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Exploring Individual Perceptions of Adults Diagnosed with Asperger  
Syndrome using a Cultural Framework

By

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A thesis submitted in partial fulfillment of the requirements of the  
University of Sunderland for the degree of Masters of Philosophy

March 2016

**March 2016**

# DEDICATION

## **ACKNOWLEDGMENTS**

I would firstly like to thank Dr Stephen Macdonald for all his support throughout this thesis. I would like to thank Margaret Walker for her fantastic, invaluable and supportive teaching that drew me to the subject of Health and Social Care. I would also like to thank Dr Lesley Deacon for her guidance within the final stages. Last but not least I would like to thank my research participants for allowing me to explore their lives.

## ABSTRACT

The aim of this study is to explore the lives of adults diagnosed with Asperger Syndrome. The importance of the *individual voice* is central to this thesis as Ashy (2011) identifies numerous studies (Biklen, 1988; Biklen & Duchan, 1994; Blatt, 1981; Bogdan & Taylor, 1976, 1994; Kliewer & Biklen, 1996) that recognise how, 'too often, stories are told *about* people with disabilities and the emphasis is on the voice of the professional, not the voice of the person' (2011; online).

This thesis draws upon cultural disability studies as a framework as Lerner and Straus (2006) recognise this as something that 'understands and investigates disability as a cultural product,' (2006: xiv). This framework aids the understanding of both the development of Asperger Syndrome as a medical entity, as well as providing recognition of how individual experiences have been shaped within specific cultures.

Qualitative Methods were applied to this study using ten biographical narrative interviews (Wengraf 2011) with five males and five females; in order to collect narratives and life experiences (p.5). This particular method allowed participants to discuss their experiences in an inclusive manner; with the individual leading and sharing their story. The social model of disability could be seen to dominate this research methodology, as the work of Barnes and Sheldon (2007) demonstrates. This played an important role in the development of emancipatory research; a research paradigm that this thesis encompasses. A thematic analysis was used in this study which is 'a process for encoding qualitative information' (Boyatzis 1999:4); focusing on the emerging themes from the participants. Braun and Clark (2006:11) recognise how thematic analysis can be a useful method when exploring topics that are under-researched.

Essentially, this thesis illustrates the way in which culture shapes societal views of Asperger Syndrome, recognising the key terms that contribute to such ideas. Additionally areas are highlighted in which further research is required, including that of employment and Asperger Syndrome. Most importantly this thesis identifies that those with Asperger Syndrome are unique individuals despite a shared label.

## **DECLARATION**

I hereby declare that I am the sole author of this thesis. I authorise the University of Sunderland to lend this thesis to other institutions or individuals for the purpose of scholarly Research.

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## **Chapter I - Introduction to the thesis**

Title:

Exploring Individual Perceptions of Adults Diagnosed with Asperger Syndrome using a Cultural Framework

Research aims:

The overarching aim of this research is to explore understandings and perceptions of those with Asperger Syndrome.

The key aims are as follows:

1. To obtain individual experiences of those who have been labelled as having Asperger Syndrome
2. To identify how those who have been labelled as having Asperger Syndrome feel they are viewed by society, taking into account other people's perceptions and reactions to the disorder
3. To recognise the changes, if any, of individuals' life quality pre- and post-diagnosis
4. To identify and highlight barriers faced by individuals with Asperger Syndrome
5. To address theoretical development in relation to the social model of disability with regard to Asperger Syndrome
6. To recognise the impact of culture upon individual experiences

## **Introduction to thesis**

The aim of this thesis is to explore the lives of adults diagnosed with Asperger Syndrome and the way in which culture has shaped their individual experiences. At present in the United Kingdom, Asperger Syndrome is currently defined as a sub-category of Autism therefore research carried out within this area may be termed under the broader label of 'Autism'. Autism itself is defined by Frith (1991; 2) as 'a developmental disorder' whereby behaviours usually include impairments in socialization, communication and imagination. The term Asperger Syndrome is defined as 'neurobiological disorder that manifests itself in impaired communication and emotional processing' (Dubin: 2007:29). The National Autistic Society recognise that there are a number of additional characteristics that are defined under the category of Asperger Syndrome which include; repetitive behaviour and routines, highly focused interests and sensory sensitivity. Asperger Syndrome is also discussed under the category of Autism Spectrum Disorders, Neurological Impairment and Disability. As can be seen, there are many categories and complex definitions of Asperger Syndrome and it is this which underpins the reason to research this particular topic. Dubin (2007) and Boyd (2014) both recognise that Asperger Syndrome is a 'complex construct' (Dubin 2007:29) and is 'a notoriously complex condition which even the experts find it hard to understand' (2014:27).

A number of studies have been carried out with individuals experiencing Asperger Syndrome, such as Malloy and Vasil's (2004) research with adolescents; and Edmons and Beardon's (2008) focusing upon social relationships. This research study however differs in the sense that there is no set area of discussion, as participants discuss topics that they feel are important; not identified by the researcher. This approach allows data to be

representative of the individuals, as well as highlighting the role of individual voice. The work of Ashby (2011: Vol 31, No 4) states 'one of the critical questions facing Disability Studies is how to make central the voices of individuals with disabilities in research'. This thesis was developed with this aim, to listen to, and present straightforwardly, the narratives of individuals thus affording a voice. The work of Jones (2007) highlights that there is a gap in the research for the voices of individuals who experience disability to be heard. Research carried out by Goodley and Moore (2000) recognise the importance of individual voice; although their work focuses on learning disabilities, as opposed to Asperger syndrome, it does however recognise the role of researchers in facilitating voices and has been an area of great consideration within this research. By enabling individuals to have a voice that is not focused upon medicine or childhood, it allows understanding of the disorder being shaped by real life accounts. This was highlighted when reviewing the literature as there is a dominant emphasis on medical research within the area of both autism and Asperger Syndrome. Rutter (1996) supports this claim recognising the vast amount of literature regarding autism is focused upon causes and interventions of Autism, and not enough on individual accounts, especially in adulthood. Stoddart et al (2012) records the dramatic proliferation of research within the area of Asperger Syndrome over the past fifteen years, proposing that this is focused upon children and diagnosis.

This thesis is underpinned by Cultural Disability Studies (CDS) and is based upon the work of writers such as Dan Goodley, Rosemarie Garland Thomson, Nick Watson and Tom Campbell. The work of Lerner and Straus (2006) provide a number of definitions of CDS stating it 'understands and investigates disability as a cultural product, as a way of interpreting bodily variation and a social concept that widely influences our collective thinking and processes' (2006: xiv).

A general history of disability is provided within this research, due to the term Asperger Syndrome not being coined until 1943. The general history of disability will also draw upon a number of influential writers such as Lennard Davis, Michel Foucault and Henri-Jacques Stiker. Such writings discuss the concept of the 'abnormal' body recognising how these bodies were identified, labelled and pathologized. The labelling of the bodies into distinct categories allows us to recognise how those with characteristics that would now be defined under the label Asperger Syndrome have been treated throughout different time periods. Stiker (1997) states 'without this historical diffraction, what could we know about disability, how could we situate it, which possibilities and which pitfalls would we be capable of charting?' (p.13). Historical studies therefore recognise the changing cultures that exist in regards to disability.

Medical discussions both historical and current play an important role within this thesis, demonstrating the power structures that exist within specific cultures. The medical model of disability is discussed in regards to the way disability has been interpreted throughout history viewing 'disability as something that must, whenever possible be cured' (Beith et al. 2005:315). This thesis rejects this idea of the medical model and favours a social model approach as it is important to recognise both models in regards to the cause of disability. The social model of disability recognises disability as something that is created by society removing the emphasis of blame away from the individual. This is supported within the work of Oliver (1996) where it is noted that the social model 'does not deny the problem of disability but locates it squarely in society' (p.32). The social model underpins this thesis, and is recognised in regards to the deinstitutionalization of individuals through legislation such as the *NHS and Community Care Act (1990)*.

The methodology of this thesis adopts a biographical narrative approach, which allows the individuals within this study to articulate their own experiences in great depths, thus promoting the notion of individual voice. As previously suggested, Goodley (1996) advocates the importance of listening to individual life stories of underrepresented groups of disabled people. It is recognised that there has been a growing interest with the use of biographical narratives being used to explore disability (Shah and Prestley 2011:17) which could be due to the inclusiveness of this approach. This study explores the lives of ten adults, five male and five female who have been diagnosed with Asperger Syndrome. The data within this study is analysed using a thematic approach recognising both the shared and individual areas of interest amongst participants; highlighting particular periods and institutions in which disabling barriers and negative stereotypical ideas exist. Additionally, exploring the impact in which culture has played upon the understanding of individual experiences.

This layout of this thesis will commence with a literature review which is organised into three sections. The first to be discussed is chapter 2, providing a historical overview of the history of disability, recognising the way in which 'abnormal' bodies are recognised, labelled and treated. Chapter 3 recognises the development of the specific label Asperger Syndrome, it also recognises the role of the social model and the fight for equality amongst disabled individuals. Chapter 4 recognises the 21<sup>st</sup> century ideas regarding disability and the characteristics that are currently defined as Asperger Syndrome. Chapter 5 provides a methodological overview recognising the research aims and the way in which this study was carried out. Both Chapters 6 and 7 will explore the individual accounts: Chapter 6 will focus upon accounts prior to diagnosis; and Chapter 7 will explore accounts provided post diagnosis. To conclude Chapter 8

recognises the way in which culture has impacted upon modern day experiences of disability.

## **CHAPTER 2 – THE CHANGING CULTURE OF THE BODY**

*Note: A 'pre-capitalist society' is one before the rise of industrial labour, medicine and economic growth, and is known as a feudalistic society.*

*In regards to a 'capitalist society' this is a society in which all of these things are encompassed.*

### **Introduction**

The study of historical, academic and scholarly literature is an essential starting point when attempting to understand the development of Autism, or more specifically Asperger Syndrome (AS) (a form of Autism), as it is believed that 'the study of history can contribute to a sense of identity' (Atkinson et al. 1997: 12). Additionally, it could be argued that 'we need the past in order to be able to understand ourselves; we need it in order to believe in our future, if we have come from nowhere, where are we going to?' (Hall Carpenter Archives 1990: 1). Providing historical accounts of individuals that who are currently defined as 'autistic' is a task of great complexity. As Autism was not classified in the early modern period, it proves difficult to find an accurate historical description. This chapter will

therefore explore the ideas that exist in regards to the 'abnormal' body, recognising how different cultures treat those who possess characteristics that are constructed outside the cultural norm. There will be a particular focus upon the historical categories such as 'idiot' or 'mad' as these were often the labels given to individuals displaying medicalised cultural discourses (i.e. medical symptoms) that in the 21<sup>st</sup> century we would now recognise as characteristics of Autism. This is not to suggest that all autistic individuals fell into one of the above categories as some literature would suggest; for example the work of Murray (2008) discusses Autism as once belonging to the 'general categories' of 'idiocy' or 'retardation'. Additionally, the use of the term 'idiot savant' is also linked to Autism, as the writings of Gilberg & Coleman (2000) demonstrate, making reference to the remarkable mental skills that can occur in some cases of Autism, while recognising the inaccuracy and offensive stigma attached to this term.

Autism is subjective to the individual. When discussing histories of specific groups the notion of individuality can often be diminished, however this thesis aims to highlight individuality and asserts that the exploration of two histories – both 'idiocy' and 'madness' – will prove beneficial to this aim. As the title of this chapter 'The changing culture of the body' suggests, societal treatments of those individuals within the discussed histories change along with the times. This chapter addresses these shifts in culture and how they reflect on the understanding and treatment of those people categorised as 'idiots' or 'mad'. A cultural history is defined by Mark Poster as

The study of the construction of the subject, the extent through which, and the mechanisms through which, individuals are attached to identities, the shapes and characteristics of these

identities, the role the process of self-constitution plays in the distribution or stabilization of political formations, and the relation of all these processes into the distinctions of gender, ethnicity and class. (1997: 10)

Providing such histories allows us to compare and contrast modern day interpretations of those with medicalised cultural discourses that would now be recognised as disabling. Additionally, such histories allow for an exploration of how particular ideas were created. This chapter aims to explore the key discourses that surround particular characteristics, and how they objectify, measure and pathologize individuals. This chapter will draw upon a number of influential writers that have influenced Cultural Disability Studies such as; Foucault, Garland Thompson and Davis.

### **The culture of the 'normal' body**

The culture of the normal body is an area of great discussion within Disability Studies, and is reflected within the many writings of; Hall, Davis and Garland Thompson. According to Davis (2006) the concept of the norm and the normal body are components to understanding the disabled body. The 'norm' is described by Canguilhem (1982: 39) as a 'dynamic and polemical concept', proposing that there is an 'outside world that stands to be corrected'. Hacking (1990:163) advises that the word 'normal' is used 'both to say how things are, as well as how things ought to be'. It is important to recognise in regards to CDS the idea of the norm has been culturally constructed as this section of the thesis will demonstrate.

Although norms and expectations exist on a global scale, cultural norms are a set of values and beliefs that are shared within a particular culture. Such beliefs can be interchangeable, and this can be demonstrated in the treatment of those that would now be defined as 'disabled' throughout history. It proves difficult to locate an exact point in history when ideas regarding the normal body were established. Cave (2002) suggests differences within the human body have always been 'recognised'. The work of Stiker (1997: 24) identifies disability 'if not all, both physical and mental' within the bible. This work establishes the distinction between the disabled and non-disabled in regards to religion. Stiker states; 'Disability is the uncommon element, but this uncommonness establishes the difference between the other and the earthly man' (1997: 29). Creamer (2010) also outlines how specific religions once regarded disability, noting how the Hebrew bible called for segregation of disabled individuals from the general public. This idea of segregation is discussed by Stiker (1997) in regards to cultural ideas of uncleanness. The status in which disabled people held, is thought to be the same as both prostitutes and of women who menstruate, thus regarding them as unclean beings. The exclusion of specific conditions such as 'leprosy' is also noted; 'lepers were at times obliged to rights of mourning, which warned others to keep their distance from these unclean beings, excluded from the land of living' (1997:25). Although illness and disability are now recognised as two different entities this account allows us to recognise the regulation and exclusion of 'abnormal' bodies prior to medical practice. Preston (2016) confirms how religious ideas later change and are thus discussed in regards to medicine. 'The medical world would later modernize this circuit of ideas by moving from the language of sin to the language of "medical ethics". (2016:6)

When exploring the history of disability it becomes apparent that a significant number of labels have been used to define those who do not conform to the norms that exist within specific cultures. Becker's (1963) early work regarding 'labelling theory' describes the ways in which labels are attached to people who fall outside of the social norms; in turn these labels become attached to individuals as a form of self-identity that influences their behaviours. Ferrante proclaims 'labelling theorists maintain that an act is deviant when people notice it and then take action to label it as violation and apply sanctions' (2013: 135). Foundations of this theory can be developed from sociological writings carried out by writers such as Cooley (1964), from whose work titled 'Human Nature and the Social Order' we can begin to examine some of the early conceptions for this theory. The labelling of individuals who do not conform to these norms could be discussed in regards to power structures. Whereby those whose bodies fit into this idea of the 'norm', have superiority over those who do not. The work of Garland Thompson (2017) identifies the way in which hierarchies are created by the ideas regarding the body. The term 'normative' is used to describe a created identity that people can represent themselves with, suggesting that those who identify with the 'normative' have power over those who do not. The term 'corporal inferiority' is used to describe this process.

When discussing power and the 'normal' body the work of Foucault (1997) can be discussed. Foucault uses the term 'docile bodies', highlighting the construction of normative processes which create the notion of the normal and abnormal body. By rendering a body as *docile* Foucault suggests that this body can then be 'used, transformed and improved' (Foucault 1977:136). This *docile* notion could be seen as a way of controlling bodies thus creating a hierarchy between the classification of 'normal' and

'abnormal' bodies. Foucault's work demonstrates a strong emphasis upon medicine and the practicing institutions as a form of control although this is not to say control was not present prior to medical practices. It is believed that the idea of disability within history highlights power relations that could be seen to affect everyone (Dolmage 2014;9).

As previously noted the two particular labels that will be discussed within this thesis are 'idiocy' and 'madness'. The characteristics of 'madness' are discussed within the work of Lindeman (2010), these include; bodily harm, threats to family, flouting authority, going naked, rendering one's clothes as a sign that 'all was not right', and showing indifference to one's surroundings also indicated a troubled mind. Additionally characteristics such as lack of eye contact, unusual gait and obsessive actions are amongst the discussed characteristics that are currently defined under the category of AS. The following quotation from the work of Neugebauer (1966) discusses 'idiocy' in regards to low intellectual ability, however it is important to recognise that autism is not primarily based on or associated with low intellectual ability, Frith (2008) supports this claim recognising that autism is associated with low intellectual ability in about 50 per cent of cases, however the other 50 percent is associated with average and even 'superior' levels of intelligence. This definition from an early 17<sup>th</sup> century legal dictionary defines an idiot as

A fool natural from his birth and knows not how to account or number 20 pence, nor cannot name his father or mother, nor of what age himself is, or such like easy and common matters; so that it appears he has no manner of *understanding or*

*reason*, nor government of himself, what is for his  
profit or disprofit.  
(1966: 25)

As this definition demonstrates, different names have been employed when discussing the term 'idiot', such as 'fool' in this example, and such individuals were also abstracted into the categories of 'natural fools', 'idiots' and 'feeble-minded'. 'The criteria for being identified as a fool or even a fourteenth century 'idiot' would not necessarily include those diagnosed as 'idiots' in the nineteenth century' (McDonagh 2008: 6). What we must remember, however, is that although the general concept of 'idiocy' will remain somewhat similar, times and periods will have changed in regards to what is thought of as 'normal' and 'acceptable'. In regards to the term 'madness', Rutter and Quinton (1984) note that terms such as 'mad', 'lunacy', 'insanity', 'psychosis' and 'mentally ill', among others, have been employed.

The notion of inclusion for those individuals defined by specific cultures as 'idiots' or 'mad' is an area of great controversy as the following discussions will demonstrate. The early writings of Foucault (*Madness and Civilization*, 1989) discuss this ideology of inclusion, whereby the 'mentally different' were included in the social body, welcomed, tolerated and even venerated (Crang and Thrift 2003: 235). Foucault describes the periods surrounding late medieval Europe as a time when the 'fools' and 'mad' were loose in the land (Middelfort 1999: 22). The work of Porter (2004) delineates that the inclusion of the 'mentally disturbed' was a 'fact of life to English people throughout the early modern period'(p.50). This is not to say that the cultural norms and expectations were not in place, but that the culture at this particular time accepted this variation. This would suggest that individuals of

all abilities were accepted and integrated into society and even accepted into the work force. However, the notion of integration and acceptance in the early modern period is not accepted by all. Edward Shorter (1997) is among the writers contesting this notion, suggesting that

People of villages and small towns possessed a horror of those who were different, abandoning any romantic notion of the insane within the history.

(1997: 2)

His work then goes on to illustrate the ill treatment of those classified as 'mad' during this period. He recognises that in 1817, a member of the House of Commons from an Irish district said:

There is nothing as shocking as 'madness' in the cabin of an Irish peasant... When a strong man or woman gets the complaint, the only way they have to manage is by making a hole in the floor of the cabin, not high enough for the person to stand up in, with a crib over it to prevent his getting up. This hole is about five foot deep, and they give this wretched being his food there and there he generally dies.

(Shorter 1997:1-2)

This particular statement, if true, would suggest that this was a cultural punishment of the 'mad'. Those who did not know or understand this disorder initiated a set of discourses that led to such improper treatment.

Such punishment could also be seen to exercise power from those who are like the majority of the population onto those who are not. Explorations surrounding the periods before 'madness' was better understood are described by Foucault as 'doubtless an uncomfortable region', suggesting that in order to explore this period a renunciation of 'the convenience of terminal truths' is needed. Foucault proposes that 'we must never let ourselves be guided by what we may know of madness' (Foucault 1967: ix). Foucault's work is as much about disciplining general society – to keep us docile we need to see what happens to the 'mad'.

The question of *who gets to label someone as 'mad' or an idiot?* is an important question within this thesis, this section has identified that it is not possible to pinpoint any one key component that has been responsible for implementing such labels prior to medicine. However, neighbours, families and societies all witnessed behaviours that were not within the 'norm' and thus placed individuals into one of the above labels. The work of Gillman (1985) recognises that it is often things we fear or glorify that we assign labels to.

The idea of an 'overlapping' history influenced the decision to provide an overview of 'idiocy' and 'madness' within this chapter. The previously discussed definitions of 'idiocy' by Neugebauer (1966) and 'madness' by Skull (2011) address the notion of 'reason' and create the idea of 'impaired reason' as a shared entity. Neugebauer discusses the 'idiot' as having 'no reason' while Skull identifies 'disturbances of reason' as a defining characteristic of 'madness', suggesting that the two both feature some form of 'unreason'. The inability to effectively divide these two categories throughout history could be due to the 'scarcely' written history of idiocy, as well as the 'common currency' amongst contemporary historians of society

regarding the constructions of madness (Goody 1996). Additionally the cultural representations that were constantly shifting and being interpreted in new ways could also be a contributing factor. The work of Neugebauer (1996) is also influential in recognising that there has not always been such a prominent divide between the two categories of idiocy and lunacy, suggesting that the two were often 'lumped together'.

### **Regulation of 'abnormal' bodies**

Although the treatment of 'madness' and 'idiocy' is an area of great controversy, what we can see is the recognition of those who do not conform to the culturally constructed norms throughout history. The role of medicine could be thought to play a huge part in the regulation of these 'abnormal' bodies. The term 'medicalization' of disability can be used to describe the growing use of medicine. This term is discussed within the work of Conrad, and is used to describe a process where non-medical problems become defined and treated as medical problems, usually in terms of illness and disorders (2007: 4). Medicalization can be seen as conforming to the theory of normalisation, aiming to cure disabled or impaired people by changing the abnormal bodies or behaviour, ignoring exclusionary attitudinal and economic barriers.

Medicalization is also prodigious in relation to the creation of power statuses, specific periodic 'knowledge' that accrues, and the creation of identity through the use of medical discourses. Although 'labels' and 'power roles' have always been present, the medical transformations of the 18<sup>th</sup> and 19<sup>th</sup> century were a determinant that allowed society to possess the sociologies of knowledge, enabling us to analyse those changes and view them as an ephemeral expression of knowledge/power. The treatment of

individuals of whom possessed characteristics that the 18<sup>th</sup> century would label as 'mad' can be traced back to the 1400s. During this period it is believed that the concept of idiocy held that it was an incurable condition, this is represented in the land, permanent confiscation of land, and whereas 'madness' was thought curable, so temporary measures were implemented. Although the divides between idiocy and 'mad' have been noted, historical literature affirms that there are periods when the two concepts overlapped and in some cases conjoined; this, however, is not to state that the two are fully interlinked. This alongside the overlapping histories could be seen to represent the cure of the 'mad' opposed to the 'idiot' within specific time periods.

