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University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

**Eliciting the Voices of Children and Young People with Complex Needs:
Identifying Innovative Methods and Using Digital Stories for Supporting
Transitions**

by

Stephanie Adeline Claire Lewis

Thesis for the degree of Doctorate in Educational Psychology

27th June 2022

University of Southampton

Abstract

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By

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The importance of eliciting the voices of children and young people and their participation within decision-making on matters that affect their lives is robustly supported within government guidelines and legislation. However, previous research suggests that due to perceived communication barriers, autistic children and young people are frequently excluded from decision-making and consultations relating to their education planning and omitted from research studies. Autistic children and young people residing in residential schools who have complex needs are further underrepresented within research and decision-making. It is therefore crucial that research develops and evaluates novel and creative methods to ensure the views and voices of young people with complex needs are heard, listened to, and understood.

To address these gaps in the literature, I carried out a systematic literature review (Chapter 2) to explore innovative methods that have been developed to elicit the voice of children and young people with complex needs about their educational experiences and preferences, and explored how young people's voices are represented in these methods. The findings suggest that it is possible to access the views of children and young people with the most complex needs through the creation and use of inclusive methods, which are novel, creative, and individualised to the child or young person. However, crucially, more needs to be done to ensure that their views are acted upon, given due weight, and influence change. In an empirical study (Chapter 3), I have extended and evaluated the use of Digital Stories as a methodology to facilitate knowledge co-creation of young people's transition trajectories to adulthood. This has been achieved through co-creating three Digital Stories in partnership with autistic young adults and their families, and the care staff and other professionals working within a residential special school. Semi-structured interviews were conducted with key stakeholders to understand their perspectives, experiences, and views on the Digital Story methodology, and its use and impact within each young adult's transition. Reflexive thematic analysis of interviews led to the generation of five themes: benefits of Digital Stories; humanising approach; ownerships and agency; ethical considerations; and direct impact on practice. The findings suggest that Digital Stories are a powerful methodology, which enable young people's voices to be heard within transition to adulthood and can provide an authentic, personalised, and positive representations of young people's views and perspectives.

Table of Contents

Table of Contents	i
Table of Tables	v
Table of Figures.....	vii
Research Thesis: Declaration of Authorship	ix
Acknowledgements.....	xi
Definitions and Abbreviations	xiii
Chapter 1 Introduction	1
1.1 Context for research	1
1.2 Digital Stories as a creative and inclusive method to access the views and voices of autistic children with complex needs	2
1.3 Research paradigm	2
1.4 Reflexivity	4
1.5 Ethical challenges.....	5
1.6 Dissemination activities and future plans.....	6
Chapter 2 Creative methods developed to elicit the voices of children and young people with complex needs: a systematic literature review.....	9
2.1 Abstract	9
2.2 Introduction	9
2.3 Methodology	12
2.3.1 Search Strategy.....	12
2.3.2 Quality Assessment	16
2.4 Findings	17
2.4.1 Overview of studies.....	17
2.4.2 Methods developed and used to elicit voice.....	18
2.4.3 Participant characteristics.....	19
2.4.4 Representation of voice	26
2.4.4.1 Space: Has the child or young person been invited and encouraged to express their views?.....	26
2.4.4.2 Voice: Has the child or young person been given the opportunity to ‘freely’ express their views and where appropriate, facilitated to form their views?.....	28

Table of Contents

2.4.4.3	Audience and Influence: Has the child or young person's views been listened to and has the child or young person's views been acted upon, as appropriate?	31
2.5	Discussion	33
2.5.1	Strengths and limitations of the review	36
2.6	Conclusion and implications for professionals	37
Chapter 3	Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood.....	39
3.1	Abstract	39
3.2	Introduction.....	39
3.3	Methodology	45
3.3.1	Context for the research	45
3.3.2	Research Design	45
3.3.3	Recruitment.....	46
3.3.4	Participants.....	46
3.3.5	Procedure	48
3.3.5.1	Co-creating the Stories.....	48
3.3.5.2	Sharing the stories	53
3.3.5.3	Evaluating the impact of the stories	53
3.3.6	Ethics.....	54
3.3.7	Data analysis	55
3.4	Analysis.....	55
3.4.1	Theme 1: Benefits of digital stories – “so much more than a video”	56
3.4.2	Theme 2: Humanising approach – “it's who they are”	58
3.4.3	Theme 3: Ownership and agency – “it's their story”	60
3.4.4	Theme 4: Ethical Considerations – “but that doesn't mean it can't be done” ..	61
3.4.5	Theme 5: Direct impact on practice – “the missing link”	63
3.5	Discussion	64
3.5.1	Ethical Considerations	66
3.5.2	Strengths and Limitations	67
3.5.3	Conclusion and Implications for practice	68
Appendix A	Reflexive journal entry	69
Appendix B	Quality assessment of included studies	71

Appendix C	Caden’s Digital Story visuals.....	89
Appendix D	Emily’s ‘I am...’ Digital Story framework (adapted).....	91
Appendix E	Topic guide for semi-structured interviews	93
Appendix F	Mental Capacity Act information	94
Appendix G	Best interest proforma	95
Appendix H	Caden’s consent form.....	96
Appendix I	Assent Comic Strip Visual	97
Appendix J	Stages of Reflexive Thematic Analysis	99
Appendix K	Participant information sheet.....	101
Appendix L	Consent forms	111
Appendix M	Thematic map development.....	115
List of References	117

Table of Tables

Table 2.1	<i>Search syntax</i>	13
Table 2.2	<i>Inclusion and exclusion criteria</i>	14
Table 2.3	<i>Descriptive summaries of studies included in the review</i>	20
Table 3.1	<i>Young person demographics and nature of their transition</i>	47
Table 3.2	<i>Participant information illustrating who was interviewed specifically around each young person</i>	48
Table 3.3	<i>Process of Digital Story creation</i>	49

Table of Figures

Figure 2.1	<i>Preferred Reporting Items for Systematic Review and Meta Analyses (PRISMA) diagram (Moher et al., 2009) to show paper identification and selection.....</i>	16
Figure 3.1	<i>Emily's Digital Story storyboard.....</i>	52
Figure 3.2	<i>Caden's Digital Story storyboard</i>	52
Figure 3.3	<i>Adi's Digital Story storyboard</i>	53
Figure 3.4	<i>Thematic map of five main themes (circles) and sub-themes.....</i>	56

Research Thesis: Declaration of Authorship

Print name: Stephanie Adelise Claire Lewis

Title of thesis: Eliciting the Voices of Children and Young People with Complex Needs:
Identifying Innovative Methods and Using Digital Stories for Supporting Transitions

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date: 27th June 2022

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Definitions and Abbreviations

ACoRNS	Autism Community Research Network @ Southampton
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
BESD	Behavioural, Emotional and Social Difficulties
CASP.....	Critical Appraisal Skills Programme
CYP	Children and young people
DfE	Department for Education
DHSC.....	Department of Health and Social Care
DoH.....	Department of Health
EP	Educational Psychologist
ESRC.....	Economic and Research Council
HI	Hearing Impairment
ILP.....	Individualised Learning Plan
ISEC	Inclusive and Supportive Education
MCA.....	Mental Capacity Act
MLD.....	Moderate Learning Difficulties
NHS.....	National Health Service
PECS	Picture Exchange Communication System
PMLD.....	Profound and Multiple Learning Disability
PRISMA.....	Preferred Reporting Items for Systematic Review and Meta Analyses
RTA.....	Reflexive Thematic Analysis
SaLT.....	Speech and Language Therapist
SCERTS	Social Communication, Emotional Regulation, Transactional Support
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability
SEND CoP	Special Educational Needs and Disability Code of Practice
SLCN	Speech, Language and Communication Needs
SLD	Severe Learning Difficulties
UK.....	United Kingdom
UNCRC.....	United Nations Convention of the Rights of the Child
USA.....	United States of America
VI	Visual Impairment

Chapter 1 Introduction

1.1 Context for research

This thesis journey began in 2011 when I worked directly with autistic children and young people (CYP) and their families at a residential special school. This experience contributed to a personal and professional commitment I hold to improving outcomes for autistic CYP. Initially at the school, I worked directly with the CYP as a support worker, where I was afforded a deep insight into the unique qualities and many strengths and challenges that autistic CYP face daily. It was this insight and understanding which, I believe, enabled me to be a better advocate for autistic CYP and their families when I later secured the role as an assistant psychologist at the same school. Within this role I developed a passion for developing and using creative methods to enable CYP to be listened to and heard within all aspects of their daily lives. I regularly reflected on the tensions I experienced within meetings where decisions were being made *for* the child, rather than *with* the child. Hence, I sought opportunities to include the voice of the CYP whenever I could through: creating pupil support plans written in first person in collaboration with adults who knew the CYP best; working closely with the Speech and Language team to explore ways to enable CYP's voices to be heard and argued for their inclusion within meetings; and, crucially, when this was not possible, seeking creative ways to inclusively represent them, using photographs and videos.

It is these core values and beliefs which have informed and influenced my desire to carry out research *with* autistic CYP and to explore, through my research, inclusive ways to enable their voices to be heard and listened to within matters which affect their lives. During a taught session at university in my first year, this interest developed further following a talk exploring the initiatives and aims of the Acorns Community Research Network @ Southampton (ACoRNS). One of their key aims is to co-construct research with the aim of improving the lives of autistic CYP by centralising their voices in all that is done (Parsons et al., 2019). This initiative aligned with my values and research interests and, hence, provided me with the unique opportunity and inspiration to conduct my research in an area I was, and continue to be, incredibly passionate about.

1.2 Digital Stories as a creative and inclusive method to access the views and voices of autistic children with complex needs

This thesis contains two separate pieces of research. In my systematic literature review (Chapter 2), I review the extant literature to explore the inclusive methods which have been developed and used in education to enable CYP with complex needs to have a voice within decisions relating to their education. With an understanding that there are very few inclusive methods which enable autistic CYP's voices to be accessed and heard, I set out in my empirical paper (Chapter 3) to extend the 'I am...' Digital Story framework, which was initially developed in a nursery school for autistic young children, for use with older autistic people with complex needs. Through this research, 'I am...' Digital Stories are co-created in partnership with the carers and educators at the school that collaborated with me on this research, the young people's families and, where possible, the young person themselves. This methodology enables their views, experiences, and perspectives to be included in their Digital Story, which supports their transition from their residential school to adult services. Although the findings within the systematic review highlight the infancy of research exploring the development and use of inclusive methods to enable the voices of autistic CYP with complex needs, Digital Stories demonstrate an inclusive way of not only gaining their voice, but also how young autistic people with complex needs can be afforded prominence within decisions that affect their lives. Findings from both papers have implications for a range of educational, health and social care professionals about how we can enable and centralise the voices of CYP within their own educational and residential planning. They also ensure that the voices of autistic CYP who are frequently marginalised are front and centre of this decision-making.

1.3 Research paradigm

This research was conducted in partnership with the Autism Community Network @ Southampton (ACoRNS). It is from this collaboration that an established partnership was formed between myself as a researcher and Hill House School, a partner of ACoRNS. Central to the ACoRNS research agenda is the epistemological position of knowledge co-construction, which

seeks to narrow the gap between research and practice by collaborating on research questions derived from practice and working in partnership with practice to find the answers to these questions. It is an approach which contrasts with the traditional views of knowledge transfer and exchange; instead, knowledge co-construction enables a shared space to be created where novel insights and theories can be developed for both research and practice (Guldborg et al., 2017; Parsons, 2021). The present research took a qualitative, participatory approach, emphasising the importance of the research process being carried out *with* rather than *on* participants (Cahill, 2007; Morris, 2003).

Specifically, this research was based on a critical realist epistemology, which considers the way in which experiences are understood or made sense of by individuals and, consequently how their understanding is socially constructed (Willig, 1999). In addition, a critical realist position considers how an individual understands and makes sense of reality and how this can be influenced by the social context (Willig, 1999). It also identifies how our actions are influenced by the meaning we attribute to objects and concepts (Mustafa, 2011). This means that the individual beliefs and experiences held by participants in this research, principally, how they conceptualise *voice* and their prior experiences of transition planning, will influence their comments and evaluation of the Digital Story methodology shared within the interviews. Thus, different perspectives on reality are seen as valid, because “meanings, beliefs and values held by individuals are part of the reality we seek to understand” (Maxwell, 2018, p. 22). Critical realism is also concerned with “emancipation and transformation” (Mustafa, 2011, p. 26) and aims to endorse social change by “challenging the status quo in a more radical way” (Mingers, 1992, p. 105). Indeed, the Digital Story methodology is an “non-orthodox” method (Parsons, Kovshoff et al., 2020, p. 11) to elicit the voice of children and young people who are frequently marginalised and frequently denied a voice within matters which affect their lives. By adopting a critical realist position in my research, I endeavoured to promote the voice of a frequently marginalised group, that is, autistic young people with complex needs.

1.4 Reflexivity

Integral to conducting qualitative research is reflexivity, the acknowledgement that my research is shaped by my personal and theoretical viewpoints and world view (Willig, 2012). I acknowledge how my involvement, my assumptions, my expectations, and my design choices have influenced and shaped my research. I am aware how my personal and professional background and my epistemological stance have implications on all aspects of this thesis project and, crucially, how I have understood and interpreted my findings. Throughout my research I maintained an awareness of my active role as a researcher in knowledge production through the process of co-constructing meaning informed by my data.

To ensure that I was reflective and thoughtful when engaging with my data, I kept a reflexive diary (Braun & Clarke, 2021; Nadin & Cassell, 2006) which, in combination with supervision, provided me with a space where I could reflect on my beliefs, values and experiences throughout the research process (see Appendix A for an example reflexive journal entry). Indeed, this also aided transparency and is an important technique for ensuring quality (Nowell et al., 2017). Reflexive journaling throughout the research process also enabled me to reflect on my research practices and assumptions as they evolved and developed over time. Through this process, I reflected on how my prior assumptions and knowledge shaped my interpretation of the data. This process created a protective space for me to be able to reflect on any assumptions which may have restricted my engagement with the data, as well as consider alternate ways of interpretation. As emphasised by Braun and Clarke (2021), it was important that I reflected *beyond* simply what came to my mind, and I considered my emotional responses to the data, inclusive of how participants made me *feel*. To further aid reflexivity, I regularly used supervision with my thesis supervisors to discuss and reflect on my analysis as it progressed and developed. My own reflections, coupled with my supervisors' questions and interpretations, enabled clarification of analytic insights and allowed me to gain a rich and more in-depth understanding and interpretation of my data.

Keeping a reflexive diary throughout this research also enabled critical self-reflection of how my experiences, thoughts and feelings shaped the research. It has been a challenge at times due to the tensions I experienced in an effort to best represent the voices of the participants and, crucially, trying to make sure I represented Emily, Adi and Caden's stories well - doing *their* Stories justice.

Indeed, a crucial element of reflexive thematic analysis (TA) is to allow enough time to fully develop a rich analysis and interpretation of the data, a process which moves beyond extracting surface level, superficial meaning. Reflexive TA is demanding, not only through the process of analysis and writing, but also to allow space for insight and inspiration through reflection, thinking, asking questions, and exploring my own assumptions. It is through these reflexive processes that I have engaged deeply and meaningfully with the data.

1.5 Ethical challenges

Inherent to developing an inclusive methodology which pushes the boundaries to enable the voices of young people who are frequently marginalised and “unheard” (Parsons, Ivil et al., 2020, p. 15), are the ethical tensions that exists when developing such an approach. Indeed, researchers have expressed caution when using methodologies to enable voices of CYP who have limited or no verbal communication, due to the risk of over-interpreting their behaviours and actions and the “high degree of inference” which has been associated with such methods (Ware, 2004, p. 178). Consistently, Ware (2004) argued that methods that attempt to ascertain the views of CYP with communication and language needs may only capture immediate preferences and fail to truly enable a CYP to express a *view*. Indeed, how well and to what extent the Digital Stories, that were co-constructed as part of this research, achieved the aim of representing the young people’s views and voices, is ultimately dependent on the reader’s (your) own beliefs and theoretical standpoint. Therefore, it is imperative that the Digital Stories are watched by readers so that conclusions can be drawn. I therefore kindly request that Caden and Emily’s Digital Stories are viewed in conjunction with reading the empirical study. A link to Caden’s and Emily’s Digital Story can be found here, respectively: https://youtu.be/641-Pt_5Q9g and <https://youtu.be/WhO2dZtzdMQ>.

Moreover, the Digital Story methodology does not seek to interpret the experiences of young people, instead the Digital Stories provide a lens through which to gain a holistic, strengths-based understanding of a young person. Currently, autistic young people with complex needs are all too frequently denied an opportunity to have their experiences, preferences and perspectives included within transition planning. Instead, current practice in this domain relies heavily on professionals’ and families’ views, and decisions about the young person’s future is typically made *for* them, most

Chapter 1

likely informed by observations or written accounts of a young person which may only focus on a very narrow space in their lives. Instead, Digital Stories offer a way for a young person to be better represented as a three-dimensional person, and to contribute their voice within their transition where they otherwise would not be afforded this opportunity. Digital Stories enable stakeholders to gain a rich understanding of the nuances of each individual young person and seek to humanise and depathologise. Of course, with any representation of reality there is a degree of interpretation. However, knowledge co-construction is at the heart of the Digital Story methodology, and it is this collective understanding of the young person from the young person themselves and/or familiar, attuned adults who know the child well, which enables a holistic understanding to be represented in the Digital Stories, providing a sense of *who they are*.

1.6 Dissemination activities and future plans

The initial findings of this research have been shared with three Educational Psychology Services in the south of England. I have also collaborated with colleagues from Educational Psychology and Speech and Language Services to embed the use of Digital Stories within practice in three local authorities. I have had the opportunity to present, in partnership with my collaborators from Hill House School, these research findings at an ESRC Festival of Social Science event hosted by ACoRNS and the University of Southampton on 13th November 2020 and attracted colleagues from a range of education, research, health and social care backgrounds. A link to the recording of the session can be found here: <https://m.youtube.com/watch?v=y2WjuTDe-oQ&feature=youtu.be>. I have also presented this research at the Inclusive Supportive Education Conference (ISEC) hosted by University College London on 4th August 2021. My intention is to continue to disseminate my research within a variety of events and conferences to share the Digital Story methodology more widely.

I have written two research papers which I intend to publish in peer-reviewed journals. Therefore, each paper has been written according to the style requirements for the journals I aim to submit to. The peer-reviewed journal I will submit my systematic literature review to is the 'European Journal of Special Needs Education' (EJSNE). This is an international journal that focuses on significant developments within the field of special educational needs at all levels of

education from primary through to early adulthood, making it an appropriate choice for the aims and scope of my review. In addition, my research follows on from Fayette and Bond's (2017) systematic literature review, which explored qualitative methods to enable the voice of autistic children, and has also been published within this journal.

The journal I intend to submit my empirical paper to is the 'Journal of Autism and Developmental Disorders' (JADD). This is also an international journal which seeks to advance theoretical and applied research within the field of autism and developmental disabilities. An analogous study identified within my systematic literature review also published their research within this journal. This research explored the development of a method entitled a 'Talking Wall' – which enabled communication of the views, preferences, and experiences of autistic young people with complex needs, who also attended a residential special school (Richards & Crane, 2020). I felt that aiming for this journal would allow me to contribute to the field through dissemination of another valuable methodology – Digital Stories - to the readership of this journal.

Chapter 2 Creative methods developed to elicit the voices of children and young people with complex needs: a systematic literature review

2.1 Abstract

This systematic literature review explores creative methods that have been developed and used to elicit the voice of children and young people with complex needs about their educational experiences and preferences. Additionally, methods were considered in relation to Lundy's (2007) model of Space, Voice, Audience and Influence. Fourteen qualitative papers published between 2003 and 2021 were included in the review. Findings emphasise how it is possible to access the views of children and young people with complex needs. However, more needs to be done to ensure that their views are acted upon, given due weight and influence change. The implications for educational professionals are discussed.

Keywords: complex needs, children, young people, education, experience, voice

2.2 Introduction

Over 30 years ago, the United Nations Convention of the Rights of the Child (UNCRC, 1989) stated – amongst other fundamental rights - that children and young people (CYP) have a right to be listened to and for their views to be given due weight (Article 12). Since its publication, the UNCRC has been ratified in 168 countries. However, despite this international commitment, the way that 'voice' is conceptualised frequently results in the exclusion of CYP from being actively involved in matters that affect their lives, including within educational decision-making (Davis & Watson, 2000; Hesjedal, 2021; Lundy, 2007). CYP with special educational needs and disabilities (SEND) are particularly vulnerable to marginalisation (Cascio et al., 2021, Courchesne et al., 2021; Fayette & Bond, 2017; Flutter & Rudduck, 2004; Pellicano, Hill, 2014 & Pellicano, Dinsmore et al., 2014) and are frequently denied participation in decision-making due to a "double denial" of their voice i.e. doubts about their competence to form and express a view because of being: (a) a child and (b) a disabled child (Lundy, 2007, p. 935). Additionally, it is suggested that

Chapter 2

professionals working with CYP are unaware of the existence and scope of Article 12, and even when there is an awareness of CYP's right to have a voice, the requirement to consider the 'age and maturity of the child' is used as a caveat to exclude them or overlook their inclusion (Bloom et al., 2020a; Gersch et al., 2014; Lundy, 2007).

In England, there is an increased emphasis on promoting 'pupil voice' for *all* CYP with SEND, and it is mandated that their views must be represented when making decisions about their education. Specifically, the SEND Code of Practice (DfE/DoH, 2015) requires Local Authorities to "ensure that children, their parents and young people are involved in discussions and decisions about their individual support and about local provision" (p. 20). Yet, despite this acknowledgement, CYP, especially those with more complex needs¹, are denied the right to be agentic (Morris, 2003) and are often "multiply marginalised" within formal processes (Parsons, Ivil et al., 2020, p. 3). Thus, there is a significant gap between what is stated in legislation and guidance and what happens in both research and practice. Consequently, efforts need to be made to value *all* forms of expression, not just those which privilege verbal communication. Only then can barriers to the voices of *all* CYP being represented and elicited be removed (Ellis, 2017).

This issue emphasises how crucial it is for research to explore *where* and *how* to facilitate CYP's voices within decisions impacting their education. Although there are examples of more inclusive methods being used for gathering the views of CYP, there is an overreliance on methods which privilege the spoken word. Fayette and Bond (2017) conducted a systematic review to identify the qualitative methods used in research for eliciting the views of autistic young people about their educational experiences. The main conclusion was that only a relatively narrow range of methods were used in the literature and, therefore, voices heard. Indeed, a reliance on autistic young people who had a "high level of language ability" and "no diagnosed intellectual ability" were purposefully selected in some studies to ensure data could be analysed (Browning et al., 2009, p. 38; Van Hees et al., 2015, p. 1675). Moreover, where CYP's voices were gathered to develop an understanding of their educational experiences, the voices represented were much more likely to derive from older young people and those who preferred to communicate using speech.

¹ Children and young people with significant communication and/or cognitive impairments: a subgroup who are identified as those most commonly excluded and marginalised within research and practice.

