

How do Mothers of Autistic Girls Perceive and Experience the Potential Affordances and Constraints of Diagnosis for their Daughters?

Dr Mairi Evans-Wickens

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How do Mothers of Autistic Girls Perceive and Experience the Potential Affordances and Constraints of Diagnosis for their Daughters?

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Authors Declaration

I, Mairi Evans – Wickens, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have drawn on or cited the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis or any part of it is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- Parts of this work have been published as indicated on page iv & 75.

Abstract

Research highlights increasing awareness that autism can present differently in girls, and that girls in the UK wait longer to be identified, referred, and diagnosed in comparison to their male counterparts. Whilst there is a growing body of research about girls, and the experience of mothering an autistic girl, less is known about the impact of the diagnosis itself. This study, conducted from a social constructionist viewpoint, explored the diagnostic journey of 12 mothers in the UK to identify the meanings attributed to their daughter's diagnosis. A thematic analysis identified 18 sub-themes which were grouped into perceived affordances, perceived constraints/constraints of perception, experienced affordances, and experienced constraints. Themes were then examined through the lens of the CMM LUUUUTT model (Pearce 1999, 2007) exploring the stories lived and told by the mothers and how these stories influenced, and were influenced by, the autism diagnosis. The analysis highlighted affordances and constraints in relation to diagnosis. A significant theme was the impact of autism myths and stereotypes which influenced identification, referral, diagnosis, and ongoing support for the girls, and which led to the majority of the mothers feeling that their early concerns went unheard. Myths and stereotypes told about autism, also played a significant role in the mothers lived experience of the diagnosis and diagnostic process for their daughters. An affordance of diagnosis was a new understanding about their daughter's needs, which led to them adapting their parenting styles, letting go of blame, and resisting perceived societal 'oughtisms' about how parenting should be. Whilst the diagnosis was seen as useful and relationally transformative, all of the mothers described challenges in accessing emotional or educational support for their daughter's post assessment, with the suggestion that they were seen as 'not broken enough'.

This research has potential to inform policy and practice and to increase awareness and understanding about autism diagnosis and girls. In particular the impact of societal myths and stereotypes about autism, the importance of listening to mothers when they raise concerns about their daughters, and the need for pre assessment support and information that can support mothers, and fathers, in understanding the specific needs of their daughters with, or without, an autism diagnosis.

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List of Publications

Evans, Mairi (2019) "**Oughtism and Oughtistic Narratives in the Lives of Autistic People and their Families,**" *Ought: The Journal of Autistic Culture*: Vol. 1 : Iss. 1 , Article 9. Available at: https://scholarworks.gvsu.edu/ought/vol1/iss1/9

Simon, Gail; Evans, Mairi; Cano Urbistondo, Francisco & Helps, Sarah (2020). **Autism and Systemic Family Therapy.** In *Vol. IV Systemic Family Therapy and Global Health Issues for Family Therapy*, *The Handbook of Systemic Family Therapy,* (Ed.) Karen Wampler. Wiley.

List of Conference Talks and Presentations

Evans, Mairi (2018) **Autism, Girls and 'Oughtism'.** https://tvscn.nhs.uk/wp-content/uploads/2018/07/2-Mairi-Evans-Autism-Oughtism-and-girls1.pdf

Evans, Mairi (2019) **Autism, Girls and 'Oughtism'.** All About Autism Conference 2019: Autism, Girls & Oughtism - YouTube

Evans, Mairi (2021) **Autism Untold: A telling and an Un-telling of the Autism Story.** https://systemicautism.com/2021/07/08/autism-untold-a-telling-and-an-un-telling-of-by-mairi-evans/

Evans, Mairi (2021) **Borderline Normal: The affordances and constraints of autism diagnosis as told by the mothers of autistic girls.** https://systemicautism.com/2021/07/11/borderline-normal/

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‘That Lightbulb Moment’ by Mahlia Amatina a young female and autistic artist who created a series of artworks ‘On the spectrum’ in 2017. ‘That Lightbulb Moment’ is about the moment of her diagnosis (permission to share granted).

1. Introduction

"Hopefully this and further research can be used to educate not only professionals but also society to try to dispel the myths many of us had regarding Autism, especially as the number of girls being diagnosed is increasing. Wouldn't it be great to see girls being identified and supported at a much earlier age, with no stigma attached, before they mask and spiral down to poor mental health." (Amy, research participant and mother to Liza diagnosed at 17)

1.1: Setting the context

Whilst there is growing awareness that autism can present differently in girls they continue to be identified, referred, and diagnosed later than their male counterparts. This additional delay in diagnosis, in an often already protracted wait, means that the parents of girls are left in a position of 'not knowing' even longer as they wait for their daughters to be assessed. Once a diagnosis is received, lack of awareness about autism and girls can lead to a continued battle for appropriate information, support, and advice. Previous studies have explored parental experience of autism diagnosis and waiting times, and there is a growing body of research about the experience of mothering a daughter with an autism diagnosis. However, little is known about the experienced affordances and constraints of the diagnosis for the mothers of autistic girls.

To receive a medical diagnosis of autism, a condition first defined by Leo Kanner in 1943, an individual is currently (in the year 2021) required to meet a set of criteria as defined in DSM-V (American Psychiatric Association, 2013) and ICD-10 (American Medical Association 2004). Language is impairment based and the following needs to be observed for a diagnosis to be made: persistent deficits across three areas of social communication and interaction including reciprocity, non-verbal communication and developing and maintaining relationship, and two of four types of restrictive behaviours, including stereotyped behaviours, insistence on sameness, fixated/unusual interests and hyper or hyperactivity to sensory input. Current estimates are that between 1 and 2 % of the Western population are autistic (Russell 2012, Baio et al 2014, CDC 2020, NAS 2021). However, calculating global prevalence is hard due to significant variations, different cultural normalcies and differing scientific approaches (Hughes 2011). Hughes (2011) explains that "most experts agree that methodological and cultural factors explain the bulk of difference in autism prevalence around the world, but they don't rule out the possibility of genetic differences amongst populations" (pg.3). As well as

impacting on prevalence figures these variations will influence the numbers of people seeking a diagnosis, either for themselves or for their child, which in turn will inform service delivery, demand and waiting times.

Research into diagnosis in the Western world, as well as my own clinical experience, has highlighted long waiting times and diagnostic delays (Smith-Young et al 2020, Jacobs et al 2019, Legg and Tickle 2019, Potter 2016, Crane et al 2018 & 2015, Siklos and Kerns 2007) and parents have been described as "isolated and helpless" (Weale 2020) as they wait to have an autism diagnosis confirmed or denied for their child. Once a diagnosis is given, parents have reported dissatisfaction in the diagnostic process (Legg and Tickle 2019, Crane et al 2018) as well as inadequate diagnostic support (Crane et al 2018). It has also been suggested that more work could be done to prepare parents for the "likely reactions" to their child's diagnosis (Legg and Tickle, 2020, pg. 1907) which includes a range of mixed emotions including relief, shock and despair (Smith-Young 2020, Legg and Tickle 2019).

There is a growing body of research that is exploring how autism is different for girls and what further impact this may have on identification and diagnosis (Attwood 2007, Lai et al 2011, Riley-Hall 2012, Krieser and White 2013, Goldman 2013, Baldwin and Costley 2015, Szalavitz 2016, Mandavilli 2015). As well as longer delays in identification, referral and subsequent diagnosis (Navot et al 2017), once identified there can still be scepticism (Anderson et al 2020, Navot et al 2017) and disbelief (Anderson et al 2020) from professionals, with mothers experiencing blame for their daughter's difficulties, and having their ability to parent brought into question.

Whilst referrals for males and females are on the rise and our understanding of autism changes, the legitimacy of autism as a defined condition has been questioned. It is argued that there is "no single underlying condition" (Hassall 2016, pg. 49) and that there is no point attaching a diagnostic label to something when "the cause is not known, it doesn't predict outcome and there is no cure" (Latif 2016, pg. 294). Suggesting that even when the, often long and protracted, wait for an assessment is over, an autism diagnosis may not bring all that was hoped for.

So, after the wait, what does it mean when a diagnosis of autism is given? What informs and influences those meanings and how does this impact on lived experience? If the diagnosis brings affordances to those who receive it, such as an informed understanding of a child or individuals needs or abilities, and if this makes their life better, one could argue that a unified agreement about cause, outcome or cure is not necessary. If the meaning of the diagnosis is

in its use, and if that use makes lives better, then surely the diagnosis itself is useful and meaningful. However, confusion about what autism is, how it is caused and what, if any, cure, or treatments are effective can hold risks. It has been suggested that as well as growing as a diagnostic category autism has become a commodity that is "produced, exchanged, traded and consumed" (Mallett and Runswick-Cole 2016, pg. 110) but that like many consumer products its promise is never fulfilled leaving parents "high and dry" (Mallett and Runswick-Cole 2016, pg. 126). This can lead to some parents pursuing a 'cure' for their child which leaves them vulnerable to exploitation from practitioners (medical and non-medical) who claim they can cure their child. Cures suggested have included the use of chlorine dioxide (bleach) (Shukman 2020), electric shocks (Pilkington 2011) and Applied Behaviour Analysis, a treatment which has been reported to result in some autistic children experiencing post-traumatic stress disorder (Kupferstein 2018). Whilst as clinicians, practitioners and researchers, we may not be able to give parents a unified description and understanding of what autism is or isn't, it is still vital that we are able to inform them of their child's diagnosis in a way that is supportive, meaningful and useful, and most importantly does not do harm, for both them and for their child.

1.2: Research question and aims

Whilst research has indicated that autism can present differently in girls, and that parents and carers of girls may have to wait longer for diagnosis (Wayman 2020, Fowler and O'Connor 2020, Navot et al 2017, Hiller, Young and Weber 2014), there is limited research into how mothers experience the diagnosis, and diagnostic process for their daughters and of what benefit, if any, the diagnosis itself can bring.

I believe it is important to know this, because with increased referrals, long waiting lists, and diagnostic delays this understanding is vital if we, as clinicians and service providers, are to adapt and improve services to provide adequate information, support, and advice pre and post assessment. What benefits, identified as a consequence of diagnosis, can be given before or without a diagnosis being made, and what challenges and disappointments can be avoided once a diagnosis is given. If we can answer these questions we, as clinicians, practitioners or researchers, can adapt and provide support so that mothers can understand their daughters specific needs, strengths and challenges, with or without a diagnosis. This will surely have benefits for both the mother and her daughter as well as their relationship including a potential reduction in the pressure to conform with parenting or behavioural 'norms' and expectations. It will also reduce the possibility of all hopes being pinned on the diagnosis itself as being the thing that will make all the difference, a stance which is reported to result in dissatisfaction (Crane et al 2018). Whilst focusing on mothers of girls, it is likely that this will provide information about supporting both mothers and fathers whilst they wait for an autism

assessment for their child. My central aim in conducting this research was to gain a better understanding of this experience to inform clinical practice, policy, and service delivery. I was guided by the following question:

How do mothers of autistic girls perceive and experience the potential affordances and constraints of diagnosis for their daughters?

The aim of this question was to get a better understanding about the perceptions first held about autism by mothers, prior to their daughter's diagnosis. What did they hope or fear the diagnosis might bring, and what informed these hopes and fears? Once given, what difference did the diagnosis make? Did it bring the support they anticipated, or did it fail to live up to their expectations? Importantly, did the diagnosis change their relationship with their daughters and what advice would they give to other mothers at the start of the diagnostic journey for their child?

My research focuses on the experience of one group of mothers and should not be interpreted to represent all mothers of all autistic girls. However, there are themes and experiences which can usefully inform practice, service design, and policy and which highlight potential areas for future research. By clarifying that I am researching mothers as opposed to 'parents' I am hoping to be clear that I am not representing the experiences of fathers, which may differ due to different societal roles and stories about fatherhood and the 'responses to' and 'expectations of' fathers. Cheuk and Lashewicz suggest that reviews of parent involvement in studies of autistic children highlight the "conflation of mother and father views that can occur when views are combined as 'parent' views without distinction and analysis by gender" (2015 pg. 351). For the purpose of this study I am focusing on the experience of mothers due to my own clinical experience and how I have perceived mothers of autistic girls to be labelled as over anxious or exaggerating their daughter's challenges, and due to a historical portrayal of mothers as 'causing' their child's autism. However, I am interested in the unique experiences of fathers, and I feel that there is potential to repeat my study, with the focus being on father's experience of parenting either sons or daughters who have a diagnosis of autism.

One of my aims as a researcher is to challenge ableist narratives (Mueller 2020) and to consider the impact of the language I use, as advised by Bottema-Beutel (2020). I also aim to give the mothers who participated in the study a voice, and a platform for their stories to be heard. My intention is to gain, and promote, a better understanding about the lived experience of the mothers of autistic girls. What is the impact of the diagnosis on their understanding of, and relationship with their daughters, and/or their identity as a mother, and what are the affordances and constraints that this brings? This aligns with some of the aspects of research the autistic community are reported to want to see, as highlighted by Clark and Adams (2020),

and Pellicano et al (2014). Taking the advice of Gillespie-Lynch et al (2017 and Clark and Adams (2020) I discussed this aim with autistic adults, including the mother I interviewed in my pilot interview. I discussed the aims with the mothers within the study, as well as with professionals working with autistic children and their families. Once I had completed the interviews and analysed the data, I shared a research summary with the mothers to gain their views on the themes generated in the study. This summary included my observations and potential implications for practice. In particular I asked if the research represented their views, if there was anything they disagreed with, if anything surprised them, and what they felt the most important message from the research is. The feedback I have had is that the research outcomes and themes do represent their views, and that they feel it has an important role in getting their voices heard.

I believe this study will inform a number of significant practice implications and considerations across a range of contexts including policy and strategy, commissioning services, diagnostic services and therapy/clinical practice. Of particular importance for all contexts is an understanding of the impact of how autism is 'talked about' (stories told) by and within services and society, and how mothers are 'talked with' or 'talked to'' about autism. This includes how mothers are talked to, and listened to, if and when they first raise concerns to professionals that their daughters are struggling, or different to their peers in some way. This is important because how autism is talked 'about' and the stories told about autism, influence how the diagnosis of autism and/or being autistic, or being the parent of an autistic child, is experienced and ultimately lived with (stories lived). A greater understanding of the experience of these mothers will also help inform pre and post diagnostic support. With long waiting times this includes pre-assessment support that can help mothers (or fathers) to get a better understanding of the specific needs of their daughters before a diagnosis is given, as well as preparing them proactively for the highs, lows and challenges that they might experience once a diagnosis is given.

2. My own 'lived and told' autism story

2.1: A journey

I would like to start with an explanation of my own 'lived and told' autism story. I am doing this as I want to invite you to understand my own relationship with autism and my chosen area of research both personally and professionally. This gives context for my choice of study, in which I could be a participant as well as a researcher and am also a clinician and a service provider. This connection with the study has meant that I have had to be mindful of how my own experiences, personal and professional, have shaped and formed my actions as researcher including the collection and interpretation of data. To do this I will share with you both my personal and professional experience as a clinician, as a service provider and as a mother to two autistic children.

When I started work in Child and Adolescent Services (CAMHS) in the UK over 20 years ago, autism was rarely considered or discussed. For me as a practitioner there was a sense of 'otherness' about it. 'Other' people worked with autism, 'other' people had autistic children, 'other' people needed to know about it. 'Autism' touched the lives of 'other' people. I had previously had some contact with autistic adults when I worked voluntarily with a charity when I was 18, taking art and drama into care homes and day centres, but these were people who also had significant learning difficulties and needed high levels of care. Two of the people there stick in my mind. The first was a young woman in her early twenties who had no speech. She would paint lines and lines of colour whilst rocking back and forth. There was no eye contact and no verbal exchange, but we would sit together, and I would offer different colour paints for her to use as she repetitively marked the page. We would somehow connect but remain disconnected at the same time. The second, a large man in his late twenties took me by the arm and led me to a bathroom. He anxiously made noises at me, but I did not know why. His hand tightened on my arm and I could not get away and I was becoming increasingly scared. Eventually, after what felt like an eternity but was probably only a few short moments, a member of staff came and led him away explaining I shouldn't worry, he had just wanted me to give him a bath.

