An in-depth exploration into secondary school pupils' experiences of having autism spectrum disorder

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A thesis submitted for the degree of Doctorate in Child, Educational and Community Psychology

The Tavistock and Portman NHS Foundation Trust

The University of Essex

May 2019

Abstract

The experiences of young people (YP) with diagnoses of autism spectrum disorder (ASD) are under-represented, despite legislation placing greater emphasis on pupil voice. Whilst there is a large body of research into professional and parental experiences of children and young people (CYP) with ASD, there is a scarcity of research exploring what it means for YP to live with an ASD diagnosis. The research presented here is an in-depth exploration into YP's experiences of having a diagnosis of ASD.

The Grid Elaboration Method (GEM) and semi-structured interviews were carried out with four participants (aged eleven to sixteen years old) across three mainstream secondary schools to elicit their lived experiences of having a diagnosis of ASD. All participants had diagnoses of ASD.

The data was then analysed using Interpretative Phenomenological Analysis (IPA) in an attempt to understand the participants' experiences. The analysis revealed five overarching themes – 'Impact of ASD on everyday life', 'Questioning identity', 'Relating to others', 'Emotional response' and 'Where from here?' The implications of the findings are discussed in relation to the original research question, existing literature and theory, and Educational Psychology practice.

Acknowledgements

I would like to thank my family, friends, OB and supervisors. Thank you for your invaluable support, be it through listening to me, understanding me, encouraging me, challenging me and/or feeding me. Most of all, thank you for believing in me.

Thank you to the SENCos and other school staff members who helped to ensure that the research could take place in your schools. You made the organisation of the interviews so much easier and smoother, which I am immensely grateful for.

Thank you to the parents of the young people who took the time to listen to my research project, to meet with me or to speak on the phone. Of course, without your time and consent, this research would not have been possible.

Lastly and most importantly, thank you to the four young people who I interviewed. I absolutely loved meeting every one of you and listening to your perspectives. You were brave, reflective and worked hard. I hope you found the interviews meaningful in some way. Without you, this research would most definitely not have been possible. I hope you keep sharing your thoughts, feelings and experiences and find a way to be your true selves.

Confidentiality

This thesis does not contain any personally identifiable information. Pseudonyms have been used throughout in order to protect the identities of participants, parents, school staff and the Local Authority (LA) in which the research took place.

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Chapter One – Introduction

1.1 Background

More than 1 in 100 people in the United Kingdom (UK) have a diagnosis of ASD (National Autistic Society (NAS), 2016a). Outcomes for YP with ASD can be poor, including social isolation, bullying, educational exclusion, unemployment, mental health difficulties and a struggle to live independently (Reid, 2011; Rosenblatt, 2008; NAS, 2016b; Ambitious about Autism, 2017; Smith, Greenberg & Mailick 2012). In order to help prevent the occurrence of such outcomes in later life, effective support needs to be provided to YP during their school years (Symes & Humphrey, 2011). Educational Psychologists (EPs) are well-placed to equip school staff and parents with the skills and knowledge required to support the YP (Squires et al., 2007). An integral part of this support involves listening to the perspectives of the YP with whom the diagnosis is attached (Harding & Atkinson, 2009).

In addition, there is the contentious issue around whether a label of ASD is helpful or a hindrance to CYP. This debate often evokes a polarised position (Ravet, 2011). Crucially, the perspectives of YP with the diagnosis need to be elicited in order to understand what meaning the diagnosis holds for them and to enable the development of self-identity. Exploration of YP's experiences of having an ASD diagnosis can support professionals to understand the YP more effectively, leading to better life outcomes (Gilling, 2012). Thus, this research sets out to understand YP's experiences of having a diagnosis of ASD in order to provide effective support and outcomes.

1.2 Terminology

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) outlines ASD as a life-long neurodevelopmental condition affecting social communication, social interaction, interests and behaviours (American Psychiatric Association (APA), 2013). As a spectrum condition, people are affected in different ways. The diagnosis covers a range of autistic presentations, including those with co-morbid learning difficulties (LDs), those without LDs and those with high IQs. Further, some people with ASD may live fully-independent lives, whilst others may need high levels of daily support (NHS, 2019).

The cause of ASD is not known, yet there is a large body of research suggesting that there is a genetic component involved (Yates, 2012). ASD is not an illness and it cannot be cured (NHS, 2019).

ASD may also be referred to as autism spectrum condition (ASC), Asperger's Syndrome, Pervasive Developmental Disorder, high-functioning autism, low-functioning autism and autism.

In particular, there are distinct connotations and implications of the terms ASD and ASC. A 'disorder' is defined as a problem or illness which affects someone's mind or body or as a lack of order; disarray; or confusion (Collins Dictionary, 2019). Whereas, 'condition' is defined as the particular state that something or someone is in (Cambridge Dictionary, 2019). With these different definitions in mind, the term ASD can be viewed as stigmatising and pejorative, whilst ASC may be seen as more respectful and encapsulate difference rather than disorder (Baron-Cohen, 2012). On the other hand, some argue a preference for the term ASD as it implies severity and difficulty, enabling access to services (Baron-Cohen, 2012). However, research and the neurodiversity movement has illustrated that autism is a difference rather than a dysfunction, which therefore leaves a question over the relevance of ASD as outlined in the DSM-5 (Baron-Cohen, 2012). Further, it is important to recognise that the DSM-5 has been heavily critiqued for its medicalised approach and, subsequently, is not universally accepted (Pickersgill, 2014).

Despite this, in accordance with the most recent terminology used in the DSM-5 (2013) and for consistency throughout this thesis, the condition will be referred to as ASD.

Different definitions of ASD

Although the above definition of ASD is outlined in the DSM-5 (2013), there has been extensive research into different definitions of the condition (Volkmar, State & Kiln, 2009). Definitions of ASD may be determined by the models it is approached from.

A medical model may define ASD according to the DSM-5 (2013) criteria. Here, ASD is typically considered as a within-person disability, whereby difficulties are located in the individual for who the label is attached (Gilling, 2012). For the purposes of diagnostic criteria, individuality and uniqueness may be lost (Mackay & Parry, 2015). Research conducted from a medical approach may explore finding a cure of ASD (Larsen, 2018).

Alternatively, rather than seeing ASD as a universal truth, a social model may understand the condition as a label which has been socially constructed by professionals for causation and treatment purposes (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). More recently, a neurodiverse paradigm of ASD has evolved from the social model, whereby ASD is recognised as a form of cognitive difference. Rather than promoting an idea that there is a typical or atypical presentation, the neurodiversity movement advocates that everyone's brains are wired *differently* and that these differences are invaluable to society because of their inherent varied strengths (Larsen, 2018; Silberman, 2015). Rather than focusing on finding a cure, the social model strives for society to accommodate differences such as those in individuals with ASD (Larsen, 2018).

The neurodiversity movement argues that the medical model depicts ASD as a deficit-based condition, dominated by language such as 'impairment' and 'abnormality' (Waltz, 2005). Language such as this is seen to be pejorative, leading to attempts to change behaviour to fit in with society (Milton and Bracher, 2013; Kitchin, 2000). This view is strongly opposed by the neurodiversity movement (Kitchin, 2000). In a report compiled by Beardon and Edmonds (2007), this idea is captured in the following participant's response regarding how people with ASD should be supported:

> 'I don't have a problem: I'm me. It's society that has no idea about acceptance, compassion or freedom to choose how I want to live' (p. 332).

Further, rather than focusing on the difficulties associated with ASD, a neurodiversity lens recognises the strengths, such as memory, attention to detail, analytical skills and dedication to a subject (Van Hees, Moyson, and Roeyers, 2015).

This research will approach ASD as defined by the DSM-5 (2013), since this is widely used on a national and local level. Crucially, however, it is acknowledged that there are a number of ways of defining ASD, which are all considered valuable in light of this research.

1.3 National Context

1.3.1 Prevalence of ASD

Approximately 700, 000 people in the UK have a diagnosis of ASD (NAS, 2016a). The past forty years have seen a dramatic increase in the amount of children diagnosed with ASD nationally in the UK (Taylor et al., 1999; Baird et al., 2006; Baron-Cohen, 2008). Further, ASD is one of the most widely studied conditions within mental health fields (Matson & Kozlowski, 2011), highlighting the importance of research for CYP living with the diagnosis.

1.3.2 Diagnostic Process of ASD

In the UK, multi-disciplinary teams (MDTs) typically made up of a Paediatrician or Child Psychiatrist, Speech and Language Therapist, Occupational Therapist and a Clinical Psychologist or EP, will be involved in the assessment of ASD in children (NAS, 2018). Since the condition cannot be identified through biological markers, observations, interviews and clinical judgements are used in diagnostic processes (Filipek et al., 2000; Gray et al., 2008). There is variability across the UK in how ASD is diagnosed by professionals and the type of post-diagnostic support provided (Rogers, Goddard, Hill, Henry & Crane, 2016). However, all diagnosticians should follow NICE Clinical Guidelines (NAS, 2016a).

1.3.2 The Labelling Debate

There is an ongoing debate within Educational Psychology practice, as well as the wider health care profession, about medical labelling and the utility of such for CYP with ASD (Calzada, Pistrang & Mandy, 2011). Often these differences in opinion are polarised, whereby labelling either leads to stigmatisation and marginalisation or it results in better understanding and inclusivity (Ravet, 2011).

On the one hand, it is extensively argued that medical labels such as ASD are social constructions, rather than representative of any universal or objective truth (Ravet, 2011). Ravet (2011) further outlines this perspective regarding labels as follows:

> ...'autism' are...social constructions based on a very particular set of taken-for-granted assumptions about 'normality' (p.669).

Subsequently, CYP with an ASD diagnosis are positioned as having a deficit or impairment, leading to negative assumptions and lowered expectations by others (Gillman, Heyman, and Swain 2000).

By way of contrast, it has been well-documented that the diagnosis of ASD is immensely helpful for CYP with the condition and for supporting adults. Knowledge of the diagnosis supports CYP, parents and teachers to understand the condition and to learn how to manage it effectively (Jones, Quigney & Huws, 2003).

Whether a label is deemed to be useful or not needs to be carefully considered from the perspectives of parents, teachers and, most importantly, from the YP with the diagnosis (Lauchlan & Boyle, 2007). The main arguments for and against the utility of having a diagnosis are elaborated on as follows.

(i) Access to resources vs. ineffective interventions

Having a diagnosis can often lead to resources and funding for YP with whom the diagnosis is attached (Gillman et al., 2000; Lauchlan & Boyle, 2007). It is argued that these resources would not be available if there was no diagnosis (Sutcliffe & Simons, 1993). However, access to resources does not necessarily mean effective support for YP. Whilst a label can provide context around a child's difficulties, it does not ensue solutions (Ogilvy, 1994). As such, labels can support teacher practice through the application of generalised strategies recommended for that particular condition. Yet, the strategies may not be suitable for all individuals, meaning that more personalised approaches may be required. Therefore, whilst acquisition of a label may be regarded as helpful in providing YP with additional support, in reality, the value of a label is questionable where support is not well-planned and is not delivered in an individualised way (Lauchlan & Boyle, 2007).

(ii) Increased understanding vs. stigmatisation

Labels lead to increased awareness and the promotion of understanding of YP's difficulties (Gross, 1994). Labels can provide context to difficulties and explanations to CYP and parents about their differences (Severs, 2017). Dissemination of knowledge about a condition to peers of YP with the label can lead to more effective inclusivity for children with SEN in mainstream settings (Gus, 2000). Lauchlan and Boyle (2007) highlighted that labels provide comfort to CYP and their families, since the anxiety of the unknown is alleviated and an explanation of difficulties is provided. Further, in a book written by a teenager with dyspraxia, the young person expressed the relief that she felt from learning about her diagnosis, as she had learnt that there were reasons for her difficulties. Whilst advising YP to use the label, she also recommended for the YP not to be defined by it, since this could create an over-reliance on their condition (Biggs, 2014).

On the contrary to enhanced understanding, it is argued that a label can lead to stigmatisation. Often labels remain with a person for life, as is the case for ASD. Therefore, the stigmatised feelings associated with the label may also be life-long. Despite YP achieving successes, the implications of having a label may be that the associated negative connotations remain at the forefront and, subsequently, become internalised (Haywood, 1997). In this sense, the label can lead to a within-child deficit approach. Rather than exploring environmental factors which contribute to a child's presentation, thinking can be reduced to characteristics being simple due to the given condition. Such an approach can lead to lowered expectations towards the CYP (Lauchlan & Boyle, 2007). Stigmatisation of a label includes bullying and exclusion, often leading YP to conceal their diagnosis (Lauchlan & Boyle, 2007; Sutcliffe & Simons, 1993; Gillman et al., 2000). To protect against stigmatisation, legislation prohibits the discrimination against any individual on the basis of disability (Department for Education (DfE), 2015).

However, it is also argued that a label does not cause stigmatisation, but rather that stigmatisation exists prior to diagnosis. Stigmatisation was seen to result from a child's difficulties, rather than the actual label for a child with dyslexia (Riddick, 2000). It is unknown whether this finding can be extended to ASD (Lauchlan & Boyle, 2007).

(iii) Shared language by professionals

Labels can facilitate a shared language for professionals where complex information can be managed in a condensed and quick way (Lauchlan & Boyle, 2007). On the other hand, such a shared language can lead to generalisations and oversimplification of individual strengths and needs. Additionally, the meaning of language between professionals may be ambiguous, where each person has a slightly different perspective. Discrepancies in opinions and subjectivity can lead to questionable diagnoses or even misdiagnoses (Lauchlan & Boyle, 2007).

Overall, labelling is a complex issue, which has rarely been researched directly with YP (Mogenson & Mason, 2015; Calzada et al., 2012). Mogenson and Mason (2015) highlighted that any existing research into the effects of labelling for YP has been based on the medical model, whereby researchers typically take up an expert position, resulting in YP being objects rather than subjects whose first-hand accounts are central to the findings. Related to this, researchers have also justified the need to understand YP's experiences of ASD due to the depiction of the condition from a within-person perspective, whereby individuality can become lost (Mackay & Parry, 2015).

1.4 Local Context

The LA in which the research took place is a deprived borough in Greater London. The LA is one of the most ethnically diverse in the country (Diversity in *** profile, 2018). In the LA, there are currently 638 CYP up to the age of 18 with diagnoses of ASD who attend mainstream schools.

There is a specialist outreach service for CYP with ASD within the LA. In order to receive involvement from the specialist team, CYP must have a diagnosis of ASD.

This exemplifies the idea that labels provide access to services (Gillman et al., 2000; Lauchlan & Boyle, 2007). The type of support the outreach service offers is wide-ranging, including training school staff, as well as disclosing diagnoses to CYP. The latter is typically delivered in a single session before transition to secondary school.

In recent years, there has been an upsurge of requests for CYP to be assessed for Education, Health and Care Plans (EHCPs), more often than not resulting in plans being granted. Subsequently, funding is becoming increasingly stretched, leading to limited availability and strict criteria for entry into specialist educational provision. This is particularly the case for CYP with ASD, in light of increasing diagnosis levels (Taylor et al., 1999; Baird et al., 2006; Baron-Cohen, 2008). In turn, there is more pressure on mainstream teachers to provide inclusive education for all CYP, regardless of individual need, which implicates EPs.

Further, in accordance with legislation emphasising the importance of the pupil voice (DfE, 2015), professionals within the LA are focused on understanding what CYP think in order to inform the development of services.

It has been documented that outcomes for YP with ASD can be poor, including social isolation, bullying, educational exclusion, unemployment, mental health difficulties and a struggle to live independently (Reid, 2011; Rosenblatt, 2008; NAS, 2016b; Ambitious about Autism, 2017; Smith, Greenberg & Mailick 2012). However, it is important to reiterate that there are people with ASD who consider the condition to be a positive identity, particularly within the neurodiversity movement (Kapp et al., 2013). There are certain areas of employment, such as tech companies, that specifically recruit people with ASD due to their cognitive skills being highly regarded, which can result in encouraging future outcomes (Felicetti, 2019).

Nevertheless, in light of the poor outcomes outlined combined with growing numbers of diagnoses and EHCP requests, complexity around labelling, varying definitions of ASD, increasing strain facing mainstream teaching staff and a professional duty to elicit the pupil voice, there is a need to better support YP with ASD through understanding their perspectives.

1.5 Personal Interest

ASD in YP became an interest of mine after working in various contexts with this group. As a Trainee EP, I have become increasingly aware of the stigma that is often attached to ASD and, more generally, to labels. Whilst diagnoses can offer some comfort and explanations for differences on one hand, they can also lead to a lack of curiosity and limited thinking by those around YP. Further, I have noticed the generalisations that are commonly used to talk about individuals with certain diagnoses. These generalisations can be damaging to YP when assumptions are made about what they can or cannot achieve, without considering individuality and uniqueness. I believe that every child and young person, regardless of diagnosis, should be thought about in his or her own right. This mindset can often be challenging for school staff to adopt, given large class sizes and academic pressures. EPs are well-placed to support school staff to consider an individual’s strengths and needs. In order to provide effective support for YP with ASD, I believe that an understanding of their thoughts, feelings and experiences is required.

1.6 Research Rationale

This section will outline the rationale for the research being carried out – exploration of YP's experiences of having a diagnosis of ASD. There are three main reasons drawn upon – the importance of eliciting the voice of CYP; the value of understanding oneself to develop a self-concept; and the need to improve outcomes for CYP with ASD.

(i) CYP's voice

As has been discussed, ASD is a highly prevalent area on a national and local level. The dramatic surge in diagnoses over the years has led to ASD becoming one of the most studied areas in mental health (Matson & Kozlowski, 2011). However, up until now, research has largely focused on the views of parents, siblings and professionals regarding CYP with ASD (DePape & Lindsay, 2016). There is a paucity of research exploring what the CYP themselves think about ASD and what sense they make of living with the diagnosis. Research that does exist focusing on the lived experience of having ASD has involved adults, rather than CYP (DePape & Lindsay, 2016). Further, Connor (2000) acknowledges the lack of the CYP's voice in research, while Jordan (2007) recognises the existing gap 'between the research and the researched' (p. 10).

There could be various reasons why there is a paucity of research exploring the lived experiences of CYP with ASD. It has been acknowledged that one reason could be due to the difficulties with communication and interaction that are largely inherent in ASD (Stevenson, Cornell & Hinchcliffe, 2016). There is thought to be minimal intrinsic motivation for CYP with ASD to socially interact with others and, in particular, with unfamiliar adults (Preece, 2002). Additionally, it could be difficult for CYP with ASD to understand the purpose of the interviewer, especially when research is exploratory. Participants may believe that there is a single correct answer, creating anxiety if they are unsure of the response (Menzies, Waller & Pain, 2011). Subsequently, it is much easier to elicit the voice of those around the CYP, such as parents, siblings and professionals. Further, challenges to interviewing CYP with ASD may be linked to difficulties at a cognitive level – cognitive or attention deficits can impact how able children can participate in interviews, leading to age of interviewees being a factor to consider (Scott, 2008). Overall, CYP with ASD are a hard to reach group, meaning that their voices are largely unheard (Begley, 2000; Davis, 2017; Curtis et al., 2004).

Whilst it is recognised that it is difficult to obtain firsthand accounts from CYP about living with ASD, this does not negate the need to do so (Winstone, Huntington, Goldsack, Kyrou & Millward, 2014). Increasingly, research has highlighted the importance of eliciting the voice of those people who live with the condition (Hurlbutt & Chalmers, 2002; Jones, Quigney & Huws, 2003). Further, elicitation of the voice of CYP is a step towards reducing the power imbalance that exists between adults and CYP (Billington, 2006). Harding and Atkinson (2009) recognise that involving CYP in decisions about them is instrumental in practice. Furthermore, the importance of qualitative research with CYP with ASD is highlighted by Daniel and Billingsley (2010) as follows:

> ...precisely this kind of research is important in giving these participants a voice and affording them the opportunity to understand their difficulties and

> strengths, as well as contribute to policy decisions that would otherwise be made on their behalf without taking their views into account (p. 193).

As well as widely documented research, Government legislation stipulates that CYP need to be actively involved in decisions concerning them and emphasises the importance of client-centred approaches to supporting CYP (Children & Families Act, 2014; DfE, 2015). As stated in Article 12 by the United Nations (1989) ‘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’ (p.5). The Special Educational Needs and Disability (SEND) Code of Practice (2015) specifies that professionals have a responsibility to regard:

- the views, wishes and feelings of the child or young person and their parents;
- the importance of the child or young person and their parents participating as fully as possible in decisions and being provided with the information and support necessary to enable participation in those decisions;
- the need to support the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood. (p. 19)

Therefore, professionals have both a legal obligation and an ethical responsibility to ascertain the views of CYP and to ensure that these views are regarded during decisions about the individuals. This idea is poignantly captured by Costley (2000):

> We would not think of constructing a case study without collecting the opinions of the adults involved in a situation, so why would we ignore the views of the consumers of education – the children? (p. 172)

(ii) Development of self-concept

Another important reason for conducting research into YP’s experiences of having a diagnosis of ASD is to enhance the development of their self-concept. Stevenson et al., (2016) suggest that YP need to understand themselves in order to acquire self-acceptance and, in turn, to develop a self-concept, self-esteem and cope with the differences that ASD can present. The researchers acknowledge that this understanding is especially important in adolescence, when YP may become increasingly aware of the discrepancies between themselves and their peers, as well as the bearing that their ASD could have on their futures. This is reiterated by Peeters (2002): ‘Knowing about your identity is a pre-requisite for everything else’, (as cited in Stevenson et al., 2016, p. 210). Further, Franken (1994) highlights the importance of one's self-concept as follows:

> There is a great deal of research which shows that the self-concept is, perhaps, the basis for all motivated behaviour. It is the self-concept that gives rise to possible selves, and it is possible selves that create the motivation for behaviour. (p. 443)

Self-concept is closely linked to self-esteem – people who have a good awareness of their identity produce effective outcomes, since they are aware of their abilities (Franken, 1994). This therefore emphasises the importance of the development of self-concept in YP.

Making sense of one’s identity may be difficult for YP with ASD to do through conversing with peers, highlighting the benefit of an external professional in facilitating this (Stevenson et al., 2016).

(iii) Outcomes for people with ASD

An ASD diagnosis is life-long and undoubtedly leads to considerable consequences for those individuals, involving a complex range of responses. Research suggests that outcomes for CYP with ASD are poor – they are likely to experience social isolation and bullying – 34% of a sample of CYP with ASD reported that being bullied was the worst thing about school (Reid, 2011). CYP with ASD are also disproportionately affected by both formal and illegal school exclusions and fewer than one in four YP with ASD continue their education beyond school, despite 70% of CYP with ASD having attended mainstream schools (Ambitious about Autism, 2015, 2017). Further, research reports poorer conditions in adult life for people with ASD compared to their peer group in terms of employment social inclusion and mental health (Department of Health (DoH), 2010). This is demonstrated by the following statistics; a third of adults with ASD suffer mental health difficulties; and just 16% of adults with ASD are in full-time employment (Bancroft, Batten, Lambert & Madders, 2012; Rosenblatt, 2008; NAS, 2016b). By comparison, one in four people in the UK experience a mental health difficulty each year and 75.7% of the general population are in full time employment (McManus, Meltzer, Brugha, Bebbington & Jenkins, 2009; Office for National Statistics, 2018). Further research following 48 people with ASD into young adulthood found that by 24 years old 46% of the sample had developed poor outcomes in terms of work, friendships and independence, as well as having poor health conditions, such as obesity (Eaves & Ho, 2008). Comparatively, the Health Survey for England found 28.7% of the general adult population to be obese in 2017 (NHS, 2018).

Transition from adolescence to adulthood can be particularly stressful, since coping with change is a difficulty commonly found amongst people with ASD (Smith, Greenberg & Mailick, 2012). Findings by Smith et al., (2012) revealed poor outcomes for adolescents with ASD, in terms of employment, social integration and independence. With this in mind, it is important to understand the YP’s experience of having an ASD diagnosis in order to inform future support. Such an idea was similarly captured by Knott, Dunlop and Mackay (2006):

> Attempts to equip children with the necessary skills to make and sustain relationships with others will not necessarily succeed if children's beliefs about their skills are not taken into account…Further exploration of the ways in which children and young people see themselves…would assist in the development and implementation of effective interventions. (p. 616)

Currently, interventions for CYP with ASD are mainly based on professional opinion and research. Whilst these can be effective for the time that the CYP spend in school, outcomes for later life indicate that the positive impact is often not sustained or transferred to life beyond school (Harris & Handleman, 2000). Listening to the voice of CYP with ASD and asking how they experience their diagnosis can therefore help with planning and implementation of interventions (Knott et al., 2006). Subsequently, parents and professionals can provide better support to enhance social integration and to promote achievement in education and beyond for the YP. Intervention is a key part of the EP role (Fallon, Woods & Rooney, 2010). EPs are therefore well-placed to apply their understanding of how YP experience having a diagnosis of ASD to support school staff with intervention planning and implementation.

1.7 Research Aims

The current national and local contexts have illuminated the need to provide better outcomes for YP with ASD. As has been demonstrated, there is limited research looking at insider perspectives of CYP with ASD, despite legislation espousing for the elicitation of pupil voice. In light of the national and local contexts, the research aimed to explore and understand YP's experiences of having a diagnosis of ASD and, in turn, to lessen this gap in existing research. It is important to note the distinction between exploration of the lived experience of having an ASD diagnosis and exploration of the experience of receiving the diagnosis. Whilst the latter phenomenon is significant and may be drawn upon when making sense of having an ASD diagnosis, the research's focus is on the former phenomenon.

A hope for this research was that exploration of YP's experiences of having an ASD diagnosis would enhance parental and professional understanding, and contribute to the Educational Psychology profession. Eliciting insider perspectives from YP was hoped to better inform the labelling debate, as well as work towards understanding how YP perceive their identities. An enhanced understanding of the YP's lived experiences could lead to more effective support and outcomes for YP with ASD. The research also aimed to highlight the importance of eliciting the voice of YP and the value of including their voice in decision making concerning them.

Chapter Two – Literature Review

2.1 Introduction

In light of the current national and local contexts for YP with ASD, a systematic literature review was carried out to find out what YP's experiences of having the diagnosis are. The literature review aimed to address the following question:

What does existing literature say about YP's experiences of having ASD?

This chapter includes the search strategy undertaken, the relevant literature and findings produced, and a critical evaluation of the literature. Implications of the reviewed literature are then presented. The identified gaps in existing knowledge, research and practice lead to the overall research question.

2.2 Search Strategy

A systematic search of existing literature regarding YP's experiences of having ASD was carried out using the following databases one by one; Psych Info; Psych Articles; Psychology and Behavioural Sciences Collection; PEP Archive; Education Source; and ERIC. These databases were used because they are credible and relevant to Educational Psychology practice. The terms used within the search are presented in Table 1.

Table 1: Terms used to carry out the literature search

autis* (AB)	young people	experience*	United Kingdom
asperger* (AB)	young*	perspective*	UK
ASD (AB)	teenage*	perception*	
ASC (AB)	adolescen*	understand*	
	secondary school	Sense	
	high school	realit*	
		Meaning	
		insight*	
		lived experience*	
		insider knowledge	
		identit*	
		self-conceptualisation*	

Limiters were applied (see Appendix 1) and 89 results were produced. These limiters included articles published between the years 1998 and 2018, in order to ensure the most relevant results. Dissertations were also excluded since they were not peer reviewed. Inclusion and exclusion criteria (see Appendix 2) were then applied to the results, leaving five relevant articles.

Given the small number of articles produced, references of each of the five articles were searched for any further relevant results. From here, two more relevant articles were found. Therefore, the literature search left seven articles for review (see Appendix 3).

Two of the seven articles looked at the perspectives of parents with children with ASD, as well as those YP with the diagnosis. These two papers were included in the literature review because, although parents were not the primary focus of the literature search, YP's experiences were explored in the same papers. Further, the parental perspectives helped to contextualise the YP's experiences. Although one paper was conducted outside of the UK, it was included because it provided valuable insight into the meaning YP associated with their ASD label. In two papers, some participants were as young as eight and nine years old. These papers were included in the review because participants went up to sixteen years old and both papers addressed the literature review question.

The articles were read and critiqued using the Critical Appraisal Skills Programme (CASP) for qualitative research. The CASP was used to critique the trustworthiness, relevance and findings of the literature because it is a reputable tool which effectively produces succinct information (Nadleson & Nadleson, 2014). Using the same tool to critique all seven papers allowed for a more systematic and comparative evaluation of the literature. An example of the results from the CASP applied to one of the papers is presented in Appendix 4.

Following critique using the CASP, data was extracted from the literature and collated into a table in order to access the key information (see Appendix 5). Extracted data included research aims, participants, design, analysis, findings and overall strengths and limitations of each paper. As well as making the information more accessible, the table helped to draw similarities and differences across the literature.

The findings of the literature were then synthesised. Common themes across the literature emerged as a result, which are discussed below. In addition to the findings presented, the studies are critiqued in an attempt to evaluate their trustworthiness and credibility. The themes that emerged in the literature when trying to understand

YP's experiences of having ASD were comparison to others; perception of self; time; effects of diagnosis; and strategies to manage diagnosis.

2.3 Findings of Reviewed Literature

2.3.1 Comparison to others

Research revealed that YP with ASD made sense of their diagnosis by drawing comparisons with others (Huws & Jones, 2015; Winstone et al., 2014). In IPA research looking at YP's perceptions of autism, Huws & Jones (2015) found that participants viewed themselves more positively in the present compared to the past; in a better position than others with more severe autism; and better-off than people with, what they considered to be, a proper disability. The YP believed that people had different degrees of autism, with others having it worse than they did. This idea of people having different severities of autism also emerged in research by Stevenson et al., (2016). In research by Huws and Jones (2015), the YP perceived themselves to have heightened abilities to those with and without ASD. However, some participants spoke about ASD as holding them back from achieving things in life, such as a certain career. YP also referred to different degrees of ability, placing autism as less severe than other disabilities. For instance, one participant said that having autism means that she is only a bit disabled, while others spoke about the disability as just affecting their minds.

Similarly, research by Winstone et al., (2014) revealed that when YP were interviewed about their self-identity, one of the themes that emerged was comparison of self to others. Participants provided much more detailed responses during activity-oriented interviews than in traditional semi-structured interviews.

The former method incorporated pictures that participants had drawn in advance of things they like and self-portraits. During this method, participants made comparisons to others, using themselves as a reference point. This study highlights the value of using more creative methods to elicit YP's perceptions of ASD, rather than relying solely on verbal communication.

2.3.2 Perception of self

A second theme that emerged across a number of reviewed studies was perception of self (Winstone et al., 2014; Mogenson & Mason, 2015; Stevenson et al., 2016; Mackay & Parry, 2015). There were a range of ways in which YP spoke about their self-perception, which were often influenced by contextual factors, such as time of disclosure, parental language and constructs, and method of interview. YP perceiving their selves as 'different' emerged across the literature (Mogenson & Mason, 2015; Stevenson et al., 2016). Whether this difference was regarded as positive, negative or indifferent varied across the literature and between participants within a single study.

In research by Stevenson et al., (2106), some participants considered the diagnosis to be positive as it provided strengths and unique characteristics, making a person who they are. On the contrary, others believed that a person makes them who they are, not their ASD diagnosis. Some YP spoke about ASD as being unimportant, whilst others were ambivalent about the condition, constructing it as both positive and negative in a single statement (Stevenson et al., 2016). Often in the case of the latter, this ambivalence was linked to a sense of confusion over what the condition means and how the diagnosis was revealed to them. For instance, being told that having ASD meant that something was wrong, but not knowing the cause resulted in confusion over identity (Stevenson et al., 2016).

In one study, when interviewed using only semi-structured methods, YP dissociated from their ASD diagnosis (Winstone at al., 2014). They described autism as affecting other people, rather than using themselves as a reference point. However, when YP were interviewed using more concrete and activity-based methods, they provided more detailed responses and connected to their diagnosis. This was demonstrated by a shift to first person in responses and by descriptions of difficulties faced by the YP.

Research by Mogenson and Mason (2015) revealed that an ASD diagnosis led to YP negotiating their identity. Some participants viewed the diagnosis as oppressive due to a struggle of feeling different, whilst others considered it to be liberating, to facilitate control and to lead to a positive identity. The diagnosis was experienced as liberating by some YP because they felt that the diagnosis had led to an enhanced understanding of their selves, including reasons for certain behaviours. Through understanding their behaviour better, these YP had reframed problems and accepted them as part of their identity. Another participant spoke about the label as helpful in providing a reason for difficulties, in turn leading to ways to cope. Building on from the diagnosis being liberating, participants expressed irritation that they had not learnt about their diagnosis earlier, as they believed that doing so would have led to an explanation for being different. In this sense, the label facilitated control – being aware of being different, yet not understanding why, seemed to create a struggle for control, which was restored upon learning about the diagnosis (Mogenson & Mason, 2015; Huws & Jones, 2008).

Further, YP with ASD perceived their difference as positive and central to their identity (Mogenson & Mason, 2015; Stevenson et al., 2016). This was particularly the case when YP had grown up knowing about their diagnosis and had integrated it into their self-concept. One participant, who had known about his ASD diagnosis for four years when interviewed, did not believe that the condition made him different to his peers. Yet, he did think that other people perceived him differently, demonstrated by adults making allowances for him, such as often being excused at home and receiving easier work at school (Mogenson & Mason, 2015).

An alternative way of perceiving the self in relation to ASD was seen in research by Mackay and Parry (2015), differing from the research already reviewed. The researchers concluded that CYP's descriptions of fictional characters provided insight into their self-concept. For example, researchers suggested that one participant's interest in the game Pokémon was due to the unique differences between the characters, reflecting the child's own uniqueness and differences. Additionally, the researchers proposed that YP were attracted to certain fictional characters due to the characters' abilities to defeat enemies – something that the YP were thought to identify with. As a result of YP's descriptions, it was suggested that their experiences of themselves and their interactions with the world were framed through their interests. One participant said that he enjoys having Asperger's Syndrome because it makes him different. He elaborated, saying that if he was the same as other people, he would feel like a clone from a sci-fi film. Both the participants mentioned were younger than the other participants interviewed across the literature – ten and nine years old, respectively. Therefore, externalisation techniques (White, 2006) which provided insight into their perceived selves and experiences of the world may be linked to their younger age.

2.3.3 Time

When interviewed about experiences of having ASD, time emerged as an important factor in YP's accounts (Huws & Jones, 2015; Stevenson et al., 2016; Winstone et al., 2014). Research by Huws and Jones (2015) revealed that YP perceived their selves more positively in the present, compared to in the past. Participants were relieved that ASD is a developmental condition, believing that their autistic traits had reduced over time. By growing up, participants thought they had developed their social skills and independence, considering their behaviour to now be more socially accepted by others. It was therefore suggested that when aspects of self such as social interaction and communication have improved, comparisons over time can be rewarding and can play an important part in how YP conceptualise their ASD diagnosis (Huws & Jones, 2015). However, the change in traits over time was not always straight forward. One participant described how his repetitive behaviours and interests would not change over time, as they were just part of him (Huws & Jones, 2015). Further, in research by Stevenson et al., (2016) YP questioned whether ASD could be cured. The YP's hopes for their ASD to disappear were echoed in discussions with parents, suggesting that YP's experiences may be influenced by others.

The theme perceived changes over time was further demonstrated in research by Stevenson et al., (2016) and Winstone et al., (2014). In both studies, themes about the future self emerged. YP spoke about their aspirations, including a desire to be independent and to live a meaningful life. Hopes to own a home, to have a family and to be happy, as well as being able to go out independently were mentioned. Others spoke about careers they wanted and their desires to make their families proud. However, alongside these aspirations were feelings of anxiety (Stevenson et al., 2016). YP were worried about their transition to adulthood, and questioned if and how they would cope. One person mentioned wanting to form friendships over time, but thought that the ASD diagnosis would stand in the way. Following concerns about the transition to adulthood, YP discussed ways to manage – taking things slowly, accepting support and making a greater effort than others may need to (Stevenson et al., 2016).

As demonstrated throughout research by Winstone et al., (2014), activity-oriented interviews facilitated more in-depth descriptions of a future self, than in the traditional semi-structured interviews. In the former, pictures that participants had previously drawn acted as stimuli for richer dialogue. Therefore, YP can provide rich insight into their future selves when appropriate methods are utilised.

2.3.4 Effects of diagnosis

Participants demonstrated varied responses regarding the effects of the diagnosis. The positive effects of having an ASD diagnosis focused around YP receiving practical support and others acquiring a better understanding of the YP's needs, leading to better treatment. Practical support for one young person referred to receiving help at school (Calzada et al., 2012). For others it meant access to services, such as attending a specialist ASD provision at school. Access to this provision was believed to lead to improved behaviour and the formation of new friendships (Huws & Jones, 2008).

A negative effect of the diagnosis was commonly revealed as the stigmatisation of the label (Huws & Jones, 2008; Calzada et al., 2012). In particular, YP felt that they were different to their peers and were worried about what others would think of them or how they would treat them. In research by Huws and Jones (2008), this stigma was felt rather than enacted (something that had happened). Additional limiting effects of the diagnosis were revealed to be its failure to encapsulate and communicate the YP's needs, as well as the insufficient information it provides regarding one's strengths and difficulties (Calzada et al., 2012). Huws and Jones (2008, 2015) further found that some YP considered the diagnosis to disrupt daily functioning and future plans, including school work, behaviour, choice of further education provision and career prospects. This was particularly seen to be the case when YP were not made aware of their diagnosis early on.

Although YP (and parents) had mentioned that the diagnosis may increase understanding for other people, it did not seem to alter the YP's understanding of their selves (Calzada et al., 2012). Most of the YP did not attempt to explore the meaning of the diagnosis. For the few YP who did try to understand, they tended to define it in terms of their own difficulties, such as conceptualising ASD as having difficulty making friends since that was something that the YP experienced. Three out of the nine YP, who also all suffered with anxiety, believed that the diagnosis had not had any impact at school (Calzada et al., 2012). Parents and one young person mentioned that the heterogeneity of the label which is often described makes it difficult to relate to.

In addition to the negative effects of the diagnosis seen in research by Huws and Jones (2008) and Calzada et al., (2012), Mackay and Parry (2015) revealed different perspectives. In this study, YP described certain behaviours and obsessions as being affected by ASD. These behaviours included specific eating habits, such as eating limited foods and being averse to mixing certain foods. Interestingly, YP used the same professional language as their parents when describing these behaviours – 'limited range of foods' and 'obsessions' (Mackay & Parry, 2015, p. 1420-21). One child in particular articulated how he understands his interest in games as being an obsession, due to his mother's comments: 'My games are definitely an obsession, as mummy keeps reminding me' (p. 1421). Therefore, YP's views about the effects of their diagnosis may be influenced by their parents.

Mackay and Parry (2015) proposed that the professional language used by parents and YP highlight the influence of the medical model of ASD. Within a medical model, ritualistic behaviours and obsessions are often interpreted as problematic and non-functional, requiring modification. Such an approach was said to have implications for the development of identity and self-esteem in YP with ASD.

However, the researchers also found differences between parental and YP's accounts. In the former, obsessions and rituals were considered to be highly restrictive, whereas, in the latter, YP demonstrated agency around their interests and they rarely referred to ritualistic behaviours. With this in mind, it is important to consider the contextual factors that may influence YP's perspectives about their ASD diagnosis and any similarities or differences between their own accounts and parental accounts.

2.3.5 Strategies to manage diagnosis

Research by Stevenson et al., (2016) uniquely revealed the ways in which YP developed strategies to manage having a diagnosis of ASD. In this sense, through negotiating their identity, YP had actively constructed their own meanings of the diagnosis. Strategies they used included; trying to hide or minimise their autism; understanding and accepting the diagnosis; developing self-belief; creating opportunities; and talking to others about the diagnosis. These are elaborated on below.

Some YP spoke about how they conceal their diagnosis, whilst others mentioned managing their ASD by researching what they should and should not do. As demonstrated under the theme 'Time', YP questioned whether the condition could be cured through brain development or whether it was life-long. Interestingly, this idea of ASD being cured was congruent with a parent's belief, that once improvements had been made, her child could leave the specialist provision and attend a 'normal school' (Stevenson et al., 2016, p. 225).

Contrastingly, YP spoke about understanding and accepting their diagnosis. Whilst one participant acknowledged that he had previously wished away his autism, this was no longer the case as he had begun to accept having the diagnosis. Again, similarities were drawn between participant responses and those by parents. Further, ideas about *how* to understand and accept one's ASD diagnosis emerged in participant responses as being the development of self-belief. Through learning to value oneself, as well as attempting to quash other people's voices which imposed limits on the abilities of YP with ASD, participants developed acceptance of their diagnosis. Enhanced self-belief and acceptance were not only discussed with regards to individuals with ASD, but also on a more societal level – one participant spoke about the need to raise awareness of the condition for those without ASD (Stevenson et al., 2016).

As identified in research by Calzada et al., (2012) and Huws and Jones (2008), positive effects of having ASD included being able to access specialist services and receiving extra support. Similarly, YP had managed their identity by taking advantage of the supportive opportunities that the diagnosis offered. However, one participant articulated that he did not want his ASD label to become an excuse for him (Stevenson et al., 2016).

Lastly, YP worked towards managing their identity by talking to others. Through sharing experiences with others who have the diagnosis, the stigma around ASD was felt to be lessened. Further, having open dialogues about ASD reduced a feeling of isolation, since YP became aware of other people with the same diagnosis. Sharing experiences also allowed YP to express feelings and thoughts that they had been suppressing (Stevenson et al., 2016).

2.4 Validity of the Literature

Huws and Jones (2015) and Winstone et al., (2014) recognised a limitation as being that findings were not discussed with participants to check whether their interpretations were accurate of their experiences. Although, this was somewhat accounted for within the interviews through the ‘double hermeneutics’ process, whereby interpretations were checked out with participants. However, the credibility of findings within research by Huws and Jones (2015) and Winstone et al., (2014) may have been compromised by approaches to recruitment. It is not clear how participants were recruited, how many people initially showed interest in taking part and any reasons for exclusion or withdrawal. Therefore, there could have been potential bias from the start of recruitment which impacted on sampling and findings.

A further limitation concerned the relationship between the psychologist and participants (Huws & Jones, 2008, 2015). The psychologist recruited participants who he knew prior to the research. This was mentioned in the research, but there were no details about the nature of the relationship and the potential bias involved as a result. Similarly, in research by Winstone et al., (2014), the interviewers were already known to the participants, since they had previously worked at the school. Across both studies, there was no mention of any measures taken to reduce the impact of this potential bias. Therefore, findings should be interpreted with caution in light of unclear recruitment methods and pre-existing relationships between the researchers and participants.

There was little reference to the effect of the relationship between researchers and participants, and measures taken to reduce any bias (Mogenson & Mason, 2015; Stevenson et al., 2016; Mackay & Parry, 2015). This may have affected how participants felt about taking part in the research and what they said during interviews. Further, although the stages of thematic analysis and the resulting findings were presented, there was no mention of researchers critically examining their roles during data collection and analysis. Recruitment methods were unclear – researchers did not explicitly outline the recruitment strategy used, how many people showed interest, whether anyone declined, was excluded or withdrew and reasons for this (Mogenson & Mason, 2015; Mackay & Parry, 2015). More specifically, in research by Mackay and Parry (2015), YP who were 'deemed capable of consent' were recruited and those with 'severe autism' were excluded (p. 1419). However, there was no further detail about how this was measured, reducing the study's rigour.

