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Thesis Title

‘It’s autism, it’s just a name’: Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis.

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Individuals regarded as being on the autism spectrum are commonly understood to experience difficulties with social communication and to have an inflexible style of thinking (APA, 2013). Recent research has proposed a prevalence rate for autism in the UK of 1.04 per cent (104 in 10,000) (MacKay, Boyle and Connolly, 2016). Autism 'diagnosis' in the UK is a National Health Service-led process, whereby professionals involved, compare a child or young person's behaviours against a behavioural checklist (NICE, 2011): hence the use of medical language or terminology around this topic.

For children and young people autism diagnosis tends to be 'done to' or 'given', rather than 'done with' or 'sought'. I wanted to hear the views of adolescents who had been given an autism spectrum diagnosis and to explore the impact of this diagnosis on their relationships, their sense of self and their future aspirations. I hope that health and educational professionals and young people will be interested in hearing these voices and viewpoints.

I decided to focus upon adolescent females, a group whose voices are missing from much of the literature around this subject. There are many more males diagnosed with autism than females and autism could therefore be regarded as a predominantly male 'disorder' or 'condition'. Adolescent females who are diagnosed with autism experience a dual difference: difference from their 'typical' peer group and being in a female minority of people 'diagnosed' with autism.

Six females aged between 14 and 20 participated; five participants were attending mainstream schools and one participant is a university student. Interpretative Phenomenological Analysis (IPA) was used to analyse or make sense of participants' accounts and to identify superordinate themes for individual participants and across the group. IPA aims to offer insights into how a person makes sense of a given phenomenon, in the case of this research, having been given an autism spectrum diagnosis. Three superordinate themes for the group emerged from IPA analysis: Understanding Autism, Acceptance or Rejection and Self and Autism.

Table of Contents

Contents	Page
Chapter 1 – Introduction	6 – 9
Chapter 2 – Literature Review	
<u>Part 1: Autism, an Overview</u>	10
The History of Autism	10 – 11
Prevalence	11
Causation	11 – 12
Psychological Theories	12
Diagnosis	12 – 14
Treatments	14 – 15
<u>Part 2: Critical Perspectives</u>	16
Critical Autism Studies	16 – 22
<u>Part 3: Gender Differences</u>	23
Research	23 – 27
Insider Voice	27 – 28
<u>Part 4: Adolescence</u>	29 – 30
<u>Part 5: Autism and Education</u>	31
Inclusion	31 – 32
Intervention	33 – 34
<u>Part 6: Friendships and Peer Relationships</u>	35
Chapter 3 – Methodology	
<u>Part 1: Epistemology and Methodology</u>	36
Aims and Research Questions	36
Epistemology	36 – 38
Methodology	38
Phenomenology	38 – 40
Hermeneutics	40
Idiography	41
What is IPA?	41
Why IPA?	41 – 43
<u>Part 2: Research Design</u>	44
Ethics	44 – 45
Methods	45
Semi-structured Interviews	45 – 46
Sample Size	46
The Interview Schedule	46 – 47
Conducting the Interview	47
Sampling	48
Recruitment Process	48 – 49
Sample	49 – 50
Validity	50 – 51
Reflexivity	51 – 52
Analysis of Interpretation using IPA	52 – 53

Chapter 4 – Research Findings	
Introducing my Participants	57 – 58
<u>Superordinate Theme 1: Understanding Autism</u>	60
Diagnosis in a Problem Context	60 – 62
What is Autism?	63 – 64
Communication	64 – 66
It’s not me, its Autism	66 – 67
Siblings and Autism	
<u>Superordinate Theme 2: Acceptance or Rejection of Autism</u>	
Acceptance	69 – 71
Dissonance	71 – 73
Rejection	73 – 76
<u>Superordinate Theme 3: Self and Autism</u>	
Struggling with Sense of Self	78 – 82
Stronger Sense of Self	82 – 86
Chapter 5 – Discussion	
Literature	87 – 88
<u>Research Questions 1 and 2</u>	88 – 95
<u>What can be learned by Educational Professionals?</u>	
The Importance of Voice	95 – 96
Transition	97
Educational Psychologists	97
<u>What can be learned by Health Professionals?</u>	
Diagnosis	98 – 99
Labelling	100
Chapter 6 – Conclusions, Limitations and Recommendations	
<u>Conclusions</u>	101
<u>Limitations</u>	101
<u>Recommendations</u>	
Educational Professionals	102 – 04
Health Professionals	104 – 05
Educational Psychologists	105
<u>Recommendations for future research</u>	105
References	106 – 19

Appendices:	
Appendix 1: Recruitment Poster	117
Appendix 2: Information sheet for participants	118 – 20
Appendix 3: Information sheet for parents	121 – 23
Appendix 4: Written consent form for participants	124 – 25
Appendix 5: Written consent form for parents	126 – 27
Appendix 6: Interview Schedule	128
Appendix 7: Ethical Approval	129
Appendix 8: Transcript 1 – Interview with Kerry	130 – 39
Appendix 9: Emergent themes for Kerry	140 – 41
Appendix 10: Example of a photograph showing how connections across emergent themes were organised for Kerry	142
Appendix 11: Emergent themes grouped into themes for Kerry	143 – 46
Appendix 12: Superordinate and subordinate themes for Kerry	147 – 49
Appendix 13: Superordinate themes for each participant	150 – 51
Appendix 14: Reflections on each interview, comments on participants' communitive style and summative interpretations	152 – 158
Figures:	
Figure 1: Superordinate and Subordinate Themes across the Group	56
Figure 2: Superordinate Theme 1	59
Figure 3: Superordinate Theme 2	68
Figure 4: Superordinate Theme 3	77

Chapter 1 – Introduction

Prior to starting educational psychology training I worked for a local authority (LA) as a specialist advisory teacher (SAT) for students who were diagnosed with autism, or who were going through the diagnostic process. This was not a role that I actively sought, but came about through a Children's Services restructure. My previous post was a specialist teacher for students with social, emotional and behavioural difficulties. Hence I unwittingly stepped into the world of autism. My SAT role was primarily to support staff in mainstream primary and secondary schools, in improving educational outcomes for this group of children and young people.

In the course of my SAT work I met with children and young people and listened to their views. Although I was curious about how they viewed their autism diagnosis I did not feel comfortable asking about this potentially emotive subject. For some of the young people their parents had chosen not to tell them about their autism diagnosis, so they were possibly not aware that they were spoken of / regarded in this way.

Upon reflection, I realise that many of the teachers and support assistants, parents, medical professionals, the children and young people diagnosed with autism, and perhaps even I, had developed a somewhat positivist view of autism. That is, once an autism diagnosis had been given by medical professionals, then the children or young person would be expected to, or would expect to, experience a certain set of difficulties which would continue into adulthood.

A requirement of my role was to undertake a Post Graduate Certificate in Autism Studies. During this time I had the opportunity to attend study weekends and autism conferences. I heard young people and adults who had been diagnosed with autism speaking about their lives, for example, Temple Grandin (Grandin, 1995), who had been diagnosed as a young child, and Wendy Lawson (Lawson, 2000) who had been diagnosed as an adult. There was a common theme running through these engaging accounts: speakers accepted autism and their autism diagnoses, and diagnosis often provided a largely welcome explanation for difficulties.

My involvement with this group of children and young people has continued during educational psychology training. Autism is regarded as a spectrum or continuum disorder or condition (Gillberg, 1999). Whilst I have met children and young people whose behaviours are similar to those described by Kanner (1943), I have also met many children and young people who appeared to have few if any 'symptoms' typically associated with autism. I wondered how these young people made sense of their autism diagnoses.

My interest in girls who are diagnosed with autism was sparked by watching an ITV documentary about Limpsfield Grange in Surrey, a school for girls diagnosed with autism. Some experts in the field of autism consider 'autistic' girls to have a different behavioural profile from 'autistic' boys (Atwood, 2007; Gould & Ashton-Smith, 2011). I decided to explore the views of girls and young women who had an autism diagnosis. Although I became aware of similar doctoral studies (Rogan, 2011; Whiting, 2009), these studies included male participants.

My research study sought to explore how adolescent females with an autism diagnosis make sense of their autism diagnoses and how diagnosis has affected and influenced their sense of self or identity. I used Interpretative Phenomenological Analysis (IPA) as a methodological approach (Smith, Flowers and Larkin, 2009; Langridge, 2007) as this methodology aims to offer insights into how a person makes sense of a given phenomenon. I used research findings to attempt to suggest what professionals and parents can learn by listening to the voices of girls and young women who have an autism diagnosis.

I do not doubt that children and young people who are considered to belong to this group experience very real difficulties, and although my views on autism diagnosis (and Attention Deficit Hyperactivity Syndrome) lean towards social constructionism, it is not my place to question the validity of participants' autism diagnoses. Due to my ontological stance I refer to people and participants being diagnosed with autism rather than 'having' autism or 'being' autistic. I also prefer to use the term 'autism' rather than 'autism spectrum' or 'autism spectrum disorder' or 'autism spectrum condition' although I did use the term, 'autism spectrum', when interviewing participants as felt that they may have been more comfortable with this wider description.

When I spoke about my research with colleagues, some raised concerns about participants' ability to understand and answer interview questions and to reflect on their experiences, given their autism diagnoses. I reflected that, in my experience, young people who were considered to belong to this group and who attended mainstream school settings were capable of answering the type of questions that I planned to ask in the course of my research (McLaughlin and Rafferty, 2014).

Autism and girls could be regarded as a 'hot topic'. The Autism in Girls Forum was established in 2015 with the aim of raising the profile of girls on the autism spectrum. This forum can be found under the National Forum for Neuroscience and Special Education (NFNSE) on the National Association for Head teachers (NAHT) website. In 2016 the National Association for Special Educational Needs (NASEN) produced *Girls and Autism: Flying Under the Radar*, as one of their mini-guide series. This guidance was written by members of the Autism and Girls Forum. One of the aims

of the guidance is to identify key issues for girls with autism spectrum conditions. A Parliamentary Round Table on the topic was held in November 2016.

I attended a NAHT conference on girls with autism in January 2017 called 'Girls with Autism: The Big Shout Conference'. The main aim of the conference was to raise awareness and improve recognition and support for girls on the autism spectrum. Speakers included Professor Francesca Happé and some of the students from Limpsford Grange School. At the end of the day delegates were asked to write down their concerns and suggestions and these were collated into the following areas: diagnosis, education and training, research, mental health, parents and carers, and employment.

I found the literature reporting critical perspectives to be of particular interest, as it posed a challenge to the positivist views with which I was familiar. Critical perspectives on autism sit within the wider child and educational psychology debate, about the medicalisation of childhood behaviour (Runswick-Cole, Mallet and Timimi, 2016). Runswick-Cole (2016) calls autism a "contemporary cultural phenomenon". Latif (2016) says, "The validity of the concept itself is fluid, and changes with time and culture." (p. 293). Hassall (2016) states, "there is no reason to believe, on the basis of current evidence, that there is one single identifiable medical or psychological disorder that uniquely characterises autism." (p. 51). He asks, "When somebody receives a diagnosis of autism, what is it exactly that he or she has actually got?" (p. 59). Timimi and McCabe (2016) call for a 'serious debate' on the pros and cons of continuing to diagnose autism.

More males than females are diagnosed with autism (Dworzynski et al, 2012). The literature for this topic reveals that some autism experts believe that, as girls on the autism spectrum behave differently from boys on the autism spectrum, they can be overlooked or mis-diagnosed (Atwood, 2007; Gould & Ashton-Smith (2011).

I interviewed six females who were aged between 14 and 20. All participants were either attending, or had attended mainstream school. During interviews participants seemed open, honest and reflective. Participants were individuals with differing life experiences who had been influenced by their interests, family attitudes, educational experiences, peer relationships and exposure to contemporary culture.

My research findings indicate that some participants were uncertain about what autism is understood to be. Although some participants accepted their autism diagnoses, and one participant viewed her autism diagnosis positively, some participants rejected their autism diagnoses and some seemed unsure or diffident. Some participants appreciated the additional support they had received at school but some shared school experiences which they had found challenging. All participants

spoke of friendships, some of which had broken down, and some participants had experienced stigma, isolation and peer rejection. Some participants maintained a positive sense of self and achieved a separateness from their diagnosis, but some participants experienced low self-esteem and depression which were linked to a sense of being different. All participants had a plan for the future which involved further study leading to employment, but some feared future discrimination.

This study would not be classed as purely educational research, although participants did reflect upon their educational experiences. My research has implications for young people, parents and all those involved in the diagnostic process: medical professionals, educational professionals, including educational psychologists, who have involvement with children and young people who have an autism diagnosis and can be involved in the diagnostic process (Brown and Paterson, 2013; BPS, 2016).

Chapter 2 – Literature Review

The literature review is separated into six parts: autism: an overview, critical perspectives, gender differences, adolescence, autism and education and friendships and peer relationships. These topics all have direct relevance to my research. Throughout this chapter I reflect on my own response to the literature.

Part 1: Autism: an Overview

The National Autistic Society describes autism as “a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them” (www.autism.org.uk). Current prevalence rates in the UK are thought to be around 1 in 100 (Baird et al., 2006).

Autism is classed as a disability under the Equality Act 2010 and is estimated to cost the UK economy around 32 billion pounds per annum, mostly due to lost earnings (Knapp, Romeo and Beecham, 2009). The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM – 5) suggests that many individuals diagnosed with autism, even without intellectual disability, “have poor adult psychosocial functioning as indexed by measures such as independent living and gainful employment”. (American Psychiatric Association, 2013, p. 57). The Autism Act was passed in the UK in 2009 and this has helped to embed autism into the local commissioning of services. The UK Government has also published an autism strategy for adults in 2010 (DH, 2010), which was updated in 2015 (DH, 2015).

Autism is an extensive topic: a recent internet search on ‘autism’ brought up 110,000,000 results. In the UK 99% of the general population have heard of autism (YouGov: What the World thinks, 2015). Autism is “big business”, with products, books, intervention programmes, TV programmes, magazines, journals, consultancy, conferences and schools devoted to autism (Runswick-Cole, 2016). It has been suggested that some famous historical figures were autistic, for example, Mozart, Michelangelo and Einstein (listverse.com/2011/12/05/top-10-alleged-autistics-in-history).

The History of Autism

In 1911 Eugene Bleuler, a Swiss psychiatrist, originally used the term ‘autism’ to denote a state of social withdrawal (Bleuler, 1911). Autism as a diagnostic construct was proposed by Leo Kanner, an Austrian - American psychiatrist, in 1943. He described a group of 11 children, 8 boys and 3 girls, who were intellectually impaired and showed an extreme preference for aloneness from infancy (Kanner, 1943). By the 1960s Kanner’s ‘infantile autism’ had become a recognised diagnosis for what

was considered a rare disorder which was primarily found in children with intellectual impairments. In 1944 an Austrian Paediatrician, Hans Asperger, published a paper in which he described 4 children, all male. These children were without intellectual impairment but experienced social communication problems (Asperger, 1944). Verhoeff (2013), Solomon (2010), Silberman (2015) and Evans (2017) have all written accounts of the history of autism.

Prevalence

Estimates of the global prevalence of autism vary considerably but reach up to 1% of the total population and even higher in some countries (Elsabbagh, Divan et al., 2012). Russell et al. (2014) estimate a prevalence of 1.7% among the primary school children in the UK. Autism diagnoses have increased in prevalence. Taylor et al. (2013) suggest that there was a five-fold increase in the UK during the 1990s.

Causation

In the United States (US), in the 1950s and early 1960s, autism was attributed to harsh upbringing of children by cold and rejecting parents which led to the child seeking comfort in solitude (Bettelheim, 1967). Although this theory was discounted, there is as yet no single, widely accepted explanation as to why some children develop autism.

The biomedical view of autism first emerged in the 1940s with the work of Leo Kanner (Kanner, 1943). Autism was regarded as a cognitive disorder: hence this is a 'deficit model' of thinking which is focused on causation and treatment. The work of Simon Baron-Cohen (Baron-Cohen, 2002), (Baron-Cohen, 2004) and Uta Frith (Frith, 2003) sits within this cognitive deficit model.

Latterly, a new model of understanding autism as a neurobiological difference, has emerged (Kapp et al., 2013). The neurodiversity movement fights for the rights of people with autism and argues that autism is a naturally occurring brain difference and not a disorder. Runswick-Cole (2016) believes that the neurodiversity movement does not trouble the 'dominant construction' of autism.

In the UK between 2007 and 2011, £21 million was spent on autism research, with the majority of funded projects focusing upon reducing 'symptoms' or identifying causation (Pellicano et al., 2014). Happe (2014) recognises that there is little agreement, even among top autism researchers, about causation. She states that the 'holy grail' of autism research seems to be identifying the genes that cause autism or knowing which parts of the brain are affected. No single gene for autism has yet been identified.

Wozniak et al. (2017) recognise autism as 'highly variable, both behaviorally and neuro-developmentally'. They identify four factors which they believe to contribute to this variability: genetic processes, environmental events, gene and environment interactions, and developmental factors. They conclude that the relevant processes are so complex that it appears 'unlikely' that autism spectrum atypicalities can be attributed to any one causal mechanism.

Some researchers acknowledge that there is a substantial degree of separateness between the 'triad' of impairments (Happé & Ronald, 2008). This is characterised by Happé and Ronald as the 'fractionable autism triad'. They argue that each of the 'impairments' frequently occurs by itself and that the separate aspects of the triad "seem to have largely independent causes at the genetic, neural and cognitive levels". (p. 55). They maintain that people can have all three impairments together and that this is autism, which is "worthy of a distinct diagnostic label" (p. 229).

Psychological Theories

Theoretical concepts to explain the biological basis of autism have been developed. Baron-Cohen, (1985) proposed that a lack of Theory of Mind (ToM) was the central deficit found in autism. ToM is the ability to attribute mental states, such as beliefs, intents and desires, to oneself and others and to understand that others have beliefs, desires, intentions, and perspectives that are different from one's own. Typically developing children are thought to begin develop ToM at around the age of three (Baron-Cohen, Leslie & Frith, 1985).

Restricted, repetitive behaviours, activities or interests have been associated with deficits in executive functions (Ozonoff, 1997). Some children and young people who are diagnosed with autism demonstrate relative strengths or special abilities, for example being able to memorise by rote. Frith (1989) proposed that these patterns of relative strengths among difficulties can be explained by weak central coherence.

Baron-Cohen later proposed the 'extreme male theory' of autism (Baron-Cohen, 2004) which attempted to address the gender disparity in autism. Baron-Cohen argued that people with autism match an extreme of the male profile with an intense drive to systemise and a low drive to empathise.

Diagnosis

Following their 1979 epidemiological study, carried out in London, Wing and Gould proposed that autism is characterised by a 'triad' of symptoms (Wing and Gould, 1979). Autism was first formalised as a diagnostic category in 1980 in the third edition of the Diagnostic and Statistical Manual of Mental Disorders, (DSM – III) (American Psychiatric Association, 1980) when it was defined by the 'triad of impairments'. The 'triad' was retained in DSM – IV (APA, 1994). The most recently published criteria for diagnosis appears in DSM-5 (APA, 2013). There is now a single diagnostic category of 'Autism Spectrum Disorder', without any of the previous subdivisions such as Asperger's Syndrome. Autism affects individuals in different ways and is therefore considered to be a spectrum condition (Gillberg, 1999).

In the UK today autism spectrum disorder in children and young people is currently diagnosed by a multi-agency team in a clinical setting; this team will usually include health professionals but can also include educational psychologists (NICE, 2011; Brown and Paterson, 2013). The diagnostic procedures vary depending on the local health pathway. Assessment will usually include a discussion with parents, including a developmental history, and observations of the child or young person (NICE, 2011). Educational psychologists now work with young people up to the age of 25 (DfE, DH, 2014). There is an adult pathway for autism diagnosis (NICE, 2012).

To meet the DSM – 5 criteria for autism spectrum diagnosis, an individual must display 'persistent deficits in social communication and interaction' and 'restricted or repetitive behaviours and interests'. These 'symptoms' need to have been present during the child's early development and must be causing 'clinically significant' impairment of the individual's functioning (APA, 2013). The World Health Organisation, International Classification of Diseases (ICD-10) (WHO, 1992) has similar diagnostic criteria to DSM – IV (Hassall, 2016). Autism can be diagnosed alongside learning difficulties (LD) and other medical disorders and conditions (NICE, 2011).

Specific assessments may be used to aid diagnosis: for example, the Modified Checklist for Autism in Toddlers (M-CHAT) and the Childhood Autism Spectrum Disorders Test (CAST) (Fuentes et al., 2014). Nichols et al. (2009) position the Autism Diagnostic Observational Schedule (ADOS; Lord et al., 1999) as a 'gold standard' assessment instrument. (p. 26).

Russell (Runswick-Cole, Mallet and Timimi, 2016) recognises that early diagnosis and hence early intervention for autism has become a 'recognised research priority' (p. 253). She says "The belief is that the earlier the diagnosis is made, the greater the chances of success in normalising a child's developmental trajectory, before windows of opportunity have closed." (p. 255). Happe (2014)

recognises that there is an emphasis on early identification guided by the idea of early intervention but she warns that the risk of false positive diagnosis could be higher for younger children.

Many children and young people who are diagnosed with autism are reported to experience hyper or hypo sensory sensitivity. Sensory differences are included in the DSM - 5 under 'restricted or repetitive behaviours and interests'. Some experts believe that differences in sensory processing are central to the condition as a whole (Bogdashina, 2003). Leekam et al. (2007) found that over 90% of their sample of children with autism experienced 'sensory abnormalities' and had 'sensory symptoms' in multiple sensory domains, particularly touch and smell / taste. For example they experienced hyper sensitivity to touch and / or smell / taste.

Individuals diagnosed with autism are more likely to experience stress and anxiety (Grodén, Baron and Grodén, 2006). Simonoff (2008) proposed that 70% of children diagnosed with autism meet the criteria for a co-occurring mental health condition and 40% meet the criteria for two co-occurring mental health conditions. Leyfer et al. (2006) found high rates of comorbid psychiatric disorder in children diagnosed with 'high functioning' autism. These included depression (24%), specific phobic disorder (44%), OCD (37%) and ADHD (31%). Joshi et al. (2012) found a high incidence of psychiatric comorbidity in adults who were diagnosed with autism.

Treatments

There are structural programmes designed as 'treatments' for autism 'impairments'. Applied Behaviour Analysis (ABA) focuses upon the principles which explain how learning takes place, for example, positive reinforcement, when a behavior is followed by some sort of reward, the behavior is more likely to be repeated. An adult might use ABA to encourage a child to develop communication skills such as looking, listening and imitating. Alternative and Augmentative Communication (AAC) seeks to supplement or replace speech or writing for children who experience impairments in communication. The Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) is a method of structural teaching. A TEACCH classroom contains separate, defined areas for tasks, such as individual work, group activities, and play. There is a reliance on visual learning, which can be a strength for many children diagnosed with autism.

Bond et al. (2016) undertook a systematic literature review of the educational interventions for children diagnosed with autism. Interventions were assessed and classified as providing most;

moderate; some; or a small amount of evidence. Interventions with the most evidence focused on younger children and the 'core difficulties' associated with autism.

I started my literature review with an overview of autism, as autism diagnosis is central to my thesis. During the course of my research I found it useful, and fascinating, to read about the history of autism (Solomon, 2010; Silberman, 2015), including chapters on the autism rights movement. Authors offered explanations for the huge rise in autism prevalence: changes to the diagnostic criteria over time and raised awareness of autism.

Much of the literature referenced in this section is positivist and 'scientific'. Baron-Cohen, Frith, Gould and Atwood are clinical psychologists, who either work in a university research department, or in a clinical setting. Happe and Gillberg are psychiatrists, Happe works in a university research department and Gillberg works in his own clinical setting. These theorists have spent their careers researching the causation and 'treatment' of autism.

Writing this section of my literature review helped me to reflect on my own beliefs about autism. As a SAT and TEP, I have had involvement with multi-agency, diagnostic teams, so I have knowledge and experience of the diagnostic process in one locality; I am aware that the process is open to subjectivity. I have met children and young people, mostly boys, and mostly children and young people who attend special schools, or schools with strategic autism provision, whose behaviours fit with the criteria set out in the DSM-5 and ICD-10. I have also met with children and young people who have an autism diagnosis, and whose behaviours do not seem to match current diagnostic criteria. Happe and Ronald's (2008) theory of the 'fractionable autism triad' was new to me. I found this theory helpful in explaining why some children and young people, who have been diagnosed with autism, seemed to experience problems with either communication and interaction or rigidity in thinking, but not both.

Part 2: Critical Perspectives

Latif (2016) says that modifications to the construct of autism led to the 'expansion' of the concept of autism, from a 'rare and specific set of behaviours' in the 1940s to a wide spectrum today (p. 290). Hacking (2015) asks if autism should be called a 'human' spectrum, whilst Frith (1991) suggests that autism could be viewed as a 'normal personality variant'. McGuire (2011, in Runswick-Cole, Mallet and Timimi, 2016) describes how slow development and / or developmental delay within autism is framed as an underlying biomedical problem that must be corrected as early as possible as it threatens the productivity of neo-liberal societies. Verhoeff (2012) argues that the concept of autism is inseparable from prevailing norms of the kinds of behaviour regarded as acceptable or unacceptable within contemporary society.

Timimi et al. (2010) argue that autism is a social construction. They say that patterns of behaviour associated with autism have always existed but have only become a concern as society has changed over time. Timimi et al. argue that a key issue is the increasing emphasis on "the type of social and emotional competences that are thought to be necessary for the functioning of societies dominated by neo-liberal economic and political foundations" (p. 7). They point out the disproportionate rate of diagnostic labelling experienced by boys compared to girls as their behaviour does not always conform to adult expectations.

Critical Autism Studies

Critical autism studies is an emerging field which is concerned with two interrelated questions: is the diagnosis of autism critically valid? And, is a diagnosis of autism useful to those so labelled? (Runswick-Cole, Mallet and Timimi, 2016).

Critical autism advocates do not accept autism as a biologically based biomedical disorder or brain difference. Runswick-Cole (2016) argues that autism does not exist at a biological level and "can only be understood through examining 'it' as a socially / culturally produced phenomenon." (p. 9). She suggests a move away from diagnosis and an emphasis on service provision for people who experience the type of difficulties associated with autism.

Timimi and McCabe (2016) position themselves within a disability studies perspective and critique the 'science of autism'. They point to the 'lack of clear evidence' that autism is genetic (p36). They

also argue that neuroplasticity needs to be considered. They state that they have not found evidence to demonstrate that particular interventions help those diagnosed with autism (p. 39) and argue that until there is evidence that specific treatments for autism work then the diagnosis has no clinical value. They consider the heterogeneity of autism to be 'particularly problematic', as autism 'symptoms' are common in a variety of mental health diagnoses and go on to present evidence for the overlapping of psychiatric and other presentations with autism (p. 40 / 41).

Timimi and McCabe (2016) consider the "dominant cultural beliefs and practices around gender" (p. 42). They argue that some boys and men are at risk of 'alienation' in regard to culture, education and employment and that it is mostly boys, who behave in ways which challenge teachers and are deemed to require 'corrective interventions' from 'experts'". (p. 44). By giving an autism diagnosis 'experts' provide the rationale for 'special' measures to be taken.

Timimi and McCabe (2016) point out that "the boundaries associated with the label have expanded rapidly without any accompanying evidence that this expansion is informed by new biological knowledge on the condition." (p. 44). They view the current definition of autism as the result of 'ideological changes' rather than 'new scientific knowledge' (p. 45) but recognise the challenges that would be involved in discontinuing or limiting the use of the label, including a culture change.

Timimi and McCabe (2016) suggest that diagnostic tools and screening instruments have acquired the status of 'medical tests'. They also suggest that as these are questionnaire-based they are subjective and dependent on "the perception of the person answering the questions" (p. 159). They argue that current questionnaires "should not be used for diagnosis, screening or clinical practice." (p. 179).

Hassall (2016) asks 'What is autism?' He states that, "there is no single underlying condition which can be regarded as the defining characteristic of autism and which accounts for all the varied symptoms displayed by those individuals who have received their diagnoses." (p. 49). He also states that "no genetic or neurological basis for autism has so far been reliably established" despite extensive, worldwide research (p. 50). He describes autism as a "rather loose umbrella concept" for a "diverse range of characteristics and symptoms" (p. 51).

Hassall (2016) points out that autism, as it is currently understood, appears to be 'significantly different' from the condition described by Leo Kanner in the 1940s, as the two 'impairment' categories in the DSM – 5 are much wider than those originally described by Kanner. The first formal

criteria of autism (Kanner and Eisenberg, 1956) referred to a 'very rare' disorder characterised by a 'profound lack of affective contact' and 'repetitive ritualistic behaviour which must be elaborate'.

Hassall (2016) talks about 'natural kinds' of diseases. It is difficult to identify mental disorders as 'natural kinds' as they do not have 'identifiable biological signs', and diagnoses are based upon 'descriptions of symptoms' (p. 61). He states, "There is no reason to believe that everyone with an autism diagnosis suffers from one unique and identifiable disease or disability." (p. 63).

In regard to diagnosis, Hassall (2016) talks about the 'enormous power' exercised by members of a diagnostic service over the person being assessed. (p. 64). Simon (2016) says that "diagnosis is usually a monological activity by one person about another" (p. 285). She talks about Compulsive Diagnosing Behaviours (CDB) and Symptom Spotting Tendencies (SST). She calls for 'systemic' approach in which all participants are positioned as 'collaborative action researchers' (p. 286).

Mallet and Runswick-Cole (2016) suggest that autism has become a 'commodity', to be "produced, exchanged, traded and consumed". (p. 110). They highlight published research which suggests that, "over the past decade, the institutional exchange of autism 'knowledge' has become big business." (p. 118). Examples of commodification are big businesses selling products, contemporary culture such as films, plays, TV programmes, museum exhibitions, novels, autobiographies and newspaper articles all re-presenting autism for mass markets.

Mallet and Runswick-Cole (2016) describe a 'marketplace for autism expertise'. 'Expert' professionals "coherently produce autism as a thing because they perceive a need for certain behaviours and symptoms to be explained and remedied." (p. 120). Parents interact with medical professionals and 'consume' autism in order to 'understand and better care' for their children (p. 120).

Davies (1995) talks of normalcy. Normalcy conceals the power of the norm as a social construct through 'ostensible' evidence of 'normal' human behaviour and 'normal' human development. Ability is synonymous with 'normal'. Hence being not normal or disabled is undesirable (p. 153). She talks about the emerging field of 'Studies in Ability'. She describes an ableist view of autism, that "autistic people live in a world of their own, and, like aliens on the wrong planet, are only spectrally present in 'the real world'." They "lack those very qualities that make people human: empathy and an ability to understand other people's thoughts and feelings." (p. 132).

Gillman, Heyman and Swain (2000) identify three of the most significant ways in which labels can marginalise and exclude children. Professionals use labels to justify interventions which are usually

focused upon making labelled children as 'normal' as possible. Labels lead to the disempowerment of parents and non-medical professionals as medical professionals give the label and parents and non-medical professionals can lack expertise in the particular 'syndrome' given to the child. Labels can also lower the expectations of others.

Hodge (2016) examines schools and labelling. He exposes labels as, "tools of capitalism that are used to segregate, control and expel to the margins of community those children who are exposed as economic burdens of the state (Oliver, 1990)" (p. 187). He argues that "disabled children continue to be positioned as an economic burden on the state and as a consequence are subject to marginalisation and expulsion." (p. 188)

Hodge (2016) asks 'Why do people cling to labels?' He argues that "zones of expulsion do exist within the education system and that labels are one of the tools through which they are enabled." (p. 194). As labels are "imbued with the status and power of the medical profession." (p. 196), they can be a means of explaining symptoms of others, parents can seek diagnosis as an "official acknowledgement of the 'reality' of the problem" (Avdi, Griffin and Brough, 2000, p. 248). "Within the current system of educational provision a label is often the only means of access to specialised support and enhanced financial resources so parents are compelled to seek it (Hodge, 2006)". (p. 197).

"Labels can locate the 'problems of development' within the child or young person thereby removing any need for assessing and changing the impact of the social and educational environments." (Hodge, 2016, p. 199). He urges teachers to recognise and celebrate the "individuality of children, responding to them as people with their own way of learning rather than as members of an impairment group who all are and learn the same." (p. 200).

