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What right do we have to label? Understanding the impact of Asperger's syndrome on self-identity, anxiety, depression and self-esteem.

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Abstract

This study aims to explore the links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem. The initial interest in this research subject was sparked after discussions with individuals who felt they have Asperger's syndrome and questioned whether a diagnosis was right for them? Following this I read Portway and Johnston's (2005) article: "Do you know I have Asperger's syndrome? Risks of a non-obvious disability", Within this they questioned the need of a diagnosis on no obvious disabilities such as Asperger's syndrome. I found this article following this I decided to explore the potential impact that this may have on self-identity, anxiety, depression and self-esteem as they are all known to affect one another. The research followed an interpretivist research paradigm, aiming to explore the lived experiences described by the participants, with the hope of interpreting their answers in relation to the research questions (Gray, 2014). In addition to this the research followed an Epistemological stance which has been constructivism, through this I believe that knowledge is developed through our experiences and the people we surround ourselves with. Constructivism views individual knowledge as buildable and unique (Gray, 2014). The methodological standpoint has been phenomenology, as this research has explored the individual, unique experiences of the individuals taking part. Five participants took part in this study who have all been diagnosed with specifically Asperger's syndrome, and all participants were over the age of 18 whilst taking part in the study. Each participant gave informed consent prior to the interview, through a consent form. The consent form explains that they understand what the research aims to achieve and what will be expected from them throughout the research. They were also made aware of the sensitive topics that were to be discussed within the interviews and that they have the right to withdraw at any point. As the participants are in a vulnerable position, due to both their diagnosis and the sensitive topics discussed, steps were taken to ensure that they were capable of providing informed consent and were kept safe throughout the interview process and following the interviews. Each participant took part in a 4-part semi-structured interview which followed a phenomenological approach aiming to explore the lived experiences of each participant. These interviews were conducted via telephone calls and through email then later transcribed. Following the interview's, the findings were analysed through a thematic analysis approach attempting to answer the proposed research questions. The overall findings of this study have suggested that all of the participants were able to provide a high level of self-understanding. Additionally, some of the participants expressed how a diagnosis enabled them to understand their strengths and weakness', giving reason to why they struggled with certain things. This suggests that in terms of self-identity a diagnosis of Asperger's syndrome was beneficial. However, in terms of self-esteem, although some individuals appeared to have low self-esteem there was no indication that this was due to their diagnosis. Finally, I was unable to indicate whether the participants diagnosis had an

impact on anxiety and depression, although some participants stated that they related to different symptoms, as described by the NHS, they did not state that they had been diagnosed by any professional. Following on from these findings, I have suggested within the discussion that in order to fully answer these questions the study would benefit from a longitudinal case study following the lives of individuals throughout their diagnostic process.

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Chapter 1 – Introduction

1.1 Introduction

This chapter introduces the research study, within this I will clarify the research questions and aims of the research. Additionally, I will provide some brief background information about Asperger's syndrome, self-identity, self-esteem, anxiety and depression which will later be discussed in more depth throughout the literature review. Furthermore, I will discuss the methods used throughout this research, which will later be discussed in depth within the methodology chapter.

The main aim of this research study is:

- To gather information about the lives of individuals who were diagnosed with Asperger's syndrome, with the aim to explore any potential links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem.

During my time studying in higher education, I have been working with children who have Autism spectrum disorder, including children who were yet to be diagnosed or were mid diagnosis. Through these experiences, I started to develop a passion for working with children who have special educational needs and disabilities (SEND). In addition to this, I have had discussions with individuals who, either believe their child may have or they themselves may have Asperger's syndrome. These individuals have expressed their worries towards being diagnosed with Asperger's syndrome and whether gaining a diagnosis is the right thing to do. They have stated that they worried about having a 'label' and the impact that it may have on them in various ways such as receiving extra support in work or education, and in turn emphasizing their differences this worry has stopped them from seeking a diagnosis. Furthermore, during my undergraduate degree, I often opted to research the Autism spectrum disorder throughout various pieces of work, including my major study. The initial interest in this research subject was sparked by Portway and Johnston's (2005) article: "Do you know I have Asperger's syndrome? Risks of a non-obvious disability". Within their research, Portway and Johnston (2005) questioned the risk involved with diagnosing Autism spectrum disorder. They also discussed the effect of labels, specifically on those with non-obvious disabilities, such as Asperger's syndrome, whose diagnosis are not always apparent when first meeting. They have named this phenomenon 'marginal normality', as the individuals involved often appear to be neurotypical, unlike those with a physical disability whose disability is apparent from the first meeting (Portway and Johnston, 2010. p. 73).

Research Questions:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

Self-identity, anxiety, depression and self-esteem are closely linked together; by having positive mental health, individuals are more likely to develop a clearer self-identity (Mee, Sumsion & Craik, 2004) and explore how they developed into the person they are today, what factors brought them here and ultimately how they personally view themselves (Jackson, Skirrow & Hare, 2011, and Hart & Damon, 1988).

The research will hopefully inform my own and others' practice when working with children who are going through diagnosis and those who are diagnosed with Asperger's syndrome, in order to understand how to support them when developing their self-identity and to manage any current or possible issues with anxiety, depression and self-esteem. Matthews (2014), suggests that whilst a label, such as Asperger's syndrome, may provide positive attributes such as providing educational support, excessive emphasis on labels may also diminish a child's self-identity. There is conflicting research surrounding the impact of labels, for instance, McKay & Neal (2009) have suggested that a label of special educational needs can stop children from being labelled with negative labels such as a "naughty" or "stupid" child; which has been reiterated by Parens (2011) who suggests that it's better to label people with a constructive diagnosis, than let them be given negative labels by society, hence suffer from them. Despite a lack in the understanding of the effect that labels can have on children, each year, the number of individuals diagnosed with Autism spectrum disorder is rising (Department of Education, 2017). Neurodiversity is a very dominant movement and surrounding the discussion of neurological differences, such as Asperger's syndrome. It states that neurological differences are to be supported and are viewed as strengths rather than from a deficit perspective. Individuals following the movement promote self-advocacy and mutual support for those with neurological conditions (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Masataka, 2017). Research has shown that with a diagnosis, there is support in place for children with Autism spectrum disorder, such as providing access to services, education resources and funding rather than trying to 'fix' or 'cure' the individual (McKay & Neal, 2009; Muskat, 2016; Mitchell, 2017; and Singh & Elsabbagh, 2014). However, many researchers have questioned when it is and is not appropriate to diagnose, and whether we understand all of the risks involved with a diagnosis (Langager, 2014; Parens; Johnston; Burke; Carey; Benedetto Vitiello; and Mango Zito, 2011; Portway & Johnson, 2005; and Whitaker, 2004). This has been reiterated by Parens, et al. (2011).

P. 27) who has suggested that; “informed, trained, caring people will thus sometimes have reasonable disagreements about where to set diagnostic thresholds and whether a mildly affected child – a child in the “zone of ambiguity” – would benefit from diagnosis.”. However, when viewed from a neurodiversity standpoint a diagnosis is always beneficial as it provides help in order for individuals to live life with less complications. As the research questions state, the aim of this study is to explore the any potential impact that Asperger’s syndrome may have on an individual’s self-identity, anxiety, depression and self-esteem and if so, whether the impact of this is positive or negative. As briefly mentioned above from the findings of this study, I hope that I will be able to inform my own and others’ practice when supporting individuals in order to have healthy mental health and self-esteem along with developing a positive self-identity. I will explore any potential impact of the diagnosis will through interviews, aiming to explore the participants’ feelings towards their self-identity, self-esteem and whether they show signs of anxiety and depression.

Throughout this introduction and continuing through this research study I have used terms such as ‘symptoms’, ‘disability’ and ‘norm’, before I continue with this introduction, I will give an explanation to some terms used that may need further explanation. Within this study the term ‘symptoms’ has been used to describe any traits or behaviours that individuals with Autism spectrum disorder or Asperser’s syndrome may have, I have chosen to use the word ‘symptoms’ as although the disorder is mainly made of traits and behaviours other more physical factors also come under this bracket such as a sensory overload (National Health Service, 2019). Additionally, the choice has been made to use the word ‘disorder’ over ‘condition’, this has been chosen as it appears to be the current preferred choice both within current literature (Li, Decety, Hu, Li, Lin and Yi, 2019, Shrestha, Dissanayake and Barbaro, 2019, MEhra, Sil, Hedderly, KyriaKopoulos, Lim, Turnbull and Absound, 2019). The word ‘norm’ have been used throughout this research, again this has been chosen due to the use of the word throughout relevant literature, for the purpose of this study these terms are used when discussing what is the average or typical within society (Portway and Johnsom, 2005 and National Autistic Society, 2018). Additionally, ‘disability’ has been used throughout this research as an umbrella term used to discuss anyone with a condition which may impact them day to day, this term has been adopted by the National autistic society (2019). Furthermore, the term disability has been used throughout the research of others, for instance Molloy and Vasil (2004) discusses what effect a diagnosis of Asperger’s syndrome has on children and how they will be perceived having been diagnosed with a disability. Additionally, although Stoddart and Stoddart (2004) has discussed Asperger’s syndrome as a disability they have also stated that pervious research indicated that the majority of children with an Asperger’s syndrome diagnosis did not view it as a disability. However, in contrast to this a common comment

throughout literature is the frustration expressed by individuals in having a hidden disability (Portway & Johnston, 2005, Molloy & Vasil, 2004 and Stoddart & Stoddart, 2014). It has been suggested that the term disabled, or disability is most often viewed from a medicalised view of disability (Stoddart & Stoddart, 2014) viewing the term from a deficit perspective (Sarrett, 2016 and Connors & Stalker, 2006). However, in recent years the term has been used in the social model of disability (Oliver & Sapey, 1999 and Woods, 2017) viewing disability as a problem in society. This research follows a social model view of disability viewing Asperger's syndrome as a societal problem.

1.2 Self-identity

As mentioned previously, part of this research aims to explore the potential impact that Asperger's syndrome has on self-identity. Waterman (cited in Chen & Yao, 2009), discusses the areas that he believes make up self-identity including: goals, values, beliefs, behaviour, decision making, self-esteem, self-evaluation, desires, fears and our future expectations. This overall definition of self-identity encompasses the areas that have been discussed within Hart and Damon's self-understanding scale (Hart and Damon 1988). Within the self-understanding scale, the seven subject areas questioned are: Self-definition; Self-evaluation, Self in the past and Future; Self-Interest; Continuity; Agency and; Distinctness (Jackson, Skirrow & Hare, 2011). Hart and Damon created this interview to understand the way individuals view themselves in the present, past and future.

1.3 Anxiety and depression

In addition to exploring the potential impact of self-identity as the research questions state I will also be aiming to explore the potential impact on anxiety and depression. Those without anxiety or depression are seen as having "healthy" or "positive" mental health, whereas those who are suffering from mental health conditions, such as anxiety and depression, are seen to have "poor" mental health (Pandya, Viridi & Stirling-Yeatman, 2019). There are many different conditions which affect an individual's mental health, however, this study will be focusing only on anxiety disorders and depression throughout, as they have been found to be the two biggest mental health concerns within the United Kingdom (UK) to date (Office of National statistics, 2012). 80% of individuals with Autism spectrum disorder suffer from at least one mental health condition and 40% with at least one anxiety disorder (Barber, 2018). Depression and anxiety share some symptoms with Asperger's syndrome that may cause them to go undiagnosed or misdiagnosed (Chandrasekhar & Sikich, 2015 and Ghaziuddin, 2005) therefore, it can be difficult to differentiate between the symptoms. Similar to self-identity, research has shown a link between mental health and self-

esteem and therefore these links will be explored within this study (Moksnes & Espnes, 2012 and Baum & Neuberger, 2013).

1.4 Self-Esteem

As discussed within the 'What is self-identity' section of this chapter, self-esteem plays a vital part in how we develop our self-identity. In addition to this, self-esteem also impacts on our mental health, including anxiety and depression (Baum & Neuberger, 2013). Due to this, I will also be exploring the potential impact of a diagnosis of Asperger's syndrome on self-esteem. Self-esteem has been defined as the opinion one has of themselves. Those with a high self-esteem see themselves in a positive light and at least as equal to others, whereas those with low self-esteem view themselves as less than (Matheson, Daoud, Hamilton-Wright, Bornstein, Pedersen, & O'Campo, 2015). In accordance with neurodiversity those with neurological disorders should be supported by society and by one another in order to create support that allows us all to be equal (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Masataka, 2017). With this in mind it suggests that individuals with Asperger's syndrome should have a high self-esteem after a diagnosis if offered more support. However, Taylor, Hume and Welsh (2010) have suggested within their research that those with SEN have shown to have lower self-esteem, similarly, Baldwin and Costley (2016) suggests that 80% of individuals with Asperger's syndrome are suffering from mental health issues, rather than the 34% of individuals without SEN. It could be argued that self-esteem is a product of society and how society views an individual. This will be explored in more depth throughout the literature review whilst discussing self-identity and self-esteem (2.3.3) along with mental health and self-esteem (2.4.3).

1.5 Asperger's syndrome

As previously touched upon, this research subject has developed through my ongoing interest in Autism spectrum disorder and more specifically Asperger's syndrome. Autism spectrum disorder is defined by the NHS (2016) as a spectrum disorder affecting social interaction, communication, interests, and behaviour. Asperger's syndrome has been described as a disorder which has the same differences regarding social interaction as Autism spectrum disorder. Individuals with Asperger's syndrome have restricted, repetitive interests, as do individuals with Autism spectrum disorder although they do not have a cognitive or language delay (World Health Organization, 1992). There are many terms used to describe individuals with and without Asperger's syndrome/Autism spectrum disorder within the Autism community. However, for the purpose of this research any individuals without a neurological disorder will be discussed as typically developing. Through a neurodiversity perspective Asperger's syndrome is viewed as a strength,

under the belief that there is no one way to think (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Masataka, 2017). the movement suggests that society should adapt for to ensure everyone is supported and given a fair opportunity.

As Autism spectrum disorder spans over such a wide spectrum where symptoms range from slight to extreme. Those diagnosed with Asperger's syndrome are on the 'high functioning' end of the spectrum (National Autistic Society, 2018 and National Health Service, 2016) meaning their symptoms are only slight in comparison to those who are lower functioning, for example they may have no language delay where as someone with low functioning Autism Spectrum disorder may have no language at all. This has factored into the decision to focus solely on Asperger's syndrome as I feel that by only interviewing individuals with Asperger's syndrome, they will be more likely to have similar symptoms to one another. Additionally, as all the individuals interviewed are over the age of 18, they will have been diagnosed whilst Asperger's syndrome was separated from Autism spectrum disorder and therefore will have gone through a different diagnostic system than those diagnosed with Autism spectrum disorder (World Health Organization, 2018). It is important that the individuals have as similar a diagnosis as possible so that the findings can be compared in order to see if there are any correlating factors or significant differences, by limiting the time span between the participants diagnosis it insures that they were all diagnosed under the ICD-10's (World Health Organization, 1992) definition of Asperger's syndrome. Furthermore, Autism spectrum disorder is known to have an impact on an individual's IQ, communication and social skills therefore it felt more appropriate to only interview those with Asperger's syndrome as not everybody with Autism spectrum disorder will have been able to provide informed consent (Hamilton et al., 2017, and Loyd, 2012).

Asperger's syndrome was once thought to be separate from Autism spectrum disorder, but with the recent change of the International Classification of Diseases 11th edition (ICD-11) (World Health Organization, 2018) Asperger's syndrome is no longer classed as a separate disorder. This change follows the pursuit of the United States (US) Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association, 2013 and National Health Service, 2012). The new diagnostic criteria now state's that those diagnosed with Autism spectrum disorder may come under 5 categories of Autism, this will depend on the impact it has had on the intellectual development and language ability (World Health Organization, 2018). Asperger's syndrome was also often previously compared to high-functioning Autism spectrum disorder and although there was much debate around the differences (de Giambattisa, Ventura, Trerotoli, Margari, Palumbia, & Margari, 2018) due to the changes in the DSM-5 mental health manual (2012), the two disorders are now categorised as one. Despite this change in diagnostic criteria, this study will be discussing

Asperger's syndrome as it is still a widely diagnosed disorder and therefore will still impact those who have Asperger's syndrome/high functioning Autism spectrum disorder; regardless of the terminology used when gaining their diagnosis.

1.4 Methodology

This research has adopted a constructivist epistemological standpoint, meaning that it holds the belief that knowledge is constructed by the individual through their individual experiences (Gray, 2014). Due to this their knowledge or 'truth' is ever changing as they experience new things and are influenced by others. In addition to this constructivist view, this research also follows an interpretivist research paradigm stating that individuals interpret what they experience to give it meaning (Gray, 2014). The epistemology and research paradigm discussed also work alongside the phenomenological approach followed throughout, aiming to explore each individual's life experience these areas have been explored further within the methodology chapter (Moustakas, 1994 and Denscombe, 2014). In order to do this, each participant has taken part in semi-structured interviews, lasting around 1 hour. A semi-structured approach has been adapted to allow both myself, as the interviewer, and interviewee, to ask extra questions surrounding any topics they feel are relevant, or that may have otherwise been missed (Denscombe, 2014; Green, Davis, Karshmer, Marsh & Straight, 2005; and Mills, & Birks, 2014,). Each interview will require a great amount of detail about the interviewee's experiences in order to explore the potential impact of their diagnosis on their self-identity and mental health (Denscombe, 2014). The methodological choices made throughout this study will be further explained within the methodology chapter. Due to the size of this study any of the findings and suggestions are relevant to only the participants taking part and is not generalisable to all individuals with Asperger's syndrome.

1.5 Conclusion

Within this chapter, I have defined the main aim and the research questions this research is intended to address. The aim of this study is:

- To gather information about the lives of individuals who were diagnosed with Asperger's syndrome; with the aim to explore the potential impact that Asperger's syndrome has on self-identity, self-esteem and mental health.

These aims will be referred back to at multiple points throughout this research. In addition to this, the key themes that will be explored throughout the research study have been defined and briefly explained within this introduction. These key themes are self-identity, self-esteem, anxiety and depression. Alongside this I have discussed the chosen methodological standpoint and methods

that have been adopted throughout. Following on from this chapter, I will be exploring the key themes in more depth, this will provide support throughout the analysis and discussion following the results.

Chapter 2 – literature review

2.1 Introduction

This literature review will outline contemporary literature, relevant to the proposed research questions which are:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

In doing so, this chapter will investigate the three main themes relating to the research topic which are: Asperger's syndrome, self-identity, anxiety and depression, and self-esteem. These three themes were chosen as they provide insight into the knowledge currently available around the three research questions. These key areas have been developed through the research questions and will aid in the development of the interview questions, along with the analysis and discussion of the collected data. The aim of these three themes is to collect an overall idea of current literature relevant to the research study. Whilst looking into the relevant literature surrounding Asperger's syndrome (2.2), I will discuss what Asperger's syndrome is (2.2.2), followed by the models of disability and what they mean for Asperger's syndrome (2.2.3). I will then discuss the impact Asperger's syndrome has on social skills (2.2.4). Following on from Asperger's syndrome, I will be exploring self-identity (2.3). In addition to this I will be discussing Anxiety and depression (2.4). Finally, I will explore literature surrounding self-esteem (2.5). To conclude (2.6) this chapter I will give a brief overview of the topics discussed throughout.

2.2 Asperger's syndrome

2.2.1 Introduction

In order to explore the potential impact of a diagnosis of Asperger's syndrome on self-identity and anxiety and depression, it is important that we first have a deeper understanding and concept of what Asperger's syndrome really is, how it impacts the lives of those who have an Asperger's syndrome diagnosis and the choice to focus on Asperger's syndrome over Autism spectrum disorder. Through exploring the different challenges that individuals with Asperger's syndrome face, we are able to see what effects this may have on self-identity, anxiety and depression along with how we are able to combat any negative effects. This chapter will discuss what Asperger's syndrome is (2.2.2), along with the models of disability (2.2.3) and Asperger's syndrome and social skills (2.2.4). Within this, I will explore what differentiates Asperger's syndrome from Autism

spectrum disorder and how Asperger's syndrome is diagnosed, how the social model and medical model impact individuals with Asperger's syndrome and how their social impairment may impact their self-identity, anxiety, depression and self-esteem and how an early diagnosis may affect their social abilities.

2.2.2 What is Asperger's syndrome?

Asperger's syndrome is a specific part of Autism spectrum disorder and therefore in order to define Asperger's syndrome we must first define Autism spectrum disorder. Autism spectrum disorder is defined within the most recent diagnostic tool, the ICD-11 (World Health Organization, 2018) as a persistent lack of ability to follow social protocol, along with restricted, repetitive, and inflexible patterns of behaviour and interests. Previously Asperger's syndrome was viewed as a separate part of Autism spectrum disorder, although still closely linked within the 2018 revised ICD-11 Asperger's syndrome, is defined as "Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language" (World Health Organization, 2018. p. 6A02.0). It is stated that individuals with Asperger's syndrome meet all of the requirements for an Autism spectrum disorder diagnosis, though are not as unequipped to adapt their behaviour and their intellectual functioning also appears to be unaffected, usually meaning that they have little to no impairment in their linguistic skills. The NHS also defines Autism spectrum disorder in a similar way, stating that it is a range of conditions which includes Asperger's syndrome and that it affects social interaction, communication, interests, and behaviour (National Health Service, 2019). Difficulties in sensory processing or hypersensitivity to external sensory stimulation, such as the flickering of fluorescent lighting, touch, smell, taste and sound levels, are often prominent in people on the Autism spectrum. There are about 700,000 people in the UK who are on the Autism spectrum, which is around 1.1% of the population (Office of National Statistics, 2012). Asperger's syndrome is different for each individual, there is no set list of traits that each individual with Asperger's syndrome will have. As these conditions are on a spectrum, this implies that no two individuals with Autism spectrum disorder or Asperger's syndrome will experience the condition in the same way. Although some may find that they have similar symptoms to one another, they may affect them differently (National Health Service, 2019 and World Health Organization, 2018). People do not need to have every single symptom associated with Asperger's syndrome to be diagnosed with the condition (Garnett, Attwood, Peterson & Kelly, 2013 and National Health Service, 2019).

Asperger's syndrome is a pervasive developmental disorder (PDD) (National Autistic Society, 2018) in which autistic social dysfunction and isolated obsessive interests occur in the presence of average

intelligence and a relatively intact language. The term 'Asperger syndrome' has been used in several ways which are to describe persons: with Autism who have an average IQ and have no verbal impairment, as a synonym for Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) and atypical Autism, as a descriptor for a group of children and adults who show a mild but distinct type of social and communication deficit, and those with intense individual interests. As previously mentioned, within the introduction, it was important to only interview individuals with Asperger's syndrome rather than individuals with an Autism spectrum disorder diagnosis as there are major differences throughout the spectrum that could affect how a diagnosis may potentially impact self-esteem, self-identity and, autism and depression. Throughout the disorder there are many different symptoms, these can vary in which of the symptoms are experienced by a given individual and how intensely they affect them. For instance, those with few symptoms and/or those who are not as impacted by their symptoms come under the Asperger's syndrome or high functioning bracket (National Autistic Society, 2018 and National Health Service, 2016). This differs dramatically from those who have severe symptoms and are low functioning. Due to this it concerns me that some individuals who have Autism spectrum disorder may not be able to give informed consent (Economic and Social Research Council, 2020). Additionally, individuals with Asperger's syndrome have no language delay unlike those with an Autism spectrum disorder diagnosis who may be completely non-verbal (National Health Service, 2019). Due to the major differences throughout the disorder, by narrowing the sample down to specifically individuals with Asperger's syndrome the participants are more likely to have similar life experiences and therefore any results will be comparable.

