and views has happened quickly and seemed to be an easy process. This is attributed to the child being more responsive, interactive and observable and, therefore, providing more cues for the adult to detect.
Relationships and responding to people	49	8	How the child initiates interaction and how adults might engage with the child. How the child responds to different people, including adults and peers, and views

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			their relationship with people around them. Differences in how the child responds to the same adult in different contexts may be an expression of preference (links to gaining attention from adults?). Some suggestion is made that familiar adults are best placed to explore the child's communication of views.
Responding to siblings	4	2	Adults talk about ways in which the child responds to their siblings. There is suggestion that sibling interaction may be different to the child's interactions with other people.
Responding to the child	10	4	The ways in which the adult thinks about and responds to the child's movements, gestures, facial expressions and vocalisations as communication in a way that influences what happens next.
Responding to the environment	25	8	Descriptions of how the child makes a response to something in their environment other than a person, e.g. a sound, tactile experience or the routine, and also how the environment and what is available in the environment may affect the child's responses and expression of views, e.g. structure versus freedom to choose
Showing intentions	5	3	The adult describes the child's actions in terms of a movement or gesture directed towards an object or person, an expression of communicative intent

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
Showing their achievements	3	1	The adult talks about ways in which the child's achievements can be communicated to others
Sounds and vocalisations	27	7	The child makes sounds and this is interpreted as communication by the adult
Surprise with child's response	4	3	The adult is surprised when the child's response does not match what they would expect. This includes when they hear about how a child is responding in a different context, e.g. home, school, community
Types of conversations with others	72	8	The adult talks about feedback to and from others being helpful in understanding the child's communication and views. The adults also mention difficulties in finding opportunities and time to communicate. Some adults suggest that informal opportunities for feedback in the context of ongoing relationships between the adults works well, ensuring the child's communicative partners have a good understanding of how the child communicates. The way that conversations are structured can keep the child at the centre. The organisation culture impacts upon the types of conversations taking place between the adults, e.g. reflective, open and supportive (see playworker H). Communication may be face to face or written. Sometimes the focus for conversation is on other aspects affecting the child, e.g. personal budget, and does not include reflection upon their needs. Adults may offer different interpretations of a child's communication from their professional viewpoint and this

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			is valued (links to maybe communication means different things?)
Uncertain of child's views for the future	4	3	The adult express uncertainty or a feeling of not knowing or guessing what the child wants for the future. There is suggestion that understanding what the child wants for the future should be something more than knowing their likes and dislikes.
Unsure what child's communication means	19	5	Adults expresses uncertainty, a feeling of difficulty or not knowing what the child is communicating or of not understanding why a child seems to like something. A trial and error approach is sometimes taken. Some adults question whether their judgement is right for the child (links to making judgements in the child's interest?)
Using words to communicate with child	11	6	The adult uses words when interacting and responding to the child, as if the child is able to understand language. Adults may also model use of language in a commentary/conversation style.
What the child can't communicate	10	4	Things that the adult believes the child is unable to communicate, e.g. the adult finds it hard to be certain about how the child experiences their disability such as their visual impairment, and the child may be unable to communicate how they experience their disability to the adult.
What the child cannot do	7	3	Activities that the child is unable to access due to their disability, needs or temperament, which affects the breadth of their experiences of the world around them and, therefore, the preferences they are able to develop. They ways in which

Name	Frequency across all interviews	Number of interviews in which code occurs	Memo
			the child is able to communicate may also be limited but may develop as the child's skills grow, e.g. physical mobility
What the child wants	39	7	The child showing agency by communicating their wants clearly, a sense of stubbornness is suggested by some adults. This may limit the child's experiences and, therefore, their ability to develop their views unless adults intervene. Cooperation is considered to be an expression of preference.
Withdrawing or engaging	8	4	The child withdraws from an activity and this is interpreted as communication by the adult versus the adult observing the child's engagement

