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A Case Study of Parents’ and Professionals’ Experiences of the Referral Process for Assessment of Potentially Autistic Children

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Abstract

The route to diagnosis for potentially autistic children is well documented to have historically long waiting times. Before an assessment can take place, a young person must first be referred for an assessment, this referral can itself take many years before a young person begins the wait for an autism assessment. This thesis examines the current referral process in one local authority in the UK in order to identify areas where the referral system could become more effective. The research is a qualitative design using case study. Professionals and parents involved in the referral process were interviewed so that perspectives were taken from people that experienced the referral process through different lenses. Grounded Theory approaches with constant comparative methodology were used in order that all prior interviews were compared with new interviews, reinforcing theory generation. Results showed that the separation of autism from Asperger's had a detrimental effect on effective referrals for autistic children, the paper-based questionnaire in this local authority was also shown to be inadequate due to the heterogeneic nature of autism. Discussion led to a new online referral system, more in line with the individual needs of each user which would lead to earlier identification and more tailored support for autistic children. It is theorised that autism is more complex than is currently explained, therefore there is a need for revised criterion with neurodivergent-friendly language in the DSM-V; the current manual used to classify and diagnose differences such as autism.

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List of Abbreviations

ASC	Autism Spectrum Condition
APD	Auditory Processing Disorder
ASD	Autism Spectrum Disorder
CAMHS	Child and Adult Mental Health Services
DCD	Developmental Coordination Disorder
DSM-V	Diagnostic and Statistical Manual of Mental Disorders
EHCP	Education and Health Care Plan
EP	Education Psychologist
GP	General Practitioner
NHS	National Health Service
OCD	Obsessive Compulsive Disorder
OT	Occupational Therapist
PDA	Pathological Demand Avoidance
PDD	Pervasive Development Disorder
SALT	Speech and Language Therapist
SENCo	Special Educational Needs Co-ordinator
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
SPD	Sensory Processing Disorder

Chapter 1: Professional Context

Introduction

The current route to referral for potentially autistic children differs greatly across the UK, however in many areas parents cannot refer their children directly for an assessment. The referral process therefore involves pre-assessments from health professionals such as speech language therapists (SALT), paediatricians and educational psychologists (Ed Psych/EP) who take evidence from teachers and parents alongside their observations to determine whether they think that a child meets the criteria to be assessed by the autism panel. This pre-assessment time is not noted in any current data relating to diagnostic waiting times for autism and it can be evidenced how this can add many years to the time that it takes for a child to be diagnosed as autistic. This thesis raises the question of what the referral process is within one area of England from the perspective of parents and professionals who have been involved in the referral of children with potential autism. I will question interviewees on their experience of the referral process and how they think that the process could change to streamline the referral process. I will also be questioning if the removal of ‘Asperger’s’ diagnosis has had an effect on the autism referral process.

1.1: Language

The way in which autism is described has changed dramatically in recent years, therefore after much thought and speaking with other autistic adults, the thesis has been written in identity-first language – ‘autistic children’ as opposed to ‘children with autism.’ Hattersley et al (2016) conducted a survey of 3470 UK residents, and although there was a great disparity in outcomes, the majority of autistic adults preferred identity-first. There is also much debate on how autism is described, and throughout the thesis there is evidence which shows autism quoted as ‘ASC’ – autism spectrum condition and ‘ASD’ – autism spectrum disorder. The thesis, unless using references to other work, simply uses ‘autism’ to align with notions of neurodivergence; that autism is part of a person’s identity, and not something that can be fixed or cured. Although this language will not agree with all members of the autistic community, this seems to be the preference of many, and therefore has been chosen to ensure that the thesis was written in a respectful way, to both autistic people and those that support them. As autism research is developing constantly with many new discoveries and theories constantly emerging, there is a cut-off point with regards to new theory, the main thesis theory collection for evidential purposes therefore ended circa 2022.

1.2: Current diagnostic process

The diagnostic process for autism in the UK is so varied, that it is difficult to state exactly what the process is. The NHS website page, ‘Getting diagnosed with Autism’ states that, ‘It is not always easy to get an autism assessment. Waiting times can also be exceptionally long’ (June 2021). The diagnostic process has been much debated and reviewed, and this is discussed in detail alongside how this could prove challenging for families and professionals when seeking help for autism referrals.

1.3: Positionality Statement

Having a son diagnosed with autism at 13, gave me a compelling reason to research referral procedures for potentially autistic children. Our own route to diagnosis was problematic and after spending time researching routes to autism, I found that our journey reflected that of many others across the UK. As part of a social media parental forum and being part of a local autism community group, I realised that we were not alone and this in fact was a problem that had been evident for many years. In addition to this, as a primary school teacher, I realised a consistent trend across school’s Special Educational Need Co-ordinators (SENCo) of frustration and despair, with many opting to leave their role citing red tape and a feeling of hopelessness in not being able to refer children to the appropriate services.

Our own journey started with talking to my son’s primary school SENCo, as suggested by the NHS website, however my son’s teacher had not noticed any of the differences that we saw at home. Instead, they saw a well-behaved young boy who was academically at expected level. We, on the other hand, saw a child that burst the moment he left school with social, emotional and fine motor skill difficulties. His ability to hide emotions or ‘to mask’ in school led to teachers not being able to give evidence towards a referral into autism services. In total, it was five years before he was diagnosed and during his assessment the professionals told us that is was clear from the evidence gathered and his presentation that he should have an autism diagnosis. With all this mind, it posed the question, why was the referral process so difficult and was this the case for other parents of autistic children? My son says that his diagnosis has given him a reason - but not an excuse. The change in him as a person is profound. If he had been diagnosed earlier on, I can confidently assume that his primary life would have been far more enjoyable, with school giving him the correct support, him being able to accept and even become proud of his autism at an earlier stage and we, as parents, would have been able to seek support for our wider family

As a parent, having a child diagnosed as autistic in secondary school left me with a feeling of guilt; that I hadn't recognised autism as part of my son's special educational needs at an earlier stage. I reflected negatively on many situations in our lives where I could have been a more nurturing parent. I also felt guilty in wondering if I was to blame. As I began to read articles about autism, I read about Kanner's statement that parents were not 'warm-hearted' (1943) followed by Bettelheim's idea of the 'refrigerator mother' which summarised that cold and rejecting parents were to blame for autistic children (1967). Since then, there has been limited research on parental behaviour as such research, 'would add to the guilt many parents of children with ASD feel about what they could have or should have done differently to prevent or correct their children's problems' (Crowell et al, 2019:21-29). Early guilt which resulted in increased stress is typical in many parents of autistic children (Jocelyn et al, 1998; Iadarola et al, 2018), caused by the lack of help and support available to newly diagnosed families. Alongside my conversations with overwhelmed SENDCo's and the break down in relationships that can occur between schools and parents, I felt that it was important to start a discussion about what the referral process is and why there are difficulties in referring children for autism assessment. Throughout the writing of this thesis, my daughter has also been referred for an autism assessment. This referral was much different and was based on the factors that (a) my son is autistic and then (b) there was enough tick-box evidence to be able to pass my daughter through the referral stage to the autism waiting list.

The tick box questionnaire is a form that is sent to the parent and the school, and based on how many points are given based on typical 'autistic traits;' then the referral is either successful or is refused. Significantly, my daughter does portray more 'typical' autistic traits: outbursts, poor concentration, learning difficulties and struggles with friendships. It could be said that my daughter portrays more typical autism traits however my son would have been diagnosed with Asperger's Syndrome, which was a different diagnosis under the autism umbrella. There is some discussion around the differences between Asperger's and autism and why the ability to diagnose someone with 'Asperger's' was removed. Within the interviews and when discussing routes to assessment, I question whether removing the Asperger's diagnosis had a detrimental effect on the autism referral process. Since writing the thesis, I have received an autism diagnosis. As an adult, the referral process was simple, a quick tick box of autistic traits and then a referral to a private company via the 'Right to Choose' platform. In all, the referral took less than one week and diagnosis took 8 months in total. I question why the referral process cannot be the same for children in this specific area of the UK and why the council have not removed a line of gatekeeping by allowing parents to refer their children directly themselves.

In January 2023, I opened an Alternative Provision that provides education for children that struggle to attend mainstream classrooms, mainly those with Special Educational Needs. We currently support over seventy children back into mainstream school or into specialist full-time schools, helping to provide evidence and support for families where they need additional help to access referrals; diagnosis; educational and emotional support and funding. Although the provision is not within the same council area as my thesis is studying, it has allowed me to have discussions with families that have been in the same position as I, it has also given me access to moments of best practise in order to share information with other parents. Developing my understanding of this area of SEND and finding ways in which I can make a difference has changed my life and will hopefully help to make a difference to the lives of many others. In September 2024, my business partner and I created and opened our Independent Special School. The school caters for children with interaction and communication difficulties.

1.4: Case of Council X

As the diagnostic process is so different across the country, the thesis is based on one LA (Local Authority) in the UK. All the interviewees are based within this LA and the council's specific autism procedures have been examined. The LA is referred to as 'Council X.'

The referral process of Council X is stated on their website's local offer:

> *Completed referrals will be accepted from the following professionals only:*
> - Speech & Language Therapy
> - Educational Psychology
> - Portage
> - Paediatricians
>
> **Please note** direct referrals from parents, GPs and schools cannot be accepted. (accessed November 2021)[1]

As parents are not able to refer their own children, those living in Council X could first speak to their GP, who could access speech and language therapists and/or a paediatrician. However, in the aftermath of lockdown current waiting times for non-urgent appointments have risen, with a current waiting time of four weeks for a face-to-face GP appointment in Council X (as of November 2021). The GP could then ask for a speech and language therapist (SALT) appointment. These are currently being handled over the telephone, with services targeted to see children within a three-month period. After the initial appointment, an assessment would then be carried out at the child's school, with an additional waiting time of four weeks. This suggests that best case scenario, 120 days have passed since the first appointment. The referral then relies on the SALT observing the child in a school setting within one day, with another appointment set to then speak to the child on a one-to-one basis. The SALT must see enough evidence in those two appointments to be able to refer to autism services, however even with the most specialised of SALT practitioners, observing autistic traits in such a small window of time faces many challenges, for example, how a child 'masks' in the educational setting.

Masking, which is also known as 'camouflaging' is where an autistic person copies societal 'norms' to blend in with neurotypical people. In an educational setting, a child may look as though they have had a settled day, with no examples of them struggling, however when they leave school, the parent describes the 'coke bottle effect' where the child then explodes all their emotions and feelings that they have kept hidden. Although this may help the child get through the day, it has implications in that the cognitive load needed to 'mask' takes away from the student's ability to learn. In addition to this 'brain drain:'

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[1] To keep Council X's anonymity for ethical purposes, the website is not listed in the Bibliography

> A perennial issue …is that of school simply not believing the child or parent…after all, the child ‘appears’ to be absolutely fine at school.’ (Lawrence et al, 2019:35)

If teachers do not see the potentiality of autism in a child due to masking, and SALT also do not see this, then the possibility of referral for autism is further prolonged or denied. This would be the same if the school asked for an Educational Psychologist (EP) to assess the young person in school. Observations by the EP are carried out in the same way as with SALT, with a small window of opportunity to view the child in a setting. This could be very damaging and could lead to years of a child not being assessed.

1.5: Original Contribution of the thesis

The problematic route to diagnosis of autism is well researched, with issues related to unclear diagnostic pathways (Rutherford et al, 2016) waiting times (Crane et al, 2015), the need to educate referrers to better identify autism (NICE, 2012) and the need for better identification of potentially autistic females (NICE, 2012). Other research studies on these issues are abundant (Howlin and Moore, 1997; Siklos and Kerns, 2007; Wiggins et al, 2006) with the first source dating back 23 years. These issues are discussed at length to show how the diagnostic process is an issue that has been apparent for many years and does not appear to be improving from the point of view of non-consistent approaches and waiting times. Even though there is a prolific amount of study in this area, the waiting times for assessment are still much longer than the NHS thirteen-week deadline with 84% of under 18’s not meeting this target (NHS, 2021).

Other circumstances that have affected the lack of progress with the time taken to assess children includes the UK government’s austerity programme which included cuts to public health services: ‘the budget for public health services is now £850 million lower than in 2015/16 and by 2021 the budget will have been cut by 25% from its 2015/16 level’ (2020 NHS Support Federation). This has affected both NHS and educational budgets which have a direct impact on children with SEN:

> ‘The National Office (2018) calculates that that high-needs funding per pupil fell by 2.5% in real terms between 2013-14 and 2017-18. The continued rapid expansion in the pupils with SEN statements or EHC plans means that such real-terms cuts in funding per pupil have certainly continued through to the present day, at least at the same pace.’ (Britton et al, 2019:52).

Even with the government’s ‘Autism Strategy 2021’ document which refers to the NHS’ ‘Long Term Plan’ for improvements in autism services with £75 million promised in the first year (DHsc, 2021), there is no information to suggest that there is an understanding of waiting times of children that are struggling to be referred to services and the years of delay that this can add to the diagnostic process.

Another factor that has led to increasing diagnosis times is the year-on-year increase in referrals which has, ‘led to massive pressure on autism diagnostic services’ (Whitney and Stansfield, 2019). Although referrals dropped by 31% at the start of the Covid pandemic in April 2020 (compared with April 2019), by November 2020, referrals had increased by 6% ((ONS, 2021). The increase has been noted across all autistic services, with some believing that the reason for the increase since the pandemic could be due to the increased contact time between parents and children and their, ‘growing concern about challenging behaviours that they have observed’ (Hey, 2021).

The financial gain in streamlining the referral process for education and health care would be beneficial. The volume of appointments that parents made for children, often more than three for the same need, would help to cut down doctor’s appointments nationwide. With around 700,000 autistic people in the UK (autism.org.uk 2020) the financial benefits of a streamlined referral process would be substantial. As governments are focused on change which has a desirable effect on the economy (Parveen, 2019)) then it is likely that the government would set about changing policy that had a positive impact on health and education budgets.

As discussed, although the route to diagnosis has been much debated and researched, the problematic route to assessment is rarely referred to. This coincides with the inconsistencies of the pathways to autism diagnosis across the UK which leads to confusion to those seeking an assessment. Previously, researchers have focused on the autistic child or the autistic adult or the diagnosis process. By interviewing parents and professionals, I have had an insight into how the referral process system has been experienced through different lenses. I have then identified ways in which the referral process could be improved.

It has been important to me that I have remained unbiased throughout the research, my strength within this research is that I am in a position that other researchers may not be: I am an autistic woman; I have two autistic children; I am a teacher; I am a SEND professional that refers children into services. I therefore could be bias from any one of these points of view. It has been essential that I focused on the importance of the study. My questioning of participants’ understanding of the referral process, their thoughts on the removal of

Asperger's from the diagnostic manual (DSM-V) and how the process could be streamlined could then be used to effect positive changes within referral practise. My original contribution is therefore as follows:

- To research the referral process from the perspectives of professionals and parents involved in the process to achieve an overview from different perspectives within one research study.
- To research the experiences of professionals and parents involved in the referral process to identify any areas of practice which could streamline services to make them more effective.
- To highlight how autism waiting times are not factual as they do not include the time taken to access a referral.

1.6: Structure of the thesis

The thesis is structured as follows:

- **Chapter 2 – Literature Review**

I will examine 'what autism is' from a historical and cultural perspective. Behavioural, biological and cognitive aspects of autism will be explained and how these different components can exist, co-exist or not be apparent in autistic people. Inconsistencies in UK referral processes will be discussed alongside the benefits of timely diagnostic referrals.

- **Chapter 3 – Methodology**

I will explain my use of qualitative research: a case study with aspects of grounded theory methodology and how this research fits well with constructivist research. I will show the differences in objectivist and constructivist approaches which becomes an important factor when I later analyse the referral process for autism versus autism itself.

- **Chapter 4 – Themes**

This chapter reveals the topics and patterns that have arisen through thematic analysis, creating three main themes:

1. The identification of autism in children
2. The differences in professional support
3. The referral process itself

Each theme is then discussed through different lenses which link back into evidence and discussion from the Literature Review.

- **Chapter 5 – Finding and Discussion**

The theme and sub themes are examined from the perspective of each of the participants. At the end of each theme there is a summary followed by a discussion at the end of the chapter which discusses the value of the evidence provided in the findings.

- **Chapter 6 – Conclusion and Recommendations**

This chapter provides recommendations about referral procedures, by evaluating the discussion alongside themes and sub-themes that have emerged from the data, then suggesting changes to create a more streamlined service as indicated from the interviewees.

My core research questions are:

- What are the experiences of parents and professionals involved in the referral process?
- Has removing Asperger's had a detrimental effect on the referral process for potentially autistic children?
- Could the referral process be changed to streamline services and reduce autism waiting times?

Chapter 2: Literature review

Introduction

In this chapter I look at the history of autism and how evolving theories have created changes within the diagnostic criteria within the DSM-V. The next section then focuses on the heterogeneity of autism: how autism is different for every person and can also be different across genders. The heterogeneity of autism itself is shown as one reason why referrals can be problematic: there is not one list of traits that are apparent in every person. The current categories of autism are then explored, with each DSM-V criteria listed and discussed. The next sections highlight Fletcher-Watson and Happe theory (2019:2-3). They identify autistic traits based on a 'diagrammatic tool' introduced by Morton and Frith (1994). This divided autism into three categories: biological, cognitive and behavioural, I have examined these categories to show why it is difficult for professionals to refer children for autism assessment based on the diagnostic criteria of DSM-V. Finally, I will look at the current referral practices in the UK and then more specifically in Council X, which has been chosen due to geographical location. Despite the fact that the current processes for referral align with a medical model of disability, I personally believe that if we followed a social model then children would be treated as individuals and not a homogenous group of 'neurodiverse.' Within the social model, the more inclusive biopsycho-social model may also be useful to reflect on an individual's neurological differences whilst also being conscious of how environments need to be inclusive for the neurodiverse. It would be helpful to bear this in mind when proposing any changes to the referral process.

Due to the complex discussion of autism and other diagnosis alongside collaborating theory, I have summarised the following discussion into a table of key theory and DSM criteria changes with dates.

Theorist	Year	Theory/Change to DSM
Kanner	1943	Observed 11 children with similar traits. Autism was professionally recognised.
Asperger	1944	Observed children with superior language, poor gross motor skills – research came to light in the 1970s
Kanner	1949	Kanner described autistic children as being reared in emotional refrigerators. 'The refrigerator mother.' "Problems of Noslogy and Psychodynamics of early infantile autism.
Bettelheim	1960's	Advocated for parent-ectomies (removing children from the care of their parents.
Rimland	Late 1960's	Refuted that environmental factors were the cause of autism and looked more towards biological factors.

	1968	DSM-II autism described as a form of schizophrenia that presented in childhood
Wing & Gould	1979	Categorised autistic children in relation to their social interaction style.
	1980	DSM-III listed specific criteria that were needed for an autism diagnosis
	1987	DSM-III revision add Pervasive Developmental Disorder added
	1994	DSM-IV listed Asperger's, Childhood Disintegrative Disorder (CDD) and Rett's Syndrome as types of autism.
Wing & Gould	1996	Viewing Asperger's as a separate 'autism' could be used to exclude a child from appropriate services.
	2013	Revision of Diagnostic and Statistical Manual of Mental Disorders – Asperger's, CDD and PDD no longer a diagnosis, all now under the umbrella of autism spectrum disorder
Fletcher-Watson and Happe	2019	Divide autism into three categories: biological, cognitive and behavioural.

Table 1: Table of key theories, DSM changes and dates

2.1: Historical Context

1940-1950

The term 'autism' is derived from German psychiatrist Eugen Bleuler's description of schizophrenic adults' social withdrawal (Bleuler, 1950) and to define autistic thinking, which he said was 'characterised by infantile wishes to avoid unsatisfying realities and replace them with fantasies' (Evans, 2013:3). Nadesan (2005:14) reports that the arrival of autism as a 'meaningful diagnostic criterion' reflects society's 'cultural and economic' transition into the twentieth century, as during the 1800's, 'the standards of normality were much broader.' In 1943, Leo Kanner observed 11 children with similar personality traits and from this, autism was professionally recognised (Kanner,1943)). His observations drew on similarities which included:

- how children were observed happiest when alone
- how they ignored outside noises, contact or motion as if it was not there
- that they did not change their posture in anticipation of being picked up by parents
- that some children were non-verbal, however, others had learned to recite and remember difficult lists, poems and facts from a very early age
- that children repeated words and were unable to move words away from their meaning to apply them to different contexts
- that children either over-ate, or refused to eat
- Change was difficult
- Children were frightened of loud noises
- Children had highly intelligent families

At the same time as Kanner's observations, Hans Asperger was observing children in Austria and he came to similar conclusions to those of Kanner, with the exception that his group of children all had superior language skills, all had poor fine and gross motor skills and that his children did not learn by rote, as in Kanner's group, but instead learned by being spontaneous (Asperger, 1944). However, this research was not brought to light until the studies of Wing and Gould some thirty years later.

1950-1960

Due to Kanner's research, there was an increase in the number of autistic children towards the 1950's (Kanner,1973), also, 'schizophrenia was everywhere' (Wolff, 2004:363) which included autistic children as it was seen to be an early manifestation of this condition. Over the following the years, there were many different theories that attempted to account for autism, many of which focused on the 'role of the environment' in the diagnosis of autism (Chevallier et al, 2011) which included Kanner's uptake of the 'refrigerator mother' theory where autism is said to be caused due to a lack of nurturing by the mother during early childhood. This could be a reason why they did not ask for their children to be assessed, as 'many mothers felt a deep sense of anguish and resentment towards child psychiatrists who often made them feel as if they were to blame for their children's autism' (Cohmer, 2014).

1960-1970

In the 1960's, Bettelheim (who agreed with Kanner) was an advocate of removing children from the care of their parents (parent-ectomies) which must have caused immense fear for autistic children's families. At the end of the 1960's, Bernard Rimland's advocacy for parents grew after helping to establish the NSAC in the US (National Society for Autistic Children). Rimland had a son, Mark, who was autistic, and he wrote a book which refuted that environmental factors alone were the cause of autism. He argued that if psychogenic factors were to be believed by biologists, then there would be no reason to continue to research the biological causes of autism. His study 'reoriented research' looked more towards biological factors (Cohmer, 2014).

1970-2000

In 1979, Lorna Wing and Judith Gould expanded on autism research by sub-categorising children in relation to their social interaction style (Wing, 1979:11-29):

Social Interaction Style	Observed Traits
Aloof	Seeks no social interactions, lacks reciprocal friendships
Passive	Does not seek social interaction, will respond to others

Active but Odd	Actively seeks interaction with others however does so in an unusual way (stands too close, only wants to play their chosen game/ speak about their interest)

Table 2: Wing and Gould's sub-categories of autistic children's social interaction styles

Alongside social interaction, Wing and Gould studied communication and imagination to look at 'patterns of impairments and behavioural abnormalities' (1979:27) which later became known as the 'triad of impairments.' This method of sub-categorising autistic traits continued; however, none have 'proven definitive' (Fletcher-Watson et al, 2019:19) and Wing's later work states that, 'assigning them (autistic children) to a subgroup is of little value' (Wing 1996:31) due to the overlapping of traits in each individual. Wing also stated that the separation of Asperger's Syndrome from autism as an 'atypical autism' was unhelpful as it could be used as, 'an excuse to exclude a child from appropriate educational services.' (Wing 1996:30).

2000 onwards

The integration of autism diagnoses, where Asperger's was no longer recognised as a diagnosis, occurred within the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V). The manual is a revision of the earlier DSM-IV, which was last revised in 1994. The changes were brought about due to developments in the understanding of, 'neuroscience, clinical and public health need' (Regier et al, 2013:92) and was published in 2013. Although the manual was created in the United States, the diagnosis criterion is used worldwide, this is in part due to the US being the 'world's most diverse country' (Alarcon, 2014:310) with the DSM-V making inroads by taking into consideration cross-cultural variations (Alarcon, 2014).

The way in which the DSM-V deleted Asperger's as a diagnosis could also have been due to the negative connotations relating to Hans Asperger himself. Described as a Nazi socialist, he was rewarded with his loyalty to the Nazi party by advancements in his career, he also 'publicly legitimised race hygiene policies including forced sterilizations' (Czech, 2018:4) and was also shown to be cooperating in the child 'euthanasia' programme where disabled children would be tested on or sent to their death. Several movements arose to remove Asperger's name from an autism diagnosis as people did not want to be negatively associated with his past. It is also said to have been removed as some people argued that autistic people and those diagnosed with Asperger's and Pervasive Development Disorder (PDD) all had similar traits which were able to be diagnosed as simply 'autism' (Linton et al, 2014). Not everyone from the autistic community agreed with the extinction of 'Asperger's Syndrome' (Giles 2014:179-195), for example many thought that the removal of the term meant that they had lost their identity, (Linton et al, 2014) also showing that fewer people with an Asperger's diagnosis now met the criteria for an autism diagnosis, particularly with regards to the diagnosis of females. This information helps to put into context why Asperger's was removed as a diagnosis which leads to the thesis question, 'Has removing Asperger's from the referral process had a detrimental effect on the process?'

2.2: Heterogeneity

As stated by Wing, the dyad of impairments overlap, autism is therefore a heterogeneous condition that makes observing common behaviours problematic. Heterogeneity 'denotes diversity or variability; it describes dissimilar parts that are somehow connected' (Georgiades et al, 2013:123); it could be productive to relabel autism as 'the autisms' to consider the many variations (Masi et al,2017). Georgiades et al developed this idea, by saying that the very nature of the heterogeneity of autism should be researched so that it can 'provide a framework' that would guide new study designs and the future measurement of autism diagnosis (2013:123-124). There has also been debate on whether any one thing can be labelled as 'autism' (Hassall, 2016:50) highlight the difficulties professionals have in identifying something that is so varied. The heterogeneity of autism across society can be evidenced through the exploration of gender differences (Kirkovski et al, 2013; Kim et al, 2011; Mattila et al, 2011). It is widely recognised that autism is more prevalent in male than females, although the gap is closing; 'the true male-female ratio … is closer to three to one' (Loomes, 2017:466). This research concluded that there is a diagnostic gender bias, because girls who meet the criteria for autism are at a higher risk of not receiving a diagnosis (Loomes, 2017). This may be due to the diagnostic process using one set of criteria designed to meet all when it is widely recognised that females are more likely to mask to disguise their differences, therefore their ability to imitate social situations do not reflect the struggles that females face. This results in people who become experts at not appearing to be autistic who are then less likely to be referred for assessment (Bargiela et al, 2016). Heterogeneity also appears within gender: many studies show that there is higher prevalence of autism within females who have co-existing conditions (DCD, ADHD etc) and those that are often described as 'lower functioning' with ratios as high as 2:1 (Fombonne 2003:13). This could be due to people who are academically more able therefore more able to socially camouflage; quicker to watch, react and respond to conversation, more likely to look for small gestures or facial expressions to decide upon a reaction. Often, it is explained that the differences that can be seen in social interactions of females and males is due to females having higher social expectations placed on them, as they 'rely more heavily on communication and reciprocal sharing of interests' (Kirkovski et al, 2013:2584). It is debated that this contrasts with boys who are more likely to play sports, watch movies or play video games which requires less interaction (Bauminger and Kasari, 2000). The expectations placed on females to be better social communicators can then help to recognise autistic traits in females (Cheslack-Posteva et al, 2012). However, if females are more active in communication, then it could be argued that they may be more experienced in 'masking' their differences as they can learn from and then imitate their peers. On the other hand, if boys are less engaged in social communication, then they are less practised and therefore their differences in 'normal' social communication instances would be more impaired. Georgidas et al (2013:123) highlighted the need to further study the heterogeneity in autism so that future research could work towards providing a general framework that could guide the 'development, implementation and interpretation of new study designs and measurements…to capture individual and subgroup differences with autism.' However, the current diagnostic tool does not reflect this and the changes from the DSM-V to the DSM-V-TR maintain the 'high diagnostic threshold' by increasing the number of criterion needed to gain a diagnosis (First et al, 2022).

Mottron et al (2020:3178) ask:

> What is common between intervention strategies supporting adults with an academic written and oral language and an intellectually disabled, syndromic autistic child with self-injurious behaviours?

If there is only one 'categorical diagnosis,' it is difficult to put interventions in place to support autistic children. As shown in the 2021 Department of Education analysis of SEND, needs remain, 'more prevalent in boys than girls. In January 2020, 15.2% of boys received SEN support compared to 8.7% of girls, and 4.8% of boys had an EHCP (Education and Health Care Plan) compared to 1.8% of girls' (DfE, 2021).

2.3: Behavioural Factors

The following diagram shows the criteria for the diagnosis of autism as shown in the DSM-V. It is important to highlight that the language used in the DSM-V criteria is problematic and only used as reference to the manual. For example, the term 'deficits in non-verbal communicative behaviours,' is a negative perception of autism, 'deficit' meaning a deficiency or failing. This is refuted by many neurodivergent people who see autism as being a difference, they see the world in a different way to others, it is not a deficit. The section following the diagram will expand on each element of figure 1.