Although, there is no question on whether Asperger's syndrome exists, there is still ongoing confusion and debate about its existence as a distinct disorder, particularly, its distinction from Autism spectrum disorder with average intelligence and high-functioning Autism. Researchers have suggested that Asperger's syndrome and high functioning Autism spectrum disorder are one and the same, both Asperger's syndrome and high functioning Autism affect social interaction, narrow interests, a need for routine and repetitive behaviours (Montgomery, Allison, Lai, Cassidy, Langdon & Baron-Cohen, 2016). However, others have cautioned against including Asperger's syndrome as a distinct category; while others have pointed out that the current description of Asperger's syndrome does not quite resemble the one that Asperger himself had in mind and therefore should stay as a separate diagnosis (Miller and Ozonoff, 1997 and Toth and King, 2008). Although there is a disagreement on whether the two should be categorised together, studies have shown that there appears to be no difference between the two conditions. Despite the debates surrounding whether the two should disorders should continue to be separate, as mentioned previously, Asperger's

syndrome has been included into Autism spectrum disorder and grouped in with high functioning Autism as of 2018.

In 1991, Wing and Gould founded the National Autistic Society's first diagnostic centre which has now been renamed to the Lorna Wing Centre for Autism (National Autistic Society, 2018). Within this centre, they provide a complete assessment for communication disorders for people of all ages using the Diagnostic Interview for Social and Communication Disorders (DISCO). DISCO was developed by Wing and Gould (Wing, Leekam, Libby, Gould, Loombe, 2002) and has since been used within the ICD-10 (World Health Organization, 1992), which has been defining what is the diagnostic criteria when diagnosing Autism from 1992 to 2018 (Beadle-Brown, 2011). Other diagnostic tools are sometimes used in aid or in place of DISCO such as the Autism Diagnostic Interview – Revised (ADI-R), the Autism Diagnostic Observation Schedule (ADOS), and Childhood Autism Rating Scale (CARS) (National Autistic Society, 2018, Gotha, Risi, Pickles & Lord, 2000, Rutter, Le Couteur & Lord, 2003, Scott, Baron-ohen, Bolton & Brayne, 2002, and Schopler, Reichler & Renner, 1986).

2.2.3 Models of Disability

This section of the literature review will be discussing what a model of disability is and why it is relevant to the topic at hand. Disability theorists (Sarrett, 2016, Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Beaudry, 2016, Dirth & Branscombe, 2017, Woods, 2017 and, Resko, 2001) are split between two different models of disability, these two models are the Social model and the Medical model. The Social model views disability as being caused by a lack of inclusion within society, whereas the medical model views disability as a problem with an individual that should be 'fixed' (Sarrett, 2016, Connors & Stalker, 2006, Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). Oliver (2009), was one of the first to describe the social model in 1983, the model is the more academic and contemporary model of the two and has previously been described as 'the big idea' whilst the medical model is discussed as 'backward-looking' (Depository, 2018). With the social model's presence dominating it has influenced modern policies and practice such as the Disability act 2010, Equality Act, 2010 and the Education Act, 2011.

Oliver (Oliver & Sapey, 1999), has suggested that the social model or "citizenship approach" views individuals with disabilities as a full and valued member of society, where society adapts for the individual thus supporting their 'impairments'. Following this, Oliver and other disability theorists have added to this theory, the model is described as externalising disability, viewing what makes an individual disabled as the individual's environment rather than the individual themselves or their diagnosis (Sarrett, 2016, Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Beaudry, 2016, Dirth &

Branscombe, 2017 and Woods, 2017) this suggests that with an enabling environment that allows everybody to have support in order to access the support they need that nobody would be seen as 'disabled'. The social model also suggests that with the view of disability being caused by society rather than the person it avoids stereotypes that are caused by negative or uneducated views of individuals with Asperger's syndrome (Woods, 2017), following the social model if society was adapted appropriately these stereotypes would no longer exist and therefore Asperger's syndrome would no longer exist. This theory suggests that our environment is what allows a disability to impact a person and not the disability itself, therefore viewing the environment as needing to be 'fixed' unlike the medical model which views the person as needing to be 'fixed'. Beaudry (2016) suggest that the social model diminishes the legitimacy of impairment, discrediting the medical and biological aspects of disability. Oliver (2013) however states that this was never the intention of the model and that the social model only ever aimed to support individuals throughout society and never intended to belittle any impairments or difficulties that individuals with disabilities may face. It has also been noted that the model focus' largely on physical impairments over any sensory impairments (Woods, 2017).

Neurodiversity is closely discussed with the social model, the two adapt similar aspects from one another. Neurodiversity for example is a movement that supports individuals with neurological disorders such as Asperger's syndrome with self-advocacy and mutual support (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Masataka, 2017). The main aims of the neurodiversity movement are viewing the strengths, differences and weaknesses as the building bricks that build a person's identity rather than viewing their diagnosis as a disability. Due to the change in the way that people now view disability, with the aid of the social model, policy and legislation have changed throughout the years to incorporate some of the ideas suggested by the model (Stoddart and Stoddart, 2014 and Oliver, 2013). For instance, the Special Educational Needs and Disability Act (2015) states that Authorities should take steps where appropriate to provide special education provisions and support to those with SEND. It has not been long since individuals with disabilities would have been sent to a separate school than most other children, however now inclusion is spoken of everyday within schools in the UK. Although this may be the case, many individuals have spoken of ways in which inclusion could be continuously improved to support these individuals and adapt their environment.

The Medical model is the older disability model between the two and is not often used within practice anymore. However, despite this it is still discussed within in both academic writing and everyday life (Beaudry, 2016 Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). Woods (2017), for example, suggests that the model is actually the dominant model within studies related to Autism

spectrum disorder and Asperger's syndrome. Although Beaudry (2016) contradicts this stating that the medical model is 'outdated and oppressive'. It is clear that the model is still used within society as Muskat (2016), who use to work in a mental health centre, suggests that families regularly sent their children to the centre to "Essentially fix their children" and that she does believes that the social model has yet to reach parents and that they are still searching for a cure. This suggests that the model is still active within certain areas and although it may not be the preferred model in a professional setting it is still relevant in the day to day lives of children with ASD. Due to this it is important that the medial model is still covered within this literature review in order to appropriately analyse the findings and as previously mentioned this research will support any questions within the questionnaire and interviews, that aim to understand the individuals view on disability. The medical model is built upon the foundation that individuals with disabilities need a cure and too be 'fixed', viewing them as essentially 'broken' individuals who do not fit in with societal averages (Sarrett, 2016, Connors & Stalker, 2006, Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). The main intention of the model in terms of Asperger's syndrome is to 'normalize' individuals within our current society, through symptom reduction, providing medication and working with neuro-a-typical individuals to change and function in a way that is perceived as neuro-typical (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Sarrett, 2016, Parens et al., 2011). Within the disability community those with neurological conditions such as Asperger's syndrome are referred to as neuro-a-typical in comparison to those without who are referred to as neurotypical.

The medical model is highly criticized within current research for a range of different issues. Kapp, Gillespie-Lynch, Sherman & Hutman (2013) have suggested that the medical model portrays individuals with disabilities as being sick and unable to make conscious designs about their own life. Dirth & Branscombe (2017) have also stated that the model opens the doors to disability prejudice. By viewing disabled individuals as needing to be 'fixed' or changed it makes way for misinterpretations and prejudices around disability which could than cause harm to that individual by dehumanizing them. This being said others such as Resko (2011), are in favour of this model, Resko makes the point that although a disability may be part of the individuals, they still need therapy and medication. Resko (2011), also suggests that people would not discuss what value a cancer diagnosis has for an individual in the way that it is discussed for neurological conditions. This makes the excellent point that although as a society we can adapt to relieve the problems that may affect individuals with disabilities, they still have a disability and society may not be able to fully support them. As the social model has previously been criticized for, by ignoring the legitimacy of disability it belittles the severity of the impairments the disabled individual lives with Beaudry (2016).

2.2.4 Asperger's syndrome and social skills

In order to explore how Asperger's syndrome affects the development of self-identity, it is important that we first explore what we already know about how individuals with Asperger's syndrome develop socially and how their social skills may differ to those without Asperger's syndrome. It is documented through all literature surrounding Asperger's syndrome that social impairment is one of the defining factors (Cooper, Smith, & Russell, 2017). These impairments are sometimes referred to as the 'triad of impairment' and were formulated by Wing and Gould. The triad of impairment is made up of three areas of impairment, which are: social interaction, communication, and imagination (Murray, 2011). Lorna Wing and Judith Gould brought about the idea of the triad of impairments in 1979 after Leo Kanner's 'Kanner syndrome' in 1943 and Hans Asperger's 'Asperger syndrome' in 1944 (Murray, 2011, National Autistic Society, 2018 and Silberman, 2015). Kanner discussed key factors that he saw within the children he observed, he called this 'Kanner's Autism'. These key factors were a lack of communication, anxiousness, and a want for routine. Kanner also stated that the children had average or above-average intelligence (Murray, 2011). This opened the doors for Hans Asperger to discuss his theory of 'Asperger syndrome'. Asperger stated in his post graduate thesis that the children he observed showed a lack of social expression, however they had good verbal and cognitive skills (Klauber and Rhode, 2004). These two theories were not discussed in much detail, until 1979, when Lorna Wing and Judith Gould redefined Autism spectrum disorder and Asperger's syndrome, which to this day still influences diagnosis (Murray, 2011, and Leekam, Libby, Wing, Gould & Taylor, 2002).

In addition to this, self-identity can also be affected by social impairment, society and our social circles (Cooper, Smith, & Russell, 2017). Due to this, it is important to discuss how individuals with Asperger's syndrome develop socially, in order to understand any possible differences that the participants may show in relation to what we already know about social development for typically developing individuals. As discussed within the triad of impairments, Asperger's syndrome is a syndrome known for affecting social communication. Gutstein and Whitney (2002) suggests that social competence is a large factor affecting the quality of individual with Asperger's syndrome life. It has also been noted that with the right resources and from early intervention, individuals can gain a greater quality of life as they are supported in developing important social skills (Scott, Bardon-Cohen, Bolton, Brayne, 2002). Harpur, Lawlor, and Fitzgerald (2006) state that the primary reason for an intervention, is to improve adolescents' social skills. Without this they have suggested that individuals may face social rejection and ultimately a number of mental illness and lowered self-esteem. As there is so much importance placed on early diagnosis in order to provide support, I question the need to diagnose later in life when the individual has missed the interventions

supporting social development. This has been reiterated by Purkis, Goodall, Nugent, Lawson, and Dempster-Rivett, (2016) who suggests that labels can be beneficial, however this is only when the label is beneficial to the recipient; for example, when helping to receive medical assistance. Additionally, Portway and Johnson (2005) questioned what right we have to label people with Autism, suggesting that labelling people anything other than 'the norm' opens them up to being misunderstood and facing stigma. Although Autism spectrum disorder is often diagnosed during early childhood, Asperger's syndrome is poorly diagnosed and is often not diagnosed until the child is 11 years of age with many individuals being misdiagnosed or undiagnosed until adulthood (Scott, Bardon-Cohen, Bolton, Brayne, 2002), missing years of support. There are multiple reasons that may impact anxiety, depression and self-esteem. One of the possible reasons is peer rejection which leads to loneliness and can lead to difficulties with social interaction (Harpur, Lawlor, and Fitzgerald, 2006 and Whitehouse, Durkin, Jaquet, & Ziatas, 2008). Contrary to this, alongside misdiagnosing individuals with Asperger's syndrome, diagnostic overshadowing also affects them. Diagnostic overshadowing is where practitioners miss a mental health diagnosis by presuming that symptoms are due to their Asperger's diagnosis (Barber, 2018, Meera, Kaipa, Thomas, & Shivashankar, 2013 and Spain, Rumball, O'Neil, Sin, Prunty, & Happé, 2017). Other conditions overshadowed and misdiagnosed include ADHD, OCD and Bipolar disorder (Beljian, Webb, Amend, Web, Goerss, & Olenchak, 2016). In addition to this, it has been suggested that there may be genetic components affecting their mental health, meaning that parents suffering from anxiety or depression have a higher chance of producing children who will also suffer from anxiety and depression (Park, Park, Kim, & Yoo, 2013). It has also been suggested that by having meaningful friendships and being a part of a group can combat loneliness and improve anxiety, depression and self-esteem (Harpur, Lawlor, and Fitzgerald, 2006). Despite this, it has been suggested that individuals with Asperger's syndrome are more likely to define themselves through social categories and group membership, as they often fail to remember life events and therefore see their self-identity to be the same as the identity of their friendship group (Cooper, Smith, and Russel, 2017).

In England, we start to follow the social development of children from birth starting with the early years foundation stage (EYFS) (Department for Education, 2018). The EYFS shows us what is expected of a child within their age band from birth to 5 years old, then from ages 5 to 16, children take part in personal, social, health and economic lessons (PSHE) (Department of Education, 2013). According to the EYFS, by the age of 5, typically developing individuals should be able to initiate conversations, take steps to resolve conflicts and understand how their own actions affect other people. However, for individuals with Asperger's syndrome, some of these tasks that others have

been working on since their early years are extremely difficult; for instance young people with Asperger's syndrome often have the most difficulty when working in groups, as they have difficulty compromising; they may feel that their way is the right way and be unable to negotiate and resolve any conflict (Marks, Schrader, Levie, Hagie, Longaker, Morales, & Peters, 1999 and Holloway, 2018). They may become emotional and are unable to see how their actions will affect the whole group. Literature tells us that individuals should be reaching the milestones shown above, and many more at a young age, but also that adolescents with Asperger's syndrome are struggling with these milestones still in their teenage years. As discussed within the previous literature within this chapter, most individuals with Asperger's syndrome are not diagnosed until adolescence or early adulthood and due to this, it is questionable how such milestones can be missed with no cause for concern within the individual's formative years.

2.2.5 Conclusion

Within this sub section of this literature review I have discussed 'What is Asperger's syndrome?'. Within this I have included the ICD-11, the UK's most recent diagnostic tool along with the DISCO diagnostic interview. Along with this, I have also discussed what defines Asperger's syndrome and the key factors that make up Asperger's syndrome. Following on from this, I have discussed both the social and medical model of disabilities. The two models have opposing views on whether disabilities are a product of our environment or whether they are a 'problem' within us that needs medical intervention in order to be 'fixed'. These two models of disability are important to this research as they provide an insight into the ways that individuals may be perceived by different people after their diagnosis and how these different perspectives may have impacted their 'knowledge', thoughts and feeling towards themselves and Asperger's syndrome. Furthermore, I outlined the affect that a late diagnosis can have on developing social skills and the importance of having an early diagnosis. In addition to this, whilst discussing social skills, I also touched upon the effect of social skills on anxiety, depression, self-esteem, and self-identity. Finally, I covered the differences in social development between those who are typically developing and those with Asperger's syndrome. Following on from this, I will be exploring self-identity, what it means, its relation to Asperger's syndrome and how it affects self-esteem.

2.3 Self-Identity

2.3.1 Introduction

Throughout this section, I will be discussing self-identity. Whilst doing so, I will define what self-identity (2.3.2) is, along with how we develop it. In addition to this, I will be exploring self-identity and its relation to Asperger's syndrome, anxiety, depression and self-esteem (2.3.4). These areas will be imperative to my analysis and discussion within the findings of this research study, as they will provide relevant information in order to answer the research question: What potential impact does Asperger's syndrome have on self-identity?

2.3.2 Self-Identity

Self-identity is referred to within literature in a number of different ways, such as sense of self, self, self-understanding and self-concept (Evans, 2012; Dainton, 2016; Terry, Hogg & White, 1999; Hart and Damon, 1988, and Thomas, 1999). For the remainder of this research study, 'self-identity' will be the only term used. Self-identity is the way one views themselves and feels that others view them in terms of their identity, personality, thoughts and feelings (Scott, 2015), alongside social interaction, communication, interests and behaviour as previously mentioned. It has been defined as "self-identity is an expression of the person's reflexive psychological, emotional, and practical response to his social-self, or to that self-in-role." (Oshana. 2010. *pp.* 11) Within this Section of the literature review, I will be discussing Self-identity. Our sense of 'self' is developed over time usually starting as a child (Thomas, 1999) and self-identity is defined as a set of characteristics as seen by them, that make a person an individual (Terry, Hogg & White, 1999, Scott, 2015). An individual's self-identity is developed both personally and socially. Whilst developing a sense of self, an individual creates an identity based on characteristics that define them personally; for example, their likes, dislikes, dress sense, music taste alongside their social identity which is affected through group relationships and the identity of our friends (Cooper, Smith & Russell, 2017). Due to this, I will be discussing both identity theory and social identity theory (Cheng & Guo, 2015, Jiang, Zhao, Sun, Zhang, Zheng, and Qu, 2016; Stets & Burke, 2000; Stets & Carter, 2011; and Terry, Hogg & White, 1999). These theories both agree that identity is affected by those around them, though they discuss different ways in which others affect this. By discussing both of these theories, it will support my analysis of the results, by informing me on the different ways these individuals may have developed their self-identity. Identity theory theorises that an individual builds their self-identity on factors surrounding the roles that they occupy, such as teacher, sibling, student (Terry, Hogg, & White, 1999). Within this theory, individuals create their self-identity through the roles they occupy, giving meaning to the things that they do (Stets & Burke, 2000). Social identity theory

theorises that self-identity is formed by our social roles such as punk, loud, or nerdy (Terry, Hogg, & White, 1999). Within this self-identity is where an individual believes that they belong; this group is usually made of like-minded people who are in a similar social category (Stets & Burke, 2000). By exploring identity and social identity theory, I am able to have a deeper discussion when analysing the interview findings. It has been suggested that when developing one's self-identity, those with Autism often replace key factors with social identity, referring to the identity of a social group over their own identifying factors (Cooper, Smith, & Russell, 2017). Hart and Damon (1988) also discussed social identity, defining the theory as the way individuals define their self-identity as social characteristics, such as who their friends are, where they live, whether they are in a sports team or extracurricular group (Hart & Damon, 1988). With this being said, it is likely that a diagnosis of Asperger's syndrome would impact an individual's social identity; however, it has been suggested that due to the social and communication difficulties that those with Asperger's syndrome face, it may make developing self-identity more difficult (Cooper, Smith, & Russell, 2017).

Additionally, individuals may find that different characteristics or 'labels' may affect their self-identity differently. For example, those with Asperger's syndrome may find that there is a stigma around Asperger's syndrome and Autism spectrum disorder, which may negatively impact their Self-identity. It has been suggested that some individuals when diagnosed with Asperger's syndrome distanced themselves from the label and favoured more socially accepted labels (Cooper, Smith & Russell, 2017 and Shtayermman, 2009). Ohan, Ellefson, and Corrigan (2015) have also suggested that both Asperger's syndrome and Autism spectrum disorder have a social stigma. Similarly, it was also found that some parents of 'gifted' children chose to ignore the label and opt for what they perceive as a more favourable label (Matthews, 2014). In contrast to this, many individuals feel a great attachment to their given label, for those who develop positive relations to their label have shown to have better physical and psychological well-being (Cooper, Smith, & Russell, 2017). Similarly, Shifer (2013) has suggested that individuals diagnosed with stigma related labels are more likely to have poorer academic outcomes. There has also been a discussion surrounding the impact of the change in diagnostic criteria from Asperger's syndrome to Autism spectrum disorder; however, there have been contrasting findings around this. Ohan, Ellefson, and Corrigan (2015) found no difference between the two labels and additionally found that the participants showed little stigma at all. However, Kite, Gullifer, and Tyson (2012) found that there was an increase in stigma with Asperger's syndrome, showing to be much more socially accepted in comparison to Autism spectrum disorder. The effect a label may have on self-identity appears to be dependent on the individual's prejudices, affecting the way they view their label. Cooper, Smith & Russell (2017) have suggested that Asperger's syndrome carries a stigma which can negatively

impact diagnosed individuals, who then struggle to accept their diagnosis and disassociate from the other 'members' of this group. Due to this, it is highly likely that a label of Asperger's syndrome will negatively impact the individual's social identity.

It has been suggested that children with Asperger's syndrome have a lesser self-understanding than typically developing children (Lee & Hobson, 1998). Howlin (2010) found that individuals with Asperger's syndrome had a delayed ability to have self-insight, as adolescents showed more difficulty expressing self-knowledge than adults. However, in contrast to this, Lee and Hobson (1998) found that children with Autism spectrum disorder appeared to have little to no difference in developing and explaining their self-identity. Hart and Damon (1988) have suggested that children of all ages have some knowledge of their self-identity but that the characteristics of this change overtime. However, it has been found that individuals with Asperger's syndrome appear to give less self-descriptions surrounding individuality and their understanding of their past, present, and future (Jackson, Skirrow and Hare, 2011). This has been reiterated by Dritschel, Wisely, Goddard, Robinson and Howlin (2010) who stated within their findings, that there appears that those with Asperger's syndrome have a profound difficulty developing their self-knowledge. Chaput, Amsellem, Urdapilleta, Chaste, Leboyer, Delorme, and Goussé (2013) also suggested that individuals with Asperger's syndrome are not able to recall as many memories as typically developing individuals and therefore showed poor awareness of themselves.

2.3.4 Conclusion

Throughout this discussion, I am aiming to explore self-identity. I have addressed key points relating to the research question: What potential impact does Asperger's syndrome have on self-identity? In order to do this, I have defined self-identity as the way one views themselves in terms of their identity, social identity, thoughts, feels and who they have been and will be throughout life (Scott, 2015 and Oshana, 2010). Within this section, I have discussed the different ways that our self-identity can be affected and how this has influenced the interview process. I have explored how self-identity can be affected by Asperger's syndrome specifically. Finally, I have defined self-esteem and touched upon how self-identity may affect self-esteem. Following this, I will be reviewing literature aiming to explore anxiety and depression, how it affects individuals with Asperger's syndrome and its relation to self-esteem.

2.4 Anxiety and depression

2.4.1 Introduction

Throughout the last segment of the literature review, I aim to review literature surrounding anxiety and depression. This will aid me in answering the question: What potential impact does Asperger's syndrome have on anxiety, depression and self-esteem? Within this segment I will be focusing on depression and anxiety, whilst exploring what defines anxiety and depression (2.4.2). I will also discuss the relation between Asperger's syndrome, anxiety and depression. Following on from this section, I will briefly recap what is self-esteem and explore the relation between anxiety, depression and self-esteem (2.4.3).

2.4.2 What is anxiety and depression?

As previously mentioned, anxiety disorders and depression can be described to be the two biggest mental health concerns to date. (Centre for Social Research, 2018 and Office for National Statistics, 2018) recently released their findings into the mental health of children and young people in Great Britain, where they found that emotional disorders such as depression and anxiety were the most prevalent mental health disorder, increasing with age. Depression is defined by the ICD-11 (World Health Organization, 2018) as:

“Depressive disorders are characterized by depressive mood (e.g., sad, irritable, empty) or loss of pleasure accompanied by other cognitive, behavioural, or neurovegetative symptoms that significantly affect the individual's ability to function. A depressive disorder should not be diagnosed in individuals who have ever experienced a manic, mixed or hypomanic episode, which would indicate the presence of a bipolar disorder.” (World Health Organization, 2018. p 06)

Similarly, depression has also been described as a health condition where individuals feel unhappy and hopeless for an extended amount of time, affecting everyday life (National Centre for Social Research, 2018, Mind, 2018, and National Health Service, 2018). It consists of symptoms such as loss of interest in pleasure, feelings of guilt, low self-worth, a change in sleep and appetite, low energy and poor concentration amongst many others (National Health Service, 2019). Anxiety, which is closely linked to depression, is described in the ICD-11 as:

“Anxiety and fear-related disorders are characterized by excessive fear and anxiety and related behavioural disturbances, with symptoms that are severe enough to result in significant distress or significant impairment in personal, family, social,

educational, occupational, or other important areas of functioning.” (World Health Organization, 2018. P. 06)

Anxiety has also been described as a feeling of worry and panic that lasts over an extended period of time (National Health Service, 2018, and National Autistic Society, 2018). Some of the symptoms related to anxiety are feeling nervous, afraid or panicked, having difficulty sleeping, feeling faint, heart palpitations, trembling, panic attacks and lack of concentration (Young Minds, 2018). However, anxiety is a term used for a variety of disorders, such as panic disorder, phobias, post-traumatic stress disorder and social anxiety disorder (National Health Service, 2018). Although Anxiety and depression are not the same disorder, they do have a few similarities and people are more likely to develop one when diagnosed with the other.