Tyrell and Woods (2018) drew similar conclusions within their systematic review, which focused on identifying methods being used to elicit the views of autistic CYP and concluded that traditional methods (e.g., semi-structured interviews and focus groups) to elicit CYP's voices were "common place", and that such methods favoured CYP who are "older" or "more able" (p. 320). Findings from these reviews align with those by Cascio et al. (2021) who highlighted the lack of representation of autistic people with more complex needs in research following a review of the research ethics literature. Therefore, there is a need to follow-on from Tyrell and Wood's (2018) and Fayette and Bond's (2017) reviews, and to address one of the major gaps identified by Cascio et al. (2021): to make a specific search for where, and how, those missing voices of CYP with complex needs may be included in research.

Lundy (2007) provided a practical framework designed to inform understanding, aid policy development and to audit current practice about children's voice and participation based on the tenets of Article 12 of the UNCRC (Lundy, 2007). There are four key elements of the model: *Space, Voice, Audience and Influence*, and although these are presented as four distinct elements, they are interrelated and are intended to reflect the full scope and meaning of Article 12 and beyond (Lundy, 2007). Specifically, the model explores the extent to which a child is given the right to express a view (*Space and Voice*) and for their view to be given due weight (*Audience and Influence*). Crucially, Lundy (2007) emphasised that Article 12 cannot be fully understood in isolation and should be considered collectively with other relevant articles within the UNCRC. Lundy (2007) also acknowledged the importance of using a range of methods and tools to enable CYP's voices to be heard, describing how "children may need practical assistance to communicate their views" (p. 936). This links with Article 13, which states when seeking ways to support CYP with complex communication needs to form a view, they must have the "freedom to seek, receive and impart information...either orally, in writing or in print, in the form of art, or through any other media of the child's choice" (p. 5). This emphasises the importance of developing person-centred, individualised methods and adapting "research tools to suit each child or young person" (Morris, 2003, p. 344). In addition, there is very little value in developing methods to enable CYP's voices unless these views are "seen to be integral and embedded within decision-making" (Lundy, 2007, p. 939; Sinclair, 2004). Therefore, as argued by Lundy (2007) "voice is not enough" (p. 927).

Chapter 2

Consequently, to successfully implement Article 12 and enable children's views, perspectives, and experiences to be authentically represented, all four elements of *Space, Voice, Audience and Influence* are necessary for CYP's views to not only be heard, but actively listened to and taken seriously. This framework provided the foundation for analysis of the data derived from the extant research literature. Specifically, the research questions addressed within this systematic review were:

RQ1: What methods have been developed and used to elicit the voice of children and young people with complex needs about their educational experiences and preferences?

RQ2: How have children and young people with complex needs' voices been represented in these methods?

Lundy's (2007) model of *Space, Voice, Audience and Influence* will be used to answer this question, specifically:

- Has the child or young person been invited and encouraged to express their views, safely and inclusively?
- Has the child or young person been given the opportunity to 'freely' express their views and where appropriate, facilitated to form their views?
- Has the child or young person's views (both verbal and non-verbal expression) been listened to and given due weight?
- Has the child or young person's views been acted upon, as appropriate?

2.3 Methodology

2.3.1 Search Strategy

A systematic search of the literature was carried out using eight bibliographic databases: Australian Education Index, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Education Resources Information Centre (ERIC), International Bibliography of the Social Sciences (IBSS), Medline, PsycINFO, Scopus and Web of Science (Figure 2.1). These databases were chosen to reflect the range of professionals and professions who may be involved in eliciting CYP's views within education (e.g., speech and language therapists, social workers, teachers,

psychologists). Synonyms for ‘voice’, ‘elicit’, ‘child’ and ‘education’ and ‘experience’ were taken from Fayette and Bond’s (2017) systematic literature review to provide initial search terms, which were further refined during scoping searches. Two additional terms central to the review question, ‘complex needs’ and ‘method’ were also included. To ensure that the main search was comprehensive and yielded relevant evidence i.e., balanced in terms of specificity and sensitivity (Boland et al., 2017), several iterations of the search using different terms was conducted. Table 2.1 details the final search terms and search syntax, which were adapted as required for each bibliographic database. The initial search was conducted in April 2021 and repeated in February 2022 to identify any relevant new publications.

Table 2.1 *Search syntax*

Search term	Syntax
Method	AB (Method* OR tool* OR technique* OR approach* OR framework*) OR TI (Method* OR tool* OR technique* OR approach* OR framework*)
Voice	AB (voice* OR view* OR perspective* OR communicat* OR participat* OR consult*) OR TI (voice* OR view* OR perspective* OR communicat* OR participat* OR consult*)
Child	TI (child* OR “young pe*” OR pupil* OR student* OR “young adult*” OR teen* OR adolescen* OR infant* OR youth* OR preschooler*)
Complex needs	TI (“complex need*” OR “non-verbal*” OR “no words” OR “pre-verbal” OR “communication need*” OR “communication impairment*” OR “communication difficult*” OR “learning difficult*” OR “special educational need*” OR “multiple need*” OR disab* OR autis* OR ASC OR ASD)
Experience	AB (experience* OR preferenc* OR decision* OR choice* OR evaluation* OR perception*) OR TI (experience* OR preferenc* OR decision* OR choice* OR evaluation* OR perception*)
Elicit	AB (elicit* OR explor* OR promot* OR gather* OR express* OR listen* OR share OR access* OR ascertain OR collect) OR TI (elicit* OR explor* OR promot* OR gather* OR express* OR listen* OR share OR access* OR ascertain OR collect)

Education	AB (educat* OR school* OR nurser* OR college* OR provision* OR setting* OR service*) OR TI (educat* OR school* OR nurser* OR college* OR provision* OR setting* OR service*)
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Due to the number of papers retrieved, articles published pre-1989 were not included in the final search as this date accords with the publication of the UNCRC (1989). Subsequently, there has been a greater focus on eliciting pupil voice to develop educational practices (Lundy, 2007; Noyes, 2005) and therefore this period was anticipated to yield articles of most relevance. Limiters were applied to exclude articles that were unpublished theses and book chapters. Articles not published in English were also excluded from the search.

This search produced a return of 3549 papers across the eight databases, which were collated in Mendeley where duplicates of articles were automatically removed, leaving 1978 papers to be screened. The papers were initially screened for relevance by reading the title and abstract only, and a further 1911 papers were excluded leaving 67 papers to be assessed for eligibility against the inclusion and exclusion criteria through full text reading (Table 2.2). Fifty-three papers were excluded, leaving 14 papers in the current review. Most papers were excluded due to not developing an inclusive methodology to elicit CYP’s views, verbal communication being a pre-requisite for inclusion in the study, and the research being carried out in a non-educational context. Each stage of the search and the process of paper selection is displayed in the PRISMA flow diagram (Moher et al., 2009) shown in Figure 2.1.

Table 2.2 *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
CYP must be aged between 0 and 25 years, which reflects the age group in which the SEND CoP (DfE/DoH, 2015) applies.	CYP are over 25 years old.
The study explores the development and use of a data collection method(s).	Inclusion within the study is contingent on the child or young person’s ability to verbally engage or cognitive ability.
The main focus of the research is on eliciting the voice of CYP who have complex needs/limited verbal communication.	The views of adults (e.g., parents or teachers) have been used as a proxy for CYP’s views.

The study has been carried out in an education setting (e.g., preschool, primary school, residential special school etc.) and focuses on understanding the views, preferences and perspectives of CYP.

Qualitative, peer reviewed research.

Written in English.

Research is focused on eliciting the views of adults and/or CYP's views have been elicited as part of a wider study involving others (e.g., parents or teachers) and their views cannot be separated from the view of adults in the data.

The study has been carried out in a non-education context (e.g., hospital, community centre

Research published pre-1989, i.e., prior to the publication of the UNCRC, which marked a shift in research emphasising the importance of eliciting CYP's views.

Research published in books, doctoral and master's theses or dissertations.

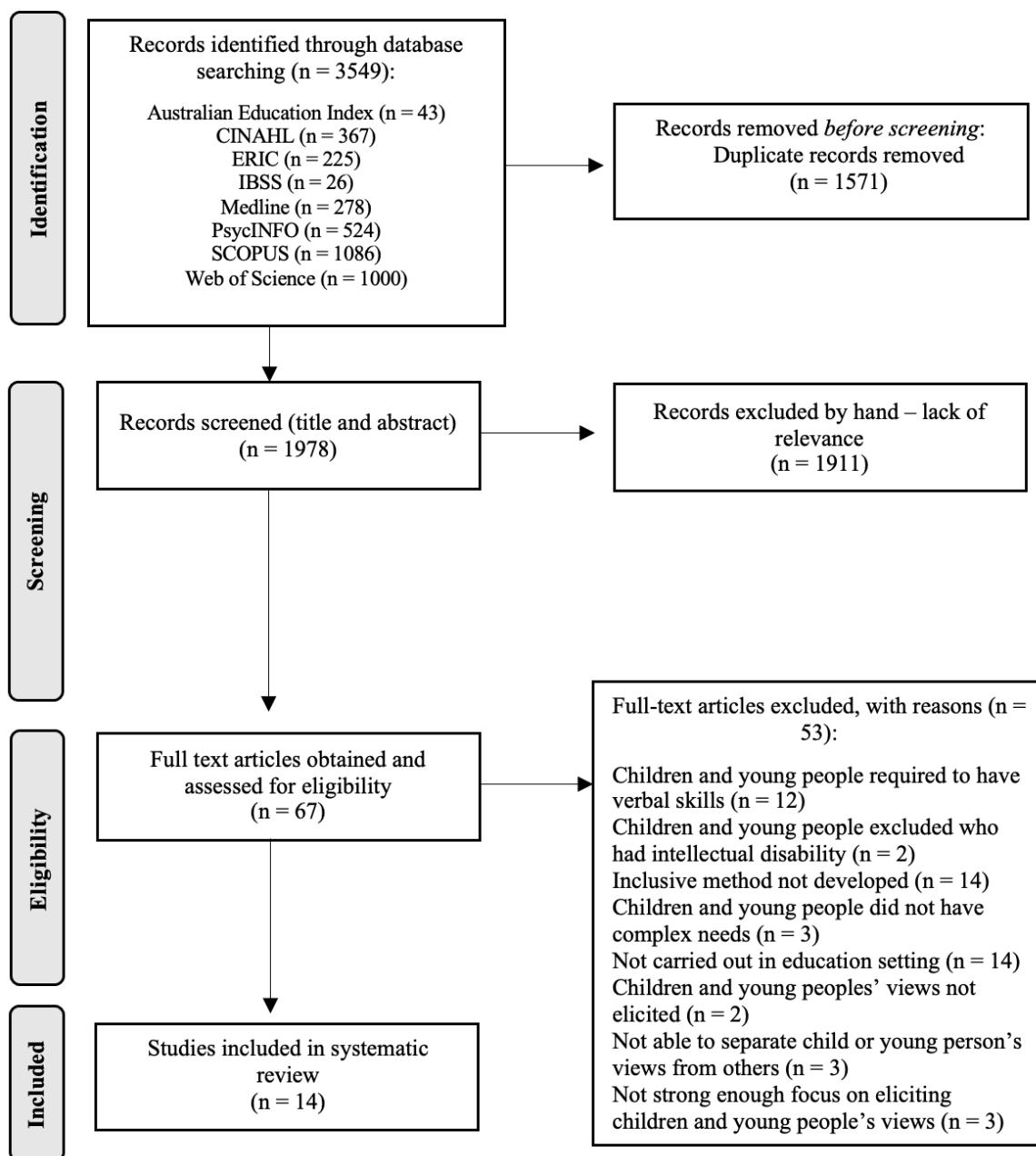


Figure 2.1 *Preferred Reporting Items for Systematic Review and Meta Analyses (PRISMA) diagram (Moher et al., 2009) to show paper identification and selection*

2.3.2 Quality Assessment

Once papers were identified for inclusion in the current review, the methodological strengths and limitations for each study were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Critical Appraisal Skills Programme, 2018). As suggested by Long et al. (2020), to determine methodological rigour of each qualitative study, the CASP tool was adapted to include a question exploring the clarity and appropriateness of a study's qualitative paradigm. This question appraised the study's theoretical underpinnings and explored whether the

guiding theoretical framework was “clear, consistent and conceptually coherent” (Long, et al., 2020, p. 35). In addition to the three original response options within the CASP (‘yes’, ‘no’ and ‘can’t tell’) a ‘somewhat’ response was added. The inclusion of this fourth response option allowed for a distinction between a ‘reporting issue’, where there is limited information within the paper to fairly appraise against the criteria and a ‘methodological issue’, where authors had partially fulfilled a specific quality domain (Long et al., 2020). The CASP discourages numerical scoring of quality domains and calculating total quality scores. Therefore, as suggested by Noyes et al. (2018), qualitative information was recorded against the quality criteria outlined in the CASP, to determine each study’s methodological strengths and limitations. Although the CASP did not provide thresholds regarding assessing overall study quality, I determined the overall quality subjectively guided by the criteria within the CASP quality assessment. Most papers included had clearly described research aims and a qualitative methodology and design was deemed appropriate for addressing the aims of the research. For nine of the papers, the recruitment strategy was not explicitly stated or not included and, therefore, it was unclear how and why the participants were selected. Eleven studies provided sufficient detail about ethical considerations (e.g., consent and assent procedures). An in-depth description of the data analysis process was missing from most studies, with only four studies providing a thorough description of the analysis process i.e., description of steps taken within the analysis and how the themes were generated from the data. See Appendix B for the full quality assessment data tables, outlining the study quality against each criterion as detailed in the CASP and qualitative appraisal recorded.

2.4 Findings

2.4.1 Overview of studies

A summary of the study context and location, participant information and data collection methods of the final 14 studies is provided in Table 2.3. The participant information column describes information on the participant characteristics including number of CYP with complex needs included in the study, age, gender, known diagnoses and verbal communication skills, where provided. The data collection method column includes information on the method(s) that have been

Chapter 2

developed and used within the study, how the CYP's voices were represented in the method and the authors' aims for developing the method. All the qualitative research included was published between 2003 and 2021. Nine studies were conducted in England, one in Northern Ireland, one in the Republic of Ireland, one in Greece, one in Canada and one in New Zealand.

2.4.2 Methods developed and used to elicit voice

All the included studies aimed to elicit the voices of CYP with complex needs on their experiences within education settings and developed and/or used a novel methodology to do so. Three studies focussed on eliciting the voices of CYP with complex needs to explore their experiences, perspectives and interactions within their education setting generally (Ajodhia-Andrews & Berman, 2009; Bradley & Male, 2017; Gray & Winter, 2011). Other studies focused on exploring CYP's experiences, perspectives, and interactions to inform transition planning (Hart, 2021; O'Leary & Moloney, 2020; Parsons, Ivil et al., 2020), to develop a child's individualised learning plan (Rouvali & Riga, 2021) and to understand CYP's feelings and experiences within specific subjects, including drama (Loyd, 2013) and physical education (Fitzgerald et al., 2003). Whitehurst's (2007) study aimed to explore CYP's retrospective views following inclusion within an inclusive drama performance.

Five studies also elicited the views of CYP about their experiences in their education setting. However, the focus was on developing the use of a specific methodology to enable CYP's voice. These studies developed and used a specific methodology to enable CYP's voices to be heard, namely 'I am...' Digital Stories (Parsons Ivil et al., 2020), 'Multimodal Talking Wall' (Richards & Crane, 2020), 'Your Voice, Your Choice Toolbox' (Bloom et al., 2020b) and 'School Preference Cards' and 'Ethnographic approach using SCERTS' - two methods developed specifically for CYP with limited verbal communication (Hill et al., 2016). Finally, Simmons and Watson (2015) developed a multifaceted approach to interpret the actions and behaviours of a child with Profound and Multiple Learning Disability (PMLD) within both mainstream and special school settings.

2.4.3 Participant characteristics

Studies included CYP aged three to 25 years, with the sample size ranging from one to 60. Collectively, the voices of 98 CYP with complex needs were represented across all 14 studies. Eight of the studies reported the views of only male participants, with the exception of Rouvali and Riga (2020), Loyd (2013), and Gray and Winter (2011). The gender of participants was not given in three studies (Fitzgerald et al., 2003; O’Leary & Moloney, 2020; Whitehurst, 2007). Research was conducted within a broad range of education settings, which included mainstream, special school, and residential special school settings, across each stage of education including preschool and nursery school settings, primary school, secondary school, and further education.

All studies included participant information regarding known diagnoses, with many studies including children with multiple needs and co-occurring conditions (Table 2.3). The expressive language skills of participants were reported in 10 studies, with the exception of Bradley and Male (2017), Hill et al. (2016), Gray and Winter (2011) and Fitzgerald et al. (2003). From the 10 studies that reported CYP verbal communication difficulties (Ajodhia-Andrews & Berman, 2009; Bloom et al., 2020b; Hart, 2021; O’Leary & Moloney, 2020; Parsons, Ivil et al., 2020; Loyd, 2013, Richards & Crane, 2020; Rouvali & Riga, 2021; Simmons & Watson, 2015; Whitehurst, 2003) 10 CYP were reported as ‘non-verbal’, 13 CYP referred to as having ‘limited verbal skills’, six CYP were considered ‘pre-verbal’; and six CYP were reported as having ‘limited or no verbal communication’.

Table 2.3 *Descriptive summaries of studies included in the review*

Study and country	Setting	Participant information			Data collection methods		
		Characteristics	Diagnosis(es)	Verbal communication skills	What method has been developed/used to elicit voice?	How is ‘voice’ represented?	For what purpose?
Hart (2021) New Zealand	Two urban special schools	N: 3 Age: 21 years Gender: male	Autism (n = 2) Autism, severe and multiple learning difficulties, visual impairment (n = 1)	Non-verbal (n = 1) Limited verbal communication (n = 1) Verbal (n = 1)	Observation - fieldnotes and photographs and videos. Adapted interviews cocreated with the young adults.	Visual methods, including objects, photographs, and videos.	To express the young adults’ capabilities, perspectives, and transition preferences.
Rouvali & Riga (2021) Greece	Mainstream Early Years setting	N: 1 Age: 6 years Gender: female	Autism and Global Developmental delay	Non-verbal	Multiple methods including observation, photographs, Talking Mats, adapted questionnaire. Mosaic approach used to triangulate and assist interpretation.	Vignettes written by the researcher. Visual methods including photographs, symbol and photo-based sorting activities to indicate preferences.	To explore an autistic child’s wishes, needs, emotions and experiences, to develop her new Individual Learning Plan (ILP).
Bloom et al. (2020b) England	Six mainstream and special schools	N: 7 Age: 4-18 years Gender: 3 males, 4 females	Verbal dyspraxia (n = 1) Down syndrome, hearing impairment, SLD (n = 1) Autism (n = 3) Autism and ADHD (n = 1)	Verbal dyspraxia (n = 1) Verbal (n = 4) Non-verbal (n = 1)	‘Your Voice, Your Choice’ toolkit (multiple methods), comprising of semi-structured interview, questionnaires, observations, reports, and the interviewers’ reflections	Photographs or illustrations of children’s experiences and emotion cue cards, used to indicate preferences.	To explore children’s feelings about their school learning and support experiences.

FAS (n = 1)							
O’Leary & Moloney (2020) Ireland	Preschool and primary school	N: 9 Age: 3-6 years Gender: N/A	Autism (n = 9)	Verbal (n = 4) Non-verbal (n = 5)	Visual elicitation methods - visual storytelling to create child-centred stories. Narrative interview method with parents.	Visual methods, including photo-elicitation and use of artifacts. Parent narratives.	To understand the early years education experiences of young children transitioning to primary school.
Parsons, Iivil et al. (2020) England	Nursery school	N: 5 Age: 4 years Gender: male	Autism (n = 5)	Pre-verbal (n = 5)	‘I am...’ Digital Stories created in collaboration with adults who know the child well. Video clips of children representing their actions and behaviours were recorded on video cameras and small Wearcams, worn by each child, which provided insight into children’s interactions and choices from their perspective.	Unique insights and children’s perspectives are represented within the Digital Stories. Wearcam footage showed children’s choices, interactions, and preferences from the child’s point of view.	To explore the experiences, perspectives, and interactions of children to support transition to primary school.
Richards & Crane (2020) England	Residential special school	N: 10 Age: 15- 26 years Gender: 6 male, 5 female	Autism and cooccurring conditions including, epilepsy (n = 4), ADHD (n = 2), Tourette’s syndrome (n = 2) and additional medical needs (n = 1)	Limited verbal communication (n = 10)	Multimodal ‘Talking Wall’ – adapted graffiti wall created by combining several elements from previously trialled methods in the literature, including: Photovoice, Talking Mats, School Preference Cards, Graffiti Wall and the Mosaic Approach.	Young people’s collective voice was showcased on “interactive collection points” i.e., the walls contained text, artefacts, images photographs and audio-based evidence (p. 4269).	To capture the experiences and preferences of autistic young people within a residential special school.

Bradley & Male (2017) England	Special school (forest school provision)	N: 4 Age: 6 -8 years Gender: male	Autism and Severe Learning Disability (n = 4).	Not specified	Multiple methods including, video footage of children's experience in school which formed a ' Forest School Movie ', one was created for each child and adapted interviews which were carried out with each child to capture their verbal and non-verbal responses to their video.	The Forest School Movie captured the children's preferences, explorations, and interactions. Children were supported through creative expression (e.g., drawings) to express their views.	To explore what children liked and did not like about Forest School, and how Forest School made them feel.
Hill et al. (2016) England	Residential special school	N: 83 Age: 8 -19 years Gender: 50 male, 33 female	ADHD (n = 2), ASD (n = 44), BESD (n = 3), SLD (n = 1), Epilepsy (n = 3), HI (n = 11), MLD (n = 3), PMLD (n = 2), SLCN (n = 13), VI (n = 1) Note: Many CYP were reported to have cooccurring needs.	Not specified	Diamond ranking activity and graffiti wall used for CYP with verbal ability. Two methods developed specifically for CYP with PMLD (n = 15) and limited verbal communication including, School preference cards , comprising photographs of the CYP's environment, which involved a card sorting activity, and an Ethnographic approach using SCERTS communication checklist , an approach which used ethnographic methods and structured observations.	Photographs and symbols were used to represent the CYP's environment. These were sorted into preference categories by the CYP. Photos of these boards were taken to capture their preferences. A first person narrative (known as an 'ethnographic narrative') about the child's life at school was written by the researcher.	To elicit CYP's school preferences, and to understand the motivations underlying their responses. To capture and describe the nature of interactions between CYP and support staff.