This for some time would be my understanding of autism. People seemingly locked into their bodies, unable or unwilling to communicate or interact with the outside world. People with learning disabilities in care homes, people who could not care for themselves. This was in the late 1980's and the film 'Rainman' had just been released to the cinema bringing autism into the public domain. In this film, Dustin Hoffman played a young man who was hidden out of sight in an institution without the knowledge of his own brother, and only 'discovered' after

their father's death and the reading of his will. Like Dustin Hoffman's character, autism was separated, out of sight and the thing of institutions.

In 2004, now a qualified family therapist, I applied for a split post between a generic CAMHS team and a Neurodevelopmental Team that provided assessment and therapy for children and young people with ADHD (Attention Deficit Hyperactivity Disorder) or Autism. I worked hard to avoid too much involvement in assessment, seeing my Family Therapy role to be more about supporting families with their relationships and communication with each other. Diagnosis as an activity did not sit comfortably with me as I positioned myself as a 'social constructionist', drawing my attention more to the meanings that were created in conversation rather than focusing on the diagnosing and labelling of 'conditions'. I resisted training in specific diagnostic techniques and left this to other colleagues.

Whilst I was resisting the act of diagnosing young people my awareness of autism as a diagnosis or description of behaviours was changing. I began to consider other young people and adults that I had previously worked with, who did not have an autism diagnosis but whose behaviour might have been seen to fit that description. The girl who was obsessed with buses and had put herself at risk of being groomed by travelling for hours on the North London bus route, the women who had been given the label of 'Personality Disordered' and avoided eye contact and rarely talked, and the little boy who had taken so much to the idea of 'sneaky poo' (White 1988) in narrative therapy that he had seemingly absolved himself of all blame and passed all responsibility onto 'Sneaky'. 'Autism' was no longer a term limited to the description of people who did not talk, or interact, or who needed constant care. Autism could also mean children in mainstream school who struggled with the interactions of daily life. It did at that time however, in my diagnostic experience, still mean younger children whose difficulties or 'differences' were apparent to most that met them, and the referrals we received were largely that of boys.

In 2006, I became a mother to my first child and daughter. I was fortunate enough to get a Family Therapy post close to home and did not return to the Neurodevelopmental Team after maternity leave. Whilst autism had become more visible to me it now began to shift out of my focus.

Autism came back into my view in 2012 when the CAMHS Team I work in was restructured. We no longer had generic CAMHS teams and 'pathways' were set up aimed at specific presentations or diagnoses. This included an Anxiety and Depression Pathway, an ADHD Team, an Autism Assessment Team and local specialist CAMHS Teams for the most complex cases. After a stressful period of interviews and redeployment, my post became split between the Autism Diagnostic Team and the Specialist CAMHS Team. It was here my understanding

and awareness of autism and young people changed considerably, both personally and professionally. As a clinician in a diagnostic team, I could no longer resist the act of assessment and diagnosis. I trained in The Autism Diagnostic Observation Schedule (ADOS) (Lord et al 2000), an assessment tool used with individuals to highlight autistic behaviours and communication, and I learnt to take autism specific developmental histories. As my awareness and knowledge about autism grew, it also became apparent to me that a significant percentage of the young people we saw in the specialist CAMHS team, who presented with self-harm, suicidal ideation and severe risk taking behaviours, could be, or had been, given a diagnosis of 'autism'.

Perhaps the most significant change in my knowledge about this 'thing called autism', was the growing awareness that I was observing, so called, 'autistic behaviours' with my children at home. This led to the assessment and diagnosis of autism, and later of ADHD, for my daughter and then my son. Autism was no longer something 'other' people worked with or that 'other' people's children had, or that 'other' people needed to know about. 'Autism' now touched my life at work and my family's life at home. When the post for Clinical Lead for the Autism Team became available in 2014, I took it. A position I would never have considered two years before as I would have seen it as a job for 'other people'. I stayed working with the Autism Assessment Team until 2019. I was then appointed as the Clinical Director for our local Children, young people and family's services (CYPF), including an all age eating disorder service. The Directorate includes a wide range of children's health and mental health services, including (but not limited to) services such as Health Visiting, School Nursing, Community Nursing, an Adolescent Inpatient Unit, CAMHS services and a School Age Immunisation team. The Directorate also includes the Neurodiversity Team, part of which is my previous service, the Autism Assessment Team.

The Autism Assessment Team is commissioned as an assessment only team, but I believe we have a responsibility to support those waiting for an assessment, as well as a responsibility to inform support and how it can be accessed after an assessment. When I started my post in the assessment team, I met with a number of local agencies, service user groups and voluntary services that work with autistic children, young people and their families. Following on from these meetings we developed a strong relationship which included a number of joint projects and 'working together' groups where we met to discuss how we could work collaboratively to improve the experience of children, young people, and families that accessed all of our services. I also worked closely with commissioners to highlight gaps in provision.

Researchers have highlighted dissatisfaction with all stages of the assessment process, including delayed referrals, long waiting times, the assessment process and post diagnostic support (Smith-Young et al 2020, Lamb 2018, Crane et al 2015). This has been evident within my own professional experience, due to complaints received about waiting times, and subsequent comments about the lack of post-diagnosis support. As a consequence, I have been increasingly interested in what people believed would change if a diagnosis was given, especially as a lot of the supports and strategies that might help should be available with or without a diagnosis. Did the reality of diagnosis fit with what parents and carers believed would happen after a diagnosis was made? If it did not fit with their beliefs what was missing or lacking? Did it make a positive improvement in their lives and the lives of their child? Did it have any negative impacts? Essentially after a long wait to be seen, did diagnosis really deliver? Whilst my research is focused on mothers and the diagnosing of girls, it is my hope that exploring some of these questions can inform services to effectively support and advise parents and carers at all stages of the diagnostic process.

2.2: My work context and the Autism Assessment Team.

I have had a number of career or job title changes since starting my doctorate in 2016, most significantly the change from the CYPF Neurodevelopmental Lead to the CYPF and BEDS (Children Young People and Families and Berkshire All Age Eating Disorder Service) Clinical Director and Principial Systemic Psychotherapist in 2019. Due to the demands of the Coronavirus pandemic, I became full time Clinical Director in 2020. As I write this in 2021, things are set to change again and alongside my Clinical Director role I will also be the Trust Neurodiversity Lead, tasked with developing and implementing a Neurodiversity Strategy across Berkshire Healthcare. This strategy will include all services, adult, child, physical and mental health, patients, their families, and the workforce. Whilst admittedly nervous about the responsibility I am incredibly excited about the opportunity and the potential to change service provision, suitability, and accessibility for our neurodiverse population. My hope is that the strategy will also promote a cultural shift about how we think and talk about neurodiversity within our trust.

Whilst my role has changed, the Autism Assessment Team still sits within my directorate and there continues to be significant focus on diagnostic autism services, both locally and nationally. In Berkshire the Autism Team consists of psychologists, speech and language therapists, assistant psychologists, specialty doctors and consultant paediatricians. Assessments are provided for children and young people from the ages of about 2 ½ up to 18. A similar team sits within the adult part of Berkshire healthcare, tasked with assessment

and diagnosis of adults, many of whom are referred via the community mental health services alongside referrals from GP's.

Children and young people are assessed by two clinicians, one will meet with the young person to complete an ADOS (Autism Diagnostic Observation Schedule) assessment (Lord et al 2000) and the other will meet with the parents to take a detailed family history. Information is also gathered from the young person's school. Information gathered is considered using either DSM-V (American Psychiatric Association 2013) or ICD-10 (American Medical Association 2004) (soon to be ICD-11).

There is an increasing number of children who receive a dual diagnosis for both autism and ADHD and one of the things achieved when I was in the post as Neurodevelopmental Lead, was the development of a combined assessment model for both Autism and ADHD. This would not have been possible before 2013, because in DSM-IV a diagnosis of Autism and ADHD together was not possible, with the diagnosis of one immediately excluding the possibility of a diagnosis of the other. This changed in DSM-V and now an individual can have a diagnosis of both autism and ADHD at the same time.

The CYPF Autism Assessment Team was established in 2012 following a service redesign. Prior to this there was a small, specialist, Social Communication Team (SoCom) who completed complex autism assessments and offered support and intervention to young people and their families. Less complex Autism assessments would be completed by Consultant Psychiatrists in the CAMHS Teams, but they were few and far between. In the year 2012-2013 referrals to the autism assessment team quickly exceeded the number of referrals that had been predicted. In the years that followed referrals to the team more than doubled with an average yearly referral rate of 1200+ children and young people. When I took my role as clinical lead for the autism team waiting times were continuously increasing and despite various projects and initiatives, they continued to rise with referral numbers outweighing the capacity for assessments. Average waiting times, as it stands in March 2021, are around 18 months with some children waiting longer due to administration or screening delays.

The team work hard to provide the best service they can despite growing demand. Leaflets are provided to parents and carers about support available prior to an assessment, and local charities have been commissioned to provide pre-assessment support groups. There is a helpline for parents to call for advice whilst their child is on the waiting list and there is an on-line support service, SHaRON (Support, Hope and Resources ON line), which enables parents to post questions, stay in touch and get support with or without a diagnosis for their child. Leaflets have also been produced for children, young people and parents post diagnosis to advise and inform them about autism in a way that is positive and supportive. The team have

worked closely with local agencies and professionals and have facilitated conferences or workshops to increase awareness and to facilitate signposting for ongoing support. In 2019 the team also worked collaboratively with commissioners to provide additional assessment opportunities via an on-line assessment provider. In the assessments, two clinicians meet with parents and/or carers and the child/young person over a face to face internet connection. Assessments include a detailed developmental history and an individual assessment informed by ADOS (Lord et al 2000) and comply with NICE guidelines. The benefit of the assessments is that the clinicians can be recruited from any part of the country, assessments are not restricted to when clinic space is available and 'appointments' can also be in evenings and weekends. Whilst the approach is not suitable for all children and young people, for example when there are specific language difficulties or risk issues, this does enable us to offer more assessments and reduce waiting times. In 2021, in part due to the impact of the Coronavirus Pandemic, the service also developed their own version of the on-line assessments which has increased capacity and recruitment possibilities further.

On the 18th of July 2018, when I was still in post as the CYPF Neurodevelopmental Lead, The Guardian published a news article about autism waiting times commissioned by the National Autistic Society (Campbell 2018). The article referred to 'scandalous waiting times' with the National Autistic Society referring to a 'postcode lottery' being exposed. Information for the report had been gained via the Freedom of Information act and a request for waiting time data from services across the country. Only 7 localities gave complete data, one of which was our own. There was no contextual information about referral numbers, service size, how contacts were recorded or what support was provided about assessment and diagnosis. The result was a report that our service had the longest waits in the country and I was contacted via the social media platform 'Twitter' to be asked "*what are you going to do about it Mairi?"*

The article was in response to the UK's National Autistic Society (NAS) campaign 'Autism Diagnosis Crisis' which was launched in 2015. In a NAS blog Crane and Hill (2017) explained that the National Autistic Society had posed the question 'Why the wait?' with the aim "to highlight the lengthy waiting times for autism diagnosis in the UK, with the goal of changing things for the better". On the 13th September 2017, and instigated by the National Autistic Society's diagnosis crisis campaign, waiting times for autism assessments were discussed in Parliament. The outcome was the Government backing a plan to record and publish waiting times for autism diagnosis and to hold local service providers accountable if the three-month standard waiting time recommended by NICE (National Institute for Clinical Excellence – guidelines first published in 2014) are not met (NAS 2021). This is against a backdrop of local services having to make cost improvement plans due to a reduction in funding from the Government.

In a 2015 study regarding parents experience of autism diagnosis in the UK, Crane and Hill reported “a delay of around 3.5 years from the point at which parents first approached a health professional with their concerns to the confirmation of an autism spectrum disorder diagnosis” (pg. 153). In Lamb’s 2018 article, Berkshire was reported to have waiting times of up to 2.1 years. Whilst this showed improvement from Crane’s in 2015 research, and Crane and Hill’s subsequent NAS blog in 2017, the report resulted in media articles and local radio interviews about long waiting times in Berkshire.

The Lamb article and Campbell’s article spoke about the importance of diagnosis in helping someone understand themselves or their child and their needs. It also reported that a delay in diagnosis meant a delay in all support stating that “long waits are traumatic (..) pushing people into anxiety and depression” with “families desperate for help and breaking down under the strain” (Campbell 2018). I felt the implication was that nothing could help prior to a diagnosis being made, and that once it was made ‘everything would be better’ with all necessary support readily available. An implication that I felt was unhelpful and unethical.

In response to the Lamb’s report, Crane and Hill’s blog, and Campbell’s article, I contacted the National Autistic Society to talk about the implications of setting expectations about what a diagnosis will bring too high. I highlighted that diagnosis is only part of the journey and spoke about the pre-and-post assessment support that is offered by our teams. The result was an agreement that I would write a blog as part of the National Autistic Society’s campaign about waiting times, but also to talk about the support that can be available in all aspects of the assessment process. The blog was published in October 2018 (appendix 1).

Current NHS structure (as of the time of writing in March 2021) is such that the Government gives money via NHS England, who give money to local Commissioning Groups (CCG’s), who then give money to providers. These providers include local health services, in our case Berkshire Healthcare Foundation Trust. The money is given under contract for example X amount of money for X amount of autism assessments. In Berkshire the team have been continuously reviewing and adapting how they can increase assessments, streamline admin processes and maintain clinical quality, but waiting lists remain. Ongoing mapping work has highlighted that due to the increasing demand for autism assessments and the relatively small size of the autism assessment team, there would need to be substantial investment, and recruitment, to reduce waiting times to below 12 months. This money, once spent on diagnosis, cannot be spent elsewhere in the NHS. Whilst I am an advocate of autism diagnosis as I have seen the positive impact it can have, especially for young people who felt different and did not know why, I also see other demands for the money. In CYPF and BEDS, whilst

the Autism Assessment Team are seen as the specialist autism team, all our services do in fact support autistic children, young people and adults. Autistic people are over-represented in Eating disorder services (Dattaro 2020) and CAMHS due to higher rates of depression and anxiety and self-harm. Autistic young people also access our speech and language service, our occupational therapy service and our dietetic service. Over the Coronavirus pandemic we have seen an increase in the complexity of referrals to the CAMHS service due to extreme levels of distress. A large percentage of these referrals are for autistic young people, including referrals for ARFID (Avoidant Restrictive Food Intake Disorder) (Waite 2020). Whilst demands on services grow, the increase in funding is limited at best, but in most cases depleted. If money from the limited pot is all directed to reducing waiting times for autism assessments, what is the impact, often on the same young people, if waiting times for CAMHS, Eating Disorder Services or Speech and Language therapy increase as a result?

Whilst a diagnosis may help a parent have a better understanding of their child it will not 'cure' or remove their autism. A lot of the support and advice suggested prior to an assessment will also be what is suggested after a diagnosis is made, and a lot of the challenges experienced pre-diagnosis will remain once the diagnosis is made. I have seen first-hand the benefits of autism diagnosis for individuals and their families and I do agree that reducing the wait for assessment is important. However, I also believe it is important to understand more about how we can improve the journey through all stages of the referral and assessment process so that help, and support are not dependant on the diagnosis itself. To do this I believe it is important to understand what the affordances of the diagnosis are and if these can, at least in part, be achieved regardless of diagnosis.

3. Literature review

3.1: Explanation of how information was sourced

In order to critically review literature and articles regarding autism and autism diagnosis I have used a number of sources. As a member of the NHS I have access to an Athens account which can complete an extensive literature search of a number of journals and articles. I gave search information to the NHS librarian who conducted a search for me with the search items of autism diagnosis, autism assessment, parental experience or diagnosis, mothers, girls, and autism. I was also registered and shown how to repeat the search on NHS Athens, which is updated regularly with NICE guidelines, research and e-books. I have used Mendeley, NCBI – PubMed, ResearchGate and Academia for a literature review and signed up for alerts regarding new articles. I have used Google and Amazon to search for articles and books, including magazine and online newspaper articles. I have subscribed to the SAGE Journal 'Autism' which has up to date autism research and articles and also subscribe to the Journal of Family Therapy and Context magazine. I have joined Autistica and have used Twitter and Facebook to follow and link in with current researchers and articles shared by autistic adults and advocates. Additionally, my mum regularly sends me cuttings of newspaper articles!