The diagnostic tool separates its criteria as follows:

A. Social communication and interaction deficits

B. Restricted, repeated patterns of behaviour
C. Early presentation of symptoms
D. Significant Impairment of current functioning
E. Not better explained by other intellectual disorders

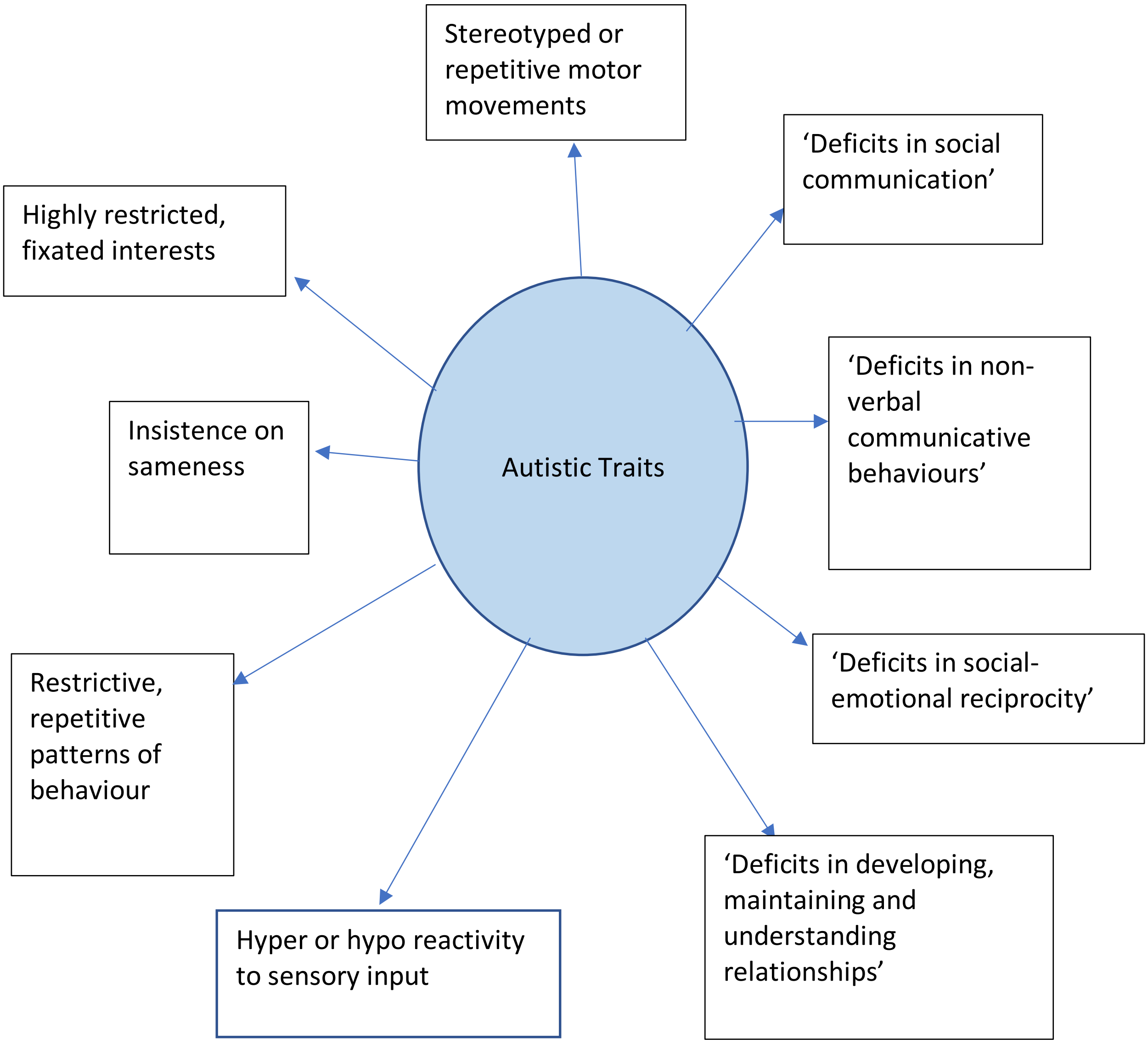

Figure 1 Behavioural Factors

2.3.1: ‘Deficits in Social Communication’

The first DSM-V criteria is: ‘social communication deficits’, which relate to: the ability to hold conversations (Belton, 2006), symbolic play (Kasari et al, 2006), the initiation of social communication (Whalen et al, 2006), and how attention is held during social interactions (Kasari et al, 2006). In research carried out by Jones et al, two types of social communication were studied, responsiveness to communication and initiating communication. The investigation examined patterns during ‘traditional dinnertime conversation’ and found that children with autism, ‘initiated fewer leads for interactions, commented less…and responded less' (2008:432). Many theorists (Lee et al:2013; Chevallier et al: 2012; Costestcu et al: 2022) believe that social communication deficits are one of the most telling signs of autism, and that if we had more of an understanding of this trait, then we would have more of an understanding of autism. However, Jones' research found that as children get older, their social communication deficits do not disappear, they are simply shown in different ways. Jones et al suggest that this finding has, 'implications for research and interventions in the future' (2009:438). This research highlights the thought that autistic people need intervention to increase their social communication skills. However, other research has shown that where neurotypical children are trained to initiate interaction with autistic children and respond to interaction, that there were more positive responses (Odom & Strain, 1986) and where non-verbal communication was initiated by non-autistic children, such as high-fives, then interaction was reciprocated (McEvoy et al, 1988). Milton describes this as a societal problem, in that if autistic people want to fit in with the societal norm with regards to conversational ability, then society claims that they need to be 'fixed.' His studies showed that, at that time, the 'subjective experiences' of autistic people were discounted as not being 'worthy of rigorous academic study' (2012:883). His study is based on recognising that:

> cognitive-behavioural discourses abstain from acknowledging the universal issue of relationality and interaction in the formation of a contested and constantly reconstructed social reality, produced through the agency of its 'actors.' (Milton 2012:884)

Milton's 'double empathy problem' refers to how two people who are communicating may have different outlooks, different life experiences, different understandings, it is not the fault of one person that miscommunication occurs, as both are experiencing it: one person's viewpoint is not more valid than another's. Social Constructionists say that truth and knowledge are created not discovered (Schwandt, 2003) and it is the subjective experience of everyday life that constitutes reality: reality is socially defined (Hammersley, 1992; Berger and Luckmann, 1991; Andrews, 2012). Andrews defines society as being objective as it is created through 'the interaction of people with the social world' (2012:16), this created world then influences people which becomes routines or habits which can be repeated 'without much effort'. These routines are then institutionalised in our society and are then objective to future generations. Andrews states that 'this objectivity is continuously reaffirmed in the individual's interaction with others.' From the viewpoint of an autistic person, the way in which they see the world can differ from neurotypical people, therefore the 'normal' objective world that others see is not the same to them. It is beneficial to view constructed society and language as subjective. Everyone sees the world differently, whether they are autistic or not, and therefore all communication is subjective, or open to interpretation. In addition to this, Burr (2003) theorises that it is society that creates our identity: it does not transpire from within. This suggests that autism is socially constructed, it has been made meaningful through language and then 'internalised by individuals' (Andrews, 2012:13). Holmer Nadesan replicates this view, stating that everyone, and not just autistic people: 'grow and change in relation to their familial and social environments,' and that society 'restrains, constrains, elicits and shapes' everyone whether they have a 'label' of autism or not (2008:80). Could it be that as neurotypical people struggle with 'others' not having the same objective view of the world and communicating in 'different' ways, that we have constructed 'autism' to help us to understand what this difference is? In constructing autism, one 'normal' type of social communication has been identified, with any other communication type in deficit. If social communication is seen as a deficit in autistic people, it could be shown as a reason why some parents do not wish to have their children 'labelled.'

2.3.2: 'Deficits in non-verbal communicative behaviours'

The second criteria from the DSM-V manual is: 'Non-verbal communication' which is defined as, 'a silent form of communicating with a person or party without using any form of speech to grab the attention of audience to exploit a message' (Phutela, 2016:43). They can include eye-gaze, motions to show interest in an object, pointing and showing objects (Mundy, Sigman & Kassari 1990, Wetherby & Prutting, 1984). Non-verbal communicative behaviours form part of autism diagnostic tools due to research carried out on autistic and non-autistic children which showed differences in non-verbal communication. Some of this research revealed that autistic children use non-verbal communication in different ways, communicating, 'less often for the purpose of establishing joint attention or commenting (Stone et al: 1997:678). Communication is said to be lacking when people cannot use both verbal and non-verbal communication simultaneously and often, autistic people will miss communication if they have poor eye-gaze, as they miss subtle hand gestures or facial expressions. This can lead to misunderstandings and social anxiety. It is argued that communication two-way and that to communicate there must be an exchange of transactions in which individuals are 'symmetrically placed, that is, they are exchanging as equals, neither being in a dominant position' (Gernsbacher, 2006:139). Gernsbacher claims that it is not autistic people that need interventions but non-autistics that need to develop their reciprocity 'more purposefully' and apply it 'more generously' towards autistic people. As discussed earlier, some autistic people are skilled in masking and replicate the actions of those around them to 'fit in.' This could show that referrals are difficult to access when autistic people are able to mask non-verbal communication and hold a person's eye gaze. It can be evidenced that lack of eye contact is seen as a deficit and that research has been undertaken to increase eye contact in autistic people (Fonger et al, 2019; Handley et al, 2015; Auyeung et al, 2015). Autistic people are often asked to look at others to show that they are listening (Trevisan et al, 2017). Research also shows that some autistic people think that eye contact is an important factor in being successful in different areas of their lives:

> (They) recognized the importance of eye contact for the purposes of succeeding in job interviews, interacting with colleagues and customers, and for dating and interacting with friends. (Trevisan et al, 2017: *In Paragraph Research Question 2*)

If non-verbal communication such as eye contact is seen as an important aspect of societal behaviour and parents also give interventions on increasing eye contact (Trevisan: 2017) then difficulties in referring children into autism assessment services could prove difficult as non-verbal communication such as eye contact may not be as apparent. When asking about parents' experiences of the referral process, it is later discussed how some professionals do not refer into services as criteria such as this is not met.

2.3.3: 'Deficits in Social-Emotional Reciprocity'

The next DSM-V criteria is: 'Reciprocal social behaviour'. This refers to, 'the extent to which a child engages in emotionally appropriate turn-taking social interaction with others' (Constantino et al, 2000:2043). Constantino developed the 'Social Responsiveness Scale' to help with assessment and diagnosis of autistic children. The scale is a questionnaire that can be filled in by parents or teachers, the outcome of which is supposed to indicate a 'level' of autism. The questions on the scale, however, do not relate solely to social deficits and this, Gernsbacher argues, has led to confusion over what social reciprocity is (2006). Some of the criteria that is questioned includes:

- Seems much more fidgety
- Has good self-confidence
- Is not well co-ordinated
- Has good personal hygiene

To provide more clarity in future, it should be made clear that this assessment does not relate solely to social reciprocity, and that it does in fact cover many 'Dyad of Impairments' from the ADOS scale. It also has many cross overs with 'Deficits in Social Communication' so much so, that these two assessment areas would be better combined to avoid ambiguity.

2.3.4: 'Deficits in developing, maintaining and understanding relationships'

The next DSM-V criteria is: ‘deficits in developing, maintaining and understanding relationships.’ Both afore-mentioned autistic behaviours relate to how children with autism may struggle to develop relationships with their peers, parents and siblings. As social communication differences can result in the child being placed into one of Wing’s categories of ‘aloof, passive or active but odd,’ autistic difference can make relationships difficult as they are seen as ‘not normal.’ As explained, lack of eye contact can lead to miscommunication or could be seen as an indifference to what the other child is saying. In addition to this, Van Roekel (2010) explains that as some autistic people struggle to understand what others are thinking or feeling, then it is also difficult to perceive whether a person has been aggressive towards them. Van Roekel states that bullying can be more prevalent towards autistic children due to them struggling to make friendships and therefore having fewer peers to help them in negative situations

2.3.5: ‘Hyper or hypo reactivity to sensory input’

The next criteria is: ‘Hyper or hypo reactivity to sensory input.’ Sensory differences occur in approximately 90% of autistic people (Tomcheck, 2007). It refers to how the ‘central and peripheral nervous systems manage incoming information from the different sensory modalities’ (Sanz Cervera, 2017:1772) and can affect all senses: sight, touch, smell, sound, taste, vestibular (balance), proprioception (body awareness) and synaesthesia (experiencing one sense through another, for example, reading the word, ‘house’ and tasting lemons). Sensory symptoms were discussed in early autism research, however until the most recent diagnostic criteria were published, sensory experiences were seen as secondary markers of autism (Robertson, 2017) Some argue that the DSM-IV was correct in not including sensory differences, as they are common in other ‘disorders’ and therefore, ‘do not discriminate autism nearly as strongly as the core social dysfunction does’ (Siegel, 1990:293): the fact that sensory differences occur in other conditions could lead to children being mis-diagnosed; children with ADHD, for example, can have hyper and hypo sensory input. More recent research shows that sensory reactivity has been detected in children aged as young as six months old (Estes et al, 2015) and is therefore a significant early marker of autism, particularly as between 45-95% of children exhibit sensory features (Baker et al, 2008). Sensory differences are broad, Baranek et al (2006) use a wide range of terms such as: ‘sensory avoidance or sensory seeking, enhanced sensory perception, a reduction in sensory integration and over-preoccupation with sensory aspects of the environment’ (Grapel et al, 2015:19). Although sensory markers alone may not be able to be used to diagnose autism, their presence could help to show evidence towards an autism referral and could help to differentiate autism from children with other ‘conditions’ (Baranek et al, 2006; Lord, 1995) and as children display sensory features from under the age of one, they could help to achieve earlier diagnosis.

2.3.6: ‘Restrictive, Repetitive Patterns of Behaviour / Stereotyped or repetitive motor movements’

The next criteria is, ‘Restricted, repetitive patterns of behaviour.’ These are viewed as ‘hallmark symptoms of autism spectrum disorders’ (Ravizza et al, 2013:773), they have been recognised as a part of autism since autism was first described by Kanner and Asperger. They can include:

- Preoccupation with certain interests
- Repeated motor mannerisms
- Echolalia – where sounds, words or phrases are repeated
- Self-stimming such as biting nails, repetitive blinking or snapping fingers.

Autistic people have described repetitive behaviours as having a wide variety of functions; calming anxiety, generating awareness of their bodies, focusing concentration, dealing with sensations and emotions and helping to communicate their mental state to others (Deweerdt:2020). Many autistic adults have reclaimed these behaviours as ‘stimming’ and research shows that there is a lack of social acceptance in society today (Kapp et al, 2019). Kapp (2019:1782) interviewed 32 autistic adults and concluded that the destigmatising of stimming through increased understanding could help to,’ elucidate appropriate support for a variety of people.’ It could be therefore argued that if stimming is not accepted in society that autistic children may repress these motor movements which could lead to difficulties in referring children into autism assessment services.

2.3.7: ‘Insistence on sameness’

The criteria ‘insistence on sameness,’ is the ‘rigid adherence to rituals and routines and difficulties with transitions’ (Baribeau et al, 2021:21). Baribeau et al researched autistic children in relation to anxiety, and how those that displayed insistence on sameness were predicted to have future anxiety. This research could lead to early interventions for autistic children. It could also help parents and professionals differentiate between autistic and anxiety behaviours to ensure that early interventions take place. Further studies show that routines and rituals ‘play a significant role in the organisation of daily activities and the health and wellbeing of families’ (Rodger et al, 2010:22). This research discussed how many families with autistic children do not have the same rituals as families with neurotypical children, as they often did not participate in family holidays or birthdays due to the change in environment being too overwhelming for autistic children. The research stated that if families of autistic children used a family-centred approach to routine, instead of having routine as dictated by the autistic child, then the family would benefit from having, ‘interventions and strategies that up-skill and equip families to function effectively and meaningfully.’ This is an example of the pressures of society to ‘normalise’ autistic people in order that they fit in better with a neurotypical life. Nicolaidis et al (2015) researched the experiences of autistic adults within the healthcare system and their recommendations for improving the care that they were given. Some of the interviewees spoke about the bright lights of surgery walls and crowded waiting rooms which left them unable to communicate their needs. The research showed where providers accommodated their needs, that more successful interactions were experienced which led to better outcomes for them. Many autistic people struggle with the concept that autism is a difference, feeling that they do not belong (Humphrey & Lewis, 2008; Portway & Johnson 2005) with some autistic people hoping for a cure so that they become more societally ‘normal’ (Baker, 2011). This has led to a rise in the neurodiversity movement, which seeks to move away from the ‘medical model’ which, ‘aspires towards normalisation, symptom reduction and elimination of conditions’ (Kapp et al, 2013:59). Of the vast amounts of research available in this area, the majority is based on finding ways to improve an autistic child’s inability to cope with changing environments by trying to develop strategies or direct future researchers to look for specific biological markers relating to ‘IS’, as opposed to researching how people, employers, businesses could adapt to meet the needs of autistic people. This is highlighted with the challenge that autistic people encounter when starting in employment and having to, ‘decide whether, when and how to disclose their autism diagnosis and request workplace accommodations’ (Lindsay et al, 2021:597), as it is society’s expectation that autistic people need to be ‘cured’ or to adapt to fit in, this must make it difficult for autistic people to suddenly expect a workplace to adapt to their needs; some ‘reasons for non-disclosure (of their disability in a workplace) included concerns about being judged and experiencing stigma or discrimination’ (Lindsay et al, 2021:598). If autistic children are masking their rituals to become more socially accepted, then professionals may struggle to identify this DSM-V criteria.

2.3.8: ‘Highly restricted, fixated interests’

The final criteria is: ‘highly restricted, fixated interests.’ It has been found that neurotypical and neurodivergent children all engage in ‘ritualistic, repetitive and compulsive-like activity’ (Evans et al, 1997:58) which can be observed in children’s games and repetitive rhymes.

However, when restricted, repetitive behaviours (RRBs) are classified into lower and higher orders, the higher order category is more specific with autistic individuals (Van der Zee, 2020). Turner (1999:840) classified the orders as:

- *Low level behaviours that are categorised by repetition of movement* (tics, repetitive manipulation of objects and repetitive forms of self-injurious behaviour).
- *More complex or high-level behaviours* (object attachments, insistence on the maintenance of sameness, repetitive language and circumscribed interests).

More models have been developed since, including a six-factor model (Bodfish et al, 2000) and a three-factor model (Mirenda et al, 2010) to determine the differences between RRBs in autistic and non-autistic children and other 'conditions.' This research is important when considering statements made that people can all be 'a bit autistic' (Happe & Frith, 2020:218). Chown and Leatherland's response to this statement shows that this assertion has 'significant implications' and can 'add to misunderstandings about what it is to be autistic' (2020:749). They argue that it is not the presence of traits or behaviours that make a person autistic, but the underlying cause or reason for behaviours. Traits are not autistic traits but human traits and looking at those behaviours in isolation 'denies autistic people the opportunity to be identified.' This argument resounds throughout the autistic community, as neurotypical people claiming that everyone is a little bit autistic trivialises autistic individual's differences. For example, in Botha et al's study (2019:436) the participants spoke about how 'humanity was not a spectrum between autistic and non-autistic, 'not everyone is a little bit autistic.' This statement has also been identified as a reason not to diagnose a person or to make diagnosis more difficult (CaptainQuirk, 2017). This shows the importance of using RRB models when assessing autism, ensuring that specific behaviours are not spoken about as behaviours that exist in all children, again trivialising the RRBs that autistic people must negotiate daily if they wish to fit in with society's expectations of 'normal' behaviour.

2.4: Co-Concurring Conditions

Co-occurring conditions are common for autistic people, with recent studies estimating that ADHD, for example, is prevalent in up to 94% of autistic individuals (Hossain et al, 2020). Other co-occurring conditions include psychiatric disorders, anxiety, sleep disorders, epilepsy, gastro-intestinal disorder, sight and hearing disorders (Lai et al, 2019). The presence of co-occurring conditions in autistic people have implications for the diagnosis of autism and can result in misdiagnosis. Research carried out by Bougeard et al (2021) highlights the importance of raising awareness of the prevalence of co-occurring conditions stating that the high probabilities of co-existing 'disorders' should be incorporated into the clinical guidelines for assessment of autism. Also, that diagnostic assessments should involve multi-disciplinary teams that include interviews about ‘somatic signs and symptoms’ (Bougeard, 2021:744). This improved and more detailed assessment would have a positive impact on children with co-occurring conditions, as many of these ‘disorders’ have interventions and medication that can help with sensory issues. For example, Auditory Processing Disorder (APD) is one of the most reported co-occurring conditions, with Greenspan and Weider (1997) reporting that in a review of 200 autistic individuals, 100% ‘demonstrated difficulties with auditory processing’ (Tomcheck, 2007:194). Interventions for managing APD include improving the quality of the acoustic (Moore, 2006) which can be achieved through low-gain hearing aids, and ‘improving the ability of the listener to make use of the delivered signal’ (Moore, 2006:8) which can be achieved through speech, cognitive and auditory training. Another commonly reported condition is Developmental Co-ordination Disorder (DCD) also referred to as Dyspraxia, which is characterised by ‘significant difficulty performing motor skills’ (Cacola et al, 2017:11). Cacola reports that DCD and autism can be diagnosed as co-concurring conditions, however there are many differences between the two and these should be taken into consideration when assessments are carried out to ensure that the correct diagnosis is achieved, resulting in correct interventions for individuals. Studies show that interventions for individuals with DCD achieve positive results, with research by Yu (2018) stating that 85% of interventions for increased motor function showed positive effects with 88% of studies showing sustained improvements in motor function ability. This shows that hyper or hypo reactivity to sensory input could be linked to autism but could also be a result of other co-occurring conditions. This highlights the importance of accurate assessments and the need for increased knowledge in the educational and health sectors to improve correct diagnosis therefore leading to positive interventions for individuals. It also shows how misdiagnoses are possible, as some individuals are reported to have been diagnosed with other conditions mistakenly, resulting in increased mental health issues and a lack of understanding or interventions for autistic people (Jones, 2016).

Sanz-Cervera et al undertook research on Sensory Processing Disorder (SPD) and found that children with combined autism and ADHD had the highest levels of sensory dysfunction. (Estes et al, 2015). Sensory processing disorders were distinguished into three sub-categories by Sanz-Cervera et al. The groups were:

1. Sensory Modulation Disorders: over-responsiveness, under-responsiveness, and sensory seeking
2. Sensory Discrimination Disorders: the ability to identify sensory input

3. Sensorimotor integration Disorders: difficulty in transforming sensations into motor responses

The research found that children with ADHD and autism 'obtained higher levels of dysfunction' than children with 'typical' development. The vast amount of co-occuring diagnoses could be problematic for professionals when being asked to refer children in autism services. Traits may be more prevalent in other conditions which could lead to autism referrals not being accessed in the first instance.

2.5: Biological Factors

The heterogeneity of autism makes biological-causal research difficult as there are so many genetic pathways (Mingfeng et al, 2018), therefore, although there are many biological similarities with autistic people compared to people without autism, there is no current evidence which provides a specific cause of autism. Biological factors in autism stemmed from evidence from a study of twins by Bailey et al in 1995. The study 'detected a concordance of autism of 60% in monozygotic (identical) twins in comparison with 0% of dizygotic (fraternal) twins' (Piven, 1997:708). The results led to further genetic research due to monozygotic twins sharing 100% of their genes which some researchers believe show that autism is highly hereditable. Research of this kind has been carried out many times since and on much larger scales, for example, research carried out on children in Sweden between 1982 and 2006 with a follow up in 2009. This research involved over 3 million children, with approximately 15,000 of those diagnosed with autism. The research concluded that heritability was estimated to around 83%, 'suggesting that genetic factors may explain most of the risk for ASD' and 'like earlier twin studies, shared environmental factors contributed minimally to the risk of ASD'. (Sandin et al, 2017:1183). Other research carried out in the same period disagree with this, stating that environmental factors include complications in pregnancy and during birth, viral exposures and paternal age (Abrahams et al, 2008). Muhler et al (2018:514) agree, stating that autism is 'defined behaviourally...many genetic and environmental risk factors are linked to ASD.'

Many stake holders find biological research on autism controversial, as the amount of money spent on funding this research could instead be spent on helping to 'improve the lives of people on the spectrum' (Fletcher-Watson 2019:52). This approach to autism research has been criticised by many, including Berend Verhoeff, who states that the heterogeneity of autism and how autism has been defined as a disease has meant that, 'autism is imagined to exist as an objective entity independent of its embodiment in particular individuals' (Verhoeff 2012:411). This research continues however with the 'hope that identifying genetic links to autism will be beneficial both to the diagnosis and treatment of the disorder' (Hall & Kelly: 2013: 873).

Hall & Kelly explain that there are three types of research strategy used for gene identification: linkage analysis, association studies and cytogenetic analysis. O'Roak and State (2008:4) define the different types of strategies used as follows: linkage analysis; 'traces the transmission of chromosomal segments through generations.' Association studies look at genetic variants among a given population as opposed to looking at genes within a family. Association studies, 'rely on cross-sectional studies of populations.' Finally, cytogenetic analysis looks at chromosomal abnormalities amongst autistic people. Even with all this biological research, there have still been no major breakthroughs, with inconclusive results and 'fine mapping and association studies failing to identify underlying genes' (Sykes & Lamb: 2007:1).
This quest to find biomarkers has raised much debate due to ethical considerations, firstly using biomarkers to diagnose autism prenatally raises the question of whether these pregnancies would be terminated, as is the case with the pre-natal diagnosis of Down's Syndrome where in England and Wales around 90% of diagnosed foetus' are aborted (Dontscreenusout.org). Also, Hall & Kelly's language, and that of other biological researchers, is problematic; the thought that diagnosis could lead to treatment or cure of autism is troubling, especially to the autistic community that do not see autism as something that needs to be fixed (Fletcher-Watson & Happer: 2019).

There is an argument that if biomarkers were researched so that autism was diagnosed earlier, then this would be an effective way of ensuring that children received earlier interventions and support. It could also assist in problematic assessments and rule out the need of professionals having to make the decision of whether to refer children for autism assessments. Specific medication could then help with autistic traits such as sensory impairment, helping autistic people to cope in crowded, noisy areas, for example, or to 'improve synaptic function…giving a person with a learning disability more capacity to learn new information' (Fletcher-Watson & Happer: 2019:7). This argument does however lead to the debate of autistic people being impaired and that their differences in, for example, sensory output is not 'normal' and therefore needs to be repaired.

Some research into biological factors looks at the evolution of human beings, and how 'some genes associated with the autism spectrum were naturally selected and represent the adaptive benefits of being cognitively suited for solitary foraging' (Reser, 2011:207). This research suggests that autism has been prevalent since humans first evolved, and that the ability to live alone, or in conditions where group sizes were very small, led to neurological adaptations leading to the many autism genes found in the current day. Reser (2011:212) states that ‘modern social, occupational and mating practices may conceal the evolutionary of adaptive benefits. In pre-historic times, the ability to survive alone, without social contact could have been an important factor in survival. This theory was also commented on by Baren-Cohen (2000:1377) who argued that ‘excellent attention to detail exists in ASC because of evolutionary forces positively seeking brains for strong systemising, a highly adaptive human ability.’ Baren-Cohen also thought that autistic traits, ‘may have been naturally selected due to their contribution to tool construction and use. (Reser, 2011:207). The theory that autism is due to natural selection enforces the stance that autism is not something to be fixed. Reser concludes that autism, ‘should not be thought of as something to be ashamed of, but as something that represents individuality, self-determination and autonomy’ (Reser, 2011: 230).

Fletcher-Watson and Happe have shown that biomedical research takes many years to deliver results, the data is so wide that Sandin’s research took 25 years to complete. As autism funding is in part given to autism research (Pellicano et al, 2013), it is suggested that funding could instead be spent on support services for autistic people, training for professionals and autism education for the wider society.

2.6: Cognitive Factors

Cognitive aspects of autism are described as, ‘the processing of emotional information as well as learning processes and skills such as executive functions, memory and language’ (Fletcher-Watson & Happe, 2019:68). This section will explore different cognitive factors as follows:

(i) Theory of Mind
(ii) Empathy
(iii) Repetitive behaviours (related to a lack of imagination)
(iv) Language differences or mutism

Other cognitive factors also include attention differences relating to hypo/hyper sensory stimulation and auditory processing conditions; however, these factors overlap and have already been discussed in some detail.

2.6.1: Theory of Mind.