Simmons & Watson (2015) England	Special school and mainstream primary school	N: 1 Age: 9 years Gender: male	PMLD (cerebral palsy and visual and auditory impairments)	Pre-verbal	Participatory observations as a method to ‘get to know’ the child and a way of ‘being with’. Non-participatory observations led to the creation of vignettes describing the child’s interactions, behaviours and experiences. Behaviour state ethogram provided a lens to interpret the child’s behaviour.	Through vignettes (first person narratives) produced from “sensitive observation” and “co-constructed interpretation of [the child’s] behaviour and interactions” (p. 63)	To understand the child’s actions and behaviours and to explore how their social engagement across both mainstream and special school settings impacts their development and learning.
Loyd (2013) England	Autism unit at an FE college	N: 10 Age: 16 -18 years Gender: 6 female, 4 male	Autism (n = 10)	Verbal (n = 4) Limited/no verbal communication (n = 6)	Observation in drama and other lessons for 34 weeks. Multimodal interview approach (4-part process) using Talking Mats, visual support, photographs and videos of the young people in drama.	Expression of their preferences and engagement through symbols, video footage and photographs. Pupils who communicated nonverbally used familiar widget symbols to communicate their preferences.	To explore young people’s social communication and interaction skills when participating in drama education and to understand young people’s experience within drama sessions.
Ajodhia-Andrews & Berman (2009) Canada	Elementary school	N: 1 Age 10 years Gender: male	Not specified	Non-verbal	Modified Talking Mat – 62 picture symbols uniquely designed for the child using their interests. Story Board Game – storyboard reflecting a typical day at school. The board	The child’s responses in the Talking Mat and the Story Board Game were documented via digital photographs.	To provide a safe and respectful space to understand a child’s perspectives of school life.

					contained picture symbols and blank spaces for the child to complete with his responses. Digital pictures and observational field notes – the child's responses within each activity were document via digital photographs. Observational field notes were taken by the researcher.		
Gray & Winter (2011) Northern Ireland	Pre-school	N: 18 Age: 3-4 years Gender: 9 male and 9 females	18 children with disabilities included autism (n = 8), autism and ADD (n = 4), VI (n = 3), Down's syndrome (n = 2) cerebral palsy (n = 1) Note: 18 children included in the study had 'no known disability'.	Not specified	Multi-method approach was used, informed by the Mosaic Approach. A toolbox of methods was developed to represent the children's views. The toolbox included: a rag doll (used as a stimulus), stickers, smiley faces, drawings, cameras, and tape recorders.	The children used tape recorders, attached thumbs up and thumbs down signs to most and least liked objects, took pictures using the disposable cameras and created paintings.	To elicit the views and preferences of disabled and non-disabled children on their daily experiences in their preschool setting.
Whitehurst (2007) England	Residential special school	N: 6 Age: 7 -19 years Gender: n/a	Profound autism, ADHD, Down's Syndrome, Severe Learning Disabilities and Worster Drought	Non-verbal (n = 1) Limited verbal skills (n = 2)	Young people were supported to engage in an adapted interview using a range of visual methods, a combination of photograph elicitation	Description by the author using illustrative quotes as well as descriptions of non-verbal preferences made by the CYP.	To capture the views of students with profound and complex learning difficulties to understand their views and experiences

			Syndrome (a form of Cerebral Palsy). Note: Many were reported to have cooccurring needs.	Verbal skills which varied in ability (n = 3)	methods, Makaton and Talking Mats.		during a two-year inclusive drama production.
Fitzgerald et al. (2003) England	Special school	N: 8 Age: 14-18 years Gender: n/a	Severe Learning Difficulties (not formally diagnosed).	Not fully specified. Sign language-Makaton (n = 3)	Task-based approach. The researcher identified the preferred communication methods of the children and shaped the activities and tasks accordingly, utilising multiple methods and approaches to elicit the students' views.	Through their preferred communication method: symbol and photo exchange, Makaton sign language, gestures and use of objects. Young people also produced a poster which they were able to display in the school to illustrate their work during the project.	To gain an insight into the P.E and free-time experiences of students with severe learning disabilities.

2.4.4 Representation of voice

All 14 articles are discussed in the following sections, corresponding to Lundy's (2007) model of Space, Voice, Audience, and Influence, to explore how children's voices were represented within the reviewed studies.

2.4.4.1 Space: Has the child or young person been invited and encouraged to express their views?

In the context of this research, *space* means considering whether and how CYP were asked if they wished to participate through inclusive and accessible assent/consent procedures and how ongoing assent to participate was considered throughout research projects. In addition, *space* considers whether CYP's views were safely sought i.e., that there was no fear of reprisal; CYP were comfortable with the adults seeking to ascertain the CYP's voices; and were familiar with, and attuned to, their needs. Twelve studies that included participants under the age of 16 reported that informed consent had been gained from the child's parents and from relevant adults within the participating setting. Many studies also reported accessible assent/consent procedures, which were created specifically for the children to understand and contemplate their involvement within the research. In three studies the authors described approaches using a variety of visual tools and support. Bradley and Male (2017) created an accessible consent and information sheet using 'Communicate in Print', which is a programme for creating symbol-based resources familiar to the children included in the research. Similarly, Loyd (2013) sought consent from the children through "dedicated approaches devised specifically for the research" (p. 10) and finally, Whitehurst (2007) collaborated with the school's Speech and Language Therapist (SaLT) to develop individualised assent procedures, which were adapted to each child's communication skills using a total communication approach. Three further studies described how they sought assent from children using Social Stories (Gray, 2010) to help support the child's understanding of what inclusion within the study would involve (Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021). Although Ajodhia-Andrews and Berman (2009) reported that they gained child consent, no

information was provided about how this was adapted and individualised to the child's complex needs.

Many researchers described the challenges of gaining meaningful assent from children who do not have the expressive language skills to assent to their participation. Indeed, many ethical considerations were raised relating to this issue. However, where assent was not possible, many authors described the importance of a familiar, attuned adult (e.g., class teacher, teaching assistant, parent) who was responsible for monitoring the child during the time of their involvement for any indications that they no longer wished to participate (Parsons, Iivil et al., 2020; Gray & Winter, 2011; Hill et al., 2016; Richards & Crane, 2020; Simmons & Watson, 2015). Many studies also reported additional measures that were put in place to support children to communicate their wish to withdrawal or end their involvement within the study. Within three studies, the provision of a red 'stop' symbol was made available so children had the opportunity to non-verbally communicate their wish to end their participation and actively dissent (Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021).

For studies that included young people over the age of 16, gaining informed consent was reported as more challenging. Hart (2021) described how consent was creatively sought and adapted to the communication preferences of the young adults. However, Hill et al. (2016) excluded young people over age of 16 from the research process, who were deemed as not having 'the capacity to consent for themselves' using 'standard procedures' (Hill et al., 2016, p. 28). Despite efforts made to adapt assent forms for children under 16 included in the same study, no adaptations to consent processes were made for young people over 16 years, nor any Mental Capacity Assessment (MCA) or best interest decisions made for their voices to be included. The authors recognised this as a limitation and suggested future researchers should ensure a "careful process of securing permission" is outlined within ethics applications, so this does not present as a barrier to accessing the voices of this group (Hill et al., 2016, p. 29).

In two studies it was not clear how children were made aware of their choice to participate and the reasons why their views were being sought. Fitzgerald et al. (2003) did not provide a description of consent/assent procedures within the study and although Bloom et al. (2020b)

Chapter 2

described how parental consent was gained, the authors did not provide details on child consent/assent procedures.

To ensure that CYP felt safe and comfortable with the adults who were seeking to ascertain their views, eight of the fourteen studies described methods to ensure threat was reduced and CYP's views safely sought. CYP were supported to feel safe and comfortable through the availability and presence of familiar adults who already had an established rapport with them (Bradley & Male, 2017; Richards & Crane, 2020; Whitehurst, 2007). Where the authors were unfamiliar to the CYP, specific rapport building activities were carried out to support the child to feel comfortable in the presence of the researcher. Parsons, Ivil et al. (2020) and Simmons and Watson (2015) described that an in-situ researcher spent time in the settings building rapport with the child; Rouvali and Riga (2021) carried out daily intensive interaction sessions with the child for one week prior to data collection; Lloyd (2013) carried out observations of the CYP; and Ajodhia-Andrews & Berman (2009) stated that 30 minutes of playing and reading together prior to carrying out the adapted interview with the child helped establish rapport. In the remaining studies, it was not clear what measures, if any, were put in place to establish rapport and familiarity between the CYP and the researcher(s).

2.4.4.2 Voice: Has the child or young person been given the opportunity to ‘freely’ express their views and where appropriate, facilitated to form their views?

This second element within Lundy's model, *voice*, explores the opportunities children are given to express their views. Understandably, and as acknowledged by Lundy (2007), children with complex needs may need support or “practical assistance” (p. 936) to form their views and for their voice to be expressed using any “media of the child's choice” (p. 935). Therefore, *how* children have been enabled to express their views will be considered next.

2.4.4.2.1 Methods developed to elicit voice

All the included studies focused on eliciting the voices of CYP with complex needs on their experiences within education settings developed and/or used a novel and/or creative methodologies to do so. The range of data collection methods used to elicit the voices of children with complex needs are briefly described in Table 2.3. To elicit CYP's voices, five studies specifically developed

an inclusive methodology (Bloom et al., 2020b; Hill et al., 2016; Parsons, Ivil et al., 2020; Richards & Crane, 2020; Simmons & Watson, 2015), six studies combined elements from existing methods to create a novel methodology to be used inclusively with CYP with complex needs (Ajodhia-Andrews & Berman, 2009; Bradley & Male, 2017; Gray & Winter, 2011; Loyd, 2013; Rouvali & Riga, 2021; Whitehurst, 2007), two studies adapted traditional data collection methods, i.e., interviews and observation (Hart, 2021; O’Leary & Moloney, 2020), and one study identified the child’s preferred communication method and used a total communication approach to elicit their views (Fitzgerald et al., 2003).

The views of participants across all the studies were predominantly accessed through creative, usually visual, methods. Photographs were used in ten of the studies in a variety of ways: to indicate preferences on a visual scale (Bloom et al., 2020b; Hill et al., 2016), within a structured ‘Talking Mat’ activity (Ajodhia-Andrews & Berman, 2009; Loyd, 2013; Whitehurst, 2007), to capture experiences (Gray & Winter, 2011; Hart, 2021; Rouvali & Riga, 2021), to supplement parental narratives (O’Leary & Moloney, 2020), and for children to use directly to capture their own experiences (Richards & Crane, 2020). Within these studies, observational methods, or adapted interviews were frequently used alongside creative methods to make meaning and to assist with interpreting CYP’s views. Four studies used videos to capture children’s experiences, interactions, and preferences. Two of these studies used video footage to create movies, which were used as a stimulus within adapted interviews (Bradley & Male, 2017; Whitehurst, 2007). Parsons, Ivil et al. (2020) co-created ‘I am...’ Digital Stories with practitioners and families to represent preschool aged children’s perspectives and unique insights. Similarly, Simmons and Watson (2015) used a participatory approach by co-constructing vignettes with familiar adults following participatory and non-participatory observations of the child over time.

2.4.4.2.2 How were children and young people facilitated to form their views?

Eleven studies sought the involvement of familiar adults to facilitate children to form their views, though these approaches varied considerably. Rouvali and Riga (2021) stated that parents and the child’s class teacher helped triangulate responses to assist with interpretation of the child’s views. A questionnaire was given to the parents and the class teacher, and the answers were compared against the child’s responses. Although the authors stated this member checking

Chapter 2

procedure was “not a mean to overpower” the child’s voice (p. 471), it is not clear whose voice was given more weight, should the responses from the adults not have aligned with those of the child. Two studies also collaborated with parents and school staff to co-construct children’s views. Familiar adults within these studies provided a lens through which to understand and interpret the children’s responses (O’Leary & Moloney, 2020; Simmons & Watson, 2015). Three studies were conducted by at least one researcher who worked within the participating education setting. This was reported as beneficial to supporting the elicitation of children’s views due to the researchers being familiar with the child’s communication style and the having an established relationship with them, thus contributing to them being able to safely express their views (Bradley & Male, 2017; Parsons, Iivil et al., 2020; Rouvali & Riga, 2021). SaLTs who were familiar with the children, were also identified as key adults who were consulted to support with the development of methods to enable children to express their views (Loyd, 2013; Whitehurst, 2007). This was also reported to increase understanding about how each pupil communicated i.e., through identification of their preferred communication method and to individualise and personalise the methods specific to each child (Loyd, 2013). Parsons, Iivil, et al. (2020) collaborated with parents and nursery staff to ensure that the children’s experiences were accurately represented in their Digital Stories and therefore played a central role in their construction. Hill et al. (2016) developed a Young Researcher’s group who, amongst other tasks, were responsible for providing feedback on accessibility and appropriateness of the methods developed to elicit the CYP’s views. Finally, Hart (2021) involved young people as research partners. This enabled them to be agentic in their involvement in the research and were directly involved in the co-creation of inclusive interviews.

2.4.4.2.3 How are children and young people’s views represented?

An important consideration when exploring how children’s voices have been enabled, is to explore *how* and *to what extent* the child’s views, preferences and experiences have been represented in the methods used. Researchers who used more directive, adult-led activities, such as symbol or photo-based communication (e.g., Talking Mats, symbol or photo sorting tasks, cue cards) expressed limitations with these methods. For example, many studies (e.g., Hill et al., 2016; Richards & Crane, 2020; Rouvali & Riga, 2021) suggested that the child’s voice was limited by the number of symbols that were available to them within the activity, whether the symbols used were

familiar and meaningful to the young person and to what extent they responded to them with “representational intent” (Hill et al., 2016, p. 35). Similarly, Richards and Crane (2020) reported that support staff found it difficult to ascertain whether the children were demonstrating communicative intent when using the ‘Multimodal Talking Wall’ and, therefore, questioned the authenticity of CYP’s voices represented. Richards and Crane highlighted the importance of triangulation and the use of multiple methods.

Photography was used as method within ten studies. Four of these enabled children to be agentic by supporting the child to take the photographs themselves (e.g., Gray & Winter, 2011; Hart, 2021; Rouvali & Riga, 2021). Young adults in Hart’s (2021) study co-created a ‘participatory photographic interview’, which involved the young people taking photographs as a methodological tool. This was found to be the most inclusive and “influential in the agentic production of knowledge without the need for verbal communication” (Hart, 2021, p. 11). However, it was reported that this method included a ‘discussion’ during and after the photographs were taken, and therefore it is unclear to what extent this method relied on discussion to make meaning. Very few methods were identified in this review as requiring minimal interpretation from adults. Although Parsons, Ivil et al. (2020) described and acknowledged the centrality of adults in the co-creation of Digital Stories, the authors suggested the Digital Stories themselves required little interpretation from adults to understand the experiences of young children. Within this methodology children were positioned as “knowers in their lives” (p. 5) and, therefore, the Digital Stories provided a lens into the child’s world, independent of adult influence or direction. Digital Stories captured children’s experiences and interactions in ways that did not rely on expressive communication skills, rather, children’s experiences from their point of view were accessed and jointly witnessed via video clips.

2.4.4.3 Audience and Influence: Has the child or young person’s views been listened to and has the child or young person’s views been acted upon, as appropriate?

The third and fourth elements within Lundy’s model are *audience* and *influence*, and these were combined due to the degree of overlap (Lundy, 2007). This means considering how CYP’s views are listened to, not just heard by those involved in decision-making, and whether children’s

Chapter 2

views have been given due weight. These elements are also concerned with whether children's views have been taken seriously and whether they influenced change.

Very few studies reported whether the CYP's views influenced change within the education setting. Only three studies described, albeit in varying detail, how children's views had been acted upon and led to changes. The most robust description was reported by Parsons, Ivil, et al. (2020), who described how the Digital Stories were shown and jointly witnessed by families, nursery staff and, crucially, the primary school to which the child was transitioning to, to provide a strengths-based, person-centred account of the child. Watching the Digital Story enabled the receiving school to plan activities and adapt the environment to ensure that the children were included and transitioned successfully. Rouvali and Riga (2021) used multiple methods to elicit the wishes, preferences, and experiences of their child, which shaped the development of their new Individual Learning Plans (ILP). Encouragingly, the researchers reported a "significant decrease" in the child's behaviour following the implementation of the new ILP (p. 475). However, it was not reported how this reduction in behaviour was measured, how significance was determined, or who had reported this. Gray and Winter (2011) made changes within the classroom environment in response to the children's views (e.g., removed smelly bins) and provided the children with opportunities to share their views within their pre-school graduation, by presenting their photographs, drawings, and collages of their school preferences. Nevertheless, it is unclear whether the children's preferences reflected the voices of children with complex needs since children with and without a known disability were matched into pairs to collaborate and form a shared view. The researchers reported that "not every dyad was a success" (p. 319), especially where children in dyads had different communication skills. Therefore, it is unclear how much influence the non-disabled peer had over the construction of those views (Gray & Winter, 2011).

The remaining studies did not provide details on how the CYP's views were acted upon, if at all. Some studies reported that more time was needed to embed the method within the school, acknowledging that the method developed was in its infancy (e.g., Richards & Crane, 2020). Bradley and Male (2017) described that on completion of the study, all children were sent a personalised letter stating that their voices had been heard and views valued. However, within the research it was not stated how these views were acted upon. Similarly, Loyd (2013) shared that the

views of the young person would guide future lesson planning, but it was not stated whether this happened and if the young person's views affected change within drama lessons. Finally, within Hart's (2021) study, it was not explicitly stated whether the views of the young adults influenced decision-making within their transition planning to adulthood.

2.5 Discussion

This systematic literature review aimed to identify the current research on the development and use of methods which have been designed to elicit the voices of children and young people with complex needs about their educational experiences and preferences. Additionally, and unique to this review, identified methods were considered in relation to Lundy's (2007) model of Space, Voice, Audience and Influence. In alignment with Fayette and Bond (2017), this review highlights that research exploring the development and use of methods remains in its infancy, with only fourteen studies meeting the inclusion criteria. Therefore, while this review identified creative methods that have been used to elicit the voices of CYP with complex needs, far more needs to be done to enable the voices of this frequently marginalised group to be meaningfully heard within research and practice.

Many researchers suggested that their method/s were "promising" and "worthy of further development" (Richards & Crane, 2020, p. 4276) or had "considerable potential for providing greater insight" (Hill et al., 2016, p. 30). These statements reinforce that research remains at the very early stages of developing inclusive methodologies for CYP with complex needs. Moreover, efforts to elicit children's views should not stop with the researcher developing the method/the research, and more needs to be done to embed these methods in practice where they have the potential to make a meaningful impact on children's lives. Indeed, as argued by Prout (2003) "...too often children are expected to fit into adult ways of participating when what is needed is institutional and organisational change that encourages and facilitates children's voices" (p. 32).

A more holistic conceptualisation of voice needs to be embraced in research, policy and within practice to enable children's inclusion with educational decision-making on matters which affect their lives. Voice needs to be understood and valued as more than spoken words to incorporate the many ways in which *all* children communicate and express themselves. The lack of

Chapter 2

inclusive methods developed in research, and successfully embedded in practice, further marginalises children's voices and perpetuates the dominant deficit-based narrative about them i.e., that it is not possible to elicit the views of CYP with the most complex needs (Lundy, 2007). This view needs to be continually challenged and voice must be conceptualised more holistically, as encompassing the many ways in which children and young people can express their views. A child's right to express a view must not be contingent on their perceived capacity or skills to express one, not least is having this right, at least in England, embedded in the SEND Code of Practice (DfE/DoH, 2015).

This further highlights the importance of creating “non-orthodox” methods (Parsons, Kovshoff et al., 2020, p. 11; Pascal & Bertram, 2012), which do not rely on verbal communication/discussion to make meaning. Although the use of symbols can helpfully be used to make choices and state preferences, in some studies it was suggested that CYP responded to these visuals (e.g., cue cards, symbols) without representational intent (Hill et al., 2016; Richards & Crane, 2020). It is well documented that visual systems such as Talking Mats can provide an understanding on preferences i.e., what the child ‘likes’ and ‘does not like’. However, there is a concern whether the child's voice is limited by the symbols that they have available to them or the number which hold representational value. This suggests the value of symbol or photo-based communication when used *alongside* other methods to elicit the views of CYP. Indeed, no studies included used symbols in isolation, and symbols were combined with other communication strategies to make meaning. For CYP who may express minimal spoken language, it is especially important to consider a range of methods, including more embodied approaches, that do not require verbal discussion (Parsons, Ivil et al., 2020; Simmons & Watson, 2015) and for children's views to be explored “flexibly, collaboratively and variously” (Lewis & Porter, 2007, p. 229).

Researchers have a commitment to developing and evaluating the impact of the methods they develop and use in research but, crucially, these methods need to be accessible and replicable so that they can be applied in education settings and embedded in practice. Ultimately, this impacts the extent to which children's voices are not only heard, but actively listened to, acted upon, and taken seriously. Indeed, another key finding was that most studies failed to demonstrate how CYP's views were given due weight. Several studies reported that understanding children's perspectives,

experiences and views had led to changes in practice, but failed to describe how the child's views had been acted upon and, specifically, the impact children's voices had on educational decision-making processes. Concerningly, even when this was addressed as a specific aim or research question within the study, there was no discussion within the findings about how the child's views were taken seriously and acted upon (Fitzgerald, 2003; Richards & Crane, 2020). There seems very little value in developing methods to enable CYP's voices unless those voices are "seen to be integral and embedded within decision-making" (Lundy, 2007, p. 939).

A strength identified within many of the studies was the importance of including familiar adults within the research who have an established relationship and, therefore, an in-depth understanding of the child to enable methods to be personalised and individualised to the child's unique strengths and needs. Three studies highlighted the value of co-constructed methods to elicit voice, and how co-construction with key personnel who know the child well can support these methodologies being used within practice (e.g., Hart, 2021; Parsons, Ivil, 2020; Simmons & Watson, 2015). Crucially, such co-construction of knowledge should include the CYP (e.g., Parsons, Ivil et al., 2020) but Fayette and Bond (2017) found that many studies failed to engage children within research, therefore impacting how person-centred and individualised the methods developed were. As highlighted within this review, concerns continue to exist in the literature about research being carried out *on* people rather than '*with*' people (Morris, 2003; Parsons, Ivil et al., 2020). This further highlights the need for participatory approaches that not only include adults, but also the CYP themselves.

Future research could also consider using Lundy's (2007) model as a framework when developing and evaluating methods to elicit the voices of CYP with complex needs to ensure that Article 12 is successfully implemented. This would ensure that children's views, perspectives, and experiences are authentically represented by considering all four elements of *Space, Voice, Audience and Influence* and, crucially, ensuring that CYP's views are not only heard, but actively listened to and taken seriously. Using Lundy's model in this way will ensure that children's rights are met in accordance with the UNCRC (Article 12).

Researchers also need to ensure inclusivity is embedded within their methodology, at the earliest stages of research design, by developing accessible consent/assent procedures. Many

Chapter 2

researchers included within this review described the challenges of gaining consent/assent from children with learning and communication difficulties. Indeed, in one study young people over the age of 16 who were considered as lacking capacity to consent to participate in the research were excluded (Hill et al., 2016). These difficulties are commonly reported in the literature with some authors suggesting that “obtaining informed consent may be a considerable undertaking and daunting to achieve” (Lewis, 2002, p. 111). However, boundaries must be pushed and as identified in this review, flexible individualised and multimodal (predominantly visual) approaches must be developed to obtain meaningful consent/assent (e.g., Loyd et al., 2012). Additionally, for children under 16, where this is not possible, their continued assent to participation must be monitored on an ongoing basis via familiar staff. Therefore, a key implication of these findings is the importance of researchers developing accessible assent and consent procedures to enable *all* children and young people to participate, and for their voices to be included within research which aims to include voices of children who are frequently marginalised.

