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Experiences of self and belonging among young people identified as
having learning difficulties in English schools

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Declaration

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It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text.

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Experiences of self and belonging among young people identified as having learning difficulties in English schools

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Young people identified as having special educational needs and/or disabilities (SEN/D), remain some of the most marginalised learners in the English education system. These young people are one of the most likely groups to face exclusion from school and evidence suggests that discrimination against disabled adults and children, in England, is on the rise. Within research debates on education, the voices of those identified as having SEN/D remain on the margins.

Six story-telling case studies were undertaken, exploring the experiences of young people identified as having learning difficulties in a mainstream, mainstream faith and special school in England. Specifically, the way in which the young people described themselves and experienced a sense of belonging was examined. An ethical and robustly inclusive methodology using arts-based methods was developed to empower the young people to share their experiences on their own terms. Embracing the potential of video voice, self-portraiture and life-mapping as ethical, participatory and inclusive research methods, this study has captured multi-sensory narrative data. Offering a detailed description of how the methods operated inclusively contributes to the field and, supports other researchers to undertake inclusive research alongside young people identified as having learning difficulties.

The voices of the six young people are examined to show the ways in which they demonstrate a resistance to othering discourses in society, through describing themselves and articulating their sense of belonging. The young people's reflection on difference and disability demonstrated that their knowledge of disability and specific 'diagnoses' was limited. Moreover, the way in which they described themselves and their peers reinforced a dichotomy of 'normal' and 'other'. Hence, I argue within this thesis for the further development and dissemination of a social model of learning difficulty. This model rejects the notion of essential difference and offers an understanding that learning difficulty, similarly to disability, can be viewed as socially constructed. Based on the young people's reflections on belonging, I also problematise the use of special educational needs (SEN) labels within school settings arguing that, discussions around the use of labels must involve the voices of young people. In relation to SEN labels, I also examine the geographies of SEN/D using the young people's reflections to underline how nurture or inclusion units can have the potential

to both offer refuge and reinforce notions of difference.

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List of Abbreviations

AS	Autism Spectrum
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CoP	Code of Practice
DfE	Department for Education
DfES	Department for Education and Skills
DoH	Department of Health
EHCP	Education Health and Care Plan
ELSA	Emotional Literacy Support Assistant
LA	Local Authority
ONS	Office for National Statistics
OT	Occupational Therapist
PISA	Programme for International Student Assessment
SaLT	Speech and Language Therapist
SENCo	Special Educational Needs Coordinator
SEN	Special Educational Needs
SEN/D	Special Educational Needs and/or Disabilities
TA	Teaching Assistant
USB	Universal Serial Bus
WHO	World Health Organisation

Chapter 1. Researching in a real and changing world

1.1 Beginning my journey

Across the globe, tensions persist regarding the rights of disabled people. Despite most countries committing to the UN Convention on the Rights of Persons with Disabilities and hence, committing to the development of “inclusive education at all levels” (UN, 2006, Article 24), questions still remain as to where young people identified as having special educational needs and/or disabilities (SEN/D) should be educated. Whilst increasing numbers of young people are accessing education globally, those identified as having SEN/D are still less likely to be attending school than their counterparts (UNESCO, 2018). There is no singular definition of inclusive education and increasingly the notion is becoming contested, particularly in southern contexts where northern rhetoric is being questioned (Singal, 2019; Singal, Ware and Khanna-Bhutani, 2017). England is no exception to the global challenge of ensuring all children access to quality inclusive education. For instance, in recent years changing British governments have influenced inclusive policies and the geographies of schooling for young people identified as having SEN/D. In the last decade, the right-leaning Conservative-led coalition has called for an end to the “bias towards inclusion” (DfE, 2011, p.5), and stopped the closure of special schools instigated by the previous left-leaning Labour government. Despite the continuing change of policies in relation to the schooling of young people identified as having SEN/D (see Chapter Two), little inclusive and participatory research has been undertaken in an English context examining the lived school experiences of young people identified as having learning difficulties. This thesis feeds into these continuing policy debates by directly exploring the voices of young people identified as having learning difficulties in different school settings, including a special school, a mainstream school and a mainstream faith school.

In academia, it remains the case that the voices of children identified as having learning difficulties are often excluded from mainstream debates and hence, rigorous research elucidating the lived experience of disabled people has been minimal (WHO, 2011; Pisani and Grech, 2015; Liddiard et al., 2018). Moreover, there are many challenges when aiming to ensure research is inclusive and participatory for people identified as having SEN/D. This is particularly so for those identified as having learning difficulties, or for people who are neuro-diverse (Milton and Sims, 2016). When undertaking research with young people identified as having SEN/D, I assert that *all* people should be ‘heard’ within academic discourse and should be treated as experts regarding their own reality. In undertaking this

research, I aimed to contribute to the shifting of positionality: seeking to start from a point of researching *with* young people identified as having learning difficulties rather than *about* them (Curran and Runswick-Cole, 2014).

My research experience has been iterative, moving and reforming as the political world around us changes. Initially this work started life as a study exploring the experience of belonging of children identified as having SEN/D who had migrated to England from Eastern Europe. In the first academic year of my PhD, the United Kingdom voted to leave the European Union and many Eastern European families experienced a significant increase in prejudice and hate crimes. This led me to reform the scope of the research, whilst holding tight to the notion of belonging, and to explore experiences of children with SEN/D, specifically those identified as having learning difficulties, across different school settings. I argue within this thesis that researching from a point of belonging is crucial so as to not reproduce disabling notions, such as 'Other', which is prevalent within disability studies (See Chapter Three). The complexity of researching in the real world has led me to focusing deeply on the way in which we, as a society, work with and prioritise young people identified as having SEN/D and to champion the voices of those engaged in this study as being vibrant and valid.

On a personal level, this study brings together key facets of myself: my lived experience of mental health since childhood; my professional experience as a special educational needs practitioner running Local Authority funded Alternative Educational Provision for young people identified as having severe learning difficulties and complex needs and; as an educational researcher searching for ways to facilitate young people identified as having SEN/D sharing their experiences through creative and inclusive means. My specific and substantial experience of working on the ground with young people with complex needs has led me to the point of feeling that questions regarding where children should be best educated are highly complex and that often young people's own points of view are not fully taken into account. Moreover, the continued pathologisation of human diversity and the deficit lens through which young people identified with SEN/D are often seen is problematic and harmful to their educational experience. For, this does not take account their rich lived experiences as expressed by themselves. In line with these concerns, and through immersing myself in the literature, three questions are posed:

1. What are some of the ways in which young people identified as having learning difficulties describe themselves?

2. What are some of the ways in which young people describe and experience a sense of belonging in their educational settings?
3. How inclusive are self-portraits, videovoice and life mapping as research methods for enabling young people identified as having learning difficulties to describe themselves and their experiences?

1.2 Reflections on terminology: “Why should I be like bloody Rain Man?”¹

Chambers (2012) rightly underlines in his work on participatory research that, “words and labels matter” (p.72). I wholly acknowledge the problems surrounding the word ‘disability’. The challenging nature of this terminology has led me to utilise specific phrases when referring to disability, autism and special educational needs as descriptive characteristics within this research. The rationale for each of the terms used is discussed in this section.

When writing on a social context, and particularly about adults, I will use the term **disabled people**. As this research is being undertaken in an English educational context, respect has been given to the term **disabled people**, which disabled people and disabled academics most commonly utilise when discussing themselves (Corker, 2001; Longmore, 2003; Oliver, 2002; Shakespeare, 2014). This phrasing pertains to the Social Model of Disability, which is prominent in England, whereby disability is theorised as a societal construct. Accordingly, people are considered disabled owing to the barriers in society, rather than through their impairment or physical/neurodiversity (Oliver, 1990). The model has particularly been adopted in countries with a Euro-North American heritage, especially the UK and USA (Shakespeare & Watson, 2001). It should be noted that this theory of disability is not so widely accepted in other contexts. In fact, it has been suggested in some countries that more attention should be given to the product of impairment or physical/neurodiversity as opposed to focussing entirely on societal barriers (Chouinard, 2014; Grech, 2009; Singal, 2010).

The phrase **young people identified as having SEND**² will be used in education specific contexts when writing about literature or the context of this research. This phrasing, whilst also acknowledging the diversity within this population, enables the consideration of the child *first* before any constructed label. The current SEN Code of Practice (CoP) identifies a child as having SEN/D, “if they have a learning difficulty or disability which calls for special

¹ MacLeod et al., 2013

² Within the literature, others make reference to ‘children who have been identified as having special or additional support needs’ (Black-Hawkins & Florian, 2012, p. 568).

educational provision to be made for him or her” (DfE & DoH, 2015, p. 15). Disability is further defined as, when someone “has a significantly greater difficulty in learning than the majority of others of the same age” or “has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools” (DfE & DoH, 2015, pp. 14–15). It has been suggested that the term SEN/D was implemented in order to move away from a deficit view of disability (Norwich, 2010). However, definitions used within the current SEN/D CoP focus disability on the individual having an impairment that affects *their* ability to function, rather than placing disability under *socially* created barriers that limit participation (DfE & DoH, 2015; Oliver, 1990; Shakespeare & Watson, 2001; WHO, 2011). This suggests that, despite the advocacy for the social model of disability in England and its inclusion in holistic transnational frameworks and conventions,³ English educational policy is still deficit focussed and determinist. The phrase **young people identified as having SEN/D** is adopted here in order to bring this research in line with the current English education policy terminology, whilst also maintaining a critique of SEN/D as a judgemental constructed category ascribed to people.

When referring to the participants in this study, I will use the terms **autistic young people identified as having a learning difficulty** and **young people identified as having a learning difficulty**. In referencing autism, I wanted to provide differentiation between learning difficulty and the condition. I have further made the decision highlight autism, first, due to one of the participants, i.e. Nameless, specifically describing himself as autistic and this he saw as being integral to his self-identity. Hence, the term appears first in the order of description. With respect to the use of the phrase **identified as having a learning difficulty**, this is utilised due to the fact that that the formal diagnosis of the learning difficulty was a sampling criterion for the current study. I use the word ‘identified’ in the phrase to underline how this is a judgemental category imposed on young people and to acknowledge that they may well not self-identify as such. Moreover, I chose to use the term **learning difficulty** instead of learning disability after considering research undertaken by others, such as Emerson et al. (2005) and the Learning Difficulties Research Team (2006), who demonstrated that in situations where labels are to be used people who are given them prefer this term. This also concurs with my own professional practice, where the people I work with also utilise the term learning difficulty more frequently than learning disability.

³ Such as the World Health Organisations International Classification of Functioning, Disability and Health (ICF), a “bio-psycho-social” framework for considering disability that integrates environmental, psychological and biological factors and combines elements of the medical and social model of disability, providing a holistic understanding of disability (World Health Organisation, 2011, p. 4).

Conversely, when using terminology to refer specifically to individuals without formal identification of SEN/D I will use the term **physically/neuro typical**. This is currently the most appropriate nomenclature that I have come across within the sector, being used, in my experience, by many educational practitioners and parents. Any reference to '**normal**' will be made using inverted commas to underline my own view that this is an artificial socially constructed concept that is often used to create and sustain unequal power relationships in society (Davis, 1995; Foucault, 1975).

However, I end this section by urging caution with the words of Hans Reinders:

“negative connotations do not reside in words but in the mind. Negative connotations are attached to words because of how people think about disability; thus, without changing their habits of thinking, people will use new words just as they used the old ones” (2009, p.46)

1.3 Understanding participants' needs

The young people aged between twelve and nineteen, who took part in this study, were all formally identified as having a learning difficulty. Whilst they were identified as being on the Autism Spectrum (AS), they also had an additional identification of a learning difficulty. Their learning difficulties were categorised as mild to moderate, which meant that all of them had either an educational statement (which ceased to exist on 1st April 2018) or an Educational Health Care plan (EHCP). As well as indicating the formal diagnosis, these documents detail the needs of the young people, expected outcomes, the necessary educational provision for achieving the desired outcomes and additional support or therapy each was entitled to. The following pages contain short 'pen portraits' of some of the special educational needs and/or disabilities the young people participating in this study were identified as having. The following portraits are left nameless and sexless as it is not the intention, here, to capture the personalities of the participants. Rather, I have chosen to focus here on their special educational needs and/or disabilities (SEN/D) to give the reader a background understanding of the needs that the young people participating in this study had. I also believe that this information uncovers why it was integral to the research to have an inclusive and participatory methodology underpinning this work.

Portrait A

One young person who took part in the study had cerebral palsy as well as a genetic condition, ectodermal dysplasia. The cerebral palsy had caused developmental delay as well as physical impairments meaning they had to use a wheelchair and they lacked fine and gross motor control. The ectodermal dysplasia caused their skin, hair, teeth, nails and sweat glands to develop atypically, with lattermost conveying that they were at risk from developing dangerously high body temperatures. Their speech, language and communication needs meant they found it difficult to speak. As I got to know them more, I was better able to understand and communicate without relying on a Teaching Assistant (TA) to help interpret. Once the young person was more confident in my ability to communicate effectively with them, they started speaking to me directly rather than to the TA.

Portrait B

Another young person had a diagnosis of acquired brain injury as well as epilepsy. They had difficulty with cognition and learning, thus needing significant support to access the curriculum as well as assistance with life-skills and gaining independence. They were able to have short conversations, but found it difficult to initiate communication beyond learnt formalities or immediate needs. Additionally, the young person had behaviour which was identified by teachers as challenging. When I met this young person, they had, in the main, managed to learn techniques to help deal with difficult situations. However, for much of their educational life, they had had to deal with the aftermath of violent outbursts.

Portrait C

One young person had a diagnosis of global developmental delay resulting in significant speech, language and communication needs. Their attainment was significantly below the expected levels and they were regularly taken out of class for 1:1 intervention. The young person often had 'meltdowns' and would be unable to access the classroom and would lie on the floor and cry. The young person had low levels of concentration and found it very difficult to stay 'on task' in school, often only talking about what they were interested in. The Special Educational Needs Coordinator (SENCo) did not feel the school was meeting the young person's needs and was pursuing a transfer to alternative specialist provision.

Portrait D

Another young person also had a diagnosis of global developmental delay resulting from being born extremely prematurely. They also had asthma. They had been held back a year in primary school and were very conscious of being older than their peers and choose to hide this fact from classmates. The young person was regularly taken out of class for small group interventions. The school was worried about their social skills and felt they were

particularly vulnerable and at-risk in relation to child protection issues.

Portrait E

One young person had been identified as being high functioning on the Autism Spectrum (AS) as well as having a learning difficulty. They found communicating socially with their peers very difficult and were aware of their social isolation. They experienced high levels of stress and anxiety and talked about feeling depressed. The young person often seemed quite angry, but had a strong fear of authority and being told off and so it often felt like they suppressed their feelings. When they had a chance to speak about their anger, they spoke about wanting to chop people's heads off and it was the fear of the law that stopped them.

Portrait F

Another young person who was also identified as being on the AS, had difficulty understanding social behaviour and interaction as well as using and understanding non-verbal and verbal communication. Whilst they had strong relationships with the staff in the school, the young person had very few positive social relationships with peers. The school had some concerns about the level of familiarity and touch the young person had in some relationships with teaching assistants. Transition and change in school caused the young person difficulties, often resulting in behaviour seen as challenging, which meant they were not allowed to access the classroom.

In progressing through this thesis, I hope the young people will become alive and their multifaceted selves become a reality.

1.4 Thesis structure

The initial section of this thesis (chapter two) comprises a literature review. The cultural context of the research, namely England, is examined and the changing policies affecting the education of young people identified as having SEN/D is discussed. Following this, I probed the extant research exploring the voices of young people identified as having SEN/D. I discuss findings relating to the way in which they describe themselves, their educational experiences and their experiences with peers. I conclude the literature review by contending that this kind of research should begin from a place of belonging rather than assumed stigma. I also articulate my own understanding of 'belonging' and 'self' for the purpose of this research.

I then move on to the methodology (chapter four), where I outline the philosophical assumptions underpinning this research. I advocate for having used a case study approach comprising the arts-based tools videovoice, self-portraits and life mapping. I explain how these tools were augmented so as to be inclusive for the young people in my research. I discuss the real-world challenges involved in making research tools accessible and offer insights from the two pilots undertaken to develop these tools as well as reflections from the main research study. The schools and participants are presented in order to offer insights into the ways in which the young people can retain control over their representation and specifically, work undertaken with them focussing on meaningful pseudonym selection. Following this, I describe the analysis procedures undertaken. Consideration of the ethics and trustworthiness were fundamental to this research and are discussed in detail, explaining how the young people participating were facilitated to assent or dissent throughout the data collection. Within this chapter data is presented pertaining to research question three.

Chapters five to seven present the findings relating to research questions one and two. Chapter five presents data for addressing research question one, in particular, regarding the ways in which the participants described themselves. This chapter also examines the manner in which the young people talked about themselves in relation to disability, either embracing or distancing themselves from the concept. Chapter six presents the data connected to research question two, exploring the ways in which the young people related experiences of a sense of belonging. Chapter seven engages with the adults who participated in the research, elucidating the extent to which their views confirmed or contested those of the young people.

The final two chapters (chapters eight and nine) contain discussion on the findings and the conclusion. Chapter eight examines the ways in which the young people's narratives challenged and navigated othering discourses. I argue that the young people's reflection on difference and disability was limited, which tended to lead to reinforcement of a dichotomous sense of 'normal' and 'other'. Accordingly, I posit that further development and dissemination of a social model of learning difficulty is needed. I also problematise the use of SEN labels and the geographies of SEN in schools. In the final chapter I offer reflections on the strengths and limitations of the study. Finally, future avenues for investigation are proposed.

Chapter 2. Mapping the landscape: A review of the context and SEN policies of England

2.1 Introduction

This chapter examines the changing narratives in England on the education of young people identified as having special educational needs. I make the argument that, due to the changing political landscape it is vital for research be undertaken across the range of different schooling provision in England, with the focus being on the experiences of the young people as expressed by themselves.

2.2 The Context of England

England, one of the four countries that makes up the United Kingdom (UK), has a population of 55,977,000 (ONS, 2019). As of January 2019, there are approximately 8,820,000 on the school roll (primary and secondary) (DfE, 2019a). Of these young people, 14.9% (1,318,300) are identified as having SEN, a rise for the third consecutive year (DfE, 2019b). Within the population identified as having SEN, 3.1% (271,200) have an Education Health and Care plan (EHC plan), whilst 11.9% (1,047,200) receive SEN support and in both cases, this is an increase of 0.1% on the previous year (DfE, 2019b).

In England and the rest of the United Kingdom, formal education is compulsory from the age of five to sixteen years old, with fifteen hours of free early years education provision beginning at the age of three for all children as well as additional provision for those coming from low-income families (DfE, 2018a). In recent years, required participation in education or training, in England, has been extended until the age of eighteen years old. If students do not wish to continue with full-time education (such as going to a college), then they must start an apprenticeship or traineeship, or spend 20 hours working/volunteering whilst undertaking part-time education or training (DfE, n.d.). Moreover, as of 2014, education guidelines stipulate that, if a young person does not hold a maths and/or English GCSE⁴ grade A* to C or equivalent at age sixteen, then they must continue to study this until they turn eighteen or until gain the appropriate qualification, whichever comes sooner (DfE, 2017). For young people identified as having SEN/D, who have an EHC plan, the statutory

⁴ General Certificate of Secondary Education refers to national exams administered at the end of secondary school when age 15 or 16.

guidance mandates that they should have free access to further education from 19 to 25 years old in the same way that free education is provided to all 16 to 18 year olds (DfE & DoH, 2015).

Despite the compulsory nature of formal education in England, significant disparities remain in educational attainment. Data from the 2015 Programme for International Student Assessment⁵ (PISA) indicates a gap of “over eight years” of schooling between the top ten and bottom ten percentiles in England (DfE, 2016 p.6). This disparity is more significant than in most other Organisation for Economic Co-operational and Development (OECD) countries, with the Department for Education (2016) reporting that this is due to socio-economic status and citizenship status. For children identified as having SEN there is significantly more disparity, with only 22% of children identified as having SEN/D reaching expected levels in reading, writing and maths in Key Stage two⁶ national assessments (DfE, 2019c). Furthermore, in 2017, the United Nations (UN) published a report citing discrimination and rights violations of disabled people in the United Kingdom (UN, 2017). Focussing on young people specifically, the report notes concerns regarding increased incidences of “bullying, hate speech and hate crime against children with disabilities” (UN, 2017, Section 20e).

2.2.1 Examining discourse: How policy has shaped the education of children identified as having SEN/D in England

In 1944, The Education Act set out a pathway for a twin-track system of mainstream and special schools. Since then, the government view has changed multiple times as to the best place to educate children with disabilities. In this subsection, there is a brief outline of the development of education policy in the UK along with coverage of key discussions around the education of children identified as having SEN (see Figure 1).

The Education Act of 1944 stipulated that children who were identified as having “disability of mind or body” should receive education in a special school, or “special educational treatment” appropriate to their needs (Part II, Section 8(c)). The act set out a twin-track

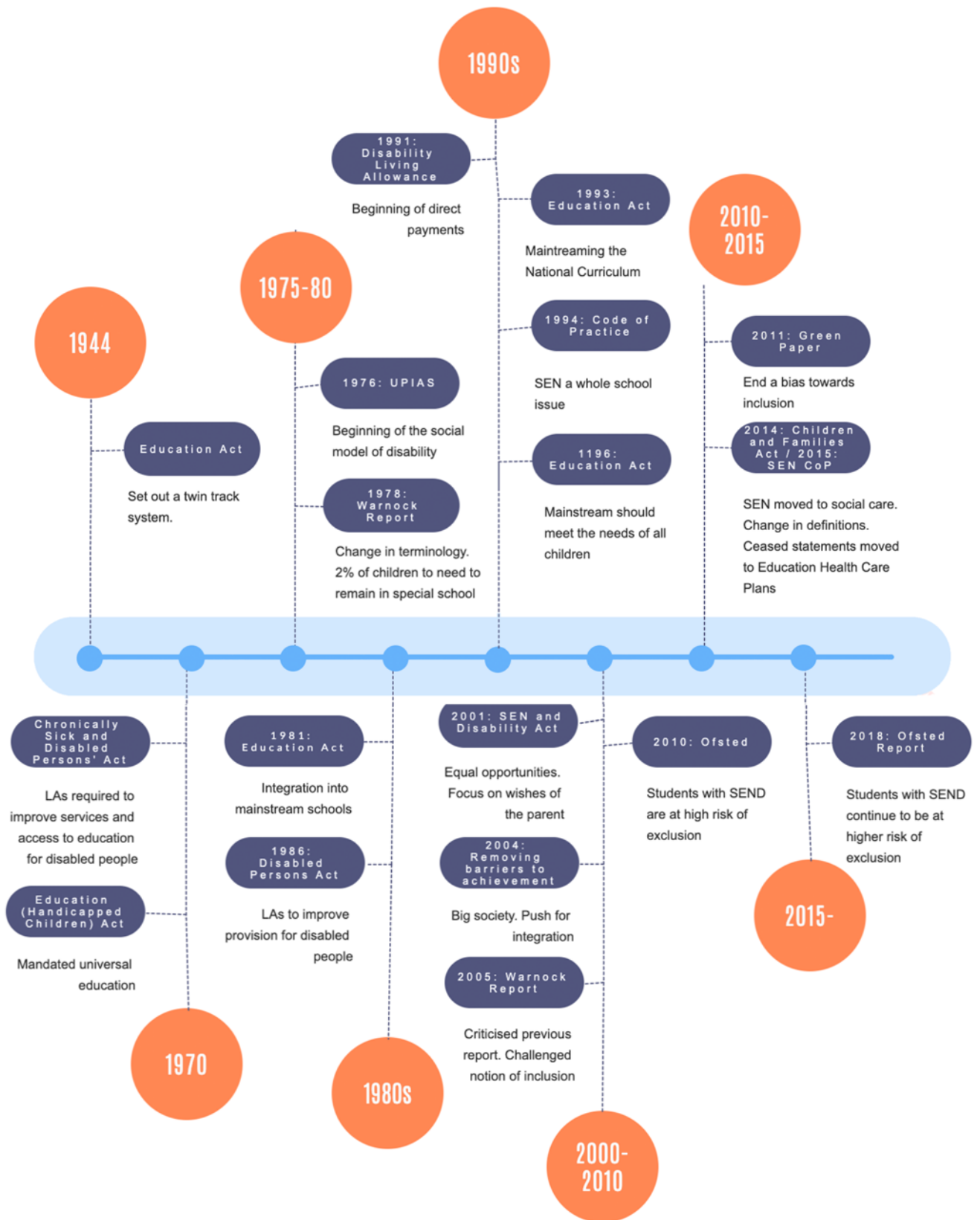
⁵ PISA data is based on students aged 15, which typically excludes students identified as having SEN from its sampling.

⁶ Key Stage 2 is the stage taught between years three and six in primary school, when the child is aged seven-eleven years old.

Figure 1

Timeline of SEN policy in England 1944-present

Source: Researcher



system outlining the profile of students who should attend mainstream and special school, explaining that young people identified as having severe disabilities should attend special schools. In the case of young people, for whom attending special school was “impracticable” or, for those identified as having mild disabilities, they were to be able to access education in any school maintained by the government (Part II, Section 33(2)). Subsequently, in 1970, universal education was mandated in the Education (Handicapped Children) Act, where it was stipulated that children “suffering from a disability of the mind” should no longer be considered as “children unsuitable for education at school” (Section 1(a)). Following this, the 1978 Warnock report significantly changed the language of disability and education, recommending that terms, such as “educationally sub-normal”, be replaced with new ones, such as “children with learning difficulties” (Warnock, 1978, p.43). Within the report, it was argued that this change would end the categorising of children using terms that evoked stigma, and rather, simply be used for “descriptive purposes” (p.44). The report was also a landmark in the debates on inclusive education, recommending that all children should be educated in mainstream in classes with peers of the same age. However, it also held that 2% of children were likely to need to remain in special schools (Warnock, 1978, p.101).

The report received criticism at the time and retrospectively, particularly for the assertion that one in five children would experience learning difficulties during their school career. Ainscow and Muncey (1989) argued that this assertion made in the Warnock Report (1978) led to schools citing the lowest achieving 20% of pupils as having special educational needs. Hence, where the report sought to disrupt the medical model of categorising deficits, it instead, justified a greater identification of children as having special educational needs. In response to the Warnock Report (1978), the 1981 Education Act introduced Statements of Special Educational Needs for children who were seen as facing severe learning difficulties. It was mandated that the local authority should assess these young people and provide schools with additional resources to meet their needs, thus providing the impetus to move them towards mainstream integration.

Further moves towards mainstreaming happened during the 1990s, particularly the 1993 Education Act and the mainstreaming of the National Curriculum, mandating that all children, including those identified as having SEN, should have access to a broad and balanced curriculum. The 1994 Code of Practice (DfE) delineated SEN as a whole school matter and outlined the role of the Special Educational Needs Coordinator (SENCo), which would later become compulsory in all schools. A review of progress into the quality of the education of young people identified as having SEN/D highlighted that, whilst schools had set up new practices in line with the 1994 Code of Practice (DfE), most SENCos were untrained and

schools were struggling to adapt the curriculum to being accessible (Ofsted, 1996). The 1996 Education Act outlined that mainstream was the preferred setting for children identified as having SEN/D as long as it was deemed an “efficient use of resources” and ensured “efficient education for the children with whom he will be educated” (Section 316). Given the focus on “market forces” under the Conservative government from 1979-1997, it has been argued that the matter of inclusion was financially driven rather than based on an inclusive ideology (MacBeath et al., 2013, p.3).

Shortly after the turn of the millennium, the new Labour government brought in measures aimed at bringing more equity to society. The 2001 revised Code of Practice (DfES) set out a new definition for students identified as having SEN. This was coupled with the 2001 Special Educational Needs and Disability Act, which specifically sought to protect the rights of students with SEN/D in schools and legislated against educational discrimination. This act further underlined the 1996 Education Act’s dictat that children identified as having SEN/D should be educated in mainstream schools. This act removed the 1996 clause focusing on the efficient use of resources and replaced it with a statement on the importance of “the wishes of his parent” (Special Educational Needs and Disability Act, 2001, Section 316). However, despite legislation mandating the inclusion of children identified with SEN, in 2002, an Audit Commission’s report highlighted significant and continuing challenges to inclusion, specifically in relation to children being turned away from mainstream schools (House of Commons, 2006).

In 2004, the Department for Education and Skills (DfES) (previously and currently the Department for Education) published a report entitled Removing Barriers to Achievement outlining the government’s strategy for children with SEN. It underlined the need for better integration of services inside and outside of school as well as reiterating a call for inclusive practices being embedded in every school (DfES, 2004). It was argued that improved teacher training and hence, teachers better meeting the needs of all children, would reduce educational disparity (DfES, 2004). In the same year that the DfES published its report, Ofsted published another stating that children identified as having SEN were not properly catered for and the current education system was too inflexible, thereby creating more barriers for children identified with SEN/D (Ofsted, 2004). The following year another significant report was published by Mary Warnock, in which it was argued that two significant recommendations from the previous report, the “integrationist approach” and the mandate to “transform” terminology of SEN/D, had in fact, damaged the prospects of children identified with SEN/D (Warnock, 2005, p.20). In relation to terminology, it was contended that the shift to special educational needs failed to acknowledge an individual’s actual needs and hence,

students lacked individualised provision. In terms of mainstreaming, Warnock now argued that due to bullying, exclusions, and shortages of professionals, the ideology of inclusion needed to be reviewed. Further, she suggested that “children should be included under the common education project, not that they should be included under one roof” (Warnock, 2005, p.37). Following Warnock’s report challenging the very notion of inclusion itself, Ofsted published a report in 2010 highlighting continuing and troubling disparities in the education of children identified as having SEN/D. The report highlighted that children identified as having SEN were disproportionately from disadvantaged backgrounds as well as being more likely to be excluded from school and to have poorer outcomes than other children (Ofsted, 2010). Moreover, it was argued that there was an over identification of children as having SEN/D, which would not be the case if teaching and learning processes were improved to meet the needs of all children (Ofsted, 2010).

Since 2010, the number of children identified as having SEN/D has decreased. However, over the last three years the rates have, once again, begun to rise from 14.4% in 2017 of the pupil population being identified as having SEN to 14.6% in 2018 and 14.9% in 2019 (DfE, 2018b; 2019b). In the years 2010 to 2016, it is likely that the dramatic fall in the numbers of children being identified as having SEN (from 18.3% in 2010 to 11.6% in 2016) was in reaction to Ofsted’s claims regarding over identification (Ofsted, 2010). In response to the challenges highlighted by Warnock (2005) and Ofsted (2010), the DfE (2011), under a new Conservative-Liberal Democrat coalition, released a Green Paper calling for an end to the “bias towards inclusion”, aiming to give parents real choice over school placements and whether to follow a special or mainstream route (p.5). After a significant drop in the amount of government-maintained special schools in the early 2010s, the numbers of such schools have now risen beyond the level of 2006 and currently there are 1,044 (DfE, 2019b). Linked with this, as of 2019, there are 120,000 children in state-funded special schools; 6,500 more than in the previous year (DfE, 2019b).

Most recently, and under a Conservative government, initially as a coalition and as a majority party since 2015, two new key pieces of legislation and statutory guidance have been rolled out concerning children identified as having SEN - the 2014 Children and Families Act and the most recent Code of Practice (DfE & DoH, 2015). Under these regulations a child is considered as having Special Educational Needs (SEN), if she or he has difficulty in learning or a disability, which “calls for special educational provision to be made” (DfE & DoH, 2015, p.15). Disability is given the same definition as in the 2010 Equality Act, whilst learning difficulties or disabilities are defined as a young person who “has a significantly greater difficulty in learning than the majority of others of the same age

or, has a disability that prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions” (DfE & DoH, 2015, p.16). Since the Warnock Report (1978) highlighting the potential for some terminology to heighten stigma, there has been a continuous shift in policy terms used to refer to children identified as having special educational needs, and the recent terminology of special educational needs was implemented within a policy agenda aimed at moving away from a deficit-focused medical model of disability (Norwich, 2014).

However, when examining the language currently used for defining disability and special educational needs, in the 2010 Equality Act, 2014 Children and Families Act and the most recent Code of Practice (CoP) (DfE & DoH, 2015), the construct of disability remains located in the individual. It hinges on his or her perceived inability to access facilities that are generally provided, rather than addressing barriers inherent in the facilities themselves. This concern was raised in the 2017 United Nations report on the implementation of the CRPD, in full in which it states concern about a “failure to incorporate the human rights model of disability in public policies and legislation concerning children and young people with disabilities” (UN, 2017).

Under the current CoP, four categories of SEN are delineated: communication and interaction, cognition and learning, social emotional mental health, and sensory and/or physical needs (see Figure 2.) (DfE & DoH, 2015). The 2014 Children and Families Act specifically notes that a child cannot be considered to have SEN solely because the native language of the child’s home is not English.

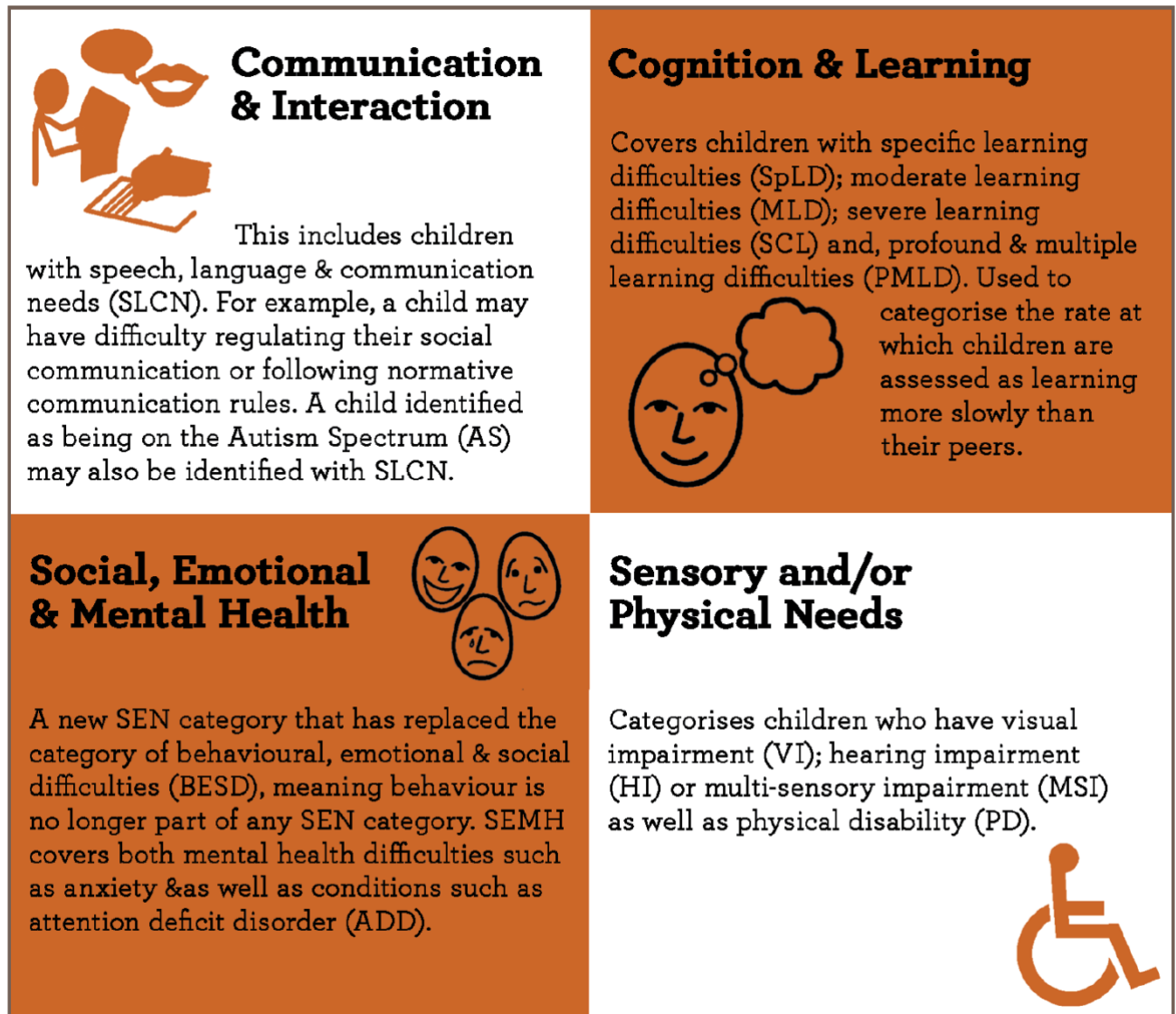
In conjunction with the 2015 SEN CoP (DfE & DoH, 2015), the 2014 Children and Families Act has changed the way children are identified as having SEN and are provided for. As of 2015, a student can now either be on SEN support in school or be assessed for an Education Health Care Plan⁷ (DfE & DoH, 2015). SEN support is provision that is managed entirely in a school, including identification, educational interventions, transition planning and therapeutic provision (DfE and DoH, 2015). If a young person does not make effective progress on SEN support, or has been identified prior to beginning school, then assessments can be made for an Education Health Care Plan. This plan is led by the local authority and determines the educational, health and social care needs of the young person. A budget is attached and managed by the local authority or parents, which aims to ensure adequate education provision as well as adjunct services collated under a Local Offer (DfE

⁷ The legal test as to whether a child needs to have a Education Health Care Plan remains the same as it was for Statements of Educational Need, as outlined in the 1996 Education Act.

and DoH, 2015).

Figure 2

*Categories of SEN in the 2015 Special Educational Needs and Disability Code of Practice
(Illustration from Singal, Ware, Khanna-Bhutani, 2017)*



An annual review published by Ofsted in 2018 underlines the continued tensions in the education of children identified as having SEN in England. The significant findings show that secondary school children identified with SEN are five times more likely to face permanent exclusion than their counterparts without any identification. Moreover, outcomes for children identified with SEN/D are inconsistent, so too their access to services. For example, the report highlights that children identified as having autism can wait two years for a formal diagnosis and during this time may not have access to any education (Ofsted, 2018, p. 12).

Whilst Education, Health and Care plans were now deemed to be “in place”, the variation in quality of these documents meant that “the gap in performance and outcomes for children with SEN/D is widening between the best and the worst local areas” (Ofsted, 2018, p.13).

2.2.2 Department for Education statistics: Current characteristics of children identified as having SEN

In 2018, Autistic Spectrum Disorder (ASD) overtook Moderate Learning Disability (MLD) as the primary type of need for pupils with an Educational Health Care Plan (or statement), with 28.2% of this population having this stated as their primary need, rising to 29% in 2019 (DfE, 2018b; 2019b). In 2019, Speech, Language and Communication needs (23.4%) also overtook (MLD) (22.8%) as the primary need (DfE, 2018b). This data may suggest that young people, both those with EHC plans and on SEN support, are getting more specific diagnoses/identifications. Examining the 2019 data from the Department for Education indicates that certain characteristics, particularly age, gender, socio-economic status, language status and ethnicity considerably affect identification rates.

Boys continue to be twice as likely to be identified as having SEN/D than girls, in both SEN categories. There have been small year on year increases and in 2019, 15% of boys were receiving SEN support compared to 8% of girls. Similarly, 4.4% of boys had an Education Health Care (EHC) plan, whilst only 1.5% of girls had one (DfE, 2019b). Autism Spectrum Disorder is also now the most frequently identified primary need for both boys and girls who have an EHC plan, with 33% and 18%, respectively having this diagnosis stated on the plan (ibid.). When examining those on SEN support, MLD is the most prevalent SEN category for girls (26%) whilst Speech, Language and Communication needs are most identified for boys (25%) (ibid.). Age is a factor in the rate of formal assessment as well as the identification of primary need. As children get older, they are more likely to have a formal assessment through an EHC plan and the data shows that the numbers of teenagers on SEN support decreases (ibid.). Children aged sixteen children are least likely to have this formal identification (4%) (ibid.). Moreover, as children on SEN support grow-up they are less likely to have certain identifications. For example, 59% of four-year olds have Speech, Language and Communication needs as their primary identification, but this reduces to 9% of fifteen-year olds (ibid.). The data does not show such explicit trends for children who have EHC plans. Identification of Speech Language and Communication needs also decreases as young people age, but with less significance than for those on SEN support. Moreover, identification of Social Emotional and Mental Health and MLD occurs more frequently in older children who have EHC plans (ibid.).

Free school meals, the main determiner of socio-economic status in school level data, demonstrate that students identified as having SEN remain more likely than those without such identification being eligible to receive them. In 2019, over a quarter (28%) of children identified as having SEN were eligible for free school meals compared to 13% those who were not (DfE, 2019b). Further, young people identified with EHC plans were more likely to be eligible for free school meals than those on SEN support; 33% compared to 27%, respectively (ibid.).

When analysing the data on SEN and ethnicity, identification of SEN continues to occur more frequently in Irish heritage (30%) and Roma Gypsy (26%) traveller pupils than any other ethnic group (DfE, 2019b). The national average of having an EHC plan is 3.1% of all pupils, however, travellers of Irish heritage and black Caribbean pupils are more likely to be given one, at 4.5% and 4.4%, respectively (ibid.). In contrast, pupils with an Indian heritage (1.9%) are least likely to have an EHC plan (ibid.). When probing the literature, it is evident that relatively limited research has been undertaken on ethnicity and SEN. Extant research suggests that people from Black and Minority Ethnic (BME) groups face barriers to accessing the services and provision they need in England (Hubert, 2006). Furthermore, it has been argued that institutionalised racism in England creates tensions between service providers and families from minority ethnic groups (Rizvi, 2015). Evidence also suggests that there is a disproportionate representation of some children with BME backgrounds assessed as having SEN in England. Notably, data shows an overrepresentation of young people from such backgrounds being identified as having SEN/D. Specifically, Strand and Lindorff (2018) note an overrepresentation within the MLD category for students from Black-Caribbean and Pakistani backgrounds, which they argue is due to socio-economic inequality. In the category of SEMH there is an overrepresentation of young people from dual heritage (Black and White) and Black-Caribbean backgrounds. The authors highlight the overrepresentation, noting that, Black African pupils, despite being a group facing socio-economic deprivation are not overrepresented in the category of SEMH. Instead, they argue that school context plays a significant part in the overrepresentation of these young people in SEMH - yet it remains unclear within the data as to what levers within the school setting triggers this situation (ibid.). Interestingly, Strand and Lindorff (2018) also note there is an underrepresentation of an identification of Autism in young people with Asian backgrounds, with the possible reasons for this being connected to level of parental education and community awareness. Hence, the intersection of ethnicity and disability could present multi-layered oppression, which could result in specific challenges in the classroom (Rizvi, 2015; Oliver & Singal, 2017).

It has been suggested that families from minority ethnic groups may construct, experience and understand disability in a different way to white British families, due to the different nature of the combination of culture, migration and religion (Rizvi, 2015). An example of this can be seen in discourses on disability from the global South, where there has been a call to consider the product of impairment, or the way in which “impairment is produced” through different societal devices, including violence, exploitation, labour and poverty (Chouinard, 2014, p. 340). This different focus on disability might change the way in which a person identifies as being disabled and also, the manner in which they interact with services and provisions in England. However, in contrast it has been argued that limited opportunities and circumstance actually plays a bigger role in navigating SEN than cultural factors (Hubert, 2006; Rizvi, 2015; Oliver & Singal, 2017). Furthermore, it has been proposed that stereotypically supportive familial networks do not always exist for those with South Asian heritage (Rizvi, 2015). It is possible that limited opportunities and circumstances may stem from institutionalised inequalities systemic within the provision of services, which often take a “colour blind” approach; ignoring any variation in need or circumstance (Baxter et al., 1990, p. 1). The recent 2015 Special Educational Needs Code of Practice illustrates this colour-blind approach, for despite being applicable for *all* children with SEN the guidelines make no mention of any variance in culture and/or ethnicity (DfE & DoH, 2015). The approach taken of ignoring culture within the CoP demonstrates the political tendency to consider children with SEN as being “culturally neutral” (DfES, 2006:3 as cited in Oliver & Singal, 2017), which may lead to the individual cultural preferences of young people identified as having SEN/D being overlooked. The only explicit acknowledgement of variation is the directive stating that extra measures should be taken when identifying a child with SEN/D, who has English as an additional language. In relation to this, it is interesting to note that students with English as a first language are more likely to be identified as having SEN/D (15%) than those for whom English is an additional one (12%) (DfE, 2019b).

In considering how culture and cultural identity play a part in the schooling experience of children with SEN from migrant families, the school community is likely to be an important factor to consider. This could be addressed through exploring whether notions of citizen and non-citizen exist as well as how narratives of belonging are constructed within the school community (Pinson et al., 2010). Furthermore, whether there is any sense of national identity within the school and if so, in what ways is it constructed, needs to be investigated in relation to the educational lives of young people identified as having SEN/D. In a qualitative study, Oliver and Singal (2017) question what effect the homogenous white British teaching staff has on the inclusive atmosphere of the school. However, their research did not involve seeking the views of the children themselves. Hence, further such investigation including

these voices was deemed a fruitful avenue to pursue, whilst also including the perspectives of school staff and the children's families.

Writing about British Pakistani mothers' experiences of having a child with a disability in the UK, Rizvi (2015) suggests that families face challenges "decoding" the special education system (p.2). This links with research suggesting that Polish mothers who migrated to England faced similar difficulties in navigating mainstream schools (Lopez Rodriguez, 2010). What is interesting to note in both of these studies is that the experiences of the children themselves were not included. Research undertaken with migrant Polish families in mainstream English education highlights the view that Polish education is more rigorous than that in England. However, research undertaken with migrant families in English special schools suggested that, for some, the well-being and quality of education for children with SEN in England was a particular draw in the decision to migrate (D'Angelo & Ryan, 2011; Oliver & Singal, 2017). It was further suggested, in contrast to parental feelings of alienation from English mainstream schools, that the potential "ethos of care" in an English special school can help parents to overcome barriers leading to disengagement (Oliver & Singal, 2017). Nevertheless, some cultural conflicts between parents and special schools were highlighted within the work of Oliver and Singal (2017), particularly in relation to managing different expectations and addressing child protection issues.

2.3 Conclusion and implications for research

In exploring the English political landscape surrounding the schooling of young people identified as having SEN/D, it is apparent that a clear consensus does not exist as to the perceived best place to educate these young people. Hence, it is important to research simultaneously across mainstream and special schools to engage with notions of inclusion and educational engagements of children identified as having SEN. This thesis has not set out to answer this question, rather given the changing political narratives on the best place to educate young people identified as having SEN/D, it strives to elucidate the experiences of young people learning in different educational settings. Moreover, it is clear that certain characteristics - and specifically ethnicity, changes the way young people are identified and are likely to access provision. Engaging with notions of intersectionality could help identify implications and priorities for children with SEN from BME backgrounds. Given the lack of acknowledgement of cultural variance within the 2015 Special Educational Needs Code of Practice, it is pertinent to assess acculturation and the agency of culture in the context of children with SEN given the multicultural nature of England, and to question whether the provision they are accessing is underpinned by "White cultural assumptions" (Baxter et al.,

1990, p. 2). Furthermore, research is needed to explore experiences of migrant families, particularly in special schools, to understand how the schools, parents and children work together to navigate potential barriers to engagement. In line with these concerns, the sample of this thesis will reflect the rich diversity of English society and seek to include young people from different backgrounds, not only White-British young people.

Chapter 3. Setting the scene: Self-description and a sense of belonging

3.1 Introduction

This chapter focusses on two areas, the voices of young people with SEN/D in the literature and operationalising my research concepts in relation to the relevant literature. I begin by highlighting the voices of young people identified as having SEN/D, exploring how the way they have described themselves and their school experiences within the literature. I underline the way in which the voices of the young people conflict with disabling discourses typical in society. I acknowledge limitations in the field and explain the decisions made as to which studies to include in the present review. I then offer a rationale for my research questions, making the case for the importance of researching directly with young people identified as having SEN/Ds, thereby further elucidating upon descriptions of themselves and their sense of belonging within educational settings.

Next, I discuss how the self has been addressed within British disability studies, focussing on the collective politicised self, prominent within the social model of disability. Subsequently, I operationalise the concept of self-description for my own research, guided by the premise of researching rich descriptions of self, rather than political notions of identity. Next, I argue that in a research context, to begin with the premise of a collective disabled identity that is 'other' has the potential to compound the notion of 'normal' and 'other' and, does not fully take into account all lived experiences. Instead, I argue that researching through a lens of belonging ensures that participants have the agency to present themselves on their own terms. Following this, I articulate how I engage with belonging through seeking to understand young people's experience of a sense of this. When operationalising this term, I acknowledge that there is diverse cognitive participation within this research.

3.2 Researched lives: Examining descriptions of self and experiences of belonging in school-aged young people identified as having SEN/D

Historically, the voice of disabled people and particularly those identified with learning difficulties has been excluded from research (Goodley, 1996; Atkinson, 1997). When research has focussed on people identified as having learning difficulties, but not included the person themselves, researchers have used proxy responses from professional or

families to avoid methodological challenges. This becomes particularly problematic when they have attempted to gather intimate details of people's lives, such as quality of life and resettlement, for those questioned may find it difficult not to express their own views, rather than those of the targeted individual (Hollomotz, 2017). Much of the research using proxy responses is often deficit focussed offering largely negative perceptions of the experiences of young people identified as having SEN/D (for example, Harnett et al., 2008; Doody, 2012; Cummins and Lorraine Masters, 2002). For instance, Harnett et al. (2008), when working with parents and staff to ascertain views on the quality life whilst attending a day service, reported how the respondents were positive regarding the service users, saying things as "love it" and that they were "treated so well" (Harnett et al., 2008, pp.159, 160). However, the study failed to determine whether the service-users themselves agreed or not with these sentiments.

In contrast to the research that utilises proxy responders, there is a body of literature focussing on eliciting the voices of people identified as having learning difficulties. However, much of the literature undertaken directly with disabled people, including those identified as having learning difficulties, is adult centric, and it has only been in recent years that research has significantly shifted to address the voices of young disabled people and to view them as active research partners (Liddiard et al, 2018). In seeking to review the literature concerning young people from 2000 to the present comprehensively, I set out clear search terms as: "disability/disabilities/disabled/impairment/impaired/special/special needs"; "children/adolescents/youth/child/teenager"; "identity"; "self"; and "belonging". I then searched the highly reputed database the British Education Index as well as probing key journals, including *Disability & Society* and the *Journal of Special Educational Needs*. It became clear that with much of the research, the focus is primarily on those who have physical impairments (cf: Skar, 2003; van Amsterdam et al., 2015), those who are considered to be on the Autistic Spectrum (AS) (for example, Baines, 2012; Williams et al., 2019; Cribb, 2019), those identified as having SEMH (for example, Castlin, 2019, Karlsson, 2019); or comments on childhood retrospectively by adults looking back to their own childhoods (for example, Haraldsdottir, 2013; Najarian, 2008). Research that is retrospective in nature is difficult to relate to today's educational experience given that the adults are reflecting on their experiences in school systems that were considerably different to those of the present. Few studies focus on the lived experiences of young people identified as having learning difficulties (Potter, 2014); the interest of my own research. Even fewer, are studies involving young people with PMLD (Simmons & Watson, 2014). Having examined the extant literature undertaken with young people identified as having SEN/D, the salient findings were young people describing themselves on their own terms, highlighting their strengths, and

consistently rebutting notions of difference and deficit.

Moreover, there is limited research within special education on intersectional identities (Hernandez-Saca & Gautmann Kahn, 2019). In particular, there has been a lack of investigation undertaken with young people identified as having SEN/D in addressing issues such as, culture, race, sexual orientation and gender. The paucity of research undertaken with young people with MLD means there is a real gap within the literature, which offers the opportunity to add new knowledge through undertaking my present research focusing on descriptions of selves and sense of belonging.

In making decisions about the literature to be presented, I was guided by the key tenet of the British disability movement, which argues for “nothing about us, without us” (Charlton, 2000). Hence, I decided only to include literature with a methodology that directly engages with the voices of school and university aged children/young people. Furthermore, when examining the participant sampling in the literature, I made the decision to focus on that which has involved school or university-aged young people, with my secondary focus being on retrospective literature, where disabled adults are looking back to their schooling experiences. I did not use geography as a strong limiting factor, but rather, focussed on England, including countries within the European Union, Australia and North America due to shared commonalities under the foremost and a common language and social structure, as with the latter two. I have arranged the literature presented here into two distinct areas connected to the themes of my own research: the way in which young people identified as having SEN/D describe themselves and the way in which they reflect on their school experiences. In the later section, I do not focus on literature concerned with eliciting young people identified as having SEN/D’s views on pedagogy or teaching and learning processes (for example, Cranmer, 2020) as this does not relate to the aims of the research. Instead, the interest lies specifically in research concerned with young people’s reflections on social experiences and that pertaining to their views on experiences of belonging within school settings, both in relation to their peers and the school as a whole.

3.2.1 Descriptions of Self: Rejecting and embracing a multi-faceted and/not disabled sense of self

In examining research undertaken directly with young people identified as having SEN/D, or adults looking back to their childhoods, there are examples of those who embrace a disabled or neuro-diverse identity (MacLeod et al., 2013; Cribb et al., 2019, Mueller, 2019) and those who reject it (van Amsterdam et al., 2015; Connors and Stalker, 2007; Haraldsdottir, 2013;

Mueller, 2019; Calderon-Almendros & Calderon-Almendros, 2016). Where young people either reject disability or do not identify disability as part of their sense of self, they typically describe themselves as similar to their peers. For instance, Connors and Stalker (2007), who undertook semi-structured interviews in Scotland with 26 young people identified as having SEN/D, including those with learning difficulties, found that many reported the ways in which they were similar to their peers. Interestingly, this was in contrast to the parents' perspective, who thought that their child viewed themselves as different (ibid). Rather than speaking about disability, the young people spoke of impairments and had a strong medical focus as well as talking about their daily lived experience (ibid). Notably, their narratives did not reflect a 'tragedy' model despite the links in their language with individualised models of disability.

Skar (2003), researching in Sweden with 12 adolescents aged 15 to 19 with restricted mobility, noted how none of the participants spoke about their disability when asked to describe themselves. Moreover, the young people explained that they were "just like all teenagers" (ibid., p.640) and instead, focused on their personal attributes, such as being "happy, kind, determined and careful" (ibid., p. 640). Similarly, Haraldsdottir (2013), a disabled adult reflecting on her own experience as a child and writing in the emerging field of disabled children's childhood studies, states: "I didn't realise about my impairment, or at least found it as normal as having glasses, blond hair or brown eyes. I even thought that breaking a bone a few times a month was what everyone did" (p.14). Haraldsdottir illustrates how, in contrast to the often-assumed disabled identity, as a child she was not aware of the given label of 'disabled'. Mueller (2019), undertaking research in America with four boys identified with learning difficulties and/or behavioural difficulties aged between fourteen and fifteen, reported that three of her (four) participants criticised the term disability and distanced it from themselves. The young people in her study sought to distance themselves from the explicit labelling of themselves as a disabled person and instead, talked about any difficulties they faced in relation to their individual education plan (ibid.). Similar findings were noted by Baines (2012) carrying out research with two male teenagers identified as being on the AS, who attended an American mainstream school. Both of the young men attempted to distance themselves from the label of autism and in the case of Mark, he chose to describe himself as a "recovering autistic" (ibid., p.550). Another example of a person rejecting disabling discourses is found in the autobiographical work by Spanish brothers Calderon-Almendros & Calderon-Almendros (2016). Rafael, the brother who was identified as having Down's syndrome, described his own identity during the research and rejected stigmatising labels ascribed to him, such as "he is Down's" (ibid., p.104). He pointed out that his own wishes to construct his identity as a person first were often overridden by the people

around him. The authors commented how hegemonic social systems create stigmatising discourses on disability that lead to exclusion and anxieties surrounding self-identity. However, in Rafael's case, music offered him a way to fight the oppression he experienced, with him saying "I opened the coffin and here I am" (ibid., p.110).

In contrast, some research, and particularly studies undertaken with autistic people, highlights a neuro-diverse or autistic identity as being an integral part of the self (for example, MacLeod et al., 2013; Cribb et al., 2019). An example of this is the work of MacLeod et al. (2013), who undertook research with higher education students identified as being on the AS or having Asperger syndrome. The participants described autism as being a key part of themselves, with one saying that: "Autism is much more a part of someone's identity in the same way that someone's gender is or someone's sexuality or whatever" (ibid., p.43). It should be noted that the participants in this study were significantly older than those in that of Baines (2012 - see above), which may have made a significant difference to the level of acceptance the young people had of themselves. This is also the case for the work of Cribb et al. (2019), who undertook research with autistic university students and their parents, where some participants also spoke about autism being a core part of their identity. In contrast to some young autistic people who see autism as an integral and positive part of themselves, Caslin (2019) highlights problematic ways in which others internalise labels of SEN/D as part of their identity. Specifically, in her study of 13 young people identified as having social, emotional and behavioural difficulties (SEBD), they spoke about having "too much stuff wrong" with them, being "weird", or being unable to be "fixed" (p. 175). She argued that these notions of self-failure can be linked to school and teacher discourses highlighting young people as not fitting in with the acceptable ways of being.

When examining how the literature represented young people identified as having SEN/D's perceptions of themselves, there were also instances of them speaking about their aspirations. For instance, Salt et al. (2019), who undertook semi-structured interviews with 11 students with (borderline to) mild learning difficulties in their final two years of secondary school in Scotland, reported the young people's perspectives as being very similar to the perspectives of those without identifications of disability. When considering their perceptions about their futures, there were expectations about living independently, being financially independent and having jobs (ibid.). Skar (2003) noted how disabled females specifically were looking for jobs with a caring element, such as being doctors or nurses, whilst males spoke of wanting to work in IT. Mortier et al. (2011), researching in Germany with six children aged nine to 18 identified as having SEN/D, reported diverse career aspirations, such as: gardener, fireman, film director, ballet teacher, teacher, childminder and working in

graphic design. Further, the work of Skar (2003), who researched only with older adolescents, demonstrates that a strong discourse for the young people's was the desire to have a romantic relationship.

Some research has been focussed on the sexual identities of young people identified as having disabilities. For example, the work of Azzopardi Lane et al. (2019), undertaken in Malta with nine young women aged between 18 and 33, highlighted their desire live independently so they could pursue their wish to have romantic relationships. The authors reported a strong sense of heterosexual normativity in the way in which the women described their desires, speaking of sexual relationships only within the confines of marriage. In a photovoice study in New Zealand undertaken with four young women aged 18 to 32 identified as having congenital disabilities, the participants spoke about the challenge of viewing themselves as women with romantic desires, but being viewed by others only as disabled (Payne et al., 2016). Similar to the research by Azzopardi Lane et al. (2019), the young women contextualised sexual relations within the bounds of a romantic relationship.

When considering the limitations of the literature regarding the selves of young people identified as having SEN/D, it was noted how few studies have been undertaken, thus far, to explore the intersectionality of cultural or national identity, immigration status or the racial identities of young people identified in this way (Oliver and Singal, 2017). One such study that has been identified which takes account the intersectional views of young people themselves, is that of Bunning and Steel (2006), who researched the self-concept of young Jewish adults identified as having a learning disability. The researchers used Talking Mats to engage with the four participants aged 18 to 21 who were living in England. The three key themes that connected the young people's views of themselves were: "having a disability", "being Jewish" and "being young" (ibid., p.46). However, whilst all of the young people spoke about their Jewish selves talking about festivals, food, drink and prayer, only two of the female participants directly spoke about disability. This could suggest that disability was in fact a smaller part of the young people's description of themselves than was presented by the authors. Another study was undertaken in America with two young people with intersecting identities of sexuality, nationality and disability (Hernandez-Saca & Gautmann Kahn, 2019). Specifically, the research, which involved combining ethnographic research with interviews and focus groups, elucidated the experience of these two young people aged 14 and 16. When describing himself, Daniel, one of the participants, who embodied a Mexican American and learning-disabled identity, described himself primarily as a human resisting labelling himself in relation to society's identification of him (ibid.). In contrast Luna, who identified as transgender, bi-sexual, disabled and Arab-American, embraced self-

labelling as an emancipatory way of reclaiming his identity and exploring his self (ibid). The diverse ways in which the young people within the literature describe themselves demonstrates a resistance to disabling and deficit-based discourses. Importantly, as historically disabled people have been marginalised from research (Liddiard et al., 2018), there is still considerable space to add more voices, in particular, those of people identified as having learning difficulties.