Russell (Runswick-Cole, Mallet and Timimi, 2016) identifies the 'underlying assumptions' of the early diagnosis literature: that early intervention is effective, that children identified as autistic will not 'get better' without intervention and that diagnosis will not have a negative impact on children and their families. She offers three counterarguments to the push for early diagnosis of autism: the literature on the effectiveness of early interventions is inconclusive: some studies show that children with 'serious symptoms of autism' may improve to a 'subclinical' level as they grow older without intervention (Russell et al., 2012) and that there can be negative effects from attaching diagnoses to children.

Hacking (1995) talks about a 'looping effect': when someone is diagnosed with a psychiatric disorder, the individual's awareness of the diagnosis alters their behaviour: for example, behaving in ways that further reinforce the diagnosis. Russell (2016) talks about 'labelling theory' which hypothesises that "diagnosing and labelling a child as autistic will lead to shifts in expectancy and attitudes of those in contact with the child, as well as altering the self-identity of the child, and this will serve to reinforce the abnormal 'autistic' behaviour." (p. 262). She talks about research on self-fulfilling prophecies in children (Rosenthal and Lawson, 1964) and expectancy bias studies in education (Jussim et al., 2000).

Latif (2016) explores the ethics of autism diagnosis. He says that a 'consequence' of the biomedical model is that psychiatric diagnoses operate in practice as categorical, like other medical or surgical diagnoses, where an illness does or does not exist. (p. 288). He points out that arguments about whether autism exists are essentially semantic' as it is "more of a matter of the use of specific language to describe certain presentations amongst professionals and the public, resulting in these presenting behaviours being bestowed with a certain meaning" rather than uncovering an "essential truth about the nature of the presenting behaviours." (p. 288)

Latif (2016) acknowledges that there is no dispute about the existence of autism type behaviours but about whether these behaviours amount to "a discrete naturally occurring category". (p. 288). He asks about the "evolving personality, experiences, diverse histories and contexts of a growing child with a highly plastic brain?" (p. 228) and talks about 'some major conceptual difficulties' including constantly changing diagnostic thresholds, the diagnostic process being open to subjectivity and 'significant and unaddressed' cross cultural variability. (p. 289).

Kinderman et al. (2012) talk about 'dropping the language of disorder' in their critical perspective on the DSM – 5 (APA, 2013). They also call for a 'wholesale revision of the way we think about psychological distress' and point out that distress is "'a normal, not abnormal, part of human life—that humans respond to difficult circumstances by becoming distressed". They suggest that any system for identifying, describing and responding to distress should use language and processes that reflect this position, for example, 'depressed mood'.

The World Health Organisation definition of 'disorder' highlights 'distress' and 'personal dysfunction' as important elements. Latif (2016) argues that this kind of distress may not be seen in cases of autism spectrum but can be seen in "the parents, families or teachers that brings the young person to medical attention." (p. 292)

Latif (2016) argues in favour of value-based approaches (Fulford, 2009), that is consideration of the values of the individual, their family and the wider culture. (p. 289). He questions the biomedical model and advocates the use of a more 'context-rich biopsychosocial- approach.

Latif (2016) says, "it is generally accepted that the symptoms of autistic spectrum condition can and do exist in the general population. It is the combination of those behaviours up to and beyond a certain threshold that leads to the behaviours being symptoms of a 'disorder'." (p. 292). He asks who should be given the power to decide where the cut off lies and says that the 'act of making a diagnosis' comes down to the subjective judgement of a professionals in regard to the information provided and that the information provided may not be objective. He also points out that is usually doctors who make a medical diagnosis but in the case of autism professionals from a range of medical and educational backgrounds can recommend a diagnosis.

Latif (2016) questions the usefulness of labelling as there is a lack of evidence around long term prognosis is for people diagnosed with autism. He points out that long term outcomes are likely to be dependent on many variables, for example, family and educational support. He asks what can be achieved by labelling someone with a disorder if it doesn't really predict outcomes and can lead to increased stigma? "Little has been written about the impact of messages of pessimism, hopelessness and 'chronicity' and of thinking about autism as a lifelong 'disorder'." (p. 292).

Latif (2016) says that an autism label can provide an explanation for behaviours seemed socially unacceptable. Medical professionals have been trained to use a 'narrow biomedical model' and can pressured by families and schools to make a diagnosis and young people are not always asked what they want (p. 296). Latif feels that young people who are struggling, for example, with social interaction should be able to access better services without needing a 'lifelong label' (p. 293). He says that the label can also be used as a 'defense' for behaviours that may have nothing to do with the construct of autism.

'Internal stigma' is associated with "lack of hope and an expectation of poor outcomes for the person with the label." (Latif, 2016, p. 294). Latif says that when a person is labelled with a 'lifelong' disorder by an 'expert' the burden of responsibility is shifted from the person to the 'illness'. The person is aware that they cannot be blamed for their behaviour because it is caused by something beyond their control. Responsibility is taken away from the person and "expectations for them to change as they grow and develop may be permanently altered." (p. 294).

“The use of labels can therefore lead to people being trapped in a limiting way by their own beliefs and by the reactions and behaviours to those around them to the label.” (Latif, 2016, p. 294). Latif says we should concentrate on the level of impairment and how needs can be met. He goes on to question, “What is the point of attaching a disorder label to a young person when the cause is not known, it does not predict outcome and there is no cure?” (p. 294).

Diagnosis may influence employers against giving a job. Latif (2016) points out that we are not doing any ‘favours’ to either the young person or society to labelling around 1% of the ‘future workforce’ as ‘disabled’ with an ASD diagnosis. (p. 294). He points out that some may view autism diagnosis as a means to gain financial or educational advantage, for example, the Disability Living Allowance, a disability-related benefit and that this may have impacted on requests for assessment. (p. 295).

Authors referenced in this section of my literature review are mostly academics, based at universities, but generally involved with lecturing rather than research. Some, like Billington, are educational psychologists, some are clinical psychologists and some lead on disability studies. They consider autism diagnosis from the point of view of those diagnosed. Timimi and Latif are psychiatrists, who presumably work in a clinical setting, but unlike Happe and Gillberg, they focus on psycho-social, rather than neuro-biological influences.

During my educational psychology training I became increasingly aware of social constructionism and critical psychology. This section of my literature review offers a counter argument to the positivist overview of autism detailed in part one. Many of the ideas put forward in Runswick-Cole, Mallet and Timimi (2016) resonated with me. I began to reflect on the need for a label. In the course of my work I have observed that many adults, parents and school staff, seek an explanation, and a name, for developmental and behavioural differences in children and young people. I feel that ‘autism’ has become a ‘catch all’ label for childhood differences. The fact that, causation has not been clearly identified, adds weight to the argument of autism as a social construction. I have witnessed firsthand, ‘labelling theory’ (Russell, 2016), whereby adults make presumptions about a child or young person’s behaviour and abilities based on their ‘label’.

Part 3: Gender Differences

More males than females are diagnosed with autism. Fombonne (1999, 2003) reviewed the literature on epidemiological studies of autism and noted that overall sex ratios of autism (male : female) ranged from 2:1 to 16:1. Dworzynski et al. (2012) talk about an overall male : female prevalence of 4 : 1, for intellectually able females this decreases to 10 : 1, and for females with learning difficulties the ratio increases to 2 : 1.

Three theories have been proposed to explain the cause of sex differences in autism: the Liability Threshold Model (LTM), the Greater Variability Model (GVM) proposed by Wing (1981) and the Brain Differences Model (BDM) proposed by Baron-Cohen (2002). Koenig and Tsatsanis, (2005) provide a summary of the three theories. In 2006 Schellenberg et al. proposed that different genes may be responsible for causing autism in boys than in girls and that it may take more of the 'risk genes' for a girl to be affected, hence the higher ratios of male to female.

Nichols et al. (2009) suggest that despite 'limited' research "autobiographical, anecdotal, and clinical reports strongly suggest that observed sex differences are valid and deserve attention" (p. 21).

Factors thought to influence the higher incidence in autism diagnosis in males are research studies which include more boys than girls, the ability of current assessment tools to detect the disorder in girls and the different 'symptom' presentations in males versus females.

Nichols et al. also remind us that there are sex differences in regard to typically developing children and young people. Cheslack-Postava and Jordan-Young (2012) consider how social processes based on gender, for example, patterns of social and physical interaction in early childhood, may affect the occurrence and diagnosis of autism.

Research

Asperger (1944) noted that the 'contact disturbances' experienced by the girls in his group were 'reminiscent of autism' without showing the 'fully formed' autism seen in the boys (www.nasen.org.uk).

Lord, Schopler and Revicki found that the play of boys diagnosed with autism tended to be more restricted and repetitive (Lord, Schopler and Revicki, 1982). McLenna, Lord and Schopler (1993) found that males diagnosed with autism tended to have more serious social and communicative impairments early in life, whereas females displayed more impairments in social communication during adolescence.

Lai et al. (2011) undertook a behavioural comparison of male and female adults diagnosed with high functioning autism. They found that the severity of childhood 'core autism symptoms' did not differ between the sexes. Males and females did not differ in self-reported empathy, systemizing, anxiety, depression, and obsessive-compulsive traits/symptoms or mentalizing performance. Adult females diagnosed with autism showed more sensory symptoms, fewer socio-communication difficulties, and more self-reported autistic traits than males. Females diagnosed with autism who also had developmental language delay had lower current performance IQ than those without developmental language delay. This was not seen in males.

Rivet and Mason (2011b) reviewed the available research on gender differences and autism. They found that recent studies support the hypothesis that autism is more likely to be diagnosed in females presenting with 'classic symptoms' and intellectual disability. Girls with 'milder' symptoms and a 'normal' IQ tend to be diagnosed at a later age than boys or are misdiagnosed. Girls might be simply regarded as anxious or shy, hence ascertainment bias is a problem in the identification of females with autism. They acknowledge that their meta-analysis may have missed high functioning girls which would render their findings meaningless. They conclude that females with autism show less repetitive and stereotyped behaviour than males, whereas they did not find evidence for gender differences in the domain of social behaviour and communication.

Rivet and Mason (2011b) point out that the majority of research into autism has been carried out on male samples and argue that phenotypic gender differences might lead to delayed or missed diagnosis in girls and women with autism. They refer to 'The Autism Spectrum Screening Questionnaire – Revised Extended Version' (ASSQ-REV) (Kopp and Gillberg, 2011), which was developed to better capture the female phenotype of autism spectrum disorders. Kopp and Gillberg's (2011) study revealed that some single ASSQ GIRL items were more typical than of girls than boys diagnosed with autism, for example, 'avoids demands', 'very determined', 'careless with physical appearance and dress' and 'interacts mostly with younger children'.

Soloman et al. (2012) compared boys and girls diagnosed with autism, with 'typically developing' boys and girls in regard to behaviours associated with autism and internalising symptoms. Girls diagnosed with autism were more 'impaired' than 'typical' girls but did not differ from boys diagnosed with autism in regard to autism 'symptoms'. In adolescence girls diagnosed with autism had higher internalising symptoms than boys diagnosed with autism and 'typical' girls, and had higher symptoms of depression than 'typical' girls. Girls diagnosed with autism resembled boys diagnosed with autism but not 'typical' girls and they appeared to be at increased risk for 'effective

symptoms' as teenagers. They talk of an 'altered clinical manifestation' of the disorder among 'high functioning' females and call for further research exploring gender differences.

Van Wijngaarden-cremes et al. (2013) undertook a systematic meta-analysis of published papers in order to examine gender differences in the symptomatology of autism. They found that boys showed more repetitive and stereotyped behaviour from the age of six, but that males and females did not differ in regard to social behaviour and communication. Like Rivet and Mason (2011b) they found an underrepresentation of females with average to high intelligence. They also suggest that females present a different autistic phenotype to males, possibly due to ascertainment bias, and call for more research into the female phenotype of autism, including the development of 'appropriate instruments'.

Lai et al. (2015) looked at the research into gender differences and autism and proposed a 'conceptual framework' asking the following questions: How should autism be defined and diagnosed in males and females? What are the similarities in males and females with autism? How is the development of autism linked to gender?

In regard to the similarities and differences between males and females diagnosed with autism Lai et al. (2015) found that: Females demonstrated a greater awareness of the need for social interaction and a greater desire to interact with others. Females tended towards passivity and were often perceived as 'just being shy'. Females had a tendency to imitate others in social interactions. They also had a tendency to 'camouflage' difficulties by masking and/or developing compensatory strategies. They had one or few close friendships. There was a tendency to be 'mothered' in a peer group in primary school but females were often bullied in secondary school. Females had better linguistic abilities and a better imagination. Restricted interests tended to involve people and animals rather than objects and things, which may not be associated with autism. Other tendencies were to be perfectionistic and very determined, to be controlling, high (passive) demand avoidance and a tendency to have episodes of eating problems.

The current DSM – 5 diagnostic criteria for autism are not gender specific. Wing et al. (2011) make specific reference to 'problems' of diagnosing autism spectrum condition in girls and women and feel that this should have been considered in the DSM - 5 (Wing et al., 2011). Gould & Ashton-Smith (2011) ask if girls with ASD are simply missed or are misdiagnosed. They suggest that because females with autism may present differently from males, diagnostic questions should be altered to identify some females with autism that might otherwise be missed. They recommend use of the Diagnostic Interview Schedule for Social and Communication Disorders (DISCO) (Wing et al., 2002).

Dworzynski et al. (2012) found that girls, but not boys, meeting diagnostic criteria for autism showed significantly more additional problems, for example, low intellectual level, behavioural difficulties, than peers with similarly high CAST scores who did not meet diagnostic criteria. This data suggests that, in the absence of additional intellectual or behavioural problems, girls are less likely than boys to meet diagnostic criteria for autism at an equivalently high levels of autistic type traits. This may reflect a gender bias in diagnosis or better adaptation in girls.

Tony Atwood (2007) draws on his experiences of working with this group of children and young people and he also proposes that that girls may be underdiagnosed, missed, or may express autism symptoms differently to boys. He calls for more epidemiological studies to establish the true incidence of autism in girls as he feels that girls on the autism spectrum are more likely to be overlooked and not receive the degree of understanding and resources they need.

Atwood offers a number of suggestions as to why he believes that girls with Asperger's Syndrome may be 'slipping under the radar'. He believes that girls have the same profile as boys but have a 'subtler, less severe expression of the characteristics'. Therefore if a child seems to be coping reasonably well parents are less likely to seek a diagnosis. Clinicians may also be hesitant to commit themselves to a diagnosis unless the signs are very different from the normal range of behaviour and abilities.

Atwood says that 'stereotypical' male and female behaviours affect the identification of girls with autism. Girls are more able to verbalise emotions and less likely to resort to physical aggression than boys and children who are aggressive are more likely to be referred to a paediatrician or psychologist. Atwood also considers personality, more girls than boys exhibit a passive presentation.

Girls are also more likely to be supported and included by female peers whereas Atwood has noted boys to be less tolerant of each other so a boy with autism is more likely to become isolated in a social setting. Atwood noted that girls seemed to be adept at observing and copying people and so could acquire a 'superficial social competence' by 'acting a part' or 'camouflaging' their difficulties. Girls often created imaginary friends or used dolls as a substitute for friends. Their 'special interests' were often of interests to many girls, for example, animals and classical literature. Atwood noted that for girls diagnosed with autism their tone of voice often resembled that of a much younger person, and describes a childlike quality to their speech.

During social skills lessons Atwood found that girls were more motivated to learn and quicker to understand key concepts in comparison to boys of a similar ability, therefore increasing the likelihood of a better long term prognosis for many girls.

Cridland et al. (2014) point out that many girls with ASD are not diagnosed until social relationships become more complex in the teenage years. Boys tend to 'do' rather than 'talk' but adolescent female relationships require complex skills such as reciprocal sharing. Adolescent girls with autism may need extended time to process and respond to information which can add to their difficulties in maintaining conversations. Boys and girls also differ in regard to conflict management. Boys display more overt aggression and girls tend to display more subversive behaviours such as gossiping. They can involve other girls in conflict situations, for example, isolating the 'victim'. The girls in Cridland et al's (2014) study reported getting on better with boys than they did with 'typical' girls.

Insider Voice

There are some well-known published first person accounts by women and girls: (Grandin, 1995), (Lawson, 2000), (Wiley, 1999), (Williams, 1992). Authors reflect on their childhood and adolescence. Wiley (2006) was not identified as having autism until adulthood and her diagnosis helped her to make sense of the difficulties that she had experienced. Nita Jackson, an adolescent female who is diagnosed with Asperger's Syndrome, shares her mental health struggles including depression, anxiety, low self-esteem and self-harming (2002).

Hacking (2009) argues that insider accounts are creating the language in which to describe the experience of autism. He describes autism narratives as a 'new genre'. Billington (2006) says that insider accounts provide professionals with a valuable source of information when developing practice. He compares the 'cold' clinical descriptions of autism contained in diagnostic manuals to the real life experiences of young people with autism.

Davidson (2007) examined 16 published books that contained first-hand accounts of women's experiences of autism. She talks about the tendency to regard social insularity and autonomy as 'typically male' traits. This view compounds the feelings of alienation reported by some women diagnosed with autism as their 'autistic behaviour' may confound gendered expectations. This paper suggests that many women on the autism spectrum experience a profound sense of 'distance and difference' from both the male majority of people diagnosed with autism and the culture of

femininity surrounding other women. Davison explains autism type behaviours as 'tactics' for emotional and / or environmental protection.

In regard to qualitative research there are papers that explore the views of boys and girls but limited literature that explores the views of girls exclusively (Honeybourne, 2015). Cridland et al. (2014) undertook semi structured interviews with 3 girls and 5 mothers (3 mother daughter dyads). Themes that emerged were diagnostic issues, girls being diagnosed with a disorder primarily associated with boys, school experiences, the complexity of adolescent female relationships, puberty, sexual relationships and concerns and the impact of having an adolescent daughter with autism.

Baldwin and Costley (2015) recognise that there is limited large-scale research into the lived experiences of female adults who have an autism spectrum disorder with no co-occurring intellectual disability. They present self-report data from women with high-functioning autism spectrum disorder in the areas of health, education, employment, social and community activities. The findings highlight the 'diverse and complex challenges' faced by women with high-functioning autism spectrum disorder, including high levels of mental health disorder, unmet support needs in education settings and the workplace, and social exclusion and isolation.

The research section of part three of my literature review, returns to positivism. There is a great deal of research focusing upon gender differences in autism; particularly exploring biological reasons for the higher prevalence in males. I reference quantitative studies, in which groups have been compared, in order to find differences in autism 'symptoms'. I concluded that autism 'symptoms' seem more subtle in females without learning difficulties. The findings of Lai et al. (2015) resonated with some of my own observations on gender differences between children and young people diagnosed with autism. Autistic 'insiders', such as Wendy Lawson, certainly identify with autism, but I wondered, if, for some females who were experiencing difficulties associated with autism, but were appearing to cope with life, was there usefulness in the label of 'autism'.

Part 4: Adolescence

Hall (1904) pioneered the scientific study of adolescence and termed the period as 'storm and stress'. The life stage of adolescence is one of rapid change and transition, body and brain changes, the development of identity, relationship changes, behavioural changes, mental health, sexual development and the influence of contemporary culture all need to be taken into account. The period of adolescence is usually defined by the onset of puberty and the transition to independent adulthood. The World Health Organisation defines the period of adolescence as between 10 and 19 years.

I am primarily interested in literature which focused upon the development of identity and relationship changes in adolescence. Erikson (1968) proposed that the search for identity was a key aspect of adolescence. He proposed eight developmental stages throughout a person's life span each of which had a normative crisis. According to Ericson the normative crisis for adolescence was identity versus role confusion or 'identity crisis'. Erikson also wrote about the 'psychosocial moratorium' where adolescents are given leeway by adults to explore their identity via experimentation during adolescence (Smith, 2016). Marcia (1966) tested Erikson's ideas by developing an interview schedule to ask about a young person's thoughts and beliefs in regard to occupation, religion, politics and sexual behaviour. The results indicated if the person tended towards 'exploration' or 'commitment'.

During adolescence relationships with peers usually become more influential than that of parents (Smith, 2016). A US study revealed that the time spent with same-sex peers increased steadily from 8 to 14 years but then started to decline as more time was spent with members of the opposite sex peers (Lam et al., 2014). The conception of friendship deepens during adolescence. Smith (2016) talks about using four positive elements commonly used to measure the strength of friendships: companionship, help, security and closeness. Conflict resolution is part of the security measure as friends frequently fall out and make up.

Smith (2016) talks about the effect of the internet and social networking sites on friendship. Young people can make friends online that they do not know offline and this can be regarded positively, i.e. it can supplement the young person's communication; or negatively, i.e. these friendships are superficial.

Anxiety about friendships with peers peaks in mid-adolescence (Sebastian et al., 2010). It has also been argued that there is an increase in autonomy and maturity during adolescence. Researchers have developed a measure of Resistance to Peer Influence (RPI) (Sumter et al., 2009). They found a general increase overtime but a marked influence between the ages of 14 to 18 years, with girls scoring higher than boys (Smith, 2016).

Developmental theorists have described sets of 'tasks' that adolescents complete which are critical to adolescent development (Cobb, 1996). Developmental tasks fall into the areas of physical development, social development, personal identity, cognitive development and independence or autonomy.

Participants in my study were teenagers and young adults: hence, their views need to be considered in the context of adolescence; a period of change and identity development. Literature about adolescence helped me to appreciate the importance of friendships, peer relationships, and the influence of contemporary culture for this group.

Part 5: Autism and Education

Cridland et al. (2015) found that in regard to high school (secondary school) positives identified by mother and daughter dyads were a broader range of subjects and students, and a more structured environment. Negatives identified were finding the work challenging and / or uninteresting, making friends and managing the larger school environment. These mothers felt mainstream teachers lacked knowledge of autism. Mothers considered the transition to high school difficult, due to new routines and adjusting to having lots of teachers.

Dillon et al. (2014) studied autism and the UK secondary school experience. Existing literature identified four areas that affect the quality of school experience for students diagnosed with autism: social skills, perceived relationships with teaching staff, general school functioning and interpersonal strengths of the young person. In this study students diagnosed with autism reported no differences in school experience to typically developing peers, there was little difference in the four measures between 'target' and 'typical' students. Furthermore self-report measures indicated that students diagnosed with autism reported similar levels of ability and school functioning to typical students. None of the participants in Humphrey and Lewis study (2008) reported difficulties in lessons.

Inclusion

The majority of teenagers diagnosed with autism attend mainstream schools (60%) (DfE, 2014). Webster and Blatchford (2015) point out that the development of inclusive learning environments continues to be challenging for many schools. Humphrey (2008) explored the inclusion of pupils diagnosed with autism in mainstream schools. He talked about inclusion as 'not just placing children with SEN in mainstream schools' and outlined 'evidence-based strategies to facilitate the presence, participation, acceptance and achievement of pupils with ASD in mainstream settings'. Strategies identified were: challenge stereotypes and raise expectations, create order from chaos (school environment), promote peer understanding, develop social skills, adapt academic subjects and modify conversational language.

Morewood, Humphrey and Symes (2011) examined good practice for the successful inclusion of children diagnosed with autism in a mainstream secondary school. Key elements included having a central 'agent of change', creating a positive ethos, developing the school environment, training and development of staff, policy development and embedding practice, peer education and awareness, flexible provision, and direct support and intervention.

Humphrey and Lewis (2008) found that senior managers and Special Educational Needs Coordinators reported greater self-efficacy in teaching pupils diagnosed with autism and in coping with behaviours associated with autism than subject teachers. They found that teachers lacked confidence in understanding and meeting the needs of this group of students and that support staff could sometimes be a barrier to inclusion.

Moyses and Porter (2015) undertook three ethnographic case studies in order to explore the experience of the 'hidden curriculum' for girls diagnosed with autism in mainstream primary schools. The girls in the study were able to mask their need to support which led to underachievement in school. The research also uncovered a misunderstanding of autism in girls by some teachers. Areas of difficulty were found to be class rules, working collaboratively, completing tasks and other interactions with peers. The three girls in this study all presented with behaviours that 'marked them out' from their peers. These behaviours seemed to be linked to the demands of the school day and were thought to indicate anxiety, for example, exhibiting constant movement. Moyses and Porter (2015) say that teachers "need to understand how autistic girls present, and how they learn" (p. 187).

Humphrey and Lewis (2008) talk about other people's reaction to the label of autism, for example, beginning to view and treat the pupil in a certain way, and how this will affect the pupil. Pupils can be at risk of being defined by the diagnosis and expectations can be limited, both self-expectations and those of others. They suggest change at two levels: a change in language, from 'impairment' and 'disorder' and in the way society attaches stigma and stereotypes to diagnostic labels. School leaders and staff working with children and young people should be aware of the voices of young people who have been given an autism diagnosis and of critical perspectives in regard to labelling (McLaughlin and Rafferty, 2014) (Runswick-Cole, Mallet and Timimi, 2016).

Ravet (2011) says that the debate about inclusion and the education of children who are diagnosed with autism is often characterised by "bipolar thinking, and moral posturing, and is obscured by misunderstandings and omissions." (p. 667). Ravet argues that the effective inclusion of children and young people who are diagnosed with autism requires practitioners to question two 'dominant and contradictory' perspectives: the rights based perspective, which considers the label of autism to be negative and exclusionary, and the needs based perspective, which considers the label of autism to be confirming, useful and inclusionary. She argues for an 'in between' integrative perspective which seeks to minimise negative labelling and exclusion by rejecting 'autism as a disease' metaphor.

Intervention

Almost all of the participants in Humphrey and Lewis' (2008) study talked about bullying and teasing leading to social isolation. Humphrey and Lewis (2008) highlighted the need to intervene with the peer group themselves. Ravet (2011) argues for whole school autism awareness and autism training for key staff and for all schools to aim to be 'autism friendly' with a range of provision to meet a range of group needs.

Honeybourne (2015) describes the school experiences of women on the autism spectrum and recommends that pupils need to be supported in relation to friendships, communication, and learning. Three possible areas identified in this study were that teaching staff may have higher social expectations of girls, that girls are expected to produce neater work than boys, and that perhaps girls with autism are generally more passive and keep quiet about their difficulties and so are less visible than boys with autism.

Gould and Ashton Smith (2011) emphasise the importance of schools in preparing girls who are diagnosed with autism for adult life by training staff, offering girl orientated personal / social skills classes, focusing on the 'hidden curriculum' which directly teaches the skills that typically developing girls learn 'indirectly and intuitively', such as the unwritten rules of girls' social interactions, teaching strategies to teach independence and to reduce vulnerability and need to address self-image, self-esteem and confidence building. Nichols et al. (2009) suggest that "Girls with ASDs are often alone in their ASD-ness" and suggest that access to a mentor may prove helpful.

Increasing concerns around mental health difficulties in children and young people has led to an increasing focus on the role of schools in supporting children's psychological wellbeing (DfE and DoH, 2014). A recent issue of Educational & Child Psychology (December 2016) was devoted to Mental Health and Wellbeing in Schools. Future in Mind (DoH and NHS England, 2015) focuses upon how services can improve children and young people's access to evidence based interventions. Thorley (2016) makes the case for making secondary schools responsible for early intervention. A further publication is Promoting Children and Young People's Emotional Health and Wellbeing: A whole school and college approach (Lavis and Robinson, 2015).

Clarke, Charman and Hill (2016) investigated a school-based Cognitive Behavioural Therapy Programme (CBT) with children diagnosed with autism. They used child and parental anxiety scales

(Spence, 1997) (Brodzinsky et al., 1992) and qualitative data was collected via semi structured interviews. The programme used was Attwood's Exploring Feelings: Cognitive Behavioural Therapy to Manage Anxiety for children aged 10 – 12 (Atwood, 2004). Quantitative results indicated that children in the experimental group had reduced levels of anxiety following the intervention compared to the control group. Anxiety levels remained reduced over time. Children in the experimental group became less likely to engage in behavioural avoidance strategies and more likely to use problem solving strategies.

Participants in my study either attended, or had attended mainstream schools. There is a great deal of literature about meeting the needs of students with autism diagnosis in mainstream schools (Morewood, Humphrey and Symes, 2011). Some of the secondary schools which I visit in the course of my work, have between 20 and 30 students with a diagnosis of autism. I have found that there can be a gap between the knowledge and understanding of members of staff directly involved in supporting students with special educational needs, and some senior leaders, and subject teachers, who perhaps, have more limited experience and training. I have not yet found support offered to this group of students to be gender specific. In my experience, many young people diagnosed with autism experience anxiety; and in some cases this can lead to school refusal. Hence, I found the literature about school based approaches to supporting the mental health of students to be of particular interest (Clarke, Charman and Hill, 2016).

Part 6: Friendships and Peer Relationships

Bauminger et al. (2004) found that children and young people with autism rated their friendships to be as close as those of typically developing children and young people. For children diagnosed with autism, friendship correlated positively with cognitive competency and general self-worth. Children diagnosed with autism perceived their social competency to be lower in comparison to typically developing children. Sofronoff et al. (2011) found that social vulnerability was the strongest predictor of bullying for children diagnosed with Asperger Syndrome. They also found a link between social vulnerability and 'victim status'.

Sedgewick et al., (2016) found that girls who attended a special school setting and were diagnosed with autism have similar friendship strength to typical girls. Boys and girls diagnosed with autism had different friendship patterns. Girls experienced more relational conflict and girls diagnosed with autism responded to this differently than typical girls. Girls participating in this study felt that they were not being supported in forming and maintaining positive peer relationships. Girls diagnosed with autism appeared to have qualitatively different friendships to autistic boys.

Mothers of adolescent girls diagnosed with autism have commented on the complexity of adolescent female behaviours Cridland et al. (2015). Mothers who participated in this research described their daughters as having difficulty with developing and maintaining friendships, dealing with relational aggression and some mentioned a disinterest in relationships. Some mothers said that their daughters were not interested in fashion and this stopped them from fitting in with peers. The girls participating in this research liked to socialise with boys who were diagnosed with autism.

Nichols et al. (2009) consider how female friendship changes during adolescence as friendships become about 'intimacy or the sharing of private thoughts'. This type of friendship "requires the skills of sharing information about oneself appropriately, providing emotional support to others, and managing disagreements without hurting one another." (p. 44).

As highlighted in part four of this literature review, friendships and peer relationships become increasingly important during adolescence. I looked at literature which compared the friendships of young people diagnosed with autism to that of 'typically' developing peers. In my experience, friendships and peer relationships, can be very challenging for young people who have difficulties with social communication (Cridland et al., 2015).

Chapter 3 - Methodology

This chapter discusses methodology and research design, including why this methodology was chosen over alternatives. This chapter also considers ethical issues.

Part 1: Epistemology and Methodology

Aims and Research Questions

I will briefly describe my decision-making process up to the point where I began to formulate research questions. Firstly I decided on my research topic. As I was interested in hearing first person accounts, this research would be qualitative and would therefore sit within the constructivist paradigm. I wanted to carry out individual interviews with a relatively small sample of participants and Interpretative Phenomenological Analysis (IPA) was the method best allied to my research aims. Smith et al. (2009) recommends that researchers choose an approach to data analysis before formulating research questions, deciding on data collection methods and seeking access to participants as the approach taken will influence strategies at each of these stages.

Aim:

I wanted to find out how girls / young women who have an autism spectrum disorder (AS) diagnosis view this diagnosis and what can be learned from hearing their voices.

Research Questions:

- How do adolescent females with an autism diagnosis make sense of this diagnosis?
- How does the autism diagnosis impact on their sense of self?

Epistemology

Mertens (2009, p11) provides a summary of the basic beliefs associated with the major research paradigms: post positivism, constructivism, transformative, and pragmatic. Basic beliefs include ontology, the nature of reality; epistemology, the nature of knowledge and the relationship between the knower and what would be known; axiology, the role of values; and methodology: the approach to systematic inquiry (Mertens, 2009).

Guba and Lincoln (2005) identify four basic belief systems followed by questions that help to define a paradigm. The axiological question asks, "What is the nature of ethics?" The ontological question asks "What is the nature of reality?" the epistemological question asks "What is the nature of

knowledge and the relationship between the knower and would be known?”, and the methodological question asks “How can the knower go about obtaining the desired knowledge and understandings?”