2.5.1 Strengths and limitations of the review

To my knowledge, this is the first systematic literature review that has explored this very under researched area. Thus, findings address a significant gap by identifying methods developed and used to enable CYP with complex needs to have a voice in decisions relating to their education. Lundy’s (2007) model was also uniquely applied as a practical framework, which provided the foundation for analysis of the data derived from the extant research literature. Crucially, findings from this review challenge the dominating view that the voices of CYP with complex needs cannot be captured. An additional strength of this review is the wide range of databases searched which reflected the range of professionals and professions who are involved in eliciting CYP’s views within education. Specific pre-defined inclusion and exclusion criteria may, however, have resulted in some relevant studies being missed or excluded due to this. For example, identified studies within the search were excluded on the basis that they were not conducted within education settings (e.g., Carroll & Sixsmith, 2016; Stafford, 2017). It may be helpful that future research explores inclusive methods which have been developed and used within different fields (e.g., health, community, and social care settings) to identify a broader range of methods. In addition, grey

literature was not searched and inclusion of doctoral or master's theses may have resulted in a broader range of methods identified.

Fourteen studies were included in this review and were each qualitatively assessed using the CASP (2018) to explore the methodological strengths and limitations for each study. A key finding from exploring study quality was the absence of transparency within data analysis, with ten of the fourteen studies either failing to analyse their data e.g., by presenting themes in their findings without providing detail about how these themes were generated or providing insufficient information about how their data was analysed, thus limiting transparency. In addition, the guiding qualitative paradigm in several studies was either not described or was with poor clarity and conceptual confusion. The theoretical or epistemological underpinnings or assumptions of the researchers which guide their research must be made explicit within qualitative research and is integral to understanding how their methodology and methods are understood. Therefore, it is important that future research is conducted in a way that is theoretically and methodologically coherent and researchers are clear about *how* they are analysing their data.

2.6 Conclusion and implications for professionals

The findings of this review emphasise how it is possible to access the views of CYP with the most complex needs. However, it requires researchers to push boundaries by developing inclusive methods which are novel, creative and individualised to each young person. Indeed, there are challenges and barriers to overcome when developing such methods and approaches for CYP with complex needs. However, with 168 countries having ratified the UNCRC (1989), there is a legal and moral obligation to ensure CYP's voices are heard, listened to, acted upon and given due weight. All forms of communication need to be valued and recognised for barriers to participation and expression to be removed. The findings also highlight that more needs to be done to ensure that CYP's views are acted upon and given due weight. The findings provide indications about how this can be achieved through adopting participatory approaches that include not only adults, but also the CYP themselves. Ensuring that methods to elicit voice are co-constructed with adults who know the child well and include the CYP is therefore vital. This would enable methods to be embedded in practice through closing the research-practice gap. Therefore, the most important implication from

Chapter 2

this review is that inclusive, person-centred methods continue to be developed to enable children who are frequently marginalised and excluded to have a voice within decisions impacting their education, but also, crucially, that their views are taken seriously and influence change.

Chapter 3 Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood

3.1 Abstract

The voice of autistic young people is rarely heard and listened to within transition planning and is frequently excluded from decision-making. The aim of this research, based at a residential special school in England, was to extend and evaluate the use of Digital Stories as a methodology to enable their voices to be heard in their transition to adulthood. Three Digital Stories were co-created with the young adults, their families and the school. Reflexive thematic analysis of data from semi-structured interviews with key stakeholders resulted in the development of five main themes: benefits of Digital Stories; humanising approach; ownerships and agency; ethical considerations; and direct impact on practice. Findings and implications for education, health and care professionals are discussed.

Keywords: autism, young people, participatory, co-construction, voice, transition

3.2 Introduction

The importance of eliciting the voices² of children and young people (CYP) and their participation within decision-making on matters that affect their lives is a prominent theme in research, policy and educational practice. This is robustly supported and justified within the Children Act (1975, 1989), the Children and Families Act (2014) and the associated Special Educational Needs and Disability Code of Practice: 0-25 years (SEND CoP; DfE/DoH, 2015). Specifically, the SEND CoP (2015) mandates that Local Authorities in England must ensure children and young people (up to the age of 25) and their parents are involved in “discussions and decisions about their individual support and about local provision” (p. 20). This is informed by the United Nations Convention of the Rights of the Child (UNCRC, 1989), which emphasises that CYP should not only have the right to be involved in decisions made about their lives, but for their

² The conceptualisation of ‘voice’ extends to people who communicate in ways other than speech and therefore, within the context of this research includes both verbal and non-verbal forms of communication and expression.

Chapter 3

views to be heard, listened to, and given due weight (Article 12, United Nations, 1989). Article 13 further emphasises the importance of developing effective methods to enable CYP's participation and engagement:

The child shall have the right to freedom of expression: this right shall include the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice. (p. 5)

Despite these requirements, research suggests that autistic³ CYP are particularly vulnerable to exclusion from educational decision-making and consultations about matters that affect them and are underrepresented within the evidence base. This marginalisation is largely due to perceptions of the child's competence to form and express their views due to their differences with social communication and social interaction associated with their autism diagnosis (Cascio et al., 2021, Courchesne et al., 2021; Fayette & Bond, 2017; Pellicano, Hill et al., 2014 & Pellicano, Dinsmore et al., 2014). Autistic individuals from marginalised subgroups, such as those with a high level of support needs and those who do not use speech for communication, are at a greater risk of exclusion (Cascio et al., 2021). Concerningly, research has identified autistic young people residing in residential schools who have complex learning needs as a group who are frequently underrepresented both within research and educational decision-making (Pellicano, Hill, et al., 2014). Autistic young people with the greatest support needs are consequently denied the rights to have their needs, wishes and preferences both heard and listened to. Specifically, they are denied a right to be "knowers in their own lives" (Parsons, Iivil et al., 2020; p. 3) and, therefore, their voices are missing within decisions that shape their lives.

Autistic CYP are frequently characterised according to their difficulties and challenges, rather than their strengths, abilities, and positive experiences, leading to descriptions which seek to pathologise and focus on their 'impairments' and 'deficits' (Parsons, Iivil et al., 2020; Wood-Downie et al., 2021; Woods, 2017). With this focus, it is unsurprising that many practitioners and

³ Throughout this paper the terms 'autistic person' or 'on the autism spectrum' will be used. Identity first language is used rather than person first language e.g., 'person with autism' to reflect the preferences of autistic people and their families within the UK (see Kenny et al., 2016) and avoids stigma associated with disabilities and the use of ableist language (Bottema-Beutel et al., 2020; Gernsbacher, 2017).

researchers may think that these CYP are “hard to reach” when considering their participation in decision-making, due to the children’s “complex needs” (Franklin & Sloper, 2009, p. 4). Indeed, while many authors argue for the inclusion of autistic voices within research, studies also often exclude children based on their lack of verbal ability (e.g., Cheak-Zamora et al., 2018; Coussens et al., 2020, Graham et al., 2019, Yessick et al., 2020), “intellectual impairments” (Zazzi & Faragher, 2018, p. 212) or develop methods which are not suitable for “those with the most significant cognitive barriers” (Bloom et al., 2020b, p. 202). This further perpetuates the view that “the child is to blame for their own failure to communicate” (Parsons, Ivil et al., 2020, p. 3). Therefore, as emphasised by Morris (2003), “unless there is a specific focus on including children and young people with significant communication and/or cognitive impairments, they will inevitably be excluded” (p. 344). All forms of communication need to be valued and recognised for barriers to participation to be removed. As Ellis (2017) suggests, within research there needs to be a shift away from a reliance on “traditional research methods” (p. 28) which privilege the spoken word, (e.g., interview and focus groups) towards the use of creative and visual methods to access young people’s views and perspectives. In addition, it is crucial that descriptions focus on young people’s capabilities and strengths to reframe the prevailing deficit-based narratives about autistic children (Parsons, Ivil et al., 2020 & Wood-Downie et al., 2021).

One such area in which the voices of autistic CYP may be missing is within their educational transitions. Transitions are often difficult and anxiety-provoking for all children and young people; it is a time that involves many changes to routine, uncertainty, and readjustment. These features can make the experience especially challenging for autistic CYP (Neal & Frederickson, 2016; Stoner et al., 2007) and those with complex needs who have resided in long-term residential care (Smart, 2004). Anderson et al. (2018) carried out a scoping review exploring the challenges with, and strategies to support, autistic young people transitioning to adulthood. Out of the 17 studies identified within the review, none included the transition to specialist settings or provisions for autistic young people with complex needs, highlighting that little is known about the transition experiences of this group, or how to best support young people during this crucial transition to adulthood. This is concerning since the extant literature suggests that outcomes for autistic young people with complex needs are poor (Beresford et al., 2013; Wehman et al., 2014; Wittemeyer et

Chapter 3

al., 2011) with many young people experiencing placement breakdowns following their transition to adult services (Smart, 2004).

Therefore, it is crucial that research explores ways to include young people's voices and to identify practices that enable young people to have successful transition experiences. Despite the SEND CoP (2015) stating that the views of parents must not be used as a proxy for young people's views, CYP's views are found to be "less central" within decision-making processes (Morris & Atkinson, 2018, p.133). Smart (2004) found that although parents felt they were included in the transition planning process, the young people themselves were "marginalised in the planning process, with very few being involved in any decision-making" (Smart, 2004; p. 128). Almost 20 years on from Smart's (2004) research and the voices of young people continue to be missing during this crucial transition to adulthood (Crane et al., 2021; Gaona et al., 2019). This is within a context where, despite advances in policy and legislation (e.g., SEND Code of Practice, 2015), there continues to be a significant gap between policy and practice. In one of the few studies on this topic, Fayette and Bond (2018) investigated two specialist schools' processes, which enabled the voices of autistic young people to be elicited within their transition to adulthood and identified the importance of a whole school, person-centred ethos and commitment from all staff to elicit young people's views. This was achieved by schools investing time to (1) develop a holistic understanding of each pupil; (2) supporting pupils to make informed choices; and (3) using a variety of communication methods individualised to the pupils' needs. Although the schools used a variety of creative and visual methods to access autistic pupils' views, including Talking Mats, symbols, Picture Exchange Communication System (PECS), and switches, the degree to which the views elicited were given 'due weight' was questioned by the authors, specifically whether the pupils' views shaped the planning in their transition to adulthood. It is therefore crucial that future research explores not only the development of inclusive methods which enable autistic young people's voice to be accessed and heard, but also for their views to have a direct impact on the decision-making process i.e., to be listened to and acted upon (Lundy, 2007).

Encouragingly, there has been a renewed emphasis on improving outcomes for autistic young people transitioning to adulthood through the new National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 (DfE/DHSC, 2021). Within the National Strategy,

improving the support autistic young people receive in their transition into adulthood in England is stated as a priority area. Alongside existing policy and legislation, this strategy serves as a catalyst to improve outcomes for young people transitioning to adulthood and emphasises the importance of young people's active involvement within their transition planning. Although there are some promising developments in research on developing inclusive methods to enable voice and participation for non- or minimally speaking autistic young people, there continues to be an overreliance on spoken language to make meaning of experiences (Parsons, Iivil et al., 2020). To empower the voices and perspectives of autistic young people, methods need to be created that are individualised to each young person, facilitate agency, and provide a holistic, strengths-based account without reliance on spoken words. Within Hart's (2020) work, she states the importance of enabling the agency of young people to participate within research. This participation led to co-creation of interviews adapted to the individual young people and, therefore, enabled a richer understanding of their experiences such that "more inclusive knowledge [was] gained" (p. 12). A combination of ethnography, "being with" (Morris, 2003; p. 345) the young people, as well as involving them in the research through co-creation of inclusive interview methods, allowed their perspectives to not only be accessed but "centralised amongst many of the people and processes that often distance them" (Hart, 2021, p. 11).

Given the lack of research in this area, it is therefore crucial that autistic young people are included in their transition planning to adulthood. Researchers can contribute to this area through adopting participatory approaches in which novel and creative methods can be co-created with young people and evaluated, to ensure the experiences and perspectives of autistic young people are not only valued but embedded within decision-making practices (Lundy, 2007). One such approach is the Digital Story methodology which was developed from the ideas of Joe Lambert to enable and empower the voices of frequently marginalised groups through not relying on formalised, written or spoken words to share experiences and meaning (Lambert, 2010). The 'I am...' Digital Story methodology was developed in a nursery setting to access the voices, experiences, and preferences of young autistic children as they made their nursery to primary school transition (see Parsons, Iivil et al., 2020 & Wood-Downie et al., 2021). The 'I am...' Digital Stories are "short videos designed to provide a holistic, strengths-based representation of the

Chapter 3

child through enabling them to contribute their perspectives to transition planning” (Wood-Downie et al., 2021, p. 62). The Digital Stories include footage that is targeted at capturing CYP’s interactions and engagement within their environment and participation in normal, routine activities. Research also suggests the benefits of using technology (e.g., video cameras) with autistic young people due to the perceived high motivational value for them (Porayska-Pomsta et al., 2012). The Digital Stories approach is not reliant on a young person’s verbal ability and is, therefore, an inclusive method of capturing a young person’s voice and experiences in a way that is accessible to them. Without the reliance on verbal discussion to make meaning, Digital Stories provide a lens into CYP’s perspectives though visually exploring their experiences, preferences, and interactions. Digital Stories promote CYP’s voices and provide a more holistic representation of autistic children (Parsons, Ivil et al., 2020). They are co-created by adults who know the young people best and, therefore, key adults play a central role in constructing the Stories to ensure the CYP are appropriately and authentically represented.

This thesis project aimed to adapt and extend the ‘I am...’ Digital Story framework (see Parsons, Ivil et al., 2020; Wood-Downie et al., 2021) for older young people transitioning from residential special school to adulthood. This project also aimed to identify how the original ‘I am...’ framework can be adapted and applied to older autistic young people, and the relevance of this framework to this population in supporting transition to adulthood. In addition, this project evaluated the views from key stakeholders of their experiences of the Digital Stories, both the co-construction of the Story and its use within the young person’s transition. Specifically, this project addressed the following research questions:

1. How can young people on the autism spectrum attending a residential special school be supported to express themselves through coproduction of digital stories?
2. What are the views and experiences from key stakeholders of the digital stories as a methodology to inform decisions made about young people’s transition?
3. In what ways can the ‘I am...’ digital story framework be applied and revised for older young people on the autistic spectrum with limited verbal communication?

3.3 Methodology

3.3.1 Context for the research

Hill House school is a residential school that provides specialist provision for 31 autistic young people, aged 11 to 19 years old, with learning disabilities and complex needs. Some young people have co-occurring conditions, such as epilepsy, cerebral palsy and chromosomal disorders. The school is located in the south of England and has care, education and therapeutic teams on site. All of the autistic young people have a communication difficulty and use alternative and augmentative communication and over half of the young people are non-verbal.

Hill House school is a member of the Autism Community Research Network @Southampton (ACoRNS), which is an education focused research to practice partnership that aims to build the evidence-base through the co-construction of research by working in partnership with local education settings to identify research questions and address them together. ACoRNS has a core aim of improving the lives of autistic children and young people by placing their views and experiences at the centre of research and practice (Parsons & Kovshoff, 2019), with a key focus on their trajectories and transitions. Since autistic young people's voices are frequently not heard or understood within decision-making (Pellicano, Hill et al., 2014), working in collaboration with the school provided an opportunity to develop effective practices for supporting autistic young people who are frequently marginalised within their transition to adult services.

3.3.2 Research Design

To answer research question one and two, this project aimed to extend and evaluate the use of Digital Stories as a methodology to facilitate knowledge co-construction of young people's transition trajectories to adulthood. The project took a participatory approach, emphasising the importance of the research process being carried out *with* rather than *on* participants (Morris, 2003; Cahill, 2007). Due to perceived methodological challenges, the voices of autistic children, especially those with intellectual disabilities and non-verbal children, are not "easily integrated" and are rarely captured within participatory research (Fletcher-Watson et al., 2018, p. 950). The project aimed to overcome this challenge through establishing a research-practice partnership (see

Chapter 3

Parsons, Kovshoff et al., 2021) between me, the researcher, and Hill House School⁴, who facilitated the co-construction and implementation of the Digital Story methodology within the setting involving the young people and the staff who supported them. In line with this collaborative approach, a qualitative study research design was used to explore and understand the multiple perspectives and experiences of participants through applying the Digital Story methodology and whether / how this approach impacted on practice. In addition, this project also aimed to apply and revise the 'I am...' Digital Story framework, this took the form of adapting and extending the framework following collated information which was gathered within the initial mapping stage.

3.3.3 Recruitment

Hill House School currently works in partnership with ACoRNS and therefore key staff from the school had previously established links with the supervisors of this project. This provided early opportunities to discuss the feasibility of the project and identification of young people whose participation within the project would be in their best interest. Regular contact was maintained throughout the project through virtual discussions over Microsoft Teams.

Each young person (aged 18 or over) was recruited through the school using a purposeful sampling method. The school's decision was based on an understanding of the young person's anticipated date for transition beyond the school, coupled with their knowledge of the young person and their family. Prior to gaining formal consent, families were offered the opportunity to discuss details of the project with school staff and were invited to contribute within the co-creation of the Digital Stories, recognising their central role within their child's transition to adulthood.

3.3.4 Participants

The project was focused on three autistic young people, Emily, Adi and Caden⁵, who moved from Hill House School to an adult social care setting during the Covid-19 pandemic in May 2020, August 2020 and July 2021, respectively. Table 3.1 shows their demographic information. The

⁴ Permission has been given to refer to the name of the school and in doing so, acknowledge their valuable contribution and participation within this research.

⁵ The real first names of Emily and Caden have been used throughout the paper and in their Digital Stories with the consent of parents. Where parental consent has not been obtained in the case of 'Adi' a pseudonym has been used.

young people had a formal diagnosis as being on the autism spectrum and had complex communication needs.

Table 3.1 *Young person demographics and nature of their transition*

	Young person demographics				Context of transition	
	Gender	Age (years)	Diagnosis	Communication skills	Transition date	Destination provision
Emily	Female	19	Autism	Limited verbal communication, uses PECS and symbols	May 2020	Residential setting for autistic adults with complex needs
Adi	Male	19	Autism and Hearing Impairment	Non-verbal, uses Makaton and symbols	August 2020	Residential setting for autistic adults with complex needs
Caden	Male	18	Autism	Limited verbal communication, uses PECS, Makaton and symbols	July 2021	Residential setting for adults with learning difficulties

A range of professionals, including parents and school staff, are involved in ensuring a successful transition is achieved for and with each young person. Therefore, it was critical that key stakeholders' views were captured to understand their perspectives and experiences on applying the Digital Story methodology and its use and impact within each young person's transition. In total, 17 participants took part in virtual semi-structured interviews and comprised of staff from Hill House School (e.g., care and education staff), external professionals (e.g., SaLTs, Social Workers) and parents, this ensured a range of perspectives were sought. All participants had either been involved in the Digital Story co-creation, the young person's transition or been shown the Digital Story as a part of the transition planning process. Table 3.2 shows participant information, including how the participant links to each young person.

Table 3.2 *Participant information illustrating who was interviewed specifically around each young person*

Young person	Participant	Gender	Participant			Involvement within Digital Story co-creation			Context of watching Digital Story	
			Hill House staff	Parent	External professional	Planning	Filming	Editing	Within transition meeting	Outside transition meeting
Emily	Care manager	F	x			x			x	
	Parent 1	F		x		x			x	
	Parent 2	M		x		x			x	
	Social worker 1	F			x				x	
	Future placement provider	F			x				x	
	Care worker 1	F	x			x	x			x
	Care worker 2	F	x			x	x			x
Adi	Parent 3	M		x		x	x	x		x
	Salt 1	F			x					x
	Social worker 2	F			x					x
	Home manager	F	x			x	x			x
	Assistant team manager	M	x			x	x			x
Caden	SaLT 2	M			x					x
	Social Worker 3	F			x					x
	Teacher	F	x			x	x			x
	SaLT 3*	F	x			x	x	x	x	x
	Deputy Head*	F	x			x			x	x

*Note: * indicates participants who were involved with all three young people*

3.3.5 Procedure

3.3.5.1 Co-creating the Stories

The Digital Stories were co-created between April 2020 and February 2021 following guidelines and the ‘I am...’ framework that was developed in a specialist nursery setting (Parsons, Ivil et al., 2020), this comprised of four stages: mapping, filming, describing, and editing (see table 3.3).

Table 3.3 *Process of Digital Story creation*

	Mapping	Filming	Describing	Editing
Emily	A mind map was co-created in collaboration with Emily's parents and key support staff to capture a holistic understanding about Emily: what her preferences are, what Emily enjoys, how she communicates, who and what is important to and for her, what she finds challenging and what helps her.	Two familiar care staff were identified to lead on the filming of Emily's Digital Story. Information gathered within the mapping stage was collated into the 'I am..' framework to focus the filming. Filming took place across a range of environments and during meaningful activities. The video clips were collated between April and May 2020.	All video footage were viewed by the SaLT. Informed by the initial mind map, meaningful clips, which captured the essence of Emily, were identified and 'I am...' phrases were created to describe Emily from her point of view.	Informed by the 'I am...' descriptions, meaningful clips, which best represent Emily, were identified. A plan was written detailing the video clip(s) which corresponded to each 'I am...' phrase, with the perspective of Emily remaining central to all decisions made. Emily's Digital Story was edited by the SaLT and was shown to parents and key staff and further edits were made before the final version was shared.
Adi	A mind map was co-created in collaboration with Adi's father and key support staff, to capture a holistic understanding of Adi. This captured his preferences, what he enjoys, how he communicates, who and what is important to and for him, what he finds challenging and what helps him stay emotionally regulated.	Two familiar care staff were identified to lead on the filming of Adi's Digital Story. Information gathered within the mapping stage was collated into the 'I am..' framework to focus the filming. Filming took place in collaboration with Adi's father, across a range of environments and during meaningful activities. The video clips were collated between July and August 2020.	All video footage were viewed by the SaLT. Informed by the initial mind map, meaningful clips which captured the essence of Adi, were identified and linked to 'I am...' statements to best describe Adi from his perspective.	Informed by the 'I am...' descriptions, meaningful clips, which best represent Adi, were identified. A plan was written detailing the video clip(s) which correspond to each 'I am...' phrase, with the perspective of Adi remaining central to all decisions made. Adi's Digital Story was edited by the SaLT and shown to Adi's father and key staff and further edits

were made before the final version was shared.

