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*“I feel that I have learnt to accept myself ... but I don’t think the world is ready to be understanding & supportive”:*

A Foucauldian Discourse Analysis of Adolescent Autistic Girls’  
Constructions of their Self-Concept and Social Identity.

Doctorate in Educational Psychology

2021

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## Acknowledgements

Firstly, I would like to thank all of the participants, and their parents, for contributing their time and sharing their thoughts with me. It was a privilege and honour that you trusted me with your stories. They were moving and powerful and showed the incredible insight you have gained through many years of lived experience. Yours are the most important messages of this work, and I sincerely hope that my own constructions do not obscure the important insights you all offered.

I would like to thank my research supervisors, Dr Amy Hamilton-Roberts, and Dr Ian Smilie for your guidance, encouragement and incredible patience over many online supervisions where I rambled my way through my many questions, anxieties and thoughts. To Andrea Higgins, thank-you for sticking with me and supporting me through the many ups and downs of the course, you have been such a huge support. And to my friend Angharad Jones for being so generous in sharing your own journey with Foucauldian Discourse Analysis and helping me to gain confidence in the process.

Finally, my thanks go to my husband Tim who has taken on way more than your fair share over the last three years, enabling me to complete the doctorate. To Jude and Brily, my lovely sons, who have each in your own way taught me so much. And to my lovely Rubes, who inspired my research through your own journey. Thank you for teaching me more about autism than a book ever could.

## Summary

This paper is made up of three distinct parts:

Part 1 presents an introduction to the concept of autism, an introduction to the research around girls with autism and their diagnosis in adolescence, a focus upon the theoretical understandings of self-concept and social identity, and the way that these are viewed through a relativist ontology. Next there is a turn towards the use of discursive and social constructionist paradigms and a focus upon the prominent discourses around autism. Finally, this focusses into a review of the literature into the self-concept and social identity of autistic adolescents and culminates with a focus upon the area of enquiry and the research questions that emerged.

Part 2 presents an empirical paper that sets out the research rationale, methodology and results for the study. Findings are discussed, followed by consideration of strengths and limitations, and implications for further research.

Part 3 is a reflective and reflexive critical appraisal of the research process and the role of the researcher. It starts with a narrative account of the way the research subject was selected, and how the ontological and epistemological positionality of the researcher impacted the aims, orientation, methodology and data analysis undertaken in this work. It ends with a focus upon the contribution to knowledge and practice that this research makes.

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## Definitions used in this research

It is recognised that research concerned with discourse (and the power structures it maintains or subverts) must pay attention to the definitions and terms it galvanises. The words used to identify people and any diagnosis they may have wield their own form of power, perhaps especially so when they are legitimised in research.

Based upon the researchers' readings of a range of texts:

- 'Autism' will be used as a term to cover what many researchers refer to as Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC) or any of the other sub-categories (for example, Asperger's Syndrome) that appear in the DSM V (American Psychiatric Association, 2013) or the ICD-11 (World Health Organization, 2018) under the diagnostic category Autism Spectrum Disorder.
- Labels used to identify the cognitive profiles of participants will not be used in this research. Research indicates that labels such as for example 'high functioning autism' is an inaccurate clinical descriptor and such terms should be abandoned in research and clinical practice (Alvares et al., 2020; den Houting, 2019).
- Identity first language (autistic person) rather than person first (person with autism) will be used in recognition that identity-first language is generally preferred by autistic self-advocates (Kenny et al., 2016; Jim Sinclair, 2012) and because it has been suggested that person first language is seen to increase stigma (Gernsbacher, 2017)].
- Exceptions to all of the above will necessarily occur throughout this work where participants use terminology themselves (in which case that terminology will be honoured).

Part 1: Major Literature Review

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A Foucauldian Discourse Analysis of Adolescent Autistic Girls’  
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**Word count: 11,500**

## 1. Introduction

*“Autism is a lifelong developmental disability that affects how people perceive the world and interact with others.”*

(National Autistic Society, 2020, first para.)

*“Autism spectrum disorder (ASD) refers to a neurodevelopment disorder that is characterized by difficulties with social communication and social interaction and restricted and repetitive patterns in behaviours, interests, and activities.”*

(American Psychiatric Association, 2020, first para.)

*“Autism is an ability not a disability. I am proof that autism if nurtured and understood positively, is a superpower.”*

Lorie, autistic writer of a blog on autism for ITV (ITV, 2017, twelfth para.)

*“autism is much more a part of someone’s identity in the same way that someone’s gender is or someone’s sexuality or whatever...”*

(Abby, an autistic participant in a study by MacLeod et al. (2013) p.43)

Autism is a contested discursive space, as illustrated by the quotes above. This space is occupied by voices from academia, economics, medicine, education, autism advocates, charities, autistic people and many more. A 2015 poll by YouGov reports that 99% of people in the UK have heard of autism, and 44% know somebody with a diagnosis (YouGov, 2015). The “Autism Treatment Market” (Market Research Future, 2020, para. 1) is reported to be big business and is one of the most rapidly growing industries, whilst autism itself is reported to be costing the UK economy around £34 billion a year (National Institute for Health and Care Excellence, 2015).

Within this context children, young people and adults are diagnosed. From a social constructionist perspective, the discursive repertoires that occur around autistic people and their families become part of the fabric of their daily lives. The word autism has real and lived out consequences for them, as language results in social action

(Burr, 2003). In England, over 82,800 pupils with an Education and Healthcare Plan (EHCP) were recorded as having autism as their primary type of need, accounting for 30% of all pupils with an EHCP (Department for Education, 2020). Thus, the word 'autism' in the context of an EHCP might constitute what real world supports are put in place for over 82,000 children in England alone. In this way, words are said to be 'performative' (Burr, 2003).

Further to this, social constructionism posits that "the way a person thinks, the very categories and concepts that provide a framework of meaning for them, are provided by the language that they use" (Burr, 2003, p.8). As autism discourses are used in public and private spheres, they may thus be said to be providing a framework of meaning from which autistic people come to build a concept of their own selfhood. Therefore, the self-concept and social identities of autistic people can be thought to be, in part, born out of the discursive repertoires that are made available to them. Ongoing research and increased understanding of the way that autistic individuals discursively construct self-concept and social identity is therefore relevant to all professionals seeking to support and improve outcomes in education and beyond.

### *1.1 Constructing the research rationale*

This study takes a Foucauldian approach to the analysis of autistic young people's talk in relation to their self-concept and social identity. This section will lay out the research rationale in a number of steps. To begin, we will consider the paradigmatic lens and the researcher's positionality through which 'autism' is constructed and treated conceptually. Next an exploration around why autism in girls is of specific interest, alongside an examination of the potential impact of an autism diagnosis in adolescence. Following this, some theoretical understandings of self-concept and social identity are explored, and then further considered through the lens of relativism. Next, we will consider how a study of discourse will support exploration of the subject matter, and we will then finish with a brief overview of the way that language and discourse frame constructions of autism. This will lead the reader through the background rationale and set the scene for the literature review.

### *1.2 Constructing autism*

Bottema-Beutel et al. (2021) lay out an historical overview of what they term "ableist language" (p. 18) to describe autism and autistic people within autism research. They

conclude with recommendations for how researchers should reflect on and adjust their language choices. Within this context, terms such as Autism Spectrum Disorder (ASD) and Autism Spectrum Condition (ASC), it is posited, denote a biomedical problem “that should be fixed” (Bottema-Beutel et al., 2021, p.18). Therefore, rather than using the terms ASD or ASC within this research, which operationalise a medical discourse and may, as Bottema-Beutel et al. posit, further perpetuate ableism and systemic discrimination towards autistic people, this research uses the word ‘autism’. In the same vein, identity first language will be used (‘autistic person’ rather than ‘person with autism’) in recognition that, autistic people in the UK have been found to prefer the use of identity first language in far greater numbers than person first language although autistic ‘professionals’ it is noted, prefer to use person first language (Kenny et al., 2016). Shakes et al. (2020) explored how identity first language tended to be favoured within discourses which focussed on autism as neurological difference (neurodiversity), and person first when autism was framed as a diagnosis or as a disability. This is communicated by Sinclair (2013), an autistic advocate who communicates: “It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person” (third paragraph). Bagatell (2007) reported that for participants in their study autism was “a fundamental part of who they are, not just something they have” (p.420) and identity-first terminology respects this finding. Therefore, the terms ‘autism’ and ‘autistic person’ are used throughout this research.

Autism is a neurodevelopmental diagnosis. It has been commonly described as being characterised by persistent difficulties with social communication and social interaction, alongside restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). Whilst this is perhaps the most dominant construction of autism, there are others which offer alternative constructions, in ways that avoid descriptions of how autistic people ‘deviate’ negatively from normalcy (Milton, 2017). Savarese & Zunshine (2014) reference the “perceptual acuities, 3-D drawing and pattern-recognition skills, simultaneous global and local processing strengths, and enhanced pure-tone pitch discrimination” of autistic people (p. 19). The neurodiversity movement advocates for a decentring of typical neurotypes, away from the construction of “the pathologically dysfunctional

deviant minority” (Milton, 2017, p.462) towards an acceptance of neuro diversity in which divergent ways of thinking and being are accepted and celebrated (Cascio, 2012; Ortega, 2013; Ortega & Choudhury, 2011). Milton, an autistic researcher and academic argues for the “opening up a respectful discursive space, where autistic development is not framed from the outset as ‘disordered’” (Milton, 2017, p. 461). It is within this post-colonial (Savarese & Zunshine, 2014) positioning that the current research takes place.

### *1.3 Acknowledgement of the researcher’s positionality*

Before turning towards the academic literature around autism, it is important to provide some further context on the positionality of the researcher. Harper (2003) argues that reflexivity in Discourse Analysis enables the analyst to put critical attention on to the knowledge making practices of the analysis itself, and shines a light on the “identification of those aspects of one’s social identity which might influence the analysis (e.g. Coyle & Rafalin, 2000) and a tracing through of their influence” (p. 79). Whilst a more in-depth exploration of the researchers’ positionality, and the impact this may have had, is offered in part 3, it is important to note at an early stage (Tufford & Newman, 2012) that the researcher is herself a parent to an autistic adolescent. This is likely to have impacted the way in which the researcher interacted with the research around autism, and the way in which the research questions were developed out of the extant literature.

### *1.4 Autism and girls*

McConkey (2020) reports from school UK census data that the proportion of autistic children on UK SEN/ALN registers ranges from 3.21% in Northern Ireland (NI) to 1.79% of the school population in Wales. This represents a percentage increase of 127% (NI) and 141% (Wales) over the last eight years. The rapid increase in diagnostic rates has led some authors to describe autism as a “pandemic” (Bilbo et al., 2015, p.1). Whilst reports about gender prevalence vary, Loomes et al., (2017) report in their meta-analysis and systematic review across 54 studies (and more than 13 million participants) that of children meeting criteria, the male-to-female ratio is close to 3:1. They report evidence of a diagnostic gender bias, meaning that girls who meet criteria are at disproportionate risk of not receiving a clinical diagnosis. Further to this, mean age of diagnosis has been found to be later for females than males (Brett et al., 2016).

Researchers have thus sought to understand the difficulties of diagnosing girls. There is evidence of a research bias towards recruiting males in research by as much as 15:1 (Lai et al., 2015). Goldman (2013) posits that over-representation of males in those diagnosed with autism may in part be due to clinical expectations and by the gender-biased standardised instruments used. By way of example, Solomon et al. (2012) point towards the gender bias in the Repetitive Behaviour Scale -Revised (RBS-R) restricted interests subscale (Wolff et al., 2016), which refers to objects such as trains, dinosaurs, and toy cars, which they posit are “traditionally male interests” (Solomon et al., 2012, p. 55).

Other research has looked at the way autism typically presents in girls, with autistic females displaying more reciprocal conversation and motivation for friendships, alongside a greater desire for interaction with others (Lai et al., 2015). Behavioural differences were found by Lai et al., (2011) who cited females as reporting more lifetime sensory symptoms and fewer socio-communication difficulties than males. Cridland et al. (2014b) report the literature suggests tendencies towards stronger social skills in girls including pretend play, communication, social imitation and ability to focus, and reduced behaviour problems, when compared with autistic boys. They posit that these strengths can obscure social difficulties that girls are experiencing and thus contribute to missed and late diagnoses. Kreiser & White (2014) posit that sociocultural factors have an impact on more than just the way autism is expressed in females, but also impacts the perceptions of their behaviours.

Masking (also known as camouflaging or autistic compensation) may also be responsible for the tendency towards late diagnosis in females (Begeer et al., 2013) as it is posited that autistic females use the strategy more than autistic males (Lai et al., 2017), although not all research supports this view (Pearson & Rose, 2021). Lai et al. (2011) define camouflaging as the use of strategies by autistic people to minimise the visibility of their autism during social situations, and Livingstone & Happé (2017) refer to autistic compensation as the “observed mismatch between behaviour and underlying cognition in a neurodevelopmental disorder” (Livingston & Happé, 2017, p. 729). Late diagnosed females in a study by Bargiela et al. (2016) described “pretending to be normal” (p. 3821), or making a deliberate effort to use what they perceived as “neurotypical personas” (Bargiela et al., 2016, p. 3290).

Pearson & Rose (2021) argue that masking is a socio-cultural phenomenon due to the stigmatisation of autistic people so that they consciously and unconsciously conceal their “otherness” (p. 52). Whilst camouflaging may support autistic people to assimilate into their surrounds it is posited to negatively impact mental health and wellbeing, including links to significantly higher levels of anxiety, depression, burnout, suicidality and reduced access to support and services (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Livingston et al., 2019; Pearson & Rose, 2021). Masking may provide an explanation for the significantly higher levels of internalising behaviours, including anxiety and depressive symptoms in autistic girls, when compared with autistic boys and non-autistic girls (Oswald et al., 2016; Solomon et al., 2012). With research into autistic masking still at an early stage the implications for how this impacts on identity development are yet to be fully explored (Pearson & Rose, 2021).

### *1.5 The impact of diagnosis during adolescence*

A recent study in the UK reports that around 28% of autistic children in a nationally representative population-based cohort study were diagnosed with autism after starting secondary school (Hosozawa et al., 2020). This corresponds with adolescence, when numerous changes occur for young people in academic, social and other environmental influences, and when according to (Blakemore et al. (2010) young people “typically enter a stage of profound psychological transition” (p. 926). This may in part be due to adolescents’ heightened sensitivity to environmental sociocultural signals (Blakemore & Mills, 2014). An autism diagnosis during adolescence is likely to be particularly impactful due to the key developmental tasks around the development of self and identity (Erikson, 1968; Newman & Newman, 1975). Adolescence has been put forward as a time when profound changes take place as regards concepts around the self (Sebastian et al., 2008) and diagnosis with a psychiatric condition during this key stage has been found to promote a reconsideration of identity (O’Connor et al., 2018).

Erikson (1968) postulated that the way society labels an individual, alongside self and others’ perceptions contribute to identity formation. Research has shown how young people adjust their identity in response to a diagnosis of autism, and for some it forms a core part of their sense of self (Huws & Jones, 2008; Molloy & Vasil, 2004). Molloy & Vasil (2004) propose that autism provides a sense making narrative through which

autistic young people and their families come to view and understand their experiences. Diagnosis during this key stage therefore has the potential to impact significantly on the construction of identities as young people are tasked with making sense of a diagnostic label as well as of the self. Whilst diagnosis can aid sense making of past experiences and difficulties, some report struggling with the weight of a diagnostic label (Gaffney, 2020).

In an unpublished thesis, Craig (2015) explored adolescents' and mothers experiences of an autism assessment and diagnosis during adolescence. The young people talked about a journey, with all eventually accepting diagnosis, which they accepted as part of themselves whilst simultaneously trying to separate aspects of the self from autism. Both parents and adolescents described positive aspects of having an autism diagnosis. It provided a new way for most to understand themselves and their difficulties. They also talked about negative aspects which were mostly in relation to stigma and the negative views held about autism in society.

O'Connor and colleagues (2018) conducted a systematic literature review into the impact of a range of psychiatric diagnosis on self-concept and social identity in children and adolescents. They found a range of reported benefits including self-legitimation, self-enhancement and self-understanding, but also risks to self-concept, with diagnosis prompting a reconsideration of identity, and some negative impact on self-esteem. They posit that social identity is impacted by diagnosis in both positive and negative ways. Benefits included social identification with others with the same diagnosis, but amongst the disbenefits were perceptions of stigma from others due to diagnosis. Cooper, et al. (2017) note that autistic people face the challenge of maintaining a positive sense of self despite their membership in a stigmatized group. Berkovits et al. (2020) in their study which explored adolescents' perceptions of their autism diagnosis, found that around half of participants (N=38) talked about the stigma of having a diagnosis of autism.

Cooper et al. (2017) found that while autistic participants reported poorer mental health than non-autistic controls, those with a positive autism social identity reported fewer mental health difficulties. That is, having a positive autism social identity was negatively correlated with anxiety and depression. The late diagnosed autistic women

in Bargiela et al.'s (2016) research reported diagnosis enabled access to a newly gained sense of belonging with other autistic people, resulting in a more positive sense of self. Research that has focussed on the removal of the Asperger's Syndrome (AS) diagnosis from DSM 5 (American Psychiatric Association, 2013) has also focussed on the positive identity that participants felt had been a result of diagnosis (with AS) and the sense of belonging with a like-minded 'aspie' community (Chambers et al., 2019; Smith & Jones, 2020).

O'Connor posits that psychiatric diagnosis may benefit the diagnosed due to the common language that diagnoses provides, streamlining communication between different services and clinicians (O'Connor et al., 2018). However, how does this common language impact the way adolescents go on to construct a self-concept and social identity? What resources, what ways of being and doing does this provide to an adolescent in the teenage task of identity development (Erikson, 1968)? Does every behaviour and every interest in an autistic person's life now get viewed as a 'symptom' of autism (Molloy & Vasil, 2004; Runswick-Cole, 2014)?

Narrative research into identity development and the diagnosis of a Critical Illness in adolescence found that young people drew upon dominant discourses about health and illness and used them to develop their own identity (Wicks et al., 2019). The sense making experiences of adolescents around their diagnosis of autism (diagnosed in childhood) have been explored by Jones et al. (2015) who found that the peer and family interactions that autistic adolescents have shape what they believe about their diagnosis and themselves. Furthermore, they posit that the narratives autistic young people use mediate how an autism diagnosis influences their self-perception, and how they then cope and adapt. They conclude that the language used to describe autism impacts how adolescents make meaning out of their diagnosis, and how they go on to view themselves.

Diagnosis might be viewed as creating the potential for autistic people to become defined by the pathologising language used around them, and to experience the reduction of the self to a diagnostic category (Hodge et al., 2019). Or it may support young people to reframe their self-perceptions through access to a new narrative and "essential explanation for why they find it hard" (Molloy & Vasil, 2004, p.115).

### 1.6 Self-concept and social identity

*“Making sense of oneself-who one is, was, and may become, and therefore the path one should take in the world-is a core self-project. Self and identity theories assume that people care about themselves, want to know who they are, and can use this self-knowledge to make sense of the world. Self and identity are predicted to influence what people are motivated to do, how they think and make sense of themselves and others, the actions they take, and their feelings and ability to control or regulate themselves” (Oyserman, Elmore, & Smith, 2012. p.70)*

Self-concept has been defined as "the individual's belief about himself or herself, including the person's attributes and who and what the self is" (Baumeister, 1999, P.13). It is a series of identities made up of "the traits and characteristics, social relations, roles, and social group memberships that define who one is" (Oyserman et al., 2012, p.69). Social identity is defined as the portion of the self-concept that derives from membership of social groups, together with the emotional significance attached to it (Duszak, 2002; Tajfel, 1981).

From age seven upwards children are known to make self-evaluations based on social comparisons (Livesly & Bromley, 1973) and feedback provided from others (Ruble, 1983). In adolescence this intensifies as young people become increasingly self-conscious and concerned with the opinions of others (Parker et al., 2006; Vartanian, 2000). Adolescents are more likely to compare themselves with others and to understand that others are making comparisons and judgements about them, whilst also placing higher value on others' judgements (Sebastian et al., 2008).

Parker & Gottman (1989) view the most important socioemotional task of adolescence as working through self-identity issues, with adolescent friendships as a vehicle for self-exploration through intimacy and self-disclosure. If peer groups are indeed a vehicle through which concepts of identity and self-esteem are negotiated (Erikson, 1968; Newman and Newman, 1975), there may be implications for autistic girls who report that developing and maintaining friendships becomes more complex and difficult to achieve in adolescence (Tierney et al., 2016) despite a greater desire for interaction with others (compared with autistic males) (Lai et al., 2015) and similar levels of motivation for friendship than non-autistic girls (Sedgewick et al., 2016).

The looking glass self, proposed by Cooley, (1902) and later by Mead, (1934) posits that people come to know themselves through the eyes of others, particularly

significant others. They propose that there is no concept of 'I' without a sense of the other, and that one's concept of self is derived by determining how one is viewed by the other. Sebastian et al. (2008) explore how neurocognitive development might contribute to heightened self-consciousness and susceptibility to peer influence during adolescence. Within this context one might wonder how it is to construct a self-view when one's interactions with peers are frequently negative. Insider accounts from autistic adolescents provide evidence that they frequently suffer peer rejection, bullying and social exclusion (Hebron & Humphrey, 2014; Humphrey & Lewis, 2008; McLaughlin & Rafferty, 2014) and experience social stigma (Jones et al., 2015). As Sebastian et al. (2008) point out, studies show that negative social experiences during adolescence contribute to increased incidences of depression and other affective difficulties.

For autistic girls, a self-view that is even in part constructed through the ways others view them may present particular challenge as autistic girls report higher levels of relational aggression within their friendships than both non-autistic girls and autistic boys (Sedgewick et al., 2016). Furthermore, if as discussed earlier, girls are more likely to engage in autistic masking (Lai et al., 2017) in order to avoid being othered due to stigmatisation (Pearson & Rose, 2021) the self that they see reflected in their friendships may present particular challenge, as it is less likely to include the aspects of themselves they are hiding from view.

Social Identity Theory (Tajfel & Turner, 1979), provides further rationale for making sense of how adolescents perform self-evaluations by engaging in ingroup and outgroup social comparisons (Palmonari et al., 1989; Tarrant, 2002). Social identity becomes a prominent theme in adolescence as young people strive towards a sense of belonging in a valued social group (Kroger, 2000 as cited in Tanti et al., 2011). A sense of meaning and belonging can be gained through group membership resulting in positive psychological consequences as individuals internalise this into their social identity (Haslam et al., 2009).

Tarrant, et al. (2006) report that adolescent participants who displayed high levels of identification with a friendship group reported higher levels of self-esteem and more positive experiences of personal and relational developmental tasks. Conversely,

Hedley and Young (2006, as cited in Huws & Jones, 2015) found that autistic young people who viewed themselves as being different from their peers reported higher levels of depressive symptoms.

Whilst autistic people do report high levels of social exclusion (Hebron & Humphrey, 2014; Humphrey & Lewis, 2008; McLaughlin & Rafferty, 2014), accounts from autistic young people also report experiences of finding a sense of belonging with groups of autistic peers (Bagatell, 2007; J. L. Jones et al., 2015). Cooper et al. (2017) argue that a positive Autism Identity (AI) integrated into one's self-concept, has the potential to improve mental health and wellbeing for autistic people. Thus, an autism diagnosis also has the potential to buffer some of the social impact that living with challenges around social communication (and a stigmatised label) can bring by providing access to a group of peers with whom an autistic individual identifies and feels a sense of group belonging.

#### *1.7 A relativist view on self-concept and social identity*

Oyserman and colleagues (2012) posit that the feeling of knowing oneself anchors people in a position from which they make choices in their lives and that these choices are partly based on who one perceives oneself to be. However, they propose that this "self-project" (p. 70) does not produce a stable and consistent true self that exists and can be measured, rather that people construct identities according to the environmental and social context they are in. In this way self-concept and social identity are rooted in a social interactionist framework.

Kroskrity (1999) refers to "repertoires of identity" (as cited in Versluys, 2007, p.91), reflecting the multiplicity of social identities that social actors take up in their talk, as they take on different positions (Versluys, 2007). Similarly, Kroskrity (1999, p.111) considers that identity is the 'linguistic construction' of group membership. That is, social identities and self-concepts are constructed through discourse that positions the self as part of, or apart from social groups.

These approaches reject the notion that self-concept and social identity are distinct entities that exist as fixed realities. They challenge cognitivist theories that see self-concept and social identities as entities that form and remain stable over time. Rather they are taken to be constructed dynamically in a social and linguistic context. As

Rapley (2004) argues “a social identity is (not) a fixed thing, like a handbag perhaps, which people ‘carry’” (Rapley, 2004, p.112). Rather it changes across time and across contexts so that ‘self-concept’ and ‘social identity’ are treated as dynamically constructed (Oyserman et al., 2012) within a social context.

Burr posits that “the way a person thinks, the very categories and concepts that provide a framework of meaning for them, are provided by the language that they use” (Burr, 2003, p.8). Social constructionism moves even further away from an essentialist view on self-concept and social identity, beyond linguistic determination (the idea that language determines what one can think) towards anti-essentialism. That is, there is no assumption of a ‘thing’ called self-concept or social identity that one can somehow access and measure.

### *1.8 Social constructionism, power and discourse*

Within a social constructionist paradigm knowledge claims are viewed as artefacts of the specific historic and cultural context within which they are made. Knowledge is seen as socially constructed, rather than representing an existing truth (Burr, 2003). Social constructionism posits that knowledge is constructed and sustained through language, between people in their everyday lives and that knowledge and truth claims invite different kinds of actions from human beings. These actions have a major impact upon the way people live out their everyday lives, the choices that they can make, and the way our society operates in a given time and place (Burr, 2003).

Applying this lens to the subject matter at hand, would therefore see ‘autism’, ‘self-concept’, ‘social identity’, ‘adolescence’ and even ‘girls’, as socially constructed phenomena, rather than distinct entities that exist outside of the language and social processes that define and sustain them. An empiricist might approach the literature with a view to understand knowledge amassed so far, find a gap in the scientific literature, and seek to design research which proves (or fails to prove) a theory which aims to uncover some existing truth about the self-concept and social identity of autistic people. Within a social constructionist paradigm, this is not the aim. Rather the emphasis is on how forms of knowledge are constructed through discourse and the way that this constructed knowledge plays out in the social processes around us.

Structuralists and post-structural theorists including Saussure, Barthes and Foucault propose that language is a socially constructed system shared and used by people in order to put a structure around, or make sense of our lived experiences (Burr, 2003). Saussure proposed that the sounds we use (the words) to signify a concept are arbitrarily assigned, but that any word works as long as everybody agrees that a sound refers to that particular concept. He proposes concepts are only distinct from other concepts due to arbitrary categories we have created that defines one thing from the next (Saussure, 2004). In this way, structuralists propose that we build and share meaning, as humans, around our lived experiences. Post-structuralism builds on this concept and posits that meanings change over time (and place), and that they do so to reflect the interests that are served by constructing the world in a given way (Burr, 2003). As such, language is taken to reveal a great deal about how power operates in society, and about who is able to act and have agency or access to certain ways of speaking.

Discourses have been defined as “a system of statements which constructs an object” (Parker, 1992, p.5), or to “a set of meanings, metaphors, representations, stories, statements and so on that in some way together produce a particular version of events” (Burr, 2003, p.64). The more a discourse appears to reflect common sense in the historical and cultural context in which it is situated the more powerful it is, and the more likely it is to be constructed as knowledge (Burr, 2003). In this way Foucault asserts that ‘knowledge’ – that culturally bound view of the world at that specific point in time – is bound up with power. This is because what follows from use of a certain discourse can limit or marginalise certain ways of acting, setting out what is permissible or acceptable, and what is illegitimate and othered (Foucault, 1979). For Foucault, it is not people that are powerful, but discourses which people can use, that enable people to do the things they want (Burr, 2003). Willig (2001) contends that “Foucauldian discourse analysts focus upon the availability of discursive resources within a culture – something like a discursive economy – and its implications for those who live within it” (p.107).

### *1.9 The discourses around autism*

When young people receive a diagnosis of autism, they gain access to a new discursive economy to talk about themselves that they had not previously had access to. Where

they may have in the past been labelled as 'weird' and 'strange', autistic people talking about diagnosis reflect on how a diagnosis provides them with a different framework for viewing their difficulties (Molloy & Vasil, 2004; Punshon et al., 2009). And yet discourses around autism are varied and not in themselves difficulty free.

Jones et al. (2015) talks of the "paradox of autism" (p. 1492) where the meaning making of autistic adolescents around their diagnosis takes place in the context of competing social discourses that can leave young people wanting to reject the part of their diagnosis that they dislike ('symptomology' and stigma) whilst maintaining the aspects that make them unique or talented. Similarly Brownlow, (2010) talks about the "complex and sometimes competing representations of autism that people with autism can draw upon when negotiating their own identity" (p. 20).

Autism itself has most often been constructed in terms of "disease and deficit" (Lester, 2012, first para. of introduction). O'Dell & Brownlow (2005), in their discourse analysis examining media reports surrounding the Wakefield scandal, suggest that reports drew upon "parental fear of 'damage' to their children, where 'damage' is constituted as the onset of autism following vaccination. Implicit within the debate is the notion that an autistic child/adult is less acceptable than a (supposedly) 'normal' child" (O'Dell & Brownlow, 2005, p.194). Even within the last 20 years, studies have compared autistic participants with what they term 'normal' comparison subjects (Li et al., 2014; Mayes & Cohen, 2006; Toichi et al., 2002). Research by Bilbo et al. (2015) propose that autism is "a *pandemic* of modern culture" (Bilbo et al., 2015, p.1) and Good (2018) recently published research positing that the commonly prescribed antibiotic Amoxicillin is implicated alongside other toxins in what they term an 'epigenetic epidemic' of autism (Good, 2018, p.171).

Talk of aetiology, toxins, epigenetics, epidemics and pandemics to describe autism implicitly treat autism as a biomedical problem to be solved. The "othering effect" (Waltz, 2005, p.432) of a medical discourse has direct implications for those people to which the discourse relates (Waltz, 2005). Lewin & Akhtar (2020) posit that the medical model of autism is a model of deficit, where autism is defined in relation to its deficits in relation to a non-autistic population. This potentially 'others' autistic people through a rhetoric that creates boundaries between "normal and pathological minds"

(Yergeau & Huebner, 2017, p.273) and constructs autistic people as “being on the fringe of human normality” (Pearson & Rose, 2021, p. 53).

If one takes the view of a social constructionist that the world we create through our talk invites a particular kind of action from human beings (Burr, 2003) then one might legitimately wonder, what social action does this amassed, highly constructed knowledge about autism create? What questions are the research community asking in order for these truth claims to come into existence?

In thinking about one of the most dominant theories in autism research, the theory of mind (Baron-Cohen, 1995) one becomes aware of an ironic set of assumptions that research conclusions often present. Milton (2012), coins the term “double-empathy problem” (p. 884) to make sense of the phenomena in which ‘neuro-typical’ (a term for neurologically typical) researchers posit that autistic people are unable to fully understand the mental states of the self or others, whilst simultaneously making “wildly inaccurate” (Milton, 2012, p.884) attempts at empathising with the experience of autistic people, and the differing dispositional outlooks and personal conceptual understandings they may have. In this way, autistic people are ‘othered’, neurotypicals become the normative standard and the research ‘problem’ is constructed as a phenomenon worth researching.

As Yergeau & Huebner (2017) argue, essentialist understandings of Theory of Mind actually reveal a limited theory of other minds where neurotypical minds are privileged, and autistic concepts of identity and community are undermined and delegitimised. Savarese & Zunshine (2014) propose that “theory of mind ought to work in two directions: if we’re going to judge autistics on their ability to read neurotypical minds, then we must be judged on our ability to read autistic ones.” (p.25). Heasman & Gillespie (2018) found that this misunderstanding of autistic people’s experiences and intentions extends into family relationships with family members over-estimating the extent to which their autistic family members are egocentrically anchored in their own perspectives. There has been some criticism of the way that the behavioural goals professionals set for autistic children trains them to act ‘normal’ and thus perpetuates greater levels of intolerance towards individuality and difference (Olinger, 2010 as cited in Gilling, 2012).

Constant et al. (2020) note that many influential theorists in autism studies tend to suggest that the necessary components for a sense of relational self are reduced or impaired. One does not have to search for long in order to find evidence of such studies which primarily focus upon deficiency in the abilities of autistic people and aspects of self. Lyons & Fitzgerald (2013) refer to “a fragmented and atypical sense of self in ASD” (p. 758). Zahavi, (2010) argues that autistic individuals experience specific deficits related to the interpersonal dimension of self, which are of particular importance for that dimension of self-concept that forms as a result of self-experience as mediated through others. Similarly Farley et al. (2010) suggests that autistic people are impaired in aspects pertaining to the ability to identify with others’ beliefs in relation to the self. Farmer et al. (2007) reported that children with Asperger’s syndrome had less developed concepts of their social, interpersonal selves and had a particular tendency to be more inward-looking in their reflections than non-autistic peers. Williams (2010) concludes that autistic people have decreased insights into their own mental states and emotions and Berna et al. (2016) concluded that autistic participants displayed lower clarity of self-concept than control participants.