Positivism / post positivism and constructivism could be regarded as being situated at opposite ends of a continuum (Mertens, 2009). Positivism remains a dominant psychological paradigm and is associated with the belief that there is a reality which is knowable, the researcher takes an objective stance, the inquiry is value free and quantitative methods are used to pursue systematic inquiry. Researchers using a quantitative approach may say that the objectivity is statistical rather than absolute.

In contrast constructivism is associated with the belief that there are multiple, socially constructed realities, that there is an interactive link between researcher and participant and inquiry is value bound (Mertens, 2009). Guba and Lincoln (2005) identify qualitative methods, such as IPA, as the preferred methods for researchers working from a constructivist paradigm. Denzin and Lincoln (2005) describe qualitative research:

The word qualitative implies an emphasis on the qualities of entities and on processes and meanings that are not examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning.

(Denzin & Lincoln, 2005, p10)

Oxley (2016) states that IPA is not linked to one particular epistemological position and refers to ‘epistemological openness’ with researchers choosing their own ‘epistemological stance’. IPA researchers generally take an epistemological position on a spectrum between critical realism and contextual constructivist (Oxley, 2016).

In contrast to positivists, who believe that only one reality exists (ontology), and it is the researchers role to discover that reality, critical realists believe that reality does exist but would also argue that this reality cannot be fully known because of the researcher’s human limitations, that ‘reality’ is open to interpretation (Mertens, 2009). Contextual constructivists believe that reality is socially

constructed, therefore there can be multiple realities some of which can conflict with each other. Perceptions of reality can also change throughout the research process. It is the researcher's goal to understand the multiple, social constructions of meaning and knowledge (Mertens, 2009).

Methodology

Phenomenology

The feature that distinguishes phenomenological research from other qualitative research approaches is that the subjective experience of the participant is at the centre of the inquiry (Mertens, 2009). Smith (2004) describes the 'characteristic features' of IPA: idiographic, inductive and interrogative, and considers the different levels of interpretation which are possible with IPA. Langdrige (2007) talks of a "family of methods with a common phenomenological philosophical foundation." (p. 7) and describes the different approaches to phenomenological psychology.

As a first time user of IPA, and a first time qualitative researcher, I wanted to learn about the theoretical foundations of this method. Larkin, Watts and Clifton (2006) warn that the aims and origins of IPA can be overlooked by researchers. Smith et al. (2009) and Langdrige (2007) provide an in depth discussion of the theoretical foundations of IPA. IPA is based on three areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography. "Phenomenology is a philosophical approach to the study of experience" (Smith et al., 2009, p. 11). In IPA research the researcher attempts to understand another person's relationship with the world (Smith et al., 2009).

Phenomenology is based on the thinking of philosophers such as Husserl (1859 – 1938), Heidegger (1889 – 1976), Merleau-Ponty (1908 – 1961) and Sartre (1905 – 1980) each of whom conducted philosophical investigations of consciousness. "IPA is influenced by core ideas from a number of different philosophical perspectives on phenomenology and aims to translate these into a practical research methodology." (Oxley, 2016, p56).

Husserl's view of phenomenology involved individuals metaphorically stepping outside of their everyday experience or 'natural attitude' in order to examine it. For Husserl adopting a 'phenomenological attitude' meant reflecting on the perception of experience. He suggested the idea of epoche or 'bracketing' or putting to one side 'natural attitude' in order to concentrate on the perception of an experience. His phenomenological method is to undertake a series of 'reductions' in thinking in order to get to the core or essence of a given phenomenon. Husserl was mainly concerned with first person processes, individuals conducting phenomenological inquiry in regard to

their own experiences. Intentionality is the key feature of consciousness for Husserl, there is always an object of consciousness (Langdrige, 2007).

Heidegger was a student of Husserl's. He argued that we cannot achieve Husserl's reductions as our understanding is always drawn from our own position and we can only understand a phenomenon through interpretation (Oxley, 2016). The phenomenological concept of inter-subjectivity, "the shared, overlapping and relational nature of our engagement with the world" (Smith et al., 2009, p. 17) was key to Heidegger's philosophy. Heidegger introduced the term 'Dasein' for the uniquely situated quality of 'human being' (Heidegger, 1927). Humans arrive into the pre-existing world of objects, relationships and language, hence our 'being in the world' is always in relation to something else. Heidegger saw the central role of phenomenology as being able to approach any object of our attention in just such a way that it is allowed to show itself 'as itself' (Larkin, Watts and Clifton, 2006).

Merleu-Ponty was also interested in understanding our 'being' in the world and like Heidegger he was interested in context and suggested that humans see themselves as different from everything else in the world, but that individuals can never share another's experience. He talked about the lived experience of being a body in the world, the body shaping the fundamental character of our knowing about the world (Smith et al., 2009).

Satre stressed the developmental aspect of human being. People are constantly developing and becoming themselves. He saw people as engaged in their own projects in their world. According to Satre our perception of the world is shaped by the presence of others and the projects that they engage with (Smith et al., 2009).

Larkin, Watts and Clifton (2006) consider the philosophy of Husserl and Heidegger in the context of IPA studies, recognising that it is not fully possible for researchers to remove their thoughts and their meaning systems in order to find out 'how things really are'. They suggest that both participants and researchers are situated within the world that they observe and can never escape their preconceptions.

IPA is concerned with understanding the person in context, and exploring a person's relatedness to, or involvement in the world. Larkin, Watts and Clifton (2006) point out that we can 'only glimpse' a person's current subjective mode of engagement with some specific context or aspect of the world. As researchers we focus upon the person in context, and that person's relatedness to the phenomena at hand. An account reveals something about a person, but only that person's current

positioning in relation to the 'bodies of knowledge' in their experience and culture, for example, autism (Larkin, Watts and Clifton, 2006).

Phenomenology holds that 'human beings are not passive perceivers of an objective reality, but rather that they come to interpret and understand their world by formulating their own biographical states into a form that makes sense to them.

(Brocki & Wearden, 2006, p 88)

Hermeneutics

Hermeneutics is the theory of interpretation and began with the analysis of religious texts. For example a hermeneutic question could be, 'Is it possible to uncover the intentions or original meanings of an author?' (Smith et al., 2009). Hermeneutics places emphasis on contextual meanings (Oxley, 2016).

Schleiermacher (1768), Heidegger (1927 – 1976) and Gadmer (1900 – 2002) are three important hermeneutic theorists. For Schleiermacher, interpretation involved both grammatical and psychological interpretation. Heidegger linked interpretation to 'Dasein'. He saw both hidden and visible meanings. For Heidegger phenomenology was an interpretive discipline which is concerned with "understanding the thing as it shows itself, as it is brought to light" (Smith et al., 2009, p. 24). Gadamer was also concerned with the analysis of historical and literary texts and emphasized the importance of history and tradition on the interpretive process. He believed that understanding the meaning of the text was more important than understanding the person.

The hermeneutic circle "is concerned with the dynamic relationship between the part and the whole, at a series of levels" (Smith et al., 2009, p. 28). Smith et al., (2009) provide an example, the meaning of a word only becomes clear in the context of the whole sentence and the meaning of the sentence is dependent on the meaning of individual words. In IPA studies the process can be linear, or step by step, but it can also be interactive, for example, moving back and forth when considering the data. We can enter into the meaning of the text at a number of different levels.

Phenomenology in the Heidegger tradition demands that the analyst develops a hermeneutic account of the person's relatedness to prevailing topic of interest. We need to identify, describe and understand the key objects of concern in the participant's world and the experiential claims made by the participant (Larkin, Watts and Clifton, 2006). Oxley (2016) sees Heidegger's philosophy of phenomenology being interpretive and connected to hermeneutics as 'key' to IPA.

Idiography

Idiography is concerned with the 'peculiar' in contrast to nomothetic psychology which is concerned with group behaviour (Smith et al, 2009). Hence IPA is concerned with detailed analysis of a particular experiential phenomenon; this can be a single case or small study. 'The fundamental principle behind the idiographic approach is to explore every single case before producing any general statements' (Pietkiewicz & Smith, 2014, p 8).

Oxley (2016) recognises the value in exploring the idiosyncratic accounts of small samples of 'expert groups'. She proposes that the 'idiographic nature' of IPA ensures that a richer and more holistic picture emerges. Smith et al. (2009) talk about 'theoretical generalisability' as linked to the key IPA concept of 'understanding the part to illuminate the whole'. The reader of the thesis should be able to assess the evidence in relation to their existing professional and experiential knowledge.

What is IPA?

IPA appeared in the mid-1990s with Jonathan Smith's 1996 paper (Smith, 1996). Smith et al. (2009) describe IPA as a 'recently developed and rapidly growing' approach to qualitative inquiry which is used in human, social and health sciences as well as psychology, for example, the exploration of people's experience of illness (Smith, 2011). Brocki & Wearden (2006) also refer to IPA as 'applicable and useful' in the field of health psychology. Oxley (2016) suggests that the 'holistic' approach of IPA fits particularly well with Educational Psychologists perspective of providing holistic support to pupils, schools and families. Hefferon & Rodriguez (2011) refer to IPA as 'fashionable'. There is a website dedicated to IPA (www.ipa.bbk.ac.uk), there are regional groups, an annual conference and training workshops for prospective researchers.

IPA studies usually involve a single case or a small number of participants. Each case is examined in detail before comparisons are made between cases. IPA studies aim to find a relatively homogeneous sample. Findings are limited to the group rather than generalised across a larger group or population. Data collection is usually in the form of semi structured interviews which offers some flexibility when interviewing. Interviews are usually voice recorded, transcribed and then analysed case by case (Smith et al, 2009) (Pietkiewicz & Smith, 2014).

Why IPA?

Silverman (1993) explains the difference between methodology and method: methodology refers to a 'general approach to studying research topics', for example quantitative or qualitative, whereas method refers to a 'specific research technique'. Mertens (2009) focuses upon seven types of qualitative research: ethnographic research, case study, phenomenological research, grounded

theory, participatory research, clinical research and focus groups. Popular methods employed for qualitative research include Grounded Theory (Straus & Glaser, 1967), Discursive Approaches; Foucauldian Discourse (Parker, 1992) and Discursive Psychology (Potter & Wetherell, 1987), and Narrative approaches or inquiry (Bruner, 1990), (Smith et al., 2009).

I explored each method in turn when considering how best to explore my topic of interest.

Grounded Theory sets out to generate a theoretical account of a particular phenomenon. In a Grounded Theory study the topic does not have to be psychological (although it can engage with psychological phenomena) whereas in IPA psychological similarities and differences are usually analysed within a homogeneous group. In practical terms Grounded Theory studies also require data collection on a large scale. Discursive approaches are usually used for topics which involve power and / or interaction and have a basis in social constructivism. A narrative approach focuses on how language relates to sense-making. I did not use Discursive Analysis or a narrative approach as language is not the main target of my analysis.

IPA appeared to be the method best suited to my research: "IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences" (Smith et al., 2009, p. 1): in this case, being given an autism diagnosis. I am interested in my participants' reflections on the significance of something that is presumably important or central to their lives. Larkin, Watts and Clifton (2006) talk about the potential of IPA to "properly explore, understand and communicate the experiences and viewpoints offered by its participants" (Larkin, Watts and Clifton, 2006, p. 103).

Hefferon & Rodriguez (2011) suggest that prospective IPA researchers should look at good quality IPA papers before beginning their research. Some published papers and doctoral theses cover similar ground to my proposed research topic and also use IPA. Humphrey & Lewis (2008) used IPA to explore how secondary school pupils diagnosed with AS (autism spectrum) made sense of their educational experiences. Huws & Jones (2008) used IPA to analyse semi structured interviews with young people diagnosed with autism. Rogan (2011) used IPA for her doctoral thesis which explored of the views of Key Stage 4 pupils diagnosed with Asperger Syndrome.

Larkin, Watts and Clifton (2006) point out that some other qualitative methods offer "greater methodological prescription and epistemological certainty." (Larkin, Watts and Clifton, 2006, p. 103). They talk about the 'subtlety and complexity' of IPA and suggest that it may be more appropriate to understand IPA as a 'stance' or perspective from which to approach the task of qualitative data analysis, rather than as a distinct method. Watts (2014) is critical of the idea that 'proper' application of a qualitative method will improve research findings. He states that 'methods are simply tools' and

their effectiveness is dependent on the skills of the user. He places emphasis on the 'analytic perspective and creativity' of the researcher.

There are two aims or commitments of an IPA researcher: "the phenomenological requirement to understand and give voice to the concerns of participants, and the interpretative requirement to contextualise and make sense of these claims and concerns from a psychological perspective." (Larkin, Watts and Clifton, 2006, p102).

As a researcher using IPA I wish to interpret my participants' accounts in order to understand their experience. This is known as a double hermeneutic, hermeneutics being the theory of interpretation. Hence, the first aim of my research is to produce a clear, third person, psychological informed description which is as close to my participants view as possible. The second aim is to develop an interpretive analysis which places my participants' descriptions within a wider cultural context.

I found the following summary from Pietkiewicz & Smith's (2014) to be helpful, "IPA synthesizes ideas from phenomenology and hermeneutics resulting in a method which is descriptive because it is concerned with how things appear and letting things speak for themselves, and interpretive because it recognises that there is no such thing as un-interpreted phenomenology." (Pietkiewicz & Smith, 2014, p8).

Part 2: Research Design

Ethics

I followed ethical guidance from both The British Psychological Society (BPS) Code of Human Research Ethics (2014) and The University of Sheffield Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue (version 6). BPS (2014) talks about the Principles of Best Practice in Ethics Review: independence, competence, facilitation, transparency and accountability.

Psychologists value the dignity and worth of all persons equally, with sensitivity to the dynamics of perceived authority or influence over others and with particular regard to people's rights including those of privacy and self-determination'

(BPS, Code of Ethics and Conduct, 2009, p.10).

During the Ethics Approval Procedure I was asked to make changes to the recruitment process. It was my original intention to use purposeful or selective sampling. I intended to ask colleagues in the Educational Psychology Service and Specialist Advisory Teaching Service to identify potential participants and planned then to make a direct approach via personalised letters. Ethical reviewers expressed concerns that making a direct approach to prospective participants and their parents could cause upset, especially given the sensitive nature of the subject under discussion. On reflection I thought that prospective participants and their parents may also have felt pressure to agree to a direct request by an adult in a professional role.

Instead, I created a poster asking for volunteers to participate in my research project (Appendix 1). The poster was displayed in the learning support department of secondary schools. Prospective participants were provided with a detailed information sheet (Appendix 2) prior to the interview taking place and were also offered the opportunity to contact me if they wished to ask further questions about the research. For participants under the age of 18 their parents were also provided with an information sheet (Appendix 3) prior to the interview taking place (via post) and were offered the opportunity to contact me if they wanted to ask further questions about the research.

Participants signed a written consent form at the time of the interview (see Appendix 4). This form covered the right to withdrawal and confidentiality, including data management. I read through the form with each participant and asked if they had any questions or concerns. For girls aged between 14 and 18 written parental consent was required before the interview took place (Appendix 5).

I gave consideration to other ethical concerns at the planning stage. Participants were invited to choose the venue and time of day for their interview; I suggested that we meet either within their educational setting, their home or a quiet public place of their choosing.

I was aware that this may have been an unexplored and potentially sensitive topic for participants so was ready to monitor their body language and facial expressions throughout the interview, and was prepared to stop the interview immediately if a participant appeared in any way upset. Hefferon & Gil-Rodriguez (2011) emphasise the importance of the interviewer's sensitivity to both verbal and nonverbal communication.

I ensured that all participants were aware that they were able to seek and receive support from a familiar member of staff or family member once the interview had taken place (dependant on where the interview took place). Participants and their parents were given contact details for my university tutor in the event that they had any complaints or concerns about my conduct or the research process.

Kerry, the first participant, did become emotional when she spoke about the effect of her autism diagnosis on her sense of self and disclosed self-harming. She became more animated towards the end of the interview when she spoke of future aspirations but I asked if she was okay after the interview had ended and she said that she had found it helpful to speak to someone about autism. I told her that I felt that I should mention her self-harming to her Learning Support Assistant, Ms L, and she said that was okay. When I spoke to Ms L by telephone she said that she was already aware of Kerry's self-harming and that she would have a chat with her and make sure that she was feeling okay.

Methods

Semi-structured Interviews and Interview Design

Smith et al. (2009) provide detailed guidance for planning and conducting IPA research and I found this guidance useful; for example, a list of questions that could be asked in a semi structured interview (p. 62). Langdridge (2007) also offers detailed guidance for a first time phenomenological researcher. From the outset I aimed to be mindful of Hefferon & Rodriguez' (2011) advice that 'less is more' in terms of participants and questions (and themes in analysis).

My primary aim as an IPA researcher was to elicit rich, detailed, first person accounts of the experiences of participants in regard to the phenomena under investigation. Semi-structured, one to one interviews are the most popular method for conducting IPA research (Hefferon & Gil-Rodriguez,

2011), although diaries and focus groups can also be used (Humphrey & Lewis, 2008) (Smith et al., 2009). During a semi-structured interview the researcher and participant have the opportunity to engage in dialogue. Semi-structured interviews also offer 'space and flexibility' for any unexpected issues to arise and be subsequently investigated (Hefferon & Gil-Rodriguez, 2011).

Sample Size

Hefferon & Gil-Rodriguez (2011) argue that student researchers using IPA often include too many participants which 'de-emphasises' IPA's commitment to idiography. They suggest 'less is more' and that fewer students should be examined in greater depth. They recommend between four and ten participants for professional doctorate research. Smith et al. (2009) also suggest between four and ten participants for doctoral research. I was aiming to recruit six participants in total.

The Interview Schedule

When I met with children and young people in the capacity of a Specialist Advisory Teacher I tended to stick to a simple script in terms of the questions I would ask but was also happy to follow the child or young person's conversational lead. As a Trainee EP I find that I have become increasingly skilled in asking open-ended questions and questions designed to elicit psychological insight into the interviewee's view of the world.

I was aware that the questions asked during the semi-structured interview would be crucial to the overall 'success' of the interviews, both in terms of how comfortable and forthcoming participants were likely to be, and in eliciting rich data. Larkin, Watts and Clifton (2006) talk about the importance of choosing the best questions to ask of particular subject matters.

Hefferon & Rodriguez (2011) recommend that researchers keep interview schedules short and advise against schedules that are 'too long, overly extensive and detailed' as such schedules may constrict the views of participants. Hefferon & Rodriguez (2011) also suggest that interview schedules should start with broad general questions that allow the participant to set the parameters of the topic. They warn against the researcher imposing their understanding of the phenomenon on the participants' narrative through overly prescriptive questions and questioning.

Larkin, Watts and Clifton (2006) acknowledge that the researcher's question choices will be based upon what we think we already know about our subject matter. IPA also offers the researcher the opportunity to evaluate what they have brought to the study which may have influenced the shape of the interviews.

My interview questions were informed by my pre-existing knowledge and experience of working directly with this group of young people, alongside reading some of the literature about females on the autism spectrum. My questions were grouped into ice breaker / general questions and three broad categories: finding out, understanding of autism, sense of self and relationships. I found the relevant sections of Smith et al. (2009) helpful in framing open ended questions. My final interview schedule consisted of 14 questions including an ice breaker and the final question; 'Is there anything that I have left out that you would like to add?' I shared the interview schedule with Educational Psychology colleagues during a team meeting and adjusted my questions in regard to their responses, for example, rephrasing questions that were deemed too abstract, especially for this group of young people.

Fourteen questions may be considered too many (Smith et al., 2009; Hefferon & Rodriguez, 2011) but I was concerned that some, if not all, of my participants would prove to be reticent and would answer questions quickly. Hence, I judged that I needed to consider a balance between the risk of running out of questions and having too many questions (see Appendix 6). My first four interviews lasted approximately 30 minutes and my last two interviews lasted approximately an hour each. Participants 5 and 6 had only recently been through the diagnostic process and both young women talked extensively about the difficulties which had led to this process.

Conducting the Interview

In qualitative research data are usually collected in naturalistic settings (Pietkiewicz & Smith, 2014), for example, schools and homes. Four of my participants opted to be interviewed in their school and two participants invited me to speak with them at their home.

Although I lacked experience in conducting qualitative research eliciting the voice of children and young people was part of my day to day work as a specialist advisory teacher and as a trainee educational psychologist. Hence prior to starting this research I felt fairly confident that I would be able to develop rapport with my participants and put them at ease. I chatted with participants before starting the formal interviewing process, for example, asking about their exams or holiday plans. I began each interview by introducing myself and briefly outlining the purpose of the interview.

Hefferon & Gil-Rodriguez (2011) emphasise the importance of researchers having developed the following interviewing skills: active listening, asking open ended questions, and the ability to gain trust and rapport. Oxley (2016) talks about practicing 'deliberate naivety' during the interview. I feel that this is skill that I have developed as a trainee EP.

Larkin, Watts and Clifton (2006) talk about the importance of taking an approach which is sensitive and responsive to the nature of the subject matter. I did not ask about autism until Question 4 when my participants had the opportunity to 'warm up'. Transcripts reveal that, dependant on the participant, I added the proviso, 'Are we okay to talk about autism spectrum?'

Sampling

Recruitment Process

Prospective participants belonged to a relatively homogeneous group: females aged between 14 and 25 who attended or had attended a mainstream school, who had autism diagnosis and were aware of their diagnoses. I hoped to interview six participants in total.

Without wishing to make assumptions I felt that older girls and young adults would be better able to reflect on their experiences and would be able to give deeper consideration to participation than younger girls. I sought participants who either attended or had attended mainstream school rather than girls who attended or had attended a special school. I presumed that girls who had experienced mainstream education would be better able to articulate and reflect than girls who may have had more significant communication and / or cognitive impairments.

I received ethical approval for my research in mid-April 2016 (Appendix 7) and began the process of recruiting participants. I decided to start with the learning support departments of secondary schools within the local authority. I was optimistic that enough participants would volunteer via the learning support departments of local schools but I also considered seeking further participants locally via an adult autism support group, further education colleges and universities.

I was undertaking my second and third year EPS placements in the LA where I previously worked as a specialist advisory teacher, hence I had already developed working relationships with a number of secondary school special educational needs coordinators (SENCOs). I contacted the SENCOs from four local secondary schools via email and asked them to display my poster in the Learning Support Department of their schools. One school did not have any students who met my criteria for participants. From the remaining secondary schools four girls volunteered to participate in my research, although one girl withdrew when I began to organise the interviews.

I also asked my placement supervisor to ask the SENCO from her 'patch' secondary school to display the poster in the Learning Support Department. This led to the older sister of a student volunteering to participate during her summer holiday from university.

I also emailed my poster to former colleagues in the Specialist Advisory Team and asked them to share this poster with the SENCOs from the secondary schools that they visit. This led to two girls from two secondary schools volunteering to participate. All the potential participants and their parents (dependent on the age of the girls) were then given an information sheet by the school SENCOs (Appendix 2 and 3).

Sample

By the end of the summer half term 2016 (27th May) I had six participants. All interviews took place in June and July 2016. I arranged the first three interviews via school SENCOs and these interviews all took place in a quiet room in the school at a time of the girls / schools' choosing. Two other girls were school leavers (year 11) and I contacted them by telephone (as agreed) to arrange a date, time and place for an interview. One girl asked for the interview to take place in school and the other girl preferred the interview to take place at her home. I liaised with the participant who was a second year university student via e mail. She preferred to be interviewed at her home.

Table 1: Overview of Participants

Participant Number	Pseudonym	Year group	Education Health and Care Plan	Age when 'diagnosed'	Date of interview	Place of interview
1	Kerry	11	yes	Primary school	22.06.16	school
2	Micha	10	yes	Primary school	04.07.16	school
3	Melody	9	yes	Primary school	19.07.16	school
4	Kiera	11	yes	Primary school	20.07.16	school
5	Maddy	11	no	Year 11	21.07.16	home

6	Ellie	2 nd year of university	no	1 st year of university	25.07.16	home
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All of my students were white British and this fits with the wider ethnic demographic of the county. Participants 1 to 4 were school-aged and made reference to having been ‘diagnosed’ with autism prior to starting secondary school. Participant number 5 was also school-aged (Year 11) but she had only recently been through the diagnostic process, so her story or experience of autism diagnosis was different from that of the first four participants. Participant number 6 had also recently been through the diagnostic process as an adult, hence she had experienced a different diagnostic pathway.

Validity

Yardley (2000) explores ‘dilemmas’ in qualitative health research. She considers appropriate criteria for assessing the validity of a qualitative analysis: sensitivity to context; commitment and rigour, transparency and coherence, impact and importance. She points out the risks associated with qualitative research: that it is a relatively new research paradigm, so is novel and diverse and open to subjectivity by the researcher, so there is a further risk to quality control.

Tracy (2010) ‘presents and explores’ eight ‘Big Tent’ key markers of quality in qualitative research. These are: a worthy topic, rich rigor, sincerity, credibility, resonance, makes a significant contribution, ethics and meaningful coherence. I found it useful to remind myself of Tracey’s key markers at regular intervals during the research process.

Smith (2011) alludes to a ‘lively debate’ within the qualitative community with regard to guides for assessing the quality and validity of qualitative research. He feels that it is important that qualitative researchers take the question of quality and validity seriously. He recommends Yardley’s (2000) criteria when thinking of assessing quality in IPA.

Smith (2004) discusses the criteria for when an interpretation is ‘good enough’. He says that most IPA has been at the ‘thematic level’, illustrated with verbatim extracts, and he suggest that there is scope for “pushing further the micro-textual analysis of small extracts of text” (p. 51).

There are some criticisms directed at IPA. Hefferon & Rodriguez (2011) discuss implications of the rise in popularity of IPA and state that IPA has become the ‘default’ option for many students as its focus on subjective lived experience ‘intuitively appeals’. They identify issues and concerns and

argue that there is a 'lack of understanding' that IPA is primarily an interpretative approach. This can lead to 'broadly descriptive IPA that lacks depth'.

Smith (2011) describes a guide for evaluating IPA research which is used to assess papers about experience of illness. He includes an IPA quality evaluation guide including criteria for 'acceptable', 'unacceptable' and 'good' (p. 17). He also provides a table titled 'What makes a good IPA paper?' (p. 24). Characteristics include the following: the paper should have a clear focus, the paper should have strong data, the paper should be rigorous, sufficient space must be given to the elaboration of each theme, the analysis should be interpretative not just descriptive, the analysis should be pointing to both convergence and divergence, and the paper needs to be carefully written.

The Role of Reflexivity

Reflexivity is the process whereby researchers are 'conscious of and reflective about' the ways in which their methods and own subject position might impact on the psychological knowledge which is the end product of the research process (Langdrige, 2007). Langdrige (2007) offers 10 questions to encourage a reflexive approach to research (p. 59).

From the outset I was aware that any discoveries made were a function of the relationship between myself as the researcher and my topic of interest, autism spectrum diagnosis. Hermeneutic phenomenology recognises that the researchers views of the world are 'inextricably intertwined' with the way in which they interpret the participants' experiences (Oxley, 2016). Hence the importance of the IPA researcher adopting a continually reflexive attitude. The researcher needs to acknowledge that his or her pre-existing knowledge and pre-conceptions are brought to the encounter. I lean towards social constructionism and am aware of the controversies around the medicalisation or labelling of behaviour highlighted in chapter 2, but did not want to give the impression that I doubted the validity of participants' autism diagnoses.

Oxley (2016) views reflexivity as an ongoing process as unconscious pre-conceptions can come to light throughout the research process. She describes the hermeneutic circle as 'The relationship, in which the researcher discovers challenges to their pre-conceptions as they engage with the data' (Oxley, 2016, p57).

Oxley (2016) talks about two 'filters' between the research and the direct experience. The participant expressing their perception of the experience and the researcher interpreting what the participant has said. Smith et al. (2009) suggest that the researcher's interpretation may 'shed light' on an aspect or aspects of the experience which the participant does not explicitly share, i.e. it is

hidden and only emerges through the researcher's interpretation of the data. As a researcher my primary concern was not with the nature of autism but with my participants and their experiences. During the research process I kept a reflective diary in order to aid and illustrate reflexivity and my diary informed the reflexive boxes included in Chapter 4.

IPA aims at giving evidence of the participants' making sense of the phenomena under investigation and, at the same time, document the researchers' sense making'.

(Hefferon & Gil-Rodriguez, 2011, p11)

Analysis of Interviews Using IPA

IPA involves the detailed analytic treatment of each case followed by the search for patterns across the cases. Where this is done, the best IPA studies are concerned with the balance of convergence and divergence within the sample, not only presenting both shared themes but also pointing to the particular way in which these themes play out for individuals.

(Smith, 2011 p. 9)

IPA provides a set of flexible guidelines which can be adapted by individual researchers according to their research objectives (Hefferon & Gil-Rodriguez, 2011). I followed the guidance set out in Smith et al. (2009). They suggest six stages that researchers should follow in order to analyse and interpret data:

Stage 1: Reading and re-reading i.e. close examinations of the transcript.

Stage 2: Exploratory commenting i.e. examining the content on a very exploratory level by making notes.

Stage 3: Developing emergent themes i.e. focusing on discrete chunks of text in order to identify what has been learned through exploratory commenting.

Stage 4: Searching for connections across themes i.e. identifying subordinate themes with related emergent themes.

Stage 5: Moving to the next case i.e. analysing each transcript in turn using the same method.

Stage 6: Looking for patterns across cases i.e. subordinate themes are drawn together to identify a number of superordinate themes for the group each with a number of related subordinate themes.

Brocki & Wearden (2006) discuss the 'lack of attention' sometimes given to the interpretative aspect of IPA. Hefferon & Rodriguez (2011) talk about the inclination for students to present too large a number of descriptive superordinate and subordinate themes with insufficient data extracts included. They suggest that a smaller number of themes will present a 'more thorough and detailed analysis'. I found Watts (2014) advice to be useful in regard to data analysis and writing a meaningful discussion of research findings in relation to the literature as he offers straightforward do's and don'ts.

Most qualitative methods reject formulating hypotheses prior to carrying out research but promote an 'open' approach to data collection and analysis (Pietkiewicz & Smith, 2014). As already mentioned earlier in this chapter, with IPA and other qualitative research methods, there is a greater focus on the transferability of findings, from group to group, than on possible generalisation (Pietkiewicz & Smith, 2014).

Analysis leads to writing a narrative account of the research. This involves writing about each theme in turn. Each theme is described with exemplar extracts included from the transcripts and followed by analytic comments from the researcher. The researcher needs to look at the data through a psychological lens and interpret it with the application of psychological concepts and theories (Hefferon & Gil-Rodriguez, 2011).

Watts (2014) states that high quality analysis is more important than adherence to method. He talks about closeness to the data by understanding each participants' words and perspectives. He advises that the researcher should aim to adopt a first person perspective during analysis and a third person perspective during discussion of the study findings. Watts warns that the final paper should reflect the participants' views about the subject and not the researchers' views about the participants.

Chapter 4 - Research Findings

I followed the six stages recommended by Smith et al. (2009) in order to analyse and interpret the data arising from my interviews. I transcribed the interviews myself, and although this was a lengthy process it helped me to gain familiarity with participant's words. I decided to complete all six transcriptions before analysing each transcript in turn.

Stage 1: I read and re-read each transcript. Re-reading of transcripts continued throughout the process.

Stage 2: Exploratory comments: I read a transcript and made three types of notes in the right hand column: descriptive comments, comments on language (blue text) and initial interpretations (underlined text). See Appendix 8: Transcript 1 – Interview with Kerry, including exploratory comments and emerging themes

Stage 3: I used exploratory comments to identify emerging themes, which I recorded in the left hand column. I then transferred emerging themes onto a table. See Appendix 9: Emergent themes for Kerry

Stage 4: I searched for connections across emerging themes by physically grouping emerging themes together in order to identify superordinate themes for the participant.