Caden	In collaboration with Caden, Caden's father and support staff, initial ideas were discussed about what and where was important to film. Adults used pictures and symbols (e.g., Communicate: In Print) to support Caden to express his views and preferences about what and where to film and what device he would like to use to film (Appendix C).	Two familiar care staff and Caden's teacher were identified as adults who would support Caden to co-create his Story. Video guidance was created for Caden to support his understanding. Caden filmed himself across a range of environments and during activities of his choosing. Adults also filmed him when necessary. The video clips were collated between December 2020 and February 2021.	Meaningful clips were identified by the SaLT in collaboration with Caden. 'I am...' phrases were created to describe what is important to and for Caden to ensure his views and perspectives were captured as far as possible within his Story.	In collaboration with the SaLT, Caden was supported to edit some video clips. Where Caden found this challenging, the SaLT carried out the editing. Caden, Caden's father and key adults from the school viewed and further edited the story before the final version was shared.
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The young person's video clips were collated in the weeks preceding their transition (see table 3.3). Originally, I had intended to spend time within the school to develop relationships with the young people and school staff ahead of co-creation of the Digital Stories with the aim of working in partnership with staff, the family and the young person, to develop their Digital Stories. However, due to Covid-19 restrictions it was not possible to visit the school. Instead, I provided remote support and guidance across all stages of the Digital Story co-creation by remaining in regular collaboration and contact with staff, virtually through Microsoft Teams. Initial discussions with Hill House staff introduced the early stages of developing Digital Stories, for example the importance of ensuring the young person remains at the centre of their Story and the inclusion of families and other adults who know the young person well. Originally, I had intended to run a workshop alongside key staff to introduce the idea of the Digital Stories to the school. Instead, I provided remote support by providing Hill House with a presentation, which introduced the Stories

and the purpose of the project and was delivered during a team meeting. The young adult's video clips were collated between April 2020 and February 2021 and regular discussion with key Hill House staff, inclusive of care and education staff directly involved with the filming, ensured that the young adult's experience and identity was represented and included within their Story and, crucially, that their Digital Story was shared within their transition.

The videos captured important aspects of the young person's daily routine and were used throughout the setting and within the community to capture their interactions with others, choices and preferences and provided an opportunity to showcase their individual strengths and skills. Parents, Hill House staff and the young people were included in the initial mapping stage, which helped focus the filming. To ensure the young adult's voice was dominant within this process, they were able assert choice through their preferred communication method, for example, Caden used Talking Mats to communicate his preferences. The 'I am...' framework was used to aid this process and contribute to a holistic understanding of the young person within their Story. The 'I am...' framework explores seven core elements of CYP's experiences and identity: spaces, people and interactions, independence and agency, objects and interests, communication and expression, skills and capabilities and support. Within this research, two further elements were added to the 'I am...' framework, including 'family' and 'community inclusion' (Appendix D), thus extending the original framework. The method of filming (e.g., whether it was directed by the young person or filmed by the staff member) varied depending on the young person's preference and engagement. Editing of the stories was carried out by staff at the school who knew the young person best, in collaboration with parents. Where it was appropriate to do so, the young adult was supported to edit their Story. Figures 3.1, 3.2 and 3.3 are storyboards of Emily, Adi and Caden's Digital Stories respectively, containing several clips taken from their Stories, inclusive of the 'I am...' statements and stills from the video footage, which represents their views and perspectives. I strongly encourage, however, that Emily and Caden's Digital Stories should be watched to fully appreciate and experience how the voice of each young person is captured and represented within this methodology⁶.

⁶ I have consent to share Emily and Caden's digital story and strongly encourage the reader to watch these Digital Stories, which form a crucial part of the Methodology.

Figure 3.1 *Emily's Digital Story storyboard*

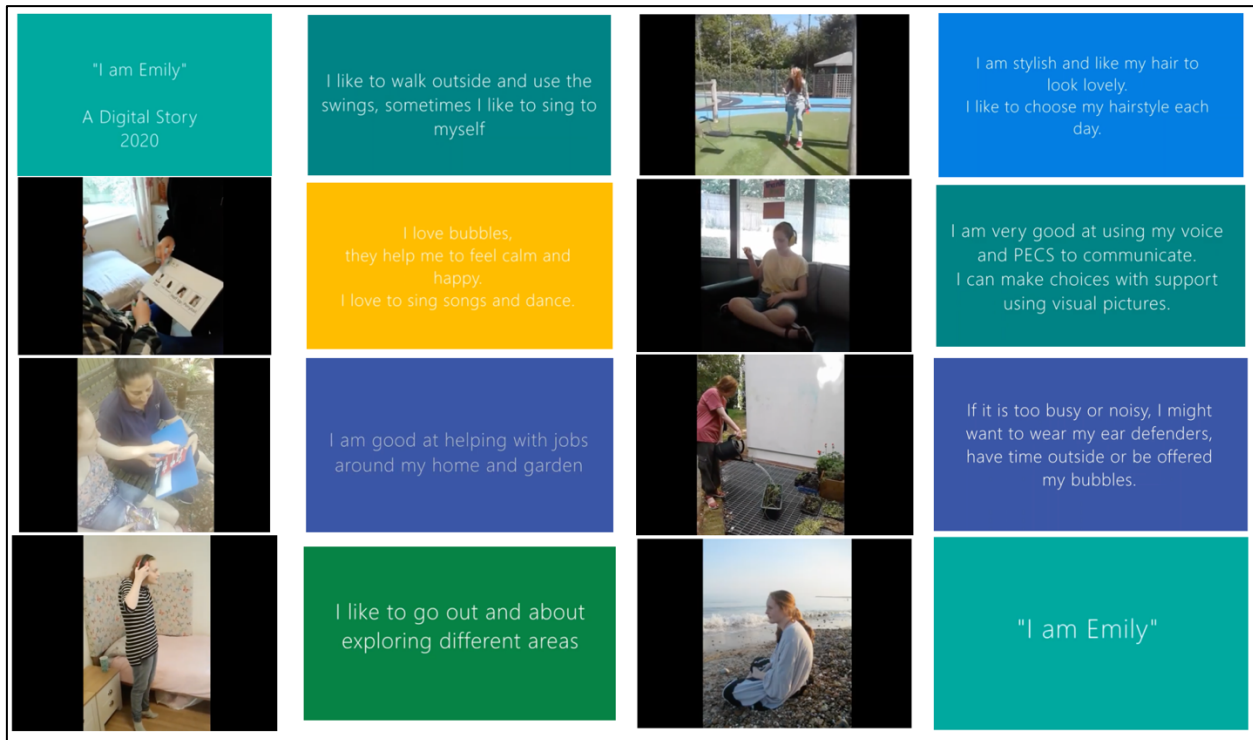


Figure 3.2 *Caden's Digital Story storyboard*

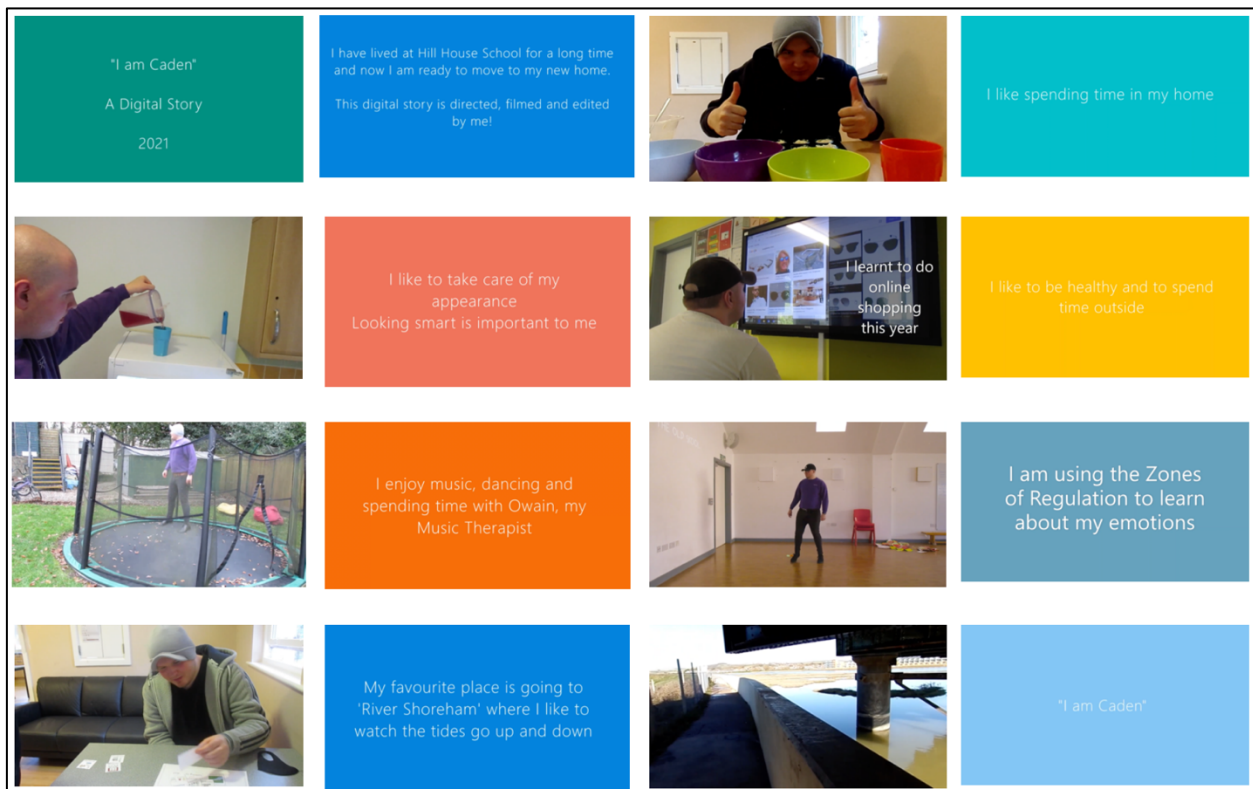
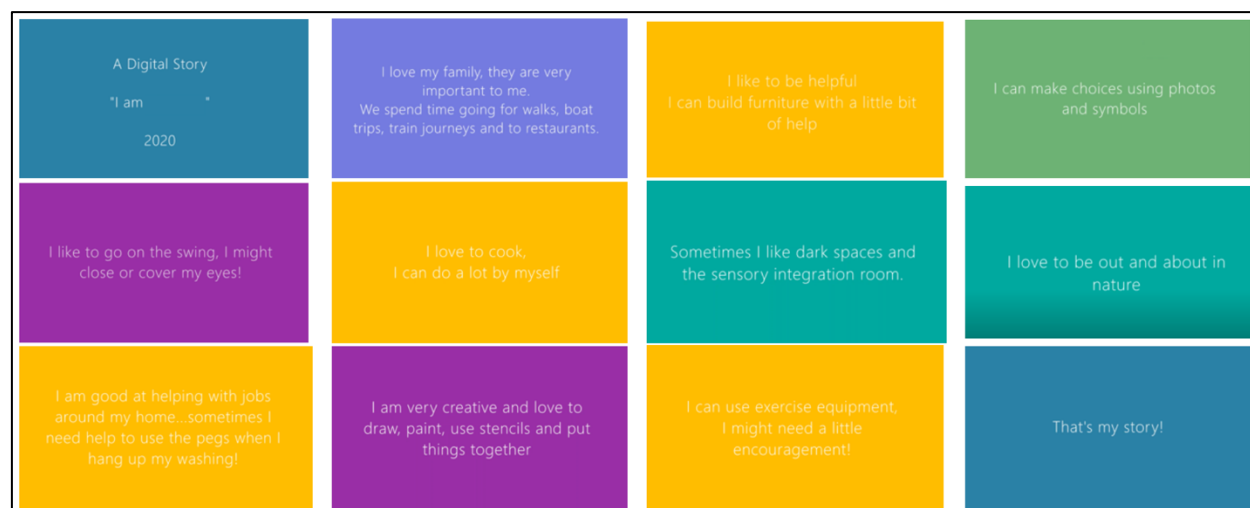


Figure 3.3 *Adi's Digital Story storyboard*

3.3.5.2 Sharing the stories

Emily, Adi and Caden were each given the opportunity to watch their Digital Story alongside key staff who were involved in its development. The Digital Story was embedded within each young person's transition process to adulthood. As a result of Covid-19 restrictions, each young person's transition was different and, therefore, the Digital Story was shared with key stakeholders at different stages within the transition process. Emily's story was shown within her final transition meeting, which was held virtually over Microsoft Teams, whereas Adi and Caden's stories were shown individually to stakeholders outside of a formalised transition meeting. Adi and Caden's stories were also shown earlier within their transition planning to embed their views earlier within the process.

3.3.5.3 Evaluating the impact of the stories

Semi-structured interviews were carried out with parents, school staff and key stakeholders to understand their perspectives, experiences and views on the Digital Stories and its use within the young person's transition to adulthood. As a result of Covid-19 restrictions, interviews were carried out virtually, over Microsoft Teams and lasted 20 – 55 minutes. A topic guide was created, which allowed for flexibility to discuss topics of interest in greater depth, whilst still affording participants the opportunity to provide detailed responses. The guide asked participants their views on the Digital Story, the impact of the Digital Story methodology on their thinking and perspectives, and their overall evaluation of the approach (see Appendix E). The interviews were

Chapter 3

audio-recorded, and post-interview researcher reflections were captured within a research diary (Appendix A). Interviews were transcribed verbatim for analysis.

3.3.6 Ethics

This research received ethical approval from the University of Southampton (UoS) School of Psychology Ethics and Research Governance Online (ERGO) system in March 2020 (ref: 55000). As each young person was over 18 years old a Mental Capacity Assessment was carried out by the Speech and Language Therapist (SaLT) at the school. This involved using a total communication approach (e.g., verbal communication and visual supports) to assess if the young person understood and had capacity to make a decision about their involvement in co-creating their Digital Story and for their Story to be shared within their transition (see Appendix F). Emily and Adi were assessed to lack mental capacity to provide fully informed consent for their participation in the project and, therefore, a best interest meeting was carried out for both (see Appendix G). There was unanimous agreement that involvement in the project was in Emily and Adi's best interest. Caden was assessed as having mental capacity and, therefore, consent was sought directly from him (Appendix H). Assent for each young person was sought in a creative and accessible way through a comic strip visual (Appendix I) to illustrate their involvement with the project. In addition, their assent to participate was considered on an ongoing basis by staff who knew them well. All parents were provided with an information sheet (Appendix K) and consent form (Appendix L) and gave written consent for their child to participate within the project. Additionally, agreement that their child's first name could be used within their Stories was also included. One parent did not consent to the child's first name being used and, therefore, a pseudonym was created. Key stakeholders were also provided with an information sheet (Appendix K) and gave their written consent (Appendix L) to be interviewed and have these audio recorded. Parents and stakeholders were informed and understood that Hill House School would be named to acknowledge their contribution and collaboration within the research. Anonymity of key stakeholders was maintained using pseudonyms, which were used in all written materials. The school securely stored the video data and where it was necessary to share the Digital Story, for the purposes of supporting the young adult's transition or dissemination of research findings, this was

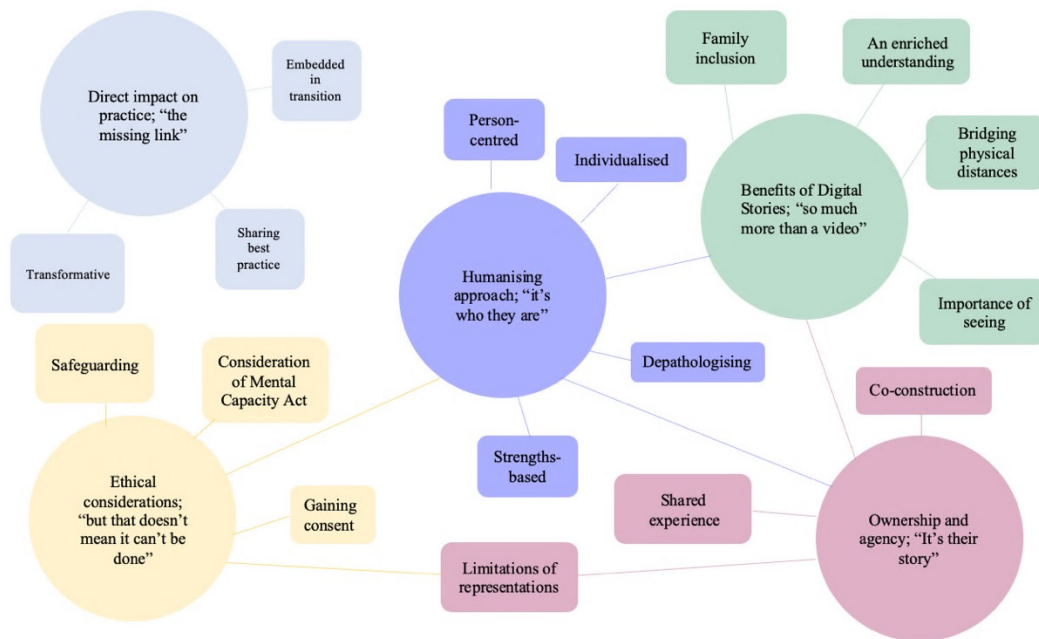
carried out using the UoS secure file sharing service (SafeSend). Additional confidential material (e.g., transcribed interview data) was securely stored on the UoS drive.

3.3.7 Data analysis

The analysis followed a recursive and iterative process using the six-step approach to reflexive thematic analysis (RTA; Braun & Clarke, 2019, 2020, 2021; Terry et al., 2017). Although I have organised the stages of RTA linearly (see Appendix K), I moved flexibly through the phases as required, as the analysis developed (Braun & Clarke, 2020). I transcribed all interview data, which ensured I was connected with and immersed in the data. An inductive orientation to coding was used and I coded both semantically (to stay close to participant language and capture explicit meaning) and latently (to focus on a deeper, conceptual level of meaning of the data). This helped organise the data to establish patterns across the codes. Themes were constructed through an active process and were continually developed and revised (Braun & Clarke, 2019). Themes were given meaning in relation to my own experience and interpretation, and relevance to the research question. In addition, discussions within supervision sessions helped to refine initial codes through exploration of their meaning and, later, reviewing and refining themes by considering their applicability, range and scope. To visually explore potential themes and subthemes and to facilitate the process of theme exploration and understanding the connections between them, thematic maps were created (see Appendix L). The central organising concept of each theme was identified and considered and the boundaries of each theme and subtheme were established to ensure they were well defined, distinct from one another and coherent (Braun & Clarke, 2021). Reflexive discussions within supervision sessions helped explore and support my understanding of how my own personal interpretations and assumptions influenced the research process, specifically within the analytic process.

3.4 Analysis

Following the coding process, seventeen sub-themes were generated and grouped into five main themes, which are shown in Figure 3.4 and discussed in turn below (sub-themes are indicated in bold text).

Figure 3.4 Thematic map of five main themes (circles) and sub-themes

3.4.1 Theme 1: Benefits of digital stories – “so much more than a video”

Participants expressed positive attitudes towards Digital Stories, emphasising the importance of being able to **see the young person** in the videos as a powerful way of representing their views and perspectives. For example, SaLT 1 expressed:

“...a Digital Story shows so much more than just a video does, it really captures who someone is, and that is so powerful to see”.

This elevated insight of the young person was valued by participants as a way of enabling them to contribute more fully and make more informed choices and decisions for the young person. For example, SaLT 1 described how their multidisciplinary team were better advocates and had an **enriched understanding** of the young person because of watching the Digital Story:

“I felt I knew him a bit more, I felt like I could advocate for him...and my team as well, Occupational Therapy and a nurse, we got lots of benefits from seeing the story because we can advocate for Adi and we can get ideas for activities and strategies”.*

Similarly, Social Worker 1 felt that seeing the young person within their story provided participants with an authentic representation:

“It was like seeing her, you hear about somebody’s interests and what they like and how they like to be assisted, but I think sort of seeing her gave a broader representation of who she actually is.”

Many participants drew comparisons with alternative methods of information sharing within the transition process and highlighted how Digital Stories provide “*intricate*” details, which can only be seen and are not captured fully within verbal or written reports, or during an observation. For example, observations were considered a “*snapshot*” where adults “*only see what is happening at that moment*” (Care Manager). By contrast, participants explained how the Digital Story was an improvement on written reports:

“They can read all they want but to be able to actually put a face to the name, and a voice to him, he is an actual person – this will massively help.” (Social Worker 3)

“I think the advantage of the digital story is that - I’m stating the obvious - that it is not just words on a piece of paper, it makes it much more human.” (Parent 1)

All participants considered the benefit of the Digital Stories within the context of the Covid-19 pandemic, where opportunities to physically visit Hill House School were restricted. The Digital Story, therefore, helped **bridge the physical distance** between everyone involved in the young person’s transition. Emily’s new placement provider reported that:

“It was a really good tool especially because we were in Covid, it was difficult because normally we would do a lot more transition visits, so things were very different than a ‘normal’ transition, so it was good, it was good to see her in her own environment.”

Many participants also recognised the benefit of the Digital Stories after the Covid-19 lockdown period had ended and reflected on how the Stories could be watched by care staff and health professionals who would not typically be involved in transition visits or limited by distance. For example, Emily’s placement provider said that:

“Even without covid, you are not going to send a whole staff team to do transition visits.”

Similarly, SaLT 1 discussed the benefit from a multi-disciplinary perspective of seeing a young person they would not typically visit due to distance:

“We have lots of complex transitions within our team and it is very rare that we are actually able to go and see the person if they are really far, so [the Digital Story] was a really positive thing to have...that was really key, really important for us.”

Importantly, participants recognised and valued the **inclusion of families** within the co-construction of the Digital Stories, highlighting the importance of their continued involvement as their child makes the next step into adulthood. For example, the Deputy Home Manager shared:

“It was lovely to be able to really kind of give families that opportunity to contribute so that made such a difference.”

Finally, Parent 3 conveyed the importance of their involvement for him:

“It was a lovely Story, when you see how things are done in the Story and how I was involved in the story with my son, with his life at Hill House.”

3.4.2 Theme 2: Humanising approach – “it’s who they are”

Participants identified Digital Stories as **person-centred, individualised and strengths-based** and that they brought the young person to life as an individual with different preferences, interests, and capabilities. This holistic and humanising understanding provided an opportunity for the young person to become central to their move. For example, participants described how the Digital Story shaped the transition meeting by ensuring the young person remained central to the decision-making process and facilitated person-centred planning:

“I think it just reminds everyone who’s at the centre of this move, whose move is this? Actually, it is for this young person, and I think it’s just really brought the child, or the young adult, into their move a lot more rather than us kind of coordinating the move.”
(SaLT 3)

“It needs to be about that child, and I think [the Digital Story] enables us to refocus and to get the child in the room, virtually so to speak, to help everyone remember why we’re all sitting in that meeting.” (Care Manager)

Additionally, the Care Manager emphasised the importance of embedding person-centred approaches, which bridge the gap between research and practice:

“...we always talk about the paramountcy of the child being at the centre of everything that we do, and those words are cheap unless you do it, and I think [the Digital Story] was very grounding and I think it made a difference [to the transition].”

The Digital Stories were recognised as being highly **individualised** to each young person, both in terms of how the story was co-created with the young person and the final Story itself. No two Stories were the same, which reflected the personality and nuances of Emily, Caden and Adi. SaLT 3 described how the young person’s unique skills, perspectives and insights were strongly represented in each Story:

“They have been personalised, and each one has been so individual, because obviously all of our children are just so different and unique and have all their individual skills and so that needs to be reflected in each digital story, doesn’t it? They all should be very different, in a way, which I think is so important.”

Crucially, this was recognised by participants who viewed the Story as a part of the transition process. For example, Social Worker 1 described:

“This really shows who she is, that was my overarching feeling about it. It is the way forward. It is an innovative and creative way to show people differently, move away from a 1-dimensional written report, and showing a bit of a 360-degree view of somebody.”