As autism is often viewed in terms of social differences (Fletcher-Watson & Happe, 2019) then autism could be explained as a human’s inability to use ‘Theory of Mind’ (Premack &

Woodruff, 1978:517) – 'being able to infer the full range of mental states (beliefs, desires, intentions, imagination, emotions etc.) that cause action.' (Baren-Cohen, 2000:169). Cohen-Baren describes a test to see if a child has 'Theory of Mind' which states that autistic children are significantly impaired in being to infer, or 'read between the lines' when they are being read books. He goes on to discuss a test in which children are shown an object that has a 'dual-identity,' for example, a candle in the shape of an apple: autistic children cannot determine that the apple is not a candle, he claims that this shows a 'deficit in the theory of mind' (Baren-Cohen, 2000:169), this 'deficit' he claims, supports the idea that autistic children find communication difficult as they are unable to construe what another person may be thinking, or saying, particularly if there is deception involved, where the autistic person has to consider what is being said against what is being intended by the speaker. Wimmer and Perner (1983) also tested this lack of Theory of Mind with another false belief task – the "Sally-Ann" task which involves participants watching a puppet scenario: there are two puppets, Sally and Ann which are next to a box and a basket. Sally puts her marble into the basket and leaves the room. When Sally is out of the room, Anne takes the marble out of the basket and places it into the box. Sally is then asked to come back into the room, at which point the test participant is asked "Where will Sally look for the marble?" The correct answer is the basket, as Sally would be unaware that Anne has moved marble (Centre for Education and Youth, 2016). Research shows that most four-year-olds were able to state correctly where the marble was, however only 20% of autistic children were able to pass the test, even though the children's mental ages were over four years (Baren-Cohen et al, 1985). Not everyone agrees with the validity of false belief tasks, however, with some research showing that outcomes may by affected based on how the participant is feeling on the day: whether the participant is tired, lacks motivation or is easily distracted. They also claim that the validity of false-belief tasks can be questioned due to them being delivered in slightly different ways, in how they are worded, on what materials are used or in the tasks that children must perform (Grant et al, 2001). After Mayes et al (1996) carried out a false belief task on two separate occasions with the same participants which found only moderate testing reliability, further research has put forward the idea of completing a test-retest on separate days to ensure that tests have more reliable outcomes (Hughes, 2000). Grant's research, which tested children using different false-belief tasks, asserts that practitioners should be wary of only carrying out one task, as some of the children that were tested were able to complete some of the tasks successfully but others not successfully. This is important when thinking about the autism referral practices for children, in that if they pass one false-belief task, that they may not be sent for further assessment. It is essential that a range of tests are carried out to make comparisons of a child's Theory of Mind abilities. The theory that this applies to all autistic people is also much debated, (Leekham et al, 1991:203) and is again problematic in the context of defining what autism is and therefore how, as professionals, we can apply tick box statements to refer children for autism assessment. In every instance there is debate and evidence to show that autistic people have individual traits and there is, 'no single underlying condition that can be regarded as the defining characteristic of autism' (Hassall, 2016:49). This is in great contrast to the early work of Asperger who thought, 'it is the constancy that makes autism a highly recognisable entity' (Asperger, 1944:68).

2.6.2: Repetitive behaviours (related to a lack of imagination)

Imagination plays an important role in many areas of human life. It is important when reading, to create the images needed to bring a fantasy world into reality; in poetry; music and art. It is associated with children's development in early years; in being able to use imaginative play which helps to develop empathy and social bonds (Mills, 2005). It is an important part of everyday communication, when people are describing other people, or situations, giving directions or describing past events; the imagination is needed to be able to relate to and see what the other person describes. Wing and Gould's (1979) 'triad of impairments' show how differences in imagination co-exist with repetitive behaviours. This belief resounds in autism theory (Happe, 1994), yet Wing and Gould's third triad, 'Impairment of social imagination' has not been included in the DSM-V, it instead: 'introduced repetitive behaviour patterns, not the impaired social imagination'. (Wing et al, 2011:768). Wing et al (2011:769) also state that, 'the underlying nature of the social instinct has yet to be investigated.' They claim that this 'social instinct' shows a clear difference when looking into the differences between an 'anti-social psychopath' and an autistic person. They say that a psychopath understands clearly what the other person is thinking and uses this to manipulate them, also that they have empathy but no sympathy. They state that autistic people lack empathy but can have: 'sympathy where they can perceive another person's distress' (Wing et al, 2011). It could be argued that if 'social instinct' was added as a diagnostic marker, then diagnosis could be made earlier, as Wing et al state that this develops after three years of age.

Imagination is linked to empathy: something that is often to be reporting as lacking in autistic people - for example - Decety and Jackson, (2004:90) who state that, 'children with autism…display a broad range of social communication deficits, and most scholars agree that a lack of empathy prominently figures amongst them.' Fletcher-Watson et al (2020:3) define empathy by breaking it down into three stages:

1. Noticing outwards signs of a person's internal state
2. Correctly interpreting that behaviour (crying with happiness or sadness)
3. To have affinity with, resonate or mirror how the other person feels

Their research shows that it is important to discuss empathy alongside autism due to the 'negative impact that it has on the lives of autistic people' (Fletcher-Watson, 2020:3) The theory of lack of empathy alongside a heightened capacity for emotional empathy is described by Smith (2009:489) as 'EE-dominated empathetic imbalance.'. This study shows the complex relationships of cognitive and emotional empathy and shows how empathy can change as emotions become more discreet, for example, if someone is crying then their emotions are more easily seen, however an emotion such as guilt would be more difficult to interpret. The study claimed that: 'any conclusion positing that most people with autism have a general empathy deficit does not seem justified.' Smith (2009:489) stated that Baren-Cohen's Theory of Mind hypothesis in relation to deficits in empathy were 'tailored to the extreme male-brain theory of autism.' Mills (2005: Paragraph 2) discusses the importance of the need for society to change, in how we view repetitive behaviours as a lack of imagination. He focuses on the work of artists that have 'special interests,' showing how their fixation on preserving very fine details can create astonishing artwork. He suggests that autistic people who have these behaviours can focus on the detail that neurotypical people may miss; it is the 'neurotypical's drive toward, 'central coherence' – 'manifested in interventions, treatments, and educational curricula' that overlooks the need for a more local coherence: – 'a single object and how it looks or functions.' Fletcher-Watson et al states that autistic people might be judged incorrectly as not being empathetic due to their differences in expressing, what society view as, a normal response, and they are, 'simply not following the same response-script as a neurotypical person' (2020:4).

2.6.3: Language difference or mutism

Language and communication differences, as discussed earlier, are among some of the main features of autism spectrum diagnostic features. Language is linked, in this instance, to Theory of Mind, 'because successful communication entails the understanding that language is a means for sharing information, beliefs and feelings with others' (Hale et al, 2005:157); also, children with autism struggle to identify the listener's point of view and they then struggle to converse meaningfully (Tager-Flusberg, 1996). Both preverbal and verbal autistic children are also shown to have difficulties with gestures, when those gestures are needed to, 'involve joint attention and require and understanding of intentionality (Hale et al, 2005:158). Hale's research states that this lack of 'protodeclarative communicative gestures' (2005:159) can help to pre-empt differences in theory of mind and language skills. Selective mutism, where there is a failure to speak in specific social situations 'where there is an expectation to speak, despite speaking in other situations' (Steffenberg et al, 2018:1163) is categorised in the DSM-V as an anxiety disorder and therefore a co-concurring condition with autism, as opposed to being an autistic trait. However, it has been researched that the appearance of selective mutism most regularly appears when a person is in a situation where there is an 'overwhelming or threatening context change' (Viana et al, 2009; Steffenberg et al, 2018); selective mutism is also most likely to occur when a child is in the classroom with a teacher, however they will be more able to talk to a student, or when they return home. This could suggest that society's expectations of social communication are so overwhelming to autistic people that they then experience selective mutism. The differences in an autistic person's Theory of Mind and their difficulty in inferring feelings, conjuring up images during interactions that require imagination could be so vexatious that they become unable to verbalise at all. Another example of how Theory of Mind links to language differences in autism is how autistic people are often referred to as being 'literal;' that is the difficulty in understanding abstract concepts such as slang words, phrases, puns and paradoxes (Centre for Autism, (no date)). Hobson (2012:35) referred to a study wherein a child had been asked if they had 'lost their tongue' which then set the child looking anxiously for it. Sugarman (1984:36) explains that 'before children can use language to communicate, they must learn what communication is.' The question is, when is any child told explicitly why we communicate and what the purpose of it is? And would this realisation not benefit all children, not just autistic children? The vast differences in autistic children are shown clearly here, some children are not able to speak and some children, as described by Asperger, have high levels of vocabulary. As Asperger's and autism are now 'autism spectrum disorder' in the DSM-V, it is argued that this is problematic for professionals when looking for specific criteria.

2.7: Cultural Factors

2.7.1: Parental Blame

Parental blame for autism has been apparent throughout the decades, beginning with the 'refrigerator mother' model of Leo Kanner where, in 1949, he 'encouraged psychiatrists to investigate what he called emotionally cold mothers' (Kohler, 2014:1381). His later paper, 'Problems of Nosology and Psychodynamics of Early Infantile Autism' (1949) refer to the parents as cold and emotionless, describing mothers that let children trail after them without looking back and fathers that admit that they would not recognise their children if they passed them in a busy street. He describes the parents as being educated with professional careers yet lacking in their role as nurturers. This parental blame was replicated with the work of other theorists such as Melanie Klein and Margaret Mahler, and furthered by Bettelheim who, after surviving a Nazi concentration camp during the war, compared parents of autistic children, particularly mothers, to Nazi guards (1967) and stated that when nursing mothers only allowed their children to breastfeed at certain times during the day, they were disallowing their new-born children the ability to be 'active'; which may have far reaching consequences for their later development (1967:16). The blaming culture continues, with parents asked to complete parenting courses (Rees: 2007) or needing observations from a teacher or other professional before their child can be referred for an autism assessment as opposed to the parent's observations being adequate. The feelings of guilt and blame that are felt by parents because of their children's diagnosis is well commented on; in 2006, Mercer et al carried out a study of, 'parental perspectives on the causes of an autism spectrum disorder in their children' and found that: "another common feeling among family members was guilt that they many have contributed genes causing their child's ASD' (Mercer et al, 2006:41). In total, over 90% of parents said that they thought that autism was caused by genetic influences. This shows that that the current quest for biomarkers and research to scientifically give us the cause of autism is continuing parental blame. Although they may no longer be called 'emotional refrigerators' they are instead being blamed for the inheritance of autism through to their children. It is important for researchers to understand the implications of their research on the wider family, and how the continued quest to find 'a cure' could lead to damaging effects on the mental health and well-being of parents with autistic children.

2.7.2: Autistic children placed in mainstream education

Children with special educational needs were classified by their individual disabilities under the 1944 Education Act; it was commonly thought that many children with SEND were not able to be educated and were labelled as 'maladjusted' or 'educationally sub-normal'. These children were educated in separate schools known as 'special schools' (Education and Skills, 2006). In 1978, the education secretary at that time, Margaret Thatcher, appointed Mary Warnock as the chair of a committee of enquiry to review the educational provisional in the UK for children with SEND, the result of this was the 'Warnock Report' which, when Margaret Thatcher became Prime Minister, formed the basis of the 1981 Education Act, which, 'gave parents new rights in relation to special needs, urged the inclusion of special needs children in mainstream classes and introduced the system of 'statementing' children to give them entitlement to special educational support' (Gillard, 2007:1). These two reports fundamentally altered how SEND was regarded within education, as a more 'integrative' and then 'inclusive' approach was introduced which was based on, 'common educational goals for all children regardless of their disabilities and abilities' (Education and Skills, 2006). The inclusion of children into mainstream schools is said to improve their academic outcomes and social growth (Kurth and Mastergeorge, 2010), it is also said to improve inclusion, as neurotypical children have more exposure to autistic children (McGregor and Vogelsberg, 1998), unsurprisingly, in this time of neoliberalism, there are arguments to support that inclusion has many financial benefits on society (Jarbrink et al, 2001). After this, many 'special' schools were closed as mainstream schools opened to children with SEND, however, there was not enough additional funding for schools (DfE, 2024) or funding for teacher training. As more children with SEND entered mainstream schooling, initial teacher training did not alter, with concerns raised regarding the lack of training on SEN given to trainee teachers to the committee of the SEND Third Report (2006). The Audit Commission report (2002) that 'teachers were feeling ill equipped to meet the wide range of needs in today's classrooms' (Education and Skills, 2006).

The rising sizes of classrooms is highlighted in the Department for Education's 'Explore our Statistics and data' site which is updated annually (https://explore-education-statistics.service.gov.uk: accessed October 2024). Although the table headlines, which are given as percentages, look quite encouraging, when examining the actual number of students in increasing class sizes, it can be seen just how much they have increased in real terms:

Class Sizes

Year Group	Year	Class size	Number of students	Year	Class size	Number of students	Increase/ Decrease
KS2	2015/16	31-35	351,098	2023/24	31-35	413,396	+62,298
KS2	2015/16	36+	9116	2023/24	36+	8159	-957
KS3/4	2015/16	31-35	286,610	2023/24	31-35	483,162	+196,552
KS3/4	2016/16	36+	18,081	2023/24	36+	24,753	+6,672

The data shows that secondary aged students face the largest increases in class sizes, with an additional 196,552 students of class sizes of between 31-35 and an additional 6,672 students in class sizes of 36+ from the year 2015 to the academic year 2023/24. Although infant class sizes have remained stable, this is due to a population decrease in infant-aged students, with 100,000 less students in KS1 from academic year 2023/24 than were present in infant classes in 2015.

Rising class sizes and inadequate funding and consequent lack of training for teachers in SEND has an immediate impact on not just the education of children but also on the accurate identification of need and then the subsequent ability to refer to the correct services for assessment and diagnosis. It could be said that specific training that caters to every child's need is almost impossible due to the heterogeneity of autism, however if this heterogeneity was included in training, then teachers may become more open minded to the individual aspects of autism, and the uniqueness of each autistic child.

2.8: Current referral practices in the UK

The current referral procedure for the assessment of autism in the UK is shown on the NHS website: 'How to get diagnosed'. It states that firstly, the person wanting a self/child referral should speak to a GP, a health visitor, any other health professional that the child sees or the school's SENCO. The website asserts that the person should, 'ask them if they think it's a good idea to refer you for an autism assessment' (accessed 29th May 2022). However, across the UK, the referral processes are not consistent. Some of the differences in the autistic diagnostic process are shown in the table below, with the first column showing how the NHS website shows how to receive an assessment compared against four alternative LA's in the UK:

Council	First Stage	Second Stage	Third Stage	Fourth Stage	Who can refer?
NHS	Speak to GP, Health Visitor, Health Professional or school SENDCo	Get an assessment	Receive a diagnosis		The person that you spoke to will let you know if it is a good idea to have an assessment – does not state who can refer
1	Professional to complete form and send to autism referral panel	Autism referral panel will decide if face- to-face assessment is relevant	Assessment carried out	If relevant, support will be agreed with family/professional	Professional including GP
2	Completion of form sent to Young People's Service	YPS decide if assessment relevant	No Further Details Shown		Anyone, including young person, parent and professional
3	Completion of form sent to diagnostic services	Initial assessment	Developmental Interview	Clinical decision meeting	Anyone, including young person, parent and professional
4	Completion of form sent to Child and Adolescent Services	CAS decide if assessment relevant – children aged 0-11 and 16+ must go to different services	No Further Details Shown		GP Social Worker Paediatrician School with common assessment framework

5	Completion of form sent to Autism Assessment Service	Unclear	Unclear	Unclear	Speech & Language Therapy Educational Psychology

Table 3: Different referral practices in councils across the UK

As shown, in one council, the 'Autism Assessment Service' do not accept referrals from a GP, two of the councils allow self-referral – even from the young person themselves - and one allows a referral from an Educational Psychologist or Speech and Language Therapist. Howlin & Moore (1997) carried out a survey of 1300 parents which concluded that over half were not satisfied with the diagnostic process. Further research found that parents with autistic children first became aware of differences at around 1.5 years of age, yet their children were not diagnosed until an average age of 5.5 years. For children with (what is often described as) 'high-functioning autism' (previously known as Asperger's Syndrome), differences were first noted when children were approximately 2.5, yet the average age of diagnosis was 11 years old (Howlin and Asgharian, 1999). In 2016, a survey of 1000 parents was carried out by Crane et al which compared its findings to those of Howlin's. The research concluded that there was still a delay of 4.5 years from a parent first noting differences, to a child receiving an autism diagnosis which showed, 'no great reduction in diagnostic delay from Howlin and Moore's 1997 survey' (Crane et al, 2016). From the perspective of adults seeking diagnosis, there is a recurring theme in the diagnostic processes, with a study from Lewis et al (2016:346) reporting that, 'the diagnostic process lacked structure, with professionals being unsure of the appropriate referral pathway and individuals feeling that they were being passed from pillar to post'.

2.8.1: Problems with slow referrals, poor information and lack of diagnosis

The delays in diagnosis and referral procedures have been reported to have a great strain on the well-being of a child's immediate family (Watson et al, 2011). Crane et al suggest that: 'the diagnostic process itself can represent an added stressor to parents' after many of their surveyed parents, 'cited the long waiting times as the cause of their stress' (2016:154). In addition to the waiting times, parents often feel overwhelmed with the realisation that their child may be autistic (Crane et al, 2016), and with a lack of services and support to help parents during the diagnostic process, there are few information services or support networks to help to parents through the process. Reports also claim that 50-60% of people with 'high-functioning autism' are undiagnosed (Baron-Cohen et al, 2009); lack of diagnosis and subsequent lack of support can lead to, 'a higher risk of depression, anxiety and suicide' (Lewis, 2016:346) with 66% of newly-diagnosed adults report having suicidal thoughts which is much higher than, 'the general population, in groups with medical or psychotic illnesses, and in previous studies of adults with ASD who were diagnosed in childhood or adolescence'

(2016:347). Lewis' research found that most participants 'described significant benefits' to being diagnosed and that receiving a diagnosis earlier, 'would have positively impacted their quality of life.' Some of the participants reflected on feeling lonely, abandoned and depressed and without a diagnosis that 'individuals feel different from others and struggle to understand themselves' (2016: 346-354). The feelings of undiagnosed children, later diagnosed as autistic is echoed across autism research, and in research and work carried out by autistic people: Judy Singer, for example, describes her childhood as:

> 'an experience of being always on the outside, looking in at the 'normal' people…clumsy and shy hovering on the edge of social hierarchy…suffered humiliations from teachers when it came to sports…it was clear that sensitivity was a condition to be ashamed of' (Singer, 2017).

Other factors relating to the diagnostic process that have been shown to have a detrimental effect on autistic people includes:

- The number of professionals seen (Howlin and Moore, 1997, Siklos and Kers, 2007).
- The standard of information given out when being diagnosed (Hasnat and Graves, 2000).
- Support given post-diagnosis (Siklos and Kers, 2007).

Overall, it is fair to say that research points to the referral process across the UK being poor, with little improvements gained since research in this area began, in the areas of timings, quality of information, support and recognition of autism in children.

2.8.2: Benefits of good diagnostic referral procedures and early diagnosis of autism

In relation to the above, the benefits to early diagnosis and clear referral practices are better well-being, reduced anxiety/suicidal thoughts, and better support in general. This support can relate to children being diagnosed in their early years, thus proving an increased opportunity for early intervention which, 'enables them to benefit from rich learning opportunities delivered when their brains are maximally malleable' (Clark et al, 2018:92). Clark's research studied forty-eight children comprising of those who had been diagnosed before three-years-old and after age three to look at their 'school age outcomes'. The research found that in comparison to the children who were diagnosed later, that the children diagnosed earlier:

- Had improved overall cognitive abilities
- Showed improved expressive language
- Were more likely to attend mainstream education

As parents with autistic children are also shown to have more stress due to autistic behaviours (Elder et al, 2017) then earlier diagnosis could lead to earlier support for parents.

Earlier diagnosis could also direct parents and families to support groups whixh help parents to have more adaptive coping-strategies (Mandell et al, 2007). In addition to this, families may be able to ask for additional help in order that they receive respite care, there could be better educational support by allowing access to SEN specialist provision. There could be intervention from Speech and Language Therapy, which has been shown to improve social competence due to an increase in communicative function (Waddington et al, 2017). Although research suggests that 'children with ASD were just as likely to be placed in a special school as in a mainstream school' (Waddington et al, 2017:2370) the outcomes of this research showed that there was little difference in autistic children's academic performance across the settings.

2.9: Referral procedure of Council X

For the purposes of this research, it is important to state the current referral practices for the area (Council X) that has been researched in this study. Council X's 'Autism Assessment Team' currently only accept referrals from:

- Speech and Language Therapy
- Educational Psychology
- Portage
- Paediatricians

However, except for Portage (which is aimed at Early Years children), these agencies are not contactable without referral from another professional. It would therefore be a GP that would refer to a paediatrician, the school's SENCO that would refer to Speech and Language Therapy or Educational Psychology. There is also an additional service which has been added whereby 'requests for support can be made directly by young people, parents and carers themselves' (accessed 29th May 2022), however, this service directs the person back to the professionals listed above. Many parents with children of school age in Council X would therefore be directed to their school SENCO. The SENCO would then ask the class teacher for feedback on autistic behaviours observed in the classroom, and a fourteen-page form would be filled in (Appendix 1) which relates to autistic behaviours as set out by the DSM-V, the form would then be sent to Council X's assessment services whereby it would be evaluated to see if the observed behaviours were sufficient to further the referral for a full autism assessment. However, if autistic behaviours were masked, or not seen by the classroom teacher, then the route to assessment in Council X is problematic. If the referral has to made by a SENCO, and they school do not see autistic traits then it is likely that no referral would be made into autism assessment services.

Chapter 3: Methodology

Introduction

This chapter explains the research methodology that has been utilised in the thesis, describes, and explains the methodological disputes. The chapter also explains why a case study was used to look at the referral process for autistic children. As the case study looks at each individual experience within the ‘functioning specific’ (Stake, 2008:119-120) -the referral process- it was important to think about how I was going to order the interviews as aspects of grounded theory methodology were utilised to collect and analyse data. Each interviewee’s experiences guided subsequent questions, as systemic analysis worked to identify patterns in meaning across the data so that a theory was developed. The thesis is therefore a case study which uses aspects of grounded theory to collect and analyse data.

3.1: Positionality

I approached my thesis from different experiential lenses. That of a parent of autistic children, as an autistic woman, as a teacher and as an alternative education provider. I liaise with health professionals, head teachers, SENDCo’s, pastoral support workers, parents and of course – the children themselves. This final experience has enabled me to see how some children thrive in other environments and how difficult it is for parents to refer to us without the diagnosis of a specific need and then the funding that comes with an Education and Health Care Plan. As I have grown professionally, my personal lens has changed which has allowed me to see the referral process from many different angles. I acknowledge that that the parents and professionals that I interview had different experiential lenses, parents that were professionals and professionals that may have children with special educational needs. In my interpretation of data, I ensured that I was both reflective of my emotions and how certain scenarios could have triggered my own experiences and also that I was reflexive, which I will discuss in more depth, to ensure that I continued to be aware of how I shaped and was shaped through the process of this research which asks parents and professionals involved in the referral process some key questions. What do they think the referral process it? What has been their experiences of it? Do they think that it can be streamlined or changed to improve current practices? Finally, do they think that the removal of Asperger’s impacted the referral system?

3.2: Research Paradigm

Positivism and Interpretivism are two key paradigms that researchers deliberate when considering their research. A researcher that adopts the positivist position would focus on facts and data without being influenced by human bias (Saunders et al, 2012) One challenge of positivist research is that ‘generalisations can lead to ignoring the intention of individuals and their actions may not be fully explored’ (Alharahsheh at al, 2020:41). As this thesis is a case study, interviewing individuals that have experienced the referral processes for autism, I fully intended to explore the actions and feelings of the people that I interviewed. This would help me to answer my questions, ‘What is the referral process? What are parent’s and professional’s experiences of the referral process? Also, in their opinion, ‘Could referrals be carried out differently?’ I am aware that I have experienced the referral process myself, and therefore have my own position of what the referral process looks like, it would be impossible for me to say therefore, that I am completely unbiased, I can say that I am aware of my position and have acknowledged how my experiences could have led me to making assumptions of what I heard. Acknowledging my positionality and reflecting on transcriptions alleviated this bias to some extent, however it would be incorrect to say that I – even on a sub-conscious level – did not interpret the data in a way that may have been different to a researcher that has no prior experience of the referral process. I cannot take a positivist position as within this research the individual’s voice will shape the recommendations. I have therefore adopted an interpretivist position. Interpretivism as a paradigm, ‘assumes that reality is subjective and can differ considering different individuals’ (Alharahsheh at al, 2020:42). The reality in this thesis is the referral process for potentially autistic children. This reality is subjective in that although it is a real thing – children must be referred to be diagnosed with autism – the way in which people experience it differs. Some referrals are passed through quickly with no question, and some referrals are bounced back and forwards as more evidence is required, also sometimes referral requests are completely refused. Therefore, some people will have a negative experience of the process whereas some people will have a positive experience. By carrying out this research I have listened to the experiences of different people involved in the process – professionals and parents – which has allowed me to generate a theory based on the outcome of everyone's individual experiences. This is not a generalisation, as with the positivist paradigm (Moustakas, 1994), but outlines the experiences of all, looking at common themes that may suggest why some referrals are quicker and ‘get through the system’ and why some are delayed or rejected. This again will help me to find answers to my questions about the positive and negative aspects of the referral process and if there is a way to streamline services to make them more effective.

3.3: Epistemological and ontological stance

To fully discuss the differences between objectivism and constructivism, I explored the extreme factors of each to compare their variations. Rand (1905-1982) introduced objectivism in her monograph, ‘Objectivist Epistemology (ITOE)’ in 1967. Her theory states that things exist and, ‘are what they are independent of consciousness,’ (Gotthelf et al, 2013:6) or as Lakoff later explains, ‘reality exists independent of humans’ (Lakoff, 1987:158). An objectivist believes that there is only one reality, we can understand this reality by acknowledging the methods of science, particularly how the world is structured, classified, and then represented using theoretical modelling and symbols (Vrasidas, 2000). At the other end of the spectrum is constructivism. The basic hypothesis of constructivism is that knowledge is constructed, knowledge does not exist without the learner. Following is a comparative model of objectivism and constructivism, based on Vrasidas’ major assumptions (2000:2-10):

Assumption	Objectivism	Constructivism
A	There is a real world that is categorised based on properties.	There is a real world which sets boundaries, however there are multiple realities.
B	The real world is correctly structured.	The structure of the world is created through interaction and is interpretative.
C	Symbols are meaningful representations of reality.	Symbols are the products of culture and used to construct reality.
D	The human mind processes symbols so that it can mirror nature.	The mind creates symbols by perceiving and interpreting the world.
E	Human thought is independent of the human organism.	Human thought is imaginative and develops from perception, sensory experiences and social interactions.
F	The meaning of the world exists independent of the human mind.	Meaning depends on the knowers’ experiences and understanding.

Table 4: Comparative model of objectivism and constructivism based on Vrasidas’ major assumptions

My research is constructivist, based on a review of each of Vrasidas’ assumptions set out above.

Assumption A

Special Education Needs are categorised, for example: autism; ADHD; PDA. Within these special educational needs are further categories as previously discussed with the DSM-V categories which form a structure for the diagnosis of autism. These classifications show that the real world does have boundaries, but there are multiple realities – as shown with the heterogeneity of autism - no two autistic people are the same. The spectrum is so wide that there are multiple 'autism realities' – what autism is to one family could be completely different to another family. When thinking about my question, 'Has removing Asperger's had a detrimental effect on the referral process for autistic people?' we can think about the diagnosis of autism and the diagnosis of Asperger's as real-world diagnoses and even though both have multiple realities, they both have different boundaries. By removing Asperger's and having only one autism diagnosis, the boundaries have been erased, autism and Asperger's are now in one sphere with the multiple realties of both now combined into one. The separation of the two has made defining autism even more complex.

Assumption B

Often, there is a structure as to how things are carried out in the world, whether this is in manufacturing, in retail or in how we are referred to different services. However, this is not always the case, as discussed there is a huge disparity of experiences of the autism referral process, and through interviewing different professionals and parents, I was able to create a reality, through my own interpretation, of what those referrals look like. By interacting with the individuals, I then interpreted what the referral system has been like for each case and then formed a structure of the micro-world of autism referrals. The thesis question, 'What is the referral process?' is an interpretation of the many experiences of each case.

Assumption C

The change in attitude towards Autism symbols reflect the way in which symbols represent our culture, especially our changing culture.

The puzzle piece, for example, which was designed in 1963 by Gerald Glasson shows a jigsaw piece in bright colours with an outline of a crying child in the centre (Figure 2). This was meant to be a representation of autism as a 'puzzling condition' and the child symbolised 'how people with autism suffer from and struggle with their condition' (Sarah Doolet Center for Autism, accessed 12th April 2023). The puzzle piece then developed over the years and became brightly covered, it was then transformed into a brightly covered ribbon by the Autism Society of America in 1999 and changed again to a blue puzzle piece by Autism Speaks, which hoped to raise awareness to find 'causes for autism' (Melson, 2021). This attitude has changed however, with the neurodiversity movement creating a design by autistic people to represent the diversity of the autistic spectrum, as opposed to a puzzle piece which is often construed as implying that an autistic person has a piece missing.

Figure 2: The development of autistic symbols

Each of these symbols were created by humans at a moment in time that represented autism thought however as autism has evolved, especially through the autistic people voice, the symbols have changed culturally with the change in attitudes and knowledge.

Assumption D

The symbols above were constructed by human perception and interpretation. Although Melson's article states that the brightly coloured ribbon is a representation of the diversity of autism, as a symbol with represents the 'ability to unlock a person's potential' (Melson, 2011) and how the piece shows us how autistic people fit into the world, it is seen as very damaging by the autistic community. As the symbol represents autism, is it crucial to listen to the voices of autistic people on the symbol that represents themselves, if autistic people see an organisation or parent using the puzzle piece, 'they will assume an organisation does not consult with actual autistic people' (Jessop, 2019:3). This shows a direct conflict of objectivism within symbols, as people have not looked to symbols so that they can mirror them, they have instead criticised the symbols and changed them so that they better represent themselves.

Assumption E

My own thoughts and the outcome of this research relied on the experiences of other people so that I was able to reach a conclusion – specifically on the individual's realities of the autism referral system.