See Appendix 10: Example of a photograph showing how connections across emergent themes were organised for Kerry. See Appendix 11: Emergent themes, grouped into themes for Kerry and Appendix 12: Superordinate and subordinate themes for Kerry

Stage 5: I moved onto the next case and analysed each transcript in turn using the same method. See Appendix 13: Superordinate themes for each participant

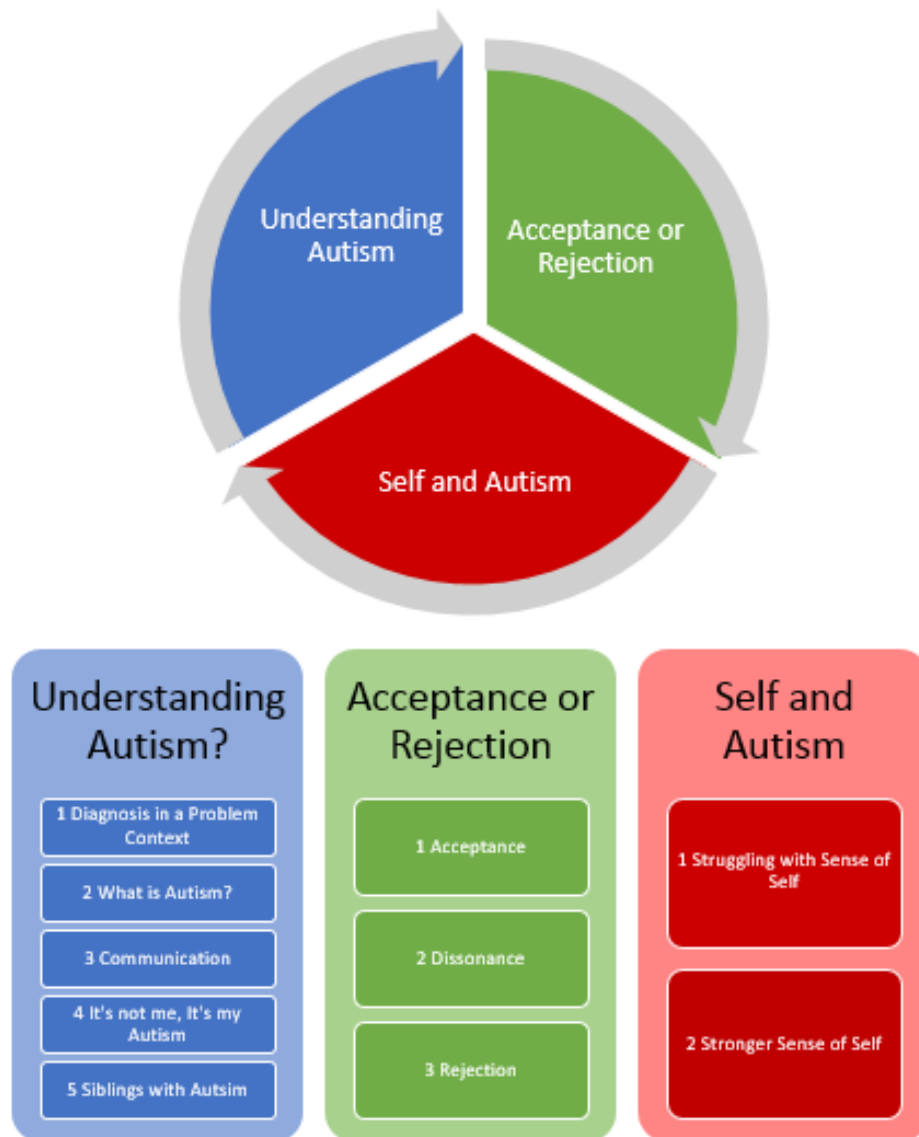
Stage 6: I searched for patterns across cases, by looking at superordinate themes for each participant in order to identify a number of superordinate themes for the group, each with a number of related subordinate themes. A number of superordinate themes had emerged for participants: difficulties they experienced, how they related to autism, sense of self, coping mechanisms, siblings with autism, friendships, peer relationships, support at school, aspirations, parental attitude and role and their understanding of autism. At this stage I was finding it difficult to fix upon superordinate

themes for the group. I shared my analysis with a colleague, who prompted me to return to my research questions in order to identify superordinate themes and subordinate themes for the group.

Hence I decided upon: Understanding Autism, Acceptance and Rejection and Austin and Self as superordinate themes for the group. I have included a colour coded diagram for each superordinate theme which illustrates the connection between participants and subordinate themes. See Figure 1: Superordinate Themes across the Group and see Figures 2, 3 and 4.

Figure 1:

Superordinate Themes Across the Group



The three overarching superordinate themes which best relate to my research questions are: Understanding Autism, Acceptance or Rejection of Autism, and Self and Autism. Each superordinate theme, includes a number of subordinate themes. I have provided a brief introduction to my participants and I will then discuss findings for each superordinate theme in turn, including direct quotations from participants. Reflections on each interview, comments on participants' communitive style and an interpretive summary for each participant can also be found in the Appendices (Appendix 14).

Introducing my Participants

Kerry

At the time that the interview took place Kerry was in Year 11 of a mainstream secondary academy. She had just completed her GCSE exams and was hoping to attend school 6th form to study for A levels. The school SENCo told me that Kerry had an Education, Health and Care Plan since primary school. I gathered from the interview that Kerry lived with her mother and two brothers, one older and one younger. She did not mention her father. The SENCo also told me that both of Kerry's brothers had an autism spectrum diagnosis and that her mother works as a teaching assistant at a local primary school. It seemed that Kerry had been diagnosed with autism when she was at primary school.

Micha

At the time of our interview Micha was in Year 10 of a mainstream secondary school. I gathered from our interview that Micha was following an alternative Key Stage 4 curriculum. The SENCo told me that Micha had an Education, Health and Care Plan. From the interview I gathered that Micha lives with her parents and siblings. It seemed that Micha had been diagnosed with autism when she was at primary school although she was not told about her diagnosis until she was in secondary school. Micha wanted the school SENCo to stay in the room while the interview took place, but the SENCo, Mrs M, did not interrupt the interview at any point.

Melody

Melody was my youngest participant. At the time of our interview she was in Year 9 of a mainstream secondary school and she had chosen GCSE subjects for Year 10. Although this school includes a Strategic Resourced Provision for students with Autism Spectrum Conditions, Melody did not have a 'Strategically Resourced' place. The SENCo told me that she had an Education, Health and Care Plan since primary school. Melody lives with her mother and father, she is an only child. It seemed that Melody had been diagnosed with autism when she was at primary school although she was only told about her diagnosis when she was at secondary school.

Keira

At the time of the interview Keira had finished her GCSE exams and had left her mainstream school. She came back into school to meet with me. Keira was waiting to start a NVQ Level 2 course at her local Further Education College. The school which Keira attended had Strategic Resourced Provision for students with autism spectrum conditions and other Special Educational Needs and Keira told me that she accessed this provision at social times. I do not know if she had an Education, Health and Care Plan as I did not meet with the school SENCO. Keira lived with her mother, step-father and younger brother. The school administrator told me that Keira's 'dad' was her step-father and that he was in the process of adopting Keira and she was changing her name. Keira had been diagnosed with autism when she was at primary school.

Maddy

At the time of our interview Maddy had finished her GCSE exams and was hoping to return to her secondary school 6th form to study for A levels. Maddy had been diagnosed with autism when she was in Year 10 and she did not have an Education, Health and Care Plan. Maddy lives with her mother, father and sister. I interviewed Maddy at her home and she asked for her mother to be present during the interview. Maddy's mother did express her own views during the interview and these are included in the interview transcript, although I did try to 'bracket' these views during analysis.

Ellie

Ellie was my oldest participant. She had just finished her second year of university when I met with her. Ellie had attended a mainstream secondary school and had not had a Statement of Special Educational Needs. Ellie had been diagnosed with autism during her second year of university, as an adult. Ellie lives with her mother, father and younger sister during university holidays. Her sister was also going through the diagnostic process for autism.

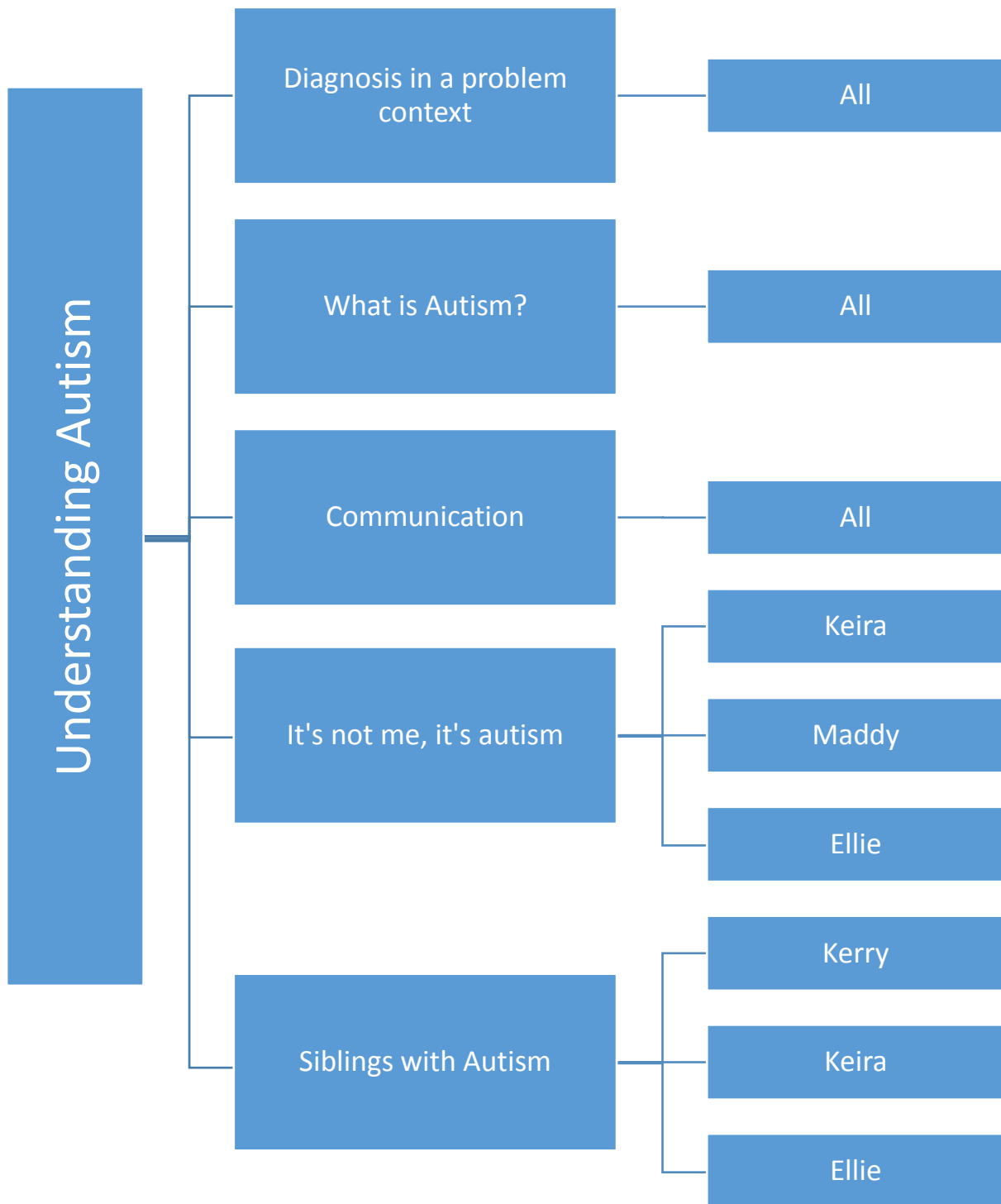


Figure 2: Superordinate Theme 1

Superordinate Theme 1: Understanding Autism

I asked each participant to share their diagnostic story. Autism, or the prompt for diagnosis, was usually situated in a problem context. Kerry, Micha, Melody and Keira were all diagnosed with autism whilst they were in primary school. Maddy and Ellie were given autism diagnoses as young adults and were actively involved in the diagnostic process.

Diagnosis in a Problem Context

Kerry was around seven or eight years old when she first became aware of her autism diagnosis:

Erm, well, like I heard my mum on the phone and all that, if she was talking to old friends and all that, erm, she normally like mentions it, and sometimes I like pay attention and sometimes I don't and all that, . . . (46 – 48)

For Kerry, autism was associated with 'problems' from the outset. She gives the impression that she was unconcerned when she heard her mother talking on the phone; autism may have held little meaning for her at that time, or perhaps it was difficult to hear those conversations. Kerry's mother later linked her problems at secondary school to her autism diagnosis (52 - 53).

Micha was told of her autism diagnosis by her mum when she was at secondary school (116). For Micha, autism is also situated in a problem context:

When I was in nursery they said that I was acting a bit different and I wasn't fitting in with the other kids . . . So my mum took me to the doctor to see what was going on and then that's it, we found out that I had autism. My mum got upset, she started crying 'cause she felt bad for me. (90 - 95)

Concerns led to the diagnostic process. Because autism is diagnosed by doctors Micha considered it 'real' and therefore unquestionable. Her mother's response indicated that that autism is not a good thing to 'have'.

Melody was told about her autism diagnosis in a meeting with her parents and the school Special Educational Needs Coordinator when she was in Year 7. She hadn't heard of autism, although she had realised that she was 'different' in primary school because she was put in a club for children with 'problems':

. . . I kinda knew, I kinda knew, that there was something different, I knew it was probably nothing and that. But like in Year 4 they started this club; it was a very nice club and I get why they did it and everyone who was autistic, disability, and they all put us, every Thursday we would have breakfast and we would talk and that, it was, it was, like a, a nice time and we would miss French so we were quite happy with that, laughs . . . And in Year 4 I was like, okay, so I'm a little bit different and that's why they've done this and I think . . . (91 – 101)

Melody seemed to accept being put in the club and played down the situation. She and her friend realised that they were regarded as different by adults in school and that that they would continue to be treated differently (107 - 113). She even finds some positivity, "*being a little bit different*". She reflects that by putting children 'in the club' the adults in school were communicating that they were different without explicitly talking to them about difference and disability (117 - 121). Although Melody says, "*loads of people are just like you*" the message she received was that she was different. She was put into a group for children with special educational needs and disability and therefore she is "*just not the same as most people*" (121).

Kiera's family moved from the city so that she could attend a small, rural secondary school. Like Kerry, she overheard her parents talking about her autism diagnosis:

Erm, and I think I learned about it when we were walking around and went into the LRC bit and they were talking about it. Erm, I think that they said that I had it. (73 - 75)

There is a sense of disempowerment, of hearing adults talking about you in a problem context. She was introduced to her new teachers as a student with autism and particular needs. Use of the word 'think' suggests some uncertainty or embarrassment on Keira's part or perhaps a distancing from autism.

Keira's parents slowly introduced her to the idea of autism:

. . . they didn't straightforward say that I had it they kinda like, what they done so that it wasn't such a shock, was that they slowly taught me about it and they slowly tell me that I've got it I think. (77 - 80)

Hesitancy on her parents' part suggests to Keira that they were aware that finding out about her autism diagnosis could have proven difficult or upsetting.

Maddy was fifteen when she was diagnosed with autism. She says that she was "*going through quite a rough time with quite a lot of stuff, like sensory issues and like social issues and stuff like that*" (134 - 136). Her mother works in a Child Development Clinic. She discussed Maddie's 'difficulties' with colleagues and requested an autism assessment. Maddy had not questioned her behaviours prior to assessment:

It was only when it was coming to the assessments that I was like, that I realised, but other than that, I just thought... well, I thought it was just like that I thought [unclear]. It wasn't all the time, but it was all the time, but because I was like used to it, I didn't really recognise that I was doing it all the time. (167 - 172)

There is contradiction here as Maddy begins to acknowledge that she was behaving in a certain way "*all the time*"; this seems to be in regard to sensory issues. Autism already had negative connotations for Maddy, as a boy who attended her school was diagnosed with autism:

. . . , and people used to be dead horrible about him, and he used to basically be horrible. So I knew that he was autistic, but I didn't really know what it was about and what... (453 - 459)

She admits that she did not really know what autism was about.

For Ellie, struggling with independent living and her studies at university was a trigger for the diagnostic process (435 – 438):

. . . it wasn't until uni that anyone kind of realised that it was something more than just like personal quirks. (198 - 209)

It seems as if Ellie had not considered her behaviours or difficulties to be 'abnormal'. Her mother is a SENCo in a nursery setting and suggested that Ellie might be on the autism spectrum. Ellie approached her GP and the autism assessment was carried out by a Clinical Psychologist (CP). She has been offered a follow-up appointment as the CP also suggested that Ellie may have ADHD. She is open to the possibility of a dual diagnosis, as ADHD would provide her with an explanation for her difficulties with organisation:

But like girls with ADHD are likely to be less kind of the stereotypical like sort of wild child and more sort of like horrendously disorganised and stuff like that. (661 - 663)

Reflective Box

For the participants diagnosed with autism as children, their parents must have had reasons for proposing or permitting the diagnostic process, but it seems that all the participants received the message that there was something 'wrong' with them. If a child is told that there is something wrong with them by parents, teachers and doctors, then this can have a negative effect on their sense of self.

Maddie and Ellie's mothers both prompted the diagnostic process for their daughters. I can only presume that they considered that a diagnosis would be helpful as their daughters made the transition into adulthood. Maddie and Ellie are intelligent young women, but they did not question the validity of autism.

I recall a strong response to Melody's account of being put into a group at school. When children are put into a group of children who are considered to have a 'disability' the message that that they are likely to receive is that they are different from their peers and need different treatment. I wondered what school staff were trying to achieve and how the impact of group work was

evaluated.

I also start to wonder where the line is between personality and a diagnosable neuro biological disorder or condition as highlighted in chapter 2.

What is Autism?

Participants found it difficult to explain autism. Kerry says:

Like, I that knew that erm, I had it, like any other person would understand but I didn't understand. (72 - 73)

She seems to think that other people, or other children, would understand what autism meant but that she didn't. She seems to question what understanding is, in the context of autism.

Micha is also unable to explain autism and began to ask questions:

Autism's like. . . I don't know what it is . . . like, I don't know what it is. Probably just, I don't know? (454 - 455)

She asked if I know what autism is (457), why people get autism (464 – 465) and how doctors know people have autism (474 – 475).

Keira says that she has struggled to understand autism:

I never fully understood it, even now I still sometimes struggle with it, erm but I know, if I'm right, then it affected my social life, because that's what it does affect. (144 - 146)

Keira's struggles with 'it'; this makes me think that she struggles with the idea of being diagnosed with autism. Saying '*if I'm right*' indicates that Keira links autism with a criterion and she acknowledges that she has struggled socially. She links her younger brother's reluctance to learn about autism to a lack of understanding:

I think like, he was at the stage I was when I was a couple of years ago, erm I think, because he doesn't fully understand it, he doesn't know what that means kind of. (375 - 377)

Melody was the only participant who reflected on the causation of autism. She says that she has experienced difficulties because she was born prematurely and was a poor feeder:

If I wasn't born that small I think I would of just turned out normal, and if I would've eaten I think I would've turned out like everyone else. (378 – 381)

Perhaps Melody has been told this, or is it something that she has formulated for herself.

Maddy attempts to describe autism:

Erm, erm, that people with autism just see the world in a different way. (434 - 435)

Maddy explains autism as “a difference in the way that you think about things and stuff” (443) but she does not give a specific example.

Ellie talks about “the autistic brain” (594) and “hard wiring” in the brain (610 - 611), in the context of autistic commonalities.

Kerry, Micha and Keira struggle to explain autism. They have been told that they ‘have’ a condition or disorder but do not seem to have been explicitly told about the core ‘deficits’ associated with autism or the diagnostic process. Micha is curious and Melody has already formulated a hypothesis in regard to why she ‘has’ autism. Even though Maddy has recently participated in the assessment process she does not provide a clear explanation of autism. Ellie has read a great deal about autism which has led to her seeing the autistic brain as biologically different.

Reflective Box

I was not overly surprised that most participants struggled to explain autism as I struggled to explain autism to Micha. If I, as a trainee EP, struggled to explain autism then perhaps parents, teachers and medical professionals find it difficult to provide an explanation and perhaps children and young adults struggle to understand or remember what has been said.

Communication

I did not ask participants about any difficulties that they had experienced or were experiencing but they all discussed aspects of their life or situations which they found challenging. For example, learning difficulties, anxiety, hypersensitivity and difficulties with concentration and organisation. It is beyond the scope of this thesis to discuss all the difficulties reported by all participants but all participants spoke of communication difficulties which have affected their social interaction.

Kerry said:

I think I find it more difficult and all that, because like, I always get like worried if I’m saying something like, like, I’m going to say something wrong and all that and erm, like when I try to be like, when I try to act like I don’t have it, like it doesn’t really help, cause like, I might say something and they will just give me a weird look but it sounds normal to me. (115 - 120)

Kerry lacks social confidence and presumably, when she feels that the other person has given her a weird look then she will end the conversation (240 – 242). Although Kerry’s anxiety during conversations is real to her I wonder if she anticipates negative responses from others because of her autism diagnosis.

Micha talks about being ‘shy’ (134 – 135). She is able to recall social difficulties at nursery:

Stepping back and all that, like not going near anyone and all that . . . I used to copy other kids as well, what does that mean, like copy? . . . Yeah, because I was a bit nervous of doing my own thing. (480 - 488)

Melody talks about speech difficulties:

. . . when I was younger, my friend and me, like she knew and we both, and I couldn’t say words more clearly and er, er, today when I was walking and talking about this she actually told me someone, two girls came up to her, they said er, why can’t M speak properly and then she said because (pause for effect) she has a longer tongue, laughs. (141 – 146)

Although Melody acknowledges her speech difficulties she makes light of other students’ curiosity and enjoys sharing her friend’s quick thinking response.

Keira has found socialising with females peers difficult (148 – 150):

With my friends I tend not, when I’m hanging around with them I don’t really say anything, I just stay quiet and follow them around a bit, unless they talk to me first. (283 – 284)

So I can normally talk to people if I have a lot in common straight away cause it’s my interest . . . But the girls they never, bring that so it feels very hard for me to talk to them. (307 - 312)

She says, “as soon as it comes to adults I’m fine” (330 - 331):

Maddy also talks about shyness and self-imposed isolation in school:

... when I meet new people I don’t talk, because... I would try to avoid talks and... or like look away and stuff, so that I didn’t have to talk to them, because they’re new people. (49 - 54)

Initially, she says that anxiety prevents her from speaking to peers (857 – 859). Then she says that she goes to school to work and not to “have crack about the weekend” (866). This sounds like self-protection, she feels embarrassed or self-conscious about her isolation in class so justifies this by saying that she is there to work.

Ellie talks about finding conversations difficult:

. . . and eye contact, I’m awful at and talking to people like, small talk I’m awful at . . . It’s really odd but I’d rather do public speaking than . . . I find that a lot easier than just trying to hold a conversation with someone. (492 - 502)

She has taught herself conversational ‘rules’ (624 – 634). Like Maddy, Ellie says that she was isolated at school and dealt with isolation by withdrawing into school work and reading:

I didn't really have many friends . . . I wasn't really good at the whole social politics thing, . . . (526 - 528)

. . . but like I had, I had my books, I had my erm work to do, I had my interests to keep me going like. I didn't really feel the need to be like, you know, best friends with people. (545 - 547)

Reflective Box

Melody is the only participant to speak about speech difficulties. Generally participants do not refer to difficulties in understanding and using language but about shyness, especially when speaking to someone new and / or people their own age. Keira, Maddy and Ellie talk about self-isolating behaviour. They seem to float around the peripheries of social groups in school. Keira has access to the LRC at her school so she can go there at social times but Maddy and Ellie hide behind work and reading. Perhaps if they avoid social overtures then they avoid the risk of peer rejection. I start to wonder if shyness, leading to social isolation, is being thought of as autism.

Under the Superordinate Theme of Understanding Autism there are two further sub themes: **It's not me, it's Autism** and **Siblings with Autism**. Each of these sub themes only apply to three participants. It is beyond the scope of this thesis to describe each of these themes in detail but I will provide a brief description.

Keira associates autism with untidiness (341 – 353):

It's little stuff like that my dad finds annoying . . . so he'll tell me off for it and we'll get into an argument but it's not my fault I don't think of it straight away and he expects me to. (341 - 353)

Ellie also talks about not being able to undertake chores at home due to her difficulties with concentration. She says, *"I can't tidy to save my life, I can't concentrate on it"*.

Maddy talks about being too open with her family (560 - 562). She seems to think that sharing school gossip with your mum is unusual and therefore associated with her autism diagnosis.

Kerry talks about her two brothers and says they have ADHD (the school SENCo told me that they are diagnosed with autism so possibly they have a dual diagnosis). She talks about her older brother:

. . . he is sort of scared and all that, . . . mum tried to encourage him to go to work but he doesn't want to go to work in case he meets horrible people and all that. And he acts like, like he has no hope and all that as well. (150 - 154)

Kerry's has seen her older brother struggling with adult life. For Kerry, this re-enforces the idea that autism is associated with problems. Kerry worries about her younger brother, recognising that although he is happy "*he might struggle sort of thing,*" in future (154 - 164). She does not consider autism to be a good thing for him.

Keira says that her younger brother is considered 'borderline' for autism. She says that he is resistant to learning about autism:

He's kinda like me, he doesn't want to learn, he doesn't want to know, but my mum keeps pressuring him because I'm his sister he should know, cause my mum's like, he should know what his sister's got, he should learn about it. (322 – 326)

Keira does not express an opinion about this situation but she reflects on his reluctance and hence reveals some of her own views, or those of her mother, that autism is real, you either have 'it' or you don't.

Ellie's younger sister is undergoing an assessment for autism and she describes her sister's autistic 'symptoms' (251 – 254). Ellie links her sister's diagnosis with getting help at university therefore considers it positively (324 – 331). Ellie thinks that her parents may also be on the autism spectrum, "*looking at how they kind of process stuff and things.*" (456 – 459). This quote also reveals Ellie's understanding of autism as a neuro-biological difference.

Reflective Box

I wonder how some participants have made the association between autism and behaviours that, as the mother of two teenagers, I would consider to be fairly typical. Like Keira, Ellie seems to be very hard on herself when it comes to her expectations of what she should be able to do. Cultural influences with regard to gender roles are emerging: for example, that girls should be thoughtful and tidy. For Keira and Maddy, who have somewhat ambiguous relationships to their autism diagnoses, autism is used as an explanation for behaviours regarded as undesirable by parents.

Participants' views towards their own autism diagnosis, for example, if it is regarded positively or negatively seems to influence how they view their siblings being diagnosed with autism. I found it interesting that Keira's younger brother repeatedly refused to engage with the subject of autism whereas Keira has reluctantly engaged with the topic.

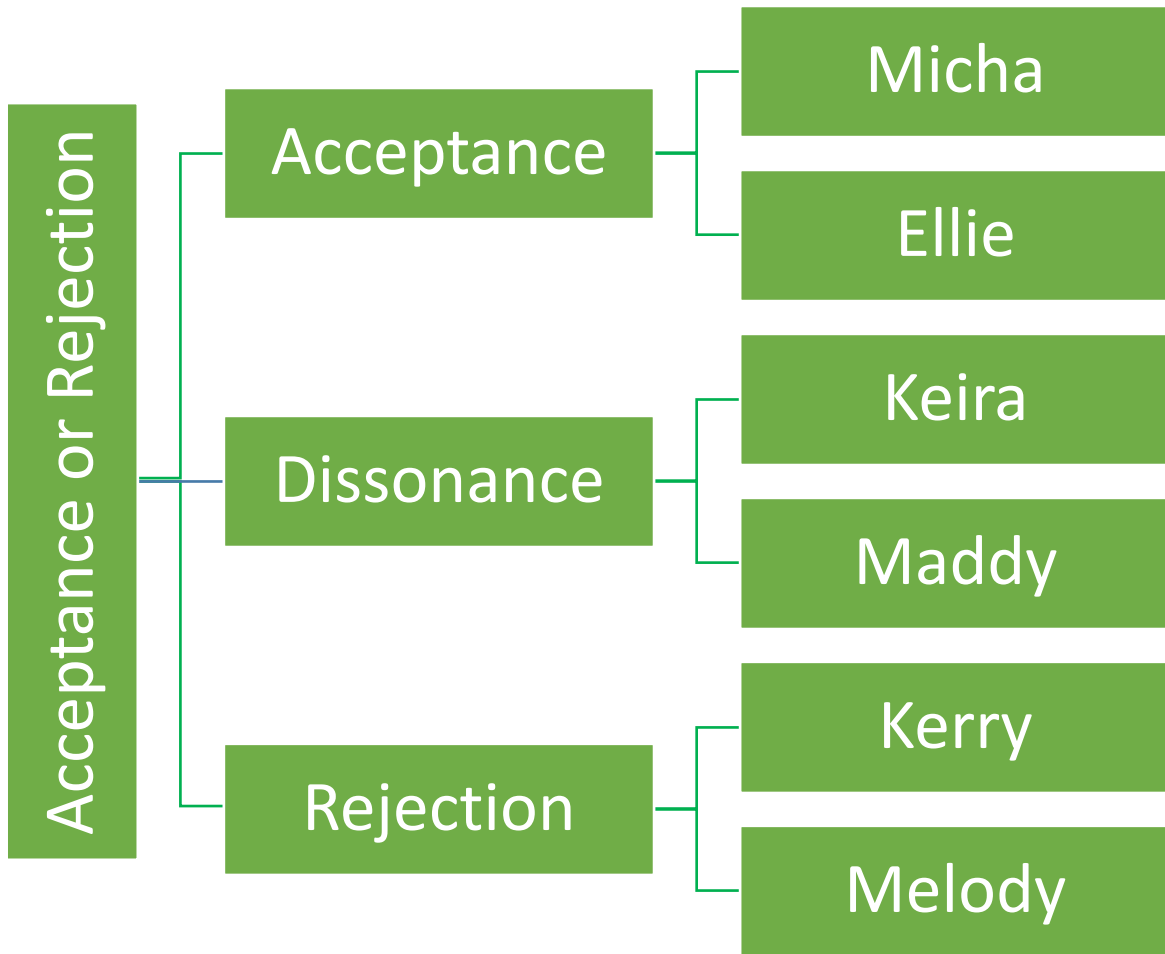


Figure 3: Superordinate Theme 2

Superordinate Theme 2: Acceptance or Rejection of Autism

Acceptance or rejection of autism diagnosis is indicated by openness to learning about autism and also influences participants' attitude to support at school or university.

Acceptance

On hearing of her autism diagnosis, Micha says, "*I knew I had it though, I knew I had autism all my life.*" (108). She could be talking about the difficulties she experienced or she may have had knowledge of autism prior to diagnosis. Diagnosis provided an explanation for her learning difficulties, "*It probably was helpful to know what was wrong with me and that, why, you know I don't know anything (laughs)*". (126 - 127). She welcomes support at school as she struggles with school work (129 – 130).

She watched a TV documentary about Lingsford Grange, a school for girls with autism. The experiences of the students resonated with her:

I felt sorry for some of the girls because people don't want to be friends with them, like normal people . . . Cause they are different to them and they act weird. You know, people with autism, they think that we act weird and that. (166 - 171)

Micha accepts that people with autism 'act weird' and that's why 'normal' people don't want to be friends with them. She uses the word 'we', as she accepts and identifies with autism. She is uncomfortable around 'normal' peers and feels at a disadvantage within her mainstream school, "*If I went to a school where all the kids have autism, I would be more comfortable.*" (179 - 180). She also attends a youth club for young people with special educational needs. Seeing other young people with differences, both on TV and in real life has helped her to accept her differences (337 – 353).

She acknowledges that the way she sees herself and / or is viewed by others, is not the best way to be, "*but, you know, it's just the way I am, I just can't help myself.*" (284). She reveals some regret, "*sometimes, I wish I was a normal person sometimes, you know, I wonder what it would like to be a normal person without any problems.*" (494 - 495). Although she accepts her difficulties, Micha tries to imagine life as a 'normal' person.

Ellie experienced difficulties when she went to university. Like Micha, she knew that there was something 'odd' about her (176) and she worried that she was 'going mad' during her first year at university (409). She describes her 'relief' on hearing of her autism diagnosis:

I was pleased. I was . . . like things to make sense and it was nice that I finally got like something to say, you know I wasn't just (162 - 164)

it was a massive relief to finally be able to say 'I am autistic'. I could say that and have people, well have people believe me but also like believe it myself. (177 - 179)

Being 'autistic' validates her as a person. She seems to need a diagnosis before she can think of herself as autistic. She describes her joy at being told of her autism diagnosis, "*I started jumping up and down. 'Yay' (laughs)*". Ellie acknowledges that autism diagnosis is not always welcomed but her question has been answered (187 – 193). Unlike other participants, autism diagnosis was not imposed upon her.