Depression and anxiety share some symptoms with Asperger’s syndrome, hence may cause them to go undiagnosed or misdiagnosed (Chandrasekhar & Sikich, 2015 and Ghaziuddin, 2005). As previously discussed, individuals may have a missed diagnosis of anxiety or depression due to being overshadowed (Beljian, Webb, Amend, Web, Goerss, & Olenchak, 2016). Overshadowing is said to be a substantial problem for those with Asperger’s syndrome as their mental health may be untreated due to the missed diagnosis (Spain, Rumball, O’Neill, Sin, Prunty, & Happé, 2016). However, in contrast to this, other researchers have suggested that people are often being misdiagnosed with other conditions such as anxiety and depression, leading to a late or completely missed diagnosis of Asperger’s syndrome (Chandrasekhar & Sikich, 2015 and Ghaziuddin, 2005). The difficulties in diagnosing Asperger’s syndrome have been suggested to stem from multiple similarities in symptoms. For instance, whilst diagnosing depression, some symptoms, such as showing signs of becoming overwhelmed due to sensory overload and impairments in communication both physically and verbally, could easily be considered to be part of the individuals Asperger’s syndrome diagnosis, when they may actually be symptoms of depression (Mazzone, Postorino, Peppo, Fatta, Lucarelli, and Reale, 2013 and National Autistic Society, 2018). However, these symptoms are still relevant when diagnosing depression in individuals with Asperger’s syndrome even though they may manifest themselves slightly differently. For example, they may change from that individual’s norm, where some individuals may already be perceived as being socially withdrawn, however, whilst depressed this may worsen or they may have an increase in ritualistic behaviours and irritability in comparison to how they usually are (Ghaziuddin, 2005). Similarly, anxiety disorders are equally as difficult to diagnose, as again, anxiety has symptoms which may be mistaken for symptoms of Asperger’s syndrome. For instance, symptoms such as easily losing patience and difficulty concentrating (National Autistic Society, 2019) can easily be mistaken for sensory overload. Additionally, other symptoms such as becoming obsessed with one

subject overlaps with the previously discussed Asperger's syndrome symptom of having highly focused interests (National Health Service 2019).

A Recent survey has found that 17% of adults surveyed for mental health and wellbeing in England met the criteria for a common mental health disorder (McManus, Bebbington, Jenkins, Brugha, Appleby, Anderson, and Wessely, 2016), with 19.7% of individuals aged 16 and older, in the UK, showing symptoms of anxiety or depression (Macrory, 2016). In comparison to this it has been stated that 80% of individuals with Autism spectrum disorder suffer from at least one mental health condition and 40% with at least one anxiety disorder (Barber, 2018). This considerable difference is shown again with 36% of individuals with an intellectual disability (ID) displaying signs of a mental health condition in comparison to 8% of children without an ID, with particular prevalence on individuals with Autism spectrum disorder (Emerson & Hatton, 2007). This has been a reoccurring finding throughout research, Wing (National Autistic Society, 2018) found that 30% of her Asperger's syndrome sample had signs of clinical depression and Tantam (1988) found that 60% of their Asperger's syndrome sample had reported depression. Overall, it appears that individuals with Asperger's syndrome appear to suffer from increased rates of mental health conditions (Cooper, Smith & Russel, (2017).

Research has shown that there is a correlation between self-identity, anxiety and depression for instance, having a positive social identity and relating to a group can increase mental health by lowering depression and increasing their sense of meaning, control and self-esteem (Cooper, Smith, & Russell, 2017). However, this is only the case for those who view their label as a positive attribute. Some individuals view their label in a negative light, which then negatively affects their mental health and self-esteem. Equally anxiety and depression impairments can impact on self-identity, as often those with mental health conditions have a loss in self-confidence and self-esteem (Baum & Neuberger, 2013) which has previously been touched upon throughout this literature review. These points reiterate the effect of stigma as discussed within the Asperger's syndrome and social skills segment of this literature review.

2.4.5 Conclusion

Within this sub section of the literature review, I have defined anxiety and depression. Following this, I have reviewed literature surrounding the relationship between Asperger's syndrome, anxiety and depression. Alongside this, I have also explored general statistics surrounding anxiety and depression and individuals within the UK. I have discussed the relationship between mental health and self-identity and how the two areas explored throughout this research study may affect one

another. Finally, I have reviewed literature surrounding anxiety, depression and self-esteem along with their relation to Asperger's syndrome.

2.5 Self-esteem

2.5.1 introduction

Within this literature review, whilst discussing self-esteem, I will be exploring and literature surrounding self-esteem in relation to self-identity, depression and anxiety. I will be defining self-esteem before exploring how it may impact those with Asperger's syndrome through its effect on self-identify, anxiety and depression. In addition to this I will also touch upon the relationship between self-esteem, stigma and labels.

2.5.3 Self-Identity and Self-Esteem

Self-esteem is often spoke of as the opinion one has of themselves (Stets & Burke, 2014 and National health service, 2018). Rosenberg defines it as the positive or negative way in which someone considers their worth, in relation to others (Punch, 2012). Those with a positive self-esteem, meaning they feel good about themselves, and hold themselves in positive light; whereas those with low self-esteem view themselves in a negative light and do not deem themselves to be 'worthy' or 'good'. A low self-esteem can affect an individual's life in many ways, for example, Individuals appear to have their lowest self-esteem whilst going through puberty, which is suggested to be due to all changes happening within the body (Moksnes & Espnes, 2012). In contrast, it is suggested that an individual's self-esteem is at its highest in preadolescence before dropping during the teenage years (McChesney & Toseeb, 2018). It has been theorised that this is due to changes to their lives and bodies; leading to a change in self-identity (Moksnes & Espnes, 2012). Adolescents often struggle with creating meaningful relationships and becoming part of a group during this time; which has also been noted to have a profound effect on self-identity as previously mentioned (Cooper, Smith, and Russel, 2017).

As spoken about within the self-identity sub section of this literature review, Griffiths (1993), suggests that self-identity or 'self-image' effects self-esteem in regard to the way that individuals want to be viewed as an ideal self and how they currently view themselves. This suggests that individuals may not express their true self-identity but present their personality and traits as something they would rather them be. Similar findings have been found by Matthews (2014), who suggested that those who's label is not favourable, will change it to a label they prefer, therefore presenting themselves in a different manner than they really are. Again, suggesting that they find the traits they have relating to said label undesirable and therefore see themselves in a negative light.

Additionally, depending on how the individual views Asperger's syndrome, it may impact on their self-esteem. It is thought that labels have been a notable factor in self-esteem, including a label of Asperger's syndrome (Punshon, Skirrow & Murphy, 2009). Punshon, Skirrow & Murphy (2009) also suggest that significant problems can occur with self-esteem when internalizing the negative thoughts of others about Asperger's syndrome. However, Ohan, Ellefson, and Corrigan (2015), have argued that the so-called stigma surrounding Asperger's syndrome does not impact individuals as much as others have suggested. It is important that individuals have high self-esteem, as it is thought that self-esteem is a big part of self-identity and building an image of oneself, and equally, a poor self-identity may negatively affect self-esteem (Griffiths, 1993; Matheson, Daoud, Hamilton-Wright, Borenstein, Pedersen, and O'Campo 2015; and Oxford University Press, 2018). Another factor that has been suggested to affect self-esteem in individuals with Asperger's syndrome is bullying (McCauley Harris, Zaiic, Swain-Lerro, Oswald, & McIntyre, 2017). It has been suggested previously within this study that by internalizing the impact of others negative views towards us that it can affect our self-identity and self-esteem (Punshon, Skirrow & Murphy, 2019). Other research has supported this suggesting that not only can bullying and the negative impact of other affect us at the time that it is happening but carry through into adulthood when experienced as a child and ultimately may lead to complications with mental health conditions, such as anxiety and depression (Dublin, 2017 and DeLara, 2016).

2.5.4 Anxiety, depression and self-esteem

Research has shown a link between mental health and self-esteem (Moksnes & Espnes, 2012), such as an increase in anxiety disorders and depression during adolescence. It would be easy to assume that individuals diagnosed with Asperger's syndrome may go through a similar experience as they face many changes during and post diagnosis. Additionally, it has been suggested that individuals with lower self-esteem are more likely to suffer from mental health condition, such as anxiety and depression (Moksnes & Espnes, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018). Adolescents with Autism spectrum disorder are likely to have lower self-esteem compared to their peers (McChesney & Toseeb, 2018), they have suggested that this is due to children with Autism spectrum disorder having difficulties with understanding the perspective of others and having difficulties with social interactions. It has also been suggested that individuals with Autism spectrum disorder have limits within their self-development for example, school aged children with Autism spectrum disorder struggle with identifying emotions, which supports the theory that children with Autism spectrum disorder have difficulties understanding the perspective of others (McCauley, et al., 2017). Other factors that will likely affect self-esteem are bullying and loneliness, which are often reported by children with Autism spectrum disorder (McCauley et al., 2017). There

is limited research surrounding Autism spectrum disorder and Self-esteem, however, the current research does show differing results. Capps, Sigman, and Yirmiya (1995) found that individuals with High Functioning Autism spectrum disorder showed lower self-esteem, whereas Williamson, Craig, and Slinger (2008) found individuals with Asperger's syndrome had no differences, as did Bauminger, Shulman, and Agam (2004).

2.5.5 Conclusion

Within this sub section I have discussed the key factors which may impact self-esteem. To start this section of the literature review have defined self-esteem as the opinion one has of themselves and how they view their worth in comparison to others (Punch, 2012). Following this I have also explored the relationship between self-esteem and stigma along with how self-esteem may change with age and the effects of labels on self-esteem. Following this sub section of the literature review I will conclude this chapter.

2.6 Conclusion

In conclusion to this literature review, I will briefly recap the topics discussed throughout. This literature review aims to support me to explore current knowledge relating to the research questions:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

To support the analysis of this study whilst answering these questions, I have first defined Asperger's syndrome as: a social communication disorder with symptoms such as restricted and repetitive patterns of behaviour with mild or no impairment to intellectual development or functional language (World Health Organization, 2018). Within the 'What is Asperger's syndrome?' segment of this literature review, I have also discussed what different symptoms and behaviours are displayed by individuals with Asperger's syndrome in comparison to those with Autism spectrum disorder. Following this, I explored the social and medical model of disabilities and discussed their opposing views on what makes someone disabled. I have also briefly explained the diagnostic process used when diagnosing Autism spectrum disorder. I have pointed out within this that Asperger's syndrome is no longer a given diagnosis and has been categorised with high functioning Autism spectrum disorder, however all the participants taking part in this study have been given a diagnosis of Asperger's syndrome. In addition to this, I have also discussed how Asperger's syndrome impacts on social skills and the effect that this may have on anxiety and depression. After discussing Asperger's syndrome, I then reviewed literature surrounding self-identity. Within this segment I defined self-identity as: the way in which someone expresses their views of themselves, psychologically, emotionally, socially, practically and throughout time (Oshana, 2010, and Scott, 2015). Furthermore, I explored the potential impact of Asperger's syndrome on self-identity. This will support me in answering the question: What potential impact does Asperger's syndrome have on self-identity? Within the final section of this literature review, I defined both depression and anxiety. Following this, I discussed the similarities between Asperger's syndrome, depression and anxiety, and the similarities that can often lead to a missed diagnosis. By exploring current literature surrounding anxiety and depression, it will support my analysis, whilst answering the questions: What potential impact does Asperger's syndrome have on anxiety and depression? Finally, I have explored the links between self-identity, anxiety and depression in relation to self-esteem. By exploring self-esteem and its impact on the areas discussed above, I will be supported in my analysis of the findings surrounding self-esteem. Following on from this

chapter, I will be explaining the methodology used throughout this research study. Within this, I will cover the epistemological standpoint, the phenomenological approach used, the interviews, sampling, validity and reliability, ethics, and analysis.

Chapter 3 - Methodology

3.1 Introduction

This chapter will explore the methodology undertaken in this study and the reasons why these methods were chosen. Within this chapter, I will discuss the epistemological (3.2) standpoint of this study, followed by the Methodology (3.3) and the Methods (3.4) used throughout. Following this, I will explain the Ethics (3.5) behind this study, the sampling (3.6) and the validity and reliability of the research (3.7). The interview process has been broken into 4 steps to ensure each area needing to be questioned has been covered (3.8). After this, I will explain the analysis followed within this study in the same format as the interviews (3.9) and finally I will finish this chapter by discussing the conclusion.

3.2 Epistemology and Research Paradigm

Epistemology is the theory of knowledge, it aims to understand how knowledge is acquired and how legitimate any knowledge acquired is (Gray, 2014, Pietersma, 2000, Audi, 2010). Through an epistemological lens we must be question what knowledge is 'true' and what makes it reliable. This research follows a constructivist approach regarding epistemology (Gray, 2014), meaning that I do not believe in one true reality, but that each participant brings their own truth and their own reality. Each individual has their own set of unique experiences which are interpreted by them to how they view the world around them and as a society we develop shared understandings of how the world works but that knowledge is buildable, adaptable and ever changing (Gray, 2014). Whilst conducting, interpreting and analysing this work I will be keeping in mind that each individual has their own personal experiences affecting the way they view the world and therefore no one person or group can speak for everyone on a whole. From this epistemological standpoint it states that the knowledge gathered from each individual maybe different and therefore there is no one set way to interoperate it and no one way that the world works (Gray, 2014). Within this constructivist epistemological approach, I will be following an interpretivism paradigm (Neuman, 2014). This paradigm works alongside constructivism as interpretivism states that people interpret their experiences through social interaction. Through this, individuals give meaning to the world around them changing and adapting their interpretations of it over time. As previously mentioned, the methodology followed throughout is phenomenology. Together constructivism, interpretivism and phenomenology agree that knowledge is unique to the individuals and developed through their own unique experiences in life (Bridges, 2016). This is important for this study, as the main focus is to understand any potential impact of an Asperger's syndrome diagnosis on self-identity, anxiety, depression and self-esteem through each individual's own life experience. Every experience is

subjective to that person, and so, their thoughts and beliefs surrounding that are legitimate and valid. As stated by Gray (2014, p. 17): “meaning is constructed not discovered, so subjects construct their own meaning in different ways, even in relation to the same phenomenon.” Therefore, each participant may have a different view surrounding their diagnosis, however, each view is valid for their individual experience. The epistemological standpoint of this research is that the knowledge provided through these interviews are valid and true to the interviewees. This knowledge is valid both to them and to this study, as it is unique to their individual experiences with their Asperger’s syndrome diagnosis.

3.3 Methodology

Following on from the previous paragraph, I will be discussing the phenomenological perspective and methodology followed throughout this research (Gray, 2014, Denscombe, 2014 & Mousakas, 1994 and Van Manen, 2016). This approach was adopted for this study, as its main aim is to gain a detailed description and exploring of the experiences of each participant’s life with Asperger’s syndrome (Denscombe, 2014). Through this methodological perspective, I will be studying the human experience of being diagnosed with Asperger’s syndrome, with the intent to analyse the findings through description and interpretation; in order to answer the proposed research questions (Gray, 2014). Similar to epistemology, as previously discussed, phenomenology views the world as socially constructed and subjective to each individuals’ phenomena. The aim when following this phenomenological approach was to explore people’s perceptions, feelings and emotions, through asking questions surrounding how they feel about a topic or situation that is relevant to their past, present and future (Denscombe, 2014, Bell & Waters, 2014, Bevan, 2014 and Hammond & Wellington, 2013).

3.4 Methods

Phenomenology’s main objective is to investigate and describe a unique event as experience (Streubert & Carpenter, 1995), which in this case is the self-identity and mental health of individuals with Asperger’s syndrome. Due to this, semi-structured interviews were conducted, as it allowed for me to question the participants answers and ask for more details, when necessary, in order to gain a full picture of the individuals experience (Moustakas, 1994 and Gray, 2014). However, I have been aware of the importance throughout to avoid asking leading questions, to ensure I receive a genuine portrayal of each individuals experience with Asperger’s syndrome. Due to the nature of Asperger’s syndrome and its effects on social interaction, all participants were given a choice in interview styles, the interviews were then conducted both through phone calls and through email. The interviews were conducted with 5 participants, as a suggested minimum when following a

phenomenological perspective, due to the small scale and time frame of this study (Gray, 2014). By using a small sample, I was able to conduct longer more in-depth interviews. The sampling approach used within this was purposive (Gray, 2014) and will be discussed more within the sampling paragraph.

3.5 Ethics

This research study follows the British Educational Research Association's (BERA) ethical guidelines (British Education Research Association, 2018) to ensure a good standard of ethics are being exercised throughout the study. Previous to the research being conducted, this study was granted ethical approval by the University of Huddersfield. This section aims to discuss the ways that these guidelines have been followed and explain why they are necessary. Before joining in with any research, the participants were provided with an E3 information sheet; within this the participants are made aware of the nature of the study; meaning that they have been made aware of any sensitive topics which will be covered within the interviews; why they have been chosen to take part; what is involved by taking part; that they will be asked to take part in a semi-structured interview covering self-identity, self-esteem and anxiety and depression; their right to withdraw at any point and how confidentiality will remain throughout. Following this, each participant was then asked to sign an E4 Consent form; and within this agreed that they had read the information sheet, stating their understanding of their eligibility to withdraw at any point in the research, their anonymity in interviews and the possibility of supervisors and markers reading their anonymised responses, as labelled the teaching team within the consent form (Wiles, 2013, Quinlan et al, 2015 and McNeil & Chapman, 2005). It is important that the participants were made aware of what the study is about, so they know how suitable they are to take part and allow them to make an informed decision on whether they would like to participate. In addition to this, it was imperative that the participants were aware that they could withdraw at any point without reason, so that they did not feel obliged to take part or stay in a situation that made them uncomfortable, if they did not wish to. It was also important to ensure they were aware that any information that they shared would be anonymised and confidential, so nobody would be aware of who they are, or be able to link them to any private information that they share. Furthermore, it was ethically important that the individuals were all able to provide informed consent. This was ensured as by researching with individuals above the age of 18 only with Asperger's syndrome rather than Autism spectrum disorder. Those with Autism spectrum disorder are documented to have a lower IQ levels and some individuals need support as an adult whereas those with high functioning Autism and those with Asperger's Syndrome are likely to live independently (Economic and Social Research Council, 2020, Hamilton et al., 2017, and Loyd, 2012). As documented within previous research (Spek, Scholte and

Van Berckelaer-Onnes, 2010), the participants who took part each showed at minimum a standard intelligence and verbal ability, all of the participants discussed the research prior to the interviews and understood and recalled what the research was aiming to achieve and why they had been asked to take part. Additionally, all the participants were independent and did not need the approval of a carer or guardian, had the participants needed additional care and were not independent secondary consent I would have attained secondary consent from the appropriate carer (BERA, 2018). I have considered the possible impact, of this research, on the lives of the participants taking part and have created a debrief sheet which was issued to each participant. I am aware that discussing these sensitive topics may have a negative impact on the mental wellbeing of the individuals, the debrief sheet given directs the participants following the interviews. The Debrief sheet questions whether the participants have been impacted negatively by the interviews and directs them to the appropriate organisations and the University (Draucker, Martsof & Poole, 2009 and BERA, 2018). Had the participants showed any distress during or before the interview, such as crying or suggesting that they are an immediate threat to themselves or other, I would have ended the interview and directed them to the appropriate organisation as displayed in the debrief sheet (Draucker, Martsof & Poole, 2009). In addition to this, it has been noted by (Mealer and Jones, 2014) that researchers asking emotional and sensitive questions may come away from their research affected by the response's. If, myself as the research, is psychologically impacted by any of the findings brought to light within this study I will be able to contact the university's education department for support or a number of support lines and agencies as shown within the debrief sheet. Furthermore, I did not approach any participants directly and each participant contacted me to ask to take part in the research after hearing about the research to ensure they did not feel obliged to take part or say yes (BERA, 2018). This research has also followed the Data Protection Act 2018 (Home office, 2018). In order to keep all of the data collected private, it will be stored on the university box and will only be accessed by myself and appropriate members of staff at the University of Huddersfield, who are relevant to the study.

3.6 Positionality

Throughout my time in higher education I have developed a great passion for working with children with Autism spectrum disorder. Within my college and university placements I have spent a lot of time working closely with young children who were going through or had been through a diagnosis of Asperger's syndrome. I found that I enjoyed supporting the children that I worked with too access all areas of education whilst in these settings and creating an adaptable inclusive environment. In addition to this I began to study topics around Asperger's syndrome throughout my time at university, I feel that in order to do the best job in supporting children with Asperger's syndrome I

need to have an extensive knowledge base around the condition. During my researching I came across the article “Do you know I have Asperger’s syndrome? Risks of a non-obvious disability” by Portway and Johnston (2005). Within this article Portway and Johnston, question what right we have to label children when we are unaware of the lifelong impact this label may leave, others have also questioned this (Parens, et al, 2011). My personal beliefs follow a social model of disability outlook, meaning that I believe that it is society which creates the obstacles rather than the ‘disability’ (Woods, 2017). I also follow a Neurodiversity viewpoint, which views individuals with neurological conditions such as Asperger’s syndrome as having differences which can benefit them given the right chance and if society enables them rather than having a deficit (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013, Masataka, 2017).

Prior to this research study I started working as 1 to 1 support within a day nursery. Throughout this job I have worked closely with children who are seeking a diagnosis of Autism spectrum disorder along with children who have already been diagnosed. Throughout this I have had parents ask questions and voice their concerns in seeking a diagnosis for their young child. In addition to the parents of young children I have spoken to adults who feel that they have Asperger’s syndrome but were unsure whether they wanted to gain a diagnosis. My hope for this research is that it will enable myself and others to appropriately adapt our environments and support individuals going through a diagnosis.

3.7 Sampling

This research study follows five participants who are of mixed age and sex. The aim of this range of participants is to work alongside the phenomenological approach that is adopted throughout this research (Denscombe, 2014). Through following this approach, this research will describe and interpret each unique individual experience and compare the findings between the participants and relevant literature in the aim of answering the research questions (Gray, 2014). Any participant who is discussed as being ‘child diagnosed’, is defined as a person under the age of 18 during this research study (NSPCC, 2019). The ages for the participants at the time of their diagnosis range from 12 to 43 and have all been diagnosed within a 12-year span. This has been shown in the table input below.

	Diagnosis age	Age now	Gender
Archie	12	26	Male
Jane	14	24	Female
Jack	18	21	Male

Katie	32	37	Female
Mark	43	47	Male

Due to the age difference of the participants, they will have all lived through different curriculums alongside how Autism spectrum disorder was viewed by other people. However, they will have all been diagnosed whilst the ICD-10 (World Health Organization, 1992) was still in place, which ultimately will have aided each diagnosis. The age difference between these participants will support the research in gathering a wide variety of experiences and exploring how different experiences over time may have impacted the findings. The participants taking part in this study have been diagnosed under the IDC 10th Edition, which, as previously mentioned, ran from 1992 to 2018, with a diagnosis of Asperger's syndrome, rather than high functioning Autism spectrum disorder, however if diagnosed today these individuals would have received a diagnosis of high functioning Autism spectrum disorder (World Health Organization, 1992). The age range of the participants, when diagnosed, has been chosen in order to explore the difference, if any, they may have encountered during their time within education, to understand the way that they were treated whilst in education. In addition to this, it has been stated that children with Autism spectrum disorder may not be self-aware until early primary age, therefore there may be some discrepancies within the findings when asking participants to think retrospectively about their childhood (Larery, 2018). By limiting the years in which the individuals received a diagnosis, it limits the amount of policy changes during this period; ensuring that the participants will have gone through similar educational experience in regard to the policies relating to education and special educational needs and disabilities (SEND). For instance, within a 14-year period between the participants diagnosis, the Disability Discrimination act 1995 (Government Equalities Office, 1995) and Equality Act 2010 (Government Equalities Office, 2010) have been the key policies affecting their diagnosis. Despite the 14-year gap between the participants diagnosis, there is a 31-year age difference between the ages of diagnosis due to 3 being diagnosed as adults and 2 who were diagnosed as children. There is a 26-year age difference between the youngest and oldest participant. It is important that all the participants were at least 18 years old at the time of the interview process as following BERA's ethical guidelines (2018). I do not feel that it is ethical to discuss a child's label directly with the child. Portway and Johnson (2005) suggest that individuals may experience a feeling of being different as a consequence of other people's actions and I feel that by discussing the impact of diagnosis, it may cause the children to feel 'different'. There were originally 8 participants for this study, however 3 decided to no longer continue with the study.