Assumption F

The meaning – and in this case – the autism referral system relied on the knowledge gained from interviewees experiences. There is an autism referral system with or without the individual's experiences, however there is no single reality as every experience is so different. I questioned whether I was chasing a reality, whether the outcome of the research could have been 'this is the referral process,' and then this becomes the one reality outside of human conscience. However, this cannot be so, not only will every reality differ, but it will also be continuously changing and developing. The reality that this research pursued, is that the reality that all experiences are different, and perhaps if this was considered, then the referral procedure would become more individualised, autism diagnosis models may become differentiated, the complete aspect of referral and diagnosis becomes constructed at each differing case. The questions that the thesis asks - 'What is the referral process? What are parent's and professionals' experiences of the process? Could the referral process be streamlined?' - are all questions that will create meaning based on the individuals' experiences and understanding of the referral process.

3.4: Qualitative Research

The research is a qualitative design study which was chosen to allow for an in-depth understanding of each interviewee's experience of the referral process for autism. Qualitative methods can, 'provide an understanding of how official figures are created through social process' (Barbour, 2008: 11). As discussed, there has been substantial research with regards to the delay in assessment of children with hidden disabilities, however much of this research has been quantitative (Crane et al, 2015; Howlin & Moore, 1997; Siklos & Kerns, 2007; Wiggins et al, 2006). The first research that was carried out examining delays in diagnosis show similar results to research carried out in the last five years. This suggests that quantitative research could be producing the figures but is not necessarily telling the stories behind the figures; previous studies have not evoked the change needed to develop a system that reduces the diagnosis time for autistic people.

Qualitative research is unpinned by ontological assumptions, this research in unpinned by a critical realist position; 'some authentic reality exists in order to make a difference' (Braun & Clarke, 2013:27). The authentic reality is the delay in the assessment process for autistic children – this is real, it exists as shown in previous research. This reality then produces knowledge that make a difference (Stainton Rogers & Stainton Rogers, 1997), in this instance the reality of assessment delays brings about knowledge from each interview - parent or professional - so that we can learn about what the referral process is from each point of view. However, I also acknowledge that social reality is, 'multiple, processual and constructed' (Charmaz, 2006:12) as follows:

- The referral process for each family has differences, therefore it is multiple.
- There are many processes involved such as requiring evidence from a schoolteacher/parent or requiring form filling from as GP – therefore it is processual.
- Each person's experience differed; they therefore construct their own understanding of the process based on this – it is constructed.

A critical realist position, 'underpins a number of different qualitative approaches, including some version of thematic analysis, grounded theory, discourse analysis and interpretative phenomenological analysis' (Braun & Clarke, 2013:27): this research uses aspects of grounded theory approaches.

3.5: Research Approach – case study with grounded theory elements

3.5.1: Case Studies

Case Studies have been undermined as the lesser research method for many years. Some say this is due to case studies analysis of, 'an individual unit (as a person or community)' (Flyvbjerg, 2011:301) as opposed to collecting masses of data that can generate more accurate hypothesis (Gerring, 2004:341). It can be shown how earlier quantitative studies, such as Crane's (2016) which highlighted a delay in the assessment and diagnosis of autistic people has not evoked change, evidenced with the reality that delays in assessment times remain as high, therefore a more personalised analysis of the experiences of the people that have encountered the referral system, with the use of this qualitative case study, may lead to a theory that could evoke positive change. The case study is defined as:

> an empirical method that investigates a contemporary phenomenon (the "case") in depth and within its real-world context (Yin and Davis, 2007:75)

By choosing an empirical method, I was able to see the experiences of the people involved in the referral process. I can now see each journey in detail and how their feelings changed throughout the process, instead of taking a snapshot of a more generalised feeling about the experience. For example, there may have been parts of the referral process that were positive, for a parent this could have been the experiences of a certain individual or a particular service that they encountered. Or for a professional it could have been a process that was more effective at one moment in time. If a quantitative methodology was used, then the overall view would be taken of the experience, without being able to delve into the process more thoroughly. A quantitative methodology would also not allow me to answer the thesis questions with regards to the participants experiences of the referral system and whether the removal of Asperger's from the DCM-V had a detrimental effect on the referral system.

This is an example of the way in which symbolic interactionism is used to construct theory. This is a perspective that shows how human actions construct 'self, situation and society,' as humans interact with each other; their language and actions affect one another as they change our interpretations of what, or has been happening (Charmaz, 2014:261-262). By using grounded theory, I was able to listen to the experiences of a person, capture their reality of what happened at each moment in time. By viewing their journey, I was able to interpret how each experience led them to the next step in the referral process, how each experience shaped a new reality, a changing interpretation of the process. By using grounded theory, I was able to alter my questioning to look at whether similar experiences gave each interviewee the same outcome of thought, of emotion, and if this led to similar outcomes and similar feelings towards their own thoughts about the referral process. For example:

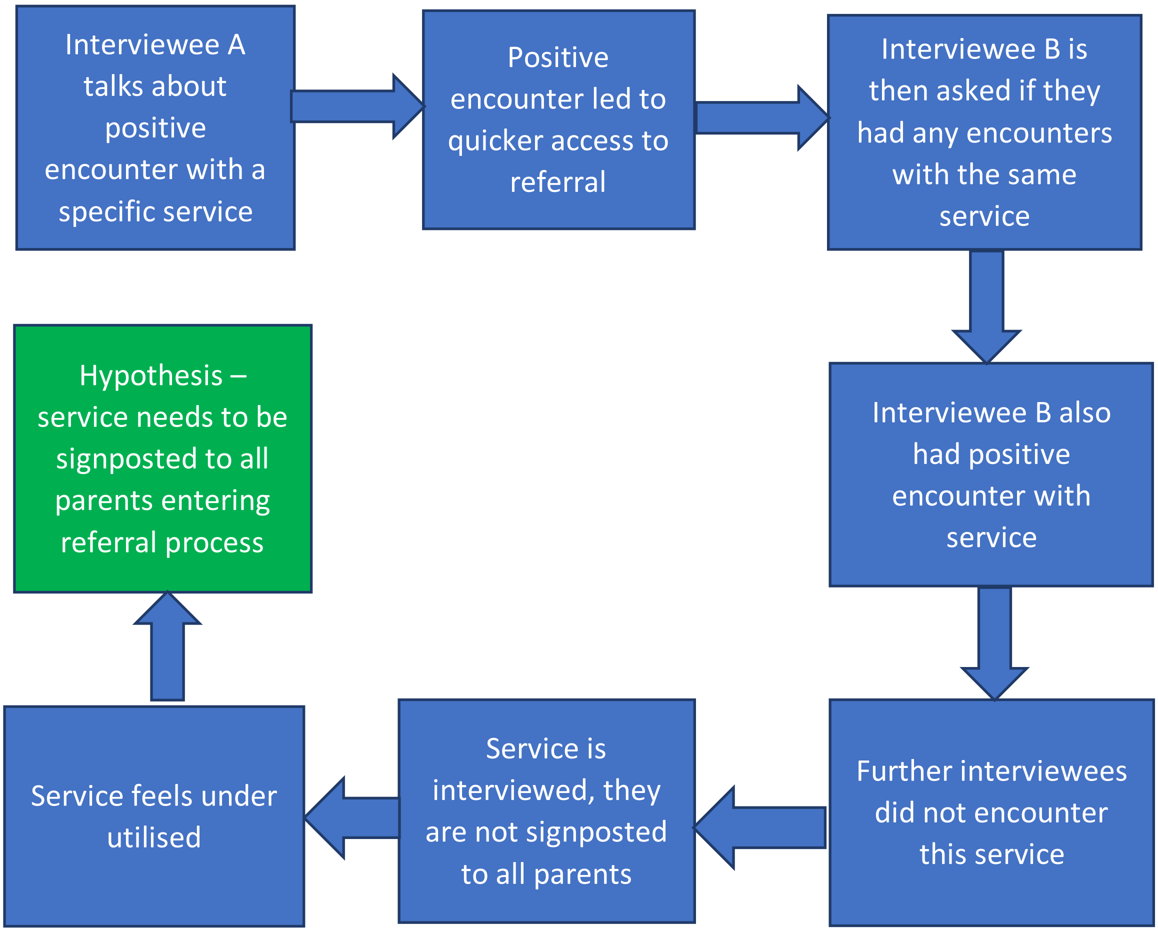

Figure 3: An example of grounded theory interviewing and outcomes

This shows a fictitious example whereby an interviewee speaks about a specific service that was instrumental in their child being referred. This then becomes a question to include in subsequent interviews which guides future questioning. The conclusion would be in understanding how people are referred which could assist in more adequate referral systems, helping to answer the question, 'Could the referral system be streamlined to improved efficiency?'

By interviewing professionals who form part of the referral process for autistic people, I have also been able to identify experiences from each perspective which helped to counteract subjectivity (Yin, 2008:14). By interviewing teachers and SENCOs alongside parents, I was able to see the differing experiences of their own journeys, allowing me to be subjective by looking at the bigger picture. Grounded Theory helped to guide this, for example, if 'Parent A' stated that a service led to a longer referral waiting time, then the question to the SENCo would have been asked about this service to see if they have had similar experiences and to see this service from a professional's perspective. They are more likely to see if a service is underfunded, if a service is lacking staff or experience whereas a parent may see this merely from the lens of them waiting for a long time to be seen, as not being valued, or overlooked. Case studies could be criticised as it uncertain whether results can be generalised beyond the results. This case study could therefore be defined as 'microscopic' as it may be seen as not having, 'a sufficient number of cases' (Giddens: 1984:12). It is important to acknowledge that this study is a fraction of families and professionals that have experienced the referral process and identified themes will not appear in all such cases. I cannot give penultimate evidence, but I can reveal how the process has been experienced for some people that have tried to gain a referral for their child to gain a diagnosis of autism, whether they have been referred or if their referral was rejected. I have then theorised how the differences of experiences had different factors, for example, if the child has traits that would have previously led to a diagnosis of Asperger's, or if the child was referred early in their lives due to being non-verbal. I then theorised how these different factors led to different experiences in the system. I was able to theorise about the different services that parents were referred into, such as speech and language therapy or parental classes and I also theorised about the different experiences due to school structures and local council structures, for example if a child masked well in school and there was no professional evidence from teachers to assist with a referral. This theory could lead to similar case studies in other areas of the UK to highlight good practice which could lead to a more routine and regulated practice across the country.

3.6: Grounded Theory

Grounded Theory was developed in the 1960's by Glaser and Strauss who were researching people who were dying in hospital (Glasser & Strauss 1965). The researchers both argued that meaning was derived from social interaction (Blumer, 1969) and that researchers should not be concerned with testing theories, but that theories should be derived from the people that were being studied, 'thus, researchers construct a theory that is grounded in their data' (Charmaz, 2014:1). Grounded Theory has many different versions – constructionist, constructivist and contextualist - this research follows Charmaz' Constructivist Grounded Theory approach: in that we do not find our theory in the data that we collect, we, 'construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices' (Charmaz, 2006:10).

Charmaz states that grounded theorists use the same strategies which makes them distinctive from other actions. The first five strategies that she lists are stated as evidence that grounded theory has been used in this thesis. Each of the strategies are listed below with a description of how this research falls into the grounded theory category:

Strategy	Description
Conduct data collection and analysis simultaneously in an iterative process	I carried out each interview, then transcribed it and then analysed it. The analysis of each interview led to the next interview, either by a change in questioning led by conversations arising from the interviews or by similarities appearing that need revisiting. Any repetition of actions or processes across interviews refocused further questioning. Any new themes of interest with regards to the referral process were then adopted for further questioning. The process therefore was Interview, transcribe, analyse. New interview, transcribe, analyse, compare. New interview.
Analyse actions and processes rather than themes and structures	The analysis of interviews was initially focused on the process of autism referral. What were everyone's experiences of the referral process? What did they see the process as being? The knowledge that arose from this method of analysis was constructed from the experience of everyone involved in the referral process. Analysing the actions of interviewees constructed knowledge pertaining to values, perspectives and decisions. Analysing actions is finding out what a person did and did not do or what they are going to do and how they felt, which although may not be spoken about, is often hidden in the actions that they carry out.
Use comparative methods	Constant comparative methodology incorporates four stages (Glasser & Strauss, 1967:105) 1. Comparing incidents applicable to each category 2. Integrating categories and their properties 3. Delimiting the theory 4. Writing the theory After each interview, all the prior interviews were compared with new interviews, reinforcing theory generation where applicable.

Draw on data (e.g. narratives and descriptions) in service of developing new conceptual categories	When interviews were analysed, narratives and descriptions were analysed carefully to develop 'conceptual categories' – those which arose from emotions or other abstract ideas – for instance during interviews when a participant described the emotions they felt during the referral process, or the relationship development between themselves and others involved in the referral process. These similarities or repetition of emotions across different interviews became conceptual categories. It may have been that professionals have the same conceptual categories or parents have the same categories, or that emotions and feelings were replicated across all participants.
Develop inductive abstract analytic categories through systemic data analysis	Examining the purposes of using inductive analysis, I ensured that the following intentions were met: 1. Condensing extensive and raw text data into a summary format. 2. Establishing clear links between the research objectives and summary findings and ensuring that links were transparent and defensible. 3. Developing a model or theory about the underlying structures or experiences or processes that are evident in the text data. (Thomas, 2006: 237)

Table 5: Charmaz's strategies of constructivist grounded theory within the research

Charmaz also acknowledges subjectivity, and due to my own personal experiences in relation to the study, it was important to recognise how I interpreted and constructed the data, for although I always attempted to attend to my own personal influences, recognising them throughout the study by, for example, not asking leading questions, it would be unrealistic to state that I, as the researcher, had no influence at all on the theory. As with all grounded theory methodologists, even though our approaches vary, we all intend to 'develop theoretical analysis and value grounded theory studies for informing policy and practice' (Charmez, 2016;15).

3.7: Data Collection – Interviews

Interviews can be categorised as structured, semi-structured and unstructured. A structured interview has predefined questions which would all be asked in the exact same order to all the interviewees (Zhang et al, 2009). There are some critics to the use of structured interviews within qualitative studies, as this data could be collected 'more easily and cheaper' using other methods (Carruthers, 1990:64) such as questionnaires in a quantitative study. This method of interviewing may be used to minimise how an interviewer could interpret interviews as there is no diversion from the questions. Unstructured interviews are often given caution, as they are said to be incredibly difficult to carry out, requiring a great deal of skill and training to be effective (Borg and Gall: 1983). Unstructured interviews have no predetermined questions, they rely altogether on the social interactions between interviewer and interviewee. The unstructured interview is said to enable interviewers to ask questions without imposing any categories (Punch, 1998), leaving each interview completely subjective. For these reasons, I chose to use semi-structured interviews. Questions were predetermined as it was impossible to state that I had no prior knowledge of the referral system for potentially autistic children. I therefore could not justify the use of unstructured interviews as, even if I did not write questions down, I subconsciously had the questions that I would like answered, to see if my experience were replicated in the experiences of others, to see if the qualitative research that exists which tells us that waiting times are so long could be partly due to the referral process itself. Although each question was not written in detail, the foundations of the thesis questions remained as a scaffold throughout:

- What is the referral process?
- What are parents' and professionals' experiences of the referral process?
- Has removing Asperger's had any effect on the referral process?
- Could the referral process be changed in any way to help streamline services and make them more effective?

To start interviews unstructured would be carrying out conversations that would have been led, whether I meant to do this or not. I also could not have carried out completely structured interviews, mainly because this is not something that interests me, I did not want to know the data or the numbers, I wished to have a personal connection to the people that were going to guide the data and the results and felt that structured interviews would have done them an injustice. By carrying out semi-structured interviews using aspects of grounded theory methods, I was also able to triangulate, which Guba describes as, 'collecting data from a variety of perspectives…triangulation may be used to examine the same phenomenon from multiple perspectives" (1985:604). As I interviewed the phenomenon of the autism referral process from the perspective of parents and professionals, this allowed for, 'deeper dimensions to emerge' (1985:605). By carrying out semi-structured interviews, I was able to construct 'meaning-orientated' responses (Kvale: 2007:11) which led to more in-depth discussions about the topics raised. By listening to the answers, reading between the lines and inferring meaning, I was able to formulate further questions based on each answer. This is also meaningful within grounded theory, as the responses that I gained led on to further semi-structured questioning of the next interviews – the conversations that arose from each person gave meaning for each step of the data collection process. This was an incredibly empowering process as it could be argued that this helped to balance the power dynamics of interviewer-interviewee.

In whichever way the interview is structured, the interviewee/interviewer power relationship could be unbalanced. Both interviewee and interviewee could be put into a position of being less powerful: this could be due to gender; educational or professional status;

socioeconomic; or ethnic identity (Anyan: 2013). A power imbalance could also be caused by the interviewer achieving their own goals by imposing their own experiences to control and constrain the dialogue (Wang:2006) or by the interviewee refusing to answer questions, by concluding the interview before all questions are answered or where the interviewee answers particular questions in such a way that the interviewer is not able to continue questioning of the same nature (Anyan:2013). In general, however, it is assumed that the interviewer has the greater power, even if this is perceived by the interviewee. This is due to the researcher being the person that, 'sets the stage, controls the setting, controls the script and initiates the questionings in accordance with his or her research interest' (Brinkman & Kvale: 2005:159). By informing the people that I interviewed about grounded theory and giving them an understanding of how they were shaping the next interviews with their answers, I hoped to empower them by showing them that they were integral to the research outcomes as they themselves shaped the next interviews. It was important that even though I felt that this process was empowering for each respondent, that there may still have been the perception that I was the person with the power, as I would be entering interviews with a semi-structured questioning from the prior person. Even though this gives the prior interviewee the power, it is I that will be asking the questions, even if I was not fully in control of where the dialogue would lead the questioning. It was important to remain reflective on this power, ensuring that by constantly checking back on my main thesis questions that I remained as constant as possible, otherwise I may not have gained the full experiences of each participant.

3.8: The Problem-Centred Interview

Witzel and Reiter (2012:1) explain how most of our knowledge is gained through language, either by reading, hearing or asking about things of interest to gain a better understanding of them. Brinkmann (2007:471) also proposes that interviews have been carried out by people since the time that language was mastered, therefore, 'qualitative research interviewing makes the most of the ancient human habit of asking and answering questions' (Witzel and Reiter, 2012:1). Qualitative interviewing techniques are varied and Kvale and Brinkmann (2009: 48) developed two distinct methods to describe the interviewer: the miner or the traveller. The miner-interviewer goes into each interview with a set of interests and specific information that they find most valuable, they look out for certain themes and turn these into a collection of 'nuggets of knowledge' (Kvale and Brinkmann 2009:48). The traveller-interviewer starts the interview with a more 'tabula- rasa' approach, encouraging new conversations to uproot interviewees' experiences. These experiences then co-construct knowledge which also modify their own opinion. Both of these approaches would have been difficult to adopt with this thesis, for one, it would be impossible to take the route of miner-interviewer, as although I have experiences that have guided me into this research, I was led by each interview outcome to redesign further questioning, therefore although there were a set of question that started interview 1, each new interview was dependent on answers given, and my own set of interests were chipped away at, leaving a broad overview of the experiences of the interviewers themselves. The traveller-interviewer approach is also difficult, as although the interviewees were able to guide my questioning, I do have experiences that have led me into this research, and to say that I had no initial concept as to why referral times are so delayed would be untruthful and therefore would lead to a dishonest and unreliable outcome. The way in which I approached the research as an interviewer, therefore combines both traveller-interviewer and miner-interviewer. This, in part, coincides with Witzel and Reitel's 'problem-centred interview' (PCI). PCI interviewers:

> Take on the role and attitude of well-informed traveller: they … start the journey on the basis of background information. Yet the trip they finally make depend on the people they meet on the road. (2012:3)

Although this was in line with my interviewing technique, the PCI interview takes on a more structured approach as described by Scheibelhofer (2005):

1. Open beginning of narrative-style interview
2. Structured guideline interview
3. Short questionnaire with regards to the collection of socio-statistic data

The beginning of this interview could align with this thesis approach, in that each interview started with the basis of what the interview was about – expanding on the information sent pre-interview. Ensuring that any questions that the interviewee wished to ask were covered, ensuring that they were comfortable and that they could have an open discussion. The next section, however, was less structured, as although there were set interview questions so that the interview was guided and did not lose track, questioning was able to divert when themes arose that were important to the interviewer. This enabled the questions to be developed across the next interviews. The interview also did not end with a short questionnaire as I felt that this aligned more with quantitative interviewing techniques and led to a less personal approach. Ensuring that the interviews captured participants experiences of the referral process could help to make services more efficient or highlight best practice with interviewees that had a first-hand experience of the process.

3.9: Reflexivity

In addition to how I interpreted the data, it was important to be aware of how I intended to shape and also be shaped by the research process, and in doing this acknowledge that, ‘reflexivity in research constitutes part of the research findings’ and that I attempted to be aware of my own, ‘contributions to the construction of meanings and lived experiences throughout the research process (Palaganas et al, 2017:426). As discussed, I have my own lived experiences of the referral process which could have had two outcomes on my research due to the questions that I posed and the way in which I interpreted the data. I was aware that my own opinions would also be challenged during the process. Barusch et al (2011) identified that only 16% of researchers used reflexivity to ensure that their work is stringent, which Palanagas et al (2017) say could be due to a fear of authors disclosing personal features or that this disclosure would not be well regarded by editors. Having both self-awareness (Riley et al, 2010) and a ‘level of consciousness’ (Palangas et al, 2017:427) helps researchers to identify their own changing values and how their own experiences can shape the research process (Hesse-Bieber, 2007). Having self-awareness and continuing to challenge oneself ‘enriches the research process and its outcomes’ (Palangas et al: 2014:427).

Van der Riet (2000) identifies the difficulty in managing how participants react emotionally during interviews, and how their reactions can influence the researcher’s own feelings. This is in additional to being aware of how researchers pose questions, of our own body language and approaches during interviews to ensure that both spoken and unspoken body language is not interpreted by the participant, and therefore influencing the outcome of their responses. Obviously, many of these signs are unconsciously given, being aware that this could be happening is another example of reflexivity – the acknowledgement that it is impossible not to affect the interviews in some way, offers a more robust outcome to the end theory. Being conscious of my own internal reactions to interviewee responses and my overall emotions after each interview helped me to reflect on how this could have influenced my future questioning. Redirecting my questioning through self-awareness and refocusing on the interviewee’s answers, emotions and body language helped to ensure that I was aware of how responses could have been influenced by own actions and questioning. Since writing the thesis, I have received an autism diagnosis. On reflection, I can see how some of the interviewee’s non-verbal responses may well have been missed as this is in area that I find difficult to interpret due to relying on more verbal answering. I am, however, an intuitive and empathetic person, and even if I did not pick up on non-verbal cues then I think that I would have been more in tune to their tone of voice or small hesitations in their answers. On balance, the deficit in not realising non-verbal cues would have been compensated for with a surfeit in verbal response intuition.

3.10: Data analysis approach

As discussed earlier, 'everything begins with data' in grounded theory (Wasserman, Clair and Wilson, 2009:358) and the data also remains foremost 'throughout analysis and theory building' (Birks & Mills, 2015:64). To add the depth and scope required for a credible grounded theory study, I chose to interview both professionals and parents that have experienced the referral process. This has helped me to triangulate data collected using theoretical sampling whereby I was able to, 'jointly collect, code and analyse data and decide what data to collect next and where to find them in order to develop theory' (Glaser and Strauss, 1967:45). Although I recruited interviewees pre-data collection, due to the distinctive characteristics of theoretical sampling, it was not known in which order the participants would be interviewed. Also, it could have been necessary to extend or decrease the participants, if the themes generated led the theory in another direction, for example my, 'engagement with the data generation made (me) aware of issues that required expansion, clarification or confirmation' (Birks & Mills, 2015:68). For example, if a school SENCO was interviewed and told of the process that they had followed for a referral involved another professional, then it may have been necessary to interview the next professional to see what their thought of that specific process was. The interviewees' accounts could have been similar or may have had differences. This could also mean that interviewees could have been required to be re-interviewed when differing experiences had been collected to ensure that there was a depth of understanding.

There are differing points of view with regards to when theoretical sampling should commence. Charmaz (2014) states that theoretical sampling should only start to take place once categories have been developed, however Birks & Mills (2015) believe that theoretical sampling should take place immediately from the first interview as some concepts will start to take place which will then lead to 'broader and more diverse types of data' (2015:69). I followed the Birks and Mills example and started to look at concepts after the first interview. After the second interview, I then compared interviews to look for more specific themes or similarities to decide which interview will take place next. To ensure that I did not leave participants wondering when their interviews would take place, I ensured that my method of data collection was clear during recruitment so that they were not left waiting or thinking that the interviews would not take place. I also ensured that although the themes and questions were led by participants answers, that the ideas that sparked the thesis remained central to the questioning: 'What is the parents' and professionals' experiences of the referral process?' With primary questions in mind, participants' experiences could then lead into questions to be asked of the next interviewees. Were their experiences the same or different? Did they feel that removing Asperger's from the DSM-V have any effect on the process? Did they think that the referral process should change and if so, how?

3.11: Ethical Considerations and Implications

Ethics for this thesis have been approved under reference number: RECCOUN00041

Being part of the autistic community, from my point of view, is in relation to my son being autistic, my daughter being autistic and myself being autistic. In addition to this, I own and run an Alternative Provision for autistic children. I join forums and community groups that are grounded in the education and support of autistic people to ensure that I am learning and supporting in the best possible way, based on the experiences of other autistic people. I am conscious that even though I am surrounded in autism that I am still not the voice of all autistic people, as we are all different, I therefore am very aware of ethical decisions that I have made in my research. I do not speak on behalf of all autistic people and I am also an advocate in ensuring that the autistic voice is heard, by acquiring knowledge directly from the autistic person. This sets up a conundrum therefore, as a researcher, acquiring knowledge, interpreting it and concluding based on the experiences of parents of autistic people. Many autistic people can speak for themselves of their own experiences with their personal route through referral to diagnosis, however I have collected the experiences of parents due to the autistic people being children, some of whom may not be aware that they have been taken through a referral at all. I speak from the point of view of a parent that has attempted to guide my son through the referral process, from the point of view of a teacher that has had experience of helping parents with the referral process in the school setting and also from the point of view of an alternative provision provider, helping parents to find an alternative to mainstream education. My critical perspective is not an attempt to further marginalise the oppressed, but an attempt to, 'join the struggle for solidarity with those that have been oppressed and inequitably treated' (Cannella & Lincoln, 2011:83). Asking what the interviewee's experiences of the referral process was to shape recommendations for best practice or new procedures.

Glesne (2007) introduced four ways in which qualitative enquiry combines with alternative ethics, I have listed each strand and related each to my study as follows:

3.11.1: Research Purpose

Glesne asserts that 'presumption and arrogance often accompany our claims to understanding which are partial at best' (2007:.2). When interviewing, I did not presume to know what experiences the participants had based on my own. As, 'a primary motivator seems to be the need to make a difference and a belief that we can help' (Glense, 2007:2) I ensured that I did not enter my research with the attitude of 'I am here to help' as I would have then placed myself in the position of authority: I see all of your struggles and I am here to stop this because you were not able to – would be the presumption and arrogance that Glesne warns the researcher.

3.11.2: Data Collection through Participant Observation

Glense states that observing participants does not align itself with the solidarity model as, 'the process of an outsider noting actions and words is objectifying and often offensive (2007:2). To avoid the act of observation, the data was collected through recording, enabling me to be fully 'present' in the interviews.

3.11.3: Data Collection through Individual Pre-Structured Interviews

So that further solidarity is created when interviewing, Glesne suggests that a researcher should ask the participant if they have any questions to ask. This was sent out pre-interview with the questions, it was also asked at the start of the interviews and at the end of the interviews. In an interview that Glesne conducted in an indigenous village in India, a student asked the villagers if they had any questions for them:

> Their questions of us helped us learn as much about the women and their lives as their answers to our questions. We also saw our own lives differently. The one-on-one interview used in many qualitative enquiries is a recent construction that depends upon the individualisation of the self, rather than a 'collective' self. (2007:3)

By allowing myself to be questioned I attempted to remove the researcher's position of power and instead placed myself in the shoes of the participant. This again helped to remove an arrogant perspective and helped to build a position of solidarity.

3.11.4: Data Interpretation through Pre-Set Lenses

Glense's research states that:

> Our framework for understanding the world, our categories for segmenting the world, are culturally determined mythologies and difficult to see. In a solidarity research model, we would work to listen to and respect many different perspectives for understanding the world. (2007:3)

As the interviews are semi-structured, the interviewer's answers allowed me to pick up on themes that arose directly from the participant. I listened for other issues, other experiences that led to the construction of further knowledge and the construction of further questions. By recording the interviews, I had the opportunity of revisiting each interview, ensuring I did not miss any new themes or new shared experiences. I ensured that the participants were aware of this, so that they understood that although there were some set interview questions, that they were very much part of the evolving process of the research.

At the centre of ethical treatment of participants in educational research is the concept of informed and free consent. Participants were given their free and informed consent to take part in the interviews before the research took place (Smythe and Murray, 2000:313). Signed documentation was taken with consent forms whilst also recognising that, 'informed consent is the result of a process of reaching an agreement to work collaboratively, rather than of simply having a consent form signed' (Simpson et al, 2003:494). To ensure that prospective participants were, 'voluntarily consent(ing) to participate in research and are not induced to do so by using any forms of undue influence or coercion' (Smythe and Murray, 2000:313), I sent a standardised email outlining the research question and asking if they would like to participate. Interviewees were given the option to opt out at any time during the interviews with a cut-off point of two weeks post-interview, so that participants were aware of exactly when data analysis would be completed and when the report would be finalised.