In research by Mackay and Parry (2015), all participants were English-speaking, white British and all parents, except one, were mothers. With this in mind, findings were not representative of people from ethnic minorities and fathers. Additionally, the researchers described YP speaking about their favourite games and characters, yet it is unclear how participants came to mention these. An interview schedule was not included in the paper and vignettes of the YP's comments were rarely prefaced with the initial interview question. This lack of information makes it difficult to contextualise participant responses and to understand if YP were directly asked about their interests or whether they spoke about them spontaneously. Further, the claim that characteristics described by the YP reflect their experiences of their selves lacks rigour. An example in research by Mackay & Parry (2015) is as follows:

> Jonathan highlights the unique differences between Pokémon characters as a significant aspect of his interest...it may also reflect Jonathan's own experience of himself as different and unique. (p. 1421)

The above vignette highlights the tenuous nature of some of the conclusions drawn since it is not clear that Jonathan was referring to himself. The researchers acknowledge that a limitation of their research was difficulty in obtaining YP's perspectives because of communication issues. Whilst they overcame this limitation to an extent by using flexible interview methods, such as video recordings, there were still issues. For instance, the age of some participants (eight to ten years) may have made it difficult for them to express their views and experiences about ASD accurately. However, there are findings which provide more weight to the conclusion drawn that YP identify with fictional characters. An example of this is where participants explicitly relate to a character, such as 'my favourite is Roy Mysterio. He is cool. He is little like me but still won lots' (p. 1422). Yet, as mentioned, without knowledge of the questions asked, it is difficult to draw conclusions about YP's experiences of ASD.

Although findings about the effects of an ASD diagnosis are valuable for understanding YP's experiences, all participants in research by Calzada et al., (2012) were again White British, and mainly mothers were interviewed during parental data collection. Therefore, the voice of ethnic minorities and fathers were not represented, which is likely to have affected the findings.

In research by Calzada et al., (2012), whilst the setting of the data collection was mentioned (participants' homes), there was no discussion regarding the choice of location and the potential effects during interviews. Related to this is the limitation around interviewing parents and YP together. The researchers mentioned that participants were given the choice of being interviewed together or separately, where most opted for the latter. However, researchers did not specify which interviews were conducted with both parents and YP together, the potential effects of this and measures taken to reduce bias. It has been acknowledged that YP's responses occasionally mirrored parents' responses, yet it is unclear whether this was contributed by the interviews being conducted together or not. Additionally, as identified by the researchers, the credibility of findings may also be reduced due to response bias – the adults interviewed had actively sought out an ASD diagnosis (Calzada et al., 2012).

Huws and Jones (2008) identified limitations in their research as being the absence of parental involvement and researchers not accessing participant files to verify diagnosis. Without checking the latter, it is possible that participants did not have ASD diagnoses, which would therefore impact the overall validity of the research.

2.5 Implications of Findings

The reviewed literature has significantly contributed to the growing body of research around YP's experiences of having ASD. Findings have highlighted the importance of capturing YP's voice regarding thoughts, feelings and experiences about their identity and the meaning of having a label of ASD. However, limitations of the studies have brought to light implications for future research. The small amount of literature that exists around YP's experiences of having ASD alone speaks to the need to further explore this area since, in accordance with legislation, more emphasis on pupil voice is needed to improve outcomes (DfE, 2015). Whilst all studies emphasised the importance of further exploration into the perspectives of YP with ASD, the implications that arose from each study regarding the reasons for doing so, as well as *how* to go about this differed. These varying implications are outlined below, contributing to the overarching research question.

Research by Calzada et al., (2012) highlighted the factors that affect the utility of an ASD diagnosis – validity of the diagnosis and the cultural, legislative and economic context. Researchers emphasised the important point that validity of a diagnosis is only useful if the contextual factors surrounding YP with ASD are supportive of the condition. Based on this, implications for future research were for wider populations to acquire a greater understanding of ASD, for example through post-diagnostic services effectively communicating with schools to ensure understanding and support for YP. Eliciting the views of YP is a crucial starting point in disseminating knowledge to wider systems. As discussed, the research revealed that individual characteristics and co-morbid conditions, such as anxiety, influence the utility of an ASD diagnosis. Subsequently, an implication for future practice was for quantitative research to be carried out to measure the effects of such additional contextual factors on the utility of the diagnosis. Researchers also identified the need to explore other variables such as age of participant, age at diagnosis and time since diagnosis by the point of interview (Calzada et al., 2012; Huws & Jones, 2008).

Another implication that emerged from the reviewed literature concerned creating opportunities for students in mainstream schools to share experiences of having ASD (Stevenson et al., 2016). This implication arose from the researchers' finding that participants who attend a specialist ASD school found it helpful to share experiences with others to support their understanding of the diagnosis. The researchers suggested that this supportive strategy may be even more important for students with the diagnosis in mainstream settings as a way of learning what ASD is; managing the differences that may arise; and developing self-belief and resilience.

The use of more creative and concrete methods, as opposed to traditional questioning is another important implication for future research (Mackay & Parry, 2015; Winstone et al., 2014). By using client-centred techniques during data collection, more detailed and in-depth experiences can be obtained. Subsequently, professionals may incorporate more client-centred approaches into practice, such as during intervention (Mackay & Parry, 2015). The elicitation of rich data further implicates knowledge regarding ASD, since the deficit model characterised by CYP being able and unable is challenged. Instead, this is replaced by ideas about self-identity as being on a continuum (Winstone et al., 2014). In order to bring the latter to light, appropriate interview methods using creative, concrete and personalised approaches need to be employed.

There were also implications on a national level – research findings illuminated the important role that social policy has in minimising the stigmatisation of ASD and to provide space for CYP to explore their identities and to have control over their lives (Mogenson & Mason, 2015). The researchers' findings about YP's varied experiences of the diagnosis challenged the wider medical model's homogeneous approach to ASD, where YP are depicted as being impaired or at a deficit to others (Mackenzie, Cologon & Fenech, 2016).

As a result of YP making sense of their identity as being 'better-off' than others, the need for future research to recognise the diversity of experience across those with ASD was identified (Huws & Jones, 2015). It was considered to be problematic if a young person's self-acceptance is dependent on perceiving him or herself as better-off than others. Therefore, it was recommended for future research to explore the heterogeneity of the ASD experience.

Involving parents in research was recognised as an area for future research (Huws & Jones, 2008). Researchers identified not exploring emerging themes with parents as a limitation and suggested that doing so would enhance future research. As well as exploring themes with parents, researchers recommended asking parents about disclosure of the diagnosis, including how and when this occurred, and the effects of their thoughts and feelings about diagnosis. As was demonstrated in research by Mackay and Parry (2015), YP's language and constructions of ASD are often influenced by those of their parents. With this in mind, it would be useful to acquire an understanding of how parents speak about the diagnosis, in relation to how their children do, as a way of exploring any similarities and differences in the discourse around ASD.

In conclusion, the literature reviewed holds valuable implications for future research and practice around YP with ASD. Namely, the effects of contextual factors on the utility of a diagnosis for YP are to be considered; knowledge is to be disseminated from an individual level to organisational and policy levels; more client-centred approaches are to be used to elicit YP's voice; and there should be greater emphasis on exploring the heterogeneity of having a diagnosis of ASD. Contextual factors include details around any co-morbid conditions which YP have, as well as details around disclosure of the diagnosis and parents' perspectives about this (Calzada et al., 2012; Huws & Jones, 2008). The research highlighted the role that post-diagnostic services have in communicating with schools to support YP (Calzada et al., 2012). Additionally, implications have focused around creating opportunities for YP to share experiences about their diagnosis with others in mainstream settings, in order to develop a positive self-concept and resilience (Stevenson et al., 2016). Research has emphasised the importance of eliciting YP's voices through the most appropriate means. Rather than providing YP with traditional verbal interviews, researchers call for flexible, creative and concrete methods to ensure that YP can express their experiences at an in-depth level (Mackay & Parry, 2015; Winstone et al., 2014). Lastly, the reviewed research brings to light the importance of exploring the heterogeneity of the experience of having ASD, in order to illustrate the diversity across YP (Huws & Jones, 2015; Mogenson & Mason, 2015). Doing so will help to shift away from a medical model, whereby individual characteristics can become lost, and towards a more accurate representation and richly-informed understanding of YP's experiences of having a diagnosis of ASD.

2.6 The Research Question

A review of the literature revealed that YP with a diagnosis of ASD made sense of this in a variety of ways. Some regarded the diagnosis as positive since it led to better understanding, an increased sense of control and access to support (Mogenson & Mason, 2015). Negative effects of the diagnosis were considered to be stigmatisation, disruption to future plans and ineffective communication of an individual's strengths and needs (Huws & Jones, 2008, 2015; Calzada et al., 2012). For some YP, the diagnosis did not seem to have much impact (Calzada et al., 2012). Additionally, the literature review found YP to question the longevity of ASD, as well as it revealing strategies that YP adopted to negotiate their diagnosis (Huws & Jones, 2015; Stevenson et al., 2016; Winstone et al., 2014).

The implications of these findings were for the effects of contextual factors on the utility of a diagnosis for YP to be considered; knowledge to be disseminated from an individual level to organisational and policy levels; more client-centred approaches to be used to elicit YP's voice; and for greater emphasis to be placed on exploring the heterogeneity of having a diagnosis of ASD. Based on these implications and the initial research aims, the following research question was formed which guided the rest of the research:

> *What are mainstream secondary school pupils' experiences of having a diagnosis of ASD?*

Chapter Three – Methodology

3.1 Introduction

This chapter begins by reiterating the research aims. The researcher's orientation is then presented, which helps to form the outlined research purpose, design and methodology. Interview methods employed are included, as well as the rationale for choosing these, followed by an overview of the participants, recruitment methods and procedures undertaken throughout. The stages of analysis used following data collection are presented. There is a comprehensive account of the ethical procedures adhered to in order to ensure that the research was as ethically sound as possible. The measures taken to enhance the trustworthiness and credibility of the research are also provided.

3.2 Research Aims

The aim of the research was to explore YP's experiences of having a diagnosis of ASD. The reason for carrying out the research was to gain first-hand insight into the experience of having the diagnosis, since this is an under-researched area. Understanding YP's perspectives aimed to inform the labelling debate, as well as provide systems around the YP with a better understanding of the implications that having an ASD diagnosis may have. In turn, it was hoped that this would enhance support for YP with ASD to achieve better life outcomes.

3.3 Orientation – Epistemology and Ontology

Ontology concerns what is reality – the theory of being – and epistemology concerns how you know this reality – the theory of knowledge (Furlong & Marsh, 2010). Therefore, the ontological assumption you make about reality will affect how you approach science, whilst the epistemological assumption will shape how you try to find out about it.

Ontology

The ontological position of the research is that of critical realism. This stance acknowledges that there is a reality, which is independent of individual perspectives and experiences, whilst also believing that individuals construct their own meaning of that existing realty (Eatough and Smith, 2008). This position was considered most appropriate for the current research because an assumption has been made that ASD exists (the reality). However, the research is concerned with understanding what meaning the existing condition holds for each individual, in accordance with a critical realist orientation.

Epistemology

The epistemology of the work is phenomenological. A phenomenological position focuses on the meaning that emerges from individual experiences, absent of any pre-existing theoretical preconceptions (Smith, Flowers & Larkin, 2009). Given that the research focused on the phenomenon, the individual experience of having a diagnosis of ASD, a phenomenological epistemology is the most appropriate.

In the current research, it was the individual experiences that created an understanding of what it means to have a diagnosis of ASD. However, the recognition that ASD exists means that the overall ontological position is critical realism and the nature of the knowledge is phenomenological.

3.4 Research Purpose and Design

Since the research aimed to understand YP's experiences of having a diagnosis of ASD, its purpose was exploratory. The research was concerned with exploring in-depth personal accounts of YP, meaning that the design was qualitative. The researcher did not approach the research with a set of hypotheses or preconceptions to be tested. Instead, the overarching research aim was used to guide the research process. For this reason, an inductive approach was adopted whereby the analysis was driven by the data, rather than by pre-existing theory or literature, as is the case with deductive approaches.

3.4.1 Methodology

In order to address the identified research question it was decided to use an IPA approach. IPA research is exploratory, concerned with process rather than outcome, and focused on meaning, instead of causes or consequences of events (Smith et al., 2009). IPA is used to analyse qualitative, experiential research. It was first introduced as a way of deepening psychological knowledge, after the over-emphasis placed on quantitative research methods (Smith, 1996). A fundamental feature of IPA research is the idea that individuals are actively engaged in their everyday experiences, which they reflect upon as a way of making sense of them (Smith et al., 2009). The research involves a two-stage process whereby the participants try to make sense of their experiences and the researcher attempts to make meaning of these experiences. Therefore, the IPA researcher is actively involved in the data collection and the interpretation of lived experiences (Pringle, Drummond, McLafferty & Hendry, 2011). There are three core features of IPA; phenomenology; hermeneutics; and idiography. These are outlined further below.

(i) Phenomenology

Phenomenology is the philosophical study of lived experience, exploring how humans might come to understand their experiences of the world (Smith et al., 2009). This principle involves IPA researchers staying as close to the participants' language as possible in an attempt to examine lived experiences in their own right, in the way in which they occur. Researchers are not prescribed by any pre-existing assumptions. For IPA researchers to adopt a phenomenological stance, they must be reflexive and enter a shift from engaging in everyday activities in the world towards attending to their experiences of these activities. The former needs to be bracketed off (set aside), in order to attend to the latter. Although, doing so does not eliminate the attention paid to everyday activities (Smith et al., 2009). It has been acknowledged that while IPA researchers can attempt to understand others' experiences, the lived experiences can never be fully captured as they belong to the individuals (Smith et al., 2009). In the current research, the researcher attempted to bracket off every day experiences in order to attend to participant experiences through the recording of thoughts and feelings in a research diary and through triangulation of interpretations with others.

(ii) Hermeneutics

The second theoretical underpinning of IPA is hermeneutics – a theory of interpretation (Smith, et al., 2009). The language and context in which human action occurs is fundamental to understanding it (Robson & McCartan, 2016). It is not possible to fully access the inner perspective of participants during the research process, meaning that interpretation is required (Huws & Jones, 2008). Thus, the role of the researcher is a dynamic one (Smith & Osborn, 2007). Researchers in IPA aim to engage with participants' reflections on their experiences (Smith et al., 2009). Within such a process, researchers are involved in a double hermeneutic; participants attempt to make sense of their own experiences, whilst researchers attempt to interpret these sense-making experiences. The researcher brings their own experiences, assumptions and preconceptions to their interaction with participants and to the analysis of data. This cannot be avoided entirely, but it highlights the importance of trying to remain reflexive, as well as sensitive and responsive to the participants' accounts, ahead of the researcher's own preconceptions (Larkin, Watts & Clifton, 2006).

Rather than being a limitation to the process, the role of the interpretive analyst can act as facilitative. For instance, if participants are struggling to express their thoughts and feelings, the researcher's role is crucial in interpreting their mental and emotional states (Huws & Jones, 2008). Philosophers of hermeneutics have gone as far to say that the 'interpretative analyst is able to offer a perspective on the text which the author is not', (Smith et al., 2009, p.23). Smith et al., (2009) suggest that this value that the interpretative researcher brings to understanding lived experience may result from the systematic data analysis, knowledge of psychological theory and from having an oversight of the whole set of data.

(iii) Idiography

The third underpinning of IPA is idiography. In contrast to nomothetic approaches which make general claims about a whole population, idiography is concerned with the particular (Smith et al., 2009). Idiography in IPA research involves commitment to the particular at an in-depth level of detail, requiring systematic and thorough analysis. Additionally, idiography involves understanding how particular phenomena have been made sense of by particular individuals, in a particular context. Therefore, small and purposive samples are used in IPA research.

Since the aim of IPA is to explore participants' lived experiences, making generalisations to wider populations is not the primary focus (Smith & Osborn, 2007). In-depth examination of individual experiences enables researchers to make specific claims about these particular individuals. However, that is not to say that generalisations are exempt from IPA research. Rather, general claims may be made, but they will be done so cautiously, as they will be located in the particular (Harre & Secord, 1976). Analysis in idiographic research begins with in-depth examination of each individual data set, before moving to look at the similarities and differences across all the data (Smith et al., 2009).

3.4.2 Rationale for IPA

IPA was chosen because it is the most appropriate analysis method for the research question – *What are mainstream secondary school pupils' experiences of having a diagnosis of ASD?* IPA has been recognised as a valuable approach for an area that has a scarcity of research (Reid et al., 2005). Since the current literature has mostly focused on parental, professional and siblings' perspectives, resulting in a lack of research into the experiences of having a diagnosis of ASD as told by the YP, IPA was a suitable fit to elicit the voice of YP. Additionally, as stated by Smith et al., (2009), IPA is committed to understand the meaning that individuals make of their major life experiences. Having a diagnosis of ASD is life-long and is therefore likely to be a major life experience, evoking reflection from the individual. IPA is an appropriate method to attempt to engage with these personal reflections (Smith et al., 2009).

The research aimed to explore the particular experience of having an ASD diagnosis for each particular participant, at an in-depth level. This meant that an idiographic approach was at the core of the research, which led to the recruitment of a small and homogenous sample. Research underpinned by idiography and that which features a small, homogenous sample are central characteristics of IPA. Employing idiography in the research was also appropriate because the explored phenomenon was complex, sensitive and ambiguous. Thus, a method looking specifically at particular experiences, rather than those that are universal, was required (Smith, Harré, & Van Langenhove, 1995).

3.4.3 Interview Methods

Part 1 – Grid Elaboration Method (GEM)

Smith et al., (2009) state that a fundamental part of interviewing participants is for them to feel comfortable in the researcher's presence. Establishing a good rapport is important for obtaining rich data. Creating this comfort is important to do right at the start of the interview, before any questioning. Further, the reviewed literature proposed for future research to use creative and concrete approaches to elicit YP's voices, rather than traditional questioning (Mackay and Parry, 2015; Winstone et al., 2014). Providing participants with the opportunity to draw images can enable them to express more emotional information that may be difficult to articulate verbally (Coates, 2002).With this in mind, the GEM was used at the beginning in order to get participants used to talking about and listening to the topic, before the interview began. As stated by Smith et al., (2009), ‘The most important thing in the opening phase is to help the participant get used to talking’ (p. 64).

The GEM involved providing participants with a blank piece of paper, divided into four sections, and asking them to write and/or draw anything that came to mind when they heard the word ‘autism’. The GEM is unique in tapping into people’s naturalistic and implicit thoughts and feelings. Emotionally implicit dimensions tend to be complex and difficult to access, particularly through direct questioning. In keeping with the exploratory purpose of the research, the GEM elicits data that is entirely unexpected by the researcher (Joffe & Elsey, 2014). Additionally, the GEM is suitable for phenomenological research since it allows the researcher to drill down on the particular phenomenon being explored and set aside any preconceptions (Hein & Austin, 2001).

Although it has psychoanalytic underpinnings and is primarily used as a free-associative technique, its use was adapted for this research. Since YP with ASD can often have difficulty with social interaction, communication and abstract concepts, the concrete, visual and structured features of the GEM aimed to facilitate thought and dialogue and alleviate anxiety that may be associated with open-ended conversations. The GEM aimed to put participants at ease and to familiarise themselves with the researcher before beginning the interview, without having to directly interact with the researcher – the drawings from the GEM acted as a shared reference point between the researcher and the participant. Further, the tool aimed to elicit ecologically valid material and minimise interference from the researcher, since the dialogue that followed was guided by participant responses on the grid (Joffe & Elsey, 2014).

Part 2 – Semi-structured interviews

Semi-structured interviews were considered to be the most suitable data collection method for IPA research, since participants were invited to provide in-depth accounts of their experiences. In-depth interviews facilitate the elicitation of rich information concerning the phenomenon being explored (Smith et al., 2009). Through entering the unknown, away from controlled surveys or experimental work, the IPA researcher is able to find out more about the participant's perspective, rather than one's own. The interview schedule acted as a loose guide – the researcher was directed by the participant's experience and used the schedule flexibly. The participant's response acted as a guide regarding what to ask next, meaning that each interview varied in its use of the interview schedule (Smith et al., 2009). The questions that participants found easy or difficult to answer could not have been predicted, making a less structured approach more suitable. Participants were able to return to earlier questions later in the interview when they had made more sense of their experiences. Additionally, Robson (1993) recognised semi-structured interviews to be the most appropriate data collection method for occasions when the interviewer is also the researcher, such as was the case in the current research.

Despite the flexibility inherent in semi-structured interviews, it was important to develop a schedule before data collection to address the research question and to anticipate any difficulties. For YP with social communication difficulties, who may be less forthcoming and prefer a more structured approach, having a prepared schedule was beneficial. When participants were having difficulty responding during interviews, the schedule was useful to draw upon. Another reason why face-to-face interviews were chosen was because they allow non-verbal behaviours to be recognised, which could later be interpreted during analysis.

A combination of the GEM and semi-structured interviews seemed to be an appropriate way to achieve a balance between free associative thoughts and feelings, and experiences elicited from direct questioning. The two methods provided opportunities for participants who prefer to draw and/or write, without having to interact directly with the researcher, as well as for those who prefer to respond to given questions.

3.5 Participants and Sampling Method

Participants were recruited through purposive sampling. Letters were sent out to Special Educational Needs Coordinators (SENCos) at every mainstream secondary school in the LA outlining the research aims, procedures involved and criteria for participants (see Appendix 6). Information sheets and consent forms were also attached with the recruitment letters to ensure that participants willing to partake were fully informed about the nature of the research (see Appendix 7). The criteria for recruitment were as follows:

(i) Participants must have a diagnosis of ASD or Asperger Syndrome

It is acknowledged that Asperger Syndrome was removed from the DSM-5 in 2013 and classified under the wider term ASD. However, anyone who was diagnosed prior to 2013 may have a label of Asperger Syndrome and therefore should be considered for recruitment. It is important that participants have a diagnosis of ASD or Asperger Syndrome. This is because the research is exploring YP's experiences of having a diagnosis of ASD.

(ii) Participants must know about their ASD diagnosis (and preferably have known for at least one year)

Participants must know about their diagnosis before being interviewed because the research is exploring the phenomenon of having a diagnosis of ASD. Therefore, the research would be invalid if participants did not know about having ASD. Further, it would be unethical for participants to learn about their diagnosis for the first time during the interview.

It was preferable for participants to have known about their diagnosis for at least one year by the point of data collection to increase the likelihood that they have come to terms with the diagnosis and, in turn, to reduce the risk of the research giving rise to unprocessed thoughts and emotions. Additionally, a time lapse between disclosure of diagnosis to YP and data collection means that the research can focus on the phenomenon, the experience of having an ASD diagnosis, rather than the experience of *receiving* a diagnosis. It is thought that the latter would likely become the focus if participants were interviewed very soon after learning about their diagnosis.

(iii) Participants must attend mainstream secondary school

The research is concerned with exploring the perspectives of secondary-aged pupils who attend mainstream schools, meaning that this must be a criterion. Participants will be discussing personal information, for which language is required. Further, IPA involves interpreting verbal responses. Therefore, pupils who attend mainstream school, as opposed to specialist provisions, are more likely to be able to have the language to verbalise their responses during interview. Further, reviewed literature proposed for students in mainstream school to have opportunities to share their experiences of having ASD (Stevenson et al., 2016).

(iv) Participants must be able to speak and understand English

Having a good understanding of the English language will support participants to provide coherent responses which accurately reflect their experiences. YP who have English as an additional language will be able to take part in the research, so long as their SENCo and/or parents deem that they will be able to fully access the research procedures and verbally articulate their responses during interview.

(v) Participants must not have any other diagnoses

It is important for the phenomenon explored to be the experience of having an ASD diagnosis. Any other existing diagnoses may interfere with this phenomenon, as other experiences may be difficult for participants to set aside, potentially making it unclear if YP are talking about their experiences of having an ASD diagnosis or another condition.

SENCos from three different schools informed the researcher of potential participants based on the above criteria, before approaching those YP and their parents to see if they were interested in taking part. The SENCos provided the identified YP and parents with the information sheets and consent forms, as well as verbally discussing the research with them. Once interest or consent to participate had been provided, the researcher arranged to meet these parents at the schools. These meetings are discussed further in ‘Procedure’. Participants were selected on a first come, first serve basis in order to prevent certain participants or schools being chosen ahead of others.

After one parent verbally informed the school that she was happy for her son to take part in the research, she later withdrew her consent prior to data collection. The parent was reluctant to agree due to a worry that the interview would evoke confusing and difficult thoughts and feelings for him, associated with his ASD diagnosis.

The final sample was four participants (see Table 2). Four to six participants is the recommended amount for IPA research in order to commit to its idiographic nature (Smith et al., 2009). In this type of research, less is more; it was more beneficial for fewer participants’ experiences to have been analysed at greater depth, rather than studying more participants’ experiences at a shallow level (Reid et al., 2005). The sample was homogenous in terms of the phenomenon being explored – YP’s experiences of having a diagnosis of ASD. Participants were from three different schools; two from the same school and two from separate schools.

Table 2: Overview of participants

Participant	**Pseudonym**	**Gender**	**Ethnicity**	**Age**	**Time known about diagnosis**
1	Sarah	Female	White Other	16 years	8 years
2	Leo	Male	White Other	12 years	16 months
3	Mik	Male	Black Caribbean	15 years	5 years
4	Elena	Female	White Other	11 years	14 months

3.6 Procedure

The aim of the interviews was to explore what having a diagnosis of ASD means for each participant. Prior to the interviews, it was ensured that all participants were aware of their ASD diagnosis and had provided informed consent to take part in the research. Acquisition of informed consent is discussed further in 'Ethics'.

3.6.1 Parent interviews

Once participants were recruited and the researcher had checked that they were eligible according to the specified recruitment criteria, individual meetings were held between the researcher and parents. The purpose of these meetings was to reiterate the research's aims and procedures to parents and to provide an opportunity for any questions to be answered. Additionally, the meetings allowed the researcher to explore circumstances around diagnosis, such as when the individual was diagnosed; when and how disclosure of the diagnosis was made to the individual; how the individual responded to the disclosure; and whether any conversations about the diagnosis had happened since disclosure. Gathering details about diagnosis and parental views was an implication that had emerged from the reviewed literature – the need to explore variables such as age of participant, age at diagnosis and time between diagnosis and data collection was identified (Calzada et al., 2012; Huws & Jones, 2008). Meeting parents also allowed the researcher to pay attention to their constructions of ASD and to consider how these relate to the YP's constructions – another implication that had resulted from the reviewed literature (Mackay & Parry, 2015). An interview schedule was created for the parent meetings as a brief guide to follow (see Appendix 8). The information ascertained from these meetings is included in the Findings Chapter.

During analysis of data, the information obtained from the parent meetings was compared against the participant responses as a way of looking at any similarities and differences between their perspectives. This was useful to consider where participants may have developed their beliefs about their diagnoses from and, in turn, to think about the influence of contextual factors on participant experiences.

3.6.2 Participant interviews

The SENCo informed the participants where the interviews would be held in advance to reduce any anxiety about the unknown and to make the process more predictable. The interviews were held in quiet areas of the schools. A 'do not disturb' sign was placed on the interview room door.

At the beginning of the interviews, information sheets were provided to remind participants of the research's purpose and procedures involved. They were also reminded of their rights to pause or stop the session at any point, either by using the ‘stop’ card provided or by using their words. They were told that some of the things may or may not be difficult to talk about and some of the questions they may have been asked before, whilst others they might never have spoken about.

Participants were informed again about what would happen to their data following the interviews, and that they could withdraw at any time until the point of data analysis. Participants were told that the interviews would be audio-recorded, then stored on password-protected software accessible only by the researcher, and later transcribed verbatim. The researcher reminded participants about who she was and what her role meant. Further, participants were informed about why the research was considered important to be carried out.

Once the researcher was confident that participants were fully informed about the research and were happy to take part, participants were told that there were no correct or incorrect answers and that the researcher was only interested in hearing about their experiences. They were also told that the interview may seem a bit one-sided with the participant doing most of the talking. The participants were told to take their time to think and to answer.

3.6.2.1 Part 1 – GEM

Participants were handed a pencil and a blank sheet of paper divided into four quadrants. They were then asked to draw and/or write something different in each section to describe what they think of when they hear the word ‘autism’. They were told that this was not a test. Rather, it was a way of the researcher understanding more about their thoughts and feelings regarding ASD. Following the GEM, participants were asked to verbally explain each section of their sheet. Participants were thanked and told that they would next be asked questions about having ASD. The GEM grid was often referred back to either by the participant or the researcher throughout the interview. Copies of the GEM grids completed by each participant are in Appendix 9.

3.6.2.2 Part 2 – Semi-structured interview

Participants were individually interviewed for approximately one hour. Interviews were audio-recorded and later transcribed verbatim.

The interview schedule (see Appendix 10) was used as a brief guide to elicit information from participants. It was used flexibly with each participant. Often the researcher checked that she had understood the participant correctly by asking for clarification. For those participants who provided answers to the questions on the schedule without being asked them, those particular questions were not repeated.

Once the interviews were finished, participants were thanked and asked how they had found the session. They were reminded about the purpose of the research and the processes from that point on. The researcher checked if they were feeling okay to return to class and informed them that if they wanted to speak to anyone about the session then it might be useful to do so with a staff member and/or their parents. Any concerns raised could be passed on to the researcher, who would try to support those specified to support participants.

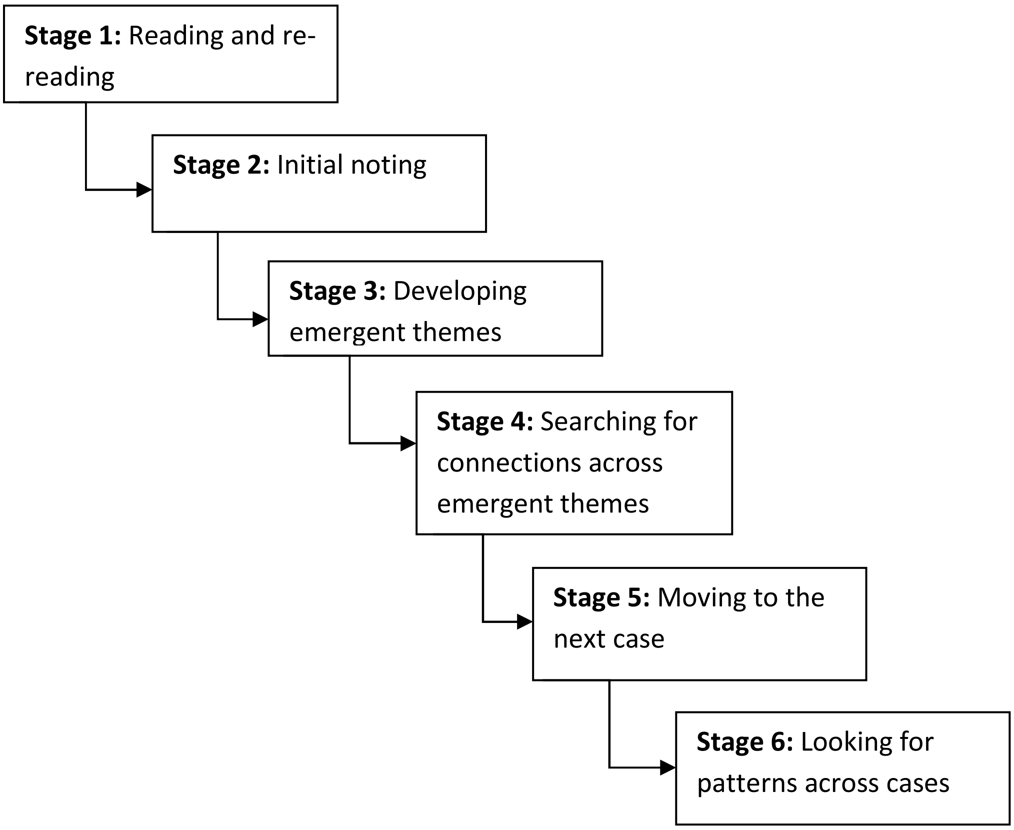
3.7 Data Analysis

Interviews were audio-recorded and stored on password-protected software until transcription. GEM grids were scanned on to the same password-protected software. Interviews were transcribed by the researcher, rather than an external person in order to develop an in-depth understanding of the data from the beginning. The data was then analysed using IPA, following procedures by Smith et al., (2009). Interviews were analysed one by one, in order for the researcher to fully immerse in the individual account before moving on to the next interview.

Stages of Analysis

Below is an overview of the stages involved in the analysis of data. Despite the stages appearing to be linear, the analysis was in practice much more circular, with movement taking place back and forth between the stages. The stages are summarised in Figure 1.

Figure 1: A summary of the stages of analysis



Stage One – Reading and re-reading

After interviews were transcribed, each one was read and re-read in order to immerse in the original data. As recommended by Smith et al., (2009) the audio-recording was listened to whilst reading the transcript in order to strive towards a richer analysis. During this stage, the researcher's initial impressions were recorded in a research diary (see Appendix 16) in order to bracket off thoughts and feelings that could interfere with analysis, allowing for enhanced focus. Further, repeated readings of the transcript, in conjunction with listening to the audio recording, illuminated the interactive process between researcher and participant. Often participants began interviews feeling more anxious than they did by the end. Subsequently, the content of participant responses differed throughout. This change was appreciated by reading the whole interview.

Stage Two – Initial noting

Stage two involved recording a comprehensive set of comments about the data. In order to achieve this, a table was created with three columns – initial coding, transcript and emergent themes. Within initial noting, there were three categories – descriptive, linguistic and conceptual comments. Descriptive comments involved describing the content of participant responses. Linguistic comments concerned the participants' use of language, such as pronouns, pauses, repetition and hesitation. Conceptual comments focused on a more interpretative understanding of the data, where explicit claims made by participants were often moved away from. This stage added depth to the analytic process, where questions were raised and there was a shift away from descriptive analysis and from the original transcript. An entire transcript was coded for descriptive comments, followed by linguistic and, lastly, conceptual comments.

Stage Three – Developing emergent themes

Stage three involved developing emergent themes based on the initial comments made in stage two. The initial notes were closely examined in an attempt to reduce them to a single statement, whilst maintaining the complexity of the data. The emergent themes, therefore, encapsulated the researcher's interpretations as well as the participant's experiences. Certain emergent themes recurred for some participants. Two participants' transcripts with initial codes and emergent themes are included in Appendix 11.

Stage Four – Searching for connections across emergent themes

Stage four involved looking at all the emergent themes and searching for connections across them. This was done in two stages. Firstly, all themes were collated into a separate document in the order in which they originally appeared. Following this, the themes were closely examined to see how they fitted together, before being moved around to form clusters of connected themes. Not all emergent themes were used, since some did not fit into a cluster and were not deemed as significant. Once clusters had been made, they were collated into a table (see Appendix 12).

Specific methods used to arrange the themes into clusters were abstraction, numeration and polarisation (see Appendix 13). Abstraction involved placing similar emergent themes together to create a cluster with a new name (Smith et al., 2009).

Numeration involved looking at the frequency at which a theme occurred to indicate its importance (Smith et al., 2009). For a couple of participants, many of the emergent themes occurred only once. Therefore, numeration was used to consider whether the theme represented a significant experience for the participant. Polarisation involved the recognition of opposing relationships between emergent themes. Each new cluster formed a superordinate theme.

Stage Five – Moving to the next case

Once this process was completed for the first participant, it was repeated for the remaining three, one by one. In accordance with the idiographic nature of IPA research, reflections that arose from analysis for each participant were bracketed off in the research diary. A time lapse of one day was left between analysis of each participant, in a further attempt to honour the individual experience.

Stage Six – Looking for patterns across cases

The final stage involved looking for connections across cases (participants) to form the final overarching themes. This was achieved by collating the superordinate themes for each participant into boxes and then colour coding the themes which were related (see Appendix 14). This stage involved the relabeling and reconfiguring of certain themes, as suggested might be the case by Smith et al., (2009).

3.8 Ethics

Ethical approval was obtained from The Tavistock Research Ethics Committee before informed consent was sought (see Appendix 15). The ethical guidelines outlined by The British Psychological Society (2018) have been adhered to throughout the research. The ethical issues covered include informed consent, confidentiality, safeguarding, storage of data, protecting risk to participants and rights to withdraw.

Informed Consent

Informed consent was sought from the Principal Educational Psychologist at the LA, followed by school staff (Head Teachers and SENCOs), parents and participants. Since some of the participants were less than sixteen years old, parental consent was required. Information sheets and consent forms were distributed to schools to pass on to participants and their parents (see Appendix 7). The information sheets differed in their language and format. The participant information sheets contained visuals and more simplified language than the ones for parents. Nevertheless, the content of the information was consistent for both participants and parents. The content included the purpose and aims of the research, the procedures involved, information about data storage, confidentiality and anonymity. Information about rights to withdraw from the research and what would happen to the data after interviews was also included.

Participants and their parents were given the opportunity to ask questions about the research before providing written consent. Participants were directed to school staff, rather than the researcher to reduce the chance of them consenting out of pressure. The researcher met one-to-one with parents before data collection in order to verify that they were happy for their child to participate. This was also an opportunity to reiterate the contents of the information sheet in person and to allow parents to ask any questions, as well as to explore details around diagnosis and disclosure of diagnosis. This was particularly important for any parents whose first language was not English and/or had any difficulties reading. The same process was then repeated with participants before beginning interviews.

Confidentiality, Data Storage and Safeguarding

Confidentiality was maintained as much as possible from the point of recruitment. Once data was collected, audio recordings and scanned GEMs were stored securely on password-protected software which only the researcher could access. The recordings were then deleted from the original audio device and drawings from the GEM were shredded. From the point of transcription, pseudonyms were used to protect the identity of participants. No information was included within the research which identified the participants, their parents, school, school staff or the LA. However, it was made clear from the beginning that given the small sample size, there was a chance that participants and their parents may identify their own and their child's data, respectively. Participants and their parents were informed about instances where confidentiality may have to be breached in the case of a safeguarding disclosure.

Participants and their parents were informed that the data would be written up into a thesis, which could be accessible by the public at a later stage. They were also informed that, in line with the fifth principle of the Data Protection Act (1998), data would be retained for more than ten years.

Protecting Risk to Participants

Since the participants all had diagnoses of ASD, they were considered to be a vulnerable population (Humphrey & Lewis, 2008). People with ASD can struggle with changes to their routine and unpredictability (Howlin, 2004). In order to prepare them for the process and reduce anxiety about the unknown, information sheets were provided to participants two weeks before the research. In order to protect the participants' interests, the researcher enquired from the school SENCos about the participants' communication, attention, ability to manage emotions and how they respond to new people, and the type of support provided for these in school. Based on the information gathered, the support was incorporated as much as possible, making the procedures person-centred and consistent with the participants' usual methods of support. For example, visual prompts were included and, for one participant in particular, conversations about his interests were incorporated into the interview in order to help build a rapport.

It was recognised that for participants who may not have understood or accepted their diagnosis, there was a risk that interviews could exacerbate confusion and difficult feelings. The inclusion criterion that '*participants must know about their diagnosis and preferably have known for at least one year'* was included as a measure to reduce the level of psychological risk involved. Participants, who had known about their ASD diagnosis for at least one year, were likely to have processed the news more than those who had found out about it closer to the point of data collection. The length of time that participants had known about their diagnosis was initially established by SENCOs. SENCos were provided with the inclusion criteria and only recruited YP who fit the criteria. Upon meeting parents, the researcher verified details around diagnosis. All parents confirmed that YP had known about their diagnoses for at least one year by the point of data collection.

Whilst the interview may well have led to further questions about self-identity and ASD for participants, these questions are considered to be useful in the long-term, since the development of a self-concept is important in enhancing self-esteem and achievements (Franken, 1994).

People with ASD can struggle with communication and interaction (American Psychiatric Association, 2013). The first stage of the methodology, the GEM, was included to protect participants from feeling overwhelmed and to reduce the demands of social interaction, including non-verbal and verbal communication. Here, participants were not required to make eye contact or to talk, but rather were drawing or writing. Therefore, the GEM acted as a reference point between the participants and the researcher.

If participants were to display signs of distress at any stage, then the interview would have been paused or stopped. This would have been either by the researcher or by the participant. In the case of the latter, a visual prompt was provided. Any concerns that arose would have been passed on to the parents and SENCo. Having worked extensively with YP with ASD, the researcher was confident to draw upon knowledge and skills in supporting the participants if they became distressed at any stage of the research process. The researcher also had access to support and supervision within the LA and the university, which was used when required. No participants became distressed during or after the interview process and therefore did not require any additional support.

Participants were debriefed fully after the interviews in order to reduce the likelihood of them leaving the session feeling distressed. Participants were asked how they found the interview process and, in turn, talked through anything that arose, including difficult experiences and emotional responses. Participants were provided with an opportunity to ask any questions. Participants were reminded of the aims of the research and that their data would contribute to a thesis which could be accessible to the public at a later stage. They were thanked for taking part in the research and informed that they could refer to familiar adults in school after interviews if necessary. Additionally, the researcher was available to be contacted after data collection for participants, parents, and/or school staff if needed. Participants, parents and school staff were also signposted towards specialist ASD services, including the Educational Psychology Service, the LA's specialist ASD service and The National Autistic Society.

Rights to Withdraw

Participants were informed of their rights to withdraw from the research at any stage until data analysis via information sheets and during interviews. They were informed that they could tell their parents, school staff or the researcher if they decided to withdraw. It was made clear that there would not be any consequences for withdrawing, nor would participants need to provide a justification for doing so.

During data collection, participants had the opportunity to pause or stop the interview. This was either by verbally saying 'stop' or by holding up a provided stop card. A visual aid here aimed to be useful for YP whose communication skills may have been strained during anxious moments. If it was recognised that participants seemed too distressed to continue talking, then the researcher would have stopped the interview. None of the interviews were stopped and no participants withdrew from the research during or after data collection. As mentioned earlier, one parent withdrew consent prior to data collection.

3.9 Trustworthiness and Credibility

Validity and reliability are terms that have for the most part been used to assess the quality of quantitative research. For this reason, there is increased dissatisfaction when the two terms are applied to qualitative research (Smith et al., 2009). Since quantitative and qualitative methods differ in terms of their philosophical positions and purpose, alternative terminology and standards should be used to assess rigour (Noble & Smith, 2015). Terms such as trustworthiness and credibility are widely considered to be more appropriate for qualitative research methods. However, it is important to note that there are no universally accepted criteria against which to evaluate qualitative research. Further, the creativity characteristic in IPA means that any criterion which evaluates the quality of the research needs to be applied flexibly (Smith et al., 2009). Smith et al., (2009) advocate the use of criteria by Yardley (2000, 2008) to assess the quality of IPA research. For this reason, the current research focused on criteria by Yardley (2000).

Yardley (2000) draws upon four main principles to assess the quality of qualitative research – sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. The following section will outline how each of these principles has been adhered to during the research process.

(i) Sensitivity to context

Yardley (2000) suggests that sensitivity to context can be demonstrated by conducting a good quality interview whereby the participants are made to feel at ease, any power imbalance is recognised and attempts are made to diminish it, and the researcher presents as empathetic. These were all demonstrated in the interviews conducted.