I asked Ellie if she thought that it was better to be diagnosed with autism as a young adult and she reflected on past experience, "*it just kind of all sort of clicks into place, but if what you're doing now . . . you go, 'Oh, oh, oh, oh'.*" (321 - 323). She views her earlier experiences through an autism lens. She theorises that characters on TV and in books are autistic (385 - 386). She feels that people with autism are drawn to one another:

there's something about the way in which an autistic brain works that likes other autistic people. So it like, you know, the social rules and stuff are different so you kind of, I think, you naturally flock together. (592 - 597)

Micha spoke of seeking to spend time with other people who experienced difficulties as she felt uncomfortable around 'normal' people whereas Ellie is talking about autistic commonalities. She prefers communication with 'neuro-divergent' people, "*relations with them are naturally different to with normal people*" (608). She says that it is 'easier' for people with a "*similar kind of hard wiring in their brain*" to get on. (606 - 612). She sees herself as belonging to an autistic community (722).

Although Ellie accepts her autism diagnosis she recognises stigma, "*I think it would be nice if it wasn't treated like a sort of dirty secret any more, something to be ashamed of . . .*" (795 - 797). She shares an internet post which resonated with her (819 – 827). This reveals that she sees herself as 'high functioning' and acknowledges that outwardly she seems to be doing well, but that for her, life can be an ongoing struggle.

Ellie enjoys learning about autism and uses the Internet to find out how other people have coped (359 – 364). People sharing their experiences online accept and often embrace their autism diagnosis. Ellie does not mention any critical viewpoints in regard to the validity of autism diagnosis. She has carried out research into girls on the autism spectrum. She talks about girls being more effective communicators than boys (621 – 623); she acknowledges cultural influences on gender (639 – 641); she also suggests that girls with autism are underdiagnosed because their 'special interests' are 'mainstream' (750 – 754).

Reflective Box

Micha accepts that something is 'wrong' with her and she accepts autism as an explanation or name for what is wrong. Ellie has experienced difficulty, both at school and at university. She knew that she needed help and now has an explanation for her difficulties. It seems that she needed a name for the difficulties she experiences and she now relates many factors in her life autism. Hearing both accounts I was struck by the importance of recognising that other people have similar problems; that you are not the 'only one'.

Dissonance

Each time I asked Keira how she felt about her autism diagnosis she continued to talk about learning about autism, "*because I stayed in the LRC for ages and learned about it, so that's when I fully came to grips with it.*" (136 - 139). She avoided talking about how she felt about her autism diagnosis but revealed that her autism diagnosis was something that she has grappled with.

She doesn't question her diagnosis, for example when talking about her younger brother learning about autism "*seeing as how I've got it.*" (186 – 188). Like Kerry she says 'it' rather than autism indicating a distancing from her label. Autism is real, something you either have or have not got.

There are further indications that Keira has struggled to accept autism. Her mother wanted her to watch a TV programme, *The Autistic Gardener*, but she was initially reluctant, (220 – 224):

... erm you know when you get to that stage when you like don't really want to learn about because you kinda want to forget you have it a little bit. (232 - 234)

Later in the interview, when talking about her younger brother, Keira says, "*He's kinda like me, he doesn't want to learn, he doesn't want to know.*" (359 - 360), revealing a reluctance to think about autism.

When I ask her again if she thinks that the diagnosis of autism has made a difference to how she feels about herself she seems more accepting:

I think that if I didn't know about it I wouldn't be me I am now because I have always been, I would never have learned about it and be able to erm, like, I would say to teach myself how to cope if that makes sense. Like how to accept it and erm, talk, like learn how to socialise with people, and like, I wouldn't have learned different ways to talk and everything, and I wouldn't be, I probably wouldn't be the same person that I am now if I hadn't learned about it. (255 – 263)

She links acceptance to understanding and overcoming difficulties. She makes a positive association by attributing her creativity to autism (382 – 387). She has come to an acceptance over time, “*I’ve just kinda come to accept it now, I know that I’ve got it, I’m trying to use it to help me.*” (443 - 445). Perhaps she is thinking of seeking support in Further Education?

Keira recognises that her ‘autism’ is not obvious, as she recognises that she has overcome her nervousness during conversations. She shares her autism diagnosis with peers.

I know a couple of people didn’t know I have autism til I said it because of how I’ve acted, because my confidence is boosted up now, so I can kinda talk to people without getting nervous, so, some people don’t see that I’ve got autism socially or like. (471 - 476)

Like Keira, Maddy has moved between rejection and acceptance of autism diagnosis. Micha and Ellie have always known that there was something different about them but Maddy says, “*My mum’s always known there was something up with me . . .*” (145). I wonder if this is something she heard or sensed and I wonder how this knowledge has affected her sense of self.

For Maddy, like Micha and Ellie, autism diagnosis offered an explanation,

“I think it was quite a good thing, because it was an explanation for the way that I would like . . . the way things had been and stuff, and I think I accepted it (330 - 333)

She says that she ‘thinks’ that she accepted it, revealing some hesitation. She acknowledges that her family found her diagnosis helpful, so perhaps she was accepting to please her parents, “*it was good for them to have a bit of like closure in it*”. (336 - 337). She goes on to say that members of her extended family, the school nurse and a teacher queried her diagnosis:

it kind of put doubt in my mind, because at one point I didn’t really think that I was autistic any more. I thought, ‘Oh, well, maybe I’m not autistic; maybe they’ve just got it wrong’, because people were saying that, it’s not like, it’s just normal, she’ll grow out of it and stuff. (359 - 363)

Lack of acceptance by others led to confusion on Maddy’s part. By saying that others doubted her diagnosis Maddy is saying that she is not entirely convinced herself. She believes that autism is real but hopes that she might outgrow it. Autism diagnosis is something medical professionals either get right or ‘wrong’. Relatives were challenging the diagnosis by describing her behaviour as ‘normal’ or a stage of development. She later remembers that her Clinical Psychologist had also queried her diagnosis (780 – 783):

Despite her doubts, Maddy has found her diagnosis useful in providing an explanation for her ‘issues’, she links autism to sensory differences:

Say, if I do something in a different way I can say, well, 'Oh, that's just a sensory issue, or that's just...' So I feel like, yes, I understand it ... because it was like an explanation. (461 - 468)

Autism diagnosis also provided her family with an explanation for her behaviours and her parents have subsequently become more accommodating.

She did not want her wider peer group to know about her autism diagnosis and talks about stigma:

I was embarrassed about it a little bit, . . . Because I know that people can take the mickey out of people who have something wrong with them and who would have difficulties and stuff, so I didn't really want people to know, because I didn't really want to be made fun of. (708 - 715)

Maddy speaks of her embarrassment at going to the Learning Support Department but recognises that she needs support (975 – 977). She has found support staff at school to be more accommodating than subject teachers. She emailed her teachers to ask for adjustments in lessons to lower her anxiety but nothing changed:

. . . they just brush it off sometimes, because I think they don't really like treating people differently to everybody else in the class, so they just prefer to treat everyone the same. (588 – 591)

Maddy uses the Internet to find out about autism. Like Keira her mother wants her to learn about autism and has introduced her to an online blog and an online autism community. She does not mention any contact with other members of the online community.

Reflective Box

My questions challenged Keira. I picked up on her reticence and asked her if she found having an autism diagnosis helpful but she was unable to give a response. Perhaps she felt that if she said she found the label unhelpful then she would be disloyal to her mother. She could only reflect on her life now, which, for her, is more positive. Maddy was able to say that she began to have doubts because others queried her diagnosis. She also seems to be under parental pressure to accept her diagnosis.

Rejection

Like Maddy, Kerry does not want to be seen by peers to be needing additional support in school but admits that she sometimes needs 'help', *"To me it feels like I don't need help; then I know that I do need help."* (46 – 55).

She does not question autism, or the validity of her autism diagnosis, but says that she ‘hates’ ‘having’ autism:

Well, I was really sad and all that like, I knew from like day one that I hate it, sort of thing. (62 – 63)

I still hate it and all that, but now like if I had a choice, this might sound daft but if I had a choice between not existing and having this I would choose not existing, because I hate it so much and all that . . . (79 - 82)7

Kerry has always had a negative response towards her diagnosis, perhaps because she had witnessed her older brother’s difficulties. There is a sense here that autism diagnosis is something that has been forced on Kerry, as she says that she has no choice (65 – 66). She seems to be asking why has this happened or why has this happened to her (68 – 69). Peers associate autism with learning difficulties and she hates being treated differently (86 – 88). It seems as if Kerry has been struggling with the weight of this diagnosis for a long time and she feels that it is spoiling her very existence. Her life seems to be unbearable.

She does not want ‘autism’ in her life:

. . . I wish that sort of, I wish, that I don’t have it and don’t want to know, I don’t like saying that I have it, cause for me it don’t feel comfortable saying it, it feels something not right. When I speak with people who don’t have anything wrong with them it feels awkward and all that for me. (103 - 108)

Because Kerry hates autism she does not want to know about it. She distances herself from her diagnosis. There is no ambiguity in Kerry’s views on autism. She does not want to have an autism diagnosis. She associates autism with being impaired and she feels at a disadvantage around people she regards as ‘normal’. I ask her if there are any advantages to having an autism diagnosis and she says ‘no’. (141).

Kerry does not want her wider peer group to know about her autism diagnosis. She does not want to be seen visiting the Learning Support Department:

I feel embarrassed when like I say, I’m going to LS and all that. And when it’s assemblies and all that, getting awards once a week and all that. And like, when erm, when I like got an award from Learning Support in tutor and all that, and someone said something and all that and it was for me and all that, I don’t want it. (130 - 135)

I wonder why staff were seemingly unaware that Kerry would feel uncomfortable receiving this award in front of peers. She has tried to act as if she didn’t have ‘it’ (167 - 168) and on reflection I wished that I had asked Kerry how she did this and how acting ‘normal’ felt.

She worries about future discrimination by potential employers:

. . . cause I can't see myself having a profession or whatever. Like it affects me to see what will happen in the future and all that. Like, if I like had a job, I won't want to tell them I have it but want to keep it a secret even though . . . it's quite frustrating and all that, cause like I feel like when I'm older and all that, it might feel awkward and all that as well. (82 - 90)

When she talks about continuing to feel 'awkward' I interpreted this as socially awkward. I wonder if she feels awkward because of actual communication difficulties or because of low self-esteem. She considers her autism diagnosis as a 'block' to future hopes:

. . . cause I feel that I'm not going to succeed when I'm older and all that, like. Like I said before I can't see myself doing any professional job and all that. I feel that I probably can't get there because of it and that's the only thing, like stopping me. (182 - 186)

It seems as if failure to reach her goals will be blamed on her autism diagnosis. I strongly suspect that seeing her older brother unable to work due to social anxiety has influenced her thinking.

Kerry accepts autism as 'real', it is something that you either have or you don't, and she has 'it', *"it's like everyone else and all that when they definitely haven't got it."* (238 - 239). Throughout the interview she refers to autism as 'it', which indicates distancing from autism. It feels as if Kerry is the only person with this diagnosis although she does mention two boys in her school who have autism (145 - 148).

Like Micha and Ellie, Melody says that she knew that there was something different about her before she knew of her autism diagnosis, *"I just knew I had it but I just didn't know what to call it."* (81 - 82). Again, there is a sense that autism is real, it is either something you have or you don't. Melody was put into a social skills group at primary school and was visited by Specialist Advisory Teachers (p. 7). This was why she knew she 'had' something.

Although she sometimes refers to herself as 'autistic', there is a reluctance on Melody's part to accept the validity of autism:

Like I would describe as 'we are the same as you, we can talk like you, we can do things like you, there's nothing different, it's autism, it's just a name'. (216 - 218)

She says that she can do the same things as everyone else and rejects the label of autism. By saying 'we' and 'you', she rejects the label on behalf of others. Although she has been treated differently by adults in school she doesn't see herself as different as she talks about sameness. She views the label 'autism' as a descriptive rather than a disabling or self-defining truth.

I asked Melody if her autism diagnosis has made a difference to the way that she feels about herself. She says that she was self-conscious when she was younger but doesn't care anymore (284 - 286). She continues to challenge the validity of her diagnosis and feels that it is no longer applicable:

Like, but I think, since I was younger I'm not autistic just I kinda, I've grown up, I can read like my friends can read, er, I can write properly, I've grown up and I'm like, I'm pretty much the same as everyone else. I'm just a little bit behind, I just need to catch up one day. (284 - 291)

Melody distances herself from disability by saying that if she was posting clips on YouTube she would want people to be interested in 'her thing' rather than how she overcame disability (218 – 221). She has resisted reading any insider accounts (278 - 279). Unlike Kerry who cannot bear to read about autism, Melody's reluctance to engage with autism literature seems to be linked to a refusal to see herself as a person with autism.

At secondary school Melody was put into a small group for literacy instead of French lessons. Even though she and her parents complained she had to continue attending literacy lessons. She does not want additional support in lessons, "*I don't like them hovering over me, I'm fine on my own.*" (353 - 354). She enjoys challenging supply teachers' assumptions:

I think I shock people, because, erm the supply teachers, they thinking, because I'm autistic they think, the new ones 'Oh yeah, I'm gonna help her, . . . they then like come over and then they're like 'oh, oh, you need help don't you' (mimics panicked voice) and I'm like 'Nope' (deadpan voice), 'ha, ha'. (344 - 350)

Like Kerry, Melody fears future discrimination by potential employers:

I'm just going to say, 'oh I'm autistic' and then they can't do anything and so they close the folder . . . I know that one of them are going to see that I am autistic, . . . (393 - 395)

Melody associates autism with stigma. People diagnosed with autism are unemployable. Although Melody minimises her difficulties, like Kerry, she fears that her difficulties are obvious to others (397 – 398).

Reflective Box

Kerry rejects autism rather than the validity of autism diagnosis. She doesn't want to be seen to be different. Her views are stronger than those of Keira and Maddy, who both let autism diagnosis sit beside them. This makes me wonder what it must be like to have to live with a label that you do not want. Kerry is angry. Melody outwardly appears to go along with her autism diagnosis but seems to have worked out that she isn't actually very different from her peers. For her autism is, "just a name". On hearing Melody say this I decide to include this quote in my title, as Melody seems to be putting the label of autism firmly in its place.

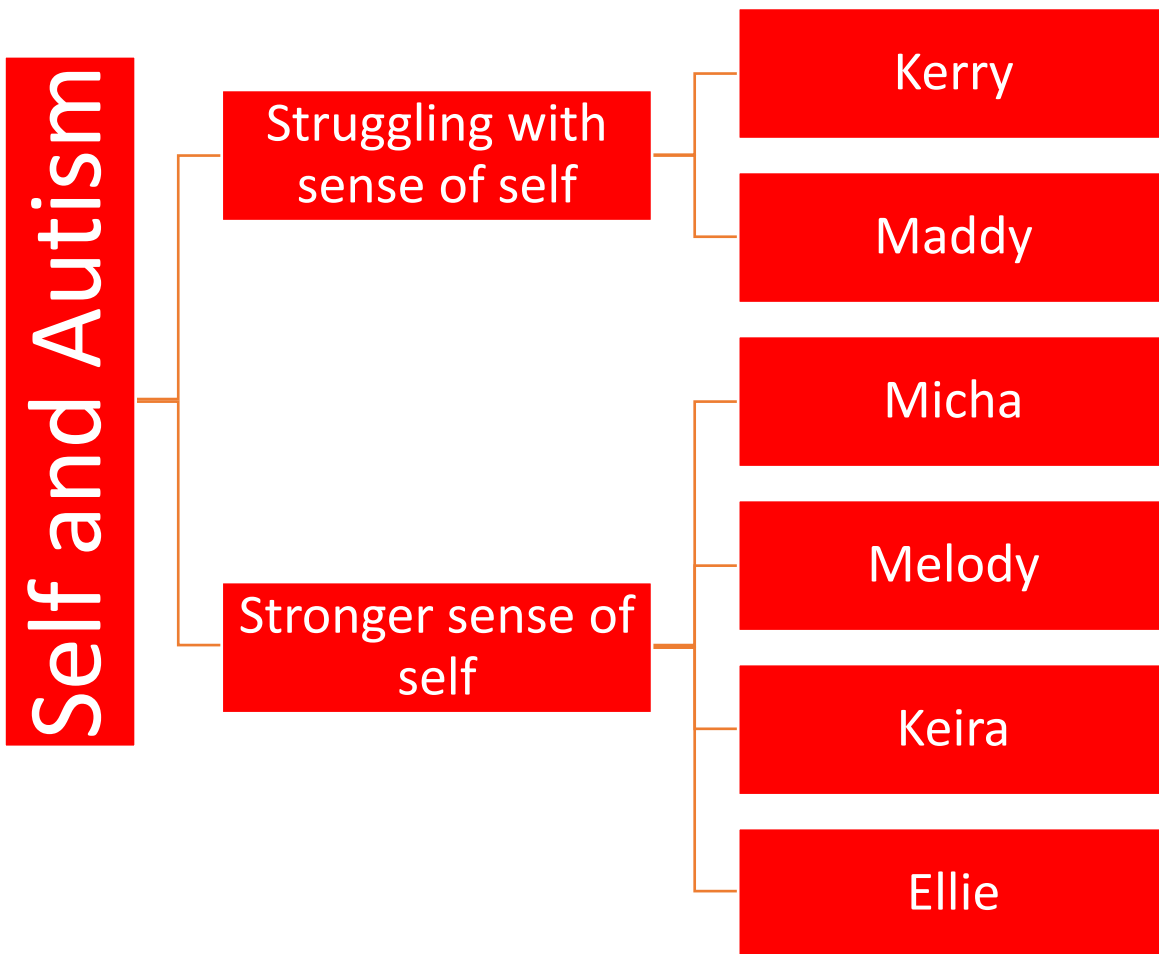


Figure 4: Superordinate Theme 3

Superordinate Theme 3: Self and Autism

During the interview, participants were invited to talk about their interests, to describe themselves, and share their strengths and future aspirations. Relationships are intertwined with sense of self and participants talked about and reflected upon their relationships with parents and siblings, friends and their wider peer group.

Struggling with Sense of Self

Kerry struggled to describe herself:

I'll have to like, remember what other people have said, like Miss J (LSA) and my mum and all that . . . they'd say that I'm nice and all that, kind and friendly, erm, quite cheerful and all that; (hesitates) that's it. (20 - 23)

Her sense of self seems to be defined by others. Staff perceive Kerry to be cheerful, yet during the interview she talks of depression. This suggests that she puts on a cheerful face at school and hides her unhappiness. I wondered if 'that's it' indicated that she wanted to change the subject or if she perceives that this is all that others have to say about her.

Kerry shares her strengths, but again, she shares her support assistant's views, "*I'm a hard worker and all that, . . . and like I do try to aim for my goals and all that.*" (26 - 28). Despite her depressed feelings, Kerry retains the motivation to do well at school and wants to go to university. She is hard on herself:

they think that I'm a pessimist and all that . . . cause I always say that I'm not doing enough and they say that I'm doing more than enough and all that. (228 - 230)

When she talks about autism it becomes evident that diagnosis has had a detrimental effect on Kerry's sense of self. She talks emotionally about her 'cheery' younger brother and shares her fears about how his autism diagnosis will affect him in future:

I know that there will be a certain point when he's gonna realise that enough is enough sort of thing, that he can't be who he is sort of thing. (161 - 164)

Autism stops people from being their true selves. There is a feeling here of inevitability, of giving in to the diagnosis and letting it constrain and define you.

Kerry reveals deep unhappiness which has led to self-harming in secondary school:

I did like self-harm a bit because I got sick of everything and all that, I hated everything erm, yeh, and now and all that. Sometimes I just want to feel pain sort of thing, like when I'm older and I get a car I'll probably want to drive it into a tree, not to kill myself, (laughs), I dunno, I'll feel that I have to do it and all that, I feel like, that's when I feel down and all that,

when, most of the time, when I have a bath and all that, that's when I harm myself and all that, that's what I feel. (173 - 180)

Perhaps hurting herself or wanting to hurt herself is the only control that she feels she has. It seems as if she is turning her pain against herself, punishing herself.

Kerry speaks of trusting, reciprocal friendships with two girls who also suffer from anxiety (214 - 216) but she feels totally rejected by her wider peer group:

all the messages I get from them is that they hate me, and I know for a fact that if there is a gunman in the school and all that, and I didn't make it into class for a lockdown and all that, everyone would stand there and sort of watch and not help, and that's how I feel, like. That's how most people treat me during primary school and secondary school and all that, and other years and all that, that they don't want me here and all that, they want me gone, gone. (202 - 210)

This is a powerful analogy and I wonder how Kerry has come to feel so rejected. Earlier in the interview she spoke of bullying by peers which may contribute towards an explanation.

She talks about depression caused by autism diagnosis:

Well, for my older brother and all that, cause we've both got depression, we both hate it, we've both feel that we have no hope for the future and all that, erm, well, lots of the time I do get upset a lot . . . (258 - 261)

There is a sense of hopelessness and passivity here, of Kerry and her brother allowing autism diagnosis spoil their future.

Kerry acknowledges that her sense of self has been affected by her diagnosis:

Yeh, it does make a difference to me and all that, cause I know that if I want to fit in, try to act like I haven't got it, it's like everyone else and all that when they definitely haven't got it, . . . (237 - 238)

She wants to be the same as everyone else so feels that she has to act like 'everyone else'. She doesn't allow herself to be herself. It sounds as if Kerry is carrying a great burden.

Reflexive Box

I found it difficult to hear some of Kerry's answers and I became concerned about her wellbeing during the interview, especially when she spoke of depression and self-harming. I did feel the urge to stop the interview and move into counselling mode but it seemed that she wanted to keep talking and share her feelings. Her mood seemed to lift part way through the interview, so we carried on and had a chat afterwards (see Chapter 3).

Kerry also utilises positive coping strategies, for example, drawing (271 – 273). She likes to walk outdoors and talks about the freeing effect of the natural world (3 – 4). She also uses music, film and books to escape via imagination (6 – 10):

it helps me to leave where I am and go to a different place which helps me, and all I feel more comfortable. (94 - 99).

Although she worries about the future (183), Kerry says that she wants to go to university. She has identified a preferred university and two possible courses (267 – 271). Even though Kerry is finding life difficult her aspirations indicate hope for the future.

Maddy describes herself as “quiet and shy” (49). She describes some personal qualities: being ‘funny’ and ‘friendly’ (59 – 61):

I’m really trustworthy and really caring about my friends, and loyal, because I make sure that everyone’s okay all the time, and stuff. (61 - 63)

She knows how to be a good friend. It sounds as if she might put other people’s needs before her own. Like Kerry, she talks about determination as a strength:

if I want to do something it might take me a while, but I will always do it, and I won’t stop till I’ve done it, like, I’ve done it to like, the best of my ability. (71 - 77)

Maddy experienced peer rejection at primary school:

I didn’t really have many friends, . . . I had a lot of friendship issues with people in my year, because they always wanted to be with like the popular people, but the popular people never really accepted me because . . . I wasn’t seen as like I fitted in with them, so I had a lot of friendship issues. (200 - 211)

She was given a buddy but the buddy didn’t stay with her (233). Eventually she refused to go to school. She reflects that it was the ‘popular’ people who did not accept her. Perhaps she is uncomfortable around ‘popular’ people as she seems to have low self-worth. Secondary school provided a fresh start for Maddy in terms of friendships but she has changed friendship groups a number of times. She talks about not being liked, being left out and people being ‘nasty’ towards her throughout the interview. She doesn’t repair relationships but moves on to another friendship group.

Like Kerry, Maddy has a small group of ‘true friends’ but says that even they can be unkind. She shares her autism diagnosis with her friends in the hope that they will be kinder, “*they eased off me a little bit, and they weren’t like, as nasty to me anymore*” (736 - 737). Her ‘true’ friends support her in school (743 – 745). Feeling supported is important for Maddy. She talks about a boy in her year group who is aware of her difficulties and supports her in school (865 – 875).

I ask Maddy if her diagnosis has made a difference to the way that she feels about herself:

it's given me like reasons for the way that I do things, which means that I'm not just a freak any more that does things like weirdo . . . Because my sister never used to do it, and then my mum and dad used to tell me off for it, and they used to, 'why are you doing that?' And I used to think, oh, am I weird or something? But now that I've been diagnosed with autism, I feel like it's just . . . (602 - 609)

Thinking of herself as a 'freak' or 'wierdo' does not indicate a positive sense of self but autism diagnosis has helped with reframing.

Maddy isolates herself in school (755 - 756):

But it's like a vicious circle, because some . . . if people don't smile at me, I won't smile at them, because I get the impression that they don't like me or they don't want to talk to me (893 - 896)

She automatically perceives that people don't like her and protects herself from rejection by avoiding interaction. She thinks that other people perceive her to be standoffish when she is actually suffering from social anxiety. She speaks eloquently about how she feels about herself and how she thinks she is perceived by others:

Yes, and like that I love myself or I'm too good for them, when I'm not. In actual fact, I feel like I'm not good enough. Because I don't talk to anyone, people . . . I sometimes think people maybe get the impression that I love myself and that I think I'm it and stuff, and it's not the case, . . . Like there's a lot of people in my school that are like, I'm really jealous of and I wish I could be like. And I have a lot of like self-esteem problems, and in a way, that's what causes me to always feel anxious and that, because . . . I'm not feeling good about myself on the inside, it shows on the outside, and then I just don't feel approachable, because I'm not feeling happy. And like anybody who's not feeling happy, they're not going to be smiling and all that, and that's what it's like on a regular basis when I'm in school or around a lot of people. Because of that, I feel that bad about myself, it just shows on the outside. (932 - 948)

She compares herself unfavourably to others. I wonder if her low self-esteem stems from her isolation in primary school, feeling that she is not liked or is unlikeable, and that family attitudes have led her to believe that she is 'weird'. Unlike Kerry, she does not seem to make a direct link between her autism diagnosis and low self-esteem or depression. Like Kerry, Maddy talks about mental health issues. She has received support from the Child and Adolescent Mental Health Service in regard to her anxiety.

Maddy wants to attend school 6th form and has chosen A level subjects. She is worried about making new friends in 6th form. She is unsure if she will go to university and is considering a higher level apprenticeship. Like Kerry, she would like a future career in forensic science. She has visited New York and wants to work for the New York Police Department, "It's not impossible, is it?" (945).

Reflective Box

It was difficult to hear Kerry and Maddy's accounts. They both struggle with self-acceptance and / or self-image and have low self-esteem. They compare themselves unfavourably with others and feel that they are disliked by their wider peer group. Maddy seems to be able to apply some analysis to her feelings and behaviour, perhaps because she has received psychological support. I wonder how much their self-worth has been undermined by having a diagnosis of autism or in Maddie's case being told off by her parents for exhibiting the 'odd' behaviours which led to her autism diagnosis. Neither Kerry nor Maddy seems to think that they have family acceptance for who they are.

Stronger Sense of Self

Despite the difficulties that they have encountered, Micha, Melody, Keria and Ellie seem to have developed a stronger sense of self.

Micha struggled to describe herself. I attributed this to the ambiguity of the question, rather than a lack of self-awareness. Given a prompt, Micha told me that she is good at art, trampoline and badminton. Micha adds the proviso of 'but' when she shares a strength. She seems self-effacing. Unprompted, she shares a personal strength, *"I'm really good at making people laugh."* (71 - 76). Micha actively seeks social contact with peers in school and seems to receive positive feedback in return.

Micha feels comfortable around 'people like her' (284 – 286), *"Yeah, I'm alright with boys, yeah, mostly people who are like me."* (315 - 316). She was rejected by her two friends from primary school, *"they just ditched me. They just stopped calling for me and that."* (306 - 310). Micha mentions this rejection a couple of times during the interview and is understandably angry. She also complains repeatedly of isolation out of school (203 - 205).

Micha's family are supportive. Her mother is angry with Micha's former friends (308 – 309). She also accompanies Micha to youth club until she is able to go by herself.

Micha finds certain situations challenging, but she has managed to overcome difficulty, for example, collecting awards in assembly:

I just look at my feet and take deep breaths and do my Heart maths that I do with Miss C yeah. . . . I take deep breaths, like what she's told me to do and just look at my feet and don't look at the crowd. (273 - 276)

Micha says that she finds getting older 'harder' as she does not like change (150 - 152). She is unsure what she will do after school but thinks that she will go to the Local Further Education College to study life skills, and her mother has suggested that she might be a cleaner. Micha will let adults decide what is best for her.

Melody identifies her friends and family as strengths. She talks about her father's encouragement while she was learning to read and that she was a much longed-for baby. She participates in a drama group out of school and has a part in the school play. She says that she is good at English. When I ask Melody what she is like as a person she says, "crazy, . . . and a drama queen sometimes . . . if it's just one of those little things that someone does and I'm like in a mood then I'll go down into a tantrum." (36 - 42). Teachers tell Melody that she is shy (444 - 445). There appears to be some contradiction between the 'true' Melody and the Melody perceived by her teachers. I wonder if she suppresses her emotions in school. She explains the reason for her 'shyness':

it's just, in Year 7 I made the mistake of putting my hands up, . . . it was really funny because in PD someone made the mistake and I sighed so loudly and then put my hand up and the teacher she said 'no, that's not right' and I was like 'oh, uh oh', so . . . (448 - 460)

'Making a public mistake' caused Melody to become shy and self-conscious and I wondered if teachers had any awareness of her fear of making another 'mistake'.

Melody is included in a friendship group and has a best friend (304 - 306). Her friend's positive attitude towards her reinforces Melody's view that she is the same as everyone else.

She talks of being treated differently by her wider female peer group. She becomes passive when she is 'put' in a group with 'smart' girls (308 - 327) and has allowed herself to feel intimidated. Throughout the interview Melody uses rationalisation to protect her self-esteem, but the way in which these girls treat her has made her feel and act in a way that is not smart. The group hierarchy is established, and although Melody challenges the way in which she has been treated with an internal monologue, she is not socially skillful enough to challenge these girls and so she continues to act passively in a group situation.

Melody has high aspirations. She would like to go to a London university to study drama, then she would like to be an actress or director and live in America.

Keira describes herself as 'shy at first' but sometimes 'bubbly' (26 – 35). Like Melody, there seems to be a difference between public Keira and private Keira. She talks about how she has gained confidence since Year 7, *"you would see a massive change in me."* (493 - 495).

As with Micha, Keira's mother seems to act as an advocate, for example, interceding in arguments between Keira and her stepfather.

Keira has physically isolated herself from peers in school by going to the Learning Support Department at social times. She tried to 'hang around' with the girls in her year group when she started Key Stage 4 but realised that these were not real friendships as they had nothing in common (282 – 284), *"I say that they're my friends and stuff but I never actually been friends; even now I don't talk to them, I've unfriended them and stuff."* (392 – 394). Her real friendships are with three boys with whom she shares common interests (298).

Keira would like to go to university in Manchester or London to study art. She wants to live in a city as she wants to connect with contemporary culture. She does not see her autism diagnosis holding her back.

Ellie has wide-ranging interests: folk music, reading sagas and Shakespeare. She also has an unusual hobby: taking part in historical re-enactments. She describes herself as *"very honest, very well meaning"* (83) but somewhat 'awkward' and 'unsociable' (83 – 88):

So like sort of difficult to get to might be another one . . . Introduction to stranger like 'tread with caution, she's strange'. (93 - 102)

Like Maddy and Keira, she finds conversations difficult. I wonder if Ellie lacks interest in socialising or if socialising is difficult so is best avoided. She recognises, like Maddy, that other people may perceive her as 'strange', but they are unlikely to be aware that this is because she is feeling socially awkward. (106 – 109).

Like Maddy, she is able to identify personal strengths:

. . . doing my best to see the best in people and not wanting to upset people and working very, very hard to not upset people. (106 - 108)

Like Kerry, Micha and Maddy, Ellie sees herself as friendly. She is sensitive towards other people's feelings and may even put other people's feelings and needs before her own. Like Kerry and Maddy, Ellie talks about mental health. The letter confirming her autism diagnosis states that she has *"a history of depression and anxiety"* (277 - 279). Ellie refutes this and attributes her anxiety to frustration (275 – 279).