Milton (2012) asserts that these impositions of positivist, cognitive behavioural worldviews upon autistic people, can become internalised. Thus the negative connotations that result from this “normative model of pathological difference becomes a self-fulfilling prophecy” (Milton, 2012, p.885) within the autistic community. In this way, research around autism, that is likely conducted with the intention of supporting better outcomes for autistic people, feeds into a discourse of deficit which potentially further stigmatises and ‘others’ autistic people. Indeed Tangen (2008) argues that focussing only on difficulties when conducting research adds to the discourse of stereotyping and disregards individual difference.

Whilst historically the academic and medical community has constructed autism from a position of deficit, there is also a counter discourse of diversity (Rosqvist et al., 2015) that is challenging the hegemony that this had created. The neurodiversity discourse constructs autism as a naturally occurring neurological variation (Singer, 1998), rather than a pathological disease that needs a cure (Barnes & McCabe, 2012). Proponents argue that autism should be viewed as a way of being, rather than a health condition (Kapp et al., 2013), that autistic people are different to neurotypicals not deficient

(Brownlow & O'Dell, 2009; Cooper et al., 2021; Kapp et al., 2013) and recognition that autistic people have a profile of both strengths and challenges (Pellicano & Stears, 2011), as do all other neurotypes. It provides access to a critical discourse with which autistic people might challenge the negative and disabling mainstream models of autism (Brownlow & O'Dell, 2013).

Neurodiversity finds its roots within the social model of disability (Oliver & Sapey, 1983) as it challenges the notion that autism is merely a problem that resides within autistic people. It advocates the positioning of autistic people as a minority group, disabled by a society built around a neurotypical population, and arguing society must change rather than the individual (Graby, 2015). Rather than focusing on 'within person' pathology, this model emphasises societal barriers that inhibit inclusion. Disability results from a poor fit between the attributes of the person and the conditions of their social environment.

One of the said failures of society towards its autistic members might be thought of as the stigmatising language it uses to describe aspects of people that they consider to be a very part of their identity (Bury et al., 2020; Wicks et al., 2019). In contrast, the neurodiversity discourse offers opportunities for the construction of an autistic identity that is strengths based and engenders a pride in who one is and to a community that one belongs (Cascio, 2012; Bagatell, 2007; Bumiller, 2008).

Research within a neurodiversity paradigm explores the differing profiles of strengths and weaknesses in different neurotypes, and the ways in which particular tasks might be achieved in divergent ways. It does not deny the existence of a neurobiological difference between autistic and neurotypical people, but it argues for a "dethronement of privileged neurotypicality" (Savarese & Zunshine Prof., 2014, p. 20).

Alongside a reframing of what constitutes what autism is, proponents of the neurodiversity paradigm argue that the voices of autistic people should become central rather than peripheral: "until recently, those with the loudest voices in debates over autism have tended to be (non-autistic) parents and professionals" (Davidson & Henderson, 2010, p.157).

This challenge to a deficit discourse has not contained itself to a niche corner of the internet, but rather it has enabled alternative constructions to enter wider social

discourse. Lewin & Akhtar (2020) conducted a content analysis on articles about autism in the *Washington Post* over a nine-year period and reported a shift towards a language of neurodiversity as time went on. Over time, there were increasing mentions of autistic people's strengths, more talk about accommodations, and less of a focus on causation. However, they also note a continued use of negative terminology throughout the period covered, as well as a lack of autistic people's perspectives. In the UK, the website for the National Health Service provides a definition for autism that very clearly attempts a move away from a medical discourse, to one of difference: "Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people...Autism is not a medical condition with treatments or a 'cure'" (*What Is Autism?* - NHS, 2020).

In the academic arena, Houting (2019) notes in a 2019 editorial for the journal *Autism* that some outcomes of the neurodiversity movement include improvements such as an increased focus on strengths based approaches to intervention and support, with treatment goals more focussed on issues that concern the autistic, rather than neurotypical community.

Within these contested, public discursive spaces, autistic people are diagnosed. Discourses which seek to define what autism is, and what it is to be autistic become highly relevant. If one aligns with a social constructionist view and agrees that "language is the prime site of the construction of the person" (Burr, 2003, p.53) then the discourses that permeate a culture about a significant aspect of a person, may be taken-up in their constructions of self-concept and social identity.

### *1.10 The current study*

This study takes a Foucauldian approach to the analysis of adolescent girls' discourse when discussing their self-concept and social identity in the context of receiving a diagnosis of autism in adolescence. The research aims are to identify the ways in which self-concept and social identity are constructed through the language that young people use, and to explore how individuals are positioned by the discourses they employ. The following review will focus upon the literature in relation to how autistic young people talk about self-concept and social identity. It will begin with an introduction to the search terms used when reviewing the literature. Secondly it will examine the themes that emerge from the relevant literature. The chapter will

conclude with a rationale for the approach taken within the current study and an introduction to the research question.

## 2. Literature Review

### 2.1 Search terms and inclusion criteria

The initial task in reviewing the literature began with a search of Psycinfo, ASSIA, SCOPUS and Medline databases to undertake a systematic search of the literature (see Appendix A) followed by a critical review (Grant & Booth, 2009). This form of literature review was chosen in order to ensure a comprehensive search strategy was used so that all relevant studies were included, but also so that the most significant themes in the literature could be drawn together and set the scene for the current study. The keyword search included a range of the most relevant terminology including social identity, identities, self-concept, adolescence, autism, autistic and Asperger's. 'Mendeley' reference management software was used to then sort through the references. After duplicates were removed, titles and abstracts were read to select any potentially relevant studies, and then in a second screening process those providing insufficient information in the titles/abstracts to apply eligibility criteria were read to establish eligibility for inclusion, and from this point a snowball approach was taken in identifying any further literature to include. Studies were included if they were written in English, peer reviewed, used a qualitative methodology, included primarily adolescents and the abstract or title referred to the self-concept, identity or social identity of autistic\* young people (\* including Asperger's or any other category included in DSM V). This approach aimed to ensure that no relevant material was excluded due to terminology alone, while limiting the scope of the review to those peer reviewed studies most relevant to the present area of interest. This process resulted in 14 studies which were then subjected to critical review (see Appendix A) using the CASP Qualitative Studies Checklist (Critical Appraisal Skills Programme, 2019). These studies will now be presented through a narrative synthesis (Grant & Booth, 2009).

### 2.2 Construction of self-concept and social identity in autistic adolescents

#### 2.21 *Exploring the impact of diagnosis on the sense of self*

Gaffney (2020) explored the impact of an autism diagnosis on the sense of self with six adolescent girls, two of whom had been diagnosed during adolescence. Using Interpretative Phenomenological Analysis (IPA) Gaffney developed themes identified

from semi-structured interviews. As a sense making tool, autism was used by the girls to understand the self in terms of their past and current behaviours, although there were differing levels of acceptance of autism ranging from acceptance: “it’s just the way I am” (p. 141) to rejection “if I had a choice between not existing and having this I would choose not existing” (p. 142). Similarly, some of the participants struggled with a sense of self, although this was not uniformly attributed to the diagnosis of autism, and others had reframed their sense of self positively due to their diagnosis: “I feel better about myself...as a decent autistic person rather than like doing a terrible job of being normal” (p.142). Whilst critical analysis of the study supports the view that this was generally a robust piece of qualitative research, there is some evidence that the way findings are summarised are misleading. Ella, for example, is cited as accepting her diagnosis (“I was pleased...it makes sense” p.141) and of experiencing a stronger sense of self and yet on p.145 the researcher writes “Autism diagnosis and associated difficulties can have a negative impact on mental health but some participants had achieved a separateness from their diagnosis and seemed to enjoy positive wellbeing”. This suggests a link between enjoying positive wellbeing and achieving a separateness from diagnosis – however Ellie is cited as a participant who welcomed her diagnosis and achieved “self-acceptance” and a “strong sense of self” (p. 142).

In an earlier study Jones et al. (2015) also used a phenomenological approach to explore the impact of diagnosis with 10 autistic adolescents, two of whom were female. They too found that participants reflected how an autism diagnosis enabled them to understand the self, around which they built a narrative that led to self-understanding and acceptance. Social comparisons with other autistic people focussed on the heterogeneity of autism. All participants had concerns about the stigma of the autism label and people’s responses due to that, but there was also talk about finding belonging and pride in being autistic. The participants distanced themselves from a disability label, using downward social comparisons that focussed on physical disabilities. Despite using a phenomenological methodology, the researchers did not discuss the researcher’s own subjectivities, or ontological and epistemological positioning, and the way these potentially impacted the research decisions and subsequent analysis. Jones and colleagues conclude that the interactions autistic teens have in their community shape what they believe about autism and about themselves.

They posit that the narratives autistic adolescents create around autism (taken in part from the interactions they have and the discourses around autism) impacts directly on self-perceptions, coping and adaptation.

MacLeod et al. (2013) used Social Identity Theory and Interpretative Phenomenological Analysis to explore the interplay between the ways six young people in higher education made sense of autism as a personal label or as an aspect of their identity, and the information to which they have access. MacLeod and colleagues found that the autistic young people they interviewed tended to employ generalisations and distance themselves from those with autism when describing autistic people they knew. The researchers offered the view that this may represent an act of agency or self-determination around construction of the self, or a strategy to distance oneself from a disordered identity. At the same time, participants were eager to learn or connect with other autistic experiences, and recognised autism as an integral part of the self, or what they termed an autism identity. The young people identified how others viewed them as different, but they did not particularly focus on a sense of feeling different themselves. All but one of the participants had received a relatively recent diagnosis by which one might assume they received diagnosis during adolescence. For most, diagnosis was constructed as a turning point, enabling a growth in self-awareness and more understanding from others. Whilst challenges were acknowledged most participants were accepting of and positive about their autism diagnosis, although the authors note that as university students all had to have achieved a level of resilience and coping to get to this stage in their education. Participants made clear that the descriptors of autism that dominate the professional literature and research do not reflect their personal experiences, rather first-person accounts from autistic people provided a more nuanced and recognisable social text with which they could identify. Despite providing helpful insights into the way autistic young people negotiated social identities, the study lacked enough detail around ethics and methodology to be replicable.

Mogensen & Mason (2015) adopted an ethnographic approach to explore diagnosis and identity with five young people, aged between 13 and 19. Participants shared their views through a preferred communication option including interviews, drawings, photos, communication cards and e-mails. Thematic Analysis using an interpretative

framework facilitated exploration of themes developed from the data. Not fitting in and feeling different was commonly reported, although for some this resulted in seeing diagnosis as oppressive to a sense of self, whilst others were able to reframe their differences through the autism diagnosis, gaining a sense of liberation and control. Some fully accepted autism as a core part of their self-concept, using it as a lens through which to understand the self, whilst others communicated it was not an important aspect of their identity. The young people in this research were cognisant of society's deficit view of autism, a view which they rejected and asserted needed change. Social contexts and how they impacted on social identity were explored by the participants who found that the extent to which they felt different or felt 'normal' could be reliant on the social expectations and setting they were in. One participant explored a new sense of feeling "normal" (p. 264) after leaving school and being in an inclusive church and workplace, whilst another recalled the way that interventions she was subjected to (PECS) made her feel patronised and removed her agency. This research pointed towards the significance of environmental factors which can marginalise autistic young people and heighten their sense of stigma and difference, or can promote acceptance and a sense of belonging as they seek to construct identities in social spaces. The implications for practice pointed towards a need for social policies that minimised stigmatisation and opened up avenues for control, but it stopped short of providing concrete examples of what this might look like.

### *2.22 Exploring how life with autism impacts concepts around self*

A mixed methods study by Berkovits et al. (2020) involving 38 autistic 15 year olds aimed to explore perceptions of living with autism, including how this impacted self-concept. They conducted thematic analysis on interviews which were then coded into negative, positive or neutral statements by the researchers. They found that on average, adolescents reported more negative statements about their diagnosis of autism than positive. However, one of the quotes selected and categorised as negative by the researchers, under 'symptoms and co-morbidities' appears to be a reflection of the assumptions of the researchers, rather than the young person: "I sometimes talk to myself and make weird sounds. I sometimes repeat things other people say. And it just, it naturally makes me feel good" (p. 837). It may be that the question this was in response to marks this out as a negative response (this is not immediately obvious from the paper) but it is of note how the young person states it makes them 'feel

good'. It is not clear as a reader that the young person sees this a negative impact at all. In the conclusions to their research Berkovits and colleagues conclude that "adolescents with ASD may have more accurate insight into their diagnosis than previously understood" (p. 843) due to the fact that their descriptions of their own lived experiences matched up to clinical depictions of autism. This statement implies that clinical definitions represent the 'truth' of what autism means, whereas autistic people's own insights into their experiences can potentially be inaccurate. This illustrates the way in which research can inadvertently centre around neuro-normative values and de-centre the people it seeks to represent.

In a study by Cage et al. (2016) 12 autistic adolescents (including one female) aged between 12 and 15 years were interviewed to explore their reputation concerns. One of the findings put forward was that more than half were more concerned with staying true to themselves, rather than "being cool" (p. 12). This was reported as a deviation from what research with non-autistic adolescents had found and was a way in which the researchers felt that their participants differed from neurotypical teens. The benefits of such an identity construction were not considered by the researchers. For example, adolescents with a strong personal identity show particular resistance against peer conformity, buffering the effects of peer group pressure (Dumas et al., 2012). Rather than explore such benefits, the research retained a focus on the ways in which autistic teens either conformed or deviated from the expectation that adolescents are typically concerned with 'being cool'. At times, conjectures put forward by the researchers highlighted this focus more acutely, for example "reputation specifically amongst friends may be of great importance, even for\* adolescents with autism" (p. 14), and "it is plausible\* that autistic individuals would be to some degree\* concerned about what others think of them" (p.13) (\*my underlining). It might be suggested that language such as this 'others' autistic young people even where the explicit intent of the researchers is to support autistic people to have their voices heard.

A study by Cridland et al. (2015) used a Personal Construct Theory (PCT) approach to understand the experiences of eight autistic teenage boys and their families. Exploring identity was one facet of their study and focussed on both how the boys described the self, and how they felt autism impacted on their identity. They found that the boys

described feeling different or unique. For some this was classed as positive, and they felt autism defined their personalities in some way. For others, they were not sure how autism impacted them, and they construed themselves as misunderstood and isolated. Whilst this was the first time the researcher had come across participants being directly asked how they felt autism impacted their identity, which would seem a strength of the study, there were some weaknesses. It was not clear whether PCT methodologies had been employed in the interviews and it seemed unusual to include other family members when employing a PCT approach to understand the experiences of autistic boys, as the family members would be necessarily accessing their own construing. Furthermore, the researchers chose to analyse the whole data corpus together, mixing the data from the boys talk with the talk of family members. This was despite the title of the paper being *“The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology perspective”* (p. 354). The research may have been strengthened by aligning the methodology with the approach, so that the construing of the boys was central to the research, rather than decentring them by including family members views.

A number of studies focussed upon the experiences of autistic adolescents in mainstream schools, from which themes around self-concept and social identity were identified. McLaughlin & Rafferty (2014) sought to centre around the lived experience of autistic adolescents in their analysis of interviews with six young people (male and female) who attended mainstream schools, through asking the question “What is life like for you?” (p. 63). Using Thematic Analysis to explore the data they were explicit in their intention to avoid clustering themes around diagnostic criteria (a tendency they noted from their literature review. The young people in McLaughlin & Rafferty’s study gave accounts of feeling they had lost out in various ways due to Asperger’s, including exploration of how Asperger’s had impacted their past behaviour and their future paths. Participants talked about not fitting in, and a desire to appear “normal” (p. 68) by having teachers treat them like their peers. There was talk around feeling isolated and a desire to be accepted by their peers, although not all of the young people thought their peers knew, or even wanted them to know about their diagnosis. The researchers put forward the view that schools need to be cognisant of autistic youths “potential quest for normalcy” (p. 71) and for a concern around the stigmatising effect

of labels, perhaps in response to themes that often centred around the young people's sense of isolation and othering from their mainstream peers. They put forward the need to advocate for the voice of autistic young people to be represented in school through a suitable forum, without making assumptions about their desire to be involved. Whilst the open ended nature of the research methodology enabled insights that might otherwise have been constricted by a tight structure, the replicability of the research is negatively impacted by the lack of detail in the adopted methodology.

Humphrey & Lewis (2008) explored the experiences of 20 autistic pupils aged between 11 and 17 in mainstream secondary schools. Using Interpretative Phenomenological Analysis (IPA) they explored the phenomena of attending mainstream school as an autistic person. One of the themes they developed from pupil interviews, diary entries and drawings was around how young people constructed autism and how some integrated this into their identity, viewing autism as simply part of who they are. These pupils had accepted and were able to celebrate autism as part of a positive identity. For others, autism meant that they were "not normal" (p. 30) although they wished that they were. Another theme was around negotiating difference and was concerned with how pupils attempt to assimilate themselves into the school social environment and a "desire to fit-in" (p. 40). There was exploration around how perceived 'normal' or 'abnormal' behaviour impacted assimilation, with pupils forced to adapt themselves in order to fit in, and thus "compromise their identities" (Humphrey & Lewis, 2008, p.40). There was recognition for some that they experienced isolation, stigma and bullying and yet recognition that where peers were supported to understand autism, tolerance and inclusion was possible.

Both Humphrey & Lewis (2008) and McLaughlin & Rafferty's papers (2014) were included in Williams et al. (2019) metasynthesis of qualitative research into how the experiences of autistic children and youth in mainstream schools contribute to their sense-making around the self. They identified three linked aspects of experience which intermesh and contribute to many autistic pupils positioning themselves as 'different' to typical peers in a negative way, including difficulties linked to autism, relationships (particularly with peers) and accessibility of the school environment. 'Fitting in' (or not) was a thread that linked many different themes found in the literature including attempts at "passing as normal" (p.17), bullying and isolation, and how friendships

could positively counterbalance a sense of being different. Some young people felt that autism limited the path they could follow, but some accepted autism as a positive part of their identity. Engagement in social comparisons often resulted in negative self evaluations apart from where autistic participants compared themselves to peers with “more severe” autism (p. 18), or when they compared themselves with non-autistic peers in relation to a particular skill or ability they held. This paper summarised that mainstream settings may currently accentuate many autistic students sense of being different from non-autistic peers in a negative way, with engagements with peers and sense-making about themselves in this context potentially playing a particularly powerful role in shaping self-understanding. They found that the majority of papers “represented largely the voice of verbally and cognitively able, male pupils in mainstream secondary schools in Western societies” (p. 11). The experiences of females, were amongst a number of other groups of autistic experience that are largely missing from the literature (for example non-Western / pre-verbal pupils). They conclude that more research about individual sense-making about the self in autistic young people is needed, alongside methodologies that support young people to more easily share their experiences than the straight forward semi-structured interview schedule.

### *2.23 Exploring identity constructions for autistic pupils attending specialist settings*

Stevenson et al. (2016) explored the use of a multi-media project with eight autistic young people (four male, four female) in key stage 4 and 5, in a specialist school setting. The psycho-educational intervention sought to support young people in reflecting what autism meant for them personally, including around issues of identity, through the creation of podcasts, videos and through interviews conducted by the young people themselves. This participatory research approach supported the young people to explore their own identities in relation to autism as they talked together and with others about it. The research employed Thematic Analysis to identify patterns in the way that the young people explored their experiences. Being different was a major focus for the young people, with exploration of how being treated differently by others fed into their own self-concept in both negative and positive ways. Some talk focused on a medicalised and neurological view of autism (and the self). Some students had come to accept their diagnosis, viewing it as a positive aspect of the self, sharing how autism made them unique and was something they valued that made them the person

they are, whilst others felt that autism was something to deal with, that should not define the self. A theme around independence and hopes and fears for the future self were apparent in the oldest participant's talk. The project supported the students to reflect on the discourses around autism and the very concept of 'normality' as together they explored the challenges, but also the benefits of neurodiversity. Despite the research aim being for participants to explore the meaning of autism for them Stevenson et al. (2016) include data excerpts from interviews with non-autistic adults that might be viewed as deficit focussed and potentially stigmatising, including a quote from a paediatrician who described autistic people's brains as "some of the connections inside it aren't working maybe quite as well as they could" (p. 218). One autistic student then went on to discuss their concern: "I don't get it. So now I'm thinking my brain is not developed properly. Does it mean my brain? The wires in my brain are not connected? That's what, I'm confused now." (p. 220). There was no comment made within the research about the potential negative impact the project may have had on the young people's self-concepts by inviting a medical discourse into the conversation however they did conclude that professionals should be aware of the impact of the information they share about an autism diagnosis on self-conceptions of those thus diagnosed.

King et al. (2019) used photo-elicitation and semi structured interviews to explore the self-understandings of five autistic boys aged between 13 and 15 who attended a specialist school. Using Interpretative Phenomenological Analysis, they developed a number of themes from the boys' talk that were focussed around constructions of self-hood. There was a tendency toward constructing the self around interests and activities, either individually or in relationship with others, such as shared activities with a parent or friend. Participants were able to draw meaning about self from these activities. A self in relation to others was also constructed which involved identifying with or feeling different to others. In this paper, difference was something that was constructed as positive by participants, with a focus on their uniqueness and by using social comparisons that focussed on their personal strengths. There was recognition that attending a specialist school precluded the bullying that could occur for being different in a mainstream setting. A third super-ordinate theme around the self across time was constructed which was concerned with the boys' constructions of their past

selves, the ways they had changed and the future self they were aiming towards. Whilst the small sample size and methodology limits the generalisability of the findings (as is always the case with IPA) this research highlights how different methodological approaches that are more person centred around participant needs, can elicit rich and descriptive accounts. King and colleagues reflected that the use of photographs enabled elicitation of aspects of self that other research had questioned was possible with autistic people.

The use of social comparisons in autistic young people aged 16-21 who attended a specialist college were explored by Huws & Jones (2015) through Interpretative Phenomenological Analysis. Nine young people (three of whom were female) were asked to talk about their perceptions of autism in interviews and all used social comparisons in their talk. Participants expressed the view that they had changed over time and were now more independent and sociable than their past selves. Similar to Jones et al., (2015) participants constructed autism as a broad spectrum, enabling downward social comparisons as they described those with autism they perceived as worse than themselves. Participants also used downward social comparisons with non-autistic peers who they perceived lacked some of the special abilities they had as an autistic person. Some participants made unfavourable comparisons of themselves against non-autistic peers, resulting in a feeling of difference and a sense that one's future life choices were limited by autism. Some felt that autism was a core part of their identity. Comparisons with disabled people also formed a key feature of talk with participants cognisant that autism provided some extra challenge, but not so much as those who were physically disabled (also found by Jones et al., 2015). In their discussion Huws & Jones note that those who "collude with the disrespecting of other people with autism may reinforce the development of unrealistic self-concept and self-esteem levels" (p.89). Whilst the authors give some consideration about the impact of such talk, their reference to 'unrealistic' self-concept reveals an assumption that there is some external truth about an autistic person's qualities and abilities extrinsic to themselves (that is somehow judgable by others), and at the same time ignores the wider deleterious impact of talking about autism in terms of 'worse' or 'better' in ways that sustains discourses of deficit. The authors may have therefore missed an

opportunity to connect with the way in which participants' social comparisons rely upon discourses of deficit that are produced and circulated in society.

The research explored so far has used TA or IPA to explore the themes that come out of young people's talk around the self and autism, resulting in a number of common thematic patterns. These include feeling/being different (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; King et al., 2019; Mogensen & Mason, 2015; Stevenson et al., 2016), fitting in or 'acting normal' (Humphrey & Lewis, 2008; McLaughlin & Rafferty, 2014; Mogensen & Mason, 2015; Stevenson et al., 2016), judgement or unfair treatment from others impacting on sense of self (Gaffney, 2020; J. L. Jones et al., 2015; King et al., 2019; McLaughlin & Rafferty, 2014; Stevenson et al., 2016), acceptance of autism as a part of the self/ an autism identity (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; J. L. Jones et al., 2015; King et al., 2019; A. MacLeod et al., 2013; Mogensen & Mason, 2015; Stevenson et al., 2016), autism enabling sense making of the past self/behaviours (Gaffney, 2020; J. L. Jones et al., 2015; King et al., 2019; A. MacLeod et al., 2013; McLaughlin & Rafferty, 2014; Mogensen & Mason, 2015), looking forwards/making plans for a future self (Gaffney, 2020; King et al., 2019; McLaughlin & Rafferty, 2014; Stevenson et al., 2016) and distancing oneself from a disabled identity (Huws & Jones, 2015; J. L. Jones et al., 2015). The studies all have in common a focus on the individual sense making that come out of autistic young people's lived experiences. In this sense it could be said that they take a 'micro' view focussed around individual perspectives and experiences. One study in this review that took a more 'macro' perspective to the subject matter was by Baines (2012).

#### *2.24 Taking a wider view to explore sense making around identities of autistic adolescents*

Using an ethnographic Grounded Theory methodology Baines (2012) applied Positioning Theory (Harré, 2003) to two case studies of adolescent boys attending mainstream high schools in the US, one of whom was diagnosed in adolescence. They met with the boys across two years in different contexts to explore how their interactions with other people shaped their sense making around self. The study explored how their access to rights and opportunities of being and doing were shaped by their positioning in different contexts – both in formal and informal settings, such as

debate club, school and the home. They posit that both boys compartmentalised their disability in an attempt to “pass as normal” (p. 548) in educational contexts, so that they could be respected by others on their own terms through an active process of distancing themselves from autism. They did this in an attempt to belong and fit in, with one participant enacting this through positioning himself as a “recovering autistic” (p. 550). At home however, he allowed himself to “close the door to the den and jump and flap his arms to Souza marches for 15 minutes” (p.551). For the other participant, the researchers note a different relationship with autism due to his diagnosis at age 13 and observed that context determined whether his participation was valued, for what might be valued in debate was often viewed as disruptive in school. In debate or in the Young Marines Club, he was not seen as disabled, but as someone with valued expertise. The study illuminated how social context impacts and shapes the construction of identity in two autistic adolescent males. It was however unclear how the researchers had analysed the data which impacts replicability to some extent. Access to a larger gender mixed sample may have enabled consideration of how some autistic young people align themselves with a storyline of autism, rather than distance themselves as these two males did, and what ways of being and doing are made possible or denied from this.

### *2.25 Identifying gaps in the published literature*

The literature surveyed has used a range of qualitative methodologies in order to explore the experiences and views of autistic young people, including ways they view the self in relation to autism. A range of themes have been offered by researchers that highlighted the complexities of living as an autistic adolescent, with both positive and negative outcomes. They all focussed, at least in part, upon the phenomena of being autistic and how sense making around the self occurs in specific contexts. What is largely missing from the literature is a focus upon those diagnosed during the period of adolescence itself, although some studies contain young people diagnosed during adolescence, none were found that exclusively involve those diagnosed in adolescence, apart from an unpublished doctoral thesis (Craig, 2015). If 28% of autistic children in the UK are diagnosed with autism after starting secondary school (as in Hosozawa et al., 2020) then large numbers of adolescents are going through the diagnostic process at a key stage in their identity formation (Erikson, 1968, Sebastian et al., 2008). Research tells us that adolescence is a time where consciousness and

concern with the opinions of others intensifies (Parker et al., 2006; Vartanian, 2000) and that adolescents are more likely to place higher value on others' judgements (Sebastian et al., 2008). Furthermore, we know that one of the concerns of autistic adolescents is in relation to the stigma the label holds (Berkovits et al., 2020; Craig, 2015; J. L. Jones et al., 2015; Mogensen & Mason, 2015). If constructions of the self and one's social identity are dynamically co-constructed through interactions with the social world (Burr, 2003), then the act of the diagnostic process, which is in essence a discursive act, is likely to significantly impact on an individual's understanding of self. We know that diagnosis of a range of 'conditions' (including autism) during adolescence can prompt a reconsideration of self and identity (O'Connor et al., 2018). Therefore, exploration of adolescents' constructs following diagnosis in this key time of self-concept development would seem to be an area that warrants further exploration, particularly in light of the literature review which suggests that some autistic young people view autism as a core part of self (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015).

A further gap in the literature surveyed was in relation to a lack of female participants across the studies. Only Gaffney (2020) limited her research to girls, with all others either predominately or entirely made up of male participants. This lack of focus on the experience of girls is not new in autism research (Lai et al., 2015) but it potentially further contributes towards the disproportionate risk of girls not receiving a clinical diagnosis (Loomes et al., 2017) as professionals may have less understanding of the way autism presents in girls. When one considers some of the inequitable mental health outcomes for autistic girls, including higher levels of anxiety and depressive symptoms, as compared with both autistic boys and non-autistic girls (Oswald et al., 2016; Solomon et al., 2012), then one begins to appreciate why more research and support for autistic girls is important. Furthermore, if the development of a positive autism social identity is linked with fewer mental health difficulties (Cooper et al., 2017) and if adult women report that an autism diagnosis supported the development of a more positive sense of self (Bargiela et al., 2016), then specific research into the way autistic girls diagnosed in adolescence construct their sense of self seems a pertinent area of study.

Further to this, although the literature is sometimes cognisant of the impact of talking about autism in ways that potentially negatively impact constructions of the self, all but Baines (2012) used methodologies that support exploration of individual experience and phenomena, rather than taking a step back to look at the wider societal discourses around autism that impact on individual sense-making. If, as Bagatell (2004) posits, the identities of autistic people are not an underlying substance to be discovered, but constructed in social worlds, then study of the discursive social world may provide useful and unexplored insights which the existent published literature does not currently do. Furthermore, no studies have been found by the researcher which use Discourse Analysis to explore self or identity construction by autistic adolescents.

#### *2.26 DA studies exploring self or identity in autistic people*

Following a search on PsycInfo using the terms “autism OR Asperger’s OR Autism Spectrum Disorder” and “self-concept or social identity or identity or group identity or identity formation” and “Discourse Analysis” only one peer reviewed study was identified that used DA to explore self or identity construction by autistic people. Brownlow & O’dell (2006) conducted a DA on online conversations focussing on autistic identity that took place on an internet chat forum for autistic adults. They presented two themes from the data, one which challenged the ‘expert’ status of professionals involved in research around autism and asserted that autistic people themselves are the true experts. A distinction is claimed between scientific and experiential knowledge, with the latter being discursively claimed as superior. A second theme around labelling of a group of ‘AS’ (Asperger’s / Autism) versus ‘NT’ (neurotypical) and the properties assigned to each social grouping was identified. Difference between the groups was constructed by the participants as neurologically based, with the ‘AS’ group often constructed as superior to ‘NTs’. A diagnostic label was something that members regarded as positive and there was a clear rejection of the centring of neurotypical behaviours. The study was limited by the decision to not make clear what analytic steps were taken to arrive at the themes assigned.

#### 2.3 The research question

The research that follows in part 2 has been developed to explore the constructions of self-concept and social identity of autistic girls who received a diagnosis in

adolescence. Discourse Analysis has been selected as a methodology in order to support a macro level engagement with the constructions produced, rather than a phenomenological micro exploration which has already been explored by previous research. It is hoped that this approach will enable consideration of the impacts of the use of dominant discourses in relation to autism, and the way that adolescent autistic girls take up these repertoires in their talk. The research question to be addressed is:

- How do adolescent girls, diagnosed with autism in adolescence, construct their self-concepts and social identities?

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Part 2: An Empirical Study



*“I feel that I have learnt to accept myself ... but I don’t think the world is ready to be understanding & supportive”:*

A Foucauldian Discourse Analysis of Adolescent Autistic Girls’  
Constructions of their Self-concept and Social Identity.

Word count: 10,596

## Abstract

This study explores the discourses taken up by autistic female adolescents in their constructions of self-concepts and social identities following a diagnosis of autism. A recent study with a nationally representative population-based cohort in the UK found that 28% of autistic children were diagnosed with autism after starting secondary school (Hosozawa et al., 2020). For an adolescent population, diagnosis comes at a stage where self-concept and social identity are thought to be the main developmental tasks (Erikson, 1968).

A review of the literature suggests that there are range of discourses about autism that are in use in society (Runswick-Cole, 2014) .This study uses Foucauldian Discourse Analysis methodology to explore the discourses that are employed by participants in their talk about self-concept and social identity. It focusses upon the actions that are made possible through the discourses employed, and the implications for Educational Psychologists in supporting this population of young people.

Ten young people took part through interviews or written journals. Three discourses are presented which participants draw upon in their constructions of self-concept and social identity: a diagnostic discourse, an individualistic discourse and a normativity discourse. These discourses were used to construct the self as autistic, as a person with support needs, as a unique individual, as a person in the process of becoming, and feeling safe enough to be 'me'. Social identities based around constructs of fitting in and sticking out were identified.

## 1. Introduction

### 1.1 Autism and girls

Autism is a clinical diagnosis given to people where there is evidence of a range of behaviours that meet criteria set out in DSM V (American Psychiatric Association, 2013) and ICD-11 (World Health Organization, 2018), including persistent difficulties with social communication and social interaction, and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). In the UK the age at which females are diagnosed with autism has been found to be significantly later than males (Brett et al., 2016), with nine years posited as the mean age girls with Asperger's Syndrome received a diagnosis, though many are not diagnosed until they enter adolescence (Begeer et al., 2013). Girls have been found to be at a disproportionate risk of not receiving a clinical diagnosis at all (Loomes et al., 2017).