Participants were made to feel at ease through the distribution of visual and simplified information sheets prior to data collection. During interviews, participants were given an opportunity to ease themselves into the process through the GEM task. Here, participants were not required to communicate directly with the researcher and rather could focus their attention on the GEM grid. The researcher's training on delivering consultation using techniques such as unconditional regard (Rogers, 1957) and pure inquiry (Schein, 1995), as well as extensive experience working with vulnerable YP helped to create empathy during the interviews.

The power imbalance between the researcher and participants was recognised by the researcher and addressed through the non-directive nature of the interview. Rather than the interview process being directed by the researcher, the participants' responses acted as a guide throughout. Therefore, the researcher's role was to facilitate the participants' thinking about their experiences.

Sensitivity to context continued to be demonstrated during the analysis of the data. Carefully interpreting how participants made sense of their experiences required a high level of sensitivity. The inclusion of extracts in the analysis section, capturing what participants said during interviews, enhanced sensitivity to the data. Including such extracts maintained the participant's voice in the write-up of the research.

(ii) Commitment and rigour

Commitment was demonstrated by making participants feel comfortable during data collection and attending closely to their verbal and non-verbal responses. The rigour of the data was presented in the analysis, through a shift from an explanation of the data to an interpretation of its meaning. Whilst presenting an in-depth interpretation of each participant's data, the emergent themes across the data sets were also drawn upon. This balance between the interpretation of the individual experiences and the common themes is mentioned by Yardley (2000) as an important feature of rigorous research.

The researcher being so closely involved in the conduct, analysis and interpretation of interviews, raises issues with subjectivity. Therefore, it is vital to remain reflective and reflexive throughout all stages of the research. Commitment and rigour to participant data was demonstrated by self-reflexivity and triangulation methods. Namely, initial thoughts and feelings were recorded by the researcher into a research diary following each interview (see Appendix 16). This was done in an attempt to set aside any preconceptions that may influence data analysis. The research diary was referred to during analysis. Time lapses were left between each interview and analysis of each data set in order to ensure that the individual experience was honoured.

Triangulation of data analysis occurred between the researcher's supervisors and peers. The researcher attended specific IPA study groups to share samples of transcripts and data analysis. Here, interpretations could be checked by others and either validated or discredited. These forums also facilitated the contribution of additional and/or alternative interpretations to the existing ones. These opportunities enhanced the commitment and rigour of data analysis.

(iii) Transparency and coherence

Transparency was demonstrated by all stages of the research being clearly outlined earlier in this chapter, including the recruitment process; the interview procedure; transcription; and the analysis of data.

Coherence in the research was shown through its fit with the underlying principles of IPA – phenomenology, hermeneutics and idiography. Phenomenology was achieved through the phenomenon being explored – YP's experiences of having a diagnosis of ASD. The researcher engaged in a double hermeneutic process, whereby the researcher attempted to make sense of the participants' sense-making experiences. A small sample size was used to allow in-depth exploration and analysis of the particular experiences of individuals, meaning that an idiographic approach was employed.

(iv) Impact and importance

Yardley (2000) states that research is truly valid if it informs the reader of something important or impactful. The current research demonstrated both these qualities since attending to the experiences of having a label of ASD told directly from those with the diagnosis is useful for those supporting the YP. Understanding the sense that YP make from having the diagnosis is important to improve their life outcomes. The scarcity of the experiences of having a diagnosis of ASD elicited directly from the

YP, in light of the importance placed on pupil voice in legislation, further highlights the value of the topic.

Chapter Four – Findings

4.1 Introduction

This chapter presents the findings that resulted from data analysis in addressing the research question – *What are mainstream secondary school pupils' experiences of having a diagnosis of ASD?* The chapter begins with a case by case overview of the participants' experiences, followed by details of diagnosis ascertained from each participant's parents. A summary of the final overarching themes and related superordinate themes is provided (Table 3). There is then a discussion of each overarching theme and related superordinate themes. The meaning of each overarching theme is initially presented, followed by an in-depth analysis of how it applies to each participant. This has been achieved through the inclusion of extracts taken directly from the data, as well as the researcher's analytic interpretations.

As described above, the findings are presented in a 'case within theme' approach (Smith et al., 2009, p. 109). This particular method of presenting findings was chosen because it is considered by Smith et al., (2009) to be the 'most orderly sequence' (p. 109). The case by theme approach seemed to be the most systematic and transparent way of representing participants' experiences. Although a 'theme within case' (Smith et al., 2009, p. 109) approach to presenting findings was not chosen, the chapter begins with a case by case overview of the experiences of having a diagnosis of ASD. This is included in order to provide a summary of the analysis for each participant, and to ensure that the idiographic nature of the research was at the forefront throughout.

4.2 Overview of Participants' Experiences

Elena

Elena conceptualises ASD as something that people are born with. She recognises both the positive and negative emotions that a person with ASD may feel towards the diagnosis, and overall believes that it is a 'good thing' to her (line 574). Elena associates ASD with difficulty interacting with unfamiliar people. Yet, she also believes that having a diagnosis of ASD means having an ability to do something. The positive effects of having an ASD diagnosis were less clear to Elena, than the negative ones.

Elena associates ASD with having past experiences of the condition, suggesting that it is something people grow out of. A past experience Elena shared was one where a psychologist worked with her to see how she was doing and feeling. Elena seemed to struggle with these sessions terminating, yet believes that their ending signified a time for her to become more independent. Elena struggles to talk about her emotions, while the psychology sessions appeared to allow space for her to do this. When these sessions ceased, it seems that Elena's space to feel also ceased, contributing to suppressed emotions.

Although Elena states that ASD is a good thing to her, the way she publicly identifies with the label suggests otherwise. Elena only wants her parents to know about the diagnosis. She believes that people would tease or pity her if they were to find out. This has led to confusion over her identity and how much she feels able to be her true self, outside of her family context.

Leo

Leo relates having a diagnosis of ASD to four main difficulties in his life – feeling nervous in front of an audience and when meeting new people; completing his homework; wanting treats but his parents not agreeing to buy them; and becoming angry when people are unkind to him. Therefore, for the most part, Leo conceptualises having an ASD diagnosis as being a deficit. He has limited positive experiences of living with the diagnosis.

Unlike with the other participants, Leo speaks explicitly about his personal experience of having a diagnosis of ASD, using the first person and sharing memories of events that have happened to him. Leo's construction of ASD appears to be based on such personal experiences.

Leo has a strong sense of justice and he struggles when he perceives something as unfair. For example, peers being unkind to Leo leaves him feeling angry and conjuring up ideas about how to seek revenge. Often these ideas involve violence, which Leo quickly reflects on as being wrong. Rather than express his anger, due to a fear of it causing destruction, he keeps it inside. Leo has a perception that people without ASD manage their anger much better, as well as their ability to complete homework. He relates having a diagnosis of ASD as having difficulty letting things go, leading to pent up anger.

Sarah

Sarah does not consider herself to have ASD. She explicitly states this and therefore either speaks about having a diagnosis of ASD from a hypothetical perspective or talks about other people with ASD. Sarah conceptualises ASD as time-limited, rather than life-long. She believes primary school aged children to be most affected by the condition and that improvements are made throughout secondary school so that by the age of 18 or 19 years, people are ‘fixed’ (line 449-450) – they no longer have ASD.

Sarah views ASD is a disability where people have difficulties with communication, interaction, cognition and health. She believes that improvements in these areas require the help of people, such as parents, teachers and peers, who do not have ASD. Sarah considers a positive attribute of having a diagnosis of ASD to be an ability to do art.

Although Sarah does not identify with the diagnosis, the difficulties she describes to be characteristic of people with ASD share similarities with her own difficulties. For example, Sarah mentioned that she has difficulties reading, which she identified as an area of need for people with ASD. Therefore, through careful analysis, Sarah’s experience of having a diagnosis of ASD appears more complex than she portrays, whereby she is linked closer to her own conceptualisation of the condition.

Mik

Mik's experience of having a diagnosis of ASD is complex. Throughout his interview, he moved in and out of different personas – beginning as fearless and guarded, before shifting to a more curious position, and then letting his guard down to expose a more vulnerable side. This cycle would repeat itself. When adopting the fearless role, Mik dissociated from ASD, stating that he did not have the condition. He based this on his belief that people with ASD present as scared, whereas he perceives himself to not be scared of anything. In his curious state, he questioned the ASD assessment process, along with the longevity of the condition and how one can be fixed. Based on information told to him by his mother, Mik considers ASD to be a behaviour problem. Therefore, once he fixes his behaviour, he will no longer have ASD. However, he lacked confidence in this narrative and questioned whether this was accurate.

Mik believes that ASD affects the way people think and communicate. He considers people with ASD to have difficulty thinking because they think multiple things at one time and are unable to select the one thing they want to say. This leads to the wrong thing or something nonsensical being said. Subsequently, Mik considers people with ASD to be best-suited to tasks that do not involve thinking.

When Mik's defences break down somewhat and he is more open, he shares important information about his own difficulties. For example, in class, he struggles when there are lots of people talking at once and he has lots of thoughts. He results in withdrawing and remaining silent because he does not know who to speak to.

This example resembles Mik's description of other people with ASD, indicating that he is closer to his own conceptualisation of ASD than he sometimes expresses.

4.3 Parent Interviews

Elena

Elena's father reported that Elena was diagnosed with ASD at six or seven years old. She was told about the diagnosis when she transitioned from primary to secondary school by her parents. When she first found out, Elena was said to be unhappy about it. However, her parents started to think with Elena more about the condition as being a 'good thing when it is mild'. This language was also used by Elena during her interview, suggesting that parental views may influence YP's perspectives of their diagnosis. Since finding out about her diagnosis, Elena's parents have had a lot of conversations with her about it and Elena also researches ASD herself. Knowledge that Elena's parents talk to Elena frequently about ASD supports an understanding that Elena is the one participant who accepts the diagnosis the most, despite wanting to keep it hidden.

Leo

Leo's mother shared that Leo was assessed at three years old for ASD, but did not meet criteria for a diagnosis. However, Leo's mother suspected that Leo did have ASD. Leo received a diagnosis of ASD in June 2017 (16 months before the point of interview) and he found out about it at the same time from the diagnostician. Leo's mother reported that Leo said 'I knew I was different' upon finding out about his diagnosis. His mother told Leo that his anxiety was due to ASD, yet also tried to talk about the condition in an optimistic way, such as by saying that people with autism are often good at art. When asked how Leo responded to the news of his diagnosis, Leo's mother said that he is trying his best to deal with it by pushing himself to do things such as go into school on days when he has Physical Education (PE), as he does not enjoy this subject. Leo's mother has bought Leo a book aimed to support YP to deal with difficulties. From this book, Leo has learnt about anger and has said that his angry outbursts are not him, but rather are his autism. Other than saying this, Leo does not talk about ASD.

Leo's mother association between Leo's anxiety and ASD is consistent with Leo's experience of having an ASD diagnosis. Leo closely connects feelings of nervousness with his diagnosis of ASD. Leo's experience of having an ASD diagnosis as being linked to his anger is something that he may have been introduced to in the book that his mother mentioned. This contextual information highlights the influence that parental views can have on how a young person makes sense of their diagnosis and identity.

Sarah

Sarah's parents reported that Sarah was diagnosed with ASD aged two and a half years old. Sarah was told about her diagnosis by an autism outreach worker and her teacher in primary school when she was eight years old. Therefore, out of all the participants, Sarah has known about her diagnosis for the longest time (eight years). Sarah received an EHCP around the same time as her diagnosis. Sarah's parents said that they did not think that Sarah has ASD, and were interested to hear the researcher's thoughts about this. It was clarified that this was not the purpose of the research and therefore the researcher would not be providing an opinion on the validity of the label. However, this information provided insight into Sarah's parents' perspectives about the diagnosis: they were uncertain if the label given was accurate or not. Sarah's parents said that Sarah does not talk about the diagnosis.

This information is important in understanding Sarah's experience of non-identification with ASD. Knowledge that Sarah's parents do not believe that Sarah has ASD provides insight into how Sarah may have developed this same belief.

Mik

Mik's mother reported that Mik was diagnosed with ASD when he was in Year 4 and that he has an EHCP. Later in Year 4, Mik was told about the diagnosis by his SENCo, an outreach worker from the LA for CYP with ASD and his mother during his annual review. Mik's mother said that Mik did not ask any questions upon learning about his diagnosis and that he does not speak about it. Because of this, Mik's mother believed that Mik's insight about his diagnosis is poor. However, she also mentioned that Mik knows why he has support, suggesting that he does have an insight into his self-concept. Unprompted, Mik's mother spoke about Mik's academic ability and behaviour as being a concern, which may lead to a change of schools. Towards the end of the conversation, Mik's mother asked the researcher to try to encourage Mik to improve his behaviour during the interview. Mik's mother's focus on behaviour and academic ability are consistent with Mik's own conceptualisation of ASD as being related to these two areas. This highlights the influence that parental views of ASD can have on a young person's understanding of their diagnosis.

4.4 The Findings

Table 3: Overarching and related superordinate themes

Overarching Themes	Superordinate Themes
1. Impact of ASD on daily life	Negative Impact of ASD
	Positive Impact of ASD
	Deficits
2. Questioning identity	Who am I?
	Dissociation with label
	How did this happen?
3. Relating to others	Splitting (ASD vs. non-ASD)
	Comparison with others
	Social interaction
4. Emotional response	Feeling out of control
	Suppressing emotions
	Wearing a mask
5. Where from here?	Time to become independent?
	Improves/disappears over time
	Change is possible
	Widening thinking

4.4.1 Impact of ASD on daily life

This theme captures what all four participants believe the impact of ASD on daily life to be. Some of the participants discuss the impact of ASD for themselves, whilst others refer to the impact for other people with ASD. Differences in experiences between participants mainly concerned what the impact of having a diagnosis of ASD was considered to be, where these ideas had derived from and the level of introspection provided by each participant. Similarities across all participants' responses are around the strong focus on the negative impact of ASD. There were some positive aspects mentioned by participants regarding living with ASD. However, these were significantly less than the negative experiences. Table 4 provides a visual representation of the prevalence at which each superordinate theme for this overarching theme occurred for each participant.

Table 4: Prevalence of superordinate themes related to 'Impact of ASD on daily life'

	Negative impact of ASD	Positive impact of ASD	Deficits
Elena	✓	✓	✓
Leo	✓	✓	✓
Sarah	✓	✓	✓
Mik	✓	✓	✓

(i) Negative impact of ASD

As demonstrated in Table 4, all four participants discussed the negative effects of having an ASD diagnosis. The negative effects were focused upon largely throughout all interviews. However, although all four participants considered having an ASD diagnosis to be a largely negative experience, there were differences in the ways that they understood these negative experiences. These differences included what the negative impacts were perceived to be, as well as how these ideas were talked about and where their conceptualisations had originated from.

The weight of the negative impact was apparent in Elena's initial GEM drawings, as well as her comments throughout the interview. Although she drew and spoke about a range of emotional responses to the meaning associated with ASD, only one of these four drawings depicted a positive emotion, happiness, whereas the other three were negative – feeling overwhelmed, anxious and depressed. Interestingly, the reason for feeling overwhelmed, anxious or depressed was the same – being teased for being different:

> Elena: 'Cause, 'cause they may get teased about, about having autism...because they might think they are a bit different about um a bit different from another person (21 -27)

Elena's difficulty articulating this response indicates a struggle that she may experience about having an ASD diagnosis and about her own experience of feeling different from others. Congruent with this idea of being teased for being different, it transpired later in the interview that Elena was keeping her diagnosis hidden from everyone, apart from her parents, due to a fear of people making fun of her upon finding out. Being teased or bullied was also referred to by both Leo and Mik, further demonstrating the factor's contribution to the negative impact of having a diagnosis of ASD.

In addition to the experience of being teased for being different, ideas about anxiety and lack of confidence emerged from the interviews. By way of example, Leo repeatedly spoke about his experience of feeling nervous when he stands in front of an audience and when he meets people for the first time:

> Leo: So that guy on the stage is very nervous in front of the audience
>
> J: He's very nervous in front of the audience? Ok, and how come you chose that for the word autism?
>
> Leo: Because that's how I feel sometimes [said very quietly] (3-7)
>
> Leo: 'cause I do get nervous if I walk in front of an audience ...And maybe if I did not have any autism, I would like be like totally fine (141 – 145)

In the second quote, Leo links having a diagnosis of ASD to anxiety, and suggests that if he didn't have the diagnosis then perhaps he would be fine. It is unclear if Leo means that without ASD he would be rid of nerves or even entirely problem-free. Either way, the sense made is that having ASD means suffering from anxiety at the very least. This is an experience that is repeated throughout Leo's interview and therefore bears significance for him.

Leo’s use of the term ‘any autism’ implies that the condition can be divided into parts, rather than simply being something that you have or do not have. This is an experience that recurs across other participants’ responses and leads to a confusion over identity, which is explored further within the second overarching theme, ‘Questioning identity’.

Sarah’s response illustrates her beliefs around ASD negatively impacting one’s life:

> Sarah: They would not interact a lot...They’re not going to have any more confidence. Like they’re going to have like a different life (222-226)

Sarah describes the negative impact that ASD can have on one’s interaction skills, which can result in low self-confidence and a having a different life to other people. Sarah’s comment ‘they’re going to have like a different life’ is vague, yet important. It seems that she did not want to elaborate further on what this different life would look like, other than reiterating that those affected would not have much interaction with others.

Later on in the interview, it became apparent that Sarah did not identify as having an ASD diagnosis. This insight into Sarah’s world provides context around a sense of distance and vagueness in her responses. This distance and vagueness is further highlighted by Sarah’s language – rather than using the first person, Sarah repeatedly talks about ‘them’ in reference to people with ASD. This not only creates a sense that all people with ASD are affected by their diagnosis in the same way, but also creates a separation between those with ASD and those without, where Sarah identifies with the latter.

During the GEM, Sarah wrote the word ‘disabilities’ on one of the four sections upon hearing the word ‘autism’. The following interchange between the researcher and Sarah further illustrates her perspective of ASD negatively impacting one’s life:

> J: Ok, what about this one? Disabilities? Can you tell me a bit more about that? Why did you write that one down?
>
> Sarah: Like young people have like disability problems, like...
>
> J: What does the word ‘disability’ mean to you?
>
> Sarah: Social problems, care problems, they need help (50-57)

Mik describes the difficulties that he believes people with ASD to have around their ability to think and, in turn, to produce coherent speech:

> Mik: People that have autism, they’re thinking one thing, and another thing and another thing and another thing and another thing in their heads so they don’t know which one to pick out so they’re just stuck, [difficult to decipher] just thinking and thinking and thinking and then they just say stuff, and then just say something which doesn’t make sense ‘cause they’re thinking too much things (488-494)

The way in which Mik expresses himself here portrays the struggle that he experiences in organising and articulating his thoughts. The repetition of ‘and another thing’ and ‘thinking’ provides the sense that Mik is experiencing that which he is describing – an overload of thoughts which are impacting on his ability to select one and generate coherent speech. Just as Mik describes people becoming stuck with their thinking, it becomes difficult to decipher what he is saying, further indicating that the extract reflects his own experience. Mik’s extract illustrates a difference between his experience and other participants’ experiences – Mik’s negativity is related to internal thinking processes, whilst the others are more focused on the external social dimension of being teased for being different. This is something that individualises his interpretation of ASD, as it is consistently a way that he defines the condition. This is further demonstrated below:

> J: What do *you* think autism means?
>
> Mik: Someone that can't think straight (592-593)

Elena, Sarah and Mik's extracts all use the language 'they' to refer to people with ASD, rather than speaking in first person to explicitly describe their own experience. On the contrary, Leo is the only participant to speak in the first person about his experience of having a diagnosis of ASD. Although there are occasions when Leo does dissociate from the condition, in general he appears much more introspective when speaking about his experiences.

(ii) Positive impact of ASD

> J: And can I ask why people might be happy?
> Elena: Because they would like, they had an exp, experience of having autism and um...and, and, and, and they would [sighs loudly] and they would like be a bit more confident about, at, from their selfs...Because um they may, they might be different and um they might be different and probably would be would be living in a different world (53-65)

Elena suggests that some people may be happy about having ASD due to having enhanced confidence. However, her difficulty in articulating her response suggests that she is not entirely convinced by her argument. Her hesitation, repetition of speech and sigh during her response provide the sense that Elena finds it difficult to think about how having an ASD diagnosis can positively impact one's life. Although Elena is presenting the idea that people may be more confident, the way in which she expresses this is with uncertainty and a lack of confidence. She rationalises that people may have increased confidence as a result of being different and living in a different world. It seems that Elena is describing her inner world, which she experiences as different to those of others. However, she continues to use the third person ‘they’ throughout her response, demonstrating a struggle to be open about how ASD affects her own life.

When describing why people may be happy about having ASD, Elena changes her tenses – beginning with past tense and ending with present. ‘...they had an experience of having autism’ gives the impression that Elena views ASD as a condition someone has in the past, which changes over time. Elena’s experience of ASD as a thing of the past recurred throughout her interview.

Despite Elena discussing the positive impact of ASD, her extract creates a more negative impression overall. It is possible that Elena would like there to be or believes that there are positive attributes of having ASD, but struggles to talk about these because it is not something that she has experienced or has knowledge of.

Similarly to Elena, Leo’s experience of the positive impact of having ASD appears to be limited and unconvincing:

> Leo: Maybe ‘cause when you keep begging your parents to buy something, maybe they might listen to you just so they can stop begging...‘Cause maybe just they’re too tired of you keep begging or just to make you happy (on what is good about having autism)(290-298)

He suggests that having ASD may be advantageous in situations where one repeatedly asks his or her parents to buy something, as the parents may give in as a way of ending the pleading. In one way, Leo’s response indicates that his parents may buy him what he wants because the begging is irritating. Whereas, Leo’s proposal of an alternative reason that he might be bought things, ‘just to make you happy’, points towards the idea of ASD evoking sympathy from others.

However, analysis of Leo's language above provides different insight into his thoughts around the positive impact of ASD. Rather than saying that parents might buy something to end the begging, Leo says 'they might listen to you'. This is a subtle, yet important distinction. From Leo's response, it seems that he is not necessarily begging his parents to be bought things, but rather wants them to listen to him – receiving gifts appears to be metaphorical for being listening to.

Sarah proposes that the positive effect of having an ASD diagnosis is an ability to draw and colour:

> J: Ok, and do you think there's anything to like about having autism? Do you think there's anything good about it?
>
> Sarah: Well people like to draw. Draw and colour. I think that's the best thing for children, if they have autism (189-192)

Here Sarah shifts from talking about 'students' (line 186) to 'people' and 'children'. This is something that Sarah does frequently throughout her interview, creating an overall sense of infantilisation for those with ASD. The latter half of the quote reinforces this idea of infantilisation – 'that's the best thing for children, if they have autism.' This implies not only a view that all children with ASD are good at drawing and colouring, but also that this is where their abilities end. Further, Sarah's interchange of 'students', 'people' and 'children' indicates a state of confusion regarding the time in which ASD impacts one for.

Mik proposes that people with ASD may be good in areas where they don't have to think, such as sports and games:

> Mik: I don't know, probably like sports...where they don't have to think...Um...games...'Cause you're barely thinking of anything (on what people with autism may be good at) (396-397 & 425-430)

This is an interesting example since Mik previously spoke about his passion for boxing and named PE as a subject in school which he enjoys. Therefore, although he is speaking about people with ASD as other to himself through the use of the pronoun ‘they’, it seems that he may actually be talking about himself. In this sense, Mik seems to perceive himself as finding thinking difficult and as being unintelligent. Again, Mik’s experience of ASD focuses on internal thinking processes.

As with the other participants’ comments about the positive impact of having an ASD diagnosis, Mik’s response lacks conviction. Rather than describing what is positive about living with ASD, Mik’s account further highlights the negative impact of having the diagnosis – difficulty thinking. It seems that for Mik, being good at sports and games are only by-products of being cognitively disadvantaged from having a diagnosis of ASD. Both Sarah and Mik’s comments provide insight into their thinking that people with ASD have limited capabilities and therefore are better off focusing on areas which are not academically challenging.

All extracts discussed illuminate a shared experience that positive aspects of having a diagnosis of ASD are difficult to articulate and are not particularly tangible or convincing. This creates a sense that the negative aspects of having ASD are more dominant for the participants.

(iii) Deficits

ASD being viewed as a deficit was something that dominated all of the participants’ interviews. The differences between participants were around *how* the deficit impacted one’s life. Whilst Elena spoke about ASD making people feel overwhelmed due to being teased or pitied by others, Leo viewed it as contributing to anxiety. Sarah referred to the communicative and cognitive impairments that she believes are associated with ASD, whereas Mik conceptualised ASD as being a behaviour problem.

Elena provides the sense that living with ASD is a deficit, since she mentions that the label would evoke teasing or sympathy from others:

> Elena: They might feel a bit overwhelmed because if someone says ‘ahaha, you have autism’ and someone said and then someone said ‘aw you have autism haha’ [singing] and then they do a bit of a tease to them and that’s why and that’s why (41-45)

Once again, she uses the third person ‘they’ as a way of dissociating herself from the label. However, her use of quotes to demonstrate what people might say upon learning about one’s diagnosis presents a sense that she is either speaking from experience or from her imagination. Either way, the quotes provide insight into Elena’s inner world, in which she views having a diagnosis of ASD to be a deficit that leads to taunting and/or pity.

Leo draws upon his experience of feeling nervous when he goes in front of an audience:

> Leo: I still don’t like homework, I still feel a bit [inhale] nervous going in front of an audience, and I still you know feel like very angry inside if someone keeps complaining of, you know, stuff (689-692)

Leo appears to relive this anxiety by taking a deep inhale when talking about this. Although it became apparent during the interview that by ‘audience,’ Leo is referring to his experience of being on stage performing, the word may also have a dual meaning for him. Leo’s use of the word may well be reference to the literal experience of him stepping on to a stage, as he has previously done at school, yet it may also have a metaphorical meaning, whereby Leo is equating an audience to other people and being on stage to social interaction. This suggests the cost and effort that are involved with social interaction, whereby Leo's exposure may lead to him representing a false self, as well as to receiving judgement from others.

As the interview nears the end, Leo timely mentions how things have remained the same throughout his life so far: as well as still being nervous in front of an audience, he still does not like homework and still feels angry when people complain or are unkind to him, all of which Leo associates with having an ASD diagnosis. Leo's comments give the impression that he blames these difficulties on ASD. The repetition of 'I still' implies that these are aspects of Leo's self that he is unhappy with and wishes to change. Leo's hope for change points towards ASD as being a deficit in his mind.

Sarah's comment presents her belief that ASD is a cognitive deficit, leading to impaired speech and Literacy abilities:

> Sarah: I think some people like they have problems to speak like they can't speak like complicated words. They talk with like shorter words...I think like some people, they like haven't learnt how to write properly and some people like with reading, they have some difficultly like with seeing the words or they don't understand what they mean (5-7 & 24-27)

The way in which Sarah expresses herself here may be a reflection of her own difficulties. Her repetition of 'like' and the grammatical errors suggest that she too may find speaking to be a struggle at times. Therefore, the parallel between her conceptualisation of the diagnosis and the way she expresses herself creates confusion around her self-concept. The extract gives the impression that people with ASD struggle day to day, with various aspects of their communication and learning. Again, Sarah’s language highlights her experience of disconnecting from ASD – she repeatedly uses the word ‘they’ to refer to people with ASD, separating herself from the condition.

Mik describes how his diagnosis was revealed to him by his mother:

> Mik: She told me Mik you have problems, and I said what problems and she was like oh you have autism and all this other stuff and then she was like oh behaviour problems (265-267)

Mik’s conceptualisation of ASD as a behaviour problem appears to have derived from the way that he was informed about having the diagnosis. As with Leo, Mik has shifted to speak about his ASD in the first person as he recounts this event. Therefore, Mik has temporarily dropped his defence and is being more open. This is a significant moment for Mik, since up until this point, he has been reluctant to share any personal information and has presented as guarded.

Repetition of ‘problems’ emphasises that Mik sees ASD as a deficit, or that he believes other people to perceive it as a deficit. Mik’s quote is powerful as it illuminates his experience of a label having negative associations which deny individuality. When recounting his experience of being told about the diagnosis, he shifts from ‘you have autism’ to ‘all this other stuff’ and ending with ‘behaviour problems.’ All three parts of this quote leave a sense that Mik’s individuality has been reduced to labels and deficits, which may have been contributed to by other people’s perceptions.

Within Elena and Mik’s extracts, there is a focus on other people’s perceptions. Both participants frame their understanding of having a diagnosis of ASD around what other people say or think. Arguably, this is also prevalent in Leo's extract when it is understood that his anxiety is related to social interaction and being in front of an audience. Sarah's extract represents a slightly different angle, since she does not identity as having ASD. However, through dissociating with the condition and discussing her ideas about the deficits inherent in people with ASD, her experience is still characterised by perceptions of others.

4.4.2 Questioning identity

This theme concerns how the participants view themselves in light of having a diagnosis of ASD. Thinking around who they are and how they relate to ASD, in the most part, led to uncertainty and questions about their identity. Questioning one's identity not only involved thoughts about their present self, but also consideration about the past and the diagnostic process which led to today. Table 5 presents the prevalence at which each related superordinate theme for this overarching theme occurred for participants. As can be seen, all of the participants questioned their identity in some form.

Table 5: Prevalence of superordinate themes related to 'Questioning Identity'

	Who am I?	Dissociation with label	How did this happen?
Elena	✓	✓	✓
Leo	✓	✓	✓
Sarah		✓	
Mik	✓	✓	✓

(i) Who am I?

J: And do you like having autism?

> Elena: Umm yeah. People don't talk about it too much, apart from my parents...Um no one doesn't really talk about my autism really... (195-197 & 208)

Upon being asked if she likes having autism, Elena responds hesitantly. She says that she does like it, before going on to say that people do not talk about it, except her parents. Elena's response reveals a sense that she is uncertain if she likes having an ASD diagnosis, or what it even means to have the label because she does not have much opportunity to explore this part of her identity. The silence around her having the diagnosis seems to leave her unsure about who she is.

Fitting with this idea of uncertainty around identity, the latter half of the quote demonstrates further confusion. Elena tries to repeat that people do not talk about her autism. However, the way she expresses herself by using a double negative, 'no one doesn't', changes the meaning of the sentence entirely. The sentence actually translates as people *do* talk about her autism. Although this does not appear to have been Elena's intention, it reveals a sense of confusion regarding her identity. Ironically, it seems that everyone's silence around Elena's ASD makes the issue even louder for Elena. Keeping a part of one's identity hidden creates a taboo around that aspect of the person. Further, for the first time in her interview Elena says 'my autism'. This gives the impression that Elena is connecting to the condition and does regard it as a part of who she is. Therefore, Elena has integrated both fondness and shame for her ASD, creating an overall sense of confusion about her identity.

Leo tries to draw an association between disliking homework and having a diagnosis of ASD. As he does so, he questions whether he has ASD:

> Leo: Yeah 'cause even though I hate homework, I think that I have autism too (363-364)

This is the first time in Leo's interview whereby he explicitly names having a diagnosis of ASD, yet appears unsure about whether he does or not. The way Leo has phrased this statement is confusing. He is attempting to provide a rationale for hating homework, which he has previously said is due to having ASD, yet the first part of the above statement suggests that Leo does *not* think ASD and dislike for homework are connected. The perplexity Leo presents here reflects his overall confusion with his diagnosis and the impact of such for him.

Mik's questioning reveals confusion over his diagnosis and identity:

> Mik: How can one person says I have autism and then [difficult to decipher]...And then everyone else thinks I have autism? (241-244)

Mik speaks in first person about his autism, which he has mainly avoided doing up until this point, indicating a softening of his defensive self. He begins to reflect on the ASD diagnostic process and questions how one person can determine a part or even all of who is he, leading others to see him in this way too. Poignantly, Mik appears to be expressing an uncertainty about having ASD and questions how other people can perceive him as having the label if he himself does not identify with the diagnosis.

(ii) Dissociation with label

Dissociation with the ASD label was a theme pertinent to all participants, yet particularly so for Sarah and Mik. It is unsurprising that this was a dominant experience for Sarah and Mik, when considering that neither of them fully believed they had ASD. Although this rejection of the label was less clear-cut for Mik than

Sarah, indicated by his questions and contradictions, it was nevertheless apparent that he frequently dissociated from the label. Thus, the degree and way of dissociation from the label differed markedly across participants, ranging from externalisation of difficulties to explicit non-identification with ASD.

Elena attempts to describe why she does not want anyone to know that she has ASD:

> Elena: Because, because I don’t want no one to know that I have Autism Spectrum Disorder and I want, my parents know that I have it, but I don’t want no one to know that I have it (217-219)

Elena does not seem clear at this stage about the reason for not sharing her diagnosis with anyone apart from her parents, but rather repeats her point that she does not want anyone to know about it. This repetition indicates the weight of her view about the label being kept hidden from others.

Although Elena explicitly identifies as having ASD, the quote also leaves an impression that she wants to remove herself from the label, particularly in the face of anyone external to her family. Interestingly, Elena refers to ASD as its full name. It seems that Elena wants to keep her diagnosis a secret from everyone other than her parents because she considers it to be a disorder – as the name denotes.

Leo describes one of his drawings from the GEM:

> Leo: So that guy on the stage is very nervous in front of the audience
>
> J: He’s very nervous in front of the audience? Ok, and how come you chose that for the word autism?
>
> L: Because that’s how I feel sometimes [said very quietly] (3-7)

Although it becomes clear that Leo is talking about his own experience, he uses the drawings and the language ‘that guy’ as a way of externalising his difficulties. When asked why he chose to draw that particular image upon hearing ‘autism’, he very quietly responds saying that the picture illustrates how he sometimes feels. Leo’s quiet volume here indicates that it may be difficult to talk about having a diagnosis of ASD, and those characteristics that he associates with the condition (in this case, nervousness). Although Leo’s dissociation from the label in this instance and throughout his interview is much more subtle than is seen by some of the other participants, it is nevertheless apparent, and an indication of a struggle to accept having ASD.

Sarah’s response to whether she likes having autism is a much more explicit example of her dissociation from the label:

> Sarah: I don’t have autism before, so if I would, if I would have autism then the answer’s no...No, I wouldn’t like it (179-183)

Sarah states that she does not have autism, demonstrating that she does not identify with the diagnosis, but if she did have it, then she would not like it. Despite appearing clear that she does not identity with the diagnosis, the way Sarah expresses herself is slightly confusing. Rather than saying ‘I don’t have autism’, Sarah says ‘I don’t have autism before...’ The difference here provides insight into the way Sarah conceptualises the condition – seeing ASD as something that people grow out of by a certain age. This interpretation emerges repeatedly throughout Sarah’s interview.

Sarah not only dissociates from the label throughout the interview, but also dissociates from having any difficulties. Her struggle to think about her own difficulties manifested through avoidance. This is demonstrated below when Sarah was imagining how having an ASD diagnosis would impact her life outside of school:

> Sarah: Like maybe you may not like it...Time at home, like spending time – you might not like that. You'll be thinking about those problems (257-260)

This quote provides insight into Sarah's avoidance of thinking about one's difficulties: she reasons that people with ASD would not like to have time at home because this would mean time to think about their problems. Further, Sarah's avoidance in exploring herself created a sense that she may not have been as certain about her identity as she was portraying. Sarah consistently seemed to experience uncertainty about her identity.

Similar to Sarah, here Mik presents his experience of not identifying as having a diagnosis of ASD:

> Mik: So no one has autism, it's just people trying to say they do...I don't care, I don't have it (299-300 & 312)

However, unlike with Sarah, Mik's non-identification with the diagnosis appears to change throughout his interview, whereby sometimes he holds a firmer stance than other times.

Mik's quote begins with him trying to understand how people come to have an ASD diagnosis. He questions the diagnostic process and searches for evidence to reject his own (and other people's) diagnosis. Mik's thinking around diagnosticians trying to misdiagnose people as having autism indicates his resentment towards these professionals. It seems that Mik is locating blame in the diagnosticians for making incorrect judgements. The latter part of the quote reveals Mik's attempt to appear apathetic – 'I don't care'. This statement seems like a contradiction to how Mik really feels – that he does in fact care greatly about who he is as he knows himself, and who he is as other people are trying to dictate. He ends by saying 'I don't have it' – an explicit dissociation from the label.

(iii) How did this happen?

Each participant provides a different viewpoint about how he or she (or other people) result in receiving an ASD diagnosis. Although some comments are less explicitly linked to this experience than others, they still all provide insight into how each participant understands the process.

Elena describes how people are born with autism, rather than it being acquired:

> Elena: Autism means um...like um like what people are born with...Having past experiences about it (157-166)

Elena also mentions that people with autism have past experiences of it. 'Having past experiences' is something that Elena frequently talks about throughout, which relates to her conceptualisation that the condition is not necessarily fixed and changes over time.

Leo reasons that he has ASD because of things that he dislikes in life, such as homework and people being unkind towards him:

> Leo: Yeah 'cause like there's a couple of things I don't like you know in life you know...Like homework and [difficult to decipher]...People annoying me... (Reason for receiving a diagnosis) (536-541)

Leo trails off, making it difficult to hear him talk about people being unkind. His struggle to clearly articulate himself in these moments indicates a difficulty talking about these issues. It is unclear and difficult to interpret if Leo believes that he has ASD because of these two particular things that he does not like or due to disliking things in his life in general. Either way, Leo's understanding seems to be that having a diagnosis of ASD is connected to him not being able to let things go that cause him upset. Rather than being able to enjoy homework or forget about occasions when people have been unkind, Leo becomes angry and upset, yet does not express these feelings, leading to further distress. Leo's experience of ASD as being linked to his emotional responses is reinforced when he discusses how people who do not have ASD may respond to losing in a game show:

> Leo: Maybe people might feel a bit annoyed but maybe just cheer for that guy who won, the person who wins the show (759-760)

The example of how those without ASD are able to control their frustration and still be happy for the winner indicates that Leo perceives himself to have difficulties regulating his emotions, which he links to having a diagnosis of ASD. This idea relates to his experiences of feeling out of control and suppressing emotions, which are discussed later in the chapter.

The below extract demonstrates Mik's questions about the diagnostic pathway and how he came to be labelled as having ASD:

> Mik: How do you know if someone has autism? [said very quietly]...How do you know if someone has autism?...So sometimes they're not 100%. So how do you know I have autism?...How can one person says I have autism and then [difficult to decipher]...And then everyone else thinks I have autism?... I've not been for no test (223-246)

Mik begins by speaking very quietly, so much so that he has to repeat himself. This highlights a discomfort with the topic and perhaps a fear about what the response to his question will be. Despite this possible discomfort and fear, Mik remains curious and inquisitive as he tries to make sense of his label and how this came to be. Mik's language when referring to the diagnosticians, 'they', creates a sense of separation between them and him.

Mik then poses the questions to the interviewer – 'So how do you know I have autism?' His search for answers in all directions leads to an impression that he is frustrated with how things have unfolded regarding his identity. He queries how one person labelling him as having autism leads to everyone around him perceiving him as having the diagnosis. This poignant question points to the issue of power between diagnosticians and service users, particularly when the latter are too young to comprehend what is taking place. By being labelled as having ASD, Mik appears to experience a lack of control over other people's perceptions of him. Rather than being involved in a significant decision over his identity, he learns of his diagnosis later in life and then has to manage other people's perceptions of him.

'I've not been for no test' either indicates Mik not being able to remember the assessment or his refusal to accept the diagnosis. Mik's experience is unique in that it is characterised by him questioning the processes that lead to diagnosis and the validity of the diagnostic assessment.

4.4.3 Relating to others

This theme encapsulates the comparisons that participants draw between themselves and others, as well as the difficulties they experience with social interaction. Often participants tried to make sense of having a diagnosis of ASD by polarising those with ASD against those without. This polarisation or splitting appeared to serve a function for participants – rather than exploring the complexities for people with and without ASD, participants tended to locate difficulties in the former and strengths in the latter. By creating this clear-cut image of what it means to have ASD, participants restrict their thinking around the topic. For some participants, namely Sarah and Mik, splitting off negative attributes into people with ASD and positives into those without the condition, seemed to serve an additional purpose. As well as attempting to simplify a complex issue, the polarisation of attributes, on occasions, dissociated Sarah and Mik from ASD.

Table 6: Prevalence of superordinate themes linked to 'Relating to others'

	Splitting (ASD vs. non-ASD)	Comparison with others	Social interaction
Elena			✓
Leo	✓	✓	✓
Sarah	✓	✓	✓
Mik	✓	✓	

(i) Splitting (ASD vs. non-ASD)

> Leo: Maybe they would just, maybe he will just be happy to have homework – he would do it like in no times like straight when he came home, he gets changed and does his homework (about someone who doesn't have ASD) (371-374)

Leo describes how people who do not have ASD would be able to easily and happily complete their homework. He begins by referring to such people as 'they' and then changes to the singular male 'he', perhaps indicating that Leo is imagining a different version of himself, where he does not have ASD and is able to complete his homework with ease. Leo's repetition of 'just' gives the impression that beginning homework is easier for people who do not have ASD. Leo's description provides insight into his view that people who have ASD struggle to get on with a task, whereas those without ASD function more easily and efficiently. Leo's comment also suggests that these differences between the way he carries out his homework and the way those without ASD do are fixed.

Leo also seems to split the ability to emotionally regulate between people with and without ASD:

> J: Ok. Leo, do you think other people with autism get really angry inside when people are mean to them?
>
> Leo: I think some people, I'm pretty sure
>
> J: Some people, and what about people without autism?
>
> Leo: No I don't think they do much, I think they just tell the teacher (490-495)

This excerpt further illustrates Leo's belief that people without ASD manage more easily on a daily basis. He speaks about people with ASD as becoming angry when others are unkind to them, but does not apply this to those without ASD. Rather than becoming angry and not expressing it, people without ASD just simply tell the teacher.

Sarah reiterates a belief that that people with ASD have difficulties with verbal communication and reading, whereas those without ASD are proficient in both these areas:

> Sarah: People who have autism have, people who have autism have difficulties like they can say like one word only and the non-autism, who doesn't have autism, they can say longer words and longer sentences. And then with reading like, the non-autism people have good understanding of reading and while the others, whoever have autism does not have good understanding of reading, well they do but not a lot (415-421)

Sarah's description of people with ASD only being able to say single words, whilst others can produce long words and sentences, infantilises the former and makes them seem less intelligent. The description implies that Sarah experiences all people with ASD to fit into the same category, and all those without ASD to fit into a different category. These two categories are deficit and strengths-based, respectively, creating a split.

Sarah's struggle to articulate herself at first mirrors the difficulties that she is describing. Inadvertently, this connects her closer to her conceptualisation of ASD. During the latter half of the extract, Sarah retracts her statement that people with ASD do not have a good understanding of reading. Her thinking appears to have shifted here, whereby she contemplates that the differences between reading ability in people with and without ASD may not be so straightforward. Sarah concludes that people with ASD do have some understanding of reading, but not a lot. It seems that polarising abilities of the two groups helps Sarah to make sense of the complexities.