3.2.2 Educational experiences: Experiences of belonging, stigma and relationships with staff and peers

Within the school based literature, a range of student perspectives of their schooling experience are reported, including reflections on relationships with teachers (for example, Caslin, 2019; Sylvester et al., 2014; Midgen et al., 2019), views on school accessibility (for example, Mortier et al., 2011; Connors and Stalker, 2007) and relationships with peers (for example, Webster and Carter, 2012; Potter, 2014, see Subsection 3.2.2.1 for further discussion on relationships with peers). The literature also covers learning processes and pedagogy from the perspective of young people (for example, Cranmer, 2020). However, as explained above (see Section 3.2), this literature has been omitted as it is out the scope of the current research. There are contrasting reports of positive and negative reflections from young people about their experiences at school. Factors identified in the literature contributing to students having a positive school experience include positive relationships with teachers and support staff (Mortier et al., 2011) and being listened to (Sylvester et al., 2014). In contrast, reasons why young people identified as having SEN/D might have a negative school experience, include: having an identification of SEMH (Caslin, 2019); feeling unheard by teachers (Skar, 2003); teachers having deficit views of disability (Connors and Stalker, 2007, Caslin, 2019); and receiving too much support (Mortier et al., 2011).

Using the survey tool KIDSCREEN-27, Sylvester et al. (2014) undertook quantitative research in Scotland with 91 young people aged five to 18, who had been identified as having SEN/D; it should be noted, however, that not all respondents gave their age. The survey had four specific questions on the young people's schooling, with 79% of respondents reporting as being moderately happy to extremely happy with their experience of school in the preceding week (Sylvester et al., 2014, p. 771). Similar findings were made regarding how the young people felt they "got on" in school, with 61% reporting as having "always, very often or quite often been able to pay attention" and 15% replying that they had "never" or "seldom" been able to do so. In terms of relationships with teachers, the vast majority of respondents believed they got on well and 40% of the young people felt they

were listened to (ibid.). It is interesting to note that when comparing the participant's views to the views of Scottish school children more generally, Sylvester et al. (2014) found that those identified as having SEN/D were only slightly less satisfied. Whilst this survey illuminates the feelings of the young people in the study towards school, it fails to account for the reasons as to why they felt this way. Moreover, the research also fails to address whether the responses change, if categorised by age, gender or on the basis of where they were educated as most of the respondents were attending mainstream schools. Respondents were not asked to disclose impairments and so the research lacks understanding as to whether those with physical impairments had a different experience to those with identifications of being on the AS or having learning difficulties.

In contrast to the findings of Sylvester et al. (2014), qualitative research undertaken by Connors and Stalker (2007) in Scotland highlights the potential of learning environments to create experiences of difference or inclusion. The 26 young people in their study attended a range of schools: special, integrated (units within mainstream schools) and inclusive (mainstream). One of the participants who used a wheelchair was trapped inside his mainstream school during a fire drill. In an integrated school, one of the participants questioned whether he had done something "wrong" to be put into the unit (ibid., p.27). Furthermore, in one of the special schools a teacher categorised the students as "wheelchairs and walkers" (ibid., p. 27). A student who used a wheelchair reflected on this and explained that, "it's sad because we're just the same. We just can't walk, that's all the difference" (ibid., p.27). The researchers found that some of the young people who attended mainstream schools experienced barriers through the 'assistance' given by Special Needs Assistants (SNA). One of the participants reported that at breaktimes her SNA took her to the younger children's playground, rather than the one where she could mix with her peers. Another participant reported a similar experience, where she was taken to the nursery owing to the SNA being friends with the nursery workers. Connors and Stalker (2007) also found that young people described experiences of feeling different when they were given support such as specialised equipment or taken out of lessons for more intensive work. However, there does not seem to have been exploration into whether this additional support created barriers for the young people. Skar (2003), researching in Sweden with teenagers with restricted mobility, noted discontent. The young people participating who had restricted mobility reported a lack of interaction with the teachers as they were wholly managed by teaching assistants. She specifically observed that they felt they were held in "contempt" by their teachers, given they were often ignored (ibid., p.643). Another study, which involved taking an in-depth look at the school experience of young people identified as having SEN/D, is the work of Caslin (2019). Specifically, she undertook in depth case study

research using innovative methods, including activity sessions which involved using life grids in order to ascertain the experience of 13 males and females aged between 14 and 16 with social, emotional and behavioural difficulties (SEBD). It is important to note in this case that all the young people participating in the research had been excluded from mainstream schools due to their behaviour and were currently accessing alternative provision. The young people reported a sense of being blamed in school due to their disabilities, particularly in relation to a perceived lack of understanding from their teachers owing to their ascribed label of behavioural difficulties. The author uncovered that within the schools researched (from which the young people had been excluded) there was a troubling discourse that the young themselves had failed, rather than the school had not met their needs. This narrative reinforced a deficit focussed and individualistic understanding of disability. This finding is particularly important in that the young people within Caslin's (2019) study identified, in some cases, teachers' behaviours and their interaction with teachers as leading to behaviour considered by the school to be challenging.

When addressing accessibility both through physical structures and educational support, Mortier et al. (2011) undertook interviews (including photo elicitation) and focus groups with six children aged nine to 18 identified as having SEN/D, who accessed support in their inclusive mainstream schools in Germany. The young people identified different ways in which they received support in school: "peers, adults, adaptations and aids/devices" (ibid., p. 212), and their responses were generally positive, stating that this helped them to remove barriers in school. The research shows the agency of the young people in understanding themselves and the types of support they needed in certain situations. That is, the researchers noted the students were able to "specify exactly for which part of the activity they need what kind of help" (ibid., p.212). The young people, whilst acknowledging the positive effects of support received, also detailed the ways in which receiving it also functioned as a control mechanism. For example, receiving assistance from adults could create barriers, such as limiting peer to peer interaction; having to sit at the front of class and never being out of view of the teacher; and receiving comments from peers or adults who were supporting them, remarking on the quality of the individuals' work or grades (Mortier et al., 2011). Linked to the notion of control, all the young people identified as having SEN/D in the research felt that they received too much support. For some, a particular issue with this was that they felt this limited their ability for independence and compounded feelings of "inadequacy" (ibid., p.214). The problematic nature of support also played out in the day-to-day decisions the young people faced. For example, one of the participants described confusion about how to act when their support staff entered the room and whether to greet the person or to continue interacting with friends and ignore them (ibid). Specifically, this

research identifies a tension in school, where the young people had a greater sense of similarity to their peers than the adults around them perceived, thus leading to higher levels of support than that preferred being provided. As with the literature cited in the section above, the young people did not report having a strong disabled identity (ibid). Nevertheless, similar to Sylvester et al. (2014), the study undertaken by Mortier et al. (2011) failed to present the results based on characteristics such as age and gender. Specifically, much of the research refers to “all” or “one” (Mortier et al., 2011, p.212), offering relatively little nuance about the individuals’ characteristics, nor giving detail of the types of impairments the young people were identified as having.

An American life history study conducted with 10 deaf women highlights how learning in different educational settings can affect the sense of self (Najarian, 2008). Transitioning into a specialist deaf college had a profound effect on the deaf women’s construction of their own sense of self. Initially, learning in mainstream (oral) schools had led some of the women to discuss feelings of resentment towards being deaf and a sense of rejection. One woman described feeling an “oral failure” (ibid., p. 123). Attending deaf colleges and learning American Sign Language enabled the women to embrace their deaf identity - rejecting the label of disability and instead, subscribing to an identity of being part of a linguistic minority. It is interesting to note here how the power of educational settings influences an individual’s discussions on the sense of self. Within the mainstream setting, one woman spoke of hegemonic order in an oral school for deaf children, with those who were verbal being considered superior to those who found speaking challenging (ibid.). Over half of the 10 participants reported feeling “culture shock” on entering a deaf college (p.123), however, they explained that after a period of adjustment, learning in a new environment turned into a liberating experience, by enabling full educational participation and also the opportunity to embrace a deaf identity (Najarian, 2008). Some of the deaf women reflected on how the segregation had challenged their ability to feel comfortable in both the hearing and deaf worlds. Perhaps this research could be interpreted not as a reflection of the successes of special education, but rather, highlighting how the mainstream environment could benefit by being more inclusive and participatory.

3.2.2.1 Experiences with Peers

With regard to research reporting young people identified as having SEN/D’s relationships with their peers, there are notable studies which high-light positive socio-interactions (for example, Potter, 2014; Webster and Carter, 2012). In contrast, studies also exist that highlight the challenging relationships young people identified as having SEN/D have with

their peers (for example, Baines, 2012; Skar, 2003). The literature highlighting positive relationships with peers appears to be predominantly related to younger people, with both Potter (2014) and Webster and Carter's (2012) research being undertaken with primary-aged young people identified as having SEN/D.

The work of Sylvester et al. (2014) highlights the complexities surrounding the friendships of young people identified as having SEN/D. The research, undertaken in Scotland, surveyed 91 young people identified as having SEN/D using the survey KIDSCREEN-27. The results showed that 49% had either "always, very often, or quite often" spent time with friends during the preceding week, whilst 30% reported "never or seldom" having done so (Sylvester et al., 2014). Using a follow-up questionnaire developed by the authors and undertaken with 53 of the initial 91 people, the authors found that participants reported a "desire to have friends, or more friends, and to be better included in social and sporting activities" (ibid., p. 770). Whilst the respondents participating in Sylvester et al.'s (2014) research had a wide age, ranging from five to 18, with some participants not declaring their age, the research fails to account for how their perspectives differed based on age or whether older participants experienced more social isolation than younger ones. Webster and Carter (2012), who undertook quantitative questionnaire-based research in Australia with 16 primary aged students with learning difficulties, found predominantly positive results when examining the mutual liking of nominated friendship dyads. This research involved using peer analysis to enable the young people themselves to inform about their relationships. In order to be seen as being a true friendship, the results of each pairing had to have three components of friendship, as defined by Howes (1983) and Bukowski et al. (1996), namely: shared interaction, mutual liking and mutual enjoyment. Half of the sample (n=8 pairs) and their nominated peer scored highly in all three components, whilst 79% of the pairings had high or medium scores across most of the questions (Webster and Carter, 2012). These results can be seen to mean that the majority of the friendship pairings examined either "always or sometimes engaged in most of the behaviours associated with traditional definitions of friendship" (ibid).

Similarly, the research of Potter (2014) highlights the need for more research to examine and highlight the social strengths of young people with SEN/D. Undertaking a rich case study, Potter (2014) explored the friendships of Ben a ten-year-old identified as being on the AS and having severe learning difficulties. This photovoice study, which aimed to be "unchallenging and enjoyable" in order to support Ben's continued engagement, facilitated him in nominating friendships and exploring the different aspects of these (ibid., p.210). The findings showed that Ben was able to understand the concept of a friend and to nominate

peers he considered to be so. Moreover, Ben was able to show reflexivity when commenting on the temporality of his friendships, explaining how when he initially joined the school, he didn't have many friends compared to now (ibid). The reflexivity shown by Ben in this study is particularly noteworthy given that this appears to be the first work of its kind in an English context exploring the friendships of a young person identified as being both on the AS and having severe learning difficulties.

The studies mentioned here offer empirical evidence that young people identified as having SEN/D are able to engage with typical friendships, as described by Howes (1983) and Bukowski et al. (1996). Moreover, the friendship dimensions contended by Hinde (1979), which continue to be used in contemporary research on the topic (cf. Blair & Perry, 2018), such as: content, diversity, qualities, reciprocity, patterns, intimacy and commitment, are also relevant to research undertaken on friendship with young people identified as having learning difficulties. Specifically, the work of Webster and Carter (2012) can be seen to adhere to notions of reciprocity, qualities, intimacy and commitment, whilst Potter's (2014) study demonstrates content and commitment. However, it is important to acknowledge that Webster and Carter (2012) and Potter's (2014) studies examined friendships of young people with SEN/D that were primary age, whilst Sylvester et al.'s. (2014) research undertaken with an age range of five to 18, demonstrates more diverse findings.

Other studies highlight a sense of isolation and bullying as well as friendship. Connors and Stalker (2007), researching in Scotland with 26 young people identified as having SEN/D, found that half of their participants aged seven to 15 and attending a range of schools had experienced bullying. Most of the young people reported not doing anything about their experiences of this. However, one girl stood up to her bullies, whilst another boy tried to bully his peers back saying, "if they started kicking us, I'd kick back" (Connors and Stalker, 2007, p. 29). Whilst the participants attended special, integrated and inclusive schools the researchers didn't confirm whether the accounts of bullying were reported by young people attending all three of the school settings.

Research undertaken with older children, and specifically those with identifications of physical impairments or being on the AS, highlight a sense of social isolation or the mediating of behaviours so as to reduce stigma (Baines, 2012; Skar, 2003). Specifically, the extant literature has identified numerous ways young people change their behaviour in order either to fit in or act out. Working with older teenagers in Sweden, Skar (2003) noted that the young people were able to reflect with some complexity about the way they managed their social relationships. Two key approaches were taken by the 12 young people with restricted

mobility to manage their social relations; one was being the joker and the other, being invisible. One young person explicated that, "I took on a new style, which made me fun. When I showed that I could joke about my handicap and that I could say all the taunts myself, it was no longer fun to tease me" (Skar, 2003, p.641). In contrast, another participant reflected that they avoided all their peers and never went outside during break times (Skar, 2003). Other strategies employed by the young people to maintain social relationships with peers in school, included playing with children who were either older or younger and who did not make the same demands as their peers. The boys in Skar's (2003) study overwhelmingly noted that they made conscious decisions to interact with girls, because "girls are kinder" (p.641). The two young men identified as being on the AS in Baines' (2012) study spoke about taking an active role in mediating their own presentation in order to manage their social relationships. Mark chose to control his perceived autistic traits by 'normalising' his behaviour whilst interacting with his peers, only flapping or jumping in the safety of his bedroom. Anthony, on the other hand, due to concern his peers might judge him as disabled, chose to act out by deliberately making fun of himself (ibid).

Bourke and Burgman (2010), undertaking research with young participants aged eight to 10 identified as having SEN/D and learning in urban and rural locations, highlighted a range of coping strategies, namely: "getting even", "ignore them" "strength with pets" and "talking with people". Many of the young people who participated in the study noted that having friends who respected their impairment was a key factor in helping them to manage their bullying experiences (Bourke and Burgman, 2010). Specifically, one of the participants, Groovy Princess, noted the need to have friends at school to ensure her safety and took active steps to initiate friendships.

3.3 Research Questions

Studies undertaken with young people identified as having SEN/D, or disabled adults retrospectively looking back to their school years, gives insight into the multifaceted lives of young people with SEN/D. As evidenced by this literature review, few studies have been focussed directly on young people with learning difficulties, with the majority of those involving researching alongside young people identified as having either physical impairments or identifications of being Autistic. Geographically, there has been little research directly with students with moderate or severe learning difficulties undertaken in an English context, thus offering a clear lacuna for my thesis to address and a significant opportunity to add knowledge to the field. In moving away from research that involves observation or proxy responses, the young people were asked to present a view of themselves and their

experiences that challenged deficit-based narratives. This inclusive perspective is crucial to my own research in that it does not start from a point of an assumed collective identity of disability, make any assumptions about social impairments nor presume a lack of friendships.

When considering the stance of the research, I did not want to impose an assumed collective political identity of disability. Rather, I wanted to create a research space in which young people are facilitated in describing themselves in their own words and, as far as is possible, on their own terms. Thus, my aim was to undertake comprehensive investigation into the way in which young people describe themselves and the sense of belonging that they experience. Given the changing political view as to where young people identified as having SEN/D can best be educated in England (see Chapter Two), I think it is vital to work with young people learning in different school settings. To this end, I aim to address three main research questions:

1. What are some of the ways in which young people identified as having learning difficulties describe themselves?
2. What are some of the ways in which young people describe and experience a sense of belonging in their educational settings?
3. How inclusive are self-portraits, videovoice and life mapping as research methods for enabling young people identified as having learning difficulties to describe themselves and their experiences?

In the following sections, I articulate the way in which I understand the core research concepts of self-description and a sense of belonging. I examine 'self' within disability studies and then operationalise it for my own research purposes. Following this, I explain why researching from a perspective of belonging is important in the field of disability and then, articulate how I operationalise the notion of a sense of belonging for the cognitively diverse participants.

3.4 Examining Self within Disability Studies

The emergence of and research within the field of disability studies has predominantly been within the UK and the USA contexts, being intrinsically connected to the furthering of the Disability Rights movement and the Social Model of Disability, engendering political change

and benefiting individuals. In addition, there has been a significant push for work being undertaken in this field to be emancipatory (Mercer, 2002); reinforcing the politicised aspect of disability studies and starting from the point of agreement with the Social Model. The overt politicising of this field of research has contributed to confirmatory studies being produced that hold to the existence of a political and collective disabled identity (Shakespeare, 2014), rather than the focus being on individual selves.

The work of Oliver (1996) and Finklestein (1993), pioneers of the Social Model of Disability, along with that of Colin Barnes (1991), contends that disability is a shared experience based on commonality of experience. Barnes (1991) also argued for the acceptance of a shared identity based on all disabled people being subjected to oppression. Furthermore, Oliver (1996) explicitly identified a disabled person through three key factors: existence of impairment, experience of oppression/barriers and self-identification as a disabled person (p.5). Through this early work in the field, a notion of “consciousness” was emerging and this shifted the interest in disability according to the self to focussing on the oppressive systems within society (Charlton, 1998, p.192). The importance of a disabled identity was considered particularly important as it sought to offer a lens through which to understand the dynamics between individuals, society and biology (Shakespeare, 1996). The Social Model of Disability proposes that disability is not individualistic and disabled people are not deviant. Rather, the constraints are manifested in the barriers present in society (such as economic, educational, social), thus meaning disabled people are socially oppressed. The Union of the Physically Impaired Against Segregation, one of the earliest disability rights movement in the UK, explained: “Disability is something imposed on top of our impairments. Disabled people are therefore an oppressed group in society” (UPIAS cited in Oliver 1996, p.22). Shakespeare and Watson (2002), who also worked on the Social Model of Disability, defined the model as having three core tenets: (1) the acknowledgement that disabled people are part of an oppressed minority in society; (2) impairment is separate from disability; and (3) disability is linked to social barriers and oppression, rather than to the impairment. The Social Model has had a profound effect on the lives and rights of disabled people in England and the collective notion of disabled identity is still prevalent in the most recent research. Peters (2000) argues for the acceptance of a “disability culture” (p.583) based on being part of an oppressed minority, contending that there is a clear, shared history as well as a common language and community. Similarly, Hughes et al. (2005) offer the notion of disability pride, arguing that “disabled people do not want to be other than they are. They are not rejecting disability as an identity or trying to escape the biological realities of impairment” (p.7).

Concerns surrounding a collective disabled identity and the Social Model of Disability were levelled from the 1990s onwards. Initially, disabled feminist scholars wrote about the lack of space within the politicised identity to discuss the lived realities, such as pain and periods (Morris, 1991). Following this, Grech (2009) levelled critiques based on the model, regarding the politicised identity being spearheaded by male, white academics who had physical impairments. Perhaps most notably where the politicised identity fails is the lack of incorporation of people identified as having learning difficulties who, whilst systemically still carrying a label of disabled, have had no voice within these discussions. Furthermore, Simmons and Watson (2014) argue that most of the literature concerning people identified as having learning difficulties and particularly those with complex needs, is constructed by others and is based on discourses of “othering” (p. 14). Connors and Stalker (2007) highlight the lack of attention within the Social Model of Disability that is paid to young people. Recently, Shakespeare (2014) has addressed some of the tensions in the field surrounding a given political identity and assumed othering, noting worries that the implications of research to date: “implies that disability identity is a given, and that impairment will automatically define personal identity” (p. 94). Through my work, I aim to contribute to the conversations, questioning the assumed identity by undertaking research that does not start from a point of either assumed oppression or assumed politicised identity. I seek to examine the ways in which young people and describe themselves.

3.4.1 Operationalising descriptions of selves for this research

When engaging with a process of questioning an assumed politically disabled identity for people identified as having a learning difficulty, I sought to step back from the notion of identity and instead, aimed to examine the young people’s sense of self. In relation to identity, the self can be seen as the “doer being the deed” (Dunn, 1998, p.195), and I acknowledge that talking about oneself contributes to the process of identity formation (Priestly, 1999). In exploring descriptions of self, I understand it to be an unformed, unfixed concept (Giddens, 1991), which is constantly changing and evolving, as Mauss (1998) argues, both social and universally. Mauss (1998) promotes a universal sense of self contending that, “there has never existed a human being who has not been aware not only of his body but also of his individuality, both physical and spiritual” (p.3). It is this understanding that must be accepted to then be able to consider the social sense of self, which is constructed through social experiences (Mauss, 1998). The notion of the universal sense, as described by Mauss (1998), offers an emancipatory position for this work by starting from the assumption that all people, regardless of cognitive ability, have their own sense of self by merit of being human. Dunn (1998) argues that as people, we are aware of

our own existence and our experiences. It is through reflexively engaging with our experiences that we consciously create our own sense of self. Hence, as Giddens (1991) argues, “self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography” (p.53). Watson (2002), in his work on self and disability, argues that the body has often been ignored in discussions of self, with the primary focus having been on the social aspects. It is important, therefore, when exploring young people’s descriptions of self, to ensure there are ways to facilitate discussions on inhabited bodies. Taking note of this, Watson (2002) remarks “we act through our bodies upon our world and it is through our bodies that we experience and comprehend the world” (p. 510). Intrinsic to my understanding of self for this research is that self is something all humans have and hence, something all develop (Lemert, 1994). Given the constant development and changing of self, for this research, enabling people to make decisions about what self they wished to be was prioritised (Butler, 1990, 1993).

Acknowledging the transience of self, undertaking this research will not ascertain fixed selves, but rather, it will offer opportunities to understand the ways in which young people identified as having learning difficulties choose to present themselves to me in a given time; in a given space specific to their education setting. That is, I recognise that the descriptions of self-obtained through this research are of the moment and specific to my presence in the social communication.

3.5 Reversing the Gaze: Subverting the notion of disabled people as ‘Other’

Within disability studies, the identity-construction of disabled people as ‘Other’ has been commonplace (cf: Oliver, 2004; Barnes, 1992; Longmore, 2003; Davis, 1995). In these works, commonly undertaken from a Social Model perspective, it is argued that the oppression faced by disabled people marks them as ‘Other’. This can reinforce a dichotomy of ‘normal’ and ‘other’ similar to the gender dichotomy highlighted by Simone de Beauvoir when commenting on the construction of the female identity. Regarding which, she contends that, “she is determined and differentiated in relation to man, whilst he is not in relation to her; she is the inessential in front of the essential. He is the Subject; he is the Absolute. She is the Other” (de Beauvoir, 1949, p. 16). In the context of disability studies, it has been argued that this dichotomy is politically salient and necessary in order to highlight the disenfranchisement of disabled people (Oliver, 2004). However, it is also problematic and has the potential to reinforce stigmatising beliefs.

In order to identify someone as having an Education, Health and Care (EHC) plan, there must be an assertion of 'normal' or 'neuro/physically-typical' through which to draw comparison. Hence, the emergence of 'judgemental' categories of special educational needs, which change every few years in the new release of diagnostic manuals⁸. Through this dichotomy, the 'Other', the disabled identity, is constructed as the 'non-typical' social category. This reading constructs a disabled identity through a 'normative' gaze and thus, identifies disability as a secondary or inessential category. In order to further the process of equality, this notion needs to be challenged and reversed. De Beauvoir (1949) argues that "no group ever defines itself as One without immediately setting up the Other opposite itself" (p.16). Here, de Beauvoir (1949) justifies the construction of the female through the male gaze by positing the notion of oppositional identities. This dichotomous construction directly suggests an opposition, or polarity, of two identities, namely male and female, positioning them as contrasting to each other. The same relationship can also be iterated in the case of 'neuro/physically-typical' and 'disabled'. These social identities, when determined as opposite and united by their polarity, or difference, continue to perpetuate difference as being negative. One identity is privileged over the other, rather than being placed side by side, thus embracing diversity.

De Beauvoir (1949) characterises females not as a single identity in their own right, but rather, through the male gaze: "she is simply what man decrees" (p.16). Rather than iterating woman alone, de Beauvoir articulates the category of the female as constructed through masculine/male culture. This formation of the female identity through the male gaze sets the relationship up as unequal; the female is the subordinate, differentiated from the "essential" by being "inessential" (de Beauvoir, 1949, p.16). Under the same guise, the disabled identity is constructed through the gaze of the 'neuro-typical' or 'normative' social identity, and historically through a medically 'normative' gaze, thus it being constructed as 'Other'. The polarisation of identity relationships as 'primary' and 'Other' perpetuates inequality and discrimination, thus reinforcing stigmatising discourses (Davis, 2006; Longmore, 2003). The assumed construction of identities as 'Other' in relationship to 'normative' needs to be destabilised in order to challenge inequality.

'Other' is a concept used frequently in different fields. Said (1978) wrote in *Orientalism*, his critique of 'Othering' in post-colonial studies, that "so authoritative a position did Orientalism

⁸ Such as the Diagnostic and Statistical Manual of Mental Disorders (currently in its fifth edition which removed Aspergers as a specific disorder and subsumed it under Autism Spectrum Disorder) and the International Classification of Diseases (currently in its eleventh revision)

have that I believe no one writing, thinking, or acting on the Orient could do so without taking account of the limitations on thought and action imposed by Orientalism” (p.3). Said (1978) posited that in engaging with the ‘Orient’, one is also engaging with the limitations that have been imposed by ‘Orientalism’.⁹ Thus arguing that engaging with ‘The Orient’ de facto makes you an ‘Orientalist’ and binds you by these limitations (Said, 1978). Using the term ‘Other’, even if doing so in the light of destabilising the notion, reiterates the power imbalance within society. Hence, engaging with the term ‘Other’ has the potential to perpetuate disablist discourses. So, it is arguably counterproductive to use ‘Othering’ as part of the framework for this research. In support of this reasoning, Cunnah (2015), working in the field of disability stipulates that, “once individuals are discredited as ‘abnormal’ they are susceptible to stigmatisation, which can be associated with stereotyping, victimisation, prejudice and oppression” (p.215). Using ‘Othering’ as a research category or researching with this perspective in mind, may breed stigmatisation, because one cannot discuss feelings of being ‘Othered’ without taking on the label of being the ‘Other’.¹⁰

In addressing the power dynamics within the relationship between ‘the Occident’ and ‘the Orient’, Said (1978) posits that “European culture gained in strength and identity by setting itself off against the Orient as a sort of surrogate and even underground self” (p.3). The strength and power of the ‘normative’ identity of ‘the Occident’ is reinforced by the subjugation of ‘the Orient’ as ‘Other’. A parallel can be drawn with the work of Davis (2006) writing on the disabled ‘Other’ and the enforcing on ‘normalcy’. This author articulates that “normality has to protect itself by looking into the maw of disability and then recovering from the glance” (p. 34). Here, not only is it being asserted that the construction of a disabled identity is done through the gaze of ‘normality’, but also, that a ‘neuro-typical’ or ‘normative’ identity reasserts itself through a direct comparison with the ‘Other’ or the “maw of disability” (Davis, 2006, p. 34). Said (1978) destabilises the notion of ‘Other’ as being valid, and challenges the discourse surrounding the validity of the academic claims of the reality of ‘the Orient’. He proposes that “Orientalism is more particularly valuable as a sign of European-Atlantic power over the Orient than it is as a veridic discourse about the Orient (which is what, in its academic or scholarly form, it claims to be)” (p.6). This argument, if repositioned within the case of disability, suggests that constructions of disabled identities as ‘Other’ explains more about the unequal power relations that exist between socially constructed ‘normative’ and disabled/‘Other’ identities than it actually explains about the disabled/‘Other’ identity itself. An example of this within the field of disability studies can be seen in the work

⁹ Which constructed ‘the Orient’ as ‘Other’ in relation to the ‘the Occident’.

¹⁰ This is not to say that a participant should not be allowed to speak about this, but rather, that ‘Othering’ should not be assumed by the researcher.

of Barnes (1992). In a significant early review of portrayals of disabled people in the media, he describes key stereotypical constructions: “pitiable and pathetic; as an object of curiosity or violence; as sinister or evil; the super cripple; as atmosphere; as laughable; as his/her own worst enemy; a burden; as non-sexual; and as being unable to participate in daily life” (p.46). Clearly, this cannot be said to be representative of the reality of the general lived experience of disabled people, but rather, can be seen as representing biases by ‘normative’ identities that subjugate disabled people (Davis, 2006; Longmore, 2003).

The work of Butler (1990) can be utilised to resolve some of the challenges from the discourse of ‘Other’ presented by de Beauvoir (1949) and then critiqued by Said (1978). Butler (1990) critiques de Beauvoir (1949) for explaining what it means to be female “within the terms of a masculinist culture” (p.vii). In response to what she deems a limiting construction of the female gender, Butler (1990) posits that if the agency of woman is instead considered in its own right, then it “reverses the gaze” (p.vii). Through this argument Butler challenges the notion that suggests woman is made in the gaze of man and is tied to him as the “inessential” (De Beauvoir, 1940, p.16). This destabilising narrative returns the agency to women as active participants in their own realities and his subversion needs to be transposed to the conceptualisation of ‘Other’ within disability discourses. Currently, disabled people are arguably limited through having to explain their experience in the terms of a ‘neuro/physically-typical society’. Instead, we should be working on the premise of ‘neuro/physical-diversity’.

Asking about feelings of ‘Other’ suggests an assumed disadvantage, creating an unequal relation between the person asking and the person being asked. In trying to overcome a label of ‘Other’, this can force disabled people into the category of ‘hero’, whereby they have to stoically proactively transcend the discrimination ascribed to them by ‘normative’ society (Davis, 2006; Harris & Enfield, 2003; Longmore, 2003). To destabilise these unequal discourses, rather than asking about feelings of being ‘Other’, one could ask about feelings of ‘belonging’. For, exploring ‘belonging’ enables a person more agency to articulate his or her own lived experience without an existing assumed disadvantage. It is, thus, the person’s choice then, if they want to express feelings of not belonging or being ‘Othered’, rather than having to navigate ascribed stigmatisation assumed by the researcher. Essentially, this can be expressed through asking myself why would I ask a child why they don’t belong, when I could ask them how are they made to feel that they do belong. This is compatible with my understanding of the social model of disability, because in asking ‘how are you made to feel that you belong’, the onus for creating belonging is still being placed on society, rather than the individual. This would appear to be aligned to aspects of emancipatory research in that

the aim was to create a “space to belong” (Nind et al., p. 643) by privileging voices previously underrepresented within such work and also to emphasise enabling participants to “revers[e] the gaze” within their narratives (Butler, 1990, p. vii).

3.5.1 Engaging in the need for belonging

The need to experience belonging is well documented in the literature, both from a political perspective (cf. Yuval-Davis, 2006; Antonish, 2010) and as a personal need (cf. Baumeister & Leary, 1995; Maslow, 1943, 1970, Guibernau, 2013). Despite the literature making it clear that experiencing it is vital to human well-being, there lacks a clear definition (Healy, 2020; Craggs & Kelly, 2017; Cartmell & Bond, 2015). When examining the personal need for belonging, Maslow’s (1943) Hierarchy of Needs identified it as the third most fundamental need for self-development and overall psychological well-being. Building on this, Bowlby (1969) described in this theory of attachment how a lack of belonging and connectedness in early life can damage a person’s ability to make connections in later life. In addition, in their psychological work, Baumeister & Leary (1995) describe belonging as one of the strongest human needs; one that important needs to be felt across different social contexts, such as home, school and community (Bowlby & Zeanah, 1988; Bronfenbrenner, 1994). Turning to the political, belonging is seen to transcend the notion of citizenship by providing a thicker account of participating in a dialogical process between the individual and the social, political and civil systems (Yuval-Davis, 2006; Guibernau, 2013).

3.5.1.1 Operationalising belonging for cognitively inclusive research

Milton and Sims (2016) argue that there is a dearth of literature focussing on the construction of the socio-emotional concept from the perspectives of those identified as having SEN/D. Hence, given the participants of this study were identified as having learning difficulties, it was possible there may be some differences in the way they cognitively engage with the notion of belonging. Within the literature it is unusual to find concepts, such as belonging de-constructed to base/key words, nevertheless, I had to find a starting point in order to make this concept more accessible to my participants for the purpose of research (Milton & Sims 2016). In undertaking this work, I was not seeking to ascertain an objective view of whether the mechanism of belonging was taking place, but rather, the aim was to examine the young people’s perception of their own experiences of belonging. Hence, as a starting point in operationalising this concept, I looked to Hegarty et al. (1992), who offer a clear bi-partite framework for understanding a person’s “sense of belonging”. First, there is the need for “valued involvement” (p.173), where a person perceives him/herself to

experience the feeling of being valued. Second is the notion of “fit”, where a person perceives themselves as being accepted in the system they are existing within. Accordingly, I re-examined the literature to pull key ideas that related these overarching concepts and further broke each down into base components. These led to the adoption of anchoring words, which it was anticipated would be used by the young people when thinking about the notion of belonging during the research. When picking the words, I made sure they were the simplest derivations of the word and to support me in doing this, I consulted ELKLAN’s PORIC programme (Woods and Acors, 1999) based on Ann Locke’s (1985) *Living Language Programme*. This resource lists 200 core linguistic concepts that students need to access at the Early Years Foundation Stage and in Key Stage 1 curricula. Hence, it was likely that the young people participating in the research would have been exposed to these words during their school careers. In Table 1 below, I provide a rationale for the anchoring words chosen (see Chapter Four for information on piloting these terms).

Table 1

Overview of anchoring words and their link to the literature

Link to the literature	Anchoring Word	Use within my research
Anchoring words linked to “valued involvement” (Hegarty et al., 1992, p.173)		
<p>Miles and Sims (2016), working with participants identified as being on the Autism Spectrum, argue different people have different needs. They suggest that when researching socio-emotional concepts with neuro-diverse populations, it is necessary to understand what elements the person considers to be important in their own life (Miles and Sims, 2016).</p>	<p>Important</p>	<p>I used important as an anchoring word to stimulate discussion on what is salient to the participants, including: important people and important events in their life. Moreover, after the research process started, important places and important objects were also introduced.</p> <p>Using the word important as a starting place, presented the opportunity to contextualise the narratives on belonging from individual perspectives.</p> <p>By beginning from a point of asking the participants what was important to them, I was able to offer valued involvement within the research process.</p>

<p>Links to Maslow's (1970) Hierarchy of Needs. Happiness can be connected to the notion of self-actualisation and in order to achieve this Maslow posits: having psychological needs met; having ones need for safety met; experiencing inter-human connection offering love and belonging; and having self-esteem.</p>	<p>Happy</p>	<p>Included as a key concept in ELKLAN's PORIC programme (Woods and Actors, 1999). Hence, happy is a word that would have been most likely already familiar to my participants as it is frequently used in special schools.</p> <p>I used happy to facilitate discussion on positive aspects in the person's life.</p>
<p>Drawing on debates in the field of migration and sociology, Yuval-Davis (2006), conceptualises belonging through the lens of a person feeling "at home" or safe in their social context (p.197) and so this became an important word to explore.</p> <p>Also connected to Maslow (1970) and the practical sense of having safety needs met such as not being at risk</p>	<p>Safe</p>	<p>It was considered of relevance to explore how my participants' interaction with their context or place informed their experience of belonging. Using a turn of phrase. such as 'at home', could have been misleading for my population as it could have been construed literally, which would have been confusing when talking about a school context.</p> <p>Safe, was considered as being a familiar term in the special school context (e.g. 'safe place' or 'safe touch') and needed to be explored sensitively in order to understand what 'safe' meant to the young person.</p> <p>A key expectation for a child to have the "best possible start in life", as articulated in the Early Years Foundation Stage framework (Department for Education, 2017, p.5).</p>
<p>This links to Maslow (1970) and the importance of human</p>	<p>Friend</p>	<p>'Friend' is a term that is commonly talked about in educational settings and was</p>

<p>interaction satisfying the need for love, friendship and intimate relationships. Engaging and maintaining friendships are seen as critical for the well-being of children. They serve as resilience factors reducing the likelihood of bullying and social isolation, whilst also supporting positive attitudes towards schooling (Potter, 2014).</p> <p>This also links to the more politicised notion of the collective (Arnot and Swarts, 2012; Yuval-Davis, 2006) and exploring social networks or their social milieu (Nind et al., 2011).</p> <p>Three defined areas of friendship: “shared interaction, shared enjoyment, mutual liking” (Webster and Carter, 2012; Howes, 1983).</p>		<p>deemed likely have been familiar to all of the participants prior to me meeting them.</p> <p>‘Friend’ stimulated discussion on how the young person experienced other people around them and directly elicited discussion on who they choose to identify as their ‘friend’.</p>
<p>Anchoring words linked to “fit” (Hegarty et al., 1992, p.173)</p>		
<p>Drawing on the politicised construction of belonging and the notion of the collective (Arnot and Swarts, 2012; Yuval-Davis, 2006).</p> <p>Nind et al. (2011), in their narrative work with girls</p>	<p>Same</p>	<p>Searching for commonality offered an opportunity to explore whether the young people were aware of discourses on group membership, such as gender, SEN/D labelling etc.</p> <p>I simplified the phrase ‘in common’ to ‘same’ to stimulate discussion on what my</p>

<p>identified as having behavioural, emotional and social difficulties (BESD), highlights how they worked with articulated belonging as encompassing a need for attachment with people and spaces, often expressed through finding a sense of commonality.</p> <p>Draws on the second part of Hegerty et al.'s (1992) two-part conception of belonging: "fit" and feeling you fit in with your surroundings (p.173).</p>		<p>participants had in common with other people and how this made them feel. For example, this was utilised in the exploration of: Who is the same as you? Who looks the same as you? Who acts the same as you? Who likes the same things?</p> <p>ELKLAN's PORIC programme (Woods and Actors, 1999)</p>
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3.6 Conclusion

This literature review has situated my work within the field. I have identified a gap in the literature by highlighting the paucity of research undertaken in England directly with young people identified as having learning difficulties. I will add to the field by conducting this research alongside young people identified as SEN in England learning in different settings. I have also argued for the importance of researching from a perspective of belonging, with the aim of avoiding the reproduction of stigma by engaging directly with the notion of 'Other'. In explaining and showing how I operationalised a sense of self-description and belonging, I assert that I have clarified how my research is cognitively inclusive. Further work participation and inclusivity will be undertaken in the explanation and justification for the methodology utilised for this research in the following chapter.

Chapter 4. Elicitation and participation: Making research accessible for diverse participants

4.1 Introduction

The purpose of this research is to explore the way in which six young people identified as having learning difficulties describe themselves and their experiences of belonging in different learning environments. In undertaking this research, the most important tenet was to ensure the voices of these young people remained central. A participatory and inclusive story-telling multi case study was undertaken in order to understand and describe, in rich detail, the multiplicity of experience, as told by young people identified as having learning difficulties (Burr, 2015; Gergen & Gergen, 1988). Oliver (2002), a pioneer of the Social Model of Disability, argues that, epistemologically, research must reject the notion that it is investigating the world and rather, replace it with an understanding that “research produces the world” (p.14). In testament to this, for my research, I sought to adopt an approach that enabled the participants to express themselves, as far as possible, on their own terms. Within this research, the young people were conceptualised as active participants and collaborators, aiming to make the ‘researcher’/ ‘researched’ relationship more dynamic. Disabled people have often been excluded by the traditional mechanisms of academic discourse and are especially underrepresented on their own terms (Pisani & Grech, 2015). Hence, the centrality and authenticity of the active participants’ narratives were the most important foundations of this research.

Len Barton (1998), in his work on emancipatory research alongside disabled people, set out six key questions I have continuously asked myself throughout all the stages of this project, these being:

- “1. Who is this work for?
2. What right have I to undertake this work?
3. What responsibilities arise from the privileges I have as a result of my social position?
4. How can I use my knowledge and skills to challenge the forms of oppression disabled people experience?
5. Does my writing and speaking reproduce a system of dominance or challenge that system?
6. Have I shown respect to the disabled people I work

with?" (Barton, 1998, p.34)

These questions constantly percolated my thoughts and at points during this research process I have struggled with some of them. In particular, I found it hard to tackle what right do I have to undertake this work, and does my writing reproduce a system of dominance? Words are incredibly important and have the potential to reinforce ableist or oppressive notions, and so I have spent much time reflecting on the words used within the whole of this thesis (see note on terminology in Chapter One). In this methodology chapter, I explain the way in which these questions have influenced this work, both explicitly and implicitly.

4.1.1 Structure

This chapter contains both the methodology and a presentation of the data in answer to research question three on the inclusivity of the methods used within this research. It begins with a discussion the ways of knowing and the philosophical assumptions that inform and underpin this research. Next, the research design is described, and I argue for the use of a story-telling multi-case study. Following this, the research schedule is documented and the instruments utilised for the study are examined. This includes explanation on the pilot study, which sheds light on the development of the methods. Next, the real-world challenges of the research are discussed. This includes the processes undergone in selecting the sites and finding the active participants. Discussion is also provided on the research relationship and what was considered as data for analysis. The methods for analysis are explained and the coding schedule is outlined. The chapter concludes with sections that address the ethical considerations and trustworthiness of the research, thus grandstanding the rigour that underpins this work.

4.2 Ways of knowing: preliminary considerations and philosophical assumptions

Here, I articulate the ways in which some of my own experiences have affected my world view in an attempt to reduce the bias in my interpretation of the young people's co-generated data (Creswell, 2013). I present these beliefs within the context of the paradigms and perspectives that best represent my own understanding of the world. Ontologically, my own experience speaks to the understanding of multiple realities in the world (Creswell, 2013), whereby I see each person as having inside them their own "inner world" or 'reality' (Lieblich et al., 1998, p. 7). I hope that the outcomes of this research shed light onto some of

the lived experiences, as described by each of the young people who take part in this research. I acknowledge that these realities and experiences are likely to represent a different reality to my own and therefore, I must be careful not to impose my own understandings onto the co-generated data.

Epistemologically, I believe in a narrative way of knowing, understanding and living in the world. I think the most effective way to access a person's reality is through listening and interpreting the narratives/stories they tell, to themselves, and others (Burr, 2015; Chase, 2011; Lieblich et al., 1998; Pinnegar & Daynes, 2007). In order to hear these narratives, there is a need to develop relationships with the individuals taking part in the research. The understanding of the knowledge obtained through a person's stories speaks to a subjective view of knowledge. Hence, it was important that all the data collected in this research was steeped in a person's natural setting, thereby contextualising the knowledge (Creswell, 2013). When initiating a relationship and asking questions, the narratives must not be seen as being generated wholly by the person communicating them. The production of data within this project was not one sided, occurring and extracted from the inactive participant without any stimuli or outside forces (Chambers, 2012). Rather, the data produced in this work was co-generated in a context where two people were contributing to its emergence.

The assumptions adopted here are associated with a social constructionist reading of knowledge. I think a person's context, for example social, historical or temporal, contributes to and shapes his or her understanding of the world alongside his or her own experience and interpretations and thus, knowledge cannot be understood without context (Burr, 2015). I believe that society prioritises some people's ways of knowing over others and thus, creates relationships in society made up of unequal exchanges of power (Foucault, 1975). These beliefs are intimately connected to my axiological, or "value-laden", assumptions (Cresswell, 2013, p.20). Davis (2006) encapsulates this when commenting that, "normal has to protect itself by looking into the maw of disability and then recovering from the glance" (p.15). The systemic disenfranchisement and oppression, as described by Davis (2006), continues to be played out today in England, as captured and demonstrated in a recent UN report citing the violations of the rights of people with disabilities (UN, 2017). Moreover, this is evident in the documenting of premature deaths and lower life expectancy of people with learning difficulties in the UK, which is attributed to "institutional discrimination" (Mencap, 2012, p.8; University of Bristol & NHS England, 2017).

My own personal life experience should be characterised as being "value-laden" and hence, my axiological assumptions may have brought bias to this work (Creswell, 2013, p.20). Having been formally identified with mental health 'problems' myself and experiencing

stigma based on this, has influenced my construction of the world and the values I place upon this research. This, along with working in special schools and for community-based organisations in the disability sector, seeing first-hand the discrimination people with disabilities face, renders my understanding of society as being constructed through unequal power relations (Foucault, 1975). Hence, when undertaking this research drawing attention to the inequality of the 'researcher'/ 'researched' relationship was very important, both on a personal and a theoretical level. Due to the limitations of this research in time and scope, I could not fully destabilise this unequal relationship, however, I attempted to make it more dynamic by being as inclusive and participatory as possible. Co-generating data for this work and facilitating the young people being in control of the direction of this process enabled them to be the story tellers; presenting their way of knowing themselves and their experiences, on their own terms. It is hoped that this action can be considered a contribution to the process of social change through foregrounding otherwise marginalised stories. I hope that in explicitly acknowledging how my own life experiences and ways of understanding affect this research, I have minimised my own presence within the stories of the young people honoured within this work.

4.3 Undertaking a story-telling multi-case study: rationalising the research design

Creswell (2013) argues that qualitative data is a diverse and evolving field, which lacks a singular definition. Nevertheless, there are many agreed upon characteristics common to such data and I highlight in the following table (see Table 2), how these elements relate to my work.

The figure below (see Figure 3) gives an overview of this research design. The design of this research owing to its aim to work collaboratively with the participants involved an iterative and reciprocal process, one often found in qualitative work (Maxwell, 2005; Robson, 2011). The flexibility of the design was particularly important, for this enabled adjustments for the participants to be made when the necessity arose. For example, one young person, who chose to be referred to as Nameless within this work, told me of negative experiences, where his peers had recorded videos of him on their phones without his consent. In his case, using the instrument of videovoice was not deemed appropriate. Instead, the flexibility of the design allowed for the co-constructing of narratives without using the device. The young person decided instead to bring in important objects and also some of his schoolwork to help share his experiences and stimulate discussion.

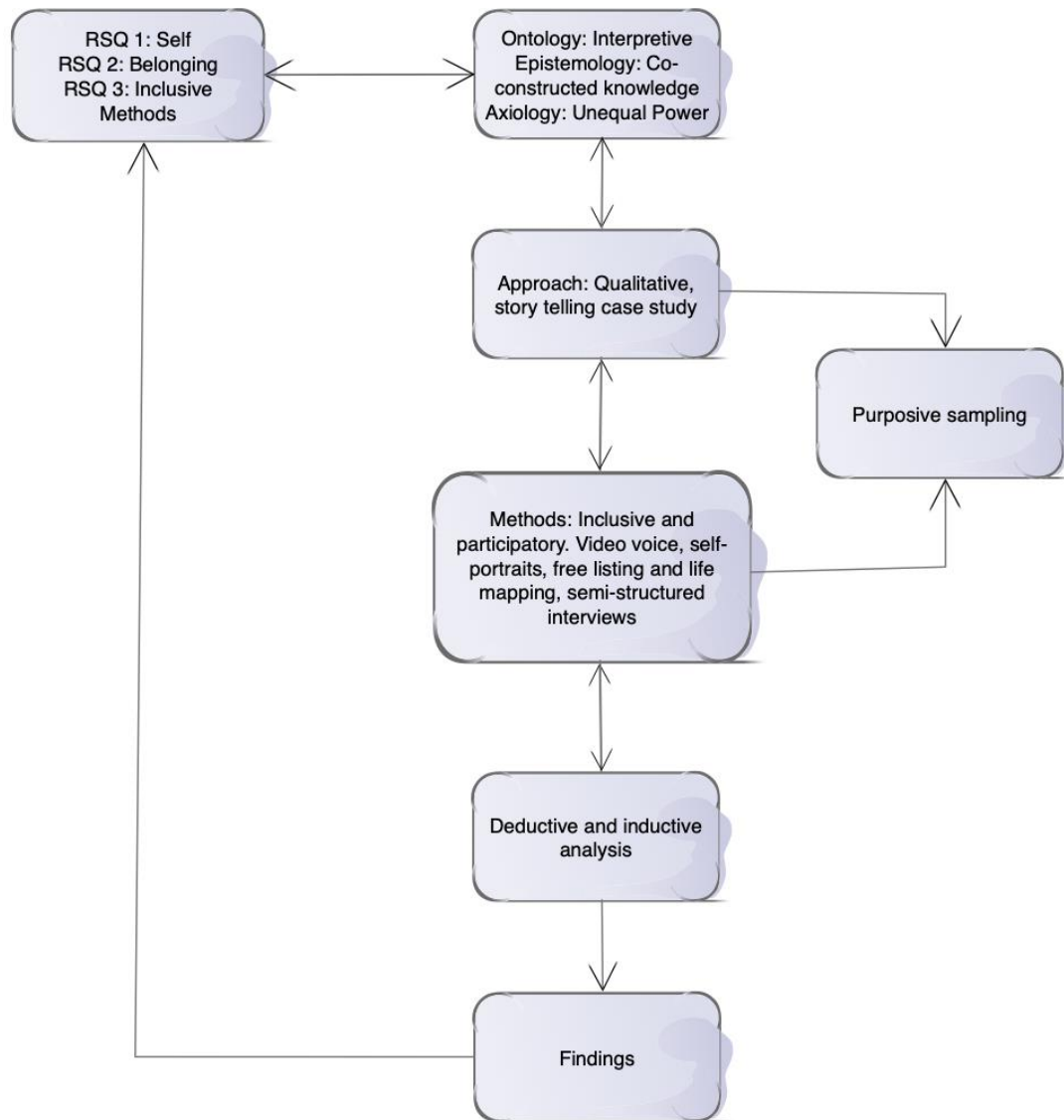
Table 2

Summary of the characteristics of qualitative data

Characteristics of qualitative data	Relevance to my own work
Qualitative data is collected in a “natural setting” (Creswell, 2013, p.45)	<ul style="list-style-type: none">• This research was undertaken with young people in their own social and educational contexts.• Prolonged face-to-face contact with the children taking part in this research was crucial to establishing relationships and a rapport with the young people, being integral to understanding and hearing their voices.
Subjectivity of qualitative data (Creswell, 2013)	<ul style="list-style-type: none">• I recorded and collected different forms of narrative data justified on the basis of my acknowledgement that knowledge is subjective, that multiple realities exist and these are subject to change.
Appropriate method of analysis for qualitative data.	<ul style="list-style-type: none">• Inductive and deductive collaborative logic was utilised in order to reason, re-story and find patterns and themes in the data collected, whilst also staying faithful to the active participant’s own meanings and narratives (Creswell, 2013; Lieblich et al., 1998).• Throughout the process of this research there was space to reflect and continuously consider how I positioned myself in relation to the participants and how this informed. my own interpretations - this reflexivity is a central facet of qualitative work (Creswell, 2013).

Figure 3

Overview of the research design and methods

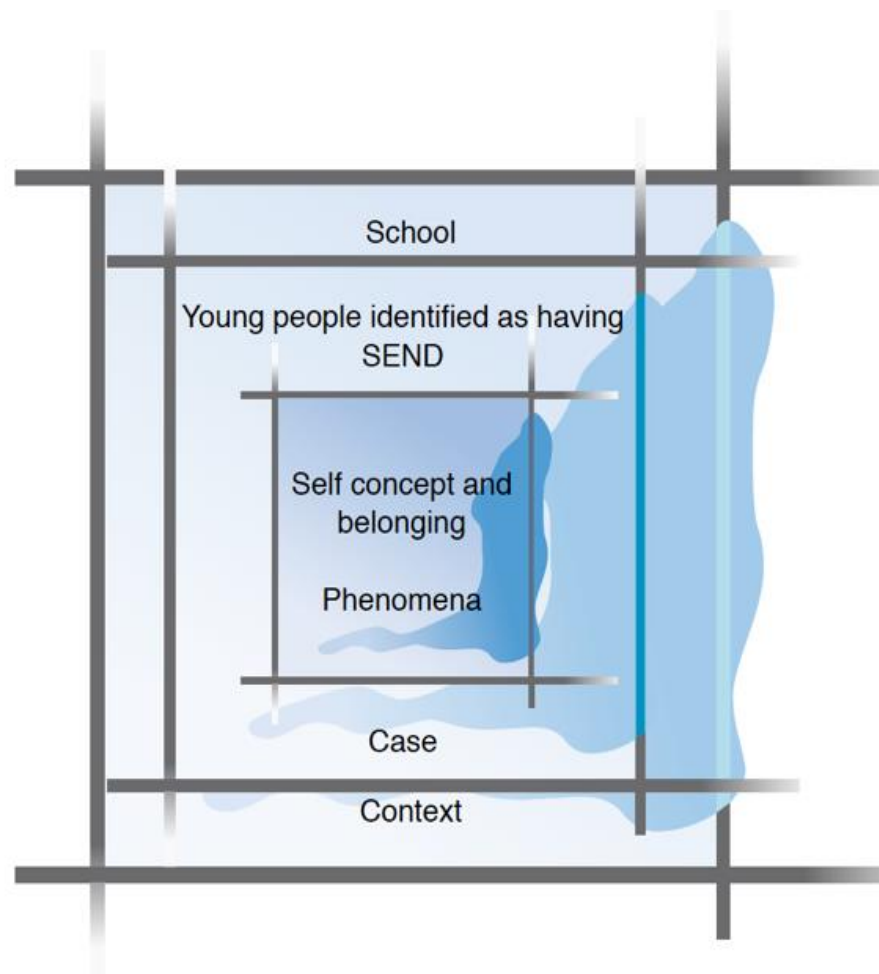


Swanborn (2010) describes case studies as research into “a *phenomenon* or a process as it develops” (p.9) within either one case, or multiple cases. In the case of this research, I studied the phenomena of how the young people conceptualise themselves and experienced belonging. The phenomena were accessed through a narrative instrument. The young people were the social units, or cases, in this study and therefore. this research was undertaken at the micro-level (Swanborn, 2010). Their schools were the context. I purposefully decided to have the young people as the cases, as opposed to the schools,

because I wanted to prioritise their stories and experiences within this research. In particular, the obfuscation of people with disabilities within research (WHO, 2011) was an important factor in ensuring that the importance of individual experience was prioritised and hence, the decision to make the young people cases, rather than the schools. The following figure (see Figure 4) gives an overview of how each case has been bounded.

Figure 4

Overview of one case study



For this research, I have used the notion of a storytelling and picture-drawing multi-case study, adapted from Bassey (1999). He characterises story-telling case studies in the context of educational research as, “narrative stories and descriptive accounts of educational events...which deserve to be told to interested audiences, after careful analysis” (p.62). Essentially, this is what others have referred to as a ‘descriptive case study’ (Yin, 2014) or an ‘intrinsic case study’ (Stake, 1995). However, I have chosen to use the notion of a story-telling case study as I felt it is the most apt descriptive name for the research I undertook. That is, the phenomena of interest in the study were accessed through obtaining

stories told by the young people about their own experiences. Specifically, in undertaking a small scale multi-case study I did not seek to obtain any statistically generalisable findings, but rather, I sought to learn as much as I possibly could from each case, with the aim of generating deeper insights into the lived experience of the participants (Colley, 2010).

4.4 Eliciting voices

“We do not want to contribute to the public silencing of voices from the margins. Instead, we want to do research in a way that creates opportunities to reclaim and re-name that experience. We want methods that will enable people to identify and examine how living on the margin affects their lives, their opportunities, the way they think and act. In this way we can begin to focus on the social relations which daily help us to construct that experience. In particular, methods from the margins must focus on describing reality from the perspective of those who have traditionally been excluded as producers of research.” (Kirby & McKenna, 1989, p.64)

The primary consideration when designing the research instruments, as detailed below, was ensuring the young people were able to participate on their own terms and be fully included, particularly in terms of their understanding, of what was going on during the data collection and early analysis stages. The methods were used to facilitate, as far as possible, the sharing of data on their own terms. It was important that the research tools were autobiographical in their design, as this enabled the young people to collect detailed data on their own lives that they felt best represented them (Bagnoli, 2004). Life is generally experienced through multiple senses and therefore, the creative art-based data collection instruments were designed with the inclusionary idea in mind that “not all knowledge is reducible to language” (Bagnoli, 2009, p. 547).

The collection of data followed an iterative process, where the raw data (for example film) was used to inform and stimulate a collaborative conversation, which contextualised the arts-based data the young people had produced. In order to co-generate different types of data that informs different research questions, for example, everyday stories and “self-narratives” (Gergen & Gergen, 1988, p. 19), a range of instruments were used. Semi-structured interviews were undertaken with the adult participants in order to provide additional contextualising in-depth data. These adult interviews, along with the use of different methods, helped to deeply contextualise the young people’s experiences (Noble-Carr, 2006). An overview of the instruments, how they addressed the research questions

and offered contextualising data can be seen in Table 3. In the following sections, the methods are explained and interrogated in terms of how inclusive and participatory the self-portraits, video voice and life mapping were as research methods in relation to enabling the young people within this research to express their own experiences on their own terms.

Table 3

Overview of research methods

	Videovoice (young people)	Self- portrait (young people)	Free lists and life mapping (young people)	Semi- structured interviews (adults)	Self- reflexive element
1. What are some of the ways in which young people identified as having learning difficulties describe themselves?	(Minor)	Main	(Minor)	Context	Research Diary
2. What are some of the ways in which young people describe an experience a sense of belonging in their educational settings?	Main	(Minor)	Main	Context	Research Diary
3. How inclusive are self-portraits, videovoice and life mapping as research methods for enabling young people identified as having learning difficulties to describe themselves and their experiences?	Main	Main	Main	Context	Research Diary

4.4.1 Videovoice

Photovoice is an established participatory data collection instrument, initially documented by Wang and Burris (1997) as a research method, with the aim of enabling health researchers to obtain “the viewpoint of the people who lead lives that are different from those traditionally in control of the means for imaging the world” (Ruby, 1991, p.50). Since then, this research has been utilised within educational research, specifically in the Global South, to engage

“voices on the ground” (Lehtomäki et al., 2014, p.37) as well as to elucidate the voices of those identified as disabled (cf. Booth & Booth, 2003; Schleien et al., 2013; Povee, et al., 2014; Wickenden & Kembhavi-Tam, 2014; Vu Song Ha & Whittaker, 2016). In the Global North photovoice methods have been effectively used in educational settings with participants with low literacy levels (cf. Cremin et al., 2011).

In the case of this project, rather than a stills camera, as used in the works cited above, I worked with small video cameras, which attached to the body or could be held and hence, I refer to this instrument as Videovoice. MacDougall (2006), an ethnographic filmmaker, posits utilising film within anthropological research as a useful way to enter the “corporeal” space of others, thereby gaining insight into their lived experience (p.270). I contend that using video is a medium, which has the potential to access the “full gamut of human social experience including ideas, feelings, verbal and non-verbal expression, aesthetics, the role of the senses and the formal and informal interactions of everyday life” (MacDougall, 2011, p. 102). Moreover, Corbett (1998) suggests that using video cameras to collect data can be seen as emancipatory, promoting a “can do” approach that enables cognitive diversity within a sample group (p.61). The participants in this study communicated in atypical ways and found memory-processing activities difficult. It was, thus, important that the instrument was able to collect data *in the moment*, which could then later be reflected upon. Videovoice is inclusive for people with both visual impairments and/or hearing impairments as it records experiential data (both sound and visual), rather than only collecting visuals, as with a stills camera (cf. Booth & Booth, 2003) or audio with an audio recorder (cf. Hole, 2007). That is, a person with a visual impairment could still collect their experience through focussing on the sound aspect of the data, whilst a person with a hearing impairment could focus on the visual aspect. Furthermore, the use of a video camera reduced the need for fine motor skills (such as those needed in drawing or writing tasks) and therefore, was more adaptable to the use of a wide variety of people. Using a video camera enabled the collection of stimuli data to be undertaken by the young people themselves (with assistance as needed, for example, in switching the camera on and off), promoting participation and self-representation.

Videovoice challenges the usual power relations of photographer and subject, as the young people were active agents choosing how and what aspects of their life to record (Lehtomäki et al., 2014). The videos generated were not, by themselves, the endpoint of the Videovoice tool. Rather, the multi-sensory video data was used as a stimulus in order to co-generate communication on the videos and subsequent reflections on the young people’s lives, supported by a semi-structured interview schedule. This method did not rely on literacy and reduced the dependency on working and short-term memory processing skills that are

required from typical interviews and focus groups. This was the primary method used to produce data analysed for experiences of belonging pertaining to research question two.