A phenomenological approach has been adopted throughout, as it is best suited to small scale research, as the data collected must be explored in great depth and this would be compromised by having a larger number of participants (Creswell, 2013; and Denscombe, 2014). For example, Creswell (2013), suggests working with no more than 25 participants and no less than 5. This is reiterated by Denscombe (2014) who suggests between 5 and 20 participants. As this is a small-scale study, both in time scale and resources, 5 participants were selected for this study.

The participants were crowdsourced through online support groups, where they were given basic information about the study such as: the title; aims; contact information; and what would be expected of any participants. Following this the participants were able to approach me to take part if they wanted to. Crowdsourcing is a common contemporary method of sourcing research participants within modern society (Bell & Waters, 2014; and Hedges & Dunn, 2017). This will be used within this study, via the use of social media sites within online support groups, focusing on AS. All the participants who took part in this study were recruited through online support groups for people within the UK who have a diagnosis of Asperger's syndrome. I posted in the groups with a brief description of the research study and what would be expected of anybody who wished to take part in the study; I also attached my professional email address for individuals to contact me if they wished for more information.

3.8 Interviews

The Interviews for this research study have been chosen in order to gain an understanding of each participant's self-identity and outlook on their own mental health in regard to anxiety and depression through their individual experience. In order to do this, the interview has incorporated Rosenberg's self-esteem scale (Cooper, Smith, & Russell, 2017, and Rosenberg, 1965). As previously mentioned within the literature review, self-esteem is an important part of both mental health conditions such as anxiety and depression alongside and self-identity. Along with this I will also be conducting Hart and Damon's self-understanding scale (Jackson, Skirrow & Hare, 2011, and Hart & Damon, 1988) in order to gain an understanding of the participants self-identity, which is why it has been included within the interview process. Along with these already established interviews, the participants also were asked questions surrounding NHS signs of anxiety and depression in order to explore what suggested symptoms they either do or do not connect with. This section of the interview has been designed with the aid of the NHS guidelines for depression and anxiety (National Health Service, 2018, and National Health Service, 2019), by taking the official signs and symptoms of the conditions we are able to see how the participants identify with said conditions. Following this, the fourth set of questions aim to obtain information on their diagnosis and their feelings

surrounding their diagnosis specifically. They have been broken into four categories in order to aid the analysis of each area. By separating the questions, it also helped to break down the different areas, supporting me in analysing and discussing the findings. Throughout the interviews each participant was supported, before agreeing to the interviews and before starting the interviews the participants were made aware that they would be discussing sensitive topics and they did not have to answer any question which they didn't want to. Due to the sensitive topics discussed the participants were given a debrief sheet, as previously discussed above, within this they were signposted to appropriate hotlines and charities should any questions within the study have an effect on their mental health. A copy of the debrief sheet can be found within the appendix.

As previously touched upon the interviews conducted within this research study have been carried out either through a phone call or email. This choice has been made as some individuals had emergencies which meant that they did not have time to carry out the interview for a large amount of time and others felt more comfortable corresponding through an email conversation or telephone. As some interviews had to be conducted via email, this does question whether the interviews could have been conducted as a survey. When specifically assessing the use of email interviews I have found that some researchers have opted for this approach in order to ensure that certain participants were able to contribute in a way that they couldn't have or wouldn't have felt comfortable doing otherwise (Ison, 2009 and McCoyd & Kerson, 2006). Furthermore, Email interviews can be more convenient for the participant, allowing them to take their time, add more information that they may have missed in their previous response and allow for the researcher to extend on a topic that may require more discussion (Ison, 2009 and McCoyd & Kerson, 2006). Had a survey been sent in place of an email interview there would not have been any opportunity to discuss the responses if needed. There are both pros and cons to telephone and email interviewing over a survey, such as being able to explain and questions they may have, ask any added questions which may arise due to the participants responses and provide 'interviewer invisibility' (Gray, 2004) which may allow for individuals to open up more. Mealer and Jones (2014) states that when talking about sensitive topics such as this telephone interviews can limit the emotional distress due to the comfort of 'virtual communication' and may also create an emotional barrier allowing for researchers to remove any judgement that may be taken from visual cues. In addition to this it has also been noted that face to face interviews can often feel intrusive (Oltmann, 2011) and when given the opportunity to interview through telephone or email instead it can be empowering for the participant. However, there are also negatives to this style of interviewing one ethical implication, may be that it is harder to create a rapport without meeting face to face and additionally as a researcher I will be unable to convey compassion and empathy through non-verbal

communication and will be relying on verbal skills only (Mealer and Jones, 2014, Gray, 2004 and Denscombe, 2014). Additionally, individuals may not give their true, emotional response as they have time to change what they initially may have thought, this may also be perceived as a positive attribute of this style as some individuals were concerned that they would not be able to think about their answers beforehand and they would be able to give a more appropriate response having thought about their answer.

3.8.1 Rosenberg's self-esteem scale

The first set of questions presented within the interview is Rosenberg's self-esteem scale (Cooper, Smith, & Russell, 2017, Michael, McKay, Boduszek, Séamus, & Harvey, 2014 and Rosenberg, 1965). Just like this research study, the model has been used for research with individuals who have been diagnosed with Asperger's syndrome under the DSM-III-R after the age of 16 in order to understand social identity, self-esteem, anxiety, and depression in Autism (Cooper, Smith & Russell, 2017). The self-esteem scale consists of 10 Guttman scale questions (Elliot, Fairweather, Olsen, & Pampaka, 2016) which can be answered from 1 to 5, ranging from 'Strongly agree' to 'Strongly disagree'. This scale is important to this research, as self-esteem is one of the most defining factors within mental health and self-identity (Moksnes & Espnes, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018).

Although Rosenberg's self-esteem scale has been used by many academics and researchers throughout various areas relating to self-esteem (Alessandri, Vecchione, Elisenberg, and Laguna, 2015, Zeigler-Hill, 2013 and Cooper, Smith and Russell, 2017), the scale also has some challenges. For instance, it has been argued that the two trait factors, which this scale is known for, are not as effective as first hoped. Carmines and Zellar (1978), have suggested that even when the questions are presented in a different order the outcome remains almost the same. Other potential challenges may arise through the use of this interview section due to the sensitivity of the topic explored. It is worth noting that the questions within the Rosenberg are of a sensitive nature which can be challenging for both the participant and the researcher. Due to this, individuals provided written consent after discussing the contents of the interview and again verbally at the beginning of the interview (BERA, 2018). Following the interviews, the participants were each issued a debrief sheet directing them to appropriate organisations if they felt that the interview had negatively impacted them. Furthermore, as previously discussed if the participant's had displayed any signs of distress the interviews would have been stopped and they would have been directed to the appropriate organisation and the research department. In addition to this, should the participants show low self-esteem they would also be directed to appropriate organisations and the research

departments. Despite the emotional concerns surrounding Rosenberg's self-esteem scale it has been widely used throughout 53 countries and is thought to be a reliable way to assess self-esteem (Park & Park, 2019, McKay, Boduszek & Harvey, 2014 and Gnambs, Scharl & Schroeders, 2018).

3.8.2 Hart and Damon's Self-Understanding Scale

The second set of questions is Hart and Damon's self-understanding scale. They have defined self-identity as how one views themselves currently and how they view their past and future. They have stated that part of the interview aims to distinguish how individuals view themselves in comparison to others and have suggested that through one's self-identity, we develop our self-esteem and personal identity. Again, just as the Self-esteem scale has been used within research focusing on Asperger's syndrome, the self-understanding scale has also been used during research focusing on people with Asperger's syndrome (Jackson, Skirrow, and Hare, 2012). I feel that this interview technique is ideal when following the proposed phenomenological approach, as it aims to explore in depth into the lived experiences, thoughts and feelings of the interviewees, which is the main goal of phenomenology.

Within this part of the interview, there are 7 sections aiming to gather information around each participant's self-understanding. The 7 subject areas are: Self-definition, Self-evaluation, Self in the past and Future, Self-Interest, Continuity, Agency and Distinctness (Jackson, Skirrow & Hare, 2011, and Hart & Damon, 1988). The questions asked within each of these categories are in a semi-structured format and are there to prompt more information if it is needed. This follows the phenomenological approach, as it aims to ask questions in order to understand the individuals' experience with Asperger's syndrome and provide a detailed description of how they see themselves in the present, past, and future.

3.8.3 Exploring anxiety and depression

Following on from Hart and Damon's Self-understanding scale, the participants were then presented with statements relating to anxiety and depression. In keeping with the style of Rosenberg's self-esteem scale's two-factor scale (Cooper, Smith, & Russell, 2017, and Rosenberg, 1965), this section was designed to have staggered positive and negative statements. Whilst designing this part of the interview I was aware that I am unable to make any final, overarching statements about the individuals' mental health as I am not in a position to do so. However, with the use of the NHS's suggested symptoms of anxiety and depression I aimed to question what symptoms the participants suggested they related to, how many that they did or did not relate to and how much they felt that they related to the symptom. This was done to avoid the participants

responding to all the statements with the same answer and to make them think about the statement and their given response. Again, this was done on a Guttman scale where they were asked either extremely positive or extremely negative questions with answers from 'Strongly Agree - 1' to 'Strongly Disagree - 5' (Elliot, Fairweather, Olsen, & Pampaka, 2016).

Each question was written in direct correlation to the symptoms for anxiety and depression proposed by the (National Health Service, 2018 and National Health Service, 2018), however, they have not been used as a diagnostic tool but solely to provide an outline of any signs that the participants display regarding the NHS guidelines for both anxiety and depression. This interview segment also follows the phenomenological approach, as again, the main aim is to understand the interviewees experience with past diagnosed anxiety and depression and their thoughts towards their current mental health. I am aware that this does not provide any in-depth information, however, I will be following up these questions within the next section in order to gain a more detailed response to the questions surrounding anxiety and depression.

3.8.4 Further understanding

The final set of questions was designed to explore the participants feelings about how diagnosis has affected their life experiences, symptoms, lifestyle, mental health, and self-esteem. These questions relate back to self-esteem and mental health, as this section was made to collect more in-depth answers. Within this section of the interview stage, I aim to gain an overall look into their experiences and feelings surrounding Asperger's syndrome and how they feel it impacted on a range of areas. This last section of the interview has been developed to add to the phenomenology of this research, allowing the participants to add any extra details that may have been missed within the previous 3 sections of the interview (Maxwell, 2010). Again, this section is also fitting to the phenomenological approach followed as it allows for the participants to further explore their experiences surrounding their diagnosis and the impact that it has had on their self-identity, anxiety, depression and self-esteem.

3.9 Analysis

3.9.1 Rosenberg's self-esteem scale

In order to understand where each participant fits on the self-esteem scale, they will be rated from 10 to 50, with 50 being the highest self-esteem and 10 being the lowest (Hyland, Boduszek, Dhingra, Shevlin & Egan, 2014). Questions 1,3,4,7, and 10 are positive questions and 2,5,6,8, and 9 are negative questions. Positive questions such as "on the whole, I am satisfied with myself" that were answered with strongly agree will be given 5 points and will decrease by 1 point for each step down

the scale, with a 1 representing 'strongly disagree'. Negative questions will have a reverse point system, for example had "I certainly feel useless at times" been answered as strongly agree it would be given 1 point and strongly disagree would have been awarded 5.

Although this research study follows a qualitative approach, this use of numbers will support me in distinguishing between those with lower and those with higher self-esteem. The use of numbers in qualitative research has previously been debated, however, it has been argued that the use of numbers within qualitative research will support the data analysis and discussion by providing a precision to any statements made, when complementary to the following qualitative information and not as substitution for qualitative data (Maxwell, 2010). Following the results section, I will be discussing the analysis of the findings, where I will be covering whether the participants appear to have high or low self-esteem and whether this was impacted by their diagnosis of Asperger's syndrome. Rosenberg (cited in Zeigler-Hill, 2013) suggests that to have high self-esteem simply means that we do not consider ourselves as less than others, however, low self-esteem implies that we view ourselves as less than others.

3.9.2 Hart and Damon's Self-Understanding Scale

After conducting the interviews, each transcript will be categorised into 1 of 4 levels of self-understanding. These levels will allow for me to see how they view themselves. Level 1 consists of individuals who see themselves in simple categorical identifications. Individuals at Level 2 primarily make comparisons between themselves and others and what they perceive as the norm. Those categorised in level 3 determine who they are, by assessing their interactions with others, making comparisons about their interactions with others; they will often define themselves through their personality traits and social circles. Individuals who identify with the final developmental level, level 4, define their identity through their moral beliefs, life plans, and goals. They believe that their future is defined by their own experiences and interpretations of the world, along with their past and present characteristics. These 4 levels have been broken down into the graph below ^(*G2). Within this Graph, the 4 levels are shown across the horizontal axis and each area that was questioned in the interview correlates to the vertical axis (Hart & Damon, 1988). Theoretically those who are at a level 4 are more self-aware and have more self-understanding than those at a level 1.

Following these results, the interview transcript within this section will be analysed through thematic analysis looking for relevant themes that appear throughout the interviews (Gray, 2014). By identifying the themes found throughout the interviews I will be able to discuss the similarities

and differences between the participants with the aim to explore any potential impact that a diagnosis of Asperger's syndrome may have has on self-identity.

3.9.3 Anxiety and depression

Although this section was presented within the interview in the same way as the self-esteem scale it will not be analysed in the same way. The aim of this interview was to gain an understanding of which NHS signs and symptoms each participant relates to, if any. The interview has been conducted in this way in order to gain an overall outlook on the symptoms related to depression and anxiety in a way that is in keeping with the NHS guidelines. Whilst analysing the findings of this interview section I will be analysing how many signs and symptoms, as suggested by the NHS, the participant felt they related too. It was important to follow the NHS guidelines for symptoms directly so that I gain an outline of their relationship with these symptoms beyond their personal opinion of anxiety and depression which may be affected by their self-identity and the way they view themselves. Phenomenological research aims to gain a look into the experiences of others through detailed questioning within a semi-structured interview (Gray, 2014). However, these Guttman scale questions (Elliot, Fairweather, Olsen, Pampaka, 2016) although not typically used will aid the analysis and discussion within this research as they are followed up with questions surrounding the participants experience with signs and symptoms suggestive of anxiety and depression related conditions and their views towards it. Through these added questions this section will provide an in-depth view into the lived experiences surrounding anxiety, depression and Asperger's syndrome once analysed through thematic analysis.

9.9.4 Further understanding

This section of the interview will again be analysed through thematic analysis (Denscombe, 2014). Through this I will be looking for reoccurring themes that show relevance to the proposed research questions (Gray, 2014). The analysis of this section will strongly support both the self-esteem, anxiety and depression interview sections within this interview through providing my more in-depth answers. Therefore, this section will add more qualitative information too balance out the numerical side of the self-esteem section as previously discussed (Maxwell, 2010). Throughout this section I will also be questioning the general life experiences and Asperger's syndrome diagnosis within this section.

3.10 Reliability and Validity

Denscombe (2014), suggested that face-to-face interviews can help participants to open up as it creates rapport and trust. However, as the interviews were conducted with individuals whose social

skills do not adhere to the norm it is important that they are interviewed in a way that makes them feel most comfortable. It has also been suggested that interviews conducted by phone or email may also reduce tension and discomfort as it may feel less personal to the interviewee (Denscombe, 2014). Additionally, there is concern for the reliability of interviews that are conducted by email or phone call however Denscombe (2014) have suggested that through analysis we can see reoccurring themes throughout the interviews and within this we can review the reliability of the participant. As the participants were discussing personal experience, I felt that they should be able to feel comfortable to open up and therefore should be able to decide for themselves which interview style they would prefer.

3.11 Conclusion

The overall aim of this research is to explore the potential impact of a diagnosis of Asperger's syndrome on self-identity, self-esteem, anxiety and depression. Within this chapter I have mentioned that the research paradigm followed is interpretivism and follows a constructivist epistemological standpoint. In order to carry out this research in keeping with the epistemological standpoint and research paradigm this research follows a phenomenological approach throughout aiming to explore the unique experiences of the participants. These experiences have been captured through semi-structured interview, conducted through telephone and email, they have been broken down into 4 steps which each aim to look at different areas that are relevant to the research questions, these areas are self-esteem, self-identity, anxiety and depression and further understanding. Following the interview's, the transcripts will be analysed, section 1: self-esteem will be analysed with the aid of numbers however this will be backed up with qualitative thematic results with section 4: Further understanding (Maxwell, 2010). The rest of the interview will be analysed through thematic analysis, aiming to identify themes with relevance to the proposed research questions. Following the analysis of the data the results will be discussed again following a phenomenological approach aiming to describe, theorise and compare the findings in order to answer the proposed research questions. Following the research paradigm and the epistemological standpoint throughout this research I will be interpreting the responses from the interviews, creating appropriate themes in order to conduct a thematic analysis.

Chapter 4 – Results and analysis

4.1 Introduction

Throughout this chapter I will aim to break down the collected data and analyse the results in order to achieve the research aim which is:

- To gather information about the lives of individuals who were diagnosed with Asperger's syndrome, with the aim to explore any potential links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem.

To achieve the research aim I must first answer the proposed research questions, which are:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

In order to answer these questions, I will present the findings of this study and analyse what they mean in relation to the present research questions shown above. To do this, I will be analysing the interview findings with the aid of thematic analysis (Gray, 2014). The findings have been broken into three parts which are, self-identity, anxiety and depression, and self-esteem. Within these areas I will discuss the key themes that were brought to light within the interviews. The key themes that have been explored throughout this results and analysis chapter aim to relay the key findings that aid me in answering the research questions above.

The purpose of this study was to gather information about the lives of individuals who were diagnosed with Asperger's syndrome, with the aim to understand the impact that Asperger's syndrome on their self-identity, anxiety, depression and self-esteem. Through exploring this and gaining an insight into the unique experiences of the 5 participants who took part and interpreting the knowledge that they have shared throughout this study I aim to answer the proposed research questions.

Through exploring how Asperger's syndrome has potentially impacted self-identity, anxiety, depression and self-esteem I hope to influence both my own and others practice when working with young individuals who are going through a diagnosis or have been through a diagnosis of Asperger's syndrome. Within this I will relay the overall findings of this study and answer the proposed questions shown above. In addition to this I will also discuss the studies limitations and what could have been done differently along with any suggestions for future research.

4.2 Self-identity

Within this section I will be exploring the findings surrounding self-identity. I have found throughout my analysis of Hart and Damon's self-understanding scale that all five participants appear to be a level 4 on their self-understanding scale. They each appeared to have a clear understanding of their self-identity. All the participants within this study all deemed themselves to be unique and were able to assess their personality and traits which they believe make them unique, although not always in a positive way. I will further explore the 7 sections within Hart and Damon's self-understanding scale throughout this section of the analysis.

One of the theories I previously discussed is the Identity theory which suggests that individuals identify with the things that they do whereas social identity theorises that individuals define themselves through the people they associate with (Terry, Hogg, & White, 1999). Whilst analysing the findings I have noted that the interviewees, whilst they touched upon their social-self, rarely defined themselves through others and instead focused on defining themselves through their personality traits, beliefs, themselves over time, and the choices they have made theory (Cheng & Guo, 2015, Jiang, Zhao, Sun, Zhang, Zheng, and Qu, 2016; Stets & Burke, 2000; Stets & Carter, 2011; and Terry, Hogg & White, 1999). Through analysing the links between the participants and both identity and social identity theory I will aim to explore the impact this has had on developing a self-identity. Although most of the participants answers within the interview swayed away from social identity Archie and Jane both showed signs of identifying with their social self. This can be seen within these quotes taken from the interviews;

"I'm a follower not a leader" – Archie

"It took me years to develop a personality to such a way people will actually like it and I had something which people might want to stick around for" – Archie

"I am very impressionable, I think this used to have a negative impact on my life due to the people I'd be around, however I am now around more positive people so feel like I am a more positive person." – Jane

"I used to mimic people and their behaviour, being impressionable, but I am starting to learn what "me" is now. I think people may share quirks or habits, but that they won't all be the same, everyone has differences and similarities, but everyone is unique." - Jane

Within these quotes both Archie and Jane appear to define themselves socially through how they relate to their family, friends, and co-workers. Jane states that she is impressionable and often picks things up from her friendship groups and Archie implies that he also does the same. Literature suggests that those with Asperger's syndrome are more likely to view themselves socially rather than through their own personality and beliefs (Cooper, Smith, & Russell, 2017). However, throughout this study, as previously mentioned, these are the only few times that any participant has suggested anything linking them to a social identity. However as shown within the self-understanding scale analysis graph ^(*G2) there have been other identifiers of their social self-whilst still discussing identity theory and speaking of themselves. Within this they have mentioned their morals and personal choices as in keeping with level 4.

"Well I'm not easy to understand some of the time due to my unusual nature, I have a sense of humour which most people wouldn't understand unless they know me." – Archie

"I'd say quietly confident. I don't like to be the centre of attention. Erm, I'm the type of person that will speak up if I need to but, I'd probably rather just sit back." – Jack

"I like to think I am a nice person, but sometimes feel I am not. I am not the quietest person and find I have a sarcastic sense of humour." – Jane

"Compassionate, kind, open minded, easy going, logical, creative, but can also be stubborn, and have little to no tolerance of stupidity and ignorance with no desire to learn. I am an introvert, with a distrust of people." – Katie

"I try to understand other people and I think generally speaking they appreciate that, and they try to understand me as well." – Mark

Within these quotes you are able to see that all the individuals have theories about their own personality and what this means for others around them. They have all shown a great amount of self-evaluation here and are able to state something that they see as important to them (Oshana, 2010). This contradicts the literature reviewed within this study as all the participants are able to see how their actions affect others and to negotiate their problems when needed (Marks, Schrader, Levie, Hagie, Longaker, Morales, & Peters, 1999 and Holloway, 2018). they have also touched upon how they feel they present socially with many of the participants stating that they are outgoing and loud.

"My creativity and logical thinking." - Katie

"I'm quite outgoing, Erm, more recently I'd say confident. Quite a social person" - Jack

“sociable, quite outgoing, positive, friendly, I love my job, I love my friends, I just enjoy being myself and hanging out with other people and generally getting on with life... I try to understand other people and I think generally speaking they appreciate that, and they try to understand me as well.” – Mark

“I am not the quietest person and find I have a sarcastic sense of humour.” – Jane

Another section that Hart and Damon (1988) stated, within the scale’s analysis graph^(*G2), is important is continuity. This was a reoccurring theme within literature emphasising the importance of being able to identify with our past, present and future. The participants were able to identify how they may change over time and understood their own continuity, that we all change and develop throughout our lives, although expressing that as adults the amount they change may now differ from their past years.