3.2: Autism Research – Moving from 'aboutness' to 'withness'.

On social media platforms, such as Twitter, many autistic people have highlighted their concerns that autism research has not focused on the actual needs of autistic people, and that it has been more about the needs of the researchers. It is important to me that my research is useful and that it will give something to the lives of the people I am researching, including an enriched understanding of their lived experience.

There are numerous journals dedicated to Autism research, such as the Sage Journal 'Autism' as well as research bodies including the 'National Alliance for Autism Research' (NAAR) in America and 'Autistica', a UK charity which campaigns for ethical autism research that improves the lives of autistic people and their families. In 2011, Pellicano and Stears reported a "sharp increase in the level of funding available for autism research" (pg. 272) in both America and the UK. Despite this increase in funding and clear interest in research into autism, it was noted in an editorial by Bolte (2014) that there was a limited number of 'good quality' qualitative studies on autism and that "the number of original studies that use qualitative methods in respected peer-reviewed journals (was) negligible compared to quantitative ones" (pg. 67). Bolte reflected that one of the reasons for this lack of qualitative research was how it was viewed as "bad (or at best, incomplete) science" and that there was a "perhaps a perceived lack of need". He promoted qualitative research as a means to "ask the right

questions, (and) derive hypotheses", in order to "enable a deeper understanding of certain processes in humans" and to "give important information to teachers and service providers" and "perhaps enhanced societal awareness" (pg. 68).
In addition to a focus on quantitative research, Pellicano and Stears (2011) and Pellicano et al (2014) highlighted that a large percentage of autism research was focused on cause, prevention and/or cure, with a base in the 'new sciences'. This focus has led some to conclude that researchers have prioritised 'conformity' above the wellbeing of autistic people (Mueller 2020) with a view of autism as "something bad which should be fixed" (Bottema-Beutel et al, 2020, pg. 1)) and with autistic people studied as if they are 'mice, not as equal communication partners' (Mueller, 2020, pg. 98).

The way in which such research informs societal narratives about autism can have wide ranging consequences, with potential negative effects for how autistic people are viewed, or even how they view themselves (Bottema-Beutel et al, 2020). Mueller (2020) suggested that the majority of autism research roots itself within science "merely to discover what is there" and that it has been shaped and limited by scientific traditions, due to "a specific (normative) way of looking at people" and "a specific (neurotypical) way of interpreting their behaviour"' (pg. 95). He adds that "under the normative paradigm, neurological differences could hardly be described as other than pathological deviations from the norm" (pg. 96). In a study of perceptions about autism held by both autistic people and their families Gillespie-Lynch et al (2017) found that campaigns about "normalising and curing autistic people", "contribute to stigma toward autism in both autistic and non-autistic people" (Pg.11). Pellicano and Stears (2011) debated the ethics of research that focuses on 'early intervention' due to the potential that it could lead to parents consider aborting their unborn child, and to 'therefore eliminate autism' (pg. 274). A similar view is taken by Mueller (2020), who believes the reason that the main body of autism research is focused on children is not because they have a greater need for support than autistic adults, but because they have "more potential for normalisation, especially younger children" (pg. 101). With successful treatment being measured, not against the wellbeing of participants, but the reduction of abnormal behaviours (Mueller 2020).

The question of ethics in autism research was brought firmly into the public domain in 1998 when Wakefield et al published research that implied a direct link between Autism and the mumps, measles and rubella vaccine (MMR). The impact of this study led to widespread fear that the vaccine could 'cause' autism and in the UK the take up of the vaccine dropped to an all-time low of 80% in 2003-2004 (Godlee et al 2011, Harrison 2013). Harrison reports that what followed in 2008 was measles being declared "endemic in England and Wales" for the first time in 14 years and that "hundreds and thousands of children in the UK are currently

unprotected as a result of the scare, and the battle to restore parents' trust in the vaccine is ongoing" (pg. 2). Not only did Wakefield's research have widespread impact, investigative reporter Brian Deer (2011) also discovered that many of the claims made by Wakefield were falsified. The response by Wakefield was to write a book 'Callous Disregard: Autism and Vaccines – The Truth Behind a Tragedy' in which Harrison reports he describes "a political attempt to silence his criticism of vaccine safety" (Harrison, 2013, pg. 9). What remains despite Wakefield losing his medical licence, and many articles discrediting his research, is a level of suspicion that there could be a link between autism and the MMR which includes some professionals as well as parents beyond the UK. For example, in 2006 Leask et al found that 12 % of doctors and nurses who provided vaccinations in New South Wales "believed that there was an association between MMR and autism, with a further 29% being unsure" (Leask et al, 2010, pg. 6).

In a review of the landscape of autism research, Pellicano et al (2014) asked the question "What is the current focus of autism research? And is it commensurate with the needs and priorities of the autism communities it serves?" They found that in America the Interagency Autism Coordinating Committee (IACC) reported that in 2008 "the largest portion of funding was targeted towards identifying risk factors for autism (37%), with 24% devoted to treatments and interventions, 18% on the underlying biology and 18% on diagnosis. Research on lifespan issues and services were the least well-funded research areas (5% and 1% respectively)". The distribution of funding changed in 2010 which they state is due to "better reporting of autism-related funding projects and the influx of funds from the American Recovery and Reinvestment Act (ARRA) which allowed additional funding to be applied to the perceived gaps in autism research" (Pellicano et al, 2014, pg. 757).

At the time of their review, Pellicano et al (2014) found that focus remained on "projects in the areas of biology, brain and cognition' and that 'comparatively little research in the UK during this period was targeted towards identifying effective services for autistic people and their families (5% of funding), on diagnosis (5%), and interventions (18%), or societal issues (1%)" (pg. 758). In conversations with autistic adults, parents and practitioners, Pellicano et al (2014), and Clark and Adams (2020), found that what autistic people, parents and practitioners wanted to see was research about things which are impacting on them in the here and now, and that people "wanted to see real change and real things happening for themselves, their families and the people they work with" (Pellicano et al, 2014, pg. 760). In a study focusing on the views of parents in Australia, Clark and Adams (2020) found that what they wanted to see was research that looked into child health and wellbeing, socialisation and support, community awareness and understanding of autism, anxiety and the impact of autism

on family relationships, but despite this research into “biological aspects” remained the “most funded” (pg. 11).

Mueller (2020), warns that without talking with autistic people research becomes a “monologue by neurotypicalism on autism” (pg. 98). For research to be more in tune with what is actually wanted by the autistic community, Gillespie-Lynch et al stress that researchers need to “identify how autistic people think about autism” as a “first step toward developing research that is relevant to their interests and the needs of the community whom the research is intended to serve” (2017 pg. 11).

With an increase in qualitative research and in autistic researchers, there is evidence that researchers are recognising the “importance of engaging members of the autism community” (Clark and Adams, 2020, pg. 1), and there is a growth in research articles focused on improving the lives of autistic people and their families rather than preventing, curing or controlling them. This can be seen in the inclusion of qualitative research articles about lived experience in the Sage Autism journal, such as Crompton et al (2020), *‘I never realised everybody felt as happy as I do when I am around autistic people: A thematic analysis of autistic adults relationships with autistic and neurotypical friends and family’* and Mosely et al (2020) *‘When my autism broke: A qualitative study spotlighting autistic voices on menopause’.*

In addition to what is studied and how, who we choose to study, and the language we use to describe the participants and findings of those studies, has consequences and will inform societal narratives about autism. Bottema-Beutel et al (2020) encourage researchers to consider their choice of language when describing and reporting on their research due to the risk of perpetuating “ableist ideologies”. They advise against terms such as “special interests”, “at risk of autism” and “economic burden” due to the negative way in which they can be experienced by autistic people, instead recommending “focused interests”, “increased likelihood of autism” and “discourses that centre on the impacts of social arrangements of autistic people” (pg. 2). They suggest 7 questions that all researchers should ask themselves to consider the impact of their language when designing, planning, and reporting on their study:

> *“1. Would I use this language if I were in a conversation with an autistic person?*
> *2. Does my language suggest that autistic people are inherently inferior to nonautistic people, or assert that they lack something fundamental to being human?*
> *3. Does my language suggest that autism is something to be fixed, cured, controlled, or avoided?*
> *4. Does my language unnecessarily medicalize autism when describing educational supports?*

5. Does my language suggest to lay people that the goal of my research is behavioural control and normalization, rather than granting as much autonomy and agency to autistic people as reasonably possible?

6. Am I using particular words or phrases solely because it is a tradition in my field, even though autistic people have expressed that such language can be stigmatizing?

7. Does my language unnecessarily "other" autistic people, by suggesting that characteristics of autism bear no relationships to characteristics of non-autistic people?" (pg. 8)

As well as considering language, I believe researchers also need to be transparent and clear about those included in their studies and those not included. If 'parent' means mother, 'autistic children' means boys and research focuses on children, there is a risk of generalisation of experience across all of the autistic community, or a reinforced narrative about autism being something connected to male children. This is highlighted by Lai et al (2015) who propose that an underrepresentation of females in research and clinical practice may have contributed to a "male-biased understanding of autism" (pg. 1). The impact of the male bias in research is also thought to influence the level of diagnosis as it informs "our understanding of the expression of core deficits" as well as the "suspect validity of assessment instruments", and "gender insensitive diagnostic criteria'"(Kreiser & White, 2013, pg. 68).

This gender bias could also be said of research exploring parental experience of their child's diagnosis, because an under-representation of females in research will mean an underrepresentation of daughters. This means that the majority of studies about parental experience of diagnosis are actually informing us about the parental experience of the diagnosis of autistic boys. Conversely the one area where it appears that males are underrepresented in autism research is in studies into parental experience, as "research focus on parenting children with autism spectrum disorder continues to be skewed towards experiences of mothers" (Cheuk and Lashewicz, 2015 pg. 343), with fathers "underrepresented in both early intervention and research" (Flippin and Crais 2011 pg. 24).

3.3: **Historical and Current Conceptualisations of Autism and Autism Diagnosis**

According to DSM-V autism is a disorder characterised by 'persistent deficits in social communication and social interaction across multiple contexts' as well as 'restricted, repetitive patterns of behaviour, interests, or activities'. In the 1960's autism diagnosis remained rare with about 1 in 10,000 children being diagnosed (Russell 2012). The National Autistic Society Website (last accessed 14/05/2021) reports that this figure has now risen to more than 1 in 100 children, with a UK parliamentary report (2020) stating a figure of about 1.4% worldwide. In a 2019/2020 school census in Northern Ireland, prevalence of autism with school age children was reported to be as high as 1 in 25 children, and estimates in America rose from 1

in 88 children (Russell 2012) to 1 in 59 children (Baio et al 2014), with the most recent census reporting 1 in 54 children as having a diagnosis of autism (CDC report 2020). Calculating world prevalence is reported as challenging due to 'different cultural normalcies' and there is a question as to whether differences in reported prevalence are due to "methodological and cultural factors" or potential "genetic differences of populations" (Hughes, 2011, pg. 3) or both. A behaviour that may be seen as 'autistic' in one culture, may be considered culturally appropriate within another, e.g. in Korea it is "not socially appropriate" for a child to maintain eye contact with an adult (Hughes, 2011, pg. 3), whereas this is one of the markers for autism in Western diagnostic criteria.

The worldwide growth in autism diagnosis has led to some concern that there is an 'autism epidemic' (Timimi et al 2011). However, in some countries such as Somalia there is no 'autism' and no word for autism. Those who have travelled from Somalia and received a diagnosis for their children are reported to call it 'the western disease' (Decoteau 2017). Decoteau's research highlighted that Somalian refugees considered Autism to be caused by Western chemicals, medicines and vaccines, with a return to Somalia as a potential cure. Is it possible that Somalian people do not have the symptoms that we in the Western world classify as autism, or is it possible that the same 'symptoms or behaviours' are present but given a different meaning?

Autism as a diagnosis is still a relatively new concept. In 1943 Leo Kanner published his paper 'Autistic disturbances of affective contact' in an American Psychiatric Journal 'The Nervous Child'. This was the first time that Autism had been introduced as a stand-alone condition or disorder in children. Prior to this the first medical use for the term autistic had been by Eugen Bleuler in 1910 (Silberman 2016, Timimi et al 2011) in relation to behaviours seen in adults with schizophrenia who would withdraw from their social surroundings. The term was then used to describe similar isolating behaviours in children who were believed at the time to be suffering from childhood schizophrenia. The word autism was derived from the Greek word Auto, which means 'self, one's own, by oneself' (Timimi et al 2011, Chown 2016). Autism refers to an 'isolated self' where a person is 'removed from social interaction'. I believe this definition in itself causes some confusion. My clinical and personal experience of young people and adults who have received an autism diagnosis is that 'autistic' does not necessarily mean 'not sociable'.

In his paper Kanner (1943) shared case studies of 8 children whom he had worked with in his clinic. He claimed that the children presented with a condition that differed "markedly and uniquely from anything reported so far" and noted that further consideration was needed of their "fascinating peculiarities" (pg.217).

Whilst Kanner described autism as a new and unique phenomenon it is suggested that the behaviours that now constitute an autism diagnosis, pre-date Kanner's observations. In the words of Silverman (2013) "after Kanner Autism became visible" (pg. 37). This has led to writers reviewing historical figures and the "retrospective diagnosis" of "the great and the good" (Timimi et al, 2011), and has prompted books such as 'Different Like Me - My Book of Autism Hero's' which suggests the great thinker Albert Einstein and others such as Benjamin Banneker an American astronomer in the 1700's (Elder 2006) were all on the autism spectrum.

In 1981 Lorna Wing, an English Psychiatrist, introduced the work of Hans Asperger an Austrian Paediatrician. Asperger had been studying children with similar behaviours to the children seen by Kanner in the 1930's and 1940's but his work had been hampered by the second world war and had not become widely known. It is now believed that Kanner might have been aware of Asperger's work (Silberman 2016, Robison 2017) as two clinicians that had been working directly with Asperger had come to work with Kanner after escaping the Nazi's in Austria. However, Kanner is not recorded to make reference to Asperger's work meaning that it was 40 years before Asperger's work was shared with a wider audience.

Due to this delay 'Kanner's Autism' was the most widely known description of autism and it was Kanner and Eisenburg who contributed the first formal diagnostic criteria for autism in 1956, focusing on "lack of affective contact and repetitive, ritualistic behaviour, which must be of an elaborate kind" (Timimi et al 2011, page 144).

Kanner's early infantile autism was first added to DSM (the diagnostic and statistical manual of mental disorders) in its third edition in 1980 and the 9th edition of ICD 10 (the international classification of diseases) in 1979. Prior to this, autistic behaviours had only been referred to in relation to schizophrenia and childhood schizophrenia in DSM I and II.

Asperger's was added as a subtype to Autism in DSM IV in 1994 and the triad of impairments in social interaction, social communication and restrictive and repetitive behaviours described by Asperger, was included in the diagnostic guidelines for autism. Asperger's was later removed all together in DSM V in 2013 with all diagnoses fitting under the one description of 'Autism Spectrum Disorders'. Whilst Asperger's remained as a diagnosis in ICD-10 until 2018 it is removed in ICD-II. This has meant that for approximately 20 years a number of the autistic community were given a diagnosis and understanding of themselves that no longer exists in diagnostic terms. This was much to the surprise of a young man at a conference in 2018 when I presented a history of autism labels and diagnosis, as he had been diagnosed with Asperger's and has come to understand himself as having Asperger's.