4.4.1.1 Changes and adaptations: notes from the pilot

The videovoice instrument was trialled during the first of two pilots (see Subection 4.4.1.2 for information on the second pilot). I undertook the first pilot in June 2016, over the course of a month. It took place in two government maintained special school, with one participant in each school. I used the same sampling criteria across the pilots and the main study (see Section 4.5 for information on sampling). One school was in the South of England called The Crown School (pseudonym) and was only used for the pilot. In this school, I trialled the videovoice, self-portrait and life map. The other school, The Lane (pseudonym), was in the East of England and was used for both the pilot and the main study. In this school, I worked with Lily (pseudonym) for the pilot, who was fourteen-year-old White British female. Due to time constraints in the second school, I only undertook the self-portrait with Lily. In this section, I present information from the videovoice instrument trialled with James. The instructions for undertaking videovoice were presented to him as a text using Widgit symbols (see Figure 5) and this was followed by a discussion with James, where he asked questions about what to do.


In the space of a week, James created 23 videos with over six hours of data. Due to the large volume of data produced I asked him to choose his favourite videos to show me (n=7). Giving James such broad instructions, initially, left him without enough structure to think about what he was recording and resulted in him producing videos that were never watched. Using a set of questions (see Appendix i), we discussed the videos and he helped me to understand the context surrounding them. Our conversation was transcribed and this data became the primary data for analysis.

Fantasy experiences were the most prevalent content of James' videos that we watched together (four out of the seven videos watched). He explained that assuming a character was "fun", made him feel "happy" and helped motivate him to do things. An example of the fantasy characters James' captured in his videos is presented in the video stills below (see Figure 6) to elucidate the quality of data captured using the video camera itself. James is playing the character of Wolverine and has used pencils to be his claws. He is also interacting with a peer throughout the video.

Figure 5







Videovoice instructions used in the pilot

 Here is a  video camera.








 You can  borrow it for   one week.






 Please  use the  video camera to  film  what  you  do








 this week.









 Remember to  only  film  things  that  you  are happy to

 share  with  me.

 You can  talk or  make  sounds  in the  film  if you

 want to  tell  me  what  is happening.

 You  do not have to  show me  everything  that  you  do.

 Once  you  are finished  we  will  watch  your  film



 together  and  talk about it.

Figure 6

Wolverine extract from James' videovoice



Working alongside James during the pilot changed my thinking considerably in that he was very overt in his keenness to take a more active role as filmmaker, constructing scenes rather than filming everyday experiences. James was very excited at receiving a camera to

use, and in all of his videos we watched together there were times when he took on an active role within the video, introducing people he captured on the camera and explaining their role in his life. It was particularly interesting to note that in the background of these recordings, his teachers and classroom support staff can be heard telling him to “act natural”. In discussing this with James, he indicated he preferred to be the ‘film maker’, rather than acting ‘natural’ and having a less active role in what he was doing. His strong will to ‘create’ the data collected actively was an incredibly important aspect in facilitating the co-generation of stories young people like him actually *want* to share. Enabling a ‘constructing’ role for the participant had the potential to collect data akin to a diary.

The pilot also showed the importance of the camera attachments in that these affected the way they used the camera. That is, the different attachments gave different options for holding the camera, thus offering the young person more choice as to how they filmed their life. Initially, I only provided one attachment for the camera, such that it could be used either strapped to the body or strapped to a helmet (that a student might wear due to epilepsy). This, in itself, limited the ability for the young person to film himself physically, something James pointed out to me when he asked how he was supposed to show himself within the film. Providing interchangeable attachments to the young people (see Appendix ii) delivered more autonomy, whilst also retaining the ability to film in documentary style should the young person so wish. For example, in a classroom situation he or she can wear the camera with the body strap, so it doesn’t impede the lesson or their participation, whereas during free time at school he or she could elect to use the hand-held attachment, thereby providing the opportunity to become the ‘filmmaker/director’.

4.4.1.2 Second pilot: anchoring words for the videovoice tool

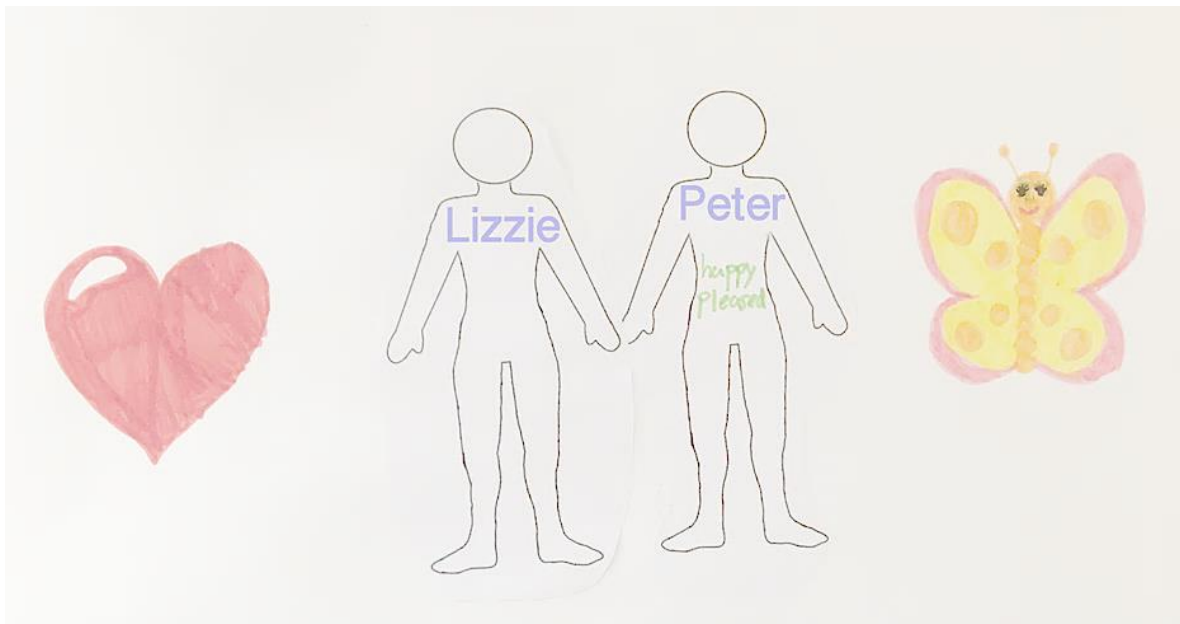
In conjunction with piloting the instruments, it was also important to pilot the anchoring words being used within the videovoice tool, to elicit data on how the young people described experiencing a sense of belonging (see Chapter Three, Subsection 3.2.1). Accordingly, I undertook a second pilot with one participant. This was conducted in January and February 2017, over the course of six-weeks, in The Crown School, a government maintain special school in the South of England, which was also used in the first pilot. The young person I worked with was called Lizzie (pseudonym), who met the same criteria as the young people I selected for the main study (see section 4.5 for more information on sampling). Lizzie identified as female and was White British. She and her family were really keen to take part in the research, as her family felt that young people like Lizzie were often excluded from research and discussions relating to education. As part of the second pilot, Lizzie

participated in the piloting of five anchoring words, as well as a second trial of the life map (see Subsection 4.4.3.1).

When undertaking the second pilot alongside her, it became apparent that she was incredibly talented at representing herself visually. I used tasks related to the anchoring words, namely important, friend, happy, safe and same, to stimulate discussion to understand some of the potential ways the concepts might be understood (see Appendix iii for information on the tasks carried out). Through using words and visual representation, Lizzie was able to show me that she had a good understanding of all five concepts and was able to relate these to specific aspects of her life. For example, in exploring the word ‘friend’, she was able to annotate figures of people and say how they made her feel (“happy”, “pleased”). She also drew a heart and a butterfly saying that her friend Peter made her feel like the latter (see Figure 7).

Figure 7

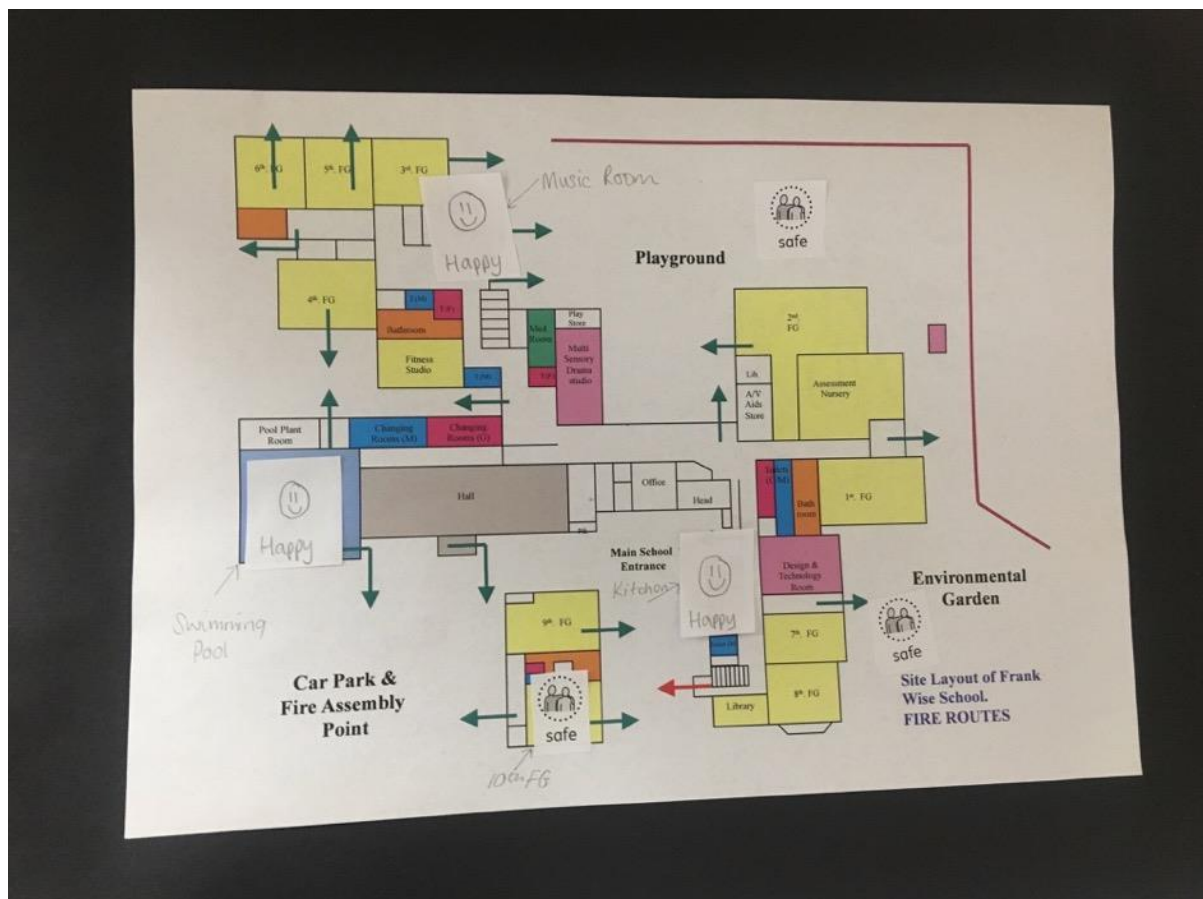
Lizzie’s description of her friend (Anchoring word: friend)



The pilot was particularly useful in examining the way Lizzie reacted to the anchoring word ‘safe’. She had a very literal and practical understanding of the word. We used a map of the school and Widget Symbols to support Lizzie in thinking about where she felt safe. She identified that she felt safe in her classroom and in the playground (see Figure 8).

Figure 8

Places where Lizzie feels safe (Anchoring word: safe)



Exploring why Lizzie felt safe in those places, she spoke about fires, saying she would be safe from them. This suggests that she had interpreted 'safe' as physically safe from hazards, rather than the combined physical and emotional safety that I had initially thought of. Our conversation around feeling safe grew and Lizzie decided to put happy icons in the swimming pool and the music room, where she said she liked to be. This was crucial in getting me to think about modulating my language and explaining to the participants in the main study that safe could mean a feeling that was both emotional and physical.

4.4.1.3 The process of videovoice in the main study

For the main study, I prepared a six-week filming schedule (see Table 4 below) and instructions to share with the young people (see Appendix iv). As can be seen in the schedule below, each week the young person would take a new anchoring word linked to belonging (See Chapter 2) and film data. The following week we would view it together and reflect on it. When actually undertaking the research, the young people wanted to spend more time on some words than others and the research process, which in some cases, ended up stretching over many months. Each week I visited them and we reviewed their films together, co-generating knowledge about these young people's lives. Often, they would

tell me stories about their experiences and the videos acted as stimuli for this. In some cases, however, they had recorded data seemingly completely unconnected to the anchoring words. Nevertheless, I still discussed this data with the young people, if they wanted to, in order to understand the videos they had made better and the reasons for making them. In doing so, I showed how I valued the time and effort they had spent collecting the video data for the research.

Table 4

Videovoice filming schedule

Anchoring word	Task
Important (week 1)	<ul style="list-style-type: none"> • This week, record things that are important
Happy (week 2)	<ul style="list-style-type: none"> • Watch the videos for important and reflect on them • This week, record things that make you feel happy
Safe (week 3)	<ul style="list-style-type: none"> • Watch the videos for happy and reflect on them • This week, record places or things that make you feel safe
Friend (week 4)	<ul style="list-style-type: none"> • Watch the videos for safe and reflect on them • This week, record things you do with your friends
Same (week 5)	<ul style="list-style-type: none"> • Watch the videos for friend and reflect on them • This week, record places, things, or activities you do that make you feel the same as other people
(Week 6)	<ul style="list-style-type: none"> • Watch the videos for same and reflect on them

4.4.1.2.1 Individual adaptations and technical issues

In the main study, with every participant, we made a test video as part of the research process. This was a way of double-checking they could use the camera without having to question their proficiency directly. Furthermore, with every camera I lent, I left step-by-step instructions and problem shooting guides to circumvent technological issues preventing data collection. Initially, I intended to use the branded GoPro cameras for the main study, however, this became impossible due to cost. Efforts were made to procure cameras from the company who made them, but this was unsuccessful. So in the end, I bought unbranded cameras made in the same style of a GoPro and whilst they did work, two of them broke during the research process and had to be replaced. In these cases, no data was lost, but the young people concerned did miss the opportunity of filming that week and thus, the research process itself took longer.

Whilst undertaking the research with the young people, there were some concerns that came up in relation to the videos and using the cameras. Asim had problems with the camera he used and one week it broke. When I brought a new camera in, he was worried about taking it in case it broke again. I had to reassure him that it wouldn't be a problem if it broke again before he would take it to continue the project. Once he had completed his videos, he told me that he was "happy made lots of videos" (Asim, special school, member checking text). Nameless expressed concerns about using the camera as part of the research, whilst Felicjan struggled with the sound of his voice on the recordings, saying that his voice "sounds weird. It also sounds quite loud. I think it sounds differently in real life" (Felicjan, special school, member checking text). Whilst he expressed enjoyment at making the videos, he wished that we had been able to change the sound of his voice and described listening to himself on a recording as being a "nightmare". Had there been more time and were this issue to have arisen again, I would have taken the videos away and changed the tone of his voice using video editing software to make it easier for him to listen to.

Before commencing the research, Nameless expressed concerns about using video as a method. On the one hand, he wanted to use it to be able to evidence the behaviour of his peers, explaining "this will really help with the whole people taking the mick out of me, because now they know they're on camera; they can get easily told off for it" (Nameless, mainstream school, transcript, week 1). On the other hand, he was worried teachers and dinner ladies would tell him off for using it during school time. He decided to not use the camera and rather, brought in objects that were important to him (such as his workbooks). He would also walk me around school during my visits and show me some of the things he would have taken videos of. Whilst I was with him, he did decide to make small videos of his experience or take photos of places using an iPad. I think he felt that my presence would

mean he was free from the worries of being told off; something he was constantly worried about.

4.4.2 Self-portraits: An overview

Historically, artists such as Van Gogh, have produced self-portraits as a method to facilitate self-understanding (Alter-Muri, 2007; Luttrell, 2003). A self-portrait is a visual representation narrating a person's view of themselves; it is a "static capturing of a dynamic thought profile, a process which attempts to reveal the inner self to the world outside" (Mukhopadhyay, 1996, p.107). It is an introspective process through which the person undertaking the self-portrait is encouraged to be "open and receptive to the self" (Alter-Muri, 2007, p.331). Hence, when used in a research context it can be seen as an approximation of a self-assessment (Mukhopadhyay, 1996).

This method, in contrast to videovoice, helps to understand the "self-narrative" or how the children describe themselves and whether they represent themselves as coherent individuals (Gergen & Gergen, 1988, p. 19). Moreover, a visual image may allow access to a different level of consciousness, communicating more holistically and the use of metaphors (Prosser & Loxley, 2008). Hence, within educational spaces this tool is often used as part of therapeutic practice rather than as a research method (cf. Alter-Muri, 2007; Smith, 2008). In such practices the self-portrait is typically used to explore the physical and emotional aspects of a person. Specifically, Cockle (1994) argues that using self-portraits when working therapeutically with children is a key medium through which to express feelings related not only to the self, but also, the environment and using this process can support the development of "personal power" (p.47).

Within educational research, there is a small body of studies where self-portraiture has been used as a key instrument rather than a therapeutic process. Bagnoli and Clark (2010) stress the importance of using creative tasks within research with young people, as they can help in sustaining interest and attention, rather than just "sitting and talking" (p.111), which can be demotivating. Luttrell (2003) used this instrument as part of an ethnographic study undertaken in America to evoke identity narratives of pregnant teenagers. Not only was she able to gather data from the images themselves, for she was also able to do so through the process of talking during the image making and the stories they told when showing the image to others (however, in the present research I did not ask the young people to share their images with other people unless they wanted to) (Luttrell, 2003). Self-portraits have also been cited as an empowering tool enabling freedom of representation for participants to

represent who they feel they are at that moment. The self-portrait process presented the opportunity for reflexivity on behalf of the young people. Creating a self-portrait enabled them to represent and communicate about themselves on their own terms and potentially subvert how other people viewed them (Riessman, 2008). In relation to this, I hoped the use of self-portraits would offer the young people the freedom to present the way they saw themselves; offering the potential for them to engage in or ignore cultural discourses surrounding disability. The process of creating a self-portrait, as well as reflecting on the final product, was used to stimulate the young people into describing themselves.

4.4.2.1 Changes and adaptations: notes from the pilot

Trialling the self-portrait during the first pilot with James (see Subsection 4.4.1.1) helped to elucidate the aspects of the instrument that had hegemonic implications underpinned by normative assumptions. For instance, this task originally demanded dexterity through fine motor skills. Undertaking the pilot self-portrait with James using only crayons and pencils highlighted his perceived expectation for the need to be able to draw likeness. Despite my protestations that it didn't need to be life-like, he felt particularly challenged when it came to him drawing a nose, and he decided he would prefer to leave his face nose-less than draw one 'badly' (see Figure 9). James elected to write down additional information on the self-portrait, rather than draw things he liked and that were important to him.

In their work designing participatory instruments, Wickenden and Kembhavi-Tam (2014) highlight the challenges of drawing as a research instrument, particularly as a young person may feel their output to be embarrassing or as having failed, if they deem it not good enough. As indicated above, this was something that James experienced during the pilot. To counter this, Wickenden and Khembhavi-Tam (2014) suggest either providing a range of materials that are suitably adapted (e.g. grip pencils or collage material) or utilising technology in order to overcome this challenge.

When working with Lily during the first pilot, I generated symbols for her to use in making her self-portrait (see Figure 10) as this was cognitively appropriate for her. Being aware that I was generating the symbols and thus, possibly having an impact on her choices, I generated an array of symbols in order to give her appropriate choice. However, this became overwhelming as there were too many to choose from. I realised that for the main study I would need a system that streamlined the way in which the young people could select symbols, whilst also having enough choice.

Figure 9

James' self-portrait

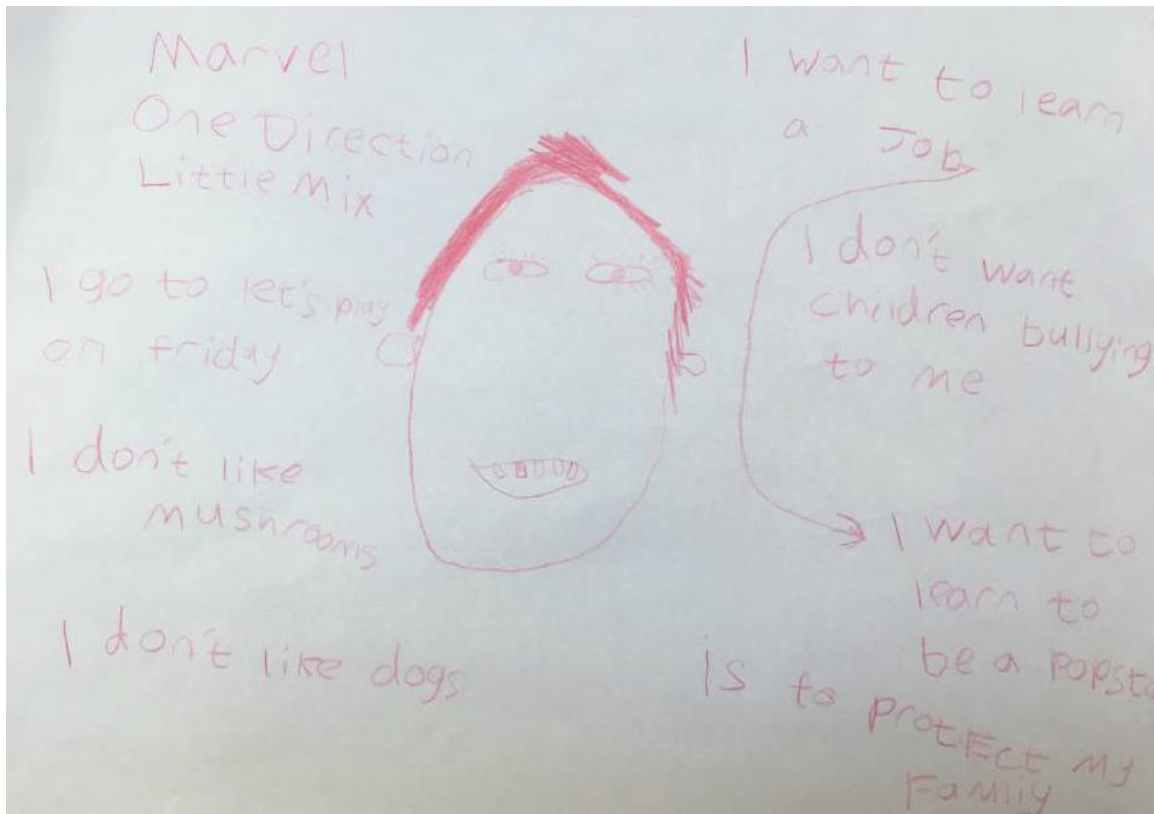
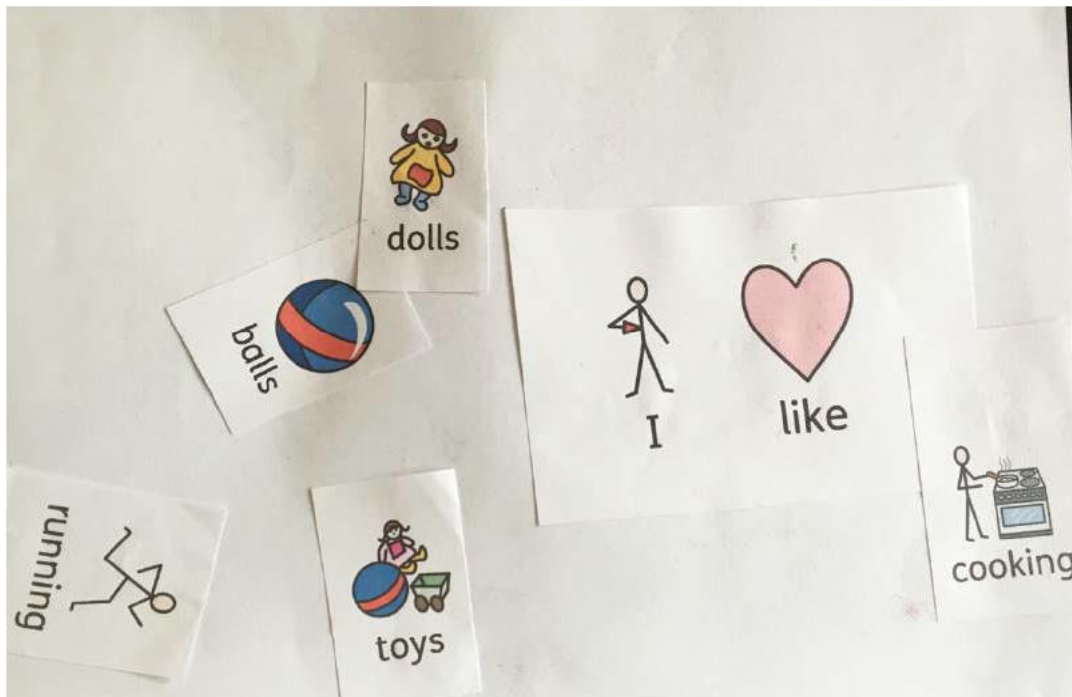


Figure 10

Lily's self-portrait



4.4.2.2 Self-portraits in the main study

In developing the self-portrait tool to be more accessible and reduce the potential for feelings of failure, I offered two routes to the young people before they started. Route one was creating a self-portrait on paper using choices of symbols, magazines for collages, and art supplies with adapted grips to help control where necessary. To overcome the issue with symbols experienced in the pilot, I produced symbol boards (see Appendix v). This offered the participants a choice of thematic boards (e.g. places) and then, the opportunity to select the preferred symbol from within this theme (e.g. school, my local area, home). Whilst this still entailed the problematic element of limiting self-representation as the symbols were generated based on my assumptions, this was a more effective process as it was similar to communication boards used by some children in special schools. To reduce my own presentation within the symbols, I produced personalised symbol boards using the information the young person had shared with me so far in the research process. Despite the limitation of this route, it was important to offer this method for creating a self-portrait as symbols are a helpful enabling communication method for many people. I had been prepared to create tactile and high contrast materials for any participants with visual impairments, however, no one in my sample had visual impairments requiring these adaptations.

The second route I provided utilised technology. I offered the use of an iPad¹¹ with a weighted pen and a laptop with a Wacom drawing board attached with pen (see Appendix vi). The iPad program Adobe Sketch offers the ability to draw, write and insert photos from the camera directly as well as through downloading images on the internet. The iPad is touch screen and is more accessible, requiring less development of fine motor skills. Moreover, it can be customised with accessibility settings, including voice activation and large font size. The computer with a Wacom attachment meant that the young people could draw as they would on paper, but in this case on a computer. Drawing on the computer destabilises the notion of traditional art classes and so, I felt this would help to debunk the notion of needing to draw perfectly.

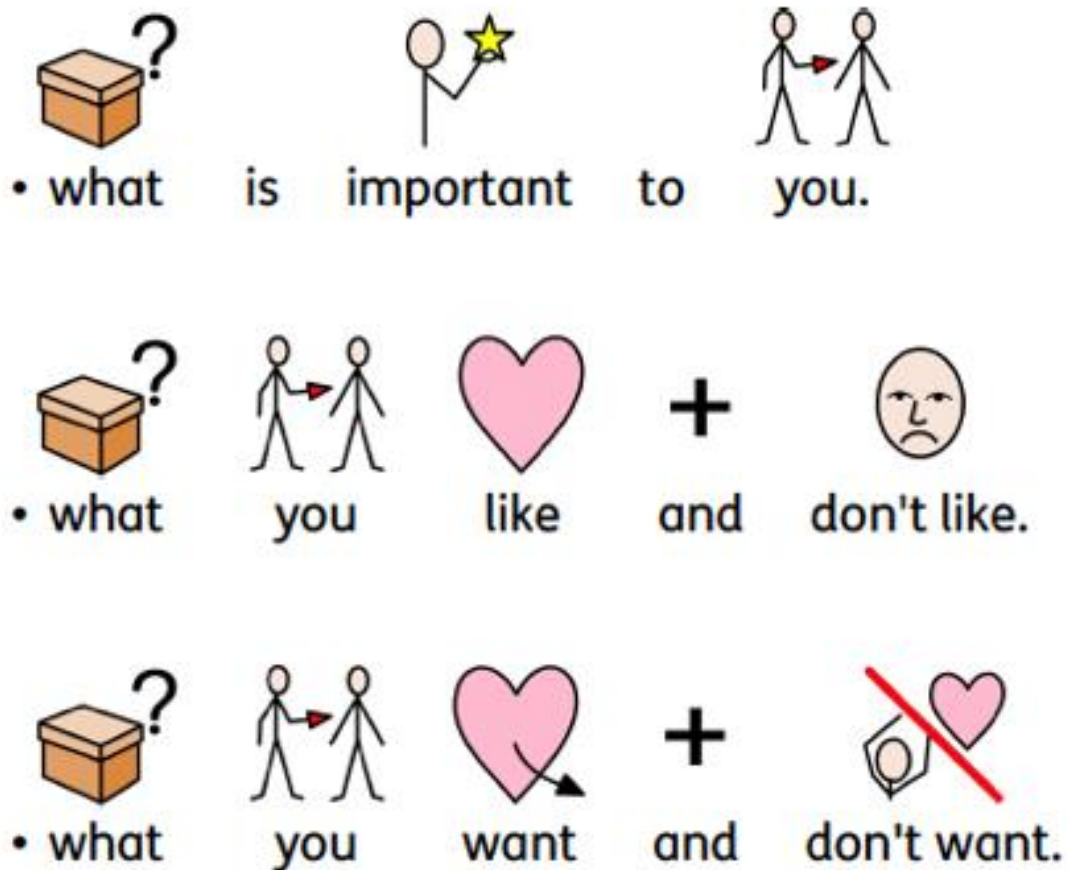
Having the ability to offer the young people a variety of ways to undertake the self-portrait creation helped to make this tool more accessible to the individual's needs and preferences. In the main study, one young person used an iPad (facilitated by his teaching assistant), three used the laptop and Wacom tablet, one used art supplies and magazines, whilst two young persons (one of whom did not complete the research process) used art supplies only.

¹¹ During the pilots all the schools I visited had access to iPads.

Alongside drawing a picture of themselves, I also used the following prompts (see Figure 11) to support the young people in engaging with the process, if they felt that drawing was difficult. Complete instructions for the self-portrait creation can be viewed in Appendix vii.

Figure 11

Self-portrait prompts



Throughout the image making process the young person and would communicate about what they were doing, and why they were making decisions (e.g. colour, shapes etc.). Once the image was finished, I would ask them to tell me about what they had included in their image. For example, in the case of one young person, who chose to be referred to in the project as 'Destroyer', he had included time blades from the film *Ninjago* as things he wanted in his life. He explained to me, in detail, how these worked and how we would use them to help him in his life (pause, rewind and fast-forward time) (see Figure 12).

Figure 12

Destroyer's self-portrait



4.4.3 Free lists and life mapping: an overview

Graphic elicitation tools can be crucial for enabling a participant to go beyond the standard way of answering a question, as it gives time for a participant to think and change his or her mind (Gauntlett, 2007). In contrast to other elicitation tools, where participants react to stimuli, in graphic elicitation the person creates and manages the process him/herself (Prosser & Loxley, 2008). Specifically, in the context of my research I used an iterative mapping process, which I termed 'Free Lists and Life Mapping'. Within education research mapping was initially used by Novak during the 1970s and 1980s to track the scientific knowledge of students, being described as, "a visual road map showing some of the pathways we may take to connect meanings of concepts in propositions" (Novak and Gowan, 1984, Section 2). Since then, the notion of mapping as a graphical elicitation tool has been drawn upon by others working in different disciplines. Specifically in the context of this research, I drew on the work of Buzan and Buzan (1993) outlining mind maps, where a person puts themselves in the centre of the map and then, uses 'branches' to connect him/herself to other concepts/people. Prosser and Loxley's (2008) contribution highlights the importance of visual methods for researching inclusive education and successfully utilising mind mapping as a method to explore the friendship groups of children identified as having special educational needs. Whilst their research demonstrates the findings obtained from the

use of mind mapping and the maps themselves, they failed to outline either the needs of the young people they were working with or the process undertaken in constructing the maps. Given the cognitive needs of the young people participating in my study, I felt that the mind map process would benefit from an initial listing activity I have termed 'free lists', not usually found in mind mapping. I appended this stage as a way to assist the young people in considering who and what they consciously ascribe as having influence in their life. This step facilitated their generating initial lists that could be used in the second task of making the map. Life mapping was then used to enable them to depict people and things in their lives, showing how they position themselves within their social context.

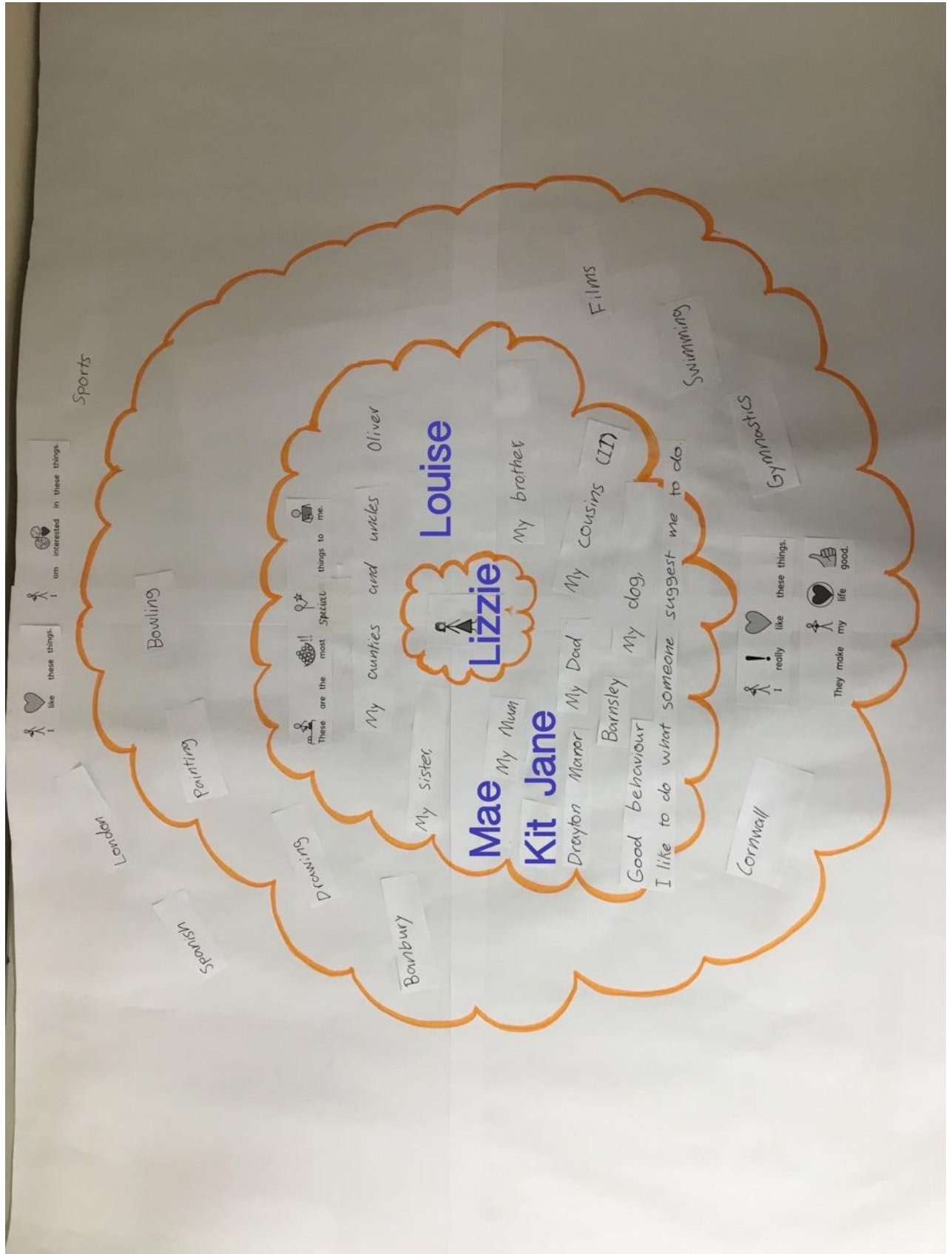
4.4.3.1 Changes and adaptations: notes from the pilot

This method was piloted twice, once during the first pilot with James and once during the second with Lizzie (see Subsection 4.4.1.1 for information on the first pilot and Subsection 4.4.1.2 for information on the second), both of whom, as aforementioned, attended The Crown School. During the first pilot, I encountered similar problems to the self-portrait with respect to the utilisation of fine motor skills for writing. The spelling of people's names was problematic for James and a barrier to participation; however, this was not the case for Lizzie in the second pilot as she was more comfortable with both spelling and fine motor skills. For James, I acted as a scribe – a useful adaptation that was offered to the young people in the main study.

A bigger challenge was presented with respect to prioritisation. I asked James to rank the people he had listed in the order of how important they were to him. He explained that this was "tricky" as they were all important to him. In their work on participatory methods, Wickenden and Kembhavi-Tam (2014) suggest that stickers can be useful in facilitating children to identify their preferences. I was concerned that stickers may cause the same problem, so in the second pilot, with Lizzie, I trialled another method, where we drew different levels of circles with the headings (using Widgeit text and symbols): 'these are the most special to me', 'I like these things, they make my life good' and 'I like these things. I am interested in these things' (see Figure 13). Lizzie then placed the items from her list into the various circle sections. This was much more effective as it facilitated discussion about why the person or object had been placed in that section.

Figure 13

Lizzie's life map

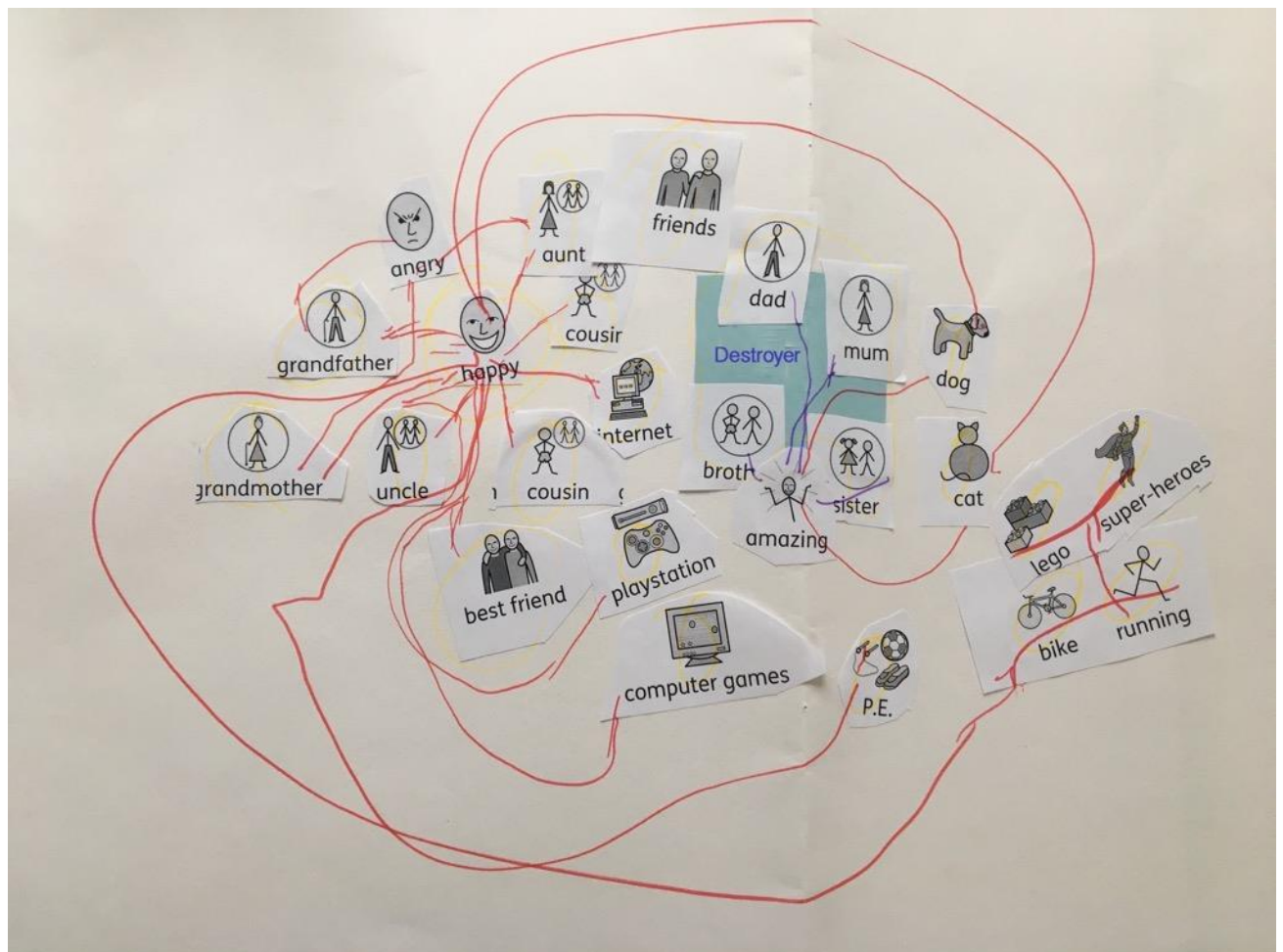


4.4.3.2. Free lists and life mapping in the main study

Taking on board the learning from the pilot, I decided to speak to each young person individually in the main study, showing them some examples from the pilot and then, we decided together how best to adapt the life map for their own needs. In terms of the accessibility of this instrument, for one young person, Destroyer, I generated symbol boards, which looked through and cut out the ones he wanted to create lists. He then rearranged the symbols to create the map. Next, he identified emotions he felt in relation to the people and objects and this triggered him into telling stories in connection with those people, which became the data used for the analysis for this method along with the map itself. His anonymised life map is shown in the Figure 14.

Figure 14

Destroyer's Life Map

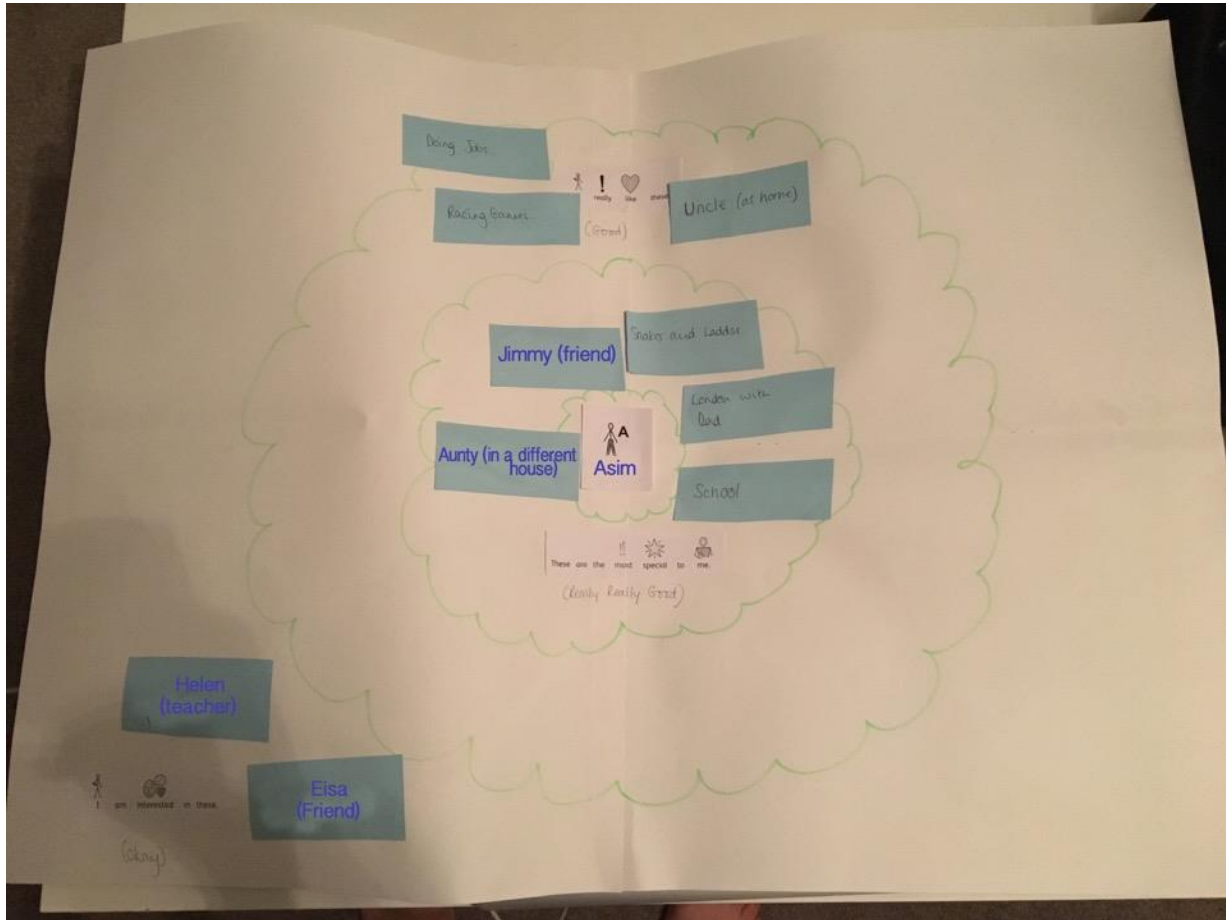


For another young person, Asim, he dictated and I scribed the list and then he cut out the words. He found reading very difficult, so I re-read each item for him and he arranged them

in the different circle sections. His anonymised map can be seen in the Figure 15 below.

Figure 15

Asim's Life Map



Nameless, a young person who was very happy using the computer, created his own life map independently and decided to add a second section for the people in his life that he disliked. He opted to use colours to highlight the different levels of people as well as placing the most important closer to himself. His anonymised map can be seen in Figure 16. As he produced the map, I was able to ask questions about how he was placing the people in his life, which became important data for analysis.

4.4.4 Semi-structured Interviews

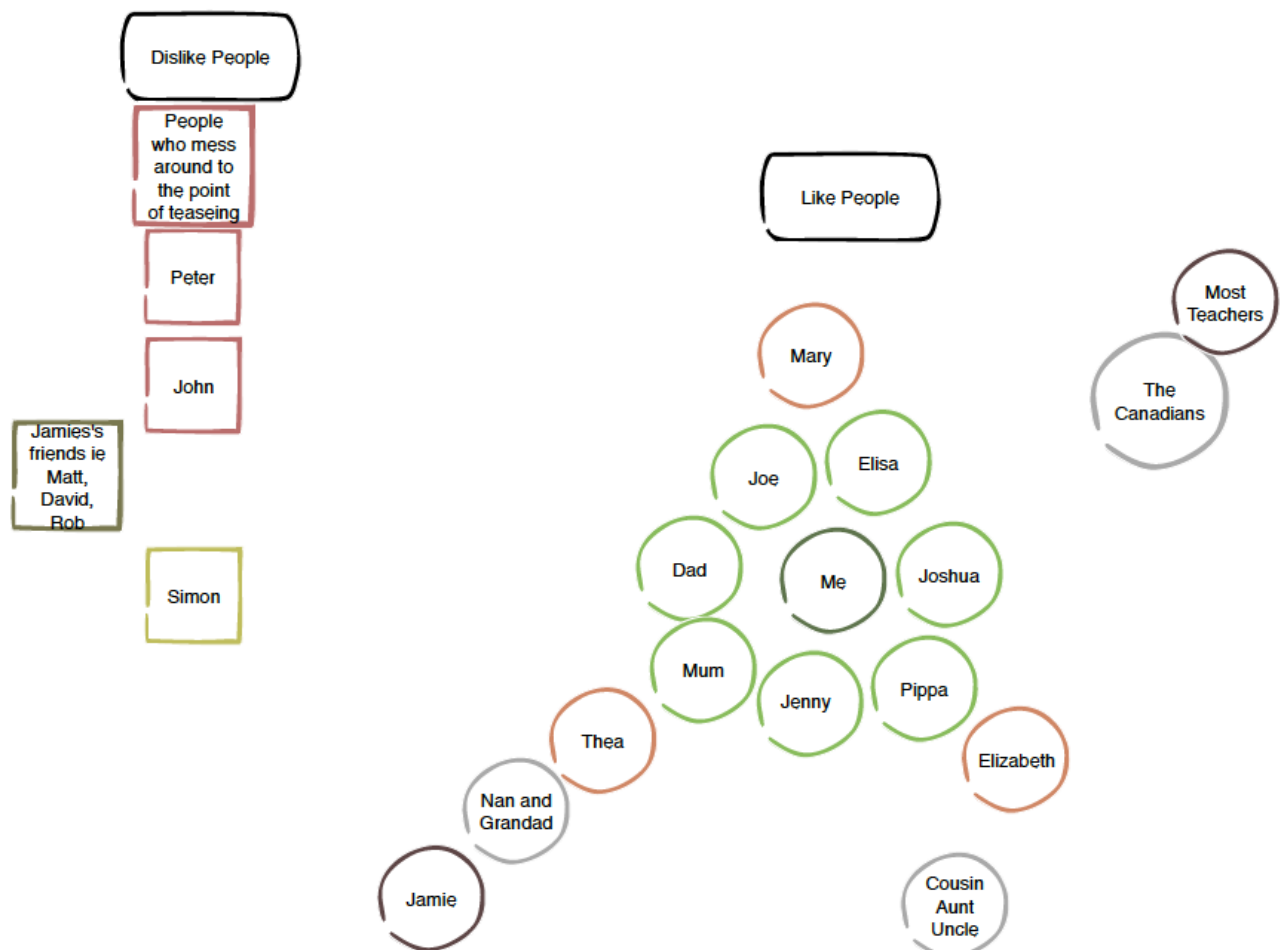
Semi-Structured interviews were undertaken with the adult participants to provide contextual data helping to situate the young people's reported situation. I drew on the literature relating to semi-structured interviews using Brinkman and Kvale's (2014) notion of funnelling to enable the staff to free-talk and then, probing deeper to ensure all the necessary topics had been covered. In order to ensure that the interview comprehensively delved into the range of

issues for contextualising the children’s narratives, a semi-structured interview schedule was developed and used (see Appendix viii).

At the beginning of the interviews, there was space provided for the interviewee to explain their own perceptions of the young person’s experiences in their own words, rather than this being elicited as a result of more directed questioning. I was apprehensive to begin with as I was worried that the people might find it difficult to talk without prompting. Nevertheless, this space was very successful in drawing out stories and quite often one story would lead to another, with the participant reminiscing and talking for an extended period of time without stopping. Before they started telling me the stories, I explicitly said that I was there to listen attentively to them and would not interrupt with my own thoughts. In order to minimise the imposition on the person and as I did not need to use any Makaton signing with the adults, the semi-structured interviews were recorded using a digital audio recorder.

Figure 16

Nameless’ Life Map



4.4.5 Reflexive research diary

I kept a reflexive field journal throughout the research and analysis process (see Appendix ix). This was a personal space to undertake scrutiny of myself as a researcher; my experiences and my positioning in relation to the participants. In this diary, I kept a detailed record of my research as it progressed as well as my thoughts and feelings relating to my own experiences - particularly in the field. As Etherington (2004) writes, keeping this written record is a way to acknowledge myself in the research process, when during the day to day work in the field I was trying to retain neutrality, in other words, this diary was a way of “making me visible” (p. 135). It was particularly useful to use the diary to maintain an audit trail during the analysis process in order to demonstrate the specific steps undertaken (Miles et al., 2019). The written information provided and mind maps drawn in the diary as part of the analysis process were useful in meetings with my PhD supervisor as a basis for discussing concerns and challenges.

I also used the field journal to record additional information, for example, my perception of the mood of the participants. This helped me to contextualise the primary data, providing me with reminders of such matters not immediately available in the transcripts or member checking texts. I completed the research journal after each meeting with a participant. Logging these experiences enabled me to note down thematic areas to probe and also allowed for very basic continuous analysis of the broad themes and concepts that come up during contact with the participants. Keeping a field journal also aided the confirmability of the research process (Creswell, 2013; Lincoln & Guba, 1985). Retaining detailed tracking of this process offered up an opportunity for reflexivity in between visits to the students as well as during the analysis stages.

4.4.6 Research schedule

In order to collect the data most effectively, I developed a 10-week research cycle for each participant consisting of one day per week in each school (see Table 5). This offered an opportunity to collect data in a staggered manner, thereby allowing more time to reflect on the videos recorded and the co-generated data. Spending prolonged time with each young person also engendered a sense of the temporally changing nature of the young people's lives. The following table outlines the process followed. In the end though, the research took longer than I had initially predicted and the schedule was extended, in some cases to over four months with a young person. The work was undertaken over three terms, namely spring, summer and the following autumn, after the summer holiday. During this process I also, where possible, undertook the adult interviews.

4.5 Real world challenges: finding sites and participants

The majority of this research was undertaken with the young people themselves, where together we co-generated the narrative data central to this work. They selected adults to participate, who they thought could provide additional contextualising information. I also sought to interview the Special Educational Needs Coordinator (SENCo) at each school to provide an overview of the school, its ethos and its approaches. It was important to find accessible “information rich” individuals, who had the required group membership credentials (Merriam, 2009, p.77), however, I also needed to get a range of different learning environments. Due to these significant requirements, network criterion-based sampling was used. That is, networks were used to connect with potential participants who fitted the research’s criteria. By its nature, criterion-based sampling is non-probabilistic and therefore, this research cannot be considered representative or generalisable (Merriam, 2009). I trawled my networks in order to find three different schools, one of which needed to be a special school. I decided primarily to speak to schools where I had either a personal connection or where a secondary contact could introduce me as a known party. In a few instances, I also contacted schools via email, ‘out of the blue’, but found this entirely unsuccessful. My experience speaks to Booth and Booth’s (1996) advice about the importance of having intermediaries known to potential participants. I used the following criteria in selecting the three schools.

- Mainstream or special government funded school
- Secondary intake
- Mixed socio-economic intake
- Presence of ethnic diversity
- Presence of children who have EHC plans

After extensive consultations with the schools, visits to discuss my research with senior management, ethical clearance and obtaining consent from the schools and parents, I secured three schools for investigation: a mainstream school; a mainstream faith school and a special school. An overview of the three schools that participated in the main study can be found in the following subsection. All the names used within this research are pseudonyms applied to ensure anonymity (see Subsection 4.5.5.3 for further discussion on pseudonyms).

Table 5*Research Schedule*

Week	Topic	Tasks
1	Speech and language assessment	<ul style="list-style-type: none"> • Explain the research and check the young person wants to participate • Start to build a relationship • Undertake a TALC test • Check preferences for the following week's self-portrait to prepare materials
2	Self-portrait	<ul style="list-style-type: none"> • Watch research video • Undertake the self-portrait using the young person's desired materials • Check preferences for the following week's life map
3	Life map	<ul style="list-style-type: none"> • Create life map
4	Important videovoice	<ul style="list-style-type: none"> • Re-watch part of the research video • Learn how to use the camera • Make a test video • Set up the anchoring word 'important' for the videovoice instrument
5	Happy videovoice	<ul style="list-style-type: none"> • Watch and reflect on the 'important' data • Set up the anchoring word 'happy' for the videovoice instrument
6	Safe videovoice	<ul style="list-style-type: none"> • Watch and reflect on the 'happy' data • Set up the anchoring word 'safe' for the videovoice instrument
7	Friends videovoice	<ul style="list-style-type: none"> • Watch and reflect on the 'safe' data • Set up the anchoring word 'friends' for the videovoice instrument
8	Same videovoice	<ul style="list-style-type: none"> • Watch and reflect on the 'friends' data • Set up the anchoring word 'same' for the videovoice instrument
9	Member checking	<ul style="list-style-type: none"> • Watch and reflect on the 'same' data • Create the avatar for the research pseudonym
10	Member checking	<ul style="list-style-type: none"> • Go through the member checking text and make changes as necessary • Reflect on the strengths and weaknesses of the research experience

4.5.1 State-Funded Special School

The Lane (pseudonym) is an Ofsted 'outstanding' special school based in the East of England that takes pupils from the age of two to 19 and has 150 in total. The school takes students with severe learning difficulties and profound and multiple learning difficulties. In addition, many students also have autism or complex medical needs. The school has Looked After Children (LAC)¹² and a third of the school population are eligible to receive free school meals (FSM). The Lane has a very diverse population, with an above average number of children who speak English as an additional language. The native languages present in the school include Panjabi, Urdu, Polish, Portuguese, Slovak, Russian, Akan and Bengali, among others. A third of the school's population (n=56) identify as being White British with the next largest group identifying as Pakistani (n=36). In response to this, the school has sought to employ support staff who can speak multiple languages, including teaching assistants and midday supervisors.

The Lane is split over two sites - one for the lower school and the other for the upper school. I was based in the secondary school, a new modern building that was built to accommodate the students who attended. The corridors are wide and the building has lots of windows meaning the school feels bright and airy. The notions of accessibility, accommodation and inclusion seemed to pervade every discourse within the school. When talking to eight adults within the school, it was clear that a central focus was on creating a loving and accepting place, where staff "love the individual students" (deputy head, special school, transcript). Due to the small population and hence, small class sizes of typically 6-8 with 4-5 staff, the students were all known intimately by those they worked with. This closeness translated into the staff constructing the school as having a "family vibe" (deputy head, special school, transcript).

There was a strong focus on life skills and skills for the workforce as well as trying to imbue the students with a sense of agency; consciously educating them to know about their rights and the fact that they deserved the same opportunities as other people. This was particularly evident in the way the deputy head spoke about the curriculum:

Throughout our Personal Social Health Education (PSHE) curriculum we've merged citizenship through 'how everybody deserves the same opportunities' and, our school is very much about giving everybody opportunities. (deputy head, special school,

¹² Children who are looked after by social services.

transcript)

The Lane is also very proactive in countering the criticism of special schools as being socially isolating. In particular to this end, they have an outreach programme to support the students in accessing the community and participating in mainstream life. The school has created a charity shop and small cafe in the centre of their local area, which the students help to run. The Deputy Head was quick to point out that all the students, regardless of ability are able to access this programme:

It's not just the able students who we SEN/D down to the hub [a satellite area of the school that works as a cafe and charity shop in the city centre]. We have some students with profound and multiple learning difficulties, who go down there as well to experience a different environment, for example. (deputy head, special school, transcript)

4.5.2 State-Funded Mainstream School

Hawthorn (pseudonym) is a mainstream secondary school based in the South of England, which in 2013 and 2015 was judged as 'requiring improvement'. Regarding children identified as having SEN/D, Ofsted specifically reported that they were not making good educational progress. In 2015, less than 30% of students achieved 5 A*-C GCSEs, almost 30% less than the national average at 57%. This means that the school is below the government's current floor standards, which sets the minimum GCSE attainment level at 40%. In the two years following the Ofsted report, the school leadership had been trying to find strategies to improve student attainment and when I arrived to research, the school was undergoing a process of amalgamation with a local federation made up of a junior and infant school. After we came back from the Easter holidays the school name and signage had changed, however, the new uniform was not going to be compulsory until the following September. The proportion of children who were eligible for FSM was also above the national average. The proportion of students identified as having SEN/D is generally in line with other schools in England, and the majority of these were male (75%). Most of these children were on SEN support, but only seven children had an EHC plan (or a statement).

Whilst the majority of students come from a White-British background, there are over 34 nationalities in the school, with a large proportion from South Asia. Moreover, the school has a higher than average percentage of children speaking English as an additional language. In the preceding few years, there had been a significant rise in Nepalese immigration to the

area. The school body had struggled with this and there were significant racial tensions within the school. Hence, the school faced significant challenges to inclusion, unrelated to children with SEN/D, in terms of trying to integrate two stratified cultures. This was articulated by the school's SENCo, who reflected that in the four years following this immigration, two groups of "top boys" had been formed - the "white boys" and the "Nepalese boys" (SENCo, mainstream school, transcript). Whilst this specific issue had been resolved by the time I undertook my research at the school, racial integration was still one of the most significant concerns and the SENCo reflected on the difficulties involved with trying to encourage the children to mix.