Participants discussed how viewing the Digital Stories highlighted the many strengths and capabilities of the young person and how refreshing this was within the transition process, for example:

“So that’s where the stories are just magical, because again, they just showcase that young person in such a positive way.” (SaLT 3)

“The digital story really focuses on the positives of this is who this young person is, this is everything that is amazing about them, and this is what you need to learn about them because actually this is the most important part of them, this is what you need to focus on.”
(Deputy Head)

Participants also described how the Digital Story **depathologises** the young person and allows the child to be seen through a lens without labels or clinical descriptions, instead the “essence” of the young person is captured and celebrated. For example, SaLT 2 commented:

Chapter 3

"It's just so nice to be able to look at [the Digital Story] and say, oh yes, there's Caden...and what that also does through doing that...is we, sort of, depathologise the young person as well, in a sense, because we say 'oh, there he is!', you know there, there he actually is."

3.4.3 Theme 3: Ownership and agency – “it’s their story”

Participants spoke about ownership and agency and described the Digital Story as being owned by the young people and not the other adults involved through enabling the young person’s voice and participation. For example, the Care Manager stated that: *“That’s Emily’s Digital Story. It is not ours.”*. Importantly, participants felt that each young person had **co-constructed** their Digital Story (albeit in different ways), which demonstrated their autonomy:

“It isn’t a story we have created; it is their story. It is showing what they enjoy doing, showing off the things they can do, all the things that create the fabric of who they are. That is what is missing from the ‘normal’ transition process.” (Home manager)

“I think I have a strong sense of character from it, if you like, I don't feel that he is to some degree kind of corralled into doing those things.” (NHS SaLT 2)

“It was clearly something that he really wanted to do, not something that was sort of, he was asked to do and he kind of just participated in it. It was evident that it was something that he was fully involved in and enjoyed.” (Social Worker 3)

“The other really important part of it is that I had a strong sense that that Caden was really aware of the film...the fact that he was in this film and so, that kind of sense of ownership, that sense of transparency around it in a way.” (NHS SaLT 2)

Additionally, Social Worker 2 described how she felt Caden had more autonomy which challenged, and exceeded, her expectations:

“I think he had more autonomy in it then, or it felt like he had more autonomy than, than I was expecting within it.”

Although each child had varying level of involvement in the co-construction of their Story and different communication needs, each young person was recognised as having their voice captured, heard and listened to. For example, Social Worker 1 recognised that:

“It’s difficult because she does have severe communication difficulties, so as much as possible, I think those are the things that Emily would’ve liked to say, you know the things that are really important to her...I think it captured her voice.”

Participants also highlighted the importance of adults viewing the young person’s Digital Story as a group to facilitate a shared understanding of the young person. Reflecting on Caden’s Story, SaLT 2 expressed that ‘[Caden] saw what we see’, hence, watching the Digital Story was considered a **shared experience** by all those involved in the transition:

“He’s still watching the same thing, we’re watching it together, we’re sharing together and also all those different individuals who are going to be involved in that transition are also all seeing the same material.” (SaLT 2)

Finally, participants reflected on the **limitations to the representation of young people’s voices** in the Digital Stories, specifically in relation to their participation and consent. For example, Caden’s teacher recognised that although he had ownership over the production of his Story, Caden may have been less sure about the audience or who would see the Story:

“I think in his mind probably, he wasn’t thinking about how this is going to be shown to other people and he probably thinking more about himself.”

3.4.4 Theme 4: Ethical Considerations – “but that doesn’t mean it can’t be done”

The previous point links directly with the ethical considerations discussed under this main theme, including **consent**, maintaining dignity, **safeguarding**, and awareness of the **Mental Capacity Act (MCA)** when making decisions in the best interest of a young person lacking capacity. For example, in relation to **gaining consent** there was a tension about the young people’s role in creating the Digital Story and their awareness and understanding of the videos capturing their interactions and choices. Participants acknowledged these ethical challenges but recognised ways to overcome these and act with respect and integrity:

“In adult services it’s not so easy, you have consent issues as well they come into play and are a bit more complex, but that doesn’t mean it can’t be done.” (NHS SaLT 2)

Chapter 3

“[The SaLT] came with a social story, so she spoke, we had a conversation with him saying, asking him if he wanted to join, take part in it and he was quite excited about it.”
(Teacher)

Participants also discussed the challenge of including behaviours that indicated distress or anxiety of the young person within their Digital Story. Within these discussions, tensions existed between what should be included to ensure the Digital Story represents a holistic view of the young person, versus what should be captured to ensure dignity and respect is maintained. Some participants felt that such behaviours should be included:

“I do think a bit more about how his behaviour is and how he can potentially be would have been, could have been a little bit um more helpful.” (Social Worker 2)

Others acknowledged the challenges this presents when considering the importance of **safeguarding** and operating with dignity and respect. For example, the future placement provider shared that:

“...it is difficult because it is about respecting people and maintaining dignity but the one thing that I say was missing is when she wasn't happy, which would have been really useful, but I appreciate that these things open difficulties too. It would feel wrong, I myself would feel wrong standing there, filming someone when they are not happy.”

Other participants described how unethical it would be to include video footage of a young person when they are dysregulated, for example:

“When you've got someone that lacks capacity to consent as well, you know, even though other people can consent in her best interest and all that... it does feel slightly unethical, to be filming some of those behavioural challenges and everyone sitting around viewing it on the video, it doesn't sit right with me.” (Social Worker 1)

Similarly, the Care Manager identified that a description of the young person's behaviour was not well situated within the Digital Story and highlighted written reports where this is better described:

“I can read that in the BSP, the behaviour support plan, I don't want to see that, it is not about that.”

Finally, there was some reflection from participants about how they would like to be represented on video:

“He’s not going to want those parts to be, to be in it at all, why would anybody? Um, I guess if you’re making it for someone who hasn’t got the capacity to say that there’s a positive or a risk... but yeah, actually would they, would they want that in there? Would anybody want that in there?” (Social Worker 3)

3.4.5 Theme 5: Direct impact on practice – “the missing link”

This theme describes how Hill House School have embedded the Digital Story methodology within their everyday practice, to support the transitions of young adults not only leaving the school, but to facilitate and enhance the transition process of children and young people joining the setting. Staff members described how the Digital Stories have **transformed** their practice and the positive impact this has had on transitions:

“They are a huge part of our or moves now and really, really positive.” (Deputy Head)

“It has really changed how we’re doing things at school in terms of preparing the children who move in with us and preparing our children who are moving out.” (SaLT)

The SaLT further described how the school ensures that care staff are also involved in the creation of the Stories:

“I’m just making sure we’re going to do them for every young person but making sure that the managers of each home are aware that that is something that is part of their transition now, it’s just something that is going to happen.”

Additionally, the Deputy Head was clear about the wider value of **sharing their experiences and practices** with the wider community:

“it’s about us being able to look outward, to work with other people that aren’t part of Hill House or the Cambian Group and really be part of something much bigger that will hopefully have an impact for other schools, other providers.”

There was already some evidence that this was making a difference beyond the school, for example SaLT 3 described that staff at the new placement continue to refer to the Digital Story to increase their understanding of the young person:

“We used it a few weeks ago to show more people that started to work with him about who he is, this is what he can do and he’s having a bit of a difficult time now, but actually we’re still using it.”

Finally, the new placement provider for Emily commented how the Digital Story would be used to support the development of Emily’s Positive Behaviour Support Plan in her new adult setting:

“...our PBS team are going to have a look at what they can take from that [the Digital Story] to then put into a kind of an ‘all about me’ section for Emily.”

3.5 Discussion

The ‘I am...’ framework for the Digital Stories methodology was originally developed in a nursery setting to enable the voices of young autistic children as they made their nursery to primary school transition (Parsons, Ivil et al., 2020; Woods-Downie et al., 2021). The aim of this research was to extend and evaluate the use of this methodology to facilitate knowledge co-construction of autistic young people’s transitions from a residential special school to adult provision. The findings highlighted that the Digital Stories for three autistic young adults, Emily, Adi and Caden, provided a powerful way of representing their views and perspectives, which enabled their voices to be heard within their crucial transition to adult settings. The ‘I am...’ framework was not only successfully applied to older young people, but extended to include two further elements, reflecting the importance of family and community inclusion (Appendix E). Importantly, these Stories were recognised as authentic, personalised and positive representations of the young person, that also appropriately challenged expectations and strengthened understanding of who the young person was. Indeed, stakeholders talked of the Digital Stories capturing the “essence” of the young person i.e., a sense of *who they are*. This enabled the young people to be seen within their transition as unique individuals with different skills, preferences, and capabilities, liberating them from deficit-focused labels and clinical descriptions which frequently dominate within the more traditional methods, such as written reports and assessments (Palikara et al., 2018). These findings challenge the view that the voices of autistic CYP with the most complex needs, including those who do not use speech for communication, may be “too hard to reach” (Franklin & Shopler, 2009, p. 4).

As key stakeholders within transitions, it was notable that parents and professionals expressed positive attitudes towards Digital Stories and highlighted several benefits to the approach. The importance of being able to *see how* the Digital Stories captured the nuances and intricacies of each individual young person was considered powerful, especially when this level of detail revealed new insights into the young person's experiences. For professionals, this enriched understanding helped them personalise the young person's provision by identifying activities and appropriate strategies aligned with the young person's strengths and capabilities. In turn, these insights meant that professionals felt they could be better advocates for the young person. It was acknowledged that verbal or written accounts provide a 'one dimensional view' which is often deficit focused. In contrast, Digital Stories go several steps further by providing a more holistic, strengths-based, and humanising understanding of each individual young person. In terms of transition planning, Crane et al. (2021) emphasised the importance of professionals playing a key role in guiding decision-making within young people's transition into adulthood and therefore, how crucial it is that they know the young people well. Considering the legal requirement for young people with SEND, and their families, to have their views and wishes taken into account for educational planning (SEND Code of Practice, 2015), this suggests that Digital Stories could be crucial in shaping person-centred discussions about their support and ensuring young people remain the focus within decision-making processes.

An important finding was the recognition that young people had some ownership of their Story. Within the co-construction of the Digital Stories, each young person was encouraged and enabled to participate, albeit in different ways relating to their different communication needs. This ranged from Emily and Adi participating in more embodied ways (Parsons, Ivil et al., 2020), to Caden who directed, filmed and edited his Story. Importantly, each Story was recognised by participants as being highly individualised and reflecting the unique personalities of each young person.

Caution should be taken when interpreting the actions of minimally or non-verbal individuals and the extent to which the 'inferred' preferences can be considered their legitimate views (see also Parsons, Ivil et al., 2020). Although some young people may have had a less active role in developing their stories, each Digital Story was co-constructed with adults who knew the

Chapter 3

young people very well (e.g., familiar care staff and parents) and had built a relationship over time. Their knowledge and awareness of what the young person liked to do and choose was important for creating informed and authentic positive representations of the young person. A related point is the concern that efforts to elicit young people's voices becomes 'tokenistic' if these views are not given 'due weight' (Crane et al., 2021; Fayette & Bond, 2018; Lundy, 2007). Encouragingly, stakeholders offered several examples of the impact of the Digital Story both pre- and post-transition and how young people's views shaped the planning in their transition. For example, in developing Positive Support Plans, to increase the new staff team's understanding of the young person, to shape individualised support strategies, and to gather ideas for preferred activities in the young person's new home. This suggests that Emily, Caden and Adi's views were not only listened to but were also embedded within the planning and practices of the teams who supported their transition (Lundy, 2007).

Particularly in the context of the Covid-19 pandemic the importance of *seeing* the young person was considered beneficial where both visits to the young person's new placement as well as opportunities for care staff to visit were restricted due to social distancing measures enforced at the time. Indeed, many participants reflected on the inherent challenges with standard practices, acknowledging the limitations with carrying out observations of a young person or one-off visits, which frequently only provide a snapshot of that young person and are typically carried out by a small number of care staff. In contrast, several participants recognised how the Digital Stories could be watched by the wider staff team, as well as health and social care professionals who may not be typically involved in transition visits or be restricted by distance. This was acknowledged as a potential further benefit of the Digital Stories methodology beyond the restrictions of the pandemic.

3.5.1 Ethical Considerations

Inevitably with an approach that involves video and young people with complex needs, there are major ethical considerations of the research. We were careful to strive for Stories that represented a young person's experiences and preferences when they have the right support in place i.e., we did not include footage when the young person was distressed or dysregulated. This

stance raised questions from some stakeholders about how ‘authentic’ the Stories were if they did not include such footage. Our position is that the Stories are intended to balance the otherwise deficit-focused narratives of young people that will accompany them through the usual formal assessments and reports; the Stories are *additional* to these ways of transmitting information about the person rather than *instead* of them. Our view is that the Stories are akin to a job or college interview where the young person is enabled to represent their best self to a new team or setting, and this is a representation of the young person that they rarely have the chance to convey in practice.

3.5.2 Strengths and Limitations

While the practical constraints of the COVID-19 pandemic impacted considerably on my original plans to be more involved in the production of the Digital Stories, there were some major benefits that unexpectedly emerged from this situation. First, Hill House School staff took on the responsibility for creating the Stories and rapidly developed the skills to do this. This skills development was recognised by staff to be the catalyst for change that enabled them to embed the approach within the school. Indeed, the making of Digital Stories is now fully embedded in their practice and are created for every young person who is transitioning from the school. Moreover, the constraints of the pandemic also enabled staff and other stakeholders to recognise the potential wider application of the methodology when time/distance may not support direct transition visits or meetings.

Nevertheless, important limitations also need to be acknowledged including whether staff involved in the making of the Stories felt reluctant to criticise the approach. While all were offered the chance in interviews to reflect on the process and discuss improvements to the methodology, they may still have felt constrained in how much they could say as participants were aware of my involvement in co-creating the Digital Stories. It was also not always possible to show the Story within the key transition meetings for each young person, which meant that it was not possible to explore whether there was additional value through the Digital Story being jointly witnessed/viewed together as a team and, therefore, gaining more of a shared understanding of the young person (cf. Smart, 2004). Where this did happen in Emily’s transition, this allowed the

Digital Story to be the focal point of the meeting and enabled a strengths-based discussion to take place. Finally, the views from the young people themselves on their experience of the Digital Story were not included as once they had moved to their new placement it was not possible to follow them up. Clearly this is an important aspect that needs to be addressed in future research.

3.5.3 Conclusion and Implications for practice

There are many ways in which the Digital Story methodology could be further applied and extended in practice to support the transitions of young people. For example, the Stories could be developed and shared earlier in the transition process to help identify suitable placements/new homes for the young people. It would also be valuable for a Story to be developed from the new adult placement so that the young person could see the staff and spaces before or in place of a physical visit. Digital Stories could also have a role when making referrals to different services such as Occupational or Speech and Language Therapy, to show the strengths, capabilities and needs of the young person so that provision and strategies can be suggested. Finally, Digital Stories could be used to demonstrate progress over time and as evidence within annual reviews, person-centred meetings, and education health and care plan needs assessments (see Wood-Downie et al., 2021). Thus, Digital Stories could be a helpful method for eliciting children's views and, also, as a more holistic and strengths-based person-centred planning tool to ensure children and young people remain at the centre of all discussions about them.

Appendix A Reflexive journal entry

03.09.2020	Semi-structured interview with parents 1 and 2	I felt a little deflated after this interview with E's parents. I was able to speak to both parents (both Mum and Dad) to gather their views/feedback/experience of E's digital story. However, they both acknowledged that it was a long time since they watched the digital story (May), and therefore they couldn't remember details of the video. The summer holidays impacted the date this interview could be carried out. This was a barrier to answering some of the questions within the semi structured interview in much detail. They were unable to provide extended responses to the question asking them to recall anything that surprised them when they watched E's story and the key messages that they took from watching the digital story. The dad also confused social stories with Digital Stories initially, which was disappointing as this further reinforced by thoughts that they did not value the Story. On reflection, I wonder if I could have either shown the video story again to parents on the teams call or have HH send it out to them again prior to the interview. This is something to consider going forward. What most stood out for me was the perceived lack of impact that the story had on them, they didn't appear to be moved emotionally by the video, which is in contrast to how HH staff have reacted to the video and my own emotions when watching E's story. I also wonder whether they thought the digital story was less 'rich' for them, i.e., they weren't learning anything new from watching the video, and possibly didn't see or experience the value of the digital story because of this? I wonder if for people who don't know Emily (e.g., future placement provider) it may be more impactful? Encouragingly, they did acknowledge that it was Emily's story and not theirs (which I think is an interesting comment as this was also a comment that was shared by the care worker in an earlier interview). Important to continue looking for patterns of shared meaning – helpful for data analysis. Plan going forward – discuss interview with H&S and K, transcribe and stay mindful and further reflect/consider alternative explanations??
04.09.2020	Supervision with Hanna and Sarah	Within supervision today I had the opportunity to reflect on how I feel and my interpretations following the semi-structured interview with E's parents. I found it helpful to discuss this as I felt a bit deflated following my interview with them. I was encouraged to consider how the parents may be feeling at this current time as their daughter transitions to adult services and the stress and anxiety that they may be experiencing. Digital Stories may not be and are not likely to be at the forefront of their minds, especially since it has been some weeks since they watched E's story. In addition, I found it helpful to consider the experience of transition and how much parents have had to advocate for their child's needs over time. Within the interview the parents shared how they did not see the Digital Stories as a tool that professionals would prioritise to view as they are incredibly busy. I reflected on the parent's

		experience of the professionals they have been involved in and how they may have felt that their child's needs have not always been understood. This understanding is influenced by my prior experience of working closely with parents in a residential special school prior to the course, where parents frequently expressed their frustrations that they didn't feel always feel like their child's needs were understood and there were a lot of time pressures on professionals involved in their children's care which limited the extent to which they were able to develop this understanding.
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Appendix B Quality assessment of included studies

Study	Hart (2021)	Rouvali & Riga (2021)	Bloom et al. (2020b)	O' Leary & Moloney (2020)	Parsons, Ivil et al. (2020)	Richards & Crane (2020)	Bradley & Male (2017)	Hill et al. (2016)	Simmons & Watson (2015)	Loyd (2013)	Ajodhia-Andrews & Berman (2009)	Gray & Winter (2011)	Whitehurst (2007)	Fitzgerald et al. (2003)
1. Clear statement of aims	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
2. Appropriate qualitative methodology	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
3. Appropriate design	YES	SOME WHAT	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
4. Appropriate and clearly stated qualitative paradigm*	YES	SOME WHAT	YES	YES	YES	NO	NO	CAN'T TELL	YES	YES	YES	YES	NO	NO
5. Appropriate recruitment strategy	SOME WHAT	CAN'T TELL	YES	YES	YES	YES	CAN'T TELL	CAN'T TELL	NO	YES	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL
6. Appropriate data collection	YES	CAN'T TELL	YES	YES	YES	YES	YES	YES	YES	YES	YES	SOME WHAT	YES	YES
7. Considered researcher-participant relationship	YES	YES	SOME WHAT	YES	YES	YES	NO	YES	YES	YES	YES	CAN'T TELL	SOME WHAT	SOME WHAT

Appendix B

8. Ethical consideration	YES	SOME WHAT	YES	YES	YES	YES	YES	YES	YES	YES	CAN'T TELL	YES	YES	CAN'T TELL
9. Rigorous data analysis	NO	NO	YES	CAN'T TELL	YES	YES	YES	CAN'T TELL	CAN'T TELL	CAN'T TELL	CAN'T TELL	NO	CAN'T TELL	CAN'T TELL
10. Clear statement of findings	CAN'T TELL	YES	YES	YES	YES	SOME WHAT	YES	YES	YES	YES	NO	NO	NO	YES
11. Valuable	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES

Note. Asterix indicates additional criteria

Article 1: Hart (2021) Agentic ethnography: inclusive interviews of young adults with significant disabilities on the transition from school					
Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				Aims were described as research priorities
2. Is a qualitative methodology appropriate	x				Yes – to understand the experiences of young people transitioning from school.
3. Was the research design appropriate to address the aims of the research?	x				Ethnographic design was clearly stated and justified as a way to evaluate transition of young people holistically over time, as each of the transitions unfolded
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				The theoretical framework applied throughout the research was the 'capability approach', which follows the assumption that each individual, regardless of ability, is agentic and able to impact decision making so long as they are given the opportunity. Reflexivity and transparency addressed throughout.
5. Was the recruitment strategy appropriate to the aims of the research?			x		Inclusion and exclusion criteria around participant selection not specified. Discussion about lack of gender diversity in study.
6. Was the data collected in a way that addressed the research issue?	x				Setting was justified (e.g., special school for students with disabilities) Clear how data was collected and a justification for use of adapted interviews was stated and how this was done.
7. Has the relationship between researcher and participants been adequately considered?	x				Research diary and field notes taken throughout study. Description of how their role and expertise shaped the research process as well as the role of the young adults and transition informants within the research. Imbalances and intersection influences were acknowledged and discussed regarding how they shaped the research, as well as how they were overcome.
8. Have ethical issues been taken into consideration?	x				Consent from parents was sought. Assent from the young adults was adjusted to take into account communication needs.

Appendix C

9. Was the data analysis sufficiently rigorous?				x	There isn't an in-depth description of the data analysis process. 'Ethnographic analysis' which was carried out inductively was stated as well as deductive analysis using 'the capability' approach as a framework. The researcher's positionality was however clearly stated.
10. Is there a clear statement of findings?		x			Methodological reflection so although the perspectives of the young men from the adapted interviews, field notes etc was not reported in the findings in this paper. The findings on the adapted interviews as a methodology were presented, but the specific findings on the advantages and disadvantages of each interview adaptation was not made clear.
11. How valuable is the research?	YES	Findings aren't considered in relation to relevant research-based literature despite existing research in relation to agency in educational research and transitions being presented in the introduction of the paper. This paper states, however, the importance of NZ making social inclusion as an intended outcome of transition a priority, and how agentic experience of taking part is an important part of the transition process.			

Article 2: Rouvali & Riga (2021) Listening to the voice of a pupil with autism spectrum condition in the educational design of a mainstream early years setting

Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				Clear aims and research question stated.
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?			x		Yes, the design was appropriate and data collection methods clearly stated and justified. However, although case study design was used, no analytical frame stated from which the data was interpreted.
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?				x	No research paradigm stated, nor guiding theoretical framework.
5. Was the recruitment strategy appropriate to the aims of the research?		x			Unclear how Maria was selected as a participant in the study. No broader discussion around recruitment.

6. Was the data collected in a way that addressed the research issue?		x			The multiple data collection methods used to involve Maria in the study were stated; however, it is unclear why these specific methods were chosen. It was not stated how data was recorded e.g., no description about how observation notes were taken, if they were taken and whether field notes/research diary was used. No justification for why the school was used as the setting for data collection.
7. Has the relationship between researcher and participants been adequately considered?	x				Observations and intensive interaction sessions were carried out to enhance impartiality (due to the authors lack of pre-existing knowledge about Maria). Intensive interaction sessions were used to allow Maria to get to know the researcher, in an aim to improve the reliability of data collected. Still unclear why this child/setting was chosen and any potential influence that impacted this.
8. Have ethical issues been taken into consideration?			x		Thorough consent/assent procedures explained within the study. Not stated whether approval was sought from ethics committee. Ethical considerations and challenges addressed. No debrief specified.
9. Was the data analysis sufficiently rigorous?				x	Data from individual tools were analysed “on their own” no description about how the data was analysed was stated. Unclear <i>why</i> and <i>how</i> experiences were selected and then reported from observations and intensive interaction session.
10. Is there a clear statement of findings?	x				
11. How valuable is the research?	YES	The authors explicitly state new direction for future research and implications for practitioners, as well as policy holders. Clear statement discussing the contribution this study makes to policy and practice. Specifically, the author states the need for the Greek Ministry of Education to review current policies to facilitate disabled children’s active involvement in their learning, through the tools and approaches stated in this paper.			