There are similarities and differences between both Kanner and Asperger's studies. Asperger described in general, a group of children and young people who had either average or above average intelligence with no language delay, whilst Kanner's children were thought to have

some intellectual disabilities as well as social communication difficulties, including a speech and language delay. Asperger's children did not need identifiable difficulties before they were three to receive a diagnosis whilst prior to DSM-V symptoms needed to be present before the age of three for a diagnosis of 'classic Kanner's autism'. Wing (1981) noted that the argument continued as to "whether they were varieties of the same underlying abnormality or are separate entities" (pg. 115) Wing also highlighted that "as with any psychiatric syndrome identifiable only from a pattern of observable behaviour, there are difficulties in determining which are essential for diagnosis" and that variations occurred from "person to person" with it being rare to find all the symptoms observed in one person (Wing, 1981, pg.115).

Whilst Wing brought recognition to Asperger's work in the 1980's, Asperger's ethical background was brought into question in 2018 when research about his practices was published. In 'Asperger's Children' Edith Sheffer (2018) uncovered evidence that Asperger had collaborated with the Nazi's. Once seen as a saviour and protector of autistic children Asperger is now understood to have sent 'untreatable' autistic children to Spiegelgrund as part of the Nazi eugenics program. Yet again the story of autism took another turn as many turned their back on the diagnosis, not due to its removal from DSM-V but due to the controversy surrounding Asperger himself.

The addition of autism into DSM and ICD made the diagnosis available to clinicians, a diagnosis which has steadily continued to rise. Alongside the increase in diagnosis there has been an increase in theories about why. Whilst some believe it is 'brought about' by Western medicine, vaccines and pollutants others believe that the increase in autism is due to the change in the parameters of diagnosis itself (Arvidsson et al 2018, Timimi and McCabe 2016, Runswick-Cole, Mallett and Timimi, 2016, Hassall 2016, Grandin 2014, Timimi et al 2011, Molloy and Vasil 2002,). In a Swedish study of two cohorts of children Arvidsson et al (2018) found that "over time considerably fewer symptoms seemed to be required for a clinical diagnosis of autism, at least for those diagnosed after pre-school years" (pg. 1). Whilst they acknowledged that this did not rule out the possibility that there was an 'actual' rise in the rates of autism they suggested the rise was in part due to 'administrative secular changes' in the diagnostic process. Interestingly Arvidsson et al (2018) and Skuse (2018) have highlighted a reduction in diagnosed intellectual disability and learning disability with "two thirds of newly diagnosed individuals (having) intellectual quotients in the normal range" and the "majority of children with autism in the UK (..) in mainstream classrooms" (Skuse 2018, Spectrum News article). Does this mean we are diagnosing a bigger percentage of children without an additional learning disability, that we have fewer children with learning disabilities or that children once given a learning disability label are now being given an Autism diagnosis instead? This is a question which is highlighted in local (Berkshire) Education, Health and

Care Plans (EHCP's) where there has been an increase in children who have autism listed as their primary need alongside a reduction in children specified as having learning difficulties. One contributary factor may be that certain specialist education provisions and support units require autism to be listed as the primary need on a EHCP in order for a child's application to be considered.

In summary, Autism was first introduced as a diagnostic term by Kanner in 1943 to describe what he then defined as something markedly unique. In the 1960's autism diagnosis remained relatively rare, estimated to 'affect' 1 in 10,000 children. Rates of diagnosis have now increased with NAS reporting 1 in 100 people as having an autism diagnosis, and other reports stating prevalence figures as high as 1 in 59 children in America (Baio et al 2014) and 1 in 25 school age children in Northern Ireland (2019/2020 school census). This has led to some referring to an autism epidemic (Timimi et al 2011). However, calculating global prevalence rates presents a challenge due to different cultural and methodological factors (Hughes 2011). Other factors thought to be influencing diagnostic rates include the changing parameters of the diagnosis itself (Arvidsson et al 2018, Silverman 2012). Social and environmental factors such as increased awareness, changes in service provisions and specific educational provision requirements may also impact on rates of diagnosis, such as the requirement to have an autism diagnosis to access a specialist educational provision.

3.4: **Parental Experience of Diagnosis**

The increase in referral numbers for children and young people to be assessed for autism brings with it an increase in parents and carers navigating the assessment journey on behalf of their child. For some this begins with an awareness that their child may be developing differently from their peers, for others it may begin with concerns being raised by an education or health professional, or even a friend or member of the wider family.

Research into parental experience of autism diagnosis suggests that the stage in which parents and carers first start to have concerns about their child's development varies from 1 to 5 years (Siklos and Kerns 2007, Howlin and Ashgarian 1999, Crane et al 2015) with concerns identified later for children who went on to get an Asperger's diagnosis (Howlin and Ashgarian 1999). Even when concerns are noted, parents may resist seeking a diagnosis due to fear of their child being stigmatised (Russell and Norwich 2012) or wait to have these concerns corroborated by teachers before seeking any form of support or assessment (Braiden, Bothwell and Duffy 2010), with an average wait of 1 year before raising concerns (O'Reilly et al 2017). Once help is sought it has been highlighted that the response of professionals can be a barrier (Makino et al 2021, Lockwood-Estrin 2020) and can contribute

to diagnostic delays due to parents receiving a response that is either passive or reassuring (Wei et al 2018). Parents report a process in which they have to “build a case” that professionals “are then able to ratify or negate”, with professionals seen as gatekeepers and “considerable variation in the extent to which services acknowledge their concerns” (O’Reilly 2017, pg. 69).

Once the journey to diagnosis begins, research and government data has suggested the waiting time for assessment can vary greatly, with parents reporting waiting times of up to 3 years (Lamb 2018, Siklos and Kerns 2007, Crane et al 2015, Howlin and Moore 1997). The most recent data (at the time of writing this paper) was reported by ‘Ambitious about Autism’ a national UK based charity in 2020 after a survey of 3842 UK based parents showed that ‘46% were waiting longer that 18 months’ with some reporting a wait of over 3 years (Weale, 2020). In a scoping review (Makino et al 2021) found that multiple researchers have identified that this wait for the assessment as a persistent concern for parents, with the wait between the initial referral and assessment as ‘especially anxiety provoking’.

Lewis, Skirton and Jones (2010) reported that without a diagnosis parents and carers experienced frustration due to an uncertainty about the future, or what services, treatments and interventions might help their child. whilst many of the parents who responded to the Ambitious about Autism 2020 survey described feeling “isolated and helpless” as they waited to discover if their child was autistic. A number of researchers have reported parent dissatisfaction with the assessment process (Makino et al 2021, Smith-Young et al 2020, Crane et al 2018 & 2015, Jacobs et al 2019, Potter 2016, Siklos and Kerns 2007) with parents who waited the shortest periods of time being the most satisfied.

Diagnosis is seen as a means to ‘acquire certainty’ (Jacobs et al 2019) and access support (Crane et al 2018 & 2015, Russell and Norwich 2012, Lewis, Skirton and Jones 2010, Siklos and Kerns 2007). The suggestion being that not only do parents have a better understanding of their child’s needs after a diagnosis is made, but that a more timely diagnosis can lead to early intervention and better outcomes for autistic children with those left waiting at a risk of “education failure, depression and low self-esteem” (Howlin and Ashgarian 1999, pg. 838). Once a diagnosis is given it can also enable parents “to look for and find each other” as well as enabling them to advocate for their children and “build a case for the reasonable adjustments (they) may need” (Bovell, in Timimi et al 2019).

But is earlier really better, and better for whom? Russell (2016) suggests not, proposing that there could also be negative consequences to early diagnosis, such as “expectancy bias and stigma,” potentially seen in a lowering of expectations described in a study of parents reactions

to diagnosis by Mansell and Morris in 2004, and an offer of early ‘treatment’ and ‘cure’. Russell claims that “several systematic reviews for early intervention have concluded to lack evidence” (pg. 258. 2016).

My own practice experience indicates that caregivers seek early diagnosis in the belief that support is not available without a diagnosis, and that once a diagnosis is given support will become readily available. Support in school, according to the Special educational needs and disability code of practice (2015), should be needs-led rather solely informed by a diagnosis. In my professional experience this is not always found to be the case, and the autism team receive a number of calls from distressed parents and carers who have been told their child will need a diagnosis to access additional help in school. In addition, research and my own personal and professional experience indicates that once a diagnosis has been given, parents, carers and supporting professionals find that the support they believed it would or should bring is still lacking (Makino et al 2021, Weale 2020, Jacobs et al 2019, Ambitious about Autism 2020, Potter 2016, Nealy et al 2012, Braiden et al 2010, Siklos and Kerns 2007, Mansell and Morris 2004).

Prior to the redesign of Berkshire CAMHS in 2012 there was not the huge demand for autism assessments that we face today (in 2021). Children and young people were referred to the generic locality CAMHS team and we would assess behavioural and emotional concerns, offering therapeutic or behavioural support as indicated, or signposting to counselling and family work in the community. There was a small Social Communication team that assessed a few children and offered intensive support for autistic children with behaviour that was described as challenging by those that either taught or cared for them

Following 2012, the initial projection of numbers for referrals to the autism assessment team was quickly exceeded, with current referral figures shown to be more than three times those expected. I feel that part of the reason for this increase, as well as the possibility of increased awareness, is the design of the pathway itself. Children that may once have been assessed and given support for anxiety and routinized behaviours are now directed straight to the autism team waiting list, creating what could be described as ‘diagnosis by pathway’. Parents are encouraged to access information and advice about strategies for supporting their children whilst waiting for an assessment rather than wait for a diagnosis. This can include reading books, joining groups, and using specific parenting strategies. However, some children or young people will not go on to receive a diagnosis. The strategies themselves will do no harm and will benefit the child, even if they do not go on to receive a diagnosis of autism. With this in mind it could be argued that it makes no sense to delay that which could be helpful. However what does this mean for a parent who, through the introduction autism as a possible diagnosis,

has come to understand their child as autistic and has already begun to identify as the parent/carer of an autistic child?

The autism assessment pathway is not unique to Berkshire and a number of other CAMHS teams across the UK have developed assessment pathways, with similar concerns about the increase in referrals. In May 2017, and in response to the increase in demand, South West London St Georges Mental Health NHS Trust was reported to have announced plans to stop autism diagnosis for children and young people unless there was evidence of significant mental health difficulties. The response in the media, especially social media, was quick with autistic adults and parents of autistic children both stressing the importance of access to diagnosis and the risks for children and young people if they were denied that access (Whittington 2017). The challenge of providing a timely diagnosis continues with waiting times increasing still further as the result of the COVID-19 pandemic due to increased staffing and delivery complications. Part of the solution presented has been the introduction of online assessments via a video link, which increases capacity and enables clinicians to work from their home and provide assessments right across the country. However, even with new developments, the demand for assessments continues to outweigh clinical capacity. With increasing financial pressures on the NHS what is the risk if commissioning is directed towards diagnosis at the cost of other support services? Services such as CAMHS, occupational therapy and speech and language therapy, all support autistic children as well as neurotypical children and will continue to be needed to improve outcomes for autistic children of all ages, regardless of diagnosis.

In summary, research suggests that parents or carers first have concerns that their child may be developing differently to their peers when they are around 1-5 years old. When they raise concerns with professionals, they can experience the received response, or lack of response, as a barrier to assessment. This can be a source of frustration as they are left uncertain about the future or their child's potential support needs. Once (and if) a diagnosis is received, it may not live up to parental expectations with many parents reporting a lack of satisfaction with the assessment process and subsequent support. For service providers the demand for assessments brings with it a demand on clinical time and resources at all stages of the process including managing increasingly long waiting lists, providing assessments, and developing post diagnostic support. This is against a backdrop of limited resources, and now in 2021, additional funding pressures as a result of the Covid-19 pandemic.

3.5: **Autistic girls - referral and assessment challenges.**

Whilst researchers have highlighted parental reports of delays in referral, assessment, and support for their children, for autistic girls these challenges are reported to be greater at all stages of the assessment and diagnostic process.

Historically, autism has been viewed as a predominantly male and Western condition or disorder. Asperger's study (as reported by Wing) focused solely on boys, and in Kanner's study boys outnumbered girls by 11:3. In 2009, studies reported that boys outnumbered girls 4:1 (Fombonne 2009), with a more recent systematic review of research suggesting the figure is now closer to 3:1 (Loomes, Hull and Mandy 2017). Data from my own service in 2017 showed a referral rate of 3 boys for every girl. In a local review of assessment outcomes in 2016-2017 70% of the boys referred to the team went on to receive a diagnosis and the diagnosis rates for girls was lower at 62%. This highlighted that in our own service, fewer girls were referred and once they were assessed fewer girls went on the receive a diagnosis.

When given a diagnosis of autism, girls have been reported to have more severe intellectual difficulties (Kreiser & White 2013) with more pronounced symptoms than their male counterparts. Interestingly gender differences in diagnosis change significantly depending on cognitive function with the prevalence rising to 1:1 or 1.95:1 for girls with severe cognitive functioning, but dropping to between 10:1 or 5.5:1 for more cognitively able females (Scott et al 2002, Skuse 2009, Lai et al 2011, Goldman 2013, Lai et al 2015)

One theory to explain the reduced prevalence of autism diagnosis for girls was proposed by Simon Baron-Cohen. Baron-Cohen (2002) presented the 'extreme male brain theory', suggesting that autism was an extreme form of maleness. He suggested that male and female brains differ in their abilities for systemizing and empathising, with males being better at systemising and females having better innate empathy skills. He highlighted how this is more pronounced in autistic people where there is a "preference for rule based, structured, factual information" and "systemising" but a reduced ability to show empathy and "specific delays and difficulties in the development of mindreading (i.e. making sense of and predicting another's feelings, thoughts and behaviour)" (pg. 252). This would suggest that females that are diagnosed as autistic have brains which have diverted from that which is typical, giving one possible explanation for why there are less. Baron-Cohen suggested that the extreme female brain, with a pronounced ability to tune into the feelings of others and a reduced ability to systemise, might be better tolerated or accepted in society. Males with a 'female type brain' may be seen as more understanding whilst females with a 'more male brain' may be labelled as autistic. The extreme male brain theory has been heavily criticised (Skuse 2009, Goldman

2013, Subbaraman 2014, Ridley 2018) with Ridley going as far as to say that it is “comparable to the claim that, because on average men are taller than women, extremely tall women have extreme male height” (2018 pg. 19). Whilst Baron-Cohen put forward the idea of autism as an extreme form of ‘maleness’, others have suggested that the female brain has a protective factor against autism. This argument proposes that genetic differences in brain structure contribute to a ‘female protective effect’ and that females require more of a ‘family etiological load’ than male counterparts in order for autism to manifest (Zhang et al 2020, Hull et al 2020, Robinson et al 2013).

It is now considered by many that rather than being a male condition, autism is more common in girls than first believed and that the early male biased understanding of autism led to a large number of girls going undiagnosed (Wood-Downie et al 2021, Hull et al 2020, Bargiela et al 2016, Riley-Hall 2012, Attwood 2007, Hiller, Young and Weber 2015, Baldwin and Costley 2015, Szalavitz 2016, Mandavilli 2015, Gould 2017, Kreiser & White 2013, Happe 2019) or ‘under the radar’ (Nasen 2016). Happe (2019) suggests that “what we think we know about autism from research is actually what we just know about male autism” (pg. 12) and this is also represented in “the media and popular conceptions of autism” (pg. 11)

Unlike suggestions that the differences in diagnosis rates are due to internal factors and brain functioning, such as a male brain type, or female protective factor, other researchers have proposed that cultural, historical and social factors have influenced the difference in diagnosis rates (Lai et-al 2011, Kreiser & White 2013, Goldman 2013). Kreiser & White (2013) propose that the underrepresentation of females in the diagnosed autistic community is not only due to a biological or symptomatic difference but also due to sociocultural differences. They suggest that how girls are socialised by their parents, educators and their community influences how autistic girls behave, how their behaviours are interpreted and how diagnostic criteria are applied. If a girl is quiet and withdrawn she may be seen as ‘shy’, or if she attempts to control others in play she may be seen as ‘bossy’. Girls may also be under-identified due to ‘protective same age friendships’ (Krieser & White 2013, Attwood 2007).