Unfortunately, I still think there's too much of a division in the school. There's not a huge amount of mixing and we try and tackle that all the time, but it is very difficult...When you've got two completely different cultures and one group of people feels that the other has been put into their world without too much reference to them. It has caused problems; I'm not going to lie. (SENCo, mainstream school, transcript)

The significant difficulty Hawthorn faced in trying to ensure cultural integration should not be underestimated, especially given the discourses around immigration prevalent at the time. These challenges may have contributed to the pragmatic approach the school was taking to inclusion - be that in relation to children with disabilities or culture. The SENCo focussed on the way in which there needed to be rules in the school to try and manage the students and prepare them for life after secondary school.

I'm a great believer that there is a line in the sand, because the children have eventually got to go out into the outside world and there are boundaries. (SENCo, mainstream school, transcript)

Moreover, Hawthorn often had staffing difficulties, having to rely on supply teachers and thus, making it difficult to provide consistency, specifically for the young people identified as having special educational needs. The SENCo spoke of the difficulties short-staffing had on managing the school and ensuring the students were known to teachers. She explained how this meant it was difficult to get the balance between strict discipline and the "children ruling the roost" (SENCo, mainstream school). In relation to this, the school had tried to create smaller staff-supervised spaces for students to spend time in during breaks and lunchtime, such as computer rooms and the library. In particular, in relation to children identified as having SEN/D, Hawthorn had opened 'The Purple Room' (pseudonym), a safe space that acted as an inclusion room for students to come to during break or lunch time and if they

needed support.

We've got so many ASC children...We're aware that they've got heightened anxiety, heightened stress that they might need to have - that's why we've got [inclusion unit] as a chill-out room at breaks. (SENCo, mainstream school, transcript)

The school used this room a lot to promote students staying in school, rather than being absent. Towards the end of the term they found that many of the students became "overloaded" and so they would change their timetable by the cutting of the final class. However, instead of the students going home early they would go to 'The Purple Room' and be able to finish the day in school without incident. Whilst Hawthorn was clearly proactive in using strategies to support its young people on the SEN register, an issue that was very difficult for the school to overcome was the inaccessibility of the building. The school had been built over the last four decades and was split over multiple buildings with two floors. The whole of the second floor of the school was inaccessible for a person who was unable to climb stairs. Recently, the food-teach room had been refurbished to make it accessible at a cost of £140,000. However, they been unable to continue making refurbishments to the rest of the school due to a limited budget. The SENCo was very upfront about this, acknowledging that the school was not very inclusive for a student with a physical disability.

4.5.3 State-Funded Mainstream Faith School

St. Christopher's (pseudonym) is a relatively small, mixed inner-city secondary school, with 500 students. The school is a Roman Catholic Convent faith school and when oversubscribed gives preference students of that faith. There is still active involvement in the school from Sisters who sit on the governing body and contribute to the religious aspects. The school has been rated as 'good' by Ofsted since 2013, when it improved from 'satisfactory'.

The students who attend St. Christopher's are primarily from black and minority ethnic backgrounds, with the leadership seeking to ensure that its staff reflect the diversity within the student body. The proportion of students who speak English as an additional language exceeds the national average. Moreover, over 60% of students are eligible for FSM. Conversely, the number of students with SEN/D, both in the case of having EHC plans and SEN support, is below the national average. When appropriate, the school is able to offer the opportunity for some children at GCSE stage to study vocational courses at a local college. The school meets the government's current floor standards, meaning that more than

40% of students achieve 5 or more A*-C grades at GCSE.

When I arrived at the school, they had been without a SENCo for six years. A member of senior management had been allocated this role, whilst a teaching assistant had been promoted to Assistant SENCo and she had been carrying out the day to day duties of a SENCo since the previous person had retired. A few months into my research at the school, a new official SENCo was appointed. Given there had not been one for six years, she found it “miraculous” the school was managing. She did, however, have many concerns regarding the interventions students were receiving, priorities and policies as well as the processes of annual reviews and Education Health Care (EHC) plans.

The last SENCo retired six years ago and so there has been no SENCo for six years, so it's actually kind of miraculous. But the thing is that, what I'm finding when I delve into the annual review reports is, for example, Nataliya [research participant] has been two years now without any input to do with autism. I'm uncovering all sorts of things that are worrying me that I'm having to pick up and accelerate on. I'm having to say: "this is what our priorities need to be. Could you please do that?" I think there's been a lack of, for example, the annual review reports read like a story, and there are things in it that are inappropriate like, "oh yeah, Nataliya is the light of my life and she's a ray of sunshine"...I'm thinking Senior Management - you've obviously not read these, and they have no knowledge of SEN whatsoever...Nobody has known. And so I think, given that, it's miraculous that it has come even to this.
(SENCo, faith school, transcript)

The new SENCo highlighted, particularly in her example of EHC plans reading as stories, concerns regarding the potential for the infantilising of students. She was worried that there were few boundaries in relation to the SENCo office and that traditionally students would just walk in and start talking. She felt that there needed to be more boundaries set in the school to promote the independence of the young people on the SEN register.

When speaking to the assistant SENCo, it emerged that she had been very conscious of promoting well-being within the school and ensuring a safe space, particularly for the young people identified as having SEN/D. She was particularly concerned with the way in which students might be affected by an overly authoritarian approach:

“We have to be mindful of and not to scream and shout in a form that’s going to affect a child”. (assistant SENCo, faith school, transcript)

Similarly to the mainstream school, during her tenure, the assistant SENCo had opened an inclusion area of the school called 'The Brambles' (pseudonym) that they referred to as a nurture space. Students were able to go there, if they were struggling, during lunch time or break-time. She felt this was particularly important as "class sizes are quite big now" (over 30) and so, she wanted to ensure that students with social development impairments had a space to "grow" (assistant SENCo, faith school, transcript). However, the new SENCo had concerns over the safety of the space, referring to it as feeling "undignified" (SENCo, faith school, transcript), particularly in relation to it being made up of many small rooms that were often unsupervised. Nevertheless, she recognised the importance of having a space where students who did not want to be in the playground could go.

I love it. But I worry about it as it is, it; it seems like they're closeted off in those little dens, it just feels...and it gets sweaty and it smells and it just feels quite undignified really. But it serves its purpose at the moment. (SENCo, faith school, transcript)

4.5.5 Selecting Participants

The main priority in locating participants within these schools was considering how to maximise their role as active contributors to the research. This meant finding young people for whom the research would be developmentally appropriate and also for whom the research might be useful, such as students who might have felt underappreciated or ignored.

The pilot was undertaken with three young people with varying cognitive processing levels, which highlighted the need for a more robust sampling criteria for the main study to ensure the research was ethically and developmentally appropriate for the participants. In the main study, due to the limitations of this research in terms of time, scope and also my own communication shortcomings, this meant that the investigation was only appropriate for children currently communicating at (or above) a basic narrative level. The research required children to communicate emotions and to retell events from their lives. In setting these parameters, it has been possible to uncover experiences that heretofore have been untold and invisible; a key strength of this work.

Initially, I used P level 6¹³ for communicating (listening and speaking) as a guide (DfE, 2014). It must be underlined that whilst engagement with this educational categorisation was used as a criterion for this research, it was used without value judgment about the person's quality and enjoyment of life. Due to the challenges inherent in levelling P scales, I also decided to utilise a Test of Abstract Language Comprehension (TALC)¹⁴ (see Appendix x) as part of the sampling process (McLachlan & Elks, 2015). Level three of the TALC identifies whether or not "the child is able to re-tell an event or a narrative and is able to empathise with the characters" (McLachlan & Elks, 2015, p. 12). Selecting participants who were communicating at level three would ensure that, ethically, the research was developmentally appropriate. Additionally, this criterion helped to improve the validity of the data collected. The full criteria used to select the participants is provided below:

- Young people who have been formally identified as having a learning difficulty and have either an EHCP or a statement of educational need. Where they have a formal identification of being on the AS, they need also to have a formal identification of a learning difficulty;
- Are between the ages of 11+ and still attending school full time, but not in GCSE years (due to the time requirement of the research process);
- Speaking or having expressive communication at P level 6 or above (meaning that the students are able to ask a basic question, such as "where's the dog?" and can sustain a short conversation: "I'm happy, I like cake");
- Have been assessed as being able to communicate at narrative level 3 in the TALC;
- Enthusiastic to participate in the research.

This led to securing seven young people who were keen to participate in the research. Due to the time-commitment requirements of the research, in discussion with the mainstream schools we decided it would be important for the participants not to be studying for their GCSEs and so this criterion was used across each of the learning environments. In the case of Hawthorn, this meant that all the students with an EHCP in years 7-9 were male - three of whom joined the research. In the case of St. Christopher's, it was particularly important to find young people who would be okay with having a relationship for a short period of time, and for whom when I finished the research, the change would not be traumatic. Due to this,

¹³ P scales are not nationally standardised and therefore, each school may interpret the guidelines differently. Hence, this criterion should be seen as a starting point subject to change based on each teacher's guidance at each school.

¹⁴ Designed by speech and language therapists McLachlan and Elks (2015) in order to help ascertain the "level of abstract language a child can understand" (p.5). So as to administer this test properly, I undertook online training with the company who produced it and have had discussions with one of the authors (McLachlan) to ensure the suitability of the test for the context of this work. An example of a completed test by one of the participants can be found in the Appendix xi.

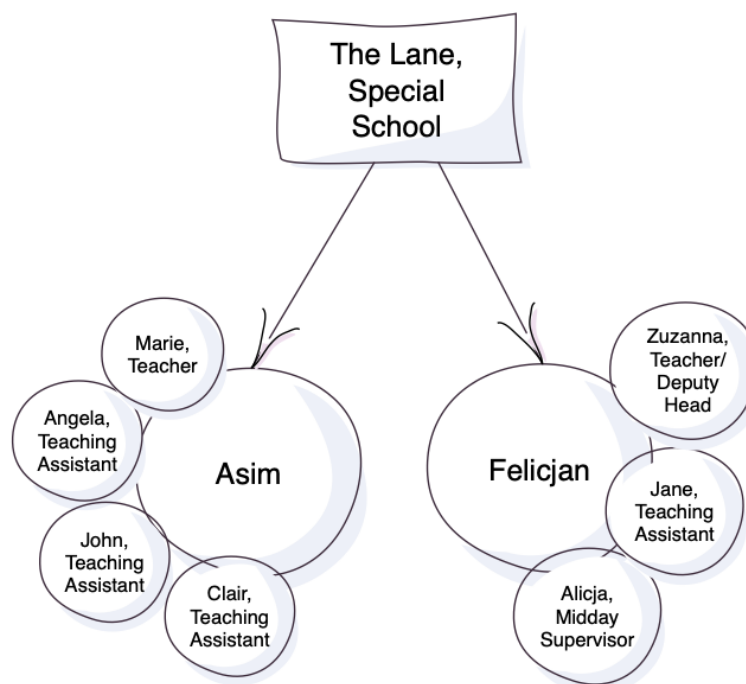
two females participated in the research from that school. In the special school, The Lane, we were committed to identifying young people who would enjoy the research and for whom it would be at the right cognitive level. A snapshot of all the participants can be found in the coming sections. Unfortunately, one young person did not complete all the research requirements (however, he did give me permission to use the data we had collected), leaving six young people’s narratives for presentation in the final analysis (see Subsection 4.7.1.1. on supporting a participant to exit ethically).

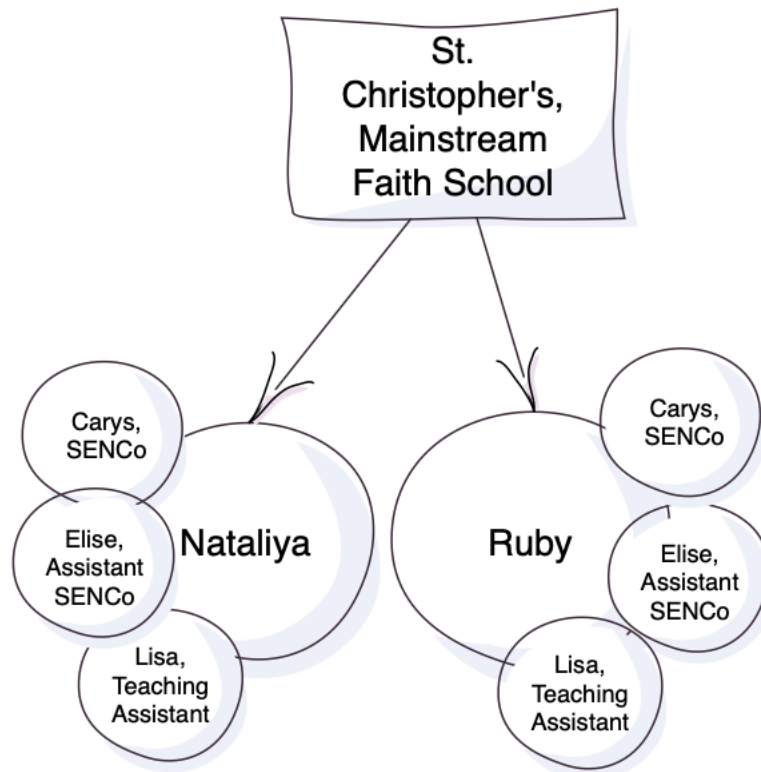
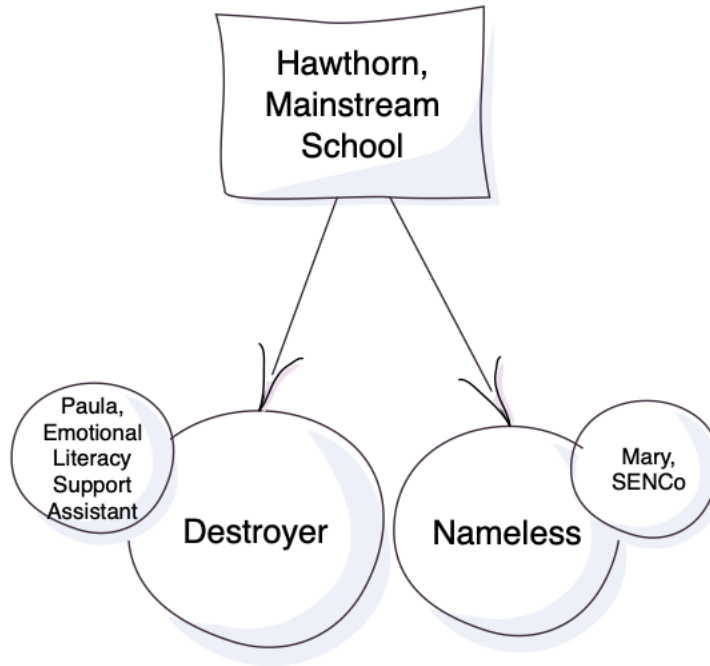
4.5.5.1 Adult Informants

The main study also involved a second stage of criterion-based network sampling, which took place once the young people were set up and a relationship had been built. They were asked, if they wanted, to identify from their social networks in school, adult participants who would be able to provide additional contextual information about their lives. The adult narratives were not to be allowed to crowd out the young people’s, but rather, were included as contextualising voices to enable deeper contextualisation of the latter’s narratives. The adults were asked to explain the cultural, social and institutional discourses that were dominant in school. Not every young person chose an adult; an overview of those interviewed can be seen below in Figure 17.

Figure 17

Overview of the adult participants





4.5.5.2 Participant Pseudonyms¹⁵

As part of designing an inclusive methodology and finding ways for the young people to have meaningful control throughout the research process and particularly in the way they are represented in this study, I designed a participatory process through which the young people designed their own pseudonyms and avatars. Representations of disability are seen in many cultural objects. Snyder and Mitchell (2006) identify “cultural locations of disability” (p.3), as spaces where groups of people hold certain beliefs about human difference, which are generally in contrast to the lived experience of disabled people. The social location of disabled people is reflected and affirmed through cultural devices, whereby disability is employed as a narrative device or trope. Davis (2006) highlights how these representations, constructed by non-disabled people, oppress disabled people, commenting, “normal has to protect itself by looking into the maw of disability and then recovering from the glance” (p.15). Hence, despite having experience of life-long mental health myself and being an ally, it was particularly important to find accessible and meaningful ways for the young people to select their pseudonyms and give these a visual representation, rather than ascribing my own to them.

The young people, where possible, selected their own pseudonym as was done in research undertaken by Bourke and Burgman (2010) when researching bullying with disabled children in Australia. In order to make the notion of pseudonyms approachable, I explained that in the research they would be a ‘character’. Four out of the six young people who finished the research process created an avatar for me to use in the write up. They cut different body parts out of magazines to create a character and then, gave them the name that they wanted me to use. Unfortunately, for Asim and Felicjan, who attended the Lane Special school, the year ended before I had a chance to deliver the avatar workshop. I was unable to go back the next academic year as Asim had transitioned to college and Felicjan had returned to Poland with his family.

In an attempt to make up for this shortcoming, I have picked names that reflect aspects of their personality they shared with me. For the young man with the Pakistani heritage, I have chosen the name Asim (عاصم). In Arabic this means ‘protector’ or ‘defender’, for when meeting with him he was always incredibly polite and was always keen to do jobs and help

¹⁵ Work from this section has been published in: Sakata, N., Christensen, C., Ware, H., & Wang, S. (2019). Addressing the messiness of data analysis: Praxis, readiness and tips from doctoral research, *Compare: A Journal of Comparative and International Education*, 49:2, 318-336, <https://doi.org/10.1080/03057925.2018.1562676>.

out wherever possible. Whenever we journeyed around school together Asim always held the door open for me and asked me to walk through first and I chose the name in honour of this. For the Polish participant, I have chosen the name Felicjan, which means 'happy' in Polish and I have selected it in recognition of his wonderful sense of humour and strong patriotism. Throughout the research Felicjan was quick to laugh and took great enjoyment in making me and Natalina, the teaching assistant who helped translate Polish in real time, laugh. In the following subsection the young people's avatars are used and an overview of each of the six young people who participated in the main study and completed the research is provided.

4.5.5.3 Meeting the participants

Asim was 18 at the beginning of the research and had his 19th birthday towards the end of the process. He is of British and of Pakistani descent and during the research he went back to Pakistan to visit family. In England, Asim lives with his Uncle and is also regularly looked after by his Aunt who lives nearby. He has a good relationship with his father, and they go on day trips together. Asim attends the special school Queenswood and has done so since primary school. As well as being identified as having learning difficulties, Asim also has epilepsy, but did not make any reference to either diagnosis during the research process.

Felicjan had his 18th birthday during the beginning of the research process. He was born in Poland and had been living in the UK since he was 8 years old. Following the Brexit referendum, and at the end of the research process he moved back to Poland. He lived with his mum and dad who were both Polish. He had had a sibling, but they had died in infancy. He has cerebral palsy and hypohidrotic ectodermal dysplasia and whilst he didn't name these conditions specifically, he did say that he was born healthy. He then went on to describe the mass bleeding and a long hospital stay that resulted in his current condition. His mother also has hypohidrotic ectodermal dysplasia.

Destroyer (avatar pictured below in Figure 18) took inspiration for his avatar from the Marvel universe and picked aspects of his favourite super-heroes. He was in year 8 and turned thirteen during the research process. He is British and Caucasian. His parents split up when he was younger and he and his sister lived with their mother, regularly visiting or staying with his father, who had a new girlfriend. He only once mentioned that he was autistic during the research process.

Figure 18

Destroyer's avatar



Nameless (avatar pictured below in Figure 19) had known about the avatar task for over a week when he came to performing it. He joked that initially he wanted to be called 'Patient #26', but had decided on 'Nameless', because he couldn't think of a better name. He also told me that it tickled his sense of humour to be called 'Nameless' and he liked the idea that he might be in meetings in the future referring to him as 'Nameless'. He was in year 7 when we met. He was aware that he had a diagnosis of autism and said that his family was also disabled. He is Caucasian identifying as both British and Canadian. His father is Canadian and his mother British and he lived with them both. He has many step brothers and sisters from his mother's previous relationships. Nameless had joined his secondary school from one of its feeder primary schools.

Figure 19

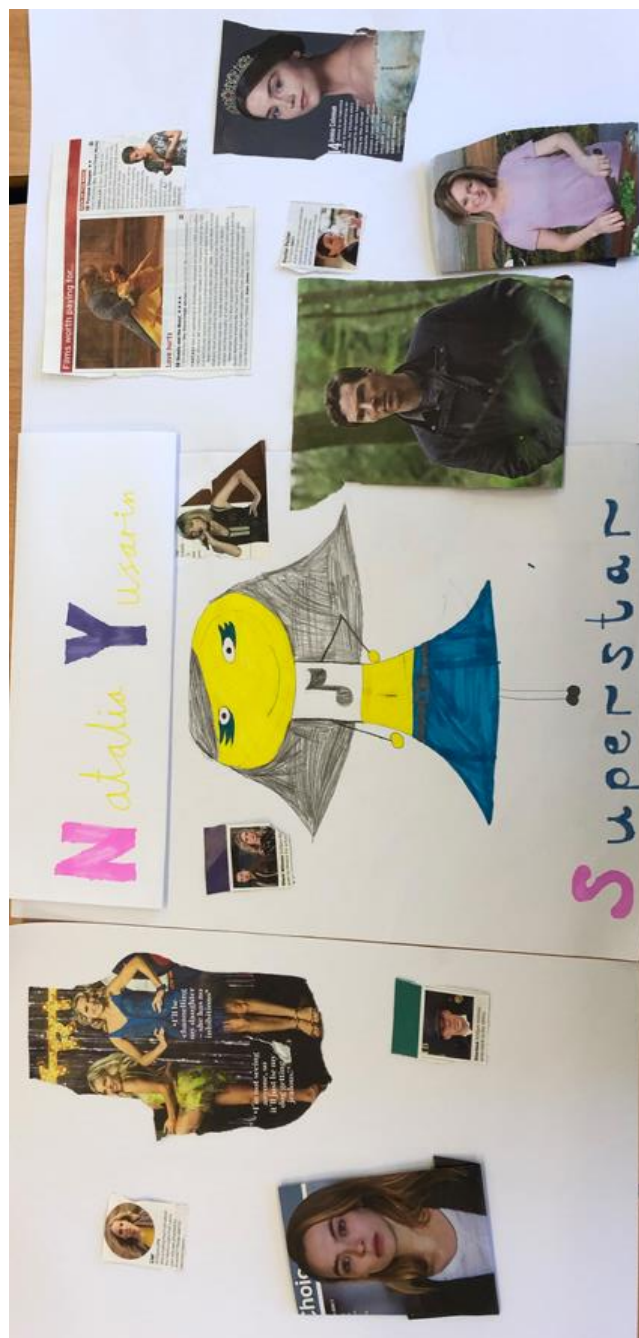
Nameless' avatar



Nataliya (avatar pictured below in Figure 20) was in year 8 at the beginning of the research project, but had transitioned into year 9 by the time the research process was completed. Nataliya was born in Bangladesh and moved to England at the age of four. She was aware that she had a diagnosis of autism. Nataliya had close relationships with the teaching assistants at her school and spent much of her time in the inclusion unit. She had a deep passion for the performing arts, as articulated in her avatar, where she depicts herself as a superstar with many celebrity friends.

Figure 20

Nataliya's avatar



Ruby (avatar pictured in Figure 21) was in year 8 at the beginning of the research process, but as with Nataliya, was in year 9 by the time the research had finished. Ruby is Black-British with Ghanian heritage, where her parents were born. Due to being born prematurely, she had been held back a year in primary school and so, she was a year older than her peers. Ruby did not appear to be aware of having a diagnosis of SEN/D and she sought to keep her real age hidden from her peers. She moved between the inclusion unit at her school and the playground, maintaining friendships in both settings. Ruby picked a picture of Ellie Goulding (a singer) from a magazine, who she wanted to use to represent herself.

Figure 21

Ruby's avatar



4.6 Analysis

In this section, I discuss decisions made as to what data obtained in the field should be considered as data for analysis. I then outline the process of meaningful member checking as well as the stages of thematic analysis undertaken.

4.6.1 What counts as data for analysis?

Whilst negotiating access to the sites of research, and throughout the research process, my role as a researcher was explicit to everyone I came into contact with and I met all the

participants (both adults and young people) prior to starting the fieldwork (Delamont 2002). When in school, I wore a visitor badge, which reinforced my 'outsider' status. In negotiating access to the school there was an understanding, on all our parts, that it was important for me to collect data on a school level as well as with the young people. This was particularly crucial in order to be able to contextualise the co-generated data within the different educational settings richly. As I spent extended periods of time in schools, critical incidents directly relating to my participants were likely to, and did occur, such as key conversations or incidents in the classroom (see Ethics section for examples). There was an ethical dilemma as to whether or not to include these within the research (Delamont 2002). Debriefing became critical in order to retain a robust ethical approach and ensure that consent was given to include critical incidents in the thesis. The data analysed was that, which was debriefed and contextualised with the young people or adults. This means that I did not undertake analysis of any material that the young people themselves had not reflected upon. For the analysis stage, the core data utilised was the transcripts produced from the recordings of the instruments along with the member checking texts, which generated more data.

A sizeable number of videos, pictures and creative writing (such as poems and stories) were co-generated throughout the research process. This was in order to stimulate conversation and they were effective in doing so. However, I did not directly analyse these so as to avoid the risk of imposing my neuro-typical readings or giving misleading interpretations. Instead, these will be used as supporting and contextualising evidence, when the young person has referenced the work directly.

4.6.2 Stage one: Member checking¹⁶

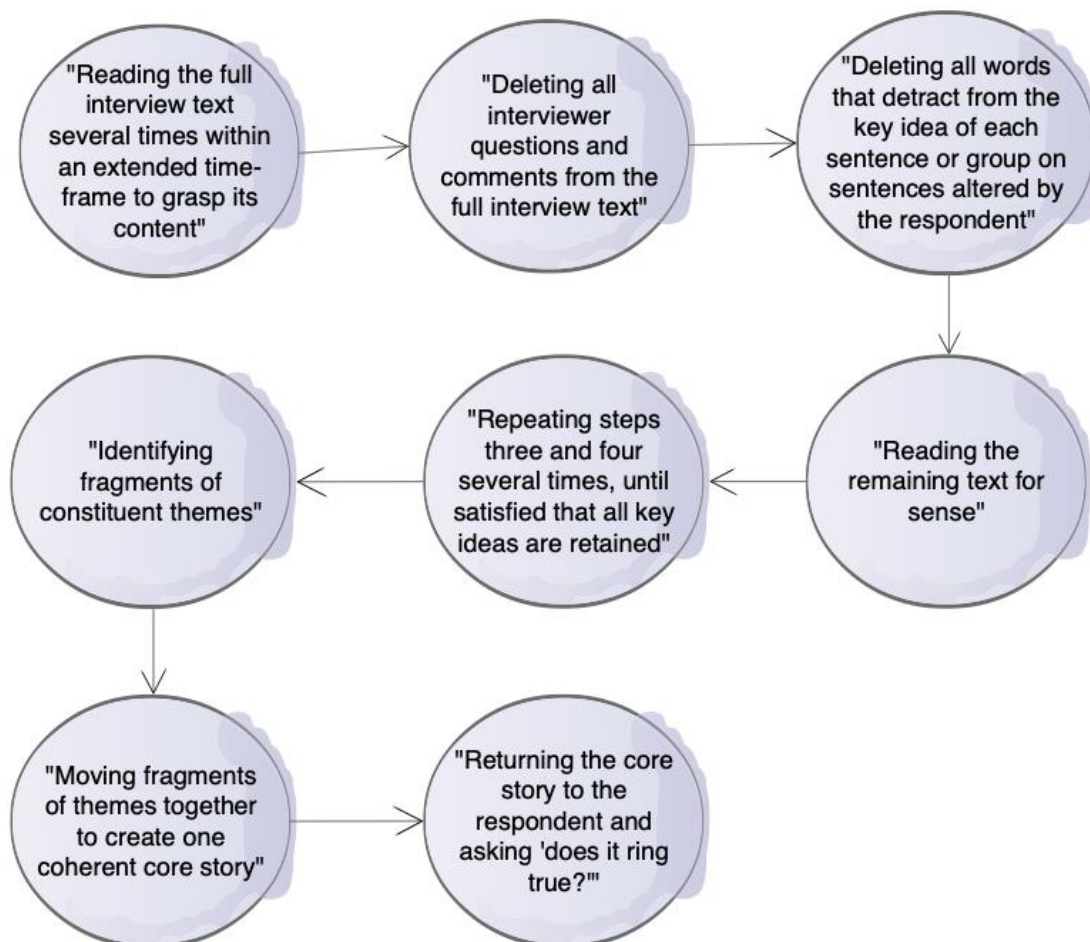
Member checking texts were created using the young people's co-generated data (see Appendix xi) In order to create the text, I drew on the idea of an "interim text" within the narrative work by Clandinin and Connelly (2000, p.133). It was important to find an accessible way to member check as SEN/Ding the young people reams of transcripts to read through would have been completely inappropriate and exclusionary. Therefore, I looked to the literature to find guidance on how to re-story transcripts into cohesive

¹⁶ Work from this subsection has been published in: Sakata, N., Christensen, C., Ware, H., & Wang, S. (2019). Addressing the messiness of data analysis: Praxis, readiness and tips from doctoral research, *Compare: A Journal of Comparative and International Education*, 49:2, 318-336, <https://doi.org/10.1080/03057925.2018.1562676>

narratives. Clandinin and Connelly (2000) suggest seeing the “interim text” (p.133) as the link between the data obtained in the field and the final research text. Creating this text using data from the field is important to ensure that through the analysis “we are not speaking for our participants, rather we are speaking about the texts we have obtained from them” (Josselson 2011, p.39). In order to produce a text that had trustworthiness for the young people to check, I utilised the steps for “core story creation” outlined by Emden (1998, p.35) (see Figure 22). She herself adapted the notion of “core story creation” (ibid., p.35) from the works of Polkinghorne (1988), among others, who has been influential in the development of aspects of narrative inquiry. Earlier works on narrative analysis, however, often focussed on socio-linguistic perspectives, whereas Emden (1998) sought to retain a “greater sense of the whole story” (p.35). In the case of my research, it was also critical for me to retain a whole-story approach in order to facilitate the young people viewing and commenting on the data.

Figure 22

Member checking text creation (Adapted from Emden 1998, p.35)



Emden (1998) researched in a medical context, working with nurse-scholars to understand their experience in academia. Clearly, the context I am researching is very different. Hence, there were aspects of the “core-story creation” process (ibid., p.35) that I needed to reflect upon to ensure that I retained the authenticity of my participant’s stories in creating member checking texts. One particular concern I had with the process articulated in the diagram above was the stage of removing words that detracted from the key ideas of the story (ibid.). I think Emden (1998) was able to do this without ethical concern as it was likely her participants spoke in a ‘typical’ and very descriptive way due to their educational status. However, most of my participants had some type of speech, language and communication need (SLCN) and thus, their speech patterns were atypical, with their often finding it difficult to articulate what it was they wanted to communicate. Consequently, I had concerns that removing individual speech patterns may, in effect, result in the removal of part of the person’s ‘identity’. I was seeking to understand the way in which young people *described* and *viewed* themselves through the co-generated narrative data, which was quite challenging. The initial member checking text became a dialogue, which thus created additional data through my facilitating checking with the participants. I produced accessible versions of these for the young people participating and utilised technology to produce interactive interim texts to be viewed on an iPad (see Appendix xi).

4.6.3 Stage two: Thematic Analysis

After undertaking the member checking I had two sets of data to analyse. Firstly, the transcripts (see Appendix xiii) of the conversations with the young people, where the visual data produced was discussed with them. Secondly, there were the member checked texts which had been checked and changed by the young people (see appendix xiv), documents that did not have any of my own speech in them. I began by analysing the transcripts and then the member checked documents - this gave me the ability to look across the data to see how the young people had clarified any meanings.

To undertake thematic analysis, I drew on the clear guidelines of Braun and Clarke (2006), who offer a rigorous and clear approach for “identifying, analysing and reporting patterns (themes) within data” (p.79). For the first stage of familiarisation with the data, I read and re-read the transcripts, noting down initial thematic ideas in a mind-map formation. Here, I tried to think about the different ways to categorise the data and ensure that I had not “glossed over relevant data” (Colley, 2010, p.187). In line with Braun and Clarke (2006) as well as Adam, Jones and Ellis (2015), I took the initial ideas for the codes, refining the mind maps I

Figure 23

First Coding Schedule

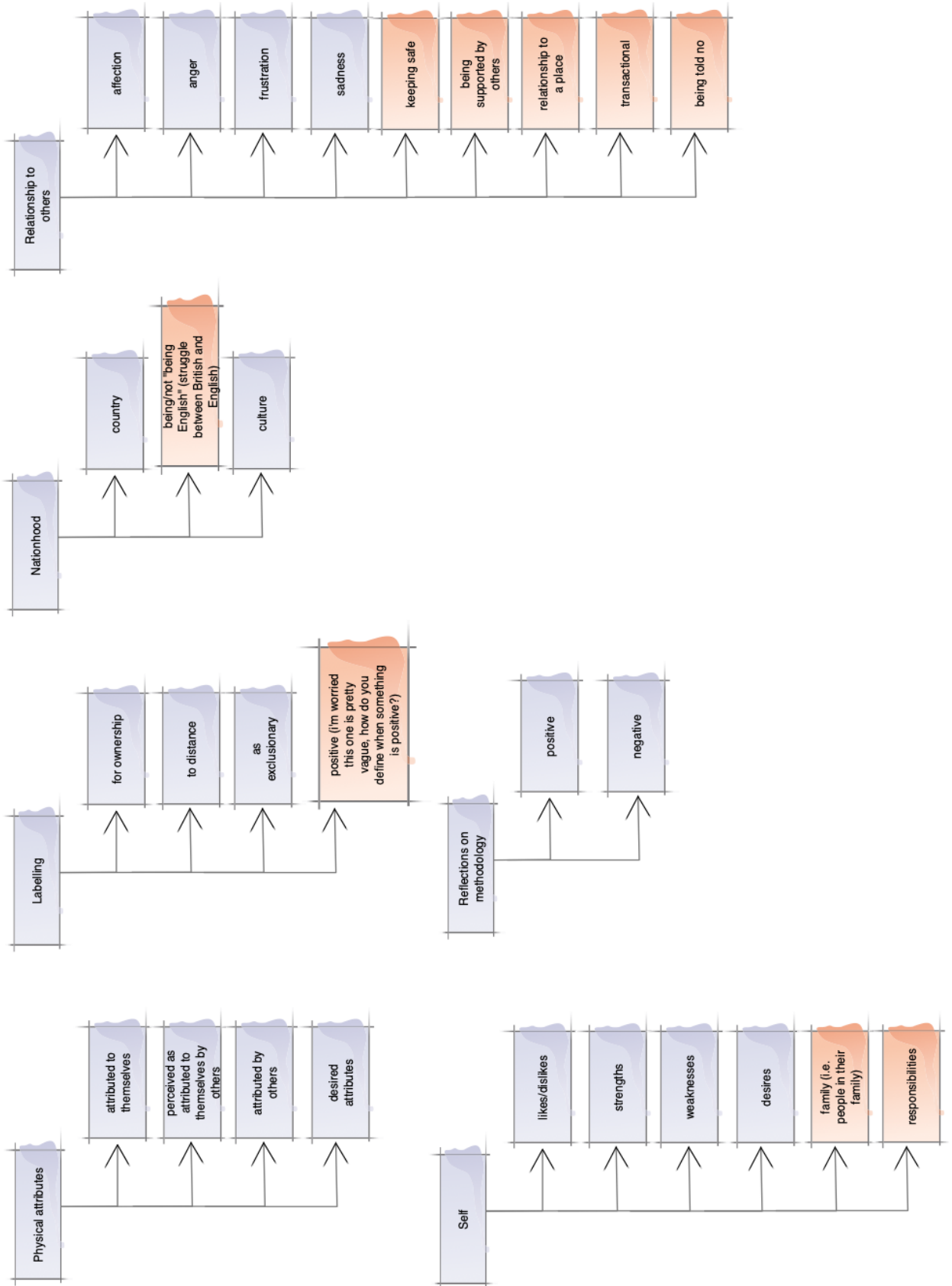
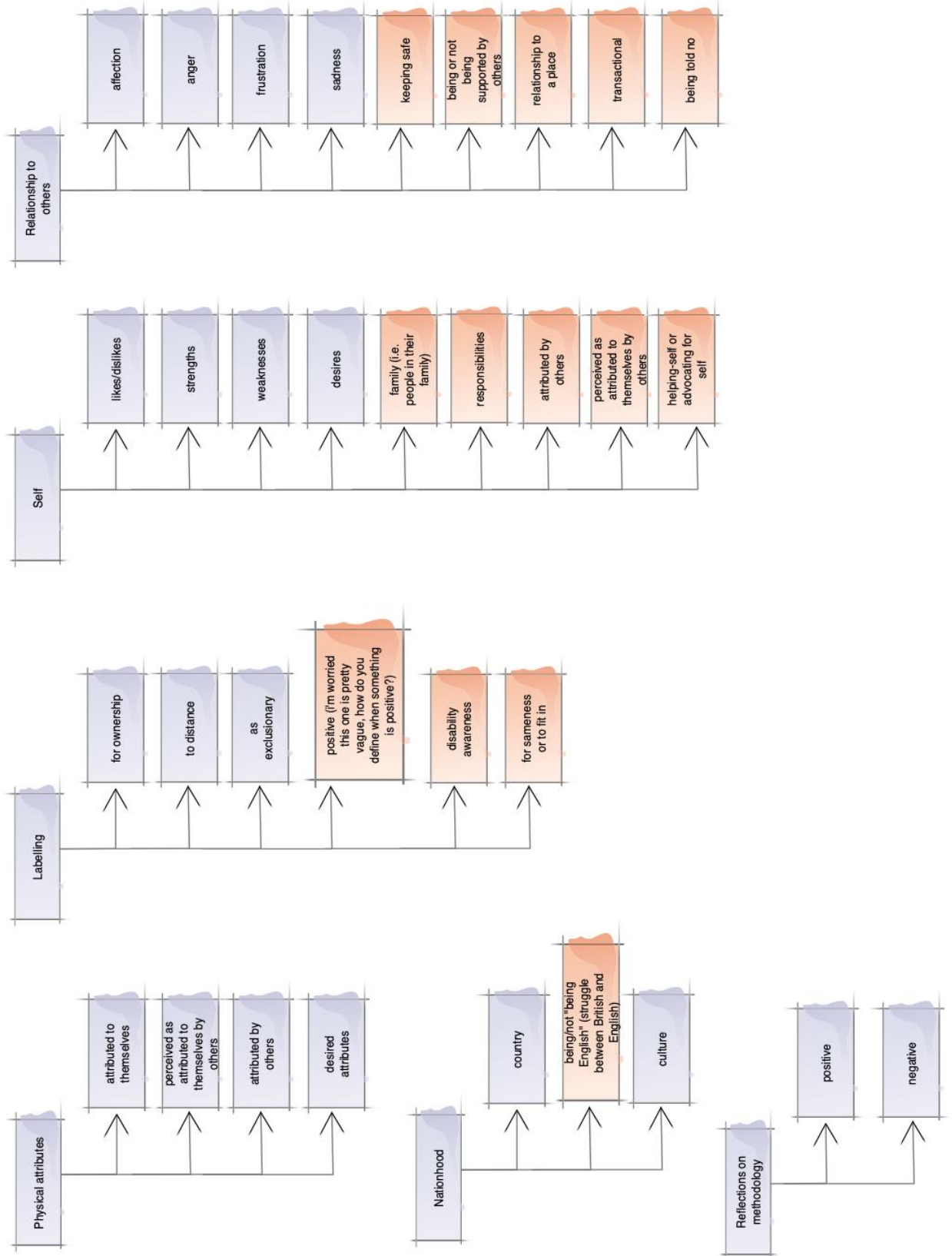


Figure 24

Final coding schedule



had created into a structured and logical groups of thematic ideas, which made up the beginning of the coding schedule (see Figure 23). Whilst my analysis was predominantly inductive - identifying themes strongly linked to the data itself - there was also some degree of theoretical input into the original design of the coding schedule (Creswell, 2014). For example, in coding for labelling I drew on the theoretical ways that labels could be used in human interaction.

I used the coding schedule as a live document applying the codes to the transcripts, whilst regularly reviewing its appropriateness and altering it accordingly, thus responding reflexively to the data (Creswell, 2014). The changes in the coding schedule are highlighted by the addition of extra orange codes. The metamorphosis of the coding schedule can be seen by comparing the original one (see Figure 23) with the final coding schedule that was used (see Figure 24).

As the coding schedule changed and developed, I had to go back and recode previously coded transcripts to ensure that the codes were rigorously and systematically applied across the data. By so doing, I underwent Creswell's (2014) articulation of data analysis being iterative, whereby I was constantly circling back on myself re-examining the data and the way I was applying the codes. Once I had finished coding the transcripts, I used the capabilities of NVivo to draw all the data for each code together, which enabled me to re-read all the data pertaining to each code in one place. It was through this process that the key discourses for each code emerged and I was able to begin to refine the data to understand the themes for each individual case. It is here I acknowledge the subjectivity of the analysis process. Whilst I tried to minimise the way in which my previous professional experience manifested itself in my interpretive work and be open to "new interpretations and phenomena" (Strauss et al., 1987, p. 43), it was difficult to shut off completely my practitioner self. Hence, I feel that the coding schedule was vital in minimising my own presentation within the thematic analysis. Additionally, as Marshall and Rossman (1999) caution, "reading, reading, and reading once more through the data forces the researcher to become familiar with those data in intimate ways. People, events, and quotations sift constantly through the researcher's mind" (p.153). I am convinced that this submersion into the data of the young people's lives further reduced the level my own presence in the final document.

4.7 Ethics: creating spaces to belong

Undertaking research has the potential to create asymmetric relationships between the

researcher and the participants, especially when working with young people (Groundwater-Smith et al., 2014). In addition to this, I was researching subjective issues with a vulnerable population (BERA, 2018). This raises important ethical questions and I explain here how I promoted inclusivity, integrity, justice and respect throughout the research process.

4.7.1 Informed consent, assent and dissent

Informed consent was sought from the adult participants and the gatekeepers of the young people participating in this research (see Appendix xv). Before consent (or assent on the part of the young people) was requested, I explained in detail and with transparency the premise of my work, whilst also offering an opportunity for all of the participants and gatekeepers to ask questions. In the case of the young people, I created an accessible animation to help explain the research, key words and also the ways to stay safe within the research process. The animation can be viewed on a smart phone using a QR code (see Figure 25).

Figure 25

QR Code



Seeking informed consent from the young people was problematic, as their ability to participate depended on the permission of the gatekeepers responsible for them, which whilst given initially could not continually be reinforced for logistical reasons (Harden et al., 2000). So, I sought informed assent from the children participating within this research on an ongoing basis, thus making it an explicit tenet of the research process. Starting with communication based on respect for the children's autonomy and dignity, we built a trusting and open relationship (Nind, 2008). I hope that having sought continuous assent restored some symmetry to the unequal relationship brought about by the limitations of this research. The young people did not always give assent, such that on some days, I would arrive at school and the participant would not want to take part in the research and so I would leave and come back again on another day. Whilst this experience was infrequent, it often happened when schedules were changed. Two excerpts from my research journal below,

detail how sessions with Destroyer were disrupted due to a change in the timetable.

“...A support staff member went to get Destroyer and he came over on his own without the support staff member. When he came in the room his eyes were red and teary. I asked him if he was okay and he said not really. When I asked why, he said because he had been in the middle of doing something that he wanted to finish. Together we decided he would go back to his lesson and then, he would come over for the next period to do our work together. He said he would probably forget so I said I would go over and collect him... Destroyer came back at the end of the period and he was bright eyed and keen to take part. I asked him to help me carry the things to our room and he did so and disappeared to go to the room before I could even say another thing - it felt as though he was keen to start. He told me that in the previous lesson he had been designing a helicopter and once he had finished making it, he planned on giving it to his dad...” (Field Journal, 30th March 2017)

“...I went with the speech and language therapist to collect Destroyer. He was in music and was definitely surprised to see me. He didn't want to miss music, but before I was able to engage him in a discussion about whether he wanted to go to do the project or not, he rushed out of the room and started heading towards the block where we do our work. When the speech and language therapist and I got to the room we found him slumped over the table. His eyes were very red, and he looked as though he was about to cry. Destroyer didn't really talk, and we tried to talk to him about the fact that he didn't need to miss music and he could go back, if he wanted to. He refused to talk and spent the period hunched over his rucksack. I sat at the next table and worked on my computer. Towards the very end of the period, Destroyer looked up from his rucksack and seized the moment to ask him whether he would like to look at the timetable and choose when he would like to do the research; he said yes...” (Field Journal, 27th April 2017)

The methods used within this research facilitated the children to represent themselves, as far as possible, on their own terms. There had to be space for silence, saying no, dissent and the opportunity to reject participating in the investigation (Lewis, 2010). Snelgrove (2005) argues that children identified as having SEN/D would benefit from showing they can decline before their assent can truly be seen to be on their own terms. I followed this advice

and ensured attentiveness was paid, not only to the verbal confirmation from the young people, but also to their actions (Groundwater-Smith et al., 2014). I explained to the children at the commencement of each data collection session the guidelines for the research in order to keep them safe and uphold their dignity, which included reminding them that they had a choice as to what they told me and that it was okay to say no. Regardless of how far a participant continues in the research process, they will always have the right to withdraw and this will be respected, with their data not being used in the analysis unless they expressly agree to it (see subsection on drop out above) (Groundwater-Smith et al., 2014).

4.7.1.1 Supported dissent: assisting in an ethical exit

Ethan, from Hawthorn, who had originally decided to participate in the research decided to pull out after four weeks. The following is an anonymised extract from my research journal detailing the experience.

This morning I went to collect Ethan from his maths class as I had arrived late due to getting stuck on the motorway. He saw me through the maths window and willingly came with me. We talked as we walked over about the bank holiday weekend and how it was good that the week would be short. Ethan said he hadn't done anything since I saw him. When we reached the learning support rooms, Ethan went to get his camera and I asked him if he had recorded something. Ethan said he hadn't. Instead, I spoke to Ethan about the fact that usually the young people taking part in the research choose adults I can talk to so I can get some more information about their experience in school. Ethan said the only adult he liked was his mum (who isn't in school). He said everyone else sucked. I drew a line with 'sucks' at one end and 'okay' at the other and we went through his timetable putting the adults from school on the spectrum. Only his PE teacher and the drama teacher were half-way up the spectrum. I asked the names of these teachers and asked Ethan, if I could talk to them. He said he wouldn't like me to, so I said that this was no problem at all. At this point I reemphasised to Ethan the fact that research was something that a person should enter into freely and it should be something that is useful for them, as well as me.

Most importantly, I said it should be enjoyable. I offered Ethan some options:

- carry on with what we are doing
- have a think about what we could do instead that he might enjoy more
- stop the research and ask me to not use any of the work we have done together
- decide he has finished the project and that I can use all the work we have done so far

At this point Ethan decided that he had finished the project, but I could use all the work we had done so far together. I thanked him for all the work he had contributed and said that it was good to have met him. He said the same and left.

Later in the morning the SENCo suggested that Ethan didn't enjoy scrutiny. I think it was difficult for him to identify positives in his life and he often said he felt that everything 'sucked' and all aspects of school were rubbish. The only aspects of school that Ethan felt were okay were PE and Drama, but even then, he didn't tend to talk about enjoying these things. (Research Journal, 2 May 2017)

Ethan's experience has been used only within the methodology. As he did not finish the whole research process and member check the data produced, I made the decision to exclude his data from the analysis.

4.7.2 Anonymity and limited confidentiality

Confidentiality and anonymity were challenging notions, particularly as my research involved vulnerable participants and some of the research was undertaken in special schools with small populations (Groundwater-Smith et al., 2014). Due to this fact, I followed two ethical protocols for anonymity and confidentiality, one that applied to my thesis (the thesis protocol) and one that applied to the contexts in which I was researching (the research protocol).

4.7.2.1 Thesis Protocol

I ensured full anonymity and confidentiality within the context of my thesis by adopting, where possible, participant chosen pseudonyms, and where appropriate, obscuring recognisable features, such as names of institutions and locations (BERA, 2018). For the presentation of visual material, I used digital manipulation techniques to anonymise faces and other identifiable features. I clearly explained how I would make all data anonymous to the participants. No young person wanted to be identified using their real name and hence, I did not need to ensure that they had considered the potential repercussions of being identified.

4.7.2.2 Research Protocol

My experience working in the sector has taught me that it would be unethical to have attempted to offer full anonymity or confidentiality to the participants, as it may have been necessary to disclose information should I be told of any safeguarding matters. I explained to each participant that I might need to get help from another adult in order to keep them safe. This enabled me to keep the data collected with the young people as private as possible, whilst also fulfilling my duty of care to them by ensuring any safeguarding matters were passed along the relevant safeguarding channels. In the case of Nameless, I passed on information (with his consent) to the SENCo about some of his experiences with his peers, particularly him having shoes thrown at him. Furthermore, as I was undertaking research, in part, in schools with small populations, it was probable that other young people would notice a new person in their setting working with some of their peers. Hence, anonymity was hard to maintain within the school setting. An example of this was working with Felicjan in the main study. Being Polish he was bi-lingual (Polish and English) and wanted to undertake the research in both languages. Particularly at the beginning, whilst Felicjan was getting to know me, he spoke in Polish. As my understanding of Polish is limited only to greetings, I had learnt to be able to exchange with him, so his teaching assistant joined us to act as a translator. She was Polish and had a strong bond with Felicjan. Together, at the beginning of the research, we all spoke about the importance of maintaining his privacy.

4.7.3 Using Cameras in School

As previously explained, the anchoring words used within the videovoice instrument were: happy, safe, same, friends, important (see subsection 4.4.1). However, also outlined earlier, when undertaking the pilot, it became clear that the word safe had a problematic element and that there were tensions surrounding some spaces in school. There are places in school

that some children might identify as 'safe' that are not appropriate to be captured on video, for example, changing rooms or toilets. During the pilot, James' teacher explained to me that often, if he felt upset, James would spend some time talking to himself in the toilet. Were James to record himself whilst he was in a vulnerable situation, such as the toilet, this would become a child protection and safety issue. Hence, it was necessary to make it explicitly clear to James, and all the young people participating in the research, that there were places that were not safe for them to record in, such as the toilet or changing rooms. Rather than using the word 'safe' to explain this to James, I used the words 'appropriate' and 'okay' so as not to conflate the issue with 'safety' in this context. Imposing these limitations on the vital grounds of child safety limits self-representation in so far as a young person may wish to illustrate audio-visually that the toilet is a safe space for them. So, I had to explain to them that it was not an appropriate space to use a camera. In order to overcome this, sensitivity was used when explaining this to each participant and words and communication were chosen on a case-by-case basis that was most appropriate for each.

Another ethical issue of using action-cameras in the classroom was the unintended capturing of challenging behaviour, which might comprise the preservation of young people's dignity. During the first pilot, when I was researching with Lily, who had been identified as having severe language communication difficulties, we were both wearing action-cameras to capture the experience and relying a lot of gestures and Makaton to communicate. One of her peers who was working in the classroom was having a challenging morning and grabbed the hair of another person; staff members went over to assist the young person to leave the classroom to have some space for themselves. On the way out, the young person who was having difficulty took hold of Lily's hair. Staff members helped resolve this, whilst I stayed with my participant and we communicated about what had happened. After we had finished working on the self-portrait, the head teacher and I sat down to look at the footage recorded and talk about what had happened. We wanted to ensure that the dignity of the young people had not been compromised. After reviewing the film, the head decided that the video data did not affect any of the young people in such a way. Had this not been the case, the section of inappropriate footage would have been deleted. This led to this described process to be implemented as an ethical protocol should any further critical incidents have been captured on camera. This was another compelling reason for only using action cameras as they have a narrower field of focus. Had I been using a professional camera it is likely the field of vision would have captured more of the classroom behaviour. In addition, having a camera on a tripod could be potentially dangerous, as it could have been picked up or knocked over.

4.7.4 Reciprocal researching

One afternoon, I was sitting with Nameless in the playground. The day was hot, and we had decided to work outside in the shade. After a lull in the conversation, he said that he had something that he wanted to share with me, but he was worried that it was very babyish. I reassured him that there was nothing he could say that would make me judge him as babyish, but that he should only tell me if he wanted to. He then proceeded to tell me about muslins that he had.

Nameless: I've got one idea, but I don't know whether I'm willing to share that one. Put it this way, it's a bit childish.

Hannah: In my eyes, there's nothing babyish that you could say.

Nameless: I don't know whether my parents would like me bringing a muslin into school.

Hannah: You could take a picture of it if you want.

Nameless: I suppose I could, yeah.

Hannah: Does it make you feel better?

Nameless: I have it with me every time I go to sleep. And some of the times, when I'm stressed, I just grab it and... suck my thumb. (Nameless Week 3 Transcript)

His experience spoke directly to my life experience. In response, I said:

Hannah: I completely agree with you. I get a bit of kitchen roll, I fold it into a square, I roll it up into a really sharp point and suck my thumb and I'm about to turn 30. So, I don't think that's babyish, I think that's perfectly normal. (Nameless Week 3 Transcript)

After I left that school, as I drove home, I replayed the conversation over and over in my head. I knew that emotionally in the situation I had done the right thing. Destroyer regularly indicated he believed he was weird and that there were no other people out there that were like him or did the same things. However, I was worried if in a research context I had overstepped the mark.

The following week I was back at his school and he said to me:

Hannah: Would it surprise you to find out your friends maybe did something

similar?

Nameless: Yeah, I mean, you surprised me telling me that things with the tissue, yeah. Veeery surprising.

Hannah: When you find out that people you don't think do it, what do you think?

Nameless: I don't think bad of them, or good actually, because at least then they know my situation. I'm not weird by myself, there's other people that are weirder out there.

Hannah: So, when I told you I did it too?

Nameless: Yeah, that's better. If I found out that my friend did it, I'd be like "oh yeah, wow, he does it as well; at least I'm not on my own, yeah."

(Destroyer Week 4 Transcript)

Nameless had also decided to bring in one of his muslins to show me and we had a bigger conversation surrounding the ways he used it. When considering the research relationship I had built with all my participants and how I shared myself with them, I first reviewed relevant literature. For instance, Chase (2011) characterises the listener's role as becoming a guide, "inviting narrator's specific stories" (p.423). However, Ellis and Bochner (2000) caution that the work undertaken in the field must retain its integrity as research and not become story telling with therapeutic aims. On reflecting more on the importance of a participatory research relationship, I felt that it was essential that the relationship be equally engaging on both sides as far as possible. My understanding is guided by Oakley's (1981) comment that there is "no intimacy without reciprocity" (p.49). The relationships I built in the research process were not pseudo ones; they were real relationships where the research was only one aspect. Working with living, thinking and breathing people also means that there is a duty to contribute yourself to the situation. Throughout the process of my PhD I have striven to keep in mind the question, "Who will benefit from this research?", a question asked by Singal (2010) and Barton (1998) among others in the field of disability. I spent much time worrying that it would only be me who benefitted. When Nameless told me hearing that other people are "weird" too made him feel that he wasn't weird by himself, he really showed me the importance of reciprocity, not only in terms of outcomes, but perhaps even more importantly, in terms instantaneous reciprocity, by, as a researcher, being prepared to give of yourself, when appropriate, through honest conversations.

Whilst the reciprocal relationship was different with each participant, it was vital for me that there was reciprocity in each of my research relationships from an ethical (Groundwater-Smith et al., 2014) and human perspective. It was crucial that the young people had a

positive experience that offered them the chance to reflect on their own lives; feel appreciated and feel heard. After the first pilot, I received an email from James via his teacher saying working with me on the research had made him feel “happy”. As part of debriefing at the end of the research process, I asked the young people if they would like to take away a version of the data. When giving copies of it, it was important to ensure anonymity was kept, especially in the cases of where the young people had recorded their peers. In these cases, I edited the videos to remove traces of other people, so the young people would be able to take the videos home. Asim wanted a copy of his videos and so, I edited his and gave them to him on a USB stick. Some did not want the data, whilst others only wanted the videos and both young women wanted to have books of all of their work and a certificate to remind them of having taken part in the research. Both Nataliya and Ruby also took home their videos on a USB stick. After all the member checking was done, I went back to the school the following week and spent time with each of these two, creating a book about their experience. Nameless did not want his data, but he did ask me to keep coming back so he could continue talking. I think he and I are quite similar as people and have definitely had some similar childhood experiences, as demonstrated in the extract above and so he had potentially felt clearly heard during the research. Whilst it was not possible for me to continue going to the school at the end of the research, together, we spoke to his SENCo to see if there was another person in school that he might be able to spend some time talking with instead.

4.7.5 Transcribing¹⁷

On exploring existent research concerning the lived experience of children or adults identified as having learning difficulties, little attention appears to have been paid explicitly to the ethics of transcribing. Most of the studies reviewed state that transcripts were either transcribed verbatim or simply that they were fully transcribed (Baines, 2012; Dowse, 2009; Lingam et al., 2014; Shah, 2005). However, Hole (2007) does discuss some of the ethical issues with transcription and authenticity that she faced in her work on the narratives of deaf women, in particular, highlighting how the challenge of translating sign language into spoken English can problematise the person’s representation. Similarly, within my own research I faced decisions about how I would transcribe the narratives spoken in English as a second language and also the diverse narratives of children identified as having SEN/D.

Transcribing verbatim presented ethical considerations with regard to the preservation of

¹⁷ Work from this section has been published in: Sakata, N., Christensen, C., Ware, H., & Wang, S. (2019). Addressing the messiness of data analysis: Praxis, readiness and tips from doctoral research, *Compare: A Journal of Comparative and International Education*, 49:2, 318-336.

dignity as a person may not wish to have stutters, repetitive hesitations, extraneous words and sounds or non-typical grammar used within the research. Conversely, altering transcripts to reflect typical patterns of spoken English posed a risk of removing or obscuring identity.

Gardner (2010) posits in his work on hermeneutics, that this type of work may be interpreted as “speech masquerading as text” (p.72). In the main study, the member checking text formed part of the dialogue with the participants. This offered transparency within the research and the opportunity to edit the data and engage with the text as a living document somewhere between speech and text. I was able to discuss the matter of how speech should be represented with Nameless, when undertaking his member checking. He wanted to correct all the errors in his transcript, including crossing out hesitations and changing words where the wrong word was used by accident. I decided on the basis of his perception of his transcript that I would edit the quotes used in reporting the findings for greater fluency.

4.8 Trustworthiness

Creswell (2013) highlights the importance for qualitative researchers to show their data is authentic in the same way a quantitative researcher might show validity. Lincoln and Guba (1985), who Creswell (2013) highlights as still being widely quoted and relied upon by qualitative researchers, suggest that trustworthiness in qualitative data should be considered under the terms: credibility, transferability, dependability and confirmability (p. 301-331). Next, I articulate how my own research adheres to these notions, thus producing work that can be considered to have authenticity.

4.8.1 Credibility

My data collection happened over a prolonged period of time, which helped me to develop meaningful communicative relationships with the young people participating in the research, as well as the adults who I interviewed towards the end of the process. In total, the relationship with each young person lasted between two and four months (excluding breaks for holidays). My extended contact with the participants, combined with undertaking reflexive member checking, means that I was able to immerse myself in the contexts of the young people, becoming a trusted known person to them and obtaining data that had credibility. Assimilating into the young people’s normal lives for a period of time, allowed for the consideration of whether some data collected contained “misinformation” (Lincoln & Guba, 1985, p. 301) - particularly data collected at beginning of the process. This was especially

the case through the member checking, where the young people looked at all the data we had co-generated, and verified it. All of the young people asked me to change aspects of the data. For some, it was fairly small bits (e.g. changing the odd word or spellings), whilst for others, such as Destroyer, there was significant editing of the names of friends he had fallen out with. Here, credibility is not being seen as some objective truth, but rather, as that the young people felt the data we had co-produced represented who they felt they were and what they wanted to say to me as realistically as possible.

Contextualisation of the young people's discourses provided by the multiple methods used to collect data. This provided the young people with many strategies to explore how they wanted to present themselves, thus giving multiple opportunities for them to articulate their experiences in different ways. Furthermore, collecting data from different agents (adults and young people) within the same context allowed for the use of "intra-team communication" (Lincoln & Guba, 1985, p. 307). Placing the young people's experiences within the contexts they were operating, provided further credibility to the data and my understanding of it (Noble-Carr, 2006). The only significant discrepancy in the data was the difference in that of Destroyer. In the first data analyses (the original transcripts), he talked a lot about his friendship group and how it made him happy. However, when analysing the second set of data (the member checked texts) Destroyer had deleted all the references to his friends as they had had a falling out between the original data being generated and the opportunity to member check the texts. This highlighted the temporality of the research and how Destroyer's experience and social positioning was not fixed, but rather, fluid.