Ellie reported isolation at school and buried herself in books and her work, “*I didn’t really have many friends . . . I wasn’t really good at the whole social politics thing*”. (526 - 528). Like Keira she found it easier to get along with boys:

I found that girls often had like, they had very clicky, very complex social politics. While I always found, like personal experience with boys, if they didn’t like you they made it very, very obvious. (536 – 539)

Like Micha, Ellie experienced unexplained rejection by a friend:

she just absolutely turned her back on me. She completely lost it with me . . . , she gave no explanation, . . . she just hated me overnight and it was really weird and it completely threw me off. (528 - 535)

Like Micha, it seems that Ellie has not tried to speak to this girl.

Ellie’s best friend at university has autism and she is only able to cope with ‘two or three’ friendships as, “*friendship takes a lot of organising*” (490 - 492)

Ellie identifies with asexuality which has added to her sense of difference:

I think it’s quite similar to being autistic in a way because, before you know there’s a term for it, you just think you’re odd. You just think you’re different and you just think you’re broken and there’s no kind of explanation. (348 - 356)

Ellie’s autism diagnosis led to self-acceptance:

It’s made me feel better I think because like I kind of know like. I’m not just, like wrong, I’m autistic, and it just means you’re different and like it means for a lot more understanding. . . . there were times at uni that were really quite difficult . . . but knowing now that I’m autistic I’m like, ‘No, there’s a thing, there’s a reason, it’s all fine’. So I feel better about myself being like, actually like a fairly decent, like functioning fairly well as a decent autistic person rather than like doing a terrible job of being normal. (402 - 414)

Ellie’s sense of self was threatened by her difficulties pre diagnosis as she struggled with things that she thought she should be able to do. She now accepts herself as a high functioning ‘autistic person’.

Like Melody she talks of experiencing humiliation in a secondary school classroom:

I missed a piece of innuendo in a poem we were doing; it just completely passed me by, I didn’t get it at all and she laughed at that, and she said, you know, she basically called me out on how innocent I was, and she and the whole class laughed while I was just sitting there. Like, just wanting to melt away into the floor. (775 - 781)

Ellie wants to raise other people’s awareness. By telling her story she hopes to help other young people:

I’m kind of so open about kind of awareness of asexuality and stuff because I never want anyone else to have to feel like that, to feel like they’re different just because they’ve never heard of what it is that they are. So I think with autism it’s the same kind of thing, like the

need to be, you know, to be more open and say no actually we should normalise this stuff, like there are loads of neuro divergent folks out there (761 - 789)

Ellie needed a label in order to explain and accept her difficulties and to accept herself. Like Micha and Melody, Ellie feels that her family accept her (474 - 476).

Ellie has just completed her second year of university. Her future aspirations seem measured. She has reflected on her personal strengths and areas of difficulties in regard to various careers. Her preferred career would be in academia.

Reflective Box

Hobbies and interests, family support and acceptance, positive peer relationships and overcoming challenge all impact positively on participants' sense of self. Micha, Melody, Keira and Ellie continue to experience challenge but during the interview they all come across as relatively upbeat. What I notice about all of my participants is their honesty, a willingness to talk openly about difficult experiences.

Chapter 5 – Discussion

Literature

I will consider my IPA research findings in regard to my research questions and relevant literature. When considering the findings of my research, I drew upon qualitative literature which involved adolescents, male and female, and focused upon the impact of autism diagnosis. I did not find any literature which focused solely upon the views of adolescent females diagnosed with autism, although I do reference Nichols et al. (2009). I also consider what educational professionals, including educational psychologists, and medical professionals, may learn by listening to the voices of adolescent females who have an autism diagnosis.

Humphrey and Lewis (2008) used IPA to explore how students with a diagnosis of Asperger Syndrome (AS) make sense of their educational experiences. The central theme arising from this study was how participants constructed their understanding of what AS meant to them. Other themes were: negotiating difference; characteristics associated with AS; relationships with peers; anxiety and stress in school and working with teachers and other staff.

Huws and Jones (2008) conducted semi-structured interviews with nine young people, with high functioning autism, who spoke about their perceptions of autism and experiences of diagnosis. IPA analysis revealed that diagnosis, and the disclosure of the diagnosis of autism, were embedded in respondents' perceptions of 'having' autism. Five themes emerged from this research: disclosure delay, providing explanations, potential effects of labelling, disruptions and opportunities, and acceptance and avoidance. Huws and Jones suggest that the effects of diagnosis, or disclosure of diagnosis on young people should be given greater consideration.

McLaughlin and Rafferty (2014) explored the findings of eight qualitative studies which focused upon the voice of mainstream adolescent students with a diagnosis of Asperger's Syndrome (AS). There were only two studies in which researchers focused on gaining an understanding of the impact of autism or autism diagnosis on the young persons' views of themselves (Humphrey & Lewis, 2008; Molloy and Vasil, 2004). A thematic analysis of conversations with seven young people, diagnosed with autism, was also undertaken. Themes arising from this research were: something has been taken away from me; it does something to me; let me be normal and fitting in.

Mogensen and Mason (2015) undertook thematic analysis of conversations with five young people who had a diagnosis of autism. Findings explored in this paper are: meanings of the diagnosis of autism at the level of individual personal identity; meanings of diagnosis for identity at the socio-relational or public level and meaning of the diagnosis in terms of negotiating impairments. They found that whether the diagnosis was experienced as advantage or disadvantage by participants depended on “the extent to which it facilitated knowledge and control.” (p 255) and suggest that “There is a lack of consideration for the effects that labels such as autism, and the associated diagnostic processes, have on the children to whom they are applied.” (p. 255).

Baines (2012) undertook an ethnographic study in a US high school (secondary school) in order to examine how two young people with autism diagnoses (both male) constructed their social identities in order to belong, compete and participate.

In regard to positivist research, the participants in my study reported similar behaviours to the gendered behaviours reported by Lai et al. (2015). Although they did not always find socialising easy, they all had a degree of social motivation. They generally described being passive within the classroom. They had developed compensatory strategies such as reading or working hard in class. They all had one or few close friendships. Some participants reported being bullied in secondary school, and being ostracised by former friends. As Ellie noted, her interests were mainstream; the interests of participants in my study included: reading, watching films, walking, drawing, sport, drama, and make up. Other tendencies noted by Lai et al. (2015) were to be perfectionistic and very determined, this trait was mentioned by some of the participants in my study.

Research Question 1: How do adolescent females with an autism diagnosis make sense of this diagnosis?

Understanding Autism

The first superordinate theme arising from my research is ‘Understanding Autism’. “A central issue in any research that examines the lived experiences of individuals who have some kind of diagnostic label applied to them is their understanding of and engagement with the label itself.” (Humphrey and Lewis, 2008). Mogensen and Mason (2015) talk about needing to consider the context in which the diagnosis is given and how children and young people understand it in relation to their personal autobiography. Nichols et al. (2009) consider what having autism might mean to a young person

who is told of this diagnosis. They identify three areas which they consider relevant to understanding diagnosis: self-determination and self-advocacy, disclosure, and identification.

Diagnosis in a Problem Context

For the participants in my research study, the diagnostic process was triggered by 'problematic' behaviour when they were children or young adults, for example, not fitting in with peers, learning difficulties, sensory issues, and shyness. Ellie pursued an autism diagnosis as a young adult, as she struggled to cope when she left home and went to university. In my study, Micha, Kiera, Maddy and Ellie, all reflected on their 'odd' behaviour when younger or pre-diagnosis, in McLaughlin and Rafferty's (2014) study some participants talked of shame and regret over their behaviour when they were younger.

In my study Micha and Melody spoke of always knowing that something was wrong prior to hearing of their diagnoses as teenagers. Some participants in Huws and Jones (2008) study talked about a 'disclosure delay', where autism had been an 'absent' or un-named 'presence' in their lives and this led to shock and disappointment. Being told that they had autism, enabled participants in Huws and Jones study, to develop a retrospective understanding of previous life events, for example, being treated differently. All of the participants in my study were able to reflect on past events in the context of autism. Huws and Jones found that the disclosure of autism diagnosis could also lead to the disrupting of future plans. Although five of my participants have aspirations for the future, Kerry and Melody worried about discrimination by employers.

What is Autism?

Some of the participants in my research study struggled to explain autism. For participants in McLaughlin and Rafferty's (2014) study, autism spectrum was also something of an unknown. NICE (2011) includes guidance on 'Communicating the results from the autism diagnostic assessment' (p. 26). This includes discussing "the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person." This includes explaining 'what autism is' and 'how autism is likely to affect the child or young person's development and function'.

For participants in my study, understanding of autism was influenced by what they had been told by parents and / or by educational and medical professionals, and what they had read or watched on TV and / or the Internet. Participants linked autism to shyness / quietness, learning difficulties, sensory differences and poor self-organisation. Melody talked about developmental delays. Keira linked autism to creativity. Ellie, talked about neuro-diversity. Humphrey and Lewis (2008) talk of young people constructing an understanding of autism: being different / not normal, having a bad brain or mental syndrome, being odd or a freak.

Communication

All of the participants in my research study mentioned communication difficulties in the context of shyness and quietness. They found speaking to peers outside their friendship group to be particularly challenging. Nichols et al. (2009) point out that approaching groups of adolescent girls can be 'both challenging and intimidating' for girls diagnosed with autism, who often "choose not to (or do not know how to) join the other girls. Rather they tend to engage in solitary activities such as reading a book, doing school work, or talking to an adult. Those that want to join in might stay in proximity to the other girls, but never really actively participate in the conversations or communicate with the same degree of expressiveness." (p. 177). This description fits with accounts given by Melody, who is passive in group work, Keira, who followed a group of female peers around school without speaking to them, Maddy, who gets on silently with her work in class, and Ellie when she read books at school social times in school.

Kerry, felt that people looked at her strangely during conversations, participants in Mogensen and Mason's (2015) study spoke of difficulties with understanding certain social situations.

Ellie said that she learned how to converse by watching actors in TV programmes, one participant in Mogensen and Mason's study described how she had learned to fit in by copying behaviour.

Research Question 2: How does the autism diagnosis impact on their sense of self?

By sense of self I mean the view participants have of themselves, which Rogers (1959) called 'self-image' as opposed to 'self-esteem', how much value you place on yourself, or 'ideal self', what you wish you were really like. Hattie (1992) suggests that self-esteem is synonymous with self-evaluation. Self-esteem is often linked to psychological well-being and poor self-esteem is considered a risk factor for greater levels of anxiety and depression in children (Renouf and Harter, 1990). Harter (1990) describes self-esteem as an evaluation of one's worth as a person.

Acceptance or Rejection

The second superordinate theme arising from my research is 'Acceptance or Rejection' of autism. Humphrey and Lewis (2008) found a 'divergence' between young people who viewed their autism diagnosis (and themselves) negatively, mostly as 'not normal', and those who had accepted their autism diagnosis and viewed it as central to their understanding of self. Some participants in Huws and Jones (2008) study were accepting of diagnosis but some were negative: hence, disclosure could be considered 'beneficial' or 'detrimental'. Disclosure 'reworked' participants' sense of identity. Mogensen and Mason (2015) noted, "It was in their interactions with others that participants' experiences reflected the complexity of having a potentially stigmatizing label." (p. 266). Some young people in this study resisted autism as a social or public identity.

For the participants in my study, there was no clear correlation between acceptance or rejection of autism diagnosis, and positive or negative sense of self. Kerry did not want autism in her life, and her responses during interview indicated poor self-image and self-esteem. Micha acknowledged her differences and accepted her autism diagnosis, she seemed to have developed a stronger sense of self. Melody rejected her autism diagnosis as she did not see herself as different from her peers, her responses also indicated a stronger sense of self. Keira's responses revealed some distancing from her autism diagnosis, she seemed to have developed a stronger sense of self and was looking forward to the future. Maddy spoke of uncertainty about her diagnosis, and she reflected on her low self-esteem. Ellie accepted her autism diagnosis and acknowledged her differences, her responses indicated a strong sense of self.

Acceptance

In my research study Micha and Ellie accepted their autism diagnosis, or label. They saw themselves as being 'different' from peers. For Ellie, autism diagnosis as a young adult, had led to increased self-understanding and self-acceptance. Some of the pupils who participated in Humphrey and Lewis' (2008) study had grown to accept and even celebrate their difference.

Ellie is an active Internet researcher. Some of the participants in Mogensen and Mason's (2015) study found diagnosis to be 'liberating' as it enabled them to integrate knowledge about their 'condition'. Ellie no longer felt 'odd' once she was told of her diagnosis. Diagnosis could be viewed as a means of facilitating control as it gave one of the participants in Mogensen and Mason's (2015) study a reason for feeling different. Micha, who saw herself as a person with special educational

needs, and Ellie who talks of neuro-diversity. One participant in Mogensen and Mason's (2015) study spoke about sharing a common identity with others. Melody enjoyed challenging the assumptions of supply teachers. Participants in Mogensen and Mason's (2015) study suggested that too much emphasis is placed on the negative connotations attached to autism diagnosis, and one participant actively resisted negative connotations.

Rejection

Keira and Maddy both seemed to have an ambivalent response to their diagnosis and I gained a sense that they were perhaps 'going along' with their autism diagnosis to please their parents, particularly their mothers, who wanted their daughters to learn about autism.

In my study, Kerry did not want 'autism' in her life, and Melody refuted the validity of her autism diagnosis as she did not see herself as different to peers. The two male students in Baines (2012) study demonstrated 'nuanced' efforts to distance themselves from the autistic label through various acts of 'positioning' in order to change the negative perceptions of others. For one participant it was important to impress adults and fit in with what he perceived as valued in school. The other participant perceived school as less important than impressing his peers. One participant thought of himself as a recovering 'autistic' and decided that he did not want to belong in the special class. Through their positioning they attempted to 'pass as normal'.

In my study Kerry hated 'autism' and Melody felt that she had 'caught up' with her friends in terms of her cognitive development and so dismissed autism. In McLaughlin and Rafferty's (2014) study, anger and a desire for change regarding the lifelong nature of autism diagnosis were expressed as concerns. In Mogensen and Mason's (2015) study an 18 year old, female participant found her diagnosis to be oppressive: to her it meant being different as she experienced different treatment from peers. Kerry and Melody expressed annoyance in regard to unfair treatment by others, participants in Mogensen and Mason's (2015) study talked about losing control; for example, relating anger to their diagnosis. Some participants in Mogensen and Mason's study talked about maintaining control. Kerry tries to act as if she does not have autism, some participants in Humphrey and Lewis' (2008) study reported adapting to fit in. Like Kerry, participants in McLaughlin and Rafferty's (2014) study wanted to be normal, and had considered whether to tell others about their diagnosis.

Self and Autism

The third superordinate theme arising from my research is 'Self and Autism'. Hacking (2015) says, "People with autism, and especially their parents, have sought to construct and shape a condition that gives them a distinctive way of being a person and determining their identity." (p. 62). I asked participants if autism had affected their sense of self.

Although Kerry and Maddy could name personal strengths, and they both talked about working hard at school, they seemed to struggle with their sense of self. They did not want their wider peer group to know about their diagnoses as they were afraid of stigma. Humphrey and Lewis (2008) found that some young people identified a dilemma in terms of their disclosure regarding their diagnosis. Some participants in Mogensen and Mason's (2015) study had also been reluctant to disclose their diagnoses to others, due to a fear of being treated differently.

Shtayermman (2009) examined how stigma is related to mental health diagnoses: major depressive disorder and generalized anxiety disorder. Level of stigma was significantly and negatively correlated with severity of autism 'symptomatology'. Of their sample, 20% met criteria for a diagnosis of major depressive disorder and 30% met the criteria for generalized anxiety disorder.

Kerry and Maddy both spoke of depression; Kerry spoke of self-harming. Maddy had received support from a Clinical Psychologist through Child and Adolescent Mental Health Services (CAMHS). Although Kerry admitted self-harming, she did not seem to be receiving any CAMHS support. In a national 2006 study (Mental Health Foundation, 2006) researchers found at least one in 15 young people were affected by self-harm and they found the average age of onset to be 12 years. This report found that most young people who self-harmed did so in secret and as a way of coping with problems and emotional distress. There was a greater rate of self-harm in females than males.

The incidence of depression in adolescent females is higher than that of males. By age 15 the rate of depression in adolescent females is thought to be around twice that of males (Santrock, 2010).

There is evidence that girls diagnosed with autism are more likely to experience depressive symptoms than boys with autism (Rivet & Mason, 2011b).

Nichols et al. (2009) identify some possible causes of anxiety which may affect females who are diagnosed with autism: the complexity of friendships, the need to utilise organisational skills in regard to becoming independent, and academic work becoming less concrete and more abstract, for

example, the requirement to interpret a text at a deeper level. Vickerstaff et al. (2007) found that having a higher IQ predicated a lower level of self-perceived social competence and higher levels of depressive symptoms. Nichols et al. (2009) note that “Bright girls often notice the gap between their intellectual abilities and what they are able to achieve in day to day life.” (p. 165).

Nichols et al. (2009) identify factors which may affect the self-esteem of a girl diagnosed with autism (or any adolescent girl): she may have had difficulties making friends, being teased or bullied, feeling less successful than peers and may have struggled academically. Tony Atwood (2007) describes ‘reactive depression’, clinical depression that develops as a result of awareness of skill deficits and unsuccessful attempts at social interaction. Links between social comparison processes and depression in adolescents with an autism diagnosis have been established (Headley and Young, 2006).

Adolescence is key time in the development of self-identity. The young people participating in my study and similar studies, are developing a sense of self whilst negotiating a label which states that they are different. The young people in McLaughlin and Rafferty’s study (2014), described feeling that their autism diagnosis or ‘autism’ affected how they were viewed by others. In Mogensen and Mason’s (2015) study, social experiences were important in regard to the way in which participants understood themselves and related to the diagnosis, “Feelings of being different could be detrimental to their sense of self when connected with a lack of social competency.” (p. 262).

All the participants in my study had experienced difficulties fitting in with peers, participants in McLaughlin and Rafferty’s (2014) study recognised that ‘autism’ caused them to have difficulty fitting in with peers and some participants in this study talked of peer rejection. Like Melody, participants in McLaughlin and Rafferty’s (2014) study compared their cognition and communication to that of peers. One participant in Mogensen and Mason’s (2015) study did not think that he was different from his friends, but he appreciated the allowances made for him in terms of ‘easy work’, which made me think of Micha who liked ‘easy work’.

Sense of self is influenced by how people feel they are viewed by others, and by comparison to peers. Although Kerry blames all that is wrong in her life on autism, I find it difficult to solely attribute the negative sense of self which has led to Kerry’s depressive feelings and self-harming, to her autism diagnosis. Without diagnosis, she would still be Kerry. Maddy does not blame her low

self-esteem on her autism diagnosis, but rather, it seems that peer rejection since primary school and parental criticism over her 'weird' behaviours, have led to poor self-image.

Despite the difficulties they have experienced, Micha, Melody, Keira and Ellie all seemed to have developed a strong sense of self. Nichols et al. (2009) say that they have found that "girls with a strong sense of self, healthy self-esteem, and a desire to succeed in their lives are more open to the idea of disclosure." (p. 172). These four participants gave examples of occasions when they had shared their autism diagnoses with peers. Parental acceptance, is a commonality in their accounts.

All of the participants in my study had a plan for the future, often involving relocation, in Mogensen and Mason's (2015) study, one participant talked about leaving school as 'liberating' as he could make new relationships. Keira and Maddy either ignored or 'unfriended' female peers on social media after leaving school.

What can educational professionals, including educational psychologists, learn by listening to the voices of adolescent females who have an autism diagnosis?

The Importance of Voice

One of the findings of my research is that the participants have not always felt listened to by adults in school. McLaughlin and Rafferty (2014) have "highlighted the potential ability of young people who are understood through the lens of 'it' to understand and communicate their needs, and to provide a sophisticated introspection of their social functioning, when given the time and place to do so." (p. 71).

The UK Government has committed to pay 'due regard' to The United Nations Conventions on the Rights of the Child (UNCRC) when considering new policy and legislation (UN, 1989). Article 12 of UNCRC states the following:

Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Section 19 of the Children and Families Act 2014 makes clear that local authorities, 'in carrying out their functions under the Act in relation to disabled children and young people and those with special educational needs (SEN)', must have regard to 'the views, wishes and feelings of the child or

young person, and the child's parents' and also 'the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions'. Parents emphasise the importance of schools communicating with them, relationship building and trust (Falkmer et al., 2015).

Melody and Maddy made requests of teachers but reported that they were not listened to. Kerry and Micha hated getting awards in assembly because they are self-conscious, but staff seemingly did not notice. Melody and Ellie both recounted painful incidents when they were publicly humiliated by a teacher during a lesson. It seems that girls belonging to this group can be extremely sensitive (Lai et al., 2015), but school staff may not be aware of this. Kerry, Keira, Maddy and Ellie all reported feeling supported at school, particularly by pastoral staff.

Honeybourne (2015), describes girls diagnosed with autism, as an under researched group. Hence, participants' views are extremely valuable as an aid to teaching staff and parents in ascertaining the educational needs of individual pupils with autism and then in creating strategies to address any identified needs. Honeybourne reminds us that there will always be exceptions and that making an individual assessment for each pupil to identify their particular needs is best practice.

In my study, Micha, Keria, Maddy and Ellie spoke of school-based anxiety, whilst Keira identified the support base as a place of sanctuary. Hill (2014) used photo elicitation and IPA to explore the secondary school experiences of young people diagnosed with autism, hence the areas of interest were chosen by participants. Themes identified by IPA were: anxiety, sanctuary and young people as active agents. Anxiety was linked to the environment and exams.

Transition

None of the participants in my study mentioned the transition to secondary school as particularly difficult, although Kerry said that she had been bullied at secondary school. Maddy had been looking forward to starting secondary school as she viewed this as an opportunity to make new friends after becoming socially isolated at primary school. Micha said that she was finding the transition to adulthood challenging: she reported social isolation out of school and uncertainty about the future. Ellie had found the transition to university challenging as she had to live independently whilst studying.

Mitchell and Beresford (2014) looked at how to best to support a positive transition from school to Further Education for young people with high functioning autism and Asperger Syndrome. Parents, rather than professionals were found to be the most significant and valued source of support. Identified support needs were for someone to assume an administrative role in order to coordinate the transition and for emotional support. The quality of support provided by practitioners was linked to their knowledge of autism and the implications of diagnosis for individuals: "The young people were very perceptive of the extent to which practitioners understood their condition, and disliked it when practitioners made presumptions about their specific needs and situation based on ASC generalisations." (p. 166).

Educational Psychologists

Roffey et al. (2016) suggest that the profession of educational psychology is 'well placed' to support the mental health of children and young people. EPs are developing wellbeing scales, programmes, and interventions and writing literature around this topic. "As the most contextualised, applied psychology service working across the domains of home, school and community, educational psychology has much to offer in respect of the development of psychological understandings of children's mental health and wellbeing." (p. 6).

Eliciting and listening to the views of children and young people and ensuring that these views are heard could be considered a core aspect of the work of educational psychologists (Mercieca & Mercieca, 2014). The Educational Psychology Services Report of the Working Group (DfEE, 2000) identifies EPs as being well placed to ensure that children's views are both elicited and included in plans being proposed for them. Harding and Atkinson (2009) found that EPs were mindful of their advocacy role and were keen to present information that would make things better for the child. McLaughlin and Rafferty (2014) suggest that EPs are well placed to ensure that young people's voices are heard and to advocate for them and also challenge personnel in regard to making assumptions about young people diagnosed with autism.

EPs are centrally placed in the debate around the medicalisation of childhood behaviour. The 2016 BPS DECP Annual CPD event was entitled 'Towards an inclusive psychology – do labels and diagnoses help or hinder?' There is a DECP Medicalisation of Childhood Working Group. EPs also contribute to the diagnostic process for autism (Brown and Paterson, 2013). BPS guidance (2016) has been

published which outlines professional practice framework for all psychologists in regard to autism in children, young people and adults.

Calderdale EP Service has produced a document titled: *Is This Person On The Autism Spectrum?* (October, 2014). This is advice and guidance for staff and parents of children presenting with complex behavioural difficulties. Other conditions which can present as autism are listed and discussed. The authors suggest a 'process of elimination' before autism is considered as a primary cause of a child's behaviour.

Hill and Turner (2016) explored the views of EPs in regard to assessment, diagnosis and treatment of ADHD. EPs were found to play an 'important role' in increasing the awareness of contextual factors in children's behaviour and to suggest how children and young people might be supported in schools. The results of this research indicated that few children were involved in decision making about their treatment. Roffey et al. (2016) state that it is a role for educational psychologists to 'reframe understanding from a 'within child' model' to an 'interactionist model' where "possibilities for change in the context are considered, children's agency is recognised and the complexity of children's lives reconsidered." (p. 6).

What can health professionals learn by listening to the voices of adolescent females who have an autism diagnosis?

Diagnosis

Huws and Jones (2008) identify a gap in the literature around the experience of parents and / or health professionals who have to disclose an autism diagnosis to a child or young person. Four of the participants in my study had been diagnosed with autism whilst they were in primary school. The parents of three participants told them of their diagnoses when they were in secondary school. Kerry overheard her mother talking on the telephone about her diagnosis when she was seven or eight years old and her mother later discussed Kerry's diagnosis with her when she began experiencing problems at secondary school. Hence these participants were told about autism by their parents sometime after diagnosis.

Although Maddy went through the diagnostic process as a fifteen year old it seemed that she hadn't fully understood what was happening until she was informed of her diagnosis by the paediatrician. Maddie's account suggests that a young person's consent to the process is not always sought. Ellie

had actively sought an autism diagnosis as a young adult as she recognised that she needed support at university and I wondered if her positivity about diagnosis could be at least partly attributed to the control and understanding that she had in regard to the process.

It could be argued that any professionals should consult with children and young people on moral grounds. "If one is pursuing a change to another person's life, it is surely necessary to seek their views, if not their consent as far as this is possible and practicable." (Gersch et al., 2014 p 33).

The voice of the child or young person should be paramount. NICE (2011) guidance covers the issue of consent and recommends that if the child or young person is under 16, healthcare professionals should follow the guidelines in the Department of Health, 'Seeking consent: working with children' (DH, 2001). This guidance states that if children are competent to give consent for themselves then consent should be sought directly from them. The legal regarding competence is different for children aged over and under 16. Once children reach 16 they are regarded in law as competent to give consent for any medical investigations. The courts have stated that under 16s will be regarded as competent to give valid consent if they have "sufficient understanding and intelligence to enable him or her to understand fully what is proposed." (Gillick Competence) (DH, 2001, p. 9).

NICE (2011) states that:

"Good communication between healthcare professionals and children and young people is essential. It should be supported by evidence-based written information tailored to the needs of the child or young person and their parents or carers. The information patients are given about recognition, referral and diagnosis of autism should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or intellectual disabilities, and to people who do not speak or read English.

NICE, 2011, p. 6

Labelling

Gould and Ashton-Smith (2011) propose that there should be greater awareness, amongst parents and professionals, of girls who may be on the autism spectrum, as girls are more likely to be 'missed' than boys. I interviewed six adolescent females who had were diagnosed with autism. My interpretations of participants' accounts leads me to believe that, given a choice, not all children and young people would wish to be so labelled. There is a risk in saying that a person has autism, as it may be perceived that that there is something 'wrong'. By 'Compulsive Diagnosing Behaviours' (CDB)

and 'Symptom Spotting Tendencies' (Simon, 2016) there is a risk of labelling people who don't need to or want to be labelled.

There are arguments for and against labelling. Runswick-Cole (2016) says that she, "understands and accepts" that many people have a "great sense of community and indeed relief as the result of diagnosis." (p. 26). Russell (2016) identifies some potential positive outcomes for diagnosis, "appropriate and helpful treatment, and alteration to the environment, together with obtaining better resources through funding and legislation." (p. 264). Gould and Ashton-Smith (2011) believe that "having a diagnosis is the starting point in proving appropriate support for girls and women on the autism spectrum." (p. 40) and that girls and women without a diagnosis are at risk of not having their needs understood, depression and unemployment.

Russell (2016) argues against early diagnosis and labelling. In her 2012 study she found that some young people may outgrow symptoms (Russell et al., 2012). Hassall (2016) says that there has been little "systematic investigation into the personal consequences of the diagnosis on those concerned" (p. 64). McLaughlin and Rafferty (2014) say that "specific attention should be paid to the potential quest for normalcy and the potential perception of the stigmatising social construction of a diagnosis." Lauchlan and Boyle (2007) point out that the label can become the totality of the child's social identity. Latif (2016) asks what is achieved by labelling someone with a disorder if it doesn't really predict outcomes and can lead to increased stigma.

Chapter 6 - Conclusions, Limitations and Recommendations

Conclusion

Runswick-Cole (2016) says, “this *thing* called autism is everywhere; it is embedded in contemporary culture” (p. 25) but how does it feel to be given an autism diagnosis as a child or young person and to live with this diagnosis? Mogensen and Mason (2015) say, “Acknowledging children as social actors who are able to contribute knowledge about issues that are important in their lives, such as having a diagnosis, emphasises the importance of taking their view seriously and placing them centrally in research.” (p. 256). While it is not possible to generalise the findings of this research across all girls and young women who have an autism diagnosis it is my intention to offer insights into the experiences of these six adolescent females.

Two interrelated questions lie at the heart of critical autism studies: is the diagnosis of autism critically valid? And, is a diagnosis of autism useful to those so labelled? Critical autism advocates, and many other experts in the field of autism, would argue that autism diagnosis is not valid as there is no evidence of an underlying biomedical cause (Runswick-Cole, Mallet and Timimi, 2016). In regard to the question: is a diagnosis of autism useful? I am able to draw on the voices of the six adolescent females who participated in my study and of young people who participated in similar studies (Humphrey and Lewis, 2008) (Huws and Jones, 2008) (McLaughlin and Rafferty, 2014) (Mogensen and Mason, 2015). I would argue that some of those so labelled find diagnosis useful, or may find it useful at certain times, but for some young people this label can be unwanted and even at times harmful to personal identity (Marcia, 1966).

Limitations

The limitations of this research have been discussed in the Methodology chapter. Phenomenological methods call for ‘bracketing’ by the researcher which “involves a deliberate and conscious attempt to set aside ones’ personal and theoretical assumptions, expectations and proclivities before commencing data analysis.” (Watts, 2014, p. 3). Langridge (2007) argues that it is ‘impossible’ for the researcher to begin his or her research without having an agenda. Watts (2014) feels that it is not possible for a researcher to achieve a neutral or value-free perspective in regard to the data as the findings of any analysis will always reflect the ‘questioning activities’ of the researcher.

Although I made a conscious effort to bracket off my own thoughts whilst planning and undertaking this research I found it difficult to 'shelve' my responses to each participants account before undertaking the next interview. Although I aimed to be balanced in my analysis and discussion of findings, I continued to find it difficult to bracket off my own thoughts and feelings about autism diagnosis. Although I did offer feedback to participants during the autumn term they all declined, primarily as they were in a period of transition and wanted a fresh start. Hence, I did not gain any participant feedback on my interpretations.

Recommendations

Watts (2014) says that even the findings from a small study can contradict or undermine established understandings and question current modes of professional practice. Although this research is based on the views of a small number of adolescent females findings have highlighted several implications for educational and health professionals and parents and carers. Findings cannot be generalised and hence recommendations are offered with caution.

Educational Professionals

In my experience school staff have sometimes encouraged parents and carers to request an autism assessment. This is often well-meaning, for example, as a means toward better understanding a child's behaviour and difficulties. Labels have also been linked to additional funding, especially prior to national changes in school SEN funding. In the LA where I work as a TEP EHCP assessment (DH, DfE, 2014) is based on 'criteria', which are partly based on labels such as ASC and LD. This driver for funding, which is based on assessment and labelling, can sometimes override the needs and voice of the child.

Teachers and non-teaching staff should be aware of 'labelling theory' (Russell, 2016) and attributional biases associated with labels such as autism as discussed in Chapter 2. Difficulties can be attributed to within child factors at the risk of ignoring environmental and developmental factors.

Teachers may have a 'stereotyped' view of autism that does not fit with this group of 'high functioning' females. Hodge (2016) suggests that teachers should treat all students as individuals.