Article 3 – Bloom et al., (2020) Evaluating a method for eliciting children’s voice about educational support with children with speech, language and communication needs

Screening	Yes	Can’t tell	Partly	No	Comments:
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Appendix C

1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				Critical realism stated as the research paradigm that describes the underlying theoretical assumptions of the study. CR is 'woven' into the methodology developed and is conceptually coherent e.g., use of triangulation and seeking CYP inclusion in the methods developed.
5. Was the recruitment strategy appropriate to the aims of the research?	x				How participants were selected was clearly justified, as well as why the seven out of 20 case studies, were selected for the focus of the study.
6. Was the data collected in a way that addressed the research issue?	x				YVYC toolkit was created in this study and incorporated several data collection methods which, through 'contextual triangulation' were adapted and individualised to the participants strengths and abilities.
7. Has the relationship between researcher and participants been adequately considered?			x		Social desirability bias stated. Triangulation of responses as improving validity and involving multiple perspectives for concordance was discussed.
8. Have ethical issues been taken into consideration?	X				Consent was sought and gained from parents, pseudonyms used and how the data was being used in reports/publications following study completion also stated.
9. Was the data analysis sufficiently rigorous?	x				Thorough description of the analysis process, thematic map clear and how themes were generated was explained. Illustrative quotes used to support themes. Own role of the researchers influences within the analysis not stated (no reflexivity).
10. Is there a clear statement of findings?	x				
11. How valuable is the research?	YES	The researcher states how the YVYC toolkits offers services the opportunity to meet their responsibility to respect children's rights and within decision making, stating legislation (UNCRC and SEN CoP). Also states how data from YVYC can be used to help schools/service explore			

		effectiveness of interventions and strategies from perspective of CYP.
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Article 4: O’Leary & Moloney (2020) Understanding the experiences of young children on the autism spectrum as they navigate the Irish early years’ education system: valuing voices in child-centered narratives

Screening	Yes	Can’t tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study’s theoretical underpinnings clear, consistent and conceptually coherent?	x				Ecological Theory framework states as the guiding theoretical framework, influenced by the assumption that the voice of the child is collectively co-constructed and influenced by social interactions (e.g., relationships and interactions with others). This assumption guided the methodology and methodological tools used in this research.
5. Was the recruitment strategy appropriate to the aims of the research?	x				Inclusion and exclusion criteria stated, as well as why the participants were selected to answer research questions and meet the aims of the research.
6. Was the data collected in a way that addressed the research issue?	x				Data collection method of narrative interviews with parents was justified as answering the primary aim of the research (exploring and interpreting experiences).
7. Has the relationship between researcher and participants been adequately considered?	x				Yes – clearly. The role of the researcher and key reflections on ‘privilege’ were discussed in the study. Research journal kept throughout study to aid reflexivity.
8. Have ethical issues been taken into consideration?	x				
9. Was the data analysis sufficiently rigorous?			x		Although ‘I thou’ data analysis approach was stated, it is unclear what steps were taken when analysing the data within this study. Also unclear how themes were formed and developed.

Appendix C

10. Is there a clear statement of findings?	x				
11. How valuable is the research?	?	Implications for practice or research not stated.			

Article 5: Parsons et al., (2020) ‘Seeing is believing’: Exploring the perspectives of young autistic children through Digital Stories

Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				Clear aims and objectives – to develop use of Digital Story methodology to facilitate young autistic children to have their voices included in transition planning.
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				
5. Was the recruitment strategy appropriate to the aims of the research?	x				
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?	x				Participatory design, expertise and knowledge of nursery staff and parents aided interpretation of the children's Stories. Although, important to note through the nature of the DS methodology meant interpretation was minimised.
8. Have ethical issues been taken into consideration?	x				In depth reflection on ethical considerations.
9. Was the data analysis sufficiently rigorous?	x				
10. Is there a clear statement of findings?	x				
11. How valuable is the research?	YES	Utility of the methodology created clearly described.			

Article 6: Richards & Cane (2020) The Development and Feasibility Study of a Multimodal ‘Talking Wall’ to Facilitate the Voice of Young People with Autism and Complex Needs: A Case Study in a Specialist Residential School					
Screening	Yes	Can’t tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study’s theoretical underpinnings clear, consistent and conceptually coherent?				x	Not stated.
5. Was the recruitment strategy appropriate to the aims of the research?	x				How and why CYP and adult participants were selected is discussed, as well as the rationale behind choosing minimally verbal CYP. The number of staff who consented to take part but didn’t participated in piloting the Talking Wall were stated, but a discussion around participant attrition was not.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?	x				Research carried out by an ‘insider-researcher’ (SaLT assistant at the school), the author states the limitations of potential bias on the formation of the research questions and aims, design of the research etc.)
8. Have ethical issues been taken into consideration?	x				Ethical approval from UCL IoE sought.
9. Was the data analysis sufficiently rigorous?	x				Description of thematic analysis and the steps within analysis were clear.
10. Is there a clear statement of findings?			x		Unclear how the themes were derived from the data – no map? But themes were clearly stated (no sub themes?)
11. How valuable is the research?	x				New areas where research is necessary addressed Caution around generalisation but states how this method could be

					used to hear voices of more autistic children with complex needs.
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Article 7: Bradley & Male (2017) 'Forest School is muddy and I like it': Perspectives of young children with autism spectrum disorders, their parents and educational professionals

Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?				x	Not stated
5. Was the recruitment strategy appropriate to the aims of the research?			x		No recruitment strategy stated. Participant characteristics were described but it is unclear what sampling method was used and why the selected child participants were selected.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?				x	The author stated that they were also the children's class teacher and acknowledged the risk of bias in relation to this. Unclear how this was managed in the study, e.g., the author stated that a research diary was kept but unclear how this aided reflexivity. As no recruitment strategy was stated, it is unclear how the children were selected for the study and whether the authors knowledge of the children influenced recruitment.
8. Have ethical issues been taken into consideration?	x				Yes – meaningful consent from children was gained and assent was monitored throughout the study.
9. Was the data analysis sufficiently rigorous?	x				Constant comparative approach was adopted to carry out TA. Steps clearly outlined.
10. Is there a clear statement of findings?	x				Clearly stated findings. To minimise subjectivity inherent within the method of analysis used (constant

					comparative method) a second analyst was used to gain a second opinion on the themes and sub themes identified by the first author.
11. How valuable is the research?	YES	Future research suggested. Main themes generated within this study were suggested as being in line with previous research findings.			

Article 8: Hill et al., (2016) Research methods for children with multiple needs: developing techniques to facilitate all children and young people to have ‘a voice’					
Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				Aims clearly stated: to ensure that all children were able to contribute their views and have their voices heard (even those with verbal communication difficulties)
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?		x			Participatory research but no research paradigm or underlining theoretical underpinning stated.
5. Was the recruitment strategy appropriate to the aims of the research?			x		Although the participant sample and characteristics were reported, it is unclear how the participants were recruited.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?	x				Participatory design and included a young researchers' group who advised on all stages of the research, including identification of key issues to explore as well as advising and piloting the data collection methodologies.
8. Have ethical issues been taken into consideration?	x				
9. Was the data analysis sufficiently rigorous?			x		Unclear as multiple methods were presented in the paper.
10. Is there a clear statement of findings?	x				
11. How valuable is the research?	YES	Multiple methods were presented in this study and were adapted for children with limited verbal communication skills			

		their limitations were also addressed. The research provides education practitioners researchers and other professionals methods to use in current practise to facilitate the gathering of young people's views.
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Article 9: Simmons & Watson (2015) From Individualism to Co-construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities

Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				
5. Was the recruitment strategy appropriate to the aims of the research?		x			Not described how Sam was identified and recruited to take part in this study.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?	x				Member checking with key significant others aims to minimise the risk of misrepresenting Sam. Participatory design allowed the researcher to develop an authentic understanding of Sam and build a rapport with support staff. Emphasis on a 'co-constructed interpretation' of Sam's behaviour and the important role of others (i.e., familiar adults) within the research to aid this.
8. Have ethical issues been taken into consideration?	x				Ethical approval from the University of Exeter. Consent was sought from parents and school and ongoing assent was continuously sought from Sam (and monitored by the school)
9. Was the data analysis sufficiently rigorous?			x		
10. Is there a clear statement of findings?	x				Vignettes were discussed with significant others (adults who work

					with him) through an ongoing member-checking process.
11. How valuable is the research?	YES	Provides a methodology which aims to provide practitioners with an approach to develop a greater understanding of children with PMLD. However, it is unclear how this relates to previous research and policy. No future research suggested.			

Article 10: Lloyd (2013) Gaining views from pupils with autism about their participation in drama classes					
Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				Participatory paradigm and knowledge co-construction influenced the methods developed and used within the study.
5. Was the recruitment strategy appropriate to the aims of the research?	x				Authors describe how the school was selected in order to recruit participants who were the most appropriate to the studies aim and RQ.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?	x				Subjective positioning within the study addressed. Emphasis on the researcher as reflective and transparent during data collection.
8. Have ethical issues been taken into consideration?	x				Ethical approval from UCL Consent gained from parent and pupil's assent was sought through dedicated approaches.
9. Was the data analysis sufficiently rigorous?			x		Not clear how the data was analysed.
10. Is there a clear statement of findings?	x				
11. How valuable is the research?					

Article 11: Ajodhia-Andrews & Berman (2011) Exploring School Life From the Lens of a Child Who Does Not Use Speech to Communicate					
Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				Theoretical perspectives rooted in post-positivism. The author explored the shift in their understanding and value of listening to children's voice and how they now view children as 'competent social actors'. Stated participatory approach and involved child in various aspects of the research.
5. Was the recruitment strategy appropriate to the aims of the research?		x			Recruitment procedure not stated.
6. Was the data collected in a way that addressed the research issue?	x				Setting was justified, clear why the individualised methods were chosen within the study. Clear how the methods were conducted.
7. Has the relationship between researcher and participants been adequately considered?	x				Researchers influence on Ian's responses in the storyboard game acknowledge. The child was considered an active participant in the research. Researcher critically examined her own role and potential biases.
8. Have ethical issues been taken into consideration?		x			Ethical approval not stated, wider ethical implications not considered but consent was sought from both parent and child.
9. Was the data analysis sufficiently rigorous?				x	Unclear how the data was analysed; the author reports two 'themes' in their findings but no description about how these themes were generated.
10. Is there a clear statement of findings?			x		Findings presented in the write up, supported by the child's responses but no indication about how the themes discussed in the findings were generated.

11. How valuable is the research?	YES	Valuable research to elicit the child's views. In addition, clearly presents the methods used which have the potential to be replicated in the future by practitioners/researchers.
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Article 12: Gray & Winter (2011) Hearing voices: participatory research with preschool children with and without disabilities					
Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	x				Social-constructivist theory stated and influenced the methodological decisions made in the study (e.g., carried out in a naturalistic setting and observational methods used to explore and understand children's views and perspectives)
5. Was the recruitment strategy appropriate to the aims of the research?		x			Unclear how children were recruited and why this specific pre-school was chosen.
6. Was the data collected in a way that addressed the research issue?			x		Not sure whether there was justification for the specific methods i.e., not linked to previous research. Small group interviews were carried out with staff, however no topic guide stated.
7. Has the relationship between researcher and participants been adequately considered?		x			
8. Have ethical issues been taken into consideration?	x				
9. Was the data analysis sufficiently rigorous?				x	Unclear how the children's data were analysed. It was stated that data were analysed using the qualitative data package NUD*IST (Non-numerical Unstructured Data: Indexing Searching Theorising) but unclear what steps (if any) were taken through this process.
10. Is there a clear statement of findings?				x	Findings from semi-structured interviews missing.

Appendix C

					Credibility of findings missing info?
11. How valuable is the research?	YES				

Article 13: Whitehurst (2007) Liberating silent voices – perspectives of children with profound & complex learning needs on inclusion

Screening	Yes	Can't tell	Partly	No	Comments:
1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?				x	No research paradigm/guiding theory stated within the research.
5. Was the recruitment strategy appropriate to the aims of the research?		x			Participant information not stated, and it is not clear how the young people were recruited.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?			x		The researcher's role and influence in the study not addressed. Although, the importance of triangulating findings was stated.
8. Have ethical issues been taken into consideration?	x				
9. Was the data analysis sufficiently rigorous?		x			
10. Is there a clear statement of findings?				x	Two illustrative case studies.
11. How valuable is the research?					

Article 14: Fitzgerald et al., (2003) Listening to the 'voices' of students with severe learning difficulties through a task-based approach to research and learning in physical education

Screening	Yes	Can't tell	Partly	No	Comments:






1. Was there a clear statement of the aims of the research	x				
2. Is a qualitative methodology appropriate	x				
3. Was the research design appropriate to address the aims of the research?	x				
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?				x	No research paradigm/guiding theory stated within the research.
5. Was the recruitment strategy appropriate to the aims of the research?		x			Not specified how the young people were recruited and why this specific sample.
6. Was the data collected in a way that addressed the research issue?	x				
7. Has the relationship between researcher and participants been adequately considered?			x		Authors acknowledge they took the 'lead role' and drive the direction and focus of the research but not described or examined the potential bias and influence as a result.
8. Have ethical issues been taken into consideration?		x			Consent and ethics not stated in research
9. Was the data analysis sufficiently rigorous?		x			
10. Is there a clear statement of findings?	x				
11. How valuable is the research?	YES				

Appendix C Caden's Digital Story visuals





Caden's Digital Story Checklist

 cooking <input type="checkbox"/>	 chatting to dad <input type="checkbox"/>  on Skype <input type="checkbox"/>	 chatting to grandad <input type="checkbox"/>  on Skype <input type="checkbox"/>	 styling your hair <input type="checkbox"/>
 foot massage <input type="checkbox"/>	 hand massage <input type="checkbox"/>	 watching tv + <input type="checkbox"/>	 Showing stuff my <input type="checkbox"/>  clothes <input type="checkbox"/>
 listening to music <input type="checkbox"/>	 computer <input type="checkbox"/>	 dressing smart <input type="checkbox"/>	 football <input type="checkbox"/>
 cooking healthy food <input type="checkbox"/>	 talking to staff <input type="checkbox"/>	 dancing <input type="checkbox"/>	 spending time on my own <input type="checkbox"/>
 music therapy <input type="checkbox"/>	 relaxation room <input type="checkbox"/>	 baking <input type="checkbox"/>	 swings <input type="checkbox"/>








Caden's Digital Story Checklist

 shopping <input type="checkbox"/>	 walking at river shoreham <input type="checkbox"/>	 spending time with dad <input type="checkbox"/>	 trampolining <input type="checkbox"/>
 going to the park <input type="checkbox"/>	 playdough <input type="checkbox"/>	 taking photos <input type="checkbox"/>	 doing exercise <input type="checkbox"/>
 helping with jobs <input type="checkbox"/>	 drawing <input type="checkbox"/>	 arts and crafts <input type="checkbox"/>	 painting <input type="checkbox"/>
 helping at the allotment <input type="checkbox"/>	 gardening <input type="checkbox"/>	 going to the library <input type="checkbox"/>	 playing games <input type="checkbox"/>
 reading <input type="checkbox"/>	 going for walks <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix C

 You can  choose a  camera.

 Which  camera  do you  want?






 You can  meet  Steph and  on a  video call.

 You can  tell  Steph and  what  you

 want to  video.

 Steph will  send the  camera to  you that 

 you  have  chosen to use.

 This is great.

Appendix D Emily's 'I am...' Digital Story framework (adapted)

Spaces Where does Emily like to explore? In the hub on the swing and using the exercise equipment Time outside in the garden listening to wildlife	People and Interactions How does Emily like to spend her time and who does she interact with? Taking part in Lego Therapy where I work on my communication skills I like to have picnics with my friends
Independence and Agency What does Emily choose to do for herself? I like to choose my hair style each day I like to choose the colour of my nail varnish and my makeup	Objects and Interests What is Emily really interested in and likes doing? Watching the Tweenies on the computer by myself I like to play with bubbles I like to relax in my bedroom
Communication and Expression In what ways does Emily express herself? I can speak, but like to be quiet sometimes I like to look at people I can make choices with support using visual pictures	Support What behaviours show where Emily needs support? If it is too busy or too noisy, I might need to wear my ear defenders or have time outside or be offered my bubbles – Zones of Regulation photos
Skills and Capabilities What is Emily good at? Life skills? I like to choose and make my own breakfast each morning and make the bed I am developing life skills watering plants and gardening	Family What does Emily family love about her? Parents to contribute

<p>Community inclusion</p> <p>How does Emily participate in and contribute to her local community?</p> <p>I like to go to the shops.</p> <p>I visit the beech and go outside for walks</p>	
--	--

Appendix E Topic guide for semi-structured interviews

Hello, my name is Stephanie, and I am a Trainee Educational Psychologist from the University of Southampton. Firstly, I just want to say thank you for consenting to take part in this research project and taking the time to speak to me about your views on the Digital Stories and [where applicable] your experience of the use of digital stories within [the young person's] transition meeting/transition planning. I will be audio recording this interview and if you would like to stop or pause the interview at any time, please just let me know. Do you have any questions before we begin?

Just so I know, were you involved in the transition meeting for [young person]?

If not, what is your experience of the digital story? And when/in what context did you view the story?

How did you feel about the 'I am...' digital story you saw in the transition meeting?

Was there anything that surprised you about the digital story?

What were the main messages that you took away from the digital story?

What impact do you think this digital story had on the transition for this young person?

To what extent do you feel the young person's views (versus an adults) were captured or reflected by the digital story?

To what extent has the digital story (digital story) been able to capture this young person?

Do you feel it represented them well? How does this compare to other methods used? E.g., pen portrait, written information, observation etc.

How do you think the digital story captured the voice of the young person within their transition to a post 19 setting?

What can be done to ensure the young person's views are prominent?

Is there anything you would have liked to change about the digital story?

Is there anything that you have thought about or done differently (or might do in the future) because of watching the digital story?

Do you think the digital story made a difference to the meeting and or transition for this young person? If so, can you explain in what way(s)?

Similarities /differences with other meetings/transitions you have attended/experienced?






Could the digital story have been used in better or different ways?

Do you think these kinds of digital story could be used more widely to support planning the transition to adulthood? If so, in what way(s)?









Is there anything else you'd like to share about your thoughts on supporting young people's transitions? Or the digital stories?

Thank you very much for taking part, I will e-mail you a debrief form following this interview, if you are able to sign this and return it to me that would be great.




Appendix F Mental Capacity Act information




Some people need to know about you in the future.




Is it ok for staff to film you to help people learn about




what you like?



no



not sure



yes

Appendix G Best interest proforma

Best Interest Meeting Record Form
Mental Capacity Act (2005)

If a person has been assessed as lacking capacity, then any action taken, or any decision made for, or on behalf of that person, must be made in his/her best interests (see Section 4 Mental Capacity Act 2005 (MCA)).

Meeting Held On:	08.04.2020	Name of Individual:	[REDACTED]
Venue:	Hill House School	Address:	[REDACTED]

Indicate the nature of the decision(s) that need to be made:

Is it in Emily's best interest for her to be involved in digital 'I am' stories to support her transition into her adult placement?

MCA question was: 'Is Emily able to understand and consent to staff members filming her in order to create a digital 'I am' story to support with her transition into her adult placement?'

Chair:	Decision Maker:	Minute Taker:
[REDACTED]	SLT	Kirsty Marsden

Name of Participants	Designation / Location	Invited	Present	Apologies sent
[REDACTED]	Parents	<input type="checkbox"/>	X	<input type="checkbox"/>
[REDACTED]	Head	<input type="checkbox"/>	X	<input type="checkbox"/>
[REDACTED]	Deputy Head	<input type="checkbox"/>	X	<input type="checkbox"/>
[REDACTED]	Assistant Team Manager	<input type="checkbox"/>	X	<input type="checkbox"/>
[REDACTED]	Social Worker	X	<input type="checkbox"/>	<input type="checkbox"/>

Is there anybody (e.g. family members, person appointed with Lasting Power of Attorney) that you intend to consult as part of this process regarding the decision(s) to be made? (See s.4(7) MCA for usual consultees) If so, please indicate why.

Name	Job Title or Relation to person

Who was consulted as part of the best interests process?

Name	Job title or Relation to individual
[REDACTED]	Parents

Consultation may have been done through varying forms of communication such as direct meeting, telephone conversation, or in writing.

Version: 1
Next Review Date: May 2019
Print Date: 8-Apr-20

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Policy Name: Capacity and Consent
Page 1 of 3

Approved by: Dr Romero
Date: May 16
Reviewed: L. Lechacki June 17

Best Interest Meeting Record Form
Mental Capacity Act (2005)

From consultation with others and/or a best interests meeting what opinions regarding the 'decision in question' have been expressed? Please be as specific as possible, recording down any differences in opinion that may have been expressed.

This meeting took place via a video conference call due to the current pandemic of Covid 19 and social distancing so a face to face meeting was not possible.
The best interest meeting was held within her transition meeting about her move to [REDACTED] her new adult placement.
[REDACTED] explained that a mental capacity assessment was completed in the morning (see MCA report) and Emily does not have capacity to understand and consent to this decision by herself.
Everyone consulted at the meeting agreed that it is Emily's best interest for a digital 'I am' story to be created to support with Emily's transition to [REDACTED]. This will be especially beneficial at present when social distancing will mean that the initial stages of Emily's transition will be more 'virtual' than would typically happen during the transition process.

From meeting with the persons consulted, what is the person's past and present wishes and feelings in respect of this for similar decisions? Did the individual hold any values or beliefs that would have been likely to influence this decision? (e.g. religious, cultural, moral or political) If the person has previously indicated an 'expressed wish' please record down what this is and how it was communicated.

No

What is the decision and are the decision-making options?

That it is in Emily's best interest to create a digital 'I am' story to support with sharing information in support of transitioning to her adult placement.

What are the views of the other relevant people in the person's life? (Family, Friends and Advocates)

Emily's parents are in favour of creating a digital 'I am' story

What is the justification for proposed care / treatment?

The digital 'I am' stories will support with the sharing of information and for her new staff team to get to know her in more detail, before they're able to start shadowing her.

Are there any risks relating to proposed care / treatment?

No

Are there risks related to not carrying out the proposed care / treatment?

That Emily's new staff team won't be able to get to know her in as much detail with the current Covid 19 pandemic

Is the best interests decision/action the least restrictive option (as required by one of the five statutory principles of the MCA)?

Yes

Under what circumstances will this decision need to be reviewed?

If filming Emily seemed to be causing her any distress

Is the person likely to gain capacity in respect to the decision(s) above in the future?