4.8.2 Transferability

Due to my data being in depth snapshots of six young people's experiences in different learning environments, claims of statistically significant and generalisable findings cannot be made. Rather, in the words of Bassey (2001) it is possible to make "fuzzy generalisations" (p.5). Importantly, Bassey (2001) notes that these generalisations, whilst not statistically reliable, can be useful to practitioners and policymakers, but cautions qualitative researchers to use caveats, such as 'may'. Specifically for practitioners who may read this research, I hope that the in depth nature of this case study, where "thick description" is utilised (Geertz, 1973, p.3), will serve as a form of transferability, where they may recognise the findings as useful for their own setting.

Moreover, the detailed methodology as set out in this chapter forms the basis for a strong potential for transferability. By deeply reflecting on the successes and barriers of the

research process in this chapter through the lens of the third research question, I have been able to appraise the participatory and inclusive nature of the methodology. I am of the view that by providing detailed descriptive analysis as well as transparency on how the research was undertaken, this gives the reader an opportunity to conclude whether or not they feel transferability is possible (Lincoln & Guba, 1985).

4.8.3 Dependability

Guba and Lincoln (1985) characterise dependability as ensuring that more than one person is involved with a project. My supervisor has scrutinised and challenged me at every stage to check that I have been enacting a rigorous and ethical approach regarding the research. Additionally, the young people had a crucial involvement in the first stage of analysis through member checking. They were able to examine the way in which we undertook the research, giving their feedback on the experience as well as double-checking and editing the data that was obtained during the research process, thereby ensuring that they were happy with what I would apply the coding schedule to.

4.8.4 Confirmability

As explained above in the section on methods, I kept a reflexive field journal throughout the entire research and analysis process. This reflexive process in conjunction with adhering to strict ethical guidelines; complete transparency; and having my work scrutinised and audited by my supervisor and advisor, ensured that this research is authentic and hence, confirmable (Lincoln & Guba, 1985).

4.9 Conclusion

Barton (1998), commenting on the ethics of research in the field of disability studies, puts forward key questions about rights and responsibilities arising from undertaking such research, including “who is this for” and “what right have I to undertake it?” (p.34). In addressing the first question, I must acknowledge this work was primarily undertaken for myself in order to fulfil the requirements of my PhD. Despite this, I believe that it involved creating a space to belong for the participants, facilitated their representation on their own terms and contributed to their lives in some small way. In terms of the field and society, I hope this research has contributed by bringing marginalised stories to the fore using creative arts-based, inclusionary, and participatory methods. When questioning myself as to what right I have to undertake this research, I hope that my experience working both with children and adults identified as having SEN/D led to my undertaking ethical, participatory and

inclusionary research where the dignity of the participants was at the heart of the project.

The young people's stories uncovered through this research reveal the way experiences are expressed and lived out in the human condition (Creswell, 2013). Implicit in this understanding, is the thought that these experiences are affected by the forces within society (Chase, 2011). The phenomenon of narrative is considered as the way individuals can make meaning of their fragmented lived experience and can be understood (through their form and content) as a window into a person's life (Burr, 2015; Chase, 2011). Pinnegar & Daynes (2007) argue that narrative is "one, if not *the* fundamental, unit that accounts for human experience" (p.4, emphasis my own). Essentially, it is suggested that the stories we tell, both to ourselves and to others, can be understood as the way we piece together and bind the different, fragmented, and sometimes contradictory aspects of ourselves and our experiences, into one continuous person. The co-generated narratives were analysed in relation to belonging as well as the ways in which the young people described themselves. In the generation of this data wide ranging topics were brought up by the young people ranging from their thoughts and feelings about zombies to Jeremy Corbyn's self-reported fascination with drain covers. The vast diversity of topics discussed demonstrates how the research methods ensured that the young people were able to explicate what was important to them as well as indicating their freedom to discuss the research themes on their own terms.

I contend that stories accessed through arts-based research tools are powerful means to uncover lived experience and should be utilised more widely than the often promulgated hegemonic view that narrative consists only of the spoken or written word. This research provides robust evidence that picture-drawing and video-recording are effective vital tools for accessing the narrative lives of children identified as having SEN/D, who may not communicate in typically expected ways. Riessman (2008) clearly rejects the necessity of having written or verbal data as a primary narrative data source, pointing to the centrality of visual representations within society as evidence that photos and other visual documentation can be seen as narrative. Armstrong (2003) highlights the importance of eliciting the stories of those identified as having SEN/D, as they have the power to reveal an "ordinariness" that is not often found in the literature (p.91). It is this ordinariness that can be extremely powerful in assisting people identified as having SEN/D to, themselves, articulate a resistance to the discriminatory discourses, prominent in society. As Armstrong (2003) rightly underlines, "the insights their stories reveal can inform a socio-political critique, not only of the subordination of people with learning disabilities but also of the character of and relationship between different structures of subordination within our society" (p.91).

Chapter 5. “I’m not a man, men have moustaches”¹⁸: Exploring the way the young people described and viewed themselves

5.1 Introduction

In this chapter, I present data addressing the first research question, *what are some of the ways in which young people identified as having learning difficulties describe themselves?* The data derived from the young people is predominantly that taken through reflecting on their self-portraits and video voice. When quoting from the data, I will use brackets to identify the person, the setting and the type of data (e.g. a transcript or member checking text). Where quotes have been taken from member checking documents, a red font has been used to indicate the data added during this process.

I present the reflections thematically. The most ‘concrete’ themes will be presented first, for example reflections on the young people’s physical selves and then, more ‘abstract’ themes will be covered, such as responsibilities. First, I present physicality, focussing on the ways in which the young people spoke about themselves and other peoples’ bodies and appearances. In this section, connections are drawn between bodies’ and gender. Next, their likes and dislikes are articulated in terms of engagement with teenage culture, where the students reflect on some of the important things in their life. Following this, the way in which they describe their strengths and weaknesses is presented, focussing particularly on their lives in school. Responsibilities and the ways in which the students’ help themselves are presented, demonstrating the ways in which the young people are agents of their own lives and also, how they support other people. Next, their aspirations for their future lives are covered.

The young people used a variety of ‘labels’ in our conversations, demonstrating some of the ways they described and viewed other groups of people in their lives, individuals or themselves. I focus on the way in which they spoke about labels relating to disability. That is, I present the way in which the students spoke about disability and diagnostic labels. The most prominent label that was discussed, particularly by students in the mainstream and faith school, was ‘autism’. In the final section, I report the way in which the young people

¹⁸ Nataliya

used words as mechanisms to reinforce their status as either ‘belonging’ or ‘being an outsider’.

5.2 “I like his hair, umm it’s soft by the way”¹⁹: physicality of self and other

Despite creating self-portraits, where the young people drew themselves, none of them spent much time, when we were together, speaking about their physicality. The one who spoke the most about his body was Felicjan, who used a wheelchair. He depicted this in his self-portrait (see Figure 26), and also spoke about liking to have his legs crossed whilst he was working. He was particular about his appearance and sometimes asked his Teaching Assistant (TA) to fix his hair to make it spikier. Sometimes, when I arrived to meet him, he would motion to me to come closer and ask if I could smell his aftershave - a present he had received for his eighteenth birthday.

Figure 26

Felicjan’s Self Portrait



The other young people made quick references in passing to their physicality, for example, Destroyer, who noted he had “blondish” hair. The very few times when the young women spoke about their physicality was in relation to their experiences with other people. Nataliya, who attended the mainstream faith school and had Bangladeshi heritage, told me about an

¹⁹ Ruby

incident where she was accused of having a moustache by a young man in year 7. She had been frustrated by this and rebuffed the young man saying, "I'm not a man, men have moustaches" (Nataliya, Member Checking Text). There was another occasion, when talking about her "arch nemesis",²⁰ she speculated the reason why he did not like her was racism. She described this as "not liking immigrants by their skin colour, religion, race" and in doing so, seemed to be referencing these characteristics to herself. After she said this, however, she seemed to self-censor, appearing to change her mind and she apologised.

Natalia: He doesn't really like my singing and he doesn't even like me either from the start of year 7. I don't know why may-- Maybe because he's racist, I don't know, sorry for saying that. Racist is not liking immigrants by their skin colour, religion, race. No, no one's called me that, ever, and Luke didn't. But he doesn't really like me, really (Natalia, Faith School, Member Checking Text)

Ruby, who also attended the mainstream faith school and had Ghanaian heritage, only spoke about her physicality once during the research process, where she spoke about her hair and the hair of the young man she had a crush on. She liked his hair, because it was soft and when they were standing in line, she had touched his hair (without permission).

Ruby: I like his hair. Umm, it's soft by the way. I don't know how many times I've touched his hair. I can't remember. I don't know how I touch it. Just like - because I stand next to him in the register - I just touch his hair sometimes...My hair is not really soft. People are saying that my hair's very crispy. I don't know what that means though. If someone says their hair's very crispy, I think it means, it's hard or something. I wish my hair was longer. (Ruby, Faith School, Member Checking Text)

When thinking about their bodies, half of the young people spoke about physical challenges or needing assistance. Both Nameless and Destroyer, attending the mainstream school, spoke about handwriting hurting their hands. In the case of Nameless, he had visited an occupational therapist, who had provided assistive devices, such as a writing slope and pen adjusters, to help him write more easily. Felicjan, who attended the special school and used a wheelchair, spoke about needing to be assisted with aspects of his personal care.

²⁰ John

5.3 Expressions of self: likes and dislikes

When the young people spoke about themselves, likes and dislikes were frequently discussed, this being the basis for many of our conversations. Broadly, the young men tended to be interested in video games, playing on the computer and on consoles, sport - particularly cricket and football, and politics. One of the younger participants, Destroyer, who attended mainstream school, was particularly interested in fantasy and often talked about magical or monstrous creatures. At times, he was able to relate his interest in these to other aspects of his life. Whilst doing his self-portrait (see Figure 27), Destroyer incorporated time blades from *Ninjago*²¹. The blades were able to change time by pausing it (red blade), slowing it down (blue blade), fast-forwarding (green), and rewinding it (orange blade). He spoke about how, if he had the blades in real life, he could use them to protect himself from people attacking him.

Me: What would you do if you had the blades?

Destroyer: I would be conquering the world. Cos the good thing with slow motion, if someone tries to attack you, you could just put them in slow motion and move away...If someone did try to attack me, then I could just hit them with the slow motion and it means I could move away or hit them back, so that means I don't get hurt. With a pause blade, if someone was trying to throw me or hit me, I could pause them and punch them so I can get far away and stop in time. And with the fast forward blade, I could go technically really fast cos I'd be stopping in time. So, if someone tries to hit me I could just use that time blade to move out the way and hit them really fast. (Destroyer, Mainstream School, Transcript Week 1)

Both of the young women, who attended the mainstream faith school, were very interested in celebrities, TV soaps and programmes like *Strictly Come Dancing*. Ruby also watched programmes on Children's BBC, like *Dani's Castle* and *EastEnders*. As well as celebrities, Nataliya also had a keen interest in reading and was a fan of Shakespeare - she was able to quote extensively from his works and summarise the plays.

Nataliya: Shakespeare is such an awesome man. Really his plays are just breath-taking. When I just read them, I just can't stop. My favourite ones are

²¹ Ninjago is an animated TV series developed by WoL Film ApS and The Lego Group. It is also a 'theme' brought in by Lego in 2011 and there have been accompanying movies. The story line revolves around a group of young Ninjas as they battle evil forces.

Twelfth Night, Midsummer Night's Dream, Romeo and Juliet. I am good at quoting Shakespeare. (Nataliya, Faith School, Transcript Week 2)

Figure 27

Destroyer's Self Portrait



Each of the young people had specific things that they didn't like, often relating to sensory input: Ruby didn't like the bits (of pith) in aloe vera juice or white icing, Asim didn't like gluing, and Natalia didn't like feeling bored. Particularly notably, when Felicjan spoke about things he didn't like he showed himself to have strong political views, including being anti-immigration as well as having negative perceptions about English people's drinking habits:

Felicjan: (member checking) Sometimes I feel bored here. I have school friends, but no life in England, only friends drink beer in England and vodka a lot and I don't want that... I think the terrorist attack in London was a tragedy. It made me feel angry, anxious. I wanted to go to London, but now I am afraid it is not safe to go to London. I do feel safe in my town, because Mum and Dad are here and the school is here so it makes me feel safe. I think, for sure, I will feel more safe in Poland, because everyone is speaking Polish there. There are police there. It is safer than England. I don't think terrorist attacks will happen in Poland, because there is no immigration from the Asian countries. Immigration in Poland from those areas is unlikely as Polish

politicians do not want to invite them. They are not welcome in our country. I think the world would be safer if everyone stayed in their own country. I've been here for ten years and now I am finally going back home. (Felicjan, Special School, Member Checking Text)

Aside from being scared of dogs, Nameless spoke in detail about how his state of mental well-being affected whether he liked himself or not. He seemed more aware and was certainly more vocal than any of the other participants about mental well-being. He also spoke about depression and stated that, if it continued, he would need to visit the child and adolescent mental health services (CAMHS).

Nameless: I mean when I'm feeling bad about myself, I think that I'm worse than everyone and it just kind of overwhelms me. I can't think of any positive things. It just doesn't work as much as I like to be able to. And when I'm feeling really good about myself, I think I am better than everyone else in a way. And one of my best things I don't want to happen is getting embarrassed. One of my strongest feelings - being made weak or in a way not impressive. (Nameless, Mainstream School, Transcript Week 1)

Natalia and Nameless, who both self-identified as being autistic and attended mainstream schools, spoke about how they found things that changed challenging, particularly with regard to their routines. Nameless was able to separate the types of change that he found were acceptable and those he didn't like. He didn't mind changes that he didn't perceive to affect him, for example he was not bothered by the fact that I dyed my hair a different colour during the research process. However, change that affected his daily routine was very stressful. He also included people picking on him in his conceptualisation of change.

Me: Does it bother you that I changed the colour of my hair?

Nameless: No. Why would it? It's not exactly gonna affect me physically or emotionally.

Me: Okay. It's not all change? So, are there specific types of change?

Nameless: Yeah, I'd say.

Me: Can you be specific about what change is stressful change?

Nameless: Yes. Stuff where it will affect me physically or emotionally. Emotionally being other heads [people] picking on me, physically being a certain change of timetable and I have to do other things that I don't usually do. (Nameless, Mainstream School, Transcript Week 4)

5.4 Reflections on strengths and difficulties

All of the young people were able to identify at least one strength they had in school. Those attending mainstream schools were all able to name a national curriculum subject that they felt they were good at, or at least enjoyed: English (Nataliya and Ruby), maths (Nameless) and history (Destroyer). The two young men, Felicjan and Asim, who attended the special school, focussed on the life skills they were good at. Asim spoke about being able to cook rice and saving money, whilst Felicjan was proud of his job taking the register from the class to reception. Ruby and Nataliya, who attended the mainstream faith school and Destroyer, who attended the mainstream school, also identified subjects that they found difficult: geography (Ruby), theme days (Nataliya) and maths (Destroyer).

When speaking about difficulties in life more widely, issues with peers and friends were a common challenge identified by the young people. Two, Nameless and Nataliya, who attended different mainstream schools, spoke about feeling misjudged and overlooked by their peers. Nataliya, specifically, spoke about how she did not have any friends in her class, and she felt that they did not appreciate her:

Nataliya: I have a few friends up here in The Brambles, but not in my class. It makes me feel a bit absurd. Because up here [The Brambles], I've got my own friends, whilst in my class it's just compulsory and strict and weird. I sometimes feel that my class under appreciates me. And there's one girl that I call a heart breaker, because she sometimes annoys me, a lot. I ask her to leave me alone many times. Everything's just complicated. (Nataliya, Faith School, Member checked text)

All of the young people attending mainstream school spoke about bullying. Nataliya and Nameless spoke about experiencing this first-hand, whilst Ruby and Destroyer talked about wanting to stop bullying or about it occurring in their schools:

Nataliya: If I have a problem, sometimes I talk with friends and sometimes

with my teachers. Sometimes it's easier to talk to teachers, because the teacher's got more responsibility. They all know what it's been like - about what Luke might be doing to me, if he's saying some rude stuff about me, bullying me, just telling lies. I would just say the truth. Well, last week, he just lied that I just pushed him on the stairs, which I didn't. And then I told Miss my story and she believed me and then she got Luke. And then Luke said didn't really mean it, but he just said sorry to me like this "sorry" - like angrily, like he absolutely hates me. (Nataliya, Faith School, Transcript week 5)

Nameless: We have Charlie, throwing shoes at me, doing all the stuff that he does. (Nameless, Member Checking Text)

....

Nameless: Sometimes the canteen feels safe. Sometimes it's year 11s who are a bit meh²². But at least when they come at you they only say one sentence like "I like your brick phone", and then they're gone. They're not going to stay like year 7s, who I do not get on with: "oh, you've got a brick phone, hey, everyone, come and look at this guy, he's got a brick phone, ha ha ha!" (Nameless, Mainstream School, Member Checking Text)

Ruby: And they [bullies] keep saying stuff about people. I think they say it to wind people up, because usually when people get wound up, they just start hitting them and punching and that. They say something mean to just wind people up and that. (Ruby, Faith School, Transcript Week 3)

Me: If you ruled the world, what would you do?

Destroyer: I have no....stop bullying. (Destroyer, Mainstream School,

²² Meh: a word used to express a lack of enthusiasm

Transcript Week 1)

In the special school neither young men spoke about bullying. However, Felicjan commented briefly about a young woman, Cleo, who used to be in his class, who he was nervous around. She had behaviour that challenged and sometimes threw objects about the room and as he could not easily move out of the way, Felicjan was worried he would get hurt.

Felicjan: I don't feel stressed anymore in school, **but I used to about Cleo.**
(Felicjan, Special School, Member Checking Text)

Aside from challenges with friends, Nameless also spoke about having low self-esteem and struggling with depression. He was able to relate how an experience of not doing as well as he had hoped in a maths test contributed to his feelings of anxiety. He was very aware of services aimed at supporting young people and had been told by his mother that, if these feelings continued, he would need to get professional support:

Nameless: What do I do to express my feelings. I mean last night was it was really bad for it actually; worst ever. Maybe it's just puberty adding on to it. Mum says it could be depression and stuff like that; it's not diagnosed yet. I haven't even seen the doctors about it, but I just let it out in tears and started a massive meltdown about it...My mum says, if it gets really bad then you'll go to CAMHS (Child and Adolescent Mental Health Services) and hope they try to sort out...It usually happens when I don't have anything to put my mind on, like projects...So usually, when I'm bored; not a lot to do. Tired, hungry, all that can contribute to it and then, I find something that I don't like about myself and eventually it will come. It will just escalate. I'll just go *poofffff* and explode. I mean last night I was the lowest in the maths class: 9 out of 20 it was. Yes 9 out of 20. Very disappointing there. Yeah, I mean I've been getting 10 or 11 just going on and off, but everyone this time seemed to get like 16 out of 20 - they found it really easy. Nobody else got 9 or below, so lowest in the class. I don't want to be put into the middle maths set. I want to be kept in the top. Currently, I don't know whether that's a gonna be happening, so you know....(Nameless, Mainstream School, Transcript week 1)

5.5 Responsibilities to self and others

A sense of the importance of personal independence and having responsibility was something that percolated through many of the young people's discussions. Being responsible with money was something that came up in two of the young men's lives. Nameless had two bank accounts, where he deposited his pocket money and when I enquired what he intended to do with it he proudly responded, "let it rise". Asim had also been saving money by working after school at his Uncle's take away as well as sometimes receiving money from his dad when he went to help him with his limousine business in London. In contrast to Nameless, Asim was waiting until his money boxes were full and then, he intended to spend his earnings on either a phone or a game. He was very proud to report that he had separated his money into two separate boxes - notes and coins.

Feeling 'adult', or more responsible than others, was also something that came up in conversation. Ruby spoke about things in her life that she was able to do that her younger siblings were not, such as sitting in the front of the car. Asim highlighted how assisting teachers made him feel "bigger". Asim and Felicjan often spoke about jobs and responsibilities during the time we spent together. Both attended work skills classes at their special school and had various jobs/responsibilities that they took on during the school day. For Asim, jobs were a central aspect of his life in and out of school. Outside of school, he was particularly proud to tell me about working in his Uncle's take-away shop, where he helped "making pizza and packing". In school, he was able to help the head teacher, John, prepare for the school fete and also, regularly helped his male teaching assistant to do a safety check on the school bus.

Me: Do you like helping out? I saw you this morning helping John.

Asim: Oh, the TV stand, putting it in Shana's office. I can pick up the TV and then John carry it.

Me: Do you like helping people to do jobs?

Asim: Yes, yeah, yep. I like taking the seats out on Thursdays. Sometimes I struggle with the seats. Pete showed me how you do the seats - free them, and then I done it myself on Thursday. (Asim, Special School, Transcript Week 2)

Destroyer spoke about being tasked with responsibility by his Emotional Literacy Learning Support Assistant (ELSA), with whom he had 1:1 sessions throughout the week. During one of these sessions, Destroyer was able to nominate a friend from his class to bring into the session with him. When he told me about this, he also talked about how this made the session better. Destroyer also took on responsibility himself with respect to what he thought I might consider 'naughty' or 'inappropriate'. A few times he told me a story that involved swearing or rude jokes and when it came to expletives, he would omit them. When I asked him what words he was omitting he would tell me that I would not want to hear them. It seemed he was censuring himself on two levels: on one, I think he thought that, if he told me the words I might tell him off for saying them, whilst another it seemed as though he wanted to protect my well-being by not subjecting me to obscenities. Another situation where Destroyer showed a sense of responsibility for the well-being of others and keeping them safe, was when we were watching one of his videos. In the video, one of his friends lifted his t-shirt and showed his tummy. After watching the video, Destroyer talked to me about needing to talk to his friend to remind him that it was not a good idea to show people his tummy:

Destroyer: I see Tommy just lift up his top. I'm going to speak to him about that.

Me: What are you going to say to him?

Destroyer: Next filming, do not show your tummy to people. (Destroyer, Mainstream School, Transcript Week 3)

Many of the young people also spoke about ways in which they helped themselves with different aspects of their lives. It was particularly interesting to see that the level of responsibility they sought to take on was different. Ruby, who attended the faith school, reflected on both the short and long-term nature of responsibility, thinking about herself in the present and pondering about the future. When thinking about her present self, she was very proud to talk about her spelling ability and how she worked hard at this at home:

Ruby: Yeah, I can stick all of it into my head. When there's, like, really long spellings I get them muddled up with where they go. Like, really long spellings. I know how to spell mischievous and complicated and other words.

Me: How do you get them to stick in your head?

Ruby: Just practice and practice each time. It sticks into my head; I never forget though. I just keep practising, practising and practising... because if you didn't practise you won't really know what you're doing. So, better to practise first, because if you have a spelling test you have to learn all the spellings. (Ruby, Faith School, Transcript Week 5)

Thinking about the skills she would need for the future, she spoke about wanting to learn how to cook to enable her to take care of herself and become more independent from her family. Specifically, she wanted to learn how to use the oven and be able to make meals:

Ruby: I want to learn how to cook food and put stuff in the oven. To know how to turn the oven on and to turn it off. And I want to cook a lot of things at home.

Me: Why do you want to learn how to cook?

Ruby: So, when I get older, I don't have to depend on my parents to be helping me and stuff.

Me: Is it important not to depend on your parents?

Ruby: Only sometimes you can depend on your parents. Only if you need help or something. And if you really struggle, it's best to see what your mum's cooking, so in the future you will learn how to cook. (Ruby, Faith School, Transcript Week 5)

Ruby was also keen to take responsibility within her friendship group, describing herself as a "role model" to Jemima, who she saw as being less able than herself. Ruby was often paired with Jemima for study skills sessions in the library, working with a teaching assistant. In these sessions, Ruby saw an opportunity where she was able to help Jemima with her spelling and her writing.

Destroyer and Nameless, who both attended a mainstream school, focussed on the way in which they took ownership over their present well-being by showing agency in self-care. Nameless, talked about how he had worked out and taught himself a coping strategy to help him with his fear of dogs:

Nameless: And another thing I do, although I think this is everyone as well. I've now learnt a self-calming technique. I'm going to have to stand up to demonstrate. I've got a phobia of dogs. If a dog's going by me, and it's a thin path about that big [demonstrates a small space]. First of all, I've got to see the edge, then, hands out to the sides, put your tongue up and then you blow into it and then you kind of just, look ahead, putting your stomach like this [shows tensing his stomach] and focusing on all those things at once, and you forget to think about the dog. You have to not breathe while doing it - it's not very good that way.

Me: Where did you learn that?

Nameless: Self-taught. (Nameless, Mainstream School, Transcript Week 4)

Destroyer, who was conscious of the importance of being part of a friendship group, took responsibility and initiative deciding to start going to the park in the hope of making friends. Unfortunately, by the end of the research he was no longer doing this:

Destroyer: Usually, on Fridays I go to the park. I see some people at school and I just ask, if I can play like 'it' with them, and they say yes. And then we just, like, have fun.

Me: Did you do that before or is that a new thing.

Destroyer: It's a new thing.

Me: Why did you start doing it?

Destroyer: Because I want to get more friends and so people stop picking on me. (Destroyer, Mainstream School, Transcript Week 3)

5.6 Perceptions of future and adulthood

Nameless, who attended a large mainstream school, was equivocal about the future, when questioned about where he saw himself going. He thought that, if he were to get good grades, then he would be able to have a career he wanted, for example, working with

computers or working in the government, where he could improve the system.

Nameless: That's for debate. If I get good grades and stuff when it comes to the GCSEs and stuff, I picture myself in a good computerised kind of job or maybe even the government. Maybe I can talk to some governments. Maybe I can try and sort the services out. Or I can try that sort of thing making games, computers and that stuff. (Nameless, Mainstream School, Transcript week 1)

Later on in the research relationship, he reflected on the potential impact of being autistic. He saw autism as a limitation for another autistic young man, Jim, in his year. However, he was not yet sure how being autistic might shape his life.

Nameless: Jim, his autism is his downfall.

Me: Do you think your autism is your downfall?

Nameless: I'm going to wait and see. Wait and see until I'm older and what job I get. (Nameless, Mainstream School, Transcript week 5)

One key vision Nameless had for his future was to have a routine that did not involve change:

Nameless: When I'm older I don't plan to have a lot of change. I'm just going to have a timetable. So, I'm gonna buy exactly the same thing for each day. I'm going to do the maths and say "right it's going to cost me exactly 70 quid sixty three pence every day and I'll be making a profit of duhduhduhduh". Exactly the same, every day, and I'll take this amount of time for everything. There will be no change. Everything will be all right and I'll just be at work doing exactly the same stuff. (Nameless, Mainstream School, Transcript week 5)

Asim, who worked part-time in his uncle's take away shop during the research until he was fired for a mistake in the kitchen, was clear that he would prefer a job in an office, rather than in a take-away. He attended a special school which ran 'work skills' lessons and would sometimes come in wearing a suit and practise skills that might be needed in an office, such as shredding paper. Felicjan's desires were for the short term and his hopes and dreams

were wrapped up in returning to his homeland of Poland:

Felicjan: Soon we will go back to Poland. I will go to a new school. Lots of Polish people left Poland, but nowadays lots of people are going back, because of the politics. To begin with, we couldn't find a place to live, but now we have. It was hard to find the right place. I was worried that we wouldn't find the right accommodation, but now we have a flat. I have a big bedroom. I haven't been Poland for a long time, so I don't know what the schools are like at the minute. I am very excited to go to my new school, because I can't wait to talk in Polish all the time. I don't feel nervous about changing schools.
(Felicjan, Special School, Member Checking Text)

Ruby and Nataliya, who both attended the mainstream faith school, were passionate about their future careers. Both young women wanted to have a career in the public eye: Ruby as a news reporter, which was related to her perception of herself as being a good reader - something she was proud of. Nataliya wanted to be a superstar singer and actress - singing was something that enabled her to feel completely herself and free.

Nataliya: When I sing, I feel like I'm completely myself. It's just that, I just want to be free. I want to get my future now. That I am what I am. The Selena Gomez song - This song is about letting go of stress on the dance floor and enjoying a sweaty dance—Good, sweaty dance party.
Yes, I still like Selena Gomez and her songs, and I also feel free when I'm doing some singing. (Nataliya, Faith School, Member Checking Text)

She often spoke about her “future celebrity friends”, such as Selena Gomez and Benedict Cumberbatch. She didn't often speak about peers as friends, whilst in her future career she strongly positioned herself within a group of famous peers who would be her friends.

5.7 Owning and rejecting labels of difference

Four of the young people, Natalia, Ruby, Nameless and Destroyer - all of whom attended mainstream schools - used the diagnostic label ‘autism’ during our time researching together. Destroyer only used the term once as we were transitioning from the room we were working in, to the school's SEN room to play computer games (the way we usually ended our sessions). In a seemingly off-hand remark, he mentioned how he was autistic (interestingly this diagnosis is not made in Destroyer's Education Health Care Plan (EHCP)).

Natalia, Nameless and Ruby used the term more frequently during our sessions. Nataliya and Nameless both self-identified as either “autistic” (Nameless) or “hav[ing] autism” (Nataliya). All three participants used the term to describe other people in their schools. Nataliya used it to describe “social problems” that both she and others “have” (Nataliya, Member Checking Text). She further explained that people who come to The Brambles - the inclusion unit within her mainstream faith school - have autism. When speaking about her own autism, Nataliya seemed to construct it as something that you ‘have’ rather than something that you ‘are’, which shows a sense of separation from an autistic self and rather, hints at a medicalised understanding of the condition. Additionally, she seemed to construct autism as something negative - something that makes you go “crazy” or that “messes with you mentally and physically”.

Nataliya: I like The Brambles a lot, really. Because I can sit here, read my book, listen to the radio. The people that come to The Brambles, well, some would have autism, social problems. Autism, it's something to do with us when we're going crazy. I don't know. **I still do love The Brambles. I still sometimes feel like that, I'm going to go crazy, I'm going to lose my mind, feel like I'm in a battle field, where enemies, friends, kings, queens come on top and everyone is fighting for their throne. Like I feel like there's war going on between us - in life. Autism sometimes messes with you mentally and physically. I have autism.**

Me: Who told you?

Nataliya: I just knew. (Nataliya, Faith School, Member Checking Text)

Ruby predominantly used the term to describe other people. She distanced herself from the label clearly stating that she didn't “have autism”. Similar to Nataliya, who she attended school with, the notion of “having” autism suggests a medicalised understanding as a condition rather than embodied way of being. Moreover, Ruby also reflected on the way in which the term Autism was often used by other students as a way to make “fun of people” or to “wind people up”. This, again, suggests a negative connotation being exploited in the way her peers used the term to aggravate other students.

Me: Do lots of people who have autism come here?

Ruby: Yeah, like, Nataliya has autism, Jemima, lots of people. Sir keeps

saying I have autism, but I don't have autism. Lots of people keep saying that. It seems like everyone in this school has autism even if they don't.

Me: Why do you think people say that?

Ruby : I think to just wind people up, to just kind of, make them jealous or something. I think they're trying to say "oh, this person has autism, that person has autism". Maybe they just say that just to make fun of people, just say stuff just to wind people up to make them get in trouble.

However, Ruby did reflect on what autism meant to her when she thought about what impact it had on her friendship with Jemima, who she identified as autistic. Here, she shows that she didn't see autism as being unsurmountable and that she could make friends with a person who did "have autism" (Ruby, faith school, transcript week 4). She subverted a discourse of 'normality' by explaining that people who "have autism" "still do act normal, just in different ways" (Ruby, faith school, transcript week 4). She tried to 'normalise' difference:

Me: If a person has autism does it matter?

Ruby: No, you can still make friends with them even if they have autism. It's not really a big problem if someone has autism anyway, because they [autistic people] still do act normal, just in different ways. Jemima's my friend and she has autism. I make friends with people like that. Even if they had autism, I would still make friends with them, because it doesn't matter if you have autism or not everyone, is still the same. Some people are dyslexic in this school as well, and I still make friends with them. (Ruby, Faith School, Transcript Week 4)

In contrast to Ruby who distanced herself from autism, Nameless had ownership over an autistic identity and gave examples of how he used this in his schoolwork (see Appendix xvi). He spoke about how he found it "easy" to self-identify as "autistic", but he also highlighted that it was up to other autistic people as to whether they identified themselves so:

Me: Do you feel pretty comfortable in school talking about autism?

Nameless: Yeah, I would do, yeah.

Me: Would you talk, would you happily tell, like, a person or someone in your class that you're autistic?

Nameless: Yeah, yeah definitely.

Me: Do you think all autistic people should be able to say that?

Nameless: Their choice I suppose. I mean - I find it easy, I don't know whether they would. (Nameless, Mainstream School, Transcript Week 4)

In conjunction with autism, Nameless also owned a disabled identity - something that he also identified his family as having. For Nameless, being autistic and hence, disabled, contributed to a political identity where he saw Conservatives as bad and Labour and Jeremy Corbyn as being good and doing the right thing:

Me: Are there specific things that you want in your life, like now or in the future?

Nameless: Ha, go over an entire list of it. Get rid of May, new government...

Me: Which government?

Nameless: Labour, labour needs to get in.

Me: Do you like Corbyn?

Nameless: Yes, as much as a lot of people don't. Corbyn - he'll do the right thing, because he has before I think. And besides labour's just a better government anyway. All rich people, they'll vote for the conservatives. All poor people vote, they'll vote for Labour. That's how it goes pretty much. More rich people. Cos, Conservatives, I read a thing this morning about how they're going to refuse to, to, to say that they're not doing any cuts on disabilities. It's a problem, because all my family is pretty much disabled. (Nameless, Mainstream School, Transcript Week 1)

Felicjan, who attended the special school, self-identified as having cerebral palsy, however,

he spoke only in medical terms about why he “was like this”:

Felicjan: Life is not the same for everybody. Children have different diseases and illnesses. I was born healthy and then, I had bleeding from my ears, eyes and nose. I lost quite a lot of blood and that left me with cerebral palsy. I was in hospital in Poland for quite a long time. The doctor **who was Australian** came and did a lot of tests, some on my head when I had to be connected to the computer **like a helmet**. This is who I am now. **My brother is dead, he died when he was small – he was like me and lost a lot of blood.**
(Felicjan, Special School, Member Checking Text)

Asim, who also attended the special school, only once made a comment regarding disability and this was in respect to people in wheelchairs not being able to access his uncle’s limo that he was using for his school leavers’ prom:

Asim: My uncle is bringing his limo to my prom, it’s got the lights and screen - everything it’s got. You can’t put your seat belt on, it’s got no seat belts. You can have a drink, anything...It’s got all the seats.

Me: So, everyone can sit in it?

Asim: Yeah apart from wheelchairs. Because, uh, wheelchairs can’t come in.
(Asim, Special School, Transcript Week 3)

5.8 Using labels to ‘normalise’ themselves in society

The young people used labels to position themselves as ‘normal’ in two distinct ways - either by identifying themselves as part of a group, or by distancing themselves from the ‘other’, so as to be seen as ‘normal’. Nataliya, who attended the mainstream faith school, used normalising labels as a way to identify herself with others. She used wider cultural discourses on teenagers as being grumpy to identify herself as part of teenage society. Through this group identifier, she made connections with teenage pop stars, who she saw similarities with - particularly Selena Gomez.

Nataliya: Welcome to the teenage age. When we’re teenagers we’re just like, moody and wanting to break free types. **Yes, yes it’s still true. I’m a teenager now, I’m thirteen and I’m gonna be fourteen after the half term on Monday**

30th. So, that's one thing we have in common. There's Selena Gomez, who I think is the same as me, because when she was a teenager, just like me, she wanted to be a star and I want to be a star like her too. (Nataliya, Faith School, Member Checking Text)

Destroyer, who attended a large mainstream school, was very aware of the potential for him to be seen as 'different', or 'weird', by his peers. He wanted to counteract this and had a strong desire to be seen as the 'same' and hence, minimise the chance of being singled out by children in school. We often walked around school when we were researching together and talking as we walked. One day I asked him to walk around the football pitch (which he referred to as the square) with me, but he was concerned it would "look weird", if people saw us. This was an example of the way he not only mediated his behaviour and used labels to reduce the risk of being 'othered', but also, how he showed his awareness of the normal and 'other' discourse in society.

Me: Yeah, let's walk around the pitch...

Destroyer: Why? Because there's only going to be us on the square [football pitch], it will look weird...

Me: Why can't we walk around in a square then?

Destroyer: Because there are people, like, watching.

Me: And if they see us doing something, what might happen?

Destroyer: They might come up to me and be, like, "why did you do that?"
(Destroyer, Mainstream School, Transcript week 4)

Similarly, Nameless, who attended the same school, was also conscious about the way he was perceived by his peers and hence, made sure to mediate his behaviour. There was another young man with autism in Nameless' year, Jim, however his condition was more apparent. Nameless would have liked to be friends with Jim, but he was concerned to associate with him due to being stigmatised as more different. If he hung out with people without autism, he thought, on the whole, that he would get more acceptance from the general school population.

Nameless: "I suppose I'm normal enough for them to say "right, yep, he's good." (Nameless, Mainstream School, Member Checking Text)

Nevertheless, despite trying to present himself as being 'normal', he still felt an overall sense of not fitting in.

Nameless: Belonging. If you were asking the students and how they think of me, no. If you were asking the teachers and how they think of me, yes.
(Nameless, Mainstream School, Transcript week 5)

5.9 Using labels in 'othering' ways

All of the young people, apart from Asim, used 'othering' discourses, which could be seen as ableist or exclusionary in reference to other people. Felicjan, when watching a videovoice clip he had recorded of his school's community cafe, referred to one of the customers who had a learning disability as a "retard" (Felicjan, Week 4 Field Notes). Similarly, despite his use of "NT" (Neuro-typical) and "autistic" and strongly advocating for "human rights", Nameless still often used discourses of 'normal-ness'. When describing autism, he explained that he viewed it as an "entirely different species, but still human" (transcript, week one). When discussing other autistic people he knew, such as Jim in his class or his TA, who identified as Asperger's, he reviewed their 'normal-ness':

Nameless: Mr Hinton, he generally just hides it I suppose. Because you can tell there's something with him, but he hides it. So, he's somewhat a normal person, but his interests are very Asperger's like. Strange, not anything that a normal person would usually like. I mean Asperger's people, they like weird things, like, I used to have an obsession with planes, trains, cars and space. You know, so just weird - what I would classify as weird things.
(Nameless, Mainstream School, Member Checking Text)

In reflecting on his relationship with Jim, he placed Jim and himself on a spectrum of "weirdness". He was clear that the reason for positioning himself as less 'weird' was due to the fact that he tried to "contain" his autism, whereas Jim didn't.

Nameless: Jim, who I'm not really friends with, because he is, undoubtedly, even more unpopular than me. Being friends with him would do a lot to my reputation, not that I've got a lot anyway, but it would just get rid of all that

I've got. Jim is autistic and I find that autistic people are a lot friendlier than normal people, when they're young anyway. Jim has no friends. None whatsoever, which is why I'm not bothering. He does his own thing anyway, so if I were to play with him he'd probably just be like, "Yeah, yeah, I'm doing my phone so just, you can do whatever, you don't need to--- yeah". He definitely is more autistic than me, because unlike me he actually goes in front of the class and is more weird. I try to contain it even if sometimes it doesn't work. He doesn't try. (Nameless, Mainstream School, Member Checking Text)

Similarly, Ruby also identified other students as being disabled or autistic. Her understanding of disability seemed to be focussed on deficits and hence, it was particularly interesting that when I questioned whether either she or I were disabled or only her friend Jemima, she did not self-identify as disabled.

Me: Can you tell me some stories about Jemima?

Ruby: Yeah, she's shy; she doesn't really talk that much. And lots of people say, "why doesn't Jemima talk?" She finds it hard to write and she's disabled. And sometimes some people might have to write something on a piece of paper for her and she copies it out.

Me: What does disabled mean?

Ruby: I think it means when, umm, someone finds it hard to write properly and they could find it hard to walk or something.

Me: Yeah?

Ruby: Yeah, so she finds it hard to write properly.

Me: Are you or I disabled, or is it just Jemima?

Ruby: It's Jemima and there's lots of people that are autistic in this school. (Ruby, Faith School, Transcript week 3)

5.10 Key issues intersecting with the literature

The young people's voices in this study challenge, as Singh and Ghai (2009) put it, "the expectation that 'disabled' children are 'different' or 'deficient'" (p.138). In this section, I link the themes explicated above with the relevant literature examining the ways in which the findings align with or challenge the extant research. I reflect on the manner in which the young people's descriptions of themselves refute deficit discourses surrounding those identified with SEN. Additionally, I consider how the young people spoke about notions of difference as well as the way in which they used disability or SEN labels and how this relates to prior scholarship.

5.10.1 Challenging discourses of passivity and tragedy

The way in which the young people described themselves clearly demonstrates a sense of self rejecting discourses of passivity and tragedy. This can-do approach demonstrated by them is also reflected in the work of Mortier et al. (2011) when researching in Germany and Skar (2003), who focussed on Sweden. The findings within my own study also connect to the emerging field of Disabled Children's Childhood Studies (DCCS). This nascent area combines the critiques of disability studies (rejecting a medical narrative) and contemporary childhood studies (rejecting the normative narrative of a typical child) to articulate strongly the importance of explicating the experience of individual childhoods (Curran & Runswick-Cole, 2014). Most of young people in the study rarely spoke about themselves medically, with the exceptions of Felicjan, who did talk about his experience in hospital as a young child and Nameless, who spoke about mental health concerns. The young people did not touch upon experiences of therapy, rehabilitation or the impact of impairment, such as is the concern of much research on young people identified as having special educational needs (cf: Oliver and Sapey, 2006; Bekken, 2014), only briefly speaking of help received from teachers or teaching assistants. Rather, they spoke about themselves in a practical sense, talking about daily experiences, focussing on their strengths, what they did and didn't like and what they wished for. They did talk about problems they encountered, but this was primarily in relation to friendships, or lack thereof, or tangible issues they faced at school.

To illustrate, I draw a connection between the way Asim spoke about himself and Freyja Haraldsdottir's (2013) writings in the context of DCCS. He did not focus on the identification he had been given as having special educational needs, nor did he describe himself as having difficulties or disabilities resulting from an impairment. Rather, he described and viewed himself in a very practical way, talking about his daily experience and focussing on

his strengths and how he liked to support those around him by helping them and taking on an adult role. Haraldsdottir (2013), a disabled adult reflecting on her own experience as a disabled child, states: "I didn't realise about my impairment, or at least found it as normal as having glasses, blond hair or brown eyes. I even thought that breaking a bone a few times a month was what everyone did" (ibid., 14). Haraldsdottir (2014) illustrates how, in contrast to the often-assumed disabled identity, as a child, she was not aware of the given label of 'disabled'.

Thinking about their future careers was important for four out the six participants, Ruby, Nataliya, Nameless, and Asim, demonstrated the importance of education and desires for the future through describing the careers they aspired to have. Asim (special school) wanted to work in an office, often coming into school dressed in a suit and tie for his work-based classes. Nameless (mainstream school) thought about either computer science or working for the government to make real systemic change. Nataliya and Ruby (mainstream faith school) dreamed of being in the public eye, with the former wanting to be a singer and the latter a newsreader. This is similar to the findings of Skar (2003) researching in Sweden and Mortier et al. (2011) in Germany, who reported their participants as also having wide ranging career aspirations, such as being ballet dancers, doctors or graphics designer, among others.

Whilst Felicjan and Destroyer did not talk about career aspirations, they were still strongly engaged in talking about themselves. Felicjan had strong right-wing political views, which he was keen to articulate - particularly his anti-immigration stance, which he linked to his fear of terrorism. Destroyer was very engaged in popular culture and often imagined himself inhabiting a superhero universe. Rather than taking on board lay discourses of 'inability' prevalent in society (cf. Huws and Jones, 2010), the young people in this study showed a strong sense of self and a focus on aspirations, dreams and strengths. These findings support the contention by Watson et al. (1999) that self-identity is about things they want and can do and not about their relationship to disability. Moreover, the narratives of the young people reveal them as being active in their own lives, with complex selves that challenge the notions of 'tragedy' and passivity.

5.10.2 Essentially the same and different

Four of the young people, Ruby, Nataliya, Asim and Destroyer, conceptualised themselves as essentially the same as other people. Only Nameless and Felicjan considered themselves to have essential differences to non-disabled people. Those who described

themselves as essentially the same rejected societal discourses of essential difference as well as creating tensions with the Social Model of Disability and the notion of a collective disabled identity (Oliver, 1996; see Chapter Two Examining Self within Disability Studies). This links with other research undertaken with young people identified as having SEN/D. That is, Jahoda et al. (1988), researching stigma and the self-concept of people identified as having learning difficulties and/or autism, found that the majority of their participants viewed themselves as “essentially the same” , i.e. as non-disabled people (p.103). Similarly, Skar (2003), researching with disabled fifteen to nineteen-year-olds, found that the teenagers described themselves as regular members of groups, whilst their peers described them as different, because of their disability.

For Nameless and Felicjan, who considered themselves to have essential differences, there were apparent factors as to why this may have been the case. Nameless clearly identified himself as autistic and coming from a “disabled family”. He explained his feeling different to others and having opportunities to assume a disabled identity through his family life. Felicjan spoke of his difference in very medicalised terms, explaining that many young people experience difference due to medical disability. He spoke in detail about how he understood his experience of cerebral palsy and of extended stays in hospitals as a young child. He was also conscious of the dangers for him of overheating and so had to be aware of the ambient temperature.

Jahoda et al. (1998) also included the perceptions of participants’ mothers, finding that in contrast to the participants themselves they viewed their children as “essentially different” from non-disabled people. Similarly, the parents who participated in the research of Connors and Stalker (2007) thought their children would describe themselves as different to others on the basis of having been identified as having SEN/D. Whilst the parent narratives in the work of Jahoda et al. (1998) and Connors and Stalker (2007) offer a different and more intimate familial parameter compared to the teachers’ voices in my own study, there are still some similarities. The adults who worked at the mainstream and mainstream faith schools conceptualised Nataliya and Ruby as different to their peers due to their disability. It should be noted, however, that the adults in the special school did not make the same distinctions and rather, tried to minimise differences, presenting Asim and Felicjan as “typical” (Deputy Head, Special School, Transcript).

Connors and Stalker (2007) contend three potential reasons for the focus on sameness within the discourses of young people identified as having SEN/D: 1) the pressures on young people to be normal could cause them to “minimise or deny their difference”, which

links with the notion of “passing” (p.30); 2) young people have agency “choosing to manage their day-to-day lives and experiences of disability in a matter of fact way” (Connors and Stalker, 2007, p.30), with disability not being at the forefront of their identity; and 3) the young people were not “in denial, nor fully in command of resisting the various barriers they face”, but rather, they did not have the necessary language to talk about difference and disability in a nuanced way, whilst they also lacked disabled role models (Connors and Stalker, 2007 p.30). It is possible that these rationales play a part in the way the young people described themselves to me and my presence as a white able-bodied researcher may have contributed to any pressure they may have felt to describe themselves in a certain way. The argumentation Connors and Stalker (2007) make for this third point regarding lacking the language to describe difference in a nuanced way bares some similarities to the young people’s experiences in my own work. The participants, with the exception of Nameless, never spoke of any disabled people who they looked up to, with few of them describing disability in a positive light (see the following subsection). This is similar to the participants in the work of Connors and Stalker (2007) who elicited that they lacked disabled role models. It is interesting to note in the case Ruby, who was black and had been identified as having learning difficulties, when it came to creating an avatar and pseudonym for herself, she chose to cut out a picture of Ellie Goulding, a white non-disabled woman, from a magazine. Connors and Stalker (2007) found the young people in their study had few opportunities in their lives to discuss disability or share stories about their lot. The scope of my research meant that this was not directly addressed with the young people and most of them did not choose to address this themselves, with the exception of Nameless. Two of the participants in my study, Felicjan and Nameless, did describe themselves as disabled or different. Nameless, as he put it, came from “a disabled family”, which gave him many opportunities to discuss his daily experiences of difference at home and he had a strong disabled identity linked to his knowledge of the Social Model of Disability. Felicjan had had a very medicalised experience and had physical impairments as well as having been identified as having a learning disability. For him, his experience had been characterised by hospital stays as well as having to be careful of not over-heating. For the other young people, however, the collective disabled identity, as described within the Social Model of Disability (see chapter three) does not fit. Further research needs to be undertaken to explore more young people’s experiences in order to shed more light on the degree to which young people’s experience of disability resonates with the Social Model of Disability in England.

5.10.3 Words have meanings

Words and phrases were used as tools that enabled the young people to position

themselves as well as others as either belonging to or distanced from social groups or peers. All of the young people seemed highly aware of the perceptions of other people towards them as well as their peers' (and their own) stigmatising view of disability. Goffman (1963) contends that "the stigmatised individual tends to hold the same beliefs about identity that we do" (p.7). This understanding is demonstrated by Ruby, who was keen to distance herself from the label of autism explaining: "Sir keeps saying I have autism, but I don't have autism". She goes on to say that her peers use the label of autism as a taunt "to just wind people up...to make fun of people". In England, there is growing evidence of discrimination against disabled people and rising levels of hate crime (UN, 2017). Nameless, Ruby, Nataliya and Destroyer can all be seen to have internalised some level of stigmatising beliefs held by society that disability is "deviance, lack and tragedy" (Corker and Shakespeare, 2002, p.2). For example, Nataliya described autism as "mess[ing] with you mentally and physically" and its being "something to do with us when we're going crazy".

Three of the young people also self-regulated in order to pass and thus, minimise the chance of being identified as different to their peers. Similar to the findings of Hodge, Rice and Reidy (2019), who also identify the process of self-regulation, Nameless speaking about the way he mediated his own behaviour by trying to "contain it" suggested some sense of shame, such that he felt he needed to hide aspects of himself so as to be considered "normal enough" by others. Nameless further demonstrated active navigation of his perceived stigmatised identity through his choice not to be friends with a classmate who was also autistic, but who he considered to be "undoubtedly even more unpopular" than himself due to his "weird" behaviour. This was also echoed in the experiences of Destroyer and Ruby. Destroyer was very worried about being identified as different and was agitated about people "watching him", who then might consider his behaviour to look "weird" (Transcript Week 4). Ruby tried to keep hidden the fact that she had been held back a year in primary schools and avoided telling her classmates her real age. The navigation of the stigmatised self in relation to the other perceived 'normal' person highlights Tregaskis' (2003) contention that disability is most profoundly experienced in relationships with non-disabled people.

When looking across all the young people's descriptions, Nameless was unique in his ownership of a politicised disabled identity. Through this identity, he overtly engaged with the Social Model and was able to identify barriers in society, rather than internalising disability as wholly individual (cf. Oliver, 1990; Shakespeare and Watson, 2002). Uniquely, among the group of participants, Nameless came from a family where everyone was "pretty much disabled" and had strong political views. He linked the Conservative party with disability cuts and saw Labour as advocates for the rights of disabled people. The way in which Nameless

challenged the enactment of stigma through highlighting institutional practices is echoed in the work of Oliver (1990), who challenges Goffman's theory of stigma on the basis of it only focussing on interpersonal interactions and not effectively encompassing institutional practices. Nameless was able to offer reflections at both the micro and macro level. On an interpersonal level, he was conscious of how other people perceived him and mediated his own behaviour, whilst on a macro level he held that the disenfranchisement of disabled people was enacted by institutions, for example the Conservative government making cuts that directly affected the lives of disabled people.

5.11 Conclusion

The young people in this research were able to engage in describing themselves, actively speaking about the things they wanted and could do. Their voices highlight the nuanced ways in which young people identified as having learning difficulties are able to describe themselves and challenge lay perceptions of the 'tragedy' of disability or passivity. This research links in with the emerging field of Disabled Children's Childhood Studies by providing evidence of the rich ways in which young people identified as having learning difficulties are able to describe themselves. Four of the young people did not actively describe themselves as disabled or different to other people, thus posing challenges to the Social Model of Disability and its lack of accounting for their experiences. Specifically, whether the notion of a collective disabled identity (Oliver, 1996) applies to young people who have been identified as having a learning disability has been brought into question with the findings of the current research. Moreover, in accordance with Connors and Stalker's (2007) work in Scotland, I challenge whether the young people have adequate disabled role models or the space and support to discuss notions of difference and disability. The young people also actively described themselves in ways that either rebutted stigma surrounding disability or navigated the stigma by acknowledging and commenting on it. The four young people who did not describe themselves as being disabled or different had a very individualistic experience of encounters with stigma and so, further research needs to be undertaken to explore how the young people processed the stigma they encountered.

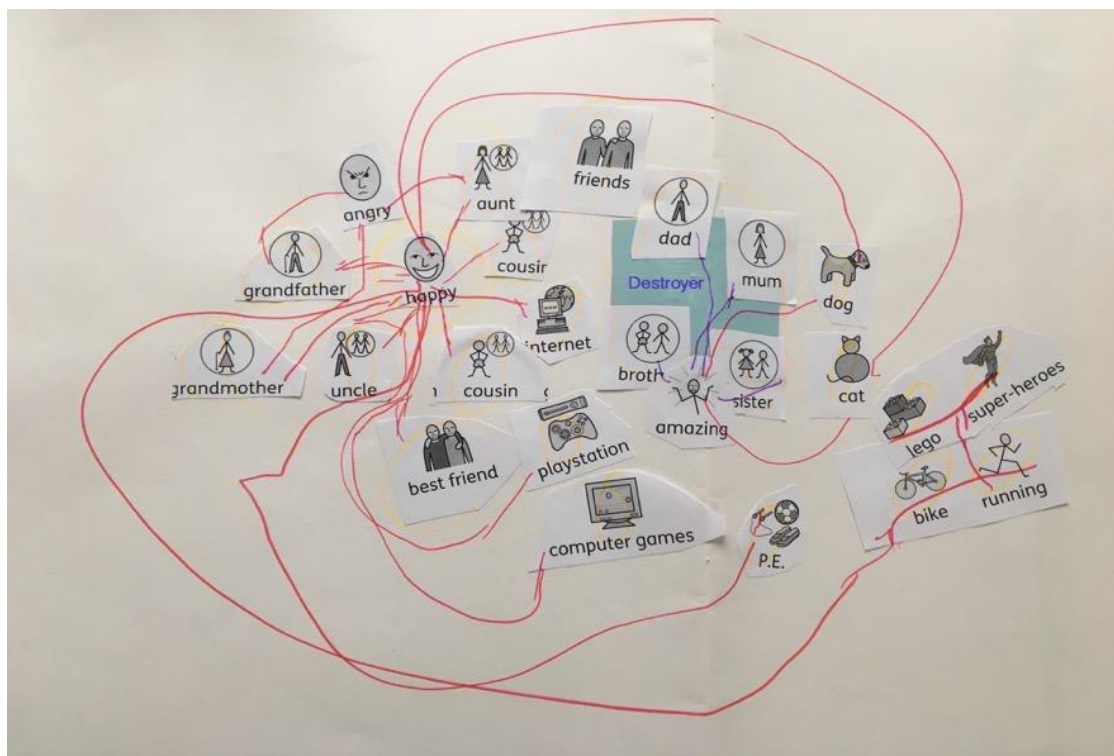
Chapter 6. To belong, or not to belong: Exploring the data

6.1 Introduction

The findings presented in this chapter relate to the second research question: *what are some of the ways in which young people describe and experience a sense of belonging in their educational settings?* The data is predominantly derived from the use of life-mapping and videovoice instruments. Life-mapping involved collecting data directly on the participants' positioning in relation to the people and things around them, thus being vital for generating data on belonging (see Figure 28).

Figure 28

Destroyer's Life Map



The first section documents the ways the young people spoke about their relationships with people in and outside of school. Here, the focus of belonging is explored through relationships presented as affectionate and interactions, which could be understood as expressions of frustration, sadness or anger. Next, the importance of place is elucidated focussing on spaces inside of school and local areas. To end the chapter, the ways in which

the students reflected on their nationality is presented. Ownership and rejection of countries and nationhood, as well as conversations relating to politics, immigration laws and regulations are examined.

6.2 Affectionate relationships as expressions of belonging: “It makes me happy, because for the first time they actually know my name” (Ruby)

All of the young people regularly spoke about people in their lives who were important to them. They talked about those they knew and had contact with in their daily life, whilst Nataliya also placed a great deal of importance on the connections she felt to people in the public eye.

6.2.1 Peer friendships

There were significant differences in the ways the young people navigated relationships with their peers. Ruby and Destroyer, who attended different mainstream schools, had friendships with peers that were very important to them. Asim, attending a special school, spoke about friendships, but placed comparatively less importance on them. Felicjan and Nataliya, attending special and mainstream faith schools, respectively, rarely spoke affectionately about friends of a similar age and positive relationships with peers were mainly incidental or transactional. Instead, adults formed the majority of affectionate social interactions for both of them.

Four of the young people - Destroyer, Ruby, Nameless and Asim - named and spoke about current friendships with their peers at school. Destroyer and Ruby, who attended mainstream and faith schools, respectively, identified how friends and peers played a central role in their school experience. Destroyer talked about how his group of six was integral to making his time at school bearable. His group featured in eleven out of the thirteen videos he made about his life. He would play games with them at break-time, usually in the library, and talk with them in lessons. Destroyer also walked home with his group, but despite having been at secondary school for two years, his friends had not been inside his house.

Similarly, Ruby spoke about the central role her friends played during her time at school. She also placed a lot of importance on peers at school knowing her name as a sign of being important and accepted by the wider school society. When I met Ruby, she was in her second year of secondary school and she had noticed a change from the previous year in respect to how many people knew her name.

Ruby: I think about friends when I'm in school. That's what, that's the only thing I think about, just friends. People in my form, they're my friends. Lots of people know my name now. Because if they didn't know my name, they would just be walking around school looking at people. It makes me kind of happy, because for the first time they actually know my name. (Ruby, Faith School, Member checked text)

As mentioned previously, Ruby had a close friendship with a girl in her class, Jemima, who was non-verbal and had also been identified with SEN/D. However, during the research the friend left to attend specialist provision. They used to sit together and they often were taken out of classes together to work with a teaching assistant. Ruby took on a pastoral role in the friendship dynamic, seeing herself as 'more able' than Jemima and thus, in a position where she could be a "role model" for her.

Ruby: I think Year 8 is better than Year 7, because we're more grown up. If you're grown up you are more mature, like being respectful towards people. And helping people out - being a role model to someone. I'm a role model to Jemima. (Ruby, Faith School, Transcript Week 5)

After Jemima left, Ruby's experience with her peers, especially at lunch times in the canteen. Initially, she spoke about disliking the canteen due to not liking the food. However, after Jemima left Ruby changed the member checking text to explain that she now enjoyed being in the canteen. She indicated feeling more accepted and included by her peers, with her becoming increasingly involved in social exchanges during lunch time.

Ruby: Well, usually, I don't really eat in the canteen that much, but sometimes I buy stuff from the canteen. Sometimes I don't; I eat in The Brambles. We're allowed to eat there. The canteen doesn't really wash the cutlery properly. So, I don't really like it and I don't like that food as well. It's too oily, which is disgusting, but I like the pudding though. That's apple crumble over there [indicating to the video]. I sit with Jemima, Mary, Tom, Amara, Dionne, those people are my friends. **Well I don't feel like that anymore, I feel kind of happy in the canteen now. There's lots of people to talk to now Jemima is gone; there's lots of people talking to me. I feel kinda happy. I still miss Jemima though; I wish she could come back. I miss her a tiny bit.** (Ruby, Faith School, Member Checking Text)

In contrast to Ruby and Destroyer, Nameless talked about how he actively chose his friendships. He had a best friend Paul, and a group of acquaintances that he hung around with because Paul did. The two of them had known each other since reception class. Despite Paul being friends with some people who Nameless did not like, he was intent on preserving his relationship with him and would put up with the other young people in order to do so.

Nameless: Paul, known him since year R. Literally follow him and do whatever he does. Even if he is the person that chose to hang out with these people that I'm not exactly keen on. He is my friend in general, and it should stay like that. (Nameless, Mainstream School, Member Checking Text)

Asim saw all the young people in his class and the next-door class as his friends, but when talking about 'playing' with friends, he named fewer people. His main past-time with his friends was board games.