In a study comparing parent’s pre-diagnosis concerns for autistic boys and girls Hiller, Young and Weber (2014) found that girls were 13 times less likely to have concerns raised by school staff. In a more recent studies, Whitlock et al (2020) found that educational staff were less likely to identify autism in girls and that they were “more sensitive to the male phenotype in comparison to the female phenotype of autism” (pg. 1367), whilst Hill et al (2020) and Lockwood-Estrin et al (2020) found that girls were less likely to be identified by teachers or community providers. Whilst girls ‘autistic’ behaviours may be less evident, or ‘invisible’ (Anderson et al 2020) in school, research has highlighted more aggressive and externalising

behaviours in the home (Anderson et al 2020, Fattigh-Smith 2010, Hiller, Young and Weber 2014, Frazier et al 2014), with no variation in the age at which parents first become concerned about their child according to sex differences (Begeer et al 2012). This has the potential to create a situation in which mothers reports of difficulties are not corroborated by school and are met with 'scepticism' (Anderson et al 2020, Navot et al 2017) and 'disbelief' (Anderson et al 2020), making the journey from early concerns to diagnosis even longer for girls.

It has been suggested that the experience of raising a girl on the spectrum is qualitatively different to that of raising a boy, but at the start of my research journey I found no studies with a specific focus on the maternal experience of raising an autistic girl. I have since identified three qualitative, thematic studies published with a specific focus on Mothers and autistic girls by Fowler and O'Connor 2020, Anderson et al 2020, and Navot et al 2017.

Fowler and O'connor (2020) identified "the task of parenting girls with autism" as "entailing unique challenges" due to "female specific social pressures", such as "mental health risks and diagnostic barriers" (pg.2). Themes included "challenges in securing a diagnosis", "concern about stigma" and issues of mental health for both the mothers and the daughters. They noted that "challenges were overcome" by the mothers resilience "buttressed by the pride in their daughters and support from other women" (pg. 9)

Anderson et al (2020) identified 5 themes in their study, relating to a different presentation of autism in girls, camouflaging, the impact of the diagnosis and the impact on the mothers and on everyday life. Whilst the mothers were identified to have an "early sense of something being different" about their daughters "most did not arrive at autism as the explanation for this difference" (pg. 1549), again highlighting the important role of professionals in raising autism as a possibility. They found that the diagnosis helped increase the mothers empathy due to a new understanding about the behaviour of their daughters, and proposed that "mothers hold a vast amount of knowledge on their daughters autism spectrum condition which could inform the diagnostic process and clinical practice" (pg. 1546).

As well as the potential for "scepticism and delayed diagnosis" Navot et al (2017) found that Mothers of autistic girl's experience "a sense of exclusion from the neurotypical population and male dominant ASD population". Their findings also suggested that whilst mothers may have expected a "close and intimate relationship" with their daughters, the mother-daughter relationship underwent a transformation, "which re-shaped maternal competence, reshaped expectations and created a different bond between mother and daughter" (pg. 536). Girls and their carers also face specific challenges which change at stages of development with mothers "reporting that while their daughters were physically maturing there was a greater gap between

their daughter's behaviour and cultural expectations of the female identity" (Navot et al 2017 pg. 543).

In the UK, growing awareness of how autism may present differently in girls has been supported by increased media coverage including a Channel 4 documentary in 2015 regarding Limpsfield Grange a specialist school for autistic girls (Neustatter 2015) and through the work of advocates such as Carly Jones, a late diagnosed autistic woman who was awarded an MBE. It is felt that one of the reasons girls are not picked up by teachers and referrers is because they score better on reciprocity scales (Backer et al 2017, Kreiser & White 2013) and are less likely to identify themselves by isolation from others and they will 'mask or camouflage' autistic behaviours (Lockwood-Estrin et al 2020, Hull et al 2020, Wood-Downie et al 2021, Dean et al 2016, Gould 2017, Sutherland et al 2017, Lai et al 2016, Bargiela 2016, Hiller, Young and Weber 2014 & 2015, Goldman 2013, Gould and Ashton Smith 2011). This may be less possible for girls with greater cognitive difficulties, whilst girls with average or above average abilities may be more able to compensate by masking and camouflaging the social challenges they experience (Goldman 2013). Girls are also believed to present with less restricted and repetitive behaviours and interests than boys, or at least have interests that are more in line with their peers. This has an impact on early identification and also the diagnostic process with the belief that it leads to under-diagnosis in the assessment process itself (Wood-Downie 2021, Hull et al 2020, Duvekot et al 2016, Dean et al 2016, Gould 2017).

When assessing girls our clinicians are careful to interpret girls 'scores' in the ADOS within the knowledge that they may mask certain "autistic features" or feel the need to pretend to be normal (Bargiela et al 2016). This involves straying from male dominated assessment tools such as the ADOS, which mainly focuses on observed behaviours and in which "clinical diagnosis is in the eyes of the beholder" (Goldman 2013), to asking questions based on the young persons lived experience. Whilst this change creates a move away from focusing on 'observed autism' to inquiring about 'experienced autism', Goldman says that even when information is gathered the interpretation of results will still be influenced by gender expectations held by the examiners. This is within an already complex diagnostic process in which there can be "uncertainty caused by contradictory narratives" and where "autism can present but not seen (due to compensating or masking); seen but not present (due to behaviour that 'look like' autism such as anxiety); or seen by some and not others" (Hayes et al 2020, pg. 9).

Loomes, Hull and Mandy (2017), liken the search for a diagnostic framework that effectively identifies autism in women, to a search for "the holy grail". One assessment and diagnosis tool, which is proposed to be more sensitive to the female presentation of autism is The Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al 2002). The

DISCO is a semi-structured interview with “examples given of how the behavioural manifestation in the girls and women can differ from the males” (DISCO Team 2017, pg. 2). However, the interview is long, reported to take up to three hours. Training to use DISCO is expensive and only available at the Lorna Wing Centre making its use in busy assessment services a challenge both financially and logistically. In my view, this highlights the challenge of transferring practices and tools from research into the running and provision of everyday services.

Whilst girls and women potentially mask behaviours which need to be observed to make the identification and diagnosis of autism more likely, Keiser & White point out that “due to core social and communication deficits, these young girls still experience distress and functional impairment and may be at increased risk for the development of internalising problems due to repeated experience of negative societal reactions, despite compensatory efforts” (2013 pg. 9) With the ability to mask and “blend in better” only extending to “looking normal” not “feeling normal” with the impact of “communication and unwritten social rules” still threatening her emotionally (Fattigh-Smith 2010, pg. 55). This has potentially devastating consequences with camouflaging and unmet support needs highlighted as one of the key risk markers for suicidality in autistic adults (Cassidy et al 2018).

However, whilst there is growing awareness of how autism may present differently in girls, there is also caution not to create binary distinctions between ‘male autism’ and ‘female autism’. Strang et al (2020) advise that “characteristics that have been associated with a ‘female’ versus ‘male’ version of autism are not isolated to one sex or gender” (pg. 540) and we are reminded that camouflaging and masking can occur in the non-binary and male population too. An area which I believe warrants further research, and which is illustrated by Milton (in Timimi et al 2019) in reference to his experience of ADOS (Autism Diagnostic Observation Schedule) training:

> *“Girls on the spectrum were presented by the trainer, as often to have more ‘typical interests’, or interests in social science subjects ‘sparked by their underlying difficulties’, seemingly missing that I had announced that I was an autistic social scientist myself at the beginning of the training, and if I am not mistaken present as male” (pg. 9).*

In summary researchers now suggest that there has been a male bias in the understanding of how autism presents, how to identify it and in the creation and application of the tools used to diagnose it. This has led to girls being referred later than boys despite parent’s early concerns, the potential for mothers and carers to be seen as exaggerating symptoms, and the risk of girls not being diagnosed even when a referral for an assessment has been made. Whilst

there has been the suggestion that girl's brains are different to boys and that this has led to the lower levels of diagnosis, others have suggested that autistic girls mask and camouflage their social difficulties whilst experiencing high levels of anxiety and internalising symptoms, which in turn are less evident when using assessments which largely rely on observable behaviours. The potential impact on the girls themselves is delayed diagnosis and a delay in the understanding and support this might bring. For the mothers and carers of autistic girls there is the likelihood of a delay in referral, a longer journey to diagnosis and the potential of disbelief from professionals who do not see overt behaviours suggestive of autism. I am curious about how mother's experience this journey, do they feel their concerns are not taken seriously or that professionals see them as exaggerating, do they feel their daughter's diagnoses were delayed and protracted and do they feel that, once given, the diagnosis brought the understanding and support that they had hoped for.

3.6: **Mothers, Fathers, blame and stigma.**

As previously discussed, whilst referring to 'parent's views', research into parenting and autism tends to be 'skewed towards the experiences of mothers' (Cheuk and Lashwicz 2015). This combining of the experiences of both parents does not allow for an exploration of different experiences due to gender, parental-child relationship and the social and cultural expectations placed on parents about what it is to be a mother or a father. The consequence being that the results are generalised for 'all parents of all autistic children'. In a systematic review of 48 articles and studies exploring parental stress and coping in mothers and fathers of autistic children Flippin and Crais (2011) found that whilst mothers reported higher levels of stress or anxiety in the majority of studies, the source of stress for mothers and fathers was different. Mothers were most likely to experience elevated stress levels due to their child's 'regulatory behaviour', such as feeding or sleeping whilst "fathers reported that their child's externalising behaviours (e.g. tantruming) were the greatest source of their child-related stress"' (pg. 40). Additionally, Flippin and Crais found that fathers and mothers were both "affected by partner related stress" with fathers being "affected by the mother's mental health" (2011, pg. 40). This suggests that where mothers report increased levels of stress the impact this has on their own mental health may in turn have an impact on the emotional health of their partner.

An examination of the changing roles of fathers (in western culture) in recent years highlights a move to sharing more of the caring and nurturing role with their children, especially with the increase in dual income families (Shave and Lashewicz 2016). When a child has additional needs, it is possible that a father becomes even more involved with child rearing. Shave and Lashewicz (2016) suggest that "disability-specific demands provide impetus for father-child time and part of this impetus is a relatively pronounced sense of the need to work in

partnership with their wives, not only to ensure the needs of the children are well met, but also so each parent has opportunity to pursue individual interests" (2015 pg. 504). However, whilst still finding it an emotional journey fathers feel 'excluded' and 'unsupported' in the diagnostic process with 'greater focus' on the needs of the mothers (Potter 2016). This further highlights the need for researchers to clarify who is the focus of their research, mothers or fathers, rather than generalising 'parents' as the impact on the parental roles and how they fit with cultural and personal expectations of parenting may be different for each.

Whilst studies have suggested an increase in the stress of mothers, due to their child's regulatory behaviour (Flippin and Crais 2011), other researchers have identified additional challenges for mothers as they "facilitate their child's sociality and the accommodation of their needs by mediating between them and the broader world" (Rocque 2010). Rocque suggests that "mother's mediation aims to increase inclusion and acceptance of their children as people who understand and interact with the world in sometimes fundamentally different ways, but whose existence and personhood are fully valid nonetheless" (2010 pg. 486). This may be achieved by educating others about their child's specific needs and behaviours so they can be understood by those less familiar with autism, including extended family (Nealy et al 2012) and also in helping their child understand the unwritten rules of social interaction and behaviours.

In a qualitative study of 45 mothers of children with 'invisible disabilities' such as ADHD and/or autism, Blum found that despite a move away from citing parenting as the direct cause of a child's disability, nearly all "encountered blame and stigma and proximate cause, for failing to sufficiently discipline, buffer or case manage a child already made vulnerable by nature" (2007 pg. 3), with their maternal fitness brought into question. In addition to experiencing stigma in connection with their child's needs mothers were also having to adapt 'maternal vigilance' in their negotiation of support for their child against a backdrop of limited resources (Blum 2007).

Landsman suggests that in America mother-blame is a cultural phenomenon that predates the birth of a child due to health campaigns about healthy eating and lifestyles when pregnant. The implication being that if you have a child with a disability this is due to something you as a mother did wrong when they were in your womb. She goes as far to say that "American Mothers have given birth in a context in which the foetus is widely viewed as a potential victim threatened by its mother during pregnancy and in which women are generally held accountable for any damage to a foetus" (2009 pg. 53). This is likely to be reinforced by questions asked in the autism assessment process about drug and alcohol use in pregnancy.

The source of mother-blaming narratives exist across more than one culture but the content of the stories can differ. Landsman refers to women in Mozambique being seen as the source of a child's disability due to bad spirits being brought from her family, and in some Latin American cultures a child's disability is seen as the direct result of a mother being cursed (Otufat-Shamsi 2005). Recent news has also promoted an image of the mothers of autistic children as victims due to a lack of information about the side effects of medication that they are taking, for example Sodium Valproate (Christensen et al 2015).

In its early days, the autism story was very much one of mother blame. Kanner's early work referred to the cold nature of the parents of the children he observed, particularly the mothers. This story was later reinforced by Bruno Bettleheim in his book 'The Empty Fortress' (1975) which led to the term 'Refrigerator Mothers'. The cause of autism being firmly located in the behaviours of the mother and her withholding warmth and love from her child. In this respect, the diagnosis of autism was as much about the woman's impairments as a mother as it was about that of the child.

This suggests that however Autism is viewed the mother could be seen as responsible at some stage, either for not looking after her unborn child sufficiently, or for interacting in a way that 'caused' autism once her child was born.

An alternative story for the mothers of children with disabilities is that of the 'special mother for a special child'. Landsman suggests that whatever the narrative that surrounds a mother of a disabled child they are "not construed as morally equal. Either they are worse than others, 'bad' mothers who avoid pre-natal care and risk harms to their foetuses or they are 'better', special mothers chosen by God" (2009 pg. 89). Russell and Norwich (2012) suggest there is a 'Tipping Point' between a parent defending their child's 'normal status' and resisting a diagnosis for their child, before they feel diagnosis is necessary to get their child the support that they need. One could argue at this stage it is also their normal status as a parent that is being protected not just the normal status of their child. Interestingly, mothers in South Korea are reported to deliberately take the blame for their child's condition in their attempts to protect their child's normal status. An autism diagnosis is seen as a 'genetic mark of shame' and has considerable impact on marriage opportunities and the family as a whole, and the preferred diagnosis is 'reactive detachment' caused by 'extreme parental abuse'. (Grinker and Cho 2013, Hughes 2011).

When a mother starts the assessment journey for her child, she may have to negotiate numerous referrals, professionals and waiting lists and this may also involve telling the story of her child's birth and development many times. As this occurs different stories may begin to have more power or influence over each other as she comes into contact with various educational and medical professionals. As diagnoses are suggested they are invariably about

deficit, impairment and what will not be. Research suggests that mothers experience “a sense of anxiety and concern” (Nealy et al 2012, pg. 194) for the future of their autistic child and hopes and dreams for their child may be brought into question. Will he or she go to school? Will they have friends? Will they get a job, get married or have children of their own? With this her own stories of what it might be to be a mother may also change as they potentially face years of negotiation with professionals and services to get their child what they feel they will need. The ‘deficit’ stories may also be in contrast with a mother’s hopes for their child’s achievements ‘in spite’ of their diagnosis (or even because of it). Whilst research has highlighted (and perhaps reinforced) the negative emotional impact on mothers of caring for an autistic child, such as heightened levels of anxiety and depression (Dale et al 2006), mothers have also spoken about the positive aspects of looking after their child. In an Iranian study mothers referred to their child as a blessing and gift from god (Heidary 2015), whilst the mothers in study by Bultas and Pohlman (2014) described parenting an autistic child as having a ‘positive side’ and a ‘silver lining.’ Charles and Berman (2009) found that the mothers in their study had discovered an “inner voice”, a “positive aspect of their mother-child relationship” which led to a “transformation for them” as well as their child (pg. 190).

Fowler and O’Connor’s study found that mothers took on the role of advocate for their children and “rolled up their sleeves to demand the best possible opportunities for their daughters” finding “reserves of determination and self-reliance. Traits that they also purposely sought to cultivate in their daughters” (2020, pg. 9) Charles and Berman (2009) highlight the importance of services broadening their focus to facilitate and acknowledge this positive side of the relationship between mothers and their autistic children, as well as understanding the additional challenges mothers may face as they negotiate resources and support for their daughters, themselves and their families.