No




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

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Page 2 of 3


Approved by: Dr Romero
Date: May 16
Reviewed: L. Lechacki June 17


Appendix H Caden's consent form





 At  your review  meeting  you






 spoke to  some new people  who


 are going to help  you in the future.




 These people are  your new





 adult support team.



 We have an  exciting project  for  you.


 We want to  help  you make a video  for  your






 new adult support team.




 This video  is called  your Digital Story.


 This video  will  help  your new




 adult support team  get to know  you.





 This is great!



 You  will be  able to  video  your  favourite



 activities  and  places.

 This is great.


 When the  video is  finished  you can  show it to

 your  dad,  grandad,  your   team  and


 your new  adult support team.

 Well done  Caden.

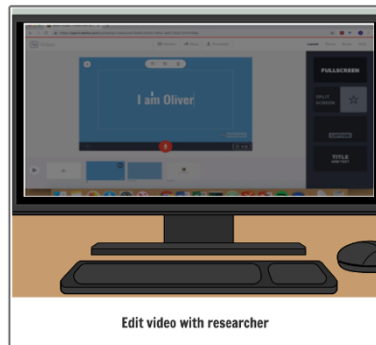
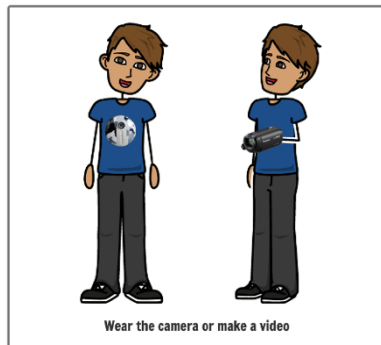
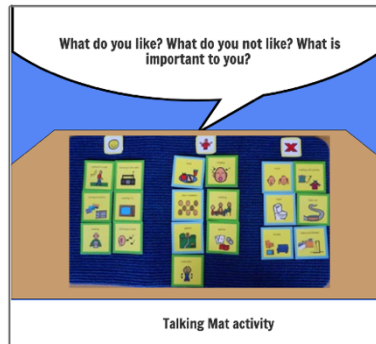
 Do you  want to make a  Digital Story?

 no

 not sure

 yes

Appendix I Assent Comic Strip Visual



Appendix J Stages of Reflexive Thematic Analysis

Stages	Description
Data familiarisation and writing familiarisation notes	Initially, each interview transcript was checked for ‘accuracy’ against the audio recording. Through iteratively listening to the interview audio-recordings and reading and re-reading the written transcripts, I immersed myself in the data. Initial analytic observations (interesting features) from the data set were noted.
Systematic data coding	Succinct and meaningful codes were generated to highlight important features of the data, across all of the data items. A bottom-up, inductive orientation to coding was applied. Initial semantic coding ensured that the analysis stayed close to the words and meanings from participants, where a combination of in-vivo and descriptive codes were applied (Saldaña, 2021). With continued immersion in the data corpus and an iterative reflexive process, latent codes were developed to explore the deeper meaning underpinning the semantic description. Supervision sessions were used to explore meaning of initial codes and relationship between codes. NVivo 12 was used to identify and organise the initial codes.
Generating candidate themes from codes and associated data	Codes were developed into initial candidate themes by organising similar codes into coherent clusters of meaning, which share a similar underlying concept.
Developing and reviewing themes	Themes and sub themes were generated and organised into thematic maps (see Appendix L for examples thematic map development), this stage helped identify and define the relationship between themes by exploring how each theme relates to the others, and the relevance of each theme to the research question. Themes which did not address the research question were reviewed and, if not relevant, removed at this stage.
Revising, defining and naming themes	Further revisions and refinement at this stage led to a deep, nuanced understanding of the applicability, range and scope of each theme and sub theme, which were then outlined through a thematic map. Theme names were revised and defined in supervision sessions to ensure they clearly and concisely captured meaning, were related to the research questions, and captured the voice of participants through the use of direct quotes.
Writing the report	To reflect the interconnection between themes, theme order was considered within the report to ensure themes ‘build on’ each other to form a logical flow and cohesive analytic narrative. Quotes to illustrate themes were included in the report.

Appendix K Participant information sheet



Project Information for Parents/Carers

Study Title: Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood

Researcher: Stephanie Lewis
ERGO number: 55000

- Your child is being invited to take part in the above research study.
- This document provides information about the project. We ask that you please read it in full.
- You can contact Stephanie, the researcher or Kirsty Marsden at Hill House School if you have any questions.
- If you are happy for your son/daughter to take part, you will be asked to sign a consent form.
- If you are happy for your child to take part, you will also be invited to take part in this research project by providing your views on the use of Digital Stories as a tool to support your child's post 19 transition.

What is the research about?

This project is being carried out in partnership between me, Stephanie Lewis, and Hill House School. I am a Trainee Educational Psychologist from the University of Southampton; this project forms part of my doctoral thesis and will also contribute to the work carried out by the Autism Community Research Network: Southampton (ACoRNS) research group, of which Hill House School is a partner. Throughout the project I will be supervised by Hanna Kovshoff and Sarah Parsons from the University of Southampton.

Together with Hill House School, we will be supporting the young people to be involved in co-creating Digital Stories, which aim to capture young peoples' unique experiences to inform their transition post 19.

Digital Stories are short videos that aim to show who the young person is and are a creative way of supporting young people, who may have limited verbal communication, to express themselves. This method allows young peoples' voices to be captured and heard within discussions and planning around their transition to adulthood. The young people and key adults, including parents/carers and keyworkers, will be asked for their views on the digital stories and their experience of the use of digital stories within the young person's transition meeting.

Why has my child been asked to participate?

Your son/daughter has been asked to take part because they are a young person at Hill House school and are aged between 17 and 18 years old.

If you consent to your child taking part in this research, you will be asked to provide feedback through taking part in a semi-structured interview, in order to evaluate the use of the Digital Stories within your child's transition meeting.

What will happen to my child if they take part?

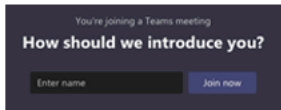
- Your child will be supported to create a digital story to support their transition from Hill House School to a post 19 setting.
- Your child will be supported to plan, **through their preferred communication method**, what their Digital Stories should include. For example: who the young person is, what is important to them, their likes and dislikes, how they communicate, how they manage transitions (including access to the community) and their areas of perceived challenges.
- Filming of the digital stories will take place over a three-month period (the duration of filming may change depending on your child's transition date) and will record your child within environments and activities that they choose and are meaningful to them. Young



people will have opportunities to film and narrate themselves, and/or use small wearcams to capture their experiences, preferences, strengths and capabilities.

- Once filming has taken place, the digital stories will be edited and co-created in collaboration with the support staff from Hill House and, as far as possible, from the young person's point of view.
- The digital stories will be used within your child's transition meeting to bring their voice into the transition process, to help plan for their move from Hill House School to a post 19 setting.

Your child's Digital Story will be shown during their transition meeting to help plan their move from Hill House School to a post 19 setting. Therefore, parents/carers, alongside others in attendance at the transition meeting, will be asked to give feedback through a semi-structured interview, to help evaluate the use of the Digital Stories. In accordance with government guidance of social distancing in response to COVID-19, the semi-structured interviews will be carried out remotely, through Microsoft Teams. You will receive an e-mail which will invite you to a Microsoft Teams meeting, simply click the joining URL to connect. You will see the following prompt to enter the meeting:



Are there any benefits in taking part?

I hope your child will enjoy co-creating their digital stories. Also, as the digital stories will be used within the young person's transition meeting, and the hope is that this will support young people's transition to adulthood by providing a creative way for the young people to express their views through digital storytelling. Little is known in research and practice about how to capture the voice of autistic young people living in residential schools within their transition to adulthood. This research aims to improve our current understanding and create a method to ensure the views and voices of young people with complex needs are heard and understood.

Are there any risks involved?

Not really. Your child will be supported with their allocated support staff at all times and will be involved in creating their digital story. Videoing within Hill House School is standard practice; therefore, the filming of digital stories will not be unfamiliar to the young people involved with this research project.

What data will be collected?

I will collect the following information on the consent forms:

- Your son/daughter's name and age
- Your name and contact information

This information will be kept confidential. It will not be passed onto other people. If consent is gained, your son/daughter's name will be used within their digital story.

During the project I will also collect the following data for my own analysis:

- Raw video data from the filming of the Digital Stories
- The edited Digital Stories themselves, co-created by the young people and Hill House
- Notes and a research diary detailing the process of creating the stories
- Audio recordings and transcribed interview data

The Digital Stories will be shown during the young person's transition meeting. The Digital Story may be shown at presentations about the project and used on the ACoRNS website. In order to support the young person to have ownership over their Digital Story and be credited for their contribution, the young person's name will be included. In cases where consent is not gained for children's names to be used within the project, pseudonyms will be created.

Will anyone else know they have taken part?

These are the people who will know your son/daughter has taken part:



- Staff at Hill House School
- Professionals who attend your child's transition meeting (e.g. social worker, staff from future placement provider)
- Stephanie (researcher) and two supervisors

If consent is given, the Digital Stories will be used on the ACoRNS website where the child's name will be included (as described above). Should consent to use the child's own name not be given, a pseudonym will be created.

Given the contribution of the school to this project, the school itself will be a **named** contributor to the work.

I will take notes and keep a research diary during the creation of the Digital Stories, in which case I will use your child's first name only. Where consent has not been given to use the child's name, your child's name will be replaced by a pseudonym, and the physical copies will be destroyed. The information I collect about them will be kept strictly confidential.

Hill House School will securely store the video data, all editing will be carried out within this setting. Additional confidential material (e.g. transcribed interview data) will be securely stored on password protected computers.

Will anyone know I have taken part?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Does my child have to take part? Do I have to take part?

No, it is entirely up to you to decide whether or not you are happy for your child to take part, and whether you are also happy to take part. If you decide you are happy for you and your child to take part, you will need to sign a consent form. We must receive your consent form by 01/05/2020.

What happens if I change my mind?

You can withdraw your consent for your child to take part from the Digital Story co-creation up until the point of video editing.

If you consent to providing feedback on the digital stories, you can withdraw your consent up until the point the interviews have been transcribed.

What will happen to the results of the research?

The results of the research will be written up as a thesis project as a part of the requirements of the Doctorate in Educational Psychology. The results may also be published in academic journals.

Reports and publications will only include your child's name where you have provided specific consent. Where consent has not been given, pseudonyms will be used instead.

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Where can I get more information?

Please contact me (Stephanie) at the University: stephanie.lewis@soton.ac.uk



You can also contact Kirsty Marsden (Kirsty.marsden@cambiangroup.com) or Louisa Burden (Louisa.burden@cambiangroup.com)

I am also happy to meet you in person to discuss any part of the project and answer any questions or queries you may have.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to Stephanie or Kirsty Marsden first.

If you are still unhappy or have a complaint about any part of this project, please contact the University of Southampton Research Integrity and Governance Manager (02380 595058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

By law, the University of Southampton has to protect and use the information collected in this project in specific ways. This can sound very formal and complicated.

The main thing to know is that we treat any information carefully. There is detailed information about this that we have to let you know, and this can be found on the next page.

Thank you for taking the time to read this.

Stephanie Lewis



Data Protection Privacy Notice



The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legal/services/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information – may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legal/services/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.



Project Information for Stakeholders

Study Title: Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood

Researcher: Stephanie Lewis

ERGO number: 55000

- You are being invited to take part in the above research study.
- This document provides detailed information about the project.
- Please read this document in full.
- You can contact the researcher - Stephanie, or Kirsty Marsden at Hill House School if you have any questions.
- If you consent to take part, you will be asked to provide your views on the use of Digital Stories as a tool to support young people's post 19 transition.

What is the research about?

This project is being carried out in partnership between me, Stephanie Lewis, and Hill House School. I am a Trainee Educational Psychologist from the University of Southampton; this project forms part of doctoral thesis and will also contribute to the work carried out by the Autism Community Research Network @ Southampton (ACoRNS) research group, of which Hill House School is a partner. Throughout the project I will be supervised by Hanna Kovshoff and Sarah Parsons from the University of Southampton.

Together with Hill House School, we will be supporting the young people taking part in this study to be involved in co-creating Digital Stories, which aim to capture young peoples' unique experiences to inform their transition post 19.

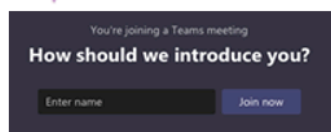
Digital Stories are short videos that aim to show who the young person is and are a creative way of supporting young people who may have limited verbal communication, to express themselves. This method allows young peoples' voices and views to be captured and heard within discussions and planning around their transition to adulthood. The young people and key adults, including parents/carers, will be asked for their views on the digital stories and their experience of the use of digital stories within the young person's transition meeting.

Why have I been asked to participate?

You are being invited to participate as you are a parent/keyworker/teacher/future placement provider/social worker. You will be asked to provide feedback through taking part in a semi-structured interview, to evaluate the use of Digital Stories within the young person's transition meeting.

What will happen if I take part?

- The young person's Digital Story will be shown during their transition meeting to help plan their move from Hill House School to a post 19 setting. You, along with other key stakeholders, will be asked to give feedback through a semi-structured interview, to help evaluate the use of the Digital Stories within this meeting. In accordance with government guidance of social distancing in response to COVID-19, the semi-structured interviews will be carried out remotely, through Microsoft Teams. You will receive an e-mail which will invite you to a Microsoft Teams meeting, simply click the joining URL to connect. You will see the following prompt to enter the meeting:



Are there any benefits in taking part?

As the Digital Stories will be used within the young person's transition meeting, the hope is that this will support young people's transition to adulthood by providing a way for the young people to express their views through this method. Little is known in research and practice about how to capture the voice of autistic young people living in residential schools within their transition to a post 19 setting. This research therefore aims to improve our current understanding and create a method to help ensure the views and voices of young people with complex needs are heard and understood.

Are there any risks involved?

We do not think there will be any risks associated with you taking part in the study.

What data will be collected?

Your name and contact information will be collected through completion of the consent form; these will only be used to contact you, should we need to. They will not be used for any other purpose. Your name will be kept confidential, and any reports on the project will make use of pseudonyms to maintain your confidentiality.

Given the contribution of the school to this project, the school itself will be a named contributor to the work.

Your consent forms will be scanned, and you will be assigned a pseudonym which will be used to refer to the rest of your data. This data will be stored on the university network, and on encrypted devices belonging to me, the researcher. Audio files from the semi-structured interview will be deleted once transcription and analysis has been completed. Direct quotations from transcripts may be used in written reports of the project. However, where direct quotations are used, your name will not appear alongside the quotations to maintain your confidentiality.

Will my participation be confidential?

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep their information, as a research participant, strictly confidential.

Your name will only be recorded on the consent form. Consent forms will be stored securely in a locked room which only the researchers have access to.

I will be completing a research diary and keeping field notes to document the process of creating the stories and to capture the experiences and feelings from staff, and the young person, about how they believe the stories are progressing and their use within transition meetings. Where necessary, I will use your first name only. When my notes and research diary are typed up, your name will be replaced by your pseudonym, and the physical copies will be destroyed. Your name will never be used directly in reports on the project, instead I will use a pseudonym to refer to you.

Do I have to take part?

16.04.2020 v3.0

ERGO number: 55000



No, it is entirely up to you to decide whether or not they take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to participate.

What happens if I change my mind?

You have the right to change your mind and withdraw up until the point of interview transcription, without giving a reason and without your rights being affected.

You can withdraw by emailing me directly (stephanie.lewis@soton.ac.uk)

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The results of the research will be written up as a thesis project as a part of the requirements of the Doctorate in Educational Psychology. The results may also be published in academic journals.

Where can I get more information?

Please contact me (Stephanie) at the University: stephanie.lewis@soton.ac.uk
You can also contact Kirsty Marsden (Kirsty.marsden@cambiagroup.com) or Louisa Burden (Louisa.burden@cambiagroup.com)

I will be happy to provide further information about the project and answer any questions or queries you have about taking part.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak me, the researcher, or Kirsty Marsden first.

If you are still unhappy or have a complaint about any part of this project, please contact the University of Southampton Research Integrity and Governance Manager (02380 595058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton is legally obliged to protect and use the data collected in this project in specific ways. This can sound very complicated but the main thing to let you know is that this means that we treat any information provided within research projects with very high levels of care and consideration.

There is detailed information about this that we are required to let you know, and this can be found at the end of this form

Thank you for taking the time to read this.

Stephanie Lewis



Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information – may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Appendix L Consent forms



CONSENT FORM

Study title: Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood

Researcher name: Stephanie Lewis
ERGO number: 55000

Please initial the box(es) if you agree with the statement(s):

Your initials
go here
↓

I have read and understood the information sheet v3.0 16.04.2020 and have had the opportunity to ask questions about the study.	
I agree to let <u>my child</u> take part in this research project and agree for their data to be used for the purpose of this study.	
I understand that <u>my child</u> taking part in the study involves video recording (creation of Digital Stories) which will be used within my child's transition meeting.	
I understand <u>my child's</u> participation is voluntary and I may withdraw them up until the point of video editing.	
I understand that the Digital Stories may be shown when this project is presented in academic talks or available on the ACoRNS website, but that it will not be made publicly available without my permission.	
I agree that <u>my child's</u> name can be used within their Digital Story.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw for any reason without my participation rights being affected, up until the point of interview transcription.	
I understand that feedback on the use of Digital Stories involves interviews which will be audio recorded. Audio recordings will be transcribed and then destroyed for the purposes set out in the participation information sheet	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (<u>e.g.</u> that my name will not be used).	
I understand that parents/carers of other children involved in the project will receive copies of their child's Digital Story, and that my child may feature in others' videos.	
I understand that personal information collected about me and my child such as my name or where I live will not be shared beyond the study team	

16.04.2020 v3.0

ERGO number: 55000



Name of your child (print name)

Age of your child.....

Your name (print name)

Contact number/email address.....

Signature.....

Date.....

Name of researcher (print name)

Signature of researcher

Date.....



CONSENT FORM

Study title: Using Digital Stories to facilitate autistic young people to have a voice in their transition to adulthood

Researcher name: Stephanie Lewis
ERGO number: 55000

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (16.04.2020, v3.0) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw, up until the point of interview transcription, for any reason without my participation rights being affected.	
I understand that if I withdraw from the study that it may not be possible to remove my data once my personal information is no longer linked to it.	
I understand that I will not be directly identified in any reports of the research.	
I understand that the project evaluation involves interviews which will be audio recorded. Audio recordings will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that I may be quoted directly in reports of the research, but that I will not be directly identified (e.g. that my name will not be used)	
I understand that personal information collected about me such as my name will not be shared beyond the study team.	

Name of participant (print name)

Signature of participant.....

Date.....

16.04.2020 v3.0

ERGO Number: 55000



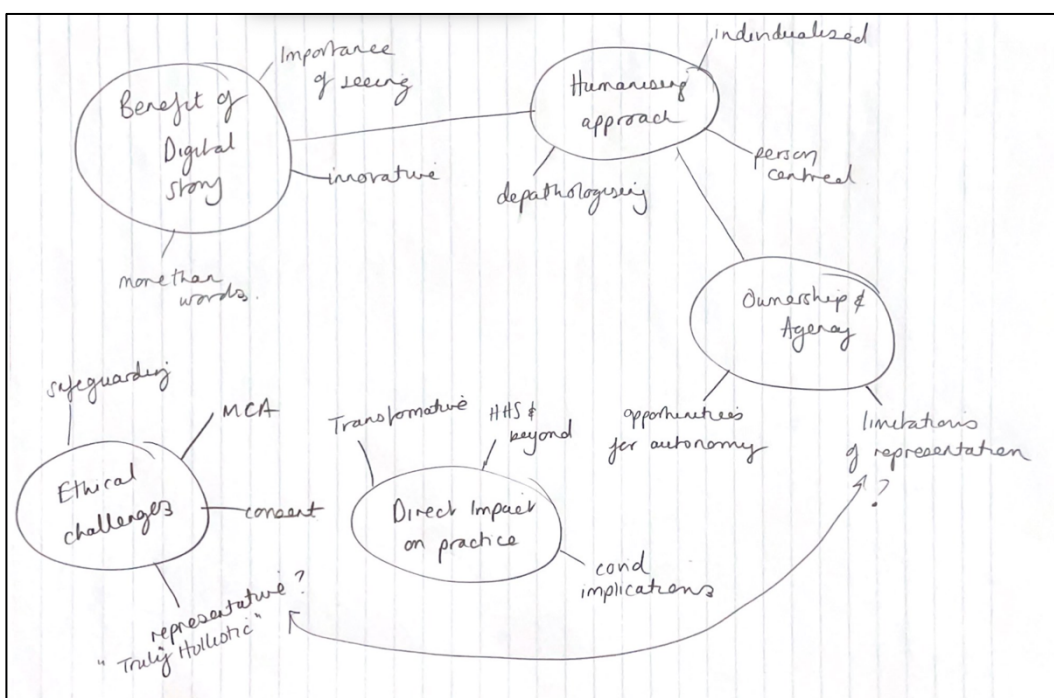
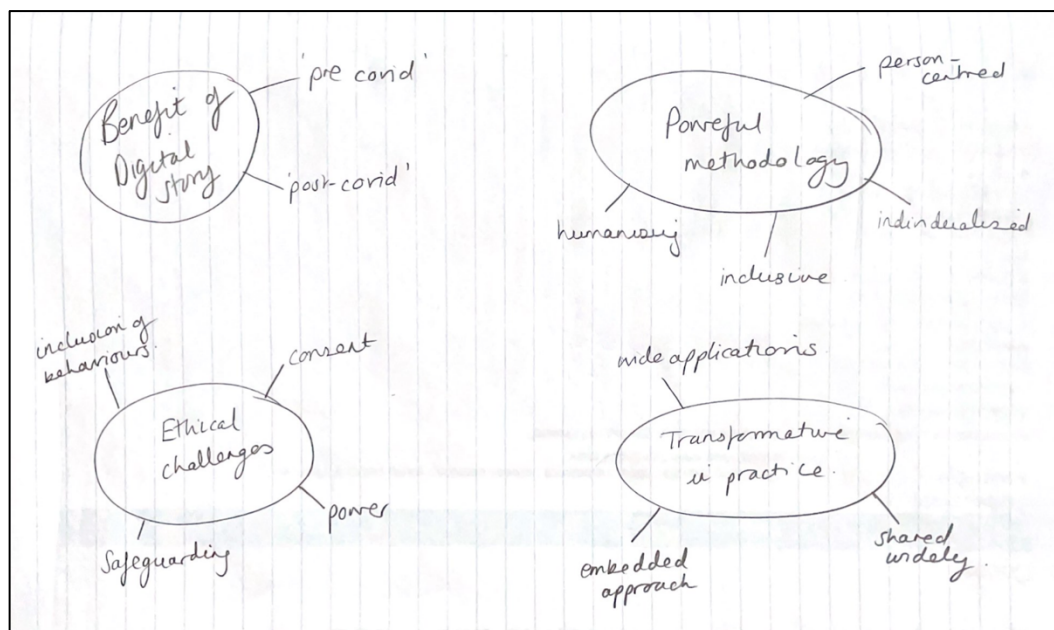
Name of researcher (print name)

Signature of researcher

Date.....

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Appendix M Thematic map development



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