Asim: Sometimes I play with Ahmed - snakes and ladders. I always win and then sometimes I lose; Ahmed wins snakes and ladders. (Asim, Special School, Transcript week 5)

6.2.2 Intense relationships

In the data, a strong gendered dimension emerged in relation to intense and particularly romantic relationships emerging, but only in regard to the young women. It is important to note that I did not explicitly ask any of the young people about these types of relationships. The fact that this data emerged in only the young women's narratives could be due to the fact that I am also female, relatively young and hence, they felt comfortable sharing these types of intimate details with me - especially as we were on a first name basis and they did not see me as a teacher-figure. It is possible, also, that due to my ascribed gender the young men may have felt less willing to share these kinds of stories. Both Nataliya and Ruby, who attended the same mainstream faith school, were interested in relationships and had romantic feelings for people of the opposite sex. Throughout most of the research process Ruby had a crush on a young man in her class, Duc, who had moved to the school from Vietnam. Ruby regularly talked about him, saying she "like[d] him", however, she struggled to articulate why:

Ruby: Duc is the boy I like...I don't know why I like him...Because I think he's smart at things, that's why. He doesn't come to The Brambles. He hangs in the playground with his friends and other places around the school. He is from Asia; somewhere around Asia. I see him walking to school. Sometimes I see him going home from school. We don't talk, not that much. I don't talk to him a lot. Just sometimes I talk to him. He already knows I like him though. (Ruby, Faith School, Transcript week 3)

Nataliya regularly spoke about romantic feelings for figures in the public eye, particularly Benedict Cumberbatch and Jonny Labey - neither of whom she had met. She wrote poetry in her spare time to express herself and she would often bring poems to the research sessions. She explained that I was the first person she had shown her poems to. When exploring her feelings for Jonny Labey, she wrote a poem that she planned on SEN/Ding to him for Valentine's Day.

From the moment I was born,
I didn't know a thing about you.
I even didn't see
you on TV too.

As I heard of Eastenders, my
parents said no to watching it.
Said it's too violent, shouty,
lovely and you're too fit.

As I got on with my life,
I didn't watch your soap or your face.
But when 'Dance, Dance, Dance' came,
I knew you would be in that race.

When you started dancing, I
knew you would steal my heart.
When 'Scream' and your girlfriend came on, I
knew where my heart was going to start.

When I heard you won,
I knew it all along and was right.

I also loved Lucy Jo Hudson,
but with you that's fine.

Listen, Jonny Labey, as I'm going
to say this til the end.
I love you so much
and it's more than a friend.

Your body, talents, voice and
loving type really pull my heart strings.
On the TV, you
really do the right things.

I love your work and dancing, but
you've really got the loving kind.
As this the end of my poem, I'll
say this, Jonny Labey, you're my East Wind.
(Natalia, Faith School, Poem)

As well as celebrities being very important, Nataliya also felt a great deal of affection for William Shakespeare - she spoke about him in the present tense and in same way that she spoke about people that she knew. His plays were crucial to her and she would often stand in the corridor and recite lines from his plays to self-sooth after experiencing difficulties in class, resulting in behaviour that challenged her teachers and/or becoming upset. She explained that when she was on stage, she could feel the presence of Shakespeare behind her.

Nataliya: Shakespeare is such an awesome man. Really, his plays are just breath taking. When I just read them, I just can't stop...**It's all still true, I really love Shakespeare and his plays, and when I'm on stage I can feel his presence behind me.** (Nataliya, Faith School, Member Checking Text)

6.2.3 Relationships with school staff

For Nataliya, Felicjan and Asim, staff were of central importance to their school experiences. Nataliya and Felicjan had the least strong connections with their peers of all the young people, but in turn, had the strongest relationships with staff. Asim, on the other hand,

navigated relationships with both his peers and staff in school, having particularly strong relationships with the male staff in school. Nataliya, who attended the mainstream faith school, spoke about the teaching assistants she worked with as her friends.

Nataliya: Miss Smith - well, I meet her most of the time to see how we're getting on. We meet each other in the library, we have so much fun talking. Watching clips, learning. She's a good friend, and teaching assistant. **Miss Smith is still beautiful and great to be with. We still meet each other in the library and we still come here [The Brambles] in the morning. I still see her and at theme days too. We still have lots of fun together.** (Nataliya, Faith School, Member Checking Text)

Asim and Felicjan, who attended the special school, also had significant relationships with school staff. Asim got on particularly well with the male teachers and teaching assistants, liking playing sport with them and speaking about cars. He had a close relationship with one of his male Tas, with whom he would regularly do the safety-check on the school bus. Felicjan, who was Polish, felt most connected to Alicja a Polish midday supervisor. Being able to speak Polish in school was significant for Felicjan, particularly as his family were preparing to move back to Poland in the coming months.

Felicjan: Alicja is my friend. When I leave school, I would like her number as I would like to keep in touch with her. I need to ask her if this is okay. Alicja is very important, because I can speak Polish to her in school. I like talking to her because it makes the time go really quick. (Felicjan, Special School, Member Checking Text)

6.2.4 Importance of family

The importance of family was a common theme within the lives of the young people. One of the most important things about their families was the ways in which they were supported by them. Ruby spoke about the connection with her family in a functional sense, reporting the ways in which her family supported her in her day-to-day life. She focussed particularly on the help she received from her younger sister, for example, communicating with members of her family who did not speak English or helping her with schoolwork.

Ruby: Because they were speaking the Ghanaian language as well; I don't understand the Ghanaian language. My sister understands quite a bit, well

not that much. I had to keep asking my sister what are they saying? I don't understand. And she had to keep explaining it to me. And because sometimes when the WIFI's not working I always ask my sister to fix stuff for me.

Me: Yeah.

Ruby: And I think their parents [her cousins' parents] keeps saying "why do they keep asking her to do everything for them?" And we said that because we don't know how to do it, so we just ask someone that's like, good, to help us with things. Because my sister, she's good at maths, but I'm not that good at maths so she helps me. (Ruby, Faith School, Transcript week 3)

In contrast, all the young men, namely Destroyer, Felicjan, Asim and Nameless, spoke about the socio-emotional importance of family and how their parents or carers looked after them. It was particularly interesting to see the ways in which they reflected on the way in which their relationship with their families was integral to their well-being. Destroyer focussed on how his family made him feel amazing, because he knew, emotionally, they were there for him.

Me: You feel amazing?

Destroyer: Yes. I'm with my family. With my mum dad brother and sister. They all make you feel amazing.

Me: What do they do that makes you feel amazing?

Destroyer: Being there for me. (Destroyer, Mainstream School, Transcript week 2)

Felicjan and Asim focussed on the nurturing aspect of family and the way in which they did things with it.

Felicjan: Mum makes me feel good, happy, calm. I help mum do cooking **sometimes**. Tata [dad] makes me feel good; the same as mum. We watch TV together, football, and we do things together on the computer. (Felicjan, Member Checking Text)

In the case of Asim, he spoke about his aunt and uncle as the key parental relationships as they were his primary care givers.

Me: So, think about people or things in your life. Who is really special, or what is really special to you?

Asim: ...Aunty and Uncle

Me: Why?

Asim: Cares, sometimes helps me, or watches what I'm doing. Sometimes I go with Uncle to meet Aunty. Aunty had a baby and came to our house and stayed at our house. (Asim, Special School, Transcript week 2)

When speaking about his familial relationships, Nameless focused on a connection based on seeing each other in the same way. He spoke a lot about the way in which his parents understood and shared the same experience of being autistic. He described his parents as both being autistic and disabled, whilst his mother also had diabetes. The support from his family meant that he was able to open up at home and express his feelings.

Nameless: Having parents with autism is definitely helpful. If I had to live with someone else who was NT [neuro-typical], I'd probably just, stay up in my bedroom or something, instead of trying to talk it through. I wouldn't be angry at them, but it just wouldn't be as easy. (Nameless, Mainstream School, Member Checking Text)

6.3 Tensions of belonging expressed through anger and frustration with peers: *"If there was no punishment, a few people would be dead"* (Nameless)

All of the young people experienced highs and lows in their friendship groups. As I spent many months with them, I was party to the peaks and troughs of their relationships with other people. This was particularly highlighted through undertaking the member checking process by which point some of the young people's friendships had ended. This was especially the case for Ruby and Destroyer, who attended different mainstream schools. Ruby had had romantic feelings for a young man, Duc, throughout year 8. She had struggled to understand why and was frustrated by the fact that, he didn't reciprocate or even want to

be friends. By the time we member checked together, the summer holidays had passed, and it seemed as though she had come to terms with his lack of interest by now explaining that she no longer liked him and that she wasn't romantically interested in anyone currently. In reflecting on her feelings for Duc, she also said that her teaching assistant had told her that she had "bad taste" in young men. It is interesting to note that she seemed to be influenced by this idea even though she did not seem fully to understand the meaning.

Ruby: I'm sad when people say that they're not my friends. Like Duc, Duc's the only person that says we're never going to be friends again. I just don't know why he said that. But I still want to be his friend. But he said that he doesn't want to be my friend anymore. I still like him though. I don't really have anyone else. I've got other friends, but I don't like them that much. **Well I don't really like Duc anymore; I don't like anyone anyway. I used to like Ahmed, but I don't like him anymore, I like him as a friend. And apparently, Miss Smith says I've got bad taste in boys - but I'm not sure what that means though.** (Ruby, Faith School, Member Checking Text)

Destroyer, who was in year 8 at the mainstream school, reported having typical frustrations with his friends. On the whole, he explained that his friends made him "happy", but he also reported that on occasion there could be tension.

Destroyer: Sometimes they can make me angry.

Me: What do they do to make you angry?

Destroyer: Oh, cos Mike and Ram were playing a joke by beating me up and Kobe was just laughing, which I did not get.

Me: And that made you angry?

Destroyer: No, it made me sad. (Destroyer, Mainstream School, Transcript week 2)

When we came to member check all his data, the relationship with his friendship group, and particularly two of the young men (who were twins), had completely disintegrated. As we went through the member checking text, Destroyer asked me to scribble out every time the twins' names appeared. Initially, when I asked him what had happened, he indicated he was

uncomfortable using hyperbole and telling me he wasn't able to tell me, because he'd have to kill me.

Destroyer: I'm not friends with them anymore. I can't say why because I'd have to kill you (Destroyer, Mainstream School, Member Checking Text)

Later during our session, he elaborated, without prompting, that the reason he wasn't friends with them was because of name calling, where they had called him "gay". This had made him very angry and he had decided that he no longer wanted to communicate with them.

Destroyer: Kobe and Mike said something I didn't like – that "I was gay". I got cross with them. I don't know why they said it. I don't think I'll ever talk to them again. They keep on saying it. I've told a teacher. I just want them to leave me alone. (Destroyer, Mainstream School, Member Checking Text)

Two of the young people, Nameless and Nataliya, who attended the mainstream and faith schools, respectively, had more significant challenges with peers than the other students. These were the only students to talk about "enemies" (Nataliya, Faith School, Member Checking Text) or people they "hated" (Nameless, Mainstream School, Member Checking Text). Nataliya spoke about instances in school where other students had come up to her in the playground or corridor and made fun of her in different ways - for example, telling her she had a "moustache" or saying "oh ho ho ho like a big bad monkey". During the research sessions Nataliya spoke three times about having a "number one enemy", Luke.

When thinking more generally about relationships with peers, Nataliya felt that in the special education unit (The Brambles) she had friends, whilst in class she did not. She felt that she had been underestimated by the other people in her class and this frustrated her. She went even further during the member checking stage, where she spoke about having no friends and everyone leaving her, resulting in a broken heart. This was most likely in relation to her favourite TA, who had left in the summer.

Nataliya: I have a few friends up here in The Brambles, but not many in my class. It makes me feel a bit absurd, because up here I've got my own friends. While in class...whilst in my class it's just compulsory and strict and weird. I sometimes feel that my class under appreciates me. It's still true, I don't have many friends in my class. I feel like I've been underrated by most of them. It's true everything is complicated in my life, with the class, with my

teachers, my class. I've got no friends, everyone leaves me, my heart is broken. (Nataliya, Faith School, Member Checking Text)

Similar to Nataliya, Nameless had experienced challenging relationships with his peers for the last few years. However, he was quite rational in his reflecting, being able to look back at his school career so far and isolate when the difficulties had started - in primary school in his case.

Nameless: I mean, yeah, I was fine socialising years 3, 4 - year 5 started to become a problem cos I was in a group of friends. Years 3, 4 - only minor arguments. 5 - massive arguments, fallings out stuff like that. Year 6, one of my friends just decided to play football and another one left. So then, I don't like football. I don't like sports in general. (Nameless, Mainstream School, Transcript week 1)

He explained that since arriving at secondary school some of the challenges had intensified - particularly with young men (in his year and above) who threw shoes at him or recorded him on their phones to show other people. Experiencing regular harassment at school had left Nameless feeling very angry - something he bottled up for fear of punishment:

Nameless: I get angry, but I don't know whether it's to do with the autism. I mean I'll get really angry, I've wanted to chop several people's heads off and would, if the opportunity had ever come. If I had no punishment, I would have, but the fact that there is a punishment - I don't bother. If there was no punishment, a few people would be dead. I mean, NT [neuro-typical] people: Will, Charlie, Harvey. I suppose it is a little irrational for me to say you have to go through it [autism] in order to understand, but there's other ways to do it I suppose. Like, actually mentally doing harm to get them to understand. Embed it into their brains. I've wanted to kick them in their area [groin] and then punch them in their head and watch them fall to the floor like a weakling and stuff. (Nameless, Mainstream School, Transcript week 5)

In further discussing the consequences he wanted for those that bullied him, Nameless, explicated at length on larger social structures and solutions. His rationale was that in his case the bullying occurred because others saw him as different. He concluded that whilst he wanted to belong to society, he thought neuro-typical people did not want him to. Hence, he explained that inclusion was something society was not yet ready for due to the failings of

the neuro-typical population. He felt that the best solution would be to live in a segregated society until the general population was better and kinder. To make society better, he thought the most effective way would be harsh punishment:

Nameless: Society should be separated, yeah - separated. But, if you can get those normal people good again so that they are not teasing all the autistic people, there's no reason as to why they should be separated. It's just for the first generation of years where they've got to sort these kids out that they need to be separated. But, if the plan was going to go long term, the next generation of years that would come through would need to have them all together, because then the parents are decent making the kid decent. They just need some stuff put into them....You've heard my ideas about, like, how autistic people should ~~just be dumped~~ **be put** in another school, **just put in another school if that's another way of saying it**. And the people without autism should be treated with discipline. Negativity thrown at them and then eventually their next generation - because the parents are good then they'll be good, and then it will be time for the autistic people to come back in again...The normal people, if they did something to an autistic person (which is classified as not very nice), they should get the living daylight punched out of them. Not being sarcastic there, maybe a tiny bit, not too much. It's in their blood to be bad. (Nameless, Mainstream School, Member Checking Text)

There were significant differences in the way the young people attending special and mainstream schools identified reasons for feeling angry or frustrated. Those who went to mainstream school predominantly reported frustration and anger in relation to negative social interactions. For the young people attending the special school, concerns and frustrations reported to me pertained to personal space. Felicjan, previously, had a student in his class who regularly threw objects (as part of her behaviour), which concerned him as he was worried that he would not be able to get out of the way quickly and so would get hurt. Similarly, Asim spoke about making sure he preserved his personal space, as some of the young people in his class were prone to grabbing/pinching:

Asim: Ahmed - sometimes I don't want him to stand close. Sometimes he grabs people and that's why I sit down near the other side; so he don't grab me. Sometimes I don't sit with him close, because I need the personal space. (Asim, Special School, Transcript week 8)

6.4 “Teachers’ got more responsibility”: Being or not being supported by school staff

There were stark differences in the ways in which the young people participating felt they were supported by teachers. At the special and mainstream faith schools, they were, on the whole, very positive about their interactions with the teachers and support staff, often describing them as friends. The young people gave many examples of how the teachers supported them with work or in offering them social interaction and forms of friendship, as well as helping them to keep safe. For example, Asim spoke about how the teaching staff supported him in taking on more responsibility, whilst also noting that staff shortages meant that he was not always able to do pursue these tasks.

Asim: Paul helps me be careful. Checking the bus on the Friday, checking them. Checking the wheels, so there’s no damage. Fill the sheet. Check it, check other side and wheels again. Checking there are no marks or no damage. **We don’t do it no more; we didn’t have the staff.** (Asim, Special School, Member Checking Text)

Moreover, the young people also saw the teachers as being in a position of responsibility and being able to solve problems and advocate for student safety. Nataliya specifically saw the teachers as having responsibility to resolve issues; she had faith that the teachers would believe her side of the story. At the mainstream school, both young men, Nameless and Destroyer, were a lot more circumspect about the teachers, noting those they considered good and bad. Each young man was able to name one member of staff in school, who they saw as having an important role in their educational lives. For Destroyer, it was the Emotional Literacy Support Assistant (ELSA), who had helped him “get better at school”. For Nameless, it was his English teacher, who had helped him improve his handwriting by changing the type of paper he wrote on.

Nameless: She just came up with the idea of doing squares. My English teacher...they help. Even if it's a bit slower and it hurts a bit more. It does make sure that when you're neat, you're neat. (Nameless, Mainstream School, Transcript week 8)

Despite identifying positives in the teaching, Destroyer and Nameless never referred to any

member of staff as a friend and this suggested that they saw a clear demarcation between peers who could be friends and adults who were only teachers. Nevertheless, Nameless was clear that he felt more acceptance from the staff than from the other students.

Me: Thinking about the overall sense of belonging, do you feel like you belong in this school?

Nameless: If you were asking the students and how they think of me, no. If you were asking the teachers and how they think of me, yes. (Nameless, Mainstream School, Transcript week 5)

Destroyer and Nameless were also critical about some of the teaching practices in the school. Both the young men mentioned one teacher, in particular, who was known for being very strict and who would often give out detentions.

Destroyer: I don't like science. Well I can, sometimes, depending on who the teacher is. I have two, one who's really strict and then the other who's really nice. I don't know why he is strict; I think it might be because of his past life which is why I do not want to ask. It's a bit weird, if I were to do this, "so what about your past life?". If we forget a pen we get a detention, which I do not like. You just sit there and do nothing for like an hour or half an hour. We all have to be quiet and he's really strict. If we say one thing out of line or—or just like speak, we get told off. When he's out we do talk. When he's in we're all quiet. (Destroyer, Mainstream School, Member Checking Text)

Nameless also felt that not all the teachers working in the learning support unit had a good understanding of the young people's experiences - he particularly identified the strategies the SENCo at his school used as being negative. Her teaching style, he believed, was not conducive for people on the spectrum, but he commented about being too "shy" to tell her.

Nameless: The [SENCo] is entirely negatively towards everyone pretty much. Nobody likes her I suppose, it's not really just me. She's full on negativity to everybody and that's just not good. She's negative to normal people, but just not negative enough to do severe punishments - that's not good. And she's negative to autistic people and that's just not good as well. She's ideally the worst teacher... She's told me off for handwriting once. And the thing is that she doesn't know - I suppose I'm just too shy to tell her - is

that it hurts every time I do good handwriting. (Nameless, Mainstream School, Member Checking Text)

6.5 Geographies of belonging: emotional and physical relationships to places and spaces

When exploring the geographies of belonging, i.e. spaces where the young people felt accepted and safe, there was a significant difference in the way in which Asim, who attended the special school and the young people, who attended the mainstream school spoke about their environments. Asim felt a strong attachment to the school as a whole as a place for him to belong and specifically, because of the people who were there.

Me: What makes your life really really really good?

Asim: School

Me: Why does school make your life really good?

Asim: Doing work, helping teachers or staff, sometimes people struggling writing or with desk work. (Asim, Special School, Transcript week 1)

This was in contrast to the young men at the mainstream school, who felt school was something to be “suffered” (Nameless). Destroyer had a general dislike of school; however, he also had an attachment to it as a place that he knew and that he went to. When the school became part of a federation and changed its name, he found this very difficult and would have preferred that the place he knew had not changed.

Me: I saw all the new signs when I was driving here today.

Destroyer: Do...do you like the new signs?

Me: Do you?

Destroyer: Nope.

Me: Why not?

Destroyer: Because I do not know why we just need to change everything.
(Nameless, Mainstream School, Transcript week 4)

Both young men attending mainstream school, as well as Nataliya who attended the mainstream faith school, had strong positive attachments to specific physical spaces within their schools. The young men had 'secret' places they would go with their friends during the school day - for Nameless this was an area near the bins by the back of the school (See Figure 29).

Figure 29

Nameless' Safe Space



Nameless: Behind the canteen, near the dumpsters. No one really goes there. Me and my, I should say on-and-off friends, Stefan, Archie, Calum. And my best friend, who I've been friends with since year R, Paul, also goes there...We go behind there and mess around. It is a safe place. Although if I'm on the verge of a really bad situation, then I'll go elsewhere. Sometimes, on rare occasions, someone like Charlie will go there and I really don't like Charley. But he'll be quickly out. Or on even rarer occasions he'll bring his group and when his group come, we get out of there. Paul absolutely hates Charlie. He's more likely to try and get out of there before he punches him. Stefan has mixed emotions. If they wanted to be friends with Charlie, they could have been by now. We're on-and-off friends, because sometimes they can be idiots. And they video me when I don't want them to do so.

Sometimes Charlie and his friend will come from through there and that way [pointing where they come from]. We're allowed to be here. Adults have seen us here before and they've not had any questions. (Nameless, Mainstream School, Member Checking Text)

At lunchtime, Destroyer and his friends went to a classroom where there were computers and he and his friends would play games on them:

Destroyer: [Standing in a computer room] We go here. Ramm goes on this one [indicating a computer], I go on this one [indicating the adjacent computer], me and Coby will play gun mania. We've done, I think, 6 or 5 levels. (Destroyer, Mainstream School, Transcript week 4)

When exploring places that were important to them, Ruby and Felicjan focussed more on those they didn't like. Ruby spoke about the playground being boring and how she wanted to change it.

There's not really much things to do in the playground anyway - just have to sit and talk. Some people play football, but I don't know, I do like football, but I just don't want to play. Not that much games, not that much equipment to play on. It would be better if there was hula-hoops and see-saws and places where you can do stuff like netball and that. There's not that many things there and I really want there to be a soft net. (Ruby, Faith School, Transcript week 7)

Felicjan spoke about his dislike of being at home - this was intimately bound up with his readiness to leave England and go back to Poland.

Felicjan: It's stressful in England, because in the house I live in I feel like a prisoner. There are no places to go. We are far from the Polish shops (at least 20 minutes). (Felicjan, Special School, Member Checking Text)

The young people attending mainstream and mainstream faith schools also had access to spaces in the schools where only people on the SEN roll were allowed. This was not something that existed in the special school. The mainstream school called the space an inclusion unit, whilst the mainstream faith school called it a nurture space. In the mainstream school, the inclusion unit, The Purple Room, was on the ground floor of a classroom block.

The SENCO was based next to it and it was also attached to a room that was used for internal exclusions. In the mainstream faith school, the nurture space, The Brambles, was located in the playground and had previously been the old caretaker's house. It consisted of a group of rooms on one floor and included a kitchen and activity room as well as smaller rooms, some of which were also used by therapists.

Nataliya and Ruby used The Brambles a lot during their school day and spoke very positively about the space, referencing it at during every meeting we had together. Nataliya spent almost all of her free time in school in The Brambles. She usually sat on a beanbag next to the radio, which she flicked between her favourite stations.

Nataliya: I like The Brambles a lot, really. Because I can sit here, read my book, listen to the radio. The people that come to the Brambles, well, some would have autism, social problems. Autism, it's something to do with us when we're going crazy. I don't know. **Yes, I still do love The Brambles.**
(Nataliya, Faith School, Member Checking Text)

Ruby also went to The Brambles at break times and lunchtimes, rationalising visiting the nurture space, because she did not like sitting in the playground as it was "a bit boring" (Transcript week 7). Ruby told me that she thought The Brambles was "great", especially as they provided free toast at break times. Ruby struggled to explain why people went to The Brambles, saying that perhaps it was because people did not have friends. However, she was clear in articulating the reason that she attended was due to finding the playground "boring".

Ruby: I don't know why people come to The Brambles. Maybe they don't-- Maybe they don't have any friends. I don't know. Hmm, just thought I'd come in because I didn't really like sitting in the playground that much. It's a bit boring in the playground. I don't really get to do that much. (Ruby, Faith School, Member Checking Text).

It was also interesting to note that Ruby also spoke about Nataliya when discussing The Brambles. Despite Nataliya explaining that she "loved" The Brambles, Ruby suggested that Nataliya was not well liked in the main part of the school nor The Brambles, singling her out as different even within the nurture space:

"Lots of people in the school are being mean to Nataliya as well and they're saying that nobody likes Nataliya because she's so mean and she shouts.

No, no one in the school likes Nataliya anyway, I don't know why. I kind of like her. It's just that she shouts too much. No one in, no one in The Brambles likes her either. It's just that she kind of shouts a lot and that" (Ruby, Faith School, Member Checking Text)

In the mainstream school, Destroyer and Nameless had different perception of The Purple room. Destroyer saw it as a space he went to when he did not go to lessons. For example, he did not have to study German as a second language and instead, went to The Purple Room. He explained that people went there when they needed "help" with their "learning" or "sometimes people go there to calm down, sometimes just to talk or sometimes just to have fun". The Purple room had a computer station the young people were allowed to use (Member Checking Text). He explained that he "kind of like[s] it", because "it means I'm away from, like, most lessons that I don't like", but he said, "I don't want to go there at break time or lunch time" and instead he went with his friends to "a secret room" (Member Checking Text).

Whilst Destroyer identified The Purple Room as a "safe space" (Member Checking Text), Nameless was more critical of the space, saying that whilst it was "a safe place" it was also "sometimes annoying" (Member Checking Text). Despite Nameless saying The Purple room was for people who were "bullied", he also felt the space could be manipulated with people who told "lies to gain access into the room", specifically rationalising this in the case of one individual, who he didn't want to attend The Purple room.

6.6 Understanding belonging through the construction of nationality

Only one young person in my study occupied solely a white British heritage - Destroyer. Four of the young people were British, but had a heritage that was linked to another country: Asim had Pakistani heritage, Nataliya was British-Bangladeshi, Ruby's parents were born in Ghana and Nameless' father was Canadian. Felicjan was Polish and had emigrated to England ten years prior to the research commencing. All of the young people, apart from Destroyer, reflected on some aspect of nationhood when they spoke about their lives. They particularly referenced nationhood and ideas of cultural sameness when talking about their experiences visiting the countries where their grandparents or extended families lived.

6.6.1 Exploring nationhood and cultural sameness

Language was a significant cultural identifier for Ruby and Nataliya. For Ruby, only speaking

English seemed to give her a strong primary identity of being British/English (despite English also being the official state language of Ghana). An inability to speak any of the Ghanaian indigenous languages and needing to rely on her sister as a translator, gave her a sense of being distanced from also occupying a strong Ghanaian identity.

Me: So, your mum and dad were born in Ghana and you were born here.

Ruby: Yeah, me and my brothers and my sisters were born in this country.

Me: Do you feel really British or do you feel a bit Ghanaian and a bit English?

Ruby: I feel more British, because I can't speak any other languages. The only language I can speak is English. Because I want to try and speak something different, but I just find it so hard to say stuff. Because when I went to Germany, I had cousins that were German and I did not even understand what they were saying. (Ruby, Faith School, Transcript week 3)

Nataliya also highlighted language as something that made it difficult for her to spend time in Bangladesh. However, having spent the first four years of her life there she was not sure whether she felt more British or more Bangladeshi. During the research, she and her family went on holiday to Bangladesh and Dubai. Before she left for the summer break, Nataliya was more interested in Dubai as English is widely spoken and hence, language was not going to be a barrier for her.

Nataliya: My family and I are going to Dubai and Bangladesh for the summer. Well, we're visiting some of my parent's family. So, yeah, visiting family and friends. My parents, they're from Bangladesh. I've been living here since I was four years old. So, now nine years have past and I've been in the UK more time than in Bangladesh. I don't know which one is home. It's going to be really difficult for me, because I don't speak much Bengali. I'm more interested in Dubai, because everyone in Dubai speaks English out there. Everyone in Bangladesh, they speak Bengali. (Nataliya, Faith School, Member Checking Text)

In the member checking text, completed after Nataliya returned, she reflected on her time on holiday and had decided that she was not very keen on Bangladesh, again highlighting language as a distancing factor.

Nataliya: Well we did have the summer holidays, but I had a mixed review about them. You see I liked Dubai, because it was a cool place to go, but I really didn't like Bangladesh, because it wasn't really posh and I wasn't able to speak Bengali. (Nataliya, Faith School, Member Checking Text)

Weather was something that came up most prominently in the discussions with the young people about their feelings when comparing England and the country where their family had emigrated from. Asim talked about being happy to come home to England, because of the weather being particularly hot in Pakistan.

Me: Did you enjoy Pakistan?

Asim: Yes

Me: Did you eat lots of food?

Asim: Yes

Me: Was it good?

Asim: Yes

Me: Is it better than what you eat here?

Asim: It's really hot in Pakistan.

Me: The food or the weather?

Asim: The weather

Me: The weather - did you like it?

Asim: I liked it a little bit, not too much.

Me: Would you like to live in Pakistan or do you like living in England?

Asim: England.

Me: England - why England?

Asim: It's better in England. It's cooler. It's really hot in Pakistan. (Asim, Special School, Transcript week 8)

For Ruby, Nataliya and Asim, the 'inbetweenness' and duality of their nationality compared with their heritage was maintained by the regular travel to the countries where their extended family still lived. However, for Felicjan (who was born in Poland) there was no 'inbetweenness', despite having lived in England for over a decade. He and his family had been particularly affected by the European Union (EU) referendum in 2016. The lead up to the referendum and resultant decision to leave the EU sparked a lot of racial hatred in his local area and the Polish centre was defaced. Felicjan's family decided that they would return to Poland during the Easter holidays in the academic year we worked together. I only met him after this decision had been made. He was very patriotic, and he was strongly focussed on the positives of Poland and distanced himself from England.

Felicjan: Poland is really important to me. It is the most important thing. I like everything Polish. I am Polish and I am used to things that are Polish... I want to go back home, because I feel bored here and my family is in Poland and I miss them. I have had enough of England. (Felicjan, Special School, Member Checking Text)

6.6.2 Culture

Felicjan explained that he and his family had struggled to integrate fully into life in England and felt socially isolated. He had concerns that all English people drank a lot, and this was something he did not want to associate with.

Felicjan: I was eight when we left Poland. Sometimes I feel bored here. I have school friends, but no life in England, only friends drink beer in England and vodka a lot and I don't want that. (Felicjan, Special School, Member Checking Text)

Politics was something that frequently came up in the narratives of two young people, Felicjan - attending special school and Nameless - attending mainstream school. However,

their political concerns were different. Felicjan, living in an area particularly badly affected by Brexit and racial tensions, was very concerned with immigration. Whilst we were undertaking the research there was a terrorist attack in London on June 3rd, 2017, an event that had particularly affected Felicjan. He was concerned that immigration was directly linked to terrorism and the world would be safer, if people stayed in their “own country”. His political feelings left him feeling worried, anxious and isolated, which reinforced his idea that he would be safer in Poland, where he would fit in better to society.

Felicjan: I don't think terrorist attacks will happen in Poland, because there is no immigration from the Asian countries and immigration in Poland from those areas is unlikely as Polish politicians do not want to invite them. They are not welcome in our country. I think the world would be safer, if everyone stayed in their own country. I've been here for ten years and now I am finally going back home. Politics in Poland is like a cabaret. I think Politics in Poland are good at the moment. I like the ruling party. (Felicjan, Special School, Member Checking Text)

Nameless was very politically engaged. He was also critical of the British Government; however, this was due to him seeing the Conservatives as being unfair; promoting the rich and cutting disability benefits. Through this narrative he positioned himself and his family as being excluded and disadvantaged by the British government. Disabled people's rights were something that was very important for him as he came from a disabled family. He positioned himself as 'pro-Labour' and a fan of “Jeremy Corbyn”, believing that Labour would do the right thing and would stand-up for disabled people. He saw there being a large split in the country with rich people voting Conservative. Nameless thought a solution to the budget crisis was simple - tax the rich more and redistribute wealth, thus creating a more fiscally equal society.

Nameless: Get rid of May, new government - Labour. Labour needs to get in. I like Corbyn - yes, as much as a lot of people don't - Corbyn, he'll do the right thing because he has before I think. And besides, Labour's just a better government anyway. All rich people, they'll vote for the Conservatives. All poor people vote, they'll vote for Labour. That's how it goes pretty much. Cos, Conservatives, I read a thing this morning about how they're going to refuse to say that they're not doing any cuts on disabilities. It's a problem, because all my family is pretty much disabled and Labour seem to have the right idea about it. Disability is not being able to work. Having a disability

meaning just not being able to do a lot. I mean you don't have to be in a wheelchair or anything like that. And if they are in a wheelchair, then definitely yes, but they don't *have* to be. If they're in a job and they've actually got a viable way of showing that they can't be in the job, then I classify them as disabled. Society doesn't look after people with disabilities. No, because of May and Cameron. To look after people with disabilities, you don't cut the tax. They're [disabled people are] having to go through really bad stuff. More stress than any normal person would have to go through. Cameron and May they are definitely not helping that. I mean there are really rich people out there, making massive profits, just taking more money from them. They don't need to be so rich, just everyone should be having equal - maybe you might say the same amount of money, or something like that. That's my view. (Nameless, Mainstream School, Member Checking Text)

Along with political engagement as interaction with cultural discourses, religion was also something that some of the young people spoke about. Asim and his family were Muslim, however, sometimes he struggled to explain aspects of Islam, for example, he knew that fasting was connected to Islam, but he was unsure why. Ruby and her family were Christians and regularly went to Church. Similarly, to Asmin, Ruby struggled to articulate fully an understanding of the meaning of different aspects of religion, although she seemed to have a much stronger connection with God than him. Both experienced religion as part of their everyday lives and this contributed to being able to interact with cultural discourses.

Ruby: Go to church, watching people speak, pray, reading bibles.

Sometimes we have this special thing. Sometimes our parents get bread and wine, because I think it's because something to do with some special thing, but I don't know what it's about.

Me: Do you believe in God?

Ruby: Yeah. I believe in ghosts as well. My sister says that, if you don't believe, you don't believe in ghosts, then it means that you don't believe in the holy spirit. She says that, if you believe in ghosts, it means that you believe in the holy spirit.

Me: Is it important to believe in the holy spirit?

Ruby: Yeah

Me: Do you know why?

Ruby: No. I think it's because of the angels, that's why. But I think that the holy spirit might be the angels or god, I don't know, or Jesus.

Me: What does God do?

Ruby: He follows everyone everywhere, but no one can see him, because he's invisible. He's like so invisible that you can't even know that he's following you. He's just like a ghost, you know, that can teleport and know where you are. But there aren't real ghosts in this country anyway. (Ruby, Faith School, Transcript week 4)

6.7 Key issues

In this section, I discuss the findings in relation to literature and specifically focus on the way in which the young people demonstrated a “desire for some sort of attachment with people and spaces” (Nind, 2012, p.653). As articulated in the literature review (see Chapter 2), belonging is intimately connected with friendship. There is an emerging field of literature focussing specifically on the friendships and peer-relationships of young people identified as being on the Autistic Spectrum (AS). However, research into the friendships of young people specifically identified as having learning difficulties is limited, as pointed out by Potter in 2014 and continues to be so. Hence, whilst I draw parallels and links with the literature, I do so cautiously, given that only half of my participants self-identified as autistic, although it should be noted that only two (Nameless and Nataliya) actually had this diagnosis documented in their EHC plan. Furthermore, added caution should be taken in drawing links with the literature owing to what Petrina et al. (2014) description of the field as “highly unrepresentative of children with autism spectrum disorder as a whole” (p.121) due to a lack of focus on young people identified as being both on the AS and having an identification of a learning difficulty. Latterly in this section, I also focus on the cultural belonging of the young people and the ways in which it intersects with mainstream educational research explicating the experience of young people with immigrant backgrounds learning in English schools.

6.7.1 Friendships and Social Isolation

Friendships are critical to the emotional well-being of children (Dunn, 2004); however, extant research suggests that young people identified as being on the autism spectrum have fewer friends (Bauminger et al., 2008). Kuo et al. (2013), looking across several studies, contend that despite having fewer friends than their neuro-typical counterparts, most young people identified as being on the AS have at least one friend. My research supports this assertion, with all of the young people speaking of at least one strong relationship with someone in their school setting. However, for Nataliya and Felicjan, who attended the mainstream faith school and special school respectively, their strong relationships were predominantly with school staff and they rarely spoke affectionately about a peer. Nevertheless, despite the student-adult relationship these experiences can be conceptualised as serving as a friendship on the basis of Bauminger et al.'s (2008) analysis, describing friendship as: "stable, frequent, and interconnected affective interactions that are manifested by certain classes of behavioural markers (e.g. sharing, play and conversational skills) that facilitate the functions of companionship, intimacy and closeness" (p.136). Within their friendships, the young people experienced highs and lows and I was able to witness the changing shapes of friendships due to the extended period of time spent in the field with them.

Research on the friendships of young people identified as being on the AS suggests that maintaining and making friendships can be challenging due to the need for developed social skills (Bauminger & Kasari, 2000; Chamberlain et al., 2007; Fuentes et al., 2012). Specifically, the literature highlights the perceived 'social impairment' of those identified as being on the AS as a barrier to the empathy needed to maintain relationships (Baron-Cohen, 1995; McDonald & Messinger, 2012). Asim, Nameless, Destroyer, Ruby and Nataliya, who attended special, mainstream and mainstream faith schools, respectively, were aware of the importance of having and maintaining peer friendships. Conversely, Felicjan (who attended a special school) only spoke of one close friend who had passed away and he did not show any interest in making new connections with peers, perhaps because he was shortly due to return to Poland. His sense of social isolation reflects the research of Skar (2003) in Sweden regarding students with restricted mobility.

For the young people who spoke about friendship within my research (Asim, Nameless, Destroyer, Ruby and Nataliya), friendship was a central theme for four of the young people, Nameless, Destroyer, Ruby and Nataliya and specifically, those young people attended the mainstream and mainstream faith schools. For example, when talking about what was important to her at school, Ruby said "I think about friends when I'm in school. That's what,

that's the only thing I think about, just friends" (Member Checked Text).

Nameless, who had been identified as being on the AS, had always attended mainstream school and he had been friends with a young man since reception class. He was keen for the friendship to last, despite the young man having made friends with a group of people Nameless did not like. His acknowledgement of the importance of having friends and his significant efforts to maintain his own social network resonates with the world of Hodges et al. (1999), who suggest that friendships have the potential to improve young people's experiences of school by reducing isolation and the chance of being bullied. Similarly, Nameless' conscious mediation of his friendship group links to Baines' (2012) finding that, rather than being isolated from the sociocultural process of identity developments, students with autism make a deliberate effort to promote a positive perception to others (Baines, 2012). Specifically, in relation to this, Nameless attempted to "contain" his autistic behaviours so as to be considered "normal enough" by his peers.

Conversely, Nataliya, who was also identified as being on the AS, spoke of a lack of friends in her class and instead, spoke of strong relationships with her teaching assistants. She found her lack of friendships in her class upsetting and this would appear to be in line with the work of Segal et al. (2002) and Skar (2003), who suggest that disabled children face challenges in making friends with young people of the same age due to the attitudes of their peers. This was reinforced by Ruby's summation that her peers were "saying that nobody likes Nataliya, because she's so mean and she shouts. No one in the school likes Nataliya" (Member Checking Text). Ruby's description of Nataliya shouting was reinforced by Jane, the assistant SENCo, who described Nataliya as "very aggressive" and "quite frightening"; however, in contrast, Jane presented Nataliya's peers as being very tolerant of this behaviour.

It is particularly interesting to note that Webster and Carter (2013) highlight how research on friendship with children identified as having disabilities often makes the assumption that the "nomination of a 'friend'" during the investigation "reflects an actual friendship" (p.374). For Destroyer participating in my research, the ELSA and SENCo working with him reaffirmed the friendship group he spoke of. Specifically, the SENCo described Destroyer's friendship group as being "real friends", where their friendship was more than "just talking across the table". Similarly, Potter (2014), who undertook research with a young man aged 10 (Ben), identified as being on the AS as well as having a learning disability, notes that there was "significant overlap" in the nominations made by Ben and the names given by the adults who worked with him (p.212). However, for Ruby, the assistant SENCo who worked closely with

her, described her as “playing another character” and that “she’ll make up her story, and particularly in reference to boys”. This implies that some of the friendships she spoke of during our research may not been recognised as active friendships by the staff.

Potter (2014) also notes in her research with an individual identified as being on the AS as well as having a learning disability, that the young man was able to reflect “in relatively nuanced ways about a complex social concept” in terms of being able to look at his friendships over a period of time (p.212). This was also something that Ruby, Destroyer and Nameless were also able to demonstrate in the context of this research. Destroyer, in the process of member checking, reflected on the transient nature of his friendships by talking about the break-up of his friendship group due to two of them taunting him that he “was gay” (Destroyer, Mainstream School, Member Checking Text). Lastly, Ruby reflecting on the change from the previous school year to the current one, said it “makes me kind of happy, because for the first time they [her peers] actually know my name” (Member Checking Text), thus showing that she felt her social status had improved over time. Additionally, Ruby demonstrated her ability to think about the complexity of friendships and her emotions. She noted during the member checking stage, how her “disabled” friend Jemima had left the school (to go to a special school) and now that she did not sit with her at lunch, her peers had begun to speak to her in the canteen and she felt “happy” despite also “miss[ing] Jemima” (Ruby, Faith School, Member Checking Text).

Nameless was particularly reflective in the way he charted his social relationships from primary school to the present, noting that he was “fine socialising” during Years 3 and 4, but from Year 5 onwards he had started experiencing problems. This was because he was “in a group of friends” and there were “massive arguments, fallings out” (Nameless, Mainstream School, Transcript week 1). Nameless’ ability to explore and track the complexity of his friendships is in contrast to the findings of Carrington et al. (2003), who, when exploring the friendships of teenagers with Asperger’s syndrome, found a lack of “in-depth discussion” of friendships (p.213).

Asim spoke about friendships comparatively more generally, and less frequently, than Nameless, Destroyer, Nataliya and Ruby. When he spoke about friends, he talked about all the people in his class and his next-door class as friends. However, when he specifically talked about playing with friends, he was able to name just one person in his own class, Ahmed, who he had a transactional friendship with, playing snakes and ladders together. Cillessen and Bukowski (2018), highlight that an important aspect of young people’s social experiences, or friendships, at school, is their status, which is linked to how members of the

peer group feel about the individual. This brings to mind Asim's conversation about his plan to arrive at his school's prom in a limousine and all his friends would be able to come inside and enjoy the experience. In Asim's description, there was a sense of pride based on being able to impress and be seen as significant, due to arriving in a limo. Similarly, Nameless also had concerns about status; however, he was more direct in his discussion, explaining how he had decided not to be friends with another autistic student due to the fact that it would most likely make him less popular than he already was.

Three out of four of the participants who attended mainstream/mainstream faith school (Nataliya, Nameless and Destroyer) all had significant challenges with some of their peers, which negatively impacted on their experience of belonging in school. Research on inclusive schools suggests that learners identified as having learning difficulties are less accepted than other peers and have fewer friends (Avramidis et al., 2018; Tip-ton et al., 2013). This understanding was echoed by the mainstream/mainstream faith school staff, who spoke of the young people as having essential differences and experiencing social isolation. Schoop-Kasteler and Muller (2019) suggest that, for students learning in special education classrooms, the types of those learning together can greatly affect the students' abilities to make friends and hence, fewer cliques are likely to be present. They further hold that in these cases, students may access the whole school's peer group context to find similar peers to connect with. Based on my own research, I contend that the heterogeneity of both mainstream 'inclusive' classrooms as well as special educational classrooms combined with experiences of stigma, means that young people identified as having special educational needs may turn to their assistants or support staff to fill the gap of lacking peer friendship or acceptance. The importance of support staff and the challenge of peers can be seen to be encapsulated by Nameless, who, when asked directly about belonging responded that from the teachers' perspective, yes, but from the students' perspective, no. For both the young people attending the special school and Natalia attending the mainstream school, support staff were key to their positive experiences of schooling.

6.7.2 A sense of cultural belonging

The young people who participated in this study had diverse backgrounds. Four of the young people, Ruby, Nataliya, Asim and Nameless, had either one or both parents who were not born in England or the UK, and three of them were BAME. Felicjan was the only first generation immigrant who participated in the research and he felt he did not fit into English society. This seemed to be compounded by the fact that, after a decade in England, following the EU referendum, his family had decided to move back to Poland. It is interesting

to look at his experience in connection with the literature, which suggests that in the case of Eastern Europeans migrating to Britain, there is a trend of “downgrading”, whereby those migrating tend to be over-educated for the level of work they undertake (Tereshchennko & Archer, 2014, p. 3). Compensating for this, whilst also shaping a new identity as a migrant, may lead some people to emphasise their self-worth in comparison to their host (in this case British) counterparts (D’Angelo & Ryan, 2011). It is also possible that Felicjan’s parents experienced the notion of ‘downgrading’ and he himself, “multiple” levels of oppression or “double disadvantage”, through his intersecting identities of being identified as both disabled and an immigrant (Baxter et al., 1990, p. 2; Oliver & Singal, 2017). It may have been the case that Felicjan was compensating for this to some extent through his contempt for English people, explaining that he did not feel at home in England. Notably, he stated how English people got drunk consuming a lot of beer and vodka, which was something he did not want to be associated with as well as reiterating his “outsider status” on his own terms (Lopez Rodriguez, 2010, p. 340).

Schools have been argued as being places where children from migrant families “first encounter in-depth contact with the host culture” (Adams & Kirova, 2006, p.2). Through this encounter, migrant children may go through a process of “cultural frame switching”, enabling understanding and engaging with the new norms of the culture they are being educated in (Adams & Kirova, 2006, p. 4). For Asim, Ruby and Nataliya, who were all second generation immigrants from Pakistan, Ghana and Bangladesh, respectively, this seems to have been the case. For these young people, the fact that they were native English speakers was a key element in their acculturation and “cultural frame switching” (Adams & Kirova, 2006, p.2). Both Ruby and Nataliya commented on how having to rely on other people to translate distanced them from their heritage. Nataliya spoke about how her summer trip to Bangladesh was “going to be really difficult for me because I don’t speak much Bengali” and how she was much more interested in her stop-over in Dubai, because people spoke English there. During her member checking process Nataliya commented how she had not enjoyed her visit to Bangladesh, saying, “I really didn’t like Bangladesh, because it wasn’t really posh and I wasn’t able to speak Bangladesh”. Whilst some research has suggested that having heritages other than British can leave some children feeling “in between two worlds” (D’Angelo & Ryan, 2011, p. 253), this did not seem to be the case for any of the participants. For Felicjan, he was clear that he was Polish and living in England was only temporary and something to be suffered until he left. For Nataliya, Ruby and Asim, there seemed to be a sense that they lived in England and spoke English and so belonged here with the connections to their heritage only being through travel to see family.

Extant research on ethnicity and SEN/D suggests that people from Black and Minority Ethnic (BAME) groups face barriers in accessing the services and provision they need in England (Hubert, 2006). Furthermore, it has been argued that institutionalised racism in England creates tensions between service providers and families from minority ethnic groups (Rizvi, 2015). However, the young people who were BAME, namely Asim, Ruby and Nataliya, did not speak about their racial experiences nor “multiple” levels of oppression or “double disadvantage” (Baxter et al., 1990, p. 2; Rizvi, 2015; Singal & Oliver, 2015). Nataliya only once mentioned racism as an explanation for bullying behaviour, but then seemed to correct herself, saying that this was not the case. It is possible that my being white prevented the young people from describing racist encounters. However, it is also possible that in the case of Nataliya and Ruby, who attended an inner-city school where more than half of the young people were BAME, racialised experiences did not play out much in their school experiences.

6.8 Conclusion

All of the young people spoke of a person, whether adult or peer, they considered to be a friend within their school setting. All them, with the exception of Felicjan, who was about to return to Poland, showed awareness of the importance of maintaining their friendships and were able to show the ways in which they did this. Three out of four who attended a type of mainstream school experienced challenges with their peers in a way that was not described by those who attended special school. Notably, Nataliya and Nameless, who had the most difficulty with their peers also had an identification of being on the AS. These findings are reflective of the extant literature undertaken on friendships with young people identified as having SEN/D and specifically the work of Potter (2014) undertaken in England, which demonstrated how a young man aged ten identified as having learning difficulties was able to reflect on his friendships in some detail.

The participants in my study were diverse in terms of ethnicity, with four of the young people being either first or second generation, immigrants. In contrast to the literature suggesting that these young people may feel conflicted (D’Angelo & Ryan, 2011), they did not seem to articulate this. Rather, for Nataliya, Asim and Ruby, not being able to speak the language of their parent’s countries meant that they did not seem to experience the same ‘inbetweenness’ articulated within the mainstream literature. The three young people of colour within the study did not talk about racialised experiences, possibly due to myself as a white woman conducting the research and so it remains unclear as to whether the young people experienced oppression based on the intersectionality of race and their identified

disability, as highlighted in the literature (Baxter et al., 1990; Rizvi, 2015; Singal & Oliver, 2015).

Chapter 7. Discourses in schools: other voices constructing other selves and belonging

7.1 Introduction

In seeking to contextualise the young people's descriptions of themselves and their school experience, I spent time talking to adults, who they identified as being "important" to them during the school day (see Chapter Four for further discussion of the schools). They selected a range of adults, including: Special Educational Needs Co-ordinators, classroom teachers, teaching assistants and midday-supervisors (see Figure 30). At the mainstream school only one of the two young people, Destroyer, was able to identify an important adult, his Emotional Literacy Support Assistant (ELSA). Nameless could not point out any adults in school with whom he felt a strong enough connection. In his case, I used contextualising data obtained from the SENCo at his school. It is important to underline here, that the student did not select the SENCo, however he explained that he did not mind me asking her questions about him.

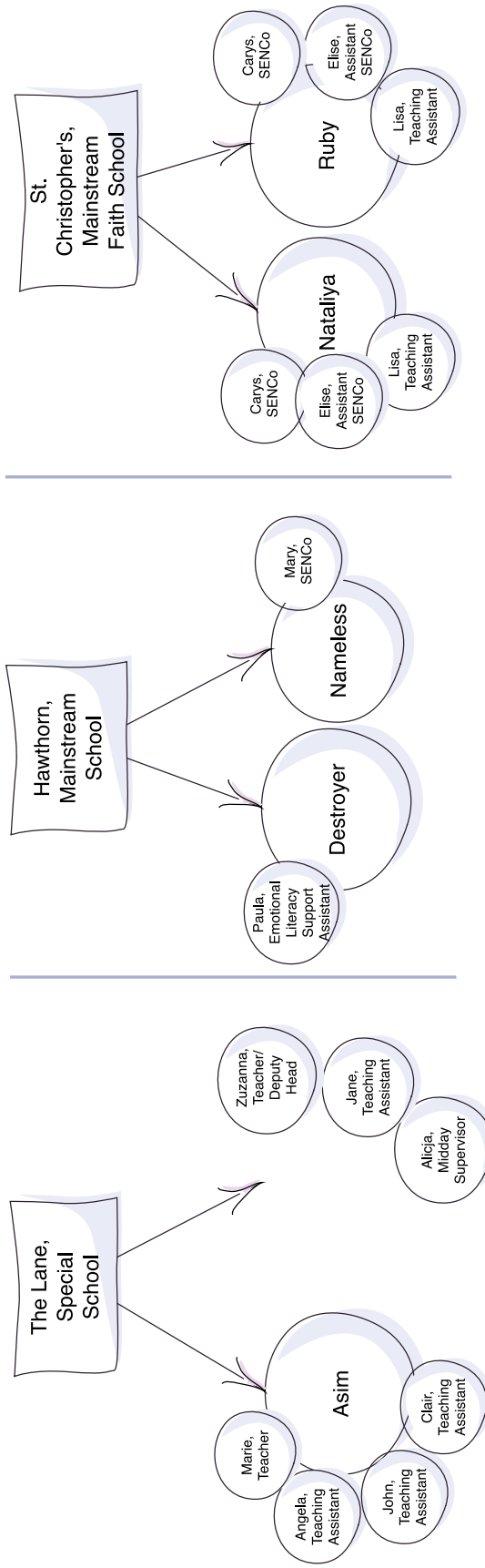
I have organised this final findings chapter into three sections. I begin by presenting themes occurring across the staff's narratives, including their discourse on inclusion, critical engagement with SEN labels and reflections on the social inclusion and exclusion of the young people. Next, I present staff data on the individual young people. I highlight the themes occurring in the way the staff described them and reflect on how this is analogous or opposed to the ways in which the young people saw themselves. The third section highlights key findings with the literature, primarily comparing and contrasting the teachers' language with individualistic notions of disability and problematising the notion of vulnerability.

7.2 We belong together: views of sameness and difference

In this section, I present themes occurring across the staff interviews. The first subsection situates the schools within their inclusive discourse and reflect discourses of acceptance, belonging and sameness, as well presenting staff's views on the usefulness of SEN labels in the school settings. In the next subsection, I focus on the ways in which the staff spoke about their perceptions that some of the young people were different or socially isolated.

Figure 30

Adult participant overview



7.2.1 Common themes across the three schools: articulating inclusion and challenging labels

Despite the significant differences in the school settings, all had similar discourses on inclusion in the broad sense of including everyone and seeking to adapt school life to meet the individual students' need. The faith school and the special school had very similar discourses surrounding difference, these schools being relatively small, with populations of c.500 and c.200, respectively. In both schools, staff used intimate language when speaking about including all students, using phrases such as “embracing difference” (Assistant SENCo, Faith School, transcript) and “love everybody” (Deputy Head, Special School, transcript). The mainstream school had a very large school population of c.3,000 students. When the SENCo spoke about inclusion, she focussed on the pragmatic approaches they had taken to ensure that the school was “as inclusive as possible” for students identified as having SEN/D, those from BAME backgrounds and children from other nationalities (SENCo, Mainstream School, transcript). The school had a particularly robust pastoral system, with a designated worker who worked with families as well as with the students in school.

The teachers demonstrated acceptance and belonging of the young people, apart from Nameless, through the relationships they had with people within school. The overwhelming association that was highlighted were attachments between the young people and staff, rather than the young people and their peers. For example, Felicjan was described as having a special relationship with his midday-supervisor, who was also Polish, and they were able to communicate in their mother tongue during the school day. Whilst these relationships were described in a positive way, for Felicjan, Ruby and Asim, the SENCo of the faith school was concerned that the relationship between Nataliya and one of her teaching assistants was “inappropriate” and had the potential of Nataliya trying to cross boundaries. Only two young people, Ruby and Destroyer, were described as having “real friends”, who they had relationships with beyond “just talking across the table” (Assistant SENCo, Faith School, transcript).

Discourses of sameness were present within staff interviews in the special school and the faith school. Here, the teachers made frequent references to the ways in which Nataliya, Ruby, Felicjan and Asim were the same as typically developing young people. Specifically, Ruby's sexual development was referenced as being in line with other young people of her age. Nataliya and Ruby's love of the media was also likened to other young people, whilst

with Felicjan and Asim, it was their sense of humour, crushes on women and stubbornness that made them “typical teenagers” (Deputy Head, Special School, transcript).

At the management level, there was critical engagement with the use of special educational labels and how this affected the positioning of the young people. All of the senior management that I spoke to, whilst acknowledging the use of labels for funding and services, challenged the usefulness of these diagnostic labels in an educational context. The SENCo in the mainstream school felt that they had the potential to “stop the children achieving” by reducing the aspirations of teachers and parents (SENCo, Mainstream School, transcript). Furthermore, she was concerned that parents and their children could hold on to labels and use them as an excuse for poor behaviour or difficulties in school. The SENCo of the faith school was concerned about their usage in a school context, as she felt there was a “lack of real understanding about things, and what it what it actually means to be autistic; what does it actually mean to have Down’s syndrome?” (SENCo, faith school, transcript). Whilst the SENCo of the mainstream school felt that labels had the potential to limit children’s achievement, that of the faith school felt that teachers might not understand and take into account impairment and hence, they might expect too much of the students. The deputy head of the special school, was perhaps the most critical of the labels. Her concern centred around the idea that diagnostic labels, such as autism, homogenise people together and erases the individual person: “Fred likes to set off the fire alarm to cause havoc, so I don’t let him near the fire alarm. That’s more to do with Fred, not to do with the fact he’s got autism” (Deputy Head, Special School, transcript). She felt that within an educational context it was better to get to know the individual person, as “with any disability they have very individual personality traits, so you are better off going with those” (Deputy Head, Special School, transcript).

7.2.2 To not belong through highlighting difference and social isolation

Difference was most prominently highlighted in the mainstream and mainstream faith schools, where teachers drew comparisons between the ability of the young people who had been identified with SEN/D and the others in school. In the mainstream school, the Emotional Literacy Support Assistant (ELSA), who worked with Destroyer, highlighted the fact that he saw himself as different to his peers in mainstream school and this was a source of anger for him. She felt that his placement in mainstream was not necessarily beneficial for him and he would be better provided for in a special school setting, where he would be on the “same” path as others (ELSA, Mainstream School, transcript).

“He's understanding that he's not the same as others around him and I think that's quite sad to see somebody who suddenly realises that he's a bit different. He gets angry about the fact that he can't do something and why can't he do it. He can't achieve like the others and I think, if he's put somewhere else, if he has another placement, I think that will allow him to be Destroyer. I think he will move and I think he will excel, because he will be going along the same path as the others.” (ELSA, Mainstream School, transcript)

For the young people in the mainstream school and the mainstream faith school, social isolation in school was a significant narrative within the teachers' interviews. Mary, the SENCo of the mainstream school, presented Nameless as being socially isolated twofold - first in his mind through him feeling that everyone was teasing him and second, because she felt his peers tended to leave him alone.

“He does have a perception that everybody's talking about him and ‘taking the Mickey’²³ out of him. I actually don't think it's true, but I think that's the ASC²⁴ bit coming through. I'm not saying they don't, because children are nasty. But from how I see him in the classroom the children actually, generally, leave him alone.” (SEnCo, Mainstream School, transcript)

Similarly, the SENCo in the faith school, described the way in which Nataliya was socially isolated from her peers. Carys highlighted the way in which she sometimes would get angry at her peers, if they did try to interact with her, the positioning the social isolation as something that Nataliya herself was creating, to a certain extent.

“Before school, at break and lunchtime she's in The Brambles. She's sitting on her little cushion in the corner with loud music on reading a book. And if anyone comes, she can actually get angry at people being there, particularly younger people being there. And so, she's very isolated that way. Because, apart from that, if she doesn't do that, she'll be wandering the corridors on her own.” (SEnCo, Faith School, transcript)

The only reflection on social isolation in the narratives of special school staff was in relation

²³ Taking the Mickey: Making fun of someone

²⁴ Autism Spectrum Condition

to Felicjan. However, in his case school was presented as his “social time”, whilst his home life was said to be isolated from the community due to his parents “having no friends” and their living a “lonely existence” (Deputy Head, Special School, transcript).

7.3 Non typical, typical teenagers: staff reflections on the young people

In this section, I present themes from staff’s reflections on the young people. I consider the views on each young person individually and highlight how the staff views connect or disconnect with the way in which the young people spoke about themselves in the previous chapters (See Chapters Five and Six).

7.3.1 Performing gender and politics: Felicjan (special school)

Felicjan chose the widest range of people for me to speak to, including his class teacher, who was also the deputy head, his teaching assistant, and a Polish midday-supervisor, who he spent time with. The staff were hugely fond of Felicjan talking about “friendship” (TA, Special School, transcript), laughter and “jokes” (Midday-Supervisor, Special School, transcript), that they shared with him, similarly to the way Felicjan identified teachers and teaching assistants as his friends. His class teacher spoke about her hopes for his future and his capacity to make a “big contribution” to the world (Deputy Head, Special School, transcript). She explained that this might not be on the basis of economic productivity, but rather, this was due to the quality of person he was. In talking about Felicjan, she frequently used adjectives, such as “amazing” to describe him as a person (Deputy Head, Special School, transcript). All these staff focussed on presenting Felicjan as a typical male teenager. There was a sense of seeking to normalise and justify him through discourses of maleness and virility. Specifically, his teaching assistant and class teacher spoke about his gelled hair, use of aftershave, and his proclivities for “the women” (Deputy Head, Special School, transcript):

“He loves the women. So, he’s a very typical teenager. He likes to have his hair done. So, if his hair gets muddled up when we’re taking his coat off and stuff, you have to make sure that it all goes up again. You can feel he’s got stuff in it. He likes to be dressed smart. He’s got some fantastic green DM [Doc Martin] boots; I love them. And he always smells of aftershave, you know. He always likes to be a man.” (Deputy Head, Special School, transcript)

The staff working with Felicjan also sought to demonstrate his agency in the way they spoke about his “sarcastic humour” (deputy head) and how he would sulk just like any other “teenager” (TA-J, Special School, transcript,). There seemed to be a greater acceptance, and almost pride in the relation of this type of behaviour. The staff used this as a mechanism for constructing ‘sameness’, presenting Felicjan just like any other teenager.