The care of the 'mad' could be identified within small-scale hospitals such as Bedlam, previously known as St Mary's Bethlehem, in London. Bedlam was founded in 1247, involving itself in the care of the 'mad' from at least the 1400s (Andrews et al. 1977). Additionally, St. Luke's Hospital also provided care for the 'mad' before the 18<sup>th</sup> century. Such early asylums recognise that although those identified as 'mad' were not yet a cultural problem, concern was still present. Foucault (1976) highlights the use of moral therapy and social control as a form of treatment for the 'mad' that was believed to be existent until the 18<sup>th</sup> century. The use of moral treatment developed from the ideas implemented within the York Retreat. The York Retreat was an institution founded by William Tuke and opened in 1796, and this establishment was run by those of the Quaker religion to provide relief to families of the 'mad' who followed the same religion. The York Retreat provided support for those labelled 'mad' or 'insane' (within the Society of Friends) based on the religious principles of compassion and humanity, and favoured moral treatments as a form of cure.

The rise of capitalism is discussed here as it is fundamental in regards to medical growth, however it is essential to recognise that cultural disability studies is concerned with the emerging cultures opposed to societal structures. A capitalist society is one that often witnesses the rise and development of industrial labour, medicine and economic growth. The increased focus on industrial labour could be deemed a fundamental factor in the increase of exclusion among disabled people within society. The requirements of the factory work are discussed in the work of Ryan and Thomas (1980) who identify the developments from self-determined and flexible work which were believed to be inclusive to those with disabilities. The work of Bagilhole (2009) states 'under capitalism more people were excluded from the production process' (2009: 40). With no means of financial support for excluded individuals such as those with 'idiocy' and 'madness' the care of these individuals could therefore become an area of great difficulty. The development of this capitalist society is believed to have changed the accountability of such individuals who required support. Such change in accountability and support transformed societal intervention from a micro level to a macro level and, as Rushton (1988) suggests, individuals were transformed into 'a public problem' as opposed to a 'private burden'. This shift in responsibility could in addition contribute to the oppression faced by disabled people by shaping their perceived role as an economic burden. The responsibility of care for these individuals would inevitably impact upon the cultural representations.

As individuals were transformed from a private burden to a public problem, this idiot/lunatic dichotomy formed the basis of official reactions.  
(Rushton, 1988; 40)

Due to the intensive development of capitalism and the financial difficulties faced by those who did not conform to the newly developed society, the housing, health and welfare of such individuals became an area of great concern for social activists; as the changing society was in a state of crisis of poverty and unemployment. Consequently, the government set up a legal duty to provide relief and curb the cost of providing for such individuals. This was in the form of workhouses, initiated by the implementation of *The Poor Law Amendment Act (1834)*, described by David Englander (1998:1) as 'one of the most important pieces of legislation that has ever been enacted'. The Act was responsible for the introduction of workhouses – public funded places that consisted of austere accommodation, offering food and residence in return for work.

For those disabled people deemed eligible for support, the workhouse or meagre outdoor relief were symbolic of the fate that would ensure recalcitrant non-disabled workers.

Roulstone and Prideaux 2012: 5

Although the workhouses accommodated a large variety of people, the 'mad' people were often placed together, and frequently the statuses of both 'madness' and 'idiocy' were unclear, as noted in the work of Digby and Wright (1996). It is recognised within the work of Dale and Melling (2006) that in England and Wales both the workhouse and public asylums were developed within the framework initiated by the *Poor Law Amendment Act*. It is however essential to recognise that the initial *Poor Law Act* was initiated in 1601, Roulstone and Prideaux (2012: 4) recognise how this Act did provide some 'rudimentary support to disabled people' however

recognises how the adequacy of provision was 'localized'. It was not until the development of the *Lunatics Act* (1845) that any real separation or distinction regarding idiocy and 'madness' individuals was enforced. Power (2012) suggests that this Act 'established the asylum system as the proper and primary system for the treatment of lunacy' (2012: 56). Additionally, this act made it compulsory for every county to develop an asylum within three years of the Act being passed. Dale and Melling (2006) recognise that during 1853 there were more insane individuals within the workhouse than in the asylums, demonstrating the difficult transition that occurred when moving from workhouses to asylums. It was evident that the workhouses presented poor and cramped living conditions, but asylums lacked capacity. As recognised within the work of Forsythe and Melling (1999), as asylums developed to house the 'mad', the concern for those defined as 'idiots' within the workhouse appeared non-existent. Literature provided by Digby (1996) makes reference to 'idiotic inmates' in the workhouses as 'outside' the main focus of concern for some time. This is demonstrated by numerous Acts; the *1808 County Asylums Act*, the *1845 Lunatics Act* and the *1845 Lunatic Asylum Act*. These Acts imply that the subject of 'madness' was becoming recognised as a social problem.

As the literature regarding the late 19<sup>th</sup> century suggests, that particular time period was highly significant in regards to both medical interest and medical interventions, not only for those classified as 'ill' but for those with classified as 'mad' or 'insane'. The work of Lawrence (1994) recognises that from about 1850 orthodox medicine was being employed to facilitate the running of Victorian society. The accumulative approaches that were used to cure the 'mad' varied among professions and historical periods, and were additionally influenced by a number of factors such as the introduction of new knowledge or ideas, and the changing discourses that surround this

particular subject. Skull discusses the changing culture in regards to the treatment of the 'mad,' stating;

The Victorian age saw the transformation of the  
madhouse into the asylum into the mental hospital;  
of the mad-doctor into the alienist, into the psychiatrist;  
and of the madman (and women) into the mental  
patient mental patient  
1981; 6

Skull (1981; 6) also notes how the concept of 'madness' was becoming recognised as a something in which only a group of 'legally recognised experts' could define. This moves away from the earlier ideas in which there was no prescribed individual that recognised 'madness'. The history of medicine is one of great interest as is clear that medical practices were carried out with insufficient knowledge. However the cultural ideas recognise the control that was asserted over the abnormal body and such control in specific periods could be considered inhumane. This could be reflected within some of the inhumane and appalling medicalised practices that were carried out such as the withdrawal of quantities of blood; this practice was based on the idea of blood and other bodily fluids causing imbalances within the body. Additionally, lobotomy and electro-convulsive therapy (ECT) are other examples of the inhumane procedures that were carried out. Little was known about the impact of such procedures, however it is visible that the dominant medical culture allowed the medical professions to trail such procedures. Lobotomy is a practice whereby a hole is drilled into the skull with the aim of releasing pressure. As Frazier (2011) notes; 'lobotomies, increasingly viewed as barbaric, were almost wholly phased out by the 1960's in the UK, as the other remedies, especially anti-

psychotic drugs, became available' (p.19). This particular statement recognises the changing ideas in regards to medical practices as a form of cure, highlighting the shift to drugs to regulate the 'abnormal' body.

Although the 21<sup>st</sup> century has welcomed effective, reliable and humane forms of medical intervention, we must remember the powerless history that allowed medical development to flourish in such an inhumane way. The development of medicine within this period could be discussed as the foundation of the inhumane treatment that has for centuries impacted on society, and has thus contributed to the disabling barriers experienced by individuals. The development of large-scale asylums that contributed to the development of medical interventions as a cure for the 'mad' provided a perfect ground to exercise medical dominance, as a large number of 'mad' inmates were confined together. As the work of Thomas Szas (1970) titled 'manufacture of 'madness'' implies, ideas of moral therapy were not a continuous ideology, and his work recognises that the same type of trial, evidence and torture that was existent within asylums was found in both witchcraft trials and psychiatric diagnostic procedures.

The work of Tremain (2015) examines the work of Foucault in regards to government of disability, within this work ideas of power are highlighted, especially in regards to the disabled body. The discussed work recognises the role of institutions in implementing particular power structures. Tremain states 'the carceral various institutions, organisations and associations are the sites in which bodies are compared, differentiated, hierarchized, diagnosed' discussing the judgments that exist around the terms 'normal' and 'abnormal' and the correction of these 'deviant bodies' (2015:29)

## **2.7. Medicine and power**

In relation to the increased use of medicine in the asylums, discussions regarding power are essential. These discussions allow us to gain an understanding of how those who were previously termed as 'mad' were subjected to such abuse. There is a predominant focus on the 'mad' within this section of this thesis this is due to the curability of the 'mad'. However, discussions regarding 'idiots' will also be continued. As this chapter highlights there has been a number of ways in which the abnormal body has been recognised throughout history. It is evident through the institutionalization of the discussed individuals that power structures have been imposed upon those who possess 'abnormal bodies'. Although this thesis adopts a social model approach it is essential to recognise the impact of medicine within the 20th century. Devlieger (2003: 99) recognises how the institution of medicine in the early 20<sup>th</sup> century became the 'centre piece of community life' recognising the powerful authority physicians were given. This powerful authority could be seen to shape the cultural ideas that existed around the body as something that ought to be cured. The literature produced by Pescosolidio et al (2011) proclaims that medicalisation has its roots in the Parsons concept of the 'sick role', a term coined by Talcott Parsons in 1951, which has become a fundamental element within the understanding of the patient/doctor role. Parsons' work demonstrates a keen interest in the 'precise' way that culture can become 'internalized within individuals', discussing the way that cultures and values are absorbed by individuals (2000: 29). The 'sick role' in regards to the power relations between patient and doctor, presents doctors with considerable power. He goes on to emphasise the role of discourse within this structure, suggesting that it is 'discourse that presents them as experts' (2003: 89). These discourses have been simultaneously influential in creating and maintaining statuses of power in which those without a disability remain higher in the hierarchy. Power is in a sense paradigmatic, being used in

innumerable ways within multitudinous theoretical frameworks, so it is essential to recognise that power can be defined using a range of definitions flexible to the subject and matter. However, the following quotation from Marconis and Plummer (1995) delineates a generalised definition of power, suggesting that power refers to 'any aspect of social life where there is inequality between two or more people and there are attempts to maintain or transform the situation' (Barton 2001: 11).

There are numerous ideologies regarding the subject of power; some in agreement with one another and inevitably some contrasting. However, it is essential to understand what power is, and how it is measured in order to be able to fully recognise its distribution and effect within society, and in this context its role within medical interventions. Types of power include political, economic and ideological power. In a well-established theory of power by Lukes (1974) it is believed that power is defined using three sets of situations: successful and observable decision making; managing the agenda; and manipulating the views of others. Focusing on the first situation, observable decision making, Lukes (2005) declares:

The focus on observable behaviour in identifying power involves the pluralists in studying decision making as their central task.

Lukes2005; 17.

The ideology of power being created prior to or during decision making processes is contested by Dahl who argues that the process of power is given after 'careful examination of concrete decisions' (1958: 466). These discussions examine the specific point in which power is created in regards to decision making, and can be applied to the decisions of

institutionalisation and the associated medical practices. Within the work of Lukes (1974) it is apparent that his ideologies relate power to the infliction of harm. This power is believed to be exercised when a person is made to act in a way which is contrary to their own interests. Pescosolido (2011) highlights the 'professional dominance thesis' that has been apparent throughout the history of medicine, stating that there has been 'a relative focus on doctors as the main agents on medicalization' (2011: 174). The types of power discussed allow us to recognise the powerless history of those who did conform to the societal norm; not only were these individuals removed of their freedom but they were also forced to endure abuse. This could have been due to the lack of knowledge surrounding these people and their characteristics, as well as the view that these individuals were somehow less than human. These discussions effectively demonstrate that it is the act of referring to another individual as 'mad', or alternatively 'insane', that initiates and creates questions regarding what it constitutes to be 'human' (Middlefort 1999: 81–82).

In regards to the 21<sup>st</sup> century's interpretations of power it is evident that such power structures exist between doctors and those who are defined by the medical profession as disabled. The use of labels and categories to understand conditions have also played a fundamental role within the power structures that exist in regards to the disabled body. The example of Foucault's docile body can be used to highlight the role in which labels have had upon those considered abnormal. Through the implementation of labels it is visible that discourse emerges shaping cultural understandings and thus implementing disciplinary practices. This can be recognised in regards to the 'docile body' where the body is rendered docile so that it will be 'subjected, used, transformed and improved' (Foucault 1977 : 136). The particular labels given, such as that of the docile body, could be seen to

include and exclude bodies through a labelling process. Parker et al. (1995 :10) recognise the role of Foucault's work in regards to language noting how; 'language is organized around different systems of meaning' these systems are could be seen to disempower particular individuals as well as asserting power to others. As we can see from the medical treatments inflicted on those 'defined as 'mad', the discourse and cultural ideas regarding the body are essential.

## **Chapter 3 – Implementation of the term ‘Asperger Syndrome’**

### **Introduction**

Generally speaking, all the authorities exercising individual control function according to a double mode; that of binary division and branding (mad/sane; dangerous/harmless; normal/abnormal); and that of coercive assignment of differential distribution (who he is; where he must be; how he is to be characterised; how he is to be recognised; how a constant surveillance is to exercise over him in an individual way etc.)

(Foucault 1995: 199)

As recognised by the previous statement provided Foucault (1995) it appears that, the ways in which the authorities exercise control over individuals are based on binary divisions and branding, and the division normal/abnormal. Foucault recognises that these divisions thus shape the treatment of specific individuals, and help to define the power structures that affect people's lives.

In regards to the control and treatment of autism we must recognise is that autism was first recognised in children, and as the work of Nadesan (2005) recognises it was not until the 1930s that children's development and progression were even monitored, therefore the distinct category of autism had not yet been defined. Nadesan (2005) states:

The conditions of diagnosing a child as autistic are rooted in the cultural practice and economy of their times.

(2005: 19)

Therefore those children who had the specific characteristics that are now defined as autistic would have been recognised under a different category. Additionally, some individuals who would today be described as 'high functioning' may not have been recognised at all. This could thus suggest that autism is therefore a cultural construct of the times. This is not to say that characteristics are not real, but it demonstrates that different medical labels could be seen to identify and define particular characteristics and therefore construct particular disorders.

This chapter aims to recognise the construction of the term 'autism' and 'Asperger Syndrome' by discussing the work of Asperger and Kanner. However, in order to gain further insight the chapter will then explore the *NHS and Community Care Act (1990)*, describing the change that this had not only on autistic individuals but on the area of disability as a whole. Lastly this chapter will look at the role of the social model of disability and how it shapes understandings of disability.

### **3.1. Constructing the label 'Asperger Syndrome'**

As the work of Nadesan (2005) recognises, the late 20<sup>th</sup> century was a time when psychiatry and medicine were developing into expert authorities. This particular period began to move away from two distinct categories of "idiocy" and 'madness' and thus began to differentiate between 'forms of adult- and childhood-specific mental illness and developmental delays'

(2005; 30) The development of psychiatry played a huge part in defining autism, not only due to the use of the term 'autism' by Leo Kanner, a child psychiatrist, but also due to the recognition of children, as the main cause for concern had always previously been adults.

The first conceptions of the terms 'autism' and 'autistic disorder' were introduced into the English language in 1943 as a result of Kanner's publication titled 'Autistic Disturbances of Affective Contact'. This study was based on observations of eleven children – eight males and three females – all of whom were placed in a child psychiatric ward.

The study claimed that the children who were observed appeared unable to relate to people or situations in an 'ordinary way'. Kanner proposed that 'There is from the start, an extreme autistic aloneness that, were ever possible, disregards, ignores, shuts out anything that comes to the child from outside' (Kanner 1943: 242–253). The primary identification of 'autism' by Kanner (1943) encapsulates presumptions regarding 'average' intelligence, suggesting that it was significantly low for those who he observed within this group. Kanner also noted other characteristics such as language challenges and repetitive behaviours, adopting the term 'early infantile autism' to describe those within this group. It was apparent Kanner was not alone in his research. Hans Asperger, a Viennese psychologist, carried out a similar study in 1944 titled 'Autistic Psychopathy in Childhood', observing the children on his ward during a summer camp programme. The article presented by Asperger discussed several case studies of children who he described as 'examples of particular and recognisable type of child' (Timimi et al. 2011: 55–56). Unfortunately for Hans Asperger the impact of his paper was significantly lower than the one published by Kanner in 1943. The timing of this paper during the Second World War combined with the

fact the language of the publication was German may have been a contributing factor. Happe (1944) discusses how the two had never met but had profound similarities in their work; both Kanner and Asperger recognised several characteristics including the child's poor eye contact, the stereotypes of words and movement, and the resistance to change (1944: 8). What is even more surprising is their shared use of the term autism. As the work of Bluestone (2005:1) recognises. The term autism, meaning 'living in self' (in Greek) was coined by a Swiss psychiatrist, Eugen Bleuler in (1911), this was used to describe self-absorption due to poor social-relatedness in schizophrenia

The writings produced by Kanner predominantly focus on autism in children rather than adults, and this is something which is still referred to in autism literature, and could be a contributing factor as to why the main focus of autism is still on children today. 'We hear the term "autistic children" so commonly that it is easy to forget that autism is a life span illness that begins in early childhood but is an incurable disease that persists throughout life' (Katz et al.2001: 147). Although this statement refers to autism as an illness and a disease, something with which this thesis strongly disagrees, it does however lend weight to the observation that children appear to be the age group discussed the most. These discussions could be due to the original discovery of autism as a childhood condition, but additionally it could be linked to the recognition of symptoms from a young age, or the perceived greater vulnerability of children with autism as opposed to adults. In regards to the 'creating' of autism, Timmi et al. (2011) discuss the need to understand 'Normal childhood' their work proposes 'To help us understand the background that made it possible for autism to be invented and become popular, we need to put a context around the history of autism and first need to look at the changing beliefs around the nature of

childhood in which it developed.’ (2011: 45) This idea of normalisation as a contributor in the creation of AS can be linked to the underpinning notion of this thesis, whereby ideas regarding characteristics and their normality are constantly changing due to changes in societal beliefs.

Although the concept of autism was developed by both Kanner and Asperger, the term Asperger Syndrome (AS) was not fully recognised until 1981 by Lorna Wing. This recognition was a result of a paper that was published regarding Asperger’s previous work. The paper addressed the clinical features of autism based on Asperger’s accounts, and within her subjects were 35 individuals who had been seen and diagnosed by Asperger. Wing proposed a new type of syndrome that allowed for better social and language functioning. Prior (2004) recognises how Wing’s original definition of AS was the original definition of autism, however better social and language functioning were encompassed than in more recent understandings of the term autism. It is suggested that, as a result of this paper, the interest in AS began to grow (Schopler et al: 1999). Several years after Wing’s paper, in 1988, a small conference was held in London where this newly developed sub-category was discussed. Attwood (2007) recognises how this resulted in the first diagnostic criteria being developed in 1989. AS was added to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) in 1994.

As the previous chapters highlight, the characteristics of AS may have previously been categorised under different labels, and thus subject to negative or derogatory treatment. However, it is not clear how many people who we would now label with AS would have been recognised during these periods. During the time when AS was gaining its popularity and becoming recognised as a diagnostic criteria (mid-1980s–1990s) the societal

approach towards psychiatry and disability were changing, as the following section regarding community care will address. Hardman et al. (2014: 275) point out that it was in fact the 1970s when treatment towards those with autism adopted an educational approach, and their work also recognises that the 1975 *Children's Act* was responsible. However, students were often labelled under different categories such as 'mental retardation and seriously emotionally disturbed'. This was due to the lack of a distinct educational category.

When analysing the literature around AS in the 1990s it proves difficult to find literature regarding the exact interventions used to cure. However, assessing this particular period it is believed that education was the favoured approach. But, as the previous chapters have highlighted, this has not always been the approach used to treat such individuals.

In regards to this particular disorder as a cultural construct, the work of Hacking (1999) should be discussed. His work chronicles the term 'niche disorders' to describe disorders that 'emerge and were specific to particular socio-historical and economic niche conditions' (Nadesan:2005 184).

Hacking (1988, 1989) identifies the cultural developments of autism, recognising that factors such as psychology and mass schooling contributed to construction of childhood autism. This particular section highlights the point of construction of the terms 'autism' and 'Asperger Syndrome' but, as Hacking identified, it was other social factors and discourses that contributed to these constructions. The *Community Care and NHS Act 1990* could be seen to have largely impacted on the care and recognition of those with autism and more specifically AS.

### **3.2. The NHS and Community Care Act 1990**

During mid-20<sup>th</sup> century, when the concept of autism was being developed and AS was not yet recognised, doubts regarding the effectiveness of institutionalisation were beginning to appear. The 1950s and 1960s as a time when movements were developing, addressing basic philosophy and the clinical and financial effectiveness of such institutions. Race (2002) discusses similar debates during the 1970s, recognising the hospital/community dichotomy. Although such discussions and doubts were apparent, the *Community Care and NHS Act* was not formally established until 1990. This Act was initiated with the intention of providing support and services within the community for those with disabilities, and this support would be provided in non-hospital or non-institutional environments. The origins of this Act are believed to stem from an investigation led by the Royal Commission on Mental Health and Mental Deficiency, during which the problems with out-dated mental hospitals were acknowledged. The work of Malin states ‘the extremely poor physical conditions and the permanent detention of patients was therefore the main motivation behind the pressures for change given in evidence to the Royal Commission’ (1995: 55).

The *Community Care and NHS Act* 1990 can be defined as an Act which enables ‘people who fall into one of the four “priority groups” – older people, younger disabled people, people with learning difficulties, and those who experience mental health problems. Although Autism had been introduced in 1944, it was still relatively new as it did not enter the DSM-III until 1980, and it first appeared as a Pervasive Developmental Disorder, Infantile Autism (Matson 2008: 9). With this late recognition it may be that a number of

individuals would have fallen under categories of mental health and learning disabilities.

Although the transition from institutions to the community aimed to improve the lives of individuals through empowerment, this Act has been described as a 'new version of an old tune; how to save money by replacing expensive institutional care with a cheaper alternative' (Blakemore and Warwick-Booth 2013: 257). In terms of care provision, there were concerns regarding informal carers, especially mothers, and this issue has been commented on by a number of authors, such as Abbot and Sapsford (1987: John swain (2003) discusses the difficulty in using parents as the main sources of care provision, stating that 'Disabled young people, particularly those with learning difficulties, may be over controlled by their parents and carers and denied opportunities for experimentation and choice' (2003: 80).

Although there may have been flaws in the development of this Act, such as costing, care provision and issues regarding societal acceptance, we must acknowledge this was a 'radical' Act, and as Basford and Slevin (2003) delineate, it could be thought to demonstrate a shift in ideological thinking, creating foundations for action. The impact of this Act for disabled individuals is immeasurable as it was a stepping stone to acceptance and moved us closer to eradicating the horrific past treatment of those who were not considered valuable members of society.