I am aware of circumstantial factors that could limit the freedom of consent (Smythe and Murray, 2000:313) for example, as I have been through the diagnostic process personally and with my children, there were several professionals that were involved in our own case, specifically SENDCo's of my children's schools, GP's, paediatricians, occupational therapists, CAMHS staff, teachers and teaching assistants. There are no professionals that have been involved with the referral or diagnosis of myself or my children. Informed consent ensures that researchers:

> Have an obligation to "provide, to prospective subjects or authorised third parties, full and frank disclosure of all information relevant to free and informed consent and do so using language that is understandable (Smythe and Murray, 2000:313).

To achieve this, I gave each participant a description of the research study which informed them of those aspects that would inform them whether to take part, as defined by Smythe and Murray (2003), these included the purpose of the research and identity of the researcher. I let the interviewee understand the details of the research, that I am interested in the referral process of potentially autistic children, from the parents or teachers first raising concerns through to the final diagnosis or final appointment/assessment. I explained that I was interviewing parents and professionals to take a rounded view of the referral process.

3.11.5: The duration of participation and the nature of research procedures

I ensured that each participant was aware that the research project was envisaged to take around two years from initially devising interviews to writing the report. I ensured that the interviewees were aware that I wished to undertake semi-structured interviews in a neutral environment (office space has been rented in advance), however that they were able to choose the environment that they felt that they would be most comfortable in.

3.11.6: Any foreseeable risks or benefits arising from participation or consequences from nonparticipation

As the research is based on the referral processes within one council in the UK, I assured participants that the council was completely anonymised and that all names were anonymised.

3.11.7: Assurance that participation and withdrawal from participation are free and voluntary

I endeavoured to ensure that all participants had the right to withdraw at any time during interviews, with a two-week cooling-off period after interviews.

Privacy and confidentiality are essential requirements of an ethical research study; it is, ‘the right of individuals not to have personal and identifying information about them disclosed without their permission’ (Smythe and Murray, 2003:313). I ensured that all names were anonymised including the names of the children with additional needs that were discussed during the interview process. I ensured that the process for ensuring confidentiality and privacy were communicated to the participants in advance of the interviews as this is said to be, ‘an essential condition for maintaining an appropriate relationship of trust between the researcher and participant (Medical Research Council of Canada et al, 1988:4)

It was important to ensure that interviewees were safe from harm when considering ethics in research and risks had to be weighed against the potential benefits of the research in terms of its contribution to knowledge (Smythe and Murray, 2003:315). There was a risk that participants could have felt emotional during the interviews as reflecting on the referral journey of their child and the impact that this could have brought out feelings of anger, helplessness or guilt. It was crucial that participants were aware that interviews could be stopped at any time, and if the interviewees were becoming emotional during the interviews that time out was taken, or interviews were suspended until a later time. It could have been the case that some parents were so emotionally invested in the subject matter that they could have been unable to complete interviews. I ensured that I was both reflexive and responsive to the well-being of the interviewees by:

> allowing participants to set the pace and depth of an interview…moving on from distressing topics and facilitating ways for participants to take time out of the interview situation (Mitchell and Irvine, 2008:35)

It is important to note that qualitative interviews share similarities with therapy (Dickson-Swift et al, 2006:856) as both are, ‘based on empathy and listening skills’ giving space for participants to talk about personal issues with someone who wants to listen.’ (Mitchell and Irvine, 2008:35) However, a researcher’s aim is not therapy, Instead, I supported the interviewees by ensuring that I gave them the results of my findings and the opportunity of discussing them in detail. I also had to consider my own emotional responses to the interviews. I ensured that I had the support around me to be able to discuss the emotional impact that the research had on me as highlighted by Harris and Huntington (2001:141) who report that, ‘thinking through and working with the emotional rather than just the technical aspects of our interactions in interviews is an important, often neglected consideration’ and also Jagger (1989:183) who has the view that, ‘emotions should be attended to seriously and respectfully rather than condemned, ignored, discounted or supressed.”

3.12: Interviews

As I have used aspects of grounded theory, it was important to evaluate which participant I would interview first and how I would then decide which participant to choose after analysing each interview. I decided to choose an interviewee that worked between parents, schools and professionals, therefore having a general overview from all viewpoints.

After I had interviewed the first participant and then carried out my analysis, I looked for emerging themes to then choose the next participant. As one of the main themes that emerged from the first interview was ‘parental voice’ I wanted to position some questioning both to a parent and to a teacher. I therefore interviewed a parent first, ensuring however that after I had analysed this interview that I still included questioning with regards to themes that emerged from the first interview. This allowed me to analyse interview 2 and 3 collaboratively, also ensuring that I did not only seek reflections of the parent based on these questions, but also of the schoolteacher. This analysing and reanalysing occurred through the process, being reflective and considerate of asking key questions during all interviews if I knew that there could be vastly different points of view, and then analysing their points both on their own merit and alongside the other participants' thoughts and experiences

Chapter 4: Findings and Discussion

Introduction

Themes arose as a direct result of the interviewees lived experiences of the referral process for potentially autistic children. The themes could evoke positive changes by offering solutions for a more effective referral process and to also highlight effective practice that has been experienced by the participants. As shown previously, the current waiting times for autism assessments are high and historically the waiting times have not reduced over the last ten-year period. As discussed, this is of interest to me due to my own personal and professional experiences; as a parent of two children with additional needs; as an autistic person; as a teacher and as a business owner of an Alternative Provision and Independent Special School catering for autistic children.

All interviewees have, as discussed, been anonymised, and given different names. Their quotes will be shown with the paragraph (P) and line (L) that they appeared in the transcription. Each theme is titled and then the data introduced and evidenced in patterns throughout the interviewees quotes. Evaluation of themes will continue throughout the chapter and then linked back to evidence that has been presented earlier in the thesis within each theme's conclusion.

The participants are made up of professionals and parents as discussed earlier in the thesis. For identification purposes within the findings, the anonymised participants are as follows:

Hayley: Parent
Bryn: Parent
Ranesh: Parent
Simon: Manager of a SEND support service that provides advice and support to parents and professionals of children with SEND.
Ryan: Newly Qualified Teacher
Lisa: Speech and Language Therapist
Iris: Mainstream School Special Educational Needs Co-Ordinator (SENCo)
Sam: Early Years SEND Area Manager

The interviews took place over a six-month period. I will be looking at each of the themes from the perspective of each of the participants. At the end of each theme there will be a brief summary of each theme followed by a discussion at the end of the chapter.
The themes and sub-themes are as follows:

Theme 1 - The identification of autism in children.

Subjectivity:

Different people see autism as different things, as it is a social construct.

Autism diagnosis post Asperger's diagnosis removal:
This theme arose due to parents and professionals discussing the difficulty of referring 'Aspergers' type children into assessment services.

Masking:
The identification of autism traits is discussed as being difficult when children masked in school.

Labelled as Poor Behaviour:
The identification of autism proves to be difficult when a child is labelled as having poor behaviours

Theme 2 - The differences in professional support.

Lack of Training:
Lack of training for professionals involved in children's diagnostic journeys has had a detrimental effect on referral.

Lack of Funding:
The issue of funding was prevalent in the interviews.

Academic Outcomes vs Emotional Wellbeing:
Academic outcomes arose as a theme within interviews where it was discussed how this was placed above the emotional wellbeing of young people.

Theme 3 – The referral process itself

Specifics relating to the council area referral practices in this case study:
This theme arose in relation to Council X's specific referral process

Parental Voice:
If parents could refer directly, many appointments could be saved, saving money and time within this sector.

Differences in Profile:
How the separation of autism and Asperger's affected referrals.

Historic issues with autism systems:
This theme was discussed in relation to parents feeling guilty at labelling their children

4.1: Theme 1 - The identification of autism in children

4.1.1: Subjectivity

In this theme, it will be discussed how autism is unique to every individual and also in comparison to other disabilities as there is no medical test, such as a scan or blood test, with which to diagnose. This makes referral difficult to achieve and if several professionals are used for different opinions there would be differentiated opinion to help gain evidence of need.

The very diverse nature of autism itself is shown to have a great impact on the referral process for autism, as three of the interviewees suggested in their own terms that when you have met one person with autism, you have only met one person with autism (Simon P13 L2; Ryan P1 L9; Hayley P12, L1-2). This is in stark contrast to the structured tick list (the autism checklist) that must be completed if you want your child to be referred for an autism assessment where questions are formed based on autistic traits. To access a referral, there must be a percentage of autistic traits shown so that the child is passed through for an assessment by professionals. (See Appendix A). However, every autistic person is different and although some may have similar traits, they may also have vastly different traits (Hassall:2016). Simon is a manager within the SEND profession who manages and attends meetings between parents and schools to ensure that young people have reasonable adjustments made at school in order that the child can meet their full potential. He, and his team, also give SEND advice and signpost parents to services. Here he tells us: (P13, L3-7):

> *It [autism] is unique, isn't it? It is the same as cerebral palsy. In my life, I have worked with people with cerebral palsy who are non-verbal quadriplegic, profoundly disabled. I work with people with Cerebral Palsy with minor movement impairments. It is a huge spectrum and autism is remarkably similar, isn't it? Which again, makes diagnosis and identification quite difficult.*

Although autism and cerebral palsy are both unique, the identification of autism is more difficult because there is no medical test for it, unlike cerebral palsy in which brain scans can be carried out to look for areas of damage or irregular brain development. Instead, testing relies on a professional's opinion as Simon tells us, (P9, L2-3):

> *It is individual people's views, and it is not something that you can have a blood test for. They go, yes, you are autistic. It is a diagnosis of opinion, isn't it?*

This shows how autistic traits are subjective. If we look at autism as constructivist (Vrasidas:2000) as discussed earlier in the thesis, we know that it exists but it is something different for every person. In addition to this, every professional is an individual with their own perspectives, experiences, or lack of experience with autistic children. Simon calls this the 'diagnosis of opinion' because opinions can differ, and this can be due to one person seeing autistic traits in a child while another sees autism as something different and misses subtle autistic markers.

Children can also act very differently with different adults or in different environments or within their lesson time in educational settings as evidenced earlier with the Sally Ann test. This could mean that autism referral outcomes and observations for each individual child can vary significantly with all these factors in mind. If one professional adheres to the autism trait tick-list questionnaire due to lack of training or experience, and then another is more knowledgeable and sees traits outside of the questionnaire, then reports could have differing outcomes of the same child.

To help overcome this difference in opinion, Simon suggested (P6, L2-5):

> *One of my pieces of advice to parents was to go back and see a different doctor because you might get one that has recently completed the autism course or have more understanding and they agree with you and put the referral though.*

Finding a second opinion could have a detrimental effect on the waiting times for referral as it adds more pressure to professionals by doubling appointment times. Simon discusses how having a multidisciplinary team (MDT) is more helpful as a team of people would be observing the child individually, and would then come together to make a joint decision based on everyone's findings (Simon, P8, L1-11):

> *What I find in the wider context, when you are having those conversations with schools is they do see things, but they do not realise that is what they are seeing [autism traits] until they have had that conversation. And the issue with all these systems is you are at the mercy of the understanding of individual people. You have got a good class teacher that knows about it, has experience with it, understands it, they will pick up little signs here and there. Then, someone that does not have that experience that well, because that is not something that they are aware of, or something that they are looking for. And that is a fundamental issue across the entire world of SEND.*

This level of multi-personnel observation is also helpful in the school environment, for example, when the school SENCo carries out an observation after discussing autism with parents. Where teachers do not always notice autistic traits, the school SENCo can then observe the child's school journey and feedback what they have seen to the teacher, for example, when Iris (SENCo) collects evidence for the referral forms, she states that (P2, L1-9):

> *Next steps would be for me to go into the classroom and observe that child, observe things like the playground or P.E. and discuss with the teacher those kinds of areas too. Because often, when you do start picking on those things with teachers, they will say, "Oh yeah, actually the child does get really upset when they lose in P.E. or in a game that they've done."*

The level of expertise that the SENCo may have, as they are qualified with a SEND qualification, in this instance helps to identify traits that may not always be so obvious or are completely different from child to child. The qualified SENCo will have observed many different autistic children and have a good overview of different children with different traits. As they also have their own section of the autism checklist to complete, an experienced

SENCo could understand how the subtleties of autism may not be able to be placed into such an inflexible model as the autism referral checklist but will need a level of explanation too. Within the school environment it can therefore be said that having more than one professional observing the child could help to identify autism and gather the much-needed evidence needed for an autism referral.

4.1.2: Autism Diagnosis post 'Asperger's' diagnosis removal

In this theme it will be discussed how the removal of Asperger's from the DSM-V had a detrimental effect on the referral system, as autism became a much wider spectrum to diagnose. This made recognition of autism more difficult for parents and professionals who speak about Asperger's being more difficult to refer into autism services.

The multi-faceted nature of autism was significant when participants spoke about an Asperger's diagnosis versus an autism diagnosis. Hans Asperger, as previously discussed, studied a group of children that all had superior language skills, all had poor fine and gross motor skills and that did not learn by rote, but instead learned by being spontaneous. If this is compared to another child, one that is non-verbal, with outbursts due to communication difficulties, the differences can be vast. As discussed, Asperger's is no longer diagnosed and there is only one referral checklist covering every autistic child. Sam, who is a professional that has worked for many years with children with various special educational needs and disabilities, discusses how it is more difficult to access a referral for children that would have been diagnosed as Asperger's than it is to diagnose children that would have been diagnosed as autistic (P17, L1-6):

> *In my experience of school-aged children, I would say it is less easy to diagnose a child with more Asperger's traits. Girls especially because they are so good at masking and it is difficult to get EHCP requests through panel if they are, academically, pretty much where they should be.*

If someone such as Sam would find referring 'Asperger's' children more difficult, then it could be said that a new teacher or a professional with limited autism training or experience could find recognising the different autistic traits challenging. If the main resource that new professionals must refer to is the autism checklist, then this could be one reason why some parents and professionals have difficulty in accessing a referral.

Asperger's as a diagnosis can also have an impact on parental understanding of autism, as shown with Hayley's (parent of autistic child) interview:

> I *did not think autism, but then when they mentioned Asperger's I thought, yes, that is my son. That is where he fits (P13, L7-9).*

The decision to remove the label of Asperger's is difficult to disagree with due to Asperger's acts during the war however it would have been a consideration to change the name, so that autism and Asperger's were still differentiated and allowed separate consideration and understanding by professionals.

Sam's interview highlighted how children with an Asperger's profile are often more difficult to diagnose which means that far more evidence needs to be collected for the referral for school to be successful, this was also emphasized by Iris, SENCo (P18, L1-12):

> *If they are not that typical, autistic profile, so it might be that they are able to socialise and speak with adults and children quite well. They may be very articulate; they like to strike off conversations. So, they are not withdrawn, and that is something that they think that children cannot mask. However, it might be that they are the other way, that they do not understand the social boundary, so they are overly familiar with people. Those children tend to get their autism referral refused. Also, if they are academic, which does not make sense at all, I know a lot of children who are autistic and are highly intelligent. The children who are severely behind, struggle with social interaction and struggle with mobility are the ones that usually get through the referral system quickest.*

This alludes to a discrimination within the referral system (Wing:1996) in that if you are a typical Asperger's type then you are identified as less autistic, or not seen as having needs that require additional support both in the classroom and in everyday living.
Hayley (parent of autistic child) stated that (P14, L1-2; P15, L1-10):

> *Autism is such a wide spectrum especially now that there is no Asperger's diagnosis. So maybe if it was back in blocks of spectrum, then maybe it would be easier to educate teachers, to show them the many differences in autism. It's not just – this is autism training, one cap fits all – it is pinpointing traits and how they can appear in different children and sometimes not at all. Showing them different children and their diverse needs.*

It could be argued that having 'blocks within the autism spectrum' could be problematic as autistic people are so individual, that one 'block' of autism would not fit every person, it is also true to say that not every Asperger's type of autism is the same just as not every autism is the same.

4.1.3: Masking

In this theme, how children behave at home, in an environment where they can 'unmask,' and how they behave at school, when they may socially mask to get through the day, can mean that autism is difficult to recognise at school as there is less evidence of need.

Many children, as discussed, also mask or camouflage their differences in school, watching how others behave so that their own actions are not dissimilar to that of their peers. Helping them to 'fit in' and not feel 'other.' Masking can be conscious or sub-conscious whereas some autistic children do not mask at all. This is another example of the heterogeneity of autism which can lead to problems with professionals' identification, where the child that is seen from the professional varies completely from the viewpoint of the parent, who sees the child when they return from masking all day. This is referenced by Bryn, who has an undiagnosed, potentially autistic child in secondary school P2, L1; P13, L1-6; P17, L1-9):

> *He (his son) will not ask for help. On the exceedingly rare occasion where he asked for help, the teacher just explained it again in the same way, and they asked if he understood and he said, yes, because he did not want to say no. And I even said to him, you know, it is okay to challenge that perception from the teachers so long as you do it in a polite way, and say "I am listening, I just don't understand" but he doesn't feel that he can do that, he is too frightened, and he will sit with his head lowered and quietly cry to himself, and then when the lesson is over, he will go and hide himself away in the toilets.*

Difficulties in asking for help is common in autistic children as they try to blend in with the people around them in order that they are not noticed or looked upon as being different. To ask for help could intensify anxiety and later upset when autistic children arrive home and unmask, releasing anxieties from the day. Bryn further discusses (P10, L1-4):

> *So, at times, when he struggles, or becomes frustrated, he will sit there and he will pinch himself or he will hit himself in the head, or he will be slapping himself on the leg, digging nails into himself. Or if he is trying to concentrate, he will be fiddling, fiddling a lot, but not discreetly.*

The differences between Bryn's son's behaviours at school and home show the difficulties in referring children into autism services as parents see a different side to their child than teachers may see at school. This shows how important the parent voice is when collecting evidence for referral. It can be shown how by having the parent alongside several professionals working towards the referral can have an enormous impact on how successful the referral is. This is because many different adults can all work together to build an image of the child, in instances where the child may be masking, as shown by Iris when she discusses the procedure of collecting evidence towards a referral (P10, L1-3):

> *So, what (the child) would do at home, those behaviours can differ massively and then that is something that I would report back to mum, speak to the teacher because obviously, that one snapshot is not going to be a full snapshot of this child.*

The communication between all stakeholders when children are masking is shown here to make a huge contribution in the successful referral of autistic children that mask their differences, as the SENCo here is invaluable in ensuring that teacher and parent both know each other's points of view. The crucial role that SENCo's, such as Iris, plays is continued with their diligence in building a full picture of the child in all surroundings, continuing by inviting other professionals in that can add reports into the referral (P10, L3-6)

> *If those behaviours are just seen at home, that is when you get Early Help involved, go to the doctors, get a letter from them. If you feel like you need any involvement from the sensory and physical team or from speech and language to get those involved…we are going to attach all those reports.*

Iris shows how building up a greater picture of the child from many different perspectives is crucial in ensuring a successful referral. Although there is a monetary aspect involved in collecting the voices of different professionals, it could lead to time and cost savings as there would be no need for the SENCo to create more evidence to have to apply for a second time.

4.1.4: Labelled as poor behaviour

The discussion in this theme relates to children who have labelled as being poorly behaved in class and how that stigma in school can lead to children not being referred into autism services.

Where adults that work and live alongside children without the knowledge of autism and its many different facets, children could be labelled as having behavioural difficulties. For example, in the instance of Hayley, who has an autistic son. When Hayley's son was in a private pre-school setting, his need to be first and his self-will to get to his destination without being able to see the effect that this had on others, was labelled as poor behaviour (P7, L1-4):

> *They just saw that he was a bit of a naughty child. He wanted to get from A to B, no matter who was in the way. And they just saw that he was pushing and pulling out of the way and not being very nice. One way or the other, I think that this should have been noticed.*

This experience was mirrored by Ranesh, when discussing her son and the behavioural strategies that they have put in place for him to help to improve his actions in the classroom environment (P1, L1; P2, L1-3):

> *It appears like he is not listening. They used to have a traffic light system, you know where they are moving from green, amber… and he would be on amber or red every single day, to the point where he now calls himself a naughty child.*

Ranesh shows how the behaviour system in the classroom has a detrimental effect on the wellbeing of her son, instead of the class teacher looking for reasons behind the behaviour and making appropriate adaptations. Behaviour policies and charts are commonplace in mainstream classrooms, and although they are not appropriate for every child, it could also be argued that they are needed due to the rising sizes of classrooms and that teachers need to have strategies within the classroom to enable them to teach effectively.

Although these behaviour strategies are needed, better funding could enable smaller class sizes and additional teaching assistants so that each student's needs could be met on an individual basis. It is well documented in educational psychology how a positive self-concept is developed from having a positive self-perception as a child (Marsh, Ellis and Craven, 2002), It could therefore be suggested that labelling children as naughty or poorly behaved can be damaging to them throughout their lives and indicates how having a diagnosis to support differences in behaviour could be essential in ensuring that children receive the correct support. This is because if a child receives an autism diagnosis, then they could be more likely to receive an EHCP with valuable extra funding. The extra funding could pay for a one-to-one teaching assistant for example, so that instead of using a behaviour chart, the student could have strategies put in place to help them to cope in the environment more successfully. Simon discusses how once a child is labelled as having poor behaviour, the label can be difficult to remove (P15, L9):

> *Once a kid gets trapped on the behaviour side of stuff, getting the school or a setting to see it as anything else can be really challenging. Because minds have been made up, and that is that.*

Simon explains that not understanding the child's differences or difficulties within the classroom environment could lead to them being misunderstood for the duration of their time in school, this could include differences in communication. Lisa, who is a qualified Speech and Language Therapist speaks about how communication difficulties can lead to children being labelled as having poor behaviour, as evidenced in her time as a teaching assistant in a mainstream classroom (P22, L1-9):

> *There were lots of children in there [the classroom] that became violent and frustrated. But now that I think about it, they were not just frustrated because they were told to do something, it was because they did not understand what the rules were, or they did not understand the steps that they needed to do it. They had loads of language, yes. They could talk to you about whatever they did at the weekend. They could talk to you about their favourite books or anything like that. But then understanding their comprehension of stories, or their understanding of what has been asked of them, or the ways that they can speak to people on the social side, the social side of it is so important.*

Misunderstanding of communication needs is also shown as being a factor with the difficulties of identifying autism as SENCo, Iris states (P12, L1-2; P13, L1-5):

> *Sometimes they [teachers] don't see the bigger picture, or those small traits within such big class sizes. Or sometimes, they misunderstand, oh yeah, they can speak fine, the pronunciation is fine. But it doesn't mean that.*

Both Lisa and Iris understand how the identification of communication difficulties is problematic but also identify a lack of training in the complexities of communication variances in autistic children. These communication difficulties are identified by Bryn when discussing his son's reading at home (P5, L11-19):

> *He really struggles with reading. And I did try to dig down into why he struggles with reading. So, when I spoke to him a few months ago, I would say, "You know when you are reading? Can you see what is going on? And if you are reading about Jack who has green eyes and red hair and freckles, can you see Jack? Can you see what he is?" And he would say he did not know what I was talking about. He describes it as, he reads every individual word and then once he has read it, it disappears.*

In a classroom situation, children are often asked to read, in primary education reading has been separated from writing in the National Curriculum and is a subject on its own. This generally equates to an hour of daily reading classes for every child. In the instance of Bryn's son where reading is problematic, this could show as a reluctance to read or a defiance against reading. When he is asked questions about the text in class and cannot answer the teacher may think he has not read the book, particularly when the questions are as literal as 'What colour was the character's hair?' This shows a case where a child may struggle due to their undiagnosed autism but is interpreted as them not listening or not making an effort to take part in class discussions.

Having more than one professional involved in the referral process is shown again to have a great impact, due to the way that professionals can help other professionals in the referral process to understand how a child acts may not always be behavioural, and could be undiagnosed SEND, as Simon discusses when he retells how a Deputy Head of a school once questioned a child's diagnosis (P18, L1-7)

> *I asked the Deputy Head if he was a qualified paediatrician, and he said, 'No.' I said, 'Well I don't think you can have that opinion then.' He was very adamant that kid's needs were behaviour. This was a child with ADHD, I was there constantly with the family for exclusions and then – he received diagnosis, received medication – and then I did not hear from the parents for the last two years of his school life.*

This shows us how the understanding of one professional with regards to the heterogeneic nature of autism is completely different from child to child. This shows the importance of having more than one professional working alongside potentially autistic children, to ensure that they are accurately represented, from school, to home, in professional observations and pre-assessments. It also shows how important diagnosis can be in many children that go through life with low self-esteem due to being told that they are not well-behaved children.

4.1.5: Summary of theme: The identification of autism in children

The data within this theme suggests that the very nature of autism itself leads to problematic identification. As discussed earlier, heterogeneity describes dissimilar parts that are somehow connected: (Georgiades et al, 2013). Masi et al (2017) went onto to say that it could be productive to relabel autism as 'the autisms' to consider the many variations. The research of Georgiades et al also stated that autism should be researched so that it would guide the future measurement of autism diagnosis (2013:123-124). The lack of experienced staff with regards to the schooling of children with Special Education Needs has been shown to be problematic, with inadequate funding and pressures on teaching staff with classrooms of twenty-five to thirty-five children common practice. This again is shown to be consistent with historical research, as children with SEND being incorporated into mainstream schools was sold as a practice of inclusion (McGregor and Vogelsberg, 1998) and a way to improve their academic outcomes (Kurth and Mastergeorge, 2010). The data has shown how important it is, in times of austerity and cut backs to SEND and schools, that to gain the best chance of receiving a referral in the face of the many barriers, even by the very nature of autism itself, is to have a team of professionals all giving their own insight and evaluation, to have children observed and spoken with in as many different environments as possible, including at home where they are least likely to shield behind a mask, and to keep an open and honest communication with parents, to fully support their viewpoints and involve them at every point of referral, ensuring that their voice is heard alongside the professionals in the referral process.

4.2: Theme 2 -Differences in Professional Support.

4.2.1: Lack of training

This theme discusses how lack of training affects autism referrals as not all teachers and SENCO's have the knowledge needed to create successful referrals. Lack of SEND training can be during teacher training, it is also acknowledged that training is not delivered on a national level and is not updated regularly. It is also discussed how Health Professionals could receive additional training to help them to identify autism in children in their early years.

Not having the knowledge that referrals can be reapplied for or appealed against indicates a lack of training which can be linked back to early teacher training, as Early Career Teacher (ECT) Ryan discusses (P2, L1-4):

> *A lot of people on my course were not happy with the lack of SEND training, I was there for two years, and we only had one full day of SEND and it was quite interesting, it went through all the history of SEN and how the terms came from special educational needs children, and the history of it; how they used to be taught and treated through to where we are now. It was interesting, and it was also heart-breaking. But I wasn't necessarily on what we should do as teachers to cater for children. To give us the history but not equip us with any strategies.*

This lack of training for new teachers going into school and the lack of training for teachers in school can contribute to poor school support as the teaching staff have not been given the knowledge and skills needed to support children in the school setting. Without appropriate training, it could be unlikely that school staff will recognise the many facets of autism or have the knowledge needed to progress successful referrals for all children. There was also some discussion about professionals within the referral team itself, as Iris discusses (P22, L4-10):

> *I have had instances where I have sent a referral off, and it has been rejected and sent back - refused to go onto the waiting list for autism assessment. I sent another referral off, slightly tweaked, and it was accepted. it wasn't massively different, so I don't know if that is perseverance or the professional that is looking at the report to see if they meet the threshold for a referral?*

This could show lack of training for the professionals that decide upon whether each case should be sent for assessment, or a lack of funding for training across the board so that professionals have the same skills across the department. it could raise questions as to what the procedure is when a case is borderline, if a manager or supervisor is approached to assess each case to ensure that there is consistency. This is unlikely to happen across the whole of the UK, and it is therefore impossible to have a consistent referral system when referrals are based on opinion – as shown by Iris – if one case can get through to referral with a small tweak yet others are consistently bounced back even with additional evidence over time.

Before a referral can even take place, autism must be identified by the school or parent. It has been discussed that this lack of knowledge can lead to children not being supported as well as they could have been with diagnosis. It has already been discussed how some teachers are not as experienced or knowledgeable as others, creating varied services across the UK. However, this has also been highlighted to be an issue both within other services and with the lack of knowledge that parents are equipped with, as discussed with Hayley (P1, L1-3; P5, L1-4)

> *I think that preschool should have picked up on it, so when it got to infant's school, they did pick up on it. Something needs to happen in health care too, you know, education there for parents. You get information on all sorts of things from healthcare at the beginning, why can't you get information with learning difficulties or autism?*

Hayley spoke about the any different tests that are carried out on children at birth, their hearing, weight gain, hip movement and although she felt that there were autistic traits present from early years, the health visitor did not reciprocate her feelings about her son (P5, L5-9):

> *I did mention it to my healthcare visitor, I went to the community centre, but they just said he was fine, so health care visitors need educating as well.*

Estes et al (2015) researched how sensory markers can be shown in children as early as 6 months old, therefore if a parent has observations about their children this young, there may be early assessments that could take place, if Health Care Visitors received the correct training and support to be able to observe and refer into services. Autism could also be included in the 12 month and 2-year progress checks by health professionals who could look for specific markers through conversations with parents and their own observations.