“He's a teenager and he sulks, if he doesn't get his own way - but that's just a teenager isn't it? He gets over it in the end. He makes his point to show if he isn't happy about things” (TA-J, Special School, transcript)

Another prominent way the staff spoke about Felicjan was how they conceptualised him as being easily swayed by his family, such as the staff being able to excuse his un-politically correct right-wing political views as not being his own. Each member of staff that I spoke to explained that these views were not really Felicjan's, but rather, he was echoing his father. This was somewhat different to the way Felicjan presenting his political views as being his own. His midday-supervisor, with whom Felicjan shared a very close relationship, was also Polish and she directly stated that “his opinion is his father's opinion” (Midday Supervisor, Special School, transcript). Whilst it is possible that her Polish identity played into this wanting to distance herself from these views, the fact that all the staff strongly reiterated this, gave a sense of agency removal, excusing him for what he was saying on the grounds that he had internalised his father's views and had not decided upon these himself.

7.3.2 Adulthood between two worlds: Asim (special school)

Asim identified his class teacher and three teaching assistants for me to speak to, two of whom, Angela and John (TAs), had worked with him for a long time, whilst Clair and Marie (TA and teacher) had only worked with him for a few months. Agency was a strong theme in the way in which the staff Asim worked with described him. This was also reflected in the way he spoke about himself explaining the responsibilities he had in school, such as setting out chairs for assembly. The staff spoke about his “heart of gold” (TA-A, Special School, transcript), and his sense of humour, being capable of gently teasing members of staff. All of the four staff I spoke to about Asim focussed on the way they respected him as an adult and how he sought to be treated as an equal. This played out in the way he wanted to have a voice within the school, sitting on the school council and also helping to interview new teachers. His class teacher also focussed on how him seeking respect meant that he was more interested in developing workplace skills than school learning.

“He likes to be respected and he likes to be treated as an equal. This really effects classroom practice, because he's very big on work skills and doing jobs and all those sort of things” (Teacher, Special School, transcript)

Asim was presented as being more able than his peers, particularly in relation to life skills, for the development of which he attended a “gifted and talented” cooking class (TA-C, Special School, transcript). Asim also reflected on this aspect during the research, explaining he was good at cooking. The staff also stressed cooking as a way to reinforce the theme of responsibility explaining how the gifted and talented cooking class offered the students opportunity to prepare food, which was offered as part of a buffet for training days and meetings.

Angela and John, two of his TAs who had worked with him for a long time, spoke about the way he had “grown into a young man” (TA-A, Special School, transcript). In relation to this, they spoke about his disability and his own perception of being “normal” (TA-A, Special School, transcript). However, they also reported on the way in which he interacted with the notion of his disability, speaking about how it could cause him frustration or anger. In this way, John appeared to describe a sense of distance between Asim and the staff around him. He spoke of how sometimes Asim’s confusion could lead to anger or embarrassment due to his seeing himself as having the same status as his uncle or the staff.

“He gets frustrated when his disability starts to make a difference to where he would have been normally. I think that frustration drives a bit of anger in him sometimes, and that might be behind why he takes his frustration out on other people, because he can't explain things. He forgets things every now and again, and he gets confused on the days. And then, he'll feel a little bit embarrassed about it, because he knows he should be—he thinks he's up with his uncle and everyone else like the TA's, and I think that contributes to his fear of failing things. You know, it's sort of, and particularly when he's had a seizure, he gets quite embarrassed about that as well, you know, for a while. He's very private and a very proud chap and he's very private as well.”
(TA-J, Special School, transcript)

Privacy was a big theme in terms of the way in which the staff spoke about Asim and how he lived his life. Angela described Asim as inhabiting “two worlds” - his life at school and his life at home (TA-A, Special School, transcript). Asim was British-Pakistani and all the staff that he chose for me to speak to were White-British. They played down the importance of Islam

in Asim's life, explaining that "he doesn't go to the mosque very often. And if he does, he keeps that to himself" (TA-A, Special School, transcript). It is interesting to note; however, that within the research context Asim did speak about Islam. Hence, there seemed to be a dissonance in the way Asim was presented and suggestions that he was a different person when at school, perhaps more distanced from Islamic culture. In relation to the notion of living between two worlds and being a private person, both teaching assistants, Angela and John, spoke about the way in which there was a sense of not knowing "the truth of the matter" (TA-J, Special School, transcript), particularly in relation to his job at his uncle's take-away. Angela spoke about the way Asim described the things he did in his spare time as "daydreams" (TA-A, Special School, transcript), suggesting that rather than these being true they were what he wished his life could be, for example, riding a motorbike.

7.3.3 Just like a five-year-old: Destroyer (mainstream school)

Destroyer chose only one person for me to speak to, his ELSA, Paula. She had worked with him since the end of year six, when he had been identified as a young person who would need a lot of support in transitioning to secondary school and had gone to his primary school. Paula spoke about Destroyer's social context, identifying five boys that he had strong friendships with and with whom he played games, whilst also spending time with them socially inside and outside of school. The friendship circle she described featured very heavily in Destroyer's own description of himself and his experience. However, when describing Destroyer, she often compared him to a "five-year old" child (ELSA, Mainstream School, transcript). This infantilisation was used both in the way she described his cognitive ability, explaining that "he can't expressive himself, his mind is at a 5-year-old - his learning and his writing" as well as in the way she described his behaviour (ELSA, Mainstream School, transcript).

"When he first came in, he was very, very angry and frustrated and couldn't understand the whole secondary school experience. So, we'd often see him having tantrums outside, much like a little five-year-old would do." (ELSA, mainstream school, transcript)

In relation to this, she spoke about how she thought Destroyer "realised that he's a bit different" and this affected his behaviour, and he would get "angry" about not being able to his work as easily as other people (ELSA, Mainstream School, transcript). This was not something that Destroyer spoke about, instead trying to distance himself from the notion of being different and was conscious about being perceived as weird. Paula also spoke about

his strong imagination, which led him to detach from “real life” (ELSA, Mainstream School, transcript), as he wove his fascination with Marvel and imaginary universes into everything he spoke about. Hence, she spoke about it being hard to know him, and how she really had to ask to find out things about him. On reflection, she questioned to what extent she had “gotten to know Destroyer as how he actually is” or whether it’s just what she saw “as Destroyer, because he doesn’t give anything away” (ELSA, Mainstream School, transcript).

7.3.4 Internalising perceptions: Nameless (mainstream school)

Nameless did not identify a specific adult for me to speak to - saying that there was no specific person who was important to him in school and hence, he “didn’t care” who I spoke to. I asked him if I could ask the SENCo, Mary, about him and he said yes. However, after speaking to her, he told me that he did not hold her in high regard, saying she did not understand him. Nevertheless, in line with the concept of providing contextualising narratives I present the SENCo’s narratives here. The reader should note that Nameless’ perceived poor relationship between himself and the SENCo may have coloured some of this data.

Mary described Nameless as “very bright”, whilst also strongly focussing on his identification as autistic saying, “he’s also quite ASD.²⁵ Very, very one track” (SENCo, Mainstream School, transcript). There was a sense of reduction, stripping his personhood down to his diagnostic traits. When reflecting on Nameless’ mental health, she positioned him as being vulnerable, particularly due to being identified as having autism. Mary presented autism as being a part of him that affected his judgement. She highlighted this by suggesting that his perception that people were teasing him was due to his being autistic and misreading the situation, rather than it being an accurate representation of his experience. This is significantly different to the way in which Nameless described his experience as authentic and offered anecdotes relating to these experiences, such as the example of people throwing shoes at him. The SENCo questioned to what extent his challenges with mental health were exacerbated by the way he perceived what was going on around him. She was clear that she did not think he was “making things up for the sake of making it up”, but she did feel he was misreading situations. In relation to this, she spoke about being “careful” with him for fear of him having a “complete meltdown” (SENCo, Mainstream School, transcript).

“It’s difficult to know how much is perceived and how much is actually reality with him. And I’m not saying he’s making things up for the sake of making it

²⁵ Autism Spectrum Disorder

up, but it is his perception sometimes and, you know, that's with the ASC and it's quite difficult. So, we are—we do monitor him and we are quite careful, because I think with him he could have a complete meltdown, if you put in too much.” (SENCo, Mainstream School, transcript)

In relation to the way in which she perceived having to be careful around Nameless, she described how he was very sensitive, “internalising everything” (SENCO, Mainstream School, transcript). To demonstrate her perception of this, she talked about the way in which she would pre-warn him, if she were to tell his class off, because she was aware that he found being told off particularly difficult.

“So, something had happened and I warned him I was going to go for the whole class. I said ‘but clearly It's not you so, don't take it personally.’ Because a couple of them stole some reels of thread, so I laid it on thick with, you know , “police next time” and “there's CCTV, you can't see the CCTV”. You know all sorts of dire warnings. But I knew that Nameless was in the class and I said ‘it's not you’ before we even started the lesson, because I know what he's like. It's really difficult because he internalises everything.” (SENCo, Mainstream School, transcript)

7.3.5 Aspiration without boundaries: Nataliya (faith school)

Nataliya chose three people that she wanted me to speak to: Elise, the assistant SENCo who she had first met when she was in primary school as part of her transition programme; Lisa, who was a teaching assistant; and the new SENCo, Carys. Lisa and Elise described Nataliya very positively, saying she was “very confident, very friendly” (TA, Faith School, transcript). Both also focussed on the way in which Nataliya was persistent and did not give up, being good at advocating for herself and being able to ask for help. Specifically, Elise identified the way in which Nataliya liked to campaign for charity and was resilient when she did not win the school talent show at the end of Year 7. However, this was something that Nataliya did not tell me about.

“By the end of year seven she had come very close to winning the talent show, where she got a prize and she was acknowledged for her wonderful performance. She was very upset and she did cry, because she didn't get the main prize, but it didn't put her off. That is the thing with Nataliya, it doesn't put her off. She is a trier and she will come back. Charity - anything

anyone wants to do for charity. She will get all the posters together and she will campaign and she does that very well.” (Assistant SENCo, Faith School, transcript)

This sense of being a trier was reflected in the way the SENCo spoke about her having many “possibilities” (SENCo, Mainstream School, transcript). Nataliya was involved with a project where undergraduates from a Russell Group university came into the school to read with the students and she was able to engage well with her mentor. Moreover, Nataliya was part of a university outreach programme giving scholarships to under-privileged students to attend programmes at university. Hence, the teachers who worked with her were optimistic about her future, believing she would go to university and have success. Nataliya shared the same positive mindset about her future, describing how she was preparing herself to become a famous and talented singer.

However, Elise perceived Nataliya as needing to continue to work on the way in which she managed her feelings and the interventions that the school used to support her; to think about the way she acted in school. She questioned to what extent Nataliya was able to engage fully with her feelings and described her lack of self-understanding as making her “vulnerable” (Assistant SENCo, Faith School, transcript). When discussing the way she managed her feelings within school, Carys drew comparisons between Nataliya and the other students in her class, describing the way in which she would lose her temper and use her physical presence to make her feelings known. In contrast, she described the other students in the class, who were not identified as having SEN/D, as being tolerant of this behaviour.

“We had to take her out. She actually physically went right up to their faces, almost like that [indicating hand in front of face] and people were pulling back, but they didn't retaliate whatsoever. They just look at me and they don't retaliate at all. They just give her her space. I've heard people come in to The Brambles and say “Hi Nataliya, how are you?” She can be very aggressive and she can be quite frightening, because she is quite big. She'll use her physical presence and then the other thing she will do is use random words. When I was in the group that day she said like this [imitating slowed intense speech] “Where are my childrrreeennnn?” and she did it twice out of the blue.” (SENCo, Faith School, transcript)

Nataliya also highlighted challenges she faced with her peers and said she had no friends in

her class. She described feeling “underrated” (Nataliya, Member Checking Text) by her peers and was confused about why this was the case.

7.3.6 Stories of vulnerability: Ruby (faith school)

Similarly to Nataliya, Ruby also chose for me to speak to Lisa (a teaching assistant), who was also her key worker, Elise (the Assistant SENCo) and Carys (SEnCo). The staff spoke a lot about how Ruby had come out of her shell during secondary school, going from being “very quiet” to “never ever stopping talking” (Assistant SENCo, Faith School, transcript). They also described her as “inquisitive” and “caring” (TA, Faith School, transcript). This relates to the way in which Ruby described herself to me. In terms of being inquisitive, Ruby was keen to learn and identified skills she wanted to acquire as she got older. She also described herself as caring, pointing out the ways in which she helped other people. The staff spoke about their concerns with Ruby being “obsessed” by television shows and the media (Assistant SENCo, Faith School, transcript). Whilst Ruby spoke about liking watching TV shows, she did not talk about them in terms of an obsession. However, Belinda, the SENCo, was concerned that she was more vulnerable to this obsession than her peers, because she was more gullible towards the messages being portrayed.

“Ruby is obsessed by the media. It’s not unusual for girls her age, and I mean younger ones, to be obsessed. But the fact that I feel Ruby’s vulnerable worries me more.” (SEnCo, Faith School, transcript)

Misgivings regarding her vulnerability were extended to concern over her approach to boys, with the SENCo describing her as having a “lack of boundaries” (SEnCo, Faith School, transcript). For the staff, there was particular concern over this, because Ruby had been held back a year in primary school and so was a year older than her peers in secondary school. Throughout the whole research process, Ruby did not mention her age or being held back a year reflecting the active way in which she ensured that those around her did not focus on her age.

“She’s actually 14 going on 15 and she’s getting those ideas that 14 and 15 year old girls have, and she’s still in a class with 13 year olds” (assistant SENCo, Faith School, transcript)

Lisa described Ruby as playing “another character” (TA, Faith School, transcript). She spoke about the way in which Ruby would construct stories, relating narratives about going to the

cinema or going to a boy's house. Lisa was very concerned about this, reflecting on whether it was more in relation to mental health or daydreaming.

“When she tells these stories there are things that maybe she's not allowed to do, so she'll make up her story, and particularly in reference to boys. Like that, she and whatever the name of the boy - they're going out together; that they've been to the cinema, she's been to his house and all these things. It's a bit alarming. Sometimes I think to myself is there a dual something going on there, or is it kind of, like, wishful thinking.” (TA, faith school, transcript)

7.10 Intertwining with the key literature

In this section, I discuss prominent themes from the teachers' narratives and link them to the literature. Perhaps most significantly is the difference between the school staff in the special school and those in the mainstream and mainstream faith schools. Disability was not a primary focus in the special school and in fact in the teacher narratives (see above), it was rare for its staff to engage with notions of disability, instead focussing on the growth and personalities of the young people. In contrast, whilst the staff at the mainstream and mainstream faith schools did comment individual characteristics, they also highlighted individualistic and/or deficit aspects of disability relating to the individual. The notion of responsibility and vulnerability was present in the teachers' narratives. Predominantly, the staff in the special school highlighted the young people's desire to be seen as adults and their assuming of responsibility, whilst the staff in the mainstream and mainstream faith schools raised concerns surrounding vulnerability. In this section, I problematise vulnerability, whereby this would appear to conflict with a lack of its report within the young people's voices.

7.10.2 Individualistic models of understanding

The staff in all the schools were person-centred in the sense that they focussed on the individual and his or her characteristics. However, the adults working with the young people in mainstream school and mainstream faith school seemed to have some level of difficulty understanding the student's experiences and, when discussing learning difficulty, there were examples of deficit and deviant discourses. For example, the SENCo of the mainstream faith school described Nataliya as “very aggressive and...frightening” (SENCo, Faith School, transcript). Additionally, the SENCo of the mainstream school also offered a reductive view

of autism, describing Nameless as “he’s also quite ASD.²⁶ Very, very one track” (SENCo, Mainstream School, transcript). This would appear to reveal the unfamiliarity of the professionals working in the school to engage with nuanced views and theories of disability, instead demonstrating a deficit view of special educational needs as being situated within the individual (Shakespeare, Lezzoni & Groce, 2009; Hodge, Rice, & Reidy, 2019). Moreover, the notion of the individual student being the problem within the classroom links to the work of Caslin (2019) undertaken with young people identified as having behavioural difficulties. Similarly, in her research, she reported that the teachers identified the young person being seen as the problem as they were not fitting in with expected norms, rather than addressing the shortcomings of the school system and unrealistic expectations.

7.10.2 Vulnerability

Linked to a deficit view of disability, some of the school staff working in the mainstream and mainstream faith school reported perceptions of the young people’s vulnerabilities. Arguably, the students who were learning in the special school were more vulnerable in society due to their complex needs than those learning in the mainstream settings. However, the narratives of the special school staff would suggest the opposite, with the staff describing the young people as a “typical teenager” (Deputy Head, Special School, transcript). In the mainstream and mainstream settings, the young people were presented as being vulnerable in relation to their ‘typical’ peers. A specific example of this is the SENCo and teaching assistant’s concerns over Ruby’s “vulnerability” and “lack of boundaries” (SENCo, Faith School, transcript) in relation to boys as well as concerns about her sexuality and how this played out in the classroom due to her being a year older than her peers (14 in relation to 13 year olds). This dichotomous explanation of Ruby by her SENCo strongly brings to mind the work of Ellis (2018), whose work with young females in secure care challenges the notions of ascribed vulnerability. The adults’ unease and construction of her as a vulnerable person with inappropriate behaviour, who was at risk of abuse (Koller, 2000; Stokes and Kaur, 2005; Grieve et al., 2006), positioned Ruby as a stigmatised individual whose right to a sexual identity was in question. Moreover, the adults seemed unsure about how to support her in gaining the tools to “establish a responsible sexual identity” (Tissot, 2009). Whilst there is a small body of literature that clearly stresses the right of people identified as having mild to moderate disabilities to engage and explore their own sexual identity (cf. Everett, 2007; Gill and Hough, 2007; Koller, 2000), there has been a significant lack of research undertaken with people who are identified as having severe or profound learning difficulties.

²⁶ Autism Spectrum Disorder

7.11 Conclusion

The staff indicated some degree of belonging for the young people, particularly in relation to positive relationships with members of staff. The way in which the staff at the special school spoke about the young people was significantly different to the way in which those in the mainstream and mainstream faith schools spoke about them. Notably, the staff in the special school made no mention of specific labels of impairment, which could be attributed to the disdainful view the deputy head had regarding the value of SEN labels.

A key discourse present specifically in the mainstream school and the faith school staff's reports was that of individualistic impairment, which resulted in social isolation. Moreover, the ELSA in the mainstream school highlighted Destroyer as being so different that his needs could not be met within the school and felt that a managed move to a special school would be better for him.

Chapter 8. DIS/cribing

DIS/cribing

[dɪˈskraɪbɪŋ]

verb

1. *giving a detailed account of personal experience by someone identified as having a learning difficulty or disability*

8.1 Introduction

The objective of this thesis was to establish effective techniques for hearing the voices of young people identified as having SEN/D, thereby being able to address the following research questions:

1. What are some of the ways in which young people identified as having learning difficulties describe themselves?
2. What are some of the ways in which young people describe and experience a sense of belonging in their educational settings?
3. How inclusive are self-portraits, videovoice and life mapping as research methods for enabling young people identified as having learning difficulties to describe themselves and their experiences?

In the previous chapters (see Chapters Five to Seven), I have presented the findings thematically and linked prominent themes with the literature. In this chapter, I draw together the findings to make my final arguments. I begin by addressing the ways in which the young people described themselves. I hold that whilst disability was not a primary descriptor for many of them, the way in which they described and related to disability was, in many cases, problematic. Moreover, I have highlighted the way in which three of the young people demonstrated masking whilst at school. In relation to this, I contend that the young people in this study would benefit from opportunities to nurture different dimensions of their sense of self. I believe that adopting and applying a model where learning difficulty is perceived as being shaped by societal barriers, has the potential for being emancipatory. This perspective would offer a supportive structure for young people to reflect on their sense of self and where they locate any difficulty.

Regarding the young people's sense of self, I continue by considering the way in which they

experienced a sense of belonging in their school setting, pointing out that all of them described some sense of this within their educational setting. I support my assertions by drawing on Hegarty et al.'s (1992) work on a sense of belonging (see Chapter Three). Drawing on my findings, I discuss the implications of the research and argue that the current use of SEN labels and the way in which SEN spaces were constructed in two of the schools posed problems to their sense of belonging.

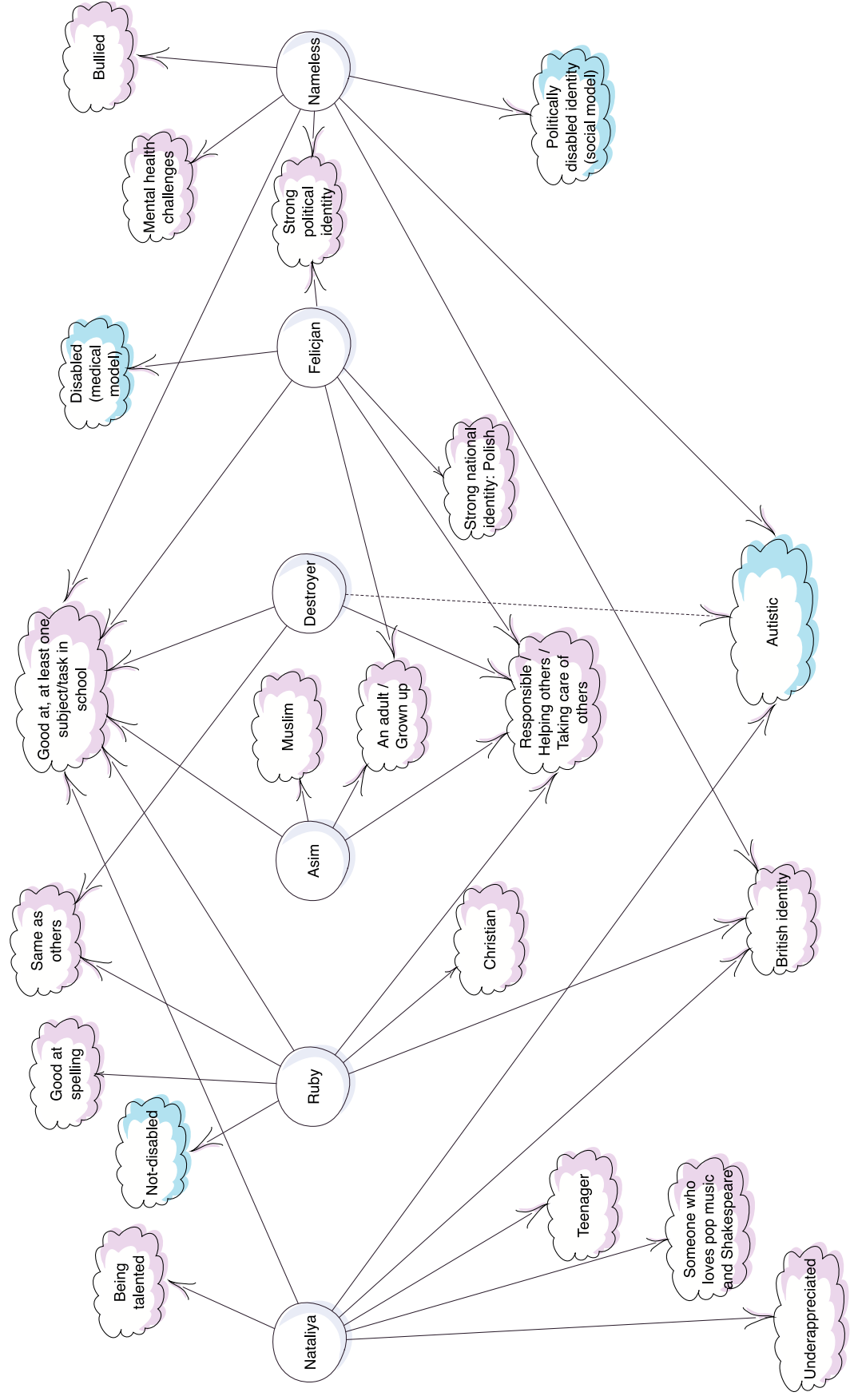
Finally, I argue that the inclusive nature of this research was effective in facilitating the young people in sharing their descriptions of themselves and articulating the way in which they experienced a sense of belonging in their school settings. I contend that it is not only the design of the research tools, but also, the way in which the researcher utilises them within the field that affects the inclusivity of the investigation.

8.2 DIS/cribing selves

In exploring self-descriptions, this research started from the emancipatory premise that all young people, regardless of cognitive ability, have their own sense of self by merit of being human (Mauss, 1998). In line with Giddens's (1991) reflection that "self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography" (p.53), the young people showed active engagement in describing themselves to me and were able, in many instances, to contextualise their stories within their own biography. The young people rebutted discourses "that 'disabled' children are 'different' or 'deficient'" (Singh and Ghai, 2009, p.138), instead demonstrating an ability to describe who they were and to reflect on their passions and strengths (see Figure 31). It is interesting to note that, when describing themselves during the process of self-portraits, the young people only briefly talked about their physical selves. Rather, they were keen to tell me about things they liked, disliked, and wanted. All of the young people, when prompted, were able to describe something they were good at and enjoyed doing in school, ranging from being good at spelling (Ruby) to collecting the register (Felicjan). The young people thought about the future and what they wanted with varying degrees of criticalness - for Destroyer, he wanted Time Blades from Ninjago whilst Ruby wanted to be able to learn to cook and look after herself. Empowerment was a strong theme that came through the young people's descriptions. Asim, Ruby and Destroyer were keen to help other people, Asim and Felicjan wanted to be considered as equals to the adults in school and Nataliya, Ruby, Nameless and Asim aspired to have what

Figure 31

Young people's self-descriptions



they considered to be important jobs. These findings resonate with those undertaken in Sweden by Skar (2003), with young people with restricted mobility and in Germany by Mortier et al. (2011), with young people identified as having SEN/D. In these studies, and my own, young people identified as having SEN/D were found to have the capacity to take an active role in describing their future aspirations.

Two of the young people described their own political engagement: Felicjan displaying very right-wing views, whilst Nameless was left-wing, a big supporter of Jeremy Corbyn and called for a better welfare state for disabled people. These findings are novel, for no other research could be identified²⁷, which has elicited the political views of young people identified with learning difficulties.

Throughout this research, I did not instigate discussion on disability nor pry into the participants' own experiences of having been identified as having SEN. When, and if, they brought up SEN or disability on their own terms, I engaged in discussion with them for as long as they wanted to. Felicjan spoke about being disabled and having cerebral palsy, whilst Nameless, Nataliya, and Destroyer²⁸, spoke about being autistic (see Figure 31), Asim never mentioned having any identification of SEN himself and Ruby actively distanced herself from the notion of being disabled. Hence, it can be seen in Figure 31, that whilst disability or neuro-diversity (highlighted in blue) was spoken about during the research, it was not the sole descriptor any of the young people used when describing themselves.

Despite some of the young people's self-describing as autistic (Nameless), having autism (Nataliya) or being disabled (Felicjan), there was still a sense in most of their descriptions that they were "essentially the same" as their peers (Jadhoda et al., 1998). These comparisons were explicit, with the young people making direct comparisons with physically/neuro typical peers or social groups (such as, teenagers). Similar findings have been declared by Skar (2003), who, when researching with disabled teenagers (who had limited mobility), found that whilst the young people described themselves as the same as their peers, their non-disabled peers described them as different. When examining the participants' descriptions of themselves, Ruby, Nameless and Destroyer, most notably, put in "additional labour" (Hodge, Rice and Reidy, 2019) to self-regulate in school so as to pass, "camouflage" (Lai et al., 2017; Hull et al., 2017), or "mask" (Mandy, 2019) as typical, and

²⁷ Search terms used were: "disability", "disabilities", "disabled", "impairment", "impaired", "special", "special needs" and "children", "adolescents", "youth", "child", "teenager", and "political views". I used the British Education Index, Google Scholar as well as searching key journals, such as Disability & Society.

²⁸ Destroyer mentioned being autistic only one. An identification of autism was not present in his EHC plan.

minimise the chances of being identified as different by their peers. When I met Ruby, she did not speak openly about being identified as a person with a learning difficulty, instead, focussing only on trying to self-regulate her difference so as not to be identified as disabled by her peers. An example of this is the way she actively hid her age from them²⁹. Whilst she was happy to be friends with people who had different needs, she positioned herself in a place of power, helping people who were less able than her. She was clear that their labels of difference, such as disabled, did not apply to her, saying, “I’m not disabled”. Masking has been primarily discussed in relation to autism (cf: Mandy, 2019) and Ruby, who had been identified as having learning difficulties, but who was not identified as autistic, demonstrated deploying similar strategies in order to fit in with her peer group. This suggests that masking goes beyond the autistic population and thus, may be relevant for people identified as having learning difficulties as well.

For the five young people who did speak about either themselves and others in relation to SEN or neurodiversity there were a vast range of understandings. For instance, despite explaining that he himself was disabled and had cerebral palsy, Felicjan used the word “retard” to describe a person in a video he had made, who he saw as having a significant learning disability. When talking about autism, Nataliya described it as something you “have” likening it to a medical condition that “messes with your head” (Nataliya, Member Checking Text). Nameless described being autistic as being an “entirely different species, but still human” (Nameless, Member Checking Text). The knowledge most of the young people had surrounding autism seemed to be primarily medicalised, focussing on their being something wrong with the person leading to “weird” behaviour (Nameless, Member Checking Text). Descriptions of disability included “someone [who] finds it hard to write properly and they could find it hard to walk or something” (Ruby, Faith School, Transcript week 3) and:

“Disability is not being able to work. Having a disability meaning just not being able to do a lot. I mean you don't have to be in a wheelchair or anything like that. And if they are in a wheelchair then definitely yes, but they don't *have* to be. If they're in a job and they've actually got a viable way of showing that they can't be in the job, then I classify them as disabled.”
(Nameless, Mainstream School, Member Checking Text)

These individualistic and medicalised understandings are perhaps, unsurprising, given some

²⁹ Ruby had been born prematurely and held back a year in primary school. During the research, she made no mention that she was a year older than her peers. When talking to the staff, they told me that Ruby was a year older than her classmates, which she hid from her peers and that she avoided the mentioning of birthdays.

of the staff discourses also offered deficit-based understandings. For example, both SENCOs identified the young people as being problems within the classroom. The SENCO in the mainstream faith school described Nataliya as having the potential to be “very aggressive” and “quite frightening” (transcript). Similar findings were reported by Caslin (2019) when researching with young people identified as having behavioural difficulties, where she underlined the way in which the teachers in her study categorised the young people as the issue rather than the system.

The difficulty of the young people in discussing special educational needs, disability or difference and the frequent linking of SEN to deviance, combined with three of the young people’s clear efforts to self-regulate and pass within school, suggests that they did not have the language or knowledge in place through which to meaningfully engage with notions of special educational needs. This difficulty was also reflected by the teachers, specifically those in the mainstream and mainstream faith schools, who lacked nuanced views of disability, demonstrating individualistic and deficit views of special educational needs (Shakespeare, Lezzoni & Groce, 2009; Caslin, 2019). These findings also strongly resonate with those of Hodge, Rice and Reidy (2019) researching in the field of autism. They elicited that when young people are not supported in developing a relationship with their autistic identity, this can “result in anxiety and the perception of a self that is not only different but ‘wrong’ and undesirable” (ibid., p.1366). Similarly, within my own research there was a sense that being autistic and/or having a learning difficulty was unacceptable and likely to mark a person as being “unpopular” (Nameless, Mainstream School, Member Checking Text), thereby ruining their social standing in school. The gap in the young people’s knowledge surrounding disability is of significant concern given the potential for their internalising negative and stigmatising discourses. It is important for the young people participating in this research that they are able to acquire more nuanced knowledge surrounding SEN, autism and disability as a protective factor in their development of sense of self.

8.2.1 A different way of knowing: advocating for the space for a Social Model of Learning Difficulty to be taught in schools

Given the way in which the young people in the present research linked SEN to deviance, the words of Hans Reinders should be kept in mind:

“negative connotations do not reside in words but in the mind. Negative connotations are attached to words because of how people think about disability; thus, without changing their habits of thinking, people will use new

words just as they used the old ones.” (2009, p.46)

Reinders’ call for a change thinking habits as well as the need to offer young people and staff the opportunity to learning new ways of thinking about learning difficulties, as previously argued, indicates that a social model of learning difficulty could prove beneficial. Instead of negating the notion of a learning difficulty, distancing selves from SEN labels, or putting in additional effort to self-regulate;, such young people could be empowered by an understanding that learning difficulties are socially constructed.

Current education legislation in English still demarcates learning difficulties as pathological and individualised, describing the young person as having:

“a significantly greater difficulty in learning than the majority of others of the same age or, has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions” (Special Educational Needs Code of Practice, 2015, p.16)

Similarly, the adults in the study who worked in mainstream schools also appeared to understand learning difficulties as primarily biological in nature. For example, the Emotional Learning Support Assistant (ELSA) in the mainstream School explained that Destroyer was starting to understand that “he’s not the same” as everyone else. None of the professionals who participated in the study made any mention of the fact that disability or learning difficulty can be viewed as socially constructed. This is not unsurprising, given that other researchers suggest that teachers and school staff are unfamiliar with socially constructed theories of disability and primarily see disability as located in the individual’s bodies (Hodge, Rice & Reidy, 2019).

Rather than continuing to pathologise the notion of a learning difficulty, a social model of learning difficulty could offer the young people an emancipatory framework through which to talk about their lives. Moreover, a socially constructed view also aligns with many of the ways in which the young people described themselves as the same as others, rebutting lay views and misconceptions. In his work on learning difficulty and the social model of disability Goodley noted that, “there is a need to work with and for an understanding of ‘learning difficulties’ as a fundamentally social, cultural, political, historical, discursive and relational phenomenon, rather than sensitively recognising the existence of an individual’s ‘naturalised impairment’” (2001, p.210). Considering Goodley’s in relation to the views of the young people in the study, Natalia, Ruby and Destroyer rebutted and challenging the notion that

they, or others, had essential, or biological, differences to their peers. For example, in the way that Ruby explained autism she also began to hint towards a socially constructed notion of normal: “they [autistic people] still do act normal, just in different ways” (Ruby, Faith School, Transcript week 4). Here, building on Ruby’s statement, engaging with the idea that behavioural norms are socially constructed, could help engender greater acceptance of people who may present in different ways. Moreover, a socially constructed view of learning difficulty could highlight the barriers in schools that create learning difficulties, rather than situating the point of difference in the individual. Refocussing the discussion on the construction of learning difficulties onto the teaching and learning processes could problematise systemic approaches, for example streaming, that separate children by ability and put emphasis on high performing and low performing groups. Challenging these processes in school from a socially constructed perspective could offer a meaningful change for young people who are currently labelled with SEN, as within the present study.

When I met Nameless, he had already begun actively to engage in the social model of disability through his family life, rather than at school. He explained that he had come from a family that was “pretty much all disabled” (transcript), and through his parents he had learnt about the social model of disability and the notion of neurodiversity. Whilst he still offered an individualistic description of disability, highlighting that it meant “not being able to do a lot” (Nameless, Mainstream School, Member Checking Text). He also focussed on a macro view, specifically pointing out how political measures, such as the Conservative government’s cuts, can impinge on the rights of disabled people. However, outside of his family home, Nameless appeared to learn in a context where no one else seemed aware of the concept that barriers in society disable people. Hence, whilst he identified some social barriers, his peers and staff appeared to view him through a medicalised model, which may have contributed to his description of being autistic as an “entirely different species, but still human” (Nameless, Transcript, week one). The staff I spoke to in his school had a strong medicalised understanding of difference, seeing autism as a condition or disorder leading to biological impairments. Due to his awareness that other people thought there was something ‘wrong’ with him, he spent much of his efforts mediating his behaviour to fit in as well as choosing not to be friends with other autistic people, who he described as being “even less popular” than himself (Nameless, Mainstream School, Transcript). He explained that his experiences at school led him to feel anxious and depressed and that he would often breakdown at home after trying to hold himself together at school due to the stress. Offering the young people in the research, their peers and staff the ability to engage in learning about a social model of learning difficulty could be a significant lever for change with the potential of increasing social acceptance. There is, thus, a clear case for research being undertaken

to ascertain whether or not this is the case. Importantly, people identified as having learning difficulties should be given the opportunity to comment on a social model of learning difficulty as a construct and to reflect upon whether it is meaningful and useful to themselves

8.3 DIS/cribing a sense of belonging: “Valued involvement” and “fit”³⁰

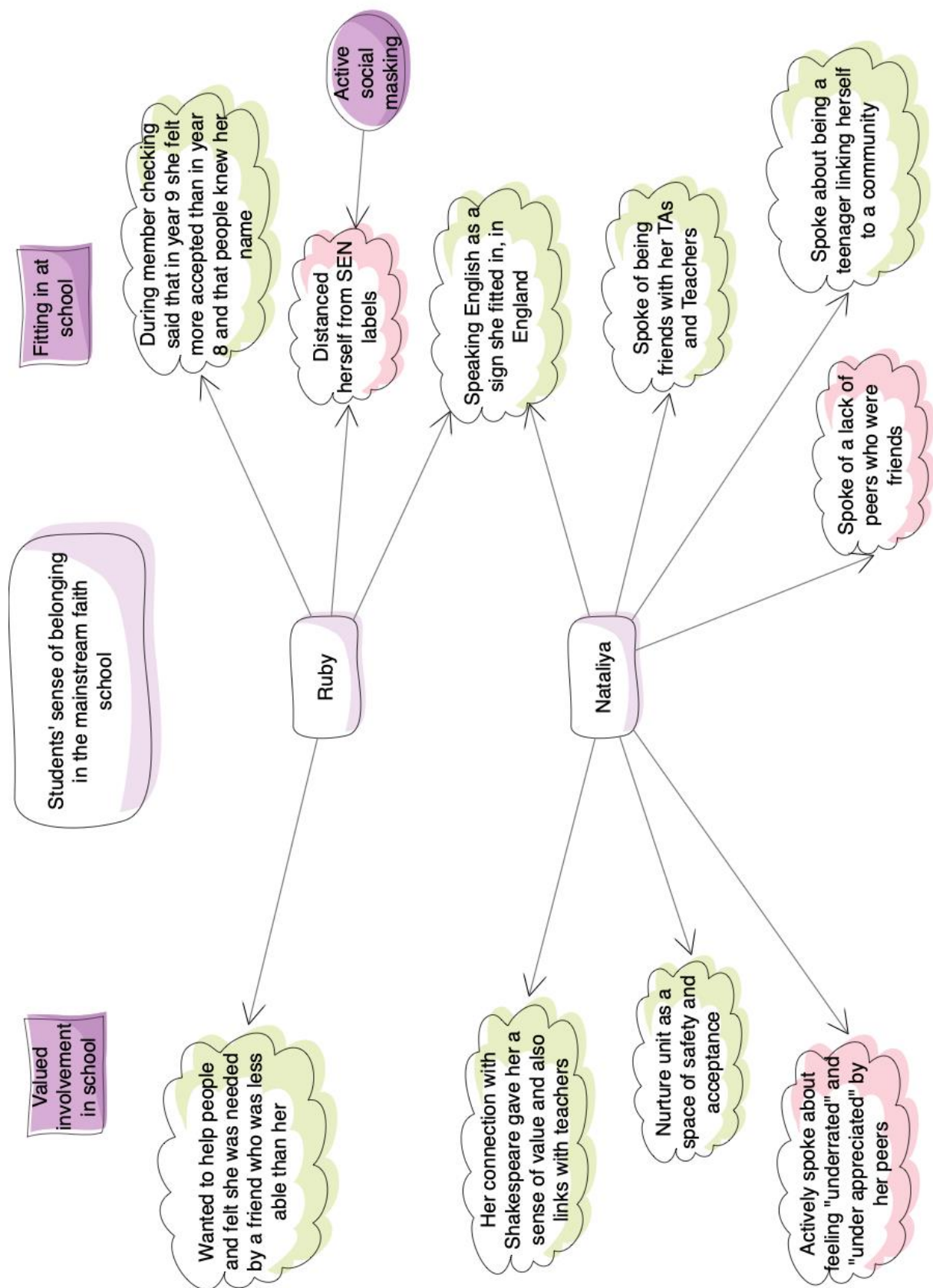
In further exploring the young people’s experiences, this research also sought to understand how they experienced a sense of belonging within their educational setting. In seeking to operationalise the notion of a sense of belonging, I drew on Hegarty et al.’s (1992) bi-partite conceptualisation pertaining to “valued involvement” and “fit” (p.173). After analysing my findings, I set out the ways in which the young people actively described their “valued involvement” and “fit” (ibid.), in their school setting (see Figure 32 - identified in green). I have also included ways in which the young people actively expressed that they did not feel a sense of belonging (see Figure 32 - identified in red).

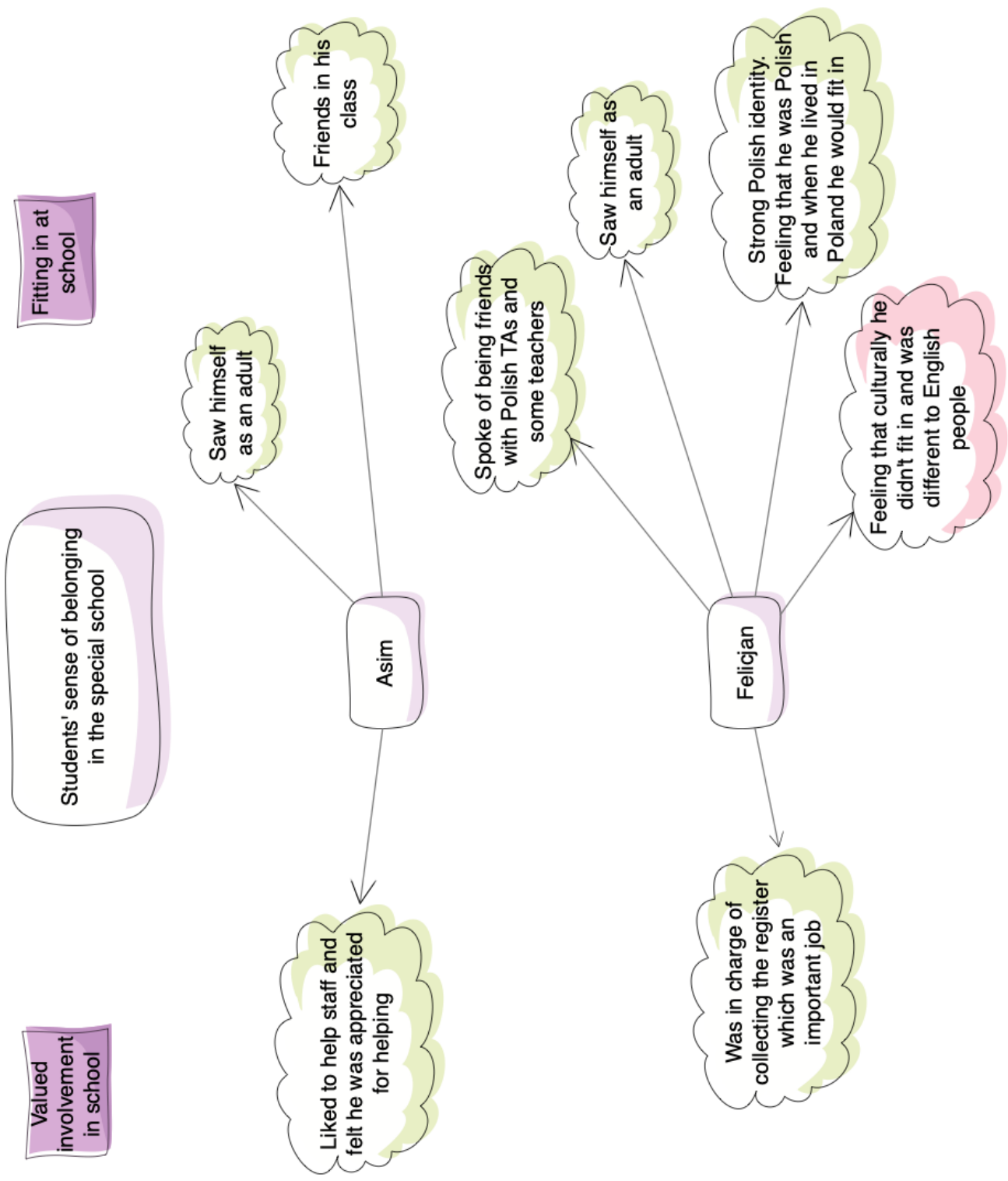
All of the young people reported certain aspects for which they felt valued in their school. Having responsibilities or feeling valued and respected by specific members of staff was a significant lever in the young people’s expression of “valued involvement” (ibid.). In the special school, Asim and Felicjan focussed on the responsibility given to them in school by their teachers. Both young men had tasks that they carried each day that contributed to the running of the school, for example, Felicjan was in charge of collecting his class’s register each day from reception. The feeling of being important was also relevant to Destroyer, who attended the mainstream school, where his Emotional Literacy Support Assistant (ELSA) had given him the responsibility of picking a friend each week to bring to his 1:1 session to play a game with. The validation of agency given by their teachers/support staff in the form of offering responsibility would appear to have been important to the way in which they experienced a sense of belonging in their educational settings. Positive relationships with staff was also a factor in relation to the young people expressing a sense of “valued involvement” (Hegarty et al., 1992, p.173). All of the young people spoke about relationships with teachers where they felt supported. Nameless, when specifically commenting on belonging, said “if you were asking the students how they think of me, no. If you were asking the teachers and how they think of me, yes” (Nameless, Mainstream School, Transcript week 5). The validation offered by staff to the young people in all three educational settings highlights the important role the former occupied in promoting the latter’s feeling a sense of

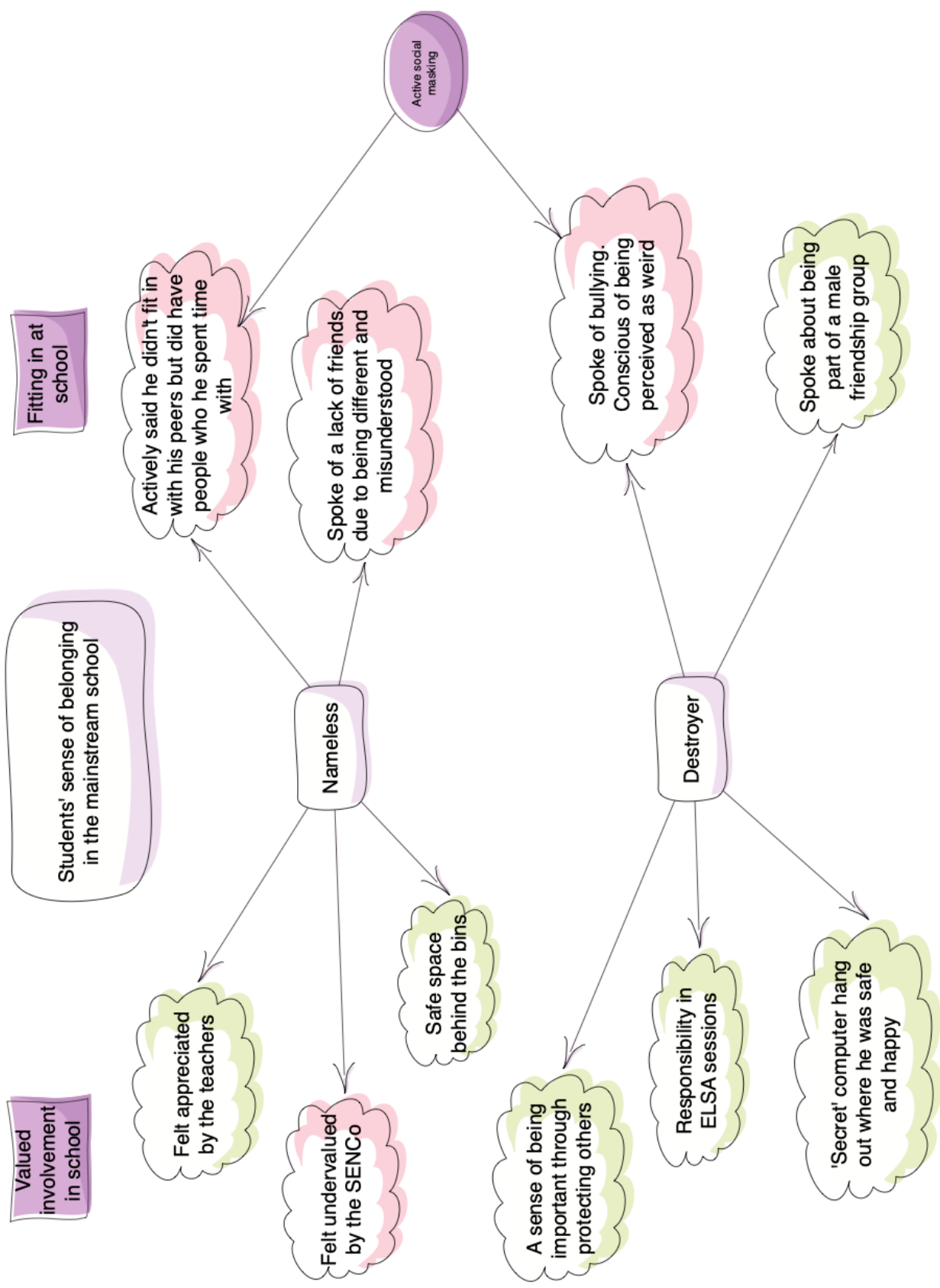
³⁰ Hegarty et al., 1992, p.173. For more information see Chapter Three.

Figure 32

Young people's sense of belonging







belonging. This relation in regard to facilitating a sense of school-belongingness is also found in the work of Dimitrellou and Hurry (2019) and Midgen et al. (2019), who also undertook research into the ways in which young people identified as having SEN/D experience belonging. For instance, Dimitrellou and Hurry (2019) carried out a Likert-scale based survey of 1,440 pupils identified as having SEN/D attending mainstream school in England. Their findings also indicate a positive correlation between the sense of belonging in school and the relationship with teachers and TAs (ibid.). Notably, both studies were undertaken across a range of school settings. In my own case, a mainstream faith, mainstream and special school, whilst Dimitrellou and Hurry (ibid) undertook research in three mainstream schools with different rankings of inclusivity.

Whilst the young people's sense of being valued was predominantly described in connection with relationships with teachers, a sense of fitting in can be seen in the ways in which the young people spoke about both their teachers/TAs and their peers.

The only participant not to be able to identify positive factors for the "fit" aspect of a sense of belonging (Hegarty, 1992, p.173) was Nameless, who explicitly said he did not feel he fitted in, in school. However, he did speak about maintaining a social group in school. Nataliya and Felicjan, who attended the mainstream faith school and special school, respectively, predominantly spoke about their relationships with staff, identifying these as their friendships in school. In contrast, the other four participants focussed on relationships with peers as a sign of fitting in. Friendships are critical to the emotional well-being of young people in school settings (Dunn, 2004). Hence, the participants' ability to identify people who they felt they fitted in with and had social-relationships with is vital for ascertaining the way in which they were able to experience the "fit" aspect of sense of belonging (Hegarty et al., 1992, p. 173). Destroyer, Ruby, Asim and Nameless all named specific people they were friends with and identified a friendship circle. Similar to other research (Potter, 2014), the young people in my study were able to reflect on the friendship dynamics in school in "relatively nuanced ways about a complex social concept" (p.212). Nameless, Destroyer and Ruby, who attended the mainstream and mainstream faith school, respectively, were consciously aware of the importance of having friendships to maintain their sense of belonging in school and made a conscious effort to nurture or hold on to friendships. This is similar to the work of Baines (2012), where both young autistic men in her study made a deliberate effort to promote a positive perception to others to foster social interactions.

8.3.1 Experiences of not-belonging: Labels “just wind people up”³¹

Whilst the research process did not involve explicitly asking the young people to identify the ways in which they felt a sense of not-belonging, five, namely Nataliya, Ruby, Nameless, Destroyer, and Felicjan, themselves identified and actively spoke about their unhappiness with either their peers or their school, in general. Asim, who attended a special school, was the only participant to not identify any feelings of not-belonging within his school. This can be seen to echo the way in which the deputy-head of his school reinforced an ethos of the familial within the school and spoke of “loving everyone” (Deputy-Head, Special School, Transcript). Felicjan’s dissonance was specifically linked to his Polish national identity and view that he did not fit in, in England. These feelings were most likely due to and exacerbated by the EU referendum and his family’s consequential decision to relocate back to Poland at the end of the current academic year (2016-17). He was very negative about all aspects of English society and whilst his not-belonging was predominantly connected to the community this feeling pervaded all aspects of his life, despite his being able to identify ways in which he felt valued. Felicjan’s experience strongly mirrors the literature on immigration and education, with his narrative reinforcing his “outsider status” on his own terms, especially through criticising English culture (Lopez Rodriguez, 2010, p. 340).

For the four other young people, who attended the mainstream or mainstream faith school, their concerns around their sense of belonging was connected to fitting in, particularly their worries about peers, being bullied and difference. Both Nameless and Destroyer, who attended the largest school of the research, had worries about being seen as different by their peers. Nameless went as far as to explain that he did not fit with his peers. Nataliya explained the relationship with her peers differently, saying she felt “underappreciated” by them (Nataliya, Faith School, Member Checking Text), and was confused as to why she did not have friends in her class. The young people’s descriptions here relate to other research undertaken in mainstream schools suggesting that those identified as having learning difficulties are less accepted than other peers and have fewer friends (Avramidis et al., 2018; Tipton et al., 2013). Ruby was very conscious of being perceived as different and actively spoke of wanting to distance herself from SEN labels. The adults with whom I spoke explained that, she hid her real age from her peers so as not to be seen as different. In distancing herself from SEN, Ruby also made the point that her peers used the term autism as a taunt to “just wind people up...to make fun of people” (Ruby, Faith School, Transcript week 3). Her discourse problematises the way in which SEN labels are used and mis-used

³¹ Ruby

in schools in terms of how they can affect and individual's sense of belonging in school. The staff who I spoke to who worked in senior management, whilst acknowledging the usefulness of labels from a funding perspective, also problematised SEN labels in the school environment. Ruby's voice, in conjunction with concerns highlighted by the staff surrounding SEN labels, underlines the necessity of including young people's views in the discussion over the value of identifying and assigning SEN labels to individual students.

Over the decades, there has been much discussion about the use of SEN labels and the consequences of doing so. In 1979, the Warnock Report highlighted the potential for terminology increasing the level of stigma surrounding an individual. Since then, there have been significant shifts in policy, including using person first terminology, and the term Special Educational Needs. Despite these developments, Norwich (2014) effectively argues that whilst the terminology has changed, the construction and understanding of disability as medical and individual remains the same. This is manifested in the current policy narratives, such as the 2010 Equality Act and the 2014 Children and Families Act (See Chapter Two).

Within education research the positives and negatives of using SEN labels have also been discussed. Laughlan and Boyle (2007) argued that they are positive as they enable extra support and resources to be offered; raise awareness; provide opportunities for clear communication between professionals; provide solace to young people and families by explaining reason for difficulty and provide a social identity. In contrast, more recently, it has been argued that, in fact, labels can be harmful and have a significant impact of young people's lives and their futures in terms of increasing stigmatisation and isolation (Arishi et al., 2017). This was echoed by the SENCo in the mainstream school, who had concerns that SEN labels could "stop the children achieving" (transcript), by reducing aspirations both of teachers and parents. Moreover, she was concerned about a generalised lack of understanding from staff about "what it actually means to be autistic; what does it actually mean to have Down's syndrome" (transcript). The deputy head teacher at the special school was, perhaps, the most critical, arguing that the labels of SEN have the propensity to homogenise people, thus erasing individual characteristics. Algrigay and Boyle (2017), in their examination of the value of the labels of SEN in an English context, conclude that, whilst their application is beneficial for professionals, overall, they are harmful, in that they poses significant problems and increase stigmatisation for the people who, themselves, have been labelled. They posit that "the crucial question that arises is: who has the power to label children and young people with SEN or disabilities? Is it medical professionals or those working in education, or both?" (Ibid.). I argue, drawing on progressive childhood studies where young people are seen as active rather than passive agents (Singal and

Muthukrishna, 2014; Curran & Runswick-Cole, 2014), that a more pertinent question on labelling is one that includes the voices of the young people, who themselves, are the ones who are being labelled: *do young people identified as having SEN want to be labelled?*

Nameless explained, during the research, that he chose not to be friends with a peer who had been clearly labelled as autistic due to his “weird” behaviour (transcript). Owing to the stigma surrounding the individual, in part from behaviour and in part from the label of autism, he was “undoubtedly even more unpopular” than Nameless (Mainstream School, Member Checking Text). As stated, extant research highlights the impact of SEN labels for people who have been identified and subsequently labelled with them. However, this research adds to debate by elucidating the the voices and experiences young people who are labelled with SEN. The young people’s views, for example Nameless’, highlight the problematic and potentially damaging nature of SEN labels when young people, who are labelled with SEN, and their peers view SEN and disability as deficit and deviant. In such cases, the use of labels can interfere with the individual’s day to day experiences in school, causing them to feel the need to put in additional effort to self-regulate so as to navigate stigma surrounding these labels. Further research needs to be undertaken where young people are the key actors in discussions about SEN labels and the way in which they are identified as having them.

8.3.2 Geographies of belonging: problematising SEN spaces

Whilst SEN labels can position young people identified with them on the margins, so too can the geographies within schools affect young people’s sense of belonging. The young people who attended the mainstream and mainstream faith schools, all reflected on specific spaces in which they felt either safe or a sense of belonging. In contrast, Asim, who attended the special school, spoke about his whole school as a place where he felt happy and that made his life “good” (Asim, Special School, Member Checking Text). He was the only participant to speak about his school in a whole entity; however, it should be noted that Asim’s school was notably smaller than the mainstream and mainstream faith schools³².

Nameless and Destroyer, who attended the mainstream school, both had very complex relationships, with former explaining it was something to be “suffered” (Nameless, Mainstream School, Member Checking Text). Nevertheless, both boys had spaces in school that were important to them, where they liked to go and where they felt accepted. For

³² The mainstream school had c.3000 students, the mainstream faith school had c.500, and the special school had c.200 students who were over two sites.

Destroyer, it was a 'secret' computer room, whilst for Nameless, he had a hideout near the waste bins, which he considered to be safe from bullies on the basis that no one else regularly went there. For the young people who attended mainstream and mainstream faith schools, they also had access to specific areas of the school that functioned as inclusion or 'nurture' units. Holt (2004), researching the geographies of two primary schools in England, maintains that the use of inclusion units or segregated spaces in school serves to "enact power by labelling and diagnosing children as 'special/disabled'". To some extent, this notion is subtly hinted at by Destroyer's discourse on The Purple Room at his mainstream school. He described it as a place people go to when people need "help" with "learning". However, he was at pains to make clear that he did not want to socialise there during break and lunch times, instead, using other areas of the school with his friends. When considering staff perspectives on belonging and spaces, it was particularly interesting to note that Destroyer's ELSA felt that accessing The Purple Room was not enough. She felt the school was not meeting his needs and did not have the means to teach him, thus feeling he would fit better in a special school.