The under-representation of females being diagnosed may in part be due to clinical expectations and by the gender-biased standardized instruments used. It has been suggested that the relatively stronger play, communication, social imitation and attentional strengths of girls can obscure social difficulties that girls are experiencing and thus contribute to missed and late diagnoses (Cridland, Jones, et al., 2014). Compared with autistic males, autistic girls are also less likely to have externalising behaviours which raise concerns by teachers, such as hyperactivity, impulsivity and conduct problems, but have been found to be more vulnerable to internalising behaviours such as anxiety, depression and eating disorders (Huke et al., 2013; Ruiz Calzada et al., 2012; Solomon et al., 2012).

Bargiela and colleagues presented accounts from autistic women diagnosed in late adolescence or early adulthood in which they described experiences of "pretending to be normal" (Bargiela et al., 2016, p.3821) and making a deliberate effort to use what they perceived as "neurotypical personas" (Bargiela et al., 2016, p. 3290). Autistic females who engage in behaviours that seek to hide their autistic traits to fit in suffer significantly higher levels of psychological distress (Beck et al., 2020). Livingston & Happé (2017) refer to compensation strategies, as the "observed mismatch between behaviour and underlying cognition in a neurodevelopmental disorder" (p. 729) and found they lead to poorer mental health outcomes alongside later diagnosis (Livingston et al., 2019).

Late diagnosis of autism is credited for a range of deleterious impacts such as being labelled (pre-diagnosis) in very negative terms by peers and adults, concerns around sexual exploitation and mental health difficulties (Bargiela et al., 2016). Similarly, Portway & Johnson (2005) found that autistic adults and their parents described late diagnosis resulting in experiences of frequently being misunderstood, alongside misunderstanding others, bullying, isolation and loneliness.

### 1.2 Diagnosis in adolescence and the impact on self-concept and social identity

Self-concept and identity formation is believed to be one of the main psychological tasks of adolescence (Erikson, 1968) with research indicating that adolescence is a key time for changes in neural activity associated with self-concept (Sebastian et al., 2008). Self-concept has been defined as "The individual's belief about himself or herself, including the person's attributes and who and what the self is" (Baumeister, 1999, P.13). Social identity is defined as the portion of the self-concept that derives from membership of social groups, together with the emotional significance attached to it (Duszak, 2002; Tajfel, 1981).

Diagnosis of a range of 'conditions' (including autism) in adolescence has been found to present important implications for young peoples' developing self-concept and social identity (O'Connor et al., 2018). Benefits around self-legitimation, with young people reporting feeling validated by their diagnosis, alongside self-enhancement and increased self-understanding are posited. However, O'Connor and colleagues also identified risks, with diagnosis prompting a reconsideration of identity, or negative impacts upon self-esteem. For some young people, their diagnosis represented the defining aspect of their self-concept. Benefits from diagnosis for social identity included acceptance and social identification with others with the same diagnosis, but potential disbenefits included stigmatisation, social alienation and social invalidation due to low awareness in their social circle or society more generally (O'Connor et al., 2018).

Erikson (1968) postulated that the way society labels an individual, alongside self and others' perceptions contribute to identity formation. Research has shown how young people adjust their identity in response to a diagnosis of autism, and for some it forms a core part of their sense of self (Huws & Jones, 2008; Molloy & Vasil, 2004). Molloy &

Vasil (2004) propose that autism provides a sense making narrative through which autistic young people and their families come to view and understand their experiences. Diagnosis during this key stage is therefore likely to impact significantly on the construction of identities as young people are tasked with making sense of a diagnostic label as well as of the self. Whilst diagnosis can aid sense making of past experiences and difficulties, some report struggling with the weight of a diagnostic label (Gaffney, 2020).

Berkovits et al. (2020) found that around half of the autistic adolescent participants they interviewed talked about the stigma of having a diagnosis of autism. Autistic adolescents face the challenge of developing and maintaining a positive sense of self despite their membership in a stigmatized group (K. Cooper et al., 2017). If peer groups are indeed a vehicle through which concepts of identity and self-esteem are negotiated (Erikson, 1968; Newman and Newman, 1975), there may be implications for autistic girls in particular who report that developing and maintaining friendships becomes more complex and difficult to achieve in adolescence (Tierney et al., 2016).

Diagnosis also has the potential to support a positive autism social identity. Participants with a diagnosis of Asperger's Syndrome identify with a sense of belonging with a like-minded 'aspie' community (Chambers et al., 2019; Smith & Jones, 2020). Whilst autistic adults report generally poorer mental health than non-autistic controls, those with a positive autism social identity report fewer mental health difficulties (Cooper et al., 2017). That is, having a positive autism social identity was negatively correlated with anxiety and depression. Similarly, when diagnosis eventually happened for the young autistic women in Bargiela et al.'s (2016) research, most reported it as helpful, with some describing the sense of belonging they experienced with other autistic people, resulting in a more positive sense of self.

### 1.3 Reviewing the research around constructions of self in autistic adolescents

A search of the literature via PsycInfo, ASSIA, SCOPUS and Medline databases (see Appendix A) revealed 14 peer reviewed studies which qualitatively explore the self-concept and social identities of autistic adolescents. Most studies involved either exclusively or predominantly male participant groups, apart from Gaffney (2020) who limited their study to exploring the experiences of girls only.

The research revealed that autistic adolescents frequently report feeling and being marked out as essentially different from their neuro-typical peer group (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; King et al., 2019; Mogensen & Mason, 2015; Stevenson et al., 2016). Some young people dealt with this by distancing themselves from a disabled identity and from other autistic people who they felt who were somehow 'more autistic' than they were (Huws & Jones, 2015; Jones et al., 2015). However, difference was not always reported as a negative experience, and in some studies with autistic young people attending specialist settings they report feeling superior to non-autists who do not have the benefits associated with autism, such as superior levels of subject knowledge and the ability to focus intently on an area of interest (Huws & Jones, 2015; King et al., 2019; Stevenson et al., 2016).

As with research in the adult autistic community (Bargiela et al., 2016) research with adolescent autists reveals a common experience of experiencing either desire or pressure to 'fit in', which often results in acting or pretending to be 'normal' around non-autistic peers (Baines, 2012; Humphrey & Lewis, 2008; McLaughlin & Rafferty, 2014; Mogensen & Mason, 2015; Stevenson et al., 2016). Often young people report experiencing judgement or unfair treatment from others, which participants report impacts on their sense of self (Gaffney, 2020; J. L. Jones et al., 2015; King et al., 2019; McLaughlin & Rafferty, 2014; Stevenson et al., 2016).

However, acceptance of autism as a part of the self or the presence of an autism (social) identity is also very common amongst the young people represented in the studies (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; J. L. Jones et al., 2015; King et al., 2019; A. MacLeod et al., 2013; Mogensen & Mason, 2015; Stevenson et al., 2016). Young people report that their diagnosis of autism enables better sense making of their past selves, so that they can better understand behaviours that had previously been framed by others as naughty, bad or weird (Gaffney, 2020; J. L. Jones et al., 2015; King et al., 2019; A. MacLeod et al., 2013; McLaughlin & Rafferty, 2014; Mogensen & Mason, 2015).

Looking forwards and making plans towards the development of a future self was a feature of young peoples' talk, with the presence of both concern about how autism would constrict their future self, and a preponderance upon how autism might impact

achievement of their own personal goals and aspirations (Gaffney, 2020; King et al., 2019; McLaughlin & Rafferty, 2014; Stevenson et al., 2016).

#### 1.4 Social constructionism and a macro view

Most of the studies used Interpretative Phenomenological Analysis (IPA) or Thematic Analysis (TA) in order to focus on the individual sense making from autistic young people's lived experiences. In this sense they take a 'micro' view focussed around individual perspectives and experiences, and go some way to exploring how autistic young people make sense of the self in the contexts of their social environments. However, if one takes a social constructionist view and agrees with Burr (2003) that "the way a person thinks, the very categories and concepts that provide a framework of meaning for them, are provided by the language that they use" (p.8) then a wider lens than the one enabled by IPA or TA might provide further insight.

Baines (2012) took a more 'macro' perspective to explore how autistic adolescents construct self by using Positioning Theory (Harré, 2003). They used an ethnographic methodology to explore the linguistic storylines of two adolescent autistic males used to negotiate their identities. They reported that the young men in their study compartmentalised their disability in an attempt to "pass as normal" (p. 548) in educational contexts, so that they could be respected by others on their own terms. They were seen to distance themselves from a storyline of autism in an attempt to belong and fit in.

If, as Bagatell (2004) posits, the identities of autistic people are not an underlying substance to be discovered, but constructed in social worlds, then study of discourse may provide useful and unexplored insights which the existent published literature does not currently do. Exploring how this plays out in the language autistic people use to describe the self may provide new ways to understand how to create more supportive spaces for autistic people.

#### 1.5 Discourse and power

Foucault (1979) argued that discourse reveals a great deal about how power operates in society, and about who is able to act and have agency or access to certain ways of speaking or being. Discourses have been defined as "a set of meanings, metaphors, representations, stories, statements and so on that in some way together produce a

particular version of events” (Burr, 2003, p.64). The more a discourse appears to reflect common sense in the historical and cultural context in which it is situated the more powerful it is, and the more likely it is to be constructed as knowledge (Burr, 2003). In this way Foucault asserts that knowledge is bound up with power. This is because what follows from use of a certain discourse can limit or marginalise certain ways of acting, setting out what is permissible or acceptable, and what is illegitimate and othered (Foucault, 1979). For Foucault, it is not people that are powerful, but discourses which people can use, that enable people to do the things they want to do (Burr, 2003).

No studies have been found by the researcher which use Discourse Analysis (DA) to explore self or identity construction by autistic adolescents themselves. One study was identified that used DA to explore the self-constructs of autistic adults. Brownlow & O’Dell (2006) conducted a DA on online conversations focussing on autistic identity that took place on an internet chat forum for autistic adults. They presented two themes from the data, one which challenged the ‘expert’ status of professionals involved in research around autism and asserted that autistic people themselves are the true experts. A distinction is claimed between ‘scientific’ and ‘experiential’ knowledge, with the latter, that knowledge held by the participants themselves, being discursively claimed as superior to that held by ‘so-called autism experts’. A second theme was identified around the labelling of social groups of ‘AS’ (Asperger’s / Autism) and ‘NT’ (neurotypical). Differences were constructed between the groups as being neurologically based, with the ‘AS’ group often constructed as neurologically superior to ‘NT’s’. A diagnostic label was something that members constructed as positive and there was a clear rejection of the centring of neurotypical behaviours through the discourses that were employed.

Whilst Brownlow & O’Dell’s (2006) research used DA to develop themes it did not take this further and apply some of the concepts proposed by Foucault around power and discourse. Applying a Foucauldian approach presents the opportunity to explore the way power is operating through the discourse, and to explore what ways of being and doing are opened up or closed down.

## 1.6 The current study and research question

This study takes a Foucauldian approach to the analysis of adolescent girls' discourse when discussing their self-concept and social identity in the context of receiving a diagnosis of autism in adolescence. The research aims are to identify the ways in which self-concept and social identity are constructed through the language that young people use, and to explore how individuals are positioned by the discourses they employ. The research question to be addressed is:

- How do adolescent girls, diagnosed with autism in adolescence, construct their self-concepts and social identities?

## 2. Method

### 2.1 Participants

Girls between the ages of 11 and 19 who had received a clinical diagnosis of autism during adolescence were invited to take part in this study. A total of 10 young people, with ages ranging from 14 to 19, opted to take part, six through writing blog/journal entries and four through a semi-structured interview (for a discussion on sample size refer to the critical appraisal in Part 3), with the interview option introduced as an additional participation method part way through data collection (see part 3).

Participants needed to have received a clinical diagnosis of autism at least six months before the point of data collection to ensure they had been able to reflect on their diagnosis over a sufficient time-period.

As regards other participant characteristics, these did not form part of the exclusion criteria as they were not deemed to be relevant due to the nature of Discourse Analysis, which does not treat the individual as the principal unit of analysis, but rather examines the phenomena at a macro-sociological level (Talja, 1999; Willig, 2001). Discourse, as opposed to individuals, is the object of study (Potter & Wetherall, 1987). Willig (2001) posits that providing participant data such as level of education, ethnicity or social class "suggests that particular social categories capture the essence of people placed within them" (Willig, 2001, p. 97) and that in doing so the researcher constructs the identities of those taking part. For example, stating that a specific number of participants identified with a particular ethnicity frames the participants as not only autistic adolescent girls (all three of which are essential identifiers in order to identify

the participant group), but then also imposes a racial identity label. Willig goes on to explain that “Discourse analysis is about exploring the ways in which social reality is constructed within particular contexts through language; an imposition of social categories at the outset is not helpful” (Willig, 2001, p. 97). That is not to say that other identifiers are not relevant in the everyday lives of the participants, or that those aspects do not intersect with constructed identities, rather that it is not what is being currently explored, and that the imposition of identity labels is unhelpful to the analysis.

Six of the participants that took part lived in the UK, three lived in the US, and one lived in Canada. It might be argued that as knowledge is culturally and historically constructed (Burr, 2001) that the discursive knowledges available to the participants might differ across national contexts. Indeed, Lee & Zhu (2020) in their research with two Asian mothers who had emigrated to Canada, argue that autism diagnoses are socio-culturally constructed and dependent on the constructions within the specific culture in which the diagnosis is, or is not, given.

It is argued that the way autism is represented in the news press has a major impact on public understanding (Yu & Farrell, 2020). Research in the way autism is constructed in national newspaper articles in the UK, Canada and the United States can provide some indication of the similarities and differences in public discourse in each of these nations.

Wolbring & Mosig (2017) in their analysis of the Canadian national press over a twenty year period (1985-2005) found that articles about autism were dominated by medicalised and negative framings. Billawalla & Wolbring (2014) found a similar dominance of both deficit and medicalised discourses in the US which dominated articles appearing between 1973 and 2012 in *The New York Times*. Lewin & Akhtar (2021) similarly found a dominance of deficit discourses in the Washington Post between 2007 to 2016, including medicalised views focussed on causes. In the UK, Huws & Jones, (2011) explored discourses around autism in British national newspapers, between 1999 and 2008. They found autistic people were often framed as ‘victims’ or ‘sufferers’ of autism. Both Lewin & Akhtar (2021) in the US and Huws & Jones (2011) in the UK noted an absence of first person accounts, with a tendency to focus on parental or professional views. Clarke (2008) notes that the now retracted

research positing a link between autism and the MMR triple vaccine (Wakefield et al., 1998) fuelled a similar rise and coverage in both the US and UK press between 1998 and 2006.

Research has thus shown similarities in the way autism discourses play out in the national press of all three nations, with a tendency towards focussing upon deficit based or medicalised discourses (Billawalla & Wolbring, 2014; Huws & Jones, 2011; Wolbring & Mosig, 2017). Only five out of the 300 articles analysed in the Canadian study mentioned the benefits of autism through a neuro-diversity discourse (Wolbring & Mosig, 2017), however this may not be surprising given the time frame covered, with neurodiversity not being coined until 1998 (Singer, 1998). Unsurprisingly, Lewin & Akhtar (2021) report an increase in the levels of neuro-diversity discourse towards later years of the period covered (up to 2016). In the UK Huws & Jones (2011) found where acuities were referenced they tended to be sensationlised and over-generalised to all autistic people.

Whilst this provides a sense of how social discourses from the countries from which participants in the current study live, one must remain cognisant of the age of participants and the likely way they are accessing information about autism themselves. Research supports the view that both during and after diagnosis of autism the internet is a prime source of information that families now use to increase their knowledge (Hennel et al., 2016) and participants in this study offered the view that most of the information they knew about autism was sourced online. Brownlow & O'Dell, (2013) argue that the internet plays a key role in the production of autistic identities, and Ortega, (2013) considers online blogging to be a major identity construction setting for autistic people. Online 'autistic spaces' (Sinclair, 2010) are posited to open up opportunities for autistic people to network and create safe spaces where "people can safely explore, express, and construct their identities as individuals or as part of a group" (Seidmann, 2020, p.2).

It was therefore felt that the cultural knowledges available to adolescent participants across three Western nations were likely to be well aligned due to the proliferation of online information, and research evidence suggesting all three nations' national press represent autism in similar ways (Billawalla & Wolbring, 2014; Huws & Jones, 2011; Lewin & Akhtar, 2021; Wolbring & Mosig, 2017).

## 2.2 Recruitment procedure

Participants were recruited through a variety of methods. Recruitment leaflets were placed on various Facebook groups for parents of children and young people with autism (see appendix Bi). Additionally, letters were sent (via email) to headteachers of secondary (mainstream and specialist) schools across Wales (see appendix Bii) with a copy of the recruitment leaflet for passing on to parents. The recruitment leaflet supplied invited interested parents / carers to contact the researcher to find out further information.

Interested parents/carers who emailed the researcher were supplied with two information sheets directed at the parent / carer and young person respectively (see Appendix C and D) and requested to contact the researcher if they wanted to take part. Participants recruited after the interview option was introduced were asked to indicate whether they wanted to write a journal or participate in an online interview. At this point, participants and parents were provided with a link to an online consent form (or assent form for under 16's) (see Appendix E and F respectively). Upon receipt of consent and assent an interview date or a target date for submission of the journals was agreed.

## 2.3 Ethical considerations

Ethical approval was obtained from Cardiff University Board of Ethics prior to recruitment for this study. The following table outlines some of the ethical considerations which resulted in particular research decisions being made.

*Table 1: Ethical considerations*

<b>Ethical problem</b>	<b>The risks this introduces plus other considerations</b>	<b>Mitigating action</b>
Higher levels of depression have been found in adolescent autistic girls (Solomon et al., 2012)	The interview or writing process might cause participants some emotional distress. It was important to consider the support structures and 'gatekeeping' in place to safeguard the wellbeing of any potential participants, whilst balancing this with the empowerment of autistic young people to	Participants were recruited through parent 'gatekeepers' who were requested in the information provided to only consider passing on information about the study if they believed their daughters would not find the process distressing (see Appendix C). Assent or consent (depending on

	decide about participation in research about them (Cascio et al., 2020).	age) was then separately sought from potential participants themselves (see Appendix F), with repeated reminders that they could withdraw at any stage from the point of consent/assent up until data analysis.
Due to Covid19, interviews were conducted virtually using Zoom video conferencing software.	The researcher was less able to pro-actively monitor the emotional state of the participants during the interview process.	Participants were offered the opportunity to have a parent sit with them during the interview process in order that they would have access to emotional support should that be required.
Confidentiality issues	As participants were recruited through parents, their anonymity from parents could not be given. However, there was potential that participants could refer to aspects they wished to remain confidential from their parent. For example, in one interview a participant asked their parent to leave the room for a particular question.	Participants who completed journals were able to email them directly to the researcher where they chose to (with the permission of the parent for those under 16). To protect participants from data extracts being pieced together in a way that would identify them, participant pseudonyms have been omitted from the data tables, with all quotes presented without their pseudonyms.

#### 2.4 Ontology and epistemology

The current research is situated within a social constructionist paradigm. This approach contends that knowledge is a product of its historical and cultural context and is produced in and through the interactions and shared meaning making of social actors (Burr, 2003). A relativist epistemology acknowledges that any research claims are

subjectively produced by the researcher, who as a social actor themselves is unable to claim objectivity, and unable to access the truth of a reality that is itself shifting within the social environment that it is situated. Therefore, this research does not make claims to have uncovered universal truths that exist outside of the cultural, historical social context in which they are constructed. Even within a positivist paradigm one would be unable to do so due to the instability of concepts around identity during adolescence (Klimstra et al., 2009). However, the paradigmatic lens of the researcher further nullifies attempts to claim truth status, and therefore decisions around methodology and analysis have been made within this context.

## 2.5 Materials

Participants writing journals were supplied with a list of required headings and short examples of starter sentences to provide an indication of what type of subject content was of interest to the researcher (see Appendix G). The provision of scaffolding in what types of information were being sought draws upon the research which suggests that autistic people tend to require concrete cues in reporting self-narrative (Losh & Capps, 2003). In the interview group, a presentation was prepared so that participants had access to a visual point of reference (see Appendix I), drawing upon qualitative research with autistic young people which has shown that provision of a concrete basis for questioning and a shared point of reference between the researcher and participant is likely to result in more effective communication (Winstone et al., 2014). The interview schedule was designed around an adaptation of the personal construct tool *Drawing the Ideal Self* (Moran, 2006, 2012), a tool that has gained recognition for good research practice with gaining the views of autistic people (Milton, 2017; Moran, 2006) and very much concerned with the subject of 'self'. Research with autistic adolescents has supported the view that personal construct tools support richer elicitation of experiences and notions of identity (Cridland et al., 2014; Murphy et al., 2017).

## 2.6 Design and procedure

This study is a Foucauldian discourse analysis. Data was collected through two different methods: blog/journal entries written independently by participants and emailed to the researcher, or through a semi-structured interview conducted online. All participants and their parents (for those under 16) provided informed consent (and

assent was gained for those aged under 16) (see Appendix E and F) after receiving information sheets (one for parents, one for young people, see Appendix C and D). Participants were informed they could withdraw at any point up until data analysis.

#### *2.5.1 Blog / journal entries*

Participants who wrote blog/journal entries were provided with section headings via an instruction sheet (see Appendix G) and asked to write as much or as little as they wished, and on completion were asked to email them to the researcher. Following receipt, participants were thanked for their participation and provided with a debrief sheet (see Appendix H). The length of journal entries ranged between 507 and 797 words. Following receipt of the blogs/journals they were fully anonymised, removing names (replacing with pseudonyms) and places or any other potentially identifying features.

#### *2.5.2 Interviews*

Interviews were conducted on Zoom. One participant chose to attend the interview without parent support, and three participants chose to have a parent present. The interviews lasted between 51 minutes and 102 minutes. A power-point presentation (see Appendix I) including visual question prompts were shared on screen with the participants in the online interviews. The individual context of each interview and participant engagement dictated how the semi-structured questions were used, adjusted or elaborated upon, or in some cases omitted completely, in order to promote a two-way dialogue with which to explore key themes (Taylor & Ussher, 2001). Following the first and third interviews amendments were made (see Appendix I) to the wording of the questions in order to support better understanding for participants, based on the researchers' reflexive review of how each interview had progressed (see Appendix Iiv). At the end of the interview, the researcher read the debrief to the participant as well as emailing a copy of the debrief script for their reference.

Following the interviews, they were transcribed orthographically. Pseudonyms were used and all potentially identifying data was redacted from the interview transcripts.

#### *2.7 Data analysis*

The methodological literature around Discourse Analysis (DA) encompasses a wide range of disciplines aligned with the social sciences. Whilst there are prominent

theorists who present their own procedural steps (Parker, 1992; Potter & Wetherell, 1987, 1995; Willig, 2001) there is no consensus in the research community about agreed procedural recommendations. Rather, it has been argued that DA researchers need to develop an approach that makes sense in light of their particular study and establish a set of arguments to justify the particular approach they adopt (Phillips & Hardy, 2002, p.74). Therefore, the epistemological and ontological assumptions of the researcher, alongside the research aims, were used to sculpt an analytic process adapted from DA approaches proposed by Willig (2001) and Parker (1992), both of whom are identified as prominent FDA theorists by Pomerantz (2008). In order to ensure rigour in the use of a DA approach, the planned steps for analysis were considered against each of the six common shortfalls in DA proposed by Antaki et al. (2003) (see Appendix J). The steps taken, and the steps in Willig (2001) and Parker (1992) they are based upon, are detailed in the following table (and photographic examples shown in Appendix K). It is acknowledged that the analysis itself represents an exercise of power by the researcher in the identification and analysis of specific themes identified from the texts (Burman & Parker, 2016).

*Table 2: The Analytical Approach to Discourse Analysis Taken*

<b>Step</b>	<b>Description &amp; rationale</b>	<b>Reference to models proposed by Willig (2001) and Parker (1992)</b>
1. Preparation and initial contact with data	Read through dataset three times over. During this stage notes were taken of any impressions, connotations and implications that came to mind whilst reading. This enabled the researcher to become immersed in the data whilst tentatively keeping one eye on the macro-sociological level that the talk may be referencing (through noting any connotations / implications of the talk). See Appendix K: step 1.	This first step equates with step 2 of Parker (1992): Exploring connotations through some sort of free association. Free association is understood as “a process of exploring the connotations, allusions and implications which the texts evoke” (Parker, 1992, p.7). People’s talk often references shared cultural meanings that are not always readily apparent at the textual level and therefore this stage supports exploration at that level.
2. Identify discursive objects	Whilst the research question focusses on self-concept and social identity (these are the psychological lenses being used)	This step aligns with step 3 Parker (1992), Identifying objects: Asking which objects

	<p>social identity is a part of self-concept. Therefore the 'self' became the discursive object for analysis. All instances of the discursive object ('the self') were highlighted when they were being talked about, either implicitly or explicitly by highlighting them in a word document. See appendix K: step 2.</p>	<p>are referred to and describing them.</p> <p>It also aligns with stage 1 proposed by Willig (2001): Identifying use of discursive objects in the text – both implicit and explicit.</p>
<p>3. Identify patterns in the way the discursive object is constructed</p>	<p>This stage involved identifying the different ways the self is constructed across the dataset (looking for shared patterns of understanding) and which wider discourses the talk was referencing or operationalising. Patterns were constructed as similar discursive constructs were identified and selected from the dataset. This initially started on paper (with quotes clustered together onto large sheets of paper – see Appendix K: step 3) then was moved across to electronic means as the most prominent discursive constructs became apparent. The dataset was revisited and excerpts selected to illustrate the various constructs. Data excerpts were clustered into emerging thematic constructs and linked into the wider discourses they were mainly located within, with tentative names given to constructs and discourses.</p> <p>The following questions were used to guide the process:</p> <ul style="list-style-type: none"> <li>• What 'general discourse' does this construct draw upon?</li> <li>• What discursive 'resources' (Edwards &amp; Potter, 2002) is the talk drawing upon?</li> </ul>	<p>In stage two of Willig's (2001) model there is a focus on the differences between the way the discursive object is constructed in different ways and locating the constructions within wider discourses (i.e. psychological, romantic etc.).</p> <p>This step involves elements of what Parker (1992) proposes in step 7, 9 and 10 of his approach: In step 7 Parker talks about mapping a picture of the world the discourse presents (what metaphors, analogies and pictures discourses paint of a reality?) In step 9 Parker's approach sets contrasting discourses against each other and looking at the different objects they constitute; Step 10 is concerned with identifying points where they overlap, where they constitute what look like the 'same' objects in different ways</p>

	<ul style="list-style-type: none"> <li>• How do other discourses interact with or conflict with each other?</li> </ul> <p>See appendix K: step 3.</p>	
4. Identify subjects and positions	<p>This stage was completed in a word table with the constructs and quotes that formed them in the left-hand column. Using a series of questions allowed exploration of:</p> <ul style="list-style-type: none"> <li>• Who are the discursive subjects created by the discourse?</li> <li>• Who can speak in this discourse? When and with what authority?</li> <li>• What ways of 'knowing'/ acting /being are opened up or closed down for discursive subjects through the talk?</li> <li>• What opportunities for resistance might be made available through use of other discourses?</li> </ul> <p>See appendix K: steps 4 &amp; 5. As these were written up in the column they formed the basis of the results and discussion sections.</p>	<p>In stage 4 Willig (2002) focusses upon the way constructions create subject positions for the discursive object, and the rights and duties for those who use that repertoire. Then in stage 5 there is a move to systematically explore the ways in which discursive constructions (and the subject positions contained in them) open up or close down opportunities for action.</p> <p>This also draws on Parker's methodology (1992): In step 5, where there is exploration of what types of person are talked about in the discourse; Then in step 6 there is speculation about what people are able to say in the discourse.</p>
5. Power in discourse	<p>This stage of the process focussed upon the way that power operates in the discourses employed. It is concerned with the questions:</p> <ul style="list-style-type: none"> <li>• How is power reproduced or resisted through the discourses?</li> <li>• Who gains and who loses?</li> </ul> <p>Again, a Word table was populated with exploration of the way power was reproduced in talk using the above questions to support the process. This section, along with the section produced in step 5, formed the basis of the</p>	<p>This stage draws from Parker's (1992) steps 17 and 18. In step 17 the focus is on looking at which categories of person gain and lose from the employment of the discourse; In step 18, looking at who would want to promote and who would want to dissolve the discourse.</p>

	<p>results and discussion section, with the ideas developed further within the research document itself.</p> <p>See appendix K: steps 4 &amp; 5.</p>	
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### 3. Results

Three discourses were constructed as the most prominent within the dataset. There is no claim made within this research that every DA researcher would identify the same three discourses, rather it is acknowledged that the researcher’s own knowledge and experience will have undoubtedly formed a significant role in their selection (Parker, 1992; Runswick-Cole et al., 2016). Discourses were identified as prominent when most participants (eight or more) used them at some point in their talk (see Appendix L). A reflexive appraisal of the analytical process is presented in Part 3. In order to protect participants from data extracts being pieced together in a way that would identify them, participant identifiers have been omitted from the data tables. Interview data extracts are marked ‘I’ for interviewer or ‘P’ for participant. Those without speaker identifiers are diary / journal entries.

*Table 3: Summary of the discourses and constructs*

<b>Discourse</b>	<b>Construct</b>	<b>Description</b>
A diagnostic discourse	Diagnosis settles it: I am autistic	Diagnosis is presented as a ‘settling of the matter’ where autism attains a type of ‘truth’ status and is used to define elements of who one is.
	Diagnosis and support: I am a person with support needs	The self is presented as being inhibited, disabled or constrained by a lack of access to the right supports, and therefore the self becomes partly defined by one’s support needs.
An individualistic discourse	Autism is a spectrum: I am unique	This construct is concerned with constructing the self as unique, and that the heterogeneity of autism is

		an enabler of that uniqueness.
	Self-actualisation: I am in the process of becoming	This construct is concerned with hopes, fears and aspirations and one's future self.
A normativity discourse	Finding belonging: I fit in or I stick out	In this construct, participants talk is concerned with social identity - being the same as or different to others, sticking out or fitting in with their social world and the way that being autistic impacts this.
	A hostile world: Feeling safe enough to be me	This discursive construct relates to the way the safety of the self is constructed in response to hostile / unsupportive spaces (where one must hide or mask) or to safe spaces (where one can show a 'true' and authentic self).

### 3.1 A diagnostic discourse

A diagnostic discourse emerged as a prominent pattern of talk within the dataset. This discourse finds its roots in a medical / clinical construction of autism as a 'disorder' or 'condition' that people have and are diagnosed with. It was made up of two discursive constructs that a majority of participants made use of in their talk that have been defined as:

- Diagnosis settles it – I am autistic.
- Diagnosis and support – I am a person with support needs.

#### 3.1.1 *Diagnosis settles it - I am autistic*

This discursive construct was concerned with diagnosis as a 'settling of the matter' where autism obtains a type of truth status. Some participants referred to others not believing their experiences or self-knowledge, even though they themselves knew they were 'different', diagnosis was a type of external validation that others were forced to

now accept. For many the struggle for being believed, and for understanding the self was now over, as diagnosis provided the answers people had been looking for. Through this construct autism becomes a kind of lens through which participants (and others) are now able to make sense of themselves and their lived experiences.

*Table 4: Illustrative quotes from the dataset: I am autistic.*

Discursive construct	Illustrative extracts from the dataset
Diagnosis settles it – I am autistic	<p><i>Overall, my diagnosis has allowed me to understand myself 10 times better. I always wondered why I had meltdowns, I knew it wasn't normal. I wondered why school was the most stressful, overwhelming and anxiety-provoking experience. Autism answered a lot of questions and for that I'm very grateful.</i></p>
	<p><i>P: And yeah, so I mean. The rest of the year after I was diagnosed, it wasn't much different but it was a bit easier. I: Yeah, ye-yeah. P: In that. You know like. We're not making it up at all.</i></p>
	<p><i>I was glad that I finally had answers as to why I was very clearly different to most people in school. It was nice to not be seen as 'the bad girl' by all the teachers because that felt really horrible, so it was good to have an explanation for my struggles.</i></p>
	<p><i>I was the one to ask to go through the diagnosis process for Autism. The curiosity was brought about when my mum mentioned that the Head of Learning Support at my high school told her that anxiety can be sign of adolescent girls having autism, I was around 13 at the time. It was brushed aside but I brought it up when I started going to CAHMS when I was 14. Through the entire process most of the adults I told, my mum, my guidance teacher, and a staff member in the Learning Support department, said that they didn't believe that I was autistic.</i></p>
	<p><i>I: So could you, I'm just gonna go back, do you want to tell me about when you were diagnosed with autism, what happened. P: I was relieved. I: You were relieved.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>P: Yeah, that was, that was, at first, obviously it hasn't happened but erm I thought I was gonna get the right support but ((laughs))</i></p> <p><i>P's mum: But we both cried a little bit didn't we?</i></p> <p><i>P: ((laughs)) yeah, I was very relieved. Um but it made me laugh, we, so we, Mr Talbott, yeah his face when I got diagnosed, because he said for ages I didn't have (autism).</i></p>
	<p><i>It took a long time to get assessed.</i></p> <p><i>I wanted to be assessed to find out why I was different &amp; was there a reason that I didn't fit in.</i></p> <p><i>My diagnosis was a relief.</i></p>
	<p><i>I: OK so thinking then, when you were diagnosed with autism, could you tell me a little bit how that happened and, you know, how you thought about it, how you felt?</i></p> <p><i>P: Um. I felt kind of relieved. Because I realised that I wasn't just like weird or something but what I had had a name to it. Um. And that other people went, like go through the same things I do. Um I can't really remember what happened, just the feelings.</i></p>
	<p><i>I: So, when you found out you had autism, or when you, when you got the diagnosis of autism, did that make sense to you?</i></p> <p><i>P: Yeah, that made sense to me after years that I didn't know why I was feeling that way. 'cause when I read up about it, I thought that's lots of similar ways I did things.</i></p> <p><i>P's mum: I think it answered a lot of questions for you didn't it?</i></p> <p><i>P: Yeah. It did yeah.</i></p> <p><i>I: Can you remember any of the specific questions it answered for you?</i></p> <p><i>P: Like, um, why I cope with friendships and stuff differently, yeah.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: 'cause I never coped really well with friendships.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: Or, like noises, so like that, yeah.</i></p> <p><i>I: Yeah. So lots of the things that you'd already experienced started to make sense for you as soon as somebody said 'you have autism'</i></p> <p><i>P: Yeah, definitely. Yeah.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>P: You know. We were just kind of wandering around blindly going, 'what could it be? Could it be this? Could it be that?'</i></p> <p><i>I: Yeah.</i></p> <p><i>P: You know. So the diagnosis meant that then we had something.</i></p> <p><i>P: Yeah.</i></p> <p><i>I: To go, so this is what it is.</i></p>
	<p><i>Something you should know is, we are not all the same. My autism is MINE and doesn't have to look like someone else to be real.</i></p>

### 3.1.2 Diagnosis and support: I am a person with support needs.

This discursive construct was used in talk that constructed the self in terms of being a person with support needs. It constructed the self as being inhibited, disabled or constrained by a lack of access to the right supports and the way in which diagnosis acted as a type of 'gatekeeper' to support. 'Functioning' talk, which related to whether people were talked about as 'high' or 'low functioning' became a feature of some people's 'self' constructions, with a focus on accessing support as a right, whereas for others the self is constructed as dependent, and possibly burdensome on those supporting them.