The *NHS and Community Care Act* does not specify which groups of people services may be provided for, as it recognises that people may be vulnerable for a wide variety of reasons that it is a personal needs that require support not there IQ score or name of their disability. (Powell 2002:10)

As the above statement recognises, the *Community Care and NHS Act* 1990 did not specifically state which specific groups services will be provided for, only that all individuals who require help and support would be included. In regards to AS this Act social services should make sure that all individuals with autism and AS and their families are made aware of their entitlement to an assessment under this Act. This Act has inevitably impacted on service provision by demonstrating that change can be made and that no individual with a disability should be segregated from society. Research carried out by the Department of Health (1990) suggests 'that people who have learning difficulties generally have little or no say in services they receive' (Department of Health 1990). Although this may have been true, we can now see that the 21st century has moved away from these ideas by adopting a person-centred approach whereby the individual is at the heart of service provision. However, Shakespeare (2013) argues that the Community Care and NHS Act has made individuals prisoners in their own homes:

Many people remain effective prisoners in their own homes. This may be because of environmental barriers, lack of money, feelings of vulnerability or problems with mobility]  
(Shakespeare :2013 191)

Although there may be individuals that still experience oppression, it must be noted that this Act was a step in the right direction and has helped to change societal perceptions regarding people with disabilities. The Putting People First Act (PPFA) (2007) has also played a fundamental role in Health and Social Care provision. Gardner (2014) identifies how this Act sets out 'shared aims and values' that would not only be used to transform not only Health and Social Care but also shape individual experiences of

using the services provided. The PPFA (2007) states 'Over time, people who use social care services and their families will increasingly shape and commission their own services' (2007;2). Commissioning their own services involved implementing personal budgets that would allow for individuals to have greater control over their own support services. The Act also recognised the need for correct support and information to inform individual choices. Gardner (2014) observes how personalisation was officially introduced within the PPFA (2007). Sanderson and Lewis define personalisation as 'more than just personal budgets it means people having real choice and control of their support on a day to day basis' (2012; 9). Following on from the idea of personalisation the Care Act (2014) was initiated, the Act aims to 'improve people independence and well-being' this Act makes it clear that the arrangement and provision of services from local authorities is essential and must be provided. Additionally, this Act looks at how local authorities can work with communities in order to provide the best service provision possible. ([www.gov.uk](http://www.gov.uk)). The regulations of this Act also makes it a requirement for individuals assessing needs to be qualified, or to consult an expert. 'The autism guidance states that this means that where an assessor lacks experience of autism, the council must ensure that an expert is consulted' (<http://www.communitycare.co.uk>). Such Acts could be seen to tie in with the Social Model of Disability, this particular model is based on an ethos of equal treatment for those with disabilities and removing the disabling factors enforced by society. This model also plays a fundamental role in the way in which disabled individuals are viewed and treated within today's modern society.

### **3.3. The social model of disability**

During the 1980s, when the criteria for AS were being developed, the term 'social model' was coined. This model is hugely influential in the way we see disability, and has also had a momentous impact on service provision. The term was originally used in 1983 by Mike Oliver and Colin Barnes, both of whom are academics, authors and disability rights activists, but the foundations for this model are traced back to Paul Hunt, a resident of the Lee Court Cheshire Home. In 1966, Paul Hunt published an essay titled 'A Critical Condition'. This particular essay aimed to highlight the oppression, stigma and discrimination faced by disabled individuals. Some years later (in 1971) he wrote to the *Guardian* newspaper proposing the creation of consumer groups within institutions, and this led to the formation of a group called UPIAS (Union of Physically Impaired against Segregation). Vik Finkelstein, a native of South Africa who was both a psychologist and activist, was of great influence within the formation of this group. Prior to his contribution to UPIAS, Finkelstein had been imprisoned and caused great controversy regarding the anti-apartheid movement in South Africa.

Within the writings of Macdonald (2009: 52) it is recognised that there were in fact disability groups developed before UPIAS, the Royal Association for Disability and Rehabilitation (RADAR) and the Disability Income Group (DIG) were amongst these. But Campbell and Oliver (1996: 64) propose that such groups were not in fact led by disabled individuals themselves but rather professionals speaking on their behalf. Additionally, Macdonald (2009) proposes that the alternative groups did not have a distinct political ideology, such as the social model of disability. The developed group of UPIAS aimed to eradicate the oppression and inequality faced by those termed as 'disabled', but with the predominant focus based on physical impairment alone, and this then became a controversial issue within disability studies, creating further segregation for the collective group of

individuals who were then labelled as 'learning disabled', deserting them in their fight for equality. Consequently the social model of disability (1983) remained focused upon those with physical impairments, aiming to eradicate the social conditions that oppress. After an astounding amount of time attempts were made to incorporate all types of what were termed 'learning disabilities' and 'neurological disabilities', including autism and one of the most recognised learning disabilities relating to a person's impaired verbal (phonological awareness) and reading (orthographic coding ability) known as dyslexia. Although AS was not initially part of this initiative which has potentially changed the way individuals labelled as 'disabled' (a category in which AS is now included), it is important to understand this model, and this thesis is underpinned by the notion that disability is created, suggesting that it is society that disables, and removing the emphasis from the individual as a problem. In order to gain a greater understanding of this model, the distinction between disability and impairment must be discussed. Within the work of Ong-Dean, impairment and disability are defined as follows:

Impairment is 'the biological condition that produces specific limitations in physical or mental functioning'.

Disability is 'the limitation of opportunities available to physically impaired people by social or environmental barriers'.

(2009: 163)

From the concepts of the social model it is thought that impairment alone is not thought to be disabling, it is only when society isolates, excludes or stigmatises people with impairments that their impairment becomes a disability (Schur et al. 2013).

The social model of disability has not only changed our society's way of thinking about disability but it has also effectively influenced service provision. Williams (2006) states that this model seeks to reverse the process of vulnerability by supporting people in valued social roles (2006: 13). The *Disability Discrimination Act* (DDA) (1995) was one of the earliest Acts influenced by the social model that provided equality for those with disabilities. Strategies such as *Valuing People* (2001) were also developed with such principles in mind, ensuring service provision and inclusion was provided to previously excluded groups. Within the writings of Jolly (2012) it is recognised that the social model does not focus on disabled people as victims of their physiology, but it does however 'offer a way to organise politically against the principles of social and economic exclusion, and oppression in a disability society.' (2012: 3).

The term 'disabled' is one that holds a multitude of interpretations, with its constructions and origins being an area of great controversy. As Campbell (2009) recognises, it proves difficult to provide a united definition of disability. Leung (2009) highlights the dissimilar views on disability between different countries as well as among individuals, emphasising that disability is not only an individual issue, but a community one too. Often interpretations of disability can be influenced by a continuously changing and developing culture. Goodley (2011) claimed that

To be disabled evokes a marginalized place in society,  
culture economics and politics... disability affects us  
all, transcending class, nation and wealth.  
(Goodley 2011: 1)

It is suggested by Barnes and Mercer (Cited in Barton 2001; 11) that 'during the last two decades or so our understandings of disability have been transformed' (2001: 11). Macdonald (2006–2009: 50; thesis) highlights that until the mid-1970s academic understandings of disability were predominately situated within medicine or its inflicted disciplines. In order to understand interpretations of disability, a number of sociological theories have been developed, and these theories can both contribute to and shape our understandings regarding disability. As Carol Thomas (2004) suggests, 'It is the nature of sociological understandings of what constitutes "disability"'. Writers such as Dan Goodley, Tom Shakespeare, Carol Thomas, Colin Barnes, Mike Oliver and Steven Macdonald are among those who use sociological theories when discussing disability. Sociological theories derive from the study of sociology; this can be defined as the study of human behaviour in society. Bury (2003) goes on to confirm that a large proportion of interest within the field of sociology is within the field of chronic illness and disability studies.

Theories can be defined as

A set of interrelated ideas that allow for the systematization of knowledge of the social world which can be used to explain the social world and to predict the future of the social world.

(George. R 2007: 5)

It is evident that within the area of disability studies the medical and social models of disability are the two dominant approaches. The medical approach was the dominant approach used within the development of autism and Asperger Syndrome. However, within 21<sup>st</sup> century

understandings it is evident that AS is still viewed by many as a medical concept, and this is reflected within the copious amounts of research into cure and medical interventions.

The two models encompass their own distinct stories regarding their views on disability, their development, and their use within society. Straus (2010) provides discussions on theory and autism, proclaiming that autism is most generally conceived within one of the two models mentioned above. He goes on to state that 'autism is also embedded within one of two sorts of cultures: the medical model and the culture of science verses the social model and the culture of the social group' (2010: 536).

It is evident that that the social model of disability rejects the ideologies of the medical model, especially in terms of the cause of disability. The social model approach allows the issue of disability and impairment to remain an attitudinal and environmental issue, removing the focus from the individual to society in order to recognise and remove social barriers. As (Shakespeare, T. 2006: 199) states, this model 'demonstrates that the problems disabled people face is the result of social oppression and exclusion not their individual deficits'. Shakespeare also discusses the belief that there are many activists and writers in the UK who favour the British social model as the only appropriate or effective analysis or definition of disability (2006: 9). In retrospect this suggests that the social model must have had a profound and influential effect on the way in which impaired individuals view the cause of their disability.

The work of Beckett and Campbell (2014) provide discussions regarding the social model seeking to understand 'what it is' and 'how it operates'. Their work proposes that the social model can be understood as an 'oppositional

device'. The aim of this is to 'understand how the model has been used politically, how it has been operated by activists and at what ends' (2014:280). This particular research highlights the way in which the social model could contribute to the shaping of individual identity.

'The social model constituted a 'we'- 'disabled people'- as an alternative to disciplining 'psycho-medical categories, which acted to individualise responsibility for disablement'.( 2014:278)

### **3.4. Conclusion**

As recognised within the previous chapters of this thesis, in the past those with impairments had no control, power or choice over the way that they were treated. This chapter recognises the how the implementation of the *Community Care and NHS Act 1990* impacted upon service provision, additionally highlights the ideas put forward by the social model of disability.

As Carlson (2009/2010: 14) suggests, the social model allowed disabled people to develop their own user-led and user-controlled organisations. Although the development of both Community Care and the social model were influential during this twentieth century the new diagnostic criteria and the surrounding discourse must be recognised, as these writings impact on modern day interpretations of people with characteristics defined as autistic.

It is evident that there has been a rapid growth of diagnosis of AS in the last decade (Lyons and Fitzgerald 2005). The exact Reason behind this growth could be a result of the growing literature and recognition of this disorder, as well as the changing societal beliefs that exist around normality. From a

cultural perspective it does not mean that more individuals now have these characteristics, but the 'normality' of these characteristics are more frequently being questioned. The medical literature regarding this subject places those with autism and AS outside the 'normal' bracket. Lyons and Fitzgerald (2005) pose the question 'was there AS before this label came into use?' Their work suggests that people would have previously been diagnosed under a number of alternative labels such as social misfits, eccentrics, loners, and obsessive-compulsives – or alternatively they may have been discussed as having borderline and schizoid personality disorders or schizophrenia. However, the exact number of individuals who were previously diagnosed under a different label (diagnostic or societal) is not known. Within their work Lyons and Fitzgerald go on to discuss the interest in Asperger Syndrome, suggesting that this topic can make us aware of the 'sometimes fluid boundaries between normality and psychopathy' (2005: 2).

This chapter aims to demonstrate that AS was born out of a medical context, but recent developments that foster a social model approach aim to reduce and remove the problems associated with the existing medical discourse.

The illusion that a diagnosis such as 'autism' gives, of having identified that the person with diagnosis does indeed have a neurologically based disorder, has many ramifications in self-concepts, others' treatment of that person, services institutional practices and so on.

(Timimi et al. 2011: 178)

As recognised within previous chapters of this thesis, the characteristics associated with the label AS can be traced back to historical ideas of 'idiocy' and 'madness' from the 18th century. Due to the developments within science and medicine it is clear that differentiating perceptions now exist regarding the culture of autism. The work of Straus identifies the changing ideas and societal development of AS within recent years. AS was not encompassed as an Autism Spectrum Disorder (ASD) until 1994. Additionally, autism was not formally recognised as its own category within the Diagnostic Statistical Manual (DSM) until 1990. It is unarguable that in recent years, since the inclusion of these disorders within the DSM, that there has been an increase in diagnostic prevalence as medical professions now have a diagnostic label for the associated symptoms.

Straus proposes that:

The rise in diagnosis and classification has fuelled a dramatic increase in public awareness, which in turn has encouraged additional diagnosis and classification.

(Straus1997: 536)

The rise in public awareness of the disorder is an area of controversy as it does not always encompass a shared understanding. These diverse understandings emerge in different cultures, where a diagnostic label can be interpreted in many forms, dependent upon factors such as language and discourse, race, religion, beliefs, etc. However, Riddel and Watson (2003) also recognise that differentiating meaning can also exist within a single culture, noting how these meanings can be constantly reinterpreted.

The work of Murray proposes that 'There is a precision to the term "autism", in what we might think of as clinical terms, with the language of medicine, education and social care' (2008: 26). This suggests that interpretations of autism may derive from a medical model perspective, whereby it is suggested that disability is intrinsic to the individual and not societal factors. Research produced by Wylie (2014: 11) claims that AS is misunderstood by both the general public and by clinical professionals.

## **Chapter 4 – An introduction to the 21st Century**

### **definitions of Asperger Syndrome**

Asperger Syndrome, known as ‘AS’ from here on, is a relatively new diagnostic classification that defines childhood, behavioural and neurological disorder (Malloy and Vasil 2002: 659). This disorder is currently (in the United Kingdom) described as a variant of autism, or more specifically a ‘sub-category’ of Autistic Spectrum Disorder (ASD). It is additionally be discussed as a Pervasive Developmental Disorder (PDD) (Atwood 1998). As this specific disorder was developed under the category of autism, as discussed in the previous chapter of this thesis, this will remain the dominant approach.

Occasional reference will be made to individuals diagnosed with ASD (including AS) as ‘autistic individuals’; this is due to a request from a number of participants within this study that believe autism is *not* an attachment of a person. However, due to the literature surrounding autism this specific terminology cannot always be used, and therefore an overlap of terminology may be visible. Additionally, the term ‘AS individual’ will be used when distinguishing between the subgroups.

### **Introduction**

This chapter will commence by exploring the 21<sup>st</sup> century literature that aims to define autism, and although medical definitions will be provided it is essential not to lose sight of the individuality of those diagnosed as ‘autistic’.

The chapter will address the ideas surrounding AS from our 21<sup>st</sup> century understanding, and these understandings are fundamentally based on medical model ideologies, which could be seen to represent the medical dominance surrounding this disorder. As an intentional counterpoint to this, the additional goal of this chapter is to highlight the importance of understanding how individual experiences of AS are constructed, and to provide the literature to make specific links between medical understandings and individuals' experiences.

Baren-Cohen (2000), a well-known writer on the subject of autism, suggests that we have grown familiar with the idea that autism is a 'psychiatric condition', a 'disorder', a 'disability' or a 'handicap'. Although this thesis draws on the idea of autism as an individual impairment, the current terminology of 'disorder' will be adopted. In reference to the other terms used to categorise autism, it is evident that autism can be viewed from a variety of perspectives, often influenced by the changing culture surrounding the term. There are a multitude of definitions that could be provided to define culture; the work of Brym and Lie (2007) provides a simplistic definition, proposing that culture is 'the sum of practices, languages, symbols, beliefs, values, ideologies and material objects that people create to deal with real life problems' (2007: 33). This chapter aims to address some of the medical and social ideologies that currently surround AS. The definitions and assumptions intrinsic to these ideologies are essential to this thesis as they are reflective of the changing culture and attitudes to AS, while also being responsible for shaping those changes. Additionally, understanding of these areas in turn allows for greater understanding when interpreting individual accounts.

#### **4.1. Introducing autism/Asperger Syndrome within a modern-day context**

What is autism? This has been an ongoing question among academics, researchers and healthcare professionals, and this question has brought with it a number of answers, most of which change and develop with current discourse and knowledge. As a consequence there have been many debates, ideas and arguments regarding the construction and interpretation of autism by both autistic and neurotypical (NT) individuals. The term 'neurotypical' was formulated by autistic people in the United States in 2009 with the aim of embracing difference amongst autistic people. In a statement provided by Nadesan it is proposed that

Efforts to define the precise essence of autism escape, the best representational practices of scientists and medical practitioners: consequently even at the dawn of the twenty first century we do not know what autism is.

(Nadesan 2005: 9)

This particular section will focus upon the medical definitions of autism, using literature from the Diagnostic Statistic Manual (DSM) and The World Health Organisation (WHO). The medical definitions provided may change due to ongoing research within the area of autism, and we must reiterate prior to providing medical definitions that not all autistic people are the same, and the disorder may have different effects depending upon the individual. Since the discovery of autism there have been a number of causes suggested, such as the environment, genetics and certain vaccinations, but there is insufficient scientific evidence to support such claims. The work of Zager (2005) recognises the strong evidence pointing

to a neurobiological etiology of autism, but states that the exact cause(s) and nature of this basic defect remain unclear.

In medical terms, as noted within the DSM-IV-TR (2005: 70) the essential features of 'Autistic Disorder' are defined as abnormal or impaired social interaction, communication and restricted activities or interests. The writings of Willey (1999) make reference to autism as an 'umbrella' that covers numerous 'subgroups' collectively referred to as Autistic Spectrum Disorders (ASD), and each group is believed to vary in 'severity'. Lorna Wing is among the most influential writers within this specific field, and her work highlights that those individuals grouped within the 'autistic spectrum' vary from high-functioning individuals to those with complex learning disabilities. 'Structural language competence' is also among the interchanging variables that occur in those on the autistic spectrum, as recognised within the writings of Tager-Flusberg et al. (2003). The categories defined within the autistic spectrum can be discussed in terms of level of 'functioning'; AS is regarded as 'high-functioning', and this refers to those individuals who are not intellectually impaired (Corker and French 1999).

Despite the variation within the spectrum, there are also areas of similarity that group these sub-categories together. Lorna Wing (1988) demonstrates this in regards to the shared difficulties believed to be encountered by all those on the autistic spectrum. The areas of shared difficulty, as noted by Wing (1988), are as follows: understanding and use of non-verbal communication; understanding social behaviour (which affects ability to interact with children and adults); and the ability to think and behave flexibly. Reference is made to these areas as the 'triad of impairments', and among those in the 'high-functioning group' previously mentioned this 'triad

of impairments' is seen to have a 'central role' (Jones 2002). Within the DSM-IV, AS is differentiated from other ASDs by the absence of impaired language acquisition and cognitive functioning. Corker and French summarise AS as a

Qualitative impairment in social interaction marked by repetitive and stereotypical patterns of behaviour, interests and activities, leading to significant impairments in social, occupational or other important areas of functioning.

(1999: 63)

The DSM-IVTR (2000:80) also indicates that the difficulty with reciprocal social interaction for such individuals is gross and sustained, leading to problems in many areas such as making friends, articulating difficulties and displaying emotions, consequently infringing upon individual inclusion within society.

With regard to the treatment of ASDs, Timimi et al. (2011) recognise that there is very little evidence of treatments that significantly alter the symptomology of this disorder. Their work goes on to recognise the reports that suggest certain interventions can benefit a child, and these include vitamin or psychopharmacological treatments. It is also essential to understand when discussing autism that autistic children grow up to be autistic adults, as it is common for the literature on this subject to focus on children, especially in regards to interventions.

When discussing autism it is essential to distinguish this 'disorder' from learning disabilities (LD) as a general term – although autistic people (mainly those on the lower end of the spectrum) may be diagnosed with additional learning disabilities, autism is a separate disorder. Previously learning disabilities were termed as 'learning difficulties', but this was changed to be more inclusive as the original term suggested it was the individual's difficulty rather than the societal limitations that disable a person. Jordan (2002) asserts that there are common misconceptions surrounding the relationship between autism and severe LD.

#### **4.2. Social Interaction**

The believed deficit in social interaction can encompass a range of characteristics which could be deemed 'abnormal'. A relevant example of this could be the inability to effectively use eye contact, which is an area of difficulty for some individuals with AS. The use of eye contact when starting or maintaining a conversation is something many people would regard as essential or 'normal', and appears to be a common cultural norm within modern day society. Rutter and Quinton (1984) discusses 'eye gaze' as a factor that establishes positive social interactions, and proposes that it is an 'essential feature' within dyadic face-to-face interactions. Lack of eye contact during a conversation can often be perceived as rude, suggesting a lack of interest or understanding, but from an AS perspective this is not the reason for such absence.

Continuing on the topic of eye contact, Argyle and Dean (1965) propose that the use of eye contact in a two-way conversation can have a variety of functions, one of the most prevalent is in regards to gathering feedback of other people's emotions. In order to understand others' emotions and

mental states the understanding of facial expressions can contribute tremendously, and the work of Ellis and Gunter supports this claim, stating:

The ability to identify faces is obviously vital in social interactions but perhaps more significantly so is the ability to identify moods of others which to some extent we do by observing facial expressions.

(1999: 196)

The work of Leo Kanner (1943) discusses the inability to read social cues and gestures as one of the most striking clinical features of this 'disorder'. The inability to understand specific emotions does not mean that AS individuals do not feel emotions, are not caring or that they act in a cruel or unfair manner. But there may often be slight confusion when specific emotions are demonstrated out of context, for example crying when happy or laughing when angry. A hypothesis called the 'theory of mind' has been used to discuss such difficulties, and is described by Sodian and Kristen (2010) as

The ability to attribute mental states (thoughts, beliefs, emotions and desires) to one's self and others contributing to understandings of others behaviour.

(2010: 189)

Ellis and Gunter (1999) recognise that this hypothesis is thought to be applicable for individuals with autism, but their work suggests different results when those with AS are assessed. Jurecic proclaims that 'It is important to acknowledge that the theory of mind hypothesis is not universally accepted especially within the autistic community' (2007: 426). The following hypothesis somewhat proposes a different way of thinking for

AS individuals: although different ways of thinking could apply in some instances, we must remember that specific differences should not be stigmatised, and additionally one's own mental state, thoughts, beliefs and emotions may be attributed to one's self but not in a neurotypical way.

In order to maintain positive social interactions a set of skills known as 'social skills' are thought to be essential. It is often believed that those with Asperger Syndrome struggle to develop such skills. Positive social skills are often thought desirable and are believed to be important for a number of reasons, as the work of Buck states:

Social skills have been found to be important in the determination of mental health over the life span of the individual; there is growing evidence of their importance in physical health as well.

(1991;85)

It could be argued that such skills have become an expectation of today's modern culture, especially in regards to 'social compensation', a term used to describe 'complicated social responses', including understanding social rules and engaging in behaviours that are expected in given contexts (Matson 2009).

#### **4.3. Areas of difficulty, including education and employment**

Elaborating on the difficulties within social interaction, it is evident that such problems can impact upon many areas of life; however, these are different for every individual. There is a growing amount of literature identifying the problems faced by those with AS, and education and employment are

amongst the areas discussed. The literature of Morgan (1996) is reflective of this, proclaiming that the lack of success in these areas is not due to the competence of the individual but their difficulty coping with the 'social context'. Individuals who fail to effectively interact could be amongst the most likely to be terminated from employment. Employment is not only essential when it comes to earning money, but also in learning new skills, meeting new people and feeling a valued member of society. The shared cultural norms and expectations, alongside lack of understanding by employers, could additionally impact upon the estimated number AS individuals employed, and the number who remain employed. Edmonds and Beardon (2008) recognise the difficulty in accessing clear figures of employment for AS individuals, however their work does suggest that less than 20 percent of people diagnosed with AS are in work at any one time. If the current figures are reflective of this then more needs to be done to ensure equal access to employment, with an emphasis on education and training about AS to ensure no individual is discriminated against. As AS comes under the category of a disability, it is essential to consider the *Disability Discrimination Act* (1995); this legislation was initiated to ensure those categorised as 'disabled' are free from discrimination in all areas of life, including education and employment.