Appendix 29. Focussed codes and coding memos

Focussed code and memo	Initial codes
<p>Communication partners The observable actions by the child to which the adult gives meaning in order to interpret the child's communication, similar to the total communication approach, which may involve paying attention to several observations simultaneously when making meaning.</p>	<p>Withdrawing and engaging</p> <p>Every little response</p> <p>Sounds and vocalisations</p> <p>Objects and visual cues</p> <p>Looking</p> <p>Movements</p> <p>Facial expression</p>
<p>Enabling environments The adult describes the ways in which the child may respond to the people, environment and activities they encounter. This may include the different relationships they may have with different people, their responses to different stimuli and their recognition of motivating activities and routines. The child's expression of views may be limited or expanded depending upon what is made available to them in their environment. It is acknowledged that the child may change their view once they have greater experience of an activity.</p>	<p>Relationships and responding to people</p> <p>Responding to siblings</p> <p>Responding to the environment</p> <p>Anticipating, repeating, and remembering</p> <p>Choices, experiences, and informed decisions</p>
<p>Comparison and understanding individuality The adult draws comparisons between the child and other children, recognising similarities with typically developing children (such as autonomy) and differences to other children with special educational</p>	<p>Different for each child</p> <p>Like any other child</p> <p>Noticing what's different or not typical</p>

<p>needs. The adult also draws comparisons between the child's responses to different experiences.</p>	
<p>Conversations, collaborations, and community The adult experiences working with other people to understand the child's communication and needs, which may be a positive or a negative experience. Conversations may be structured in different ways, ranging from informal conversation between adults with established relationships to formal meetings that are structured in a way that keeps the child, their views and what is important to them, as the main focus. Different professional perspectives may offer alternative interpretations of the child's communication and needs. The organisational culture can affect the types of conversation between adults, e.g., reflective, open, and supportive. Support for the wider community is also considered to help others to understand the child's communication and needs directly. This links to the child being able to develop their communication skills to express their views to a variety of people in order to affect plans for their future.</p>	<p>Types of conversations with others</p> <p>Interesting to see other people's views</p> <p>Difficulty or disagreement with other adults (negative case example)</p> <p>Feel like you've failed</p> <p>Inclusion and community</p>
<p>Making meaning The adult suggests what the child's communication might mean and may model this for the child or for other people using words, pictures or objects, sometimes making a judgement about what the child's communication may suggest about their personality. The adult expresses a sense of appreciation and understanding of the child's feelings and their lived experience – 'led by adults' is a negative case example where the adult advocates for the child but with limited consideration of the child's communication. Sometimes this happens consciously, with the adult questioning whether their interpretation of a child's likes and dislikes is truly reflective of their 'view'.</p>	<p>Interpreting and modelling</p> <p>Empathy for child's perspective</p> <p>Led by adults (negative case example)</p>
<p>The concepts of future and time Adults talk about reflecting upon the child's views every day as an integral part of what they do,</p>	<p>Day-to-day thinking</p> <p>Future is in-the-moment or day-by-day</p>

<p>suggesting time to be an important factor in building an understanding of the child's communication and views. Adults talk about the child giving their views 'in the moment' and construes future as 'day by day', suggesting uncertainty about knowing the child's views for the long-term future.</p>	<p>Building up a picture over time</p> <p>Really easy and quickly (negative case example)</p> <p>Uncertain of child's views for the future</p>
<p>Acting in the child's best interests The adult acts in the child's best interests, which may include ensuring access to activities, developing skills, celebrating achievements, advocacy when communicating with other people and keeping the child healthy and safe. Decision making may be informed by the child's views.</p>	<p>Making a judgement for the child</p> <p>Showing their achievements</p> <p>Advocacy for children and families</p>
<p>Agency of the child The adult describes, interprets, and responds to the child's actions as a definite expression of wants and, in some instances, an intention to interact and communicate with others.</p>	<p>Showing intentions</p> <p>Loves, likes and dislikes</p> <p>What the child wants</p> <p>Getting attention from adults</p> <p>Responding to the child</p>
<p>Affective factors The adult expresses certainty about the child being able to communicate their feelings and suggests that the child's feelings may affect their communication and engagement with the people and world around them. The time at which to explore the child's views needs to be chosen carefully to ensure other factors, such as tiredness or pain, are not affecting the child's responses, which may then be misinterpreted by the adult as a preference.</p>	<p>Emotions and mood</p> <p>Depending upon mood</p>