Table 5: Illustrative quotes from the dataset: I am a person with support needs.

Discursive construct	Illustrative extracts from the dataset
<p>I am a person with support needs</p>	<p><i>Just because I'm high functioning doesn't mean I don't still have trouble. My struggles are as valid as someone who is low functioning and I still deserve to get help and be treated with respect.</i></p>
	<p><i>The best thing about having my diagnosis is that things have been put in place to make school a much easier and pleasant experience for me, for example having access to a room I can go to at any point during the day. It just makes me sad how I needed to go through years of struggles and tough times for them a diagnosis to suddenly change everything. It makes me think that I could've had these adjustments much sooner if school were more willing to see me as more than just a badly behaved girl.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>I think coming to terms with having autism definitely became an issue a couple months after being diagnosed, it suddenly hit me that I've been coping with this my whole life and no one managed to spot it, I felt a little sorry for myself.</i></p>
	<p><i>I: So things, it sounds like you're saying that things got in the way of people seeing the real you?</i>  <i>P: Yeah.</i>  <i>I: And do you know what those things were? What things got in the way?</i>  <i>P: For years not getting the right support.</i>  <i>I: Yeah.</i>  <i>P: And yeah.</i>  <i>I: Yeah,</i>  <i>P: Yeah, them not knowing why I was different, yeah, to other people.</i></p>
	<p><i>P: I'd spent up until then, my entire life being the, not the inconvenience 'cause I know they don't think of me like that.</i>  <i>I: Yeah.</i>  <i>P: But for like, the 'I'll need to check if I can do this because P might be at home ill that day, let me check' that kind of thing.</i>  <i>I: Yeah, yeah.</i>  <i>P: Or you need to stay at home or work from home today because P is ill or 'can't go today 'cause that might stress P out' or you know, so because I'm aware of that and because I can't control it. I'm always trying to like, hmm, what can I do? What can I do to like be less inconvenient?</i></p>
	<p><i>P: She gets more support than me and she's got um, how'd you say it now, how do you say less, like, she's got, I know, she's got more support than I have and she's got erm, so her autism isn't actually as bad as mine, yeah.</i></p>
	<p><i>When I got diagnosed I thought that things would change, because primary was awful so I thought that finally something would make this a bit easier.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<i>I have struggled in situations because people wouldn't use the support strategies that could have helped me.</i>
	<i>When I was at the specialist school, I felt different to the students there as it was clear they had more complex and serious issues compared to me which led the staff to focus on them more, ignoring me.</i>

### 3.1.3 Subjects, positions and power in a diagnostic discourse

A diagnostic discourse creates a discursive space within which people can be constructed as authentically 'autistic', with diagnosis, and clinicians involved in the diagnostic process, as a barrier, beyond which access to necessary supports lie. This discourse legitimises the expert status of professionals involved in diagnosis. They are afforded access to the 'truth' over others and the 'final word'. Support needs being met are constructed as contingent on diagnosis, and experts are given gatekeeper status over the word 'autism' and those that can legitimately use it, with power to allow or deny entry.

In this space, autistic people have the right to make a discursive claim to autism as 'theirs', such as when one participant in the study writes "*My autism is mine*". They can use it to make truth claims about the reason for their 'difference' – and through it speak to a neuro-normative other who has either labelled them as 'bad' or denied them access to the support they need to live their lives. In this way, a diagnostic discourse can be a positive empowering strategy for the autistic person to claim both control over how they and the legitimacy of their support needs are able to be described by others (such as school staff).

However, the impact of constructing diagnosis as a panacea to both legitimacy as an autistic person, and to the support that should be provided, is that those without a diagnosis have no such discursive rights. If diagnosis by experts creates legitimacy for the autistic self, then it also creates the potential for illegitimacy for others, those denied access to the truth claims this discourse enables. People who may be struggling with similar lived experiences and support needs, but who have not been legitimised as autistic by a clinical expert are excluded from this discursive space.

Furthermore, where participants make use of functioning talk as part of a diagnostic discourse it enables a discursive space to other autistic people who may be classed as low functioning. And, as one participant notes, create space for the claim that high functioning autistic people require less support, and question the validity of their support needs.

Parents of autistic people are positioned within this discourse as support givers and advocates, as those who truly understand the support needs of their children. They are constructed at times as war-torn, having battled through the process of advocating for their child's support needs. Words like 'struggle', and 'battle' appear in this discursive construct. What is unsaid but appears as a natural consequence is that there is an enemy to be fought - those withholding diagnosis and support who become the silent enemy. There are explicit references to school staff not believing that participants are autistic both before and after diagnosis, and they are sometimes positioned within this discourse as opponents rather than supporters, of the young persons' needs.

This construction of the family in turn can create another potential discursive space for the autistic person, that of being a support 'burden'. One participant recalls trying to work out how to be less 'inconvenient' to their family as a person with support needs. Use of an individualistic discourse further exacerbates this construct (and will be discussed shortly).

Even so, whilst engaging in a diagnostic discourse participants are seen to actively resist the language of deficit, as when one participant states in her interview: *"I think a lot of people are like ah syndrome, it's a syndrome, or disorder (...). Or you know, and we're like 'chill man'(...). You know, but I think as long as you go into it knowing that it's not what you probably think it's gonna be (...). It's a lot easier. Because I don't have a child with autism. I don't have you know. But I am a child with autism"*. A quick word search of the entire data corpus reveals that the word 'disorder' only appears once, whilst difference or different appears 154 times, suggesting that participants, through use of other discourses, subvert the more stigmatising aspects of a diagnostic discourse.

Power might be seen to operate through a diagnostic discourse to further legitimise the expert status of clinical professionals involved in diagnosis. It does nothing to

challenge the truth claims of the clinical act of diagnosis. One only has to look towards the marketisation of the autism industry to see who the potential ‘winners’ in such a discourse are (Market Research Future, 2020). Only through use of other discourses can participants challenge the hegemony of a diagnostic discourse. For example the adult autistic participants in research by Brownlow & O’dell (2006) challenged the expert status of professionals and presented themselves as the true experts in autism.

In an unpublished thesis Rocque (2007) examines the historical discursive construction of autism, and notes how the discourses in medical and popular texts are “bound up in a mutually constitutive relationship with the disorder they define and treat” (Rocque, 2007, *abstract*). In a medical model, treatment, or some form of corrective action, is the social action that follows diagnosis, and this is seen in the current dataset, where one participant testifies: *“I have ABA therapy and I hate it, probably the worst part of my autism. Everyday I have someone come to my house wake me up and boss me around for 4 hours.”*.

Therefore, a diagnostic discourse becomes a discursive double-edged sword for autistic people. It can be used to legitimise their experiences and needs for support, but also further bolsters the power of experts to both diagnose and ‘treat’ what autistic people may not want treating. It retains the status of professionals as gatekeepers to support.

### 3.2 An individualistic discourse

An individualistic discourse was identified as a further discursive pattern in participants talk about self. This discourse, located in the neo-liberal western ideal of individualism prioritises the self over communal needs, and creates discursive spaces for constructing what a self-actualised self would look like. It is made up of two discursive self-constructs:

- Autism is a spectrum: I am unique.
- Self-actualisation: I am in the process of becoming.

#### 3.2.1 *Autism is a spectrum: I am unique*

In this discursive construct participants talk was concerned with the heterogeneity of autism, with the uniqueness of the way it presents in each person, and the way it presents in the self. Autism gets constructed as a spectrum that people are on, as

something people ‘have’, or as ‘different wiring’ that accounts for different ways of being human. In this construct, uniqueness is often (but not always) located within autism itself rather than being attributed to the uniqueness of each human. At times however, participants construct the self as separate to their autism, and communicate experiences of having their experiences ‘othered’ as autistic, rather than part of a wider human experience.

*Table 6: Illustrative quotes from the dataset: I am unique.*

Discursive construct	Illustrative extracts from the dataset
Autism is a spectrum: I am unique	<p><i>Something you should know is, we are not all the same. My autism is MINE and doesn't have to look like someone else to be real.</i></p>
	<p><i>When I first got a diagnosis, I was excited in a way because I was part of a community of people who, in my brain, were very similar to me. I have since then found out that although we are similar, we will never be exactly the same as each other.</i></p>
	<p><i>I: And so what do you think about autism now, um, having known, having learned about it in yourself and in other people? How do you think autism...Um, how do you feel about it?</i>  <i>P: Um, that like, like it's like OK. Autism is. Yeah you have it or like it makes people unique and like different.</i></p>
	<p><i>P: 'Cause it's so diverse and it's so ((pause)) non-defined.</i>  <i>I: Yeah.</i>  <i>P: That's the thing. You can define if you want to. You can try. You can really try. But you're not going to get very far 'cause there's always a new different version of it.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>P: And, like from my point of view I don't like, disassociate with the fact that I'm autistic.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: With autism, as people with autism, it's not like me, my, us, together. You know, not that I don't appreciate it, just because everyone with autism is different. If I go, well yeah, they're also autistic sometimes people assume that they're the same type of autistic as I am.</i></p>
	<p><i>I am 16 and was diagnosed with autism just before I turned 15. My favourite activity to do is art, I find it very calming and hours just pass by when I'm being creative. I definitely thank my autism for my creativeness and ability to see details. I also love writing as I can be creative with that as well and being able to see lots of detail allows me to analyse text well. I believe I also have my autism to thank for this. My weakness with this is that I find it very upsetting if something doesn't turn out exactly how I had imagined and wanted it to.</i></p>
	<p><i>I: Or anything that you think the other people should understand about being autistic?</i></p> <p><i>P: Um, that's, that it's OK.</i></p> <p><i>I: That it's OK? I agree.</i></p> <p><i>P: I mean other people have autism. Yeah, 'cause. Some people are different who have autism. I don't know, yeah</i></p>
	<p><i>Also helped me to understand that just because someone is diagnosed with autism, doesn't mean that they are affected by the same issues or that they have similar personalities. Some of the students wouldn't speak and were very shy like me whilst others were really loud and outgoing.</i></p>
	<p><i>P: Of course, in the most complicated form we're wired differently, we have all these different things we might struggle with that you don't and we've got deficiencies in the sensory department, we've got "afficiencies" in the sensory department or we've got this struggle, this you</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>know. But simply speaking we're literally just wired differently.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: I think a lot of people are like ah syndrome, it's a syndrome, or disorder,</i></p> <p><i>I: Yeah.</i></p> <p><i>P: Or you know, and we're like 'chill man'</i></p>
	<p><i>In my case I feel like although I may be different in certain ways, it doesn't mean I am not a human. My friends appreciate this but sometimes I'll be upset about something that is genuinely upsetting and I guess they just kind of pass it off as having a meltdown. Sometimes I feel like it's almost as if I can't express how I feel to teachers because they'll just throw me in a room somewhere to 'calm down.'</i></p>

### 3.2.2 Self-actualisation: I am in the process of becoming

This discursive construct of self is concerned with a self-actualised 'best self', with aspirations, goals and dreams. Journey metaphors such as 'being on the right path' or 'being held back', or 'getting there', are used in relation to plans and fears about the future. Expectations around becoming independent and self-sufficient are discussed in relation to being autistic and worries about what this means for the future, with fears of not having support or of abandonment.

Table 7: Illustrative quotes from the dataset: I am in the process of becoming.

Discursive construct	Illustrative extracts from the dataset
<p>I am in the process of becoming</p>	<p><i>P: But (I'm) like the best mentally I've been since I was maybe like three years old.</i></p> <p><i>I: Mm.</i></p> <p><i>P: You know.</i></p> <p><i>I: Um.</i></p> <p><i>P: Um. That's always progressing.</i></p> <p><i>I: Mm.</i></p> <p><i>P: You know. Three months ago. I I'm a little better than then so I can say it again and you know.</i></p> <p><i>I: Yeah, yeah.</i></p> <p><i>P: I'm going forwards and I have support that I didn't have.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>I don't quite know how to feel about being autistic as it is perceived as being rather negative, a disability that can hold you back.</i></p>
	<p><i>D: I just want to have a family that likes me, that I'm not an inconvenience and all this stuff, which I do have. But kind of like I just want to, like not trouble any of them.</i>  <i>R: Yeah</i>  <i>D: If I could, I'd be as independent as I possibly could be, you know, um, but I wanted to just seem like a normal child.</i></p>
	<p><i>I also realised that I'm going to have this my whole life and i began to stress about the future - will I be able to cope in a job? How many people will I have to explain about my autism to?</i></p>
	<p><i>My ideal life in the future is to live in a cottage with two cats maybe a rabbit and maybe a huge dog I don't know, and draw stuff for my earnings.</i></p>
	<p><i>I aspire to be a Computer Games Developer when I'm older. I think that I have a plan for how I'm going to achieve this. I am not going to rush the process and just move onto the next phase when I'm ready.</i></p>
	<p><i>I feel that I have learnt to accept myself &amp; will continue to learn to be my best self ... but I don't think the world is ready to be understanding &amp; supportive.</i></p>
	<p><i>P: So that would be my dream when I'm older, er, to work with people like myself. Yeah.</i>  <i>P's mum: And you're possibly looking at going to ((redacted)) college aren't you?</i>  <i>P: Yeah, ((redacted)) College up in ((redacted)), yeah.</i>  <i>I: Great. And what would you like to do there?</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>P: Um. There's quite a few things, so I'd love to stay residentially.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: And erm ((laughs)) Peace and quiet ((general laughter)). Erm, and, I would love to do like 'cause I am a bit behind, I'd love to do the work skills at the start yeah which, which, for people who are not quite ready to go into full at, at, how do you say it?</i></p> <p><i>P's mum: Academic?</i></p> <p><i>P: Yeah.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: And so they just give more time, just support to help gettin' there</i></p>
	<p><i>I: OK that's good. So before you were diagnosed with autism, what was your biggest fear in life?</i></p> <p><i>P: Um. ((pause)) It's the same fear I have now</i></p> <p><i>I: Yeah?</i></p> <p><i>P: Um It's the fear of being abandoned.</i></p>
	<p><i>I need to practice skills regularly to keep my confidence. I have been working on the executive functioning challenges I have &amp; working on strategies to help myself. I rely on my mum for support but we have made progress which makes me proud.</i></p>
	<p><i>I: what would be your biggest fear in life?</i></p> <p><i>P: Probably not getting the right support, yeah. When I do have to leave eventually yeah.</i></p>
	<p><i>I: Yeah, yeah OK. And if you didn't have autism what do you think the future would look like to you now?</i></p> <p><i>P: More happy and like, know that erm, they're not worried about what's gonna happen. Yeah and they would be able to just get on in their life and just not worry.</i></p> <p><i>I: Yeah um, so in a way, um, you think that having autism has sort of given you more things to worry about for the future?</i></p> <p><i>P: Yeah. 'Cause sometimes I do have unacceptable behaviour, mum could tell you about that a bit, erm, because I do just find it hard to cope, you know.</i></p>

### *3.2.3 Subjects, positions and power in an Individualistic discourse*

An individualistic discourse creates the discursive space for speakers to construct a self that is defined by aspirations and their uniqueness as individuals. By constructing autism as a spectrum, as different wiring, or as 'undefinable' participants access the opportunity to construct a self that is freed of autistic stereotypes – a space for talking about the self in terms of neurological difference, and of strengths rather than deficits. The discourse limits what non-autists can say and disarms against claims that they can make towards autistic people, for example questioning a diagnosis based on autistic stereotypes.

This discourse also opens up ways of constructing a future self. The future is constructed as a destination that one is travelling towards, with speakers referencing 'getting there' or 'going forwards' or being 'held-back'. However, in this construct, autism is potentially "something that holds you back" from pursuing a longed-for future, with one participant describing how non-autists can just "get on with their life". It creates two possibilities – being on track or being behind/off track.

One might view the notion of a functional individual – who is able to carve out a desired future based on aspirational goals and dreams - as based around a neoliberal western ideal of individualism. Speakers in this discourse are caught in a kind of discursive quandary where the dream and the ideal future is constructed and discursively available, and yet there is the fear of abandonment, of walking into a future without the supports needed to function in that future. Research with autistic females in late adolescence has indeed found an increase in separation anxiety and increasing panic around expectations of independence (Oswald et al., 2016). And so the idealistic, individualistic 'dream' creates a discursive space for being 'less than' a neuro-normative other, or of not measuring up to the ideal of independence.

It might be argued that this normative expectation is rooted in neoliberalism, which is concerned with policy agendas that pull back the role of the state, and push forward the emphasis on individual freedom, rights and responsibilities (Runswick-Cole 2014). Runswick-Cole (2014) argues that neoliberalism creates an 'us' and 'them', which others neurodiverse people who do not / cannot live up to what it defines as a good citizen. Timimi et al. (2010, as cited in Runswick-Cole, 2014) contend that autism as a

construct empowers a neoliberal agenda which positions autistic people as unproductive citizens and a 'problem' for medical experts to fix. This creates a subject position for the autistic person as being a 'burden' on those whom they rely for support, such as when one participant in this study states "*I'm always trying to like, hmm, what can I do? What can I do to like be less inconvenient?*".

The impact of this construct is noted by Milton (2017) who writes "within current hegemonic norms, the notion of the fully independent, neoliberal functional individual, the social agent who is responsible for their actions, has become the ideal to which pathological deviance is contrasted, creating categories of those who can pass as 'normal' those who severely struggle to pass, and those who cannot" (Milton, 2017, p. 3).

Thus, a discourse of individualism has the potential to further empower constructs of 'autism-as-disorder' or 'autistics-as-deviants' from the neoliberal ideal. In this way, an individualistic discourse fails to challenge the power and hegemony of neuro-normative ways of talking, rather it creates a kind of discursive trap where the ideal of an independent, self-actualised self is constructed and reached for, but ultimately fails at the hurdle of independence. A socialist discourse around community and mutual support based around equity might offer an alternative discursive space for speakers to construct a preferred future self. However, participants are not seen to take up this discursive position. Instead, they primarily use a diagnostic discourse and construct being a person with support needs as a way to lay down discursive rights to environmental supports.

### 3.3 A normativity discourse

A discourse around normativity was identified as a frequent aspect of participants constructions of self. What it is to be 'normal' is mainly absent from talk, rather talk focusses on what it is to be outside of normativity, or what 'normal' isn't. A social identity gets constructed in this space, with participants referencing belonging or not-belonging in a world that is often less than accommodating. It is made up of two constructions:

- Finding belonging: I fit in or I stick out.
- A hostile world: Feeling safe enough to be me.

### 3.3.1 Finding belonging: fitting in or sticking out?

In this discursive construct, the self is constructed in relation to how one fits in, sticks out or interacts with the social world. Most participants construct the self as different from their neurotypical peer groups and convey a sense of not belonging with them. However, belonging is dependent on the different social spaces that participants inhabit, and often groups with other autistic people present the opportunity to belong. There are also those who have found acceptance with supportive non-autistic friends, and for some they feel they belong only with their family.

Table 8: Illustrative quotes from the dataset: I fit in or I stick out.

Discursive construct	Illustrative extracts from the dataset
Fitting in or sticking out	<p><i>When I was diagnosed, I felt different to everyone around me and it wasn't until being in a specialized school for autism and being around other girls in similar situations that I felt like I wasn't alone.</i></p>
	<p><i>I hated it at first as what I had seen in the media portrayed autistic types as annoying, socially awkward men that had no chance of a normal life being used as a laugh. I was also sad/mad when I found out because it seemed unfair and I didn't want to be the weird kid with autism. I realised it wasn't an any better term according to the several boys in my school who call each other autistic when they do something stupid.</i></p>
	<p><i>I don't really have friends. I tend to be the one left out. The kids at my school think I'm weird and make fun of me. Most times I think I'm just unlikeable and don't blame my autism. I feel like I'm different because I say things that I shouldn't and "don't have a filter". I'm also different because I see things different then other people. Sometime I get "stuck" on stuff and can't move on. I think so many things but don't know how to say it in a way people understand and it makes me mad because I have so much in my head that I can't get out.</i></p>
	<p><i>P: Um, and in secondary school, before I got diagnosed, my friend group was made up of maybe four people who</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>are still known as Neurotypical and about six people who were either already diagnosed, or are now diagnosed as autistic.</i></p> <p><i>I: Yeah, yeah, mm.</i></p> <p><i>P: I, I, kind of joked with my mum after I got diagnosed 'I'm just drawn to autists, that's it, I'm an autistic radar ((laughs)). You know, like before I was diagnosed, I was like all of these people with autism really like me huh? ((general laughter)).</i></p>
	<p><i>I am different to most girls ... I don't like the things that most girls like &amp; I don't like the things that most young adults like. But I also don't like being excluded.</i></p>
	<p><i>I don't feel that I belong in any group.</i></p> <p><i>I feel I am an outcast</i></p> <p><i>I belong with my immediate family</i></p>
	<p><i>After my diagnosis, I no longer feel part of any group. Being just seen as the 'bad girl' by everyone in school for the first 3 years for school I used to fit in with the other 'bad kids'. However after my diagnosis I realised I no longer wanted to be a part of them kind of groups and I wanted to succeed in school. Unfortunately, the problem with this is the people who I would more want to be a part of now, just see me as that 'bad girl' from before. So now I just feel in the middle not really fitting in anywhere. This is the thing that upsets me the most about being diagnosed late because maybe I could've had a smooth journey through school if I had an earlier diagnosis. I also feel like I don't fit in with other autistic people as I don't have the 'typical traits' therefore it's hard to relate to other autistic people. It can be lonely knowing how much it impacts me and not having anyone that truly understands exactly how I feel.</i></p>
	<p><i>I: Do you know how can you remember how you felt then?</i></p> <p><i>P: Uh, well I felt like different 'cause I used to hang out by myself.</i></p> <p><i>I: Uh huh, yeah. And was that...did you feel happy hanging out by yourself?</i></p> <p><i>P: Hmm, sometimes, but not really, I don't know.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>When moving back into a mainstream environment I felt very self-conscious as I didn't want to stand out, I just wanted to fit in and be normal.</i></p>
	<p><i>Since then my mum wants me to get into a group with several other autistic children so I know I'm not alone, because it does feel like that sometimes.</i></p>
	<p><i>I am similar to my friends, two of which are Autistic, in that I don't like or feel comfortable in a big group.</i></p>
	<p><i>Me and my friends are the same, we all enjoy going to cat café's/ cats in general, bitching about people in our classes and Greggs. Even though they do not have autism, I find it easy to get on with them. We recently reconnected, we first met in Junior school but had gotten split up when as we went to different secondary schools. Even though we our good friends are differences are obvious when we're around other people, they find it easy to talk to others and be friendly while I can't, making new friends is hard for me. This makes me feel even more stupid as it makes it even more obvious that I'm different to everyone else. They are much more go with the flow and can be more spontaneous which leaves me feeling awkward and annoying as I like to keep a routine. When I was at the specialist school, I felt different to the students there as it was clear they had more complex and serious issues compared to me which led the staff to focus on them more, ignoring me.</i></p>

### 3.3.2 A hostile world: Feeling safe enough to be me

This discursive construct relates to the way the safety of the self is constructed in response to hostile and unsupportive spaces. Talk references a 'real' and 'open' self that is enabled through supportive spaces (usually the home) and a 'closed', 'untrusting' self that is constructed to protect oneself from the outside world (often school). In order to feel safe, some participants refer to attempts to hide their authentic selves when they are in unsafe and unsupportive spaces.

Table 9: Illustrative quotes from the dataset: Feeling safe enough to be me.

Discursive construct	Illustrative extracts from the dataset
Feeling safe enough to be me	<p><i>When I did finally get diagnosed, I became more cautious of how I acted in public, especially in school, mainly because I didn't want to be the centre of all the autism jokes, I had heard.</i></p>
	<p><i>This doesn't mean that I see having Autism as solely negative, but it does make me feel uncomfortable and more tense to make it less obvious to others that I am autistic.</i></p>
	<p><i>P: Just that I was really open before. I: Yeah? P: Yeah. I: Tell me a little bit more about being open. What do you mean when you say open? P: Um, When I didn't realise that I was different, I'd show off all the little quirks I have. But when I realised that I was different, I started getting self conscious about them. I: Yeah, yeah. P: And I stopped opening up to people.</i></p>
	<p><i>I don't understand why Other people don't understand me. I prefer to be with non judgemental people who do understand me... there aren't many people I trust. I have tried to tell people about myself but they often don't understand. So it makes me anxious to be around people who don't understand &amp; I don't like to tell people. I don't like it when I know people know I am autistic but don't understand &amp; expect me to be like them.</i></p>
	<p><i>I have struggled in situations because people wouldn't use the support strategies that could have helped me. I feel that I have learnt to accept myself &amp; will continue to learn to be my best self ... but I don't think the world is ready to be understanding &amp; supportive.</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>I: And so, what do you think. Do you think there are parts of you, you know the positive parts of you that you feel that you can show at home. Can you show them in school?</i></p> <p><i>P: No, I do find that hard to yeah.</i></p> <p><i>I: Yeah. So.</i></p> <p><i>P: Yeah</i></p> <p><i>I: So you find it hard to be happy at school like</i></p> <p><i>P: Yeah.</i></p> <p><i>I: Like you are at home.</i></p> <p><i>P: Yeah, 'cause they, 'cause they, 'cause the thing what annoys me about school. They say I'm happy but I've got no-one there at school I feel really safe with in a way, like at home.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: But I do find it really hard to just cope and stuff, even though they think I'm OK I'm really not, yeah.</i></p> <p><i>I: Yeah. So school think you're OK But you're really not inside.</i></p> <p><i>P: Yeah.</i></p>
	<p><i>I: But at home your family do know the real you?</i></p> <p><i>P: Yeah, 'cause they know what I go through.</i></p> <p><i>I: Yeah.</i></p> <p><i>P: Cause um, usually when I do come home like I usually do more meltdowns, 'cause I'm just, I'm just feeling safe.</i></p>
	<p><i>Sometimes I feel like it's almost as if I can't express how I feel to teachers because they'll just throw me in a room somewhere to 'calm down.' The only person that really listens to me when that's what's wrong is my mum to be completely honest.</i></p>
	<p><i>I am a good actor because I can mask in public and pretend that I am the same as everyone else.</i></p>
	<p><i>P: Um ((pause)) I think it's better online for me at least because I don't feel have to like , be awkward and have to look people in the eyes and fidget and all that.</i></p> <p><i>I: ((pause))And how do you feel in those groups?</i></p>

Discursive construct	Illustrative extracts from the dataset
	<p><i>P: Um. I feel happy 'cause I can talk about the things that I love without like being shut down.</i></p>
	<p><i>P: Um I think I'm a lot better with my family now than I was. Partially 'cause I'm on like the meds, the medicine now, and also because I've ((pause)) realised how to ((pause)) um, what's the word ((pause)) what's the word when you separate things in your brain? P's mum: Compartmentalise? P: Yeah, compartmentalise how I'm like different so that I ((pause)) act quote unquote normal in front of others.</i></p>
	<p><i>I: Do you feel that you're able to be yourself when you're with your friends? P: Yes. Um I actually think I'm much more often with my friends than I am at home.</i></p>

### 3.3.3 Subjects, positions and power in a normativity discourse

A normativity discourse establishes a space where discursive subjects can be constructed as 'fitting in' with or 'sticking out' from a non-defined but pervasive norm. The consequences of these constructions upon ways of being in the world are further constructed around concepts of safety and support.

Conceptualising belonging becomes a product of the normativity discourse. Through using a discourse of normativity, in-groups and out-groups are defined. In this construct there are 'people like me' - those who don't quite fit in with others. It is the 'sameness of being different' that constructs this 'in-groupness' such as when one participant writes "*I felt different to everyone around me and it wasn't until being in a specialized school for autism and being around other girls in similar situations that I felt like I wasn't alone.*". The 'people like me' are constructed as different from a non-defined 'other people' who are implicitly constructed as other and typical.

There is also an 'autistic other' that is constructed such as '*socially awkward men*' or as somebody people laugh at or '*that weird kid*'. Autistic social actors in this discourse may distance oneself from the 'other autistic' or the 'stereotypic autistic' or they might reframe difference, such as when one interviewee says "*weird but not in a bad way*". Implicitly this leaves discursive space for those who are weird in a bad way.

Speakers making use of this discourse can challenge concepts of 'normality' through 'normalising difference', such as when one participant says *"But yeah, as I went on into like secondary school, I formed another friend group and again it was most of the people who didn't fit in. I think I was kind of like drawn to them"*.

Whilst this opens up ways of belonging for some discursive subjects, a few speakers construct the self as not belonging anywhere, or of only finding ways to belong by hiding one's 'quirks' or no longer being open about one's 'true' self. One's 'true' authentic self is constructed as hiding under the guise of a 'normal' person to avoid the stigma attached to the 'other' stereotypical autistic subject.

On the other side of belonging, a hostile world is constructed as a space where the self is unsupported and misunderstood, where not being 'normal' is a difficult place to be. A 'non supportive other' is constructed in this space, who is either wilfully unsupportive and difficult or they may be lacking in knowledge about autism. But others are given agency in this construct – to give support or to refuse it, with the autistic self at the mercy of others intent. In this unsupportive space, certain ways of being are closed off to the autistic person, who can become disabled by the lack of environmental supports.

A supportive other is also constructed. Usually, a mother or family member or friend – they are constructed as 'safe' and as understanding and as a person with whom one belongs. With these supportive others, the opportunity of the authentic expression of self is possible, as one interviewee says *"Cause um, usually when I do come home like I usually do more meltdowns, 'cause I'm just, I'm just feeling safe."*

Constructs of supportive or unsupportive others links into a social disability discourse that locates the 'problem' outside of autism and in society itself, which is constructed as one participant says, as not *"ready to be understanding & supportive"*. In this way there are discursive opportunities to resist a normativity discourse through use of a social model of disability narrative, that places the onus for change upon society.

Power is reproduced in this discourse when 'normal' is defined in ways that others autistic people, where 'normal' is that taken-for-granted knowledge that does not need definition because it is so accepted within social talk. It produces 'winners' (those who belong) and 'losers' (those who are othered and outside of belonging). The social

action that results from knowledges produced in a normativity discourse often means that autistic people mask their authentic selves in order to fit in and belong, and potentially contributes to significantly higher levels of psychological distress (Beck et al., 2020). Through constructing society as unsupportive, autistic speakers are able to gain some agency and assert their rights to equity in a hostile environment, and yet they still remain reliant on society to respond in supportive ways.

#### 4. Discussion

##### 4.1 The research question: How do autistic adolescent girls construct their self-concept and social identity?

This study has utilised Foucauldian Discourse Analysis to explore how autistic adolescent girls construct a self-concept and social identity. It is suggested that participants constructed self-concept and social identity making use of three discourses identified as the most dominant: diagnostic, individualistic and normativity. This methodology has enabled exploration of how ways of being and doing are made available through certain discourses, and how power might be seen to operate through the discourses taken up in people's talk.

##### 4.1.1 *The self as 'autistic'*

A diagnostic discourse presented participants with the discursive resources to construct their self-concept in relation to 'being autistic'. This supports what other researchers have found with autistic adolescents claiming autism as a core part of self (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; J. L. Jones et al., 2015; King et al., 2019; A. MacLeod et al., 2013; Mogensen & Mason, 2015; Stevenson et al., 2016). Claiming autism as a part of one's identity (who one is rather than a 'label' someone is given) has been argued to risk reducing people to their diagnostic label (Hodge et al., 2019) whilst others argue that autism is an identity to be claimed, much like the LGBTQ community (Joyce Davidson & Henderson, 2010; Yergeau, 2018). This ambivalence was present in participants talk. Whilst some of participants discourse focussed on the uniqueness of each autistic person (through an individualistic discourse) and others explored the social consequence of being so labelled (through a normativity discourse), none of the participants rejected the diagnostic label itself. Rather, it was used to make sense of the self and to make sense of why they found particular aspects of life different to their peers.