Education is a compulsory service offered by the government to enable children to learn the correct and appropriate skills needed for adulthood. Although educational professionals recognise the different levels of ability among those they teach, the inability to effectively understand conditions such AS could impact upon students' personal achievement. This disorder is often difficult to understand, as individuals are often intelligent and fully functioning, and can often attend a mainstream school (although in some instances statements of special educational needs are required). This is not

to suggest that *all* individuals with AS can attend mainstream schools; the National Autistic Society (NAS) states that 'people with autism can find it extremely hard to make sense of the world', and this could inevitably impact upon their educational achievement (as well as other areas of life) if their learning needs are not met. Trying to understand the way in which any other person views the world is an area of great difficulty. In order to gain insight into autistic individuals' perception of the world we must first try to understand the way in which they see their environment and the spaces around them. In regards to learning, Haskell and Barret (1977) emphasise that one of the most important aspects of a child's development lies within the child's interest in his or her surroundings. The environment we are in inevitably affects our moods, our ability to learn and communicate, and can even contribute to our health and well-being. Strong-Wilson and Ellis (2007) contend that children's experiences are often limited by their surroundings, discussing their environment as having a crucial impact upon brain development. Although AS individuals are not cognitively impaired, an inclusive environment is key and can only be administered in education if an understanding of the condition is provided by practitioners. Factors such as noise levels, lighting and pupil seating arrangements could all be things that are overlooked by teaching professionals, but such little things could be essential to the comfort and learning of those placed within the autistic spectrum. The work of Lippman (2010) discusses the relationship between a learner and the environment, stating that when the environment is 'active' it is 'dynamic and reciprocal'. In order to provide an active environment we must see what environments engage each learner. Lippman (2010) highlights the essential debates that surround education and environment, posing the question 'should the individual adapt to the environment, or should the environment adapt to the individual?' (2010). Due to the newly adapted philosophy of person-centred planning, which is key to 21<sup>st</sup> century

service provision, the choice to adapt the environment around the individual would appear to be the favourable approach. However, Lippman (2010) questions this ideology, suggesting that the question we should be really asking is 'how does the environment shape the learner, and how does the learner influence the environment?'. Lippmans work recognises that both facets should be considered, and in order to achieve this we must try to understand the learner and their emotional and social needs at the time, but again this method will only prove effective if there is a good level of understanding regarding ASDs. Although it may sound difficult to adapt specific environments when there is a range of students with differing learning needs, these environmental adaptations are essential to help those on the autistic spectrum to continuously engage, socialise and develop. Often an alternative environment can prove beneficial and should be offered, so that a child experiencing sensory issues can take time out before returning to the main learning environment.

Education can contribute to the sets of milestones and cultural expectations that individuals are thought to reach; Barret (1977) states that

From the first moments of a child's life, a child is rated in terms of success or failure according to the criteria adopted by the society in which it is born.

(1977: 1)

Such expectations can be damaging to those who do not succeed or progress in the desired cultural or societal way, bringing feelings of low self-esteem or self-worth. As Rosaler (1997) notes, the associated 'symptoms' of AS can contribute to the misunderstanding and understatement of a

person's ability, and this can in turn deny them the opportunity to learn and progress.

As this section considers, those with AS may require additional support and understanding in both education and employment settings. The National Autistic Society (NAS) also makes claims addressing the concern for education being amongst the top concerns for parents; they state that 'under the current system too many children with autism are not accessing the support they need at school to thrive in later life' (NAS 2014). By providing such support and understanding the individual with AS should have less chance of being excluded, giving a greater chance that the potential of that particular individual can be met.

#### **4.4. Understanding language**

The accent, structure and sometimes the tone of our sentences are peculiar to particular societies, cultures and individuals; however, the specific languages used within cultures determine the words we use to describe things. The use of language is always evolving, introducing new words, shorter words, abbreviations, similes and metaphors, and often what we say is not what the language used was designed to describe. The work of Wing (1988) suggests that thinking and behaving flexibly is an area of difficulty for those on the autistic spectrum, creating difficulty understanding the order and meanings of words. McCabe (2003) describes words as 'pictures, connections of understanding, peace and direction'. If the words are used out of context, understanding, peace and direction could therefore be impaired. An example of the way words are used to describe something else would be the idiom 'it's raining cats and dogs outside' – some people

would interpret this as heavy rain, but for a person who is unable to think flexibly this sentence could be taken in its literal sense. Any inability to interpret these words in a different context is problematic, and increasingly so due to the developing nature of language. So the context of words would naturally be among the structures that contribute to the difficulties faced by autistic individuals. The inability to use words in other ways can also have a significant impact on social situations, and can result in avoidance as a coping strategy. AS is not a physical disability it can often be difficult for others to recognise, and therefore difficult for them to be mindful of the language they use.

In a theory developed by Locke, titled 'The Theory of Universal Knowledge', it is suggested that thinking must be flexible in order to gain understanding of things of any complexity:

Because of the limited scopes of our minds, we are unable to understand perfectly even things which are only slightly complex unless we can consider these things part by part or with respect to their different aspects.

(Ayers 1991 242)

Discussing this theory in regards to the exceptional ability sometimes present within autistic individuals (although not all), some individuals demonstrate understanding of extremely complex issues that prove difficult for most people to understand, such as mathematical puzzles. However, the stories of gifted autistic people, especially in Asperger Syndrome, can often be damaging to those diagnosed as they can spend forever searching or wondering what their extraordinary, unique talent or ability is.

Somewhat linked to the concept of inflexible thinking is the notion of truthfulness. A characteristic of AS is 'the inability to lie', i.e. being honest all the time, which may lead to unintentionally hurting the feelings of others, for example commenting frankly on the personal appearance of someone else. The notion of truth taking precedence over other people's feelings is considered to be the hierarchy that coincides with debates surrounding empathy dysfunctions. However, explicit cultural values passed on by parents and schools usually advocate truthfulness; this could suggest that the implicit cultural values have shifted over time to favour feelings over facts.

#### **4.5. Conclusion**

Although a number of characteristics of AS have been mentioned in detail there are also additional characteristics in which this thesis may have not yet addressed. These include; clumsiness, anxiety, depression, and sensory difficulties.

The work of Ghaziuddin et al (1992) recognises how clumsiness is generally associated with Asperger syndrome, however claims that this area is under researched. Additionally, this research identifies the difficulty in defining clumsiness suggesting 'an operational definition of clumsiness should be adopted and standardized tests used for its assessment' (1992; 655). Writings produced by Attwood (1988) highlights the impact of clumsiness on individual lives alongside the ongoing confusion in regards to motor clumsiness becoming a diagnostic factor.

Mental health issues such as anxiety and depression can be experienced by any individual at any given time statistics provided by the mental health foundation (2015) highlight that One in four people in the UK will experience a mental health problem in any given year. It is however suggested that individuals with a diagnosis of AS are particularly vulnerable to the discussed mental health problems such as anxiety and depression ([saspergersyndrome.org](http://saspergersyndrome.org)).

The area of sensory difficulties is also one that is largely discussed in regards to AS evidenced within the work of; Smith and Myles (2000), Bogdashina (2015) and Heffernan (2016). The National Autistic Society also recognise the impact of sensory issues for those with Autism spectrum disorders, claiming senses can be under sensitive as well as over sensitive.

There may also be additional characteristics that have not been noted, but the combination and relative intensity of these characteristics are all unique to each individual. As we can see, this chapter discusses the characteristics thought to be associated with AS, briefly mentioning the ways that these may impact upon individual life. In reflection we can see that the characteristics alone may cause difficulty, but when paired with cultural expectations and interpretations can become considerably excluding. Within the work of Straus (2010) discussions regarding autism as a social construction opposed to a medical pathology are present, stating that 'people labelled as autistic comprise a definable minority group'. This work goes on to discuss autism not as a 'defect' or 'pathology' but as an aspect of inherently desirable human variability.

The language used to define and discuss AS is an essential contributor to modern cultural understandings and interpretations. As the introduction of this chapter highlights, those diagnosed as autistic are believed to possess a 'triad of impairments'. Jordan and Jones (2001) advise that the term 'triad of impairments' would be better characterised as 'difference', proposing that the removal of the term 'impairment' would be essential in promoting greater inclusion. However, it must be acknowledged that by changing the terminology there is no guarantee of increasing inclusion, and even the interpretation of the term 'difference' will inevitably vary among groups, cultures and individuals. This is particularly true of a 'social constructionist' approach recognised by Armstrong where it is thought 'social objects' are constructed through perceptions (1994: 22). It is essential to recognise that the term 'impairment' it is one word that can have different meanings depending on the way in which it is interpreted, for example Goodley considers the term impairment as 'a medical and psychological problem to be eradicated or rehabilitated' (2001: 209), whereas Mesibov (2001) comprehends impairment as a term that does not suggest an absence in skill or behaviour, rather that factors are 'limited' or 'unusual' when compared to those of 'typical' people (2001: 27).

It is the cultural understandings at a specific time that determine the exact nature of such terms, although there is never one precise cultural definition at any one time. Although various terms are used to define the same syndrome, different cultural and societal perceptions will bear their own sets of assumptions. Reflected within literature by Stanford, misunderstandings of AS are often present because, he claims, 'many people still don't know about AS since knowledge of it has not permeated far enough for many doctors let alone the general population' (2003: 25).

Discussions of AS as a 'hidden disability' are found within a vast range of literature, including Goodley (2001), Vasil (2002) and Walz (2005). The lack of a sole definition and cause for this 'disorder' could thus contribute to the limited understanding and continuing misconceptions regarding the characteristics, and therefore to the difficulties faced by people in certain areas. The NAS also makes reference to AS as a 'hidden disability', proposing that there is an inability to recognise the disorder from outward appearances (NAS 2014). Peers (2003) uses a metaphorical description, 'AS is like a cat hiding behind the bushes, often hard to detect', to highlight the limited visibility of this disorder. Disability studies activists and scholars talk a lot about visibility, which concerns them because even at the dawn of this brave new millennium disabled people aren't very visible in our culture (Brueggemann et al. 2001). A preliminary report carried out in 2008 by the Disability Members Council suggested that hidden disabilities were being overlooked (Brooks et al. 2000). Differences that are not seen at first glance are not always understood, which can in turn ignite fear or ignorance, as people often fear things that they have little understanding of and that are not physically visible. Considering this idea of fear and ignorance being ignited by the unknown, the multitude of terms and definitions used to define AS would inevitably impact on the ways the disorder is perceived.

## **Chapter 5 – A Methodological and Reflective Account:**

### **Exploring Life Histories of Adults Diagnosed With Asperger**

#### **Syndrome**

#### **Introduction**

If we locate disability in the person, then we maintain a disabling status quo. In contrast, by viewing disability as a cultural and political phenomenon, we ask serious questions about the social world. Undoubtedly, societies subject people with impairments to discrimination. Disabled people have been hated, made exotic, pitied, patronised and ignored. Disability also evokes admiration, curiosity, fascination and sympathy. Disability studies respond to these acts of political and cultural life.

(Goodley 2011: xi)

The work of Macdonald (2006: 85) highlights the rise of disability studies and the growing encouragement of disabled people's subjectivities. As writing by Oliver (1992; 1996), and Barnes et al. (1999) suggests, these subjectivities can contribute to the broader understanding of disability from a disabled person's perspective. Research conducted by Barnes and Sheldon (2007) recognises how in the past disability research has often been dominated by medical and academic interests. Within their discussions they propose that this type of domination is often thought of as 'objective'. The adoption of a *subjective* approach, this study aims to represent individual experiences of AS using a social model approach,

whereby disability is not seen as intrinsic but created by societal and cultural phenomena. The idea of culture is central to this thesis this work is based upon ideas by a number of academics such: as Dan Goodley, Nick Watson and Tom Campbell. In relation to Campbell's (2011) work regarding dyslexia it is suggested that a particular set of characteristics have become problematized by the new concern of medical professionals in the late ninetieth century' although the time periods differ between AS and dyslexia the same principles apply. This study aims to recognise the impact of these socially constructed terms upon the individual participants.

The concept of 'voice' is fundamental to this study, and therefore the research design has been developed to enable individuals to have choice and control over the way in which their own stories are told. Such design aims to include individuals in research about their lives, but in which they are often ignored. Oliver (1992) discusses disability research as an alienating experience for disabled people, and as something that is done *to* them, over which they have no control. This study wishes move away from such inequality of power and aims to build a study that incorporates the values of emancipatory research. The work of Oliver (1992) also discusses emancipatory research as a new paradigm for undertaking research, stating:

The issue then for the emancipatory research paradigm is not how to empower people but, once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their

knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose.

(Oliver 1992: 111)

### **5.1. The social model as a theoretical framework**

As demonstrated throughout this thesis, a social model approach is adopted within this methodology, and this model largely influences the way in which this study is conducted and analysed. A reminder of the fundamental terms regarding disability will be beneficial at this point in order to remember the way in which disability and impairment are interpreted. Impairment is defined as a form of biological, cognitive, sensory or psychological difference, often within a medical context, and disability is the negative social reactions to those differences (Sherry 2007: 10). Goodley (2011) recognises that even 'impairment' is also a cultural concept, stating that 'the meaning and experience of impairment morph over time, not simply because of "scientific thinking" around the body and mind but often because of changes in social policy, government guidelines and social policy' (2011: 08). The reason that the social model is implemented within this research is due to the momentous effect that it has in facilitating empowerment of individuals. It recognises the effects of society in disabling individuals, shifting any 'problems' away from the individuals and onto society. Although this methodology aims to explore more than just the 'barriers' that exist, the subject of those barriers does provide an essential backdrop for developing inclusive research that promotes acceptance and understanding. Building on the social model, Swain and French (2000) developed a framework which they called the 'affirmative model'. These ideas were a product of the 'disability arts' movement, whereby disabled individuals told both individual

and collective stories with their own voice, which in turn allowed them to develop a sense of disability pride this model was later developed by Colin Cameron. 'The affirmative model is born of disabled people's experiences as valid individuals, as determining their own lifestyles culture and identity' (Rix et al. 2010). This particular model moves away from the tragic view of disability, recognising that disability is often shaped by more than negative perceptions. The methodology adopted by this study, although fundamentally grounded in the social model of disability, also adopts concepts of the affirmative model, such as acceptance and pride.

## **5.2. Research aims**

The overarching aim of this study is to explore individual experiences of adults diagnosed with Asperger Syndrome. This research aim was developed to give a voice to the individuals within the study in order to discuss areas they feel are important to them. The study is unique in the sense that it prides itself on the choice, control and respect given to the participants. The question which is asked allows for individuals to obtain full control over the subjects that are discussed, as well as the context in which they are discussed. This particular aim proposes to contribute to the large amount of missing literature regarding adults, both male and female, diagnosed with AS.

This study also aims to:

- Identify the impact of the term 'Asperger Syndrome' and explore how this can aid perceptions and reactions towards individuals

- Explore the culture that surrounds societal and individual perceptions of Asperger Syndrome
- Examine pre- and post-diagnosis accounts in order to assess the effect of the label on individuals
- Recognise the role of the 'norm' in regards to pre-labelling accounts
- Identify and highlight barriers faced by individuals using a social model approach
- Recognise how perceptions of AS impact upon home, education and employment.

### **5.3. Qualitative research techniques**

The choice to employ a qualitative research approach was imperative in order to meet the aims and objectives of this study, and essential in order to aid the contribution that this thesis intends to make to research in this particular field. One of the key reasons for choosing this approach was due to the in-depth exploration of subjects that it allows for. Merriam proposes that;

Qualitative Researchers are interested in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences.

(2009: 5)

This qualitative approach was also chosen to empower individuals by giving them a voice; Jackson et al. (2012) state that 'disabled people have often struggled to have their voices heard'. The concept of empowerment is

crucial – Swain et al. 2003 and emphasises the role of empowerment within disability research, proposing that without empowerment research cannot be emancipatory. Additionally, their work recognises the need for meaningful data that will impact upon the lives of disabled people in a practical manner. This research aims to impact not only on Asperger-diagnosed individuals but also on the wider community by providing a greater insight and understanding of AS and the individual impacts of its diagnosis. Thomas et al. (2004) recognise that qualitative research has become increasingly respected and popular amongst health care researchers, suggesting that this was not always the case. Creswell (2014) highlight that it was in fact a *quantitative* approach that dominated the forms of research from the late 19<sup>th</sup> century up until the middle 20<sup>th</sup> century. Recent years have led us to recognise that qualitative data in disability studies is important as it provides data that goes beyond statistics and numbers. 'From the late nineteenth century and throughout the twentieth century qualitative research methods developed, diversified and became more widely adopted across the social sciences' (Ritchie et al. 2013). There are a number of different approaches that can be used within qualitative research, as this type of research is not based on a unified theoretical and methodological concept (Flick 2002). As a consequence of this development, a wide range of methods are now available for this type of qualitative research, and this range means this approach can be easily tailored to fit a number of research aims and objectives.

It is important to recognise that there is no single, accepted way of doing qualitative research. Indeed, how researchers carry it out depends upon a range of factors including: their beliefs about the nature of the social world and what can be known about it (ontology), the nature of knowledge and how it can be acquired (epistemology), the purpose(s) and goals of the

research, the characteristics of the research participants, the audience for the research, the funders of the research, and the position and environment of the researchers themselves.(Ritchie et al, 2013)

#### **5.4. Biographical research methods**

The particular type of methodological approach adopted within this study is a biographical narrative approach. This approach allows for life stories to be researched in regards to autism and the cultural ideologies that shape and define its existence. The work of Roberts, an influential writer within the field of biographical methods, provides the following definition:

Biographical research is an exciting, stimulating and fast-moving field which seeks to understand the changing experiences and outlooks on individuals and daily life, what they see as important, and how to provide interpretations of the accounts they give of their past, present and future.

(2002: 1)

Macdonald (2006) recognises the control given to disabled individuals through the employment of biographical research methods, and claims that biographical narratives recognise the importance of the individuals' own understanding, within both a social and historical context. The use of narratives as the type of biographical research method was chosen because it allows for the participants to narrate their own story, giving them control over what they wish to disclose. Smith and Sparkes (2007) propose that 'narratives may be our best hope of capturing structures that continue to shape, divide and separate human beings'. Disability studies values

peoples first-hand narrations, and many view these accounts as credible and accountable (Shah and Priestley, 2011). Using life histories is not uncommon within social sciences, as the work of a number of academics demonstrate (Booth and Booth 1998; Chamberlane et al. 2000; Miller 2000; Macdonald 2009; Björnsdóttir 2010).

With regard to autism, and more specifically Asperger Syndrome, it proves difficult to find a comprehensive study that uses the narratives of only those with autism. A number of studies include parents and health care practitioners, although such studies may produce meaningful data it could be argued that their approach will not be truly representative of the individuals' experience as it does not reflect a reality of which they are the sole owners. The lack of studies based on individual narratives could be a result of the existing ideas and preconceptions that exist about those with autism narrating their own story; it is believed that people with autism may lack the ability to narrate their own stories, and this is an area that has been ignored within the social model of disability (DSR: 2000: 537). Breakey (2006) recognises that the exclusion of disabled people from this particular debate may be due to the nature of their condition and the ideas that exist around their neurological patterns, discussing the ideas that exist around parents and professionals 'knowing best'. They go on to state that 'whatever the reason, things are now changing and autistic people are asserting themselves and joining the debate' (2006: 26).

The research design and methods used within this study may differ from the typical study into this area as it allows for a wide range of choice and flexibility to ensure all barriers are removed. The work of Harding (2006) states that, 'in narrative interviews, it seems the idea of a strict chronological ordering of events is much less important than the events

selected and their biographical significance'. Within this study too, the chronological ordering of events is of less importance than the experience of the events, and the individuals are free to discuss experiences in any order preferred. All biographical research is said to be qualitative (Miller 2000) and therefore a range of qualitative approaches can be used to collect an individual's story regarding their life 'with' Asperger Syndrome, so the use of interviews was chosen in order to obtain the biographical narratives. Alongside interviews, a popular approach to gathering qualitative data in disability studies is focus groups. Although this type of research is commonly used within Disability Studies they were not a good fit with the particular focus of this study, which is to allow individuals to provide their own narrative and to allow for in-depth exploration. Hansen and Machin (1998:123) recognises the advantages of focus groups, but suggests that they do not allow for in-depth exploration. Interviews were chosen because they allow for collection of information: 'Interviews collect information about the ways that people understand the events and experiences of their lives' (Grbich 1995: 85). Interviews can be seen as a flexible method of data collection and can be suited to a wide range of projects and research methodologies (Hansen Machin (1998:95).

## **5.5. Interviewing**

Interviews can be conducted in a number of ways; they can use open and closed questioning, and they can be structured, semi-structured or unstructured. The interview style used in this study employed an open-ended question in order to produce a biographical narrative: 'can you tell me about your life with Asperger Syndrome?' The question itself was enough to generate data regarding the preferred terms. The question was

also designed by participants prior to conducting the research, in order to ensure they were free to discuss any areas relevant to them and were not restricted by a particular question.

The study adopted a semi-structured approach to interviewing to allow flexibility for the participants. Often semi-structured and unstructured interviews can be referred to collectively as 'in-depth interviews' (Bryman 2008: 438), and both semi-structured and unstructured interviews are the types used most often within qualitative research (Sarantakos 2005); this may be due to the degree of adaptability they allow while interviews are being conducted. Semi-structured interviews are interviews where questions can be asked in different ways and at different points, and can also be elaborated on throughout the interview. Although this type of interview allows this flexibility, the way in which each question is asked will remain the same amongst all participants. However, the particular methods used to answer the questions may differ between individuals.

The question asked to the participants was an open-ended question: 'can you tell me about your life with Asperger Syndrome?' Although all participants were asked the same question, the methods they chose to use to answer the question were solely down to them. Individuals used a mixture of the approaches to answer the question, and these were devised by the individual themselves, as these are their stories and should therefore be told in a way that is most comfortable for them. The approaches to answering were as follows: answered the question by talking or writing whatever was important to them, while the interviewer had a limited role; devising a list of points that they asked the interviewer to prompt them on; having a set of questions for the interviewer to ask; an informal style where they had points to discuss and the interviewer asked questions about these

points. Although this is an inconsistent approach to interviewing, this method demonstrates the individualistic and inclusive approach. Additionally, different individuals will naturally have different ways of telling their stories. Reflecting back on the literature regarding Asperger Syndrome, it could be recognised within the literature regarding AS that people may need structure *and* flexibility in their activities, but it is also suggested that such individuals can have difficulty in regards to structure; the work of Stoddart discusses that such difficulties can be observed when carrying out tests such as the 'Thematic Application Task', which is a type of mental health test. Stoddart's work claims that individuals with ASD 'have difficulty projecting back in time or organising thought' (Stoddart 2005: 220). Out of the ten participants, only two chose to answer the questions in a logical order by implementing bullet points, and still they moved beyond their original points and added to their lists. As a practitioner within the field of ASD, and a social researcher, I observed no difficulties from the participants reflecting back in time, although this is not to suggest that it was not present.