<p>Child's views of their health and well-being Adults suggests there are some things that the child can't communicate or that are hard for the adult to interpret, which mostly relate to health and medical needs and also the child's experience of their disability, e.g. level of visual impairment – 'child's view of provision' is a negative case example where the adult has considered what the child's view of a resource or equipment might be.</p>	<p>What the child can't communicate</p> <p>Child's view of provision (negative case example)</p>
<p>Possibilities, opportunities, experiences The adult tries new ways of engaging and communicating with the child and offers the child new experiences or choices. This approach affords the child the opportunity to explore, experience, and develop their views. The adult uses language that implies change and development is possible and does not place limits on what the child may achieve.</p>	<p>Using words to communicate with the child</p> <p>Let's try it</p> <p>Choices, experiences, and informed decisions</p> <p>At the moment</p> <p>Learning, developing, and understanding</p>
<p>Participation in decision making The child's views are used to plan activities that the child enjoys, helping them towards achieving outcomes that may have been determined by the adults acting in the child's interests.</p>	<p>Planning activities and provision</p>

<p>Self-awareness, an open mind and reflection by adults</p> <p>The adult behaves in a way that consciously raises their awareness of the child's communicative attempts, helping them to become more sensitive to the child's communication and more able to communicate with the child through a process of observing, reflecting and being open to new possibilities. The adult reflects upon different possible interpretations of the child's communication, sometimes expressing uncertainty and questioning the judgement they are making for the child. The adult is aware of how their actions may prevent a child from communicating their views when the adult is too quick to interpret on behalf of the child rather watching, waiting and allowing the child time to respond. The adult expresses a desire to learn from other people to develop their understanding of the child's communication and needs and different professional perspectives are valued – 'I just know' and 'really easy and quickly' are negative case examples.</p>	<p>Observing and paying attention</p> <p>Being more aware</p> <p>Learning by experience</p> <p>Surprise with the child's response</p> <p>I just know (negative case example)</p> <p>Really easy and quickly (negative case example)</p> <p>Maybe communication means different things</p> <p>Unsure what child's communication means</p> <p>Interesting to see other people's views</p> <p>Opportunities to communicate Finding it difficult</p>
<p>Obstacles to developing a child's views</p> <p>The child's medical needs, disability or temperament affecting their communication and also their access to activities, which affects the breadth of their experiences and the views they are able to develop. The child's actions may be linked to their needs, e.g. meeting a sensory need, rather than expressing a view of the activity. Adults suggests aspects of the child's communication that needs to develop including verbal communication, the child's understanding and communication skills that will enable the child to be understood by a range of people.</p>	<p>Meeting own needs</p> <p>Medical and developmental needs</p> <p>What the child cannot do Communication needs to develop</p>

Appendix 30. Revised framework for exploring with views of children with CLCN for person-centred planning

An approach for the whole school community

The school prioritises developing the communication skills of *both* children and adults as ‘communication partners’. Children are supported throughout their everyday activities to develop communication skills and cognitive skills, for example anticipating and remembering, to support them to develop and express their views. Adults work towards developing a better understanding of how each child communicates so that the child’s views can be understood.

The school ethos is supportive of adults reflecting upon their practice and how the actions they take can help a child to develop and communicate their views. The school supports staff to improve their skills as a child’s ‘communication partner’ through professional development activities.

Children’s views are valued by the whole school community. Children are seen as having agency and autonomy and they regularly experience the effect they can have on the world around them when their views are listened to and acted upon by adults.

Watching carefully to understand how a child communicates their views

Adults make careful observations of a child's movements, vocalisations, facial expressions, and eye gaze in response to what is happening in the environment, for example noticing how the child responds to objects, people, and sensory stimulation.

Children's responses may depend upon the people, places, and activities in which they are engaging. The time and the place for exploring a child's views may need to be chosen carefully to ensure other factors, such as tiredness or pain, are not affecting the child's responses and could be misinterpreted.

Adults consider what might have happened earlier in the day and how this could affect how the child is feeling and responding 'in the moment'. Adults are also mindful of how a child's initial response to an activity may not reflect their views about the activity and that their responses and views might change once they have become more familiar with the activity.

Assent is monitored closely when exploring a child's views by asking the adults familiar with the child to describe how the child would usually communicate that they do not want to do something or that they do not want an activity to continue. These descriptions are kept in mind while observing a child's communication for the purpose of exploring their views and observation is ceased if the child shows behaviours suggesting they wish to withdraw from the activity.

Building up a picture of a child's views over time

Exploring a child's views is not undertaken as a 'one-off' activity, for example in preparation for a person-centred planning meeting, and is seen instead as a continual process that builds a picture of the child's views over time.