Mik rationalises not having a diagnosis of ASD as being unafraid to speak his mind and not feeling threatened by anyone. On the contrary, he believes that people with ASD are scared to say certain things and perhaps do feel threatened by people:

> Mik: I don't have autism
>
> J: You don't have it, ok. So it's not something that you think you have. How come you seem quite sure about that?
>
> M: 'Cause I aint scared to say nothing
>
> J: You're not scared to say anything, ok. And you think people with autism are probably scared to say stuff?
>
> M: Yeah. I aint threatened by no one (314-320)

Therefore, Mik has created a split in the fear response between people with ASD and those without. This split appears to serve an important function for Mik – the dissociation of himself from having ASD.

The following excerpt further demonstrates Mik's split thinking between people with and without ASD with regards to cognitive processes:

> Mik: They could be thinking like, they could be thinking like 6 different things...Yeah and like they don't know which one to pick out
>
> J: And people who don't have autism, do you think they find it easy to think?
>
> Mik: Yeah (404-414)

Again, Mik associates ASD with difficulties thinking. He describes how people with ASD have an overload of thoughts and struggle to select a single one, whilst maintaining the view that people without ASD find thinking easy.

(ii) Comparison with others

> Leo: Like I don't really enjoy Maths, Math that much
>
> J: Why don't you enjoy Maths?
>
> L: I don't know, it's just...Well one person does – she *loves* Maths. She's like so good at it, oh my god. It's like I don't understand what they keep talking about (392-397)

When asked why Leo does not enjoy Maths, he responds by referring to a peer who loves the subject. Leo's pauses and hesitation highlight the struggle he has in explaining why something may be difficult for him. He results in attempting to understand himself by drawing comparisons with others. His emphasis on the word 'loves' and the exclamation 'oh my god' reveal Leo's astonishment at his peer's abilities and a sense that her skills are impossible for him to achieve. Towards the end of the quote, Leo says that he does not understand what 'they' keep talking about. Without knowing who 'they' refers to, there is an impression that Leo feels different or alone in something.

At the end of the interview, Sarah draws similarities between herself and her peers in terms of reading ability:

> Sarah: Same in reading...I think all the children like 16 or 17...They have difficulties a bit in reading (506-512)

Sarah mentioned her difficulty with reading a few times throughout her interview. Considering this in light of Sarah's belief that she does not have ASD is interesting. Earlier in the interview, Sarah spoke about people with ASD having difficulties with reading and those without ASD being good at reading. Here, Sarah likens herself to other YP of her age, saying that they all have some difficulties with reading. As the interview comes to an end, Sarah seems to make a final attempt to dissociate herself from ASD. By saying that she has the same reading difficulties as her peers, it is as if she is proposing that they all find reading a bit difficult, yet none of them have ASD. Whether Sarah's final remarks connect her closer or further away from ASD, her thinking around the issue widens. She considers that reading difficulties are not only characteristic of people with ASD, offering that there may not be such a clear-cut divide as she has previously made out.

Mik says the following statement after stating that he does not have ASD, and before questioning the diagnostic process:

> Mik: Anyone can do something then I can do it as well (239)

He draws comparisons between himself and others, saying that he is able to do things just like anyone else. Given the context around this quote – non-identification with the diagnosis – it is inferred that Mik is comparing himself with others in order to add weight to his belief that he does not have ASD. Since it has been established that up until now Mik regards ASD as a deficit, his statement here dissociates him from the diagnosis. The comment implies that people who do have ASD are not able to do things as well as those without the diagnosis.

(iii) Social interaction

> Elena: Yeah I just don't have any, much friends...Yeah 'cause I can't, um sometimes I can't, um talk to them, and I feel a bit nervous to talk, to talk to them...Um I just, I just um, I just um, I'm not sure. I think um, I just...I just, [deep inhale] I'm not really sure...um I may, um may, may st, may stay quiet or go to them and say 'hi do you want to be friends?' and yeah...I'm not really sure how to say it [said very quietly] (425-440)

Elena describes her difficulty interacting with people and making friends. Her expression vividly echoes her experience – repetition, pauses and hesitation highlight the struggle that Elena has with social interaction. The deep inhale in the middle of the extract gives the sense that making new friends is a tiring process, and one which Elena does not feel confident navigating. Elena ends by saying 'I'm not really sure how to say it', despite having just bravely shared her experience. This comment seems to have a dual meaning – Elena is not only unsure how to talk about social interaction, but is also unsure how to go about it. She explains what she does in social situations to interact – either stays quiet or approaches others and asks if they want to be friends. Knowledge of Elena's inner conflict (keeping her ASD diagnosis a secret vs. being herself) helps to understand staying quiet as hiding her identity and approaching others as exposing her identity.

Leo reiterates the connection between having ASD and feeling nervous:

> J: Could you tell me a bit more about why having autism might make people nervous?
>
> Leo: Um...'cause...maybe meeting people they've never met before

> J: Hmm, what about that – meeting people you've never met before?
>
> Leo: Um...you know it just makes you nervous you know (153-159)

Leo proposes that people with ASD might feel nervous about meeting people for the first time. However, he experiences difficulty in elaborating on why meeting people would cause anxiety. Similar to Elena, Leo's difficulty in talking about interacting with new people mirrors his experience to do so. This struggle is highlighted through pauses, hesitation and repetition of 'you know'. The use of 'you know' seems to be an attempt to alleviate Leo's discomfort around the topic.

Sarah explains her belief about people with ASD having communication and interaction difficulties:

> Sarah: Like some people like don't know how to communicate with other students...I think like some people, they don't know how to interact with other people. Like they're too scared to talk (61-62 & 136-137)

Sarah's comment, 'they're too scared to talk', creates a sense of two separate groups – those with ASD and those without. As has already been seen, both Sarah and Leo's comments insinuate that everyone with ASD share the same difficulties. Further, Elena, Leo and Sarah's quotes all focus on anxiety around social interactions.

4.4.4 Emotional response

This theme captures how three out of four participants experience an emotional response to having a diagnosis of ASD. The responses are mainly around hiding one's emotions and being an inauthentic version of oneself. Two out of three of these superordinate themes originated from Leo's interview. This highlights how Leo's experience of having an ASD diagnosis is largely characterised by strong emotional responses. Sarah's interview does not correlate with any of the specified superordinate themes (see Table 7), which is thought to be linked to Sarah's non-identification with ASD.

Table 7: Prevalence of superordinate themes related to 'Emotional response'

	Feeling out of control	Suppressing emotions	Wearing a mask
Elena		✓	✓
Leo	✓	✓	✓
Sarah			
Mik	✓	✓	✓

(i) Feeling out of control

> J: Does having autism make a difference to you at school at all? So I'm not talking about home, I'm not talking about with your parents giving you things-
>
> Leo: Oh I know...Ok so in a lesson, so like when I'm focused on the work but all the other kids just mess around and then the whole class has to stay in and I just stay in for no reason which just seems very unfair to me which [difficult to decipher]... it's not my fault if the whole class stays. It's just the people who mess about, so apparently the whole class has to stay, which just seems a bit unfair and I wish they could change that (415-424)

Leo conveys a strong belief in fairness throughout his interview. This includes his previous grievances about not being bought treats, feeling angry at people who are unkind to him and the above example, where Leo is made to stay in class during break time due to his peers being disruptive. In all these events, Leo feels wronged and conjures up ideas about how to make things fair or seek revenge. However, Leo is repeatedly met with an internal conflict upon planning his revenge or justice – he reminds himself of the consequences of his revenge seeking behaviour. As a result, Leo does not act, leaving him feeling stuck or out of control.

As with other responses provided by Leo, the above is an example of a specific event that he was involved in. His interjection when the interviewer is speaking indicates that he is eager to discuss this. Apart from at one point in the middle of the extract, Leo speaks clearly, further highlighting his readiness to verbalise this thought. Leo's clarity in his description provides the sense that this event is one that he has previously thought about, and perhaps to the extent where it has become a preoccupation.

Leo's repetition of 'unfair' emphasises his feelings towards the issue. He ends by saying that he wishes that 'they' could change the system. There is a parallel here to Leo's feelings towards his parents regarding buying him things and towards people who are unkind to him – his wishful thinking suggests that the matter is beyond Leo's control. Whilst school staff are the decision makers in the above scenario, in other examples Leo uses the language 'I wish', where he could have more control in achieving change.

Mik's loss of control seems to be contributed to by other people disclosing his ASD diagnosis, without his knowledge or consent:

> Mik: Some woman told my mum that I have autism and then from then on my mum thought I have autism and every school I went to she told them I have autism (248-250)

Mik believes 'some woman' – most likely to be the diagnostician – is to blame for other people, including his mum, perceiving him as having a label of ASD. Mik's description of his diagnosis spreading amongst people conveys a frustration. Despite these disclosures being about Mik, he does not appear to be involved in this train of communication. When Mik says 'every school I went to', there is an impression of him wanting to break this cycle by escaping the diagnosis. However, even in a new school, the news of his diagnosis follows him. Mik's position appears to be passive and helpless, whereby he does not seem to have control over other people's perceptions of him.

(ii) Suppressing emotions

> J: But you think the psychologist came to see you because of something to do with you having autism?
>
> Elena: No it's that he wants to talk to me to see how, how I'm doing, how I'm doing and yeah
>
> J: How you're doing in what?
>
> Elena: Um how I'm doing, how I'm doing, um how I'm *feeling*
>
> J: And was it a bit hard when he left? Was it a bit sad?
>
> Elena: Yeah a bit sad and my parents told me to calm down a little bit (728-736)

Prior to this excerpt, Elena shares an example of what she means when she says 'having a past experience' of ASD (line 643). The example she discusses is one where a psychologist visited her a few times. Elena said the sessions were not connected to her having ASD, but rather were to see how she was doing and feeling. She emphasises her tone when she says the word 'feeling' highlighting the importance of this for Elena.

Elena mentions that it was sad when the sessions with the psychologist were over, and that her parents told her to calm down. Her repetition of 'a bit' appears to be an attempt to dissipate the painful feelings experienced. In accordance with her parents' suggestion, Elena tries to suppress her emotions following the psychologist leaving. Without the psychologist, there is the sense that there is no more time or space to feel. As Elena is told to calm down, it seems that her feelings are buried, along with her memories of the sessions with the psychologist.

As has been illustrated, Leo has a strong sense of justice and desire to make things fair. However, he frequently faces an inner conflict between seeking revenge and not acting due to the risk of getting into trouble. This conflict is represented below:

> Leo: Yeah, it’s like when a person keeps complaining of things and, and to me and I get, I feel like beating them up so badly and you know like doing very bad stuff to him like maybe...you know...just very bad things...Yeah but I don’t want to do that because I’ll get in trouble...but it might make me like maybe better if like all my anger like came out...Yeah but I keep that anger inside and I wish I could just let it all out (446-462)
>
> Leo: Yeah so I felt like you know the same thing as this person like dropping a something, doing something bad like throwing them on the volcano...You know I mean would not want to do that you know because it’s not good (551-556)

Leo describes the anger he experiences when someone is unkind towards him. He wants to seek revenge by badly beating the person up and doing other ‘very bad things’. This description provides insight into Leo’s violent fantasies. Leo begins by talking about wanting to beat ‘them’ up, but then changes to ‘him’, indicating that he may have a specific person in mind.

Leo is hesitant when describing how he would seek revenge, pausing often and repeatedly saying ‘you know’. As his moral self takes over, Leo appears to feel uncomfortable sharing his thoughts. He then battles between wanting to and not wanting to do very bad things because releasing his anger may make him feel better. At the end of the extract, Leo poignantly reflects on how he suppresses his anger and wishes that he could let it all out. Again, Leo uses the language ‘I wish’, as if he is not in control of his emotional response. After weighing up the pros and cons of releasing his anger, he seems to resign to a passive position, since expressing anger does not feel safe.

Although all the named participants suppress their emotions in a different way, Leo is most explicit about this. His experience of having an ASD diagnosis is uniquely characterised by his internal battle between keeping his feelings inside and releasing them in a violent manner.

(iii) Wearing a mask

> J: Why do you not want people to know that you have autism, apart from your parents?
>
> Elena: It’s because that um...it’s because that people might um, might make fun about autism and um, yeah...Yeah and the way I am...Um not really sure, it’s just that I don’t really like, got um, really like hiding my...myself and yeah (250-256 & 367-368)

Elena is hesitant when expressing why she does not want people to know that she has ASD, indicating a discomfort with the topic, and perhaps a difficulty with hiding her identity. Elena explains the reason as being a worry about people making fun of her upon finding out about the diagnosis. She shifts her language from saying people might make fun of ‘autism’ to speaking in the first person – ‘the way I am...’ In the former, Elena portrays a disconnect between herself and her ASD, whilst in the latter she seems to integrate the two. Elena’s conceptualisation suggests that by wearing a mask or hiding her diagnosis she is inhibiting her true self.

The ambivalence Elena experiences around this is demonstrated in the second half of the extract (lines 367-368). Elena is unsure about why exactly people would make fun of ASD, highlighting her confusion around keeping it a secret. Whether intending to or not, Elena then proceeds to say that she does not really like hiding herself. The language speaks to Elena’s inner conflict between being herself and hiding the diagnosis. The quote creates an impression that Elena would like to discard the mask and be her true self.

Leo describes his experience of frequently losing games involving artificial money:

> Leo: ...when we play games and I’m usually the first one who loses, I feel a bit, I feel a bit annoyed and kind of angry inside...I’d feel so annoyed ‘cause I could buy so many things with that amount of money and I’d feel very annoyed, you know...Well I don’t tell them that, I just feel inside that I really wish I could win (720-737)

Although he is aware that the money is not real, he still becomes frustrated at the hypothetical loss of the opportunity to spend the winnings. Leo’s repetition of feeling annoyed emphasises his level of frustration. Leo also mentions feeling ‘angry inside’, which highlights his anger manifesting internally, rather than externally. As was explored within ‘suppressing emotions’, Leo seems to keep his feelings inside out of fear of them causing destruction if expressed. The mask he wears is further illustrated in the latter part of his comment – unprompted, Leo confirms that he does not verbalise how he feels towards the other players, but rather just feels inside how much he wants to win. Once again, he conveys his wishful thinking, implying a loss of control. Rather than being able to consider winning or *how* to win, Leo resorts to wishful thinking.

Leo’s suppression of emotions seen here lead to the adoption of a mask – since he is not allowing himself to express how he really feels, he is inhibiting his true self and presenting a false self.

Mik shares his experience of being in class, where multiple people are speaking at once and he has several thoughts:

> Mik: I’m not scared of saying anything [said very quietly]...There’s more than one person talking and loads of things going on in my head and I don’t know who to respond to. Someone’s talking to me and the teacher’s talking to me, I don’t talk to no one...Yeah, I don’t know who to talk to...I stay quiet (85 & 545-553)

Once again, Mik’s experience of ASD focuses on internal thinking processes. In the classroom, Mik does not know who to respond to, leading to him staying quiet. There is a paradox presented in Mik’s extract between the content and way in which it is said. By speaking very quietly, Mik’s view that he is not scared of saying anything, unlike people with ASD, lacks conviction. Whilst the content of his words presents a fearless persona, the way in which he says them suggests otherwise – a lack of confidence. Therefore, Mik appears to wear a fearless mark in an attempt to hide his worry about his identity, including his ASD.

Towards the end of Mik’s interview, he appears to remove his mask and reveal a more vulnerable side. He shifts from his narrative of not being scared to say anything to sharing his experience of becoming silent in lessons due to an overload of his own thoughts and others’ voices. Mik’s experience leaves the impression that he is overwhelmed, so much so that he shuts down and gives up on any attempt to interact with others. The extract provides a sense of confusion and loneliness, whereby Mik appears to experience something different to those around him, which he manages by retreating inwardly. The paradox connects Mik closer to his own conceptualisation of ASD – one where people are scared.

Importantly, prior to this point, Mik has professed that he only has one or two thoughts in his head at one time, unlike his perception of people with ASD who always have multiple thoughts. He mentioned that those with ASD are unable to verbalise what they intend to, due to having too many thoughts at once. Mik has repeatedly dissociated himself from ASD by stating that he speaks his mind without any trouble or concern about the consequences. Therefore, the above extract holds particular poignancy, since it suggests that Mik wears a mask to hide his fear or difficulties.

4.4.5 Where from here?

This overarching theme captures the participants' experiences of moving forward with regards to living with ASD. This involved a range of ideas, from ASD being understood as something that can be fixed to participants demonstrating widened thinking. These differences seemed to be largely influenced by the participants' life experiences. The participants' comments provide insight into how they envisage a future with ASD. Table 8 provides a visual representation of the prevalence at which each superordinate theme related to the overarching theme 'Where from here?' occurred for participants.

Table 8: Prevalence of superordinate themes related to 'Where from here?'

	Time to become independent	Improves/ disappears over time	Change is possible	Widening thinking
Elena	✓	✓		✓
Leo	✓		✓	✓
Sarah		✓	✓	
Mik		✓	✓	✓

(i) Time to become independent

> Elena: Yeah, so I had a past experience with my psychologist. And yeah. And he um, it was on the last day, on the 26th. And he left me because, 'cause I had to be a bit, a bit um on myself and do better, that's why...Because I had to be a bit more independent I think (683-686 & 717)

Elena is discussing her past experience of being seen by a psychologist. Without any questioning about the ending, she mentions the date of her final session and why the sessions terminated. Elena's unprompted description highlights the importance of the psychology sessions and the painful experience of these ending. Rather than saying the visits ended, Elena says 'he left me,' indicating a loss of the relationship and perhaps a sense of rejection. Elena understands the sessions as ending due to her needing to be more independent. She stumbles over the reason why the sessions terminated, repeating 'a bit' and hesitating. Although Elena is talking about the sessions terminating in order to make her independent, her use of language 'on myself' conveys a sense of loneliness. She ends the comment with 'I think', revealing her uncertainty about the future.

In light of Elena's tendency to suppress emotions, there is an overall impression that her experience of having an ASD diagnosis is that it is something that occurs in the past. Past experience may involve receiving support from a professional, such as a psychologist. The ending of this past experience appears to signify, not only the ending of support around thoughts and feelings, but also the ending of ASD. Elena is now left on her own to become independent.

As the interview draws to a close, Leo timely describes a change that has occurred in his life:

> Leo: I don't like ask my parents every single time for treats...I just get them if I want to. That's one thing that's changed (686-687)

Where Leo had previously asked his parents to buy him treats, he no longer does. Thus, he has become more accepting of parental decisions. This change in Leo's behaviour suggests that his experience of having a diagnosis of ASD is more fluid than originally appeared – whilst he associates ASD with asking his parents to buy him treats, he has demonstrated that he has some autonomy in his approach to this issue. Adopting a slightly different approach, whereby Leo asks his parents for treats less often, implies that Leo does not believe that there is a direct cause and effect relationship between having ASD and making requests.

(ii) Improves/disappears over time

> Elena: ...they had an exp, experience of having autism...Having past experiences about it...for example, me. I had um autism...and I can't remember what I was about to say (54-55 & 166-171)

As already demonstrated, ASD seems to be something that Elena believes to have occurred in her past, alongside previous experiences. As these experiences end, so does having a diagnosis of ASD. This is highlighted further in the comment above, through the use of the past tense – 'they had an exp, experience of having autism...I had um autism...' Following the latter part of this quote, Elena forgets what she was saying. This seems poignant when considering her conceptualisation of ASD as being a feature of her past. Along with her ASD no longer being present, it seems that her memories are also fading.

Sarah clearly communicates her belief that ASD improves or disappears over time:

> Sarah: 16, 17 – that's a bit tricky. I've never seen no one with autism at 16, 17...A bit but not a lot. Maybe like by 18 or 19 they've fixed, they not autism anymore – they are fixed...Yeah, they don't have autism anymore and they don't understand what to do (433-434 & 449-453)

Sarah states not having known anyone aged 16 or 17 with autism, and thinks that by such an age they may still have a bit of autism, but not a lot. This description highlights Sarah's conceptualisation around ASD as being something that can be divided into parts. Rather than either having or not having the condition, 'a bit but not a lot' implies that as people get older, characteristics of ASD gradually diminish. Sarah believes that by the age of 18 or 19, one's ASD is completely gone and the person is 'fixed.' Her language 'they not autism anymore' suggests a belief that a person is defined by their diagnosis, rather than it being one part of an identity.

Sarah ends the comment by saying that once people with ASD are fixed from having the condition, they do not understand what to do. It is difficult to accurately interpret what Sarah means by this and whether she even intended to say this. However, considering the interpretation that people are defined by their diagnosis, it seems as if Sarah is saying that once people are 'fixed' of their autism, they struggle to understand who they are and how to move forward.

Mik's understanding of ASD as being something that can be fixed alongside behaviour problems derives from his mother's account provided to him when he was younger:

> Mik: My mum yeah she said I have behaviour problems that I need to fix, then I fix it then no one will keep, then no one will say there's nothing wrong with me. Until then everyone says [difficult to decipher] that's it...and she said it can go away if you fix your behaviour...Can it go away? (257-280)

He rationalises that he has ASD because he has behaviour problems, therefore if he fixes the latter then the former will disappear. Mik's repetition of 'fix' highlights his conceptualisation that ASD is not life-long. Mik mentions that upon fixing his behaviour problems, people will no longer say there is something wrong with him. The next part of Mik's speech is unclear. The timing of this lack of clarity does not appear to be coincidental – Mik is describing the stage until his behaviour is fixed and people accept that there is nothing wrong with him. This seems to be a painful period for Mik, whereby he believes people to perceive him as having something wrong with him, which is re-enacted in his struggle to speak clearly. Towards the end of the extract, Mik repeats his mother's account that his ASD will disappear once his behaviour is fixed.

Following Mik's comments, he asks the interviewer if ASD can go away. This demonstrates a wider struggle that Mik has between believing other people's accounts of what ASD is and his own thoughts and feelings about the diagnosis. Although his understanding of ASD has been largely influenced by the disclosure his mother made to him, Mik is questioning whether this is true or not. His question reveals an anxiety about his identity and a lack of confidence in the narrative he has been told. It appears that Mik wants the narrative around behaviour problems to be true, as this means that he would be in control of the longevity of his diagnosis. The extract further highlights the importance that other people's perceptions have for Mik.

(iii) Change is possible

> Leo: In Year 7, I used to get annoyed by um about 3 people in my Maths, English and Science class. And um yeah and they really, I just couldn't stand them and you know I felt the same thing like here as well and um yeah but I think now in Year, I think this year I think it's we have like we talked with the head teacher and, you know Miss Roberts?...I can't explain but she's a person you know and she helps people who are getting annoyed and that's who I went to and we had a talk, all four of us, which was me and those three... And I think we are, we're better now...Yeah. I think that um that yeah I think that badness is over...Yeah but I mean it wasn't the first time, I mean I talked to them quite a couple of times, but for some reason this time it worked (593-614)

Leo describes an experience where positive change took place. He shares a memory from last year whereby some of his peers annoyed him, leaving him with similar feelings of anger to those which he has mentioned throughout his interview. Rather than this anger building up inside Leo due to a fear of the destruction that expressing it might cause, a teacher intervened to manage the situation. Leo identifies the teacher he approached as someone who helps people when they get annoyed, suggesting that this is how he perceives himself – as someone who needs support for his anger. As has already been demonstrated, Leo appears to closely associate his experience of having an ASD diagnosis with his anger.

Leo proceeds to discuss the meeting that occurred between the teacher and the pupils. He describes the group in three different ways – 'we had a talk, all four of us, which was me and those three...' His repetition here highlights the importance of being part of a group and connecting with others. Rather than feeling alone with his emotions and thoughts as is often the case, Leo experiences something different – an opportunity to share his perspective in a safe environment. He goes on to use the pronoun 'we' when describing the positive outcome, whereas he had previously said 'I' when speaking about the situation before the teacher intervened.

Although there is a great sense of relief when Leo talks about the improvements, it seems that he is not entirely confident that 'the badness is over'. He is hesitant when talking about the positive change, often saying 'I think'. Since Leo is so used to keeping his anger inside, this alternative way of dealing with difficulty with peers seems to be unfamiliar. Therefore, he remains cautious of the positive change lasting.

Nevertheless, overall Leo presents a more hopeful self, whereby he recognises that anger does not always need to be kept inside or expressed through violence. Rather, with the support of others, anger can be expressed safely, resulting in change.

Sarah explains why she believes that people with ASD would prefer being at home to school – so that their parents can help them to improve:

> Sarah: So their parents can *help* them more to improve them with their problems...Like they can *engage* them, like they can *join* them, they can have fun with their parents, like their parents can show them how to read, how to write, how to play, then yeah (267-272)

She emphasises her tone when she says the words 'help,' 'engage' and 'join' indicating that parental involvement is important for Sarah. The extract highlights Sarah's conceptualisation of ASD as a deficit, whereby people have 'problems' which they require help for, and are better off receiving this help in the privacy of their own homes. However, Sarah presents a view that these problems can be improved with adult support. She also refers to connecting with others as a way of creating change. Therefore, Sarah experiences ASD as problematic, yet proposes that it can be improved rather than being fixed.

Sarah further demonstrates a belief that change occurs for YP with ASD when they reach secondary school age. She discusses the age when children with ASD are most affected by social communication difficulties:

> Sarah: Mainly young people
>
> J: When you say 'young people,' how old do you think?
>
> Sarah: I think like age 3, age 4, age 6. Like primary school
>
> J: Primary school ok. And when you get older, to secondary school, do you think then people-

> Sarah: They improve more (82-87)

This excerpt illustrates Sarah’s experience of ASD as a condition whose inherent difficulties improve over time. Again, rather than saying that people with ASD are ‘fixed’ of their diagnosis by a certain age, as she has mentioned elsewhere in the interview, Sarah speaks about improvements, implying that change is possible.

The following exchange between the interviewer and Mik provides insight into Mik’s low self-confidence:

> Mik: I can’t draw
>
> J: I don’t believe you. Everyone can draw
>
> Mik: I can’t
>
> J: Some people can draw better than others, but it doesn’t mean that they can’t
>
> Mik: I cannot draw
>
> J: Well you can write
>
> Mik: Yeah but I can’t draw
>
> J: Hmm I don’t believe you but ok
>
> Mik: I’ve never done art in my life...Nah I can’t draw
>
> J: Ok
>
> Mik: I never actually drew a picture in my life
>
> J: Well maybe now’s the time to try. Want to try?
>
> Mik: Ok (633-648)

Mik did not attempt the GEM task at the start of the interview and so it was returned to towards the end of the interview. In the above exchange, Mik is adamant that he cannot draw and therefore will not attempt the GEM. However, with positive encouragement and belief in his abilities, Mik agrees to have a go at drawing. Relating this to the rest of Mik’s interview, there are similarities in the strength of his language. For example, ‘I’ve never done art in my life’ and ‘I never actually drew a picture in my life’ echo Mik’s previous statements about never feeling anxious (line 377), never being scared to say anything (line 317) and never feeling threatened by anyone (line 320). These extremities appear to act as a defence against any vulnerability. By drawing, Mik is exposing himself to the interviewer and risking being judged. Yet, eventually, Mik discards his defensive guard and decides to draw – change has occurred.

(iv) Widening thinking

> Elena: Yeah ‘cause I can’t, um sometimes I can’t t, um talk to them, and I feel a bit nervous to talk, to talk to them...Sometimes people can be a bit quiet to themselves and say [sighs] I just have to be with my normal best friends...It’s because that um when people, um I’m not sure but when people um don’t talk to anyone then I feel that they’re just too lazy to talk and yeah...It doesn’t make a difference but, but I think, I still think it’s not to do with laziness, it’s to do with um...confidence (428-429 & 458-490)

Elena’s thinking has widened in the above extract. She begins by sharing her difficulty in talking to people, other than her best friends. When asked why it might be difficult to speak to new people, Elena initially reasons that it is due to laziness. However, she then rethinks her response, and concludes by saying that the reason is related to confidence, not laziness.

The way Elena expresses herself here mirrors the difficult experience of interacting with new people. There is repetition, hesitation and a sigh. Timely, the sigh occurs when Elena is discussing wanting to be in the company of familiar best friends, rather than attempting to talk to unfamiliar people. This provides insight into the effort that is required to interact with new people and how relieving it may seem to remain with those whom one feels comfortable with. Following this, Elena’s struggle to articulate her reason about people being too lazy to talk to others demonstrates her uncertainty. It seems that Elena is trying to make sense of her difficulties with social interaction, and laziness is something that can easily be changed. When questioned further about laziness, she says ‘I still think it’s not to do with laziness’. Her wording is confusing here, as it insinuates that she is sticking with her original thought, despite the original thought having changed. This illustrates Elena’s own confusion, since it is not easy to explain why social interaction is challenging. The confusion does not appear to detract from Elena’s widened thinking, but rather highlights the complexity of the issue. The result is a richer, more thoughtful account of why people with ASD may struggle to talk to new people.

Leo’s thinking has widened in relation to the reason why his parents might not buy him treats when he asks for them:

> Leo: Actually maybe sometimes when I ask my parents to buy something, it might take them a while you know
>
> J: And do you think that’s because you have autism Leo?
>
> Leo: Um actually I’m not sure about that one
>
> J: Why are you not sure about that one? Why is that different?
>
> Leo: Because maybe just parents might say no for a reason...Um maybe ‘cause they don’t have enough money or they have to buy something else instead (233-260)

Leo offers alternative reasons to not being bought things by his parents, other than simply because he has ASD, including money being limited or them needing to buy something else instead. Where he initially said that not being bought things is something that he does not like about having an ASD diagnosis, he then alters his response by saying that he is does not think the two are related. Therefore, his thinking around the issue appears to be more considered and his understanding of ASD is increasingly fluid than was initially seen.

Another example of Leo demonstrating widened thinking is the below excerpt when discussing differences between himself and his peers:

> Leo: Yeah quite a lot of people like football...But I don’t like it much and I don’t really want to know anything about it
>
> J: Ok, so that’s a difference. So a lot of people like football and you don’t like football?
>
> Leo: Yeah, a lot of people like basketball, but I don’t really and you know a lot of, a lot of sports, to be honest and I rarely like any sports
>
> J: Ok, so that’s a difference between you and other people. And do you think that has anything to do with autism, that difference?
>
> Leo: Um nah, I think it’s just normal. It’s what happens to other people (624-637)

Leo has previously understood his own difficulties, such as anxiety and homework completion, as due to ASD. However, in the above exchange Leo suggests that the differences between him and his peers are not related to his ASD diagnosis, but rather are simply a part of people having different interests. In this sense, Leo’s thinking seems to be widened as he is no longer displaying polarised or split ideas about people with and without ASD.

Mik considers a more complex perspective about ASD than he has previously demonstrated:

> Mik: Everyone has some autism in a way and [difficult to decipher]...Everyone, everyone, if someone like people can be good at things and not be clever. People can be like...people can like, people can hate subjects and love football, people can love games and hate games [difficult to decipher]...Some people are just different...Yeah, I don’t think autism like...like you can’t like you can be good at certain things, you’re not good at everything. Something like that (447-457)

Rather than presenting the idea that all people with ASD think in one particular way and share the same difficulties, Mik provides an alternative view. He states that everyone has some autism in a way and that there are differences amongst everyone, regardless of having a diagnosis or not. Mik's difficulty in coherently expressing this mirrors the complexity of the issue. The difficulty Mik has in articulating his opinion also speaks to the discomfort that he may be experiencing in accepting that he has 'some autism' too. Further, 'some autism' indicates that the condition can be divided into parts, rather than being something that you either have or do not have.

Mik returns to the idea about people being good at certain things, such as football and games, and not being clever. Although Mik says 'people', it seems that he may be talking about himself, since he has previously mentioned not enjoying academic subjects but liking sports. Mik proceeds to say that some people are just different. This is a poignant moment whereby Mik shifts his perspective of what it means to have ASD. For the most part in his interview, Mik has presented an idea of people with ASD being debilitated, where they are unable to think clearly and have problems speaking. Whereas now, Mik widens his thinking to suggest that some people are just different, rather than at a deficit. He proposes that people with autism are good at certain things, and not good at everything. This normalises what it means to have ASD, since this statement is applicable to anyone and everyone.

4.5 Summary of Findings

This chapter aimed to address the research question – *What are mainstream secondary school pupils' experiences of having a diagnosis of ASD?* Five overarching themes emerged as a result; *Impact of ASD on daily life; Questioning identity; Relating to others; Emotional response;* and *Where from here?*

The first theme captured the participants' experiences of living with ASD day to day, or of how they perceived other people with ASD to be impacted daily. These experiences were predominantly negative, characterised by difficulties with communication, interaction and cognition. Positive effects of having an ASD diagnosis were referred to, but these were much less apparent.

The second overarching theme encompassed participants questioning their identity in regards to their diagnosis. Experiences included one participant rejecting the diagnosis entirely and others shifting in between acceptance, concealment and dissociation with the label. One participant was largely concerned with understanding the diagnostic and assessment pathway, in an attempt to build up evidence to dissociate with the label.

Participants were found to understand ASD in relation to others. This was often by polarising abilities of people with ASD to those without the condition, where the former were deemed as less able than the latter. This theme also included social interaction difficulties that are experienced by YP with ASD.

Different emotional responses to having a diagnosis of ASD emerged to form the fourth overarching theme. These included participants feeling out control, suppressing emotions and presenting a false self as ways of managing difficulties.

Lastly, participants were found to consider their futures in terms of having a diagnosis of ASD, which for some were characterised by an understanding that it was time to become independent. Others described ways to improve or be fixed of having ASD. Participants also spoke about having ASD in a different way to how they had up until this point, demonstrating widened thinking, curiosity and contemplation about the possibility of change.

Chapter Five – Discussion

5.1 Introduction

This chapter begins by reiterating the research findings regarding how participants experience having a diagnosis of ASD. The ways in which the findings relate to existing literature and psychological theory are then discussed. The limitations of the research are presented, followed by implications for EP practice. Suggestions for future research are provided in light of the research findings and existing knowledge. Finally, a reflection of the process for the researcher is outlined to demonstrate self-reflexivity.

5.2 How Participants Experience having a Diagnosis of ASD

Findings revealed that participants experienced their ASD diagnoses in different ways. Elena accepted having ASD, yet chose to keep the condition hidden from everyone apart from her family due to a fear of being teased. As a result, Elena faced an internal battle between being her true self and being a false self in order to fit in. Similarly, Leo accepted having a diagnosis of ASD and believed that the condition explained a lot of his difficulties, such as anxiety. He understood ASD as a condition that made life harder for him, whilst believing that people without the diagnosis functioned more easily on a daily basis. Sarah explicitly expressed a view that she did not believe that she had ASD, and therefore spoke about having the condition either hypothetically or as something that affects other people. Sarah also understood ASD as being a deficit condition, which caused those affected to be at a disadvantage. Lastly, Mik frequently shifted between non-identification with ASD and uncertainty. The latter was characterised by questions over the diagnostic process and the longevity of the condition. Although Mik did not explicitly express identification with ASD, his descriptions of how people with the diagnosis may be impacted were closely linked to his accounts of his own difficulties, suggesting a complex relationship with his diagnosis.

5.3 Relating Findings to Existing Literature and Theory

In relating the findings to existing literature and theory, each overarching theme is individually presented and discussed in relation to the original research question. These overarching themes were '*Impact of ASD on daily life*', '*Questioning identity*', '*Relating to others*', '*Emotional response*' and '*Where from here?*' A reminder of the research question is as follows:

> *What are mainstream secondary school pupils' experiences of having a diagnosis of ASD?*

5.3.1 Impact of ASD on daily life

This overarching theme was evident for all participants. When trying to make sense of their ASD diagnosis, YP described the effects on their daily lives. For the most part, these were negative effects, whereby ASD was experienced as holding people back from functioning like those without the condition.

Aspects of this finding are congruent with existing literature around YP's experiences of having a diagnosis of ASD. Existing literature illustrated that in an attempt to understand their diagnosis, YP also spoke about their positive, negative or indifferent responses to having the label (Huws & Jones 2008, 2015; Calzada et al., 2012; Mackay & Parry, 2015; Mogenson & Mason, 2015; Stevenson et al., 2016; Winstone et al., 2014). Similar to the dominant deficit narrative presented, existing literature revealed negative effects to be largely around stigmatisation. Felt, rather than enacted, stigma was a consistent finding across the current research and existing literature. In particular, Elena spoke about how having ASD might lead to being ridiculed by others, leading to her decision to keep the diagnosis hidden. Elena's rationale for being teased was the same rationale she provided for someone being happy to have ASD – being different. This double-edged reasoning illuminates the complexity of her experience. The difference described by Elena is consistent with findings from existing literature, whereby conceptualisation of having a diagnosis of ASD focused around difference. YP revealed feeling different to their peers and worried about how this difference would impact other people's perceptions and treatment of them (Huws & Jones, 2008; Calzada et al., 2012).

These findings from the current research and existing literature are interesting in light of the belief that people with ASD have impaired theory of mind (the ability to see things from other people's perspectives) (Baron-Cohen, 1995; Baron-Cohen, Leslie & Frith 1985). Contrary to this belief, Elena chose to conceal her diagnosis due to concern about what other people would think about her upon finding out. Further, findings from existing literature revealed that YP were worried about other people's perceptions (Huws & Jones, 2008; Calzada et al., 2012).

Other negative effects of having ASD related to cognitive, social and emotional, communication and interaction difficulties. Namely, difficulty organising thoughts, having low self-esteem, struggling with social interaction and expressive language. The generalisations of participant responses, as well as their use of third person when describing negative effects of ASD, highlight the difficulty in thinking about what the condition means for an individual. Subsequently, a medical model of ASD comes across through participant responses, where individuality and uniqueness are lost. Instead, individuality is replaced with a generalised identity, governed by discourse such as ‘people with ASD can...’ and ‘people with ASD cannot...’ (Mik, line 593). This rhetoric is mirrored by existing literature (Mogenson & Mason, 2015). This relates to the broader issue of the development of self-concept in YP.

Positive effects of having a diagnosis of ASD were much less documented than the negative effects in the current research, yet were still referred to. These focused around people having enhanced confidence, which was thought to be due to being different; getting away with things more easily; and being good at art and sports. Whilst these characteristics were spoken about as positive attributes, further exploration revealed them to be by-products of negative aspects of having ASD, rather than being qualities in their own right.

These positive effects differed from those in the existing literature. Existing literature revealed that YP felt liberated as a result of an ASD diagnosis, due to them having a better understanding of their selves, leading to feeling more in control (Mogenson & Mason, 2015; Huws & Jones, 2008). Further, YP viewed the diagnosis as a way to access services (Huws & Jones, 2008). These experiences were not mentioned by participants in the current research. A reason for this discrepancy may have been linked to the way in which ASD had previously been spoken about with the YP who took part in the current research. In parent meetings, it transpired that in three out of four cases, conversations about ASD following disclosure were limited. Often, disclosures were made during one-off conversations and were not revisited by parents. This is likely to have affected YP’s attitudes towards their diagnosis.

The difference between the positive effects experienced by participants in the current research and those in existing literature echoes the ongoing labelling debate. Contrary to the belief that a label provides increased understanding (Gross, 1994; Severs, 2017), findings around the effects of ASD in the current research illuminate the stigmatisation that can result.

5.3.2 Questioning identity

Participants in the current research struggled with their identity of having a diagnosis of ASD and making sense of how this had occurred. Despite all YP sharing the same diagnosis, there was a wide variation in individual experiences. From a critical realist perspective, this finding is unsurprising, since the research set out to explore inductively individual experiences, holding a view that whilst ASD exists, individuals construct their own meaning of the condition. The variety in individual experience is contrarian to the medical model which places YP with a shared diagnosis into one category.

Findings in the current research revealed ambivalence over identity. This was particularly apparent for Mik – ambivalence over his identity reflected the messages about ASD that he had received from others. There are similarities between these findings and those from research by Stevenson et al., (2016). In the latter, some YP expressed ambivalence about having ASD, which was based upon a sense of confusion about the condition, its cause and circumstances surrounding disclosure.

Additionally, findings in the existing literature revealed the amount of time YP had known about their diagnosis for to impact their sense of identity. When YP had grown up knowing about their diagnosis, they had a more positive view of ASD and believed that it was central to their identity (Mogenson & Mason, 2015; Stevenson et al., 2016). However, findings from the current research were contrary to the literature – although the participants in the former knew about their ASD diagnoses, the length of time which they had known for did not seem to impact their experiences. More so, despite being told about having an ASD diagnosis, Sarah believed that she did not have ASD. Out of all the participants, Sarah happened to have known about her diagnosis for the longest period (eight years) by the point of the interview. This participant's non-identification with ASD may have been contributed to by limited conversations about the label between parents, professionals and the YP.

In the current research, confusion over identity included ideas about the cause of ASD, as well as queries over the rigour of the diagnostic process. Whilst Elena understood ASD as being something that people are born with and have 'past experiences' of (line 166), Leo believed that his ASD was due to things that he dislikes in life. Mik challenged the validity of his label, proposing that the only reason that people consider him to have ASD is due to one diagnostician saying that he does. Further, the circumstances in which YP were told about their diagnosis seemed to influence their views. Mik recounts his mother telling him that his ASD was behavioural and therefore could be fixed with improved behaviour. Such a narrative led to questions over the condition, its longevity and, ultimately, one's identity.

Questioning identity in the current research also involved the frequent change between associating and dissociating with one's diagnosis. For instance, Mik stated that he did not have ASD, yet later asked questions about the longevity of the condition and the diagnostic process. Whilst this shift between associating and dissociating with ASD was not apparent in the existing literature, retrospective accounts of learning about one's diagnosis are related to this area; in research by Mogenson and Mason (2015), YP shared feeling liberated and more in control after learning about the diagnosis. The diagnosis had helped to provide explanations for certain behaviours, suggesting confusion and a lack of control over one's identity prior to disclosure. This further highlights the ongoing labelling debate, whereby findings from existing literature support the argument that a diagnosis leads to increased understanding (Jones et al., 2003), whilst findings in the current research refutes this. Rather, participants' dissociation from ASD in the current research maintains the view that a label can result in increased stigmatisation (Lauchlan & Boyle, 2007).

Dissociation from the ASD diagnosis was revealed in existing literature whereby YP spoke about the condition affecting other people (Winstone et al., 2014). This was particularly found to be the case when traditional semi-structured interviews were used. Employing activity-based methods resulted in YP associating with their diagnosis more and using themselves as a reference point to describe their experiences (Winstone et al., 2014). In the current research, the GEM was used to help YP to ease into the interview, without needing to interact directly with the researcher. Further, it allowed YP to creatively express their views through drawing and/or writing. In a sense, the GEM drawings acted as a way of externalising one's ASD – rather than difficulties that YP were describing being located within them, they were located externally (in the drawings). This technique seemed to support the YP to speak about sensitive issues, such as being teased and feeling anxious. The drawings were useful to gather YP's views and to understand how the YP associate or dissociate with the condition. Additionally, having a semi-structured interview schedule allowed for some concrete questioning when necessary. Therefore, in addition to research by Winstone et al., (2014), the current research has demonstrated that it is possible to obtain useful data from interviewing pupils with ASD, despite the limited literature that has attempted to do so. The important factor in enabling this appears to be the methods by which the pupil voice is elicited.

5.3.3 Relating to others

Both existing literature and the current research revealed that YP made sense of their ASD and their identity by drawing comparisons with others. However, the nature of these comparisons differed between the existing literature and current research. Whilst existing literature revealed that YP considered themselves to be 'better-off' than others who did not have ASD, and 'better off' than people with more severe ASD or those with a 'proper disability' (Huws & Jones, 2015, p. 88-89), YP in the current research generally thought that they were worse-off than those who did not have ASD.