However, as demonstrated within the findings of this thesis, not all literature regarding AS is reflective of the needs or wishes of the individuals concerned, so within this study a choice has been offered to ensure structure can be implemented if required, even though adopting a structured approach would have been less suitable for this study due to the need for predetermined questions, as 'Predetermined questions may not allow you to access participants' perspectives and understandings of the world (Merriam and Tisdell 2009: 109)

Interviews can be conducted in a number of ways – face-to-face, by email or over the telephone, and with recent advances a range of social media

can also be used for interviews. The interviews in this study were carried out in the way that was best suited to each individual. A range of choices was offered, including face-to-face, telephone, email, skype, social media or any alternative form of communication preferred.

The literature surrounding AS suggests that individuals have difficulty with face-to-face communication. However, using concepts developed from a social model approach this study offered all choices for the way interviews would be carried out, moving away from the stereotypical assumptions that are the result of medical discourse. Doing so proved beneficial, as six out of the ten interviews conducted were face-to-face. Out of the four participants who did not choose face-to-face interviews, three stated that face-to-face would have been the preferred choice had personal circumstances not arisen. The methods used in this research demonstrate that if research design was developed purely based on existing literature then this research would not have been emancipatory. Allowing research to be conducted in the preferred way for each individual could be seen to promote power, choice and control. The idea of moving away from the medical literature and consulting individuals prior to decision making is a process that should be adopted in wider disability research.

The main consideration for both semi-structured interviews and focus groups is that the interviewees feel comfortable in the space they are in. (Clifford et al. 2016: 110). In order to allow the participants to feel comfortable, a choice of venue was offered to the participants. Four out of the six face-to-face interviewees chose to meet within a public area. There were rooms within the university setting, and money available for room booking, and these things were explained to the participants. The time and date of the interviews were also chosen by the individuals. Prior to the

interviews I had met with the participants, or spoken to them in their preferred communication method, to ensure that they were aware of the interview process and that their involvement with this project was their own choice. We also discussed any queries or concerns. Throughout the processes of obtaining participants and explaining research aims, I never discussed a rationale or a hypothesis, or any ideas or views I may already have regarding this subject as I wanted the study to move away from the researcher's involvement.

## **5.6. Sampling**

Sarantakos (2005: 152) suggests 'Sampling enables the researcher to study a relatively small part of the target population, and yet obtain data that is representative of them all'. Although this study only targets a small amount of individuals it does not aim to be representative of the whole population. It does however aim to give a voice to particular individuals who wish to discuss their experiences, with the aim of educating society about life with a diagnosis of AS. As reflected within the literature identified by this study, the characteristics that are labelled as 'Asperger Syndrome' can be present within any sex; however, as the National Autistic Society recognises, autism is more prevalent in males than females. Fombonne (1999) recognises that the disparity in diagnoses of males compared to females is even greater with regard to the specific diagnoses of AS and high-functioning autism, claiming that the proportion of males to females diagnosed can reach as high as 10:1. As discussed further within the later Analysis chapters of this thesis, this is arguably due to a lack of diagnosis in females. But due to autism being present within both genders, the sample needed to be reflective of this by providing an equal number of both males

and females. The sample size of this study was kept to a minimum of 10 participants to ensure that that in-depth analysis can be carried out. This study includes five females and five males to ensure equality between the sexes. Currently it proves difficult to find an exact number of individuals within the UK who are diagnosed with Asperger Syndrome, but the National Autistic Society state that over 70,000 people are diagnosed with autism, and this figure includes those with a diagnosis of Asperger Syndrome.

Prior to designing and carrying out this research I was involved with some local groups that supported adults with Asperger Syndrome. Within these groups the notion of not being heard was a recurring theme, and therefore when carrying out the study I was confident that a number of participants would want to be involved. Within a group meeting I attended, a discussion regarding participant observation had taken place, and a number of individuals agreed that seeking participants through advertising was rude and oppressive. Therefore a 'snowballing' approach was used to obtain other participants. This approach requires the researcher to make contact with a small group of people who are relevant to the research, and they are then used to establish contact with others (Bryman 2008).

My attendance of these groups prior to planning or carrying out research proved beneficial, as people could recognise that my motive for carrying out the research was solely to give a voice to the unheard. Additionally, I had built up trust with the participants, and research conducted by O'Leary (2005) recognises how trust is reliant on recognising the power structures between the researcher and the researched, stating that

building trust is reliant on recognizing the power and privileges associated with your own attributes and

working to minimise any real or perceived power differential between you and the researched' (2005: 66)

Attending these groups also allowed me to learn the preferred terminology, as well as gain tips on researching individuals' life experiences, as this can often be deemed as personal

### **5.7. Data analysis**

Analysis is laid on the foundations of our understanding about how the world works, what makes it what it is (ontology), and how we, as human beings can understand and learn about the world and especially about the world of people (epistemology) (Bazeley 2013: 1)

The planning for data analysis is evident throughout the study; for example, the methods chosen and the way in which those methods are carried out contribute to the way in which the data can then be analysed. The analysis of this study was developed to ensure that the biographical narratives were truly represented and that the areas that were important to the participants were addressed, as opposed to the focus being on the researcher's interests. Because the ontological position of this study is concerned with the impact of culture and how others have shaped the way in which disabled individuals see and construct their reality, the analysis must therefore involve individuals' voices in order to better understand the construction of their reality.

The surrounding literature and theoretical position of this study will also impact on how the data will be analysed, by recognising the needs of the individual and considering how this study can be analysed without contributing to the negative and often disabling discourse which could be reflective of the medical model ideology. Before an in-depth analysis could be carried out the transcription of the individual narratives was required. Transcription is referred to as 'more than a technical and clerical task' (Guest and MacQueen 2008), as exactly what is transcribed and the structure of the transcription will inevitably impact upon data analysis. Therefore this study ensured it did not alter what the individual said at all, so that a word-for-word account was provided for analysis. Additionally, field notes were made to ensure that the researcher knew when an individual used sarcasm or a joke, as the context in which the language is spoken is also influential. Bailey (2008: 129) recognises the difficulty in representing human interaction, suggesting that 'It is impossible to represent the full complexity of human interaction on a transcript', and therefore a sensible step would be to listen to the original interview recordings in order to fully understand the data. This is something that this study did throughout the analysis processes in order to fully know the data and truly listen to the individual. The participants in the study were asked if they would like to see their transcripts prior to analysis, however none of participants who carried out verbal interviews (which were not already in a written form) wished to do so. This could be due to the fact that the data contained a lot of information about their experiences, and in most cases the oppression which they had faced at at least one point in their lives. Often reliving such experiences can have an impact upon individuals, and therefore the individuals were told that if they experienced any issues then support services could be put in place. However, no participants needed to access any services as a result of this research, and additionally the individuals were not pressed on any issues

that may cause feelings of upset or anxiety, as the interviews were conducted in the style that each participant chose.

When all the interviews were transcribed they were read and listened to thoroughly a number of times to ensure that a true representation could be provided within the coding stage, which was to follow. Prior to this, all names, dates and places were changed to ensure anonymity when the analysis would be written up. Although all participants agreed to the data prior to analysis being seen by other members of staff, for security the information was stored safely on a hard drive which only the researcher had access to. This was also to ensure that no data could be tampered with and that personal details and accounts that may contain personal information were kept confidential.

When the data was anonymised and organised it was then coded. The aims and objectives of this study were to provide an individual voice and to recognise the impact of culture upon individual experiences, so the data would first be analysed in regards to emerging themes, and codes would then be added. This was done by using a computer program called 'Nvivo'. 'There is a widely held perception that use of a computer helps to ensure rigour in the analysis process' (Bazley and Jackson 2007), however their work also highlights that good analysis skills are also required, as a computer cannot make up for poor workmanship. Although Nvivo has a number of different functions for analysing and coding information (for example searching words and making nodes, which can include recurring themes), the use of hand coding was also included to ensure that no information was left out.

## **Chapter 6 – Analysis and Discussion:**

### **Exploring Narratives Pre- and Post-Diagnosis**

#### **Introduction**

The following chapter will aim to convey individual experiences both pre- and post-diagnosis, taking into account the use of language, discourse and others' perceptions surrounding Asperger Syndrome. The use of labels will be a recurring theme throughout this chapter; Molloy and Vasil (2004) discuss the effect of labels on individuals, claiming that labels can be 'double edged swords', whereby negative or positive perspectives can both be taken. Their work addresses the fact that the implementation of labels can contribute to greater understanding and access to resources, but dichotomises this with the potential for social stigma, which in turn could lead to a devalued identity.

This chapter will commence with participants' accounts of their pre-diagnosis periods, allowing us to explore individual experiences before the specific label of AS was applied, and to recognise alternative labels that may have existed. Pre-diagnostic experiences will also address the reality of the disorder due to the recognition of characteristics in the individuals, by both themselves and others. The study will then move on to look at post-diagnosis, capturing how the participants feel themselves about the diagnosis, and how they feel they are viewed by professionals in regards to the label. This chapter will also discuss in detail how society has

constructed the concept of normality and how this has impacted upon respondents to the research.

### **6.1. Experiences of alternative labeling: pre-diagnostic accounts**

As discussed within the aims of this research, it is clear that individual experiences are at the heart of this study. However, it is vital to recognise that the discussed experiences will include accounts that take place both pre- and post-labelling. Originally this thesis aimed to have a predominant focus on post-labelling accounts; however, it became evident when analysing individual narratives that pre-labelling accounts were also an area of importance for individuals. The significance of such accounts could be backed by the prevalence of late diagnosis within this study – it is apparent that seven out of the ten participants received a diagnosis that occurred above the age of 18 (i.e. in adulthood), and four out of those seven participants were over 40. As the number of late-diagnosed participants highlights, there is a significant amount of time spent undiagnosed for certain individuals, so much so that the proportion of life undiagnosed is greater than that of life diagnosed in some cases. Baron-Cohen (2008: 4) affirms that it is common for a diagnosis of AS to be delayed, claiming that a diagnosis does not usually occur until around the age of 6, but is often much later than this, even in late adulthood.

It becomes evident when analysing the data that additional terms and discourses have been implemented to discuss individuals prior to their diagnosis of AS. Sally's narrative is representative of this, and we can see from her account that she makes a link between her pre-diagnosed experiences and the term 'weirdo'. She recollects others enforcing the

terms 'weirdo' and 'mental' by shouting them at her. The term 'weirdo' is also visible within the narratives of both Alan and Louise. Alan discusses the term 'weird' in connection with AS or 'some other form of autism', and he recognises that his sisters thought he might have been on the autistic spectrum even though he had not been diagnosed; he suggests that this is why 'people shut him in' and classed him as a 'weirdo'. Similarities of the negative use of the term 'weirdo' can also be found within the narrative of Louise, the term 'weird' being used to describe her by her mother:

She said 'I don't know, you're just different you're weird', she wasn't very nice, she didn't say very nice things and I didn't have very much self-esteem  
(Louise)

As demonstrated above, Louise notes that she has low self-esteem, and inevitably this can be linked to the use of negative labels. Research conducted by Krueger and Trussoni (2005) identifies that labels do not only have a sociological effect but a psychological one too. They assert that 'People who are labelled negatively by their peers tend to be more depressed, have a lower self-esteem, and have an external locus of control'. Writings by Emler (2001) discuss the concept of self-esteem as a basis for explaining people's own difficulties and others' failings. The following literature aims to highlight the consequence of negative labels upon individuals. Griffen and Bone (2016) specifically discuss this subject by debating ideas of self-concept in regards to labelling. They conclude that others (including family members) contribute to the shaping of the individual, additionally recognising the importance of the implemented labels. Referring back to Louise's account we can also see that she perceives others as viewing her as 'weird' – although she does not

specifically state that they use the term, she makes a link to the negative discourse provided and the term implemented by her mother:

His parents were horrible to me, they thought I was weird, they kept on saying to me, his Mum used to say to me 'When are you going to leave my son, cause he can do so much better than you', I had no self-esteem  
(Louise )

In relation to the social model of disability this could be viewed as a disabling barrier, where others' perceptions and attitudes are disabling to an individual. Rubin and Langue identify this as 'the most elusive of all barriers, negative attitudes, because they cannot be legislated out of existence' (1982: 28).

Within the accounts of Louise we can see that the notion of difference is clearly present, for example her mother questioned her normality by asking

'Why can't you be normal like other girls?'

As previous chapters highlight, to be 'normal' is to be like to the majority of society, possessing similar characteristics, attitudes etc. Often within disability studies the word 'normal' is discussed in regards to 'normalisation'. Morgan and Morgan proclaim that the process of normalisation is 'reliant upon changes in political and economic structures taking place which are far beyond the control of the individual' (1996: 37). 'Davis (1995) argues that the "normal individual" ("and the counterpart the feeble-minded, parasitic and morally questionable") is part of the history of

modernist progress, industrialisation and the ideological consolidation of the power of the bourgeois” (Davis 1995, cited in Goodley 2011: 70). The preceding statement could be seen to suggest that normality has been socially constructed, with societal development playing a dominant role. The ideas found in the work of Mitchell (2004) identify that normalisation is part of a discourse predicated on the normal/abnormal distinction. Wolfensberger (1994) suggests that this distinction is real rather than socially constructed. (Wolfensberger 1994, cited in Oliver 1999). Although the arguments and debates surrounding social construction and reality are fundamental to this thesis, the focus must be taken back to the individual experience. As recognised above, the term ‘weird’ was a term directly used by others in conjunction with ‘difference’ and ‘abnormality’.

Although previous discussions have recognised ‘difference’ from other people’s perspectives, it must also be noted that individual recognitions of their own ‘difference’ were also evident within particular narratives. Laura uses the term in terms of her own self-perception, stating:

I always knew I was different. I was very quiet as a child and was always described as shy. I would just stare at things I didn't understand, including people.

(Laura)

Jayne provides a comparable account, discussing how she was seen as different because she did not socialise. She also suggests that, had an earlier diagnosis been made, she may have had a reason for her differences:

I was seen as different because I didn't socialise and I don't know if the diagnosis would have made a

difference earlier in life where it would have been acknowledged that there was perhaps reasons why I was slightly different.

(Jayne)

The latter experiences both recognise the concept of 'difference' in relation to social interaction; it was recognised by Laura that she was 'shy', 'quiet' and 'didn't understand people', Jayne also discusses how she didn't socialise. It is well documented within the literature of this study that difficulty with social interaction is among the key diagnostic criteria of AS and these accounts would suggest that social interaction, regardless of the label imposed, is an area of difficulty for those with AS. However, cultural ideas of social interaction may have been different in the past, i.e. in a pre-industrial society where people often lived in farms and small village.

Referring back to discussions of difference, we have seen that difference is recognised by the individual themselves, but this idea of difference can still have been culturally produced. In an account provided by Louise the traumatic effects of not knowing why she was different are noted:

I had two suicide attempts as a teenager, I wouldn't say they were serious ones I think I was trying to say I need help cause I did not know what was wrong with me, in my head all of the time I was saying why am I different? Why is everything so hard? You know why don't I have a group of friends? Why I am not really accepted.

The discourse of 'difference' having a subtext of 'less value' is discussed in the work of Smith and Pandolfo (2013), whose work notes that discursive practices and 'biotechnico power' are responsible factors. They state:

It is through the analysis of biotechnico power that we suggest that all 'labels' be it handicapped, disabled, normal or a person of difference, are statements, which relate to practices that form the object of 'what' they speak. The labels and practices set people apart and assist in perpetuating the oppression of all'.

Foucault defines one of the elements of biotechnico power as a system where 'certain actions modify others' (1989: 219), and the work of Smith and Pandolfo (2013) discuss this in regards to self-image. Their work also addresses the impact that community has on the construction of disability, additionally recognising the concepts that keep community in place, suggesting that 'community is kept in place at all levels by a set of structures such as institutions and official agents such as self, family and professions'. Foucault's work recognises that the discussed structures 'use discourse more or less consciously as a manifestation of power' (Foucault 1982: 222). The concept of power is clearly visible within the previously discussed accounts of 'difference', especially in the account provided by Louise. As the historical chapters have delineated, those who possessed 'difference' were once regarded as powerless and often grouped and categorised by others, and this is especially true in cases of institutionalisation. In retrospect of historical ideologies regarding autism, a link between the characteristics of autism and mental health is provided by Sally:

They just thought it was mental illness and it's not.

(Sally)

We can see that the term 'mental illness' was used alongside 'weird' to describe her by others, and this contributes to the discussions in Chapter 2 regarding the characteristics of autism as descriptions of 'madness' as well as 'idiocy'.

## **6.2. Pre-diagnostic experiences of bullying and loneliness in school**

Within this study it becomes evident that the concepts of bullying and loneliness are mentioned in a number of cases. The discussed cases highlight the experience during the school years prior to a specific diagnosis of AS.

Within the research conducted by Dodd (2005) it is recognised how the unique characteristics of autism place both autistic children and adults at a high risk of being bullied. The National Autistic Society (NAS) conducted a study in 2006 titled 'Make School Make Sense', which looked at experiences of autistic children in school. The study proposed that two in five children with autism were subjected to bullying. However, the figures are believed to be higher for AS children, with three in five children believed to have encountered bullying. The discussed report suggests that data in this specific area could be underestimated, proposing that over 90 percent of parents with AS children believe that their children have been subjected to bullying within the past year. Research conducted by Heinrichs and Myles (2003) could be seen to support such claims regarding bullying, their work proposing that bullying amongst AS children and youths has reached epidemic proportions nationwide.

Anne notes how she was subject to bullying, and goes on to discuss how she was expelled for retaliating to the bullies and sent to a special school. Sally was also sent to a special school, and her accounts also delineate this as a negative experience. However, this was after her diagnosis therefore will be discussed further in additional sections.

I was bullied a lot at school, and eventually expelled for hitting one of the bullies, and sent to a special school. Special school was a miserable experience.

(Participant 3F)

The work of Baker and Welkowitz (2005) highlights how the discussed children need protection from bullying, and greater protection could help minimise expulsions by providing alternative options to help the child overcome such abuse. The 2006 NAS claims that one in four AS children have been expelled from school, and this statistic generates many questions regarding the support networks presently available for the discussed children. Wylie (2014) suggests that these particular children get into trouble both at home and school due to the inability for parents and professionals to recognise that these children are not necessarily being naughty wilfully. Thomas also recollects how the bullying made him more reserved. He discusses how the bullying was not physical and could have been much worse, but this does not condone these tragic events. His account recognises how he saw his home as a safe environment away from such abuse:

So I guess that, despite having to put up with some bullying from some of the more troublesome pupils which did bother me to a point and make me even more reserved, it was a good thing that I was such a

'teacher's pet'. The bullying was only usually verbal (name-calling and such) and never much more than that, so it could have been worse. I knew at the end of each school day, I could go home and get away from everyone again, back in the comfort of family surroundings, where I knew I was gonna be perfectly safe and relaxed.

(Thomas)

Alan also highlights how he was subjected to bullying and reveals the techniques he used to minimise the bullying:

I was subject to bullying and I learned to eat fast [be]cause once you have your dinner at school you need to rush to get to a particular safe haven from those who were going to attack you.

(Alan)

The work of Hull recognises the need for coping skills that help minimise bullying, such as the previous example by Alan where he 'rushes to get to a safe haven'. Hull states:

I am a firm believer that every child or adolescent who is being bullied needs coping skills to be empowered to fight back if needed, to be able to get to safety, to know where to go for help and how to get help and to be given assistance in repairing the emotional damage that accompanies any form of bullying.

(Hull 2011: 90)

Heinrichs and Myles (2003) claim that there is an astonishingly limited amount of literature covering the area of AS and bullying. Limited research and literature will inevitably impact upon the intervention strategies that can be developed to help AS individuals. The account of Paul differs from the previous accounts as it was *him* who was coined as a 'bully', although in his account it appears that he was actually being bullied himself. He discusses how he encountered physical abuse and demonstrates how he retaliated:

I was called a bully once. This is early year one. So that's pretty little kid then. I was called a bully by these kids in the class and I still don't think I bullied them. I remember they were like on this hill. We'd got like a field. And these kids were like pulling us down and like teasing us, like pulling my leg and that and tripping us. I can't remember how it stopped, but I was like pushing them. I really wasn't being vicious or anything.

(Paul)

It is evident that bullying to any child, regardless of disability, can be harmful, and bullying makes children lonely, unhappy and frightened (Dosani 2008: xiv). It appears that bullying has impacted upon participants Anne and Paul, both accounts highlighting that they had been punished as a consequence of bullying. Anne was sent away to a special school and Paul discusses how he was made to read a book on bullying. Although these punishments are on totally different scales, the one thing they have in common is the inability from the learning provider to effectively understand the children and the reasons for their retaliation. It is in these particular instances where the idea of labelling could be seen as beneficial in regards to providing greater understanding of the child. The work of Attwood

recognises how not having friends can contribute to a child being teased and bullied, stating that

Being isolated and not having friends also make the child vulnerable to being teased and bullied. The 'predators' at school target someone who is alone, vulnerable and less likely to be protected by peers.

(2007: 62)

The work of Pyles (2002) also suggests that it is hard for children to make or keep friends if they are socially 'awkward'. This difficulty in making friends is addressed by Sally where she discusses how she struggled to get on with groups and found the opposite sex easier to get on with. She recollects that it was difficult because she never knew what AS was, suggesting that the label may have been beneficial at that particular life stage.

When I was at school, mainstream school, when I was just a small child I couldn't really get on with the other groups, I mean I got on with the boys slightly better than the girls cause girls can be quite catty and it was just really difficult because I didn't know what Asperger's was then.

(Sally)

Although Jayne discusses how she found it hard to make friends, she also claims that she was fortunate as she did have two friends. These friends were present from infant school, and thus had grown up with the participant and may have been more empathetic and understanding of her characteristics.

Yeah. Hard to make friends. I was actually quite fortunate and I did have two friends at school where started at infant school the same day and were friends and are still friends now sort of umpteen years later when we sort of left school and sort of moved on.

(Jane)

The inability to make and keep friends easily can inevitably impact upon how a child feels; if a child does not have many friends they can often feel lonely. Paul goes on to discuss how during specific periods he felt lonely:

There was like a period, year four, you know, very lonely then. There's been a few of those periods. Year five, year six, kind of got back into the gang. Still like not like terribly pursuant of social relationships. I would fall into them. Make friends but not really sustain them or pursue further ones.

(Paul)

Within the narratives of Alan are recollections about how others saw him as a 'loner', although he does not specifically state he was lonely. His previous account, where he described eating his dinner fast to escape, could suggest that he may have been lonely at specific times. He makes a link between these perceptions and being in the school band, and this could suggest the cultural representations that are associated with specific groups.

At school I was seen as a loner erm and I would carry a violin and a bag around at times because I used to... I was in the school orchestra, at that time the only

instruments were the brass so it seemed like I was the violinist in the school band.

(Alan)

AS has often been referred to as a 'hidden disability' whereby it is not always recognised at first glance, with the work of Heinrichs and Myles recognising this and claiming that

Because most children with AS are average to gifted in intelligence and look 'normal' , peers and even adults often have little tolerance for this characteristic manifestation of their disorder.