In support of other research, analysis showed that an autism diagnosis was constructed as enabling self-understanding, a vehicle through which validation and acceptance of the self could take place (Jones et al., 2015; MacLeod et al., 2013; Mogensen & Mason, 2015). By positioning autism as an uncontested biological reality of “cerebral difference” Ortega (2009, p.435) argues that autistic people (and their advocates) are able to avoid stigma or blame for actions and behaviours that fall outside of the anticipated norm, thus freeing individuals from reproach.

#### *4.1.2 The self as a person with support needs*

Being ‘a person with support needs’ was closely tied into narratives around ‘being autistic’. Use of a diagnostic discourse enables access to rhetoric that legitimises the need of autistic people to have access to social and educational supports. Three participants made use of the word ‘disability’ to describe autism, and it was most often in a positive way (“*Oh, I would say that like autism is like a type of disability that some people have. And that's like OK to have a disability*”). In this way rhetoric around the social model of disability (Oliver & Sapey, 1983) can be seen in their talk. Another participant comments in her journal “*I needed to go through years of struggles and tough times for them a diagnosis to suddenly change everything. It makes me think that I could've had these adjustments much sooner*”. A diagnostic discourse clearly links diagnosis to access to reasonable adjustments and is contingent upon the construction of the self as a person with support needs. As Humphrey & Lewis (2008) recognise, support is often contingent on diagnosis but it can create a loss for those so labelled as they now have to contend with the language of diagnosis to describe the self and are confronted with unhelpful and stigmatising stereotypes used in society. This point is succinctly echoed in one of the journal entries: “*Having an autism diagnosis meant I could get help at school and have people be able to understand my struggles a little better. I was also sad/mad when I found out because it seemed unfair and I didn't want to be the weird kid with autism.*”

#### *4.1.3 The self as a unique person*

An individualistic discourse was seen in the majority of participants talk, and some constructed self-concept in terms of being a unique person with autism. This talk is reliant on a construct around the ‘spectrum’ of autism and enables the discursive ability to distinguish one’s unique self from the selfhood of other autistic people.

Whilst the word 'spectrum' became part of the official lexicon to describe autism through DSM V (American Psychiatric Association, 2013) it was not within a diagnostic discourse that participants primarily constructed this concept. Rather, through an individualistic discourse, that positions autism in a spectrum of human variability (Huws & Jones, 2015) speakers emphasized that even though the same diagnostic label applied, there was a uniqueness to each autistic individual that could not be captured in a diagnostic label. However, in many cases these claims were intrinsically connected to autism itself (rather than an assertion that autism was one small part of the self) and hinged upon the construct of the heterogeneity of autism, something famously communicated by Dr Stephen Shore "If you've met one person with autism, you've met one person with autism"(Shore, 2018, para 2) . An example is provided by one interviewee who says *"as people with autism, it's not like me, my, us, together. You know, not that I don't appreciate it, just because everyone with autism is different. If I go, well yeah, they're also autistic sometimes people assume that they're the same type of autistic as I am"*.

Constructs around the uniqueness of the self have been communicated by autistic young people in other research (Jones et al., 2015; King et al., 2019; Stevenson et al., 2016). One functional aspect of this construct is the discursive distance it enables between the self and stigmatising constructions of autistic people. This has been shown in other research where autistic young people perform social comparisons in constructions of the self, by distinguishing between themselves and other autistic people (Huws & Jones, 2015; MacLeod et al., 2013). MacLeod and colleagues posit that an 'othering' can occur in the process of comparisons that may represent an act of agency or self-determination around construction of the self, or a strategy to distance oneself from a disordered identity. Thus an individualistic discourse enables the autistic self to be constructed as part of a spectrum of difference, in alignment with a neurodiversity approach (Kapp et al., 2013) and in rejection of a disordered identity (MacLeod et al., 2013). In this way, participants might be thought to use an individualistic discourse to counter the stigmatising impacts of a diagnostic discourse, even whilst at some level it relies upon the diagnostic discourse to legitimize the concept of a 'spectrum'.

#### *4.1.4 The self in the process of 'becoming'*

A discourse of individualism is used in participants constructions of the self in the process of 'becoming' a hoped-for future self. A majority of participants talked about their future self, the ways they were trying to improve themselves or fears about the future as an autistic person. Journey metaphors were often used which constructed the future as a destination, with autism as one of the potential roadblocks to progress. Many of the young people explicitly stated that they understood they were not on the same time trajectory (towards independence) as their peers. They spoke about academic qualifications and future careers as destinations they were focussed on working towards, or of skills they were working hard to learn. This supports what other research has found with autistic adolescents who expressed their hopes and concerns about their future as autistic people (McLaughlin & Rafferty, 2014; Stevenson et al., 2016; E. I. Williams et al., 2019).

The age of participants makes this 'future focus' particularly understandable as adulthood draws closer, and is seen in research with non-autistic adolescents' constructions of self (Adamson & Lyxell, 1996). However, a further challenge for autistic adolescents is how to manage the potential dissonance between constructing the self as a person with support needs alongside a future self who will have a job, career and independent life beyond the immediate family, as is so often the normative ideal in western neoliberal cultures. For example, one participant writes in her journal "*I also realised that I'm going to have this my whole life and i began to stress about the future - will I be able to cope in a job?*". Thus, use of an individualistic discourse can create a tension when constructing a hoped-for future self. It becomes difficult to construct a neoliberal ideal of an independent, self-actualised self, at the same time as a future self who may require support and accommodations. Thus, an individualistic discourse positions autistic speakers in discursive spaces that deny full access to speak as a fully functional, fully independent and successful citizen (Milton, 2017).

#### *4.1.5 The authentic self*

Being different is something all participants talked about, in line with much of the published research on autistic adolescents accounts of the self (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; King et al., 2019; Mogensen & Mason, 2015; Stevenson et al., 2016). To construct the self as different,

one is reliant on a normativity discourse, which constitutes what 'normal' is. This is not something that is made explicit in the girls talk generally, rather they construct what it is to be outside of normativity.

As found in the research around camouflaging and compensatory behaviours (Bargiela et al., 2016; L. A. Livingston & Happé, 2017), participants recall attempts to blend in to their environments, by using strategies to enable them to fit in such as when one participant explains that her behaviour at home is better since she has learned to 'compartmentalise' her autism and to act 'normal' with others, and likewise another recalls finding strategies to 'fit-in' with peers at school. This is reminiscent of the research by Baines (2012) who found that their two participants compartmentalised their autism in order to fit in and "pass as normal" (p. 548).

In the process, normativity becomes a hostile discursive space for those who are different. Accounts of name calling, social isolation and lack of understanding and acceptance constructs what this hostile space looks like, for example one of the participants describes being an outcast, rejected and misunderstood. This echoes what Pearson & Rose (2021) argue about autistic masking, that it is a response to hostile social contexts where autistic ways of being are "stigmatised and derided" (Pearson & Rose, 2021, p. 54). Indeed, participants construct the outside normative world as a hostile and unsafe place and in contrast, home was often a space of safety, a place where the self could be expressed authentically, without the need to hide one's differences. Other safe places were described such as the internet, close friendships, or specialist school settings. What characterised these safe spaces were people in them who accepted the 'quirks' or differences that participants viewed themselves as having, which then enabled an open and authentic expression of self. This might include stimming, being able to talk about one's interests without being shut down, or simply an outpouring of emotion through meltdowns.

#### *4.1.6 Social identities: fitting-in or sticking out*

A normativity discourse was evident in the construction of participants' social identities. This discourse is reliant upon an agreed 'normal' and then constructs around how the self aligns with or falls out of this construct of normativity is used to construct whether one fits in or sticks out. In some talk difference is constructed as a uniting factor, as when one participant talks about her group of friends in high school: "I

*formed another friend group and again it was most of the people who didn't fit in. I think I was kind of like drawn to them. It's ironic 'cause in my second primary school I was the only friend to a boy who, as it turns out, is autistic”.*

Use of a normativity discourse to define who ‘fits in’ constructs the autistic as somebody who does not, however for some it provides a way to construct belonging with others who transgress normativity, an outcome that has been found in other research (Bargiela et al., 2016). Beck et al., (2020) explore how undiagnosed autistic women more often attribute social difficulties to their own personalities rather than to traits they have gained from autism, with the former correlating with poor self-concept and feelings of isolation, and the latter potentially supporting increased self-awareness and a sense of community. However, some participants in the current study report that they are not quite ‘autistic enough’ to fit in with groups of autistic people, and thus feel an outsider, whilst their differences mean they do not belong anywhere. In this sense a ‘misfit’ social identity is constructed, one which either promotes belonging with other ‘misfits’ or that creates a sense of aloneness and isolation.

#### *4.1.7 Summary of findings*

The young people that took part in this study made use of a range of discourses to construct self-concepts and social identities:

- Constructing the self as a ‘legitimate’ autistic person through use of a diagnostic discourse enabled participants to make sense of their behaviours and experiences, perhaps enabling a narrative which avoids stigma or blame (Ortega, 2009).
- Use of a diagnostic discourse has the potential effect of silencing those who would seek to challenge participants’ autistic status. And yet it is proposed that this can further legitimise the power and status of professional ‘experts’ who are given the power to gatekeep access to the word ‘autism’ as a diagnostic label.
- The implications of having access to such a label become clear when participants construct the self as a person with support needs. Participants construct having those needs met as both a right (with access to diagnosis a pre-requisite to discursively claim this as a right) and yet also as a potential burden on family members who provide support.

- Through an individualistic discourse, participants construct future selves, and reference fears about how autism will potentially block their progress towards a hoped-for future self. This discourse can be seen to be rooted in neo-liberal ideals of the independent young adult.
- For a majority of participants, constructs of their uniqueness as individuals is contingent upon the concept of the spectrum of autistic difference, rather than upon the uniqueness of human experience.
- A discourse of normativity impacts the construction of social identity, where participants construct the self as outside of normativity. Not fitting-in or sticking-out in normative environments is a construct that all participants reference.
- Belongness or 'fitting-in' is usually constructed as being a result of being with other autistic 'non-normative' people or with family or friends who accept participants for who they are.
- The outside world is often constructed as unsafe or unwilling to provide the support and adjustments autistic people require to feel acceptance and belonging. This is perhaps most succinctly put in the quote that has been referenced in the title of this research:

*"I have struggled in situations because people wouldn't use the support strategies that could have helped me.*

*I feel that I have learnt to accept myself & will continue to learn to be my best self ... but I don't think the world is ready to be understanding & supportive"*

#### 4.2 The implications for Educational Psychologists

In identifying how Educational Psychologists (EPs) might seek to apply some of the insights offered in this research, we might start with thinking once again about the performative role of language (Burr, 2003). As employees of Local Authorities, EPs are sometimes, as a consequence of their statutory role, posited to be involved in the "regulation and control" of different sections of the education community (Billington et al., 2000, p. 60). As social actors, in part this takes place through the discourses that they operationalise in reports, consultations, research and conversations. EPs are therefore in a position to challenge the deficit discourses that exist about autistic

young people through the way they conduct assessments, research, training, and consultation.

Secondly, a further principle is that of the importance of centring around the experience and expertise of autistic voices. This is perhaps best articulated by a participant in this study, who writes "*My autism is MINE and doesn't have to look like someone else to be real*". As Speraw (2009) argues, when seeking to support children and young people, they are "the most expert, most capable of telling what it is like to be them, living in their bodies, requiring assistance or accommodation" (p.736). It is put forward that EPs should treat their interactions with autistic people as a reflexive learning opportunity, with each young person having an expertise into autism and how it plays out in their own lived realities.

In this research, participants used a diagnostic discourse in ways that supported constructions of self that legitimised their autistic status, often using it to reframe past behaviours and experiences where they had experienced judgement from others. There is concern within the Educational Psychology profession that autism as a label can create "totalising identities" (Gilling, 2012, p.35), that is that children so labelled are viewed exclusively through a lens of autism. However, the way a diagnostic discourse is operationalised by participants in this discourse presents a challenge to the EP profession as the word 'autism' is used in ways that legitimise access to supports that they might otherwise not be able to claim. EP's might understandably wish to resist the labelling of young people with diagnostic categories such as autism in order to avoid young people's identities becoming constrained by a label. However, if autistic people themselves find these labels useful as a discursive resource it might be argued it is appropriate to step back, and allow those that are "the most expert, most capable" (Speraw, 2009, p. 736) to determine whether the label of autism is of use to them. It is suggested that the role of the EP should rather be in supporting the young person to explore their identity in ways that destigmatise their characteristics and celebrate their personal resources through discourses that enable this.

However, as a linguistic resource 'autism' was something that could be used in this way only once a diagnosis was given, but of course many children wait a long time for access to a diagnosis, and many others who may experience the world in similar ways, never receive one. Where school staff or parents use language to describe children or

their behaviour in ways that stigmatises or blames, EPs have a role in challenging those constructions and offering alternate repertoires of talk. Furthermore, EPs have an important role in highlighting how language has the power to impact self-concepts and social identities, and that this should be reflected both in their own reports, and in the way that EPs interact with reports written by others.

It has been suggested in this research that normative discourses dichotomise autistic and non-autistic people in ways that 'other' autistic people. EPs potentially legitimise this 'othering' when conducting assessments and formulations based around how children and young people differ from their peers, where non-autistic children are constructed to be the norm from which autistic children's 'deviance' is then measured and where targets for 'improvement' are focussed. Rather than targeting EP support around 'correcting' behaviours that deviate from a school or parent's construction of 'normalcy', EPs might support schools and parents to reframe their expectations and explore why they are focussed on specific changes being a goal of the intervention. For example, where schools set targets that have a child work towards 'quiet hands', they may be ignoring the importance and utility of 'stimming' for autistic people who report it is a self-regulatory adaptive mechanism that should be accepted (Kapp et al., 2019). This was communicated by a participant who said "*um, like when we're doing those, it like it hurts when someone says like that it's um ((pause)) gross or bad or, that we should stop doing it, ((pause)) um because like it's one of the only ways that like we can like concentrate on stuff*". EPs may find a role in supporting schools and families to accept and celebrate the differences that autistic children and young people present (and the implications for support these bring), rather than in seeking to change the behaviours of autistic young people to conform to normative behaviours.

However, it might be argued that the removal of 'problem talk' from discourse around autistic young people may potentially create a scenario where Additional Learning Needs (ALN) panels misunderstand the support needs that autistic young people have, resulting in a lack of access to needed supports. As a result, a further recommendation is that Local Authority staff who make up ALN panels should receive training on the ways in which EPs purposively use language that destigmatises and is strengths based. The supports that are needed should be clearly communicated within a provisions section of the EP report, and ALN staff should be directed to pay attention to this

section in order to understand the young person's support needs. This will support the panel to respond to legitimate needs even where a strengths-based approach is taken.

One of the negative impacts of an individualistic discourse taken up by participants is the tension between the neoliberal ideal of growing independence, and the reality of the support needs many autistic adolescents have. Consequently, it is suggested that EPs ensure they are cognisant of not adding to this pressure in their work with autistic young people. When suggesting target setting around the development of independent living skills for example, EPs need to do so with sensitivity, with the understanding that towards the end of adolescence there may be increasing concerns around expectations to be independent (Oswald et al., 2016). And where psychological approaches are used that aim to enhance autistic adolescents self-efficacy (for example, Solution Focussed Brief Therapy), one might also be aware of the need for discourse which enables constructions around young people's rights to access needed support. Cabanas (2018) explores how positive psychology approaches are rooted in a neoliberal framework and "conveys the message that we are all responsible for our successes and failures" and that "we will improve society and palliate the deficiencies and insufficiencies of our institutions by cultivating our well-being, instead of the other way around" (Cabanas, 2018, p.6). EPs have a role in ensuring children and young people are not left feeling that the weight of responsibility for change lies solely with them. Use of the social model of disability (Oliver & Sapey, 1983) might provide an inclusive narrative with which EPs can explore with young people their rights to equity through appropriate support.

In summary, recommendations for EP's and ALN panels in Local Authorities arising from this research include:

- EP's and Local Authority officers should adopt strengths-focussed language when describing autistic young people in reports and communication with schools, parents and young people themselves. This must be balanced with a focus upon the provision that will be required to meet their support needs so that young people do not miss out on the support they need.

- Local Authority officers and school staff should receive training in the role language plays in the construction of young people's identities and the implications of this upon their practice.
- There should be a focus upon centring around the voice of the young person, through the use of person-centred resources such as PATH (planning Alternative Tomorrows' with Hope).
- Targets for change should be co-constructed with autistic young people and should avoid being centred solely around the concerns held by adults around the young person.
- EPs should be sensitive to the anxiety that discourses around independence can create in autistic young people who have to negotiate greater expectations of independence placed on them through society, with the awareness of their own ongoing support needs.

#### 4.3 Limitations and directions for future research

It is suggested that this study makes a unique contribution to the literature due to its methodological approach. It is the only study that the researcher is aware of which uses Discourse Analysis to explore the way autistic adolescent girls construct their self-concept and social identity. The insights this has enabled build a further layer upon the existing literature which has explored identity and self-concept through individual experiences. Nevertheless, the study has several limitations, and there are further questions which the research raises which might provide a direction for future exploration.

Whilst the methodological approach offered a different lens through which to view the subject matter, the macro-level, to a certain extent, necessitates a de-centring of individual experience. As a result, there were certain experiences and constructions captured in data collection that fell outside of the analytic remit and research questions. In this way the research was not able to fully represent all of the views and experiences communicated by the young people. For example, some participants spent time talking or writing about their experiences of school and alluded to moving between mainstream and specialist settings, and the way they felt they belonged in these settings. Whilst there is some limited research into autistic adolescent girls' experiences of school it is generally dominated by other voices (parents and teachers

or autistic boys) rather than autistic girls themselves (Tomlinson et al., 2020). Consideration of the impact school experiences are likely to have on autistic adolescent girls' identity and wellbeing may be a future area for consideration. Furthermore, the decision to withhold participant identifiers in order to retain a focus upon the macro-sociological level and to avoid the imposition of identity labels by the researcher (Willig, 2001), this does impact upon the replicability of the study, and removes the opportunity to explore how other identity characteristics might have impacted upon the ways individuals in the study constructed the self.

The research design and analysis has been undertaken by a sole researcher who does not have a diagnosis of autism. There are important ethical debates taking place within the autistic community about research, and the importance of autistic people being 'speaking subjects' whose participation and input is used in meaningful ways in research that primarily concerns them (Chown et al., 2017; Durbin-Westby, 2009). Furthermore, the findings were not discussed with the young people that took part. Doing this would have given participants opportunities to add to, or challenge interpretations. Future studies using Participatory Action Research would not only meet a moral and ethical obligation but may also improve the real-world validity of what is researched and how it is interpreted (Chown et al., 2017).

Foucault's original work (Foucault, 1979) took a critical stance in exploring how power operates at a social level through many different types of discourse. Whilst this approach has enabled a critical stance with which to explore the discourses available to and taken up by autistic adolescents when constructing self, the data source has not provided the opportunity to examine the discourses taken up by others when constructing girls with autism. Further DA research might therefore explore how other sources of discourse construct the identity of autistic adolescent girls. Such sources might include EP reports, policies, strategies, social media content, or the views of parents, school staff, or other professionals. This might enable further exploration of the particular ways power operates through discourses that shape the way autistic people are constructed in society.

A further limitation for consideration concerns the way in which the research failed to consider how a feminist position might have added more criticality to the analysis. Emancipatory research by Kourti & MacLeod (2019) with autistic adults raised as girls

reported participants relayed powerful feelings of alienation provoked by pressure to confirm with “gender-typical” (p. 52), as well as neuro-typical expectations. Furthermore, Krahn & Fenton (2012) used a feminist lens to challenge Baron-Cohen's (2010) Extreme Male Brain theory of autism with great effect, arguing that autistic girls are being under-diagnosed partly as a product of sex stereotyping. The intersectionality of gender and autism upon identity construction may have provided richer insights into participants self-constructions. Understanding more about how discourses in society construct autistic girls, and adopting a feminist position, could support further insights into why they are more often under-diagnosed (Loomes et al., 2017), and provide further insights into the complexities of the construction of self through discourse.

#### 4.4 Conclusion

This research makes no claims of universal truths about how all autistic adolescent girls construct self-concept and social identity. Themes did not emerge, rather they were constructed as part of a research and personal journey of one individual researcher, based on understandings of what 10 autistic adolescent girls shared through journals and interviews. However, this work has enabled exploration of the way in which the use of certain discourses can be used by autistic adolescent girls in constructing self-concepts and social identities and considered some of the consequences that might result from such repertoires of talk. Consideration has been given to some of the implications for Educational Psychologists that arise from these explorations, and possible directions for future research.

It is hoped that by focussing on the discourses that are available, those professionals that are involved in working with and supporting autistic people, will gain a greater understanding of the social actions that may potentially result in the knowledge claims that practitioners make (Burr, 2003). Through such a focus, combined with reflexive and compassionate practice, autistic people may be more likely to experience supportive and understanding spaces that enable authentic and safe expression of self.

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*“I feel that I have learnt to accept myself ... but I don’t think the world is ready to be understanding & supportive”:*

A Foucauldian Discourse Analysis of Adolescent Autistic Girls’  
Constructions of their Self-concept and Social Identity.

**Word count:** 6500 words

## 1. Introduction

The following section presents a critical appraisal of the research outlined in part 2. It will take both a reflective and reflexive stance towards the research process, and to the contribution to knowledge made by the study. It will present an account of the inception of the study, methodology, philosophical worldview, ethical considerations, analysis of the data and implications for knowledge and practice. It will be written in the first person, to reflect the present and active role of the author in all aspects of this research.

## 2. Inception of the research

I first became interested in the constructions of autism in my role as an Assistant Educational Psychologist. I was involved in a multi-disciplinary Social Communication Assessment Team (SCAT) that was tasked with assessing children and young people to see if they met the criteria for a diagnosis of autism. I was struck by the imprecise nature of the assessment process. I listened to Paediatricians, Speech Therapists, Occupational Therapists and Educational Psychologists (all of whom I constructed as experts in their field) discuss, define and assign meaning to the behavioural presentation of children and young people.

I reflected on the ways that an autism diagnosis was talked about by professionals who conjectured over the utility of providing a diagnosis in particular cases and was struck at times by the absence of the young person's voice. I noted the power held by professionals over what had the potential for wide-reaching impacts on the support and ongoing provision a child or young person would receive. For example, access to a particular local educational provision was contingent on a diagnosis of autism. I wondered, alongside colleagues, whether the young people concerned would find a diagnosis helpful or limiting, and to what extent a label like autism might come to define their lived experience.

My journey to this subject is also a personal one. When I started to engage with the literature around autism in girls (Bargiela et al., 2016; Cridland, Jones, et al., 2014) I began to notice more distinct patterns within my child's behaviours and the way they appeared to experience the world. My own constructions of autism were challenged, and I began to explore it as a lens through which I might be able to make sense of the way they may be experiencing the world around them.

On the journey to diagnosis, I noticed that as a mother I started to consider behaviours, events and experiences and I wondered whether diagnosis prompted a reframing of self for those who were diagnosed during adolescence when identity formation is posited to be the main developmental task (Erikson, 1968).

It is important to acknowledge these professional and personal experiences, as they have influenced my choice of research questions, and may also have influenced the analysis of data. In order to manage this, I kept a reflective journal (see Appendix M) throughout the research process (Ahern (1999) as cited in Tufford & Newman, 2012), as well as bringing any pertinent reflections to supervision. At times, participants stories resonated with the experiences my child has shared with me and it was therefore essential to reflect on that in my journal. This was for two reasons, both explored by Tufford & Newman (2012) in their examination of bracketing in qualitative research. They posit that bracketing enables researchers to “mitigate the potential deleterious effects of unacknowledged preconceptions” (p. 2) and “protect the researcher from the cumulative effects of what may be emotionally challenging material” (p .2). Whilst bracketing is most commonly associated with phenomenological and grounded theory approaches (Tufford & Newman, 2012), I considered that it was a highly relevant practice to adopt in this research, in recognition of my own personal connection to autism.

My motivation in researching this area, prior to the literature review and development of research questions was to:

- Explore how young people construct an understanding of the self in the context of an autism diagnosis.
- Relate the findings to the practice of professionals supporting autistic young people.

### 3. Ethical considerations regarding researcher reflexivity

Before continuing it is important to make note of the ethical considerations I have needed to consider in the writing of this critical appraisal in relation to the more personal inceptions of research and about my positionality as a ‘mother-researcher’ (to be explored later). Whilst not a participant in this research my child’s presence in my journey towards this research area and process has been acknowledged in order to

provide a fully reflexive account. This brings with it two ethical difficulties, firstly in relation to consent, and secondly in relation to anonymity and confidentiality.

In exploring the question of consent, I considered the potential power imbalance of a mother-child relationship, and whether consent from my child for them to be referred to in this appraisal was fully possible (Runswick-Cole et al., 2016). However, as they are 17 years old, we both (myself and my child) consider they have the capacity and reflective ability to fully consider their inclusion in this appraisal. After fully exploring this with them, and the fact that this critical appraisal would be published in an online repository, they were able to confirm they were happy that I explore my experiences as a mother to an autistic child in my account. In terms of anonymity, by way of the fact that I as researcher am identifying myself, then I am also implicitly identifying my child. Again, this was explored together, and we agreed that I would not include any reflections or details of their personal journey or experiences in order to ensure I did not encroach on their right to confidentiality.

#### **4. Philosophical worldview**

I was not hoping to make broad truth claims about the lived experiences of all autistic people. Even if one sets aside the instability of identities in adolescence (Klimstra et al., 2009), as researcher I positioned myself alongside Potter & Wetherell (1987), who advocate the abandonment of the concept of the self-as-entity: “the question becomes not what is the true nature of the self, but how the self is talked about, how is it theorised in discourse?”(p.102). This positioning is firmly located within a social constructionist and relativist worldview. This philosophical positioning would form the basis of many of my research decisions as discourse, rather than individuals, would form the object of my study (Potter & Wetherell, 1987).

#### **5. Locating my research within the theory and research and conducting the Literature Review**

The process of locating my research within the relevant theoretical frameworks and broader research base was complex due to the many elements that my research interest encompassed. There was the need to provide a context for understanding why autism in girls, the development of self-concept and identity during adolescence, the impact of diagnosis on identity were all important, and to present the way in which I viewed the intersection between the different areas. Each of these areas have vast

amounts of research and theoretical considerations, and whilst they formed the basis of my research question it was outside of the scope of a medium sized piece of research to provide in depth literature reviews in each area. What I sought to do was provide a very brief context of what key themes, theories or studies were of relevance in each area in order to set the scene in which my research, and how I designed my literature review were set. For example, in considering the question of why adolescence was particularly relevant in considering identity construction I felt that Erikson's (1968) widely cited and seminal research was important to reference, alongside some of the more recent research around the neural correlates of self in adolescence (Sebastian et al, 2008).

In deciding what was of interest for my literature review I focussed upon what the current peer-reviewed, published literature could tell me about my research question, that is how do autistic adolescents construct their self-concept and social identities? Due to my ontological positioning, it was more relevant to explore qualitative studies as these would be able to tell me about people's constructed versions of self, rather than quantitative studies which, for example, focus on the categories or statement types autistic adolescents use to describe the self (Lee & Hobson, 1998). I realised that I was unlikely to find many qualitative studies that asked what I was asking explicitly but felt that I may likely find themes of self-talk within studies with autistic adolescents that had other research questions. I therefore developed my search terms to encompass studies that included the terms 'autism', 'adolescence', 'self-concept', 'identity' and 'social identity' (including variations of all of these terms – see Appendix A for the detail on search terms used). I decided not to restrict myself to studies about girls only as I felt that this would result in too few studies to review due to the lack of research with autistic girls (Lai et al., 2015). This ended up being true, with only one study (Gaffney, 2020) which focussed exclusively on girls.

Following training in the University on Conducting Systematic Searches I conducted a systematic search of the literature to ensure I included any studies that were of relevance. I provide more information on this in Part 1.2.1.

After the process of sifting through studies following a literature search I considered how I was going to review the literature I had found. In considering what type of review to conduct I was again cognisant of the purpose of the review. I wanted to

understand how the published literature had already sought to address my research question – that is how do autistic adolescents construct their self-concept and social identity? A paper by Grant & Booth, (2009) presented a summary of the different types of reviews that are found in the published literature. On reflecting on the purpose of my review I settled on synthesizing the literature in a narrative style. Grant & Booth (2009) term this type of review a "Systematic Search and Review" (p. 95) and argue it offers the benefits of the systematic search to ensure all relevant literature is included, alongside the criticality element of a critical review. They suggest that such reviews can be structured in a narrative style organised in a number of ways. I opted to organise mine into sections determined by the broad aims of the research paper being discussed. When it came to present a summary of the literature search in part 2 however, I opted to organise the research around themes found across the studies in order to summarise how the current research suggests autistic adolescents construct the self.

## 6. Methodology and Analysis

Whilst I had made the decision that I wanted to understand how a concept of self was constructed in light of a diagnosis of autism I needed to understand what form of analysis would best suit my research aims.

### 5.1 Deciding on a methodology

Willig (2001) provides an accessible introduction to the different methodologies within qualitative research methods overall. I had been reading this text alongside my deliberations for my thesis topic and I was drawn back to Discourse Analysis (DA, a method I had used in my undergraduate dissertation 20 years previously). This triggered some reflections for me about the social action (Burr, 2003) that results from the way EPs' construct and co-construct the children and young people, families and systems that they work with. Social constructionism is at the core of COMOIRA (Gameson et al., 2003) and consultation (Wagner, 2016), both of which I was using in my everyday practice as a Trainee EP. I reflected on the way that EPs constructions are likely to be taken with more gravitas by people, due to our perceived 'expert' status. These thoughts were triggered when reading both Burr (2003) and Willig (2001) writing about Foucault's theories around power and language, and in response to a paper by Billington (1995) which explored the way in which Discourse Analysis can be

used by EPs to explore not only social relationships, but the “existence of power relations which can be connected to structured social positions” (p. 37). This fed into my reflections about how the Clinical Psychologist’s formulation for my child around autism opened up ways of talking that I had not felt were fully legitimate until that point.

Discourse Analysis is an approach with a range of methodologies within it. In an edition of *Educational Psychology in Practice* Pomerantz (2008) explores how researchers can determine which DA methodology is most suited to their project. She presents a table of the most commonly used DA methodologies, and places them on a continuum from micro to macro approaches, which is reproduced in a summary form below.

*Table 10: Summary of commonly used DA methodologies, adapted from Pomerantz (2008)*

Micro analysis of discourse 'as an end in itself'		Macro analysis of discourse 'as a means to some other end'			
	<b>Conversation Analysis</b>	<b>Ethnography of communication</b>	<b>Discursive Psychology</b>	<b>Critical Discourse Analysis</b>	<b>Foucauldian Discourse Analysis</b>
<b>Aims</b>	Investigates language above the sentence. Looks for patterns in structure and organisation of talk.	Seeks to identify what speech patterns occur in a particular community or culture. Considers social / cultural significance of speaking in certain ways.	Aims to identify how people use discursive resources in order to achieve interpersonal objectives in social interaction.	Shows how phenomena are constructed through acts of speaking and writing. Exposes issues of power.	Recognises that people’s identities, subject positions and objects of which they speak are continually restructured and redefined through discourse. Examines how power in society is supported by ‘regimes of truth’

(Adapted from Pomerantz, 2008, p.7)

In exploring which approach to use I went back to my original interest – how did autistic adolescents construct their knowledge of self and what social action might this result in (Burr, 2003)? This clearly put me on the right-hand side of the above table as I was not so much concerned with interpersonal objectives at the individual level, rather I was interested in the discursive worlds that autistic adolescents are living in, and the ways of being that this offers to them.

Willig (2001) explored how Discursive Psychology explores how participants “manage stake in social interactions” (p. 121) at the interactional level and helped me to decide that this was therefore not the best methodology to explore my research aim as it did not support exploration of the macro-sociological level.

This left me with a decision to either use Critical Discourse Analysis (CDA) or FDA. Van Dijk (2001) writes that CDA explores how power, abuse, dominance and inequality are enacted, reproduced and resisted in social and political discourse. Critical discourse analysts take an explicit position, and seek to understand, expose and resist social inequality. Whilst I did want to explore issues of power, I was not sure that this was the end-goal of my research aims. Furthermore, Pomerantz (2008) cites critique of CDA which suggests power is often accrued to some individuals and not others, and how it does not give enough attention to “how these issues of power are constantly under negotiation by participants in the talk” (Pomerantz, 2008, p.10). In applying this to my research I considered that I would hope to explore ways that participants in my study resisted issues of power through their talk. Pomerantz further contends that poststructuralist approaches (like FDA) offer up ways of exploring how different positionings can provide opportunities for the development of resistance.

I considered that I was seeking to explore further how power works through available and ‘common sense’ discourses. This had perhaps arisen from my reading of Billington (1995a) who posits that in order to practice reflexively Educational Psychologists should make explicit to themselves power relations in their work; should explore the multiple meanings of talk; and explore the reasons that certain meanings gain privilege over others. Billington argues that “attention to discourse can begin to address, not only meanings, but also those power relations which remain active in all our work but which would otherwise be invisible or unremarkable” (p. 40). As such, I concluded that FDA was the DA approach most closely aligned with my research aims.