Despite this discrepancy, there were some similarities between existing literature and the current research. For instance, although YP presented a mainly negative depiction of ASD, compared to people without the condition, Elena mentioned on a couple of occasions a belief that ASD provides certain abilities. This finding was also revealed in research by Huws and Jones (2015), whereby YP perceived their selves to have heightened abilities to others. Again, in the current research this finding may have been due to the way in which YP learnt about their diagnosis and the conversations that had taken place about ASD since. Such a hypothesis is supported by information gathered in the meeting with Elena's parents. When her parents disclosed the diagnosis, Elena was told about the positive attributes of ASD and about famous people, such as Albert Einstein, who are thought to have had the condition. Therefore, although Elena lacked confidence and conviction in the positive aspects of ASD, her belief about it providing people with certain abilities seems to echo her parents' account of the condition.

A distinct finding that emerged from the current research was around the splitting between people with ASD and those without. Splitting is a defence mechanism used to shut out unbearable feelings, whereby all positive attributes are located into one person or object and negative ones into another (Pellegrini, 2010). Splitting between people with ASD and those without denied the existence of good attributes in the former and negative qualities in the latter. Further, in the current research, the defence mechanism appeared to serve an additional function – to minimise the complexity of ASD, as a way of making sense of it. YP attempted to make sense of their experiences of having autism by polarising abilities between the two groups of people. For the most part, participants experienced all people with ASD as sharing the same difficulties and all people without ASD having the same strengths. Participant responses on the whole portrayed a view that those without ASD are in a better position than those with ASD across many aspects of life. For Sarah and Mik, the splitting seemed to serve an additional purpose, whereby they could dissociate from the label and align their selves to people without ASD.

Another finding that emerged in the current research which differed from the reviewed literature concerned social interaction. Three participants referred to difficulties interacting with others, which were characterised by feelings of anxiety and feeling exposed. Elena presented two different options of managing her difficulties with social interaction as either ‘staying quiet’ (lines 425-440) or approaching people and initiating a conversation. This suggests an internal conflict between hiding and exposing herself. The commonality in social interaction that was referred to by participants indicates the importance of this area for YP with ASD.

Social interaction difficulties are a central characteristic of ASD (APA, 2013). Extensive research has documented poor outcomes for YP with ASD in terms of social isolation, bullying and mental health (Smith et al., 2012; DoH, 2010). With this in mind, findings of the current research illuminate the ongoing support that YP with ASD need with social interaction to promote emotional well-being and a sense of belonging at school and beyond. These implications will be discussed later in the chapter.

5.3.4 Emotional response

Whether having a diagnosis of ASD enhanced or reduced a feeling of control differed between findings in the current research and those in existing literature. Current research revealed that for Leo and Mik, having an ASD diagnosis led to them feeling out of control. Leo often spoke about things being unfair. Despite conjuring up ideas about how to make situations fairer, he would soon give up on these ideas out of a fear of the damage they could cause. Subsequently, Leo tended to resort to wishful thinking. He had experienced a loss of control over certain situations, which he associated with having a diagnosis of ASD. Mik's loss of control seemed to result from the way in which he received his diagnosis and other people's perceptions of him. Once again, the latter provides an alternative argument for the belief that people with ASD have impaired theory of mind. Mik expressed frustration about a clinician telling his mother that he has ASD and, from that point on, everyone being informed about his diagnosis. Mik appeared as though he wanted to escape the label which continued to follow him from school to school. However, even more apparent was that regardless of how Mik felt about having an ASD diagnosis, decisions were made about him without his involvement. Therefore, Mik did not feel in control of the information that was shared about him.

On the contrary to the experiences discussed above, existing literature found that a label of ASD enhanced control for some people (Mogenson & Mason, 2015). The label provided an increased understanding of difficulties, as well as ways to cope. Having an awareness of being different but not understanding why, prior to disclosure of diagnosis, created a loss of control (Mogenson & Mason, 2015; Huws &

Jones, 2008). An explanation for this difference in current findings and those from the existing literature may be linked to the circumstances in which the diagnosis was disclosed and the conversations that have or have not occurred since. With this in mind, the current research has provided alternative insight into experiences of having a diagnosis of ASD, whereby YP might experience a loss of control. In accordance with legislation, those supporting YP with ASD must work to ensure that the pupil voice is at the centre of work and decisions involving them (DfE, 2015). Doing so is likely to provide YP with increased control and agency over their lives.

Another key finding that emerged from the current research was the suppression of emotional responses for participants. Elena, Leo and Mik's experiences of having a diagnosis of ASD were all characterised by hiding their authentic feelings and selves, leading to them presenting a false self. Elena faced an ongoing conflict between hiding her diagnosis and being her true self. This was powerfully demonstrated when she attempted to explain why she hides her diagnosis: '*I don't really like hiding my...myself*' (line 367-368).

Similarly, research by Stevenson et al., (2016) found that a strategy YP used to manage their identity was to hide or minimise their diagnosis. YP reported researching what they should and should not do as a way of concealing their autism.

Building on from this idea of hiding ASD, the current research explored the reasons for doing so. Through questioning, it was revealed that Elena had decided not to share the diagnosis for fear of being teased or pitied. Hiding the diagnosis illustrates the stigmatisation that can result from having a label, as proposed in the labelling debate (Lauchlan & Boyle, 2007). These findings highlight the importance of YP understanding their self-concepts, in order to enhance self-esteem and to improve outcomes for later life.

Further, the current findings revealed that Leo's emotional response to having an ASD diagnosis was to bury his feelings, due to a fear of the damage that could result if expressed. He frequently battled between wanting to seek revenge for unfair treatment and keeping his feelings inside because of the consequences of his actions. This ongoing dilemma left Leo feeling stuck, whilst also having suppressed anger.

Mik's adoption of a 'mask' is less explicit than is described by Elena and Leo. He wore a fearless mask, yet shared a more vulnerable side by describing the difficulties he faced in the classroom. As a way of managing the magnitude of classmates' voices, Mik becomes silent. Therefore, similar to Leo, rather than expressing his frustration or confusion, Mik withdraws. Inadvertently, Mik's description of his difficult experience in the classroom leads him closer to his own conceptualisation of ASD. In Mik's case, the interview process supported him to reveal a more vulnerable side over time. Therefore, it is important to provide YP with opportunities to explore their self-identity. These opportunities could allow YP to remove their masks and to speak openly about the difficulties that they encounter, enabling them to show their true selves.

Self-reported experiences of suppressing emotions and wearing a mask in response to having an ASD diagnosis, which appeared in the current research, were not apparent in the reviewed literature. Existing literature saw YP attempt to understand their diagnosis by exploring its effects on their identity (Huws & Jones, 2008, 2015; Calzada et al., 2012; Mackay & Parry, 2015), yet did not produce findings around the defensive positions YP adopt in relation to their diagnosis. Without finding a way to surface these feelings, YP are in danger of feeling alone with their emotions, possibly leading to social isolation. This could have a longer-term impact on mental health. It is important to address this area since it is known that there are poor outcomes for YP with ASD in terms of social isolation and mental health (DoH, 2010).

5.3.5 Where from here?

The findings in the current research saw YP reflect on moving forward with regards to their ASD diagnosis. The idea of moving forward was depicted in different ways by participants. These included becoming more independent; ASD improving or disappearing over time; change occurring; and thinking widening.

Elena understood ASD as being a feature of her past and something that is grown out of. She associated the diagnosis with past experiences, such as seeing a psychologist. The ending of these psychology sessions appeared to signify a time to become independent in her mind. Mik and Sarah's responses highlighted this belief further – that autism disappears or improves over time. Sarah stated her belief that by 18 or 19 years, people are fixed or cured of their autism. Mik believed that his autism will disappear when his behaviour is fixed.

These findings share similarities with those from existing literature. In the reviewed literature, time was an important factor in YP's experiences of their diagnosis. Research by Huws and Jones (2015) found that YP were relieved that ASD is a developmental condition, where they believed their autistic traits to reduce, and their independence and social skills to develop over time. This has echoes of Sarah's belief that communication, interaction and academic ability can improve in YP with ASD. Extending this idea further was Sarah's view that these improvements eventually lead to YP being fixed, so that they no longer have any ASD. This idea is similar to existing literature whereby YP questioned whether ASD could be cured (Stevenson et al., 2016). These inaccuracies about the longevity of ASD are likely to be problematic and present a barrier to understanding one's self-concept. Whilst experiences of having an ASD diagnosis are believed to be constructed from the YP's perspectives, the idea that ASD exists and is a life-long condition is considered to be important for the development of self-concept. A belief that ASD can be cured presents a within-child deficit model, rather than an interactionist approach whereby various factors in a young person's system interact and impact on his or her difficulties.

However, although Sarah held the perspective that improvements lead to ASD being cured in YP, she still proposed that change is possible. Similarly, Leo provided a viewpoint that positive change can occur following a difficult social situation with peers, which does not result in either suppressed emotions or violent outbursts. Such positive change was supported by a member of school staff who brought the key students together.

Further, change occurred for Mik throughout his interview. Despite not being a linear process, Mik eventually softened his defensive guard and fearless persona by the end of the interview. While he began by responding mainly saying 'don't know,' by the end of the interview he had shared his experiences and thoughts around having a diagnosis of ASD. The softening of his defences led to Mik questioning the narrative he had been told about his ASD, including its longevity and the diagnostic process. In Mik's case, change had occurred experientially – through exploration of his experiences over the course of the interview.

This draws upon ideas of Attachment Theory – YP who have formed positive relationships with others will be more likely to take risks with their thinking and experiences, leading to richer learning (Bowlby, 1958). The positive experiences of a relationship with another can be internalised to form new Internal Working Models. Leo seemed to have internalised the positive experience of being supported by the staff member to resolve conflict with his peers. This had led to Leo believing that change was possible. Ideas about positive change also relate to Growth Mindset (Dweck, 2016), which will be elaborated on later in the chapter.

Positive change occurring was also revealed in existing literature, although this was around the effects of receiving a diagnosis – positive effects included access to specialist services and educational provision, which could lead to improved behaviour and new friendships (Huws & Jones, 2008). Further, YP managed their identity through understanding and accepting it. This was the case for one person in the existing literature who had previously wished away his autism and then began to accept it (Stevenson et al., 2016). However, this positive change did not occur as a result of the interview process, differing from the current research.

An original finding which emerged from the current research, relative to the existing literature, concerned widened thinking. Participants appeared to have developed their thinking through the interview process. Elena had widened her thinking around her difficulties with social interaction as being related to confidence, rather than due to laziness as she had initially said. Leo considered alternative reasons regarding why his parents might not buy him treats, rather than it being due to his autism. Mik proposed that people with ASD are just ‘different’ (line 455), rather than speaking about people with ASD as being unable to think or do certain things as he had previously described. He began to integrate strengths and difficulties by suggesting that people with ASD are good at certain things, yet not everything, just like everyone.

By the end of the interview, Mik also stated a belief that everyone has *some* autism in a way. This idea that people can have aspects of the condition, rather than either having ASD in its entirety or not having it at all goes against the widely-held view that people with ASD have black and white thinking. Black and white or polarised thinking has been considered a typical characteristic of people with ASD and is said to preclude flexible and adaptive responses (Mazefsky et al., 2013). In the case of Mik, polarised thinking was most apparent when he disengaged in the interview. Yet, when he became more comfortable and communicative, his thinking widened and became increasingly flexible. This change seemed to have been aided by the process of the interview. Therefore, the interview process seemed to have an impact on YP’s beliefs about their diagnosis. The change in thinking by participants is also contrary to the widely professed idea that people with ASD are inflexible learners (APA, 2013).

This widened thinking differed from findings in existing literature which revealed YP’s self-concepts to be determined by comparisons with others. YP with ASD made sense of their identity as being better-off than people with more severe autism or more severe disabilities (Huws & Jones, 2015). Whilst it has been demonstrated that participants in the current research often conceptualised people with ASD as being worse-off than those without, this had somewhat shifted by the end of interviews. This highlights the importance of the EP role in promoting a more accurate narrative around thinking patterns in YP with ASD.

5.4 Limitations

Limitations of the current research will be outlined below. Measures taken to minimise the impact of these limitations will be discussed.

(i) Generalisability

The sample size used in the research was small – four participants. For this reason, generalisability of findings to the wider ASD population is limited. However, the aim of the research was to explore individual lived experiences, as opposed to generalising information to other people. Honouring the individual experience is at the centre of IPA research and therefore was a priority when conducting this piece of research. That is not to say that conclusions cannot be drawn and used to inform wider contexts, namely EP practice. The research is valuable since a greater understanding of the under-researched phenomenon – YP's experiences of having a diagnosis of ASD – is provided by an under-represented group. This understanding is important to enhance support for YP with ASD. Further, patterns that existed across cases were explored as a way of drawing out similarities and differences.

(ii) Recruitment

Participant recruitment was an area of difficulty and a limitation of the research. Whilst four YP were eventually recruited, the process took longer than originally anticipated. This was thought to be due to the researcher relying on school staff to pass information on to YP. Related to this was an issue around what information was communicated to pupils by school staff. The researcher decided not to speak to parents and YP directly during initial stages of the recruitment process, in order to reduce the likelihood that YP would feel obliged to take part. However, on one occasion a young person had entered the interviews slightly uncertain about the research purpose. Whilst this issue of informed consent was dealt with effectively, by the researcher fully informing the participant about the research and checking whether the individual wanted to continue or not, it was nevertheless a limitation in recruitment methods. Based on this experience, it is recommended that once potential participants are identified by school staff, the researcher then steps in to speak to the YP directly. This would ensure that the information regarding the research was communicated as initially set out.

Another possible reason for difficulty in recruiting participants was due to the sensitivity of the topic being explored. This was pertinent for one parent who initially consented for her son to take part and later withdrew. Upon withdrawal, the parent explained that she was worried about the interview leading to her son having more questions about his ASD. However, on reflection, the interview process enabled YP to think about their experiences of having a diagnosis of ASD and ultimately led to widened thinking. Therefore, whilst the interviews may have led to YP questioning aspects of their identity and diagnosis, these questions were important in leading them to a richer understanding. Further, despite reluctance for parents to consent to the research, measures to reduce the risk of emotional distress had been outlined. These included providing emotional support during the interviews, debriefing afterwards and signposting YP to key staff members and to external services, should they require it.

(iii) Limited time

A further limitation was around the length of time of interviews. Each participant met with the researcher on one occasion for 60 minutes. Whilst this amount of time was deemed appropriate when considering the ages of participants and how long they may be able to attend to the topic for, participants may have benefited from a follow-up interview. Since the research had employed an inductive approach, whereby preconceptions are set aside as much as possible prior to interviews, the experiences that emerged could not have been anticipated. However, some YP's responses were around issues that may have benefited from further exploration, such as being teased and perceiving oneself as unintelligent. Therefore, although these issues were not the phenomenon under investigation, setting a second session aside to explore these sensitive topics further may have led to richer data, as well as providing more containment for the YP.

(iv) Communication with school

At the beginning of Mik's interview, it was a challenge to engage him. He took a long time to respond to questions with language other than 'don't know.' However, understanding that Mik had been internally excluded on the day of the interview was important in providing some context to his emotional state. This information was only shared with the researcher by school staff immediately before the interview. Mik was preoccupied by the exclusion. As a result, the interview was paused and a discussion took place about the events leading up to the sanction. Upon continuing the interview, Mik was much more engaged and communicative. Despite rich insight into Mik's lived experience being elicited by the end of the interview, a limitation of the research was the lack of information sharing in advance regarding anything that may impact participant engagement.

(v) Terminology used with participants

A final limitation recognised by the researcher was around the terminology 'ASD' used with participants. By writing ASD on participant information sheets and consent forms, there was a risk that participants may have conceptualised the diagnosis in a negative way, which they not have done had the term ASC been used. The rationale for using this terminology is consistent with that mentioned in Chapter One – to be coherent with the DSM-5 (2013) criteria. However, throughout the interviews the term 'autism' was used, minimising the possible impact of the terminology on participant response.

5.5 Implications for EP Practice

Whilst it is acknowledged that the experiences described are only representative of the four individuals in the research, there are nevertheless important implications for EP practice as a result. These implications will be discussed below.

5.5.1 Reducing stigmatisation and promoting understanding

An implication of the research for EPs is to reduce stigmatisation and increase understanding for YP with ASD. Findings demonstrated a largely negative depiction of the impact of ASD on daily life. However, most of the experiences described were based on inaccuracies such as ‘people with ASD can’t think straight’ (Mik, line 593) or a belief that ASD can be fixed by a certain age. These experiences counter the wider labelling debate argument that diagnoses lead to increased understanding (Jones et al., 2003). Therefore, there is an implication for diagnosticians to provide service users with a clearer explanation about the condition and its potential effects, including positive attributes, as well as clarification around ASD being a life-long condition, which cannot be cured.

Rather than having a one-off conversation about ASD during disclosure of the diagnosis, further conversations will help to embed understanding about the condition. Follow-up support could involve EPs working with parents, school staff and any other relevant professionals through consultation to promote the positive characteristics of the condition, whilst crucially promoting its heterogeneity. EPs should work to draw out strengths of YP with ASD, to shift away from the within-child deficit model that was apparent in the research findings, and towards an interactionist approach. Rather than difficulties being primarily located within the young person, EPs can strive to facilitate thinking around the different parts that each member of the system contributes.

Solution-focused psychology could be applied by EPs in consultation with school staff and parents, to realise YP’s strengths. Crucially, YP should be supported to enable independent recognition of their strengths and development of self-concepts. EPs must be vigilant in challenging descriptions which place limitations of YP's abilities. Rather than passively accepting ideas which derive from medical models of ASD, assuming all people with ASD to share the same characteristics, such as impaired theory of mind or cognitive rigidity, EPs should seek out alternative views to represent individuality.

Stigmatisation around ASD could also be reduced by YP and their surrounding systems being more exposed to difference. This could be achieved following disclosure of diagnosis through a psycho-educational programme which aims to teach YP about ASD, as well as other conditions. Within this programme YP could learn about the strengths and difficulties that may be characteristic of the conditions, whilst essentially understanding that all individuals are unique, regardless of a shared label. PEGASUS is an example of an evidence-based programme which fits these aims (Gordon et al., 2015).

At a LA level, there are implications for the specialist service which work to support YP with ASD, schools and families. In accordance with most recent legislation which calls for more MDT work (DfE, 2015), EPs in the LA should strive to work more collaboratively with this specialist service. Since the specialist team begin work with YP soon after the acquisition of a diagnosis, it would be beneficial for EPs to join up with the service to think about how the label could be disclosed and what ongoing support could look like, with the aim of increasing understanding and reducing stigmatisation. Since the current research revealed that parental views influence how YP conceptualise their diagnosis, it would be useful for EPs to work alongside the specialist service to support parental understanding of the diagnosis, as well as YP's understanding.

5.5.2 Developing self-concept

Another implication for EP practice concerns the development of self-concept in YP with ASD. Participants typically experienced people with ASD as 'other' and as all having the same strengths and difficulties. They also tended to split off any negative characteristics into people with ASD and positive traits into those without the condition. Consideration of this finding alongside existing research which revealed YP to make sense of their identity by drawing comparisons with others (Huws & Jones, 2015; Winstone et al., 2014), implicates EPs. An awareness of this defensive process by EPs is important to support YP to widen their thinking. By understanding one's identity in relation to others as being better or worse-off, a person is not appreciating their qualities to exist in their own right. Such comparisons have been associated with loneliness and the development of poor-quality friendships in YP with ASD (Bauminger & Kasari, 2000). Thus, EPs have a role to promote YP's exploration of their self-concept.

It has been acknowledged that self-concept is closely linked with self-esteem – awareness of identity leads to positive outcomes (Franken, 1994). This is relevant for YP with ASD transitioning to adulthood, since life outcomes are currently poor (Smith et al., 2012). In order to improve outcomes, EPs could support school staff and parents to understand the importance of YP's self-concept. EPs could also work directly with the YP to develop their self-concept. An ongoing intervention in which an adult can support YP to explore their self-concept, including their ASD diagnosis is recommended. The intervention should incorporate flexible and creative ways for YP to express their selves, and should allow enough time for the building of a rapport. Due to the variability amongst ASD and person-centred planning as outlined in the SEND Code of Practice (DfE, 2015), a highly-personalised approach is required for each individual.

5.5.3 Supporting social integration

Findings further revealed that YP associated having a diagnosis of ASD with social interaction difficulties. Whilst these difficulties make up the diagnostic criteria for the condition and are well-documented in existing research, they continue to have a significant impact on everyday life and future outcomes (Mazurek, 2014). One participant expressed confusion over the cause of her struggle with social interaction as being laziness or low confidence. Difficulties interacting with others led to risks of self-exposure or to staying silent. With this in mind, EPs could offer school staff and parents consultation on social interaction difficulties. Consultation could focus on exploration into the emotional impact of such difficulties on YP, as well as possible interventions to support with this area. Social interaction could be supported through a group intervention, such as Circle of Friends (Forest, Pearpoint & O'Brien, 1996), which aims to ensure social inclusion for CYP with SEN. EPs are well-placed to deliver such interventions due to their psychological knowledge and skills. Through the implementation of strategies and interventions, YP can form friendships and develop a sense of belonging in their school setting, rather than resorting to either feeling exposing or being silenced. Through forming friendships with others, YP are likely to have increased self-esteem and reduced loneliness (Bauminger, Shulman & Agam, 2004).

5.5.4 Supporting YP to take back control

Findings revealed that YP experienced feeling out of control in relation to their ASD. Further, emotions were suppressed and true selves were masked in response to having an ASD diagnosis. These findings implicate all those supporting YP with ASD.

It could be useful for EPs to apply a psychodynamic lens to understand the defensive processes that YP may experience regarding their diagnosis. Direct work could involve the delivery of an evidence-based talking and/or creative therapeutic intervention, dependent on the individual's preferred method. For indirect work EPs could apply psychodynamic theory during consultation to support school staff and parents to understand the thoughts and feelings underlying behaviour, and to shift away from treating presenting behaviour. Attempts to only treat behaviour, rather than the underlying processes, are unlikely to result in positive change (Kazdin, 1987). Additionally, Work Discussion Groups (WDG) or supervision could be facilitated by EPs with school staff to similarly understand the experiences of YP with ASD. Forums such as supervision or WDG support staff to reflect on their practice, which is crucial when working with such complexity day to day (Evans, 2013).

One participant expressed that conversations had been held between his mother and school staff about his diagnosis, without his involvement. Consideration of this finding combined with knowledge of legislation emphasising the importance of the child voice (DfE, 2015) implicates EPs to ensure that YP are involved in decisions involving them and that their views are obtained. Whilst it is important to inform school staff about YP's diagnoses, this could be done with YP being present or being consulted beforehand, in order to ensure that their perspectives are represented. Further, EPs can highlight the importance of understanding how YP feel about and make sense of their diagnosis, as this may well affect how they present in school and at home, as well as impacting their self-concept.

Obtaining the YP's feelings and thoughts about their diagnosis can be achieved either directly by EPs or by those working closely with the YP. Given that reflecting on one's own thinking or metacognitive strategies might be difficult for YP with ASD, EPs can work to overcome this by using flexible and creative methods, as was done in the current research. Thus, it is recommended for EPs to begin direct work with a creative activity, such as drawing, to allow YP to ease into the process and to reduce the demand on social interaction. Further, as seen in the current research, externalisation techniques taken from Narrative Therapy (White, 2006), are recommended for EPs to use or to encourage school staff to use with YP as a way of speaking about their experiences. This may be particularly useful for discussion around more sensitive issues that YP associate with their diagnosis, such as difficulties with social interaction.

5.5.5 Facilitating change

Research revealed that YP widened their thinking around their conceptualisation of ASD, particularly where a safe way of expressing emotions was provided. One participant had for the most part struggled to manage his anger towards injustice and ill-treatment by peers. He suppressed his anger out of fear that expressing it would cause destruction. However, he later demonstrated an alternative perspective whereby emotions could be expressed safely, resulting in positive change.

Attachment Theory (Bowlby, 1958) relates to the finding around the possibility of change, since the participants demonstrated adapted thinking and experiences following positive interactions with adults. With this in mind, it would be beneficial for EPs to support school staff to understand the impact that positive relationships can have on YP's self-concepts, self-esteem and ways of thinking. One way to achieve this would be for EPs to deliver training to school staff about Attachment Theory and its impact on YP at school. Within the training, staff could be supported to promote healthy emotional expression in YP, which does not result in suppressed feelings or destructive behaviour. Further, the delivery of Cognitive Behavioural Therapy by EPs to YP one-to-one may be useful to normalise emotional expression, to reduce any shame associated with emotions and to encourage a safe and healthy outlet for thoughts and feelings, in turn impacting behaviour.

Widened thinking also seemed to result from the interview process. Having a protected space to explore what it means to have ASD facilitated richer and more in-depth thinking, than was demonstrated at the beginning of interviews. EPs are well-placed to either facilitate a therapeutic space themselves or to skill-up others, such as support staff, to offer this for YP. Ongoing opportunities for YP to share their thoughts, feelings and experiences regarding ASD may lead to a shift away from the split position YP were found to have adopted and towards more considered thinking. Again, it is important to allow time for a relationship to build between the facilitator and the young person and to incorporate creative and flexible approaches into the therapeutic intervention.

The emergence of the idea that change is possible for YP fits with Growth Mindset (Claro, Paunesku, & Dweck, 2016). The premise of Growth Mindset is that intelligence can be developed, rather than being fixed. This finding is particularly interesting in light of the idea that people with ASD are typically considered to be rigid thinkers (APA, 2013). This implicates those supporting YP: rather than assuming that every person with a diagnosis of ASD has cognitive rigidity, it would be beneficial to apply principles of Growth Mindset. With targeted teaching, thinking can be adapted. Therefore, it is important for EPs to be promoting ideas of Growth Mindset to teaching staff and parents, and to challenge any rhetoric around YP with ASD being inflexible learners.

5.6 Suggestions for Future Research

The current research found YP's experiences of having a diagnosis of ASD to be largely characterised by a negative conceptualisation of the condition and its debilitating effects. Further, YP often shared painful experiences, whether enacted or felt. Therefore, it may be useful for future research to continue to explore YP's experiences of having an ASD diagnosis, and to allow time for follow-up interviews to discuss difficult issues that arose in the initial interview. This could provide more in-depth accounts of these experiences, as well as the opportunity for the researcher to contain the emotionality of the discussion.

The current research revealed that contextual factors, such as parental views, influenced how YP conceptualised their ASD diagnosis. With this in mind, another suggestion for future research could be to explore YP's experiences of having an ASD diagnosis and the origins of these experiences. This would help to understand more about the impact of certain contextual factors on YP's experiences. Doing so could support YP and their surrounding systems to reflect on their perspectives and their origins, and ultimately to work towards altering these perceptions where helpful. This could be achieved by including additional interview questions about the origins of YP's experiences.

Lastly, in order to further develop the relationship between findings and the wider context for YP with ASD, it would be useful to research the type of support YP consider effective. This would implicate EPs, school staff and parents, and ultimately work towards improving life outcomes for YP with ASD. Given the current experience of eliciting pupil view, it would be beneficial to use flexible and creative interview methods with the YP. This could include a drawing task, such as the GEM, for YP to draw and talk about how they would like to be supported. Importantly a flexible approach would be most beneficial, which incorporates the YP's preferred method of communication.

5.7 Self-reflection

The research journey has evolved from beginning to end. Before carrying out the interviews, I was surprised by the lack of existing research exploring YP's perspectives, particularly in light of the emphasis legislation places on person-centred approaches (DfE, 2015). It seemed that national and local contexts espouse for pupil voice to be at the forefront of involvement, yet in practice this can look different. Initially, I understood that a possible reason for the scarcity of research was likely to have been due to the difficulty in eliciting the voices of YP with ASD. However, rich and useful data was acquired through the interview process. The type of questions asked and the use of the GEM supported YP to provide more in-depth responses. Therefore, as outlined by Mackay and Parry (2015) and Winstone et al., (2014), creative and concrete methods are effective in eliciting YP's voices.

Another poignant and surprising moment was during Sarah's interview when she said that she does not have autism. Reflection in action was crucial to effectively manage the remainder of the interview. Rather than continuing to ask Sarah about her experience of having ASD, I reframed the questions to ask her about people with ASD. Further, reflection on action was necessary to try to understand Sarah's experience. I recorded my reflections in a research diary following the interview and discussed the issue with my supervisor before analysis, in order to bracket off any preconceptions. By the end of the interviews, I had learnt to appreciate the diversity of each person's experience, ranging from non-identification with the diagnosis to a belief that everyone has some autism. Holding a critical realist position supported me to consider each individual's lived experience as equally valuable, where there was no single truth beyond the existence of ASD. Rather, multiple truths existed which were reflected through different experiences. Thus, taking the case of Sarah, it was important for me to recognise and respect her experience of having an ASD diagnosis as non-identification with the condition.

5.8 Conclusion

The research aimed to explore mainstream secondary school pupils' experiences of having a diagnosis of ASD. This area was chosen due to the dramatic increase of CYP being diagnosed with ASD (Baron-Cohen et al., 2008) and because there is a paucity of research looking at first-hand accounts of having ASD by YP (DePape & Lindsay, 2016), despite legislation stipulating the importance of pupil voice and CYP's involvement in decision making involving them (DfE, 2015; Children & Families Act, 2014). Further, the research was conducted due to the importance of self-concept development in YP. YP need to understand themselves in order to acquire self-acceptance, develop a self-concept and cope with the differences that ASD can present (Stevenson et al., 2016). Related to this, outcomes for YP with ASD are poor, in terms of employment, social isolation, accommodation and mental health (Ambitious About Autism 2017; DoH, 2010; Smith et al., 2012). Therefore, it was rationalised that in order to provide effective support, YP's experiences need to be illuminated.

Findings of the research revealed five overarching themes, summarising YP's experiences of having a diagnosis of ASD – *Impact of ASD on daily life; Questioning identity; Relating to others; Emotional response;* and *Where from here?* The impact of having an ASD diagnosis was perceived to be largely negative, characterised by deficits with social interaction, communication and cognition. In attempt to make sense of having a label of ASD, YP experienced questions and confusing feelings about their identity and the diagnostic process. Despite discrepancies in responses, all participants made some attempt to dissociate themselves from the ASD label, supporting the labelling debate's argument that diagnosis can lead to stigmatisation. Participants further conceptualised having a diagnosis of ASD in relation to other people and, in particular, to those without the condition. The latter were deemed as being more able, whilst those with ASD were portrayed as being at a disadvantage. The participants' emotional responses of having ASD were characterised by a loss of control and suppression of strong feelings. False selves were presented in an attempt to avoid explosive confrontations and to conceal the diagnosis. Experiences moved to focus on the future, including thoughts around becoming more independent and positive change. Lastly, there was a shift in the deficit-driven depiction of ASD that had largely dominated responses – thinking widened as YP adopted a more curious stance.

Implications of the research for EP practice in light of the findings were identified. These included providing YP, families and school staff with more effective support and understanding about what ASD is, its longevity and the heterogeneity of the condition during diagnosis and afterwards; promoting YP to explore their self-concepts and support them to find a way to be their true selves; continuing to ascertain the voice of YP and involve them in any decisions which concern them; supporting schools to plan and implement interventions which provide YP with emotional support around their diagnosis, particularly with regards to social interaction; and promoting methods to facilitate widened thinking in YP with ASD. In order to promote positive life outcomes, more support must be given to these areas, which EPs are well-placed to provide.

The research has proven that through appropriate methodologies, it is possible to obtain in-depth experiences from YP with ASD regarding their diagnosis. Participants demonstrated widened thinking as a result of the interview process, illuminating the importance of providing YP with a space to explore their understanding of their diagnosis. Further, the research highlighted that cognitive theories of ASD are not representative of all YP with the diagnosis. Therefore, EPs have an important role to play in challenging medical models of ASD which place limits on YP’s abilities and strengths. Instead, they should strive to seek out alternative narratives, by listening to YP’s experiences. Supporting YP who have ASD through these named approaches is important for the development of their self-concept and ultimately for the achievement of better life outcomes.

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Appendices

Appendix 1 – Limiters applied during systematic literature search

Limiters

- Language: English
- Publication Type: Peer Reviewed Journal
- Age: Adolescence (13-17 years) & young adulthood (18-29 years)
- Publication Year: 1998 -2018
- Population Group: Human
- Methodology: Interview
- Exclude Dissertations

Produced: 89 results

Appendix 2 – Inclusion and exclusion criteria for systematic literature search

	Inclusion Criteria	**Exclusion Criteria**
1	Article focuses on the experiences of YP as told by them	Experiences are told by anyone apart from YP, e.g. parents, teachers, professionals
2	Article focuses on the experience of having ASD, rather than the experience of another phenomenon	Article focuses on the experience of having a phenomenon other than having ASD, e.g. the experience of bullying for YP with ASD
3	Article focuses on the condition ASD	Article focuses on a condition other than ASD, e.g. ADHD
4	Participants are aged between 12 and 25 years old	Participants are aged below above 12 years and/or above 25 years old

Appendix 3 – Articles excluded and included

Reason for Exclusion	Number of Articles Excluded	Excluded Articles
Article focuses on the experience of having a phenomenon other than having ASD, e.g. the experience of bullying for YP with ASD	72	Joyce, C., Honey, E., Leekam, S. R., Barrett, S. L., & Rodgers, J. (2017). Anxiety, intolerance of uncertainty and restricted and repetitive behaviour: Insights directly from young people with ASD. *Journal of Autism and Developmental Disorders*, *47*(12), 3789-3802. Murphy, M., Burns, J., & Kilbey, E. (2017). Using personal construct methodology to explore relationships with adolescents with Autism Spectrum Disorder. *Research in developmental disabilities*, *70*, 22-32. Rai, D., Lee, B. K., Dalman, C., Newschaffer, C., Lewis, G., & Magnusson, C. (2017). Antidepressants during pregnancy and autism in offspring: population based cohort study. *bmj*, *358*, j2811. O'Hagan, S., & Hebron, J. (2017). Perceptions of friendship among adolescents with autism spectrum conditions in a mainstream high school resource provision. *European Journal of Special Needs Education*, *32*(3), 314-328. Landor, F., & Perepa, P. (2017). Do resource bases enable social inclusion of students with Asperger syndrome in a mainstream secondary school?. *Support for Learning*, *32*(2), 129-143. Stewart, C. S., McEwen, F. S., Konstantellou, A., Eisler, I., & Simic, M. (2017). Impact of ASD traits on treatment outcomes of eating disorders in girls. *European Eating Disorders Review*, *25*(2), 123-128.

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Article focuses on a condition other than ASD, e.g. ADHD	4	McKinnon, A., Brewer, N., Meiser-Stedman, R., & Nixon, R. D. V. (2017). Trauma memory characteristics and the development of acute stress disorder and post-traumatic stress disorder in youth. *Journal of behavior therapy and experimental psychiatry*, *54*, 112-

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Experiences are told by anyone apart from YP, e.g. parents, teachers, professionals	7	Turner, H., Remington, A., & Hill, V. (2017). Developing an intervention to improve reading comprehension for children and young people with autism spectrum disorders. *Educational and Child Psychology, British Psychological Society*, *34*(2), 13-26. Peckett, H., MacCallum, F., & Knibbs, J. (2016). Maternal experience of Lego Therapy in families with children with autism spectrum conditions: What is the impact on family relationships?. *Autism*, *20*(7), 879-887. Griffith, G. M., Hastings, R. P., Petalas, M. A., & Lloyd, T. J. (2015). Mothers' expressed emotion towards children with autism

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Participants are aged below above 12 years and/or above 25 years old	1	Rydzewska, E. (2016). Unexpected changes of itinerary–adaptive functioning difficulties in daily transitions for adults with autism spectrum disorder. *European Journal of Special Needs Education*, *31*(3), 330-343.

Final articles included for review

Article	
Stevenson, K., Cornell, K., & Hinchcliffe, V. (2016). 'Let's Talk Autism'–a school-based project for students to explore and share their experiences of being autistic. *Support for Learning*, *31*(3), 208-234.	Included
Mackay, S. J., & Parry, O. (2015). Two world views: Perspectives on autistic behaviours. *Journal of health psychology*, *20*(11), 1416-1426.	Included
Huws, J. C., & Jones, R. S. (2015). 'I'm really glad this is developmental': Autism and social comparisons–an interpretative phenomenological analysis. *Autism*, *19*(1), 84-90.	Included
Calzada, L. R., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, *42*(2), 230-243.	Included
Winstone, N., Huntington, C., Goldsack, L., Kyrou, E., & Millward, L. (2014). Eliciting rich dialogue through the use of activity-oriented interviews: Exploring self-identity in autistic young people. *Childhood*, *21*(2), 190-206.	Included
Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, *37*(2), 255-269.	Included (found through searching references of papers listed above)
Huws, J. C., & Jones, R. S. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, *33*(2), 99-107.	Included (found through searching references of papers listed above)

Appendix 4 – Example of results from the CASP

Paper for appraisal and reference: Calzada, L. R., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, *42*(2), 230-243.

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
   Yes – clear statement of aims and why the research is relevant.
2. Is a qualitative methodology appropriate?
   Y*es – qualitative methodology is appropriate as the research is an in-depth exploration into participants' lived experiences.*
3. Was the research design appropriate to address the aims of the research?
   Yes and the authors have justified why they have used the chosen method in relation to the research aims.
4. Was the recruitment strategy appropriate to the aims of the research?
   Yes – the recruitment strategy is explained and there are discussions around why some participants chose not to take part/were excluded. The authors explained why the population chosen were suitable.
5. Was the data collected in a way that addressed the research issue?
   Yes – clearly states that semi-structured interviews were used and why these were chosen. Appendix includes the interview schedule. Authors mention audio recording interviews and transcribing them verbatim before data analysis.
6. Has the relationship between researcher and participants been adequately considered?
   No – researcher does not explicitly examine his own role during formation of the research question/data collection. The authors mention that interviews took place at the participants' homes, but does not explain why this was the chosen location and the possible effects of this on the results.

Section B: What are the results?

7. Have ethical issues been taken into consideration?
   Yes, to an extent – ethical approval acquired from ethics committee is mentioned. However, there is no mention of informed verbal/written consent, confidentiality, anonymity and debriefing.
8. Was the data analysis sufficiently rigorous?
   Yes – steps explained and sufficient evidence is included. Researcher examined own role in analysis by checking out interpretations with other authors.
9. Is there a clear statement of findings?
   Yes and these are discussed in relation to the original research question.

Section C: Will the results help locally?

10. How valuable is the research?
    The research is valuable – the authors discuss the contribution the study makes to existing knowledge and research, as well as the implications for future research. The authors acknowledge that the findings have limited applicability to other populations.

Appendix 5 – Data extracted from the reviewed literature

Author	Article Title	Aim	Participants	Design	Data Analysis	Findings	Critique
Calzada, Pistrang & Mandy (2012)	High-Functioning Autism and Asperger's Disorder: Utility and Meaning for Families	To directly explore the utility of a diagnosis for children with ASD and their parents	10 families – 9 YP, aged 9-16 years, and parents	Exploratory and qualitative using semi-structured interviews	Framework analysis (Ritchie & Spencer, 1994)	The main theme advantages of diagnosis emerged; including brings understanding, practical support and empowerment. These were mainly representative of parents' views, not YP's. Second main theme – limitations of diagnosis, including diagnosis ineffective as communication, provides limited information & stigma. These represented both parents' and YP's views.	Strengths Rationale for research is clearly outlined in relation to existing literature. Statement of aims is explicitly mentioned. Chosen method is appropriate to the research question and rationale for the method is provided. Recruitment method is clearly explained, as well as providing information about the initial amount of sign-ups, how many withdrew and how many were excluded and why. Inclusion and exclusion criteria was mentioned and rationalised. The methodology and

							analysis is transparent – interview schedule is included in appendix, findings are discussed along with evidence (quotes and analysis). Ethical approval obtained from ethics committee mentioned. Researchers accounted for potential bias/inaccuracies of analysis by triangulating data with other authors. The findings are discussed in relation to existing research and practice. Implications for future practice are clearly explored. Researchers have identified own limitations of the study and outlined how they accounted for these limitations.

							Limitations Participants were all White British – not representative of population. Fathers were largely absent from study. The applicability of the findings to the population of YP on the autism spectrum are limited, as the YP included were all high-functioning. The sample size was small. The researchers did not critically examine their own roles. Did not discuss their relationships with participants and the potential effects of such. The setting for data collection (participants' homes) was mentioned, but the choice of the setting was not

							elaborated on, e.g. why and potential impact on the findings. Ethical procedures are not thoroughly explained – no mention of informed verbal and/or written consent, confidentiality, anonymity and debriefing.
Stevenson, Cornell & Hinchcliffe (2016)	'Let's Talk Autism' – a school-based project for students to explore and share their experiences of being autistic	To reflect on and share experiences of having autism in order to raise awareness for autistic and non-autistic communities	2 discussion groups, each made up of 4 participants from key stage 4 and sixth form	Exploratory and qualitative design, using semi-structured interviews Orientation – critical realist? Acknowledges ASD exits, but explores the meaning for individuals	Thematic Analysis (following Braun & Clarke, 2006)	Overarching theme – making sense of autism & negotiating identity, which comprised of the sub-themes; experiences of the diagnosis; experiences of difference; and strategies to manage diagnosis. Theme 2 – growing up with autism	<u>Strengths:</u> The rationale for the research was clearly outlined. The method was also clear, outlining each stage at a time. The value of the research was clearly considered and outlined in relation to current knowledge, as were the implications for future research. Ethical issues were frequently referred to throughout the article, including

							informed consent, right to withdraw and measures put in place to reduce any emotional distress for participants. Limitations: The relationship between the researchers and the students was not explicitly mentioned. Whilst it was acknowledged that the researchers knowing the students well could have compromised the objectivity of the data, there was no mention of measures taken to reduce the chance of potential researcher bias, e.g. reflexivity diary. Themes were discussed with evidence provided from the interviews,

							but overall findings were not explicit and did not appear to be critically examined, e.g. there were no contradictions/exceptions in data mentioned
Mackay & Parry (2015)	Two world views: Perspectives on autistic behaviours	To interpret and understand experiences of autism	10 YP, aged 8-16 with a diagnosis of ASD, & 10 parents from local schools and autism advocacy groups	Qualitative study using semi-structured interviews and/or video recordings	Thematic analysis using ethnomethodological methods	The social construct of autism is reproduced in experience through everyday discourse. Parents problematise what children with ASD do as pathological (obsessive behaviours). YP's language is influenced by parents, but differently, they use their hobbies and interests to interpret their worldview.	<u>Strengths</u> Rationale for research is outlined. Research is relevant. Methodology is appropriate and justification for choice is provided. Ethical issues mentioned, including informed consent (verbal and written), ethical approval from committee obtained, flexible data collection methods used for YP with ASD. Analysis mentioned and evidence of findings presented. The research discusses its own limitations and the measures taken to

							account for these. Implications for future research are discussed. Limitations Aims of research are not explicitly mentioned in the main body. Recruitment is slightly vague – 'All YP were deemed capable of consent' – no mention of how this was determined. No mention of how many YP and parents initially wanted to take part and how many were turned away. The relationship between the participants and researchers is not mentioned, nor is the relationship between parents and children and how this was accounted for. There

							is no mention of how the researchers critically examine their own roles through data collection and analysis. A sample of the interview schedule is not provided. The steps of analysis are not provided and the credibility of findings is not discussed (e.g. triangulation of data).
Huws & Jones (2015)	'I'm really glad this is developmental': Autism and social comparisons—An interpretative phenomenological analysis	To explore YP's perceptions of autism	9 YP, aged 16-21 from a specialist college for ASD	Qualitative study using semi-structured interviews	IPA	Overarching theme – making comparisons and 3 sub themes – changes over time, degrees of autism and degrees of ability. The YP viewed themselves as; more positively now in comparison to the past; in a better position than others with	Strengths Authors discussed current literature around social comparison processes for YP with ASD and the contribution that their research makes to this existing knowledge. They also discussed implications for future research. Checks were made throughout research process to increase

						ASD; better-off than others without ASD due to heightened abilities; and better-off than those with a different disability.	credibility, e.g. field notes were written after each interview to capture the researcher's feelings and any issues that were raised during the interview. These field notes were referred to during analysis and were checked by a second person to see if emerging themes were representative of participants' responses. Data analysis was sufficiently rigorous, with all stages of the data analysis being outlined clearly. Findings were clearly explained. Data was presented from the original sample to support the findings and themes. Ethical issues were explicitly and

							thoroughly mentioned, including ethical approval and informed consent being obtained, participants' rights to withdraw, protecting anonymity and confidentiality and measures taken to reduce researcher bias (such as the psychologist obtaining informed consent, rather than the researcher). Also, measures taken to ease participants on the way to the interviews were outlined. Debriefing processes were described, as well as measures taken to protect participants from experiencing any emotional distress following the interviews.