(2009:6)

This statement recognises how those with AS can be undetected visually, however the characteristics they have are not classified as 'normal' within contemporary society. It is evident throughout these accounts that there is a power hierarchy created between those who conform to social norms and those who do not. Such norms are reflective of the cultures in which they exist, and can also be dependent on specific institutions. This particular section recognises the culture which inevitably exists within the educational setting. Little research has been done regarding pre-diagnostic experiences within the school years for those specifically with AS, but the previous accounts suggest the impact of late diagnosis on individuals with AS. Although this thesis does not advocate the use of medical labels, it appears that without them support and acceptance of 'difference' do not exist, and the cultural attitudes towards those with difference is often negative and oppressive. These attitudes could stem from the historical periods of institutionalisation, when those with 'difference', whether it be intellectual, physical or mental, were removed from society. Our modern society,

although it claims to be moving towards inclusivity, appears to only do this when a label is attached. As the above accounts demonstrate, without a label individuals are looking for an identity – a reason why they are different. It could be argued, however, that all of us are different, and it is what the particular culture defines as an ‘acceptable’ or ‘normal’ level of difference that impacts on the treatment received.

### **6.3. Individual interpretations of the diagnostic label ‘Asperger Syndrome’**

As discussed within the earlier chapters of this thesis, the label AS is often defined from a medical perspective. Malloy and Vasil (2002) identify problems with the medical classificatory approach, claiming that there have been several issues or areas of contention in terms of the diagnosis and evaluation of AS, stating that

the medical model approach to developmental disorders is largely counter-productive; the basis for this criticism being that once children are labelled they tend to be defined by their diagnosis thereby losing their individuality and limiting other people’s expectations of them.

(2002: 60–61)

This previous statement refers directly to the labelling of children, but it is evident from this particular study that diagnosis of AS can be made at any age. The work of Tony Attwood (2007) effectively describes how the recognition of the signs of AS in the media can be the starting point for a diagnosis. This is especially true in regards to the narratives of Jayne and

Dave whereby diagnosis has derived from media sources. AS also continues to make headlines in various news media and has been presented within many cultural narratives including film and literature (Lyons and Fitzgerald 2005: 1). Additionally, the work of Macdonald (2009: 66) suggests that 'individuals with autism have developed their own political understanding owing to the internet'. Jayne addresses how her diagnosis was a consequence of a newspaper article that made a book recommendation, and she discusses how she found similarities in the book with herself, as did her family.

The diagnosis originally came through... I'll rephrase that. I'd read an article in a newspaper and I thought that what was being described within the article was met to a T and it also recommended a book, which I then went on to read. Read the book and everything that was described within the book was me to a T and at that point I got sort of my family to read the book and they said everything that was in the book was again me to a T and at that point I went to see sort of our local GP who said they were happy to refer for a full diagnosis of Asperger's Syndrome knowing that I had dyslexia and dyspraxia, because they thought it would be in line with what we already knew that I had and was then referred for a full diagnosis and it came back as yes. I did have Asperger's Syndrome.

(Jayne)

This account recognises the processes that lead to diagnosis, and how easy it is to identify a set of characteristics that historically many have been labelled as 'mad' or 'idiotic', or in some instances have not been recognised at all. What also proves interesting is the want and need for a diagnosis in

order to explain difference. The work of Wylie claims 'The autistic adult's personal transformation typically begins with feeling different during childhood and continues beyond those dates of self-identification until the individual fully accepts his or her new identity' (Wylie 2001:23). Similarities can also be drawn with Daves narrative, whereby the media representation of AS led to the push for diagnosis. Daves diagnosis was initiated through the characteristics of AS being displayed within the local paper, however prior to this being recognised he knew there was a 'problem', but he states this was during his early thirties. This could be discussed in regards to the normal and abnormal dichotomy created within this specific culture:

So when I got to me early 30s we kept wondering what the problem was and in the end me Mum read a piece in the paper, it was a local paper about Asperger's Syndrome and she showed it to me and she said, do you think you might have that, so I read it properly, some of the things some of the characteristics that that person had there applied to me but others didn't.

(Dave)

This account shows how not all individuals relate to all of the categories specified within AS criteria. Additionally, it reveals the term 'problem' that Dave assigned to himself as a result of not conforming to societal norms. When he realised that he did not fit all of the criteria he discussed the situation with his GP:

so I talked about it with my GP and she said, have you thought about what your Mum said? And I said, yes I've thought about it and she said, your Mum is very supportive but she's not going to be around forever.

The above statement demonstrates the role of the medical profession in assigning labels. The conversation between the GP and Dave could be seen to be suggesting that he obtains a diagnosis to ensure that he receives support in the future. The narrative of Thomas is similar in the respect that it was his mother who suggested the diagnosis of Asperger Syndrome, however the Psychiatrist he was seeing at the time did not believe that this was the correct diagnosis:

my mum even brought up the possibility with my psychiatrist that I might have Asperger's Syndrome, but significantly and clearly very wrongly, he just dismissed it out-of-hand

This lack of recognition was discussed by Rosenham in (1973) with regard to the literature 'being sane in insane places', whereby an experiment carried out suggested that psychiatrists could not correctly differentiate between those who are sane and those who are insane. Thomas claims that his lack of diagnosis denied him valuable support in the year when he was not at university. He discusses the use of anti-depressants during this period; it is evident that a large proportion of AS individuals suffer with depression, and Kiam's *Autism Asperger Network Empowering Individuals* (2014) discusses how the cause of this depression can be a result of the struggles, exhaustion, rejection and failures believed to be present, or could be linked to the 'mysterious neurology of AS'.

When analysing what diagnosis means to the individual it is clear that this is an area that evokes uncertainty. Alan recalls his initial thoughts on diagnosis in terms of losing his sense of self. He states 'I did wonder if I'd be losing me', suggesting that the diagnosis may change the way he is as a

person. Comparatively, Anne discusses her concerns about being diagnosed and how this would impact upon both her relationship and her employment status. This account is a classic example of the impact of the label in regards to self-identity. Anne assesses all areas of her life due to the diagnosis, exploring and questioning what being an 'Aspie' means for her (the term 'Aspie' is used in place of Asperger Syndrome):

Now I have to explore what being an Aspie means for me. How will it affect my career now I know about it? Should I be in a relationship or should I stay single? I have realised I can't handle too much going on in my life. It's either work OR a relationship but I can't handle the stress of both.

(Anne)

Although she does not particularly specify, there could be a number of reasons why the participant feels she can no longer cope. The individual may have always struggled in the identified areas, and obtaining a formal diagnosis has helped her make sense of this, restructuring the way she approaches these areas. Alternatively the individual may feel that she should live up to the applied label, which can often be influenced by a range of medically dominated discourse:

Labelling theory states that people tend to act in accordance with the labels that others assign to them. When a person is assigned a label they tend to view themselves and act in such a way that promotes them to be labelled in that way.

(Krueger and Trussoni 2005)

Research produced by Sandel and Dodd (2010) recognises that labels are essential to the way we make sense of our social worlds, however they also recognise that they need to be approached with care. This particular section aims to explore how the individuals in this study interpret the given label, and this will include accounts from both negative and positive perspectives, although there may be some instances where the two are interlinked. As Macdonald states, 'The consequences of labelling or not labelling are often thought as either positive or negative, but in fact they have positive and negative out comes' (2016: 35). Norwich (2008; 2009) suggests that weighing up the benefits verses the disadvantages of receiving a diagnosis is often designated as a dilemma in the research literature.

As Cohen (2006) distinguishes, 'numerous investigations reveal negative effects of labelling on stigma related processes' (Cohen 2006: 854). Although the experiences around stigma will be noted in the following chapter of this analysis, it is important to recognise the impact of stigma around specific terms on negative life outcomes. The term 'disability' is among the terms thought to carry stigma and oppression. Jung (2002) states that 'Disability is a label, a signifier that inaugurates consignment to an identity category, which signifies disadvantage and oppression' (2002: 179, cited in Goodley (2011: 9). Alan discuss a negative experience in conjunction with the term 'disability', and he voices his fears about the generalisation of the term 'disabled'. He recalls how he had a negative experience of being termed 'disabled', as someone used this reason to get him removed from a specific team. This is an example of the discourse and cultural ideas that can often exist around such terms, suggesting a belief that one is not as capable of a specific job role if they are 'disabled':

I had a negative experience in 2000 with someone who took exception to someone with a disability being put on their team without their consultation and they ended up managing to find a way to use it to get me excited.

(Alan)

Sally also discusses the term 'disability' in relation to a negative experience; she believes that the reason she was not bridesmaid for her sister's weddings was due to an inherent disability prejudice. She recollects how she thought that they were ashamed of her:

Both weddings I wasn't even a bridesmaid. I was just forced into the corner as if I wasn't even, as though they were ashamed of me, and part of that is just in built disability prejudice.

(Sally)

Willie (2010) makes suggestions that a family's feeling of shame regarding a loved one with disability is more common than we'd like to think. The term 'disability' was also discussed by Sally in regards to the way she views having AS. In her account she identifies AS a gift for many but not herself; she views it as a disability as she feels it does not encompass the gifts that she sees in others.

I think for some people it's a gift for some people who are obsessive and are very good with technical things, logic, it's very typical of Asperger's. I see mine personally as a disability, because it's something..., I'm not one of the gifted ones.

(Sally)

Both participants Paul and Alan make a link to these 'special skills' by discussing the term 'idiot savant' and 'savant'. This particular term, 'idiot savant', appears within the historical chapters of this thesis whereby pre-industrial ideas regarding the 'mad' and the 'idiots' were linked to autism and Asperger Syndrome. This term is used to describe a person that may be an 'idiot' in the sense of 'abnormal' behaviours, but one who displays exceptional ability within specific areas. Within the work of Hiles (2001) it is documented that the term 'savant syndrome' was recognised in 1887 by Dr J. Langdon Down. He coined the term 'idiot savant' with the meaning of low intelligence combined with the French for 'saviour', 'knowing' or 'wise'; it was used to describe those who had extraordinary memory but with a great deficit in reasoning power (Hiles 2001). Although this is believed to be a characteristic of autism (in some cases), it must be noted that not all individuals have this specific ability, as later definitions will demonstrate. Alan recognises that people mix up autism and savant syndrome, and relates this largely to the film Rain Man:

The problem is other people mix up autism with savant syndrome, and the film which caused this, or so I'm told was Rain Man with Dustin Hoffman, people wonder what your special skill is, especially talking about children with autism.

(Alan)

Miles (2001) highlights how the movie Rain Man has led to the term savant being more widely recognised. Draaisma (2009) states that:

There is a strange discrepancy between the research that their directors, script writers and actor put in when

they make a film featuring autistic persons and the actual characters they come up with... they all want an *absolutely* sincere and truthful rendition of autism; what they come up with is an autistic character with freak-like savant skills, unlike anything resembling a normal autistic person.

(2009: 147)

This work also recognises that media representations of talent and special abilities can contribute to a harmful image of autism, thus contributing to negative and stigmatised views.

The narrative provided by Paul discusses the term 'idiot savant' in regards to intellectual ability:

I think people kind of... Some people kind of think I'm like this know-it-all, this like idiot savant, but I think my knowledge is deep and wide and I think it's not only [unclear – 00:16:32] but I can use it in many different contexts and ways and stuff. So I think that some people think of us like that. I think that it's very divided. Like people's opinion on my intellectual ability which means a lot to us between, 'he's stupid', 'he's clever'. It's a very sharp divide. Like as is the term idiot savant per se.

(Paul)

Within this statement he notes 'some people think of us like that' – the term 'us' can be reflective of others' opinions being generalisations about a particular collective set of people. It is often mentioned that the stereotype of autistic savant raises expectations to an unrealistic level, causing

disappointment and frustration for the many autistic persons not so gifted (Draaisma 2009). Molloy and Vasil (2004) propose that medicalised labels limit expectations, however in the case of extraordinary abilities it appears that expectations are *heightened*. The links to historical terms suggests that historical perceptions that once existed still shape the concepts of AS in the 21<sup>st</sup> century.

Sally highlights how the very idea of these abilities and expectations make her wish she never had AS, claiming 'I've not got any of the gifts and all of the anxiety and obsessionality'. This statement is reflective of the societal ideas that exist in relation to the 'gifts' possessed by those with autism. Within the above demonstrations we can see how the media impacts upon these discussions, and how they clearly impact upon Sally's view of herself. We can see from her narrative that she feels that others have been given these gifts and she has not, and in a sense rates her own worth as below others who obtained these gifts. Mark believes that he possesses these 'marvellous talents' and 'many gifts', and thus sees them as a beneficial; this is the only participant to see this as a positive aspect of Asperger Syndrome.

With my special talents, once I put my mind to the test  
I am determined to succeed.  
(Mark)

It is reported by Tickle and Stott (2010) that few people with ASD (Autism Spectrum Disorder) actually have these exceptional talents, and their work also highlights this misconception that everybody with ASD has an exceptional talent. It is of great difficulty to distinguish if such talents are specific to Asperger Syndrome, but mark does propose that his talents gain him the admiration of others:

My projects not only reflect my many talents but they also gain the admiration of those closely associated with me.  
(Mark)

Referring back to the negative outcomes of diagnosis it is evident that Paul regards autism as a negative. In his account he uses the general term autism as opposed to his specific diagnosis of AS when discussing the negative aspects.

I think autism's generally a negative thing and the way I've seen it, apparently so do many autistic individuals.  
(Paul)

Paul's narrative also implies that he rejects the label of AS, and he recommends that the people should not be assessed with regard to AS but instead with regard to vulnerability:

I think that people should, everyone from birth should be assessed as to whether or not they are vulnerable. Not assessed as to whether or not they're Asperger's or dyslexic or this, that, this, that. And from that have that diagnosis of vulnerable, invulnerable.  
(Paul)

The work of De Chesnay (2005) recognises the term 'vulnerability' as a general concept that means 'susceptibility', noting its specific connotation in health care as 'at risk of health problems'. As proposed by Jamieson and Jamieson (2004), those diagnosed with AS are susceptible to mental health problems and depression. Their work also proclaims that mental health

difficulties can also increase the vulnerability to problems with eating, sleeping etc. Lastly they suggest that such problems are not apparent until late adolescence or early adulthood, dismissing ideas of vulnerability being measured from birth. The idea of imposing a collective label of 'vulnerable' or 'not vulnerable' could be damaging to individuals who receive specific health care for their condition. In regards to labelling, Jane proposes that people should accept being different and identify the individual opposed to the attributed label:

I think just accepting people are different, and the way people's brains are wired are different, and how people see things and do things are completely different. And accepting people as an individual rather than a label.

(Jane)

The notion of acceptance is strongly advocated within this thesis and, as Jane highlights, people may differ but the emphasis should not be on labelling those differences. The social model of disability, as previously discussed, aims to address and remove the barriers created by society, and these include the stigma that is associated with labelling. Carson (2009) also recognises factors such as the denial of opportunities, the restriction of choice and self-determination, the lack of control over support systems alongside the dominance of the medical model. Watson (2004) states

The importance of the social model cannot be downplayed. It challenged understandings of disability and sought to dislodge the association of disability with mental or physical incapacity.

(2004: 2)

Paul discusses how it is individuals themselves that need to change, suggesting that 'autistic people' should overcome the traits that are associated with their diagnosis:

I think that autistic people should work to overcome those traits. I think it should be a two-way street. I disagree with like certain autistic leaders' views that society, you know, the pubs, the shops whatever, should just accommodate, entirely accommodate them. I think that they should, you know, stop spitting on the floors and should maybe get a job and, you know, they will find some pleasure in like social relationships. Shouldn't let it hold you back. I've got Asperger's so I guess I cannot speak of low functional autism.

(Paul)

The participant proposes that it is a 'two-way street' and suggests that those diagnosed should find jobs and pleasure in social relationships. This way of thinking could stem from the medical culture that surrounds disability and the emphasis that has been put on the body. In an account by Sally she recollects how she tried overcoming AS, discussing this in terms of mimicking behaviour:

I've had to disguise it because I've learnt how to mimic normal behaviour and gradually it's become more and more natural.

(Sally)

She confers how she tries to disguise the characteristics of AS by mimicking others, noting on occasions that it trips her up. Thomas also recognises how he is prone to do the same:

Throughout my life, I've become good at 'putting on a mask', and acting 'normal'. It's become second nature to me to do that. But it soon takes its toll, to the extent where I may just 'zone out' from what someone is saying, because I can't concentrate on them and work out what I want to say afterwards.

(Thomas)

Attwood (2006) discusses the process of mimicking as a compensatory adjustment strategy to being different, and he recognises some benefits but notes there could also be dangers, for example missing a diagnosis of multiple personality disorder. Wylie (2004) states that 'pretending to be normal is a common survival strategy for people on the autistic spectrum', and proposes that pretending to be someone else can damage self-esteem and mental health. Additionally he recognises increased stress, anxiety and mental exhaustion as consequences. Louise talks about how she acts outgoing, however claims she is the opposite. She goes on to recollect the conversation she had with her therapist regarding coping strategies:

I had my diagnosis with \*\*\*\* and I said to her, I feel like I'm falling apart at the moment I feel like everything I was is just disappeared and she explained to me how throughout your life when you don't know you have Asperger's you create coping strategies around and structures so you kind of fit in an manage and then often, and she saw this with women of a certain age from your late 30s up to 50.

(Louise)

Her particular narrative is interesting in regards to culture as she states that her diagnosis led her to feel 'more autistic'. She discusses how the diagnosis has changed her by eradicating her former self, concluding how she struggles with identity:

It's like you become more autistic and suddenly things that were really easy for you to do are suddenly not easy and it's really quite traumatic cause everything you knew you were just gets stripped away and having Asperger's I struggle with an identity.

(Louise)

The idea of being given a label appears to have had a huge impact upon this participant. This could be a consequence of late diagnosis, whereby the individual has spent a large proportion over 40 years of her life developing ways to cope with the characteristics of AS. However, the idea that the label itself made her feel more autistic could be due to the expectations and the discourse that surrounds the disorder. Additionally, the label may have impacted on the way others treated, whether consciously or sub-consciously, but labels do have the ability to affect how we approach and interact with each other..

Conversely, Jane has a different perspective on the implementation of the label, as she recollects how her perception of the label was beneficial to her and describes it as a relief:

I did have Asperger's Syndrome, which was sort of quite a relief for me because it was like I could then

explain symptoms that I had were all in line with the Asperger's Syndrome and it wasn't me being completely abnormal and it was well in line with the Asperger's Syndrome.  
(Jayne)

She goes on to discuss how she can relate the 'symptoms' she has to Asperger Syndrome. She also discusses how she has learnt to embrace it and accept it as 'normal': 'It's perfectly normal and accepting it as normal and moving on and sort of saying, "Right. I've got it." I can't change it accepting it and moving on' (Jane). This account discusses the recognition of the label in relation to normality, suggesting that the implementation of the label normalised the particular behaviours as they are now viewed from a medical perspective. She recognises how the diagnosis gave her closure. 'I think it sort of put closure on knowing that the things that I thought were abnormal and weren't abnormal, they're all part of the Aspergers' (Jayne)

Thomas discusses how the diagnosis helped him at university in regards to support services:

Going back to those extra assignments, the diagnosis meant I could get extra support and understanding when it came to my attempts to get them finished and out of the way.  
(Thomas)

Additionally, Louise recognises the positive impact of diagnosis and the online support networks available. She discusses how diagnosis was a relief, and also going on to discuss how the diagnosis has led her to shut out her partner.

She gave me a positive DX. I felt relieved. I had joined a lot of Aspie support groups online and it felt amazing to finally fit in somewhere after 44 years. I really felt understood for the first time in my life. I love my new online family. There is someone around any time of the day or night to help pick you up and make you smile. I've started shutting my partner out and just burying my head in my phone, chatting to other fellow Aspies. My partner has developed lots of habits that have started to affect me and make me irritable. I'm heading backwards and becoming the person I was when I was married.

(Louise)

There is a large amount of literature surrounding the diagnosis of Asperger Syndrome, and the work of Wylie (2004) provides a specific focus on those who obtain late diagnosis. He recognises that most individuals who are diagnosed later in their lives had always known that they were 'different' but they did not know how or why until a diagnosis allowed for self-identification. The following account provided by Jayne discusses how she is not sure what impact diagnosis would have had on her in earlier life. However, she recognises the concept of 'difference':

I don't know if the diagnosis would have made a difference earlier in life where it would have been acknowledged that there was perhaps reasons why I was slightly different.

(Jayne)

Louise suggests, after diagnosis, that the difficulties within her life were related to Asperger Syndrome. Although this could be true, the elements of

this account could be linked to a number of reasons, and it may be that the participant is linking her life events to the given label.

Erm, I think I'm one of those classic Aspey women, late diagnosis, has managed to function reasonably well in the world on surface level but if you actually dig deep through my whole life there's nothing but problems and trauma and jobs failing, relationships failing, and I know now if I knew when I was 18, 14 I had Asperger's it would have made so much difference because you stop saying to yourself what's wrong with me, you start saying 'I have Asperger's' then you start looking at your limitations and you learn what you need but when you go undiagnosed you just do not know what is going on it's very confusing.

(Louise)

Alan explores what would have happened had he obtained a diagnosis, and this is interesting as this participant would have been a child when AS was defined but no one suggested he had AS until later on in life. This could be a result of the growing culture that surrounds AS, but his account recognises that if he had been diagnosed earlier he would have received a different treatment than he would today. He feels that he would have been sent to a special school or put in residential care to be 'forgotten about':

If I'd been diagnosed earlier that probably would have happened, I went through a mainstream school and during my time you could either be sent to a special school and forgotten about and there'd probably be boarding schools as well so you're put in a home and forgotten about or there was the mainstream schools,

whereas when I tried Teacher Training, which didn't work out, at that point you had an adult who would be some kind of helper, who would sit with a person.  
(Alan)

Sally recalled the lack of information she received about her diagnosis; she discusses how she thought AS was 'asparagus syndrome'. Her account highlights how she was in fact sent to a special school. She also highlights how she asked a number of professionals about her diagnosis but did not have any real response. She discusses this period (the 90s) as a period when people were less aware of AS:

I was 12 when I was first diagnosed and I didn't know what Asperger's Syndrome was, I thought it was asparagus syndrome hence the title of the book but it took me a few years to realise what it was, when I was sent to the autistic school, I was asking people lots of questions which I think annoyed them, asking what was autism, and I don't even think some of the staff knew, mind this was back in the 90s when people were less aware.  
(Louise)

Paul felt that an early diagnosis would have been more beneficial to him as AS was prevenient to his behaviour, so he suggests having his diagnosis later has had a negative effect.

#### **6.4. Conclusion**

This chapter has been beneficial in exploring pre-labelling and post-labelling accounts. It proves interesting that a large proportion of individuals' stories was given to this subject. In regards to the pre-labelling accounts it is visible that bullying had occurred prior to the implementation of the label. Six out of the ten participants chose to discuss the difficulties that they faced in schools, and this could be a result of societal perceptions around the concept of 'normality'. This could be an area in where further research would help to ensure that more is done to support children in this situation, calling for greater emphasis on schools to provide training and support regarding the concept of 'difference'. The accounts within this chapter highlight the derogatory treatment that still exist in society regarding those who do not conform to the societal norm. The perceptions that exist in regards to these individuals can be reflective of the institutional culture that once existed, whereby individuals who were 'different' were thought of as invaluable members of society. Within these accounts the participants recognise that they do in fact have some inabilities, and struggle in specific areas such as making and obtaining friends, but it is not these differences that disable individuals it is the cultural attitudes and beliefs that surround these differences and norms.