Foucauldian Discourse Analysis (FDA) facilitates a wider focus on the social discourses that can be detected in people’s talk, and examines how social actors are constrained by, or are able to resist and reconstruct the discursive object. Rather than focussing primarily on the performative value of certain ways of talking through a discursive psychological approach (Willig, 2001) in FDA the power agendas are located within the discourses that a society makes available to its discursive subjects (Burr, 2003). This

analytical approach provided a lens through which to explore participants personal accounts in the context of wider societal discourses, and I hoped it might also support exploration of the 'so what' for Educational Psychologists, who contribute to the dominance of discursive repertoires made available in society. In other words, by examining the discourses that participants draw upon to construct self, I hoped that FDA might enable exploration of the social actions that might result from such constructions, so that as EPs we might reflect on our own use of discursive repertoires around autism.

## 5.2 Data collection

### 5.2.1 *Designing data collection*

In considering how to collect data I considered other DA research around autism. Some made use of pre-existing and naturally occurring datasets for analysis, such as newspaper articles (O'Dell & Brownlow, 2005), social media content (Shakes et al., 2020) and online chat forums (Brownlow & O'Dell, 2006). I was also aware of narrative approaches that explored constructions of autism by studying vlogs made by autistic advocates (Angulo-Jiménez et al., 2019; Angulo et al., 2019) and initially considered whether vlogs might provide a naturally occurring dataset. However, both the ethical considerations of gaining consent, and the requirements of the doctoral program necessitated a different approach.

At this point in my research journey Covid19 had begun to impact work practice and I was concerned that data collection would be impacted by national lockdowns. I opted to design data collection around the assumption that face-to-face contact would be severely restricted during the timeframe I hoped to collect data. Initially, I held some ethical concerns about conducting virtual interviews with a vulnerable population during a time of heightened anxiety due to Covid19. In exploring other options I noted that Humphrey & Lewis (2008) made use of diaries in their research with autistic adolescents, positing that they can present a less intrusive and anxiety-provoking option, and facilitate access to personal information that might not necessarily emerge in an interview context. From this, I developed the idea of requesting participants to write journal / blog style text entries based around the themes that I was seeking to explore.

I produced a writing guide for participants with some very brief sentence starters to provide a concrete example of what each heading was seeking to find out. Whilst I was cognisant of not wanting to direct what participants wrote I was also aware of the need to support the likely need for scaffolding in this specific population to produce personal accounts (Stevenson et al., 2016 citing Goldman (2008)). Whilst I did wonder whether my concrete examples would influence the content too strongly, in reality the diversity of writing in the journals showed that this was not the case.

### *5.2.2 Participant recruitment*

The online nature of the recruitment methodology (for most participants) meant that there were no checks in place to ensure that participants had a clinically confirmed diagnosis of autism, rather I took on trust that parents and young people would only sign up if they met the criteria. I considered that this is a question for all online research, in that how can one be assured of the 'true' identity of participants, given the anonymity that communication via the internet offers (Brownlow & O'Dell, 2006). Furthermore, whilst I was in the recruitment phase a potential participant got in contact to say that they now identified as male but they had still identified as female at the time they were diagnosed. I reasoned that as my research was upon the linguistic construction of self, it did allow both natal female and those identifying as female to take part, and therefore if participants identified with my recruitment criteria that they were welcome to take part (this young person decided not to take it further). However, this did prompt some consideration of my criteria as it potentially excluded people who are outside of the gender binary, especially in light of the research which suggests that there are higher levels of gender variance in autistic populations, with autistic natal females displaying lower gender identification than both autistic natal males and non-autistic natal females (Cooper et al., 2018).

### *5.2.3 Amending data collection*

As I recruited participants and as the data started to come in, I began to become concerned that the data corpus would be too small for a doctoral research study. Upon considering the research methodology literature it became clear that sample size was not a simple question to answer. I was unable to find clear recommendations in the literature around sample sizes in DA, however Braun & Clarke (2013) suggest that in a small sized project a minimum of 1 interview or 10 participant generated textual data

sources are common in pattern based DA projects. At the same time Braun & Clarke (2013) recognise that there are no agreed rules for sample size that can be applied. The present study uses two types of data collection methodology and I was unable to find clarity in the literature about sample sizes needed for medium sized DA projects. However, using the concept of saturation (Bowen, 2008 as cited in Braun & Clarke, 2013) I considered that a decision on sample size may need to be made once data started to be collected. Using the questions put forward by Morse (2000, as cited in Braun & Clarke 2013) to understand how 'shallow' the data was and about how much data was collected from each participant would determine whether more data needed to be sought for analysis. Braun & Clarke (2013) advise "What you want to make sure is that you have enough data to tell a rich story, but not too much that it precludes deep, complex engagement with the data in the time available" (p. 56). Consequently, I used this as a basis for decisions about whether further participant recruitment was required.

I wondered about opening up the range of data collection methods and was satisfied that this was acceptable within Discourse Analysis which frequently involves a range of data sources for analysis (Willig, 2001). I found research by Dodds & Hess (2020) which was concerned with the move to online data collection using Zoom video conferencing technology with a vulnerable participant population during the Covid19 pandemic. They found that participants reported that the experience of participating online included being comfortable, non-intrusive and safe, engaging and convenient, and easy to use (Dodds & Hess, 2020). Despite my initial concerns, this prompted me to wonder whether virtual interviews may in fact present opportunities and benefits for vulnerable participants who might find face-to-face contact more anxiety provoking.

I came across research around elicitation methods with autistic young people, including Winstone et al. (2014). Winstone and colleagues had used activity-oriented interviews with young people to elicit their self-descriptions and compared the richness of descriptions with those produced in a semi-structured interview. They found that the use of concrete activities increased the complexity and depth of self-descriptions autistic young people produced. Similarly Anger et al. (2019) found that autistic adolescents shared autobiographical accounts with much greater clarity and detail (and to the same degree as non-autistic controls) when there was a visual

prompt, than when relying on free recall alone, and Norris et al. (2020) found episodic memory recall improved for autistic adults when visual-verbal prompts were used.

The activity in Winstone et al. (2014) that elicited the richest self-descriptions from young people was the self-portrait activities. This reminded me of *Drawing the Ideal Self* (Moran, 2012) for exploring self-esteem. I considered using this with the use of the drawing pad on Zoom but when I trialled this at home I found that ease of use was limited by the use of whatever internet access device was being used (for example access to a drawing pad as opposed to a mouse). Eventually, I settled on adapting the structure of the method, with use of a visual point of reference that I could share on the screen using PowerPoint.

Following ethical approval to amend data collection methodology, participants were provided with the choice to take part in an interview or produce a written text entry. One participant who had already agreed to take part through writing journal/ blog entries but had not yet submitted their entry was contacted and also offered an interview if that was a preferred communication option (all others had already submitted). She chose to take up the interview option rather than proceed with a blog / journal entry.

#### *5.2.4 Conducting the zoom interviews*

I had initially planned to conduct a pilot interview and had recruited an autistic young woman I knew to run through a pilot interview in order to check that the questions and approach would support exploration of self-concept and social identity. However due to illness the pilot interview was cancelled and with the first interview scheduled for three days later there was no time to rearrange. In retrospect, I would have arranged a larger gap between the pilot and the first interview. A pilot interview may have provided the opportunity to understand how the interview schedule supported exploration of the subject matter and to amend the schedule in response to how the interview progressed. However, I did also consider that each interview and the way the questions were received were likely to be highly individualised. Autistic adolescents are a heterogeneous group and therefore one could not reasonably predict how each young person would interact with the interview materials.

What I was able to do was to look at my proposed PowerPoint presentation with my child who was able to reflect with me on whether the wording and the supporting images made sense to them as an autistic young person. This was of huge value as they suggested a new question which was then included within the interview: “What did you think of autistic people / autism before you were diagnosed?”. This admittedly unplanned and last-minute addition to the process highlighted for me the invaluable contribution and value of having an ‘insider-view’ in the research process (Joyce Davidson & Henderson, 2010). I reflected on the benefits and the ethical imperative of ensuring autistic voices are central in autism research (Chown et al., 2017) and how as a non-autistic researcher I am likely to be applying my own neuro-normative worldview to every stage of the process.

As I conducted each interview, I made reflections on how the questions were received and how I needed to make amendments to fit them to the young person I was interviewing (see Appendix I). I understood an influential study in conducting DA (Taylor & Ussher, 2001) had recommended taking a flexible approach to conducting interviews based on the needs of the respondent, and thus took a similar approach, sometimes re-ordering the questions, or skipping over them where content had already been covered naturally through earlier conversations. After reflecting on the research which suggests some people with autism have difficulty with auto-biographical memory recall (Coutelle et al., 2020) I wondered whether reframing questions from ‘how did you (question) before an autism diagnosis’ to ‘how do you imagine you would (question) if you did not have autism?’ would support greater elicitation. Therefore, the last iteration of the interview used that approach rather than relying on auto-biographical memory (see appendix liii).

I reflected that the changes in the interviews may have supported the increasing amounts of data being elicited across each of the interviews, although with only four participants involved in interviews it is difficult to judge whether this was just by chance. I wondered whether if I had used the final interview schedule with my first interviewee, whether I would have elicited different responses. Upon reflection, I consider that whilst it is likely that the conversation may have developed in different ways, autistic people are not a homogenous group, and it is perhaps more important to work dynamically with the individual with whom one is talking, than to imagine that

a pre-written interview schedule will meet the needs of all participants in the same way. I wonder whether it is in the increasing confidence of the researcher as an interviewer that supports a greater ability to respond in the moment, and therefore supports greater elicitation of their views. Primarily however, the decisions made about the way I conducted interviews were borne from an ethical perspective, seeking to build an approach based around the needs of participants (MacLeod et al., 2014).

### 5.3 Ethical considerations

The ethical considerations around participant wellbeing, confidentiality and informed consent are discussed in part 2. Reflections concerning the wider ethical considerations of my research journey are considered here.

Brinkmann & Kvale (2005) present a compelling exploration of the ethics of qualitative interviews and research and posit:

*Being ethical means being open to other people, acting for the sake of their good, trying to see others as they are, rather than imposing one's own ideas and biases on them. This kind of objectivity involves an understanding of the social and historical context of one's viewpoint, for we always "see" something against a larger background of tradition, history and community... Ethical as well as scientific objectivity is about letting the objects object to what we do to them and say about them.*

(Brinkmann & Kvale, 2005 p.161)

In examining whether my research lives up to Brinkmann & Kvale's analysis of ethical research I am cognisant that whilst I have indeed sought to act for the sake of their good, and being open to their ways of being, I do not feel I can claim to be free of my own biases or ideas. However, Foucauldian Discourse Analysis aligns itself with a radical stance in the field of Psychology as it focusses upon discourse as the object of study rather than individuals (Potter & Wetherell, 1987). In this sense, any of my biases and ideas might be seen to be impacting upon the discourses I present, rather than the individual lived experiences that participants explored. I have not intended to make claims about the participants own inner realities or lived experiences.

However, this leads me on to consider another ethical dilemma I found myself confronted with throughout the research process, and that is that I wondered whether

participants expectations of how their stories would be analysed might differ from my analytic approach. In other words, would they find that in using DA to analyse their personal stories, that their individual personal experiences had been lost in the macro level of analysis? In a DA thesis Jones (2019) cites Brinkmann & Kvale (2015) as suggesting that omitting information about the nature of a discourse analysis may be considered deceptive. Whilst the recruitment information I provided (see appendices B and D) did make reference to the way I would pay attention to the ways they spoke about the subject, it did not make an explicit reference to DA. I believe I could have provided a greater level of information to participants, explaining that my analysis would be focussed at the level of language rather than individual experience. However, this may have resulted in participants becoming very self-conscious about their use of language rather than being able to speak freely, causing further anxiety and potentially limiting how much they contributed to the journal or interview.

#### 5.4 Data analysis

##### *5.4.1 Developing the analytic steps*

Initially, I had hoped to replicate the steps from a peer reviewed study and read widely in the DA literature with the hope of ascertaining which study presented a widely accepted analytic process for Foucauldian DA. However, my reading of the literature revealed that Discourse Analysis is more of an approach than a tightly defined series of steps (Billington, 1995; Boréus & Bergström, 2017; Edley, 2001; Greckhamer et al., 2014; McLaughlin & Rafferty, 2014). DA theorists largely agree that analysis is not about following rules or strict procedures, rather following ‘hunches’ and noticing emerging patterns tentatively, and being willing to abandon or revise as the analytic process develops (Wetherell & Potter, 1988; Wetherell et al., 2001). Edley (2001) writes about the idea of DA as a ‘craft skill’ and the importance of knowing one’s data well in order to develop an analytical process that serves the aims of the work.

As a novice DA researcher, I found this a daunting prospect. However I was also cognisant that many aspects of qualitative research intrinsically involve what Tufford & Newman (2012) describe as the ongoing challenge of “being comfortable with ambiguity” (p. 5). Through peer supervision with another doctoral DA researcher, I came to appreciate that the journey of building an analytic process whilst being firmly rooted within the principles of FDA, was part of what constitutes doing DA. Through

reflective conversations and through these readings I developed enough confidence to explore what analytic steps would support exploration of the data considering my research aims.

Pomerantz (2008) in her summary of DA approaches cites Parker (1992) as one of the prominent theorists to have developed Foucault's approach further into an analytic technique for FDA, and Willig (2001) had also produced guidelines for conducting FDA. I was drawn initially to the apparent simplicity of Willig (2001) but found that explicit steps for exploration of the use of power was missing from that approach. Parker (1992) on the other hand, presents an apparently complex series of steps, that nevertheless does enable such explorations. Using Parker (1992) and Willig (2001) I started to craft an analytic process (Edley, 2001) that would support exploration of how participants construct the self through discourse, and what ways of being and doing, or in other words what social action results from such constructions (Burr, 2003). I present an account of how my analysis corresponded with elements from Parker (1992) and Willig (2001) in part 2.

#### *5.4.2 Data analysis*

The first step of data analysis started with immersion in the data through repeated readings alongside free associations. I was aware of not rushing through the analytic steps as Antaki et al. (2003) cites Widdicombe (1995) as saying:

*“the analytic rush to identify discourses in order to get on with the more serious business of accounting for their political significance may be partly responsible for the tendency... to impute the presence of a discourse to a piece of text without explaining the basis for specific claims” (Widdicombe, 1995, p. 108).*

It was important for the data to be something I could sit with, notice and reflect on so that I could identify any patterns. Parker (1992) does recommend that any free associations should be undertaken alongside another person to enable a wider frame of reference. Unfortunately, I was not able to do this due to the Covid19 lockdown in place at the time, and I wonder what direction my results might have taken if I had been able to include other people at this stage. It may have been particularly insightful to involve a focus group of autistic people at this stage, which would further centre the analysis around an autistic insider voice (Joyce Davidson & Henderson, 2010).

Step 2 involved identifying all of the instances in the text where the discursive object was mentioned, either explicitly or implicitly (see Appendix K). As I was seeking to understand constructs around self-concept and social identity, the 'self' became the discursive object. At times it became difficult to establish whether implicit self references were being made. For example, in talking about their mother having a diagnosis of autism, could this be viewed as an implicit reference to an autistic self, or rather was this more of a construction of 'autism' as the discursive object? I considered it was the latter but certainly there were decisions that had to be made about whether participants self-talk was constructed in talk that was explicitly referencing something else.

In step 3 there was a move to identifying patterns in the way the self was constructed. Initially I did this on paper, clustering around some initial patterns that I had started to notice in step 1 and adding to them as I worked through the dataset (see Appendix K: step 3). This stage was complex, and I found I needed to step away from the dataset at times in order to re-enter the process with a clearer mind. As I assigned quotes to the emerging construct patterns I noted which participant had said them in order to produce a tally (see Appendix L). Where less than half of participants made use of a construct, they were discarded and thus I came to focus on those constructs where more than half of participants made use of them. I then moved over to a Word table where I was able to easily move quotes around and develop the constructs more fully. I found that some quotes were used in multiple constructs and discourses due to different aspects of what they communicated.

I found this the most challenging stage and was concerned at times I was moving towards thematic analysis due to the way that I was clustering quotes around themes. I wondered how this was different to Thematic Analysis, and whether I was simply producing themes of talk. However, I have subsequently read a paper by Braun & Clarke (2019) who acknowledge that reflexive or critical Thematic Analysis is a very similar analytic approach to DA. Furthermore, TA does not, as a general rule, then delve further into themes to discuss wider implications of use of such themes in talk, and it does not retain a focus upon the performative role of language.

In steps 4 and 5 I moved towards analysis of the discursive patterns and constructs that had been identified from the dataset. I used a series of questions (set out in part

2) which supported me to view the data through a DA lens. It was an iterative approach which essentially felt quite 'messy' as talk does not assign itself to one discourse within which it stays positioned, rather it is fluid and moves between differing and often competing discourses and ideas. I felt as I became immersed into a specific discourse, exploring the many different ways of being and doing that are opened up or shut down, there was a sense of being engulfed and lost within the concepts. I found it hard to retain a sense of whether my analysis made sense outside of my own construction of it, and worried that I was losing sight of the data itself. In order to sense check, another DA researcher read through my results and discussion at first draft stage and chatted through with me my unease and sense of disorientation. I also found taking breaks from writing and returning after a few days had passed enabled me to regain a sense of clarity and judgement.

#### 5.4 Reflections upon researcher subjectivity in the analytic process

Gadamer (1989, as cited in Boréus & Bergström, 2017) states that every reader of a text approaches it with their own prejudices. These are historically and socially conditioned, a product of the individual's own history and experiences. These will vary widely based on individual experience, understanding of the world, social, historical and cultural contexts, and a myriad of other influences. Gadamer argues that these prejudices are the very starting point from which it is at all possible to interpret meaning, but that the result is that it is impossible to fully reconstruct what the author wanted to say through the text, as it passes through the interpretation of the reader and their prejudices. In this way the text is never 'a clean slate', rather a layer of meaning that has been constructed by the reader.

In this vein, it is important to recognise how I, as researcher, have brought to bear my own experiences, worldview, biases and prejudices to the interpretation of the texts I analysed. As researcher, I have approached this research with a myriad of life experiences, personal constructs, beliefs and social contexts. I cannot claim objectivity in the sense that an empiricist would hope to claim, rather I have brought my subjective experience and prejudices to bear in the act of interpreting what the young people in my research have offered. As a mother, I have experienced the diagnostic journey of my child, who was diagnosed with autism aged 16. To imagine that in

researching this area I could somehow distance myself as researcher from the experience of mothering is not a viable position to take.

Katherine Runswick-Cole (2016), writes about the dilemma of the “mother-researcher” (p. 20) who fears that her research will not be “taken seriously in (often male-dominated) academia or that, even in the context of qualitative research that pays attention to the ‘positionality’ of the researcher” that her work will be “dismissed as ‘biased’ and ‘partisan’.” (P.20, Runswick-Cole et al., 2016).

As mother-researcher I approach the task of presenting my research with a similar fear. I acknowledge that objectivity is not an achievement of this work. But, at the same time I assert that this does not invalidate the conclusions the insights I offer. Rather the hermeneutics involved bring another layer for the reader to be aware of.

A social constructionist stance has supported a level of reflexivity that I felt was important to adopt as a person with personal lived experience as a mother to a child with autism. As mother-researcher (Runswick-Cole et al., 2016), I may recognise some of the discursive repertoires identified in my research in my own lived experience. I may have used them myself, and I may have witnessed them in my child’s constructions of self. But I am not alone in that endeavour. As a reflexive practitioner I have borne witness to the ways both I and others use language to ‘do something’ beyond just represent ideas. We all bring our own prejudice (Gadamer, 1989), be it as a teacher with stretched out resources, an LA officer balancing the meeting of needs and budgetary constraints or as an EP seeking to find some agreed change issues between school and home. The discourses we privilege will create social action and shining a light on the possibilities for action that result from certain constructions can offer profound insights that support reflective practice.

After writing up the first draft of my thesis I attended some training on gendered classrooms and the professor alluded to her interest in the way autistic girls experience gender. As she talked, I thought about my own dataset and recalled many occasions where participants’ talk about self was highly gendered. For example, one interviewee talked about her friendships with a group of boys and why that had been preferable to one with girls, and another about how she felt she was different from peers due to not liking make-up. I became aware of a potential pattern in the data that

I had not focussed upon and became concerned that I had missed the opportunity to explore gendered constructions of self-concept and social identity.

This is an area of the current research that represents a limitation as it fails to take account of the ways that a feminist lens might add to the criticality of the analysis. For example Krahn & Fenton (2012) used a feminist lens to challenge Baron-Cohen's (2010) Extreme Male Brain theory of autism with great effect, arguing that autistic girls are being under-diagnosed partly as a product of sex stereotyping. When I returned to the dataset, I could see patterns in some of the participants talk that referenced gendered identities and the ways that they often found themselves falling outside of them. If I had adopted a feminist lens at the outset, it would have likely supported further insights into the ways gendered discourses intersect with constructions around autism, and the ways these feed into constructions of self. My omission to do so was a result of the complexities in trying to pull together various strands of theory and disciplines into a concise research focus. My energies were focussed upon trying to understand and present a narrative that pulled together identity and self-concept, autism, diagnosis in adolescence, and the particular issues impacting girls with autism. However, I feel it would have added to the criticality if I had adopted a feminist lens from the outset.

This provided a further opportunity to reflect on the research process and my own subjective viewing of the data, it was further 'proof' that the lens through which one looks at a dataset has a significant impact on the way one constructs the 'results' of research. It is a point made by (Gaffney, 2020) when they assert "It is through the possibility of a 'multiplicity of meanings' (Radley, 1979), interconnections and power relations that we can then see more clearly the individual subjects of our psychological practices, and can begin to see ourselves also" (p. 37). The findings thus presented through my research are therefore an account not only of the way that the young people in my research construct self, but also of the way I, as an individual with my own lived history, make sense of those constructions.

## **7. Implications for knowledge and practice**

This research does not seek to be an objective analysis of the way autistic young people construct their self-concept and social identity in their talk. It is not seeking to present objective realities that exist independently of the social structures they

operate in. Rather, it is an admittedly value laden exploration of the way discourses of 'the autistic self' can be utilised, subverted and reproduced in the discourses of autistic young people. It has sought to explore the discourses that are available and taken up by autistic adolescent girls, possibly in ways that their non-diagnosed selves did not have access to. It has sought to consider what social action (Burr, 2003) this may then result in.

In this regard, I consider that this research has done what it has set out to do. It has offered some tentative, constructed knowledge about what discourses are recognisable in participants talk, and then explored what ways of doing and being are opened up or closed down through such talk. To my knowledge, there are no peer reviewed research studies that have sought to explore constructions of self-concept and social identity in an adolescent autistic population through Discourse Analysis.

The constructions that participants offered were recognisable in other research, as discussed in the discussion in part 2 of this work, however the discourses that were drawn upon through those constructions are new offerings in this subject area. The extant published literature takes a micro-view of the lived experiences of autistic adolescents, and whilst this is important, FDA does offer a wider lens through which to explore the discursive roots and implications of such constructs. It enables a framework through which to explore the social action that results from social constructions (Burr, 2003) in a novel way, and in a way that recognises the power at play through language.

Whilst I have sought to represent the voices of autistic young people in this research, I do not claim that I have captured the very essence of what they sought to communicate in an exact and undiluted way. Rather, I have sought to extract and shed light upon the discourses that I noticed running through their talk, to think about what these discursive repertoires may produce in the social world, and to consider what this might mean for Educational Psychology practice. Whilst I am cognisant of my fledgling status as a DA researcher, and of the shortcomings of my work, I do feel that I have offered some valid considerations of which repertoires of talk might be helpful, and which might result in a loss of power and agency for young women diagnosed with autism.

I put forward the view that it is essential that reflective practitioners consider the impact of the discourses they choose to use about autism (and any number of medicalised and deficit centred diagnoses) and to consider the potential impact upon the children and young people with whom they work. I propose that it is essential that we build into our practice a consideration of the way that our social constructions are being brought to bear on the children and young people we support. Use of a framework such as COMOIRA (Gameson et al., 2003) which holds at its core the recognition of social constructionism might support such an endeavour. My research journey has further embedded this awareness into my worldview, and I intend to incorporate this into my future practice as an Educational Psychologist.

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## Appendices

Appendix A: Literature Search & Review

*Details of Literature Search - Psycinfo Database*

Psycinfo – Search 21/07/2020 (Hits = 336)

Database: PsycINFO

1	self-concept.mp. or Self-Concept/	79084
2	social identity.mp. or Social Identity/	15951
3	identities.mp. or Group Identity/	29574
4	identity.mp.	132160
5	Adolescent Development/ or Early Adolescence/ or Adolescent Attitudes/ or adolescence.mp.	120196
6	teenager.mp. or Adolescent Psychology/	5719
7	adolescent.mp.	386114
8	youth.mp.	99861
9	autism.mp. or Autism Spectrum Disorders/	54813
10	autism spectrum condition.mp.	118
11	Asperger's. MP.	2460
12	autistic.mp.	16162
13	1 or 2 or 3 or 4	203576
14	5 or 6 or 7 or 8	470449
15	9 or 10 or 11 or 12	57051
16	13 and 14 and 15	336

Re-run of original search on PsycInfo on 21/10/2020

Limiting to all research published in 2020: 6, (4 of which were duplicates from previous search, resulting in an additional two studies to include).

Searches on other databases on 21/07/2020

Database	Search string	Results returned																																										
ASSIA	((teen*) or (adolescen*) or (youth) or (young n/2 person)) AND (identity OR identities OR self n/2 concept) AND (autism OR autistic OR asperger*)	1723																																										
SCOPUS	((teen*) or (adolescen*) or (youth) or (young W/2 person)) and ((autism OR autistic OR asperger* OR "pathological demand avoidance") and (TITLE-ABS-KEY("identity formation" OR "social identity" OR "group identity" OR "ego identity" OR self W/2 concept)))	1469																																										
MEDLINE	<table border="0"> <tr> <td>1</td> <td>self concept.mp. or Self Concept/</td> <td>58769</td> </tr> <tr> <td>2</td> <td>social identity.mp. or Social Identification/</td> <td>9974</td> </tr> <tr> <td>3</td> <td>identity.mp. or Social Identification/</td> <td>162182</td> </tr> <tr> <td>4</td> <td>Psychology, Adolescent/ or Adolescent/ or adolescent.mp. or Adolescent Development/</td> <td>2078240</td> </tr> <tr> <td>5</td> <td>teenager.mp.</td> <td>2739</td> </tr> <tr> <td>6</td> <td>youth.mp.</td> <td>74497</td> </tr> <tr> <td>7</td> <td>autism.mp. or Autistic Disorder/</td> <td>51387</td> </tr> <tr> <td>8</td> <td>Autism Spectrum Disorder/ or autism spectrum.mp.</td> <td>27324</td> </tr> <tr> <td>9</td> <td>asperger's.mp.</td> <td>1036</td> </tr> <tr> <td>10</td> <td>autistic.mp.</td> <td>25947</td> </tr> <tr> <td>11</td> <td>1 or 2 or 3</td> <td>214677</td> </tr> <tr> <td>12</td> <td>4 or 5 or 6</td> <td>2100526</td> </tr> <tr> <td>13</td> <td>7 or 8 or 9 or 10</td> <td>53436</td> </tr> <tr> <td>14</td> <td>11 and 12 and 13</td> <td>264</td> </tr> </table>	1	self concept.mp. or Self Concept/	58769	2	social identity.mp. or Social Identification/	9974	3	identity.mp. or Social Identification/	162182	4	Psychology, Adolescent/ or Adolescent/ or adolescent.mp. or Adolescent Development/	2078240	5	teenager.mp.	2739	6	youth.mp.	74497	7	autism.mp. or Autistic Disorder/	51387	8	Autism Spectrum Disorder/ or autism spectrum.mp.	27324	9	asperger's.mp.	1036	10	autistic.mp.	25947	11	1 or 2 or 3	214677	12	4 or 5 or 6	2100526	13	7 or 8 or 9 or 10	53436	14	11 and 12 and 13	264	264
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9	asperger's.mp.	1036																																										
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## Screen print of the literature selected for inclusion in the literature review in Mendeley

Mendeley Desktop

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systematic lit review articles used

Authors	Title	Year	Published In	Added
Berkovits, Lauren D.; Moody, Christine T.; Blacher, Jan	"I don't feel different. But then again, I wouldn't know what it feels like to be normal": Perspectives of Adolescents with Autism Spectrum Disorder	2020	Journal of Autism and Developmental Disorders	18/12/20
Gaffney, Joanne Claire	'It's autism, it's just a name': Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis.	2020	Educational and Child Psychology	23/07/20
Baines, AnnMarie D	Positioning, strategizing, and charming: How students with autism construct identities in relation to disability.	2012	Disability & Society	23/07/20
Cage, Eilidh; Bird, Geoffrey; Pellicano, Liz	'I am who i am': Reputation concerns in adolescents on the autism spectrum	2016	Research in Autism Spectrum Disorders	22/07/20
King, Mary C.; Williams, Emma I.; Gleeson, Kate	Using photographs to explore self-understanding in adolescent boys with an autism spectrum condition	2019	Journal of Intellectual and Developmental Disability	28/02/20
Huws, Jaci C.; Jones, Robert S.P.	'I'm really glad this is developmental': Autism and social comparisons - An interpretative phenomenological analysis	2015	Autism	15/02/20
McLaughlin, Sharon; Rafferty, Harry	Me and 'it': Seven young people given a diagnosis of Asperger's Syndrome.	2014	Educational and Child Psychology	24/07/20
Humphrey, Neil; Lewis, Sarah	'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools	2008	Autism	23/07/20
Jones, Jennifer L; Gallus, Kami L; Viering, Kacey L; Oseland, Lauren M	'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses	2015	Disability and Society	16/02/20
Stevenson, Kathryn; Cornell, Katie; Hinchcliffe, Vivian	'Let's Talk Autism' -a school-based project for students to explore and share their experiences of being autistic.	2016	Support for Learning	24/07/20
MacLeod, Andrea; Lewis, Ann; Robertson, Christopher	'Why should I be like bloody Rain Man?!' Navigating the autistic identity	2013	British Journal of Special Education	21/02/20
Cridland, Elizabeth K.; Caputi, Peter; Jones, Sandra C.; Magee, Christopher A.	The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology perspective	2015	Journal of Intellectual & Developmental Disability	24/07/20
Williams, Emma I.; Gleeson, Kate; Jones, Bridget E.; Et, Williams; K, Gleeson; BE, Jone...	How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis.	2019	Autism : the international journal of research and pr...	23/07/20
Mogensen, Lise; Mason, Jan	The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder	2015	Sociology of Health and Illness	23/07/20

*Critical Review of selected studies using the CASP*

STUDY→	<i>Gaffney (2020)</i>	<i>Jones et al. (2015)</i>	<i>MacLeod et al. (2013)</i>
QUESTION FROM CASP↓			
Was there a clear statement of the aims of the research?	Yes, clearly stated in abstract.	Yes, clearly stated in abstract.	Yes, stated in the summary.
Is a qualitative methodology appropriate?	Yes, IPA was used. Exploring sense making and lived experiences.	Yes, they were exploring sense making narratives of participants.	Yes, exploring perceptions and experiences.
Was the research design appropriate to address the aims of the research?	Yes, and gave rationale for use of IPA.	Yes. Although the study did not provide detail of the steps taken in analysis – rather it provided a reference for the methodology used.	Yes, although did not provide rationale of why IPA over other methodologies. Overarching but not detailed steps provided. It is a homogenous group which makes it suited to IPA.
Was the recruitment strategy appropriate to the aims of the research?	Yes, although as the researcher themselves say, the group was not as homogenous as one would hope for in IPA	Yes. Although the group was not homogenous and there was no discussion about the impact of the heterogeneity on the analysis and methodology used. Recognition that as all participants accessed through a support group, they may have a more positive view due to higher levels of support.	Don't know, it doesn't provide details of recruitment methodology.
Was the data collected in a way that addressed the research issue?	Yes, mostly. Collected through interviews however there does not appear to have been an attempt to make the interviews accessible for the needs of the participants (i.e. by using a shared point of visual reference). The researcher does say that they 'struggled to explain autism' – could this be why?	Yes. Collected through interviews with adolescents. Although it is unclear how or if the interviews were adapted to meet the needs of participants.	Yes. Collected through different means depending on needs of participant.

Has the relationship between researcher and participants been adequately considered?	Yes, in IPA there is a reflexive process acknowledging one's own positioning and the researcher followed this.	No. Researcher reflexivity was not discussed.	No, this was not considered by the authors. No mention of double hermeneutics.
Have ethical issues been taken into consideration?	Yes, ethics approved and process clear.	Can't tell. While the study states the University Review Board gave the go ahead for the study, the steps taken to ensure ethical considerations were taken into account are not made explicit.	Can't tell. Ethics and review not discussed.
Was the data analysis sufficiently rigorous?	Can't tell. It was clear how the researcher had analysed and produced the themes and there was sufficient data to support claims. However, this was a sole researcher and therefore more open to the subjectivities of the researcher.	Yes. There were a number of researchers involved in analysis and cross referencing took place. While the paper does not go into detail about the steps taken in analysis it provides a reference for the methodology used which would enable a reader to follow the same steps.	Can't tell. Steps of analysis only briefly described. However, a strength of the study was that participants were able to comment on the results and analysis.