Children have regular opportunities to develop their views and to practise communicating their views during their everyday activities. Adults provide a broad range of opportunities for children to explore what their views might be. This helps children to make an informed decision once they have experienced the options available to them.

Children's views are not seen as 'fixed' and adults are open to the possibility of children changing their mind, both in the moment and over time, and are willing to revise their thinking about the child's views accordingly.

Working together

The significant people in a child's life have regular conversations to share their understanding of how the child communicates and what they think the child's views might be. These conversations are in addition to more formal opportunities to work together such as during a person-centred annual review meeting.

Everyone's contributions are valued equally when thinking about what a child's communication means and what this tells us about their views. This may include family members, children who know the child well (for example siblings, cousins, and family friends), school staff, adults from other settings that the child visits, and professionals such as a speech and language therapist or an occupational therapist.

Thinking about the meaning of a child's views

Adults take time to reflect upon different possible interpretations of a child's communication. A variety of different sources of information about the child's responses are drawn upon and 'triangulation' takes place to ensure the child's views do not relate to 'one-off' events.

Adults use a process of comparison when thinking about their interpretations of a child's views – noticing how a child responds differently to different activities and in different environments as well as noticing when a child responds differently to the same activity or environment but at different times.

Adults show willingness to question their judgement when considering the different possible interpretations of a child's views and are open to revising their thinking in light of new information.

There is opportunity for an adult who is not part of the child's everyday life to act as a 'critical friend' and challenge interpretations of a child's views on behalf of the child.

Decision-making and planning for the future

Adults agree the timeframe over which they think a child is able to express their views. Adults may infer the meaning of a child's views about what is

important to the child for the future from their understanding of the child's views in the 'here and now'. They show regard for the views a child has been able to express about their immediate activities and they learn from the child's views to inform their decision-making.

The child's views are considered by adults when thinking about the child's aspirations for their future and also when planning the provisions that can be made to enable the child to develop the skills needed to achieve their goals.

Adults are open and honest about when they make decisions on behalf of a child and provide a clear rationale and basis for their decision-making, for example to ensure a child stays healthy and safe.

Appendix 31. Ingram's (2013) description of epistemological approaches to exploring children's views

Ingram suggests that a social constructionist approach to exploring children's views may be problematic. She expresses concern for adults being unable to reach agreement when socially constructing a child's views and for whether alternative perspectives will be considered. The example she gives to support her argument relates to using diagnostic labels in a problem-solving context. She states that a diagnosis is unlikely to be considered as socially constructed and, therefore, alternative perspectives from the child or other adults that challenge the diagnosis are unlikely to be explored. She is critical of a positivist approach too, stating that an objective truth about a child's views which discredits alternative interpretations is unlikely to be achieved through extensive data gathering. She argues in favour of a critical realist approach, based upon the premise that an objective truth exists but may not be revealed

through the child's views as individual perspectives are social constructions of reality. She considers a strength of this approach to be that a child can be asked their views of a problem as well as being asked their views of alternative interpretations of the problem as constructed by an EP or other adults.

Appendix 32. Transcript example (4)

Interview extract with PW_2

Can you think of anything we haven't covered in relation to <child_2> that you wanted to mention?

PW_2: Erm, I don't think so, I think we've covered all things with <child_2>

Ok, and finally is there anything that you'd like to ask me at all?

PW_2: Erm, no I don't think so

It's all been ok?

PW_2: It's been nice and easy

Has it been what you expected?

PW_2: If you'd had a video camera in front of my face that would have gone very badly <both laugh>

Interview extract with Parent_2

Parent_2: It does open your eyes what you're saying though because sometimes I think I just blindly go ahead and think oh we'll do this for <child_2> and that for <child_2> and because he is so happy, whether I'm just

bombarding him, with his brother we give him choices, do you want to do this, do you want to do that and he'll say yes, no etc. etc. but, erm, most of what you do for <child_2> he enjoys, so, yeah I mean we do a Saturday club a couple of times a month with other families with, erm, special needs, so we do we start off with a music therapist for the first half hour it's in the sensory room which is quite focussed, the second half hour is out where all the trampolines are and that's when <child_2> decides he doesn't want to do it and he crawl off and go and just tell people I'm not going to do it, sometimes you can drag him back and, erm, he'll look away and I'll think there's just no point if you don't want to do it

And he's communicating that quite clearly through his actions and through his behaviours?

Parent_2: Yes, exactly