Access to the internet and social media has played an important role in increasing the resources available to mothers when they are learning about their child’s needs and abilities in relation to a potential diagnosis. With autism, this includes reports of famous people and scientists who are known or believed to be on the autism spectrum and can potentially lead to a resistance of “the power of medical practitioners to define and set the limits for their disabled children” (Landsman 2009 pg. 103). This change in balance is one that Landsman believes can lead to a move away from the “physician giving and the parent receiving bad news” to one in which “diagnosis and prognoses may instead be negotiated amongst actors”. Landsman went on to say that “mothers believe that the story one tells and can get others to hear matters. It may affect the mobilisation of resources, the support of extended family members, the commitment of a mother herself, and the allocation of interventions” (2009 pg. 141). In this way, mothers move from being disempowered and blamed for their child’s condition such as

the Bettelheim's refrigerator mothers, to empowered advocates fighting for their child's needs. This battle for their child's needs may include that of receiving an autism diagnosis for their child from the medical professionals they perceive as having the power to give.

Farrugia (2009) describes the moment of diagnosis as "an especially important event for parents. Since the normal appearance of children diagnosed with ASD can make interpreting their behaviours difficult and ambiguous" (pg. 1016) and parents can blame themselves for their child's challenging behaviours (Jacobs et al 2019) or can feel blamed by others (Jacobs et al 2019, Bultas and Pohlman 2014). In two separate studies of parental experience Faruggia (2009) and Anderson et al (2020) found that diagnosis enabled parents to resist self-judgements (Anderson et al 2020) and stigma from others, such as the view that they are "bad parents with naughty children" (Farrugia 2009, pg. 1016). Farrugia (2009) and Gray (1993, 2002) suggest that it is the 'normal' appearance of children with autism that can lead to the biggest challenge for parents. This is potentially even more so for girls who are believed to mask their behaviours in school whilst showing more aggressive and concerning behaviour in the home (Sarris 2015, Hiller, Young and Weber 2014, 2015). Unlike in the 1940's,50's and 60's when parents were put forward as the potential cause of autistic behaviours by Kanner and Bettleheim, diagnosis now enables parents, especially mothers, to prove to others that their child is not 'naughty or bad' (Anderson 2020) but there is something 'different' about their child.

In other cultures, such as Hong Kong and China, the diagnosis of a child may increase stigma. McCabe (2007) and Tait et al (2015) report devastating consequences when parents have revealed that they were "so affected by a fear of community stigma and feelings of shame that they did not tell anyone, preferring to send their child with autism away to rural and remote areas of the country, often to be raised by relatives" (Tait et al 2015 pg. 1165). The impact of shame on families in Hong Kong and China is not only reported to increase stigma for parents but also has an associated risk for the diagnosed child, with higher reported incidents of abandonment, abuse and neglect (Tait et al 2015).

In summary, research into the experience of diagnosis that combines the experience of both mothers and fathers under the term 'parents', does not take into account that their experiences may be different due to socio-cultural expectations and pressures, different family dynamics and differing caring roles. When a child does present with additional needs both mothers and fathers can experience a change in their roles and an increased need to negotiate with professionals and others from outside their family as they seek a diagnosis and support for their child. Historically for women in western cultures, there has been the added pressure of 'mother blaming' where the lifestyle choices, healthcare and parenting styles of mothers has

been considered, at least in part, to have contributed to their child's additional needs. Whilst there is now a suggestion that diagnosis can help to protect mothers from blame and stigma in western cultures, in other cultures such as Chinese cultures, Latin America and Mozambique mothers can still be seen as the cause of their child's disabilities. With the increased risk of stigma for mothers, comes the added risk of abandonment and neglect for their child.

3.7: **The ethics of autism diagnosis – who decides and who is it for?**

Autism itself is now widely thought to be a 'neurodevelopmental' disorder, however it is debated by some, such as Timimi, Gardener and McCabe (2011) and Hassall (2016) that despite the growing number of children being diagnosed, autism is not a disorder at all. It is argued that there is no such thing as autistic traits or behaviour (Chown 2016), "no known biological basis" (Chapman 2020) and that Asperger Syndrome is just a "neurological difference that has been constructed as a disorder" (Molloy and Vasil 2002, pg. 659).

This counter argument to autism diagnosis is that there is no "single underlying condition that can be regarded as the defining characteristics of autism" (Hassall 2016) just behaviours that happen across everyone in the population but may be more often seen in autistic people than non-autistic people, and that it has little use as a 'disorder classification from a medical perspective' (Chapman 2020). Whilst others go as far as to say that a diagnosis of 'autistic' "seems to mean little more than that the individual concerned is socially awkward" (Hassall pg. 64, 2016). A view that is not responded to well by some of my autistic friends, especially those who experience high levels of sensory processing difficulties, anxiety and social fatigue. In fact, if the position is taken that our worlds are socially constructed through language and communication, difficulties with (or in particular differences in) social communication could be the most disabling of all 'impairments'.

In 2017 a local Reading artist, Mahlia Amatina, diagnosed as autistic in her twenties, displayed a series of abstract paintings, with the title 'On A Spectrum'. The individual pieces of artwork represent different parts of her experience, such as sensory overload, anxiety and her diagnosis. She has titled one painting, which depicts the moment of her diagnosis, as 'That lightbulb moment' with a narrative that things became much clearer to her once she had received her diagnosis. She now identifies as an autistic artist and presents autism, 'being autistic,' as a positive part of her identity. I am aware hers is only one experience of diagnosis, and whilst Mahlia refers to a lightbulb moment, research about parent's emotions at the diagnosis of a child has gone as far as to compare the emotion felt to that of a bereavement (Fernandez-Alcantara 2016).

As previously discussed, parents can wait years for their children to be assessed for autism. An assessment which, in most assessment services, is currently binary in nature with the only two potential outcomes being ‘autistic’ or ‘not autistic’. A review of our assessments within Berkshire highlighted that approximately 60 % of the children seen for assessment receive a diagnosis of autism. The impact of waiting for years and not receiving a diagnosis is an area which would warrant further exploration, especially if the caregivers have potentially started to identify as a caregiver of an autistic child and joined autism related support groups and websites.

Parents of children on the waiting list for assessment in Berkshire have been known to call the helpline with concerns that support will not be put in place for their child in school unless they have a diagnosis. I, along with others such as Hodge (2016) advocate needs led support in schools and our service has been working closely with local authorities to provide support regardless of diagnosis. However, some parents in contact with our service not only report that support is not available prior to diagnosis but it is not available post diagnosis either. Again, this is especially difficult with girls who are more likely to ‘camouflage’ and not overtly present as having additional needs at school or in the classroom. In these circumstances the diagnosis enables parents to have a line of communication with the school about the hidden needs of their child under the heading ‘autism’. Parents also report that they need a diagnosis in order for their child to get an EHCP (Education Health and Social Care Plan) in school, which is a means to accessing additional support. The reality is that an EHCP is not automatically awarded if a child is autistic and a large number of autistic children will not receive one.

Locally, in Berkshire, parents have reported that they needed a diagnosis in order to access targeted autism parenting services and support however, support that is available post diagnosis is provided for most families’ pre-diagnosis in Berkshire. Even with the availability of groups, workshops, training, and activities, one parent spoken to as part of a West Berkshire CCG (Clinical Commissioning Group) review reported that they felt as if they ‘had been dropped off a cliff’ when the diagnosis was made.

As more parents seek a diagnosis for their child, the impact on the NHS has been great. Waiting lists for assessment continue to increase, complaints about waiting times persist and have to be managed, and parents seek out additional support and understanding of children where autism has been raised as a question. In my professional opinion, whilst there may be many benefits of diagnosis it can for some bring some disappointment, especially for parents and carers. Whilst it might give a helpful understanding of why their child struggles it is just a

description of behaviours and should not be considered in its entirety as ‘a goal in itself’ (Jacobs et al 2019) as it may not bring about the change or resources they had hoped for.

Lewis, Skirton and Jones (2010) advise that “professionals may want to highlight that even with a diagnosis, families still face similar challenges, uncertainties and joys” (pg. 814). Yet despite reports of dissatisfaction referral rates and requests for assessments continue to rise. As one explanation for the increase in referrals Mallett and Runswick-Cole (2012, 2016) suggest that autism has become ‘a commodity’ that is “produced, exchanged, traded and consumed” (Mallet and Runswick-Cole 2016, pg. 110). Murray (2020), warns ‘buyer beware’ due to the focus on ‘areas of lack’ being ‘where the money goes’ with autism. She states:

“The pressures to buy are huge, the adds seem authoritative and the criteria for atypicality are presented as pathological: all set to embrace more and more types of humans essentially ill just for being who they are” (pg. 20)

The consumeristic nature of autism can be seen in the growing number of private clinics providing assessments for large sums of money, companies providing treatments and therapies for autistic children promising their parent’s significant changes in their children’s behaviours, and a growing number of books for parents, carers and autistic people themselves. Additionally, there is merchandise such as t-shirts, bracelets and posters for parents to announce their love of an autistic child and multitudes of ‘autism friendly’ products such as sensory toys and weighted blankets being sold over the internet. Even diagnostic assessment modules can be financially driven. This point is illustrated by Timimi, who explained that on asking a trainer about an assessment module for use with adults with little or no language, he was told that such a model had not been developed because it was not “commercially viable” (Timimi et al 2019, pg. 4). Timimi’s view is that the assessment model is “infected with the Western Colonial arrogance where the creators, sellers and now the many examiners who carry out these assessments, believe that they ‘know’ how the universal culture, gender, sexually neutral person should and shouldn’t function” (2019, pg. 7). Not only is autism presented as a medical diagnosis, there is an additional culture attached in which autism is packaged and sold, with the advertising campaign relying as much on the promotion of ‘normal’ as it does on the naming and identification of that which is ‘not’.

Is it possible that autism, as with other consumer products, has a ‘use by’ or ‘obsoletion’ date? This idea is put forward by Mallett and Runswick Cole (2016) who describe autism as a “promise that is never fully fulfilled” (pg. 121). With parents being left ‘high and dry’ when they experience a ‘loss of satisfaction’ when autism diagnosis does not hold the same value as

once anticipated. As with all consumerism they believe it is then that “the loss of satisfaction is a moment exploited for further market expansion and profit as the consumers desire is simply channelled in another direction (Mallet and Runswick-Cole 2016, pg. 121). I have seen examples of this re-channelling in practice over the past few years with a number of parents reporting that their child’s behaviour has not improved with autism specific strategies. This can lead to a search for a further diagnosis, and in more recent years, in my own practice, this diagnosis has been PDA – Pathological Demand Avoidance. PDA as a diagnosis is not readily recognised in the UK, but it is in DSM-V and recognised in America. There is one centre that assesses children for PDA in the North of England and assessments are not commissioned by the NHS. Whilst we will acknowledge demand avoidant behaviours in autism assessments, I have seen some parents insist that they need a PDA diagnosis for their child, despite strategies and supports being available to use with or without a diagnosis, as if this is ‘proof’ of what they are managing. This could be seen to fit with Farrugia’s theory of diagnosis as a way for resisting stigma for parents.

If diagnosis protects parents from public stigma, who is a child’s diagnosis actually for? The change in understanding about the ‘cause’ of autism, and the increase in parent advocacy groups, has led to some promoting the notion of superparent’s loving their children against all odds, with T-shirts and merchandise sold saying ‘I am an autism supermum’. But ultimately who should get to wear the t-shirt? Murray (2020) has observed *a* “tendency for other people’s concerns to be magnified and elevated at the expense of (those) who are being worrying” and “however lovingly these concerns are felt and expressed, they can impose negative expectations which become part of the persons identity, perhaps sometimes to the detriment of their lifelong wellbeing”*(pg. 20&21).* The suggestion that it is only a supermum that can love such a child is now in dispute by autistic adults who argue against the focus on the parents stressing that we should be listening to those that are ‘#ActuallyAutistic’. It is a difficult challenge, as if we do not help parents to feel heard and supported how will they feel able to support and truly ‘hear’ their child? How can we learn about the lived experience of autism from autistic adults, and hear the challenges faced by parents of autistic children in a way which does not leave those autistic adults feeling marginalised and disrespected?

I have found that in a lot of the meetings I attend disputes arise about around terminology, especially the use of ‘autistic child’ or ‘child with autism’, or ‘challenging behaviour’ and ‘child who is being challenged’. Seemingly it is often parents of autistic children, and autistic adults that seem to differ in their views with parents preferring person first definitions and adults preferring ‘autistic adult’. Whatever ‘autism’ is, the story of autism is a political one, and the coherence of this story could be described as a confused one. Pearce (1989) states, “if we tell

confused stories, we will be confused, and if we pursue confused stories too literally, they can drive us mad. If our stories are too far out of touch with the facts of life, we will experience recurrent problems, if our stories provide sufficient affordances, they facilitate co-ordination" (pg. 69).

The more the scope of autism broadens, the ethics of its use as a diagnosis has been questioned. Latif (2016) asks "what is the point of attaching a disorder label to a young person when the cause is not known, it does not predict outcome and there is no cure?" (pg. 294, 2016). This could be argued to be the case with a diagnosis that is based on impairment and deficit, with young people potentially left with a narrative of "there's something wrong with me" (Ida, 2020, pg. 79). Murray (2020) suggests that the pathologizing nature of autism diagnosis "casts a dark shadow over the concept of autism" (pg. 25), and young people who may once have had a passion or preoccupation that excited, interested or soothed them, may now find this interest described in negative terms, or in the case of some targeted for behavioural intervention. This links with a medical view of diagnosis as something which is connected to the reduction or elimination of symptoms (Kapp et al 2013), and does not consider the benefit of understanding difference and/or the provision of support without the push to change, heal or 'fix' it.

For some the ethical question has not been diagnosing a condition that has no cure, but if the search for a cure is in itself ethical. Autistic advocates have strongly opposed treatments, such as Applied Behaviour Analysis (ABA), as unethical due to their attempts to modify autistic behaviours in order to conform to the social norm (Hendry 2018, Lynch 2019). Brown suggests that on a political level, "there are many occasions where a condition is diagnosed, yet there is discretion about whether it is treated. That discretion is often a matter of how the condition is socially constructed" (1995 pg. 47). If autism is seen solely as something medical, something divergent from the norm and something 'wrong' the focus is on the individual. It is the autistic person who is then expected to change, be changed, or fit in, even if it is by going against their nature. If they are excluded, they are to accept it is not because the world is inflexible, but because they are. Chapman (2020) warns that by naturalising autism we can "make the limitations autistic people often exhibit that are a produce of social exclusion (eg. from education, work etc) seem like they are naturally grounded internally in autism itself" (pg. 44). As clinicians, the challenge is to find a way to support individuals in identifying if and why they feel different in some way, be that autism or any other form of neurodiversity, without restricting them, or putting all the responsibility on them to be the ones to change to 'fit in' with a poorly constructed consensus of that which is 'normal'.

In summary, whilst it is argued by some that there is no such thing as autism, there continues to be a rise in the number of children, young people and adults referred for assessments and with an increase in waiting times to be seen. The benefits of diagnosis have been debated. Whilst autism is not a 'treatable' condition some of those who have received the diagnosis define it as a life changing moment which brings clarity about past and current challenges and strengths. Others have argued that endeavours to treat or 'manage' autistic 'symptoms' or 'behaviours' has led to abusive attempts to control and change autistic people just because they do not fit within poorly constructed cultural normalcies.

3.8: **The Social Construction of Diagnosis, Diversity and Difference.**

As autism diagnosis is on the rise (Russell 2012), with increasing numbers of females being identified, researchers, healthcare providers and the media (to name a few) have asked questions about why. Is it due to factors such as food additives, ultrasounds and vaccines? Is it due to time spent on computer games? Is the rise due to an increased understanding of what autism is and better diagnostic tools, or is it on the rise due to changing and widening diagnostic categories that encompass more and more people that may once have gone through life with no diagnosis at all?