“Like when I was in school because I’d not really experienced stuff I just kind of stayed the same. So though experienced all the work experience, education, and just general life stuff really. That’s helped to shape it” – Jack

“Things at work could change, maybe I could be a team leader. They’ve never seen me as a potential team leader. But that would be a change for me and maybe it’s just possible I could step up to the plate and be a team leader at work.” – Mark

“I don’t think anyone can live without changing. I like to think I become a better person each year.” – Jane

“I developed a personality, I’ve built my confidence, I’m more open to communication with strangers, I have a sense of humour which I adapt to be more understanding to people, I build my own understanding of different personalities and adjust accordingly, I’m more understand of other people as an overall so avoid certain hot topics such as politics and things which get heated quickly, I’m more appropriate to situations, I’m a lot more respectful and all of these things are constantly being developed and grown to be a better person.” – Archie

“I change through understanding and knowledge.” – Jane

Within these few quotes it is apparent that each participant was able to present a clear understanding and memory of their past, present and future. Jackson, Skirrow and Hare (2011), suggested within their work that individuals with Asperger’s syndrome would be less likely to understand their continuity. In addition to this Dritschel (et al., 2010) also suggested that those with Asperger’s syndrome would have a profound difficulty in developing self-knowledge and remembering key past memories. These theories have not been evident within any of the interviews as they were each able to show a clear understanding of their own continuity and recall

memories and experiences in relation to the times that they have changed. Furthermore, participants were able to show agency throughout their interviews having each given multiple personal and moral evaluations of themselves (Hart and Damon, 1988).

“I’m most proud of is more managing to get through the last 6 years of my life to re-establish what I had lost.” - Archie

“My inability to see the bad in people regardless of how obviously bad they are.” - Archie

“what I’m especially proud of about myself is to do with Autism, ‘cause I grew up with Autism and I think I have to a large extent overcome it because I think to a large extent I have, when I was younger had no prospects in life at all and partly through luck I managed to find a way, a way out of it and to overcome it and that’s what I’m most proud of.” – Mark

“I suppose I’m not very good at being a leader, at being a decision maker, a manager.” - Mark

“I’m self-employed and I’ve been able to run that alongside my uni course.” – Jack

“struggle with confidence at times and I’m quite sensitive in different situations” - Jack

“I think I’m proud of how I got through university.” – Jane

“My temper. I was a very violent person and used to lash out at people for no reason” – Jane

“Not sure how or why, but people online drift to me for help or advice. I have supported strangers online in the middle of the night who were suicidal, etc. I guess I am proud that they feel comfortable enough for me to help” – Katie

“My Anxiety.” - Katie

Each participant has shown great self-evaluation throughout the interviews and were able to discuss things they felt they had done well and equally things they had not. As previously mentioned, it has been suggested that individuals with Asperger’s syndrome have difficulty seeing things through the eyes of others and knowing that their way is not always the right way (Marks, Schrader, Levie, Hagie, Longaker, Morales, & Peters, 1999 and Holloway, 2018). However, though this they have shown that they are able to see how they could change and how they do not do everything right. Alongside Agency within these quotes you are able to see how the participants have shown their understanding of their active self and physical self through the reflection. In addition to this the participants were all able to display an understanding of distinctness sharing that they are all unique individuals due to their individual experiences that are unique to them.

“I’d like to think I’m a unique individual due to my own ability to understand my own Autism and work alongside it to develop my own life to be as comfortable as possible instead of it being the sole driving force in my life. “– Archie

"I suppose it's just the mix of all the personality traits and how I like things to be that makes me a bit different." – Jack

"I am individual. I used to mimic people and their behaviour, being impressionable, but I am starting to learn what "me" is now. I think people may share quirks or habits, but that they won't all be the same, everyone has differences and similarities, but everyone is unique." – Jane

"No, I think we are all unique." – Katie

"Well I suppose the thing that would make me different from everybody else is not some major psychological difference that I experience but more that you know my personal journey that nobody else that has exactly followed. I've been to this job and that job. I've met this person and that person and that's what's has made me be unique and the person that I am." - Mark

Within these quotes you are able to see that that each individual is able to understand that they are their own person. This again brings up their social identity going against the theory that individuals with Asperger's syndrome define themselves socially rather than individually (Cheng & Guo, 2015, Jiang, Zhao, Sun, Zhang, Zheng, and Qu, 2016; Stets & Burke, 2000; Stets & Carter, 2011; and Terry, Hogg & White, 1999). Furthermore, I feel that each participant was able to show a both the general organization principal. However, although they were able to show some level of understanding of their psychological self throughout the interview, I do feel that they were not all able to establish their own self-esteem and mental health. Jack and Archie often discussed how they currently have high self-esteem throughout the interview. Despite this, they have shown signs of low self-esteem within Rosenberg's self-esteem scale along with the negative comments they made about themselves.

"A walking disaster with a yo-yo mood. Lazy and unhealthy but kind and forgiving. Strong willed but low confidence." – Archie

"I struggle with confidence at times and I'm quite sensitive in different situations. So, I can get upset quite easily or kind of lack in confidence sometimes when I don't need too." - Jack

In addition to this, each individual expressed what their diagnosis meant to them within the interviews, although there were many similarities within their feelings towards being diagnosed with Asperger's syndrome they have also extreme difference with some participants feeling that their diagnosis has been a huge relief and provided support whereas others have kept their diagnosis a secret and actively tried to change themselves and hide their symptoms rather than seeking support. This finding is supported by the chosen methodology, that has been followed

throughout. Constructivism, as discussed within the methodology chapter, follows the belief that knowledge is acquired through our environment and influenced by the people around us (Gray, 2014). Similarly, interpretivism states that individuals interpret their personal experiences to form beliefs and knowledge (Gray, 2014). Every individual experience's life differently and therefore each person forms their own thoughts on said experiences and creates their own opinions, feelings and thoughts which are ever changing. Additionally, I have discussed the affect that this may have had on their self-identity throughout. whilst reviewing literature surrounding self-identity and Asperger's syndrome in the literature review, I have mentioned that some individuals feel a deep connection with their label whereas others may reject their label completely (Cooper, Smith, & Russel, 2017). This statement has shown to be accurate to some degree, although all the participants acknowledge their label to some degree and are willing to take part in research surrounding Asperger's syndrome. One of the things that the adult diagnosed participants appear to agree on within this study is that a diagnosis has been a positive thing for them. Each one expressed how they felt it had been a positive experience in giving them a reason for their sometimes 'unusual' life experiences.

"I wanted a direct explanation for how things have been the way it's been. I found the effect on me has been more a positive than I could have anticipated because it's enabled me to talk about it to other people" - Mark

"It's been a very good thing to have because it's not just a certificate that says why you had a difficult childhood, it is that and that's important to me but it's also helping to improve my life."
- Mark

"I felt a weight had lifted from me." - Katie

"I think it made me feel, like a bit more comfortable with myself knowing what it was because I've always expected that there was something there but until I got that I never knew what it was." – Jack

As previously mentioned, individuals with Asperger's syndrome are often not diagnosed until 11 years old and many still don't receive a diagnosis until adulthood (Scott, Bardon-Cohen, Bolton, and Brayne, 2002). These findings reiterate the importance of an early diagnosis has discussed throughout the literature review. These participants each spoke of feeling better and more comfortable with who they are after their diagnosis. This suggests it may have affected their self-identity in a positive way, the diagnosis has supported them in changing the way they think about their symptoms and differences. I mentioned within the literature review that I questioned the

need for a later diagnosis when the individuals had missed years of support that may have been offered during their childhood (Harpur, Lawlor, and Fitzgerald, 2006). However, this backs up the need for a diagnosis even in later life. In addition to this these 3 participants have also noted that their diagnosis has had a positive impact on the way that their family, friends, and co-workers have treated them. They each discussed how they felt people had shown a deeper level of understanding towards them than before they had been diagnosed.

“it’s enabled me to talk about it to other people: to my employers my family and it’s part of a process that has sort of strengthened the understanding of it which the people I work with and live with so it’s really helped it’s really helped.” – Mark

“I suppose the people that I have told there’s been a different level of understanding.” – Jack

“Some family won’t accept it. Others are great support.” - Katie

The adult diagnosed participants have discussed how others have reacted to their diagnosis, suggesting that those who they have told about their diagnosis have been positive and supportive towards them. As previously discussed, our self-identity and self-esteem is highly impacted by our social circles as is our beliefs (Cooper, Smith, & Russell, 2017, Gray, 2014 and Punshon, Skirrow, & Murphy, 2009), through their family, friends and co-workers gaining a level of understanding it appears throughout the continuing findings that their self-identity and self-esteem have improved through gaining this understanding. Although, as noted above Katie has stated that some of her family have not accepted her diagnosis. This has been reflected within the interviews as Katie has displayed quite low self-esteem throughout. In contrast to this Jane has found that people have haven’t been as understanding as the other participants have found. Equally, as mentioned above, although Katie mentions that some people have been supportive, she has also found others to be unaccepting.

“People treated me different during the time of diagnosis because I was in school. I had to take days off to go to the 'mental health' hospital for appointments. The others in my class were always questioning "what's wrong with you? Why do you keep skipping school? " - Jane

“Some family won’t accept it. Others are great support.” – Katie

In addition to this, some of the participants have decided not to share their diagnosis or accept any support or in their own words ‘special treatment’.

“I mean I haven’t really told anyone about it. I didn’t feel the need to.” – Jack

“I kept my diagnosis secret from everyone except teachers and managers and I didn't feel I was treated differently.” – Archie

“I'm also proud that I've managed to 'hide' my Asperger's, so people don't know when they first meet me.” – Jane

The decision to keep their diagnosis a secret may stem from wanting to preserve their social identity (Cooper, Smith, & Russell, 2017). We often fear how other people will treat us or react when given a label and therefore often choose to define our own labels and reject the given label (Matthews, 2014, and Brooker, 2006). It appears from these findings that both Jack and Archie have rejected their label to some degree as they are worried about being treated differently than others. Matthews (2014), suggests that this is the main reasons that individuals often do not identify with their labels or share their label with others. By internalising their label, it will likely have impacted their self-identity. Hart and Damon (1988), have stated that self-identity also includes our social self which is made up of our social personality and relations. In addition to this, Brooker (2006), suggests that our self-image is created through what we believe our role in society is. Many individuals with Asperger's syndrome and Autism spectrum disorder have discussed how they 'camouflage' their symptoms by copying others in hopes to hide their symptoms (Baldwin & Costley, 2016).

Cooper, Smith, and Russell, (2017) have suggested that some individuals when diagnosed with Asperger's syndrome distanced themselves from the label and favoured more socially accepted labels. This reiterates what I have previously mentioned when theorising that these individuals who have kept their diagnosis secret may have rejected their label, at least socially. By hiding their symptoms and changing themselves both Jane and Archie have defined what kind of person they identify as separately to their Asperger's syndrome diagnosis. Overall, I feel that the participants each showed great self-understanding and self-identity and I believe that this will continue to develop over time due to their understanding of continuity (Chen & yao, 2009). Following on from this section which aimed to analyse the potential impact of Asperger's syndrome on self-identity I will be discussing anxiety and depression.

4.3 Anxiety and depression

Within the interviews each participant answered strongly agree to strongly disagree when questioned regarding NHS suggested symptoms of anxiety and depression. This will not state whether or not the participant has anxiety or depression but will provide me with an overall understanding of whether they relate to any anxiety and depression related symptoms. In addition to this due to the strong connections between anxiety, depression and self-esteem the Rosenberg's self-esteem scale has been conducted as well and the findings from this will be analysed through a point system. The self-esteem of the individuals will be touched upon within the section of the results and analysis, however it will be further discussed within the self-esteem section. Within the anxiety and depression section of the interview process there were some similarities between the participant's results. For instance, 4 of the participants stated that they have interests, enjoy taking part in their hobbies, and they find it difficult to make decisions. Although these statements are anxiety and depression related symptoms, they are also symptoms of Asperger's syndrome (Chandrasekhar & Sikich, 2015 and Ghaziuddin, 2005). Those with Asperger's syndrome are known to have highly focused interests and struggle to stray from routine (National Autistic Society, 2018) which is represented in these statements. Due to the overlap between anxiety and depression symptoms and Asperger's syndrome symptoms individuals are often misdiagnosed (Chandrasekhar & Sikich, 2015). However, it has also been suggested that individuals with Asperger's syndrome are overshadowed (Beljian, Webb, Amend, Web, Goerss, & Olenchak, 2016), meaning that other conditions such as anxiety and depression go without diagnosis and support due to them being categorised as a part of their Asperger's syndrome diagnosis. There were also many more differences between those who related to some symptoms of anxiety and depression, as suggested by the NHS, and those who showed no signs at all. For instance, both Jane and Katie stated that they related to some of the NHS suggested signs of anxiety and depression and connected with statements such as I continuously feel sad, I often have a feeling of hopelessness and I have suicidal thoughts. Unlike the other statements that the participants agreed with these are not Asperger's syndrome related symptoms. Following on from these individuals also stated they feel some relation to other suggested symptoms such as such as.

"I can't think what I hope for in life, other than some days to live, and others to not live." – Jane

"I have battled Depression and Anxiety from since I was a small child" – Katie

"I was recovering from a Mental Breakdown. My husband and parents were on 24hr suicide watch." – Katie

“still pick/bite my nails, but I have a fidget ring which helps control the anxiety so that most people don't see it as obviously.” – Jane

However, unlike Jane and Katie although Jack and Archie discussed past struggles with mental health and did not state any relation to any of the signs suggested by the NHS.

“when I was 20, I was in an abusive relationship. Sort of spiralled me out of control to going into psychiatric hospital and losing pretty much everything I had built up myself over the years. I'd say what I'm most proud of is more managing to get through the last 6 years of my life to re-establish what I had lost.” - Archie

“It's going back to like having everything in a routine and not wanting to change that was one of them and then, erm, a couple of years ago I had issues kind of meeting new people and making friends which I don't have now but that was one of the things that lead to me being checked out for it and then all the worrying, anxiety.” – Jack

It has been suggested that depression and anxiety are more common in those with Asperger's than those who are typically developing (Tantam, 1988, Emerson & Hatton, 2007 and Barber, 2018). So, it is no surprise that the majority of the participants in this study stated that they previously suffered with anxiety and depression at one point during their life and related to some of the current NHS suggested symptoms. The diagnosis itself did not seem to be the factor which helped these two participants overcome any possible problems with anxiety or depression, Archie has suggested that he did not start having any problems with anxiety or depression until after his diagnosis. Katie and Jane both currently show signs of anxiety or depression and Mark has shown no signs of currently or every having suffered from anxiety or depression. However, Jack states that he does feel that his diagnosis aided him in overcoming his problems with mental health.

“I'd say it was worse before. Again, because I didn't know what I was a bit different with certain things. It kind of caused it to be a lot lower than it is now.” – Jack4

Unlike the other participants throughout the interview Mark never mentioned any previous issues with anxiety, depression or low self-esteem. This is quite unusual as I have previously stated 80% of individuals with Autism spectrum disorder suffer from a mental health condition (Barber, 2018), which is an extremely high statistic in comparison to the 17% of typically developing individuals (McManus, Bebbington, Jenkins, Brugha, Appleby, Anderson, and Wessely, 2016). Although they gave great indications of their self-identity and analysed who they are and how they would like others to perceive them not all of the individuals were able to analyse their self-esteem alongside their past diagnosed issues surrounding anxiety and depression and whether they feel any relation

to the symptoms suggested by the NHS. Within this section I have explored the varying self-esteem, anxiety and depression findings through all participants. It has been unusual to see that although most of the individuals still appear to be struggling with low self-esteem they state that they are mostly no longer appear suffering with anxiety or depression (Moksnes & Espnes, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018), as mentioned within the literature review those who have lower self-esteem are far more likely to suffer with an anxiety or depression related disorder. However, it is noted that those who do suffer from low self-esteem have previously suffered with their anxiety and depression. Following this review of anxiety and depression, I will be discussing the positive and negative impact of a diagnosis of Asperger's syndrome as found from the interviews.

4.4 Self-esteem

Within this section of the review and analysis I will be exploring the impact on self-esteem. Whilst conducting the Rosenberg's self-esteem scale participants had the ability to score between 10, as the lowest form of self-esteem and 50 as the highest. The scale the participants were each presented with is a 10-point Guttman style scale, within this they answered each statement from 'strongly agree' to 'strongly disagree'. Each positive answer is the equivalent to 5 points, this number lessens whilst working down the scale to strongly disagree which is equal to 1 point. From the self-esteem scale I have found that 3 participants scored 30, Mark scored 49 and Jane scored 27. This suggests that the 3 participants scoring 30 suggesting that they have low self-esteem, Mark displayed high self-esteem almost scoring full marks. Additionally, as mentioned Jane also scored low within Rosenberg's self-esteem scale, as she received a score of 27 suggesting that she has the lowest self-esteem within the group. In addition to this Jane answered disagree to the statement I have a high self-esteem within the anxiety and depression interview section, equally adding to factors suggesting that she has low self-esteem.

"Even now I struggle sometimes. My self-worth is low too sometimes." - Jane

Alongside Janes display of low self-esteem, she also stated that she relates to more of the NHS suggested symptoms of anxiety and depression than the other participants, along with discussing previous diagnosed conditions as discussed in the previous sub section of this chapter. In addition to this, Katie also stated that she has low self-esteem within the 'anxiety and depression' interview. This suggests that there may be a link between anxiety, depression and self-esteem as discussed within the literature review (Moksnes & Epnas, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018). However, Archie and Jack did not believe that they have low self-esteem when asked what their relationship with self-esteem is, it appears different to that of Janes, whilst Jane discussed her current self-esteem as being low throughout Archie and Jack each mention that they are happy and confident.

"I've gone from a bumbling mess who spent a great deal of time hiding in the psychiatric hospital shower, hoping death would come sooner rather than later with absolutely nothing to my name. to a more established adult, happy, confident, person." – Archie

"I do like lots of qualities about myself at the moment." – Jack

"But with time, over the last couple of years it definitely has gone back to quite high self-esteem, what it used to be. I just had a dip really where I lost all the self-esteem that I built up."
– Jack

“No self-esteem at all due to relentless bullying and mental health wasn't any sort of factor in my life at that time because I just lived life the same way every day.” – Archie

Despite these quotes both Archie and Jack answered negatively to questions such as I feel that I am able to do things as well as most other people, I feel that I am a person of worth, at least on equal plane with others and agreed with statements such as at times I think I am no good at all. These statements along with their self-esteem score suggest that they still currently have quite a low self-esteem. This has been further backed up by statements made throughout the interview such as;

“I struggle with confidence at times and I’m quite sensitive in different situations.” – Jack

“A walking disaster with a yo-yo mood. Lazy and unhealthy but kind and forgiving. Strong willed but low confidence.” – Archie

Unlike Jane and Katie, Jack and Archie do not appear to relate much to the NHS suggested symptoms of anxiety or depression although they do appear to show signs of low self-esteem which differs from the expected outcome as suggested previously that there is a link between anxiety, depression and self-esteem (Moksnes & Espnes, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018). However, they did both state that they had previous issues with their mental health.

As these findings show, 4 of the 5 participants of this study appeared to suffer from low self-esteem. Although this study is unable to speak for all individuals with Asperger’s syndrome, it does suggest that those with the condition are more likely to display signs of low self-esteem. This is backed up by McChesney and Toseeb (2018), who also suggested that individuals with Asperger’s syndrome are more likely to suffer from low self-esteem than their peers. One of the key factors discussed as being a likely reason as to why individuals with Asperger’s syndrome are more likely to suffer from low self-esteem is loneliness and bullying (McCauley et al., 2017 and Storch, Larson, Ehrenreich-May, Arnold, Jones, Renno, Fujii, Lewin, Mutch, Murphy, & Wood, 2012). This was also a noticeable theme throughout the interviews as Jane, Katie and Archie have all discussed times when they were bullied or without friends.

“Lonely in regard to socially. I did not mix well with others my age, due to shyness and anxiety, as well as different interests.” – Katie

“I feel isolated sometimes as most people understand jokes or chat in conversation and I don’t. I feel uncomfortable in social situations, where some people I know love that, people seem to get on with each other easily, but I have difficulties making small talk and understanding

people's reactions/facial expressions, meaning I'm usually left behind in social meetings.” – Jane

“When I was in high school, I was heavily bullied to such a degree that I didn't ever want to go to school” – Archie

Many studies have shown the impact that bullying has on decreasing levels of self-esteem on school children (Zablotsky, Bradshaw, Anderson, & Law, 2013, Hebron & Humphrey, 2014, and, Dubin, 2017). It has been suggested that even as an adult those who were bullied as children and as adolescent's are likely to still suffer from the experience, taking low self-esteem and possibly other mental health conditions through into adulthood (Dubin, 2017 and DeLara, 2016). The findings of this study suggest that is may be the case as those who did face bullying as a child have shown signs of low-self-esteem throughout. In contrast to these 4 participants Mark showed no clear signs of low self-esteem and presents himself as having extremely high self-esteem throughout the whole interview. Additionally, Mark has not mentioned any loneliness or bullying in neither the past nor present throughout his interview.

“if I'm being completely honest there isn't much that I completely don't like about myself. “– Mark

Mark has accepted his diagnosis with open arms and as shown throughout the analysis he has discussed his diagnosis with others and felt that it has provided him with a great deal of comfort. However, the way one views their 'label' may be impacted by the opinions of others, Pusnshon, Skirrow and Murphy (2019), suggested that internalising the negative opinions of others can affect one's self-esteem and change the way one views themselves. Despite the positive affects felt by the those who were adult diagnosed, those who were child diagnosed spoke of hiding their symptoms or trying to change them rather than embracing them as part of who they are (Pusnshon, Skirrow & Murphy, 2019).

“It gave me something to read about on a night and how to change things about myself if I could.” - Archie

“I don't think so; I think I was just more aware of them. It in a way, yes, because I noticed them more, so tried to stop the symptoms and hide them from people.” – Jane

By changing and 'camouflaging' their Asperger's syndrome symptoms it seems that they feel negatively about these traits that they have which will likely have impacted upon their self-esteem (Pusnshon, Skirrow & Murphy, 2019). These findings do suggest that those with Asperger's syndrome are more likely to show signs of low self-esteem, this is backed up by Capps, Sigman,

Yirmiya (1995) along with others, which have been mentioned throughout. However, Williamson, Craig, and Agam (2004) found no difference in self-esteem between typically developing individuals and those with Asperger's syndrome. As stated, this research suggests that those with Asperger's syndrome show signs of having low self-esteem however, as previously mentioned, this study is not able to state whether all individual's with Asperger's syndrome show signs of low self-esteem.

4.5 Conclusion

Within the results and analysis section I have relayed the finding of the study within the three main areas that have been questioned throughout which are self-identity, anxiety and depression, and self-esteem. Within these three main areas I have used thematic analysis to establish key themes throughout and analyse the findings. Within the self-identity sub section (4.2) I have discussed the key themes which came to light throughout the interviews which are their social identity, the positive and negative experiences of being diagnosed, and the impact on other people. Alongside this I also broke down the 7 key areas that were proposed by Hart and Damon (Jackson, Skirrow & Hare, 2011, and Hart & Damon, 1988), to be the key areas on building one's self-identity. These key areas are the: general organizing principal; physical self; active self; social self; psychological self; continuity; distinctness; and agency. Following this I discussed and analysed the results surrounding 'anxiety and depression' (4.3). Although, within this sub-section I could not make any resounding conclusions about mental health as I have no qualification to do so, I have discussed how each participant related to the NHS suggested symptoms surrounding anxiety and depression. The key themes explored throughout their relation to NHS suggested symptoms surrounding depression, their past diagnosed anxiety and depression, and the links between self-esteem, anxiety and depression. Finally, within this chapter I have discussed the results in relation to self-esteem (4.4). Within this I have analysed Rosenberg's self-esteem scale (Rosenberg, 1965), from this I gained a brief understanding of each participants self-esteem. Following this, I explored the key themes that were brought to my attention throughout the interviews which are the links between anxiety, depression and self-esteem along with the impact of bullying. Following this results and analysis chapter I will be aiming to answer the 3 proposed research questions within the discussion (5), along with presenting any limitations and suggestions for future study.