							Limitations Recruitment method was not sufficiently explained – authors mentioned that forms were given to potential participants, but the actual method of recruitment was not included. Further, the authors did not mention how many people were approached for recruitment and how many declined. The relationship between the psychologist, who recruited participants, and the participants was not adequately considered. The authors mentioned that the psychologist knew the participants, but did not elaborate on the capacity of this relationship, or how

							knowing participants may have affected recruitment. Measures taken to reduce the impact of bias/any issues regarding this prior relationship were not mentioned. Findings were not discussed with the participants to check whether the researcher’s interpretations were accurate. However, IPA uses ‘double hermeneutics’ during interviews, whereby the researcher’s interpretations were checked out with the participants.

Huws & Jones (2008)	Diagnosis, disclosure and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism	To look at the retrospective accounts of being told about having ASD by young people with autism	9 YP aged 16-21 years with high-functioning autism (IQ in normal range or above) from a college for YP with autism	Qualitative study using semi-structured interviews	IPA	Superordinate theme was 'diagnosis, disclosure and having autism' and within this were 5 themes – 'disclosure delay,' 'providing explanations,' 'potential effects of labelling,' 'implications and opportunities' and 'acceptance and avoidance'	Strengths Rationale for research in light of current literature is clearly explained. Researchers justify the choice of participants – high-functioning ASD – to ensure they have the cognitive, verbal and developmental skills to provide accounts of their experiences. Ethical measures thoroughly discussed, including approval granted by ethics committee, informed consent, confidentiality, anonymity and debriefing. Measures taken to increase credibility are mentioned – field notes written after interviews which were

							included during analysis and use of external auditor to check interpretations of data. Implications for future research explicitly discussed, as well as recognition of own study's limitations (as follows) <u>Limitations</u> Lack of parental involvement, e.g. not exploring the emerging themes with parents and not asking them about their decisions to disclose the diagnosis to children. Researchers did not access participants' diagnostic information in their files, reducing the rigour of research.

							The relationship between the research and participants and the psychologist (who recruited participants) has not been adequately examined. No mention of the potential impact of the psychologist knowing participants on their decision to take part. Researchers do not explain if any participants chose not to take part and if so the reasons for this. Reason behind IPA being used is only briefly mentioned in discussion. Theory of IPA presented, but not applied to current research

Mogenson & Mason (2015)	The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder	To learn about the experiences of young people diagnosed with autism	5 young people aged 13-19 years diagnosed with autism	Qualitative research using communication methods chosen by participants, (including semi-structured interviews, drawings, photos, communication cards and emails)	Thematic analysis	Themes were young people's struggles with personal identity, their social relations and the ways in which they negotiated impairment	<u>Strengths</u> Ethical issues were well considered (including informed consent, recruitment, confidentiality, using flexible methods depending on participants' needs). Researcher's position was clearly stated, along with rationale for the research and for methods employed. Process of analysis clearly described. Findings were thoroughly explained and discussed in relation to existing literature, policy and practice. Implications for practice were clearly outlined. <u>Limitations</u> Researcher does not critically examine own position and/or

							relationship with participants. Therefore, no mention of any potential bias and attempts taken to reduce it. Recruitment methods were explained, but there was no mention of whether participants were turned away/said no to taking part/withdrew. No limitations of the research were discussed by the authors.
Winstone, Huntington, Goldsack, Kyrou & Millward (2014)	Eliciting rich dialogue through the use of activity-oriented interviews: Exploring self-identity in autistic young people	To explore the self-identity of YP with ASD through the use of activity-oriented interviews	13 boys, aged 12-14 years (5 boys in study 1 and 8 boys in study 2)	Qualitative methodology divided into 2 studies; semi-structured interviews; activity-oriented interviews	Thematic analysis	Four themes emerged; self-perception and self-awareness; description of the future self; perception of self as a person with autism; and comparison of self to others. The activity-oriented interviews	Strengths Aims of the research were clearly outlined, as was the rationale for the research in relation to existing knowledge and practice. The methodology used was appropriate and researchers comprehensively discussed why the

						provided much more in-depth information than the traditional interviews.	chosen methodology was used. A justification for the sample (age and gender) was provided. Data collection procedures were clear – an overview of interview topics and activities was provided. Researchers mention that interviews were audio-recorded and later transcribed verbatim. Type of analysis and justification for this were provided. Steps of analysis were outlined. Findings are clearly presented with evidence from original interviews (quotes and interpretations). Findings are discussed in relation to original research aims and in the context of existing knowledge and

							practice. Implications for future practice and research are discussed in light of the current findings. Researchers identity own limitations with study and discuss measures taken to reduce impact of such. Limitations The recruitment method was not explicit – the setting where recruitment took place was mentioned, but no mention of how participants were recruited. No discussion about the amount of YP who originally showed interest, the exclusion criteria and drop-out rate. Researchers only briefly mention relationships with participants, but little

							examination into the potential impact of this on findings. Within ethics, there is no mention of confidentiality, anonymity and debriefing processes. Researchers do not critically examine own roles during analysis, for example no mention of triangulation of findings.

Appendix 6 – Recruitment letter to schools

The Tavistock and Portman NHS
NHS Foundation Trust

Dear all,

My name is Jodi Cooper and I am a Trainee Educational Psychologist, studying at the Tavistock and Portman NHS Clinic and working on placement in [redacted] Educational Psychology Service. As part of my doctoral training, I am conducting research in [redacted] mainstream secondary schools.

The research will be exploring young people's experiences of having Autism Spectrum Disorder (ASD). Whilst there is a large amount of research looking into parents' experiences of having a child with ASD, professionals' experiences and siblings' experiences, there is a sparsity which explores children or young people's perspectives. I believe that it is important for young people's voices to be heard more, in order for others to better understand how best to support them. This is important to help young people to achieve the outcomes that they want to throughout their lives.

I am looking to recruit 4 to 6 young people, aged between 11 and 18 years old. The research will involve me individually interviewing each young person for about an hour in school (please see attached information sheet for further information). The young people who take part in the research must meet the following criteria:

- Participants must have a diagnosis of ASD or Asperger Syndrome
- Participants must know about their ASD diagnosis (and preferably have known for at least one year)
- Participants must attend mainstream school
- Participants must be able to speak and understand English
- Participants must not have any other diagnoses

If you have any students in mind who meet the above criteria and you think would like to be involved in the research, please contact me to let me know. The participants will be selected on a first come, first serve basis. I am hoping to come into schools before the end of the summer term to interview participants.

I have attached participant and parent information sheets which detail the research further, as well as a consent form for the young people to fill out if they would like to take part.

If you have any further questions, please do not hesitate to contact me on [redacted] or [redacted]

Kind regards,

Jodi Cooper

Trainee Educational Psychologist
[redacted] Educational Psychology Service

Appendix 7 – Information sheets and consent forms

Participant Information Sheet

The Tavistock and Portman NHS
NHS Foundation Trust

Young People's Experiences of Having Autism Spectrum Disorder

Who is doing the research?

- My name is Jodi Cooper and I am studying a course in Educational Psychology. Here is a photo of me →
- I am doing this piece of research as a part of my course.

Would you like to take part in research?

- I would like to invite you to take part in my research study.
- Before you decide whether you would like to take part, you need to understand why the research is being done and what it would involve for you.
- Please take time to read the information carefully and decide whether or not you wish to take part.

What is the aim of the research?

- The aim of the study is to find out about young people's experiences of having Autism Spectrum Disorder (ASD) so that people can better understand what it might be like to have ASD.
- I would like people to understand this better so that young people can receive better support at school and even after they leave school.

- This support might help with friendships and with school work.

Who has given permission for this research?

- [redacted] Educational Psychology Service (where I work) and the Tavistock and Portman NHS Foundation Trust (where I study) have given me permission to do this research.
- When I was thinking about my research idea, a committee of people at my university helped me to think about how I could carry out the research safely in order to make sure that you are okay during and after the interviews and that your rights are protected.

Who can take part in this research?

- I am looking for young people who have ASD and are able to talk with me about their experiences of having ASD.

Do I have to take part?

- You do not have to take part, and it is up to you to decide.
- You are free to withdraw (stop taking part in the research) at any time until I start typing up the data (in December 2018).
- You do not need to give a reason if you decide not to take part or to withdraw. You will not get into any trouble and nobody will be upset or annoyed at you if you choose not to take part or to withdraw.

What will I have to do in the research?

- You will be told where and when to meet me in school by your SENCo. It will be during a school day.
- The room that we meet in will have a sign on the door telling people not to enter to stop anyone from entering.

- I will ask you some questions about having ASD. You may also do a short drawing task. It will all last for 1 hour.

- The meeting will be audio recorded (the things that were said will be recorded; there will not be any video recordings).

- You can decide to stop taking part in the research at any time. If you decide during the meeting with me that you want to stop then you can tell me using words or you can hold up a picture of a stop sign that will be on the side.

- Only I will have access to the recordings and drawings and they will stored securely on a

computer using password-protected software (only I will know the password to open the files where the recordings are stored).

- The recordings will be deleted once I have typed them up and the drawings will be shredded once I have scanned them.

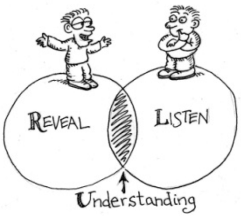
- Your names, your school name and the area that your school is in will be removed from the information I type up so that everything you say in the interviews is kept as confidential as possible.

- However, because I am interviewing a small group of young people (between 4 and 6 people), there is a chance that people who know you very well (such as your family) might be able to guess which responses are yours.

Will I need to bring anything when I meet you?

- No, you will not need to bring anything or prepare in any way before you meet me.

What are the possible benefits of taking part?



- There is not much research that looks at young people's experiences of having ASD.
- Your opinions and thoughts are really important for my research because they may support people who work with you to understand you better.
- I think it would be very useful for people to understand you better so that young people, such as you, can receive better support at school and after school. This support might help with friendships and with school work.


What will happen to the findings from the research?

- The findings will be typed up and will make up my thesis which will be part of my Educational Psychology qualification.
- When my thesis is completed, it will be accessible by the public on the internet.

What will happen if I don't want to carry on with this research?

- You can decide to stop taking part in the research at any time. If you decide during the meeting with me that you want to stop then you can tell me using words or you can hold up a picture of a stop sign that will be on the side.

- If you decide you no longer want to be in the research after the meeting, then you can leave at any time until I start typing up the data (December 2018) without explaining why.
- You will not get into any trouble and nobody will be upset or annoyed at you if you choose to stop taking part in the research.

Will my taking part in this study be kept confidential?

- Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected will be kept strictly confidential. All records related to your participation in this research study will be handled and stored appropriately.
- Your identity on these records will be indicated by a pseudonym (a made up name) rather than by your name.

- The data will be kept 10 years or more. Data collected during the study will kept in accordance with the University's Data Protection Policy.

Are there times when my data cannot be kept confidential?

- If you tell me something that makes me concerned about the safety of you or someone else then I might have to share that information with others in order to keep you or someone else safe. I would always aim to discuss this with you first when possible.
- Because I am meeting with 4 to 6 young people, there is a chance that you and people who know you very well (such as your family) may recognise some of the things you said in my research.
- To protect your identity, your name will be a pseudonym (a made up name) so that others are less likely to be able to recognise you and what you said.
- The name of your school and the area of your school will not be mentioned in the research to protect your identity even more.

Further information and contact details

- If you have any questions or concerns about any part of the research, please let the SENCo know and she/he will pass these concerns or questions on to me.

If you have any further questions or concerns about the research, you can contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

Parent Information Sheet The Tavistock and Portman NHS
NHS Foundation Trust

Young People's Experiences of Having Autism Spectrum Disorder

Who is doing the research?

My name is Jodi Cooper and I am studying a course in Educational Psychology. I am doing this piece of research as a part of my course.

What is the aim of the research?

The aim of the study is to find out about young people's experiences of having Autism Spectrum Disorder (ASD). This is so that people working with these young people can support them better and understand more about what it may be like to live with an ASD diagnosis. If better support is provided for young people with ASD then outcomes in their lives are likely to be better. These outcomes may include social and educational achievements.

Who has given permission for this research?

[redacted] Educational Psychology Service has given me permission to do this research with young people who would like to take part. The training institution that I am studying at is called the Tavistock and Portman NHS Foundation Trust and they have given me ethical approval to do the research. This means that my research proposal with all the relevant details was submitted to a group of staff who decided that the research meets ethical standards to be carried out, ensuring that all the measures have been carefully considered to protect the rights, safety and well-being of participants.

Who can take part in this research?

I am looking for young people who have ASD and are able to talk with me about their experiences of having ASD.

Does my son/daughter have to take part?

Your son/daughter does not have to take part, and it is entirely up to him/her. Your son/daughter is free to stop taking part in the research at any time until I start processing the data (in December 2018). He/she does not need to give a reason if deciding not to take part.

What is involved in the research?

- Your son/daughter will be told where and when to meet me in school by the SENCo. It will be during a school day.
- The room that we meet in will have a sign on the door telling people not to enter.
- I will ask some questions about his/her experience of having ASD.
- He/she may or may not find it difficult to talk about having ASD. Either way, it is okay, and if he/she becomes upset and decides to stop the

interview then he/she is free to do so. There will be a visual stop sign provided which they can use, or they can use their words. At the end of the meeting I will debrief with your son/daughter and reflect on how they find the session.

- The whole meeting will last up to 1 hour.
- The meeting will be audio recorded. Only I will have access to the recordings and the drawings and they will all be stored securely on a computer using password-protected software (only I will know the password to open the files where the recordings are stored). The recordings will be deleted once I have typed them up and the drawings will be shredded once I have scanned them in.
- The information I type up will also be anonymised (participant names will be removed). However, because I am interviewing a small group of young people (between 4 and 6 people), there is a chance that the participants and/or people who know them very well (such as you) will be able to guess which responses are theirs.

Will my son/daughter need to bring anything for the meeting?
No, he/she will not need to bring anything or prepare in any way before meeting me.

What are the possible benefits of taking part?
There is not much research that looks at young people's experiences of having ASD. Their opinions and thoughts are really important for my research because they may support people who work with them to understand them better. Understanding the young people better may lead to better social and educational outcomes for them and for other young people with ASD. Additionally, through hearing the voices of the young people, professionals who diagnose ASD may learn more about what to include in the diagnosis process or what questions may be important to answer.

What will happen to the findings from the research?
The findings will be typed up and will make up my thesis which will be part of my Educational Psychology qualification. When my thesis is completed, it will be accessible by the public on the internet.

What will happen if my son/daughter does not want to carry on with this research?
Participants can decide to stop taking part in the research at any time. If they decide during the meeting with me that they want to stop then they can tell me verbally or by holding up a picture of a stop sign that will be on the side. If they decide that they no longer want to be in the research after the meeting, then they can leave at any time until I start analysing the data (December 2018) without explaining why.

Will my taking part in this study be kept confidential?
Yes, I will follow ethical and legal practice and all information about participants will be handled in confidence. All information that is collected will be kept strictly confidential. All records related to their participation in this research study will be handled and stored appropriately. Their identity on

these records will be indicated by a pseudonym rather than by their name. The data will be kept for 10 years or more. Data collected during the study will kept in accordance with the University's Data Protection Policy.

Are there times when participant data cannot be kept confidential?

If participants tell me something that makes me concerned about the safety of them or someone else then I might have to share that information with others in order to keep them or someone else safe. However, I would always aim to discuss this with the young person first when possible. Because I am meeting with 4 to 6 young people, there is a chance that participants and people who know them very well (such as you) may recognise some of the things said in my research. To protect their identity, the name of the school and local authority will not be used, and their name will be replaced with a pseudonym so that others are less likely to be able to recognise them and what they said.

Further information and contact details

If you have any questions or concerns about any part of the research, please let me or the school SENCo know, who can then inform me.

Email: jcooper@tavi-port.nhs.uk

If you have any further questions or concerns about the research, you can contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

The Tavistock and Portman NHS
NHS Foundation Trust

Parent Consent Form

Young People's Experiences of Having Autism Spectrum Disorder

Please initial the statements below if you agree with them:	**Initial here**
1. I have read and understood the information sheet and have had the chance to ask questions.	
2. I understand that my child's participation in this research is voluntary and he/she is free to withdraw (stop taking part) at any time until the data starts to be processed (December 2018) without giving a reason.	
3. I agree for my child's interviews to be recorded.	
4. I understand that my child's data will be anonymised to reduce the chance of people linking the data to him/her.	
5. I understand that the information my child provides will be confidential unless he/she says something that the researcher thinks means that he/she may be at risk of harm to him/herself and/or others.	
6. I understand that my child's interviews will be used for this research and cannot be accessed for any other purposes.	
7. I understand that the findings from this research will be published in a thesis and available for the public to read.	
8. I am happy for my child to take part in this research.	

Your name…………………………….........Signed……………………Date…../…../…..

Researcher name………………...............Signed……………………Date…../…../…..

Thank you for your help

Participant Consent Form

The Tavistock and Portman NHS
NHS Foundation Trust

Young People's Experiences of Having Autism Spectrum Disorder

Please initial the statements below if you agree with them:	**Initial here**
1. I have read and understood the information sheet and have had the chance to ask questions.	
2. I understand that my participation in this research is voluntary and I am free to withdraw (stop taking part) at any time until my data starts to be processed (December 2018) without giving a reason.	
3. I agree for my interviews to be recorded.	
4. I understand that my data will be anonymised to reduce the chance of people linking the data to me.	
5. I understand that the information I provide will be confidential unless I say something that the researcher thinks means I may be at risk of harm to myself and/or others.	
6. I understand that my interviews will be used for this research and cannot be accessed for any other purposes.	
7. I understand that the findings from this research will be published in a thesis and available for the public to read.	
8. I would like to take part in this research.	

Your name……………………………….........Signed……………………Date…../…../…..

Researcher name……………….................Signed……………………Date…../…../…..

Thank you for your help.

Appendix 8 – Parent interview schedule

The Tavistock and Portman NHS
NHS Foundation Trust

1) Can I check that ... knows about his/her ASD diagnosis?

2) When was ... diagnosed?

3) When did ... find out about the diagnosis?

4) Who revealed the diagnosis to...?

5) How was the diagnosis disclosed? What was said?

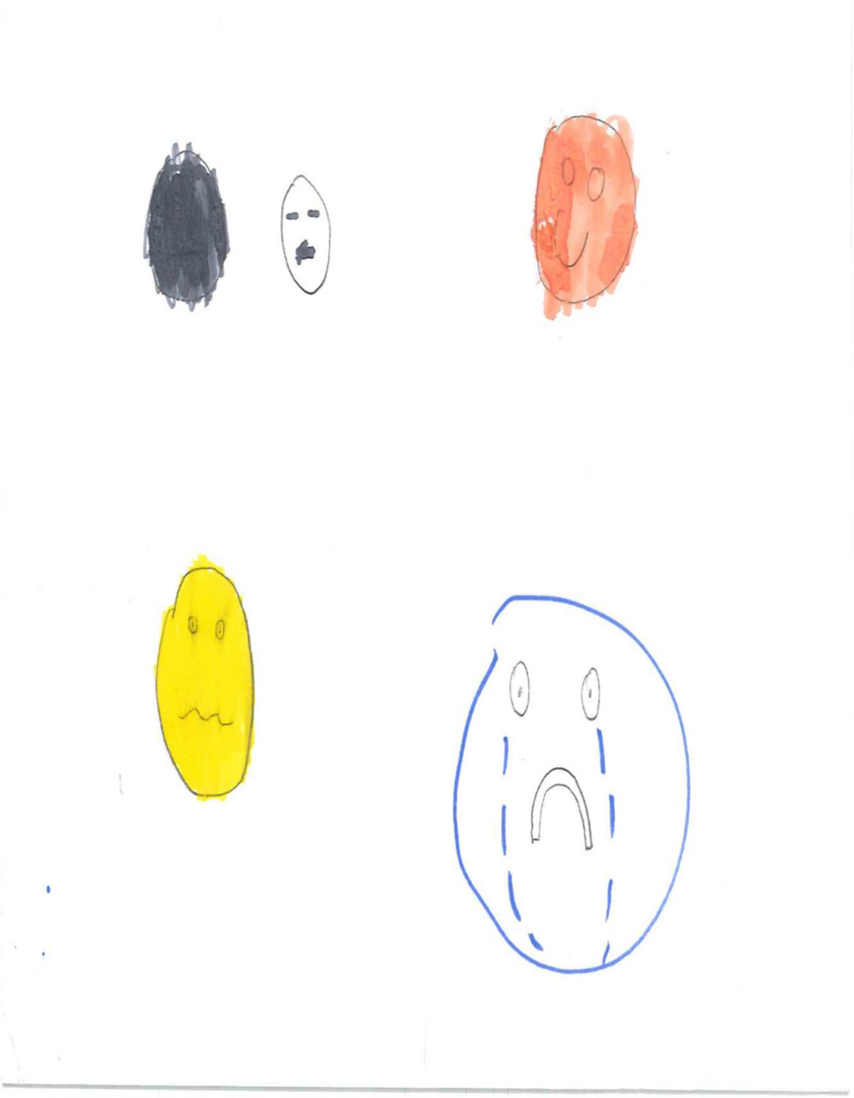
6) How did ... respond to the disclosure?

7) Have there been conversations since about ASD?

8) Does ... have any other diagnoses?

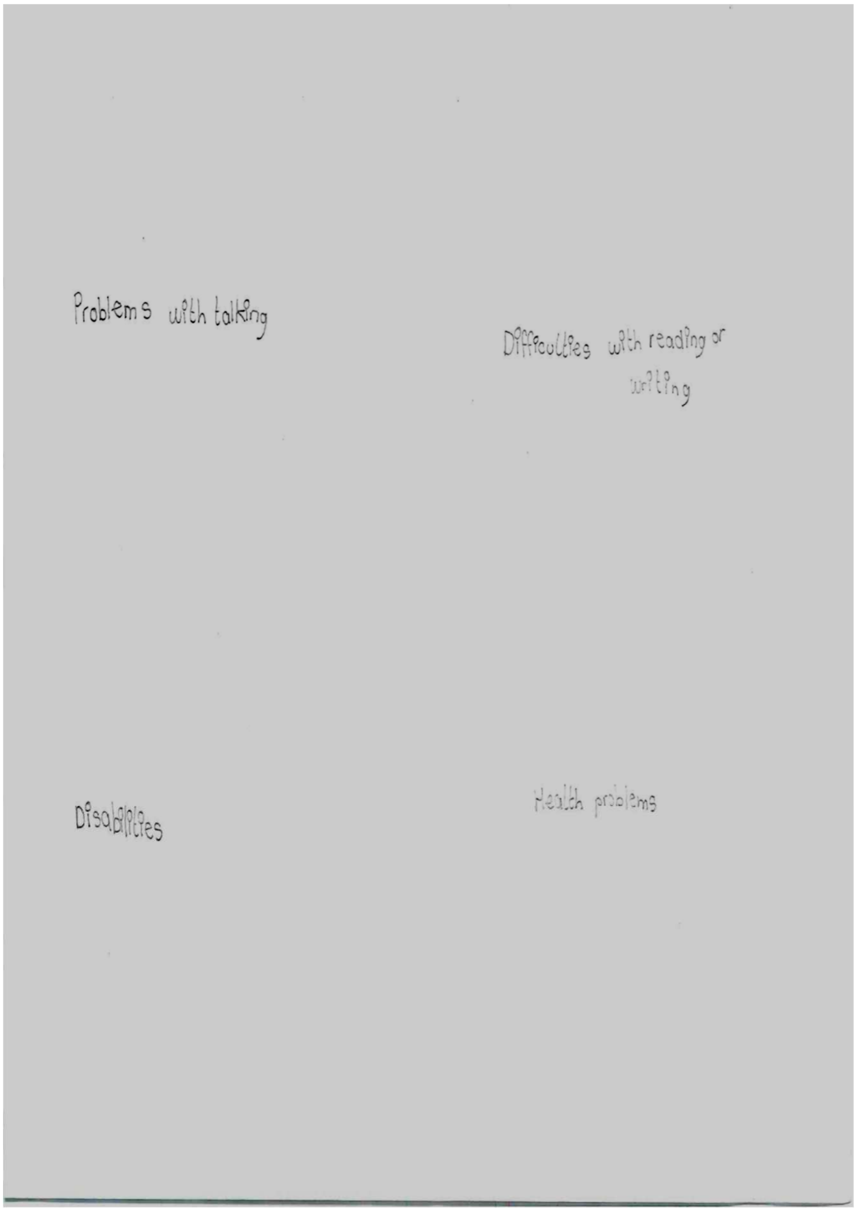
Appendix 9 – GEM grids

Elena's grid



Leo’s grid

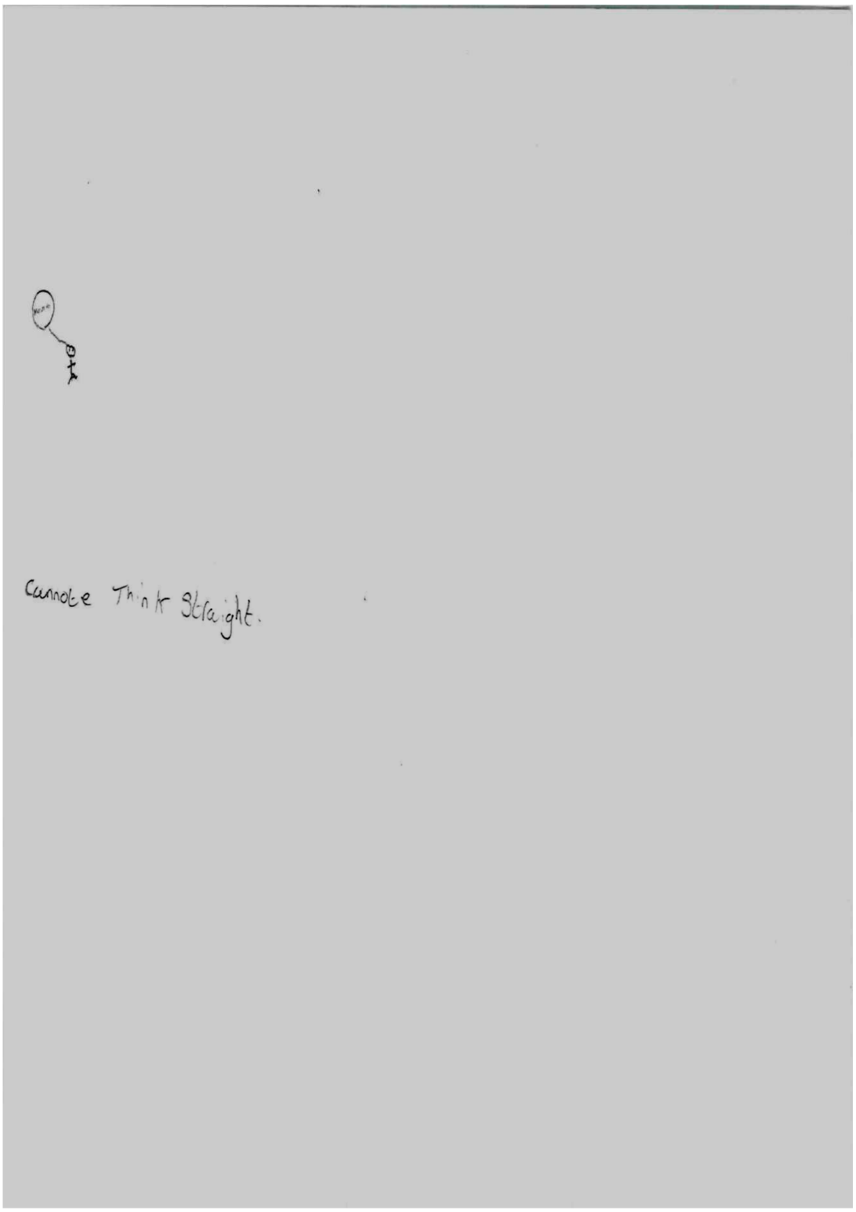
Sarah’s grid



Sarah has written the following in each section of the grid:

- ‘Problems with talking’
- ‘Difficulties with reading or writing’
- ‘Disabilities’
- ‘Health problems’

Mik’s grid



Cannote Think Straight.

Mik has drawn a stick man with a speech bubble containing random symbols. Below the stickman, he was written ‘cannot think straight.’

Appendix 10 – Interview Schedule

Participant Interview Schedule

Young People's Experiences of Having Autism Spectrum Disorder

The following interview questions will be used as a guide for participants who may struggle to answer the first question. Therefore, all seven questions may not necessarily be asked to all participants.

1. What does it mean to you to have ASD?

2. Do you like having ASD? If so, what do you like about having it?

3. What do you not like about having ASD, if anything?

4. Do you think having ASD makes a difference to your life? If so, how? If not, why not?

5. Does having ASD make a difference to you at school? If so, how? If not, why not?

6. Does having ASD make a difference to you outside of school, e.g. at home? If so, how? If not, why not?

7. Why do you think you were given an ASD diagnosis?

8. Do you feel or think any differently now to before you knew who had ASD? If so, in what way?

9. What, if anything, do you think are the differences between young people who have ASD and those who do not?

10. In what ways do you see yourself as different to other pupils?

11. In what ways do you see yourself as similar to other pupils?

Appendix 11 – Stages 2 and 3 of data analysis for Leo and Mik

Descriptive Comments – blue Linguistic Comments – orange Conceptual Comments – green

Initial Comments	Line No.	Transcript	Emerging Themes
		Part 1 – GEM	
	1 2	J: So Leo, the first one you drew was this one. So tell me about this – what is this?	
L's free associative drawing was a male feeling very nervous as he stands in front of an audience. 'That guy' – taking focus away from himself and in next response changes to first person – 'that's how I feel as well.' Speaking very quietly indicates that the drawing is exposing L's feelings, which are difficult to share. By referring to the figure in the drawing as another guy, perhaps Leo is finding comfort in the idea that he is not alone in how he feels about standing in front of an audience.	3 4	L: So that guy on the stage is very nervous in front of the audience	Standing in front of an audience nerves
	5 6	J: He's very nervous in front of the audience? Ok, and how come you chose that for the word autism?	
	7	L: Because that's how I feel sometimes [said very quietly]	Difficulty being exposed
	8	J: Pardon?	Avoidance of self
	9	L: Because that's how I am sometimes as well	
	10 11 12	J: That's how you feel sometimes as well. So sometimes you get nervous too? And you think that might be because of your autism?	Comfort from identifying with others
	13	L: Yeah	
	14 15	J: Ok and how about this one? What's going on in this picture?	
Second picture depicts a child being told to do homework by a female, but the child does not enjoy doing homework and does not want to do it. L relates this to ASD because he doesn't like homework. Described the picture in the third person again – 'this child' – before moving to first person to explain his reasoning.	16 17	L: She's saying that I should have to do homework and this pers, this child doesn't like it and doesn't want to do it	Dislike for homework
	18 19 20	J: Ah, but this one doesn't like homework and doesn't want to do it, ok. And that's the teacher. And why does child not want to do his homework or her homework?	
	21	L: Because he doesn't enjoy doing it	Comfort from identifying with others
	22 23	J: He doesn't enjoy doing it. And is that what you think of when you think of autism?	
	24	L: Yeah	
	25	J: How come you think of that?	

	L: Yeah because sometimes I don't like homework much	
	J: Because sometimes you don't like homework much. Ok, and is there any subject in particular or is it all homework?	
	L: Pretty much homework	
	J: Ok	
Third image depicts a kid wanting treats (chocolate and sweets) which his dad says that they can't buy, possibly because the treats are not good for them. Third person for the description of the image and first for the reason it is linked to ASD. Distinction between child in image and L – was once like the child in image but not anymore. Now accepted that parents make the decisions about whether to buy treats. Reflection on how he has changed over the years – now more mature than the 'kid' in picture 3? Adults/figures of authority appear explicitly in two out of the three pictures and perhaps more implicitly in first one (the person on stage is in a position of authority). L describes each picture without any prompting/questioning – keen to tell his narrative? Final image is a kid bullying a guy and the guy thinks up a way to seek revenge by dropping a 'huge metal' object on his head. Repeated use of quotations in images – retelling specific memories? 'Kid' is used for the bully and	L: And this is the kid that wants the treats and his dad says 'we can't buy'	Parental control
	J: Ah so they want sweets and chocolate and stuff?	
	L: Yeah	
	J: Why can't they buy?	
	L: 'Cause they don't want to	
	J: 'Cause they don't want to? Why not?	Acceptance about parental control
	L: I don't know, 'cause it's not good for them	
	J: 'Cause it's not good for them	
	L: Yeah	
	J: And why does that remind you of autism Leo?	Change over years
	L: 'Cause I used to be like that, but I'm not anymore I guess. It's up to mum and dad if they want to buy treats	
	J: You used to want treats? But now you've kind of learnt not to want them all the time?	
	L: Yeah. And this one here says, it's like a kid who's bullying this guy so he says ' so useless' and this guy thinks about dropping an anvil on his head	
	J: This one thinks what sorry? Sorry say that again	
	L: This one is very angry and he wants to drop an anvil on his head	Bullying
	J: An amble?	Seeking revenge
	L: Yeah	
	J: What's an amble?	
	L: Not amble, an anvil. Anvil	

‘guy’ for the one being bullied. ‘Guy’ was also used in image 1 – significant of someone more mature? L himself?	56	J: What’s an anvil?	
	57	L: I don’t know, something like a huge metal thing	
	58	J: So he wants to drop it on his head?	
	59	L: Yeah	
	60	J: And how come you drew that Leo?	
How anger takes form when people call L useless. Repetition of ‘angry.’ Use of the word ‘really’ emphasises the distress that L experiences.	61 62	L: Because when I’m angry and people say that to me, I really feel like doing something bad to them	Unkindness leading to anger
	63	J: Do people say that to you?	
Repetition of ‘I feel like doing something bad’	64 65	L: Um not every single person, but sometimes it happens and I feel like yeah doing, doing something bad so	Revenge (doing something bad)
	66 67	J: Yeah I understand. Is it people in your year group that say things like that?	
Comments are from people in L’s year group. Hesitation in saying yes – took 4 attempts – didn’t want to get anyone in trouble/didn’t want to admit that comments were coming from his peers?	68	L: Not in, well actually, mostly yes, actually yeah	Embarrassment about being teased
	69 70	J: Mostly yes, ok. And do these things all remind you of the word autism?	
	71	L: Yeah	
	72	J: That was what came to mind?	
Imagery and comments were extremely clear and instant – almost like he knew what he was going to do before I started? Were these thoughts triggered by the word ‘autism’ or were they preoccupations of his that he was eager to share and work through? Is drawing a good medium for L to express himself through?	73	L: Yeah	Vivid memories
	74 75	J: Well you’ve done really well Leo. You’re really good at drawing. Do you like drawing?	Desire to share memories
	76	L: Um yeah, it’s ok	
	77 78 79	J: Well I think you’re really good at it. Ok so now, we’re going to move on to something else, so now I’m going to ask you some questions	
		Part 2 – Semi-structured Interview	
	80	J: So Leo, what does it mean to you to have autism?	
Unable to say what autism means to him. Hesitant (particularly relative to part 1)	81 82	L: Well um...you know...it’s just...I can’t really explain that question	
	83	J: You can’t explain it?	