In its simplest form, the medical model of diagnosis is one which "aspires towards normalisation" (Kapp et al 2013, pg. 1) leading towards treatment, which will 'reduce or eliminate' symptoms. In a history of diagnosis Berger (1999) states that "the first medical diagnoses made by humans were based on what ancient physicians could observe with their eyes and ears", beliefs about causation of illness ranged from 'punishment' for sinful behaviours, to 'witchcraft' and 'possession', with treatments including ritual sacrifices. Advancement in technology and the introduction of microscopes, the x-ray and later computerised technology then led to the study of organisms and cell structures, brain structures and genetics which has enabled physicians to identify bacteria, infections and differences or variations from 'the norm'.

The advancement of mental health diagnoses and developmental disorders has, in some respects, stayed in the early stages of diagnosis as most conditions are still diagnosed by what can be observed by a clinicians 'eyes and ears'. There have been studies into chemical brain activity for conditions such as depression and schizophrenia with widely agreed differences in dopamine levels (Howes and Kapur 2009), but diagnosis is still dependant on subjective observation and diagnostic tools. The cause of autism and the working of an autistic brain have also been studied, with studies including (but not exclusive to) genetics, studies of the brain, and social and environmental factors, but there has been no agreed way to predict,

diagnose or potentially ‘treat’ autism. Diagnosis continues to be carried out in the same way as ancient physicians would diagnose through what can be observed with their ‘eyes and ears’, with the diagnostic tools that are used being in dispute, such as the ADOS which is said to have a gender bias and miss the diagnosis of autistic girls and women.

Brown (1995), makes a distinction between the social construction of medical knowledge and the medical knowledge of illness. The social construction of medical knowledge is interested in the professional belief systems, with diagnosis and “ways of knowing based on dominant biomedical framework, contemporary moral and ethical views, the socialisation of medical providers, the institutional practices of the healthcare systems and the larger social structures of society”. The social construction of illness “deals mainly with the illness experience” *(*pg. 37). Whilst these both differ in focus one is likely to influence the other. Whilst it is widely understood as a condition or disorder rather than an illness, how a diagnosis such as autism is constructed and the social, cultural, family, individual and medical narratives about autism will influence how a person experiences being autistic, and how they are perceived by others. For example, if a person does not tell their employer for fear of being judged and therefore reasonable adjustments are not made which would have supported them, or a family does not tell their neighbour, or a girl who feels she has to hide her diagnosis from her friends. The context or culture in which a condition such as autism is experienced, how it is portrayed, how it is responded to, and the policies that are created regarding the condition (Conrad and Barker 2010) will all impact on ‘how’ that condition is experienced.

Quoting Goffman, Conrad and Barker state that “the social meaning of impairment does not emanate from the impairment itself, but from the fabrics of everyday life” (2010 pg. 70). Whilst Brown (1995) describes a ‘multiplicity of social forces’ that join to ‘create and modify’ a phenomenon, such as autism:

“Rather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux. This social constructionist perspective looks at how the phenomenon was identified and acted upon. This involves the impact of the underlying social stratification system, and the roles of professionals, institutions, governments, media, pharmaceutical companies, patients, and people with illnesses and disabilities as well as their families” (Brown, 1995, pg. 37)

Both Brown (1995) and Conrad and Barker (2010) suggest a number of differing classifications of diagnoses of illness. This includes those which are widely accepted, those which are contested, those which are not accepted and those yet to be classified (such a newly identified chromosomal abnormalities). Brown highlights that ‘not all diagnoses will fit neatly’ into one singular category, and this can be said for autism. It has enough acceptance to be in both

DSM and ICD and the practice of diagnosing of autism is accepted by medical institutions such as the NHS. However, what autism is, how it is 'caused', and the boundaries of what autism is and what autism is not, is widely contested with some questioning if it is even a disorder at all.

Psychology and child development have an underpinning in what constitutes 'normal behaviour' and what is seen as deviating from the norm. The view being that "frequently occurring behaviours in a population are normal so infrequent behaviours are not normal" (Rogers and Pilgrim, 2014, pg.5). If this viewpoint is taken along with the view that autistic behaviours are present in non-autistic people as well as autistic people, does this just make autism a different kind of 'normal', or as Prizant and Fields-Meyer (2015) put it, simply "a different way of being human?" The concept of normality itself is questionable. F. Murray (2020) suggests that "if you stop to think about it, it should be pretty obvious that there is no one 'normal' way of thinking, but most people never give it much thought" (pg. 105). Mueller (2020) refers to the idealised 'norm' being "unmarked and unnamed, only defined and created by its deviations" (pg. 97) but due to the invisibility of the norm it is not possible to challenge it. It is the concept of 'normal' that D. Murray (2020) argues is one of the 'fundamental errors' in understanding autism and/or neurodiversity, as it suggests that there is a 'fully functional rational type of being' against which a 'pathologized autistic phenotype can be measured' to deviate against. Milton (in Timimi et al, 2019) highlights that it is this concept of normal plays a key role in ADOS (Autism Diagnosis Observation Schedule) training, where "all behaviours need to be coded in terms of deviation from the 'typical' norm". A process in which "the power relations presented by the tool places the clinician firmly at the centre" (pg. 9). A power dynamic Timimi felt is not acknowledged in diagnostic training where the assumption is that the "examiners side of the relational dynamic" is seen as "non-significant" and that anything that "emerges in the assessment is (seen as) purely the result of the interiority of the patient" (pg. 5)

Baron-Cohen questions if "autism is properly characterised as a disorder and whether the neurodiversity framework should be embraced" (2017 pg. 744). He proposes that "the term *'disorder'* implies that the natural order has gone awry and that the individual's underlying cognition and neurobiology is dysfunctional in some way – even if for environmental reasons" (2017 pg. 744). This can be seen across the diagnostic manuals where the focus is almost exclusively on impairment and deficit. The neurodiversity movement challenges the medical view of autism as something 'wrong' within the individual, perceiving autism as a part of an autistic person as much as their gender or skin colour. Unlike the medical model, rather than focusing on prevention or cure, the neurodiversity movement celebrates autism and autistic

people. Milton (2020) explains that neurodiversity acknowledges that “all brains to a degree are unique”’ and is “in contrast to an individualised medical model of disability, which contrasts ‘normal’ development with that of ‘abnormal’ traditionally framed in terms of deficiency and dysfunction” (pg. 3). Whilst there is an acknowledgement that autism has its challenges, the challenges are perceived as largely caused by outside factors such as sensory overload caused by modern lighting or being forced to conform to specific social behaviours such as eye contact. Baron- Cohen (2017) highlights that “when we examine the cognition and biology of autism, arguably what we see is not evidence of dysfunction but rather evidence of difference” (pg. 744). This is an alternative view to seeing autism as a ‘problem within the individual which needs to be rectified’ (Baron-Cohen 2017, Lai et al 2014).

Ida (2020) claims that in celebrating difference, Neurodiversity brings with it an ability to open up human potential and challenge “crude binaries of being normal, or not” (pg. 80). As a concept it challenges ableism and the view that a disability makes someone less or ‘inferior’ (Campbell 2020). It brings with it, its own complexities as whilst celebrating difference it is important to be mindful of some of the challenges that come with being autistic or neurodiverse, both in modern society or in any given context and time. This is a point highlighted by F. Murray (2020) who states “it is misleading to suggest that all disability is caused by other people’s attitudes and the barriers put in peoples way, but it is true that disability can never be disentangled from its social context” (pg. 107). This is something I observed growing up, and through the stories shared with me by my mother. Born with cerebral palsy she has a number of physical difficulties which she has had to live with and overcome that would exist with or without social discourse. However, I am aware of a number of challenges that have made her life harder, such as other people’s attitudes, discrimination and lack of consideration with planning public buildings and services.

In research into neurodiversity and difference, Kapp et al (2013) found that an awareness of the neurodiversity movement can influence how a parent experiences the diagnosis of their child. They found that “many of the tensions between the neurodiversity movement and the medical model focus on aspects of parenting, such as acceptable goals and means of intervening” (pg. 61) Parents who were aware of neurodiversity were more likely to ‘endorse positive emotions’ about autism. Parents who had less knowledge of the neurodiversity movement were most likely to think in line with the medical model with an interest in treatment and cure. The impact of parents’ ability to share their child’s diagnosis with them in a positive way should not be overlooked. In a study about parental disclosure of an autism diagnosis to their children, Riccio et al (2020) found “preliminary evidence that open discussions about autism may foster positive identity development” for young people with a diagnosis of autism,

whilst “those who had not been disclosed to voluntarily viewed autism in stigmatising ways and struggled to reconcile an autism diagnosis with their sense of who they are” (pg. 381). At its most extreme, the differing views of parents and members of the neurodiversity movement has resulted in petitions and actions to stop parents talking about how they view their child’s autistic behaviours, such as the petition to ban the book ‘To Siri With Love’ (Newman, 2016) written by a mother about her autistic son and in which she comments about his future relationships and fears of him having children.

With changing emphasis on causation, ‘blame’, aetiology, ownership of diagnosis (giving and receiving) and the variation in diagnostic criteria over time, the diagnosis of autism becomes a highly subjective and value laden act, especially with Wings own admission that it is difficult to identify exactly what observable behaviours can constitute a diagnosis. This is evident with the changes in diagnostic categories between the editions of DSM and ICD and the inclusion and later removal of Asperger’s. Similarly, homosexuality was included as a diagnostic category in DSM-I and according to Datta (2014) ‘begrudgingly’ removed from DSM-II. Is it possible that in years to come we will see the diagnosis of autism as a disorder in the same way many of us now view the ‘diagnosis’ of homosexuality as a mental illness? If the diagnosis was removed what would that mean for those who currently have it. Would it be freedom from a label that constrains and defines them, or would we risk a generation of children no longer receiving the specialised support that helps them to function in a neuro-typical (non-autistic) world. Would the removal of autism as a medical diagnosis leave a group of people feeling different and not understanding why, or would individuals be empowered to identify as ‘autistic’ (by whatever name) by themselves? A question raised by Uselton (2020) in a blog about her own self-diagnosis, where she stated “I don’t feel the need to have a doctor tell me something I already know about myself. There is no medication or treatment for autism, just awareness and strategies for living a happy life”.

Chapman (2020) suggests that the classification of autism, and what is classed as autistic traits is a matter of “power dynamics, ideology and social norms” rather than a picking out of “pre-existing classification” and that “the way we group and frame these is more related to social processes than simply being a matter of trying to understand nature” (pg. 45). Like me Chapman takes a ‘both-and’ position, both accepting the biological basis for some of the traits defined as autistic which may be present in any context, and also acknowledging the social processes that collectively groups them together to define a condition or disorder. He argues that “autism is constituted as much by the external world as much as internal traits, in such a way where it is both a construct and objective part of the world” (Chapman, 2020, pg. 41). This is a perspective supported by Williams (2020) who proposes ‘neuro-constructivism’ in which “genes, brain, cognition and environment all interact multi-directionally” (pg. 38). Rather than

get drawn into the argument about ‘does autism exist or not?’, we can instead consider: ‘Why do we group together the traits that we do to give a diagnosis?’ ‘Why do we exclude others?’ ‘How does Autism diagnosis change over time and what influences this change?’ ‘Who has the power to decide who is autistic and who is not?’ ‘How does the defining of autism or not differ in different cultures or contexts?’ ‘What is being made when a diagnosis of autism is given?’ Autism does exist as a construct, because we have made it exist by constructing it. To question this does not mean to deny it, rather it is a means to understand what has made autism come to be what we understand it to be today (and to consider the possibility that it may be something else tomorrow!) Chapman (2020), is careful to make the point that taking a position in which the diagnosis of autism is considered as a construct does not have to mean denying the lived physical, emotional and social experience of autistic people:

“The issue is not about whether the traits are real (clearly they are real), or whether they are biological (clearly this is often a significant factor). Rather, it is about how we decide to construct various clusters of traits into different classifications, and in turn to claim that these classifications themselves are naturally grounded rather than being human constructs” (pg. 43)

This is a view supported by Shakespeare and Watson (2002). They argue that no-one’s body (including the brain) functions perfectly and that we all have impairments of some sort. However, the limitations caused by those impairments, either physically, mentally, socially, and due to socio-environmental factors, vary greatly from person to person. They say that the grouping of these impairments, such as in the diagnosis of autism, “are socially and culturally determined” (pg.16) and that “different major groupings of impairments, because of their functional and presentational impacts, have differing individual and social implications” (p.g12). Promoting the social model of disability Shakespeare (2018), Shakespeare and Watson (2002) and Oliver (2004) propose that disablement is imposed on people by society in response to their impairments not as a direct consequence of the impairments themselves. An example is the barriers experienced by autistic people in everyday life, such as sensory overload caused by loud, busy supermarkets with harsh strip lighting. While, for example, some supermarkets now adopt ‘autism friendly’ shopping hours when lights are dimmed and music is turned off, or down, for those who need such accommodations shopping is limited to those hours. Nevertheless, adaptations such as softer lighting and reduced noise would be beneficial for the majority of shoppers, not just autistic ones. With this in mind society can be seen to create autism as a disability in more than one way. First in the naming and diagnosing of autism based on an everchanging grouping, and categorising, of individual impairments, and secondly by creating environments in which barriers are put in place for those who have some or all of those impairments.

Sadler (2005) suggests that the clinicians are lured into practicing unreflective psychiatry by diagnostic manuals, with the risk being that clinicians believe they know a person because they "fit a category". This is a viewpoint shared by Gergen, who expressed his alarm at the "expansion and intensification of diagnosis" and that "diagnostic terms help us to think that we are all working on the same phenomena" (Gergen, Hoffman and Anderson, 1996, pg. 102). According to Silberman even Kanner's early psychology tutor 'pointed out the deceptively seductive power of naming a condition' and that 'labels describe constellations of behaviour that can be related to any number of underlying conditions' (Silberman 2016). Given the variety in presentations of individuals diagnosed with autism, the changing diagnostic terms and definitions and more recent understanding of differences across gender as historical and cultural interpretations of behaviour, there is a strong possibility that the belief everyone is working with the same phenomena is questionable. As Gergen, Hoffman and Anderson (1996) puts it, 'the same actions and the same descriptions may mean different things at different times and with different consequences' such as the previous examples of homosexuality and DSM-I, and the removal of Asperger's from DSM-V or a 'western' diagnosis of autism to the child of a Somalian parent.

In social media and newspaper articles autistic adults diagnosed in their 30's or 40's have heralded the increase in diagnosis as a positive step, talking about how this new understanding of themselves has enriched their lives and answered questions they had about their struggles at school or the workplace (Jones 2015, Harris 2016, Cross 2016). I informally asked a number of autistic children and adults what their diagnosis meant to them. One young man in his twenties said "I don't view autism as a disability. For me autism is a different view, it's the ability to stand outside of social norms and look in with an inquisitive mind, without autism I wouldn't be me, and without truly being me I wouldn't be autistic". An 11-year-old girl said, "It's just good to know. It doesn't change anything about me, it's just good to know... and it helps because without it I wouldn't be able to get the help that I get when I am struggling with something...cos people understand me more". An 8-year-old boy said it was good to know he had autism because "all the people around me feel different and it would feel weird if I didn't know the reason why". For one 14-year-old, after years of feeling 'not normal' and different to her peers the diagnosis or understanding of her behaviours using the definition 'autism' helped her to understand why she found things difficult. Where in the past she had felt disconnected and different she was now able to connect with a new 'tribe' and understand herself in a new positive light. So, whilst Latif suggests the diagnosis is unethical, it could be asked is it ethical not to offer diagnosis, when some who have received it describe it as a way of understanding themselves that has been helpful. However, my CAMHS experience has shown that not everyone will experience a diagnosis in the same way. One girl felt a diagnosis of autism had

defined her in a negative way and that when people saw her, they saw autism before they saw her and perceived her as defective and ‘not normal’. Another girl was very angry that she was autistic and felt that it restricted her from being who and what she wanted to be.