School leaders and staff working in schools and further education should actively seek, listen to and if possible act upon the wishes of children and young people who have an autism diagnosis. Simon (2016) suggests that young people should be part of processes that affect them. School staff should be mindful that this is not a group of students who are likely to be forthcoming. They could ask students what they want others to know in terms of their autism diagnosis and the type of support that they would find helpful or unhelpful. My research findings indicate that this group of young people may benefit from school staff consulting with them as how to best support their communication, for example, do they want to be asked direct questions in the classroom and could they participate in a small discussion group with carefully chosen peers. In my study one participant said that she had open access to the Learning Resource Centre at break times. School staff could find out how all students belonging to this group are coping during social times and if they need a place to go and / or the support of a suitable buddy or buddies.

If young people have an Education, Health and Care Plan, which includes recommendations and is accompanied by funding, then it seems likely that school leaders feel obliged to provide interventions. The findings of my research suggest that children who are diagnosed with autism are included in intervention groups without a firm evidence base and without prior discussion. Hence, interventions should be carefully considered.

Educational professionals, especially if they are providing pastoral support, would benefit from awareness of research about friendships and peer relationships for this group. When the participants in my research study fell with friends, or rather when friends fell out with them, they did not attempt to repair these relationships. Calder et al. (2012) highlight the need for adults to ascertain the perspectives of young people with autism on their friendships and to 'consider the social and ethical implications' of when and how to intervene. School staff could also consider how to raise peer awareness and understanding.

For this group, discussions about maintaining positive mental health may prove beneficial. The findings of Clarke, Charman and Hill's study (2016) suggest that school-based CBT programmes could be helpful for children who are diagnosed with autism and experience anxiety.

Health Professionals

Autism diagnosis can be seen as a means of increasing understanding; self-understanding and understanding of others, and accessing additional support. My research suggests that the role the child plays in the diagnosis, their understanding of it and the long term consequences of diagnosis need to be carefully considered.

My experiences of participating in multi-agency diagnostic meetings suggest that health professionals can have a positivist view of autism. Health professionals should be more aware of critical perspectives.

Latif (2016) asks what is achieved by labelling someone with a disorder if it does not reliably predict outcomes and can lead to increased stigma. If autism does not exist at a biological level then surely it could be considered unethical to tell children and young people that they have 'it'. I believe that health professionals should be aware of the risks involved in labelling a child or young person. Being labelled with autism can have a negative impact on self-esteem which can affect mental health and life chances.

Some young people may outgrow childhood symptoms or behaviours (Russell et al., 2012). Perhaps there should be a reassessment of autism when the child reaches adolescence. The young person could be given the opportunity to share their views and ask questions.

The participants in my study only mentioned social communication difficulties in some contexts, and although it is not for me to question the validity of their diagnoses I do wonder if the first four participants would meet the criteria for autism spectrum disorders in the DSM – 5. My interpretations of participants' accounts suggest that some of the participants in my research study would take the opportunity to dismiss or lose their autism diagnoses if this was possible.

The participants in my study mostly had a positivist view of autism, accepting that as autism is diagnosed by doctors it must therefore be real and lifelong. I feel that children and young people who are either going through the diagnostic process, or who are diagnosed with autism, should be given clear and consistent guidance as to what autism is thought to be and what it is not, for example, a booklet or film clip produced in consultation with young people who belong to this

group. They should also be made aware of critical autism perspectives, with regard given to the individual's level of linguistic competence to understand.

My research also indicated an inequality in access to local mental health services. One participant said that she was depressed and admitted that she was self-harming yet she did not appear to be accessing any targeted support in or out of school. Although she may have been offered mental health support and declined.

My research indicates that transition from school to sixth form, FE College and especially university can be challenging for young people and they may need increased levels of support.

Educational Psychologists

Educational Psychologists are using research to capture and share the voices and views of vulnerable groups, such as children and young people diagnosed with autism. EPs have the scope to influence many of the tentative recommendations suggested above, as they are situated within schools, in diagnostic teams and regularly consult with parents and young people.

Recommendations for future research

Participants in my research study spoke at length about friendships and peer relationships and their school experiences. This could be a focus for further research. I also found the reactions of family members to autism diagnosis interesting, as seen through the young person's perspective.

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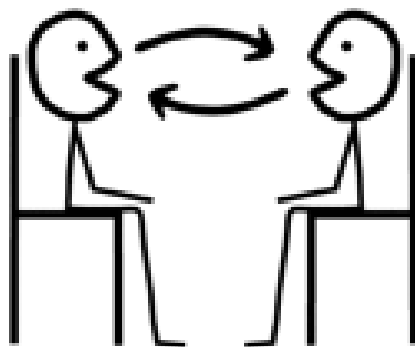
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**Research Project
Participants Wanted!!!
Making sense of Autism Spectrum
Diagnosis: Female Viewpoints**

Are you:

- Female?
- 14-25 years old?
- In education and /or attending an autism support group?
- Diagnosed with an Autism Spectrum Condition?



Would you:

- Have half an hour or so spare?
- Be willing to speak to me about your Autism Spectrum 'diagnosis' and what it means for you?

If so contact me via text, email or phone call:

(Or ask a member of staff or parent to contact me on your behalf)

Joanne.gaffney@cumbria.gov.uk / 07810181571

Joanne Gaffney, Trainee Educational Psychologist

Thank you!!

Appendix 2: Information sheet for participants

Participant Information Sheet

Making sense of Autism Spectrum diagnosis: Female viewpoints

You have been invited to take part in a research project. Before you decide whether to participate or not it is important for you to understand why the research is being undertaken and what participation will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The aims of this project are to find out:

- How do girls / young women diagnosed with Autism Spectrum Disorder (ASD) make sense of this diagnosis?
- What can educational and health professionals learn by listening to the voices of girls and young women who have an ASD diagnosis?

Why have you been invited?

You been chosen as you responded to a flyer displayed in your educational setting seeking participants willing to talk freely about how they feel about their autism spectrum diagnosis. As well as yourself, five other girls and young women will be taking part in this research.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form and you can still withdraw at any time. You do not have to give a reason.

What will happen if you take part?

If you do decide to take part you will be interviewed by me for approximately one hour during the summer term at a place and time of your choosing; for instance, your home, your educational setting or a quiet public place. You will be asked a few open-ended questions to help you to talk about your views. If possible, I would like you to talk at some length and in some depth about how you felt and / or how you feel now about your autism spectrum diagnosis. I would be interested to hear about both positive and negative thoughts.

Will the interview be recorded, and how will the recorded media be used?

The interviews will be recorded on a Dictaphone, stored on my computer and will then be transcribed. I will analyse what has been said and will try to find some common themes among all the interviews. I will want to discuss my thoughts with you and check that you are happy with any conclusions I reach.

The audio recordings of the interviews carried out during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

Are there any risks?

Because I will be asking you about a personal matter, there is a small chance that you may experience some unhappy thoughts and this may cause you some upset. However, it is up to you to decide what you want to tell me.

What are the possible benefits?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will be able to help educational and health professionals to understand how to make the diagnostic process better for children and young people.

What if something goes wrong?

If you feel at any time that you need to make a complaint about any aspect of the research, then you may contact my supervisor at the following address:

Dr Anthony Williams

University of Sheffield

Department of Educational Studies

388 Glossop Road

Sheffield

S10 2JA.

Tel: 0114 222 8119

If you do make a complaint and are not happy with the way it is handled, you may contact the University's Registrar and Secretary at the same address as above.

Will my taking part in this project be kept confidential?

All the information that I collect during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications. However, I may need to discuss my analysis of your interview with my supervisor but you will remain anonymous during these discussions.

What type of information will be sought and why is the collection of this information relevant for achieving the research project's objectives?

I am interested in trying to understand how you feel about and make senses of your experiences of autism spectrum diagnosis. Most research is conducted on rather than with people on the autism spectrum by people who do not have an AS diagnosis. Your

information will help me to inform others about what girls and young women with AS feel would be helpful in terms of the diagnostic process.

What will happen to the results of the research project?

The results of this research will form part of my thesis and some aspects of this may be published in an academic journal. It will also be shared with other students at the University of Sheffield. However, you will not be identified by name in any report, publication or lecture.

Who has ethically reviewed the project?

This research proposal has gone through ethics review and been approved by The School of Education, University of Sheffield.

Contact for further information:

Joanne Gaffney

County Psychological Service (West)

Blencathra House

Whitehaven

Cumbria

CA28 7UW

Tel: 07810181571

Dr Anthony Williams

University of Sheffield

Department of Educational Studies

388 Glossop Road

Sheffield

S10 2JA

Tel: 0114 222 8119

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for your interest in the project.

Appendix 3: Information sheet for parents

Parental Information Sheet

Making sense of Autism Spectrum diagnosis: Female viewpoints

Your daughter has expressed an interest in taking part in a research project. Before she decides whether to participate or not it is important for you, as her parent(s), to understand why the research is being undertaken and what participation will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not your daughter should take part.

The aims of this project are to find out:

- How do girls / young women diagnosed with Autism Spectrum Disorder (ASD) make sense of this diagnosis?
- What can educational and health professionals learn by listening to the voices of girls and young women who have an ASD diagnosis?

Why has she been chosen?

She been chosen as she has responded to a flyer displayed in her educational setting seeking participants willing to talk freely about how they feel about your autism spectrum diagnosis. As well as your daughter, five other girls and young women will be taking part in this research.

Does she have to take part?

It is up to you and her to decide whether or not to take part. If she does decide to take part you will be asked to sign a consent form and she can still withdraw at any time. She does not have to give a reason.

What will happen to her if she takes part?

If she does decide to take part, she will be interviewed by me for approximately one hour during the summer term at a place and time of her choosing, for instance in her educational setting, at her home or in a quiet public place. She will be asked a few open-ended questions to help her to talk about her views. If possible, I would like her to talk at some length and in some depth about how she felt and / or how she feels now about her autism spectrum diagnosis. I would be interested to hear about both positive and negative thoughts.

Will the interview be recorded, and how will the recorded media be used?

The interviews will be recorded on a Dictaphone, stored on my computer and will then be transcribed. I will analyse what has been said and will try to find some common themes

among all the interviews. I will want to discuss my thoughts with your daughter and check that she is happy with any conclusions I reach.

The audio recordings of the interviews carried out during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

Are there any risks?

Because I will be asking her about a personal matter, there is a small chance that she may experience some unhappy thoughts and this may cause her some upset. However, it is up to her to decide what she wants to tell me.

What are the possible benefits?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will be able to help educational and health professionals to understand how to make the diagnostic process better for children and young people.

What if something goes wrong?

If you feel at any time that you need to make a complaint about any aspect of the research, then you may contact my supervisor at the following address:

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S10 2JA.

Tel: 0114 222 8119

If you do make a complaint and are not happy with the way it is handled, you may contact the University's Registrar and Secretary at the same address as above.

Will my taking part in this project be kept confidential?

All the information that I collect from your daughter during the course of the research will be kept strictly confidential. She will not be able to be identified in any reports or publications. However, I may need to discuss my analysis of her interview with my supervisor but she will remain anonymous during these discussions.

What type of information will be sought from her and why is the collection of this information relevant for achieving the research project's objectives?

I am interested in trying to understand how she feels about and makes sense of her experiences of autism spectrum diagnosis. Most research is conducted on rather than with

people on the autism spectrum by people who do not have an AS diagnosis. Her information will help me to inform others about what girls and young women with AS feel would be helpful in terms of the diagnostic process.

What will happen to the results of the research project?

The results of this research will form part of my thesis and some aspects of this may be published in an academic journal. It will also be shared with other students at the University of Sheffield. However, she will not be identified by name in any report, publication or lecture.

Who has ethically reviewed the project?

This research proposal has gone through ethics review and been approved by The School of Education, University of Sheffield.

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Dr Anthony Williams

University of Sheffield

Department of Educational Studies

388 Glossop Road

Sheffield

S10 2JA

Tel: 0114 222 8119

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for taking time to consider this information.

Appendix 4: Written consent form for participants

Participant Consent Form

Title of Research Project: Making sense of Autism Spectrum diagnosis: Female viewpoints

Name of Researcher: Joanne Gaffney, Trainee Educational Psychologist

Participant Identification Number for this project: _____

Please initial each box

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point at which the data is analysed without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I understand that my responses will be kept strictly confidential. I give permission for the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I understand that my responses will be digitally recorded, stored and kept in a safe location until the research is successfully completed, at which point this material will be destroyed.

5. I agree to take part in the above research project.

Name of Participant	Date	Signature
---------------------	------	-----------

Lead Researcher	Date	Signature
-----------------	------	-----------

To be signed and dated in presence of the participant

Copies: Once this has been signed by all parties the participant will receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form will be placed in the project's main record (e.g. a site file), which will be kept in a secure location.

Appendix 5: Written consent form for parents

Parental Consent Form

Title of Research Project: Making sense of Autism Spectrum diagnosis: Female viewpoints

Name of Researcher: Joanne Gaffney, Trainee Educational Psychologist

Name of potential participant: _____

Please initial each box

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my daughter's participation is voluntary and that she is free to withdraw at any time up to the point at which the data is analysed without giving any reason and without there being any negative consequences. In addition, should she not wish to answer any particular question or questions, she is free to decline.

3. I understand that her responses will be kept strictly confidential. I give permission for the research team to have access to her anonymised responses. I understand that her name will not be linked with the research materials, and she will not be identified or identifiable in the report or reports that result from the research.

4. I understand that her responses will be digitally recorded, stored and kept in a safe location until the research is successfully completed, at which point this material will be destroyed.

5. I agree to my daughter taking part in the above research project.

_____	_____	_____
Name of Parent	Date	Signature
/ Legal guardian		

_____	_____	_____
Lead Researcher	Date	Signature

Copies: Once this has been signed by all parties the participant's parent(s) will receive a copy of the signed and dated parental consent form, the information sheet and any other written information provided. A copy of the signed and dated parental consent form will be placed in the project's main record (e.g. a site file), which will be kept in a secure location.

Appendix 6: Interview Schedule

Question number	Question
1	Can you tell me about your interests?
2	How would you describe yourself to someone who doesn't know you?
3	What do you think your strengths are?
4	Can you tell me how you found out about your autism spectrum diagnosis?
5	Can you remember what you thought of this?
6	What was your understanding of AS at this time? Has your understanding changed (over time)?
7	Have you read any books, looked at online information or watched any TV programmes about AS?
8	Do you think that having an AS diagnosis has made a difference to the way that you feel about yourself? (If so can you explain?)
9	Can you tell me how AS affects your relationships with other people? (What are the benefits and challenges?)
10	What do you think other people's opinions of you might be?
11	What are your plans for the future?
12	Do you know anyone else who has been diagnosed with autism spectrum?
13	Do you think that there are differences for boys on the autism spectrum and for girls? (What do you think they are?)
14	Is there anything that I have left out that you would like to add?

Appendix 7: Ethical Approval



Downloaded: 19/04/2016
Approved: 18/04/2016

Joanne Gaffney
Registration number: 140109403
School of Education
Programme: DECP 2014

Dear Joanne

PROJECT TITLE: Making sense of Autism Spectrum diagnosis: Female viewpoints
APPLICATION: Reference Number 008068

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 18/04/2016 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 008068 (dated 15/04/2016).
- Participant information sheet 1017152 version 1 (15/04/2016).
- Participant information sheet 1016509 version 2 (15/04/2016).
- Participant consent form 1017153 version 1 (15/04/2016).
- Participant consent form 1016510 version 2 (15/04/2016).

The following optional amendments were suggested:

Change the flyer: Consider changing girl to young person and female participants Also consider changing 'diagnosis' to 'identify as having ...'

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Professor Daniel Goodley
Ethics Administrator
School of Education

Emergent themes		Original Transcript 1 – Kerry	Exploratory comments
<p>She takes active steps to relax Walking outdoors helps her to relax</p> <p>She escapes into imaginative world by listening to music</p> <p>Relies on others' descriptions of self Key adults say that she is nice, kind cheerful and friendly</p>	<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25</p>	<p>Okay, so, I'll just go through these questions, there's no rush.</p> <p>Okay, question 1, can you tell me about your interests?</p> <p>Ha, I like to go outdoors and all that, like whenever I'm outdoors for a walk I feel all free and all that (hesitates).</p> <p>Yeah, that's good</p> <p>I like listening to music a lot (hesitates).</p> <p>Do you find that relaxing?</p> <p>Yeah, it like helps me and all that, helps me to think, it helps me to imagine sort of thing, that's what I like about listening to music.</p> <p>Anything else?</p> <p>Em, I do like to read books, but, like, during this year there hasn't been any time to, and all that.</p> <p>Yeah, not much time to read fiction books, Yeah</p> <p>Okay, great, K, this may sound like a strange question but, how would you describe yourself to someone who doesn't know you, but would like to get to know you?</p> <p>(Hesitates)</p> <p>How would you describe yourself?</p> <p>(Hesitates) Well, erm, I'll have to like, remember what other people have said, like Miss J (LSA) and my mum and all that, they'd say that I'm nice and all that, kind and friendly, erm, quite cheerful and all that, (hesitates) that's it.</p> <p>Okay, that's good, so this is a similar question really, but what do you think your strengths are?</p> <p>Erm, that I'm a hard worker and all that, like that I work hard and all that, and like I do try to aim for my goals and all that</p>	<p>Likes to be outdoors, goes walking, knows this helps her to relax</p> <p><u>Free from worry?</u></p> <p>'And all that', assumes that I know what 'all that' is. This phrase is repeated throughout the interview. Perhaps she uses 'and all that' to fill in for what she can't or doesn't want to say?</p> <p>Likes listening to music</p> <p>Is affected by music, songs have meaning, <u>what does she imagine?</u></p> <p><u>Sort of thing, struggles to, or is reluctant, to articulate a fuller description</u></p> <p>Leisure activities serve a purpose i.e. relaxation, she offers an explanation of why she engages in chosen activities without prompting</p> <p>Grounds her answer by drawing on the concrete, what others say about her, a good strategy to answer a somewhat abstract question.</p> <p>Offers qualities: nice, kind and friendly, <u>does she need to tell me that these qualities have been noted by others rather than saying 'I am nice'?</u></p>

<p>She works hard to achieve her goals</p>	<p>26</p>	<p>(hesitates).</p>	<p>Lots of erms, contemplation or finding an appropriate word. Use of 'likes', like is used whilst searching for an appropriate word.</p>
	<p>27</p>	<p>Good, sounds like you're well motivated</p>	
	<p>28</p>	<p>Yeh</p>	<p>She has been told that she is a hard worker, she confirms this. Says that she tries to aim for her goals rather than sharing examples of success, <u>is this humility or lack of self-esteem?</u></p>
	<p>29</p>	<p>I'm sure there are lots of strengths?</p>	<p>Doesn't agree (or disagree) with my compliment</p>
	<p>30</p>	<p>Dunno really, well personally I don't know.</p>	<p>'Well personally' is an example of good use of vocabulary</p>
<p>She struggles to name her strengths</p>	<p>31</p>	<p>Okay, that's fine, are we okay to talk about the autism spectrum?</p>	<p>Checking that she understands my question, <u>wants to get it right.</u></p>
	<p>32</p>	<p>Good, I'm really interested in this, so, could you tell me how you found out about your AS diagnosis?</p>	<p>Moved from another area, <u>has this impacted on her sense of belonging?</u></p>
	<p>33</p>	<p>Yeah</p>	
	<p>34</p>	<p>So you knew before you moved up?</p>	
	<p>35</p>	<p>Erm, like I knew for definite and all that, like when I moved up here in 2006 and all that.</p>	
	<p>36</p>	<p>Were you quite little then? six or seven?</p>	
	<p>37</p>	<p>I knew like after and all that.</p>	
	<p>38</p>	<p>Okay, erm, so who told you about this?</p>	
	<p>39</p>	<p>I knew like after and all that.</p>	
<p>She was around seven or eight when she found out about her autism diagnosis</p>	<p>40</p>	<p>Okay, erm, so who told you about this?</p>	
<p>She was not told about her autism diagnosis</p>	<p>41</p>	<p>Erm, well, like I heard my mum on the phone and all that, if she was talking to old friends and all that, erm, she normally like mentions it, and sometimes I like pay attention and sometimes I don't and all that, erm, erm. Like one time I got really upset at home because I was like being bullied and all that, for no reason, erm. Well, I just talk to my friends and all that, obviously I knew that I had it, when I went to W (secondary school) and that, yeh, I'd get upset really a lot and all that, she says it's probably like . . . To me it feels like I don't need help, then I know that I do need help.</p>	<p>She was not told that she had an autism diagnosis but overheard her mum speaking. <u>What must that have felt like hearing her mum discussing her with friends in telephone conversations? Why didn't she ask her mum about AS?</u></p>
<p>Her autism diagnosis was discussed in problem contexts</p>	<p>42</p>	<p>Okay</p>	<p>This suggests that she was not overly concerned or is she letting me know that she was not overly concerned.</p>
<p>She has been bullied at school</p>	<p>43</p>	<p>I know that doesn't sound, make sense, but erm, but erm.</p>	<p>This sounds as if her mum talked to her</p>
<p>There is a struggle between not wanting</p>	<p>44</p>		
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<p>help but knowing that she needs it</p>	<p>56 57 58 59</p>	<p>I'm listening and it does make sense. So when you heard your mum talking to old friends and explaining to you that you got upset because of autism spectrum, can you remember what you thought of it?</p>	<p>about autism when she was upset about being bullied at school. She says that she was bullied for no reason, <u>unfairness</u></p>
<p>She has hated autism or autism diagnosis from the outset She doesn't want to tell people about her autism diagnosis but feels that she has to She either finds explaining autism difficult or wonders why she has an autism diagnosis She views autism as her lack of understanding</p>	<p>60 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76</p>	<p>Well, I was really sad and all that like, I knew from like day one that I hate it, sort of thing (hesitates). Okay It really annoying and all that having to tell people, but I have no choice, okay, if I have it I know (hesitates). Yeh And erm, like after that I'd get upset, saying why and all that (looks upset). Okay erm, when you were younger, seven or eight, how did you understand or make sense of autism spectrum? Like, I that knew that erm, I had it, like any other person would understand but I didn't understand. Okay, so you think that it affected your understanding? Yeh, a bit Okay, so, you said that when you started at secondary school it was sometimes difficult but how do you feel about it (AS) now?</p>	<p>She talks to her friends about bullying / she talks to her friends about her autism diagnosis? She calls AS 'it' She doesn't want help but says that she sometimes needs it, <u>for her 'help', not needing help and admitting or realising that she does need 'help' is important.</u> She is already emotive and struggling to articulate information that is important to her, she acknowledges that her answer may not be coherent. The AS diagnosis made her sad, she did not want to 'have' AS, <u>but she does not say that she rejects the diagnosis, has she ever questioned the diagnosis?</u> She doesn't like telling people, <u>embarrassed?</u></p>
<p>She hates AS Autism diagnosis is ruining her existence She sees her autism diagnosis as stopping her from having a profession</p>	<p>77 78 79 80 81 82 83 84 85</p>	<p>I still hate it and all that, but now like if I had a choice, this might sound daft but if I had a choice between not existing and having this I would choose not existing, because I hate it so much and all that, cause I can't see myself having a profession or whatever. Like it affects me to see what will happen in the future and all that. Like, if I like had a job, I won't want to tell them I have it but want to keep it a secret even though. Cause people who know and all that, people who know that I have support and that I have it treat me as if</p>	<p><u>Why does she feel that she has no choice but to tell people about her AS diagnosis?</u> She accepts the diagnosis but wonders why this has happened to her, <u>AS diagnosis is separate from her, she seems to regard it as an illness</u> Sees autism as affecting her ability to</p>

<p>She would want to keep her diagnosis secret from future employers</p> <p>She associates AS with a perceived lack of capacity by others</p> <p>Others treat her differently and unfairly</p> <p>She worries about continuing to feeling awkward when she is older</p> <p>She uses fantasy to escape from her reality</p> <p>She does not want to know about autism because she does not want to have autism</p> <p>She is not comfortable admitting that she has autism</p> <p>She is ashamed of 'having' autism, it is something shameful</p> <p>It makes her feel like a lesser person when she compares herself to</p>	<p>86</p> <p>87</p> <p>88</p> <p>89</p> <p>90</p> <p>91</p> <p>92</p> <p>93</p> <p>94</p> <p>95</p> <p>96</p> <p>97</p> <p>98</p> <p>99</p> <p>100</p> <p>101</p> <p>102</p> <p>103</p> <p>104</p> <p>105</p> <p>106</p> <p>107</p> <p>108</p> <p>109</p> <p>110</p> <p>111</p> <p>112</p> <p>113</p> <p>114</p>	<p>I'm five and all that. I'm like 'No, I'm your age'. Like it's quite frustrating and all that, cause like I feel like when I'm older and all that, it might feel awkward and all that as well.</p> <p>Okay, erm, right, K, have you read any books, or been online or watched any programmes that have maybe helped you or informed you or just out of interest?</p> <p>Erm, hesitates, well erm, like films and all that like, I like Marvel and all the super hero stuff, erm, I also like action and fantasy. For books I like sort of fantasy, horror, that sort of thing, cause I can put it in my imagination and all that, like it helps me to leave where I am and go to a different place which helps me, and all I feel more comfortable.</p> <p>Yeh, lots of people have a nice escape by reading. Have you read up on autism spectrum online or joined any chat rooms?</p> <p>See, I don't really want to know and all that, I wish that sort of, I wish, that I don't have it and don't want to know, I don't like saying that I have it, cause for me it don't feel comfortable saying it, it feels something not right. When I speak with people who don't have anything wrong with them it feels awkward and all that for me.</p> <p>I haven't really looked into it but there are chatrooms for young people who are diagnosed with autism who can chat to each other but it sounds like you haven't thought of joining one. Okay, you're doing really well. Can you tell me how you think autism spectrum affects your relationship with other people?</p> <p>I think I find it more difficult and all that, because like, I always get like worried if I'm saying something like, like, I'm going to say something wrong and all that and erm, like when I try to</p>	<p>understand, i.e. a cognitive difficulty</p> <p>Hates autism so much that she would prefer to not exist, <u>this makes me question the usefulness (ethical) of her diagnosis</u></p> <p>Believes that her AS diagnosis will affect her future job prospects because potential employees will think that she lacks capability, <u>discrimination</u>. Does not want to share her diagnosis, <u>keeping her diagnosis secret in future</u>. This is based on her experiences at school, peers do not treat her as equal, but she does not accept this, <u>inequality</u>. She sometimes feels socially awkward and is worried that this will continue into adulthood, <u>ongoing difficulty with social communication</u>.</p> <p><i>Strings together a coherent argument, one point leading onto another</i></p> <p><i>Some presumption that I can make sense of what she is saying, 'them' for employers and 'people who know' for other students. Again, good use of vocabulary.</i></p> <p>Misunderstands my question.</p> <p>Mentions her imaginary life, <u>escape from reality through imagination</u></p> <p>Does not want to have autism, does not</p>
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<p>people who are 'normal'</p> <p>She worries that she will get conversations 'wrong'</p> <p>She feels that she can't act as if she doesn't have autism because she gets conversations 'wrong'</p> <p>She has been able to become more open with friends over time</p> <p>Friends and teachers understand</p> <p>She does not want other people to know</p> <p>She was embarrassed when she got an award from LS</p> <p>She admits that she needs additional pastoral support in school</p>	<p>115 be like, when I try to act like I don't have it, like it doesn't</p> <p>116 really help, cause like, I might say something and they will just</p> <p>117 give me a weird look but it sounds normal to me. But erm, it's</p> <p>118 difficult, like, with my friends now and all that, like at first it</p> <p>119 was like 'alright I'll see you later on', it's just that now and all</p> <p>120 that I'm getting used to saying I'm going to LS, and I've got a</p> <p>121 support teacher and all that, erm that's just recently now, but</p> <p>122 years before and all that I didn't want to say anything.</p> <p>123 How does that feel now, when you say to people in your</p> <p>124 class 'I'm just going to see Miss J' (TA)?</p> <p>125 I'm not really comfortable like saying it and all that, to anyone</p> <p>126 else apart from friends and teachers, cause I feel that they</p> <p>127 understand. But erm, like, like I feel embarrassed when like I</p> <p>128 say, I'm going to LS and all that. And when it's assemblies and</p> <p>129 all that, getting awards once a week and all that. And like,</p> <p>130 when erm, when I like got an award from Learning Support in</p> <p>131 tutor and all that, and someone said something and all that</p> <p>132 and it was for me and all that, I don't want it.</p> <p>133 Ah, that's interesting to know</p> <p>134 I don't want anything to do with Learning Support but I know</p> <p>135 that I need it.</p> <p>136 That's really helpful. Erm, do you think that are any benefits</p> <p>137 at all? I've listened to what you've said.</p> <p>138 No</p> <p>139 Okay, do you know anyone else in school who has an AS</p> <p>140 diagnosis, or in the community, or at home?</p> <p>141 Well, my two brothers and all that both have got ADHD, and</p> <p>142 that's all I know of. (Contemplates) But there is someone who</p> <p>143 used to go to my primary school and he went here and all that, him and his brothers and all that, like have it as well.</p>	<p>want to share her AS diagnosis, <u>does 'something not right' mean that she does not believe that she has autism or that others will see her as 'not right'?</u></p> <p><u>Does she feel awkward because of communication difficulties or because she compares herself unfavourably to others, or because they are aware of her AS diagnosis?</u></p> <p>Mentions communication problems again, saying the wrong thing, getting weird looks.</p> <p>Trying to act normal</p> <p>Has started to say to friends that she is going to LS and has a support assistant, <u>why is she able to do this now?</u></p> <p>Feels that friends and teachers understand.</p> <p>Does not want other students to know about AS.</p> <p><u>Wonder why she needs LS?</u></p> <p>Sees no benefits to AS.</p> <p><u>Her two brothers are also diagnosed with</u></p>
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<p>ADHD is a more acceptable label than AS</p> <p>Her older brother suffers from social anxiety and doesn't work</p> <p>Fears that autism diagnosis will make her younger brother unhappy</p> <p>Her younger brother will need to take on a disabled persona</p> <p>She has tried to act as if she doesn't have AS</p>	<p>144 They live in like F. But erm, that's it, that's all I know of.</p> <p>145 How does the ADHD affect your brothers?</p> <p>146 Well, my older brother, he is sort of scared and all that, he's in</p> <p>147 his twenties, mum tried to encourage him to go to work but</p> <p>148 he doesn't want to go to work in case he meets horrible</p> <p>149 people and all that. And he acts like, like he has no hope and</p> <p>150 all that as well. But my little brother, he's about eight and all</p> <p>151 that, he's happy and all that. I think he'll get to a certain age</p> <p>152 when he'll realise that, but I hope it stays longer for my little</p> <p>153 brother (emotional) and all that, cause he is cheery and happy</p> <p>154 and all that. But then I know that, the sad thing is that when I</p> <p>155 go to 6th form and all that, when I leave, because hopefully I</p> <p>156 want to go to university (laughs) and all that, that I'll be</p> <p>157 leaving him at home and he might struggle sort of thing, I</p> <p>158 know that there will be a certain point when he's gonna</p> <p>159 realise that enough is enough sort of thing, that he can't be</p> <p>160 who he is sort of thing.</p> <p>161 Do you think? I suppose we can't really know what will</p> <p>162 happen?</p> <p>163 That's how I felt growing up personally, I was like trying not to</p> <p>164 act like erm, I don't have it.</p> <p>165 Did you find . . . , it's not on my list of questions, but what</p> <p>166 was the difference in primary school, knowing that you had</p> <p>167 these difficulties, AS diagnosis, and secondary school?</p> <p>168 It's hard and all that, erm in secondary school and all that, I</p> <p>169 did like self-harm a bit because I got sick of everything and all</p> <p>170 that, I hated everything erm, yeh, and now and all that.</p> <p>171 Sometimes I just want to feel pain sort of thing, like when I'm</p> <p>172 older and I get a car I'll probably want to drive it into a tree,</p> <p>173 not to kill myself, (laughs), I dunno, I'll feel that I have to do it</p>	<p><u>ASD, she sees ADHD as a more acceptable label?</u></p> <p>Knows two other bothers with ASD, does not offer further information – <u>I wonder how this has influenced her views</u></p> <p>Her older brother has depression and anxiety, <u>does she attribute this to AS?</u></p> <p>She sees herself as having no hope</p> <p>She anticipates that her younger brother will become increasingly unhappy as he gets older, <u>narrative around hopelessness</u></p> <p><u>Laughs when she mentions her ambitions</u></p> <p><u>S stops you from being who you want to be</u></p> <p>Rejection of AS, <u>AS as something real</u></p> <p>Talks about the result of her difficulties at</p>
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<p>She found secondary school hard and started self-harming She sometimes wants to feel pain She talks about compulsions She feels down most of the time She feels that she won't succeed when she is older AS is blamed for future failings</p> <p>She feels that other students hate her, she feels rejected</p>	<p>174 and all that, I feel like, that's when I feel down and all that, 175 when, most of the time, when I have a bath and all that, that's 176 when I harm myself and all that, that's what I feel. During 177 school, when I've been growing up, like at times I just feel that 178 I've had enough sort of thing and I want to stop it, cause I feel 179 that I'm not going to succeed when I'm older and all that, like. 180 Like I said before I can't see myself doing any professional job 181 and all that. I feel that I probably can't get there because of it 182 and that's the only thing, like stopping me. 183 Well, we'll just the finish the questions and maybe we could 184 have a chat. Yeah, you've been really honest and said some 185 of the things you feel K, what about the other young people 186 in year 11, how do you think that they might see you? 187 Well, how people see me? (considers) 188 Oh, what their opinions might be? 189 I dunno, apart from my friends all the messages I get from 190 them is that they hate me, and I know for a fact that if there is 191 a gunman in the school and all that, and I didn't make it into 192 class for a lockdown and all that, everyone would stand there 193 and sort of watch and not help, and that's how I feel, like. 194 That's how most people treat me during primary school and 195 secondary school and all that, and other years and all that, 196 that they don't want me here and all that, they want me gone, 197 gone. That's how they treat me and all that. 198 What about your friend's opinions? You've mentioned your 199 friends a couple of times. They seem to be quite 200 understanding? 201 Yeh, well, they're comfortable with it and all that, well two of 202 my friends they both suffer from anxiety as well, and like so 203 they understand and all that, erm, one of my friends had a bit</p>	<p>secondary school and self-harming, <u>it sounds like depressive thinking led to self-harming</u> Doesn't value herself, <u>self punishment?</u> Feels down Worries about the future, blames AS, <u>is she depressed because of how AS has affected her self-concept or has AS type difficulties made her prone to negative thinking? Does AS fulfil a useful role in taking the blame? Her bother does not work, how has this influenced her expectations for the future?</u></p> <p>Perceives widespread rejection by the majority of her peer group, <u>how must that feel?</u> <u>Uses a powerful example to emphasise her point</u></p>
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<p>Her friends also experience anxiety and a lack of understanding</p>	<p>211 212 213 214 215 216</p>	<p>panic attack and her dad had a go at her saying that's stupid, but she knows that it was just her anxiety and all that.</p> <p>Scary yeh</p> <p>So I think that her and my other friend understand, and not everybody understands, and it's okay and all that, they're comfortable with it.</p>	<p>Her friends also suffer from anxiety, share / understand each other's' difficulties, <u>depression and anxiety are part of her everyday normality</u></p>
<p>Reciprocal support from friends</p>	<p>217 218 219 220</p>	<p>What are Miss J's opinions?</p> <p>Well, she tells me that I'm a hard worker and all that, she says that I'll get far, but erm, well between Mr W and all that, and Miss J and all that, they think that I'm a pessimist and all that.</p>	<p>Her friends understand her difficulties / accept her AS diagnosis</p>
<p>She is a hard worker Teachers perceive her as pessimistic</p>	<p>221 222 223 224</p>	<p>They think that you're a pessimist?</p> <p>Yeh (tone lightens), cause I always say that I'm not doing enough and they say that I'm doing more than enough and all that.</p>	<p>Members of staff focus on her academic progress / attitude to learning, they have picked up on her negativity and challenge her</p>
<p>She is a perfectionist</p>	<p>225 226 227 228 229</p>	<p>I think maybe more of a perfectionist maybe! Okay, let me just ask you this question, I think you've kind of answered it but, do you thinking having this AS diagnosis has made a difference to the way that you feel about yourself? Can you explain a bit of that to me?</p>	<p>She is hard on herself</p>
<p>She sees herself as different from everyone else Tries to mask AS AS is a definite thing</p>	<p>230 231 232 233 234 235 236 237 238 239 240 241</p>	<p>Yeh, it does make a difference to me and all that, cause I know that if I want to fit in, try to act like I haven't got it, it's like everyone else and all that when they definitely haven't got it, but erm, then when I talk and all that, sometimes I get all weird looks and obviously that tells me that they probably don't understand, that's somethings not right and all that, and erm (hesitates).</p> <p>So it sounds as if it's difficulties, maybe, having conversations?</p> <p>Yeh (hesitates)</p> <p>What do you think the other difficulties are that come with</p>	<p>Seeing herself as different to everyone else. Mentions difficulties with social communication, <u>does she really experience difficulties when having conversations or is she making presumptions?</u></p>