	84	L: No, I’m actually not sure of that question, I’m not sure	
	85	J: You’re not sure?	
	86	L: No	
	87	J: Ok, well we’ll move on and maybe we’ll come back to it. It’s	
	88	quite a difficult question eh? What about – do you like having	
	89	autism?	
Doesn’t like having ASD because he gets	90	L: Um not really	Dislike towards ASD
into trouble	91	J: Not really – how come?	
Less grammatically correct than L has	92	L: ‘Cause not really it’s good	
spoken during the interview – unsure	93	J: Why don’t you think it’s good?	
how he feels about ASD? ‘Get myself in	94	L: ‘Cause um I get myself in trouble	
trouble’ – implies he is responsible	95	J: You get yourself into trouble – what kind of trouble?	
Gets told off by parents for fighting with	96	L: Well I get told off by my parents	Getting into trouble with parents
sister	97	J: Ok, what kind of things do you get told off for?	Parental control
Repetition of ‘maybe’ and hesitant, whilst	98	L: [repeatedly banging an object on the table] Oops sorry, um	
banging object on table – angry? ‘you	99	well like things like I don’t know maybe my sister and I maybe	
know’ – didn’t want to go into too much	100	got into a little fight or something maybe, you know	
details?	101	J: So your sister and you got into a little fight and maybe...	
Repetition of ‘yeah’ – not wanting to	102	L: Yeah	
elaborate on answers?	103	J: And that kind of thing gets you into trouble?	
	104	L: Yeah	
	105	J: Ok, so you don’t think it’s good because sometimes you get	
	106	into trouble with your parents for getting into fights	
	107	L: Yeah	
	108	J: What kind of things do you get into fights about with your	
	109	sister?	
Arguments with sister over toys	110	L: Um well um...maybe just ‘cause she keeps maybe ‘cause	Strained relationships
Repetition of ‘maybe cause...’ – tentative	111	like um I just want to play a bit with her toys and then she	
– reluctant to blame self or sister	112	doesn’t let me	
explicitly. Hesitant saying this – difficult	113	J: Mm ok	

to reflect on fights with family members	114	L: By the way, what time is it?	
Enquires about time – avoidance of	115	J: It's about 10 to 3	
current conversation/anxiety evoked?	116	L: 10 to 3?	
	117	J: Yep, is that ok?	
	118	L: So that means...	
	119	J: We're going to be here until half 3 so we have about 40	
	120	minutes left	
	121	L: Ok	
	122	J: So sometimes you think having autism gets you into fights,	
	123	gets you into trouble with your parents?	
	124	L: Yes	
	125	J: And you said it's not good – why else is it not good?	
Getting into trouble is the only reason for	126	L: That's pretty much, well...that's actually pretty much the	
not liking ASD which affect L– lack of	127	only thing	
conviction in response. Repetition of	128	J: The only thing that's not good about it is that-	Holding back
'that's pretty much', a pause and 'well'	129	L: Actually maybe there could be other ones but maybe I	
suggest hesitation. Interrupts to change	130	don't have problems with those things	Giving more with encouragement
response.	131	J: Ah, what things do you other people might have that you	
There may be other things that are not	132	don't have problems with, with autism?	
good about having ASD, but doesn't have	133	L: Actually I'm not sure, I'm not sure	Uncertainty about impact of ASD
a problem with these. Unsure what these	134	J: You're not sure?	
other things are.	135	L: No	
	136	J: Ok so you think that the only problem that you have is that	
	137	you get into trouble sometimes with your parents?	
	138	L: Yeah	
	139	J: But when you drew that Leo, those really good pictures,	
	140	you said quite a few different things about having autism	
	141	L: Well maybe actually 'cause I do get nervous if I walk in	
	142	front of an audience	
	143	J: Ok	

Impact of ASD – being nervous in front of an audience. ‘...any autism’ – conceptualisation that autism can be divided into parts? Could a small amount of autism have less impact? ‘...like be like totally fine’ – doesn’t sound confident with this idea. Does ‘totally fine’ mean not being nervous? Fantasy of what life would be like without ‘any autism’	144 145 146 147 148 149 150 151 152 153 154	L: And maybe if I did not have any autism, I would like be like totally fine J: So you get nervous if you are in front of an audience? L: Yeah J: And you think that maybe if you didn’t have autism you would be fine? L: Yeah J: So do you think having autism makes people a bit nervous? L: Yeah, I think so J: Ok, I’m really interested in that Leo. Could you tell me a bit more about why having autism might make people nervous?	Impact of ASD – nervousness in front of audience ASD as parts ‘if I did not have any autism, I would be totally fine’
Impact of ASD – being nervous about meeting people for the first time. Pauses, ‘maybe’ – difficult to discuss/working hard to think. Repetition ‘you know’ – habit/way of normalising a difficult topic?	155 156 157 158 159 160 161 162 163 164	L: Um...‘cause...maybe meeting people they’ve never met before J: Hmm, what about that – meeting people you’ve never met before? L: Um...you know it just makes you nervous you know J: Mm and you think people who have autism might find it a bit more difficult to meet people they’ve never met before? L: Yeah J: So Leo, do you find it difficult to meet people for the first time?	Impact of ASD – nervousness to meet people – social interaction Difficulty discussion social interaction
A bit shy meeting people for the first time, but not as much as going in front of an audience. Repetition of ‘going in front of an audience’ throughout – significant experience ‘the only one’ – alone? Different? Difficulty saying this – reflective of the difficult experience? Repetition of ‘nervous’	165 166 167 168 169 170 171 172 173	L: Hmm well actually not as shy as going in front of an audience but a little bit J: Ok and can you describe to me how it feels when you stand in front of an audience? Have you done that recently? L: Yeah I have, but um once well I...mostly with some other people but if I was the only one who had to go up, which I think I did that once which was, which made me of course very...nervous J: Can you describe anymore about how you felt, apart from	Shyness going in front of audience > meeting people ‘The only one’ – alone/different Nervousness

Recounts experience of going in front of an audience – nervous and really did not want to do it	174	nervous?	
	175	L: Like I really did not want to do it	
	176	J: Yeah	
	177	L: I was literally like it's once I had an assembly at (named	
	178	school) over there	
	179	J: Uhuh	
'the first one' 'and stuff' – makes it easier to talk about if minimises the part he played? Often uses quotes to describe experiences – provides vivid accounts	180	L: And um I don't remember what it's called and I had to be	Vivid accounts
	181	the first one to go up to the stage to say 'welcome to our	
	182	assembly' and stuff	
	183	J: Ok	
	184	L: And also to say when it's fin, and also to say 'thank you for	Celebrating success
By retelling this event, L is able to reflect on and celebrate his achievement in facing a significant challenge – by sharing the details, there's a sense of pride coming through from L. Would this provide the same sense of pride without 'any autism?' We are talking about what is not good about ASD, but are we actually talking about what is difficult but meaningful/rewarding in the end?	185	watching' as well	
	186	J: Wow, and that was scary was it?	
	187	L: Yeah, it was pretty scary	
	188	J: Did you manage to do it?	
	189	L: Yeah I did	
	190	J: Well done. Ok so Leo you said that two things you don't like	Difficult yet rewarding
	191	about having autism – so you said it's not really good because	
	192	sometimes you get into trouble with your parents and	
	193	sometimes it's not good because it can make people nervous.	
	194	Maybe it's standing in front of audiences or maybe meeting	
	195	people for the first time	
	196	L: Yeah	
	197	J: Ok, is there anything else about autism that you don't like?	
Feelings towards ASD – dislike due to having to do homework when parent says so. Repetition of homework throughout – significant. Authority figure giving demands surfaces again here	198	L: The homework 'cause like I can do it like straight away	Dislike towards ASD – dislike for homework
	199	when my mum tells me to do it	
	200	J: Your homework – you have to do it straight away when	
	201	your mum tells you to? Is that what you said?	
	202	L: Well I sometimes say please can I just stay a bit more and	Parental control
	203	then I do it	

	204	J: Please can you stay a bit-	
Attempts to bargain with parent re	205	L: No please can I just like maybe stay a bit, like relax a bit and	Bargaining with parents
homework, which sometimes works.	206	then I’ll do my homework	
Repetition of L seeking a fairness	207	J: Ok and does that work?	Seeking fairness
throughout interview	208	L: Um sometimes it does, not all the time	
	209	J: Ok so do you think homework can be difficult because you	
	210	have autism? Is that what you mean?	
	211	L: Yeah	
	212	J: So why do you think having autism makes it difficult to do	
Relates homework being difficult to	213	homework?	
having ASD due to not being bothered to	214	L: I cannot be bothered to do it	
do it. Does not elaborate on why these	215	J: ‘Cause you’re not bothered?	
two are linked	216	L: Hmm	
Repetition of ‘pretty’ – pretty sure, pretty	217	J: And do you think that’s because of your autism?	Uncertainty about how dislike for
much – not entirely certain/reluctant to	218	L: I’m pretty sure	homework relates to ASD
respond further?	219	J: You’re pretty sure. Why do you think that?	
	220	L: ‘Cause I think so	
	221	J: [laugh] ‘Cause you think so. Do you have any other reason?	
	222	Why would this thing – autism – make it difficult to do	
	223	homework?	
‘Cause you know like’ – about to say	224	L: ‘Cause you know like, pretty much that’s it actually	Holding back
something and backs out. Lack of	225	J: That’s it, ok. So you’ve mentioned 3 things – homework can	
confidence in what he has to say?	226	be difficult, you get into trouble with your parents sometimes	
	227	and standing in front of audiences and meeting people for	
	228	the first time can make you nervous. So those are 3 things	
	229	that you don’t like about having autism. Is there anything else	
	230	that you don’t like about having autism?	
Repetition of ‘that’s pretty much it’ –	231	L: Um I think that’s pretty much it	Gives more with time
holding back and then interjects to offer	232	J: That’s pretty much it-	
more. Negative feelings towards ASD –	233	L: Actually maybe sometimes when I ask my parents to buy	Negative feelings towards ASD –

parents taking a while to buy something after L has asked. 'You know' – softens the comment?	something, it might take them a while you know J: It might take them a while L: Yeah J: And do you think that's because you have autism Leo? L: Um actually I'm not sure about that one	parental control re buying things
Changes mind about this being related to ASD – unsure if it is or not	J: You're not sure? L: No J: Why are you not sure about that one? Why is that different?	Uncertainty about the connection between buying things and ASD
Hesitant. Again, starts to say something and then retreats – is L anxious about saying something wrong? Does he lack confidence in what he has to contribute?	L: 'Cause maybe that's just...actually I don't know J: Hmm I think you do know because you were about to say something really interesting and then you stopped L: Hmm J: Why do you think not getting what you want or people not buying you things – you said I'm not sure if it's about autism – why are you not sure about that?	Holding back – lack of confidence
Rationalises that parents may say no to buying things for a reason (unrelated to ASD). Yet, unsure if not having ASD would result in the same situation or not.	L: Because maybe just parents might say no for a reason J: Yeah, maybe they're saying no for a reason. And do you think if you didn't have autism they would say no or would they say yes to buying things? L: I'm not really sure J: You're not sure? L: No J: But there could be a reason to saying no to buying things do you think?	Rationalising not being bought things
With prompting, suggests alternative reasons as to why parents may not buy things, e.g. not having the money/needing to buy something else.	L: Um maybe 'cause they don't have enough money or they have to buy something else instead J: So maybe it's not to do with having autism, maybe it's for another reason. Maybe it's about not having money or wanting to buy other things	

	264	L: Yeah	
	265	J: Yeah?	
	266	L: Uhuh	
	267	J: Ok so that's 4 things that you've said you don't like about	
	268	having autism – standing in front of an audience, meeting	
	269	people for the first time, um having to do your homework	
Repetition of dislike for homework.	270	L: Yeah I really don't like that	Dislike for homework
'...really...' emphasises how much L	271	J: You really don't like that	
dislikes it.	272	L: Yeah	
	273	J: And you mentioned about sometimes not getting what you	
	274	want so your parents maybe don't buy you things, but you're	
	275	not sure if that was to do with autism	
	276	L: Yeah	
	277	J: And was there anything else that you don't like about	
	278	having autism?	
	279	L: I don't think so	
	280	J: You don't think so, that's it?	
	281	L: Yeah	
	282	J: Ok and Leo, I asked you this question before but I'm going	
	283	to ask you again – is there anything that you do like about	
Positive feelings towards ASD – none	284	having autism?	Feelings towards ASD
Hesitant, pauses, starts to offer	285	L: [Loud exhale] Well...um...maybe just one...actually I don't	Holding back
something and retreats, ending up saying	286	think so, no	
'no'	287	J: Maybe just...?	
	288	L: Nothing no I don't know	
	289	J: I think you were going to say something	
Repeats 'nothing' three times and then	290	L: Nothing, nothing, nothing...actually ok. Maybe 'cause when	
changes mind. Second person. Repetition	291	you keep begging your parents to buy something, maybe they	
of 'maybe' and 'might' – tentatively	292	might listen to you just so they can stop begging	Hopeful
expressed, almost hopeful? Positive	293	J: Ah, and do you think that's to do with having autism?	Positive feelings towards ASD –

feelings towards ASD – repeatedly	294	L: I think so	begging pays off
begging parents to buy something might	295	J: So why would having autism make them give in and make	
work in order to stop the begging/to	296	them give you what you want?	
make you happy. Interestingly, L says that	297	L: 'Cause maybe just they're too tired of you keep begging or	Being heard
begging leads to parents listening (rather	298	just to make you happy	
than buying stuff). Is the listening the	299	J: Just to make you happy because you have autism?	
crucial part?	300	L: Maybe yeah, I'm not sure	
	301	J: Not sure, ok. So sometimes you think having autism can be	
	302	good if it means that your parents give you what you want	
	303	after you keep asking to stop you begging for things?	
	304	L: Hmm yeah	
	305	J: Ok, thanks Leo, that's really interesting. And is there	
	306	anything else that you might like about having autism?	
	307	L: I don't think so	
	308	J: Maybe that you don't see in yourself, but you might see in	
	309	others? Do you know anyone else with autism Leo?	
	310	L: Um no, I don't think so	
	311	J: You don't think so, ok. Ok so my next question Leo is – do	
	312	you think having autism makes a difference to your life at all?	
Impact of ASD – doesn't think it makes	313	L: I don't think so	Holding back
any difference to life. Hesitant and	314	J: You don't think it changes you at all?	Change of response with
interjects to change response – 'actually'	315	L: Um nah	encouragement
– seems to be confident in saying that	316	J: Or does it make things harder or easier or-	
autism makes things harder when given	317	L: Actually it makes things harder, yes	
the opportunity. Says 'yes' at end – more	318	J: Yeah ok – what kind of things does it make harder?	
definitive tone. Impact of ASD –it makes	319	L: Pretty much just being nervous and stuff	Impact of ASD – it makes things
things harder, such as anxiety when	320	J: Being nervous, so like standing in front of people?	harder
standing in front of an audience and	321	L: Yeah	Nervousness standing in front of
meeting new people. 'Pretty much	322	J: Are there any other situations where you feel a bit nervous,	audience & meeting new people
just...and stuff' – attempt to minimise	323	apart from standing in front of an audience?	

difficulty. L has returned to two of his initial associations that he made in his drawings – feeling nervous when standing in front of an audience & doing homework. Repetition of these issues indicates the weight that they hold for L, as well as their relationship to ASD.	324 325 326 327 328 329 330 331	L: Hmm nah, maybe just when I said about meeting new people and I think that's it J: Ok so meeting new people and standing in front of an audience. And you think maybe having autism makes those things a bit harder L: Yah J: Ok, so apart from those two things, is there anything else that makes life harder?	
	332 333 334	L: I think that's it J: You think that's it? L: Yeah	
Impact of ASD – nothing more than two given issues (standing in front of audience and meeting new people)	335 336 337	J: So everything else is just normal? Just like for people who don't have autism, it's just the same? L: Yeah	
	338	J: Ok and-	
Interjects to change response 'err actually...' Repetition of homework. Impact of ASD – hating homework. Mentions that other people hate homework too, not just him – i.e. I'm not alone in this: 'I'm not the only person...'	339 340 341 342 343 344	L: Err actually well people I'm not the only person who hates homework, there are some other people who hate J: You're not the only person who hates...? L: Homework J: Homework? Oh ok L: Yeah there are some other people who hate homework too	Hatred for homework Comfort from feeling similarly to others 'I'm not the only person...'
	345 346	J: There are some other people who hate homework too. And do the other people have autism who hate homework?	
Belief that the other people who hate homework also have ASD (despite previously saying that doesn't know anyone else with ASD) , but not certain – 'um...think so...ah ok'	347 348 349 350 351 352 353	L: Um yeah J: They do have autism? L: Think so J: How do you know? You said to me before you don't know anyone with autism? L: Ah ok J: I'm really interested to know what you think Leo. I think	Homework and ASD Uncertainty about link between homework and ASD

	354	you're right – you're not the only person who hates having	
	355	homework. Loads of people hate having homework don't	
	356	they?	
	357	L: That's true	
	358	J: And then I asked you if you think the other people have	
	359	autism, so do you think they do or not?	
Confirms that thinks other people who	360	L: I think they do	ASD causes homework hatred
hate homework also have ASD and that	361	J: You think they do. And do you think that's why they hate	
hating homework is caused by ASD. Does	362	having homework?	
not think there are people without ASD	363	L: Yeah 'cause even though I hate homework, I think that I	
who hate homework. Rationale – L has	364	have autism too	
ASD and hates homework.	365	J: Ah ok. So do you think there are people who hate	
Language is confusing – 'even though I	366	homework who don't have autism?	Uncertainty about link (homework
hate homework...' – is L also confused	367	L: Actually no I don't think so	and ASD)
about the connection between	368	J: You don't think so. Say there was a kid in your class who	
homework and ASD? 'I **think** I have	369	didn't have autism, how do you think they would feel about	
autism...' – perhaps not certain?	370	homework?	
Significant moment where mentions	371	L: Maybe they would just, maybe he will just be happy to	Questioning identity – 'I think that I
having autism for the first time, whilst	372	have homework – he would do it like in no times like straight	have autism'
also questioning it – 'I think'	373	when he came home, he gets changed and does his	
Impact of ASD – people who don't have	374	homework	
ASD might be happy to have homework	375	J: Ah so maybe for people that don't have autism, it's easier	
and will complete it without any trouble.	376	to do your homework if you just come home and do your	
Changes from plural to singular male	377	homework straight and then it's done?	
third person. Repetition of 'maybe...just'	378	L: Yeah	Ease for people without ASD
– gives the impression that things are	379	J: Mm interesting	
easier for people who don't have ASD?	380	L: And by the way, are we having this meeting again next	
Would L like to be able to complete his	381	Thursday?	
homework in the way he described the	382	J: No, it's just today. Is that ok?	Fixed patterns
boy without ASD does? Does he feel	383	L: Err	

unable to do so? Are these differences	384	J: Why? Did you want it again?	
fixed?	385	L: Yeah kind of	
L checks if we will meet again next week	386	J: How come you wanted it again?	Being heard
and says he would like to – enjoying	387	L: I don’t know, ‘cause I like these kind of meetings	
exploring his experience of having ASD?	388	J: Do you? Why is that Leo?	
	389	L: ‘Cause I get to draw and...	
	390	J: Ah ‘cause you get to draw and you get to miss a lesson	
	391	maybe?	
Would like to meet again to miss Maths	392	L: Yeah maybe a lesson I don’t like. Like I don’t really enjoy	Dislike for Maths
as doesn’t enjoy it.	393	Maths, Math that much	
	394	J: Why don’t you enjoy Maths?	
Comparison to peer who is very good at	395	L: I don’t know, it’s just...Well one person does – she *loves*	Comparison to others
Maths and L doesn’t understand what	396	maths. She’s like so good at it, oh my god. It’s like I don’t	
‘they’ talk about. Is ‘they’ the girl and	397	understand what they keep talking about	
teacher? When asked why L doesn’t like	398	J: Ok and why don’t you like Maths Leo?	
Maths, mentions a peer. Emphasis on	399	L: Pretty much the same thing I just said like	
‘loves’ and exclamation ‘oh my god’	400	J: Just don’t-	
highlight L’s focus on others. Reminder of	401	L: It’s just a bit boring	Alone/different
earlier themes of being alone in	402	J: Just a bit boring ok. So I’m just going to go back to the	
something/different?	403	questions Leo. You said to me that autism can make it harder	
	404	to do homework sometimes and it can make you a bit	
	405	nervous. Does having autism make a difference to you at	
	406	school at all? So I’m not talking about home, I’m not talking	
	407	about with your parents giving you things-	
Interjects – actively engaged	408	L: Oh I know	Gives more with time
	409	J: Yep	
Impact of ASD at school – L being	410	L: Ok so in a lesson, so like when I’m focused on the work but	Impact of ASD at school – being
punished for other pupils’ disruptive	411	all the other kids just mess around and then the whole class	unfairly sanctioned
behaviour, when whole class miss break	412	has to stay in and I just stay in for no reason which just seems	
time. Apart from the end being hard to	413	very unfair to me which [difficult to decipher]	

hear, L is v articulate – clear and passionate about what he wants to say. No hesitations/pauses	J: Sorry, say that again	
	L: So like when I'm focusing on my work and all the kids are messing around and the teacher says that the whole class has to stay in but like I didn't even do anything, which is just very unfair	
	J: So you're getting into trouble when other people are messing around because the whole class has to stay in?	
Repetition of this being 'unfair' Wishes this punishment could change	L: Well like the whole class, I mean like not when I...it's not my fault if the whole class stays. It's just the people who mess about, so apparently the whole class has to stay, which just seems a bit unfair and I wish they could change that	Unfairness Wishful thinking to achieve change
	J: Mm	
Suggests an alternative solution – teacher keeping a list of pupils who mess about to keep, rather than the whole class – trying to implement fairness. Already thought of this before?	L: Maybe if they like draw a list of the people who keep messing about and keep those people in instead of the whole class	Making things fair
	J: Yeah so it doesn't sound fair that the whole class has to stay in. And do you think Leo that has anything to do with autism?	
Doesn't think this issue is related to ASD, it's just stressful. Repetition of 'it's just you know' and 'stressing.' Emphasises how stressful L finds it. Although doesn't relate this to ASD when questioned here, when first spoke about this issue it was in response to 'does autism make a difference to life at school?' Therefore, he associated this issue with autism. After further consideration, is the association between the two 'stress'?	L: Actually I don't think it is, it's just you know, it's just stressing. It's just stressing you know	Unfairness is stressful
	J: Is it quite stressful?	
	L: Stressful yeah	
	J: Yeah, I can understand that. So is there anything else at school Leo, apart from that, that means having autism means that things are a bit different at school?	ASD and stress
	L: Um no I don't think so, there isn't	
	J: Ok, I just want to go back to this picture Leo that you drew about people not being very nice and saying things like 'you're so useless' and you getting angry and wanting to hit something on the head. Um when I asked you what the word	

Impact of ASD at school – people being mean to him/complaining (as drawn in picture) which leads to L wanting to seek revenge. Hesitant, repetition of ‘you know’ and ‘bad’ – has difficulty giving examples of the ‘very bad stuff’ – feels guilty hearing himself/moral self? ‘beating them up so badly’ – violent, angry, frustrated. Thoughts seem to have taken him to one person in particular – ‘him...that guy...’ Internal conflict between seeking revenge through violent means whereby anger can be let out vs. staying out of trouble and keeping anger inside. L is battling with these two ideas, weighing up the benefits and repercussions of each. Self-reflection: ‘I keep that anger inside...’‘I wish I could just let it all out’ - exasperated, without hope? Is wishing the only way to achieve change? Wishing feels like a way of thinking when things feel outside of our control. Does L feel like releasing his anger is outside his control? Maybe something he’s not able to do safely, without getting into trouble/causing physical injury to someone. What is the anger doing to L if he keeps it inside?	‘autism’ means to you, you drew that, so is that something that makes school a bit difficult? L: Yeah, it’s like when a person keeps complaining of things and, and to me and I get, I feel like beating them up so badly and you know like doing very bad stuff to him like maybe...you know...just very bad things J: So when people aren’t very nice to you L: Yeah but I don’t want to do that because I’ll get in trouble J: Mm, sounds like a sensible decision not to L: Yeah but I just feel so badly like you know beating that guy up J: Yeah, I don’t think beating anyone up will help anything will it? L: No but it might make me like maybe better if like all my anger like came out J: So maybe you’ve got a lot of anger Leo because people aren’t being very nice sometimes? L: Yeah but I keep that anger inside and I wish I could just let it all out J: You wish you could let it all out. And Leo, do you think that all that anger you have inside and people being mean to you – do you think that’s something to do with having autism or not? L: I don’t think it’s having autism J: What do you think it’s to do with? L: I think it’s just the same like when the class has to stay in, the whole class has to stay in, it’s like the same like that J: Ok, so how come you drew it on there when I asked what autism means? L: Sorry I didn’t know what else to draw	Difficulties at school – people complaining Seeking revenge Violence Anger, frustration Internal conflict: seeking revenge vs. keeping anger inside Wishful thinking Anger is not safe

Impact of ASD at school – doesn't relate the meanness and anger with ASD when asked again, but rather thinks it's the same as the example of the whole class staying in. Stress, anger, unfairness – ideas that relate these two given examples? 'Sorry I didn't know what else to draw' – lack of confidence in his contributions. Sense of doing the wrong thing	J: No it's ok, don't say sorry because I think you drew it for a reason. I think it came to your mind and I'm just wondering why it came to your mind? L: Yeah ok and by the way, how many minutes left until 3.30?	Contradiction about connection between ASD and unkindness
	J: Um twenty minutes L: Twenty minutes until 3.30?	Stress, anger, unfairness
	J: Yeah L: Ok J: Um, I guess I'm really, really interested in this picture and why you drew it when I said the word autism and I know you said you didn't know what else to draw, but I think you drew it for a reason L: Yeah J: Is there anything else you wanted to say about that picture or about people not being very nice?	Lack of confidence in contributions
Chooses not to say more about people being unkind. Hesitant – perhaps wants to say more	L: Well...nah I think that's it J: Ok. Leo, do you think other people with autism get really angry inside when people are mean to them?	Holding back
Impact of ASD on emotional regulation – thinks some other people with ASD get very angry when people are unkind to them. 'I'm pretty sure' – sounds confident	L: I think some people, I'm pretty sure J: Some people, and what about people without autism? L: No I don't think they do much, I think they just tell the teacher	Emotional dysregulation – people with ASD get very angry
People without ASD just tell the teacher, rather than getting angry.	J: They just tell the teacher. Ah so people with autism get really angry inside you think? And get really frustrated, but maybe don't say anything to anyone? And people without autism tell the teacher? L: Um yeah J: Ok, I'm really interested in that. Why do you think that there's a difference? Why do you think people with autism just get really angry inside and people without autism tell the	Emotional regulation – people without ASD just tell the teacher

	504	teacher?	
Asks for the question to be repeated	505	L: Pardon, can you say the question again?	
	506	J: Yeah, yeah sure. So you said to me you think people with	
	507	autism might get really angry inside when people are mean to	
	508	them, but they won't say anything to anyone and you said	
	509	people *without* autism tell the teacher. You said they don't	
	510	get angry inside, they just tell the teacher	
Tired – losing interest/difficult topic?	511	L: Yeah [yawns]	
	512	J: So I'm really interested to know why do you think people	
	513	without autism just tell the teacher and people with autism	
	514	get angry? Why is there a difference between the two?	
Rationale for difference in approaches	515	L: Because that's normally what I do but I wish I could beat	
(telling teacher/getting angry) – 'because	516	that guy very like, I wish I could hit him so hard, you know but	
that's normally what I do...' Returns to	517	I can't because I'll get in trouble	Rumination about violent revenge
ruminate about fantasy to beat 'that guy.'	518	J: Yeah, but why do you think people without autism can just	
Violent language, repetition of 'I wish',	519	tell the teacher?	
talking about one particular person again.	520	L: ...Yeah just to like to not get into trouble	Wishful thinking
Moral self/fear of getting into trouble	521	J: Ok, do you think there's a difference in the way they are	Moral conscience/getting into
makes him decide against it again.	522	able to speak about things?	trouble
Impact of ASD on		L: Um I don't know, I don't think so [starts whistling]	No impact of ASD on communication
communication/emotional regulation –	523	J: You don't think so, ok. And what about um at home Leo, do	
doesn't think there's a difference in the	524	you think having autism makes a difference to you outside of	
way people with and without ASD speak	525	school? So not in school, but at home or if you're doing	
about things	526	something at the weekend or in the park? Do you think	
	527	having autism makes a difference to your life in that way?	
Impact of ASD at home – none (apart	528	L: ...Um no	
from what was said earlier when it's	529	J: No?	
directly mentioned)	530	L: No	
	531	J: But maybe just what you said before about getting into	
	532	trouble sometimes with your parents and maybe sometimes	

	533	not getting what you want but then sometimes getting it?	
	534	L: [Yawns] Yeah	
	535	J: Ok, and Leo why do you think you have autism?	
Reason for diagnosis – because there are things L dislikes in life, i.e. homework and people being unkind. Repetition of ‘you know.’ Difficulty hearing him at end – trailing off with own thoughts?	536	L: [Whistles] Yeah ‘cause like there’s a couple of things I don’t	Reason for diagnosis – disliking things in life
	537	like you know in life you know	
	538	J: Like what?	Homework
	539	L: Like homework and [difficult to decipher]	Unkindness
	540	J: Homework and	
Recounts his sister’s birthday where there were people who were rude, who he did not like. Struggles to say this – hesitates and pauses. Difficulty verbalising reflective of the actual experience for L? Change from past to present tense (548) – as if the kids are still saying rude words (not just at that one event) – ongoing	541	L: People annoying me and um and um and maybe just like	
	542	going to someone else’s party but having people that I did	Specific events
	543	not want to see like, like I have some er like at my house I	
	544	have...this year was my sister’s birthday, and she invited	
	545	some kids upstairs and er they were very rude. I did not like	
	546	them at all so	
	547	J: Hmm. How come you didn’t like them?	Ongoing rudeness
	548	L: Yeah ‘cause they just you know, I don’t know they just say	
	549	rude words	
	550	J: Did they say rude words to you?	
Anger evoked by people being rude to L: thoughts about seeking revenge through violence. ‘...doing something bad...throwing them on the volcano’, ‘the volcano’ rather than ‘a’ suggests that L has already had thoughts whereby a volcano appears. Confirms that he will not act on these thoughts – moral self emerges again – ‘because it’s not good’	551	L: Yeah so I felt like you know the same thing as this person	Rumination about seeking revenge through violence
	552	like dropping a something, doing something bad like throwing	
	553	them on the volcano	
	554	J: Ok	
	555	L: You know I mean would not want to do that you know	
	556	because it’s not good	
	557	J: It’s not good but it’s also not nice for people to be mean is	
	558	it?	Moral conscience
	559	L: No	
It’s also not good to be mean to people – by not acting out of fear of causing destruction, L experiences himself	560	J: And it must feel really horrible when people aren’t very	Internal distress vs. external destruction
	561	nice	
	562	L: Yeah	

internal distress? Are these the only two	563	J: So I'm going to go back to my question Leo and that was	
options in his mind?	564	'why do you think you have autism?' and you said it's	
	565	because there's things that like you don't like, like homework	
	566	and people not being nice to you. So do you think that's why	
	567	you have autism because of those things you don't like?	
Does L think that he has autism because	568	L: Yeah, I think that's why I have autism	
he doesn't like things in general/because	569	J: Can you tell me anymore about that?	
of those particular things he doesn't like?	570	L: [Yawns] I don't think so	
Is his conceptualisation therefore that he	571	J: So you think someone decided that Leo has autism because	
has ASD because he cannot let things go	572	he doesn't like homework and because he doesn't like people	Reason for diagnosis – difficulty
or even like things in life?	573	not being nice to him?	letting things go?
	574	L: Hmm yeah	
	575	J: Do you think there are any other reasons?	
	576	L: Nah, I don't think so. They are all the reasons	
	577	J: Ok, and Leo when did you find out about having autism?	
	578	When did your mum first mention it to you?	
Doesn't remember a conversation with	579	L: [Yawns], sorry. I don't really remember	
parent about ASD	580	J: You don't remember?	
	581	L: Yeah	
	582	J: Do you remember anything that she said about it?	
	583	L: Nah, I don't think so and I don't think she said anything	
	584	about it	
	585	J: Ok. So Leo, are there any ways that you see yourself as	
	586	different to other children or young people in your year? So	
	587	you're in Year 8?	
	588	L: Yeah	
	589	J: Are there any ways that you feel different to other people	
	590	in Year 8?	
Remembers something to say – people	591	L: No but let me, oh I forgot to also say something	
annoying him in three different lessons	592	J: Yeah?	Memory of getting annoyed by peers

last year. Reflects that 'felt the same thing like here' – as in the other incidents shared? Now thinks that this issue has been resolved as a result of teachers intervening	L: In Year 7, I used to get annoyed by um about 3 people in my Maths, English and Science class. And um yeah and they really, I just couldn't stand them and you know I felt the same thing like here as well and um yeah but I think now in Year, I think this year I think it's we have like we talked with the head teacher and, you know Miss Roberts?	
	J: No	
	L: Well she's like one of the...	
	J: Head teachers?	
	L: No, like she's like a teacher	
	J: Ok	
Teacher helps people who get annoyed. '...we had a talk, all four of us, which was me and those three' – uses 4 different ways to portray a group. Repetition due to happiness at being part of a group where the outcome was restorative? '...we're better now...I think the badness is over' – relief, although difficulty saying this. Perhaps anxious that it isn't really over/may return. Sense of relief from L here – hearing him speak of someone who he can approach to help him when he gets annoyed, rather than anger being used dangerously/left to build up inside him. Sounds like L perceives himself as someone who needs help for his anger.	L: I can't explain but she's a person you know and she helps people who are getting annoyed and that's who I went to and we had a talk, all four of us, which was me and those three	Being part of a group
	J: Yep	
	L: And I think we are, we're better now	Restorative outcome
	J: You think you're better now?	
	L: Yeah. I think that um that yeah I think that badness is over	
	J: It's over. So talking to the teacher helped, did it?	
	L: Yeah but I mean it wasn't the first time, I mean I talked to them quite a couple of times, but for some reason this time it worked	Adult support for anger – safe outlet
	J: Ok, why do you think it worked this time? Is there any reason why it worked this time?	
	L: I have no idea	Angry self
	J: No idea, ok well I'm glad it's better now with those kids	
	L: Yeah, it's better now	
	J: That's good, that's good. So just going back to the question Leo – are there any ways that you see yourself as different to the other children in your year? Or maybe when you think	

	623	about Year 7 or Year 6, are there any ways you feel different?	Differences with peers
Differences to peers: others like a lot of sports, which L doesn’t and isn’t interested in	624	L: Yeah quite a lot of people like football, ok	
	625	J: Ok	
	626	L: But I don’t like it much and I don’t really want to know	
	627	anything about it	
	628	J: Ok, so that’s a difference. So a lot of people like football	
	629	and you don’t like football?	
	630	L: Yeah, a lot of people like basketball, but I don’t really and	
	631	you know a lot of, a lot of sports, to be honest and I rarely like	
	632	any sports	
	633	J: Ok, so that’s a difference between you and other people.	
	634	And do you think that has anything to do with autism, that	
	635	difference?	Other people are normal: ‘It’s just normal. It’s what happens to other people’
Doesn’t believe these different interests are related to ASD. ‘...it’s just normal. It’s what happens to other people’ – if difference is not related to ASD and it concerns other people then it’s just normal. Is something related to ASD which concerns L (or ASD population) abnormal?	636	L: Um nah, I think it’s just normal. It’s what happens to other	
	637	people	
	638	J: Yeah, I think so too. I think it’s just people like different	
	639	things, don’t they?	
	640	L: Yeah	
	641	J: So you don’t really like football and sports and some other	
	642	people do. But there’s things that I think you’ll probably like	
	643	that other people don’t like. Is that right?	
	644	L: Yeah	
	645	J: Ok. And in what ways do you see yourself as *similar* to	
	646	other people in your year group or in other year groups, to	
	647	other children? So you’ve told me about the things that are	
	648	different – so not liking football or basketball or other sports	
	649	– what are the things that might be the same or similar?	
	650	L: I think that’s it	
	651	J: Is there anything that is the same between you and any	
	652	other kids?	No similarities with peers

Similarities to peers: nothing (initial response)	653	L: Nah	
	654 655	J: *Nothing?!* There's nothing the same? You're *completely* different?	Similarities to peers – arts
Similarities to peers: rethinks and changes response – arts (unrelated to ASD)	656	L: Oh actually some of them like arts, which I like	
	657	J: Mm ok	
	658	L: And some of them don't	
Unprompted, adds in that some don't like art – subtle shift back to differences.	659 660	J: Some of them like art which you also like and some of them don't	Differences to peers
Does L find it easier to talk about differences than similarities between him and peers? More aware of the differences? Adds to sense of loneliness	661	L: Yeah	
	662	J: And do you think liking art has anything to do with autism?	Loneliness/difference
	663	L: No	
	664 665	J: No, I don't think so either. Ok so Leo, just before we finish the interview-	
	666	L: Wait, how many minutes left?	
	667	J: Um we have 10 minutes left before half 3	
	668	L: Ok	
	669 670 671 672	J: So just before we finish, I want to go back to the very first question I asked you. Do you remember what it was? And you said it was too tricky. You said you didn't know how to answer-	
	673	L: What was the question again then?	
	674 675 676	J: It was 'what does it mean to you to have autism?' And now I think you can answer it because you've spoken quite a lot and thought a lot about-	
What it means to have ASD – a lot of things you don't like, other things you want but parents won't let you & feeling nervous to go in front of an audience.	677 678 679	L: Well it's like you know there's a lot of things that you don't like and stuff and then other things that you know you just really want but your parents don't let you	Nervousness in front of audience Disliking things Parental control over buying things
	680	J: Mm	
Inhale here suggests that L is thinking	681 682	L: Yeah so... [inhale] yeah and today I still feel nervous about going in front of an audience. I still feel nervous about that.	

hard and perhaps find these things difficult to reflect on – requiring a moment to take a deep breath before continuing to summarise the meaning he associates with having ASD. Changes over time – no longer ask parents for things all the time, just if he wants to? More self-restraint? Drawing towards the end of the interview, L aptly and spontaneously mentions changes re self in his life. Indicates that he may be thinking about change often? What he wants/'wishes' to change but feels unable to. How in control he feels in his life? What it means to have ASD – homework, nervous in front of audience, anger towards people complaining. Inhale before 'nervous' again – reliving anxiety. '...you know, stuff' – still difficult at end of interview to name people being unkind/hurtful. These images are the same – did L expect/hope these feelings to have changed throughout the course of the interview? Could that be why L was ready with specific examples of difficult situations in his mind at the start – hope to resolve them?	There's a few things that have just changed in my life, so like I don't ask my parents for things every single time J: Your parents what sorry? L: I don't like ask my parents every single time for treats J: Ok L: I just get them if I want to. That's one thing that's changed. And to be honest all the images are still the same – I still don't like homework, I still feel a bit [inhale] nervous going in front of an audience, and I still you know feel like very angry inside if someone keeps complaining of, you know, stuff J: Yeah, oh so when you say things haven't changed, do you mean between the beginning of the interview and now? L: Well maybe like, um like beginning of like, like when I was born and stuff J: Oh when you were born, ok L: So like all these 4 images, they will, this is what was happening right now but this is like the one that's changed J: Ah so these 3 are still the same L: Yeah J: But this one's changed a bit? L: Yeah, this one – I don't really ask them much for treats. I do sometimes but not every time because I think I barely even ask anymore J: Ok, so these 3 have stayed the same but this one's changed a bit because you don't really ask as much L: Yeah J: But these ones are 3 things that having autism means to you? Tell if I'm wrong Leo ok? Because it has to be what you think. So for you it means that you get nervous in front of an audience; that people can be mean to you and you get angry	Increased self-restraint – changed self Hope for change Control over change- sense of being stuck Homework Nervousness in front of audience Anger towards people complaining Hope for change

	713	and want to hurt them; and that teachers give you homework	
	714	and you don’t want to do it. Is that what having autism	
	715	means to you?	Uncertainty about meaning of having
Uncertainty when summarising the three	716	L: Yeah, I kind of think so yeah	ASD
identified areas as things that having ASD	717	J: You kind of think so, ok thank you. Is there anything else	
mean	718	that having autism means to you that we haven’t spoken	
	719	about?	Losing
What having ASD means – remembers	720	L: Let me think. Ah oh right so um, when we play games and	
another thing – losing games first and	721	I’m usually the first one who loses, I feel a bit, I feel a bit	
feeling angry inside, especially if the	722	annoyed and kind of angry inside you know ‘cause I mean, it	Loss of opportunity to buy things
games were to win money because there	723	doesn’t normally help [difficult to decipher] but I mean not	
are lots of things that the money could	724	every time so like imagine that we were playing a game and	Angry inside
buy. Repetition of ‘I feel a bit’ and feeling	725	whoever wins, wins a thousand pounds and, I mean, there	
‘annoyed,’ mention of feeling ‘angry	726	isn’t any game like that but just if there was	
inside’ again. Does L’s anger always	727	J: Mm	
manifest inside rather than outside his	728	L: I’d feel so annoyed ‘cause I could buy so many things with	
self? Who is ‘we’? Repetition of idea	729	that amount of money and I’d feel very annoyed, you know	
about being able to buy things.	730	J: Yeah	
	731	L: So yeah, like you know something like that	
	732	J: So you think maybe um losing a game and getting really	ASD & losing
	733	annoyed is something to do with having autism?	
Confirms that losing a game and getting	734	L: Well yeah I actually kind of think so, yeah	
annoyed is connected to having ASD.	735	J: Ok	
Doesn’t share how he feels about losing	736	L: Well I don’t tell them that, I just feel inside that I really wish	Keeping feelings inside
with the other players, rather just feels it.	737	I could win	
Repetition of feeling something inside	738	J: Yeah	Wishful thinking
and not expressing it and ‘I really wish…’	739	L: I mean I do win sometimes, but to be honest I barely even	
Even when playing games with others,	740	win	Mismatch between feelings and
often feels something different to what	741	J: And do you think um you don’t win because you have	expression
he expresses – ‘I don’t tell them that, I	742	autism or do you think you get angry because you have	

just feel inside...' Unsafe to express anger/disappointment? Believes anger is related to ASD. Started to say the first – you don't win because you have ASD, and then changed answer – ASD to blame for losing games? Phrasing of response suggests L gets angry with his autism – unintentional but perhaps significant in thinking about the responsibility that autism holds for anger, as L sees it. Emotional regulation for people without ASD – if in a games show might feel a bit annoyed but will be able to cheer for the winner. Changes mind about whether they would get annoyed about whoever wins a game – at first maybe not, then maybe a bit. Difficulty considering what anger looks like for people without ASD/anyone other than L? Response suggests that there are different levels of anger/emotional regulation for people with and without ASD e.g. L who feels really angry inside but doesn't express it and people without ASD who might get a bit annoyed but are still able to cheer for the winner. Despite amount of anger	autism or am I wrong with both of those? L: I think the fir, you get angry with your autism J: You think you get angry with your autism, ok. And you've mentioned that a couple of times Leo, because you've mentioned it here as well, about when people are mean, getting angry. Why do you think having autism can make people angry? Why do you think it's difficult to stay calm? Have you any idea? L: I don't really think I have any ideas. I think those are like the two only things that like, yeah J: And just before we finish Leo, do you think that people who don't have autism get angry? L: Wait, what did you say? J: Do you think that people who *don't* have autism get angry? L: Maybe not about the games like whoever wins. Actually maybe they actually could for like if in like a games show, you know. Maybe people might feel a bit annoyed but maybe just cheer for that guy who won, the person who wins the show J: Ah ok, so you think if you don't have autism then you might get a bit angry but maybe not really, really angry and you can still cheer for the person that wins? L: Yeah J: But if you have autism then you just get so angry and you might not even cheer for the person that wins? L: Yeah J: Is that right? L: Yeah, I think so J: You think so, ok. Thanks so much Leo, I'm going to stop there	Emotional expression is unsafe ASD & anger Emotional regulation for non-ASD Different anger levels for ASD & non-ASD Expression of emotions

differing, expressions of feelings appear similar? Both masking feelings.			

Initial Comments	Line No.	Transcript	Emerging Themes
		Part 1 – Semi-structured Interview with Mik	
	1	J: So my first question is what does autism mean to you?	
ASD means nothing to M	2	M: Nothing	Defining ASD – no meaning
	3	J: Nothing. Do you think you have autism?	
Unsure if has ASD	4	M: Don’t know	Uncertainty about identity
	5	J: You don’t know	
Doesn’t know what ASD is	6	M: I don’t know what it is	Defining ASD – uncertain
	7	J: You don’t know what it is, ok. But you’ve heard the word	
Short responses, defended/guarded? Not wanting to expand	8	you said?	Defensive, guarded, closed
	9	M: Yeah	
	10	J: Where have you heard the word?	
Heard of ‘autism’ from mother	11	M: My mum spoke about it	Exposure to the word from others (parent)
	12	J: Oh you’re mum spoke about it, ok. What kind of things did	
	13	your mum say about it?	
	14	M: I wasn’t listening. She wasn’t talking to me about it	
	15	J: Ah, ok. Do you know who she was talking to?	
	16	M: No	
	17	J: Not sure. So you’ve heard your mum say it. Is that the only	
	18	person that you’ve heard say it or have you heard it	
	19	anywhere else?	
Only heard the word from mother	20	M: No just my mum	
	21	J: Just your mum. And Mik, I spoke to your mum on the	
	22	phone and she mentioned that someone from **** – do you	
	23	know ****?	
Heard of organisation that supports young people who have ASD	24	M: Yeah	
	25	J: Can you tell me who **** are?	
	26	M: Don’t know. I’ve heard of it	
	27	J: So she told me that someone from **** came and maybe	
	28	spoke to you once?	