Hayley also went to see a dietician as her son struggled with foods, something that is, 'common in autistic people – issues such as only eating a few foods, not being able to eat at school, going long periods of time without eating and pica' (autism.org.uk, 2024) Hayley discusses the appointment with the dietician (P6, L3-8):

> *She said have a yoghurt, east more fruit and vegetables and I mean this is a child that does not do any fruit or vegetables or anything with lumps in or things like that. So that's another area that needs to be looked at too.*

These instances could be argued to show that there is a lack of experience or training within some early health care provision. It is well-known that the NHS has been underfunded for many years, with political reasons cited as the demise in funding which has led to understaffing and pay increases that have not been in line with inflation. More recently, this has seen an increase in NHS workers striking, including nurses, ambulance staff, Consultants and Junior Doctors. The lack of funding for the NHS has inevitably led to lack of staffing and training which could mean that more recent developments in autism may not have been relayed to staff members. Without accurate and up to date training in this sector, it is unlikely that early health workers focus on identifying autistic traits in young children. In the interview with Sam, who works closely with Early Health Workers, it can be shown that steps to increase training and support within this sector has started to make great steps forwards within Council X (P27, L1-16):

> *A few years ago, I know that the health system was really struggling, particularly with losing staff and people retiring and people with long-term sickness. But we have got some fantastic health visitors on board now. Every child who is referred to early support gets an allocated health visitor, they are not just on universal caseload where they would see lots of different people, the family have one main point of contact. We are in contact with the health visitors so that if we are not sure about anything then we have someone direct to email for information and then they can be tasked to carry out x, y, z. So, for instance, when new referrals come in, we can request health to be tasked to complete questionnaires so that the early support team have the information that is needed. This would help the team to assess what the child's scores are and which areas they might be struggling with as to whether they would meet criteria. Because we have been given that extra funding, that extra*

> *training – Boom! We can get things done. This is one thing that I feel that we have really fine-tuned and worked hard at getting good things in place for children and their settings.*

If this practice was continued throughout the child's life, in that a key worker could be allocated at any age, not just Early years, then this could be one solution when collecting the vital information that is needed to be able to access an autism referral.

As autism cannot be diagnosed though a test, as Simon stated earlier 'it's a diagnosis of opinion' then attempting to refer potentially autistic children in their early years is a complicated process. When considering this alongside the autism assessment checklist it is evident that there are very few questions that would enable a professional to meet this testing criteria, particularly in the areas of social-emotional reciprocity and relationships and play due to the age of the child and them not yet meeting those developmental milestones.

Although more training for services such as the NHS has an essential role to play in autism referral, it is evident that in some instances even if these services had referred earlier, that some parents would not have been equipped to be able to proceed with the referral for their children. Hayley discussed how she found it difficult to accept that her son was autistic (P9, L1-4):

> *I wasn't ready. I thought that I knew there was something and I researched ADHD, I was researching everything. And I just thought that there was something, but I wasn't ready for someone to come and assess him.*

Hayley discussed how it was a contributing factor that she did not have the knowledge about autism and the differences in each individual autistic child, as Hayley discussed earlier, if she had understood autism and the variances between the previously diagnosed 'Asperger's Syndrome' then she may have been more emotionally ready to pursue a diagnosis sooner. Hayley also spoke about feelings of guilt (P21, P4-12):

> *I blamed myself because of the way he was born. I had major blood clots on my lungs and was given a 20% chance of survival. I wasn't with him those first few days, not from the Sunday until the Thursday. I thought all of that contributed. Parent guilt everywhere. I went for counselling and was put on medication because it got me down.*

Parental guilt may be avoided with more adequate training in health services and education, with additional information on offer to equip both parents and professionals with knowledge about autism, helping to eradicate parental blame. There have recently been changes to the SENCO qualification, from obtaining a NASENCO (Masters) award to an NPQ award, with more face-to-face learning, a focus on practical assessments and conferences so that new SENCO's have the chance to speak to experienced SENCO's. Although it is accepted that different training for SENCO's is needed, there is no facility to have ongoing, national training which could offer SENCO's access to updated information in line with the fast-changing developments in autism knowledge.

4.2.2: Lack of funding

This theme discusses how a lack of funding contributes to lack of training, there is also a focus on the differences between funding in state school nurseries and private nurseries and how this affects the training that is delivered across the different settings.

Poor training in educational settings was discussed in relation to a lack of funding across state schools and nurseries with Sam (manager within Early Years SEND) (P13, L1-2):

> *Schools are funded very differently to private nursery settings, from my perspective, it would be better not to have children in a school nursery if they have additional needs.*

Sam explains how private day nurseries are funded differently and therefore can use that funding to train their staff. The training that Sam can deliver includes (P11, L1-4):

> *…speak and sign training, support plan workshops, EHCP planning workshops, inclusive practice workshops, sensory workshops, communication and safeguarding.*

This shows the extent of knowledge and training available within this council, if schools can afford it. Sam also discusses how schools have been desperate to access the additional training on offer, but she is not allowed to deliver it due to lack of funding (P16, L6-8)

> *Somebody published our training offer to schools, and I had at least six schools contact me, and I had to say that I was sorry, but I was not allowed to deliver it to them.*

Where schools here are trying to become more successful with their offer for children with SEND, to give teachers the training that they need and parents and children the support that they require, it is clear to see that often the problems lie with inadequate school funding. This does not just affect the inability to pay for the training, but also the inability to pay for staff to cover shifts when teachers are in training, which affects all educational settings, as Sam discusses (P12, L 1-6):

> *Settings are struggling because they are struggling for staff, so they are struggling to release staff to attend training. We offer after hours sessions, but we are conscious of staff that do a long day anyway and then are expected to do three hours of training on top.*

Sam continues to say that educators are often happy to do the training as they can see the benefits to them and how this then has a positive impact on training for children. As Sam is a professional with Early Years Settings, she has also experienced how private nurseries and nurseries attached to schools can often give differing levels of support, due to the very nature of what they are. For example, private day nurseries do not need to have a qualified teacher, however they must have a higher ratio of nursery staff working with children. In school nurseries, there must be a qualified teacher in the setting, which means that they are able to have lower ratios of staff. Sam discusses how she thinks that it is easier to recognise autistic traits in children that are placed in private day nurseries above those who are in school nurseries (P16, 1-2)

> *When you think of eye-on-eye time with kids, in schools the kids are in bigger ratios, I think that must be hard in schools. And in private settings, there are more adults so more people likely to notice those little traits.*

This shows the pressure that school-based nursery teachers are under, a lack of funding to pay for training, a lack of funding to cover lessons so that they can attend training and then in addition to this, such high pupil-teacher ratios throughout classrooms in schools across England (Schools, pupils and their characteristics, 2022-23) with an average ratio of 20 students to every one teacher (School Workforce in England, 2022). As Sam explains (P29, L7-9):

> *Schools are struggling. They are struggling for staff; they are struggling with budgets and until the government give equitable funding then it is going to be difficult.*

The difficulty for Sam, where she has the knowledge and expertise to go out and help schools and help to train staff but is held back by the school's inability to pay for her services for the training that they are calling out for.

There are some instances however, where it is shown that support and training has been offered for free and is not taken up by some educational settings. This is the case for Speech and Language Therapist, Lisa, who goes into schools to help staff with strategies on how to help children post-diagnosis (P29, L12-17; P13, L1-7)

> *I remember working as a teaching assistant, one to one, it was not until the therapist came in and said, "So what targets have you been working on?" I just told her what we had been working on, and she said, "Oh, well he has these targets that you actually need to work on" and then gave me the care plan which I had never seen before. So as a Speech and Language Therapist I would say to teachers, "can I speak to you about it first?" and then ask them if they were carrying out interventions, I would then find out that they had not even printed any of it off, so I knew that they could not have done it.*

Even though Lisa would feel disheartened by the lack of intervention, she understands the pressures of school life and budgetary constraints and would always do what she could to assist the teaching staff to be able to give best the possible outcomes for children P30, L1-4; P11, L1; P11, L6;

> *When I go into settings now, I address it, I give a pack to the SENCo and one to the teaching assistant. I will print packs off for the teachers in advance. I explain why I am observing so that the teachers do not feel judged. I ask the headteacher if the*

> *assistant can have more time so that they can print off the resources that they need. I think that in some settings, they are not getting paid a lot to do their jobs anyway, to then do extra work on top.*

This is also mirrored by Sam, when she discusses the differences between Private Day Nurseries in contrast to that of the schools in her local area when discussing being made of aware of children that need a referral to SEND services (P5, L1-5; P6, L1-6):

> *Private settings are pretty good. The SENCo's that we work with are certainly the ones where we would see children going down the diagnostic route. They're really on board. In my experience, there are some settings and SENCo's out there where they are more reluctant, they're not really on board with the paperwork and they don't engage with us very well in terms of flagging children that they have concerns about or wanting to put the time into creating reports and carrying out referrals. In my experience, there is more resistance in schools than in Private Day Nurseries.*

This reiterates the earlier idea of support being different based on how much funding has been given or how much training so that the teachers are more able to give individualised support. It identifies that the support that each child receives is dependent on the professional or setting that is supporting the child. This can become another barrier for communication between parents and schools, as some parents struggle to understand why support is not given, even when it is seen, as Bryn discusses (P3, L1-3; P4, L1-3):

> *A fitting example is when I took him to options evening. We sat with the teachers, but he would not look them in the eye, even if they are talking to him, he will be looking to the right or the left. It is downhill, then glance up for a few seconds but it is never maintained. When I have said to a couple of teachers, "I am sorry, he struggles to maintain eye contact" they have replied that they knew that. So, they acknowledge that he cannot maintain eye contact, yet this is not being flagged up?*

Lack of funding and lack of training can both be said to also impact teacher retention. The patterns that have emerged point to not just to having a well-trained and multi-personnel team to help to observe and assess, but also having staff that have been with the children for some years and can comment on their needs over time. It is well documented that there is a teacher crisis with more staff leaving the profession than ever before:

> 'The latest workforce survey by the Department for Education (DfE) found that 40,000 teachers resigned from state schools last year – almost 9% of the teaching workforce, and the highest number since it began publishing the data in 2011' (The Guardian, 2023)

This could be seen to affect the support that is given in schools, as not only is there a less experienced workforce but also teachers that have spent less time with the children that are in their care. Iris (P17, L1-4) stated that:

> *Because I worked at the school itself for six years, it was easier for me because I was aware of the children, more than a new SENCo would have been. It might take*

> *someone longer who is new to a school because they are not familiar with different children.*

It could be argued therefore, that poor teacher retention plays a part in poor school support. This could also be a factor when considering the earlier issue with poor communication when children transition from year group or to other schools because if teachers are leaving that have been supporting children, then transitionary information may not be available to be passed from past teacher to future teacher. The issue with the lack of consistency across this region, is not only from school-to-school or town-to-town but is also apparent within schools. This inconsistency of support could be said to be shown where some professionals have undertaken further training due to individual experiences or interests. As Ryan states:

> *I did my own research project based on trauma attachment, so I suppose if you wanted to, you could gain that knowledge yourself.*

Simon discusses how this is also apparent within same school settings, and the teachers that have gained further experience or training, or have personal experience of SEND, often identify autism and other SEND over and above other teachers (P14, L1-12):

> *If the training around SEND that teachers get as they go through their careers is like the training that they get for autism, then I cannot imagine that there is a great deal of knowledge, that is where it is down to the individual. For example, at one school that we work with, 70% of the SEND gets picked up by the year two teacher. She is really in tune with that and identifies things that were not picked up in reception or year one. That's just her experience.*

It could be argued that in any other profession, in retail or leisure, staff would be given the training to do the job that are expected to do. Working with and supporting children with SEND and identifying need to help to refer in for diagnosis and other services is an essential part of any teacher's duties, however funding for schools to train teachers to assist in this area is still arguably lacking. SEND funding is also given to schools as part of their delegated funding and is not based on how many children each school has with SEND, but is based on how many children the school have on free school meals and how many children are underperforming in English and Maths. This means that SEND funding is not allocated to specific children and therefore can be spent in different ways. It could be said therefore, that even if a school is receiving enough funding for SEND that it may not have SEND priorities. This leads to the argument that schools should be given funding based on how many SEND children they have and that schools should be challenged on how the SEND funding is spent.

4.2.3: Academic Outcomes vs Emotional Wellbeing

This theme discusses how children with good academic attainment are sometimes overlooked for autism referral and how some schools place more emphasis on academic outcomes than on the emotional wellbeing of children.

It can be shown that for some parents, they feel that academic progress is more important to schools and teachers than the emotional wellbeing of their children, as even though Bryn's son was not flagged for poor eye contact, he is flagged for being behind expected academic levels (P6, L1; P7, L3):

> *And he is down as 'on watch' for most of his subjects. I mean, he really struggles to focus on things. At school they say, 'He needs to read more' but he can't, it's just not as easy as that.*

Bryn followed this with a visit to the Head of Year (P18, L1-3):

> *All I got was that all the usual assessments, you know dyslexia, he hasn't got it. He's a bit below but it's not concerning.*

Academic targets were also the reason for Ranesh's child to not hit the threshold for school to access a referral into services (P9, L1):

> *I think it was more because he had not been affected academically – it wasn't affecting his results.*

This links back to the heterogeneity of autism, and with such a wide spectrum how many children are missed for diagnosis and referral or seen as not 'severe' enough to need to act upon. Anxiety is well documented as often co-occurring with autism (White et al, 2009; Hollocks et al, 2018) and within the interviews it was discussed that schools sometimes miss the emotional impact of autism as schools focus on academic targets that are reported on national tables, as opposed to focusing on children's mental health in schools, as discussed by Hayley, when her son went through an extreme bout of anxiety and depression: (P17, L4-7):

> *That bit of anxiety at the beginning came to something much worse, which it did at high school. It got the point where he self-harmed at school. Then he asked me to buy a firearm and shoot him.*

Hayley related this episode to the issue of not only not receiving support for mental wellbeing in school, but also not being able to access support from other services, such as CAMHS (Child and Adult Mental Health Services) (P17, L1-3):

> *I think that they are concentrating more on the severe side of autism, rather than the children with milder autism, because it looked like just anxiety and yet he didn't get put onto the anxiety pathway.*

In addition to the pattern of lack of support for mental health, parents also discussed the lack of teaching essential life skills as discussed by Bryn (P30, L1-10)

> *I can't see him going to an interview, getting a job, getting a house. I have said he needs to be able to speak to people face to face or on the telephone, but he lacks these skills. Part of life is going shopping, but he can't walk into a shop, he becomes so anxious. And that is where I am slightly concerned, that I just can't see him doing all these things.*

There seems to be a disparity between what is deemed as successful outcomes to some schools (academic outcomes) and what are deemed as successful outcomes to some parents (emotional wellbeing and skills for life), with SEMH (Social, Emotional and Mental Health) needs overlooked by academic outcomes, yet it could be argued that the two go hand in hand, with poor mental health then children are not going to reach their full potential. There are clearly, on the other hand, some excellent examples of emotional support for children in practise which is shown to have a positive impact on the relationship between school staff and parents, as discussed by school SENCo, Iris (P4, L1-3; P5 L1-6)

> *Even if we are not doing much in the classroom, it might be trivial things like social emotional things elsewhere, all those things need to go onto a plan every term. And then once that has been reviewed, we can also put things in place to help parents at home. So, if it is struggling to get the child into school, we might discuss getting a transitional object or pictures, a task that they like to do when they come into school.*

This points to evidence that being in a school with well-trained staff that is funded to provide adequate staffing per student, is more likely to lead to better outcomes for not just the child, but the whole family, having staff that are well trained and having a full team of people which includes a Speech and Language Therapist all working together to deliver the best possible outcomes for each child, including observations to highlight differences such as communication difficulties. Having a team of professionals alongside a fully qualified SENCo could help teachers to overcome the barriers that they have to referring children for autism assessment, as with Iris (P14, L1-20):

> *I have had teachers on the team that put up a barrier, say that they don't see those kind of (autistic) behaviours. I will say, "Maybe it's time that we applied for an EHCP?" And in some cases, will answer that they are not doing anything. I unpick the behaviours: sitting out at dinnertime, crying in PE; not being able to participate in afternoon sessions. I just don't understand why they put that barrier up, as surely it would be easier for them to have an extra pair of hands if we received additional funding from an EHCP?*

Having a SENCo challenging teachers, unpicking autistic traits that may not have been picked up on due to inexperience or lack of training, could be the solution to teachers applying for referrals, as they have the support and knowledge of the professionals around them to help distinguish autistic traits and also to work together to fill in the lengthy paperwork needed for a referral or EHCP application. Having an experienced SENCo or team of professionals could have helped Hayley when her son was experiencing severe self-harming and depression, as the professional would know how to access services (Iris, P16, L1-10):

> *I guess it is pointing parents to help lines, such as the Early Help Support team that can go into the family home if they are struggling. Giving them contact numbers such as the crisis teams, making sure that the child has not had any suicidal thoughts or self-harming because there is another team that we can suggest that they can through for that too.*

It is important to reflect that all the interviewees live or work within the same council area. For one parent to have a self-harming child that has asked her to end his life with no suggestion of support for their family when there is clearly support within the region, as Iris has shown, could arguably show that poor communication of services that schools can access must be something that has to be developed. In a time when 'Suicide in young people is a global public health threat. Worldwide, suicide is the fourth leading cause of death among 15–19-year olds' (Hughes et al, 2023:381). If a parent flags that their child is self-harming or has suicidal thoughts, then it would be thought that this would be an instant opening into services, unfortunately this is not the case, and as such, in some cases, it is shown that when teachers do not see evidence of this, then the parents can be blamed instead, as Iris shows (P14, L4-5):

> *I hear some teachers say, 'Why can't they (parents) get their child into school? That's not my problem. I am the teacher. I don't see that in school, so I don't need to do that'.*

It could be said that in some instances teachers feel that parents are not 'pulling their weight' and instead burdening the schools with the support that is requested, however.
the viewpoint from parents of not wanting to be 'that parent' that constantly complains about lack of support was echoed throughout the interviews (Bryn, P30; Hayley, P3; Ranesh, P15), which felt that they were almost apologetic for needing the support that they were asking for. Parents were also incredibly complimentary about teaching staff, even when the correct support was not being given, (Hayley, P4, L1-5):

> *I mean, the teachers were brilliant. Teachers were brilliant – the teacher did more than the school itself. Yeah, it's school that could have done a lot more.'*

This is mirrored with the interview with Ranesh (P1, L2-4):

> *And his teacher is really, really great. She's really, really kind. She's a nice person.*

Even when there is a breakdown in communication or a lack of correct support, parents and other professionals, it could be said, are still determined to give teachers credit. This again highlights the understanding by the public of the pressures and financial constraints on teachers in schools, with high class sizes and low staff to pupil ratios when comparing to that of Private Day Settings.

4.2.4: Summary of theme: Differences in Professional Support

The patterns that have emerged from this theme relate to the differences in support across professional bodies, across schools and across the professionals themselves. There is an overriding sense of poor communication, as in some instances, there are excellent practises of referral and knowledge of where to signpost families for support and then also the complete opposite, where children are shown to be at risk of suicide and yet still are not signposted to the services that are on offer. The lack of funding for schools is apparent which leads to poor training of staff as there is little budget for staff training and even less budget for the staff needed to cover other staff's training days, as shown in the literature review where the SEND Ofsted report showed that, 'many of its concerns still remained...as there were serious gaps in external provision and training...which included staff training, access to specialist skill support and commissioning of services by local authorities (Supporting SEND, 2021). This lack of training could be shown to lead to poor support in some schools, as staff are unaware that they are able to re-refer once they have collected further evidence from professionals, therefore leading to delays in diagnosis and subsequent support being put in place. There has been shown to be communication difficulties during transitionary times, such as children moving up into the next year group or into different schools, this has been shown to not just be poor communication skills but could also align with the high number of teachers that are leaving the profession with the poorest teacher retention since records began. It has also highlighted again the differences in school support from private nursery settings, where there is more budget available for training compared with school settings. It has also focused attention on how higher staff to student ratios in nursery settings can lead to autism and other SEND being identified, even though private nurseries do not need a fully qualified nursery teacher unlike school nurseries. This theme has also called attention to the difference in support across schools where there is funding to provide the training needed to be able to support children with SEND and where there is little funding or training available. Also, where some teachers and professionals take it upon themselves to train themselves in the area of SEND, or where professionals have a personal interest or stake in the area of SEND, this has led to some schools or classrooms identifying children with SEND, including those with autism, as they are more knowledgeable and how this could be the case for all schools, all teachers, if funding was given for schools to be able to afford to give the training that their staff need to be able to support the children in their classrooms, as the Ofsted SEND report recommendations that teachers needed, ‘regular, continuous professional development’ (Ofsted, 2021) which could be said to be impossible if schools are not given the funds that they need to train their staff to these standards.

4.3: Theme 3 -The Referral Process Itself

Introduction

The referral process itself refers to the processes which a parent or professional must follow to gain an autism assessment for a child. The referral process in this thesis only relates to one council area in the UK as the differences between referral UK wide are completely different, as discussed previously in the thesis. To gain assessment in this council area, the professional must request an assessment, and they are then sent a questionnaire which has a section for parent and a section for a person in the child’s education, either the teacher, key worker or SENCo, for example. The questionnaires are then returned to the Neurodiversity team who then assess the questionnaire to see if there is enough evidence to be referred in for an autism assessment. As discussed, the referral system has been shown to not align with the heterogeneic nature of autism, with a structured tick box that is difficult to deviate away from. If a child does not receive an adequate number of points on the autism questionnaire, then the referral does not progress to the assessment team. As every council area in the UK has a different process, there are specifics to focus on which relate directly to this council’s practice. To ensure that the council remains anonymous, the website references have been omitted.

4.3.1: Specifics Relating to the council area referral practices in this case study

This theme discusses the referral process specific to the council area that has been utilised within this thesis, this is due to the variations in referral practices across the UK. It is discussed how gatekeepers, within this area of the UK, can add further time implications to the referral process.

During the interview process, the referral process in this case study’s council area had altered so that parents themselves could refer direct into autism services, as Simon discusses (P8, L1-7):

> *The current system allows for parents to directly contact the neurodiversity pathway themselves, which is great because it removes barriers, however it has flooded the*

> *system and there is now an eight week pause on new referrals coming in because they cannot handle the demand, which to me, is incredibly naïve.*

This *was* the case for the referral system at one point, however the option for parents to refer themselves has now stopped and the Neurodiversity Services website[2] states that referrals will only be accepted by a list of professionals. This means that there is a 'gatekeeper' level, and without the gatekeeper on board then they will not send a referral to the team. This has been shown to create a more problematic referral service as previous interviews suggest that more successful referrals are made when professionals such as teachers and GPs are more experienced or have had recent training in autism, therefore if the potentially autistic child has a professional that has not had recent training or does have experience in autism, then children in some areas are less likely to be referred into services. Simon spoke about the referral system which did not support parental referrals (P5, L1-19):

> *It was a paediatrician that could refer to autism services, an educational psychologist or a speech and language therapist. But to get access to that, you had to go through somebody else generally. So, to get to the paediatrician, you needed your GP to refer you to one, to get to an educational psychologist you needed the school to refer you to one. It created an extra layer of gatekeeper and that was the biggest blockage in the system.*

This does show that the referral system has progressed in that the school SENCo can refer in to assessment services, without the need of evidence from an Educational Psychologist, meaning that there is not a double layer of gatekeeper, however it could be said that if the Neurodiversity team had the staff available to process the increase in assessment requests, then enabling parents to continue to refer into services without any professional gatekeeper may have helped the backlog of other services that are having to continue to refer potentially autistic children into services. It has been discussed previously that the SEND Code of Practise clearly states that professionals should listen to the opinion of parents, as they know their children the best, however this Code of Practise does not align with the referral procedure, as it does not allow the sole opinion of parents in order to have children referred into autism assessment services.

It could also be argued, that if there are a team of professional people gathering evidence to put forward to another professional team, then having seen the child first hand, it could be beneficial for those professionals to be the referring team, as Iris states, it can be problematic having professionals decide whether a child receives a referral based on paperwork alone, (P26, L1-3):

> *It is so lengthy and difficult for us to constantly fight against a team of people who have never met the child.*

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[2] As the council is anonymised, there is no reference for this web page.

If there is a team gathering evidence by meeting and observing the child, they would be in a better position to speak about whether they would send the child forward for an autism assessment. Instead, the procedure in this council, and many others, has all the paperwork sent to a team of professionals who then assess whether there is enough evidence to put the child onto the autism waiting list. This again creates a gate keeper, even if all the professional reports point to an autism diagnosis, it must still follow this route to assessment. The child is unseen in paperwork, the team of professionals in the neurodiversity team will be unlikely to ever meet them, or their families.

4.3.2: Parental Voice

Within this theme, difficulties with referral are discussed as parents must rely on other professionals to refer their children into autism services due to the parents not being able to refer their children in themselves.

As referrals cannot be accessed by parents in this case study council area, parents must rely on professionals to access a referral into autism services. It is unjust that variations of autistic profile can affect the success rates of referral, however some professionals are aware of this and adjust their working practices in order that the referrals are a success, as Iris states, (P19, L1-2)

> *If it does not fit that 'usual' autistic profile, then we collect increased evidence and we just keep going back.*

Not all professionals have this experience however, as was the case for one of our parents, Ranesh (P12, L1; P7, L7; P8, L3-4):

> *So, it got referred, got knocked back. And then they did nothing, even though it was the SENCo who was his class teacher at that time that had flagged his struggles. There was still nothing in place throughout his time in Year One. I think CAMHS had bounced it back because they thought he was too young, they thought 'there is a reception aged child who cannot sit still'. And then the SENCo said, 'I think it's just his age' as the rest of the children cannot sit still too. So, they did not put the referral in again. And then it just went no further.*

In Ranesh's case, because the referral was not successful, the process to diagnosis was stopped and Ranesh did not think that there was anything more that could be done. If the professional within the school setting also believe that this is the case, and they do not know that referrals can be immediately resubmitted with additional evidence, then children in these schools are less likely to be referred into services. This repeats Simon's idea, who referred to this as, 'a postcode lottery to a degree, or a school lottery' (P9, L1) as where professionals have more experience or more training, then the individual is likely to receive better support and subsequently more likely to be referred into autism services.

Often, when there is not enough evidence to support an autism referral going through to an autism assessment, the communication between stakeholders can be poor and this can be shown to influence the relationships between the parents and the schools. When a referral is refused, the school and the parent receive a letter simply stating that the referral cannot be processed at that time due to a lack of evidence, which does not support an autism referral. The professional (usually school SENDCo) receives no more communication than the parent. When parents then question why the referral has not been successful, schools are not able to effectively respond as they have no more information to offer. As Iris (mainstream school SENCo) states (P22, L2-5):

> *We will just get the letter because we have done the referral, it is frustrating because I want to speak to them [the professionals that refused the referral] so I can get first-hand what our next steps are.*

Iris also speaks about trying to chase the neurodiversity team by telephone call, how it can be difficult to get through (P22, L8-10):

> *When I do try and ring the team, they are terribly busy, it takes a long time to get through and then the person will be off that day.*

It would be difficult for parents to see the amount of work that professionals put into to each referral, and the problems that they also face in trying to gain information. If the parent thinks that the SENCo has all the information as to why a referral is refused, then it could be said that this could cause a breakdown in relationship between schools and parents. There can also be issues with children transitioning into other schools, into other year groups or even crossing into other classrooms as Hayley discusses (P3, L1-8):

> *He received diagnosis in year two, so that was his last year with infants. So, the junior school would have had all the information passed to them at the start of year three. We got to year five and had a chat with the SENCo about how he was getting on, this was the first discussion we had with her, in year five. She didn't even know that he had a diagnosis.*

The lack of information passing is replicated with Ranesh (P5, L1-3):

> *So, I said to the teacher, "Are we going to go for an assessment again?" And she said, "What?" I said, "You know? We went for a referral for assessment last year?" And she went, "Oh yeah, I suppose it could be that couldn't it?" And I just thought, you have been teaching him all year! We have been putting these strategies in place all year and I speak to you at least every week and now you are asking me what happened last year?*

The difficulties that the teachers must face without being given the correct information from previous years, or previous schools would have a negative effect on the support that is given to children with SEND and would impact the cycle of support that would be put forward as evidence when there is need for an EHCP. Without a graduated response through a Termly Support Plan, created by teachers, parents and the student which follows through their academic years, then the support given to children could be haphazard, poorly thought out and not assessed for outcomes.

There are many varied factors that could mean that professionals do not see autistic traits in a child in the same way that the child's parents do, this could be due to children masking, to professionals' lack of skills or training this area, as Simon discusses (P7, L1-7):

> *We see that constant differing of views constantly…it is one of the single biggest issues we support with because it is one of the things that does the most damage to the relationship between parents and schools…because school have said that they don't see it, see X, Y Z, and that's quite difficult to then deal with.*

The autism referral tick box list is very structured and if the child is not portraying traits in school, then the professional can only tick off what they see. This means that that there may not be enough evidence for the referral to proceed to an autism assessment. In this instance, the referral would be sent back. This leads me to question the structure of the autism checklist and its efficiency due to the heterogeneic nature of autism. If parents see autistic traits at home and educators see none at school then the referral is unlikely to be successful. As Simon discussed above, this was 'one of the single biggest issues' that his team supports with, not that professionals do not believe the parents, but that the referral system in place in this council simply does allow for the professional to include the parent's voice within their report. It could be argued that if parents continue to be unable to refer into autism services, then there will be continued pressure on schools and other associated professionals. If parents could refer in, then this would not only save time but funds that could be released to support children that are diagnosed as opposed to the work that is needed to access autism assessments.