Chapter 5 – Discussion

5.1 Introduction

The purpose of this study was to gather information about the lives of individuals who were diagnosed with Asperger's syndrome, with the aim to explore any potential links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem. By exploring this and gaining an insight into the experiences of the 5 participants who took part in this study I have aimed to answer the two research questions which are:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

By understanding how Asperger's syndrome has impacted both self-identity anxiety, depression and self-esteem I hope to influence both my own and others practice whilst working with young individuals who are going through a diagnosis or have been through a diagnosis of Asperger's syndrome. This study was developed due to my growing interest in the Autism spectrum disorder that developed throughout both my time at university and work. Additionally, the questions explored throughout have been formed after talking with close friends of mine who feel that they have Asperger's syndrome but have avoided seeking a diagnosis due to the unknown of being labelled. Within this discussion I will relay the overall findings of this study and answer the proposed questions shown above. In addition to this I will also discuss the studies limitations and what could have been done differently along with any suggestions for future research.

5.2 Does Asperger's syndrome have an impact on self-identity?

Whilst presenting the results and analysing the findings of this research study I have explored the statements made by the participants in relation to self-identity and analysed the statements made in agreement with Hart and Damon's (1988) self-understanding scale. Within this scale Hart and Damon outlined the factors which make up our self-identity along with the questions to ask within an interview to explore how individuals understand themselves. Through this I have found that the participants were all able to provide an in depth understanding and evaluation of themselves. As mentioned within the analysis this is a surprising finding given that it has been found within some previous studies that those with Asperger's syndrome give less self-descriptions when discussing their individuality and continuity (Jackson, Skirrow, & Hare, 2011 and Dritschel et al., 2010) who stated that individuals with Asperger's syndrome find it difficult to develop their self-knowledge. However, others have found little to no difference in self-identity and self-description in individuals

with Asperger's syndrome (Hart and Damon, 1988). In addition to this I also found the participants who were diagnosed as adults found great comfort within their diagnosis and felt that it gave them an explanation too the way that they act and who they are. This was a different outcome in comparison to the findings of those who had known about their diagnosis from childhood. Those who were diagnosed as a child appeared to 'camouflage' their symptoms and did not seem too embrace their diagnosis (Baldwin & Costley, 2016). Within this I was also able to see that possible low self-esteem appears to have also impacted on the self-identity of the participants, those who displayed signs of low self-esteem described themselves negatively at times in comparison to the participant who's interview suggested that he has high self-esteem. When interpreting the results of this study, the participants do appear to be impacted by their diagnosis both positively and negatively, however this is not representative of all individuals with Asperger's syndrome as the research has provided no conclusive data. The impact for some has supported them in accepting their traits and personality and understanding which parts of them are impacted by Asperger's syndrome. Whereas others have hidden their symptoms and worked at changing them, actively attempting to reduce the impact that Asperger's has on their traits and personality. Through these findings suggested that the participants were able to describe and evaluate their self-identity I would hope that it will impact my practice in supporting individuals going through or with a diagnosis too accept and understand their traits and personality. However, this may not be true for others who have Asperger's syndrome due to the scale of this study I cannot generalise for individuals as a whole

5.3 Does Asperger's syndrome have an Impact on anxiety and depression?

This research study also aimed to explore the mental health of individuals with Asperger's syndrome. In the aim to explore the possible impact that a diagnosis of Asperger's syndrome may have on anxiety and depression they were questioned on their current symptoms along with whether they suffered from anxiety and depression prior and post diagnosis. This research hoped to explore whether the participants involved appear to relate to the NHS approved symptoms of anxiety and depression or whether they previously have been diagnosed with Anxiety or depression but now do not feel that they relate to the symptoms that they previously did. Within this the participants stated whether they agreed or disagreed to statements in relation NHS approved anxiety and depression symptoms. The participants who stated that they related to some symptoms linked to anxiety and depression also appeared to have low self-esteem according to Rosenberg's self-esteem scale. However, not all the participants that appeared to have low self-esteem stated that they related to the anxiety and depression symptoms that were previously discussed. This is

representative of previous research which has found that individuals with low self-esteem are more likely to suffer from anxiety and depression related conditions (Moksnes & Espnes, 2012, Cooper, Smith & Russell, 2017 and McChesney & Toseeb, 2018). Cooper, Smith, and Russell, (2017) hypothesized that a diagnosis of Autism spectrum disorder would improve anxiety and depression symptoms. Within this research 4 of the 5 participants suggested they related to some of the suggested symptoms of anxiety and depression at one point within their life. However, both female participants stated that they currently feel some relation to the most suggested symptoms presented within the interview. The research questions whether a diagnosis of Asperger's syndrome has any possible impact on anxiety and depression. However, I am unable to say whether or not the individuals were impacted by their diagnosis, although some participants stated that they related to the symptoms suggested by the NHS I cannot state whether this has an impact on their mental health or whether their relation to the symptoms is due to their diagnosis. It has been reiterated throughout by the participants that their diagnosis has had a positive effect on them by providing an explanation and another level of understanding, however no participant stated whether their diagnosis had an impact on their mental health. As discussed within the literature review (Scott, Bardon-Cohen, Bolton, Brayne, 2002) an early diagnosis may have been helpful to these participants in allowing them access to support for anxiety and depression as multiple participants stated that they previously suffered from a mental health condition. The findings of this study are not generalizable and are only true for the participants who took part.

5.4 Does Asperger's syndrome have an Impact on self-esteem?

In order to understand the impact that Asperger's syndrome has on self-esteem I have conducted interviews including the Rosenberg's self-esteem scale (Rosenberg, 1965), within this the participants each rated statements such as 'I feel that I am a person of worth, at least on an equal plane with others.' From strongly disagree to strongly agree. Additionally, they each touched upon their self-esteem throughout the interviews and within the 'further understanding' section of the interviews. Some participants showed more signs of low self-esteem than high self-esteem throughout this study. Previous research has indicated that individuals with Asperger's syndrome are more likely to suffer from low self-esteem than their peers (McChesney & Toseeb, 2018 and Capps, Sigman & Yirmiya, 1995), others have suggested that there is no difference (Williamson, Craig & Slinger, 2018). Due to the small scale of this research, I am unable to state whether or not I feel that self-esteem is lowered specifically by an Asperger's syndrome diagnosis itself without further research over time with more participants. However, one could theorise, as displayed within the interviews, that bullying may have had a possible impact on their self-esteem (Zablotsky, Bradshaw, Anderson, & Law, 2013, Hebron & Humphrey, 2014, and, Dubin, 2017). This

would suggest that whilst an individual's diagnosis may have been a reason they were targeted by bullies. As discussed previously bullying in childhood can have a long-term impact on one's self-esteem (Dubin, 2017 and DeLara, 2016), it is suggested that this is due to internalizing the negative opinions of others (Skirrow & Murphy, 2019). Further research would be useful in order to explore the impact of bullying on self-esteem in individuals with Asperger's syndrome. Although the findings suggest that 4 of the 5 participants may have low self-esteem, none of the participants scored lower than 27 out of 50 on the scale. This suggests that although they have some signs of low self-esteem none of them showed defining evidence of low self-esteem within the self-esteem scale. Due to the small number of them and the small scale of the overall study there is a possibility that these select participants are anomalies and therefore I am unable to give a conclusive answer as to whether a diagnosis of Asperger's syndrome impacts self-esteem.

4.5 Limitations of the study and suggestions for further research

Throughout this there have been limitations which have affected the outcome and how the study has been conducted. One of these limitations has been the time limit for this study. The study could possibly have benefited from multiple interviews to explore whether the participant's self-identity, self-esteem and potential issues with anxiety and depression. Though further interviews I would have been able to observe whether these areas had changed over time and their thoughts and feelings towards the possible impact that their diagnosis may have had on these areas. Additionally, with more time this study could have benefited from a larger sample size as the small scale of this study does not account for any anomalies that may have been different given more participants. The lack of substantial findings has been greatly influenced by the sample size within this study, which decreased the strength of any findings. Due to the limitations and the findings of this study I would suggest that the impact of a diagnosis of Asperger's syndrome be explored through a longitudinal case study following individuals throughout a possible diagnosis in order to assess the impact on one's self-identity and self-esteem along with possible anxiety and depression through a comparison of the pre and post diagnosis findings. Through a longitudinal study I would be able to create a stronger rapport with the participant, building trust and comfort which would hopefully allow the participants to feel that they are able to take part in face-to-face interviews along with being open and honest throughout the interviews. In addition to this by conducting multiple interviews I will also be able to see reoccurring themes throughout and therefore notice any differences.

5.6 Conclusion

Within this discussion I have attempted to explore the proposed research questions. In order to do this, I have explored the key findings within self-identity, anxiety and depression, and self-esteem. Within these areas I have discussed what has been found from this study, however I have also stated that these findings can only speak for the 5 participants that were involved within this study. Due to the small scale of this study I cannot give a conclusive answer to any of the questions. In order to explore the impact on the general population of individuals with Asperger's syndrome I have suggested a longitudinal case study following participants throughout their diagnosis. A longer study following more participants and therefore conducting more interviews would create more accurate findings. Following this discussion chapter, I will be concluding this study. Within this I will explore the reasons for the study, the literature discussed, methodology, findings, analysis and discuss whether Asperger's syndrome impacts on self-identity, self-esteem and possible anxiety and depression.

Chapter 6 – Conclusion

Within the introduction of this research I defined the aim of this study and presented the research questions. Following this I briefly outlined the key areas discussed throughout which are self-identity, anxiety and depression, Asperger's syndrome, and self-esteem. These key areas were followed throughout in order to aid the analysis of the research questions which are:

- What potential impact does Asperger's syndrome have on self-identity?
- What potential impact does Asperger's syndrome have on anxiety and depression?
- What potential impact does Asperger's syndrome have on self-esteem?

Following this, I then explored the literature surrounding these key areas, as stated above, in order to support the analysis of this study. During the literature review I defined each area and analysed the relevant literature surrounding them. The literature review also aided the interview design by providing an insight into what we already know, what we could know more of and what questions would be best suited too this research. The interviews were then carried out in keeping with the phenomenological approach that has been carried out throughout this study aiming to gain a detailed insight into the experiences of individuals who have been diagnosed with Asperger's syndrome and how this may have impacted on their self-identity, anxiety and depression, and self-esteem (Gray, 2014, Denscombe, 2014 & Mousakas, 1994 and Van Manen, 2016). The methodology chapter explains that the analysis has be conducted through description and interpretation as phenomenology dictates that the key purpose of the approach is to investigate and describe the unique experiences of others (Gary, 2014 and Streuber & Carpenter, 1995). Additionally, the methodology chapter also explores the constructivist epistemological standpoint, the interpretivism research paradigm and the ethics followed throughout. In order to describe and interpret during the analysis I have used thematic analysis (Gray, 2014) which has highlighted the relevant themes throughout each interview. In addition to this, the Rosenberg self-esteem scale was analysed through a scoring system, as is explained in detail within the methodology chapter.

The participants who took part in this study appear have shown a great deal of self-understanding and evaluation according to the self-understanding scale. Most participants appeared to be able to assess how Asperger's syndrome impacts their day to day life and expressed how a diagnosis has given them a 'reason'. In addition to this, I was unable to give any definitive answers regarding anxiety and depression. The participants who took part each resonated with different symptoms, as described by the NHS, with in the interview and some participants suggested that they had previously been diagnosed with either depression or anxiety. However, there was no

evidence to suggest that there was any impact due to their diagnosis. Lastly, I discussed self-esteem as its own topic, within this I analysed the relationship between participant sand self-esteem. Furthermore, whilst exploring the impact of a diagnosis of Asperger's syndrome on self-esteem I found that some participants showed very slight signs of low self-esteem however, there was no correlation between their diagnosis and their self-esteem. Overall the findings appear to suggest that a diagnosis is supportive in regard to self-understanding, as individuals suggested that a diagnosis supported them in accepting and understanding their own behaviour. The findings, in regard to anxiety, depression and self-esteem are inconclusive. I would suggest that these questions should be asked again within a large, long term study following the lives of many individuals with Asperger's syndrome

In order to answer these questions further research should be done to understand the impact of Asperger's syndrome on self-identity, anxiety and depression, and self-esteem. As discussed within the discussion chapter, in order to do this, I would suggest that a longitudinal case study be carried out. The main aim of this research study was to gather information about the lives of individuals who were diagnosed with Asperger's syndrome, with the aim to explore the links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem. Although I have gathered information about the lives of individuals with Asperger's syndrome, I have not been able to understand the full impact that it may have on self-identity, anxiety, depression and self-esteem due to the small scale of this study and the limited participants.

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University of Huddersfield

School of Education and Professional Development

Participant Information Sheet (E3)

Research Project Title:

What right do we have to label? Understanding the impact that a diagnosis of Asperger's syndrome has on developing a self-identity.

Thank you for reading this. I am inviting you to take part in my research project. This sheet gives you a little information about it. Please ask me if something isn't clear.

What is the purpose of the project?

This research project is being carried out as part of my research master's degree; the aim of this research is to attempt to understand the impact that a diagnosis of Asperger's syndrome has on self-identity. It is hoped that this research will inform both practitioners and parents of the affects a diagnosis has on various aspects of an individual's life for example, self-esteem, mental wellbeing, and relationships.

Why have I been chosen?

You have been chosen to take part in this study as you have a diagnosis of Asperger's syndrome and this study aims to understand the impact of a diagnosis on self-identity through discussing you're experiences prior to, during and after your diagnosis.

Do I have to take part?

You have no requirement to take part and you may withdraw at any point, without giving any reason.

What do I have to do?

You will be invited to take part in an interview, this can be done via email or via phone call depending on what you would feel most comfortable with. The interview should not take longer than 1 hour.

Are there any disadvantages to taking part?

Not, as far as we know. If you are worried, please talk more about this please email me.

Will all my personal details be kept confidential?

Yes. Any information about you which is collected will be strictly confidential. Data will be anonymised before being used. Any data collected will be stored on the university box to ensure that I will be the only one with access to the data collected. It will comply with the Data Protection Act and BERA ethical research guidelines and principles.

What will happen to the results of the research study?

The results of this research will be written up for my master's study with the possibility of publication. If you would like a copy of this, please contact me by email.

Name & Contact Details of Researcher: -

Chloe Cutting

Chloe.cutting2@hud.ac.uk

8.2 Consent form

University of Huddersfield

School of Education and Professional Development

Participant Consent Form (E4)

Title of Research Study:

What right do we have to label? Understanding the impact that a diagnosis of Asperger's syndrome has on developing a self-identity.

☐

I confirm that I have read and understood the participant Information sheet related to this research and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

☐

I understand that all my responses will be anonymised.

☐

I give permission for members of the teaching team to have access to my anonymised responses.

☐

I agree to take part in the above study

Name of Participant:

Signature of Participant:

Date:

Name of Researcher: Chloe Cutting

Signature of Researcher:

Date:

What right do we have to label? Exploring the links between Asperger's syndrome and self-identity, anxiety, depression and self-esteem.

Participant Debrief Sheet

Thank you for taking part in this study! The aim of this study has been to explore the links between Asperger's syndrome and self-identity, anxiety and depression and self-esteem. I hope that you have enjoyed taking part in this study and have not been negatively impacted by any of the topics discussed. However, if you have been upset or negatively impacted by this research and wish to contact the university's Education department:

Address: School of Education and Professional Development
University of Huddersfield
Queensgate
Huddersfield
HD1 3DH

Telephone: 01484 478249

Email: sepd@hud.ac.uk

Additionally, if you feel that you need more support following your interview please contact one of the following organisations:

Samaritans – Suicide hotline

Telephone: 116123

Email: jo@samaritans.org

Anxiety UK – Support for those suffering with Anxiety

Telephone: 03444775774

Website: www.anxietyuk.org.uk

Mental Health Foundation - Support for those with mental health problems and/or learning disabilities

Website: www.mentalhealth.org.uk

8.4 Interview questions

8.4.1 Rosenberg's Self-esteem scale

Answer: (1) Strongly agree, (2) agree, (3) disagree, (4) strongly disagree

1. On the whole, I am satisfied with myself.
2. At times I think I am no good at all.
3. I feel that I have a number of good qualities.
4. I am able to do things as well as most other people.
5. I feel I do not have much to be proud of.
6. I certainly feel useless at times.
7. I feel that I am a person of worth, at least on an equal plane with others.
8. I wish I could have more respect for myself.
9. All in all, I am inclined to feel that I am a failure.
10. I take a positive attitude toward myself.

(Cooper, Smith, & Russell, 2017, and Rosenberg, 1965)

8.4.2 Damon and Hart's 1988 self-understanding scale

- Item 1: Self-definition: What are you like? What kind of person are you? What are you not like? How would you describe yourself?

Probes: What does that say about you? Why is that important? What difference does that (characteristic) make? What would be different if you were not like that?

- Item 2: Self-evaluation: What are you especially proud of about yourself? What do you like most about yourself? What are you not proud of? What do you like least about self?

Probes: What does that say about you? Why is that important?

- Item 3: Self in the past and future: Do you think you'll be the same or different 5 years from now? How about when you're an adult? How about 5 years ago? How about during your childhood?

Probes: What will be the same? What will be different? Why is that important?

- Item 4: Self-interest: What do you want to be like? What kind of person do you want to be? What do you hope for in life? If you could have three wishes, what would they be? What do you think is good for you?

Probes: Why do you want to... be that way?...wish for that?...believe that is good for you? What else do you...hope for?...wish for?...believe is good for you? Why is that good for you?

- Item 5: Continuity: Do you change at all from year to year? How (how not)? If you do change from year to year, how do you know it's still always you?

Probes: In what ways do you stay the same? Is that an important thing to say about you? Why?

- Item 6: Agency: How did you get to be the way you are? How did that make you the kind of person you are? How could you become different?

Probes: What difference did that make? Is that the only reason you turned out like you did? What else could make you different? How would that work?

- Item 7: Distinctness: Do you think there is anyone who is exactly like you? What makes you different from anyone you know?

Probes: Why is that important? What difference does that make? In what other ways are you different? Are you completely different or just partly different? How do you know? Are you different from everybody or just from some people? How can you be sure you're different from everybody else when there are many people in world you do not know?

(Jackson, Skirrow & Hare, 2011, and Hart & Damon, 1988)

8.4.3 Anxiety and depression scale

Answer: (1) Strongly agree, (2) agree, (3) disagree, (4) strongly disagree

I continuously feel sad.

I feel that I have a high self-esteem.

I often have a feeling of hopelessness.

I am usually patient with others.

I usually feel tearful.

I have interests.

I often feel guilty.

I am motivated.

I find it difficult to make decisions.

I enjoy my life.

I often feel worried and anxious.

I have energy.

I have suicidal thoughts.

I sleep fine.

I don't talk to my friends often.

My work is going well.

I often feel irritated.

I enjoy taking part in my hobbies.

I am often restless.

I don't have difficulty concentrating.

I often feel very worried.

`8.4.4 Further understanding

If you remember or are aware of them what symptoms related to Asperger’s syndrome do you feel that you displayed before diagnosis?

Has this changed after receiving a diagnosis?

What would you say are your most challenging “symptoms”? Have these changed throughout your life?

Again, if you remember or are aware how would you describe your self-esteem before your diagnosis?

(child diagnosed participants – did you feel you were able to do certain activities: how did you feel about talking to others, were you a confident child)

Did this change after your diagnosis?

Similarly, to the last question, how would you describe your mental health before your diagnosis?

(How did you usually feel: happy, angry, sad?)

Did this change after your diagnosis?

Do you feel that you were treated differently by others before diagnosis?

Did this change after your diagnosis?

What ways were you treated differently?

Did you feel a sense of community or part of a group after your diagnosis?

If you were diagnosed as a child at what age do you feel that you became aware of your diagnosis?

How would you describe yourself?

8.5 Hart and Damon's self-understanding graph (*G1)

Level 4	Level 3	Level 2	Level 1	Questioned areas
Systematic beliefs and plans	Inter-personal Implications	Comparative assessments.	Categorical identifications.	General organizing principal.
Physical attributes reflecting volitional choices, or personal and moral standards	Physical attributes that influence social appeal & social interactions.	Capability – related physical attributes.	Bodily properties or material possessions.	Physical self.
Active Attributes that reflect choices, personal or moral standards.	Active attributes that influence social appeal & social interactions.	Abilities relative to others, self or normative standards.	Typical behaviour.	Active self.
Moral or personal choices concerning social relations or social-personality characteristics	Social-personality characteristics	Abilities or acts considered in light of other's reactions.	Fact of membership in particular social relations or groups.	Social self.
Belief systems, personal philosophy, self's own thought process.	Social sensitivity communicative competence, & other psychologically related social skills.	Knowledge, cognitive abilities, or ability-related emotions.	Momentary moods, feelings, preferences & aversions.	Psychological self.
Relations between past, present and future.	Ongoing recognition of self by others	Permanent cognitive and active capabilities and immutable self-characteristics.	Categorical identifications.	Continuity.
Unique subjective experience and interpretations or events.	Unique combination of psychological and physical attributes.	Comparisons between self and other along isolated dimensions.	Categorical identifications.	Distinctness.
Personal and moral evaluations influence self.	Communication and reciprocal interaction influence self.	Efforts wishes and talents influence self.	External uncontrollable factors determine self.	Agency

8.6 Archie transcript

Me: Hi Archie,

I just want to start off by saying that your name and any other identifiers mentioned within this interview will be changed in the transcripts. If there are any questions that you don't quite understand or that you don't want to answer don't worry about saying so.

Do you have any questions before we start?

Archie: No none at all.

Me: Ok, then the first set of questions are designed to look into your self-esteem and there are 10. I'll send each one at a time and if you could reply to each statement with either strongly agree, agree, disagree, or strongly disagree.

On the whole, I am satisfied with myself.

Archie: Agree.

Me: At times I think I am no good at all.

Archie: Agree.

Me: I feel that I have a number of good qualities.

Archie: Strongly agree.

Me: I am able to do things as well as most other people.

Archie: Disagree.

Me: I feel I do not have much to be proud of.

Archie: Disagree.

Me: I certainly feel useless at times.

Archie: Strongly Agree.

Me: I feel that I am a person of worth, at least on an equal plane with others.

Archie: Disagree.

Me: I wish I could have more respect for myself.

Archie: Strongly Agree.

Me: All in all, I am inclined to feel that I am a failure.

Archie: Agree.

Me: I take a positive attitude towards myself.

Archie: Agree.

Me: Thank you, the rest set of questions is designed to explore your self-understanding and is the longest part of this interview. They are very open questions. Feel free to give as much detail as you would like to.

How would you describe yourself?

Archie: A walking disaster with a yo-yo mood. Lazy and unhealthy but kind and forgiving. Strong willed but low confidence.

Me: What are you not like? so, what traits would you say that you don't identify with?

Archie: Can you explain a little more? Traits like angry, easily annoyed, unapproachable?

Me: Yes, so any traits such as those but also positive ones like the ones you mentioned before.

For example, someone might say I am moody but also friendly, I am pretty colourful, and I love animals. I am not loud or outgoing. I am not mean to others. I am not always likeable; I am an acquired taste.

Archie: Well I'm not easy to understand some of the times due to my unusual nature, I have a sense of humour which most people wouldn't understand unless they know me, I'm intellectual but unsure where to apply it, I'm amazing with map reading but would prefer to be left alone if were lost. I'm a follower not a leader, I'm not very proud of myself when I'm out in public and shy away from any form of communication. I'm not one for maintaining conversation and prefer for it to be over as soon as possible but at the same time would love to have a nice

conversation. The battle between me and my head is pretty much a walking oxymoron. (This is the best way I can answer the question)

Me: That's a great answer. Thank you, some of these questions may appear a bit 'samey' at times but it's just to ensure we get a really good understanding of how you see yourself. What parts of you are important?