Despite the critique of inclusion units as having the potential to reproduce power, the work of Holt, Lea and Bowlby (2012) examining the perceptions of students identified as being on the AS, who used inclusion units in mainstream secondary schools, also found they could be sites of safety, offering "a space of refuge from the mainstream school" (p.2200). This was also articulated by the four participants in my study attending mainstream school, all of whom identified the space as safe. Similar findings regarding the positivity of these types of safe spaces can be found in the work of Hall (2010), who argues that, for people identified as having learning difficulties, sites of safety where they can "attain the feeling and status of belonging without being exposed to the rigours associated with 'normal' social inclusionary positions" (e.g. in an educational setting, the playground) are important and beneficial (p.56). This notion was particularly prevalent in the girl's voices, who used The Brambles (the nurture unit) a lot during their school day. Ruby spoke of it as being a retreat from the "boring" playground, whilst Nataliya explained how she was able to use the space to do things she liked doing, such as reading her book or listening to the radio. Whilst the girls highlighted the safety of the space, Nameless contended there was the potential for the safety of the space to be manipulated by people who he felt "lied" (Nameless, Mainstream School, Member Checking Text) about their situation to gain access to the space. This poses the question about who has the right to use the space.

Nurture units or inclusion units remain spaces of tension, with the possibility of reproducing notions of difference associated with explicit identifications of SEN. However, they can also

act as spaces of refuge and comfort acting as spaces, offering acceptance for young people and promoting a sense of belonging within the wider school setting. Further research should be carried out to elicit the views of students who use these spaces and the ways in which, whilst they can offer refuge, they can also reproduce stigma. It would also be beneficial to explore gender within this to ascertain whether females felt a greater sense of needing a refuge than males.

8.4 Inclusive research and researcher

Offering young people, identified as having learning difficulties, a voice within research is vital. Specifically, investigation into inclusive education through listening to young people's descriptions of themselves and their sense of belonging within school settings deserves much further attention. Relatively little research undertaken directly with young people identified as having learning difficulties has been explicit in pursuing the goal of their views being central to the research process (Liddiard et al., 2018; Bailey et al., 2014). Hence, the detailed descriptions of the instruments and the adaptations made contribute to the field in terms of promoting inclusivity and participation by those being researched (see Chapter Four). This research has been innovative in the way in which it is engaged young people, with the aim of getting them to share their thoughts, as far as possible, on their own terms. All of the young people who completed the research were able to produce responses that stimulated discussion on topics relating to the research questions. I believe that taking part in this research offered the children a space to belong within the research itself, where their voices were listened to, they felt trusted and they were "empowered" by being invited to be expert witnesses to their own lives (Nind, 2008, p. 13). I would like to think that this process may have also contributed to their lives in a small way, as the retelling of one's story is said to lead to the possibility of growth (Clandinin & Connelly, 2000). After undertaking the pilot, one young person sent me an email via his teacher thanking me for coming to visit and saying the research had made them feel "happy". In the main research, all the young people also expressed their happiness at taking part at different points in the research. Nataliya explained that "doing the research makes me happy, that we get to do these video recordings and we get to do interviews" (Nataliya, Faith School, Member Checking Text). Additionally, Ruby and Nataliya both wanted to make books at the end of the research collating all the work they had done as part of it. This highlights the potential for the young people to take positives from such research, whereby they can experience a sense of belonging within the research itself through myself, as a researcher, offering them a sense of "valued involvement" (Hegarty et al., 1992, p.173).

The research tools in a practical sense were inclusive and participatory, as they were designed to be multi-sensory based on the premise that, “not all knowledge is reducible to language” (Bagnoli, 2009, p.547). In particular, I think that videovoice and life mapping were the most innovative and inclusive methods within this research. Videovoice challenged the usual power relations of researcher and researched, as the young people were active agents choosing which aspects of their life to record and in what way they shared them (Lehtomäki et al., 2014). The life mapping was particularly aided by the creation of an initial stage of listing, which supported the young people in engaging in the activity effectively, whereby they were able to illustrate and reflect on their social networks (see Chapter Four). Despite the self-portrait being adapted through technology to make it accessible, not all of the young people felt confident in their drawing skills and so this limited the inclusivity of the tool, to some extent. The most inclusive stages of the research tools were the way in which the multi-sensory data, initially produced through the arts-based practices, were used as stimuli in order to co-generate discussion communication on the videos. This was particularly inclusive and effective as it significantly reduced the reliance on working and short-term memory processing skills that are required from typical interviews and focus groups. This enabled the young people to describe their experiences in detail over a period of weeks, as they had multi-sensory stimuli to engage with each week, rather than being faced with didactic questioning.

Another aspect which supported the methods being more inclusive was the flexibility in the field to adapt to the young people and their specific needs (see Chapter Four). Moreover, as I am a special education practitioner, I was experienced in modulating my own language for clarity as well as being fluent in Makaton (sign language specifically developed for people identified as having learning difficulties), which I was able to use to support my verbal communication. Hence, I posit that the methods themselves, whilst being innovative in structuring the research as inclusive and specifically taking account of cognitive diversity, were also enacted in an inclusive way. Moreover, they were implemented by a researcher experienced in being in the classroom and working directly with young people identified as having SEN, which I believe has increased the robustness of the findings.

8.5 Conclusion

In their work on the DisHuman child, Goodley et al. (2015) write, “it is also imperative to recognise, claim and to celebrate the **dis** in order to trouble the norm: ‘[a] dis/human position mean that we recognise the norm, the pragmatic and the political value of claiming the norm, but we always seek to trouble the “norm” (p.4, emphasis the authors’ own). However, few of

the young people I researched with were in a place in their lives where they were able to talk easily about differences and 'dis' within their own life experiences, let alone celebrate them in school. Additionally, three of the young people reported modifying their behaviour so as to promote positive perceptions of themselves to their peers or to promote friendships with peers. The mainstream and mainstream faith schools in this research need urgently to offer young people contemporary understandings of learning difficulties, from the perspective of these being socially constructed. Perhaps, if the young people in this study learned in settings where the social model of learning difficulty was taught as a framework through which to discuss difference, then their day to day experience would have been different. Further research should be undertaken offering young people identified as having learning difficulties the chance to engage with and reflect on a social model of learning difficulty.

All of the young people described, on some level, having a sense of belonging within school. The only one who was unable to identify positive factors in both aspects of the sense of belonging was Nameless, who explicitly said that he did not fit in to his school. However, he did identify social circles that contributed to a sense of fitting in and acknowledged positive relationships with some teachers. The positive relationships the young people spoke about with their teachers and support staff were vital in promoting a sense of belonging in their educational setting. In terms of fitting in, the young people identified relationships with peers and teachers and factors that helped in making them feel part of the school. Nevertheless, many were worried about how being seen as different and/or having SEN labels might affect their schooling experience. These worries led me to question the validity of how the system demarcates young people with labels of SEN, without taking their voices into account. The action of labelling combined the young people's deficit view of SEN has the potential to "result in anxiety and the perception of a self that is not only different but 'wrong' and undesirable" (Hodge, Rice and Reidy, 2019, p.1366). In the current research, SEN spaces were also identified as having the potential to reproduce stigma and yet, also offered some young people a sense of refuge. Going forwards, it is vital that further research is undertaken with young people identified as having SEN/D aimed at examining further geographies of SEN and the use of labels within schools.

Chapter 9. Parting Ways

9.1 Introduction

This thesis has contributed knowledge by researching with young people identified as having learning difficulties by giving volume to their voices. Specifically, I have identified some of the ways in which young people describe themselves and experience a sense of belonging in their educational environments. This study was novel as it sought to deeply engage directly with young people identified as having learning difficulties, learning in schools in England, and using innovative and inclusive methods elucidate the way in which the young people described themselves and experienced a sense of belonging. This research offered new perspectives and added to extant debates by directly highlighting the voices of the young people themselves. On the basis of the findings, I have argued for the consideration of a social model of learning disability to help both young people and staff to develop their knowledge surrounding disability as well as to challenge deficit and individualistic models of understanding. I have also questioned the validity of SEN labels within school settings, highlighting the ways in which the use of SEN labels may disrupt a young person's sense belonging in school. I have problematised the use of nurture/inclusion units within schools, for whilst these offer a sense of refuge, they also have the potential to reproduce stigma, thus negatively impacting on young people's sense of belonging in school. Furthermore, I have added new knowledge to the field by offering a detailed account of the way in which I implemented inclusive tools to facilitate the young people in describing themselves and their experiences.

In this final chapter, I begin by discussing the strengths and limitations of this research. Next, I draw on the findings and discussion to offer some implications resulting from the research. I finish by offering suggested directions for future research.

9.3 Strengths and Limitations

A strength of this study is that it has provided a rich and detailed account of the young people themselves. It is my view that they were able to describe clearly who they were, judge what was important to them and reflect on their own feelings of a sense belonging in their educational settings. From this perspective, this research has offered important insights into the lived experiences of young people who have been identified as having SEN/D and given an EHCP. It has given a window into both the joyous and yet, challenging worlds of

young people identified with SEN/D.

The main limitations of the study are the small sample size as well as the lack of representation of female participants, both in the special and mainstream schools and there being no male participants in the mainstream faith school. I decided to research alongside the young people in this study, because they were interested in participating and felt they would find it a valuable experience. I considered that this was more important than obtaining a balanced representation of sexes across each school setting. Nevertheless, this study cannot be seen to be an unbiased sample and representative of the entire population of interest. In particular, there is little representation of those who are transgendered and diverse sexual orientation. It is possible that the findings would also have been different if there had been more young people included in this study, in that more themes may have been discovered. The inclusion of young people who had been identified as both having a learning difficulty and being on the AS may have also broadened the findings. Specifically, the inclusion of young people identified with this dual identity may have increased the findings in relation to neuro-diversity and the politics of disablement.

Another limitation of the study is the challenge of insider vs. outsider. Researching as a person who has not been identified as having a learning difficulty with participants who have, had the potential to bring about misinterpretation of their input (Allan, 2011). Conscious of this, and of the limited work undertaken in operationalising research concepts for cognitively diverse participants (Milton & Sims, 2016), I used my experience as a special educational practitioner along with the wisdom from the literature to ensure that the young people were very clear about what I was trying to ascertain. As did not participate in the thematic analysis, undertaking meaningful member checking was vital in order to ensure that they were able to “authentically mediate their own voices within the research” (Sakata, Christensen, Ware & Wang, 2019, p.325). This, I believe, mitigated my own bias in interpretation and the conflicting tensions of insider vs. outsider research. Furthermore, the young people also engaged in participatory pseudonym generation; creating their own avatars to be used when writing up the research. This was a powerful tool as it enabled them to gain control over the way in which they were represented in the research and thus, to some extent, disrupted the power imbalance (ibid.).

9.4 Implications

This research adds to a small field of research undertaken in English schools with young people identified as having learning difficulties. Whilst the findings cannot be generalised

beyond the sample to a wider population, the narratives illuminated through this small scale case study are important, because they come directly from a group of young people with disabilities by activating their voices and not by such means as researcher observations or third party reporting. It is hoped that the rich detail in which the findings have been presented chimes with young people identified as having learning difficulties and practitioners working in classrooms with those who have been identified in this way.

The young people's views in this thesis challenges the deficit-based rhetoric and question the ongoing reproduction of stigma in their educational lives. It is vital that social discourses that are present inside schools, particularly the mainstream and mainstream faith schools within this research, change. Practitioners need to question deficit and deviant understandings of learning difficulty and SEN found within some schools as these have the potential to impact on the way young people labelled as having SEN describe themselves and experience belonging in their schools. Moreover, the views of the young people in this research, suggest that developing their own knowledge on disability would be useful. Specifically, whole schools (including staff) learning about a social model of learning difficulty might offer individuals, staff and peers new perspectives through which to consider their own understanding of themselves and others, as well as the society they operate in.

This research has also highlighted the way in which SEN labels can affect the sense of belonging, specifically in the case of those young people learning in mainstream and mainstream faith schools. It would be beneficial for schools, especially the mainstream and mainstream faith schools within the research, to consider reducing the utilisation of SEN labels in the classroom. In connection with this, it has emerged that SEN labels also affect the geography of young people's belonging in school. Schools should question whether they are taking a whole-school approach to SEN, as seen in the special school, or whether they focus on specific spaces of inclusion, such as the nurture spaces. Specific sites of inclusion, whilst offering some young people sites of safety, also have the potential to reproduce stigma. Hence, the schools involved in this research should examine the ways in which they could create inclusive belonging school-wide, rather than simply establishing SEN spaces.

9.4 Directions for future research

Further research needs to be undertaken to shed more light on the ways in which young people with lived experience of learning difficulties conceptualise these. It is vital to give people identified as having learning difficulties the opportunity to comment on and develop further a social model of learning difficulty. An important next step in policy and praxis is to

take into account the lived experience of young people identified as having learning difficulties when making decisions. More opportunities should be given to them to discuss and reflect on their own lived experiences and this should be used to develop policy affecting young people, rather than focussing on collective or homogenising identities described and ascribed by adults. Further studies should also be undertaken with people who have been identified as having severe or profound and multiple learning difficulties, with the research methods being attuned to their specific needs. Such knowledge is essential for ensuring that the voices of the heterogeneous population of young people identified as having learning difficulties are represented in decisions made at every level.

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Appendix i






Set of questions used to discuss the videos with James in the pilot






1     
1. What are you doing in the film?

2     
2. Do you do it by yourself or with other people?

3   
3. Do you do it every day?

4   
4. Why do you do it?

5     
5. What does it make you think about?

6     
6. How does it make you feel?

Appendix ii

Interchangeable equipment available to use with camera for video voice

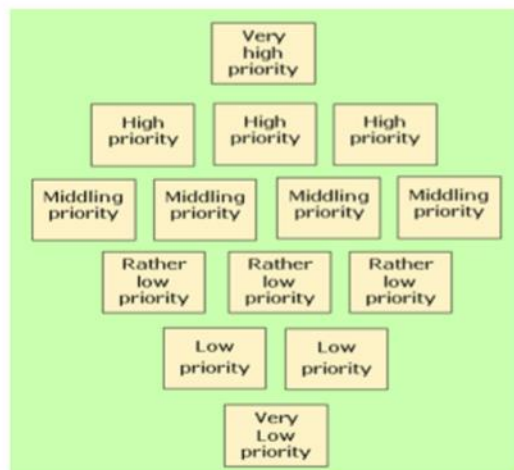


Appendix iii

Tasks undertaken in the second pilot to explore the anchoring words

Important

- Mind map words related to important (people, places, things inside of you (morals, beliefs), behaviour)
- Arrange in diamond nine formation so most important are at the top and least important are at the bottom.



- Explore:
 - What/Who is this?
 - Why is it/are they important to you?
 - What do you do with them/it?

Happy

- Draw and label things and people that make you happy.



- Explore:
 - Who/What is it?
 - Why?
 - What do you do with them/it?

Safe

- Explore:
 - What does safe mean?
 - Where do you feel safe?
- Here's a map of your school, circle all the places you feel safe.



- Explore:
 - What do you do here?
 - Why do you feel safe here?
 - Why don't you feel safe here?

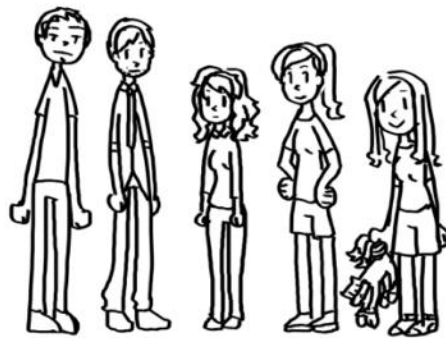
Same

- Look at the pictures, match pictures that are the same together in pairs. Glue them together on a piece of paper and write the reason they are the same underneath.



Friend |

- Make a cartoon strip of what you do with your friends (either drawing or on the iPad).






- Explore:
 - Who is this?



- What are you doing with them?
- Do you do this: every day, once a week, on special occasions?
- Why do you like them?
- How do they make you feel?

Appendix iv


Video voice instructions in the main study

  
 Researching with Hannah

 is a  video camera. You can  borrow  while  we do the

 
 research together.

     
 Each week you will make films about different topics. The

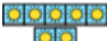









 topics are:










 **1**   
 Week 1. Important. Film what is important to you.






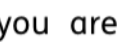



 **2**    
 Week 2. Happy. Film what makes you happy.




3

 Safe.
 
 Film
 
 what
 
 makes
 
 you
 
 feel safe.


4

 Friend.
 
 Film
 
 what
 
 makes
 
 you
 
 think
 
 of
 
 friends.


5

 Same.
 
 Film
 
 what
 
 makes
 
 you
 
 feel
 
 the
 
 same.

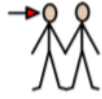

 Remember
 
 to
 
 only
 
 film
 
 things
 
 that
 
 you
 
 are
 
 happy
 
 to
 
 share


 with
 
 me.


 Remember
 
 if
 
 you
 
 film
 
 other
 
 people
 
 you
 
 need
 
 to
 
 ask
 
 them



first.



If

they

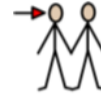


say yes

then it's okay to

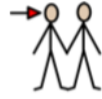


film



them.

If



they



say no

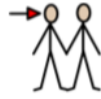
then you



can't



film



them.



You can



talk

or make



sounds

in the



film

if you



want to.



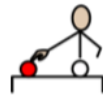
You do not have

to




show me

everything




that

you do.








 Each week we will watch your film together and











 talk about it. Here are some of the questions I will ask

you:




 • What are you doing in the film?








 • Do you do it by yourself or with other people?



 • Do you do it every day?



 • Why do you do it?




 • What does it make you think about?




 • How does it make you feel?

Appendix v

An example of symbol boards

The participant could pick one of the large categories and then would be shown another board with all the symbols linked to that category.



Appendix vi



iPad, weighted stylus, Wacom board














Appendix vii







Instructions for self-portraits

 Today  you can  make a  self-portrait  and  we  will

 make a film  about it.

A  self portrait  is a  picture of  who  you are  now.

A  self portrait  shows me  who  you are  today.

A  self portrait  shows me  how  you  feel  about  yourself










 today.

 Please  can  you  include:








 • what  is important  to you.



 • what  you  like  and  don't like.

 • what  you  want  and  don't want.

 I  will  ask  how  you  feel  when  you  look at

 your  self-portrait.

 Remember  you  don't have  to  tell  me  everything.

 You can  say no.

Appendix viii

Semi-structured interview schedule

Teachers/Teaching Assistant Stage 1:

H: "I'm collecting stories about (child's name) from adults in their life to help contextualise and give depth to their narratives on belonging and identity. Everything you tell me will be kept confidential and anonymous, the school will not be told what you have said.

Take your time as we have as much time as you need to tell me about your life and (child's name)'s life. **I want to listen to you speak first without interrupting you.** I might take some notes to ask you questions once you are finished about things you have said. So, can you tell me about (child's name)'s life since he started in your class, the events and the experiences that you think have been important to him/her up until now?"

Teachers/Teaching Assistant Stage 2:

Based on the notes from the interview follow up questions in the same order as they were mentioned in the narrative. This will help to keep to the chronology of the narrative as ordered by the participant.

Teachers/Teaching Assistant Stage 3:

Aim	Main questions	Write down probing questions as used.
Understanding the young person's journey and experience through school.	<p>How long have you worked with (child's name)?</p> <p>How do other children treat (child's name)?</p> <p>How does (child's name) treat the other children?</p> <p>Can you tell me about (child's name) life at school? What do they do on an average day?</p> <p>How is (child's name) part of the school community?</p>	

	What is the relationship like with (child's name)'s family?	
Understanding the school's interaction with the wider community.	<p>Does the school interact with the wider community?</p> <p>Can you tell me what you think people from this community think about disability? Is there any variation?</p> <p>What is it like when you take the children out into the community?</p>	
Understanding the school context, community and construction of inclusion and how the school approaches, difference, disability, nationality, citizenship and teaching British Values.	<p>How does (school's name) construct itself as inclusive?</p> <p>How does (school's name) teach about inclusion?</p> <p>How does (school's name) approach nationality and citizenship?</p> <p>Does the school talk about difference, for example disability, ethnicity, citizenship? What does it say?</p> <p>Does the school talk to the children explicitly about special educational needs and disabilities? What does it say?</p>	
Understanding how the school approaches, difference and disability	<p>How does (school's name) approach diversity, such as disability, ethnicity or religion?</p> <p>Does the school talk to the children about special educational needs and disabilities? What does it say?</p> <p>How important is a young person's SEN/D identification to their experience in school?</p> <p>Do you speak to the young people about having SEN/D?</p>	

<p>Understanding how the changes in SEN policy over the last few years has effected the school.</p>	<p>How have the recent changes in SEN policy, such as the 2015 SEN CoP, affected your school?</p> <p>What has the move from statements to EHC plans (and from school action plus to SEN support) been like?</p>	<p>The government suggest that the move to EHC plans means that assessing young people will become more child centered, is this something you feel has happened in your school?</p> <p>Have the government level policy changes changed your school's policies?</p>
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Appendix ix

Extract from research journal

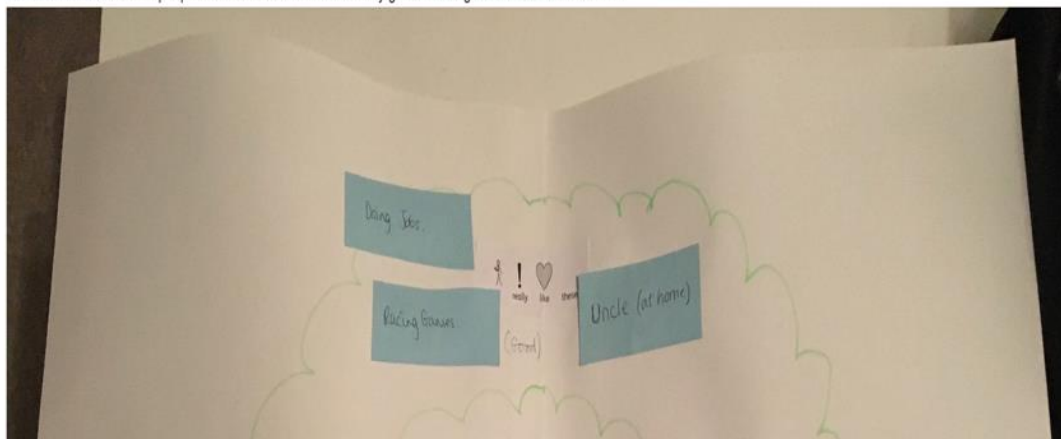
New List Calendar Maps More

6 Mar 2017

I went into [redacted] for a long day on Monday to catch up with [redacted] who had been away the previous week and then continue the research process with [redacted]. I also undertook an interview with [redacted] teacher [redacted] who is also an assistant headteacher. The interview was the first thing I did, [redacted] was very open and friendly and spoke for an extended period about [redacted]. She was also able to talk about school level discourses on inclusion and nationality. [redacted] clearly has a very strong bond with [redacted] and I witnessed her during the day telling him she loved him. [redacted] seems to have a very strong relationship with [redacted] too and spoke about her a lot - for example when we were thinking about what [redacted] might record for important, the first thing he said was that he wanted to record [redacted]. [redacted] also talked about her fears when [redacted] returns to Poland in May. Post-Brexit, [redacted] family, particularly his father, decided that they wanted to go back to Poland. [redacted] had visited a couple of special schools in Poland with the headteacher of [redacted] [redacted] who is leaving) and she described the schools as having (metaphorically) like an above ground presence where the kids with dyslexia learn and then a below ground level where all the people with PMLD or more severe disabilities are. She was worried [redacted] was excited about going back but didn't fully comprehend the changes that he would experience in his life.

After I met with [redacted] I went to hang out with [redacted] who was being supported by [redacted] to make a book of memories of his time at Phoenix. [redacted] told me about his 18th birthday the previous week and told me to smell him - [redacted] had bought him some aftershave and he was very proud to be wearing it. We undertook the self-portrait, [redacted] decided he wanted to use the iPad and he tried to use the stylus which had special weighting so it was better for those who have less control over fine motor skills, but he wasn't satisfied with what he had drawn so he decided to direct [redacted] to draw on his behalf. There was an amusing moment after he had directed [redacted] to draw his face/body/chair that he said (in Polish although I could understand) that he wanted to be holding a cappuccino - Justyna was like "what? really?!" and [redacted] was very insistent that he wanted a cappuccino in the picture. This seemed to relate to what the adults always say about [redacted] that he sees himself as being 'less disabled' than the other young people and more like a member of staff. It felt as though by adding in the cappuccino [redacted] was presenting himself as refined and adult. As part of the self-portrait we spoke about what is important to him and what he liked and didn't like. [redacted] presented himself as being very proud to be Polish and often said he liked Polish things more than English things and that things (such as fishing and swimming) were better in Poland than in England as they were cheaper. He also spoke briefly about politics, but did say that "politics isn't everything". Once we had finished the self-portrait I asked Norbert if he wanted to do the life mapping or go on to the camera task - [redacted] said he wanted to use the cameras and we set them up and learnt how to use them. As [redacted] said he wanted to film [redacted] we went to find her but the camera had run out of battery so we just chatted to her and [redacted] showed her the stuff.

After lunch I went back to [redacted] to work with [redacted]. We started by doing the life map - because [redacted] can be very verbal sometimes it is easy to forget that he doesn't necessarily have all the processing or reasoning skills that his language suggests and this came up during the life map research activity. Rather than trying to put the words in levels of importance and linking them we used the words "really really really good" and "okay". [redacted] wanted a label that said going to London with Dad but he didn't want Dad to have his own label. I could tell towards the end that [redacted] was feeling quite apathetic to the task and was ready to finish so I asked him and he said he wanted to finish. [redacted] seemed a lot keener on the camera task and I found out the next day that he had taken each member of staff into the storage cupboard one by one and explained to them his job and what he was going to do with the camera. I think [redacted] finds 'why' questions quite challenging and tricky and sometimes struggles to answer questions about how he feels about people/situations. However he is really good at telling me stories about his life.



Appendix x

Example of participant's responses to TALC

Maximum of 80 questions
TALC Picture Assessment Score Sheet
 Elklan
 Child's name: **A** Date of birth:

80% needed for competency level
 Date of assessment I:
 Date of assessment II:
 Date of assessment III:

1. Colouring

Blank Level	Question	Child's response	Sub Total			Level
			I	II	III	
1	1 Point to the book	pointed.	1			Level 1
Sub Total			2			
2	2 Show me a big flower	pointed	1			Level 2
3	3 What are the girls doing? (Point to the girl on the right)	painting	1			
4	4 This girl is using a felt pen. What else can they colour with?	brush	1			
5	5 What could they use to paint with?	brush & paint	1			Level 2
Sub Total			4			
3	6 Which girl is not wearing trousers?	pointed	1			
7	7 How do the girls feel?	happy (yellow) not happy (blue)	1			Level 3
8	8 What are they saying to each other?	don't know	0			
Sub Total			2			
4	9 How do you know they are friends?	talking	1			Level 4
10	10 Why should the girl put the lids on her felt pens?	so they don't get lost	1			
Sub Total			2			

3. Going to the park

Blank Level	Question	Child's response				Sub Total			Level
			I	II	III	I	II	III	
1	21	Point to the swing	pointed			1			Level 1
	22	Where is the slide?	pointed			1			
			Sub Total						
2	23	What else can the children play on?	roundabout			1			Level 2
	24	(Point to the boy and girl by the roundabout) Look at the boy and the girl. Show me the boy's boots.	pointed			1			
			Sub Total						
3	25	Point to the boy at the top of the slide and then the girl who is pushing the round-a-bout	pointed			1			Level 3
	26	What happened to the baby?	slipped in pram			1			
	27	How does the baby feel?	not happy, wet			1			
	28	What is Daddy going to do?	pick			1			
	29	What is Daddy saying?	pick			0			
			Sub Total						
4	30	(Point to the girl on the swing) The girl wants to swing high. What could she do?	push			1			Level 4
				Sub Total					

4. Getting Dressed

Blank Level	Question	Child's response				Sub Total			Level
			I	II	III	I	II	III	
2	31 (Point to the first picture) What is on the bed?	clothes	1						Level 2
	32 What goes with socks?	shoes	1						
	33 You put shoes on your.....	feet	1						
			Sub Total			3			
3	33 This boy is getting dressed. Put the cards in the right order	(trunk words - aratic?) put on socks, trousers, t-shirt, shoes	1						Level 3
	34 Tell me the story		1						
	35 What does the boy put on after his jumper?	shoes	1						
			Sub Total			3			
4	37 Why is the boy wearing a jumper?	cold	1						Level 4
	38 If it was a hot day, what should he wear?	t-shirt	1						
	39 How do you decide whether to wear a jumper or not?	maybe hot or cold	1						
	40 Tell me two things which make you feel hot	jumper, sweaty	1						
			Sub Total			4			

Elkkan
TALC Picture Assessment Summary of Scores

Date of Assessment I... 13/2/17

Transfer the sub total scores here:

	Level 1	Level 2	Level 3	Level 4
1. Colouring	1	4	2	2
2. Party	2			
3. Park	2	2	4	1
4. Getting dressed	1	3	3	4
5. Going in the car				
6. Shopping				
Total	3	9	9	7
Maximum possible Score	3	9	11	7
Score needed for 80% competency	2	7	9	6
Competency achieved	✓	✓	✓	✓
If competency not achieved, percentage scored				

Date of Assessment II.....

Transfer the sub total scores here:

	Level 1	Level 2	Level 3	Level 4
1. Colouring				
2. Party				
3. Park				
4. Getting dressed				
5. Going in the car				
6. Shopping				
Total				
Maximum possible Score	6	18	17	18
Score needed for 80% competency	5	14	14	14
Competency achieved				
If competency not achieved, percentage scored				

Date of Assessment III.....

Transfer the sub total scores here:

	Level 1	Level 2	Level 3	Level 4
1. Colouring				
2. Party				
3. Park				
4. Getting dressed				
5. Going in the car				
6. Shopping				
Total				
Maximum possible Score	6	18	17	18
Score needed for 80% competency	5	14	14	14
Competency achieved				
If competency not achieved, percentage scored				

Appendix xi

Excerpt of Destroyer's Member checking text

Me

That's me, I'm happy, that's not my eyes but...that's kind of like my hair but it's a bit blondish. These are little blades, you see them, red, orange and a blue. I've draw the red one what is pause, blue is slow motion, green is fast forward and orange is umm, rewind. In the Ninjago they're the time blades. Umm, in the past, the elements masters they had loads of elements, there was a time of elements, two twins, the time twins, used their power to take down the the elements masters, but two people put their people in blades and they're using the blades to take over Ninjago. If I had the blade, I would be trying to conquer the world. Cos the good thing with slow motion, if someone tries to attack you, you could just put them in slow motion and move away, so it means if someone did try to attack me, if I was, then I could just hit them with the slow motion and it means I could move away or hit them back, so that means I don't get hurt, with a pause blade, if someone was trying to throw at me or hit me I could pause them and punch them so I can get far away and stop in time. And with the fast forward blade, umm, I could go technically really fast cos I'd be stopping time, so if someone tries to hit me I could just use that time blade to move out the way and hit them really fast. If I ruled the world I would stop bullying. And with the rewind one, so if someone got stabbed I could rewind time to stop that person from getting stabbed and then that person will be fine. If people get like shot or something, then that means I could just rewind it or stop it. Sometimes I have dreams when I sometimes get stabbed, don't know why. I don't get them anymore. I don't know why they have stopped. **That only happened once. Sometimes when I play Lego I kill myself, or I make new one and I'm alive.**

I want a dragon too. Just fly around, burning stuff, putting it out, just...I don't know, I won't draw that. I'll just leave it like that. They're not real, so it's kind of sad.

Sometimes I am good, sometimes I am bad. Like being nice, and sometimes I can be quite mean, but not...Umm, I say things to people that they sometimes make fun of me about. Then I go make fun about them. People make fun of me all the time. I would use the time blade to go back and instead of saying it to me, I quickly say it to them. If people stopped making fun of me, I would be kind of happy cos that means no one will put down my confidence and I will be happy

I like loads of things...Lego, games, TV, my family. I like Going on computers and playing games. I don't like then teachers saying that we can't play games on it. I don't like spiders. I don't want spiders to take over the world.

Sometimes I'm not trusted with sharp scissors. Umm, I sometimes cut my hair. I get told off. **(That's sometimes, I do it like this, "I'm a hairdresser")** And I get banned from my electronics. It is very sad for me. Every time I go home I just go on my electronics.

Have you ever said something What's weird and demonic before? I mean something really weird, like really odd. I said, "blood, death and happiness. One of my friends said I'm beyond help...like therapy help. I felt happy...I Was kind of sad at the same time.

You got to be happy. You just have to be happy.

Appendix xii

Accessible member checking text




This is an extract from Asim's member checking text. The names have been obscured for anonymity.











Me

I'm  I'm **18**. I go to  school.

I  like  computers and  iPads. You know small  iPads, I've got

that at  home. And I got a big one. One is  broken. I  dropped

it,  accident,  broke. You know the circle, big screen is  cracked. I

 told Uncle,  he's got  no time to  fix it. I  buy the

 new smaller one. I got a  case. I  play games on it.  Racing



at Weekends. Or, you can come back from school. At home, you



can do that. Anytime. Monday Tuesdays, weekends. Anytime you

can.



I got Xbox at home as well. I got racing and you that,



you know, you know do the missions. I got Batman games.



4

Lots of games I've got. I nearly buy Playstation 4 and then my








1





Uncle said you have to buy Xbox 1. That one's





1

too expensive. That's why I chose it, Xbox 1.

I  like  cars.  BMW.  White.  Uncle, he's had them one day but




now it's gone. My  dad  sold  limo to my  Uncle now.






Because  he  don't do jobs anymore. My Uncle had it first time

and then my dad had it, and now my Dad sold it, give it to

Uncle. Sometime people  ring you can  go do  jobs. My  Uncle





 bringing limo in my  Prom. Mine and Phil's prom. It's got the


 lights and  screen, everything it's got. You  can't put your





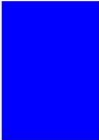
 seat belt on, it's got  no  seat belt. You  can have a  drink,



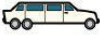
anything. It's got all the  seats for everyone apart from






 wheelchairs. Because  wheelchairs,  can't come in One day, you





know,  **A** Asif  prom and my  uncle bring him and then he  didn't

 give a ride, and then my Uncle had the small one and the big

one. He  bring **2**  limousine and he  didn't  ride. 

 had a meeting and then they  sort the  limo out.

 Games. I  like  snakes and ladders, I  like  computer games. I

 like  racing. I have to use...my  uncle take me  eyes tested and

I have to use glasses. Uncle choosing the black ones, and

uncle said you have to use it, you can use it when iPad or

computers, you can use it, not all every day. No break

them. I like the glasses. I didn't see anywhere and the

doctor said you can't see anywhere. He put plastic glasses,

and he says try and then got a big screen with numbers. 123

Then I see wrong, I had three wrong and two right,

that's it.

I nearly have a pet but Uncle said we don't got enough



space.

Appendix xiii

Example of transcript: Ruby, Week 1 Transcript in full

1. Ruby week 1 Transcript

Hannah: Cool. So, I've got the instructions here. So—So today you can make a self-portrait and we'll make a film about it. Umm, a self-portrait is a picture of who you are now. So, it tells me who you are today, when we've met and it shows me how you feel about yourself. So, once you've drawn a picture of you can you include like, in the picture as well, things that are important to you, things that are really, really special. Things that you like and things that you don't like and things that you want and things that you don't want. Is that okay?

Ruby: Yeah.

Hannah: Does is all make sense?

Ruby: Yeah.

Hannah: Cool. What do you want to use?

Ruby: Umm, paint please.

Hannah: Cool. Let me go get you some water. Here we go. While you get started I'm just going to quickly pack up the computer, okay?

Ruby: Yeah.

Hannah: You can use these if you want to mix any of the colours. Is this your face?

Ruby: Yeah.

Hannah: Watch out for your blazer so it doesn't get yellow on it. Is that your hair?

Ruby: Yeah.

Hannah: Do you like it—Wearing your hair when it's down or when it's up?

Ruby: When it's up.

Hannah: When it's up. In the picture is your hair going to be down or up?

Ruby: Umm, I don't really know. Probably both of them. Because I don't really like my hair

down. Because it looks odd when my hairs down sometimes.

Hannah: Why?

Ruby: I don't know. It's just-- Just that it looks so weird.

Hannah: Who does your hair?

Ruby: Sometimes my mum, sometimes I do it by myself.

Hannah: Do you like doing art?

Ruby: Yeah. I'm not really good at drawing though, that much.

Hannah: But as long as you're enjoying it, right?

Ruby: Yeah.

Hannah: In the picture, how do you feel?

Ruby: Erm, happy.

Hannah: Why have you chosen these colours?

Ruby: Erm, just to look different in the picture.

Hannah: Yeah? Do you want to add anything else in the picture?

Ruby: No.

Hannah: Finished. Okay, so, that's you. So, can we add-- Oh, the instructions say, can you add what you like and what you don't like. You can write, you can draw, you can stick some stuff on it. It's up to you.

Ruby: Erm, probably stick some stuff onto it.

Hannah: So, you can just have a look through here and you can just rip it out and stick it on. That's alright. What do you like?

Ruby: Erm, this one and this stuff.

Hannah: What do you like about them?

Ruby: Umm, just that they're colourful and they're very like, big. And there's a lot of space.

Hannah: Would you like them in your garden at home?

Ruby: Yes.

Hannah: Do you want to stick the whole page on or just a little bit of it?

Ruby: Umm, some of it.

Hannah: Some of it. I don't think we have scissors but we could rip it like, really carefully like this. You can use this page as well if you want. Shall we write 'I like' up here?

Ruby: Yeah.

Hannah: What do you want to write it with?

Ruby: Umm, crayons.

Hannah: These?

Ruby: Yeah.

Hannah: What's your favourite color?

Ruby: Umm, purple and blue.

Hannah: Okay? What other things-- What do you like in school?

Ruby: Umm, hanging-- Hanging around with my friends.

Hannah: Do you want—Shall we write that or can we draw it?

Ruby: We write it.

Hannah: Write it. What else do you like?

Ruby: Umm, I like pizza.

Hannah: Do you want to write that or draw it?

Ruby: Umm, write it.

Hannah: Cool. Cool. What else do you like?

Ruby: I like hanging—Hanging around with my brothers and sisters and my cousin.

Hannah: Do you want to write that down? Cool. Are there any other things you like or do you think you're finished with I like?

Ruby: I'm finished now.

Hannah: Okay, can you think about things you don't like?

Ruby: Erm, I don't like erm, to eat like, Ghanaian foods. I would like to eat English food.

Hannah: Do you want to write—Do you want a new page to write that down? What is your country?

Ruby: Ghana.

Hannah: Ghana. Were you born in England or Ghana?

Ruby: Oh, I was born in this country and I'm from Ghana. My parents were born in Ghana.

Hannah: Yeah.

Ruby: I want to-- I wish I was born like, in America or something.

Hannah: Why?

Ruby: I just like that country.

Hannah: Yeah.

Ruby: It's such a big country that's why. I wanted to—We were meant to go to America, this time our mum said that we can't go.

Hannah: Oh.

Ruby: Because umm, we have to buy a car.

Hannah: Yeah.

Ruby: And I want to go to America not buy a car. And next year I'm going to Ghana. And my mum said I might not go because she has to check on me and my brother to make sure that we're behaving well. Because I don't know if I'm going to go or not.

Hannah: Do you want to go to Ghana?

Ruby: Yeah. It's just—It's just the (inaudible) is because hot weathers I usually wear like, coats, jumpers and that. That's what kind of like, I used to wear on hot days.

Hannah: Why?

Ruby: I don't know, it's just like, too hot. And I get in the (inaudible) the sun's going to burn me or something. So that's why I wear like, jackets and that.

Hannah: Yeah.

Ruby: In the hot weather.

Hannah: Do you feel even more hot when you wear a jacket or do you feel better?

Ruby: Sometimes better, sometimes a bit hot. Sometime—Sometimes I have to stay indoors because it's so hot outside.

Hannah: Yeah.

Ruby: Though I can still breath outside because it's like, hot. And I have to like, keep using fans to flap myself because it's really hot there.

Hannah: Yeah.

Ruby: Well, it's not like, that hot. Compared to like, this country. It's just a bit hot.

Hannah: Yeah.

Ruby: It's just I'm so hot in that country. That sometimes I can't even like, get out of bed or something because—because the weather is really, really, really hot. And after you're drawing the curtains because it's really hot. And—And it's just—It's just really hot there. And I wish I went to America. We were meant to go this year but my dad had—Wants to get a car instead because sometimes we might go shopping or something. To like, really far places. And it's always—It's always me that sits at the front because I'm the oldest in the family.

Hannah: Yeah.

Ruby: Because my sister is umm, 10—Like, I've got 2 brothers, 1 of them is umm, 3 years old and 1 of them is 12 and I'm 13 years old.

Hannah: Yeah

Ruby: And—And sometimes my brother gets to sit at the front because when we went shopping the other time. Because we went to look at these brand-new like, TVs that we wanted to buy.

Hannah: Yeah.

Ruby: I wanted to sit at the front but my dad said I have to sit like this. I wanted to sit at the front but my mum said I have to sit erm, at the back because of—Like, in the second row in the car. I had to sit in the middle because umm, because it's always me that sits at the front and (inaudible) has to sit at the front because umm—Like, dad said if umm, little children sit at the front they'll get like, arrested or something. So, they're not allowed to umm. They're not allowed to sit at the front. Because only I'm allowed to sit at the front. And I'm going

to—Umm, and mum said that when I'm 16 I'm going to have a driving license.

Hannah: Yeah?

Ruby: To like, know how to drive a car. Because I need to learn how to drive because when I get older I can drive to places.

Hannah: Do you want to learn how to drive?

Ruby: Yeah, but I don't think I'm-- I'm—Because if I learn—Because when I have a driving lesson and start driving I might crash into other peoples' cars because I'm not very good at driving cars. Because the other time we had to drive these toy cars and we kept bumping into other peoples' cars. So, I don't think I'll be good at driving in the future. So, it's just the best if I just start walking instead of like, driving a car. Because I'm not good at driving cars. But I drove—I drove a toy car.

Hannah: Yeah.

Ruby: And I kept bumping into other people's cars and I couldn't even move at all like, the car. Me and my sister were sitting next to each other when we were driving the car and my cousins' kind of good at driving the car. So, yeah, and my cousins' name's Daniel, he's 17 years old.

Hannah: Yeah.

Ruby: And he—And he lives far from here. But I think this summer holiday I might go to his house.

Hannah: Do you like him?

Ruby: Well, not really, he's kind of, annoying.

Hannah: What does he do?

Ruby: He keeps saying stuff about me and my brothers and my sisters. Because my brother always wears the same clothes every time. When my cousins comes he keeps wearing the same top, the same trousers, every time my cousin comes. And every time he comes—Umm, every time he comes umm, he keeps telling to my sister "why—Every time when I come to umm— Our, umm, our house why does umm, Freddy keeps wearing the same clothes?" And he said that "does he-- Does he have other clothes to wear?" And Freddy says "yes, obviously" and umm, he says that "if he had other clothes why didn't you wear them?" Because once, my brother, every time he keeps wearing the same jumper, the same top, every day outside. And when we were like, going to the shop, going to different places and that. And err, and my mum said that—And people outside get fed up of him and were wearing the same clothes. So, my mum said that he has to start wearing different clothes. And my mum said that erm, if you go outside then people are going to keep—Are going to look at him wearing the same clothes and some people get really fed up. Because every

time they walk past him every day and he's always wearing the same clothes.

Hannah: Do you think it's okay that he wears the same clothes?

Ruby: No, because it sticks of (inaudible). Just makes me want to faint or something.

Hannah: Yeah.

Ruby: And no, because, every day—It is every day he wears the same clothes. Last week he wore the same clothes, today he wore the same clothes, yesterday he wore the same clothes. And he wears the same clothes to bed. It's like he doesn't change his clothes or anything.

Hannah: Do you know why he wears the same clothes?

Ruby: Err, because—Err, yeah, because sometimes his clothes get dirty and you still feel like putting it in the washing machines. He just decides to wear the same clothes every day and he—And he has other clothes in his desk to wear, he doesn't even bother to wear those clothes. So, he just like—Just wearing the same clothes every day and my mum has to keep shouting at him. It has to keep saying to him of, "why—just wear some different clothes and stop wearing the same clothes because it is getting boring and..." And she said, "if you keep wearing the same clothes everyday then the people outside are going to keep looking at you." And it's really boring when he's wearing the same clothes every time. It's like, every single day he's wearing the same clothes and it gets boring. Umm, sometimes when he wears the same clothes I just have to keep standing away from him because he sometimes stinks. Sometimes wearing the same clothes is not good.

Hannah: Yeah.

Ruby: And he's so weird at home. He keeps saying that—He keeps saying weird stuff about people. And do you know that he has—He sleeps in the bottom and he keeps shaking it so much and it's so annoying that I can't even get to sleep at night. Because every night I look up outside my—Outside my window because me and my brothers and my sisters share a room because our house is really small. It's not that small but it's just like—It's just we live in a flat. Umm, and umm, every time I look outside the window I see this light on his computer. He's always playing games at bed—When he—At—At night time when he's meant to be going to bed. Every time I see him, every time. Playing games with his computer. And this-- And this (inaudible) I said to my brother "is he okay?" And he said "yes." And my sister said that we have to give him a piece of our minds. And just because he was in the toilet for so long. I couldn't even stop laughing like, for so long. Because...

Hannah: What do you think about the man playing games?

Ruby: He's just so weird. He's a grown up and he's a man and he's playing games and watching football every night when he's meant to be going to bed. Every day I see him playing games, watching football, playing like, games like, what like-- what people in his school play. Every time I look outside the window to him watching games and playing stuff

on his computer. He was doing this thing yesterday—Yesterday he was watching football.

Hannah: Do you think it's really important that people follow rules and do the right thing?

Ruby: Yeah.

Hannah: Do you think he should behave—Do you think the man behaves like an adult?

Ruby: No, he just plays boy games like all the boys. And one time—Because me and my brothers were trying to—Were calling that man to tell him something and he say—And we kept on calling and calling his name and the—And the man said "if you call me—If you keep—If you knock at the window and call my name 1 more time I will call—I will call the police or call your mum to come—Come and like, umm, come and tell you to stop knocking at the window. Because we kept calling that man and the man kept getting fed up.

Hannah: What were you trying to call him to say?

Ruby: I don't know. We wanted to talk to him about something but I can't remember what we were going to talk to him about. I think it's err, something to do with like, something like, why he keeps playing games on the computer.

Hannah: Yeah.

Ruby: Then that man got so fed up. He said if we call his name 1 more time he was going to call out parents.

Hannah: How did that make you feel?

Ruby: It just so—It's just so annoying when he kept saying that. We were just trying to tell him something and he just said umm, umm he just said to us "if you don't stop calling me I'll call your mother or I'll have to call the police to come and sort you kids out. And it's just so annoying to see that man because we kept calling and calling him and telling him about something but I don't know how he-- I think his window was open. We kept calling the man, every time. And he was shouting at us and saying to us, umm, "stop calling my name." And he got a headache of it so we stopped calling. Maybe that's why he doesn't open his window anymore because of us. Because then we had this person that lives opposite us, 46 people. My mum always has this argument with them, it's always my mum. And-- And they keep blaming out family because of—We put rubbish at their door even though it's not—Even though it's now ours. And my mum said, because of the—The 46—I think Abigail's mum—That's her name, Abigail. Her mum umm, copies everything my mum says apparently and I don't know why. And, umm, which is just so annoying because we always have an argument with these people every morn—Not every day, just sometimes. And he mum—Abigail's mum kept having an argument to see like, who takes the rubbish off the door. My mum said that she's not going to take the rubbish off the door because about—because umm, she said that she didn't do it in the first place. And the 46 umm, people said that umm, it—It must have been you guys that left the rubbish at the door but none of us left the rubbish at the door. It must have been already there, you must have blamed another

person for it. And he said that if you don't take the rubbish off my door I'm going to call the police.

Hannah: Why do you think those people at 46 think your family put the rubbish there?

Ruby: Err, because we always have an argument all the time. And every time we have an argument, umm, they keep blaming it's us even if we didn't do this in the first place. And it's just really annoying when umm, when they keep saying stuff to us. And they just copy everything—Everyone in my family.

Hannah: Do you like where you live?

Ruby: No, it's too small. It's cramped because my room's so small there's not even—There's just no like, space to keep like, anything. And we have to keep—Keep the clothes under the bed and the wardrobe is not that big and I want to move into—Because we're going to move soon but I don't know when. Because we go on this website about housing to check what house. We want to move into but I don't think my parents does that anymore. I don't think that they move, umm, I don't think that they (inaudible) anymore. Because they were—They were meant to do the housing. (Inaudible)

Hannah: Do you remember what you were going to write here?

Ruby: (Inaudible)

Hannah: You were going to write about what you don't like.

Ruby: Yeah.

Hannah: Is this potato?

Ruby: Yeah.

Hannah: You don't like potatoes? Cool. What else don't you like?

Ruby: I don't really know.

Hannah: A little while ago you said that you don't like eating Ghanaian food, you like to eat English food.

Ruby: Yeah.

Hannah: Why?

Ruby: Umm, I like eating (inaudible) rice and some bits but... It's just that some of the food just doesn't taste—Doesn't taste nice. It doesn't have any flavour in it. And sometimes it doesn't taste good. So, sometimes I do like eating it but—But I like English food more (inaudible) country food. But I want to try like, American food. Because I really want to go to

America. But—But—But my mum umm, says that we can't go but I really, really wanted to go because last year we went to Germany and it was kind of, good.

Hannah: Whereabouts in America would you like to go?

Ruby: Hmm, I don't know. I think that Mississippi. I think that place. I don't know if (inaudible) is in umm, America.

Hannah: I think it is, I can't remember.

Ruby: Maybe 1 of those places, (inaudible) or umm, Mississippi.

Hannah: Umm, do you feel—So, your mum and dad were boring in Ghana and you were born here.

Ruby: Yeah, all—Me and my brothers and my sisters were born in this country.

Hannah: Do you feel really British or do you feel a bit Ghanaian and a bit English?

Ruby: Umm, I feel more British because I can't speak any languages. The only language I can speak is English. Because I want to try and speak something different-- Another language but I just find it so hard to say some stuff. Because—Because when I went to Germany I had cousins that was umm, German, I did not even understand what they were saying.

Hannah: Where they talking in English?

Ruby: Yeah, a bit of English, lots of umm, German. I couldn't even understand what they were trying to say. I was saying "huh? I don't understand what you're saying." And they'll just keep talking to my-- I had to keep asking my sister what they're saying.

Hannah: Yeah.

Ruby: Because they were speaking Ghana language as well. I didn't-- I don't understand Ghana language. My sister understands quite a bit, well, not that much. I had to keep asking my sister what are they saying? I don't understand. And she had to keep explaining it to me. And she keeps ask-- Because sometimes when the WIFI's not working I always ask my sister to fix stuff for me.

Hannah: Yeah.

Ruby: And my-- And I think their parents keeps saying that "Why do Freddy keep asking (inaudible) to do everything for us?" And we said that because we don't know how to do them so we just ask someone that's like, good to help us with things. Because my sister, she's good at math, but I'm not that good at math so she helps me.

Hannah: How old's (Inaudible)?

Ruby: Err, she's 10 years old.

Hannah: She's 10 years old.

Ruby: She's in year 5.

Hannah: Yep.

Ruby: And my brother is in year 7.

Hannah: Yeah.

Ruby: And I really wish I was really good at math but I don't know why I'm not good at math. I'm good at some bits of math but not all bits of it.

Hannah: What bits of math do you like—Are you good at?

Ruby: Umm, something to do with times, addition and that.

Other Speaker: Thank you!

Hannah: No problem!

Ruby: Something to do with like times..

Other Speaker: Do you mind if I put the radio on?

Hannah: Err, can you just give us 1 minute and then you can put it on? Actually, I think, is it break time now?

Other Speaker: Yes, it is.

Hannah: Okay, alright, umm. Are you—Are you okay for me to stop now? Can we finish this next week?

Ruby: Yeah.

Hannah: Cool, and then we've got—So, next week and then probably the week after we can start using the camera. Is that alright?

Ruby: Yeah.

Hannah: Cool. Thank you so much Ruby.

Ruby: You're welcome

Appendix xiv

Member checking text with changes made by Nataliya

Names have been obscured to preserve anonymity

<p><u>Things I like and don't like</u></p> <p>Pink is my favourite colour.</p>	<p>Hannah</p>	<p>In the summer we went to Bangladesh.</p>
<p>These things make me happy: Music, good grades, good remarks, Shakespeare. It's important to get good grades. Sometimes I feel happy in myself.</p>	<p>Hannah</p>	<p>Celebrities</p>
<p>I don't like boys that are rude to me, A.K.A. [redacted] [redacted] is a year 8 who is not in my class but is up here and he says that "you will never be a super singer in the future." But sometimes I just ignore it. [redacted] comes to [redacted]</p>	<p>Hannah</p>	<p>[redacted] just annoying me in class and ↓</p>
<p>I would like to live in New York, because the view out there is great. It's got so many lights. Really and the city is just big. You don't know what the chances are-- might be of having opportunities there.</p>	<p>Hannah</p>	<p>But also I would like to live in Dubai ↓</p>
<p>I don't want assassins coming after me, because assassins kill the most important people and some of those assassins might kill the best pop stars too. When I'm older I don't want that. And I get the feeling that Luke might want to kill me. But when he does something <u>wrong</u> I will tell miss. Like, I'll-- I will never let that happen, ever. I don't worry about assassins much, I am strong.</p>	<p>Hannah</p>	<p>I think we could just ignore it. How ↓</p>
<p>I don't want injustice. Injustice means a lack of justice. Justice is just treatment then there's legal proceedings. Injustices are taxes being too high. High crime rate.</p>	<p>Hannah</p>	<p>Just ignore all of that.</p>
<p>I don't like sauces. Just don't like the tastes of it. Well, it tastes weird.</p>	<p>Hannah</p>	<p><u>Yes</u>, it's still true.</p>
<p>I don't like being bored. I feel bored when I feel like going to sleep. When there's not much to do. When I don't have my book with me. The book that I have-- That I have now is called 'So Big.' Yeah, I feel like that sometimes.</p>	<p>Hannah</p>	<p>But now I've got a new book called 'Thp</p>
<p>[redacted] is important to me.</p>	<p>Hannah</p>	<p><u>Yes</u>, and also, [redacted] you (Hannah), ↓</p>
<p>Music is really important to me. I haven't made any music yet, but I am singing. I will be famous. Well, I do like singing and maybe going to The Round House choir could help me maybe when I'm on the stage. And maybe I could go in through that and maybe I could become a solo artist. And, you know, sing my heart out. I've just started writing lyrics on my phone. Well, there are some that aren't finished but I can't show them to you yet. Or sing them to you yet. But they will be--They will be finished.</p>	<p>Hannah</p>	<p>Well usually I don't do choir, and ↓</p>
<p>Shakespeare is such an awesome man. Really his plays are just breathtaking. When I just read <u>them</u> I just can't stop. My favourite ones are Twelfth Night, Midsummer Night's</p>	<p>Hannah</p>	<p>It's all still true, I really love ↓</p>

Dream, Romeo and Juliet. I am good at quoting Shakespeare. [redacted] comes and meets me and she knows that I love Shakespeare and that I know a lot of Mid Summers Night Dream. That I can quote really good. Well, there are a few that are my favourite. Romeo and Juliet. Err, Midsummers Night's Dream. Twelfth Night. |

Friends are special. Some of them come to [redacted] some of them don't. Some of them are in year 8. Some of them are in year 7. I have a few up here in St. Patrick's, but not many in my class. It makes me feel a bit absurd. Because up here not—I've got my own friends. While in class—Whilst in my class it's just compulsory and strict and weird. I sometimes feel that my class under appreciate me. And there's one girl that I call a heart breaker. Because she sometimes annoys me. A lot. Umm, I ask her to leave me alone many times. Everything's just complicated. |

I like [redacted] a lot, really. Because I can sit here, read my book, listen to the radio. The people that come to [redacted] well, some would have autism, social problems. Autism, it's something to do with us when we're going crazy. I don't know. |

Hannah
Yes still true – some of the friends I have in [redacted] are called [redacted] and usually we don't do a lot but when we are waiting for the [redacted] door to open we do a little talking and running around. Yes sometimes the area outside of [redacted]

It's still true. I don't have much friends in my class.

I feel like I've been underrated by most of them (people in my class)

It's true – everything is complicated in my life, with the class, with my teachers, my class, I've got no friends everyone leaves me, my heart is broken.

Hannah
Yes, I still do love [redacted]

I still sometimes feel like that, I'm going to go ~~crazy~~, I'm going to lose my mind, feel like I'm in a battle field, where enemies, friends, kings, queens come on top and everyone is fighting for their throne.

Like I feel like there's war going on between us. In life.

Autism, sometimes messes with you mentally and physically. I have Autism. (Me: who told you) I just knew.

Appendix xv

Consent forms: Accessible Consent Form Gatekeeper, Consent Form Adult (Teachers, TAs, SENCOs)



Hannah Ware
PhD Candidate
Faculty of Education
University of Cambridge
184 Hills Road
Cambridge
CB2 8PQ

Dear Parents/Carers,

Your child has been chosen to take part in the project Identity and Belonging.

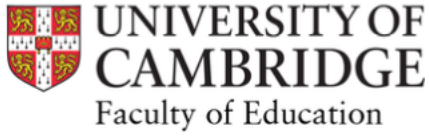
The project is being done with the University of Cambridge.

Your child will make videos and draw pictures during the project. The videos and pictures your child make will be used in the PhD. Your child's name will not be used. No videos of your child's face will be used.

Please sign the permission slip on the next page and return it as soon as possible if you would like your child to take part.

Yours sincerely,

Hannah Ware



Hannah Ware
PhD Candidate
Faculty of Education
University of Cambridge
184 Hills Road
Cambridge
CB2 8PQ

Name
Address

Date

Dear

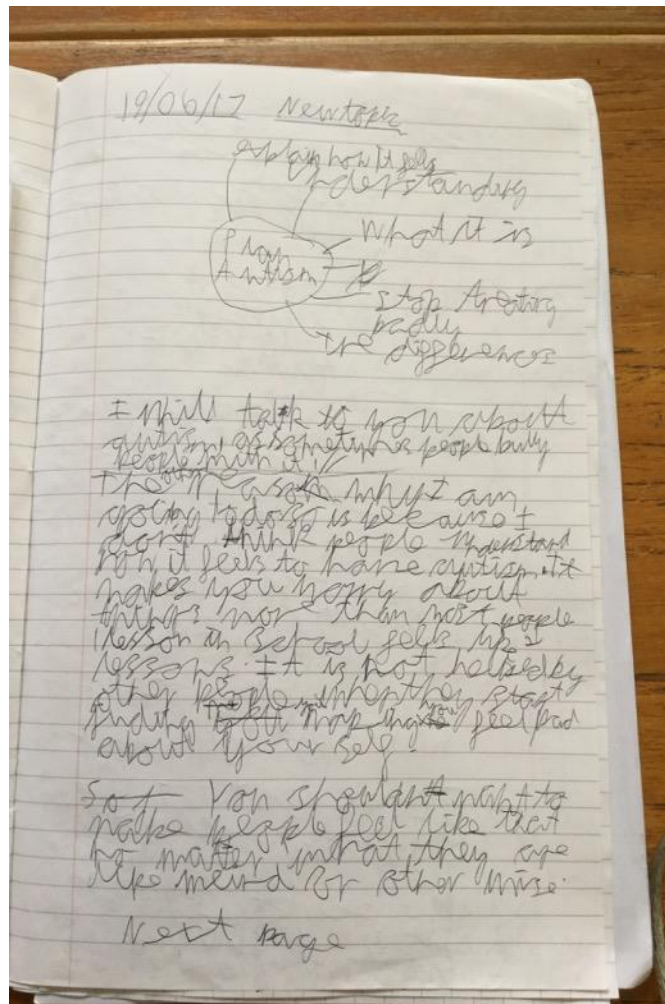
I am asking you to sign this document agreeing to take part in the research project *Identity and Belonging*, that I am conducting. As a research participant, you will take part in semi-structured interviews. We will agree together when and how often to meet.

I am also asking you for your consent in letting me use the audio-taped material for my project. I can guarantee you that all this material will be kept strictly confidential, and that I will use it only for research purposes. Anytime I will refer to your data, this will be indicated with a pseudonym that you will choose yourself.

Signed: Date:

Appendix xvi

Example of Nameless' English work where he had written on Autism



I will talk to you about autism, as sometimes people bully people with it.

The reason why I am going to do so is because I don't think people understand how it feels to have autism. It makes you worry about things more than most people. 1 lesson in school feels like 21 lessons. It is not helped by other people when they start finding you making and making you feel bad about yourself.

You shouldn't want to make people feel like that no matter what they are like, weird or otherwise