<p>Is there a clear statement of findings?</p>	<p>Yes. However, the summary statement and a few others are potentially misleading. Ellie, for example, is cited as accepting her diagnosis (“I was pleased...it makes sense” p.141) and of experiencing a stronger sense of self and yet on p.145 the researcher writes “Autism diagnosis and associated difficulties can have a negative impact on mental health but some participants had achieved a separateness from their diagnosis and seemed to enjoy positive wellbeing”. This suggests a link between enjoying positive wellbeing and achieving a separateness from their diagnosis – with no mention that Ellie both welcomed her diagnosis, had achieved “self-acceptance” and a “strong sense of self” (p.142).</p>	<p>Yes, provided through the abstract and a bulleted list at the beginning of the study.</p>	<p>Yes, the findings are discussed clearly and summarised in the summary at the beginning.</p>
<p>How valuable is the research?</p>	<p>Clear recommendations are provided and future directions for research.</p>	<p>Recommendations are provided alongside directions for future research.</p>	<p>Valuable for understanding how autistic higher education students negotiate social identities. Not generalisable due to methodology but provides important insight into the implications for constructing autistic identities.</p>

STUDY→	<i>Mogensen &amp; Mason (2015)</i>	<i>Berkovits et al. (2020)</i>	<i>Cage et al. (2016)</i>
QUESTION FROM CASP↓			
Was there a clear statement of the aims of the research?	Yes, to the extent that this is possible with participatory action research (PAR) where the aims are set by the participants themselves.	Yes.	Yes.
Is a qualitative methodology appropriate?	Yes, exploring the impact of diagnosis.	This was a mixed methods study. The qualitative element enabled exploration of themes though they were mostly shaped by the questions asked.	Yes, there is a good argument provided for why qualitative methods suit the research questions.
Was the research design appropriate to address the aims of the research?	Yes, PAR very much supported the young people to explore impacts of diagnosis. Good epistemological fit with an ethnographic and phenomenological approach.	Yes.	Yes.
Was the recruitment strategy appropriate to the aims of the research?	Yes, through schools and through national autism charity enabled range of participants.	Not clear. AS part of a larger cohort study the recruitment methodology for the larger study were not disclosed.	Don't know, as full details of recruitment not provided.
Was the data collected in a way that addressed the research issue?	Yes, very much in response to individual need and the responses of participants.	Don't know. The questions seemed rigidly applied so that some participant data was deemed not to meet the standards of the study – for the participant group was a rigid methodology appropriate?	Yes, and questions were shown beforehand alongside a visual schedule to support participant understanding. However the interviews appeared very short.
Has the relationship between researcher and participants been adequately considered?	No this was not considered.	No this was not considered and in fact this is problematic given the fact that they coded responses as positive or negative (value judgements on others statements without exploring subjectivity).	Building rapport was discussed. However there is no discussion on researcher subjectivity.

Have ethical issues been taken into consideration?	Yes.	Don't know, not discussed.	Yes, this was discussed.
Was the data analysis sufficiently rigorous?	Don't know, the steps of analysis not adequately discussed. However, the young people were involved in reading the analysis and feeding back which is a strength.	2 analysts, however no checking analysis with participants. The interviews asked 'what are the problems of ASD?' And then there is a theme under negative implications of ASD, under separate sub themes. Deductive? The coders then deciding whether these are negative or positive statements is a little value laden, but the researchers do not explore their subjectivity.	Independently coded by two researchers, then series of discussions to agree final themes. The steps taken not fully explained but they do reference the paper they base the steps on.
Is there a clear statement of findings?	Yes, there is a summary and full discussion.	Yes, there is a summary.	Yes, there is a summary.
How valuable is the research?	Recommendations are provided however not clear what policy changes should be enacted in order to avoid increasing stigmatised autistic identities.	Because of the way the researchers always asked for the negatives of having ASD before the positives – and because they frame it in this way – it is hard to see how they could have got any other results and this impacts on how valuable we might consider their findings to be.	This research does not really present many implications for practice. It supports the view that autistic young people do have concerns about their reputations but it is arguable this tells us nothing new.

STUDY→	<i>Cridland et al. (2015)</i>	<i>McLaughlin &amp; Rafferty (2014)</i>	<i>Humphrey &amp; Lewis (2008)</i>
QUESTION FROM CASP↓			
Was there a clear statement of the aims of the research?	Yes.	Yes.	Yes.
Is a qualitative methodology appropriate?	Yes.	Yes.	Yes.
Was the research design appropriate to address the aims of the research?	Not sure. The study title and the overarching aim suggests it seeks to understand the perceptions of adolescent boys and yet it involves interviews with their families as well as them.	Yes, from what is known about it. Although there is not a lot of detail about the analysis of data, merely a reference to methodology.	Yes, the design supported exploration of lived experiences of the participants. The decision-making process regarding methodology is explored.
Was the recruitment strategy appropriate to the aims of the research?	Don't know. Recruitment strategy not discussed.	Don't know. The full recruitment strategy is not discussed.	Yes.
Was the data collected in a way that addressed the research issue?	The data was collected through interviews and there was a pilot to check the wording. However, the interviews with family members create confusion in relation to the stated aims.	Yes. It was loosely based on a semi structured interview schedule but led by the participants.	Yes, the participants were able to contribute through a variety of methods
Has the relationship between researcher and participants been adequately considered?	No.	No.	Yes, researcher reflexivity explored and discussed.
Have ethical issues been taken into consideration?	Yes.	Not extensively, consent briefly mentioned.	Yes, extensive coverage of ethical considerations.
Was the data analysis sufficiently rigorous?	There were a number of raters, however it was based on the themes found in a previous study and therefore may have inherited any weaknesses from that study in terms of the analysis.	Researcher offered for participants to discuss the outcomes but they did not take this up. There are lots of quotes to back up the themes.	Yes, there is a description of analysis and the steps taken to ensure social validity of the analysis by checking with participants. There are lots of appropriate quotes from the dataset.

Is there a clear statement of findings?	Yes.	Not one statement but they are presented clearly through the results section.	The findings are presented across the themes, but they are not drawn together neatly. One needs to read the article to access them.
How valuable is the research?	There is a clear list of recommendations for practice produced in a practical list at the end of the article.	There are a number of recommendations for EPs working with autistic young people.	There are a number of insights into experiences of autistic secondary school pupils' experiences and implications for support in schools.

STUDY→	<i>Williams et al. (2019)</i>	<i>Stevenson et al. (2016)</i>	<i>King et al. (2019)</i>
QUESTION FROM CASP↓			
Was there a clear statement of the aims of the research?	Yes, meta synthesis of the research regarding mainstream school experiences of autistic adolescents.	Yes, although it was difficult to decipher whether the research element was originally part of the design of the wider project.	Yes.
Is a qualitative methodology appropriate?	N/A	Yes. although this is deduced by reader rather than explained by researcher as other methods not discussed.	Yes.
Was the research design appropriate to address the aims of the research?	Yes.	The research appeared to flow from the multi-media project.	Yes, discussed how both PET and IPA are appropriate.
Was the recruitment strategy appropriate to the aims of the research?	N/A	Yes, although it is not clear at what point they were 'recruited' for the research per se (rather they opted to be part of the multi-media project)	Yes.
Was the data collected in a way that addressed the research issue?	Yes.	Yes.	Yes, the data collection methodology was the research issue being explored.
Has the relationship between researcher and participants been adequately considered?	N/A	Yes, and subjectivity has been discussed.	Yes, explored in detail.
Have ethical issues been taken into consideration?	N/A	Unclear. Whilst ethical issues concerning the multi-media project were reported, it is not clear whether additional consent was sought for the research element of the project.	Yes, full ethical process discussed.
Was the data analysis sufficiently rigorous?	Yes.	Unclear as the analysis stage is not reported on extensively enough to judge.	Yes, provision of steps taken in analysis alongside how the researcher accessed supervision.
Is there a clear statement of findings?	Yes.	Yes.	Yes, clearly presented along with recommendations.

How valuable is the research?	Valuable as it provides clear directions for future research.	There are clear recommendations for further research and practice.	
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STUDY→	<i>Huws &amp; Jones (2015)</i>	<i>Baines (2012)</i>
QUESTION FROM CASP↓		
Was there a clear statement of the aims of the research?	Not sure, the research aims are a little vague and not made explicit. On reading the whole report one can surmise what the original research aims were.	Yes.
Is a qualitative methodology appropriate?	Yes, exploring lived experiences and sense making.	Yes.
Was the research design appropriate to address the aims of the research?	Yes, as it focusses on lived experience and so IPA is appropriate but there is no discussion by the author of this.	Yes, there is some discussion about ethnography and why it suits the study aims, although there is no exploration of other options.
Was the recruitment strategy appropriate to the aims of the research?	Yes, there is some discussion about the recruitment strategy.	Not sure, the recruitment strategy is unclear as it's part of a wider study, but the participants are appropriate for the research question.
Was the data collected in a way that addressed the research issue?	Yes, the research issue was very broad. There is however no discussion that shows they considered how to adapt the methodology to the participant needs.	Yes, an ethnographic methodology enabled a wide range of data collection methods.
Has the relationship between researcher and participants been adequately considered?	Yes, this is explored.	No.
Have ethical issues been taken into consideration?	Yes, ethical issues and processes are discussed.	Not clear. The ethical process is not discussed.
Was the data analysis sufficiently rigorous?	Yes, there is a clear account provided of the analytical process.	There is a good account given of the process of applying positioning theory to the methodology.
Is there a clear statement of findings?	Yes, through the results and discussion.	Yes, the results are clearly presented.
How valuable is the research?	There is a good level of discussion linking to other research findings, however there is only a few brief recommendations that could be developed further.	The discussion only briefly explores implications and recommendations. This could have been developed further. However the use of positioning theory to explore identity construction with young people provides a valuable contribution to the literature on autism.



## Appendix Bi: Recruitment leaflet for parents

School of Psychology, Cardiff University Centre for Human Developmental Science,  
70, Park Place, Cardiff. CF10 3AX



### **Are you the parent/carer of a girl diagnosed with autism in adolescence? A study by Cardiff University is seeking participants.**

We are carrying out research to find out what impact diagnosis of an autism spectrum condition has on adolescent girls and the way they view themselves - both as individuals, and as part of social groups.

We hope the study may help to improve the experiences of young women being diagnosed with autism in the future.

#### **Who can take part?**

- Females aged 11-19 years.
- Diagnosed after the age of 11 years old (and at least 6 months ago).
- Happy to write about themselves and their diagnosis of an autism spectrum condition OR happy to meet for an online interview, supported by yourself as parent/carer.

#### **What will happen?**

- The researcher will email instructions about writing a private blog / journal, with a number of headings and guidance about what to write about OR the researcher will arrange a time to meet over Zoom (free web app) to interview your daughter/young person, who can be supported by yourself throughout.
- For the blog option, your daughter/young person will be asked to write between 3-4 blog / journal entries under the headings supplied. There will be no expectation on number of words written. This will be up to the young person, although to be included in the final analysis the entries will need to relate to the headings provided.
- Parents will be asked to send the blog / journal entries through via email to the researcher. The blog / journal can either be written by hand and photographed OR typed.
- For the interview option, the researcher will arrange a zoom meeting. The interview will be informal and will be focussed on questions about how your daughter/young person views herself as

School of Psychology, Cardiff University Centre for Human Developmental Science,  
70, Park Place, Cardiff. CF10 3AX

an individual, and as a part of social groups, and how her diagnosis may have impacted both of these things. It is expected to take anything from 20 minutes up to one hour, depending on how much your daughter wants to talk.

- The interviews will be transcribed and completely anonymised.
- The blogs / journal entries will be completely anonymised
- The data will then be analysed alongside all participant entries.
- The research may be published in a professional journal at some point in the future.

### **How to get involved?**

If you and your daughter want to take part, please contact the researcher Rebekah Morgan by email: [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk).

**This study has received full ethical approval from Cardiff University Ethics Committee.** For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

Thank-you for your time.



Dear Headteacher

I am a Trainee Educational Psychologist at Cardiff University researching the impact of a late diagnosis of autism in adolescent girls.

I am writing to request that you consider whether there may be any students in your setting that may fit my research criteria, and who may be interested in taking part in my research.

To take part, potential participants need to be:

- Female (assigned at birth OR self-identify as female)
- Aged between 11-19
- Diagnosed with an Autism Spectrum Condition since age 11 (at least six months ago)

Involvement in the research will involve either a written blog/journal by the young person OR involvement in an online interview, supported by a parent/carer.

I have attached a recruitment leaflet (addressed to the parent) to this letter for you to pass on to any parents of students who you feel may qualify and be interested in taking part. This will not require any time in the school day.

If you have any questions, please do not hesitate to get in touch,

Kindest Regards

Rebekah Morgan

Trainee Educational Psychologist, Cardiff University

Contact: [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk)

*You may also contact my research supervisor, Dr Ian Smillie  
on [Smillie@cardiff.ac.uk](mailto:Smillie@cardiff.ac.uk)*

**This study has received full ethical approval from Cardiff University Ethics Committee.** For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: [+44\(0\)29 208 70360](tel:+44(0)2920870360); Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

Appendix C: Information sheet for parents

*This is the second version of the information sheet which was produced after the interview option was introduced to the study. The first version was identical but omitted the interview option.*



School of Psychology,  
Cardiff University Centre for Human  
Developmental Science,  
70 Park Place,  
Cardiff. CF10 3AX

## **Parent / carer information sheet:**

### **Experiences of female young people who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking to understand the way a diagnosis of autism during the ages 11-19 impacts the way girls view themselves (their self-concept) and their membership of social groups (social identity). This information sheet gives information so that you can think about whether to provide consent and support to your daughter taking part. Your daughter's consent will also be important if they wish to take part.

#### **About the researcher:**

Rebekah Morgan is a Trainee Educational Psychologist with Cardiff University, and a mum to 3, including a teenage autistic daughter. She has an enhanced DBS check that can be supplied on request. The project will be supervised by Dr Amy Hamilton-Roberts, Cardiff University.

#### **Why is the research happening?**

The aim of the research is to better understand the impact of a diagnosis of autism in adolescence and whether it has impacted the way that young people view themselves, and their membership of social groups. It is hoped that the experience will be both interesting and enjoyable for the young people who take part, as well improving the knowledge of professionals supporting young people with autism.

#### **Would my daughter qualify to take part?**

Your daughter would need to be at least 11 years old and under the age of 20 years old. She would also need to have received a diagnosis of autism during adolescence (at or after the age of 11 years old) and this diagnosis would need to have been received at least six months ago. Autism includes atypical autism, 'high functioning' autism, Asperger's syndrome, Pervasive Developmental Disorder, Pathological Demand Avoidance. Your daughter would need to have been aware of the diagnosis at the time it was given (or soon after) and be comfortable writing about it in English, or talking about it (with your support if needed) in an informal online interview. If you are unsure if your daughter qualifies, please get in touch.

#### **What does taking part involve?**

There are two ways that you / your daughter can choose between to take part in this study, and it's up to you which method you would prefer. This is the first option:

#### **Blog / journal entries:**

- Your daughter would need a copy of the attached information sheet and the instructions for writing the blog.
- Your daughter will be asked to write 3-4 blog / journal entries, either by hand or typing (it is OK for you to scribe if that is what your daughter requests).
- If your daughter is under 16 you (as a parent / carer) will be asked to email the entries – once they are all complete - to the researcher on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk).
- If your daughter is 16 or over they will be asked to email the entries – once they are all complete - to the researcher on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk). If your daughter would prefer you as parent / carer to email the entries that will be acceptable.

**OR you and your daughter can take part in an online informal interview with the researcher. Your role will mainly be to support your daughter / the young person you care for** (although if she is aged 16 or over, she can choose to not have you present). This is what would happen in the online interview:

#### **Online interview**

- The interviewer will agree a date and send a link to a 'zoom' invite (you will need to have a reliable internet connection and access to a device, such as a laptop, tablet or phone with the free zoom app installed)
- On the date and time agreed, you and your daughter (or just your daughter if she is over 16 and chooses this) will go online and talk with the researcher. The researcher will record what is being said using an iPad with the audio file being encrypted and password protected.
- I will have some questions to ask your daughter / the young person you care for about how she sees herself as a person, and how she thinks being diagnosed with autism has affected that. I may use some activities to make it more informal or less direct but I will be responsive to how your daughter wishes to structure the conversation. If she doesn't understand the question, I will find another way of asking or you can provide support to help her form an answer. There will be no rush to answer. You will be able to talk during the interview although the focus should mainly be in supporting your daughter to communicate her views most effectively, if this is something that she will find helpful. It is hoped that your daughter's views will be able to be effectively communicated throughout this informal process.
- There will be no wrong answers. Everything will be helpful and interesting to the researcher.
- The interview could take from 20 minutes up to an hour, depending on how much is said in response.
- At the end of the interview you will be able to ask any other questions.
- Then the zoom call will end.

#### **Is my daughter obliged to take part?**

No, not in any way. Involvement in the research is entirely voluntary, and in fact it is important that participants want to take part and that parents / carers feel that it

would not cause undue stress to their daughter. You do not need to get in touch if you do not want to take part.

If you say your daughter would like to take part now, you can still withdraw later without giving a reason. After the blog / journal entries have been submitted, or the interview conducted, there will be a short period of time where it will still be possible to remove consent and have the data deleted. The interview will be transcribed (written up) and anonymised within 2 weeks. The blog / journal entries will be anonymised (by providing fake names or other details to ensure your daughter cannot be identified). This will also be within 2 weeks of submitting them. **I will then bring the data together from all young people taking part in the study.** Once the data has been anonymised and analysis is underway it will not be possible to remove the data from the project as the data will no longer be identifiable to individuals.

#### **We want to take part – what do we do next?**

- If your daughter is under 16, you (as parent / carer) would need to e-mail the researcher, Rebekah Morgan on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) saying your daughter would like to take part, and whether they would like to write a blog/journal, or take part in an interview. You would also need to fill in the online consent form and your daughter would need to fill in the online assent form.
- If your daughter is 16 or over, they can get in touch independently and say they would like to take part, as well as filling in the online consent form
- Upon receipt of consent / assent forms the researcher will get in touch to agree a convenient date for the submission of the blog / journal or for the interview to take place.

#### **What will happen to the interviews or the blog / journal entries once completed?**

The interview will be transcribed (written up into words) and the recording deleted within two weeks of the interview,

To begin with, all identifying features (names/ locations/personal identifiable details) in the blog /journal entries or interview will be anonymised, with participants given a pseudonym (fake name) as well as any individuals they mention.

Once blog / journal entries have been collected, and interviews completed from all participants they will be analysed together. This will involve the researcher exploring ways that participants talk about autism, self-concept and social identity.

The final research will be written in a thesis, with some quotes selected that illustrate the themes being discussed. Only your daughter (and yourself if your daughter shares the content with you or you are present in the interview) will be able to identify which quotes in the report are hers.

The written report and anonymous blog / journal entries, anonymised interview transcript will be stored on Cardiff University secure IT systems indefinitely. The thesis will be published online, and if you would like the researcher can send you and your daughter a summary of the findings once completed.

All contact details will be saved securely on a Cardiff University server until the research is complete, after which all personal details will be deleted.

### **Are there any benefits to my daughter in taking part?**

We hope the research will be interesting and enjoyable for your daughter. Some people find it helpful to think about and make sense of their experiences in this way.

### **Are there any risks to my daughter in taking part?**

We do not expect that the process of taking part will be upsetting for participants. The blog / journal headings are not designed to seek out sensitive information, and your daughter would be entirely in control of what she would like to share. Your presence in the interview is designed to provide emotional support if your daughter / the young person you care for finds it stressful or becomes emotional and requires some support.

It is acknowledged that some young people have higher levels of anxiety and can find novel situations difficult. If, as a parent, you feel that your daughter would find taking part too stressful or difficult please do not ask them to participate. If your daughter unexpectedly finds the process stressful there is absolutely no obligation to take part, simply e-mail to say that your daughter no longer wants to be included, or even during the interview this can be cut short or paused. You do not need to provide a reason for withdrawing from the research.

### **To take part or ask any further questions:**

If you and your daughter have further questions, or agree that she would like to take part please contact the researcher **Rebekah Morgan** by email [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk). You can also contact the project supervisor Dr Ian Smillie on [smillie@cardiff.ac.uk](mailto:smillie@cardiff.ac.uk)

**This study has received full ethical approval from Cardiff University Ethics Committee.** For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

**GDPR notice:** The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and Matt Cooper is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest. This information is being collected by the researcher, Rebekah Morgan.

**Thank you for your time!**

Appendix D: Information sheet for young people

*This is the second version of the information sheet which was produced after the interview option was introduced to the study. The first version was identical but omitted the interview option.*



School of Psychology,  
Cardiff University Centre for Human  
Developmental Science,  
70 Park Place,  
Cardiff. CF10 3AX

## **Young people's information sheet:**

### **Experiences of female young people who have received a diagnosis of autism during adolescence**

#### **Hello!**

We are looking for young people who are female, aged between 11 and 19, with autism. If this is you, then you are invited to take part. This sheet contains what you might need to know to decide if you would like to take part.

Your parent or carer should have some information too, and it might be helpful to talk to them about it.

If you have any questions about the study you, or your parent / carer can get in touch with me to find out more. If you are 16 or over you can get in touch directly by email on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) .

**Thank you for reading this information sheet.**

**Rebekah**

#### **About me (the researcher) and the research:**

My name is Rebekah Morgan and I'm a Trainee Educational Psychologist. I'm interested in the experiences of females who have been diagnosed with autism since the age of 11. I'm also a mum and have an autistic teenage daughter. I hope to find out some of your experiences of being a young person with autism/autistic person and the way you see yourself.

#### **Why have you been given this leaflet?**

You may have been given this leaflet by a parent, carer or by an adult who is supporting you. If you are female, aged between 11 and 19, have a diagnosis of autism (this includes Asperger's and other 'types' of autism), and were diagnosed after age 11 (and at least more than 6 months ago) then you are invited to take part. If you are under 16, we would need your parent / carers permission (they would also need to see the parent/carer information sheet).

### **What will happen if you decide to take part?**

There are two ways that you can choose between to take part in this study, and it's up to you which method you would prefer. This is the first option:

#### **1. Writing blog / journal entries**

- You will be asked to write 3 or 4 blog / journal entries using the attached instruction leaflet. You can hand write or type your entries.
- If you are under 16 your parent will be asked to email the blog / journal entries to myself, the researcher on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk)
- If you are 16 or over you can email the blog / journal entries to me on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) or you can ask your parent / carer to do so if you prefer.

**OR you can take part in an online informal interview with the researcher, supported by a parent** (although if you are aged 16 or over you can choose to not have your parent present). This is what would happen in the interview:

#### **2. Online interview**

- The interviewer will agree a date and send a link to a 'zoom' invite (you will need to have a reliable internet connection and access to a device, such as a laptop, tablet or phone with the free zoom app installed)
- On the date and time agreed, you will go online and talk with the researcher. The researcher will record what is being said using an iPad.
- I will ask you some questions about yourself, and about what you think about autism. We might do some activities together if that makes it easier to talk. If you don't understand the question I will find another way of asking, or your parent can support you to think about what you want to say. There will be no rush to answer, you can take your time.
- There will be no wrong answers. Everything you say will be helpful and interesting to me.
- The interview could take from 20 minutes up to an hour, depending on how much you want to say.
- At the end of the interview you will be able to ask any other questions.
- Then the zoom call will end.

### **What will happen to what I have written in the blog or said in the interview?**

The interview will be 'transcribed' (written up into words) and then the recording will be permanently deleted.

If you use your name or anybody else's name (in the blog or interview), or anything that could let people know it's you the researcher will replace those with fake names / places (this is called anonymising the data).

Once all the data has been collected from all the other young people taking part, they will be analysed together. This will involve the researcher exploring ways that young people talk about or write about what is discussed.

The final research will be written into a research report, with some quotes selected that illustrate the themes being discussed. Only you (and your parent if they send the blog/journal entries to me on your behalf, or if they are present in the interview) will be able to identify which quotes in the report are yours.

The written report and anonymous blog / journal entries and anonymous interview data will be stored on Cardiff University secure IT systems indefinitely. The report will be published online, and I can also send you a summary of the results of the research once completed.

All contact details will be saved securely on a Cardiff University I.T. server until the research is complete, after which all personal details will be deleted.

### **Do you have to take part?**

No, you should only take part if it is something you want to do. If you are not sure you can always get in touch to find out more. If you say you would like to take part but then change your mind later, that's fine too, you won't need to give a reason. Once you have taken part I will make sure that all of your contributions are anonymous (give you a fake name or other details so that nobody can tell it's you) – this will take up to 2 weeks. I will then put them with what everybody else has said and analyse them. Once this has happened it might not be possible to remove your input from the research as I might not know which parts are yours.

### **What's in it for you?**

We hope the research will be interesting and enjoyable. Some people find it helpful to write about or talk about their experiences.

### **Are there any risks to taking part?**

I do not expect the blog / journal writing or the interviews will be upsetting. However, many young people can experience anxiety with new tasks or situations. You might also find it emotional to think about the subject matter. If that is the case, you can talk to your parent / carer, and if you decide not to take part that will not be a problem. You will not need to give a reason why. You can leave the interview early if you are upset, or you can take a break and come back when you feel ready. Having a parent with you in the interview might help you to feel less anxious, and you can access their support whenever you need to.

### **I want to take part – what do I do next?**

- If you are under 16 and you would like to take part please ask your parent / carer to email me on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) and let me know you want to take part, and which option you would like to take (blogs/journals or interview). They will also need to fill in the online consent form (this will be emailed to

you) and you will also need to fill in an online assent form (this will be emailed to you).

- If you are 16 or over and you would like to take part, please email me on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) and tell me which option you would like to take (blogs/journals or interview). Although if you would prefer you can ask your parent / carer to email me on your behalf. You will also need to fill in a consent form which will be emailed to you.
- If you are over 16 it is up to you if you want to have a parent present in the interview. If you would like a parent present, they will also need to fill in a consent form.
- I will get in touch to agree a convenient period of time for you to write the blog / journal entries, or to conduct the interview.

### **To take part or ask any further questions:**

If you and your parent / carer have further questions, or decide that you would like to take part please contact me, **Rebekah Morgan** by email [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk). You can also contact the project supervisor Dr Ian Smillie on [smillie@cardiff.ac.uk](mailto:smillie@cardiff.ac.uk)

**This study has received full ethical approval from Cardiff University Ethics Committee.** For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

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**Thank you for your time!**

**Experiences of female young people who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking to understand the way a diagnosis of an autism spectrum condition (ASC) during the ages 11-19 impacts the way girls view themselves (their self-concept) and their membership of social groups (social identity). You should already have read the project information sheet. Please do not fill in this form unless you have read the information sheet.

**If you consent for your young person to take part in this study, please provide the following information, and confirm you would like to take part by selecting the button below.:**

- I confirm that I have read the information sheet and am happy for my young person to participate in this research.
- I understand that taking part is voluntary.
- I understand that my young person is free to withdraw from the study without giving a reason, up until the data is analysed.
- I understand that findings from this research may be published in an anonymous form.
- I understand that at the end of the study I or my young person can be provided with information about the research findings.
- I understand that I may ask any questions at any I am free to discuss any concerns with Rebekah Morgan or her supervisor Dr Ian Smillie, at Cardiff University.
- I consent for my child to participate in the study conducted by School of Psychology, Cardiff University under the supervision of *Dr Ian Smillie*.

For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

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The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.

I consent.

I do not consent.

#### Your details

Parent / carer name   
Young person's name   
Contact email address for parent / carer

Submit

## Appendix Eii: Parent / guardian consent form for Interview

### **Experiences of female young people who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking to understand the way a diagnosis of an autism spectrum condition (ASC) during the ages 11-19 impacts the way girls view themselves (their self-concept) and their membership of social groups (social identity). You should already have read the project information sheet. Please do not fill in this form unless you have read the information sheet.

**If you consent to take part in this study, please provide the following information, and confirm you would like to take part by selecting the button below.**

- I confirm that I have read the information sheet and provide consent to take part.
- I understand that taking part is voluntary.
- I understand that both myself and my daughter / the young person I care for, are free to withdraw from the study without giving a reason, up until the interview has been transcribed and anonymized
- I understand that findings from this research may be published in an anonymous form.
- I understand that at the end of the study I or my daughter / the young person I care for, can be provided with information about the research findings.
- I understand that I may ask any questions at any I am free to discuss any concerns with Rebekah Morgan or her supervisor Dr Ian Smillie, at Cardiff University.
- I consent to take participate in the study conducted by School of Psychology, Cardiff University under the supervision of Dr Ian Smillie.

For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: psychethics@cardiff.ac.uk

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The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.

I consent.

I do not consent.

#### Your details

Parent / carer name   
Young person's name   
Contact email address for parent / carer

Submit

**Experiences of girls/young women who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking at the experiences of girls/young women who have been diagnosed with an autism spectrum condition since the age of 11. Please only complete this form if you have read the information provided about the study.

**If you would like to take part in this research please read the following statement, type in your name and click the 'I agree' button at the bottom.**

- I have talked to my parent and read the information sheet and wish to take part.
- I understand that I do not have to take part if I don't want to.
- I understand that I can choose not to take part if I change my mind without giving a reason, and I can ask for my blog / journal entries to be destroyed at any time up until they have been analysed.
- I understand that what I write is confidential, but that my parent may be able to read what I write when they send the blog / journal entries to the researcher.
- I understand that only the researcher, myself and my parents will not know what I have written.
- I understand that findings from this research may be published.
- I understand that at the end of the study I can be told about the research findings and may request a copy of the written report.
- If I have any questions or worries about the research I can ask my parent / carer to discuss my concerns with Rebekah Morgan or her supervisor Dr Ian Smillie, at Cardiff University.

For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

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The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.

I agree.

I do not agree.

Your details:

Your name:

Your parent / carers  
name:

Submit

## Appendix XX: Young person (under 16) assent form for interview

### **Experiences of girls/young women who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking at the experiences of girls/young women who have been diagnosed with an autism spectrum condition since the age of 11. Please only complete this form if you have read the information provided about the study.

**If you would like to take part in this research please read the following statement, type in your name and click the 'I agree' button at the bottom.**

- I have talked to my parent and read the information sheet and wish to take part.
- I understand that I do not have to take part if I don't want to.
- I understand that I can choose not to take part if I change my mind without giving a reason, and I can ask for my interview recording to be destroyed at any time up until it has been written into words and made anonymous (so that nobody can tell it is me).
- I understand that the interview will be treated confidentially by the researcher, but that my parent will be present during the interview to provide support and so full confidentiality cannot be guaranteed.
- I understand that findings from this research may be published.
- I understand that at the end of the study I can be told about the research findings and may request a copy of the written report.
- If I have any questions or worries about the research I can ask my parent / carer to discuss my concerns with Rebekah Morgan or her supervisor Dr Ian Smillie, at Cardiff University.

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The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.

I agree.

I do not agree.

Your details:

Your name:

Your parent / carers  
name:

Submit

## Appendix Fii: Young person (over 15) consent form for blog/journal entries

### **Experiences of female young people who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking at the experiences of female young people who have been diagnosed with an autism spectrum condition since the age of 11. Please only complete this form if you have read the information provided about the study.

#### **Participant consent form (16's and over):**

Having read the information, if you consent to taking part in the project, please tick the I agree box below, along with your name.

- I confirm that I am aged 16 or over.
- I have read the information sheet provided and wish to take part.
- I understand that taking part is voluntary.
- I understand that I am free to withdraw from the study up until the data is analysed, without giving a reason.
- I understand that what I write is confidential, and that anything I write which may make it possible to identify me will be removed or changed and therefore the data will be impossible to trace back to me.
- I understand that I can request my data or ask for it to be destroyed at any time up until the data has been analysed.
- I understand that findings from this research may be published in an anonymous form.
- I understand that at the end of the study I can be told about the research findings and may request a copy of the written report.
- I understand that I may ask any questions at any time. I am free to discuss my concerns with Rebekah Morgan or her supervisor Dr Ian Smilie, at Cardiff University.

*For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: psychethics@cardiff.ac.uk*

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*The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.*

I agree.

I do not agree.

Click to write the question text

Your name:

Your parent / carers  
name if they are the main  
contact for this study:

Contact e-mail address:

Submit

## Appendix Fii: Young person (over 15) consent form for interviews

### **Experiences of female young people who have received a diagnosis of autism spectrum condition during adolescence**

This research is looking at the experiences of females who have been diagnosed with an autism spectrum condition since the age of 11. Please only complete this form if you have read the information provided about the study.

Having read the information, if you consent to taking part in the project, please tick the I agree box below, along with your name.

#### **If you agree to taking part in this study, please tick the boxes and sign below.**

- I confirm that I am aged 16 or over.
- I have read the information sheet provided and wish to take part.
- I understand that taking part is voluntary.
- I understand that I am free to withdraw from the study up until the interview has been transcribed into words and made anonymous, without giving a reason.
- I understand that the interview will be treated confidentially by the researcher, but that if my parent is present during the interview to provide support, full confidentiality cannot be guaranteed.
- I understand that I can request my data or ask for it to be destroyed at any time up until the interview has been transcribed into words.
- I understand that findings from this research may be published in an anonymous form. I understand that at the end of the study I can be told about the research findings and may request a copy of the written report.