	29	M: Yeah	
	30	J: I think she said that you were in primary school	
	31	M: Yeah	
	32	J: Do you know what year you were in?	
Doesn’t know when someone from the organisation spoke to him	33	M: Nah	Hazy memories of professional input
	34	J: I think she couldn’t remember either but I think she	
	35	thought it was towards the end of Year 4 or Year 5 time	
	36	M: Yeah [difficult to hear]	
	37	J: Um and she told me that I think someone came from ****	
	38	and spoke to you, or spoke to your mum and your teacher	
	39	maybe? Or maybe you all spoke together, I’m not sure. Do	
	40	you remember any of this happening?	
Doesn’t remember someone from the organisation coming to speak to him	41	M: No [difficult to hear]	Hazy memories of professional input
	42	J: Ok, but just before when I asked you if you’d heard of	
	43	****, you said you had heard of them	
	44	M: Yeah but I don’t remember in primary school	
	45	J: Ah ok. So apart from when your mum said the word	
	46	‘autism,’ you’ve not heard it anywhere else?	
	47	M: Nope	
	48	J: ...Ok, um so I might ask you about how school is going at	
	49	the moment. So how is school going at the moment? I know	
	50	you’re in isolation today, but in general?	
Doesn’t know how school is going/what he likes and dislikes about school/subjects he prefers. Repetition of ‘don’t know’ – way of shutting down the conversation/keeping me out/staying in control of what is and isn’t revealed	51	M: I don’t know	Defensive, guarded, closed
	52	J: ...Can I ask what kind of things do you like about school?	
	53	M: I don’t know	
	54	J: Are there any subjects you prefer?	
	55	M: No	
	56	J: Or ok, what kind of things do you not like about school?	Remaining in control
Interview is difficult at this point – M responds to most questions with ‘I don’t	57	M: I don’t know	
	58	J: Ok, well if you want I can stop the interview and we can try	

know' – decide to take a break and come	59	to do something else?	
back to the questions after trying to build	60	M: Don't know	Importance of relationships
a rapport	61	J: ...Ok, I'll stop it	
	62	*Pause in interview*	
	63	J: So if I said the word autism to you, what does it mean to	
	64	you?	
'Autism' means nothing to M – 'it's just a	65	M: Nothing...it's just a word	Defining ASD – it's just a word
word' M's pause and expansion on his	66	J: Just a word. So if I asked you what do you think is different	
answer indicates that he is opening up	67	between you and other people in your year group?	
more and trying to engage in the	68	M: I aint scared of nothing	
interview. '...it's just a word' –	69	J: You're not scared of anything?	Disassociating with the label
disassociating with the meaning of the	70	M: No	
condition and rather just seeing it	71	J: Can you tell me anymore? What do you mean by that?	
linguistically.	72	M: I can't think of anything [difficult to decipher]	
Differences with peers – fearless. Double	73	J: So you think other people are scared of things maybe?	Fearless
negative language – 'aint scared of	74	M: Yeah. If someone told me they wanted to fight me after	
nothing' actually means M is scared.	75	school [difficult to decipher] I'd be there after school	
Difficulty hearing M perhaps indicates a	76	J: If someone told you what sorry?	
lack of confidence, rather than a fearless	77	M: They wanted to fight me after school, I'd be there after	
persona that he is describing. Wouldn't	78	school	
be scared to fight someone after school.	79	J: Oh right ok. So you think the difference might be that	Fearless persona to mask difficulties
Fearless persona to mask over difficulties	80	you're not scared of anything and other people are?	
	81	M: Yeah	
	82	J: What about in school? Are there any differences? So	
	83	maybe not about fighting, but what about other things in	
	84	school?	
Not scared to say anything in school – if	85	M: I'm not scared of saying anything [said very quietly]	Fearless to speak
something needs to be said then M will	86	J: You're not scared of saying anything?	
do so, and won't be worried about the	87	M: No	
consequences. Speaking very quietly	88	J: Have you got an example?	Fearless persona to mask difficulties

again indicates lack of conviction	89	M: If I think something then I'll say it	
	90	J: If you think something then you'll say it	
	91	M: Yeah, if it needs to be said then I'll say it	
	92	J: Oh right so if it needs to be said then you'll say it and	
	93	you're not worried about what will happen?	
'Nope' – repeated throughout interview.	94	M: Nope	Defensive, guarded, closed
Suggests confidence and a lack of care.	95	J: And do you think other people do worry more? They don't	Apathetic
	96	say things that they want to say?	
Other people worry about certain saying	97	M: Yep they think that if they say that then they'll say that	Others worry about speaking
things	98	[difficult to decipher]	
Cannot provide example of a time when	99	J: Ok, do you have an example of where that happened?	Hazy memories
M has said something that he doesn't	100	Where you've said something that you didn't care about?	
care about, apart from maybe 3 years	101	M: No	
ago. Is this more of a fantasy than a	102	J: Hmm	Apathetic mask
reality, i.e. wanting to be seen as not	103	M: In like Year 7	
caring when in reality does care how he	104	J: Huh?	
comes across and what people think of	105	M: I don't talk to any teachers anyway	
him?	106	J: None of them?	Saying what I want vs. silence
Doesn't speak to teachers –	107	M: Nope	
contradiction? *Doesn't* say whatever he	108	J: You looked like you were alright with him – I don't know	Relationships with teachers
wants because doesn't speak to	109	his name – the one who dropped you off here	
teachers. Or perhaps says whatever he	110	M: He's calm	
wants because not much to lose as	111	J: He's what?	
doesn't often speak to teachers/have	112	M: He's calm	
relationships with them	113	J: Calm	
	114	M: He'll get me in trouble, but he's alright	Importance of relationships
Containing to have someone put	115	J: Ok. And you said the Science teacher is alright didn't you?	
boundaries in place – shows care	116	M: He's [difficult to decipher]	
Difficulty talking about relationships with	117	J: Ok and do you think there are any differences between	Difficulty discussing relationships
staff – trails off and hard to understand	118	you and other people about work? So when it comes to	

	119	doing any work or learning?	
	120	M: Nope. They say some, they call out, I call out. They say	
Similarities with peers – calling out	121	something, I say something	No differences with peers
Repetition – 'they call out, I call out. They	122	J: Hmm	
say something, I say something. They	123	M: They finish the work, I finish the work. There's no	
finish the work, I finish the work' –	124	difference	
attempt to be closely tied to peers –	125	J: Ok, so those things are the same really	Closely tied to peers
reluctant to think about any differences –	126	M: Yeah	Difficulty thinking about difference
defensive	127	J: Ok, thanks Mik. And are there things that maybe you find	
	128	difficult at school?	
	129	M: No	
Doesn't find anything difficult at school	130	J: Nothing?	No difficulties at school
'Nope' – defensive, attempt to sound	131	M: Nope	Defensive, guarded, closed
certain, guarded	132	J: And things that you find easy?	Confidence to mask fear
	133	M: Yeah	
	134	J: What do you find easy?	
Finds P.E. easy at school	135	M: P.E.	Sports – ease of P.E.
	136	J: Oh yeah, you said you really liked P.E. What are you doing	
	137	in P.E. at the moment?	
	138	M: Football	
	139	J: Do you like football?	
	140	M: Nope, I just kick the ball	
	141	J: But you still find it easy?	
	142	M: Yeah	
	143	J: And do you remember before I said **** to you and you	
	144	said you didn't remember much	
Doesn't remember much about the	145	M: No...I don't remember much	Hazy memories about professional
organisation which supports young	146	J: So you don't remember much, which is fine but I'm	input
people who have ASD	147	wondering if you remember anything about them? Or	
	148	anything they might have said?	

Remembers a lady, who M saw that day – M is now expanding on his responses more than previously. Before said he doesn't remember anything and now mentions lady he saw. Letting his guard down?	149	M: I saw one lady today, that's it	
	150	J: You saw a lady?	
	151	M: Yeah	
	152	J: Today?	
	153	M: Yeah	Letting guard down
	154	J: From ****?	
	155	M: Yeah	
	156	J: Oh did she come and speak to you?	
	157	M: Yeah	
	158	J: Ah ok, what kind of things did she talk about?	
Doesn't know what woman spoke about. 'I don't know' – default response? Still struggles to communicate/be open at first. Difficulty talking about it due to embarrassment? Requires prompting	159	M: I don't even know. She said like three or four things and	
	160	then she left	
	161	J: Did she speak to you on your own or with a teacher?	
	162	M: With my teacher	
	163	J: What kind of things did she say? What three or four	Embarrassment
	164	things?	
Woman from organisation asked M how school is going, his behaviour, which lessons he likes and why he is in inclusion Points broken down in simplest form – very matter of fact, almost like a check list/box ticking exercise. 'And she told me to leave' – feeling rejected but not letting any emotion show? Being told to leave – similar to being told to leave lessons to be in inclusion. Did this interaction bear any meaning for M? What is his understand of the woman meeting him?	165	M: Like how's school?	
	166	J: Yeah	
	167	M: Behaving?	
	168	J: Yeah	
	169	M: What lessons do you like?	
	170	J: Yeah	
	171	M: Why are you in inclusion? And she told me to leave	Rejection
	172	J: Ok. Does that happen a lot? Have you seen her before?	
	173	M: I saw her in Year 9, the start of Year 9 and I never saw her	
	174	again don't think	
	175	J: Oh really?	
	176	M: Yeah [difficult to decipher]	
Saw same woman in Year 9 – expands on response – '...the start of Year 9...' –	177	J: Oh so you think you see her like once a year?	Expanding on memories/opening up
	178	M: [repeatedly dropping an object on the table]	

recalling events more now. ‘I never saw	179	J: Does she tell you anything about her job or why she’s	
her again...’ – confusion about this	180	speaking to you?	Confusion about professional input
person and the part she plays for M	181	M: Nope, I can’t remember. I think [difficult to decipher]. She	
	182	told me everything about her in Year 9, I can’t remember	
	183	anything	
	184	J: So today when she met you, she didn’t say who she was	
	185	or...?	
	186	M: Yeah, she did. She said she was from **** and her name	
	187	was...I can’t remember	
	188	J: Don’t worry, you don’t need to tell me her name. She told	
	189	you she was from ****. Do you know Mik why she was	
	190	talking to you and not other students?	
Woman from organisation speaks to	191	M: Yeah she said she talks to other students	
other students in the school – quick to	192	J: Oh right, ok	
correct me here – resistant to be alone	193	M: And that’s it, there isn’t anything else	Aligns with peers
with regards to receiving support from	194	J: Ok so she talks to other students as well	Resistant to being different
the organisation. ‘And that’s it, there	195	M: Yeah	
isn’t anything else’ – attempt to end	196	J: But does she talk to everyone in the whole school?	
conversation about this topic –	197	M: No	Embarrassment about external
discomfort/embarrassment over	198	J: So do you know why she doesn’t speak to everyone and	support
receiving external support?	199	she just speaks to some students?	
Woman doesn’t speak to all students in	200	M: Nope	
school. ‘Nope’ – guarded/defensive	201	J: Hmm. Do you know what **** stands for?	Guarded, defensive
Unsure what the acronym of the	202	M: Nope [balancing objects]	Confusion about professional input
organisation stands for. Significant	203	J: Ok	
moment whereby M initiates an	204	M: Do you know what **** stands for?	
interaction for the first time by asking me	205	J: Yeah I do. Um so the * is for *****	
what the acronym stands for – wants to	206	M: Yeah	
know more about ASD and willing to	207	J: The * is for ***, which means like going or visiting people	Curiosity
initiate conversation in an attempt to	208	all over. The A is for, well can you guess what A is for?	

find out.	209	M: Nope	
	210	J: It’s something that I’ve mentioned today	
	211	M: Can’t remember, bad memory	
	212	J: Autism	
Pause after ‘autism’ – sinking in?	213	M: ...Yeah	
Discomfort with the word	214	J: And the * is for ***. So it’s *** Autism ***	
	215	M: Oh...cool	
	216	J: Have you heard of that before do you think?	
‘Nope’ – has M really never heard of it or	217	M: Nope	
wants to make out he hasn’t?	218	J: Ok, well now you know. So I guess there’s that word again	
	219	– autism – and I’m wondering if it means anymore to you	
	220	now?	
‘Autism’ still doesn’t mean anything to M	221	M: Nope	Defining ASD – nothing
‘Nope’ – guarded again	222	J: Hmm ok	Defensive, guarded
Enquires about how you know if	223	M: How do you know if someone has autism? [said very	Curiosity
someone has ASD – very quiet volume	224	quietly]	
indicates that it’s not easy for M to ask	225	J: Say that again?	
this, perhaps embarrassed/worried	226	M: How do you know if someone has autism?	Embarrassment about curiosity
about the answer. Curious to find out	227	J: How do you know? That’s a really good question. It’s really	
more about ASD and how he relates to	228	hard to know, but there are certain signs. So sometimes	
this.	229	people can think in different ways, um they might be really	
Confirms that people aren’t 100% sure	230	good at certain things and find other things difficult. So	
about ASD diagnoses. Questions own	231	there’s lots of different behaviours maybe that people show,	Questioning identity
identity and diagnosis. Emphasis on ‘I’ –	232	but sometimes it’s really hard to know actually because-	
challenging his own diagnosis, relating	233	M: So sometimes they’re not 100%. So how do you know *I*	
the uncertainty to himself. Positions me	234	have autism?	
as the decision maker of his diagnosis –	235	J: Well, I don’t know you have autism. I have been told, so	Same abilities as others
‘how do you know...’ Able to do things,	236	what do you think Mik?	
just as other people can – does M see	237	M: I don’t [difficult to decipher]	ASD as debilitating
ASD as a debilitating condition which	238	J: Pardon	

means people cannot do things as others	239	M: Anyone can do something then I can do it as well	
can and is trying to disassociate from	240	J: Yeah, absolutely. I completely agree with you	
this? Or is he saying, in spite of having	241	M: How can one person says I have autism and then [difficult	
ASD, he can still do things, as others can?	242	to decipher]	
Questions the rigour of the diagnosis –	243	J: How can one person says you have autism and then what?	Questioning diagnostic process
one person diagnoses and then everyone	244	M: And then everyone else thinks I have autism?	
believes it. First person – explicitly	245	J: Well, I think it's really important what you're-	
making reference to self. Questioning the	246	M: I've not been for no test	
diagnostic process – important part of	247	J: You've not been for a test?	
reflecting on the label/one's identity.	248	M: No. Some woman told my mum that I have autism and	
Says hasn't been assessed, rather a	249	then from then on my mum thought I have autism and every	Denial about assessment pathway
woman told M's mum than he has ASD	250	school I went to she told them I have autism	
and his mum told his teachers. 'I've not	251	J: So some woman told your mum that you have autism?	Anger, resentment
been for no test' – double negative.	252	M: Yeah	
'Some woman' – angry? 'Every school' –	253	J: And then your mum told your schools that you had autism	Dissociation with label
can't escape the label. Attempt to	254	M: Yeah and my mum never told me until like Year, Year,	
remove himself from having ASD –	255	Year 9	Locating blame in diagnostician
locating blame in diagnostician and	256	J: Who never told you? Your mum?	
mother or maybe genuinely believes that	257	M: My mum yeah she said I have behaviour problems that I	
narrative is why he has the diagnosis.	258	need to fix then I fix it then no one will keep, then no one	
M's mum didn't tell him about diagnosis	259	will say there's nothing wrong with me. Until then everyone	Anger, resentment
until Year 9. Difficulty articulating this –	260	says [difficult to decipher] that's it	
resentful/feels betrayed? Mum said M	261	J: So you think that your mum told you in Year 9 Mik that you	
has behaviour problems which he needs	262	had...?	
to fix and no one will say there's anything	263	M: Yeah	
wrong with him.	264	J: That you had what?	
Autism was conceptualised as a	265	M: She told me Mik you have problems, and I said what	Defining ASD – behaviour problem
behaviour problem. Repetition of	266	problems and she was like oh you have autism and all this	
'problems' – ASD as a deficit. Repetition	267	other stuff and then she was like oh behaviour problems	ASD as a deficit
of 'fix it' – the way M learnt about his	268	J: Ah I see, so in Year 9 she told you that you have autism and	

diagnosis provides meaning to his understanding of it – something that's wrong/problematic, behavioural and needs fixing. Belief that M can and needs to 'fix' his behaviour for ASD to 'go away' and to be accepted by others.	you were like what's that? And she said that it was behaviour problems?	Fixing behaviour = no more ASD
	M: Yeah and she said that it can go away if you fix your behaviour	
	J: Ah and she said it can go away if you fix your behaviour, I see. So is that what you think autism is – a behaviour problem?	
ASD is a behaviour problem which can go away if one fixes their behaviour	M: Yeah	
	J: And you think it can go away if you fix your behaviour?	
	M: Yep	
	J: Ok, that's really interesting	
Questions if ASD can go away – asks another question – wants to know more. M's question reveals an anxiety about the narrative he has been told – lack of confidence in the narrative but wants it to be true. Wants to be in control of his identity	M: Can it go away?	Questioning ASD as lifelong Curiosity
	J: Um, so autism isn't something that goes away, no. But it also isn't behaviour problems. Autism doesn't mean you have behaviour problems. Sometimes you can have difficulty with behaviour if you have autism, but you know other people who don't have autism can also have difficulty with their behaviour, so it's not *only* people with autism	Lack of confidence in narrative Control over identity
Questions how you know if someone has ASD – repetition of same question earlier – wants evidence to measure self against the criteria. Wants to reassess self as a way of saying he doesn't have the label.	M: So, how do you know if someone has autism?	Questioning identity
	J: Um so I guess a lot of it is to do with how people communicate and how people interact with other people, so most people with autism can find it difficult to interact with people and to communicate or to say certain things or to act in a certain way with other people. Sometimes that's a big sign that people have autism. Um, there can be other things as well. But you know I think you're right Mik. Well when you asked me how do you know – it's actually really hard to know if someone has autism. Nobody really knows for *absolute* certain. It's people trying to make the best decisions based on information that they have, but-	Questioning diagnostic process Searching for evidence to reject diagnosis

No one has ASD – people just say you do	299	M: So no one has autism, it’s just people trying to say they	Questioning diagnostic process
– speaking louder and more clearly here -	300	do	
engaged and keen to find evidence to	301	J: Well no that isn’t what I mean. I think some people do	Searching for evidence to reject
reject diagnosis. Looking for evidence in	302	have autism, but what I’m saying is that you can never know	diagnosis
my response that supports him not	303	for absolute certain, you can never know 100% if somebody	
having ASD	304	definitely, definitely, definitely has it or doesn’t have it. Does	
	305	that make sense?	
	306	M: Yeah	
	307	J: So some people do have it, but it’s hard to know for	
	308	absolute certain. But I think it’s a really good question – how	
	309	do you know if someone has autism? And correct me if I’m	
	310	wrong, but it sounds like to you that it’s not something that	
	311	you want? Is that right? Or you don’t care?	
Doesn’t care about whether he has ASD	312	M: I don’t care, I don’t have it so	Denying diagnosis
or not, but doesn’t have it.	313	J: You don’t have what?	
Feels like a paradox – sense that he cares	314	M: I don’t have autism	Apathetic mask for curiosity &
a lot, as he is asking questions about it	315	J: You don’t have it, ok. So it’s not something that you think	anxiety
and looking for evidence to go against his	316	you have. How come you seem quite sure about that?	
own diagnosis	317	M: ‘Cause I aint scared to say nothing	
Rationalises not having ASD by being	318	J: You’re not scared to say anything, ok. And you think	Fearless of saying things
fearless of saying things and not feeling	319	people with autism are probably scared to say stuff?	
threatened by anyone – double negative	320	M: Yeah. I aint threatened by no one	Fearless of everyone
– possibly quite scared in reality. People	321	J: You’re not threatened by anyone? Uh-huh. Ok so it’s not	
with ASD are scared to say things.	322	something that you think you have, that’s interesting. And	People with ASD are scared to speak
	323	Mik, why do you think that your mum told you that you have	
	324	it. Do you think people got it wrong or-?	
Believes was told he has ASD due to his	325	M: Behaviour	
behaviour. Repetition of ‘behaviour’	326	J: Because of your behaviour?	Behaviour problems
When given opportunity, doesn’t say the	327	M: Yeah	
diagnosis was wrong, but rather than it	328	J: So you think you might have difficulty with your behaviour	

was given because of his behaviour. In this sense, does behaviour difficulties = autism for M?	329	but you don't have autism? Is that what you're saying?	
	330	M: Yeah	Diagnosis due to behaviour problems
	331–333	J: Mm...Ok, so you don't think you have autism, but if we were to imagine someone that did have autism – how do you think it would make a difference to their life?	
Impact of ASD – wouldn't make much difference to someone's life if they did have it, other than being scared to say things. Repetition of idea of 'scared to say something' Conversation feels quite circular – M talks about not having ASD, followed by being fearless and then reveals his curiosity about ASD, before saying that he doesn't have it	334	M: It wouldn't make a big difference	Little impact of ASD
	335	J: It wouldn't?	
	336–337	M: No, it wouldn't make a big difference. They might be scared to say something	Impact of ASD – scared to speak
	338	J: They might be scared to say something?	Circular dialogue (denial, fearless, curiosity)
	339	M: Yeah	
	340–341	J: Yeah, scared to say something in what situations? Like with teachers or friends or...?	
	342	M: If they're getting pressured	
People with ASD would be scared to say something if they were being pressurised	343	J: If they're getting pressured	Scared to speak due to pressure
	344	M: Yeah	
	345	J: Pressure from who?	
	346	M: Anyone [difficult to decipher]	
	347–350	J: Ok. So if people had autism, they might be scared to say stuff to other people. So are there any other things that people with autism might find it difficult to do? So they might find it difficult to say certain things	
People with ASD might get scared easily of anything, e.g. bullies	351	M: They get scared easily	Scare easily
	352–353	J: They get scared easily. What kind of things might they be scared of?	
	354	M: Anything like bullies and stuff	
	355	J: And do you think people with autism get bullied?	
Unsure if people with ASD get bullied, but probably	356	M: Probably, I don't know	Uncertainty about bullying
	357–358	J: You don't know, ok. So people with autism might get scared to say things. They might get scared of bullies. Is there	

People with ASD get anxious	359	anything else that you think they might find difficult-?	Anxiety
	360	M: Anxious	
	361	J: Anxious, oh right. What do you mean by anxious?	
	362	M: I don’t know	
	363	J: I’m interested to know what you mean	
Anxiety through shaking	364	M: They might shake, stuff like that	
	365	J: Yeah, they might shake. So they might be a bit nervous	
	366	maybe sometimes?	
	367	M: Yeah	
	368	J: Hmm. Is there anything that you think they might be	
	369	nervous about?	
Unsure what people with ASD might get anxious about	370	M: I don’t know	
	371	J: You don’t know why, but they might just get anxious? And	
	372	Mik, do you ever get anxious?	
M never gets anxious. ‘Nope’ – sounding definite, yet defended/guarded again	373	M: Nope	Fearless – never anxious
	374	J: Never?	Defensive, guarded
Is M listing traits that people with ASD might have as a way of polarising his own traits, i.e. people with ASD get scared, anxious, shake – things that he says don’t happen to him	375	M: Anxious about what?	
	376	J: I don’t know	Polarisation of ASD traits against own traits
	377	M: I don’t get anxious	
	378	J: Never get nervous? Never get scared about anything?	
	379	M: Nope	
‘Nope’ – repetition	380	J: Ok so I’m going to ask you something else now, is that	
	381	alright?	
	382	M: Yeah	
	383	J: So you’ve told me things that people with autism might	
	384	find difficult. So you’ve told me that people with autism	
	385	might find it difficult to say things, they might find it difficult	
	386	to stand up to bullies. Is that right?	
	387	M: Yeah	
	388	J: And they might also get anxious. So they might get scared	

	of things and shake. Is there anything else that they might find it difficult to do? M: Don't know J: Don't know, ok. So now I'm going to ask you – is there anything that people with autism are really good at?	
Believes people with ASD are good at things where they don't have to think, e.g. sport. Interesting example since M has mentioned that he likes PE in school and his passion is boxing – is he describing aspects of himself?	M: Yeah J: Like what? M: I don't know, probably like sports...where they don't have to think J: Ah like sports because they don't have to think M: Yeah J: Could thinking be difficult for people with autism? M: Yeah J: Yeah? Oh right. That's interesting. Why do you think it might be difficult for them – thinking?	Impact of ASD – good at sports (no thinking required)
Impact of ASD – thinking is difficult. Might be thinking multiple things at once and don't know which one to focus on	M: They could be thinking like, they could be thinking like 6 different things	Impact of ASD – thinking is difficult
	J: They could be thinking like 6 different things M: Yeah and like they don't know which one to pick out J: Ah, so they might have loads of different things going on in their head and they don't know which one to choose or to think about M: Yeah J: And people who don't have autism, do you think they find it easy to think?	Impact of ASD – overload of thoughts
People without ASD find it easy to think Split/polarisation between people with and without ASD regarding cognition Questions whether sport involves	M: Yeah J: Ok, so you think that sport doesn't involve thinking? M: No J: Not at all? M: Sometimes like quick reactions	People without ASD find thinking easy Polarisation over cognitive ability

thinking – involves having quick reactions	419	J: Quick reactions, yeah definitely. And in boxing, I imagine	
	420	you have to think about where you're aiming, don't you?	
	421	M: You only aim in one place	
	422	J: Oh ok. Ok, so people with autism might be good at things	
	423	where they don't need to think, like sport. Is there anything	
	424	else that you think they might be good at?	
People with ASD may be good at games	425	M: Um...games	
	426	J: Games. What kind of games?	
	427	M: I don't know	
	428	J: Ok, remember there's no right or wrong answers. I'm just	
	429	interested that you said games. Why do think games?	
People with ASD may be good at games	430	M: 'Cause you're barely thinking of anything	Good at games (little thinking
because they don't involve much	431	J: Oh 'cause you're not thinking much. So Mik, tell me if I'm	required)
thinking	432	wrong, but it sounds like you think that if you have autism,	
	433	you're not very clever. Is that what you think? Because you	
	434	don't have to think much?	
	435	M: Yeah	
	436	J: So you can't have someone who's clever and has autism	
Cannot be clever and also have ASD	437	M: Yeah, I don't see that	Unintelligent
	438	J: Ok	
Not being clever does not mean you have	439	M: But if you're not clever, then it doesn't mean you have	Unintelligent does not mean ASD
ASD. Made a point of adding this in –	440	autism	
does M view himself as 'not clever' and	441	J: If you're not clever, it doesn't mean that you autism –	
this is why he wanted to make a point of	442	yeah, definitely. I agree. I also think that if you are clever, it	'Not clever' self-perception
disassociating himself from ASD?	443	doesn't mean that you don't have autism. Does that make	Dissociation from diagnosis
	444	sense? So I think people who are clever can also have autism	
Everyone has ASD in some way. Trails off,	445	M: Everyone has some autism in a way and [difficult to	Everyone has some ASD in a way
difficult realisation to come to?	446	decipher]	
Reflection on how he may also have ASD	447	J: Everyone has autism in a way and then what did you say?	People with ASD can be good at
in some form is difficult. Poignant	448	M: Everyone, everyone, if someone like people can be good	certain things

moment whereby M considers having ASD. ASD in parts – 'some' People can be good at certain things and not be clever. Difficult to make sense of what M is saying here – complex in his mind too? Repetition of 'clever,' 'football' and 'games' Reinforcing idea that you can be good at things and not be clever – how he sees himself? 455 – Difficulty saying/making sense of. Some people are different and people with ASD can be good at certain things, rather than being good at everything. Another poignant moment whereby M holds the position that people with ASD can be good at certain things and may just be different – rather than not being clever/being able to think as previously said.	at things and not be clever. People can be like...people can like, people can hate subjects and love football, people can love games and hate games [difficult to decipher]	ASD as parts Connection to ASD
	J: Yeah	
	M: Some people are just different	Complicated
	J: Some people are just different	
	M: Yeah, I don't think autism like...like you can't like you can be good at certain things, you're not good at everything. Something like that	Games, football, not clever
	J: Yeah. So you think if you have autism, you might be good at certain things but not good at everything?	Complicated
	M: Yeah	Differences amongst everyone
	J: And isn't that just like everyone?	
	M: Yeah	
	J: Isn't everyone good at certain things and not good at everything?	
	M: Yeah	
	J: I think that's a really interesting answer. And I'd really like to go back to what you just said, because it's stayed in my head – you know when you said that you think everyone's got autism?	
	M: Yeah	
	J: I think I kind of agree with you, but I just want to hear a bit more about that. What do you mean when you say you think everyone has autism?	
Everyone has autism in a way – e.g. someone who has ASD will be scared to talk if being bullied and similarly, someone without ASD will also be scared to talk if being bullied. Repetition of	M: Because like you see someone without autism, they won't like certain things. They will hate certain subjects, or hate certain games, hate certain things. And someone that doesn't not like certain subjects and hate certain games. And yeah, someone that has autism will be scared, if someone's	Disliking things, subjects & games Scared of talking

disliking/hating things, subjects, games	479	getting bullied they will be scared to talk. If someone like	Bullying
and being scared of talking & bullying.	480	that doesn’t have autism, and someone’s getting bullied,	
Draws similarities between people with	481	they will still be scared to talk	Similarities between people with and
ASD and people without ASD to	482	J: Yeah so you think there are similarities between everyone	without ASD
demonstrate that it isn’t clear cut and	483	so then because people are similar, then they might all have	
everyone may have ASD in some form.	484	autism a bit. Is that what you mean?	Complicated
Only thinks about one thing at a time –	485	M: Yeah. And with other people, see me – if I’m thinking	Thinking one thing at a time
attempt to remove himself from	486	something, that’s the only thing I’m thinking	Disassociating from label
diagnosis, i.e. I’m not like people with	487	J: Yeah	
ASD who think about loads of things at	488	M: People that have autism, they’re thinking one thing, and	
once.	489	another thing and another thing and another thing and	
Impact of ASD – thinking about multiple	490	another thing in their heads so they don’t know which one to	Impact of ASD – overload of
things at once and don’t know which one	491	pick out so they’re just stuck, [difficult to decipher] just	thoughts
to focus on, resulting in being stuck and	492	thinking and thinking and thinking and then they just say	
saying something nonsensical. Repetition	493	stuff, and then just say something which doesn’t make sense	Overload of thoughts leading to
of ‘thinking’ and ‘another thing.’ Clear	494	‘cause they’re thinking too much things	nonsensical speech – impaired
description of what M imagines	495	J: Ah ok, so there’s so much going on in their head that they	communication
experience for someone with ASD to be –	496	don’t know which thing to pick out or to concentrate on and	
is this his own experience sometimes?	497	then they probably say the wrong thing because they just	
Slight contradiction to earlier point about	498	can’t pick one thing?	Difficulty managing thoughts
people with ASD having difficulty	499	M: Yeah	
thinking at all? Perhaps believes they	500	J: I see. And how do you know that Mik? How do you know	
think a lot, but struggle to manage their	501	that people with autism have that?	
thoughts.	502	M: I don’t know	
	503	J: Have you heard that somewhere?	
	504	M: Yeah	
	505	J: Do you know where you’ve heard it?	
Heard about people with ASD struggling	506	M: My mum told me	Narrative from parent
to manage multiple thoughts from M’s	507	J: Oh your mum told you. Was that in Year 9 when she told	
mum when M was younger	508	you?	

	M: No when I was young	
	J: Oh when you were young	
M's mum said that some people are different & some people are more special – repetition of earlier comment about people being different. '...something like that' – attempt to minimise the importance of the comment for M?	M: Yeah. She said some people are different from other people, something like that	People are different Some people are more special
	J: Yeah, I think she's right. Everyone's different aren't they? So she said some people are different from other people and then did she say about people with autism can find it difficult if there's loads of things going on in their head?	
Seems that a lot of M's beliefs about ASD and his identity are based on information told to him by his mother – values her input	M: Some people are more special than other people	Identity based on narrative from parent
	J: Some people are more special than other people?	
	M: Yeah	
	J: Ah. And then did she say the thing you just said about having loads of things in your head at once?	
Impact of ASD – thinking more than one thing at one time leads to hearing other people say stuff	M: Yeah some people will be thinking more than one thing most of the time. That's how you hear, that's why sometimes you hear some people say other stuff	Impact of ASD – overload of voices
	J: Yeah, ok I understand. And Mik, is that sometimes that you ever feel – like you have lots of things going on in your head at once?	
	M: Nope	
	J: Never?	
	M: Never	
	J: What, always just one thing?	
Only thinks about one thing at a time, e.g. school or boxing	M: Always one thing. Always one thing. If I'm thinking about school, I'm thinking about school. If I'm thinking about boxing, I'm thinking about boxing	Single thoughts
	J: Ok, so if you're thinking about school, you're thinking about school	
Sometimes will have two things going on in head, e.g. what he is doing today and	M: I'm thinking about boxing, I'm thinking about boxing. Sometimes I'll probably have two things in my head. I'm	

what he is doing tomorrow	539	thinking about what I'm doing and what I'm doing the next	
	540	day	
	541	J: Ok, so you might have two things, but you don't feel like	
	542	you ever have loads of things going on and you find it	
	543	difficult to pick one thing out? What about in class when	
	544	there's a lesson?	
Doesn't know who to respond to in	545	M: There's more than one person talking and loads of things	Silence to manage overload of
lessons where there is more than one	546	going on in my head and I don't know who to respond to.	thoughts and voices
person talking to M and multiple things	547	Someone's talking to me and the teacher's talking to me, I	
going on in his head. Results in not	548	don't talk to no one	
talking to anyone. Articulately expressed	549	J: Wait, say that again. If there's more than one person	
– no pauses, utterances or hesitation.	550	talking to you	
Describes his experience vividly – feels	551	M: Yeah, I don't know who to talk to	
overwhelming hearing it. Contradiction	552	J: You don't know who to talk to	Contradiction about single thoughts
to what M has professed throughout re	553	M: I stay quiet	
never having multiple things in his head	554	J: So is it easier to stay quiet than to answer back?	Connection to ASD
at once. Now describing his own	555	M: Yeah	
experience which matches that which	556	J: I see. And does that happen a lot when there's loads of	Personal experience
has been describing for people with ASD	557	people talking at once in lessons?	
– struggling to think. M's silence in class	558	M: ...Yeah sometimes	
is a result of feeling overwhelming by	559	J: Mm. What does it feel like, when everyone talks at once?	Overwhelming noise
voices and thoughts.	560	M: It feels like voices	
It's cool when everyone talks at once –	561	J: Just voices	
returns to brief responses here – back to	562	M: Yeah	Guarded, defensive, embarrassed
feeling guarded/embarrassed? After	563	J: But is it annoying or is it...?	
giving the impression that M finds it	564	M: It's cool	
overwhelming when there are several	565	J: Ok, that's really interesting. So Mik, you just told me about	
people talking at once and lots of	566	a conversation your mum had with you when you were	
thoughts in his head, he now says that	567	younger	
'it's cool' – attempt to remove himself	568	M: Yeah	Separating self from difficulties

from any difficulties?	J: Do you remember how old you were?	
	M: I think I was like ten	
	J: Ten ok. And do you know what year were you in at school?	
Memory of laughing in conversation with mother in Year 5 – conversation that at the start of interview M claimed he didn’t recall, M is now opening up more and sharing his memories.	M: Probably like Year 5	Richer memories
	J: Year 5. And do you remember anymore about that conversation?	Opening up
	M: Nope, just that...I think. Then we started laughing	
	J: Who started laughing?	
	M: Me and my mum	
	J: Oh how come?	
	M: I think she said something funny	
	J: Oh ok so you remembered laughing and you remember the bit about people are different and the bit about some people being more special and you remember the bit about um some people with autism have loads of things going on in their head at once	
	M: Mm	
	J: Was there anything else said?	
	M: Nope	
	J: Ok so Mik I think you’ve told me loads and now we’re just going to bring it back together. So if I said to you what do you think autism means – remember there’s no right or wrong answer and a lot of it you may have already said – but what do *you* think autism means?	
Defining ASD – someone that can’t think straight. Repetition of idea that thinking is difficult for people with ASD. First time M has said ‘can’t think straight’ – idea that thoughts are not straight forward? Different way of thinking?	M: Someone that can’t think straight	Defining ASD – cant think straight
	J: Someone that can’t think straight. Ok, that’s what you think. Is there anything else?	
	M: Nope	
	J: What do you mean by they that ‘can’t think straight’ though?	Think differently?

	M: They can’t like, they, they say one thing and they say another and they think another thing	
	J: Oh right ok so they say one thing	
‘Can’t think straight’ means saying one thing but meaning something different due to multiple thoughts going on.	M: Then they actually mean another thing	Overload of thoughts leads to saying wrong thing
	J: Oh so there’s so much going on in their head that they say one thing you think, and they actually mean to say something else?	
	M: Yeah	
	J: Ok, I’m hearing that. Is there anything else that you think having autism means?	
Defining ASD – doesn’t mean anything else (until prompted)	M: No	
	J: Do you still think it means behaviour problems, like you were told?	
Defining ASD – also means behaviour problems. ‘Yeah’ said quietly – difficult to consider this due to belief that M has ‘behaviour problems.’ In M’s mind, does accepting that ASD = behaviour problems mean that he has the diagnosis?	M: Yeah [said quietly]	Defining ASD – behaviour problems
	J: Yeah? Ok so you think it means you can’t think straight and having behaviour problems? Are there any other things?	
	M: No	
	J: Ok so the last thing I’m going to ask you to do, and I think you can do it now, can I ask you to do what I asked you to do at the beginning now?	
	M: Draw a picture	
	J: The picture things. So whatever comes to your head when you hear the word ‘autism.’ So I want you to draw or write. And remember there’s no right or wrong answer and it’s not a test. Try to do a different thing in each corner	
	Part 2 – G.E.M	
	M: That’s it	
	J: Did you do four things – one in each corner?	
	M: Nope	

	J: Can you do anymore? Yeah you can, 'cause you spoke about loads of things so I know you can. If you hear the word 'autism'	
Wrote one thing in GEM due to only thinking about this one thing when hearing the word 'autism' – 'I only think about one thing' – another attempt to disassociate with people with ASD?	M: I only think about one thing	Single thoughts
	J: Ok, can I see? 'Cannot think straight.' Can you draw anything?	
	M: I can't draw	Dissociation from diagnosis
	J: I don't believe you. Everyone can draw	
Wrote 'cannot think straight' – repetition of difficulty thinking.	M: I can't	Difficulty thinking
	J: Some people can draw better than others, but it doesn't mean that they can't	
Hasn't drawn anything because believes cannot draw – lack of confidence	M: I *cannot* draw	Lack of confidence
	J: Well you can write	
	M: Yeah but I can't draw	
	J: Hmm I don't believe you but ok	
	M: I've never done art in my life	
	J: Neither have I, but I can still draw. Everyone can draw	
	M: Nah I can't draw	
	J: Ok	
	M: I never actually drew a picture in my life	
	J: Well maybe now's the time to try. Want to try?	Opening up
Draws with encouragement	M: Ok	
	J: Ok	
	[Drawing]	
	M: I'm done	
	J: Ok, stick man. What's he saying?	
	M: ...Nothing	
	J: What's in the speech bubble?	
Drawing depicts someone not being able to think straight and saying	M: Squiggly lines	
	J: Was he trying to say something	

nothing/something nonsensical as a result – repetition of 'can't think straight' Drawing of stickman was very small – feeling small amongst everyone around him? Drew the stickman small because it's a small world with small people – repetition of 'small' throughout here Idea that the world is getting smaller since people are connected, without necessarily knowing it – repetition of 'I know' – final attempt for M to assert himself and his knowledge – 'I know' and 'you never knew'? Perhaps less consciously, an attempt to show that everyone is human, however different they may be, and everyone is connected in some way in this world	M: Yeah but he can't think straight J: Ah I see. I got it. He's very small as well M: And- J: Is that for a reason? M: Small world J: Small world? M: Small people J: Ah small world, small people. What do you mean by that? M: The world is so small J: Yeah, is it? M: Yeah J: I thought the world was massive? M: No J: What do you mean no? How come it's small? M: It's small like not like small tiny world, but it's getting smaller J: In what way? M: Like I know people that you probably know and you never knew I know them J: Oh right M: It's getting smaller J: So you mean everyone's like connected in some way? M: Yeah J: I see. Thank you so much Mik. Was there anything else you wanted to say? M: Nope J: Ok, I'm going to stop it	Nonsensical speech – impaired communication Difficulty thinking Everyone is connected

Appendix 12 – Stage 4 of data analysis for Leo

Change is possible	**Impact of ASD**	**Feeling out of control**	**Suppressing emotions**	**Comparison with others**
Giving more with encouragement & time	Dislike towards ASD	Parental control over buying things	Seeking revenge through violence	'The only one' – alone/different
Celebrating success	Disliking things in life, e.g. homework, parents not buying things & nervousness	Acceptance about parental control	Making things fair	Ease for people without ASD
Being heard	Uncertainty about impact of ASD	Getting into trouble/moral conscience	Violence, anger, frustration, stress	Other people are normal
Being part of a group	ASD as parts 'if I did not have any autism, I would be totally fine'	Bargaining with parents	Internal conflict: seeking revenge vs. keeping anger inside (external destruction vs.internal distress)	Similarities and differences to peers
Adult support for anger – safe outlet	Positive feelings towards ASD – begging pays off	Control over change – sense of being stuck	Emotional expression is unsafe	Emotional dysregulation – people with ASD get very angry
Increased self-restraint (changed self)	Questioning identity – 'I think that I have autism'	Wishful thinking	Moral conscience	Emotional regulation – people without ASD just tell the teacher
Hope for change	Nervousness in front of others	Losing		Comfort from identifying with others 'I'm not the only person...'
	Bullying & complaining			

Appendix 13 – Examples of methods used to cluster emergent themes

Stage 4 of data analysis

Polarisation (Leo)

Feeling out of control

Parental control over buying things

Acceptance about parental control

Getting into trouble/moral conscience

Bargaining with parents

Control over change – sense of being stuck

Wishful thinking

Losing

Change is possible

Giving more with encouragement & time

Celebrating success

Being heard

Being part of a group

Adult support for anger – safe outlet

Increased self-restraint (changed self)

Hope for change

Abstraction (Elena)

Who am I?

Secrecy around the label

Identification with ASD

Paradox ‘no one doesn’t really talk’

Secret leaked beyond home

Unsure of reason for secrecy

‘The way I am’ – appearance, race, ethnicity, gender

Internal conflict – being myself vs. hiding the label

Authentic self

Appendix 14 – Stage 6: Looking for patterns across cases

Elena

- Negative impact of ASD
- Positive impact of ASD
- Time to become independent?
- Who am I?
- Social interaction

Sarah

- Deficits
- Dissociation with label
- Improves/disappears over time
- How to be fixed
- Splitting (ASD & non-ASD)

Leo

- Change is possible
- Impact of ASD
- Feeling out of control
- Suppressing emotions
- Comparison with others

Mik

- Debilitative
- Wearing a mask
- Who am I?
- How did this happen?
- Widening thinking

Appendix 15 – Evidence of ethical approval

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699

https://tavistockandportman.nhs.uk/

Jodi Cooper

By Email

12 July 2018

Dear Ms Cooper

Re: Trust Research Ethics Application

Title: Young people's experiences of having Autism Spectrum Disorder

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Best regards,

Paru Jeram
Secretary to the Trust Research Degrees Subcommittee
T: 020 938 2699
E: pjeram@tavi-Port.nhs.uk

cc. Course Lead, Supervisors/Research Tutors, Academic Quality

Appendix 16 – Research diary extracts

Thoughts following interview with Elena – 6th December 2018

Initially I thought that Elena seemed confident to talk about ASD. She seemed confident to begin the GEM task and to speak about ASD. However, as the interview went on, she seemed to struggle to extend her answers/to evidence what she was saying.

Seemed very ambivalent about ASD – as if she thought that she *should* consider it to be a good thing (maybe because her parents have told her that it is and told her that famous people such as Einstein had it), but actually wasn't sure. More so, she seemed to think it was a bad thing at times – something to be kept hidden in case people saw you as difference or teased you.

Every time I tried to make sense of this, I felt that I lost the thread and struggled to respond coherently.

Overall feelings – confusion and uncertainty.

Elena kept repeating things that perhaps she had been told, e.g. 'previous experience', but found it difficult to delve deeper into what these things mean for her.

Answered questions to previous questions, e.g. 'what is similar between you and your friends?' Elena responded saying 'I have 3 best friends but I get nervous talking to new people.' However, when asked if people with ASD find anything difficult, she said no.

Didn't mention the other family member that has ASD which her father informed me about. Elena said that she does not know anyone else with ASD. Disconnect between her and her ASD? Hides identity from herself (as well as others)?

I had a similar experience between her father and Elena – left feeling that I wasn't sure what they were thinking about ASD and the research, despite them both providing fully informed consent to take part.

Thoughts following transcription of Elena's interview – 20th December 2018

Past tense re experiences of having autism – 'had experience of autism' – does she mean it is something from the past that is no longer?

She seemed to find it easy to draw the pictures in the GEM. She didn't take too long thinking about them – more free associative? Yet when we reached the interviews, it seemed difficult for her to explain what she meant in detail – speech and communication difficulties/emotionally challenging?

Referred to ASD by its full name 'autism spectrum disorder' and emphasising the 'disorder' – pathologising? Does she conceptualise it as a disorder or is that just simply what she has been told it is called?

Initial themes that come to mind – bullying/teasing/being different, leading to having to keep ASD a secret/shame/hiding identity. Roles in school, peers and friendships seemed important for E. 'Past experience' and 'in my opinion' mentioned repeatedly.

She seemed to experience confusion between the different professionals (SALT, primary school teacher). Each gave a different narrative of what ASD is.

Difficulty committing to an answer following original train of thought – lack of confidence?

Did Elena think that when sessions with the psychologist ended ('past experiences') that so did her ASD? Ended because she needed to be more independent? Does she understand independence as no longer needing to talk to anyone about her worries and no longer having ASD?

Extract taken from diary recorded during analysis of Elena's data

Creating emerging themes from initial codes. 'Nothing bad about ASD' – want to call it 'denial' but if I am respecting the participant's lived experience then why is my version of 'denial' accurate? Kept it as 'nothing bad about ASD.'

Extract taken from diary during transcription of Mik's interview – 27th December 2018

Very difficult to transcribe because difficult to hear him – lots of mumbling. He is clearer when he is talking about his mum telling him about ASD and when he is asked me about ASD.

I was speaking more than I would have liked to. I felt positioned to do so to keep him engaged/happy/listening?

I felt sorry for him – wanted to provide him with some answers. Should have asked him his own questions back during the interview instead and given him some information at the end.

Initial themes that come to mind – not being able to think/intelligence; lots of things going on in head at once; behaviour problems – something that can be 'fixed'; fearless/guarded/defensive; told to leave – exiled/rejected; questions identity/diagnosis – wants evidence 'how do you know?'; polarised between ASD and non-ASD/split.