When parents see that their children are struggling and may need additional support, parents did not always know what the process was to start looking for support or routes to diagnosis. As Bryn states after being asked the question, 'Do you know how to access services?' (P21, L.1-2):

> *I just don't know, no, other than going to the school and asking for help, I wouldn't have a clue how to.*

This shows how local services that are available to parents are not always known about, for instance the service that Simon manages to signpost parents for support (P1, L1-8)

> *So, the point at which we would be involved is the point in which a family member or the parent or a child or young person would contact us directly. The most common*

> *health question that we get asked is, 'I want to know about an autism referral, I want to know about an ADHD referral.' those are, by far, the two biggest health questions we get. And usually, its parents looking to understand the system.*

There is obviously a great need for services like Simon's to help parents to access support and understand how referrals work, however many parents did not know that Simon's service existed, and there is therefore an argument that, even in the world of information through technology, that services like this need to be put onto a platform so that parents know who they can first contact to reach the services that they need. As discussed with Ranesh (P16, L1):

> *I had never heard of xxxx until you mentioned it, it's like people want to keep things secret and hidden away so that parents can't access that support. Unless you already have an autistic child or you work in special needs services, how are you meant to find out?*

This could again show a lack of current and up to date training for schools with regards to how they can signpost into services. If schools do not know about services such as Simon's, they are not equipped with the knowledge to support parents. Once again, in early year Management, where our interviewed professional visited private day nurseries, signposting was widespread practice, and pre-school children's parents would be able to access the support that they needed in a more streamlined way, as discussed with Sam (P1 & P2, L1-10):

> *Yes, we do a lot of signposting parents of how they can make a referral request, if that's what they chose to do, if parents want to explore the referral route and the diagnostic route, then we signpost them and support them with how to do that. I direct parents to the neurodiversity pathway website, there's all the information on there about how referrals are made, and they can contact the front door service to talk about what happens and get more information straight from them as they know where things are up to currently.*

As discussed previously with Sam's workplace, they provide support for Early Years private providers, as they are funded differently than state schools. This means that parents who have potentially autistic children in private nurseries are likely to receive quicker support and more adequate signposting than parents of children who are in state school nurseries. This is clearly not the fault of state nurseries, but again down to funding. If state schools had the funding that equated to that of private day nurseries, then they could receive the same support and best practice signposting from professionals like Sam.

4.3.3: Differences in profile

Within this theme, there is discussion about whether some children, who are more obviously autistic, could seek quicker referral. This discussion presents some ethical challenges and debate with regards to how this could be achieved without it resulting in discrimination against other 'less obvious' autistic children.

The discussion about Asperger's versus autism and the diagnosis of Asperger's being removed has been much discussed, however in the case of referring children, it is questioned why there are not different referral processes where the prevalence of autism is not in question. As Hayley discussed, even though it was the school that first noticed autistic traits, there was still a long journey through to the assessment process of autism for their child 10, L1-10):

> *We needed the diagnosis to get him more help. So, we had the educational psychologist, speech and language, paediatrician, they all gave reports and it was quite straight forward. The teacher gave a report, the head gave a report. It was a two-year period with everyone giving all these reports.*

Hayley discusses here five different professionals who gave reports of evidence towards her child's diagnosis, with the professionals all stating that they could clearly see autistic traits in her child. However, even with all the corresponding reports, there was still a long waiting time, as Hayley continues (P12, L1-2):

> *So, it was quite a long three years then of collecting documents, just to get him referred, even though it seemed obvious.*

This again shows how the referral process can take years itself, to even access the autism assessment waiting list, which is still a waiting time of approximately two years in this council area, as discussed with SENCo Iris (P15. L5):

> *It's two to three years before you get that assessment.*

This shows an approximate waiting time of five years, even when all the professionals drafted reports which all related to positive evidence of autistic traits in Hayley's son. This same experience is repeated across the interviews with professionals, as shown above, with Sam, the Early Years Area Manager, who stated that (P17, L1-2):

> *It is less easy to diagnose children who has more Asperger's type traits.*

And again, as stated by Iris when discussing the difference between referring children with Asperger's profile as opposed to referring children with autism profile, it is far more difficult to access a referral for a child that has more of an Asperger's profile (P19, L1-12):

> *The ones who are more social, emotional, very anxious but can have a conversation...they are more often the ones that get rejected.*

Simon also discusses the referral system when referring children with different autistic profiles, (P12, L1-12):

> *I am not a medical professional, but I do sometimes think that there are very obvious cases where you go, 'Do they require x, y, z?' I suppose, what level of assessment is required to ascertain diagnosis? You might have a child or young person that is very borderline in which you want to do detailed multiple assessments. You might have a child or young person who is very clearly to anyone with any expertise*

> *within the spectrum. And I have no idea what that looks like, but I would be interested to know how that is dealt with resource-wise. Is there an opportunity to be more efficient, where there is a clear and obvious diagnosis? And do you need paediatrician, psychologist, psychiatrist, whoever it is to be able to do that? Or could you, within that situation, have our professionals do that diagnosis because it's not particularly up for debate as such?*

If there are children who are, as Simon states, more obviously autistic and could be diagnosed by earlier professionals, for example, by a trained school SENCo or by professionals within Simon's team, then this could provide many benefits. It could cut down waiting lists, as many children would be able to access a simpler, more streamlined version of the assessment process, it could lead to savings across NHS services as Educational Psychologists and Paediatricians would not be needed to assess all children and therefore their time could be spent in other areas, for example in supporting children post-diagnosis. It could lead to earlier help and support for autistic children and their families, as they would have diagnosis sooner. Iris comments on the current system when discussing the current pathways to assessment of autism for children (P20, L1-4):

> *I think that the neurodiversity team needs to have a bit of a look at how they are accessing the profiles of autism, surely, they know more than anyone that each autistic person is quite different. I think that the health system really needs to look at these assessments and how they are going to do these going forwards.*

The professionals throughout touch upon the same suggestion, that there must be a way to access quicker diagnosis for different profiles of autistic children. There are obviously ethical aspects to take into consideration, as Simon suggests, in deciding what the threshold looks like for children to be passed to a more streamlined service, and what / who would determine this.

4.3.4: Historic issues with autism systems

There is discussion in this theme with regards to how the referral system itself and the public's knowledge of long delays in accessing an autism assessment causes some barriers to children being referred. It is also discussed how some parents did not know how to access a referral or whether 'labelling' their child as autistic would give the child additional support.

Within the interviews, there has been some evidence that parents have been or are unwilling to access the referral system due to their understanding of the autism referral system, and post-support structure not being of benefit to their children and viewed as negative – even before parents start to access it. One of the issues discussed was the waiting times that children would have to wait to be assessed and how this may have a negative impact on them as a family and their children, as discussed with Bryn (P32, L1-14)

> *I am not too fussed about a diagnosis or anything like that. I am more concerned about getting him what he needs to be the best him. What I don't want to do is to put him through something what might be quite difficult for him, you know, it will pull all these anxieties up again. I don't want to be in a situation. And something takes*

> *forever and by the time you get to where you need to be then it's too late. he is in year 9 now, and it takes at least two years as there is such a huge waiting list, and it's too late, too late for him.*

This is the same interviewee that earlier spoke about how they did not know how to access a referral for autism assessment, however here they show their understanding of the waiting times to be able to access an assessment. This shows that information about autism can be shared, if the problems with waiting times can be shared then information about autism itself can also be shared with the public, raising awareness of the heterogeneity of autism and helping parents and professionals to be able to see autistic traits to gain earlier support for children. It has been discussed how autism waiting times were well documented in the press, therefore if the press was used for more information sharing for the good, instead of reporting on inadequacies in the system, then more young people may receive the support they needed.

It was not only waiting times that parents discussed when raising the question of diagnosing children, but also the question of whether it would benefit their children from having a 'label' and being seen as an autistic child, as opposed to just a child with neurological differences, again discussed with Bryn (P35, L1-3):

> *What would the benefits be? What would we get out of it? What would he get out of it? What would be the benefits for him?*

This shows how the family do not know whether there would be a benefit to diagnosis, to adding a 'label' to their child and in some ways see that as being more negative than positive. As Simon discusses in his interview, it is not necessary to have a diagnosis to receive support (P16, L9-17):

> *We do come across parents that don't want a diagnosis and don't want to pursue that route, and that's fine because again, we work in the realm of education and in education law it states that you do not need a diagnosis, it says you must have identified need. So, we have that conversation with them, we explain the legislation within that realm of the world. And, it's their decision. Our job as a service is to make sure that parents can make informed decisions. These are all our options, this is what the law says, these are all the process, whichever path you choose to go down is your decision as a family and what is best for your family. I can't tell you what is best for your family. And then we will support you as you need to with that route.*

It would suggest that due to education law (SEND Code of Practice 0-25 years) that it is not necessary for children to have a diagnosis, and if there is identified need, then the child should receive the same support as a diagnosed autistic child. However, although this is the law, it is shown to be not always common practise, as followed up by Simon, (P17, L1-3)

> *As much as the law and the guidance is about meeting need, it is much easier for everyone to be able to point to a diagnosis. I can't deny that.*

This shows, that even with a person as experienced and knowledgeable as Simon, with his skills and expertise around educational law, that he sees that a child is more likely to receive support in school if they have a diagnosis, that people cannot ignore the support when there is diagnostic evidence to support the need, as further relayed by Simon, (P18, L7-12):

> *There can often be a desire for diagnosis and there is often a perception that it is easier to deal with social care when you have a diagnosis, which is potentially because if you are looking at your child in need criteria, an autism diagnosis automatically makes a child in need, because it makes them disabled, therefore they would fall under the generalised umbrella for social care duties.*

This points to contradictions between educational and health service law - whereby laws state that children do not need a diagnosis to receive support, yet need a diagnosis to become a 'child in need' and receive social care support. Hayley also discussed throughout her interview how important she thought diagnosis was in accessing support for her child, (P25, L1-8)

> *That's why people say to me, 'I don't know whether to get a diagnosis, do you think it is a good thing to get it done? I don't want them labelled here!' And I tell them, they aren't labelling them, they are getting them help, they are allowing them to access themselves, to understand themselves. When we spoke to my son and explained to him that he has a diagnosis of autism and explained how this is why he sometimes struggles in different situations, it looked like he was relieved, like it was relief all over his face. I think that he knew that he was different to others.*

There are therefore different reasons why parents do not want their children to have a diagnosis – in that this is somehow labelling them for life – or why some parents do want their children to receive a diagnosis – in that they are more likely to receive support if the diagnostic evidence is in place. Ranesh also felt that it would help for them to have the diagnosis for her son (P17, L7-14):

> *I would not parent him any differently whether he had a diagnosis or not. I wouldn't. I would still expect the best for him. he obviously has these needs, you know? He is obviously struggling with impulsivity, so to me, it would not matter. But just recently, it feels like the school are not doing enough to support him. So, I need the diagnosis for an educational point of view, if I push for the diagnosis then I might have a leg to stand on, and then I could tell them that they are not doing enough to support them. At this moment in time, I am just being brushed off like I am one of those parents that want her child to be treated differently.*

It is evident that it should not be the case that parents have to fight for a diagnosis to ensure that their children receive the correct support in school and in other services, however, when the legislation conflicts across services, it is difficult to suggest that support should be in place without a diagnosis. It can be shown in some of the interviews, that even when diagnosis is achieved, there is still not support, enough support or in some cases the diagnosis led to support being withdrawn altogether. This can be seen in Sam's interview, when she spoke about the successes that her department had recently had with more successful referral for Early Years children leading to diagnosis (P29, L1-8):

> *However, there are some downsides to our success, as there are more children coming through into mainstream primary with EHCP's then the school will not take them in as they say that they cannot meet the child's need. So, we get the diagnosis and then we cannot get the children into a school. This is because schools are struggling so much with the number of children coming into their schools with second level support and EHCP support and there are just higher and higher numbers of these children. Schools are struggling with this; they are not given adequate funding to support the children and then they are in deficits with their budget so they just cannot take any more in.*

This shows how in some instances, early diagnosis acts as a barrier, with pre-school children unable to access a place in mainstream settings because they are autistic, compared to if they had not received diagnosis in early years then they would have been given a place in a setting. This could become a reason for parents now wanting an autism diagnosis if it could stop them from sending their children to their choice of school setting.

Summary of theme – The Referral Process Itself

This theme has shown how additional layers are added to the referral system through gatekeepers, in the case of this council case study, the gatekeepers are professionals that decide whether the autism referral can proceed to the autism waiting list, or whether it is refused due to lack of evidence. It has shown that even though the SEND Code of Practise states that the parent voice must be listened to, as they are the people that know the child the best, that the parent voice is not always listened to or cannot be heard, as if the professional does not see autistic traits, then they are not able to reference them in their own reports. The gatekeeper is also shown to be the neurodiversity team, in that the referral must pass their points-based system to be referred, even though the child has been observed during evidence collation by many different professionals. It has been suggested that the child cannot be placed at the centre of the autism referral if their voice is only heard through a report. This theme has shown how inadequate funding across services is again incremental in the lack of training of staff, making diagnostic services more difficult to obtain as staff are not up to date on autism studies. Also, how when funding is given, great changes can be made to support and training which creates more streamlined and effective services for each child. The theme has also highlighted how public knowledge about autism has led to some parents not understanding the referral system, and others being repelled from following the diagnostic route due to the long waiting lists and lack of support post-diagnosis. The theme has also opened a discussion about the Asperger's versus Autism debate, and how a child who is seen as autistic could be referred or diagnosed quicker, due to the more apparent traits, which could lead to shorter waiting times for all autistic children and cost-saving for essential services such as educational psychologists and paediatricians who may not be needed to carry out their own evaluations if diagnosis could be made from professionals within other professional services.

4.4: Discussion

Introduction

This section of the chapter discusses the value of the evidence provided in the findings. It does this by reflecting on the themes and sub themes from the research and how from these themes a theory has emerged. This is a crucial factor when carrying out research that dips into grounded methodology as Charmaz (2006:157) states, 'Emergence is fundamentally a temporal concept; it presupposes a past, assumes the immediacy of the present, and implies a future.' This aligns itself with autism research, as autism itself has evolved so much in our understanding of it, there lies with it a historical understanding, a current understanding and then, with continued research, a promise of future understanding. This is also true within the diagnostic and referral process of autism, which as our understanding develops, there is shown to be a clear need to also develop the diagnostic pathways.

It has been shown how early diagnosis of autism in children can increase the support given to children in schools but can also have a detrimental effect on pre-school children who are missing out on mainstream education as schools cannot support the number of children applying to them who have EHCP's in place and need additional support to access education. It has been shown how early diagnosis leads to a more adequate support system (Clark et al, 2018) where children who were diagnosed before the age of three had improved cognitive abilities and improved expressive language. Although the SEND Code of Practise states that children with identified need should receive support the diagnosis often lends itself to better support. This is because if there is a diagnosis then it is difficult to challenge if the young person needs support. The diagnosis has also been shown to be able to support an EHCP application which gives each student additional funding, this helps particularly in the instance of children that need specialist settings which need a higher level of funding to access them. Having a diagnosis could also help to ensure that there is gender equality, if diagnostic processes were clearer from the point of view of gender differences, then it is likely that more girls would get the support needed in school. It could be argued that it is not that autism is less prevalent in girls, but that it is simply more difficult to diagnose, therefore leaving girls lacking in support.

As stated by Baribeau et al (2021), many autistic children need routine, due to their insistence on sameness, which is a need for ritual and routine, also having difficulties with transitions. There are many transitions during a child's school life, this includes moving up classes with a change in classroom and teacher, differences in the content of lessons, changes to a school day due to themes and events. Although it would be impossible to rule out all changes that could occur in a school day, such as staff sickness resulting in a new supply teacher, lots of routines could be embedded to help support a student if the teachers were aware that they had an autism diagnosis. These routines could be as simple as not changing the school timetable, ensuring children stay in the same seats or groups, ensuring the student has an allocated seat at lunchtime or ensuring that parents are aware well in advance of any changes, where possible, so that the changes can be communicated. Having an early diagnosis can also help parents to provide good routines at home as Rodger et al's (2011) research showed earlier how routines and rituals are significant in organising activities and the wellbeing of families. With early diagnosis, parents would understand how changes to routine may be difficult for their child, they may be able to plan in holidays earlier, helping their children to adjust at an earlier age to changes in their routine, this could also count as evidence towards taking children out of school to go on holiday during term time, if a quieter holiday is needed to help the young person to cope with a change in routine and environment.

Receiving an autism diagnosis could assist the student in not only receiving academic support from school but also help with their SEMH (Social, Emotional and Mental Health) as difficulties could arise throughout their lives due to experiences that they have had during their school years which could include bullying, as discussed earlier with Van Roekel (2010). Having an autism diagnosis throughout school could lead to them being supported with school interventions such as social stories and ELSA (Emotional Literacy Support Assistant) sessions whereby students are given additional opportunities outside the classroom to work in small groups with a trained adult. It could also mean that students are more supported in times of play such as on the playground. Having an earlier diagnosis could also help schools to support students with equipment such as wobble cushions or rocking chairs which as Deweerdt (2020) showed earlier can calm anxiety, give autistic people with sensory needs a greater awareness of their bodies, help them to focus with concentration and help to deal with sensations and emotions. Having equipment in school that helps autistic children to combat sensory overload can therefore help autistic children to be more successful with an in-school, adapted sensory diet and as evidenced by Tomcheck (2007) earlier, as approximately 90% of autistic people have sensory differences, the outcomes of meeting their sensory needs by early diagnosis leading to targeted support would essentially help the majority of autistic school children to have better outcomes, whether that is academic outcomes or emotional and wellbeing outcomes.

It is concluded therefore, that in most cases, diagnosis is a key factor in ensuring that children receive adequate support in ensuring that each child meets their full potential in all areas of their lives.

There have been emerging issues around autism referrals which have been taken from the themes and sub themes of the findings.

- Lack of Funding, Lack of Training leading to a lack of understanding and support.

Although there is clearly a difference in support across services, many of these problems have been confounded by a lack of funding into services such as the NHS and education. Without funding, schools have been unable to keep training updated, leading to poor Ofsted reports, condemning councils for not continuously giving professional training to their staff. Teacher-blaming has been an ongoing issue in society, with education often used as a political pawn. Blaming schools and teachers through the rhetoric of Ofsted reporting can be seen to deflect on the one true issue: schools and other services are not adequately funded. This has led to a referral system that is out of date and a staff cohort across services that have not been adequately trained. There is no blame at the feet of our schools or our teachers, for without the funding to train them and without the funding to look at streamlining services, then there is surely no way to progress into a more deserved referral process for our most vulnerable children. Earlier, research from Fletcher Watson (2023) and Pelicano et al (2013) discussed autism funding was not always given to support autistic people but was instead used for autism research. This research suggested that autistic people should be given a say in how this funding is spent, especially as a proportionate amount of autistic people did not want a 'cure' to autism through research but instead an understanding of how neurotypical people were different, not broken. If autistic people were given the choice, it could be argued that more funding could be driven into schools and other services to support children, to train staff and buy equipment instead of using funding for research purposes.

The heterogeneity of autism can be shown to make identification problematic as it is so vastly different across every individual (Linton:2013). The 'spectrum' of autism is so remarkably diverse in its nature that boundaries at each end are extreme opposites. This spectrum of traits is difficult to identify, as discussed, as there is no scientific test or identifiable biological marker, this has made autism a 'diagnosis of opinion' and as each opinion differs, so do the diagnostic results. Previously, Georgidas (2013) developed the idea that recognising the very nature of heterogeneity could provide a framework that could help to refine the future measurement of autism diagnosis. The deletion of Asperger's as a diagnosis has been shown to inflate this issue, making the diagnosis of autism even more heterogenic in its very nature, even shown to be confusing for parents of children that would once have been told they were Asperger's and now would be told they are autistic (Linton:2013). The lack of knowledge around this heterogeneity means that some parents are unwilling to pursue a diagnosis or to label their child, therefore reducing the child's possibility of attaining the support they need, particularly whilst in education. There has also been the discussion about children who are more obviously autistic and why the referral pathways are the same for all children, all needing the same amount of evidence and observations even when autism has been evidenced early, as Hayley stated, even though all of the professionals were in agreement about her son, it still took some years until he reached the point of a diagnosis. This discussion leads us back again to the referral process and how all potentially autistic children, no matter how they present, go through the same referral process, which is a process evidenced earlier by Howlin and Moore (1997) and Crane et al (2016) as being a process that over half of parents were not satisfied with and that on average took four and a half years to reach diagnosis.

Increasing professionals' understanding of autistic individualism could also work towards reducing the gender inequalities within autism diagnosis, as discussed earlier (Kirkovski et al, 2013; Kim et al, 2011; Mattila et al, 2011) which highlighted the disparity between how many autistic boys are diagnosed compared to autistic girls which is in part due to social masking and the lack of understanding around the differences between some autistic boys and girls.

Another emerging issue is the autism referral process itself, in particular the static referral questionnaire versus the heterogeneic nature of autism itself. It has been shown that the questionnaire, with its tick box answers, does not align with an autism diagnosis. It has been shown that if the child does not receive enough points from the questionnaire that the referral will be refused, and the child will not access an autism assessment waiting list. It is discussed that a questionnaire of this type is outdated and has not kept its relevance as autism itself is in a constant state of flux, as more knowledge is acquired and continued research in this field emerges. The current questionnaire utilises autistic traits as defined by Kanner in the 1940's to refer children into autism services which highlights the need to update the diagnosis of autism, beyond that which has been classified in the DSM-V. When looking back to the earlier comparison (Table 1) of Vrasidas' major assumptions (2000:2-10), if autism is shown within the theory of constructivism and the autism referral procedure is shown within the theory of objectivism, the two do not align, they actively conflict with one another. What can be known from the research is that the referral process is not always fit for purpose, it is not inclusive and is one of the main reasons why autism diagnostic waiting times are so high.

Chapter 5: Conclusion and Recommendations

Introduction

In this chapter, two recommendations are made as a result of the themes and discussion which emerged from the interviews:

- **To overhaul the referral system**

This includes a new referral model which allows parents to self-refer, based on an online system that sends the user to new questions based on their answers, therefore making a system that is more individualised for each referrer.

- **To give adequate funding and training to professionals involved in SEND**

Adequate funding is needed in schools and more accountability is needed for where schools spend their SEND funding. Training needs to be delivered on a national basis and delivered annually, allowing for training to be delivered on new knowledge across the SEND sector.

(i) 5.1.1 Overhaul of the referral system

As discussed earlier, the referral process can be placed in the realms of objectivism as it is, 'structured and classified and then represented using theoretical modelling' (Vrasidas, 2000) whereas autism can be said to be constructed, based on Vrasidas' model – it is real, however there are multiple realities of it and therefore it is constructivist. It could be argued therefore, that the referral system needs to become more constructivist, for it not to be one thing, not one tick box that attempts to capture every autistic person, as this is surely impossible. There must be an end to the standardised questionnaire process, for this is a barrier to referral, stopping children who do not have enough points on the questionnaire's threshold so that they do not proceed to an autism assessment.

My data suggests that Linton's (2013) presuppositions, that the removal of Asperger's would mean that fewer people would meet the criteria for autism diagnosis, are correct. By removing Asperger's, the process of observing autistic traits became more difficult.

It is recommended that a separate autism diagnosis is implemented back into the DSM-V for previously diagnosed Asperger's autistic profiles.

The data has also shown that both parents and professionals recognise that some children are easier to identify as autistic. As Hayley said in her interview, (P16, L5-6) "

> *It sounds awful, but when I'm out and about, I can spot somebody [an autistic child] a mile off, I just look at the children and look at the way they are acting, you can just see it.*

Introducing a referral process that differentiates across the autistic spectrum would give some autistic children earlier support and also assist in the process for children who mask their autism to be signposted to professionals in a timelier manner due to more availability of current professionals involved in the service.

Removing gatekeepers and allowing parents and professionals (with parental consent) to refer directly into services would free up the need for professional reports in all instances, thereby releasing funding and speeding up the process.

My recommendation is to introduce a new, national referral process for potentially autistic children as shown in the diagram below. For children that have a high level of autistic markers, a co-occurring condition and genetic links to autism, they could be expedited through a referral system that then lessened the need for further professional reports. Using my professional experience and the feedback from participants in my research, I devised the table below to exemplify that potential referral system.

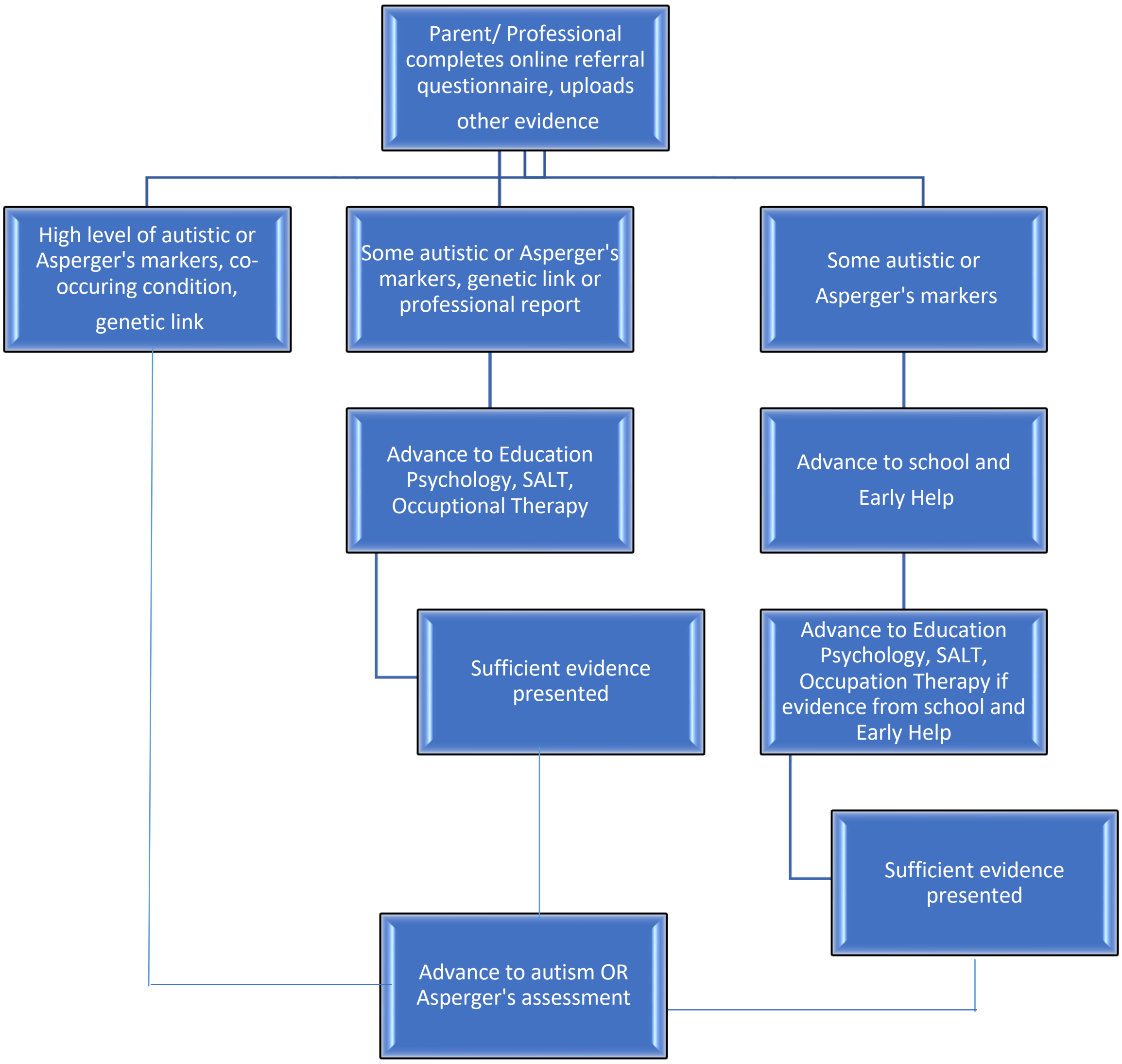

Figure 4 New referral process for potentially autistic children

In order to create a constructivist referral system, the online questionnaire would need to use technology that took the referrer into different questions, based on their answers. This could then identify whether the child had autistic traits or Asperger's traits or a mixture of both. Future questioning could be diverted into traits that are specific for those diagnoses. If the child had a set number of traits, professional diagnosis outlining common co-occuring conditions as outlined earlier or had genetic links to autism (if their sibling or parents were autistic, for example) then they could proceed directly to an autism assessment. If the child had fewer traits, no genetic link or other diagnosis, then the child could be referred into specific services based on question outcomes. For example, if the young person had difficulties with communication, they could be referred to Speech and Language. If they had gross or fine motor difficulties – Occupational Therapy. They could then also access an Educational Psychologist if reports from the professionals showed possible autism, then the young person would be referred for an assessment. If there were fewer autism traits, no professional reports or genetic links then the young person could be directed to school and referred into Early Help. This would allow both school professionals to start to evidence autistic tendencies and also allow Early Help into the home to evidence autistic behaviours at home. Once these reports were completed, they could then be referred for more professional diagnostic testing and then into autism services.