It appears that a number of participants obtained a diagnosis based upon the ideas of 'difference' or 'abnormality' being recognised by parents or the participants themselves. Six out of the ten participants in the study obtained a late diagnosis, something that is not uncommon for individuals diagnosed with AS, and therefore it could be argued that professionals who should be aware of this disorder are not educated enough in this area and may be missing opportunities to diagnose. Or, from the perspective taken within this study, it could be that the individuals were diagnosed later in life due to the rising culture that surrounds the characteristics now thought to belong to

AS. For example, the increasing requirement for social skills within education and employment, which at one time would have not been thought of as a necessity.

This study recognises that there is no single, unique way that diagnosis is interpreted, and (as the sections regarding labelling highlight) there are both positive and negative consequences. Some individuals feel the diagnosis has helped them understand why they are 'different' and helped them obtain a sense of self-identity. The label has also been seen as the trigger for support when one is experiencing difficulties, however the idea of support within the area of AS is currently a contentious issue.

Alternatively, the label of AS can have negative effects on individuals due to the expectation that they will have extraordinary abilities. This particular area is one that appears to have a detrimental effect on individuals, as they could also feel like they are not living up to their own or others' expectations. Such ideas of extraordinary abilities are not noted as diagnostic criteria, but the media plays a large role in this preconception. This particular topic also brings with it the historical terms that were mentioned in this chapter, including 'idiot savant' and 'savant syndrome'. Both of these terms are reflective of the historical attitudes regarding autism, which evidently still exist in today's interpretation of the disorder from a social perspective.

For some individuals the label appeared to be something which they felt they needed to live up to or conform to, for example participants asked 'about how will it affect my career now that I know about it' and used statements such as 'it's like suddenly you are more autistic'. Other participants felt that the label linked to the wider term of 'disability' and felt

that they had suffered abuse due to the stigma attached to disability in general.

The notion of appearing normal or acting normal was a recurring theme, whereby a number of participants discussed ways in which they could 'appear' normal. This recognises that society has created unwritten rules about the type of behaviour that should and shouldn't be accepted. It is apparent that not all individuals feel the same about diagnosis, however the idea of conforming to the 'norm' is the fundamental cause to seek a diagnosis. This study argues for greater acceptance and education from a young age that difference exists that is should be embraced.

## **Chapter 7 – Analysis and Discussion:**

### **Cultural Exploration of the Fundamental Characteristics**

#### **Associated with Asperger Syndrome**

##### **Introduction**

The following chapter aims to discuss the characteristics that make up the medical diagnosis of AS (AS). This chapter will commence by discussing social communication; currently there is a substantial amount of literature that discusses AS and the believed difficulties faced within this area. Lyons and Fitzgerald (2005) and Baron Cohen (2008) are just a selection of writers that discuss this topic. Social communication difficulties have been linked to AS since its development in 1944 by Hans Asperger and Leo Kanner. Additionally, such difficulties have been linked to the general term 'autism' from the onset, as the inclusion of this characteristic within the 'Triad of Impairments' suggests. The Triad of Impairments was first coined by Wing and Gold in 1979 to recognise the three key areas of difficulty for those with Autism Spectrum Disorders. These areas are social communication, social interaction and social imagination. The National Autistic Society website demonstrates that the Triad of Impairments is still used to today to explain Autism Spectrum Disorder (ASD). However, the DSM-5 has now replaced this Triad with two behavioural domains: social communication and repetitive stereotypical behaviours. Although the changes in DSM-5 do not apply specifically to England, it does however prove very influential. (The World Health Organisation International Classification of Disease (ICD) is the guide utilised in the UK.) Stated within *Neurodevelopmental Disorders (a Definitive Guide for Educators)* (2015)

In light of the previous discussions regarding the characteristics that currently define AS, this chapter will also explore the areas of social interaction, social imagination and repetitive stereotypical behaviours. Although physical characteristics of AS are noted within this chapter, this thesis still remains underpinned by a cultural framework, therefore the way in which each characteristic is experienced will be discussed in regards to the specific culture in which it exists. The work of Waltz (2010) recognises that, within cultural studies, meanings are produced, mediated, distributed and consumed, and all of the latter are said to create culture. Waltz also claims that 'these meanings may be shared, but are often contested as can be observed in the case of autism' (2010: 422).

As demonstrated throughout this thesis, one of the fundamental aims of this study is to empower individuals by giving them a representative voice, but additionally this thesis also fosters ideas created by the affirmative model of disability. This particular model moves away from the personal tragedy approach to disability, recognising that impairment is a part of human experience that should be celebrated. Although this model strives to highlight the existence of positive experiences, thus creating positive identities, it would not be empowering if the individual's stories regarding impairment were ignored. Therefore I ask the reader to remain mindful that the discussed characteristics associated with the diagnosis of AS are not the sole representation of the discussed individuals.

## **7.1. Employment**

When analysing the data it becomes visible that the debates that exist around communication and interaction difficulties are not only specific to

education. When discussing employment and communication it proves essential to address the relevant research, or lack of, regarding AS and employment. Within research carried out by the National Autistic Society (NAS) in 2001 it was suggested that only 12 percent of AS individuals were in employment. It proves difficult to find up-to-date and relevant figures within this area, highlighting the significant gap in AS research. The work of Edmonds and Beardon (2008) supports this claim by recognising that clear figures regarding AS and employment are not available. They do however discuss the estimated figures that claim only around only 20 percent of AS individuals are in work at any one time. They also recognise that employment may not always be consistent, and discuss a number of possible reasons for this, however there is no concrete evidence that discusses why AS individuals may struggle. This study could be seen to support previous claims around the inconsistency of employment, as 6 out of the 8 participants that discussed employment had previously been employed and weren't now in full time employment. The narrative provided by Thomas addresses the inability to obtain employment and he discusses this in regards to communication skills. He claims that most employers seek 'good communicators', stating that this is something that AS individuals are not. Hawkins (2004) supports this claim by recognising that excellent social and communication skills are amongst the top skills that employer search for.

Even with those I could apply for, I couldn't get through the interviews (most didn't know I had AS for a start, and anyone with AS who has looked for a job will know just how many seem to require 'good communicators', which I'm afraid we certainly aren't).

(Thomas)

He goes on to discuss how he applied for a placement opportunity and decided to disclose his diagnosis of AS to potential employers. In this instance he got the job, however his employers suggested that they didn't know what he felt was so different about him that he felt the need to disclose this.

And it wasn't until February before it was decided it would be a good idea to take up a placement opportunity and to tell them about my AS, hoping they wouldn't be prejudiced in any way (it probably wouldn't be allowed anyway). There were 2 jobs available between 3 students, working on the new version of an organisation's web site. As it turned out, I cruised through the interview and got one of the jobs at long last, and they even said they were wondering what was so different about me that I needed them to know about my Asperger's Syndrome in the first place! \*lol\* apparently I was so good in my interview (albeit a bit quiet) that they would never have questioned me! So that made a refreshing change from my recent past, for sure.

(Thomas)

Reflecting on this account by Thomas it appears that he has linked his previous inability to get a job to a deficit in communication skills. However, within his second interview the employer recognised none of the characteristics of poor communication, apart from quietness. This could suggest that the discourse that exists in regard to poor communication skills and AS could be influencing individual self-perceptions. Alan also recollects how he thinks a diagnosis of AS has led to a fellow colleague giving up on obtaining employment.

I'm apparently one of the few people who got into employment, one with Aspo and I have wondered if I was able to do that cause I did not know that I had Asperger's when I was looking for my current... when I was looking for a job I initially got into the Civil Service and I've met somebody who, because she had a diagnosis early on seems to have given up and blames it so she is unemployable.

(Alan)

An alternative theory regarding employment is that different jobs will have different cultures, and specific jobs will differ in their need for communication skills. For example, a customer service job will require more communication skills than a computer-based job due to the level of interaction required with the general public. Finding a suitable job that is suited to your skills is essential for anyone. Bissonnette (2012) suggests that discovering one's interest is part of the employment puzzle. She also stresses that it is a mistake to assume that because you are interested in a certain subject that you can make a living in this field. As the following account highlights, areas of interest change and tasks that were once found enjoyable can become unenjoyable:

but now my once-geeky interest in computing, for example, has waned to one of nothing more than mainstream. I used to like programming – not any more. I used to like making web sites – not any more. My range of interests was already fairly narrow, but now it's miniscule.

(Thomas )

Bringing back the discussion to communication skills and employment, Laura shares her story of employment. She discusses staff as intimidating and recalls how she struggled to fit in within the working environment, noting how this led her to question her capabilities and eventually leave employment. Louise's account reveals her plans for a future business to help AS individuals into employment. She claims she would teach them how to overcome interviews and develop effective communication skills, e.g. handshakes:

But what I want to do with my business is I want to job coach and run employment seminars for people with Asperger's cause what I do know a lot about is employment and I know how to teach them about interviews, I know how to teach them about hand shaking, I can teach them to do anything, but doing it myself is another story but I'm a good imparter of information and because I understand them, I just want to do it in a small group format.

(Louise)

Although this idea would probably be beneficial to potential employment prospects, should it be the individual's responsibility to change? Or should the employer aim to be more inclusive about difference and accepting individuals upon their merits and ability to do a job? Within Louise's account it is visible that she has the same idea about educating employers:

the other thing I want to do is do employer education programme and I want to go into big companies and I want to promote ten positive points about why they should employ people on the spectrum, all the reasons why they make good employees, not the negatives

because that's what all the Asperger's employment books focus on.

(Louise )

The previous account also recognises the cultural representation of those with AS in books as negative. Such negative representations may be seen to influence the culture that exists regarding employment of AS individuals. Sally recollects how she only has part-time employment, and she discusses the inability to understand AS suggesting that it is 'vague' and that employers have not even tried to understand it, and that 'it's just laziness on their part'. Louise goes on to recognise how employment has been beneficial to her as it has helped her learn more socially expected things to do. As this section highlights, social communication and interaction are key to a person obtaining and keeping employment, but the culture that surrounds employment is still yet to become as welcoming and inclusive to those with AS as it is to those with visible disabilities. There is a significant amount of work that needs to be done within this area in order to build an equal and diverse workforce, as it is evident that individuals are *wanting* to obtain employment, however due to the exclusive workforce, which is culturally produced, these opportunities are less available.

Although this chapter recognises the impact of social and cultural factors upon communication, it still also recognises that the individuals themselves may have physical symptoms linked with social interaction difficulties. For example, Thomas voices his struggles with social interaction, and within the following account he describes how difficult he finds it. His account also explains the strategies he has put in place to aid himself in these situations, such as taking deep breaths:

I have problems with social interaction. I find that very difficult in the sense that I'm okay for twenty minutes. After sort of twenty minutes or so I sometimes feel that I'm really floundering. Find it difficult. Find that I'm taking really deep breaths and this is how I know I have to cope with it and a lot of it's finding strategies to deal with, 'Yeah. I know it's difficult, but I've got to do it. I know I've got to do it.' And just accepting that sometimes I am going to find it a little bit tough. Normal people find it tough so just accept it as normal and move on.

(Thomas)

This account effectively highlights the cultural expectations and norms regarding social communication. Such expectations are a product of the majority of society and are linked to neurotypical people following the unwritten rules of communication. The following account provided by Laura also highlights the difficulty she faces with participating in sports that involve interaction. She discusses her ability to run due to the fact that it is a solitary sport whereby interaction is not needed.

I can run but it's because it's a solitary sport I don't have to interact, anything solitary I can do but anything that involves interaction like team games, netball, hockey anything like that I find really difficult because I have to face the people but if I do running or some kind of solitary exercise even if it's like going on me bouncy ball or me walking machine it's where I've not got to focus on other people I can just put me music on.

(Sally)

So although these difficulties do exist, it is the culture in which they exist that contributes to the difficulties faced.

## **7.2. Social communication and social interaction**

This section will commence by exploring social communication and social interaction. Social communication could be described as the words that we use and how we say those words, as well as how we communicate non-verbally. Research conducted by Quigg and Nugent (2005) suggests that social interaction refers to one's desire and ability to relate and mix with other people. Their work recognises how social interaction and social communication can be linked; if one does not wish to interact and mix then effective communication may become difficult, and vice-versa. Edmonds and Beardson (2005) propose that the inability to communicate is at the core of the Asperger 'problem'. Their work goes on to suggest that this issue is most prominent in social relationships and social interaction. The description of AS as a 'problem' is not entirely fitting to the values of this thesis, as this suggests that the individual is the source of any difficulties, and this thesis aims to move away from the medical model thinking that suggests difficulties are intrinsic to the individual, instead providing a greater focus on the social and cultural impacts.

As recognised within the previous analysis chapter, the topics of bullying and friendship were widely discussed, and they are closely related to this topic of communication and social interaction. Although the aforementioned discussions are important and will contribute to the conclusion of this chapter, there will be a more specific focus here on the times when the individuals directly use the terms 'communication' and 'interaction'. When

addressing the literature regarding AS, it appears that individuals can experience difficulties with social interaction at any given life stage and within any environment. This particular section will address both education and employment, exploring communication within the two stages of life (and environments).

Exploring social communication and interaction within the educational environment proves very difficult. As the previous chapter highlights, the majority of those within this study faced bullying within the school setting. This bullying inevitably impacted upon the way those individuals interacted and communicated during this time, but the long-term impact of this is unknown. This section will explore the relevance and importance of both interaction and communication within an educational context. The narrative of Paul reflects on his time at comprehensive school, and he discusses how he missed out on the last two years of comprehensive due to communication:

I kind of missed out in the last two years of comprehensive like of communicating. Like you just like go, 'Oh you're a dickhead. You're a dickhead', and, 'Fuck you and your life's no worth. I could kill you.' Alright. Maybe that's like something I just missed out on...

I just get very upset I guess when I see these people getting away with like friends; even their girlfriends are just getting any kind of respect for dickheads like that. I don't understand it. I do have some weird thoughts on my Asperger's.

(Paul)

Although this account proves difficult to analyse, what we can see is the frustration of other individuals being able to communicate and interact in what society would see as a 'normal' way. The work of Boyd (2014) proposes that there is a 'social code' that most people in society follow, and in most cases this is done without knowing. The discussed research highlights how AS individuals might not understand this code, and as a consequence they could face penalties such as bullying, ridicule, isolation and rejection, which in turn can have major implications. Although participant Paul demonstrates a lot of frustration around the inability to communicate, he goes on to claim that that he does not value those social connections and he doesn't want to be friends with certain people:

But I know that's regrettable. You could say that's the Asperger's talking or whatever. I don't value those social connections and I don't want to be friends with certain people. I'm not really pursuing voluntarily, in pursuance, I don't know if there's such a word, of such relationships with those people. I think it's held us back.

(Paul)

When concluding this particular narrative Paul recognises he has difficulties communicating. He claims that he doesn't want to make friends with certain people, something that is not uncommon for most individuals. Although the characteristic (unwillingness to communicate) is a reality, and is evidently causing problems communicating, at what point does the unwillingness to communicate become 'abnormal' and thus defined as a characteristic of AS? This is a question that proves difficult to answer, as often an individual can ascribe characteristics or behaviour to a medical symptom and thus

render them 'abnormal' after a diagnosis is in place. This question proves interesting, as surely neurotypical individuals wish that they could ignore and not interact with those that they don't have things in common with? However, due to the society in which we live, it proves essential to communicate with various groups of individuals in order to be included in the 'norm' and avoid such terms as 'hermit', 'loner', 'weird' or 'abnormal'. This particular participant goes on to discuss how his experience of continued education (college) wasn't particularly great, and he discusses college as a place in which the characteristics associated with AS set him back:

I think in reaching for like certain goals and I think, as I say, college which is like my journey to become like a film-maker, Asperger's has been set back in some ways and I've had difficulty communicating.

(Paul)

However, Thomas had a different experience of college in regards to communication, and he recognises how some of his other friends were at the same college as his therefore his social life remained the same as before, which was good for him. It is evident that Paul and Thomas have had different experiences of college, and this may have been due to Thomas knowing others within the college, thus minimising the need to make new social groups. However, Thomas recollects how he went to university after college, as he wasn't ready for the workplace, and describes the thought of living in halls of residence away from home with none of his current friends as exciting:

I was actually looking forward to the prospect of living in halls of residence, even though I knew I'd miss

home at the same time (it was my first prolonged period of time away from home). None of my friends from school or college were coming to the same uni as me, so it really was a case of starting from scratch. Such optimism really surprises me now, looking back, knowing what was to come. But that was how I felt.

(Thomas)

Unfortunately the experience of university was not as he had hoped; within his narrative he highlights how he felt isolated and was unable to fit in. This account may differ from his previous account of college because he knew nobody within this institution. Within the following account we can see how he did his best to avoid social situations due to what other people might be saying about him:

I started to fear the prospect of having to go into the shared kitchen and facing them, wondering what they might have been thinking and saying about me behind my back. I'd try and only go in there when the room was empty, or come back from uni really late so they'd either be out socialising or in bed, asleep.

(Thomas)

The following narrative goes on to discuss how he was then a target of abuse and cruelty, all linked to not socialising or interacting with others in a way that the majority of the society expects:

all my flat 'mates' and their friends proceeded to give me hell, banging on my door constantly, calling me offensive names, sticking all sorts of crap all over my door (including most of the food I was forced to put in a

shared fridge all year long). I couldn't cope with that – I doubt anyone could.

(Thomas)

He goes on to discuss how he went to seek help from a psychiatrist due to the socially traumatic year he had encountered. He discussed how this led to clinical depression, for which he was given medication. He talks of this period as a time when he had not been diagnosed and highlights how the help he got was 'useless', including group sessions for assertiveness, general depression, etc. Louise also discusses the lack of support, in this case for her transition from higher education to college, suggesting that there is not enough support for these transitions, and she highlights things such as supported living, relationships, support groups and post-diagnosis groups. The work of Attwood (2006 :229) suggests that some universities have a support group for people with Asperger Syndrome. Although most universities now have a learning support system, the support groups Attwood suggests aren't always in place, and very little research has been done on transitioning between educational settings. As we can see from the narrative of Thomas, the inability to diagnose has led to a lack of support which in turn has led to the medicalisation of a socially produced problem, especially when a specific diagnosis couldn't be met. What we can see here is the socially produced culture being excluding to those who do not conform to societal norms, in this instance being 'sociable'. Sally's account supports this claim. She talks of university as a time where she socialised a lot, drinking a lot of alcohol and pretending to be like others ('the Goths and all that'). Despite her ability to socialise, her account shows how trying to fit in with this expected culture left her feeling 'terrified' for most of her time at university. She talks about how she can personally communicate, but

claims that it is usually the 'Aspie' males who can't communicate and thinks she could offer them training:

I can socialise, in fact I was thinking about doing a class for male Aspies, pardon the sexism but it's usually them, about how to speak to people how not to be blunt and abrupt, how to be tactful erm for instance if there's a door and there's lots of people at the door, hold open the doors and don't slam it in their face or the politeness I have learnt over the years I think I could teach to other people.

(Sally)

Although this opinion of communication skills regarding gender cannot be supported, it is evident that the proportion of males diagnosed is significantly higher than females. But it could just be that the culture of males and females in this particular environment were different. Following sections of this chapter will address communication in regards to gender and alternative medical diagnosis. The account provided by Paul reflects on how he missed out on his dreams due to the inability to communicate, and he makes a direct link to AS as a cause. How much of not achieving his dreams was due to other factors, as opposed to the characteristics associated with AS, is unclear. This is not to suggest that communication difficulties and barriers have not occurred, but the significant point is the impact of the discourse surrounding this. It is evident that Thomas faced difficulties at university, however he had not yet been given a diagnosis and therefore he does not address himself or his diagnosis (to come) as a problem, instead he discusses the concept of normality by discussing 'them' and 'him' and recognising the difference in terms of being 'outgoing':

it became clear they were ALL outgoing, ALL party-animals, and nothing at all like me – certainly not the type of people I wanted to live with anyway. The signs were ominous – within days, after initially approaching me to go out with them, and me rejecting those offers through fear and sheer lack of guts, they started to avoid me, thinking I was avoiding them.

(Thomas)

This account also mentions the reason he did not go out was ‘fear’ or ‘lack of guts’, and additionally he highlights ‘their’ misconceptions about him avoiding them. The product of social culture, whereby those who are not outgoing and don’t enjoy socialising or partying become the ‘abnormal’ individuals, is an area of great interest. Surely education, especially higher education, should be about bringing a range of diverse individuals together? Sally also discusses how she socialised allot and tried to be one of ‘them’, and the particular language used here suggests she is not one of ‘them’ and that she sees herself differently to those that socialise. Whether she feels this is due to the label is not articulated.

### **7.3. Gender**

The issue of gender and AS is one of great inquiry, as the work of Halliday and Wylie (2015) highlights, ‘one of the most consistent findings in Autism Spectrum Disorder (ASD) research is a higher rate of ASD diagnosis in males than in females’. The work of Fombonne (1999) highlights that the disparity in males diagnosed against females is even greater in regards to the specific diagnosis of AS and high-functioning autism, and this work claims that the proportion of diagnosis of males to females can reach as

high as 10:1. The work of Halliday and Wylie (2015) goes on to recognise how little research is done in this area, and how research into gender differences would be beneficial and could lead to many advancements in the prevention or treatment of ASDs. Although this thesis aims to promote acceptance, as opposed to prevention or treatment, it does however recognise the need for further research into this area. Academics such as Postava and Jordan-Young (2012) recognise the previous research within this area, noting how many hypotheses have been advanced to explain the male–female disparity in ASD diagnosis. Although they note this development, none of these theories have been proven and often come under scrutiny. Amongst the most widely cited is the ‘extreme male brain hypothesis’ by Baron-Cohen et al. (2005). This suggests that there is a ‘difference’ between male and female brains and that this is demonstrated in cognitive and affective styles. His work proposes that female brains are better at empathising and communicating, whilst male brains are brilliant at analysing the most complex systems – ‘systemizing’. Baron-Cohen (2003: 152) states ‘adult males prefer mechanics and computing more than females do, and many people with AS pursue mechanics and computing as their major leisure interests’. In regards to the discussed theory, Thomas recognises how his interests used to include computing, however this has changed and has now become an area he dislikes. This example could contribute to the criticisms associated with this theory, as it highlights that nothing is fixed and preferences can change dependent on a number of factors, both internal and external. This theory could be seen to foster medical model thinking whereby the functioning of the brain is subject to the body in which it resides. In regards to female brains and empathy, Louise recognises the discourse surrounding AS, stating that ‘a lot of people say that people with Asperger’s don’t have empathy’, however she discusses how she is empathetic and sensitive to people’s pain.

I over empathise with people so I'm very, very sensitive to people's pain, I want to fix things if people are hurting and I do things very practically.  
(Louise)

Although this female participant is one of the only participants that discussed the ability to be empathetic, this does not support Baron-Cohen's theory. The fundamental reason is due to questioning – at no point was empathy included within the question that was asked by this study. Jordan-Young (2010) discuss how 'Baron Cohen's studies have not been independently replicated, and have been faulted on methodological grounds'. Although there may be truth to this theory, whereby autistic males prefer 'systemising' and females have a greater ability to demonstrate empathy, the roles of 'systemising' and 'empathy' may be reflected by the cultural expectations which are attached to gender.