Archie: My sanity, My personality, My own understanding of the world, My already established relationships.

Me: Why are those Important to you?

Archie: I've lost my sanity before and I'd never want to return to that place. It took me years to develop a personality to such a way people will actually like it and I had something which people might want to stick around for. If I lost my own understanding of the world I'd fear ever walking outdoors, my own understanding is the only thing which gives me enough confidence to walk outside the door otherwise I'd have no idea what to expect outside. I don't want to be left with no one, so I want to keep who I already have.

Me: What do you think would be different if you weren't the way you are?

Archie: Define weren't the way I am, as in being autistic or just me with my traits right now?

Me: Just you and the traits you have. Though if you consider being autistic as a trait or a prominent part of yourself then feel free to talk about that too.

Archie: Well, if I didn't have Autism I'd likely be working full time with a higher education, it's held me back a substantial amount academically whilst in high school where I had so many worse traits than I do now. If I didn't have the remainder of the traits I have right now, I'd likely have no one in my life, most likely I'd be in full time care with no real way to understand most aspects of the world. I'd likely just become a hermit and try and stay inside for the remainder of my life.

Me: It sounds like you've overcome a lot since your time in education and you mentioned that you previously lost your sanity for a while. What would you say you're especially proud of about your life?

Archie: When I was in high school, I was heavily bullied to such a degree that I didn't ever want to go to school, I was falling behind quite badly because I was in mainstream school with very little

disability assistance. However, I kept on going and managed to get quite a good education after it all even managed a degree. full time work, then when I was 20, I was in an abusive relationship. Sort of spiralled me out of control to going into psychiatric hospital and losing pretty much everything I had built up myself over the years. I'd say what I'm most proud of is more managing to get through the last 6 years of my life to re-establish what I had lost.
(Backstory because "the last 6 years of my life" doesn't sound as interesting an answer)

Me: I see that must have been difficult for you, it's good that you feel that you are in a better place now. What would you say you are least proud of?

Archie: My inability to see the bad in people regardless of how obviously bad they are. Case in point my previous answer.

Me: Similarly, to the questions about what you are proud of what would you say you like and dislike about yourself?

Archie: I like the fact I can make people laugh easily now. I dislike being that person who sees the good in everyone no matter how evil they actually are.

Me: I think you have commented on this a little as you said you have grown a lot over the past 6 years but what, if anything, do you think was different about you 5 years ago?

Archie: In the last 5 years? I'd probably change nothing. Thanks to what happened I've become a better person overall after it all and if I changed something the likelihood is, I wouldn't have become who I am now.

Me: How do you feel that you've changed as a person in that time?

Archie: I've gone from a bumbling mess who spent a great deal of time hiding in the psychiatric hospital shower, hoping death would come sooner rather than later with absolutely nothing to my name. to a more established adult, happy, confident, person.

Me: Do you think you'll be the same as you are now in 5 years' time?

Archie: As a person, I hope so.

Me: What do you hope for in life?

Archie: To live a long full life, get married, have children, have a full-time progressive job, have a home I own.

Me: If you could have three wishes, what would they be?

Archie: Be rich, live forever, have a special device which brings food to me from anywhere in the world for free.

Me: What kind of person do you want to be like? This is a bit similar to some of the first questions about what traits you have and don't have.

Archie: As silly as this sounds. I don't actually aspire to be any other kind of person than what I am now. Although I have my difficulties and struggle a lot with things, that's the person I've grown up to be and actually like how well I've managed with everything to such a degree I couldn't imagine not being anyone else.

Me: Do you think you change year from year? I know you said you changed from 6 years ago, but do you feel that you are continuously changing?

Archie: I've changed every single year as a person since I was 14

Me: In what ways have you changed?

Archie: I developed a personality, I've built my confidence, I'm more open to communication with strangers, I have a sense of humour which I adapt to be more understanding to people, I build my own understanding of different personalities and adjust accordingly, I'm more understanding of other people as an overall so avoid certain hot topics such as politics and things which get heated quickly, I'm more appropriate to situations, I'm a lot more respectful and all of these things are constantly being developed and grown to be a better person.

Me: I feel like you have already answered this by saying how you developed after going into hospital but you may have a different view on the question but how do you think you got to be the way you are today?

Archie: bullied in school, abusive relationship, psychiatric hospital.

Me: How do you think they changed you into the person you are today?

Archie: They gave me a view into the absolute worst things I can experience in life and showed me that's not something I ever want to go through again, so I bettered myself to avoid it.

Me: Do you think there is anyone who is exactly like you?

Archie: Possibly, but I'd like to think I'm a unique individual due to my own ability to understand my own Autism and work alongside it to develop my own life to be as comfortable as possible instead of it being the sole driving force in my life.

Me: What makes you different from anyone you know?

Archie: I'm autistic.

Me: Thanks, that's all the big questions for now. This next set of questions is created to understand your general mental health and just like the first set of questions is answered with either Strongly agree, agree, disagree, or strongly disagree. I have a continuously feel sad.

Archie: Disagree.

Me: I feel that I have a high self-esteem.

Archie: Agree.

Me: I often have a feeling of hopelessness.

Archie: Disagree.

Me: I am usually patient with others.

Archie: This is a mood dependent one. it can either be strongly agree or strongly disagree depending on the day.

Me: I suppose I should add in a neither agree nor disagree option, would that be helpful?

Archie: Vast majority of the time its strongly agree

Me: Ok that's fine, if you feel like any of the others are either neither agree nor disagree. feel free to use that too. I usually feel tearful.

Archie: Disagree.

Me: I have interests.

Archie: Strongly agree.

Me: I often feel guilty.

Archie: Agree.

Me: I am motivated.

Archie: Agree.

Me: I find it difficult to make decisions.

Archie: Neither agree nor disagree.

Me: I enjoy my life.

Archie: Strongly agree.

Me: I often feel worried and anxious.

Archie: Strongly agree.

Me: I have energy.

Archie: Disagree.

Me: I have suicidal thoughts.

Archie: Strongly Disagree.

Me: I sleep fine.

Archie: Disagree.

Me: I don't talk to my friends often.

Archie: Agree

Me: My work is going well.

Archie: Neither agree nor disagree

Me: I often feel irritated.

Archie: Agree.

Me: I enjoy taking part in my hobbies.

Archie: Strongly Agree.

Me: I am often restless.

Archie: Agree.

Me: I don't have difficulty concentrating.

Archie: Strongly disagree.

Me: I often feel very worried.

Archie: Strongly agree.

Me: Thank you, I only have a few questions left now and these ones are related to your diagnosis.

If you remember or are aware of them what symptoms related to Asperger's syndrome do you feel that you displayed before diagnosis?

Archie: The only thing I remember was being diagnosed with dyspraxia beforehand but other than that I have no idea why the diagnosis came about, only my mum knows.

Me: What would you say your symptoms are now?

Archie: I don't like to maintain eye contact. I fidget a lot. I don't like people being too close to me at all. Are some, but I don't really understand symptoms myself since I just see them as normal.

Me: If they are your normal would you say that they affect you day to day?

Archie: No not really. No one really mentions anything out of the ordinary but most people around me just accept what I do.

Me: Do you think the symptoms that you are aware of have changed over time?

Archie: I'd say they've likely adapted alongside me whilst trying to develop to be a more functioning person. Except the looking people in the eye when talking to them. I can't do that even when I try.

Me: You said you were diagnosed at 12, were you aware of your diagnosis straight away?

Archie: Yeah, mum told me about it. I was tested whilst in mainstream school over the course of a month I believe.

Me: Do you feel like you were treated differently by anyone because of your diagnosis? both in a positive or negative way.

Archie: I kept my diagnosis secret from everyone except teachers and managers and I didn't feel I was treated differently.

Me: Why did you choose to keep it a secret and did your teachers or managers support you?

Archie: Because I didn't want to be treated any differently because I was disabled, and no not really because I requested no special treatment in fear that they'd have to explain to people why I was treated differently to others if someone complained.

Me: Do you remember what your self-esteem and mental health were like before your diagnosis?

Archie: No self-esteem at all due to relentless bullying and mental health wasn't any sort of factor in my life at that time because I just lived life the same way every day.

Me: Did this change after your diagnosis?

Archie: Not for about 4 years after.

Me: Is there any way that you think that your diagnosis itself has impacted you?

Archie: It gave me something to read about on a night and how to change things about myself if I could.

Me: Did you feel a sense of community after your diagnosis or due to your diagnosis?

Archie: Nope, they tried to include me in a small disabled group in school, but I rejected it because I didn't want to be seen as disabled

Me: Thanks Archie, I think that's all of my questions. is there anything you want to add?

Archie: Nope, nothing I can think of! glad I could help!

Me: You've been a massive help, thank you.

8.6 Jack transcript

Me: Hi Jack, it's Chloe I'm just going to get up the voice recorder if that's ok, it's just to help me transcribe later.

Jack: Hi Chloe, that's fine.

Me: Have you been busy today?

Jack: I've just been at uni, what about you?

Me: I've not done much today; I've just been at home.

Jack: Yeah.

Me: erm, ok. It's working now. There are four sections to the interview, two of them can be answered just with strongly agree, agree, disagree, strongly disagree.

Jack: ok.

Me: The other ones are a bit more descriptive.

Jack: ok.

Me: But I'll let you know which one is which as we go through it.

Jack: Alright yeah, that's fine.

Me: Ok, erm, the first set of questions is erm, the self-esteem scale. So, they're not questions I've designed myself, they're from a book on self-esteem that was developed a long time ago.

Jack: yep.

Me: so, the first questions are the ones that can be answered strongly agreed, agree, disagree, strongly disagree.

Jack: Ok.

Me: The first question is, on the whole I am satisfied with myself?

Jack: Erm, I'd say agree.

Me: Agree, ok. So, at times I feel that I am no good at all?

Jack: Erm, probably agree.

Me: Agree, I feel that I have a number of good qualities?

Jack: Erm, Disagree

Me: Ok, I am able to do things as well as most other people?

Jack: Disagree.

Me: Ok, I feel I do not have much to be proud of?

Jack: Strongly disagree.

Me: I certainly feel useless at times?

Jack: Is there one that's neither agree nor disagree or?

Me: Yeah, I can put that one in.

Jack: Ok, yeah.

Me: I feel that I am a person of worth at least on an equal plane with others?

Jack: Erm, Disagree.

Me: Disagree, ok. I wish I could have more respect for myself.

Jack: Erm, agree.

Me: All in all, I am inclined to feel that I am a failure?

Jack: Disagree.

Me: I take a positive attitude towards myself?

Jack: Erm, Agree.

Me: Agree, ok. Right, that's all the questions from that section. The next bits more descriptive it's about self-understanding. So, some of the questions can feel like I'm asking you the same thing twice but it's just to sort of get every aspect of it. To get all the details.

Jack: Ok.

Me: There's seven sections to it but there's different questions in each bit. So, it might take a little while.

Jack: That's fine.

Me: Ok, so the first question says, what kind of person are you?

Jack: Erm, I'd say I'm quite outgoing, Erm, more recently I'd say confident. Quite a social person, but then as well with those other questions there's times when I just like to knock myself down quite a bit.

Me: Yeah, right.

Jack: Is that alright?

Me: Yeah, not that's fine! Erm, so the next question is quite a similar question but it's the opposite, so it's says what are you not like?

Jack: I'd say I'm definitely not a loud person. I'd say quietly confident. I don't like to be the centre of attention. Erm, I'm the type of person that will speak up if I need to but, I'd probably rather just sit back. I'm not one to be at the forefront of things all the time.

Me: Yeah, ok. What are you especially proud of about yourself?

Jack: Erm, the fact that I'm, I suppose that, I'm self-employed and I've been able to run that alongside my uni course. I suppose the fact that I've been to university even though at one stage I didn't really see myself doing that.

Me: What kind of business do you run?

Jack: Erm, so I do social media management, for different businesses.

Me: That's good, nice! what do you like most about yourself?

Jack: I suppose I'm quite motivated, I find that compared to my friends I find it easy to just get on with stuff and I suppose I'm quite creative as well, so I'd say those things.

Me: Ok, Erm. What are you least proud of?

Jack: I guess it goes back to the fact that I struggle with confidence at times and I'm quite sensitive in different situations. So, I can get upset quite easily or kind of lack in confidence sometimes when I don't need too.

Me: Do you think you'll be the same or different in five years' time?

Jack: I'm quite happy with how I am now but I'd like to say different because I'd like to grow more in that space and time.

Me: What ways do you think you'll grow in that time?

Jack: I'd like to become I suppose a bit more upfront with people than like worrying about the outcomes of different situations and that sort of thing. Just to be less nervous in these situations really.

Me: How would you say you were different five years ago, if you were different five years ago?

Jack: At school I didn't have much confidence at all, I never really spoke to many people. I was never one to get in front of the class and speak and I was just in a shell really. So yeah, I would say that's how I was different back then, but I've been able to overcome all of that.

Me: Ok, one minute I've lost my place... sorry there we go! What kind of person do you want to be?

Jack: I suppose I'd like to be, I suppose, quite a flexible and easy-going person. I still like everything planned out. So that's where I kind of fall down at the moment but I'd say about more easy going. But I do like lots of qualities about myself at the moment. That's the only thing I'd really want to change.

Me: That's good! What would you say that you want most from life?

Jack: Sorry, what was that? It just broke up a bit.

Me: What do you hope for yourself in life? Like, what do you want most?

Jack: Well my plan is to hopefully grow my business and that. Kind of be successful in that area. That's my plan at the moment anyway but, I'd like to just keep working in areas that I'm good at and then that'll hopefully let me forget about the areas that I'm not so good at stuff.

Me: If you could have three wishes what would they be?

Jack: Erm, first one short term would be to graduate uni with a 2:1 and to either go straight into a graduate scheme or you know have a go at running the business full time and see how that goes. Then eventually I would just like to be in a job that I'm happy in and that I look forward to going to work.

Me: Nice, they're good wishes. Erm, do you think you change year from year?

Jack: I think recently I have done yeah, but not always. I feel more stable with myself now I don't feel like there's any need to change. But in recent years it's been more to do with becoming more confident, more assertive really. I'd say that's helped me as I've got more experience, helped me to change as a person.

Me: I think you change a lot around those ages as well, just before you come to uni and when you first start. Erm, you've sort of answered the other questions in that section. How did you get to be the what that you are today?

Jack: I suppose through lots of positive and negative experiences. Like when I was in school because I'd not really experienced stuff I just kind of stayed the same. So though experienced all the work experience, education, and just general life stuff really. That's helped to shape it.

Me: How would you say those helped you become the person that you are? How did they impact you and your traits, your personality?

Jack: I suppose being like, trying to push myself out of my comfort zone. It's helped me to become less worried about my life in different situations that I used to really worry about previously. So that's probably the biggest thing and I suppose just taking lots of opportunities and other people giving me a chance in other areas that I didn't know before.

Me: Ok, do you think that there is any more out there that is exactly the same as you?

Jack: I'd probably say so, similar yeah. I've yet to find anyone that's really similar.

Me: What do think makes you different from anyone else?

Jack: That's a difficult question really.

Me: It is yeah.

Jack: I suppose it's just the mix of all the personality traits and how I like things to be that makes me a bit different. But yeah, I can't really pinpoint one certain thing that it is.

Me: That's fine, the next set of questions are again strongly agree, agree, disagree, strongly disagree. You can say neither if you want as well. Ok these are about mental health and the first one is I continuously feel sad.

Jack: Disagree.

Me: Disagree, right. I feel that I have a high self-esteem

Jack: Neither for that one.

Me: I often have a feeling of hopelessness.

Jack: Disagree.

Me: I am usually patient with others.

Jack: Agree.

Me: I usually feel tearful.

Jack: Disagree.

Me: I have interests.

Jack: Agree.

Me: I often feel guilty.

Jack: Agree.

Me: I am motivated.

Jack: Strongly agree.

Me: I find it difficult to make decisions.

Jack: Agree.

Me: I enjoy my life.

Jack: Agree.

Me: I often feel worried and anxious.

Jack: Again, Agree.

Me: I have energy.

Jack: Strongly Agree.

Me: I have suicidal thoughts.

Jack: Strongly disagree.

Me: I sleep fine.

Jack: Agree.

Me: I don't talk to my friends often.

Jack: Strongly disagree.

Me: My work is going well.

Jack: Agree.

Me: I often feel irritated.

Jack: Agree.

Me: I enjoy taking part in my hobbies.

Jack: Strongly agree.

Me: I am often restless.

Jack: Agree.

Me: I don't have difficulty concentrating.

Jack: Disagree.

Me: I often feel worried.

Jack: Agree.

Me: Thank you! That's all of those ones. the next ones are all around your diagnosis and less about mental health and stuff. So, the first one is what symptoms were you aware of that had to do with Asperger's syndrome before your diagnosis?

Jack: It's going back to like having everything in a routine and not wanting to change that was one of them and then erm, a couple of years ago I had issues kind of meeting new people and making friends which I don't have now but that was one of the things that lead to me being checked out for it and then all the worrying, anxiety. Things like that really.

Me: Right, do you think those changed after your diagnosis?

Jack: I think it made me feel, like a bit more comfortable with myself knowing what it was because I've always expected that there was something there but until I got that I never knew what it was. But yeah, I'd say a lot better now, I've overcome lots of them and I think part of that was having the diagnosis.

Me: So, it helped you to overcome some of the symptoms or are they easier to deal with them or you don't have as many?

Jack: I'd probably say that they're easier to deal with, like just for myself knowing. Kind of why they are and what causes them and having a better understanding really.

Me: How would you describe your self-esteem before your diagnosis?

Jack: I suppose in the time leading up to it, it was really low. Partly because I didn't know the cause of all the symptoms I'd been having.

Me: Do you think that changed after your diagnosis?

Jack: Not immediately no. But with time, over the last couple of years it definitely has gone back to quite high self-esteem, what it used to be. I just had a dip really where I lost all the self-esteem that I built up.

Me: yeah, do you think your mental health was different before your diagnosis?

Jack: yeah, I'd say it was worse before. Again, because I didn't know what I was a bit different with certain things. It kind of caused it to be a lot lower than it is now.

Me: Right, so do you think it's got a bit better now?

Jack: Definitely yeah.

Me: Do you think other people treated you differently before your diagnosis?

Jack: I think so, I mean I haven't really told anyone about it. I didn't feel the need to, but I suppose the people that I have told there's been a different level of understanding.

Me: Yeah, so they've been more understanding after the diagnosis?

Jack: Yeah.

Me: Right ok, did you feel a sense of community or part of a group after your diagnosis?

Jack: I had the opportunity for that, but I never really took it because I didn't really want to get involved with any groups or communities. Because it was such a late diagnosis, I just wanted to keep it to myself really.

Me: Ok, Erm. I think that's everything. All the other questions I have wrote down are for people whose were diagnosed as children and obviously you were diagnosed as an adult. What age were you diagnosed?

Jack: So, I was 18 I think or just turned 19 but around that time.

Me: Do you mind me asking how you were diagnosed, so what things you had to do?

Jack: So, I think first of all I went to my local doctors who referred me to the local Autism clinic and then really, they had diagnosed through a general chat and loads of questions about routine and the way I like things and certain traits about me. Then my mum was. Interviewed as well, she had a separate interview. Then they kind of gathered the results from both of us and came to a conclusion there.

Me: Right ok, that's everything. Thank you! That's been really helpful thank you!

Jack: Thanks, let me know if you need anything else as well or if you've got any other questions, feel free to just email or phone.

Me: Ok, thank you!

Jack: Thanks Chloe!

Me: Thanks bye

Jack: Talk soon, bye.

8.8 Jane transcript

Me: Hi Jane,

There are four sections to the interview two which are answered with either strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree. Then two which require more detail. If there are any questions you don't want to answer just let me know.

The first set are about self-esteem and are answered on a scale from strongly agree to strongly disagree.

On the whole, I am satisfied with myself.

Jane: Agree.

Me: At times I think I am no good at all.

Jane: Completely agree.

Me: I feel that I have a number of good qualities.

Jane: Agree.

Me: I am able to do things as well as most other people.

Jane: Agree.

Me: I feel I do not have much to be proud of.

Jane: Neither agree nor disagree.

Me: I certainly feel useless at times.

Jane: Agree.

Me: I feel that I am a person of worth, at least on an equal plane with others.

Jane: Neither agree nor disagree.

Me: I wish I could have more respect for myself

Jane: Agree.

Me: All in all, I am inclined to feel that I am a failure.

Jane: Neither agree nor disagree.

Me: I take a positive attitude toward myself.

Jane: Agree.

Me: The next set of questions are designed to explore your self-understanding.

The first question is what kind of person are you?

Jane: I like to think I am a nice person, but sometimes feel I am not. I am not the quietest person and find I have a sarcastic sense of humour.

I am very impressionable, I think this used to have a negative impact on my life due to the people I'd be around, however I am now around more positive people so feel like I am a more positive person.

I try to be helpful, but sometimes this is perceived as me butting in and interfering when I shouldn't.

Me: Thank you, what are you not like?

Jane: I'm not good in a social occasion. I can get on with people, but I will avoid any group get together. I'm better one to one of in a small group.

I struggle to read faces and I can't cope with lots of noise.

I try to be tidy but feel I am not, as some tasks, such as putting laundry away, I put off because it's too much to do some days.

I am not the happy, cheerful person everyone expects from me, and I find it difficult to smile and keep a conversation going. Small talk terrifies me as I always lose my words and can't think what to say.

I try not to be but feel I can be quite blunt with people and don't realise that I say things in a nasty way.

Me: Thank you, the next question is what are you especially proud of about yourself?

Jane: This is difficult. At first I sat and thought "well, nothing really".

I think I'm proud of how I got through university. Doing a practical course (geology & environmental hazards) I had to do residential trips. I stayed at home for my degree and commuted as the anxiety around moving out really overwhelmed me.

I was very anxious and panicky the first residential trip I went on to Scotland (from near derby) and almost went home. I overcame that feeling and have since flown for the first time with uni (no family) and also did a long-haul flight, again with uni.

I successfully completed all of my residential trips and passed all the modules.

I'm also proud that I've managed to 'hide' my Asperger's, so people don't know when they first meet me. I also work for the uni as a student ambassador, and I'm able to help potential students and tell them that uni isn't that scary and there's plenty of help. I use my experiences, both good and bad, to help encourage and inspire others.

Me: They're all great reasons to be proud. The next question is what are you not proud of?

Jane: My temper. I was a very violent person and used to lash out at people for no reason.

The fact that some things I just can't process, or it takes constant repeating for weeks for me to understand things that people can take in with being told once.

With me being impressionable I was with people who were nasty, and I would act like they did, so that they liked me. Looking back now I can see that I would be mean because they were and if I acted the same, I thought they liked me, when I'm fact I was a pawn for them to laugh at, not with.

Me: It's good that you can reflect on that and see how you've developed and changed.

The next question is do you think you'll be the same or different five years from now?

Jane: That is very difficult. I find it hard to think a week in advance sometimes.

I think I will be different, because looking back over the past 10 years and seeing how much I've changed gives me the thought that I will still change as a person. I can't see how I will change, but because I have changed, it makes sense I will carry on doing so.

Me: In what ways have you changed in the past?

Jane: 1. I used to be violent and have an awful temper. This has improved because I worked on not lashing out and automatically hit people.

2. I used to react very badly to any change. If we said we were going shopping to one shop but went somewhere else I'd get very upset and anxious and get terrible headaches to the point we had to go to the shop we said originally. I have tried to be less upset over this, and my parents helped by instead of saying "we're going to Sainsbury's" they will say "we're going shopping". I now find it easier to cope with things changing.

3. I am a lot better at going with the flow now, where I used to have to have a list for the day, what time we were leaving, where we were going. etc..

4. My nervous habit was sucking my fingers (even at 15) and I used to flick my fingernails. I still pick/bite my nails, but I have a fidget ring which helps control the anxiety so that most people don't see it as obviously.