In order to create a referral service that is more constructivist, alongside the referral system becoming more individualised, autistic and non-autistic traits need to be increased from the current system. This would be more effective if the DSM-V criteria was more autism relevant. Currently, as shown in Appendix A, there are lists of questions relating to each of the DSM-V's criteria for diagnosing autism such as:

A. Deficits in social communication.
B. Deficits in non-verbal communicative behaviours
C. Deficits in social-emotional reciprocity
D. Deficits in developing, maintaining and understanding relationships

The autism questionnaire takes each criterion and then lists questions for each, for example with social communication, the DSM-V states that the communication or interaction is in deficit, implying that it is lacking. The questions are therefore written to see if there is a lacking in social communication. However, many autistic people are very sociable, and rather than being unable to start conversations they effectively respond, include others and share enjoyment. Autistic children may have a lack of social boundaries that makes it seem as if they are very sociable and able to communicate effectively.

The DSM-V criteria could be rewritten to include more autism types that included autistic people who struggled with social communication or had excessive social communication. Instead of 'deficits in social communication' it could read 'social communication.'

A system could be created to represent many different types of social communication that may lead to a more accurate representation of the young person's autism type, strengths and difficulties. The questioning, delivered online, would have to be much more thorough and include many different autistic traits, than the current questionnaire allows, for example, they could have questions relating to the following social communication differences. I have created the following table which shows differences in social communication based on knowledge from current practise, personal experiences of autism both in myself and others including my children and the students that I have seen over the years. The table is non-hierarchical, the differences at the top are as important as the differences at the bottom. The table includes one hundred differences which is more than the current tick list questionnaire. If the questionnaire was online and responsive, there could be many more differences added, allowing for a more precise outcome of each individual.

No Verbal Communication	Selective Mutism	Difficulties with Speech Articulation	Limited vocabulary	Different intonation
Fewer/no gestures	Good eye contact	No eye contact	High level vocabulary out of context	High level vocabulary in context
Over gesticulating	Speech in context with situation	Speech out of context of situation	Takes turns in conversation	Listens and responds
Speaks in conversations about all topics	Prefers to speak about own interests	Only joins in conversations about own interests	Can stay on topic	Understands hints through tone
Understands hints through eye contact	Understands hints through gesture or body language	Can imply meaning	Can identify another's emotions in order to halt or change conversation	Can chat 121 with a trusted adult
Can chat in small groups	Can chat with groups of more than five people	Can chat with family members when at home	Uses echolalia	Answers questions immediately
Takes longer to answer questions than others	Looks interested in another person's communication	Uses phrases heard on TV or social media	Speaks in an accent	Speaks in an accent occasionally
Has become better at social communication due to learnt behaviours	Communicates their wants with others	Communicates their feelings with others	Can ask for help	Points at things that they want
Can communicate with strangers, such as asking them the time when out in public	Participates in class discussions	Will answer teacher's questions	Suffers communication difficulties when stressed or anxious	Starts a conversation with others based on others' interests

Starts a conversation with others based on their interests	Is told they talk too much	Is told they talk too fast	Looks at the person who is speaking	Looks at objects of interest when speaking
Seeks play with others	Prefers to play alone	Plays with others when related to their interests	Plays with others due to social masking	Takes enjoyment from interaction with others
Has many friends	Has some friends	Has had the same group of friends for a long time	Frequently swaps friendship groups	Finds friendship groups increases stress/anxiety
Understands intentions of others in their friendship group	Can use their imagination	Can use imagination in lesson due to being given strategies (story ideas)	Prefers non-fiction	Talks differently to others (parent, teacher, unknown adult)
Can accept an item that represents another (could use a block as a toy car)	Understands jokes	Enjoys jokes	Takes things literally	Behaves differently in different settings
Resort to social withdrawal	Have to be collected from school often	Are school refusers	Are not in school	Often cry when speaking
Greets others that they know	Greets new people	Uses appropriate level of voice for setting (indoor/outdoor voice)	Rephrases information	Repeats same question if other person says they do not understand
Recognises idioms	Recognises metaphor	Can use personification in fictional writing	Understands words with more than one meaning in different contexts	Waves goodbye
Often falls out with friends	Speaks out in class without raising hand	Falls out with people outside of friendship group	Can intuitively react to humour	Gets on well with other autistic children
Is empathetic	Understands social rules	Very honest which sometimes offends	Cannot lie	Laughs in difficult situations
Understands other's points of view	Enjoys small talk	Understands sarcasm	Prefers adult company	Sometimes sounds abrupt

Figure 5 Social Communication differences for adaptation and use in new referral system

The list for social communication is incomplete and would need examples from many different sources with other autistic people adding to the strengths and differences. However, even in this early stage it can be seen how the social communication criteria has more questions and further depth. It is recommended that this practice is carried out for all DSM-V criteria and then renamed so that they become differences and not deficits. Each criterion would then be split in all of the various differences, as with the table above. Once the online questionnaire was completed by a parent or professional, the results could be portrayed visually so that assessors could look at patterns to more accurately diagnose and also signpost into specific support services. It would also help school SENCo's and class teachers to look at specific support requirements in the classroom as individuals as opposed to having similar strategies for all autistic children. An example of a visual based on questionnaire responses could look as follows:

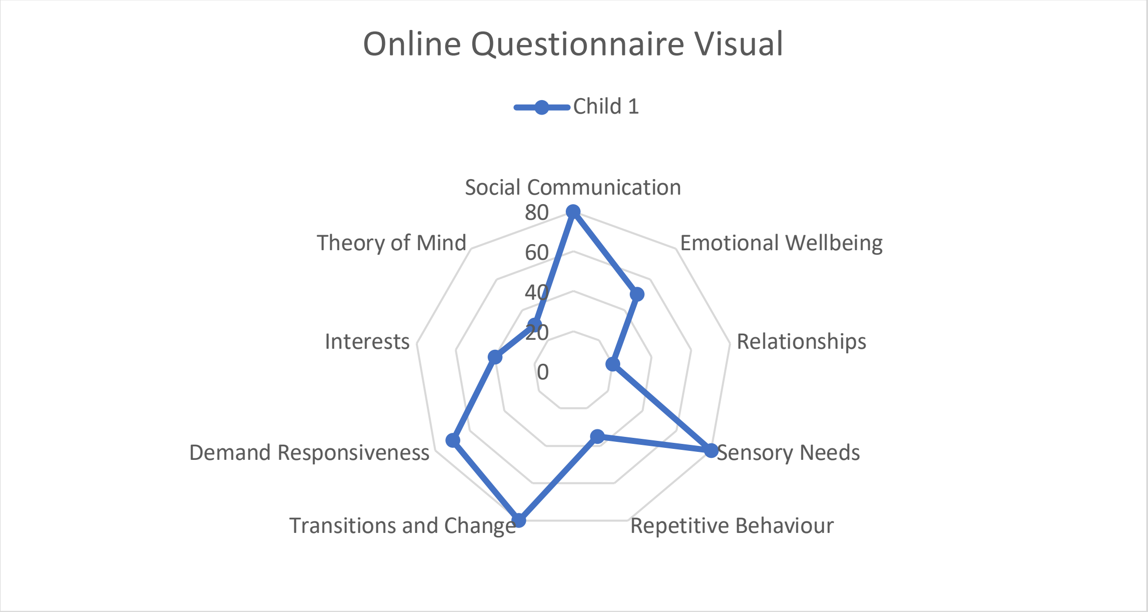

Figure 6 A visual representation of outcomes of the online autism questionnaire for Child 1

The online system is not difficult to achieve and therefore relatively inexpensive to create. In order that the system is accessible for all, there would be links and pictures added to each question in case the user did not understand the question. The questionnaire could also signpost users to SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service) which is a free service which gives information to young people with SEND and their parents/carers. SENDIASS offer online, phone or in person advice and would be an agency that could help parents and carers through the questionnaire if school support is unavailable. Moving forwards, if the online referral system was adopted, then more individualised assessments would be carried out which are more in line with the heterogeneic nature of autism. Young people would be better supported as professionals would have a better understanding of their individual needs. Children who had clear traits, other diagnosis or genetic autism links would receive quicker diagnosis. A national referral system would help many parents across the country, as everyone would have access to the same system. This is different to how referral systems currently operate, with different referral processes across local authorities.

(ii) 5.1.2 Funding and training

It is essential that as professionals are upskilled on the many variances of autism, that knowledge around autism is delivered to the public. It has been shown how many parents do not want their children to receive a diagnosis, this could be due to lack of information, knowledge around autism assessment delays or not wanting to label their children. This could also have been due to guilt as shown earlier with Bettelheim's (1943) refrigerator mother concept. Crowell et al (2019) discussed that there has been little research on parental behaviour as the research could add to the guilt that many parents with autistic children feel about whether they should have acted differently to prevent or correct their children's differences, however the interviews here have shown that parents do feel that guilt, with Hayley discussing how she suffered with her mental health due to being unwell after giving birth and not being able to take care of her son due to this. This shows that with or without research on how parents feel, that they still feel guilt, therefore by completing more research on the effects of parents involved in the diagnostic process and also giving more advice on autism when children are born would help to equip parents with a clear signpost into services if they feel that they need support for their children in the future.

There has been much discussion about the lack of training given to professionals that are involved in the referral process for autistic children and this again is a matter of budget. If schools, health care and SEN departments are underfunded then training is not going to be a priority, with the world of neurodiversity evolving so quickly, up to date training is essential in ensuring that all staff have the knowledge that they need to be able to support and observe children for evidence of needs. As discussed previously, the Warnock Report formed part of the 1981 Education Act which closed special schools so that children with additional needs were included in mainstream schools. However, as discussed, there is evidence to support that the new act and subsequent closure of many special schools had a financial benefit on society (Jarbrink and Knapp, 2001), this financial gain did not offer financial compensation to schools, offering them no money to fund additional teacher training or fund additional teaching assistants or equipment to support children with SEND.

It could be argued that continued insufficient budgets will only fuel continued lack of support and training in schools. It can be seen how the Early Years team in this council area work hard to deliver training to their local private nurseries, and how this has had a positive impact on autism referral outcomes. It can be said therefore that if this team could deliver the same package to mainstream schools, that their knowledge and skills would also be increased in this area of SEND and referrals for children in mainstream schools would be more successful, as Sam (Early Years Area Manager) explained earlier, more children are referred in this council area from private nurseries than are from state school nurseries. To achieve additional training opportunities, it is true that more funding is required, however if current services are streamlined, for example if this department within the council are already trained, then all that remains is to give school the opportunity to book this training. These kinds of solutions are essential to release money to ensure that local staff are given the training needed. In the same way that Academy schools pool resources, as staff can be trained centrally through webinars or online programs, delivering training across many schools could be an option for this council, by integrating essential training into school inset days, delivered directly from one source.

Information about the allocation of SEND funding by child needs to be made available to parents and other school stakeholders. Currently, there is no legislation for schools to have to give this information to parents and therefore there is a lack of information about how funding is spent. Currently, schools are allocated a ‘notional’ budget which is calculated by a formula based on how many children receive free school meals and how many children are not progressing as well in English and Maths. It is argued that this formula does not accurately represent SEND in schools and therefore the notional budget formula needs to be reformatted so that schools receive budget inline with the amount of SEND children alongside children on free schools meals and those that are academically disadvantaged.

5.2 Conclusion

My research aimed to look at the autism referral procedure from the perspective of people that had been involved in the process: those who wanted their children to be referred; those who were able to refer and professionals that submitted evidence for referral and professionals that were involved in signposting into services. The research took a more personal approach using case studies as previous research was more quantitative in design with facts and figures creating outcomes instead of participants’ personal points of view. I have spoken about how the long waiting times for the diagnosis of autism have not changed over many years and wanted to understand why this was and if anything could be changed to improve outcomes for potentially autistic children via quicker referral services.

It has been discussed how autism waiting times are still data collected from the point of referral instead of being collected from the first point of parent, teacher or professional asking for a referral into services (NHS Digital:2024):

> These statistics present a group of measures on waiting times for autism spectrum disorder diagnostic pathways, based on the time between a referral for suspected autism and the first care contact associated with that referral.

This shows that autism waiting times are still inaccurate as there is no accurate data collected pre-referral, from the point of time when a professional or parent asks for a referral into services.

As a mum of autistic children, a teacher of autistic children and being involved in the referral process from a professional point of view, it has been incredibly valuable to listen and collect different points of view. One overarching fact is that everyone that I interviewed had the children at the centre of their lives, their work, their practice and that they would all want to see positive change to the referral system. Although there were no interviewees that said that everything was good as it was, there were clearly moments of good practice and change being evoked from the people at ground level. There is never any doubt from anyone that a change in referral practices would be positive for the children that we work to support.

My core research questions asked:

- What are the experiences of parents and professionals involved in the referral process?
- Has removing Asperger’s had a detrimental effect on the referral process for potentially autistic children?
- Could the referral process be changed to streamline services and reduce autism waiting times?

The experiences of parents and professionals involved in the referral process highlighted that the heterogeneity of autism itself made it difficult to diagnose. Interviewees spoke about how accessing a positive referral often depended on which professional you saw and what each knew about autism based on their own experiences. Participants spoke about no autistic person being the same and therefore the tick-box referral paperwork did not always accurately represent the autistic nature of their child. The autism referral paper process is clearly outdated, with ‘yes’ and ‘no’ answers that do not give a clear view of the young person. Creating an online referral system whilst collecting professional reports and genetic links could be updated and added to as our knowledge of autism progresses. Complimenting the system with why, when, how type questioning, with examples for parents to comment on, would allow the assessment professionals more evidence with which to make a decision. The online referral system would allow for quicker referral of autistic children and give specific evidence to help educators and professionals support children based on their individual needs. The online referral system would allow parents to refer directly, taking away gatekeepers that, due to waiting times, added more time onto accessing a referral.

Removing Asperger's has had a detrimental effect on the autism referral process. This is because an Asperger's child and an autistic child are often quite different. I have exampled Linton et al (2014) who stated that fewer people with an Asperger's diagnosis now met the criteria for an autism diagnosis, particularly with regards to the diagnosis of females. Even with this early research, this removal has not been rectified or acted upon. This has made the diagnosis of autism in typical 'Asperger's' children more difficult. If Asperger's (renamed) diagnosis was reintroduced, professionals could look at autism, Asperger's and autism as a spectrum of differences and create a referral process which suited the individual, due to a richer analysis of qualifying traits for referral.

Some of these measures are controversial, giving one child preference over another with quicker access to services could be deemed unfair. But then, finding examples of a similar need for this in society is difficult, as autism is so unique. For example, if a child was suspected to have cerebral palsy, even with its many differences, they would have a brain scan and then be diagnosed. It could be argued that because autism does not have a clear diagnostic test or biological marker that every autistic child has a disadvantage to every other disabled child as they cannot be easily tested, diagnosed and supported. Thinking about autism diagnosis must be controversial because it does not fit in with any other diagnosable disability and we must, therefore, think about it in quite a different way.

It has also been shown how scientific research and looking for biological markers are also controversial, as many think that autism is not something to be cured, it is a neurological difference. It can be argued that it is not the diagnosis but society itself that choose to see neurodivergence as the 'other' instead of the 'norm.' If every workplace, retail outlet, school and home were equipped to deliver inclusivity, there may be less need for a diagnosis at all. I started the referral process for my children due to the lack of support given in school and the lack of understanding in the world around us. If the support was in place due to every child being taught in an inclusive way, then I may not have sought diagnosis at all. I understand that other autistic children have greater need, and do not suggest that autism diagnosis is removed. However, if a more inclusive world was created, if every autistic and non-autistic child was in an environment that nurtured their needs, then this may be the greatest solution to autism referral times as less children would need them. As one parent fed back to us recently:

> *Recently, when I was reflecting on how well my son was doing in your care, I reflected on the fact that when he was in your provision, he didn't have special needs. He was just a young boy, thriving in his environment alongside his peers. When he has the right place and the right support, he isn't a young boy with a label. He is quite simply 'Jack.'*

Whichever point of view is taken, the research has shown that changes must be made and in its current state, the referral process is not fit for purpose. The referral length is not acknowledged in current data, therefore autism waiting time data is incorrect. It is acknowledged that this research only considers one council area in the UK however it is evident that this is not the only council using similar processes and the impact of this reaches many more children who are waiting for the educational support that an autism diagnosis can achieve.

(iii) 5.2.1 Contribution to Practice

- The creation of an online referral process for potentially autistic children. This will allow parents to refer directly into services so that waiting times are reduced with fewer gatekeepers. The referral system identifies the variations of autism strengths, differences and difficulties so that referrals and support can be tailored to each individual which includes the differences in autistic and Asperger's children.

- Autism waiting times pre-referral must be considered when collecting national data or the data is not correct. The waiting times can be many years in addition to the time taken from referral to assessment. Therefore, national waiting times are currently not correct.

- SEND funding needs to be adequate and directed to the children that need it. Funding needs to include the ongoing training of professionals involved in the autism referral process, including early health professionals so that autism becomes part of the 8 month and two-year health checks.

(iv) 5.2.2 Contribution to Theory

- In line with my theoretical perspective, The DSM-V criterion need to be renamed in line with current autistic language preferences, removing ‘deficits’ and opening the criteria for more variations of autism and giving a more adequate explanation of the spectrum. Currently, autism is a more complex issue than is currently explained. The complexities have been debated throughout history, for example, Wing and Gould’s (1979) triad of impairments sub-categorised autistic traits. Some years later, the categorisation was dismissed by Wing (1996) as having little value due to overlapping traits. Autism is heterogeneic, however there are commonalities which distinguish autism from Asperger’s. This must be rethought and restructured in order that the current enormity of heterogeneity can be classified where there are distinct traits relating to each autism. There may be overlaps, there may be commonalities but there are also decisive traits. This could be the starting point of earlier diagnosis and a better understanding of individuals specific needs within the spectrum of autism.

There have been changes to policy since the thesis was written, this includes the SEND and AP green paper (2022) this includes: ‘children with SEND should have their needs identified promptly, with appropriate support put in place at the earliest opportunity.’ This shows how important it is to have accurate data surrounding autism referrals, ensuing that the time that parents or professionals put in a referral is the documented start time of the waiting period. The paper also highlights the needs for additional funding and the need for additional training. It has been shown how by streamlining the autism assessment process, by allowing parents to self-refer, costs could be saved. This is due the amount of professional evidence needed to currently refer children into services. It has to also be noted, that there has also recently been a change in government and it is unclear whether there will be a new SEND paper with different objectives set out.

Throughout the whole thesis, my own personal lens changed as I realised how my own experiences were often reflected in the lives of many others. Waiting for change to happen for the sake of my own children and those in my local community became very overwhelming. In educating myself and understanding the lack of provision for children with autism spurred me to continue to develop my own businesses with my business partner, Gorgi. We now have over 90 children in part-time and full-time places across our school and

Alternative Provision. We have a commitment to listening to parents and professionals, and most importantly the children that we support daily. We hope to continue to advocate for them and the changes that are needed to many of the current systems in our world of neurodiversity.

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Appendix

Council X Autism Referral Questionnaire

ASD Triage Screening Checklist

Date of referral…

This checklist is to be completed to support your request for a Specialist Autism Assessment, please also attach any relevant reports that will support the referral. This pack includes:

- Information about the young person
- Parent screening form (Part 1)
- Education screening from (Part 2)
- Education information

Referrals received without completed information will not be processed and will be returned to referrer

Please contact [redacted] for further advice and support

Information about the young person

Name	
Date of Birth	
Gender at birth	
Home Address (Inc Postcode)	
Diagnosis	
Does anyone else in the family have ASD, ADHD, LD or Dyspraxia?	

Are there any risk factors – i.e., suicidal thoughts/plans, active self-harm, violent behaviour? If yes, please also consider a referral to [redacted] as this referral is routine and will not be prioritised for risk.

What other agencies are involved with the child/young person and what support packages have been provided currently or in the recent past? Please attach copies of all reports

Please tick where applicable:	Current	Past (Date)	Never	Describe involvement	Report attached
CAMHS					
Portage					
Educational Psychology					
Education, Health and Care Plan					
Early Help Support					
Youth Offending Team					
Speech & Language Therapy					
Occupational Therapy					
Parenting/behaviour management classes					
Child Protection Plan/ Child in need plan					

Neurodevelopmental Disability i.e. Learning Disability/ADHD					
Other (please describe)					

Part 1

ASD TRIAGE SCREENING CHECKLIST

TO BE FILLED IN BY PARENTS/CARERS

Please ensure additional information is provided Q10, 26, 39, 46, 55, 58, 62

A) Social communication and interaction

A.1.) Social-emotional reciprocity

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
1	Does your child start a conversation with you?				
2	Does your child respond to conversations from others?				
3	Does your child take turns within a conversation?				
4	Can your child stick to the topic during a conversation?				
5	Does your child understand cues such as time to end a conversation or time for someone else to talk?				
6	Does your child give the appropriate responses to the content of the conversation?				
7	Does your child include others in activities or conversation of their choosing?				
8	Does your child show interest in activities or conversation of others?				
9	Does your child demonstrate shared enjoyment of shared activities?				
10	Please provided additional information to describe further the above points				

A.2 Nonverbal communication

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
11	Does your child use eye contact to initiate interaction?				
12	Does your child use eye contact in response to other interactions?				

13	Is your child able to maintain eye contact throughout interaction?				
14	Does your child look between objects of interest and people during interaction?				
15	Does your child look between different people when talking to a group?				
16	Does your child use natural gestures such as waving and pointing during interaction?				
17	Does your child use descriptive gestures such as showing size, shape or direction during interaction?				
18	Does your child show an awareness of personal space?				
19	Does your child show a good quantity and range of natural gestures? NB- Children at 16 months of age have a range of 16 natural gestures.				
20	Does your child show understanding of gestures used by others?				
21	Does your child use facial expressions when interacting?				
22	Are their facial expressions directed and shared with others?				
23	Does your child use a variety of facial expressions?				
24	Does your child use gestures, eye contact and facial expressions at the same time as speaking/making sounds?				
25	Does your child use a range of intonation and volumes of sound appropriate to the interaction?				
26	Please provided additional information to describe further the above points				

A.3 Relationships and Play

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
27	Does your child have friends?				
28	Does your child take turns appropriately when managed by an adult?				
29	Does your child manage turn taking within a group with no adult supervision?				
30	Does your child participate in group activities and actually join in?				
31	Does your child know to behave differently in different settings? E.g. In class, in assembly, school trips.				
32	Does your child show imagination in play, conversation or creative work?				

33	Does your child show imagination in play, conversation or creative work across a range of activities/opportunities?				
34	Can your child accept one item representing another? E.g., Using a banana as a telephone, algebra.				
35	Does your child allow others to play alongside them?				
36	Does your child allow others to play with them?				
37	Does your child accept and respond to others during play, conversation or creative work?				
38	Does your child respond differently to others depending on relationship or context? E.g., Talks differently to Mum, teacher, stranger				
39	Please provided additional information to describe further the above points				

B) Patterns of behaviour

B.1 Stereotyped or repetitive behaviour

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
40	Does your child repeat what you say?				
41	Does your child use repetitive speech or vocalisations?				
42	Does your child speak with their local accent or dialect as you would expect?				
43	Does your child display any repetitive movements?				
44	Does your child display any repetitive activities?				
45	Does your child use any words/phrases that are unusual to the context?				
46	Please provided additional information to describe further the above points				

B.2 Routine behaviour

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
47	Are there times when your child likes to do the same thing in the same way every day?				
48	Can your child cope with interruption or alteration of the above?				

49	Does your child have routines that don’t seem necessary to others?				
50	Does your child understand nonliteral phrases such as sayings? E.g., hit the roof, good as gold, been a monster.				
51	Does your child understand jokes they hear and tell?				
52	Does your child eat a wide range of foods?				
53	Does your child accept new foods offered?				
54	Does your child need to eat in a particular way that would be unusual for the age/development?				
55	Please provided additional information to describe further the above points				

B.3 Restricted interests

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
56	Does your child have interests similar to those expected for their age or level of development?				
57	Do those interests include other activities/conversations?				
58	Please provided additional information to describe further the above points				

B.4 Sensory behaviours

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
59	Does your child excessively seek out or avoid experiences relating to:	Please say if seeks or avoids			
	Sound				
	Taste				
	Smell				
	Touch				
	Vision				
60	Does your child respond appropriately to experiencing?				
	Pain				
	Temperature				

61	Does your child have any difficulties in core routines? E.g., Toileting, dressing.				
62	Please provided additional information to describe further the above points				

Signed: Relationship to child: Print name: Date:

Part 2

TO BE FILLED IN BY EDUCATION/NURSERY

Information about SENCO

Name of SENCO	
School	
Telephone number	
Email Address	
How long have you known the child/young person	

Comparison with school peers

	Better than peers	**Similar to peers**	**More difficulty than peers**	**Has major difficulties**
Expressive language (talking)				
Receptive Language (understanding)				
Social Interaction (relating to people)				
Friendships				
Play				
Flexibility (adapting to changes)				
Cognition (thinking) & Learning				
Sensory (noise, light, smell, touch, taste)				
Physical (balance, coordination, fine/gross motor skills)				

ASD TRIAGE SCREENING CHECKLIST

TO BE FILLED IN BY EDUCATION/NURSERY

Please tick the relevant box in answer to each question and provide examples for each section

A) Social communication and interaction

A.1.) Social-emotional reciprocity

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
1	Does the child initiate interaction with you?				
2	Does the child respond to interaction from others?				
3	Does the child take turns within a conversation?				
4	Can the child stick to the topic during a conversation?				
5	Does the child understand cues such as time to end a conversation or time for someone else to talk?				
6	Does the child give the appropriate responses to the content of the conversation?				
7	Does the child include others in activities or conversation of their choosing?				
8	Does the child show interest in activities or conversation of others?				
9	Does the child demonstrate shared enjoyment of shared activities?				
10	Please provide examples/additional information to describe further the above points				

A.2 Nonverbal communication

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
11	Does the child use eye contact to initiate interaction?				
12	Does the child use eye contact in response to others interactions?				
13	Is the child able to maintain eye contact throughout interaction?				
14	Does the child look between objects of interest and people during interaction?				
15	Does the child look between different people when talking to a group?				
16	Does the child use natural gestures such as waving and pointing during interaction?				
17	Does the child use descriptive gestures such as showing size, shape or direction during interaction?				

18	Does the child show an awareness of personal space?				
19	Does the child show a good quantity and range of natural gestures appropriate to their developmental age?				
20	Does the child show understanding of gestures used by others?				
21	Does the child use facial expressions when interacting?				
22	Are their facial expressions directed and shared with others?				
23	Does the child use a variety of facial expressions?				
24	Does the child use gestures, eye contact and facial expressions at the same time as vocalisations?				
25	Does the child use a range of intonation and volume appropriate to the interaction?				
26	Please provide examples/ additional information to describe further the above points				

A.3 Relationships and Play

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
27	Does the child have preferred friends?				
28	Does the child take turns appropriately when managed by an adult?				
29	Does the child manage turn taking within a group with no adult supervision?				
30	Does the child actively participate in group activities?				
31	Does the child know to behave differently in different settings? E.g. In class, in assembly, school trips.				
32	Does the child show imagination in play, conversation or creative work?				
33	Does the child show imagination in play, conversation or creative work across a range of activities/opportunities?				
34	Can the child accept one item representing another? E.g. Using a banana as a telephone, algebra.				
35	Does the child allow others to play alongside them?				
36	Does the child allow others to play with them?				
37	Does the child accept and respond to others during play, conversation or creative work?				

38	Does the child respond differently to others depending on relationship or context? E.g. Talks differently to Mum, teacher, stranger				
39	Please provide examples/ additional information to describe further the above points				

B) Patterns of behaviour

B.1 Stereotyped or repetitive behaviour

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
40	Does the child use echolalia?				
41	Does the child use repetitive speech or vocalisations?				
42	Does the child speak with their local accent or dialect as you would expect?				
43	Does the child display any repetitive movements?				
44	Does the child display any repetitive activities?				
45	Does the child use any words/phrases that are unusual to the context?				
46	Please provide examples/ additional information to describe further the above points				

B.2 Routine behaviour

For each item, please tick in the column which best describes this child.		**Never**	**Rarely**	**Often**	**Always**
47	Are there times when the child likes to do the same thing in the same way every day?				
48	Can the child cope with interruption or alteration of the above?				
49	Does the child have routines that don’t seem necessary to others?				
50	Does the child understand nonliteral phrases such as sayings? E.g. hit the roof, good as gold, been a monster.				
51	Does the child understand jokes they hear and tell?				
52	Does the child eat a wide range of foods?				
53	Does the child accept new foods offered?				
54	Does the child need to eat in a particular way that would be unusual for the age/development?				

55	Please provide examples/ additional information to describe further the above points

B.3 Restricted interests

	For each item, please tick in the column which best describes this child.	**Never**	**Rarely**	**Often**	**Always**
56	Does the child have interests similar to those expected to their age or level of development?				
57	Do those interests include other activities/conversations?				
58	Please provided additional information to describe further the above points				

B.4 Sensory behaviours

	For each item, please tick in the column which best describes this child.	**Never**	**Rarely**	**Often**	**Always**
59	Does the child excessively seek out or avoid experiences relating to:	Please say if seeks or avoids			
	Sound				
	Taste				
	Smell				
	Touch				
	Vision				
60	Does the child respond appropriately to experiencing:				
	Pain				
	Temperature				
61	Does the child have any difficulties in core routines? E.g. Toileting, dressing.				
62	Please provide examples/ additional information to describe further the above points				