Although this thesis does not support Baron-Cohen's theory of the 'extreme male brain', when analysing the data a number of female participants did highlight how males on the spectrum are different to females. Laura claims that the presentation of AS is different in women than in men: 'Obviously AS presents differently in girls and women as it does from boys and men'. Louise also recognises the difference between the females and males with Asperger Syndrome, and she discusses this in regards to support groups, highlighting how they are mixed groups that won't necessarily be as relevant to females. Steven talks of the support groups for AS individuals that he attends as being predominately male, suggesting that there could be a divide of gender within the support groups. Louise claims that 'Aspie' males are 'very, very different' to females and discusses how AS women find the males 'too much', suggesting that they are 'pedantic', too black-

and-white, and too 'blunt'. Sally also discusses the inability to socialise as a male trait, claiming her plans to do a class for male 'Aspies' (see previous section) is because 'it's usually them'.

The work of Rudy Simone states that 'Women on the spectrum are a subculture within a subculture'. She discusses how, although they have many of the same characteristics and challenges as men, they have their own twist on these. She notes how it is not the difference in presentation but the perception of females that differs, thus leading to this disorder being unrecognised (Simone 2004: 13). Writings by Attwood (2006) describe women with AS as being particularly good at imitating the social actions of others and more likely to be described as 'immature' or 'odd'. The idea put forward by my female participants that the males present differently could derive from the male-dominant culture of Asperger Syndrome, whereby the literature could be seen mainly to represent males over females. With regard to diagnosis, questions remain as to to what extent girls are under-diagnosed, these events could be seen to change depended on the specific culture in which it exists. The work of Meekosha (2004) discusses how gender is often understood as the cultural interpretation of sexed bodies, claiming that it is 'embedded in the whole apparatus of a society's roles and norms'. Although the area of autism is widely discussed in regards to both males and females, great difficulty exists in finding a study that focus upon the different experiences of diagnosis of the two gender roles in regards diagnosis. Often the two experiences are discussed singly, without one gender discussing the other.

A number of female participants also discussed how it was easier to get on with a males in general as opposed to females. The first participant to discuss this is Sally, who talks about the barriers that occur talking to

females and highlights how she feels she can get on better with males. She discusses how this started in mainstream school where she got on with males more than females as females could often be 'catty'. She goes on to discuss how she is able to talk to men better than women due to the nature of the conversations being talk that doesn't require emotion.

Yes, there are some barriers because sometimes I find it hard to keep up with gossip in a group of females or if they're talking about soap operas or families or babies, holidays or marriages I kind of struggle, if it's a group of men and they're talking about music or talk about films, I mean I don't really know that much about football but I can put up with it I suppose, I find it a lot easier cause it's not really emotional talk it's more about things, separate things.

(Louise)

Louise provides a similar narrative where the ability to get on with males over females was specific to a school environment, and she discusses how it was just simple communicating with them:

I gravitated more to boys more than girls and that carried all the way through my school life because I found boys were more to the point there was less peripheral rubbish to try and work out, like girls would be complicated, they'd say they liked you then they'd say to a friend 'I don't like her', that was confusing for me.

(Louise)

Louise's account here also highlights the different nature of conversations, describing males as 'more to the point' than females.

#### **7.4. Relationships**

The work of Lyons and Fitzgerald states that 'Deficits in social communication can cause severe anxieties and avoidance of specific social situations and interpersonal relationships' (2005: 49). The term 'relationships' not only refers to partners but to also to family, friends, work colleagues and a whole range of other people. The main focus of this particular section will focus upon social relationships, discussing partners and sexual encounters. Edmonds and Worton (2005) claim that relationships can be a headache for most individuals, however for AS individuals the problems encountered are often multiplied, becoming 'unmanageable'. Within the account provided by Thomas it is noted that holding down a long-term relationship was something that he once aspired to do; however, his ideas have since changed, suggesting that the passion to do this no longer remains, 'especially after the novelty of a new relationship has passed'. He discusses how he dated a female 'Aspie' but this was unsuccessful:

Incidentally the main reason we split up was after she spent about 4 days living with me here in February, when I felt really uncomfortable having someone else in my personal space, in my home environment, being messy and disrupting my tidiness and cleanliness. And she felt that awkwardness. It was enough to put her right off me as her boyfriend, even though I thought we got on pretty well in other situations, like when we

spoke on-line and when I stayed at her place over Christmas/New Year. She just decided we weren't compatible as a couple.

(Thomas)

This account suggests that the discussed individuals communicated and interacted better in a non-face-to-face environment. The work of Edmonds and Beardon (2008) discusses the use of the internet by AS individuals, and highlights the advantages of this type of communication. They go on to suggest that it masks the demands that verbal and face-to-face communication can. Due to the advances in technology and the internet, the use of social networking is constantly growing, and the previous account affirms both AS and neurotypical individuals are using the internet for a range of communication. This could suggest that neurotypical individuals also find online communication more comfortable than face-to-face interaction. However, due to the normality of using technology and social networking it is not considered problematic unless other characteristics are present. For example, if a neurotypical individual used computers or technological gadgets for long periods of time they would just be labelled as a 'geek' or 'technology addict', but if an AS individual did the same a different term may be used, as the behaviour would be seen as a product of the diagnosis. i.e. obsessive behaviour or stereotypical patterns of interest. This is an example of the way in which individuals react to behaviour once a diagnosis has been implemented, and can be discussed in relation to the study conducted by Rosenhan, 'Being Sane in Insane Places', where it is proved that specific everyday characteristics can become a symptom or a product of abnormality when attached to a label.

Referring back to the participants' accounts regarding social communication and the internet/technology we can see that both Sally and Thomas met

their partners online. Although this is not uncommon, the diagnosis of AS in both cases could lead society to think that this was due to difficulty interacting face-to-face. Sally talks about meeting her online partner face-to-face and realising that their personalities were so different:

The boyfriend xxxxxx who I met over the internet, it was very difficult cause our personalities were so different so during the day I would give him space, I would go out to the gym or I would walk up to a friends and I would let him stay in the house on the computer cause that's what he preferred to do but we both needed space because if I'm around someone for too long, say if I'm around someone for a few days I start to get very tetchy and need my own privacy.

(Sally)

The given account suggests that the relationship between the two was not working when they were in each other's physical company. This account proves interesting as the two individuals had the same diagnosis and they both agreed that the need for personal space was the key reason in which they split. Louise also discusses how she required space within her relationship, and links the need for space specifically to Asperger Syndrome. She recalls watching a TV show about an AS character that needed space:

Six Months after we were married and what I'd have to do was to create my own space. I remember watching an episode of the Swedish series..., The Bridge, about an Asperger's character, I don't know if you've watched that? Oh you should watch that, watch the series, she's got Asperger's, she's a cop but she's got

very extreme Asperger's but they've probably portrayed it a bit too strong, but there's a scene when she basically comes home and says to her boyfriend, 'Right you need to choose, either we have to have separate bedrooms or you move out, cause I need my own space', and I was like 'Yes', I totally get that.

(Louise)

The need for space can be a requirement from both AS and neurotypical individuals, as both may require space within relationships 'due to the differing needs that occur within AS/non-AS relationships each will have a need for their own space and, if room allows, maybe an area or a room in the house that they feel like is their own territory' (Aston 2014r: 117). The work of Rodas (2004 and 2008) could be seen to reiterate that the need for space is an 'autistic trait', however this thesis poses the question of whether this really is an autistic trait or is another example of attributing everyday behaviour to a product of autism due to the attached label? What is interesting in Louise's account is that she was yet to receive a diagnosis of AS at the time, but had wanted to obtain a diagnosis of AS for a number of years. It is evident that Louise is living up to the desired label by attributing everyday characteristics and requirements to the specific diagnosis, when in reality these characteristics are a product of both neurodiverse and neurotypical individuals, just interpreted differently in regards to the attached label.

The narrative of Louise goes on to discuss how she had a lot of relationships in her teens and how they were mainly bad decisions, claiming that she reads this all the time about women on the spectrum and that this is something that she would love to speak to young women about. 'The success or failure of a relationship does not depend upon the neurological

condition of either partner, but instead on the compatibility of their personalities, values, goals and interests, commitment to the relationship and whether they really care' (Aston 2014). Mark claims 'As an Autistic being I am destined never to find love, never to have sexual intercourse with either a woman or a man, never to become a parent and never to raise children'. This is a prime example of how the discourse surrounding a particular disorder can impact upon how an individual feels about themselves and their ability to be in a relationship. As Lawson states, 'We are all sexual beings, regardless of ability, disability or illness, and we have a right to live a fully sexual and satisfying life' (2005: 20). In Mark's interview we can see that the discourse and ideas that currently exist around autism are restricting him from participating in a relationship.

Although there is no denying that the body may possess some characteristics that could be considered 'different', it is the way in which society responds to this 'difference' and the discourse surrounding it that is responsible for any barriers faced. As we can see, Mark links such inabilities to the term 'autistic being' that the question of who creates this newly developed autistic culture in which we live is one of great controversy. Classic texts produced under the medical model of disability can be seen to provide the foundations by linking specific characteristics to a medical label, however the interpretation of these characteristics by individuals can itself contribute to the autistic culture that currently exists. The work of Straus (2010) claims 'We are living in a period in which a culture of autism constructed not by a medical profession but by people with autism has begun to emerge' (2010: 549).

## **7.5. Repetitive stereotypical behaviours and social imagination**

The characteristic of obsessions was among the most commonly noted characteristics within the provided narratives. The work of Jamieson and Jamieson (2012) highlights how both obsessions and compulsions are a recognised feature of Asperger Syndrome. The discussed work also suggests that these features are related to the concept known as ‘inflexibility of thought’. Within their research, the difficulty to differentiate between Asperger-type obsessions and obsessive compulsive disorder is noted. Thomas draws similarities between strange obsessions and OCD type obsessions:

I have various strange obsessions – kinda like OCD-type obsessions, but I had real problems with that about 10 years ago – now they're not so bad.

(Thomas)

In this particular instance the two are distinguished from one another, however it is recognised that the following participant suffered from both Asperger’s-type obsessions and OCD-type obsessions. The differences between the two are investigated in the research of Neziroglu and Hendricksen (2015) where the specific symptom of compulsive behaviour is key to discussions, and it is believed that Asperger individuals may have obsessive thoughts in regards to their specific interests but the stress and anxiety is less than that of OCD. Additionally, their work distinguishes that the reasons specific interests are carried out in the case of AS is due to gaining pleasure from activities, whereas in the case of OCD the minimising of anxiety is believed to be the determining factor for such behaviour. The work of Bradshaw and Happe (2013) addresses a fundamental question in regards to obsessions and Asperger syndrome: ‘when does an interest become an obsession?’ Their work proposes that greater realisation and acceptance is needed regarding the obsession as a ‘comfort zone’,

proclaiming that feelings of empowerment are a product of greater knowledge in a specific subject. Although the narrative of Sally does not describe her obsession as a 'comfort zone', she does however note that her obsessions are a form of escape:

I don't mean to be obsessed with them it's just that I think that films are sometimes a form of escape in the same as the books are.

(Sally)

The statement of 'I don't mean to be' may suggest the participant is aware of what the rest of society considers a 'normal' amount of films to watch. Such distinctions could be representative of a culture where too much of one particular interest or not enough of another sparks debate regarding 'normality'. Malloy and Vasil (2002) debate the area of obsessions in relation to normality, addressing the impact of culture. Their research notes that if an obsession allows the individual to become recognised as an expert in a particular field then it is difficult to see how an obsessive interest in itself is a disability. Linking these narratives regarding obsessions to the historical chapters we can see that, although difference in behaviour is recognised and often frowned upon or given a formal diagnosis. the way in which others react to those who do not conform to 'normality' is a lot more accepting (although this is not to say that abuse and poor treatment does not).

In her narrative, Sally claims that she also has obsessions with people with red hair. The length of time that she has been obsessed is recognised; she states that she has not always been obsessed with this specific topic, but it stems from having her hair dyed in her teens. This particular statement suggests that 'obsessions' are interchanging. The discussion regarding

interchanging 'obsessions' is also visible within the narratives of both Paul and Mark. Mark provides two accounts regarding his obsessions; interestingly, within the first account he notes that his obsessions may never change, but in his second account he dismisses the idea of a fixed state, claiming that 'some have changed over time, others have remained with me':

There are some obsessions and addictions of mine, that may never change but that is one of the many traits of the bearer of the autism gene...

My obsessions are a multitude and they vary in several different ways, I like most autistic people have many obsessions and all of these I have long lived by, some have changed over time, others have remained with me.

(Mark)

Paul recognises that obsessions change as he does not have them anymore, however this could be due to a changing culture that may have once seen his likes and interests as obsessions and now sees them as 'normal':

I don't have those little petty obsessions anymore. I don't think I have any major obsessions. I don't think I do.

(Paul)

As previously noted, the narrative of Thomas discusses his obsessions in relation to OCD-like behaviour, but he recognises how he has fought

through them and no new obsessions are generated. He claims the ones he has are the ones he is left with:

I've fought through most of them, and don't generate many new obsessions, and the only ones that are left are those I started when it was at its worst. Still takes ages for me to shave and shower for example, which can cause problems.

(Thomas )

Mark makes a direct link to his obsessions as part of his 'autism gene', and he also makes reference to other autistic people having obsessions. However, it must be noted that all those on the autistic spectrum are individual, and that there are many levels of severity in regards to the symptoms of AS. Participant 8F observes that those in society recognise the category of obsessions, and she recollects how people ask her about her obsessions. She then notes a few, claiming she doesn't know why she gets them she just likes having them. This account can be linked to earlier discussions by Neziroglu and Hendricksen (2015) whereby it is believed that those with AS obsess over things to gain pleasure.

Although this particular chapter appears to deviate from a cultural framework, by discussing the individual realities of impairment it does, where possible, recognise the impact of medical and societal discourse on shaping one's own reality. Additionally, research carried out by Waltz (2010) highlights the role of medical case studies as texts within cultural studies research. This research highlights the use of power structures and proclaims that these are used to construct 'official' discourse about those with autism. The work of Malloy and Vasil (2002) provides discussions regarding the construction of AS, and within the accounts obtained during

this research we can see that the inability to conform to particular norms can constitute impairment.

## Chapter 8 – Concluding Discussions

‘Why did the category come about in the first place, and whose interests has it served?’ (Sleeter 1986: 47 cited in Malloy and Vasil 2002)

With regard to the previous question regarding the creation of Asperger Syndrome (AS), this thesis highlights that the term was created as a result of a particular culture and their reactions to a specific set of characteristics. The idea of disability as a cultural construct is key to the writings of a number of academics, Dan Goodley, Sheila Riddell, Nick Watson, Carol Thomas and Tom Campbell to name a few. From this perspective it is believed that ‘the socially dominant culture shapes the way in which disability and impairment are viewed, and has contributed to the oppression of disabled people’ (Riddell and Watson 2024: 1). This appears to be true in relation to the historical chapters provided within this thesis, whereby those who did not conform to social norms were labelled and treated according to the surrounding discourse. It is visible within this work that the societal treatment of these individuals has continuously changed dependent on the culture in which they exist. Reflecting on the discussed literature regarding ‘idiocy’ and ‘madness’, we can see that the characteristics that would now be defined as autism, and more specifically AS, were not solely represented within one specific category; they could have been categorised as either ‘idiocy’ or ‘madness’ or both. Additionally, due to the diversity of the autistic spectrum, it is not clear whether those who would now be labelled with AS (a high functioning form of autism) would have been labelled at all.

As the historical chapters of this research demonstrate there are a number of cultural factors that have contributed to the development of the particular term 'Asperger Syndrome'. Among these is the development of the capitalist society and the growth of medicine as a form of control and power. With regard to medicine, we can see that the term AS was born as a result of the fragmentation of non-specific medical categories such as 'General Learning Disabilities'.

Within the 21<sup>st</sup> century there are a multitude of terms that can currently be used to define AS. This could contribute to the misunderstanding and lack of knowledge that currently exists around this 'disorder'. The work of Wylie (2014) states that 'It is often very misunderstood by clinical professionals, and is often very misunderstood by the general public' (2014: 11). Such inability to understand AS may have contributed to the late diagnosis of over half of the participants within this study. In regards to diagnosis of AS, this appeared to be a key area of discussion amongst the participants in the study, and the medical discourse that surrounds this disorder could be said to define 'ways of being' for a number of participants:

Where medical literature attempts to define and thereby contain different ways of being, personal stories frequently contest such definitions, whilst simultaneously engaging with them through comparison and reference.  
(Gilbert 2004)

When identifying the personal stories in this study, which are presented in narrative form, it is apparent that medical literature does in fact play a fundamental role in the definition of 'being' for a number of participants. One

particular participant highlighted how being given a diagnosis is like becoming more autistic:

It's like you become more autistic and suddenly things that were really easy for you to do are suddenly not easy and it's really quite traumatic cause everything you knew you were just gets stripped away and having Asperger's I struggle with an identity.

(Louise)

The experience of the label is important within this study as it is unique for all individuals. For some participants it provides a sense of identity and justification for why they have felt 'different', for others it helped them to access particular support networks, and for others it meant added pressure of living up to a new label:

Now I have to explore what being and Aspie means for me. How will it affect my career now I know about it? Should I be in a relationship or should I stay single? I have realised I can't handle too much going on in my life. It's either work OR a relationship but I can't handle the stress of both.

(Anne)

Prior to the implementation of the label a number of participants highlight that they had mimicked 'normal' behaviour and tried to find ways to appear 'normal', suggesting that the normal/abnormal dichotomy is key to the experiences of AS:

I've had to disguise it because I've learnt how to mimic normal behaviour and gradually it's become more and more natural.

(Sally)

Throughout my life, I've become good at 'putting on a mask', and acting 'normal'

(Thomas)

Such experiences highlight the exclusion of those with a unique set of characteristics that could in some cultures be seen as a gift. However, due to the particular norms within this society individuals are forced to change and act like the majority of society or face discrimination.

The discussions regarding bullying were amongst the key findings of this study. These accounts were of periods prior to the implementation of a medical label, and were especially applicable to the school setting. This study recognises how bullying was specific to particular institutions whereby 'difference' and 'ab/normality', rather than a medical label, were central to understandings. It has been recognised, within the literature and by the participants, that late diagnosis in AS is common, and therefore the children who the medical professional would later diagnose are essentially 'lost' during this period, with no support provision in place. A plethora of narratives highlight that these pre-diagnostic periods are and were times of great struggle due to the attached labels of 'weird' and 'different'. Although this thesis does not advocate the use of medical labels, it does however recognise that without a label no support is initiated. The negative discourse that surrounds the idea of difference could be seen to stem from the historical ideas that 'difference' is something to be eradicated not valued. It must be recognised that this thesis does not reject the ideas that

impairments exist, but recognises that it is the interpretation of those impairments that contributes to, and in most cases creates, disability. 'Impairment alone is not thought to be disabling, it is when society isolates, excludes and stigmatises these people when impairment becomes a disability' (Schur et al. 2013). This particular finding highlights the growing need for support within the schools for children who may have unique sets of characteristics but do not have a medical diagnosis. As this study highlights, six participants all chose to discuss bullying in school within their narratives. Such discussions could potentially be an area of great importance on a macro-scale and indicate the need for further research regarding disabling barriers.

The issue of employment was also central to the discourse of a number of participants, and highlights the lack of education regarding autism and more specifically AS in employers. This study identifies the difficulty that individuals have obtaining and sustaining employment, and in a number of cases relates this to social interaction and communication:

Even with those I could apply for, I couldn't get through the interviews (most didn't know I had AS for a start, and anyone with AS who has looked for a job will know just how many seem to require "good communicators", which I'm afraid we certainly aren't).

(Thomas)

Although the difficulty in communication is visible within this narrative, the changing requirements regarding communication within the workforce throughout history could be seen to disable individuals. The participants in this study highlight the lack of support services within this area, calling for more to be done by employers. The discussions regarding employment

suggest that this area is important to individuals and requires immediate attention. The lack of employer education regarding AS could be seen as stigmatising and oppressing, and thus limiting opportunities that would be available to the majority of society. The *Equality Act* (2010) was implemented to ensure that all individuals are given equal rights, and these rights apply to employment, but how can these rights be executed by the employer if they do not know exactly what AS is?

This study also highlights the need for further research regarding gender and AS. Within the narratives it was evident that some participants thought that AS was experienced differently depending on gender. For example, two female participants discussed how males on the spectrum were different to females. Louise claims that males with Asperger's are 'very, very different' to females. She discusses how AS women find the males 'too much', suggesting that they are 'pedantic, too black and white, and too blunt'.

Obviously AS presents differently in girls and women  
as it does from boys and men.  
(Laura)

This finding initiated discussions regarding the cultural expectations regarding gender and how these could link to the diagnostic prevalence in males. As previously recognised there was only one question asked within this study, and the interviews were participant-led, therefore elaborating on specific discussions proved difficult and would require a second round of studies.

In regards to historical understandings of AS, the terms 'idiot' and 'savant' were visible within the narratives of two male participants:

The problem is other people mix up autism with savant syndrome, and the film which caused this, or so I'm told was Rain Man with Dustin Hoffman, people wonder what your special skill is, especially talking about children with autism.

(Alan)

I think people kind of... Some people kind of think I'm like this know-it-all, this like idiot savant.

(Paul)

These accounts highlight how modern-day discourse around AS is still influenced by historical understandings of “idiocy”. Additionally, the pre-labelling accounts use terms such as ‘weird’, ‘abnormal’, ‘different’ and ‘mental’, and the term ‘mental’ could be seen to link with historical ideas of ‘madness’.

The primary aim of this thesis was to enable individuals to have a voice in order to develop further understanding of AS. As discussed within the methodology of this thesis, the study is unique in the sense that it only asks one question; therefore any emerging themes and the areas the participants chose to discuss were reflective of them as individuals. The participants provided a large amount of data regarding their lives, some of which may be used for further studies. However, the main findings in this study were relating to bullying (pre-diagnosis), employment and experience of symptoms. This study aimed to provoke further thinking around AS in regards to the nature of ‘disability’ as a culturally created concept. This study has highlighted that culture does in fact shape the way that we view AS, although the medical discourse plays a fundamental role as we can see that the historical ideas of ‘difference’ and ‘abnormality’ continue to be key

factors in the experience of disability by AS individuals. This thesis also recognises a number of emerging themes; however, we must recognise that all experiences of these themes were unique to the individual participants. It is evident that the area of AS is an area with significant gaps in research, but we must be mindful when carrying out research in this area that the discussed individuals are recognised as unique individuals with a range of skills and abilities, just like a person who has not been labelled with AS. Additionally, this research could be used to educate society that all individuals with AS are different, as a greater general understanding of this individuality is required.

The issue of employment was also discussed by a number of participants, and their accounts highlight the lack of employer education regarding autism, and more specifically AS. Participants discuss great difficulty obtaining and sustaining employment, and in a number of cases relate this to social interaction and communication. The participants in this study highlight the lack of support services within this area, calling for more to be done by employers. The discussions around employment suggest that this area is important to individuals and requires immediate attention as it is in fact stigmatising and oppressing individuals, and thus limiting their opportunities that are otherwise accessible to the majority of society.

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