- I understand that I may ask any questions at any time. I am free to discuss my concerns with Rebekah Morgan or her supervisor Dr Ian Smillie, at Cardiff University.

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*The information on this consent form will be held securely and separately from the research information. Only the researcher will have access to this data and it will be destroyed after 7 years.*

I agree.

I do not agree.

Click to write the question text

Your name:

Your parent / carers name if they are the main contact for this study:

Contact e-mail address:



## Instructions for taking part

### Writing your blog / journal

To take part, please write a blog or a journal entry about each of the following things (you can use each point as a title). If you want you can use the journal sheets attached (but you don't have to):

- 1. Who am I?** *In this section please introduce yourself. Tell me what you think about yourself as a person. For example: "I am an intelligent person because I enjoy finding out about things". You might want to write about your strengths and weaknesses, or the things that make you 'you'. You might want to include important memories. Remember, there are no wrong answers so you can really write whatever you want me to know about you.*
- 2. Autism (or Asperger's) and me.** *In this section, tell me how it was to get a diagnosis of autism. Did it affect the way you thought about yourself as a person? Or perhaps you feel like it did not affect you at all?*
- 3. How I am the same as, or different to, other people:** *In this section, tell me about whether you feel that you are the same or different to others. For example, do you see yourself as part of a 'group' of people who are similar to you, but different to other groups of people?*
- 4. Other things that are important to know about me:** *You don't need to do a blog / journal entry for this section, but if you would like to, you can tell me about other important things about your experience as a young person with autism here.*

### Things to remember:

1. Please don't worry about spelling or grammar – the content of what you say is the most important thing.
2. Feel free to write as much, or as little, as you like under each heading.
3. Your parent / carer can help you by typing or writing for you, or to read the tasks to you, but it is important that it is your choice of words and your ideas and answers that are written in the blog / journal entries.
4. There are no wrong or right answers – everything you have to say about the subject will be interesting and important to the researcher.
5. The blog / journal itself will be private – it won't be published online.
6. If you decide not to take part, you can just decide not to send your blog / journal to the researcher, no questions will be asked (you are under no obligation to take part).
7. If something is not clear, or you have any questions, you (or your parent / carer if you are under 16) can get in touch with the researcher by e-mail on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk).

## Who am I?

*Tell me what you think about yourself as a person. For example: "I am an intelligent person because I enjoy finding out about things". You might want to write about your strengths and weaknesses, or the things that make you 'you'. You might want to include important memories. Remember, there are no wrong answers so you can really write whatever you want me to know about you.*

## Autism & me

*Tell me how it was to get a diagnosis of autism (or Asperger's/ASD). Did it affect the way you thought about yourself as a person? Or perhaps you feel like it did not affect you at all? For example, you could start with "When I found out I had autism I thought / felt...".*

## **How I am the same as, or different to, other people?**

*Tell me about whether you feel that you are the same or different to others. For example, do you see yourself as part of a 'group' of people who are similar to you, but different to other groups of people? For example, "Me and my friends are the same, we all enjoy..."*

## **Other things that are important to know about**

**me** *You can use this space to tell me about other important things about your experience as a young person with autism here if there is something else you would like to say (but you don't have to).*



School of Psychology,  
Cardiff University Centre for Human  
Developmental Science,  
70 Park Place,  
Cardiff. CF10 3AX

## Participant debriefing

Firstly, a big, huge **thank-you** for taking part in this research. I hope you enjoyed it.

The blog / journal entries you wrote will be stored on a password protected file. Within two weeks they will be anonymised, at which point your name, others' names, anything else that might identify you will be changed to a fake name.

Up until the data is analysed you can choose to remove your blog / journal entries from the research if you no longer wish for them to be included in the research. You do not need to give a reason.

I will then be writing my research report and looking at what everybody has said about their experiences of having an autism spectrum condition diagnosis as a young person.

The written report and blog / journal entries (with identifying information removed) will be stored on Cardiff University secure IT systems indefinitely.

It is hoped that this research will help to communicate the views of adolescent girls with autism to those who may be supporting them in the future. It may help Educational Psychologists and other professionals to support young people with an autism spectrum condition more effectively.

If you have any questions about the research please get in contact with me through email on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) or you can contact my research supervisor (Amy Hamilton-Roberts) on [Hamilton-RobertsA1@cardiff.ac.uk](mailto:Hamilton-RobertsA1@cardiff.ac.uk)

**This study has received full ethical approval from Cardiff University Ethics Committee.** For more details regarding ethics and this project, or to make a complaint please contact: School of Psychology Research Ethics Committee, Cardiff University, Tower Building, 70 Park Place, Cardiff. CF10 3AT; Tel: +44(0)29 208 70360; Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

## Thank you for your time!

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## What happens next?



School of Psychology,  
Cardiff University Centre for Human  
Developmental Science,  
70 Park Place,  
Cardiff. CF10 3AX

Firstly, a big, huge thank-you for taking part in this research. I hope you enjoyed it.

The interview will now be transcribed (written up). The recording will be stored on a password protected file. Within two weeks it will be written up and anonymised, at which point your name, others' names, anything else that might identify you will be changed to a fake name, and the recording of the interview will be permanently deleted.

Up until the interview is transcribed and anonymised you can choose to remove what you said from the research project. At which point the recording will be permanently deleted. You do not need to give a reason. I will then be writing my research report and looking at what everybody has said about their experiences of having an autism spectrum condition diagnosis as a young person.

The written-up interview (with identifying information removed) will be stored on Cardiff University secure IT systems indefinitely.

It is hoped that this research will help to communicate the views of adolescent girls with autism to those who may be supporting them in the future. It may help Educational Psychologists and other professionals to support young people with an autism spectrum condition more effectively.

If you have any questions about the research please get in contact with me through email on [morganrh1@cardiff.ac.uk](mailto:morganrh1@cardiff.ac.uk) or you can contact my research supervisor (Ian Smillie) on [smillie@cardiff.ac.uk](mailto:smillie@cardiff.ac.uk)

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Thank you for your time!

GDPR Statement: The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and Matt Cooper is the data protection officer ([inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)). The lawful basis for processing this information is public interest.

**Thank-you for taking part.**

Appendix Ii: Interview presentation: version 1

<p>The person you thought you were before you were diagnosed with autism.</p>  <p>How would you describe this person to others? What kind of a person are they?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How was this person with their family?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did this person become like this? Was it from birth or did things happen to make them like this?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What would be in their school bag?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What groups did this person belong to? What were those groups like? How did they feel in them?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What did the future look like?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What would be their ideal birthday present?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did this person get on at school?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did this person view autism and autistic people?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How was this person with their friends?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What was this person's biggest fear in life?</p>	<p>When you were diagnosed with autism:</p>  <p>Tell me how that happened, what you thought, how you felt?</p>
<p>The person you feel you are now:</p>  <p>How would you describe yourself to others? What kind of a person are they?</p>	<p>The person you feel you are now:</p>  <p>How are you with your friends?</p>	<p>The person you feel you are now:</p>  <p>How did you become this person? Was it from birth or did things happen to make you like this?</p>
<p>The person you feel you are now:</p>  <p>What would be in your bag?</p>	<p>The person you feel you are now:</p>  <p>Do you belong to any groups? What are those groups like? How do you feel in them?</p>	<p>The person you feel you are now:</p>  <p>What does the future look like for you?</p>
<p>The person you feel you are now:</p>  <p>What would be your ideal birthday present?</p>	<p>The person you feel you are now:</p>  <p>How do you get on at school/college or work?</p>	<p>The person you feel you are now:</p>  <p>How did you view autism and other autistic people?</p>
<p>The person you feel you are now:</p>  <p>How are you with your family?</p>	<p>The person you feel you are now:</p>  <p>What would be your biggest fear in life?</p>	<p>The person you feel you are now:</p>  <p>Is there anything you expected me to ask that I haven't asked you? Or anything you would like other people to understand about being autistic?</p>

Appendix Iii: Interview presentation: version 2

<p>The person you thought you were before you were diagnosed with autism.</p>  <p>What did you think about yourself at the time? What words would you have used to describe yourself then?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How were you with your family?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did you become this person? Was it from birth or did things happen to make you like this?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What would have been in your school bag?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What groups did you belong to? What were those groups like? How did you feel in them?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What did the future look like to you?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What would have been your ideal birthday present?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did you get on at school?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How did you view autism and autistic people?</p>
<p>The person you thought you were before you were diagnosed with autism:</p>  <p>How were you with your friends?</p>	<p>The person you thought you were before you were diagnosed with autism:</p>  <p>What was your biggest fear in life?</p>	<p>When you were diagnosed with autism:</p>  <p>Tell me how that happened, what you thought, how you felt?</p>
<p>The person you feel you are now:</p>  <p>How would you describe yourself to others? What kind of a person are you?</p>	<p>The person you feel you are now:</p>  <p>How are you with your friends?</p>	<p>The person you feel you are now:</p>  <p>How did you become this person? Was it from birth or did things happen to make you like this?</p>
<p>The person you feel you are now:</p>  <p>What would be in your bag?</p>	<p>The person you feel you are now:</p>  <p>Do you belong to any groups? What are those groups like? How do you feel in them?</p>	<p>The person you feel you are now:</p>  <p>What does the future look like for you?</p>
<p>The person you feel you are now:</p>  <p>What would be your ideal birthday present?</p>	<p>The person you feel you are now:</p>  <p>How do you get on at school/college or work?</p>	<p>The person you feel you are now:</p>  <p>How do you view autism and other autistic people?</p>
<p>The person you feel you are now:</p>  <p>How are you with your family?</p>	<p>The person you feel you are now:</p>  <p>What would be your biggest fear in life?</p>	<p>The person you feel you are now:</p>  <p>Is there anything you expected me to ask that I haven't asked you? Or anything you would like other people to understand about being autistic?</p>

Appendix liii: Interview presentation: version 3

<p>The person you imagine you might be if you did not have autism.</p>  <p>What words would you use to describe this person?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>How would you be with your family?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>How would you have become this person? (Born this way? or become like this through your experiences?)</p>
<p>The person you imagine you might be if you did not have autism.</p>  <p>What would be in your school bag?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>What groups would you belong to? How would you feel in those groups?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>What would the future look like to you?</p>
<p>The person you imagine you might be if you did not have autism.</p>  <p>What would be your ideal birthday present?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>How would you get on at school?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>How would you view autism and autistic people?</p>
<p>The person you imagine you might be if you did not have autism.</p>  <p>How would you be with your friends?</p>	<p>The person you imagine you might be if you did not have autism.</p>  <p>What would be your biggest fear in life?</p>	<p>When you were diagnosed with autism:</p>  <p>Tell me how that happened, what you thought, how you felt?</p>
<p>The person you feel you are :</p>  <p>How would you describe yourself to others? What kind of a person are you?</p>	<p>The person you feel you are:</p>  <p>How are you with your friends?</p>	<p>The person you feel you are:</p>  <p>How did you become this person? Was it from birth or did things happen to make you like this?</p>
<p>The person you feel you are:</p>  <p>What would be in your bag?</p>	<p>The person you feel you are:</p>  <p>Do you belong to any groups? What are those groups like? How do you feel in them?</p>	<p>The person you feel you are:</p>  <p>What does the future look like for you?</p>
<p>The person you feel you are:</p>  <p>What would be your ideal birthday present?</p>	<p>The person you feel you are:</p>  <p>How do you get on at school/college or work?</p>	<p>The person you feel you are:</p>  <p>How do you view autism and other autistic people?</p>
<p>The person you feel you are:</p>  <p>How are you with your family?</p>	<p>The person you feel you are:</p>  <p>What would be your biggest fear in life?</p>	<p>Is there anything you expected me to ask that I haven't asked you? Or anything you would like other people to understand about being autistic?</p> 

I am going to anonymise data so parents can't piece together excerpts to pinpoint what their children said

20.10.2020

I've been reading about episodic memory difficulties for some / many autistic people. Now I'm concerned about the fact that my interview schedule is based on remembering before diagnosis. Feel it is appropriate to amend the wording to focus on who person is but then provide another set of questions about who they imagine they would be if they did not have autism. This might allow some insights about who they feel they are that the questions based on who they are now might not enable them to explore.

~~\_\_\_\_\_~~:

Really happy with how the interview went. I suited the order of the questions around to start with 'now' as ~~\_\_\_\_\_~~ seemed a bit stuck / confused. And that worked really well. I was struck by how powerful some of the things ~~\_\_\_\_\_~~ articulated. She really had what seemed like a secure view of her needs and her sense of self, supported by her family. Lots of laughter that supported her view of herself as 'happy'.

Antaki et al. (2003) identify six ways that research can fall short of Discourse Analysis (DA). The six pitfalls are identified below, and each is addressed in relation to the current piece of research.

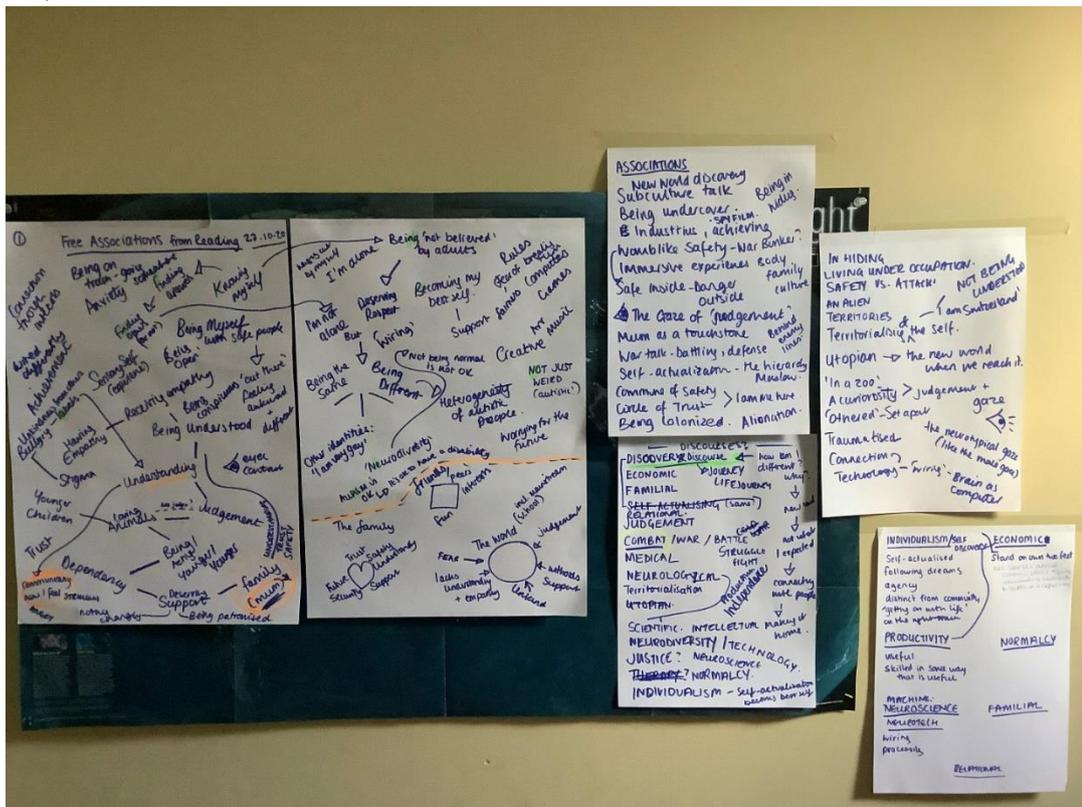
<b>Mistakes to avoid</b>	<b>The present study</b>
<p><b>Under-analysis through summary:</b> This relates to when research merely summarises what people say in themes. This means that information is lost (as the nuance of how it was said is lost) and nothing is added as it does not offer an analysis of the discourse that the speaker uses.</p>	<p>Include summary at the beginning of each construct in order to present it to reader but ensure to also display sufficient number of quotes so that the participants data is also displayed for the reader to see. Analysis is done in steps 4 and 5.</p>
<p><b>Under-analysis through taking sides:</b> This refers to research that merely offers the analyst’s own moral, political or personal stance towards what is said, which on its own, is not DA. Position taking is not analysis of itself.</p>	<p>Reflexivity as a researcher is built into the process through journaling and explored in paper 3.</p>
<p><b>Under-analysis through over-quotation or through isolated quotation:</b> This occurs when research simply compiles a list of quotations snipped from the data. It is often revealed through a low number of analysts comments to data extracts. Also, isolating a quote and expecting it to ‘stand for itself’ without providing analysis is not DA.</p>	<p>Quotes are presented but then balanced against a summary of the theme, and further analysis in steps 4 and 5.</p>
<p><b>The circular identification of discourses and mental constructs:</b> Circularity occurs when the analyst claims the presence of a particular discourse in the data, and then explains the use of it by way of the fact that the discourse ‘exists’. For example, an analyst might claim a discourse of ‘faithfulness’ and then explain use of the discourse as being reproduced due to a ‘faithfulness’ discourse. Rather the</p>	<p>Avoiding use of circularity – discursive analysis in steps 4 and 5 steer the researcher away from this tendency. There is no step in this analysis that considers the ‘why’ of participants use of discourses as this was not part of the research question (more concerned with ‘how’).</p>

<p>analyst must perform some discursive analysis of the function of people's use of discourses.</p>	
<p><b>Under analysis through false survey:</b>  This relates to the danger of extrapolating from one's data to the world at large. It is fatally easy to slip into treating one's findings as if they were true for all members of the category in which one has cast one's respondents.</p>	<p>No 'truth' claims are made about this piece of work, rather the role of the researcher in 'constructing' patterns out of the data is acknowledged. Rather than focus on 'all adolescent autistic girls' this really surveys what ways of talking (discourses) exist for constructing the self, therefore no actual truth claims are made of the participants themselves, or the 'members of the category' they represent.</p>
<p><b>Analysis that consists in simply spotting features:</b>  This refers to research which merely points to the structural features of people's utterances and labels the different aspects, as for example in conversation analysis.</p>	<p>This DA used a macro approach and so did not focus on the micro aspects of people's situated use of language, therefore did not fall into this error.</p>

Appendix K: Analytical procedure

Photographs of steps taken in the analysis of the discourse.

Step 1:



*Step 2:*

This is a screen caption of the highlighted transcript that has been coded highlighting both implicit and explicit reference to the discursive object within the data.

HOW I AM THE SAME AS, OR DIFFERENT TO, OTHER PEOPLE

I don't feel that I belong in any group.

I feel I am an outcast

I belong with my immediate family

I often find boys easier than girls

I am different to most girls ... I don't like the things that most girls like & I don't like the things that most young adults like. But I also don't like being excluded.

I like rules to be followed & I don't understand why some people get away with breaking rules.

OTHER THINGS THAT ARE IMPORTANT TO KNOW ABOUT ME

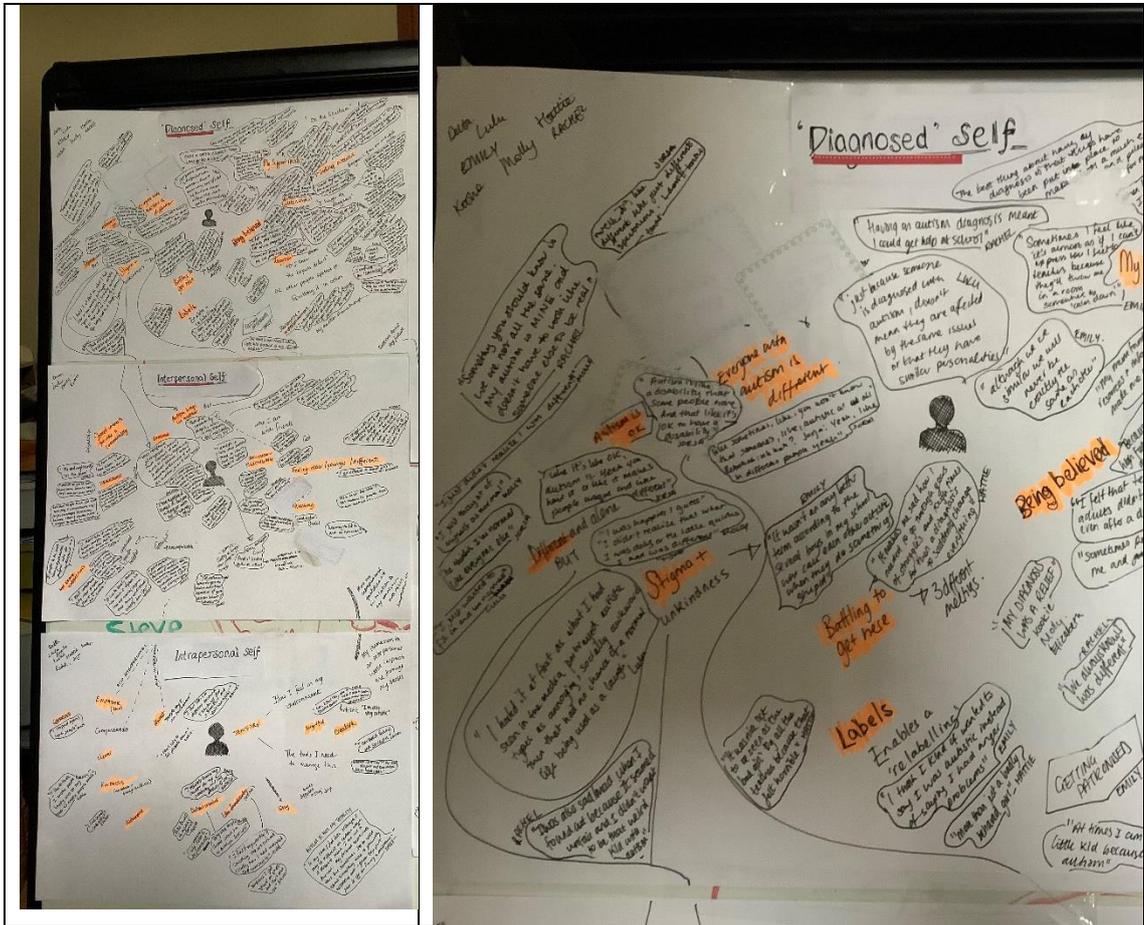
MY EXPERIENCES AS A YOUNG PERSON WITH ASC

I don't feel that people believe me ... I have often been told I am lying, making it up to get my own way, over reacting, being too sensitive ...

I felt that teachers & adults didn't believe me even after diagnosis. People said I couldn't be autistic because I can talk or I wasn't like other ASC people they

Step 3:

These photographs show some of the emergent discourses being developed at the beginning of step 3. It involved going back to the free associations made during the first stage, and cross referencing against the original data in an iterative process. Labels for constructs at this stage were later amended as clusters of patterns were pulled together into constructs and discourses.



Steps 4 & 5:

Some screenshots of steps 4 & 5 being undertaken in word tables.

Discourse: Diagnostic			
Discursive constructs	Data excerpts	Stage 4: Identifying subjects and positions	
<p><b>I am autistic</b></p> <p>Diagnosis settles the matter (experts know best)</p>	<p>D: And yeah, so I mean. The rest of the year after I was diagnosed, it wasn't much different but it was a bit easier.</p> <p>R: Yeah, ye-yeah.</p> <p>D: In that. You know like. <u>We're</u> not making it up at all.</p> <p>D: <u>Cause</u> once you have the diagnosis saying hey, look she's special</p> <p>R: Mm.</p> <p>D: You know, suddenly it goes OK well now you can look at these other schools 'cause now you actually say you actually have something saying yes, I'm different, it's not just I think she's different.</p> <p>D: It's really nice, I have control over my life, so to speak.</p> <p>R: Mm. Mm.</p> <p>D: Not as much control like in the independence department</p> <p>R: Mm.</p> <p>D: But I feel like I can say if <u>something's</u> wrong</p> <p>R: Yeah</p> <p>D: And that they might <u>actually</u> believe it.</p> <p>R: Well, is there anything new to say about how you are with your family? Do you think <u>that's</u> changed?</p> <p>D: Erm. Yeah, <u>there's</u> a lot less stress.</p> <p>R: Yeah.</p> <p>D: Or like anxiety.</p> <p>R: Mm.</p> <p>D: At least with context to me being autistic now I <u>actually</u> know what it is.</p> <p>R: Yeah.</p> <p>D: You know</p>	<p><b>Stage 4: Identifying subjects and positions</b></p> <ul style="list-style-type: none"> <li>Who are the discursive subjects created by the discourse?</li> <li>Who can speak in this discourse? When and with what authority?</li> <li>What ways of 'knowing' / acting / being are opened up or closed down for discursive subjects through the talk?</li> <li>What opportunities for resistance might be made available through use of other discourses?</li> </ul> <p>This discourse is made up of two constructs. It creates a number of subject positions: the diagnosed autistic person, the non-autistic other (for example a teacher or an administrator controlling access to resources); the non-diagnosed person who believes they are autistic, support <u>givers</u> (often mothers) and support deniers.</p> <p>For the diagnosed autistic <u>person</u> this construct creates the discursive space for truth claims about their autistic status. When others question their diagnosis (as participants explicitly state happens) it creates a discursive opportunity to provide 'proof'. At the same time, it potentially closes off spaces for questioning their own diagnosis. It is very much linked to a medical discourse where 'experts know best'.</p> <p>Some participants report 'knowing they were different' and yet this construction does not allow the discursive space to self-identify as autistic. Clinical professionals are thus constructed, implicitly, as those who are sense makers. They are not only constructed as gatekeepers to diagnosis, but as gatekeepers to an authentic sense of self-knowledge. <i>There is a sense in which this discourse 'empowers' autists as they can claim a sense of self, but at the same time that 'sense of self' is constructed as legitimate only at the point at which a 'professional' provides a diagnosis.</i></p> <p>Professionals involved in diagnosis are constructed as experts in this discourse. They are afforded access to the 'truth' over others and the 'final word'. Support needs being met are constructed as contingent on diagnosis, and experts are given gatekeeper status over the word 'autism' and those that <u>enter</u> into it, with power to allow or deny entry.</p> <p>To the person who would question the validity of a diagnosis they are put in the subject position as a non-expert, where the word 'diagnosis' refutes all other truth claims. <i>There is little discursive space to question other participants' positions</i></p>	<p><b>Stage 5: Power in discourse:</b></p> <ul style="list-style-type: none"> <li>How is power reproduced or resisted through the discourses?</li> <li>Who gains and who loses?</li> </ul> <p>Clinicians, autism 'experts' retain their expert status. This discourse reinforces it and keeps them as gatekeepers to the resources that diagnosis enables (2). It does not disrupt this, and even where participants <u>communicate</u> they suspected it – or that others did not believe it – it was the experts that gave it credence.</p> <p>Who gains? The autism 'industry'. Autistic people can get access to resources (school, i.e. Daisy).</p> <p>Who loses? People without a diagnosis but with the same underlying experiences and support needs. They are kept on the other side of the gate. Self-diagnosed autistic people.</p>

Discourse: Normativity			
Discursive constructs	Data excerpts	Stage 4: Identifying subjects and positions	
<p><b>Fitting in / sticking out</b></p> <p>(normativity and how I see myself related to it)</p>	<p>D: So they were rather down to earth people, which meant these people grew up in houses with rather down to earth people. They were all rather mature for their age.</p> <p>R: Yeah, yeah</p> <p>D: Which suited me perfectly 'cause I always felt like I was like years older than everyone else, you know so I was like, they're a bit closer to how I feel.</p> <p>D: Um. But yeah, as I went on into like secondary school, I formed another friend group and again it was most of the people who didn't fit in. I think I was kind of like drawn to them. It's ironic 'cause in my second primary school I was the only friend to a boy who, as it turns out, is autistic.</p> <p>D: Um, and in secondary school, before I got diagnosed, my friend group was made up of maybe four people who are still known as Neurotypical and about six people who were either already <u>diagnosed</u>, or are now diagnosed as autistic.</p> <p>R: Yeah, yeah, mm.</p> <p>D: I, I, kind of joked with my mum after I got diagnosed 'I'm just drawn to autists, that's it, I'm an autistic radar (laughs)). You know, like before I was diagnosed, I was like <u>all of</u> these people with autism really like me huh? ((general laughter)).</p> <p>R: And so, how are friendships now?</p> <p>D: Er. I would say <u>they're</u> like the autistic side of a typical teenage friendship.</p> <p>R: Yeah.</p> <p>D: You know, I mean, most of my friends are autistic.</p> <p>R: Hm mm.</p> <p>D: They've either been diagnosed since I got to know <u>them</u> or they were already diagnosed when I met them you know.</p>	<p><b>Stage 4: Identifying subjects and positions</b></p> <ol style="list-style-type: none"> <li>Who are the discursive subjects created by the discourse?</li> <li>Who can speak in this discourse? When and with what authority?</li> <li>What ways of 'knowing' / acting / being are opened up or closed down for discursive subjects through the talk?</li> <li>What opportunities for resistance might be made available through use of other discourses?</li> </ol> <p>This discourse constructs a number of discursive subjects: 'people like me' and 'people <u>not</u> like me', safe people and unsafe people.</p> <p>'People like me' are often those who <u>don't</u> quite fit in with others (boys, nerds, autistic people, people who like cats). It is the 'sameness of being different' that constructs this 'in-groupness'. The 'people like me' are most often constructed as different from a non-defined 'other people' who are viewed as 'other' and typical. This construction creates the discursive space for belonging but at one and the same time it also creates a group that bars one from access to it. An 'othering' of the self (and others like the self) occurs where the self is defined as different (from a non-defined group from whom one differs). Belonging as a concept is constructed when discussing where one fits, who one is the same as, where one feels comfortable.</p> <p>There is also an 'other' autistic person that is located in the media ('socially awkward men') or as somebody people laugh at 'that weird kid'. It creates a necessity to distance oneself from the 'other autistic' or the 'stereotypical autistic'. Weird is a bad word unless it is reclaimed (and some participants do this "weird but not in a bad way").</p> <p>It also constructs a 'normal girl'. They are constructed as a more homogenous group. They are not well defined, rather they come under a banner of 'normal' and are distinct as an 'other' because they don't stick out and they don't have autism. They are constructed as sociable, <u>complicated</u> and able to be flexible with plans, as being comfortable in social environments and with other people. These 'normal' discursive subjects are positioned in spaces that sometimes excludes, shames or sometimes accepts the autistic discursive subject.</p> <p>In turn this discourse positions the autistic self as needing to hide one's 'true' autistic identity under the guise of a 'normal' person <u>so as</u> to avoid the stigma attached to the 'other' stereotypical autistic subject.</p>	<p><b>Stage 5: Power in discourse:</b></p> <ul style="list-style-type: none"> <li>How is power reproduced or resisted through the discourses?</li> <li>Who gains and who loses?</li> </ul> <p>Power is reproduced in a normativity discourse by centring around neuro-normative behaviours as 'ideal'. Those who gain are those who sit within what is constructed as 'normal' and those outside of normativity are othered. Those that are 'othered' may find it hard to construct a sense of belonging and this may bring implications for wellbeing.</p>

Appendix L: Frequency of use of discursive constructs

<b>Discursive construct</b>	<b>Participant pseudonyms</b>	<b>Frequency</b>
I am unique	Rachel Jorja Lulu Emily Daisy Elizabeth Hattie Kookie	1 5 1 2 6 2 2 2
I am a person with support needs	Emily Kookie Elizabeth Rachel Hattie Jorja Daisy Lulu Molly	2 3 7 2 2 2 9 1 1
I am autistic	Daisy Rachel Kookie Elizabeth Jorja Hattie Emily Delta Lulu Molly	6 3 2 3 2 2 2 1 1 3
Fitting in /sticking out	Daisy Lulu Emily Delta Kookie Hattie Elizabeth Rachel Molly Jorja	12 4 3 4 5 1 2 2 4 5
Feeling safe to be me (authenticity)	Molly Kookie Emily Hattie Daisy Elizabeth	6 1 2 1 2 5

	Delta Lulu	2 1
In the process of becoming	Daisy Delta Hattie Kookie Emily Jorja Elizabeth Molly	8 4 1 1 1 1 2 3

Appendix M: Reflective journal entry

November 23, 2020

I have been immersing myself in the data for 3 days now and have started to lose a sense of focus. I started to develop a theme around the 'sensory self' - that is the <sup>experi</sup>experience of autistic people. However I do not feel on reflection that the participants are truly constructing 'self' by talking about their sensory experiences. Rather they are exploring a phenomenological experience that is part of their lived realities. It's an important theme in some talk but it is not within the scope of this research to explore experience, and therefore I feel I need to abandon this concept of a 'sensory self'. I feel it is a good example of trying to fit the data to ones pre-conceived notions of what types of results one wants to present. For example, a 'multiplicity of selves' presented around the key attributes of autism would probably be highly possible to 'find' in the data if one so wished. I might look for a 'restricted self' and explore the data for 'evidence' of participants constructing the self as a person with a restricted set of interests. I could then use the data to justify the actual presence of these diagnoses. However, with the DA - and the beauty of it - I could then examine what implications arise from use of that discourse - what can be said, what cannot be said, who can say it etc. Therefore DA ensures a criticality about what is being said and here it does not hold them up as 'truths'. This can be disorienting at first. It can feel like 'anything goes' and it can feel circular - i.e. it's there because I say it's there. And then I see that is exactly what Burr talks about - "the constitutive power of language" you can declare something a thing and there will always be consequences - especially when those things become established truth.