<p>She talks about difficulties with conversations</p> <p>AS has caused K and her brother depression</p> <p>They hate everything about AS</p> <p>She and her brother hate AS, it has caused depression, hopelessness and sadness</p> <p>She has identified a university and two possible courses</p> <p>She has identified a job that she would like to do</p>	<p>242 this?</p> <p>243 Well, it's not, so like, so bad that I have to go to the doctor</p> <p>244 and all that, but me and my older brother we do have like</p> <p>245 depression and all that from this.</p> <p>246 Okay</p> <p>247 Cause we hate everything and all that about it.</p> <p>248 You're doing well, just a couple more questions. I don't know</p> <p>249 if you have an opinion on this but do you think for boys who</p> <p>250 have an AS diagnosis, it's different for them than it is for</p> <p>251 girls?</p> <p>252 Well, for my older brother and all that, cause we've both got</p> <p>253 depression, we both hate it, we've both feel that we have no</p> <p>254 hope for the future and all that, erm, well, lots of the time I do</p> <p>255 get upset a lot but then, it's a similar sort of thing.</p> <p>256 I suppose the experience of being and teenager and going to</p> <p>257 secondary school is different for boys and girls anyway. So, it</p> <p>258 sounds like you do have some thoughts about the future, so</p> <p>259 what are your plans and ambitions?</p> <p>260 Well, hopefully I'll get into 6th form and all that, erm I'd really</p> <p>261 like to go to X University. Well I've got two choices and all</p> <p>262 that, like, I like the job of the forensic anthropologist, but erm,</p> <p>263 but that sort of interests me.</p> <p>264 Forensic anthropology, Is that about skeletons?</p> <p>265 Yeh (both laugh), and erm I'm interested in, I like fine art, I like</p> <p>266 art, art helps me when I get stressed and all that I draw in my</p> <p>267 book.</p> <p>268 Your book in school or your book at home?</p> <p>269 My book at home (laughs) in all my mocks I got a B in art so I</p> <p>270 know I'm doing well.</p> <p>Okay, so there's a couple of choices, have you been to</p>	<p>Says that AS has caused her to suffer from depression</p> <p>Hates AS diagnosis</p> <p>Repeats depression, hating AS, hopelessness</p> <p>Has definite plans for the future, post school, <u>no mention of AS stopping her</u></p>
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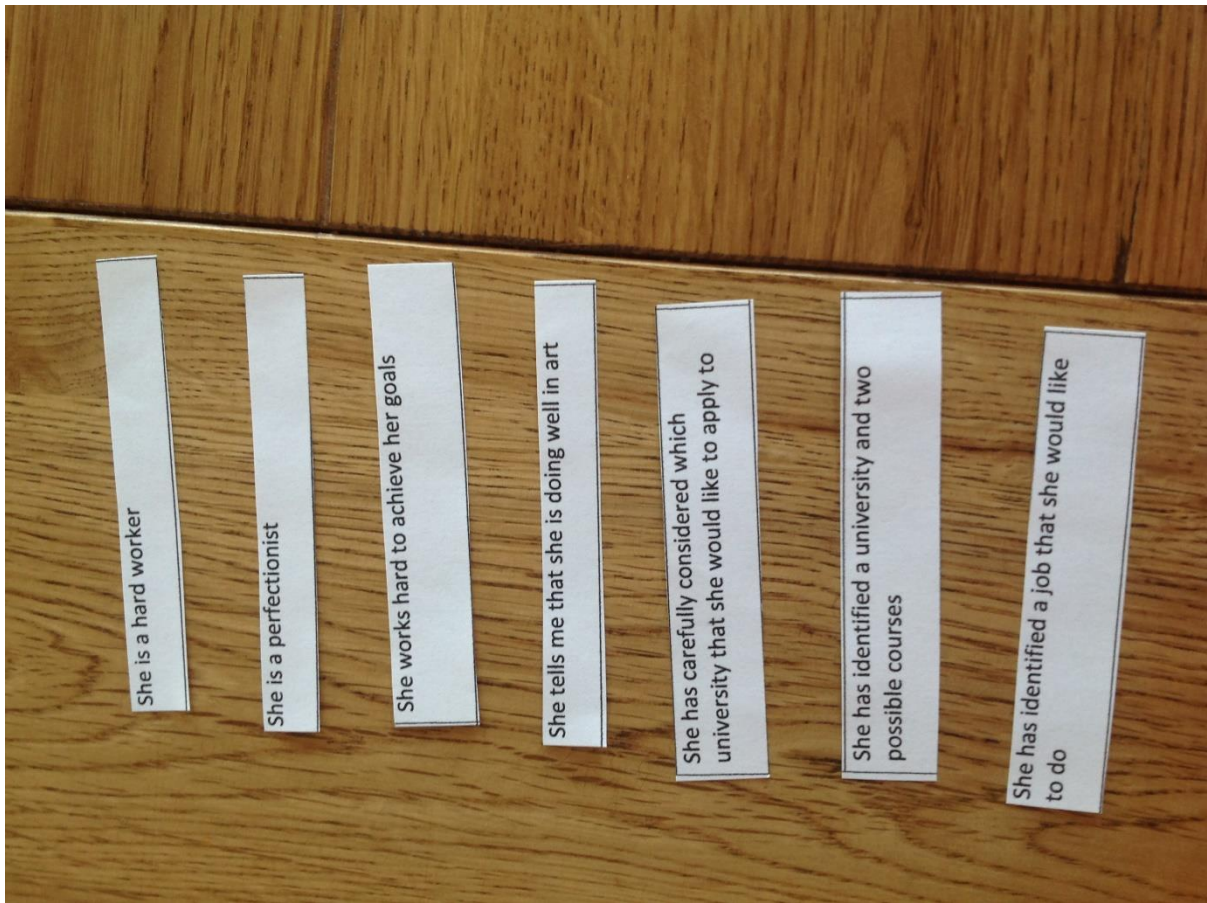
<p>She likes to draw when she is stressed She tells me that she is doing well in art</p> <p>She has carefully considered which university that she would like to apply to Walking in the countryside is important</p>	<p>271 272 273 274 275 276 277 278 279 280 281 282 283 284 285 286 287 289 290 291 292 293 294</p>	<p>Edinburgh before? Why Edinburgh? I've been once and all that, I don't know, I had the idea, like, to go to university in X, but that didn't have the course. When I spoke to other people they said education in Scotland is more better than in England sort of thing, so I thought that'll be a good idea. Also, because in Scotland, obviously it's a bit like X, but more like nice, for walks and all that, it's more outdoorsy sort of thing.</p> <p>Which comes back to what you said in the first place about what you like. Anything else for the future or is that the next step? That's the next step.</p> <p>Excellent. Okay, final question, is there anything that I've left out that you'd like to add? (Thinks) Not really.</p> <p>Okay, thank you</p> <p>()</p>	<p>Shares her good grade in art</p> <p>Has thought things through, gives reasons for her choices, outdoors is important</p>
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Appendix 9: Emergent themes for Kerry

She takes active steps to relax	Walking outdoors helps her to relax
She escapes into imaginative world by listening to music	Relies on others' descriptions of self
Key adults say that she is nice, kind cheerful and friendly	She works hard to achieve her goals
She struggles to name her strengths	She was around seven or eight when she found out about her autism diagnosis
She was not explicitly told about her autism diagnosis	Her autism diagnosis was discussed in problem contexts
She has been bullied at school	There is a struggle between not wanting help but knowing that she needs it
She has hated autism or autism diagnosis from the outset	She doesn't want to tell people about her autism diagnosis but feels that she has to
She either finds explaining autism difficult or wonders why she has an autism diagnosis	She views autism as her lack of understanding
She hates AS	Autism diagnosis is ruining her existence
She sees her autism diagnosis as stopping her from having a profession	She would want to keep her diagnosis secret from future employers
She associates AS with a perceived lack of capacity by others	Others treat her differently and unfairly
She worries about continuing to feeling awkward when she is older	She uses fantasy to escape from her reality
She does not want to know about autism because she does not want to have autism	She is not comfortable admitting that she has autism
She is ashamed of 'having' autism, it is something shameful	It makes her feel like a lesser person when she compares herself to people who are 'normal'
She worries that she will get conversations 'wrong'	She feels that she can't act as if she doesn't have autism because she gets conversations 'wrong'
She has been able to become more open with friends over time	Friends and teachers understand
She does not want other people to know	She was embarrassed when she got an award

	from LS
She admits that she needs additional pastoral support in school	ADHD is a more acceptable label than AS
Her older brother suffers from social anxiety and doesn't work	Fears that autism diagnosis will make her younger brother unhappy
Her younger brother will need to take on a disabled persona	She has tried to act as if she doesn't have AS
She found secondary school hard and started self-harming	She sometimes wants to feel pain
She talks about compulsions	She feels down most of the time
She feels that she won't succeed when she is older	AS is blamed for future failings
She feels that other students hate her, she feels rejected	Her friends also experience anxiety and a lack of understanding
Reciprocal support from friends	She is a hard worker
Teachers perceive her as pessimistic	She is a perfectionist
She sees herself as different from everyone else	Tries to mask AS AS is a definite thing
She talks about difficulties with conversations	AS has caused K and her brother depression
They hate everything about AS	She and her brother hate AS, it has caused depression, hopelessness and sadness
She has identified a university and two possible courses	She has identified a job that she would like to do
She likes to draw when she is stressed	She tells me that she is doing well in art
She has carefully considered which university that she would like to apply to	Walking in the countryside is important

Appendix: 10: Example of a photograph showing how connections across emergent themes were organised for Kerry



Appendix 11: Emergent themes grouped into themes for Kerry

Theme	Emergent themes
<p>She copes with stress by taking active steps to relax and escape via fantasy and imagination</p>	<p>She escapes into an imaginative world by listening to music</p> <p>She likes to draw when she is stressed</p> <p>She takes active steps to relax</p> <p>Walking outdoors helps her to relax</p> <p>She uses fantasy to help her to escape from her reality</p> <p>Walking in the countryside is important to her</p>
<p>She seems to have a poor sense of self – she struggles to name her strengths and relays what other people have said about her</p>	<p>She struggles to name her strengths</p> <p>She relies on others’ descriptions of herself</p>
<p>She found out about her autism diagnosis by overhearing her mum speaking on the phone – autism is associated with problems</p>	<p>She was around seven or eight when she found out about her autism diagnosis</p> <p>She was not explicitly told about her autism diagnosis</p> <p>Her autism diagnosis was discussed in problem contexts</p>
<p>To her, autism is poor communication – she gets conversations ‘wrong’</p>	<p>She views autism as a lack of understanding on her part</p> <p>She worries that she will get conversations wrong</p> <p>She talks about difficulties with conversations</p> <p>She worries about continuing to feel ‘awkward’ when she is older</p> <p>She feels that she can’t act as if she doesn’t have autism because she gets conversations wrong</p>
<p>She hates AS – she feels that AS has caused depression, hopelessness and sadness for her and her two brothers</p>	<p>AS is a definite thing – you either have it or you don’t</p> <p>She hates AS</p> <p>She has hated AS from the outset</p>

	<p>ADHD is a more acceptable label than AS</p> <p>They hate everything about AS</p> <p>She and her brother hate AS, it has caused depression, hopelessness and sadness</p> <p>Her older brother suffers from social anxiety and doesn't work</p> <p>She has fears that autism diagnosis will make her younger brother unhappy</p> <p>Autism diagnosis is ruining her existence</p> <p>She does not want to know about autism because she does not want to have autism</p>
<p>She feels shame and embarrassment at being perceived as different – she tries to act 'normal'</p>	<p>She sees herself as different to everyone else</p> <p>It makes her feel like a lesser person when she compares herself to people who are normal</p> <p>She associates AS with a perceived lack of capacity by others</p> <p>Her younger brother will need to accept a disabled persona when he is older</p> <p>She is ashamed of 'having' autism</p> <p>She does not want other people to know</p> <p>She was embarrassed when she got an award from LA</p> <p>She has tried to act as if she doesn't have AS</p> <p>She tries to mask AS</p> <p>She is not comfortable admitting that she has AS</p> <p>She doesn't want to tell people about her autism diagnosis but feels that she has to</p>
<p>She feels depressed and self-harms</p>	<p>She started self-harming in secondary school</p>

	<p>She sometimes wants to feel pain</p> <p>Teachers perceive her as pessimistic</p> <p>She talks about compulsions</p> <p>AS has caused Kerry and her brother depression</p> <p>She feels down most of the time</p>
<p>She values reciprocal support from two trusted friends – they also suffer from anxiety</p>	<p>Key adults say that she is nice, kind, cheerful and friendly</p> <p>Friends and teachers understand</p> <p>Reciprocal support from friends</p> <p>She has been able to become more open with friends over time</p> <p>Her friends also experience anxiety and a lack of understanding</p>
<p>She feels a strong sense of rejection by her wider peer group</p>	<p>She found secondary school hard</p> <p>She has been bullied at secondary school</p> <p>She feels that other students hate her, she feels rejected</p> <p>Others treat her differently and unfairly</p>
<p>She doesn't want to be seen to be receiving pastoral support in school but acknowledges that she needs support</p>	<p>There is a struggle between not wanting help but knowing that she needs it</p> <p>She admits that she needs additional pastoral support in school</p>
<p>She has high aspirations for the future – she wants to go to a Russell Group university</p>	<p>She is a hard worker</p> <p>She is a perfectionist</p> <p>She works hard to achieve her goals</p> <p>She tells me that she is doing well in art</p>

	<p>She has carefully considered which university she wants to apply to</p> <p>She has identified a university and two possible courses</p> <p>She has identified a job that she would like to do</p>
<p>She worries that autism will hold her back in future – she fears discrimination by future employers and failure to fulfil her goals</p>	<p>She would want to keep her AS diagnosis secret from future employers</p> <p>She sees her autism diagnosis as stopping her from having a profession</p> <p>She feels that she won't succeed when she is older</p> <p>AS is blamed for possible future failings</p>

Appendix 12: Superordinate and subordinate themes for Kerry

Superordinate themes	Themes
She has a poor sense of self	She seems to have a poor sense of self – she struggles to name her strengths and relays what other people have said about her
Autism is poor communication	To her, autism is poor communication – she gets conversations ‘wrong’
She hates autism – autism has led to depression and self-harming	<p>She found out about her autism diagnosis by overhearing her mum speaking on the phone – autism is associated with problems</p> <p>She hates AS – she feels that AS has caused depression, hopelessness and sadness for her and her two brothers</p> <p>She feels shame and embarrassment at being perceived as different – she tries to act ‘normal’</p> <p>She feels depressed and self-harms</p>

	<p>Her brothers are both diagnosed with autism – her older brother is anxious and depressed</p> <p>She is worried about discrimination by potential employers</p>
<p>She uses fantasy and imagination to escape from reality</p>	<p>She copes with stress by taking active steps to relax and escape via fantasy and imagination</p>
<p>She has two trusted friends who also suffer from anxiety</p>	<p>She values reciprocal support from two trusted friends – they also suffer from anxiety</p>
<p>She feels rejected by her wider peer group at school</p>	<p>She feels a strong sense of rejection by her wider peer group</p>

<p>She has come to accept that she needs pastoral support in school</p>	<p>She doesn't want to be seen to be receiving pastoral support in school but acknowledges that she needs support</p>
<p>She has high aspirations for the future</p>	<p>She has high aspirations for the future – she wants to go to a Russel Group university to study anthropology</p>

Appendix 13: Superordinate Themes for Each Participant linking to Superordinate Themes for the Group

Superordinate themes for Kerry linking to Superordinate Themes for the Group	Autism is difficulties with conversations	She hates autism; autism has led to depression and self-harming	She has a poor sense of self	She uses fantasy and imagination to escape from reality	Her two brothers are also diagnosed with autism	She has two trusted friends who also suffer from anxiety	She feels rejected by her wider peer group at school	She has come to accept that she needs pastoral support in school	She has high aspirations for the future but fears discrimination
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Superordinate themes for Micha linking to Superordinate Themes for the Group	Autism is learning difficulties, shyness and hypersensitivity	She accepts autism and being different	Her mum is a supportive advocate	She is friendly but has experienced rejection and feels isolated out of school	She uses strategies to help her to cope	She is worried about the future
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Superordinate themes for Melody linking to Superordinate Themes for the Group	Autism is a developmental difference	She rejects the autism label as she doesn't see herself as different	She has a strong sense of self	Her parents are supportive	She is resentful of different treatment at school	She has high aspirations for the future but fears discrimination
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Superordinate	Autism is social	She has	She has grown in	Her autism is	Her friends are	She feels that	She has high
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themes for Keira linking to Superordinate Themes for the Group	difficulties and a dislike of change, but also creativity	struggled to accept AS	confidence over time	central to her family, especially her mother	boys	she has little in common with female peers	aspirations for the future
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Superordinate themes for Maddy linking to Superordinate Themes for the Group	She associates autism with unusual behaviours and friendship issues	She has questioned her AS diagnosis	She is suffering from low self-esteem and anxiety	Family is her refuge	Her mother wants her to accept her AS diagnosis	She has moved friendship groups several times in secondary school	She has distanced herself from the wider peer group	Subject teachers don't understand but support staff do	She has high aspirations for the future
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Superordinate themes for Ellie linking to Superordinate Themes for the Group	Autism is struggling with social interaction, conversations, concentration and time management	She has found her AS diagnosis extremely helpful	She is really 'into' autism	She is self-accepting and accomplished	Her mother has been influential, her sister may also be autistic	Her best friend from university also has an AS diagnosis	Peers at school regarded her as odd and she was isolated. She experienced rejection by friends	She found the transition to university challenging She has realistic plans for her future
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Appendix 14: Reflections on each interview, comments on participants' communitive style and summative interpretations

Kerry

Kerry was my first participant and I felt both apprehensive and excited before the interview. I interviewed Kerry in an office within the Learning Support Department. It was evident from the outset that she hated autism. She was very emotive at times, almost on the verge of tears, and this made me feel guilty for asking her to talk about her life and things that were difficult for her. When she was talking about things that were difficult, I made a conscious effort not to move into counselling mode. I was surprised that, given her hatred of autism, that she did not question her diagnosis. When she talked about the future her demeanour changed, and she started to smile and became animated, and that made me feel more comfortable. During this interview I felt affronted on Kerry's behalf, as I did not feel that autism had been a helpful label for her in any way. In fact, I felt that her autism diagnosis had impacted negatively on her sense of self.

After I stopped recording, I asked Kerry if she would like any feedback in September, and she declined saying that she hoped that things would be different by then. I took that to mean that she viewed 6th form as a fresh start. I also asked her how she felt being interviewed. I was surprised and relieved when she said that she had found it helpful to speak to someone about her feelings. I did say to Kerry that I was concerned that she felt so upset that she needed to self-harm and said that I would ask her LSA to check that she was okay, she seemed to be fine with this. Although Kerry barely mentioned her mother during the interview, when I asked her about her plans for the summer holiday, she revealed a tension between herself and her mother. Kerry wanted to apply for part time jobs, and it seemed that her mum had suggested that she was unlikely to be offered a job. Kerry was upset about her mother's response, but perhaps her mother was being protective by preparing Kerry for the possibility of failing to secure a job.

Throughout the interview, Kerry uses the phrase 'and all that', there is an assumption that I know what 'all that' is. She struggles to, or is reluctant, to articulate a fuller description. Perhaps she uses 'and all that' to fill in for what she cannot or does not want to say. There is also a presumption that I can make sense of what she is saying without a full explanation, for example,

'them' for employers and 'people who know' for other students. There are multiple 'erms' throughout her account, this indicates contemplation and / or taking time to find an appropriate word. She also uses 'like' whilst searching for an appropriate word. Kerry was emotive throughout the interview and this may account for hesitancy in expressing her views.

Kerry was able to organise and share her reflections coherently. At times she spoke at length, for example, when she was justifying her feelings about autism. Her account is coherent and well argued, with one point leading to another. She uses vocabulary for effect, for example, 'Well personally'. When she talks about her peer group rejecting her, she uses the powerful example of a gunman on the prowl and a lock down in the school to emphasise her point. I wonder if this example is something that she has considered prior to the interview.

Although Kerry says she is doing well at school, and has ambitions for the future, she also speaks of depression and self-harming. She does not question the validity of her diagnosis but says that she does not understand autism and that she does not want to 'have' autism. She has low self-esteem and worries about how she is viewed by others. She is struggling emotionally. She speaks to her friends and support staff at school but her home life seems to have challenges. Autism diagnosis has not been helpful for Kerry.

Micha

I had not visited Micha's school prior to the interview, and had only been in contact with the school Special Educational Needs Coordinator via email, so I was both curious and slightly apprehensive. When I was introduced to Micha it was evident that she was very nervous, and I was worried that she might struggle to answer my questions, or even withdraw her participation. She asked the SENCo to stay in the room during the interview, and Mrs M sat unobtrusively in the corner of the room getting on with her work. I asked Micha if she wanted any feedback once I had transcribed the interview, and she said no. When recording my reflections, following the interview, I noted that Micha was very personable and had a good sense of humour. I enjoyed meeting Micha as she had a very fresh perspective.

Like Kerry, there was some hesitation in Micha's response to questions, for example, use of 'er' before answering. I noted at the beginning of the interview that she sometimes repeated my phrases in her responses. Throughout the interview she answered questions in a rounded way, for example, naming activities that she was, and was not, interested in. When she was not sure about the question she checked, for example, 'How I found out I had it or something?' As the interview continued our communication became increasingly reciprocal, for example, we chatted about a TV programme which we had both watched. When talking about her hypersensitivity, she offered examples without prompting. She used the term 'tsunami' to indicate stress and panic, I wondered what had prompted her to start using this analogy, had she heard another young person use it? Towards the end of the interview, she asked me if I agreed with something she said, hence for Micha perhaps the interview felt informal and chat like.

Micha knows that she is different and she accepts autism as an explanation. Like Kerry, she says that she does not understand autism. She is socially motivated but has found herself to be isolated out of school. Her family are supportive, especially her mother, who acts as an advocate. Unlike the other participants, who seem to be doing well academically and are focused on careers based on their strengths and interests, Micha is worried and uncertain about the future.

Melody

This was my third interview, and I was beginning to feel comfortable in the role of interviewer. My questions seemed to be working well in terms of eliciting rich data. When I met Melody, I was struck by her outward confidence, especially as she was my youngest participant. She was insightful, and was able to reflect on her experiences. Although I was actively trying to bracket off my thoughts about the two previous interviews it was apparent that Melody offered a much more critical viewpoint than Kerry and Micha. I asked Melody if she would like any feedback on her interview but she politely declined.

Despite the quality of her responses Melody's language was somewhat unclear, for example, she mixed up tenses, missed words out and didn't always finish words and sentences. I found this interview the most difficult to transcribe. Like other participants Melody used 'like' and 'erm' whilst organising her thoughts, and finding appropriate words. She also checked if she had understood the question correctly, for example, 'Okay, how I found out?' I noted that she used imitation to add interest to her narrative, for example, to emphasise the uselessness of advisory teachers.

Melody was the only participant who challenged the validity of her autism diagnosis. She accepts that she has experienced difficulties, but says that she is no longer different to her peers and does not want to be treated differently by adults in school. She is doing well academically, she has supportive parents, and she belongs to a long term friendship group of 'normal' girls. She strives hard to minimise difference and maintain a strong sense of self.

Keira

I recall feeling nervous whilst travelling to the school to interview Keira. I hadn't visited this school prior to the interview. As with the previous interviews, once the formalities were out of the way and the interview started, I began to relax. During this interview I noticed that I was struggling to bracket off my own negative feelings towards diagnosis. Perhaps I had been influenced by Melody's rejection of her autism diagnosis, and perhaps because, in this situation, Keira had no obvious difficulties. Keira also declined my offer of feedback on her interview, as she was leaving school to attend college, and she viewed this as a fresh start.

Keira was a fluent communicator, although there are lots of 'erm' in her transcript. She also uses the phrase 'kinda' when she is not in total agreement. She offered detailed answers and expressed her opinions. From the outset she made jokes and used irony, for example, saying 'I'm a Marvel superhero person' whilst laughing. Like the other participants, she asked for clarity if she didn't understand a question, for example, 'What do you mean by . . . ?'

Keira talks of social difficulties when she was younger. Although she isolated herself in the Learning Support Department (LSD) in Key Stage 3, she tried to hang around with the girls in her year group in year 10, but this did not work out, so she returned to the LSD at social times. Her friendships are with boys, and now that she has left school she can openly enjoy these relationships. Keira's mother wants her and her younger brother to learn to embrace autism but I felt that Keira was not really 'buying in' to her autism diagnosis. She is optimistic about the future.

Maddy

I interviewed Maddy at her home, as she had finished her GCSE exams and was no longer attending school. Interviewing a participant in their home made me nervous, as I felt that I was imposing on Maddy and her family. Maddy asked if her mother could be present, and it was apparent that her mum wanted to stay. Her mother was quiet to begin with, but as the interview progressed she began to interject. It seemed that she wanted to be heard. As we were discussing Maddy's difficulties, I was worried that her mother might say something that would upset her but they seemed very open and comfortable with each other, so a three way conversation occurred. Maddy was very reflective and insightful, and I enjoyed speaking with her. She was able to answer all my questions in depth, and was able to pursue topics that she wanted to focus upon. She did not want any feedback on the interview at a later date, as she wanted to focus upon a positive start to 6th form.

Throughout the interview, Maddy was chatty and forthcoming. She was an able communicator who was able to summarise her views. When she was talking about her friendships / peer relationships at primary and secondary school she revealed a good memory for names and events. In regard to her communicative style there was little to comment upon.

Like Keira, Maddy revealed a dissonance between herself and autism diagnosis. At times it seemed that she was only accepting for her parents' sake. Maddy's mother regarded her as different, and although they seemed attuned to each other, I wondered if parental attitudes towards her differences had impacted on her self-esteem. Although Maddy reports some positive friendships, and close relationships with female relatives, her story is one of continual rejection and isolation in regard to peer relationships. She feels that she has not received the support and understanding that she needed at school.

Ellie

I also interviewed Ellie in her own home. Ellie's mother was at home but Ellie preferred to speak to me alone. Like Maddy, she was a very reflective and insightful young person, and I enjoyed speaking with her. She had a lot to say, and as the interview progressed I became aware that her views were different from that of my previous participants, perhaps because she had actively pursued autism diagnosis and was in the process of transitioning to adulthood. At the end of this interview, I reflected how much my confidence as an interviewer had grown.

Like Keira and Maddy, Ellie was an able communicator, for example, she used a wide ranging vocabulary and dramatic analogy. She asked for clarity when she did not understand a question, for example, "I'm not quite sure what you're asking?" She admitted that she sometimes 'goes off on tangents'. I noted that Ellie was a very considerate interviewee and she offered to send me a copy of her diagnostic letter. She was also cautious and measured when offering an opinion. Ellie said that she would be interested in reading my thesis when it was completed.

Ellie reflects that she found aspects of school difficult: socialising and lacking concentration, but like Keira she got on well with her teachers. She found it difficult to cope with independent living, and managing her work load, when she left school and went to university. Like Maddy, her mother prompted the diagnostic process. Ellie has totally accepted her autism diagnosis and says that it has offered her validity as a person. Ellie accepts that she is intelligent, and she enjoys learning about autism, but she does not view autism diagnosis with any criticality. Her parents are supportive, and have been accepting of her with or without autism diagnosis. She has a high level of self-awareness and is realistic about her future.