Me: What kind of person do you want to be like?

Jane: My friend Tate.

I would like to be a positive person and be kind to everyone.

I want to see the good in everyone, where at the moment I don't tend to.

I want to have energy and not want to have a nap all the time! Like all the time, I love my bed!

I would like to be able to keep my concentration for more than 5 minutes (watching seeing bee while doing this) and I wish I could finish a task when I start it, rather than getting distracted by 10 other things and doing bits of each task, meaning none are ever finished.

*Due to a family emergency the interview was cut short and the rest of the questions were sent to the participant in one email. *

Me: What do you hope for in life?

Jane: I can't think what I hope for in life, other than some days to live, and others to not live. I want more than to just exist, but I don't know other than that.

Me: If you could have three wishes, what would they be?

Jane: 1. To have stable mental health

2. To not doubt or second guess everything I do

3. For my grandad.

Me: Do you change year to year?

Jane: Yes, I don't think anyone can live without changing. I like to think I become a better person each year.

Me: How did you get to be the way that you are now?

Jane: This took me a lot of hard work. I am still not perfectly happy with who I am, but I am happier now than I have been. I had a lot of help to become the person I am now. I used to be quite a nasty person, it took repetition to get the good habits to stick and the old/bad ones to be gone. I've controlled the 'quirks' to a minimum so that they are as noticeable to other people, who don't know me. I used to trust people too easily and was very naive, and it took getting hurt and being taken advantage of to realise that I was a door mat, so I changed it. It took a while to get right though, for a time I became too closed off, not talking to anyone so that I couldn't be hurt again. I've done to learn it's like a balancing act, being a good person.

Me: Do you think there is anyone who is exactly like you?

Jane: No. I am individual. I used to mimic people and their behaviour, being impressionable, but I am starting to learn what "me" is now. I think people may share quirks or habits, but that they won't all be the same, everyone has differences and similarities, but everyone is unique.

Me: What makes you different from anyone else?

Jane: I feel isolated sometimes as most people understand jokes or chat in conversation and I don't. I feel uncomfortable in social situations, where some people I know love that, people seem to get on with each other easily, but I have difficulties making small talk and understanding people's reactions/facial expressions, meaning I'm usually left behind in social meetings.

Me: The next set again are answered strongly agree to strongly disagree. I continuously feel sad.

Jane: Agree.

Me: I feel that I have a high self-esteem.

Jane: Disagree.

Me: I often have a feeling of hopelessness.

Jane: Agree.

Me: I am usually patient with others.

Jane: Disagree.

Me: I usually feel tearful.

Jane: Agree.

Me: I have interests.

Jane: Agree.

Me: I often feel guilty.

Jane: Agree

Me: I am motivated.

Jane: Neither agree or disagree - if I find something I like, I can get stuck on it and won't stop till I've finished, other times I don't feel motivated to do anything.

Me: I find it difficult to make decisions.

Jane: Agree.

Me: I enjoy my life.

Jane: Neither agree nor disagree

Me: I often feel worried and anxious.

Jane: Strongly agree.

Me: I have energy.

Jane: Disagree! I always feel exhausted

Me: I have suicidal thoughts.

Jane: Agree.

Me: I sleep fine.

Jane: Agree.

Me: I don't talk to my friends often.

Jane: Strongly agree.

Me: My work is going well.

Jane: Agree.

Me: I often feel irritated.

Jane: Agree.

Me: I enjoy taking part in my hobbies.

Jane: Agree.

Me: I am often restless.

Jane: Neither agree nor disagree.

Me: I don't have difficulty concentrating.

Jane: Strongly disagree.

Me: I often feel very worried.

Jane: Agree.

Me: What symptoms do you remember having before your diagnosis?

Jane: That's really difficult because I didn't know what Asperger's was until I was 13 when we met Mam (mum's wife) that I even knew anything was really different. It was Mam that picked up the symptoms in me and my mum. Looking back now I can see that I rocked back and forth a lot, I was a very picky eater, I had one seat in the house and I would always sit there, I didn't

like change, I had one friend and sort of cling to that one person until they got fed up of me, I was intense.

Me: Did these change after receiving your diagnosis?

Jane: I don't think so, I think I was just more aware of them. It in a way, yes, because I noticed them more, so tried to stop the symptoms and hide them from people.

Me: What symptoms are most challenging?

Jane: The social aspect of it. The anxiety which becomes paranoia, that whoever is near me is talking about me behind my back, making me more anxious that there's something wrong with me, causing more paranoia, etc, causing a downward spiral.

Me: Did people treat you differently after your diagnosis compared to before?

Jane: People treated me different during the time of diagnosis because I was in school. I had to take days off to go to the 'mental health' hospital for appointments. The others in my class were always questioning "what's wrong with you? Why do you keep skipping school? "

Post diagnosis, I don't think so, because I was pulled out of school at that time and home schooled, so there was no one to judge or question. People now are more open to the idea of people with Asperger's, so I don't really get treated differently.

Me: How was your self-esteem before your diagnosis?

Jane: Quite low, I didn't think much of myself because I couldn't be the same as others my age in social situations. I was also slower than most to pick some things up in school.

Me: Did your self-esteem change Post-diagnosis?

Jane: Still pretty low. Even now I struggle sometimes. My self-worth is low too sometimes.

Me: How were you diagnosed?

Jane: I am not sure. I don't remember much of it; I think I suppressed the memories. I remember the place was called; it was in ----- . It always made me and my sister, (who was going through diagnosis at same time - she has ADHD) very sad and distressed.

The doctor brought up our father, who hasn't spoken to us for 15 ish years and it upset us for days after. We always went to Morrison's for a cake and a drink on the way home.

Me: What age were you diagnosed and how old are you now?

Jane: I was 14 when I was diagnosed. I am now 24.

Me: Did you or do you feel a sense of community or part of a group because of your diagnosis.

Jane: Not really. I've always felt a little left out of everything. Even now, I struggle to find where I fit in to society. Knowing people sometimes helps, others makes me feel worse.

8.9 Katie transcript

*A note for this interview – Due to the length of the interview and the short amount of time available to conduct the interview all the questions were sent as a whole email and answered as a whole email. They were then transcribed in a coherent way. *

Me: Hi Katie, Hope you're well? I have attached the interview questions with a brief explanation before each set. To start off this interview there is a set of questions designed to understand your self-esteem. Please answer these with either; strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree. 1. On the whole, I am satisfied with myself.

Katie: Agree.

Me: 2. At times I think I am no good at all.

Katie: Strongly Agree.

Me: 3. I feel that I have a number of good qualities.

Katie: Agree.

Me: 4. I am able to do things as well as most other people.

Katie: Neither Agree nor Disagree.

Me: 5. I feel I do not have much to be proud of.

Katie: Disagree.

Me: 6. I certainly feel useless at times.

Katie: Strongly agree.

Me: 7. I feel that I am a person of worth, at least on an equal plane with others.

Katie: Agree.

Me: 8. I wish I could have more respect for myself

Katie: Agree.

Me: 9. All in all, I am inclined to feel that I am a failure.

Katie: Strongly agree.

Me: 10. I take a positive attitude toward myself.

Katie: Neither agree nor disagree.

Me: This next set of questions is designed to understand your self-understanding and require quite detailed answers. What kind of person are you?

Katie: Compassionate, kind, open minded, easy going, logical, creative, but can also be stubborn, and have little to no tolerance of stupidity and ignorance with no desire to learn. I am an introvert, with a distrust of people.

Me: What are you not like?

Katie: Cruel, violent, jealous, or outgoing.

Me: How would you describe yourself?

Katie: Someone who prefers to stay at home or garden, and away from people.

Me: What are you especially proud of about yourself?

Katie: Not sure how or why, but people online drift to me for help or advice. I have supported strangers online in the middle of the night who were suicidal, etc. I guess I am proud that they feel comfortable enough for me to help.

Me: What do you like most about yourself?

Katie: My creativity and logical thinking.

Me: What are you not proud of?

Katie: My Anxiety.

Me: Do you think you'll be the same or different five years from now?

Katie: I hope that I will be different in a good way.

Me: What about five years ago?

Katie: I was recovering from a Mental Breakdown. My husband and parents were on 24hr suicide watch.

Me: What were you like during your childhood?

Katie: Lonely in regard to socially. I did not mix well with others my age, due to shyness and anxiety, as well as different interests. Teachers believing that I was a problem child, despite being the quiet one in class. I ended up not going to school much of the time due to people misinterpreting me, and vice versa, plus finding many of lessons too easy that it was boring.

Me: What kind of person do you want to be?

Katie: A good housewife, and hopefully a mum one day.

Me: What do you hope for in life?

Katie: Peace and quiet, away from the hustle and bustle.

Me: If you could have three wishes, what would they be?

Katie: My family and friends to have perfect health for life.

My dogs to live as long as I.

To become a successful best-selling novelist.

Me: Do you change year to year?

Katie: I suppose I do a little.

Me: How do you change or not change?

Katie: I change through understanding and knowledge.

Me: How did you get to be the way you are today?

Katie: Life experiences.

Me: How did it do help?

Katie: It taught me, often harshly, that nothing is guaranteed or perfect.

Me: Do you think there is anyone who is exactly like you?

Katie: No, I think we are all unique.

Me: What makes you different from anyone you know?

Katie: My quirks and way of thinking.

Me: The next set of questions is similar to the first given that they are answered either; strongly agree, agree, neither agree or disagree, disagree, and strongly disagree.

I continuously feel sad.

Katie: Strongly agree.

Me: I feel that I have a high self-esteem.

Katie: Strongly disagree.

Me: I often have a feeling of hopelessness.

Katie: Agree.

Me: I am usually patient with others.

Katie: Agree.

Me: I usually feel tearful.

Katie: Agree.

Me: I have interests.

Katie: Agree.

Me: I often feel guilty.

Katie: Strongly Agree

Me: I am motivated.

Katie: Disagree.

Me: I find it difficult to make decisions.

Katie: Agree

Me: I enjoy my life.

Katie: Neither agree nor disagree.

Me: I often feel worried and anxious.

Katie: Strongly Agree.

Me: I have energy.

Katie: Neither Agree nor Disagree.

Me: I have suicidal thoughts.

Katie: Agree.

Me: I sleep fine.

Katie: Disagree.

Me: I don't talk to my friends often.

Katie: Agree.

Me: My work is going well.

Katie: Neither agree nor disagree.

Me: I often feel irritated.

Katie: Neither agree nor disagree.

Me: I enjoy taking part in my hobbies.

Katie: Agree.

Me: I am often restless.

Katie: Disagree.

Me: I don't have difficulty concentrating.

Katie: Neither agree nor disagree.

Me: I often feel very worried.

Katie: Agree.

Me: The next set of questions again require more of a detailed answer.

If you remember or are aware of them what symptoms related to Asperger's syndrome do you feel that you displayed before diagnosis?

Katie: I hadn't even realised until I picked up a leaflet on Asperger's, and it mirrored everything that had happened in my life.

Me: Has this changed after receiving a diagnosis?

Katie: I felt a weight had lifted from me.

Me: What would you say are your most challenging "symptoms"? Have these changed throughout your life?

Katie: Interpreting body language, tone of voice, and reading between the lines.

Me: Again, if you remember or are aware how would you describe your self-esteem before your diagnosis?

Katie: I have battled Depression and Anxiety from since I was a small child.

Me: Did this change after your diagnosis?

Katie: No, but I now understand that it is a by-product of my Asperger's and that it can managed.

Me: Similarly, to the last question, how would you describe your mental health before your diagnosis?

Katie: Not good.

Me: Did this change after your diagnosis?

Katie: I got the right support.

Me: Do you feel that you were treated differently by others before diagnosis?

Katie: I was the one that didn't get an invite because I was not 'cool' enough.

Me: Did this change after your diagnosis?

Katie: Yea, they disappeared altogether. Some family won't accept it. Others are great support.

Me: Did you feel a sense of community or part of a group after your diagnosis?

Katie: Yes and no.

Me: That's all of the questions,

Hope to hear from you soon!

Thanks again,

Chloe

8.10 Mark transcript

Me: Hi Mark, it's Chloe.

Mark: Oh, hi!

Me: Are you still ok to do the interview today?

Mark: Yeah, Yeah absolutely.

Me: Ok, there is four sections to the interview, it shouldn't take very long the last time I did it only took like 20 minutes. There is one section about self-esteem, one section about self-understanding, one section about mental health and the others asking about your diagnosis and things.

Mark: Ok.

Me: Ok, if there's any questions you don't want to answer just let me know and that's fine.

Mark: Ok.

Me: So, the first set of questions are about self-esteem and they're on a scale. So, if you say strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree.

Mark: Oh, ok great, so it's one to five.

Me: Yeah. So, the first one is on the whole, on a whole, I am satisfied with myself.

Mark: Ugh, I would say strongly agree.

Me: At times I think I'm no good at all?

Mark: Strongly disagree.

Me: I feel that I have a number of good qualities.

Mark: Strongly agree.

Me: I am able to do things as well as most other people.

Mark: Strongly agree.

Me: I feel I do not have much to be proud of.

Mark: Strongly disagree.

Me: I certainly feel useless at times.

Mark: Strongly disagree.

Me: I feel that I'm a person of worth at least on equal plane with others.

Mark: Strongly agree.

Me: Good, I wish I could have more respect for myself.

Mark: Disagree.

Me: That's great ok, all in all I am inclined to think that I am a failure.

Mark: Strongly disagree.

Me: I take a positive attitude towards myself.

Mark: Strongly agree.

Me: Ok that's all of them for those ones. The next ones are more descriptive they require a lot more in an answer. Some of them feel a bit like they're repeating themselves but it's just to get as much information as possible, so if you feel like you've already answered it just let me know.

Mark: Ok, ok.

Me: Ok so the first question is what kind of person are you?

Mark: Urm, well gosh. That's... that does take a little bit of thought doesn't it. Urm, well sociable, quite outgoing, positive, friendly, I love my job, I love my friends, I just enjoy being myself and hanging out with other people and generally getting on with life. Gosh it's a bit hard.

Me: Yeah some of them are of a bit hard.

Mark: Yeah that is quite tricky but yeah, I try to understand other people and I think generally speaking they appreciate that, and they try to understand me as well.

Me: Yeah, ok what type of person are you not like. What traits do you not have?

Mark: I don't get angry very often, or at all. If I do, I tend to try and conceal that. I don't like to complain, I don't complain very much. Even sometimes when I should, I don't. So that's maybe not entirely a positive trait. That's um a trait.

Me: That's something that you don't have, if you don't have it that's fine. The next one is what are you especially proud of about yourself.

Mark: Urm, well what I'm especially proud of about myself is to do with Autism, 'cause I grew up with Autism and I think I have to a large extent overcome it because I think to a large extent I have, when I was younger had no prospects in life at all and partly through luck I managed to find a way, a way out of it and to overcome it and that's what I'm most proud of.

Me: Ok, that's a good thing to be proud of. What do you like least about yourself?

Mark: Ooh, gosh that's a tricky one because I actually do like myself. I am comfortable with myself and who I am. What don't I like? I suppose I'm not very good at being a leader, at being a decision maker, a manager. I don't really hate myself for that, but if I'm being completely honest there isn't much that I completely don't like about myself.

Me: That's probably a good thing. The next question is do you think you'll be the same or different five years from now?

Mark: Gosh that is another interesting question because I'm different from what I was five years ago and five years ago I was very different from what I was five years before that and what I was five years before that too. So, I suppose, that I do kind of think I've reached a kind of plateau, a kind of stability. Urm, I think in five years' time I might be slightly more experienced than I am now but not very different.

Me: In what ways do you think you'll be different?

Mark: I think it's just, possible that ugh, things at work could change, maybe I could be a team leader. They've never seen me as a potential team leader. But that would be a change for me and maybe it's just possible I could step up to the plate and be a team leader at work.

Me: The next question is what kind of person do you want to be?

Mark: I almost want to say that I want to be the person that I am now. Like outgoing, sociable and I'm really enjoying the life I've got so I just want to carry on being who I am now.

Me: Ok that's good. What do you hope for in life?

Mark: Urm, I'd like to have a relationship, I guess. That's something I've not done yet that I would like to do. Other than that, I would like things to... I'm very happy with my career and I'd like that to continue.

Me: What job is it you'd like to do?

Mark: I work in IT support. But we have an IT help desk at my company. There sort of quite a large multinational company we have our headquarters in our building in Manchester. They have a help desk there and it's really good fun and I get to speak to lots of people all day and we have great banter with the guys on the team.

Me: Ok, next question is if you could have three wishes what would they be?

Mark: I'm in a walking group, walking club anyway there's this girl called Hannah and I really fancy her so I suppose one of my three wishes would be that we get together. What would the other wishes be? I guess for me to carry on with my current career until I reach retirement age. That probably will happen anyway, I don't think I need fairies to come down and deliver it. What would the other wish be? I've only got one left now. Oh, gosh. I suppose to make people happy.

Me: They're nice wishes. Ok the next question is, well you've answered it in a different question. It was do you change year from year. But you sort of answered that in the what will you be live five years from now.

Mark: I think I have changed a lot in the past it may be because I've got a good place now. I think the incentive to change is when you're not happy that's what makes people change. But I'm in a fairly good place and so with the incentive to change being removed I don't think so much in the future.

Me: Ok, yeah. How do you think you got to be the way that you are today?

Mark: Erm, well there's a certain amount of luck involved. My dad gave me a job when I was struggling to find a job and that gave me the experience to get my current job which is with a really good company. There's so much that you'd have to put in for a full answer to that

question. Erm, I think my family gave me a strong work ethic, good values and I think for people with my condition, Asperger's I think a strong work ethic is really important because so often school fails us and leaves us feeling lonely and miserable but then you go out into the world of work and you find that actually your qualities are actually really valued there and over time make good deficits in social understanding and then everything goes well. So, having a strong work ethic is really valuable because that will get you into employment and that's where recovery of the worst aspects of this condition has its roots.

Me: Do you think there is anyone out there exactly like you?

Mark: Well I don't need somebody out there exactly like me because then they'd be like a clone, like and identical twin or something. I find people interesting because of the differences between people and you know I think there certainly are people like me but are they exactly like me, probably not. Everybody is slightly different.

Me: Ok, what makes you different from everybody else?

Mark: Well I suppose the thing that would make me different from everybody else is not some major psychological difference that I experience but more that you know my personal journey that nobody else that has exactly followed. I've been to this job and that job. I've met this person and that person and that's what's has made me be unique and the person that I am, that unique person that does not set me apart in any fundamental way from other people.

Me: Ok the next set of questions are like the first ones so Strongly agree, agree, disagree, strongly disagree...

Mark: So, one to five again.

Me: They are mental health based.

Mark: I'm ok with that.

Me: Ok so they do seem quite dramatic some of them but they're just general things from the NHS. so... I continuously feel sad.

Mark: Strongly disagree.

Me: I feel that I have high self-esteem.

Mark: Strongly agree.

Me: I often have a feeling of hopelessness.

Mark: Strongly disagree.

Me: I am usually patient with others.

Mark: Agree.

Me: I usually feel tearful.

Mark: Strongly disagree.

Me: I have interests.

Mark: Strongly agree.

Me: I often feel guilty.

Mark: Disagree.

Me: I am motivated.

Mark: Agree.

Me: I find it difficult to make decisions.

Mark: I'm going to go with a neutral option, there's a neutral option in the middle isn't there. I'm going to go neutral there.

Me: I enjoy my life.

Mark: Strongly agree.

Me: I often feel worried and anxious.

Mark: Disagree.

Me: I have energy.

Mark: Agree.

Me: I have suicidal thoughts.

Mark: Strongly disagree.

Me: I sleep fine.

Mark: Agree.

Me: I don't talk to my friends often.

Mark: Strongly disagree.

Me: My work is going well.

Mark: Strongly agree.

Me: I often feel irritated.

Mark: Disagree.

Me: I enjoy taking part in my hobbies.

Mark: Strongly agree.

Me: I am often restless.

Mark: I'm going to go neural on that one.

Me: I don't have difficulty concentrating.

Mark: Agree.

Me: I often feel very worried.

Mark: Disagree.

Me: Ok that's all of those ones as well. The last bits of questions that I have now are about your Asperger's diagnosis and how that affected you and things. if you remember, you were diagnosed as a child, weren't you?

Mark: No, I wasn't diagnosed until the age of 43.

Me: 43? I don't know why I thought you were a child, I thought you'd mentioned that. Sorry. What symptoms made you look for your diagnosis?

Mark: I was looking for an explanation for why my childhood was so unhappy and why I had struggled so much in life. Because I was very socially isolated as a child and as a young adult. I didn't really have any friends until I was 30 years old and I wanted an explication for that and when I got to the age of 34, I thought that I had found an explanation for that on the internet and it was Asperger's. It was people with Asperger's talking about themselves and I thought yes that's me. So, I went to the NHS and asked for a referral and they gave me a referral to a specialist, and I spent eighteen months on a waiting list. At the end of that they refused to give me an assessment. Because I was in full time work and they said well if you're in full time work there isn't anything wrong with you, so we don't need to go any further with that. So, a few years later I realised there were private clinics that could do that and ask the right questions and give you a proper assessment because the NHS didn't assess me. I mean I do still have symptoms but they're relatively mild and they don't sort of ruin my life. I'm slightly eccentric, very much toughened my boots and I sort of talk in a very formal sort of a way and I'm very logical way of thinking. They're sort of mild symptoms than when I was a child when they were more serious then and caused me to be very isolated. I had sort of sensitivities to being around people who were random and unpredictable because I could cope with it, so I had to isolate myself away from people in order to deal with that. That was how it was when I was younger and that then led to me being a very lonely person.

Me: Ok I think you just answered about three of my questions all in one go. That's good. Would you say your self-esteem was different before your diagnosis?

Mark: Well I, when I went for my diagnosis one of the things, they wanted was kind of a trip down memory lane. I wanted a direct explanation for how things have been the way it's been. I found the effect on me has been more positive than I could have anticipated because it's enabled me to talk about it to other people: to my employers my family and it's part of a process that has sort of strengthened the understanding of it which the people I work with and live with so it's really helped it's really helped. It's been a very good thing to have because it's not just a certificate that says why you had a difficult childhood, it is that and that's important to me but it's also helping to improve my life.

Me: Ok, that's good. Do you think people treat you different before your diagnosis and did it change afterwards?

Mark: Yes, it does, it's quite subtle it's not like people with ... gloves... there's an understanding at work especially with the HR department because we have a HR department and they know about these things. But when it comes to setting job specifications and things like that, they have to come up with something that's going to suit me. It's a large company with big employers so they can do that. There's a greater understanding and expectation that I'm slightly different in some ways and work around that.

Me: So, it's been a positive thing?

Mark: Absolutely it's been a positive. I mean I wanted it, I wanted the diagnosis, so I had to go to a clinic and pay them to access me. So, I totally wanted it, but it's been more positive than I thought it would be.

Me: How did they access you?

Mark: I went through the Gillberg criteria.

Me: I only have a couple more questions left. Did you feel a sense of community or part of a group after your diagnosis?

Mark: I guess I felt reasonably well connected before my diagnosis but since then. Yes, that's probably strengthened.

Me: Great is that within an Autism community?

Mark: No, no it's not. I believe in trying to integrate into mainstream society, that's pretty much what I've done. I do have autistic friends that I do feel a strong sense of infinity with them. But I'm not a huge fan at this stage in my life in going to Autism support groups. I do go to a support group but it's a parent support group they are sort of talking about mostly their sons and I sort of try and explain to them how I felt when I was about 25 years old and they're like ahh yes that's probably what's going on inside his head. But no, it's society in general, my work, the friends I made through the open university and friend in general.

Me: Ok, that's all of my questions. That was really helpful thank you.

Mark: Ok

Me: Thanks, I'll let you know when it's finished if you want to have a look.

Mark: That would be great! Thanks

Me: Ok, bye thanks again.

Mark: Bye

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