There many meanings given to autism, from the multiple perspectives of those giving and receiving the diagnosis, those defining and agreeing what is required for the diagnosis, those researching autism and in the responses of the media and society when autism is discussed and explored. These meanings change over time and across cultures and contexts and will influence how autism and its diagnosis is experienced by autistic individuals and their families. For autism, diagnosis becomes an oxymoron, the medical diagnosis itself suggests impairment and disorder and is arguably necessary for support for the individual to reach their potential, whilst at the same time autistic people have many strengths and abilities which are to be celebrated and are valuable to our society. The majority of research about diagnosis has focused on perceived ‘facts’ about diagnosis in terms of how many people are referred and diagnosed, and the length and impact of waiting list. There is less research on the meaning attributed to autism diagnosis, what has influenced those meanings and how these impacts on lived experience. The label of ‘different’ from the norm holds both affordances and constraints and both need to be taken into consideration.

4: Methodology and Study Design

4.1: Introduction to methodology and study design section

In this chapter I describe my chosen research design, as well as the relationship between the epistemological and methodological approach taken, which in turn informed, and was informed by, my chosen research method and interview techniques. My relationship with epistemology has not always been an easy one and I share my journey, and evolving identity, as a systemic social constructionist researcher and as someone who has lived, and professional, experience in that which I was researching.

I also give information about how participants were recruited for my research, who was excluded and why, and what impact the choice of participant may have had on the data collected. I describe what ethical implications were taken into consideration when conducting the research, and what ethical implications need to be considered in the future as the outcomes of the research is shared.

Drawing on my training as a systemic psychotherapist and current practice as a researcher I revisit Burnham's 'approach, method, technique' (AMT) paper. Burnham (1999) invited therapists to consider their identities as systemic practitioners and to reflect on connections between social constructionist thinking, methods, techniques and/or contexts which they may have viewed as 'not systemic'. I combine 'AMT' with Carter and Little's (2007) framework for qualitative research, which defines the interrelationships between epistemology, methodology and methods, to create approach, methodology, method and technique (AMMT). Using AMMT I describe the interrelationship between my chosen approach, social constructionist onto-epistemology/transmaterial worlding (Simon & Salter 2019, 2020), methodology - coordinated management of meaning (Pearce 1999, 2006, 2007), methods - semi-structured interviews, reflection in and reflection on transcribing, thematic analysis and techniques – use of silence, clarifying meaning, getting the story straight and reflexive listening (Josselson 2013) .

The combined framework of AMMT enabled me to position myself as a systemic practitioner-researcher across all aspects of my research and encouraged reflexivity in stages of the study which held the potential to be more task orientated, such as transcribing data. Within the framework of AMMT I share the steps taken when identifying and reviewing themes from the transcribed interview data. Nowell et al (2017) stress the importance of qualitative researchers demonstrating "that data analysis has been conducted in a precise, consistent and exhaustive manner, through recording, systemizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible" (pg. 1). They describe

a step by step approach to exploring data and themes utilising Braun and Clarke's (2006) six phases: familiarising yourself with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Whilst they define six phases, they are clear they are not fixed and that a researcher may move between them back and forth as they revisit and redefine themes based on new information or thinking. It is important to hold in mind that a different researcher may follow the same steps with the same transcribed data and develop completely different themes due to a different research question, different interests, or different experience.

4.2: **A rationale for using Approach, 'Methodology', Method and Technique**

Whilst exploring literature about methodology I was reassured to read Carter and Little's (2007) comment that whilst "epistemology, methodology and method are fundamental concepts. Any experienced researcher should have wrestled with each of them during the time of their career" (pg. 1319). This is a struggle I have experienced as I have orientated myself between different stages of my research, sometimes due to a feeling of disconnect between my chosen epistemology and my lived experience (which I will later explain in relation to some social constructionist texts about autism on page 54) and at others due to a feeling that I have been lured into a task orientated approach, getting things done rather than 'reflecting on' what is being done, and 'reflecting in' in the doing of the doing.

I found that reflecting back on my early training as a systemic practitioner helped me to position my thinking, in particular Burnham's (1999) framework of 'approach, method and technique'. First used to define approach, method, and technique specific to family therapy, the concept was adapted to include systemic therapy thus incorporating therapy with individuals, couples, or non-family groups. Then a further adaptation included systemic practice in addition to therapy, such as teaching, supervision, or consultation. Approach includes a systemic epistemological lens, such as social constructionism, it encapsulates the practitioner's values, their selfhood, and refers to how "practitioners orient themselves to all aspects of their work" (Burnham 1999, pg. 4). Method refers to the "organisational patterns or practice protocol used both to set forth and bring forth aspects of the approach". It encapsulates the framework and structure that allows for the 'doing' of the practice and facilitates "the enactment of the approach" (Burnham 1999, pg. 5). Technique refers to the detail of what is done, the observable and accountable actions such as questions styles and techniques. The 'levels' of approach, method and technique were not seen as hierarchically fixed, and Burnham proposed that they could be used 'interdependently and independently'.

Whilst Burnham adapted the approach, method, technique framework to help systemic practitioners orientate themselves within their practice, Carter and Little (2007) proposed a similar (yet also different) framework to define the interrelationships between epistemology, methodology and methods.

Carter and Little state that "good qualitative research should be able to explain itself by presenting and arguing for an internally consistent set of elements, research epistemology (justification of knowledge), methodology (justification of method) and method (research action)" (2007, pg. 1326).

Epistemology informs choice of methodology, and methodology informs choice of method. However, the relationship is not fixed and hierarchical, rather like Burnham's Approach, method and technique. "Objectives, research questions and design shape the choice of methodology, and methodology shapes the objectives, research question and design" (Carter and Little, 2007 pg. 1323). Epistemology is described as 'axiological' as it contains the value basis for "explaining the rightness and wrongness" and "justification for" the type and source of knowledge embodied in, and enacted throughout, all aspects of the research (Carter and Little 2007).

Burnham's level of 'approach' contains epistemology and the approach to knowledge, yet unlike Carter and Little's framework, it need not be limited to epistemology. Carter and Little chose to exclude ontology, "what there is to know" (Willig 2013), from their framework proposing it was generally treated that researchers "treat social concepts as if they are real enough to be named and investigated" (Carter and Little, 2007, pg. 1326). I have found the combining of an ontological and epistemological approach to be the most coherent with my values as a systemic practitioner-researcher, where I remain curious about how social concepts and realities have been co-constructed in relationships. For this reason I find 'approach' a more appropriate axiologically than singling out epistemology.

Carter and Little reference methodology as informed by epistemology and the justification for the method. Methodology can determine "objectives, research questions and design" and also act as the lens through which the researcher will analyse and interpret data (Carter and Little 2007). A distinction is made between method as the observable and reportable actions taken in the project to create and gather the data, and the methodology as more of a guiding principle theoretical framework. I will describe the coherence between The Co-ordinated Management of Meaning, my chosen methodology, and a social constructionist onto-epistemology later within this chapter (see pg. 64). It is likely that The Co-ordinated Management of Meaning and 'methodology', in the sense described by Carter and Little, would fit within 'approach' as described by Burnham, rather than being identified as separate. For the purpose of my study

I have found it helpful to separate them to order and orient my thinking, whilst acknowledging their interrelatedness.

Method, as described by Carter and Little, "is constrained by and makes visible methodological and epistemic choices" (2007, pg. 1316). It is the method that produces the data and the knowledge, which is in turn analysed through the methodological lens, and interpreted epistemically, therefore a coherent relationship is required. In this sense Carter and Little, and Burnham, use method in similar ways, as it is the organising, or visible framework of the practice, or research, and can be described in terms of 'how things were done'. Whilst Burnham makes the distinction between method and technique, identifying specific techniques, such as question styles, Carter and Little appear to combine the two. I found that making a distinction between method and technique was helpful, as reflections on, and in practice, through an epistemic and methodological sense and enacted through the method, influenced technique (such as style of questions and reflective listening). This in turn influenced data gathered and the knowledge created. To help structure, guide, and explain my research I have used approach, methodology, method, and technique in the following ways. Approach, including ontology and epistemology, helped guide my research, it informed and was informed by my values as a systemic practitioner-researcher. Methodology, acted as a lens throughout the process of my study, including the literature review as well as the data gathering and analysis of data. It helped frame my thinking, aided my curiosity, and interrelated with the approach and method to co-produce (with the participants) the information I now have to share from the research interviews and analysis. Method describes the structure of my research, how my research activities were organised to facilitate and enact the approach (Burnham 1999) and the methodology, the 'research in action' (Carter and Little 2007). The visible, reportable and to some extent replicable part of my study. Technique, as defined by Burnham (1999) describes the specific activities such as question style. Technique can also describe specific actions taken within the process of the thematic analysis.

The following diagram illustrates my chosen approach, methodology, method, and techniques, which I then describe in more detail (See Fig 1)

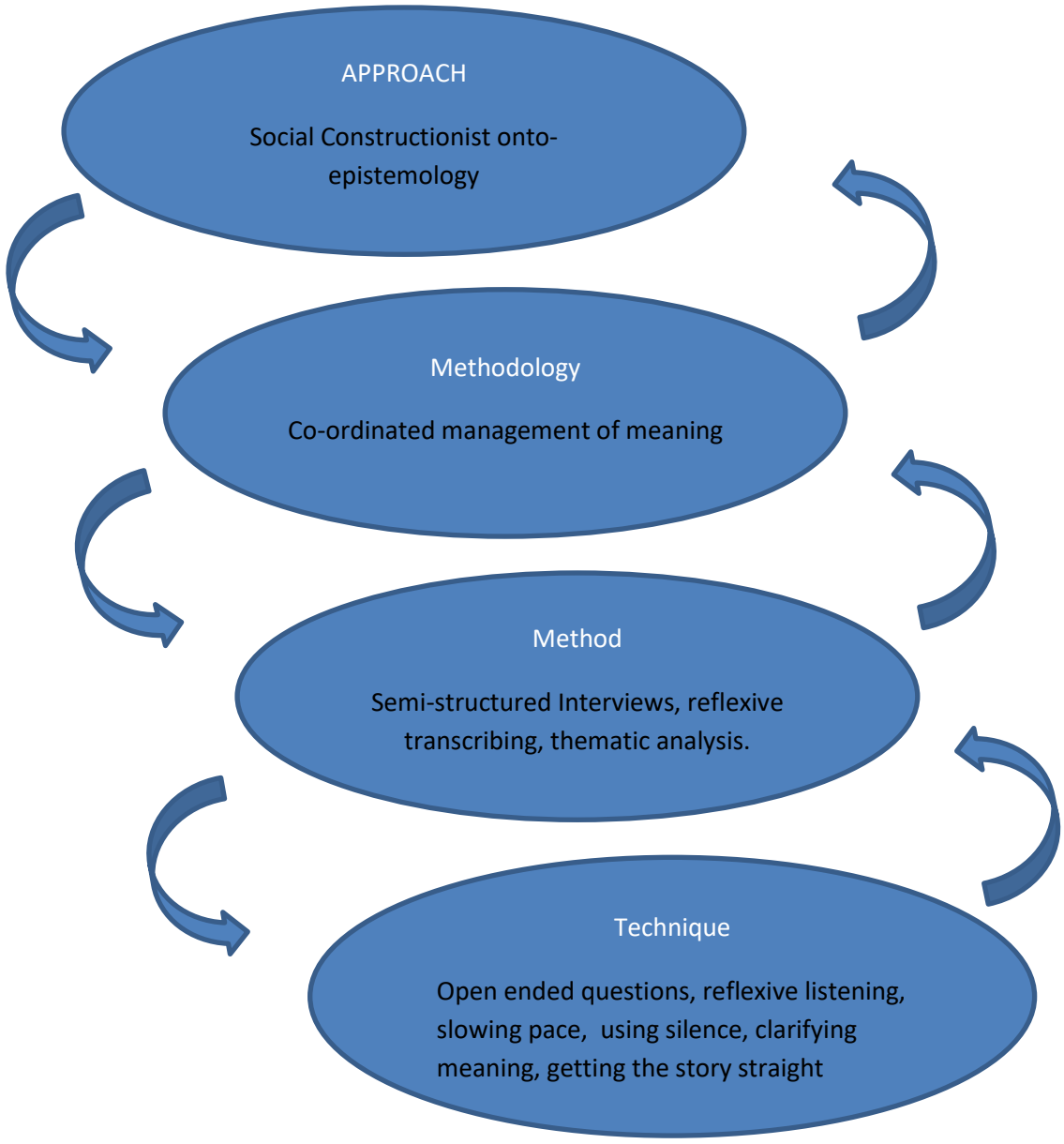


Fig 1: Approach, Methodology, Method and Technique

4.3: **Approach**

For over 20 years, and throughout my training and practice as a systemic practitioner, I have considered myself a social constructionist. However, whilst researching autism my relationship with a social constructionist epistemology and my identity as a social constructionist practitioner-researcher has been challenged. In this section I describe the context for this

experienced challenge. I offer some critique of both positivist and social constructionist epistemologies and describe how I have found taking an ethical-onto-epistemological position, also described by Simon and Salter (2019, 2020) as 'transmaterial worlding' helpful. I will describe the relationship between my chosen epistemology and method, in order to give true meaning to my research. Darlaston-Jones writes that "the ability to identify the relationship between the epistemological foundation of research and the methods employed in conducting it is critical in order for research to be truly meaningful" (pg. 19 2007).

My own relationship with some social constructionist literature about autism has been an uncomfortable one throughout my research journey, as has my relationship with some of the more positivist studies and writings. Rather like the mothers in Navot's research who felt "a sense of exclusion from the neurotypical population and the male dominated ASD population" (pg. 365, 2017), I have felt at times that I do not fit, or sit comfortably, with social constructionist thinking about diagnosis or autism, nor do I fit with those who have a more fixed view of autism diagnosis as a medical fact. In the course of my literature review I have read articles by social constructionists, such as Timimi, Gardener and McCabe (2011), Hassall (2016), Chown (2016) and Molloy and Vasil 2002) who have argued that there is no such thing as autism, just a 'neurological difference…constructed as a disorder' (Molloy and Vasil 2002), with individuals who may be nothing more than 'socially awkward' receiving a diagnosis (Hassall 2016). The label of 'autism' is seen as attached to behaviours that happen across everyone in the population but may be more in some than others. My discomfort with this view of autism diagnosis has in part been due to my own experience of diagnosis, as an individual and as a mother, which I will now explain.

After years of misdiagnosis I was diagnosed with petit mal epilepsy at 19. Whilst I had been experiencing the challenges of my condition for years, the diagnosis itself had a profound effect on my early adult life. At first I received this as an ending, I considered myself as faulty, damaged in some way. I withdrew, made some bad choices, and watched my mother question if she was to blame in some way as she asked questions such as: *"Is it because I dropped you as a baby?"* Oddly, things then turned, an awareness of my weaknesses made me stronger, I became more determined, made better choices than I had before and somehow made it through university with at least an average degree. A few years later, whilst I was working as a social worker, it was somehow picked up that I struggled with reading and writing. At the age of 23 I was sent for a dyslexia assessment, here I gained a new diagnosis. Unlike Epilepsy there was no medication, but an awareness of why I was finding things hard, as well as a very helpful tutor, enabled me to re-author narratives that I held about lack of academic ability. Much later, at 47, I was diagnosed with an auditory processing disorder, highlighting that whilst my hearing is perfect my brain can struggle to decode verbal information. Again,

no medication or cure is available, but now I understand why I miss information, am aware that I probably lip read at times and can make allowances that are helpful. My relationship with diagnosis has not just included my own journey but that of both my children, both diagnosed as autistic with ADHD and sensory processing disorder. Add my husband's MS to the mix, as well as the similarities we have to both our autistic children, and we are a family of diagnostic labels (given or suspected) all with different medical and social theories as to why we are the way we are.

This, my own relationship with diagnosis, as well as my training as a systemic family therapist, is why I have at times struggled with the epistemological perspective, for my research. Overall, diagnosis has not been experienced as a 'disaster' (Gergen, Hoffman and Anderson, 1996) or as a constraint, it has been a helpful way to understand lived experience, both physical and emotional. However, I understand that the diagnoses are socially constructed and culturally and historically contextualised. They will be experienced differently by different people at different times with the potential to constrain life chances as well as to enable them. For us too, it has meant different things at different times depending on age or context.

It might be useful to reflect on the nature of science and positivist research. Kuhn (1970) refers to 'normal science' in which researchers set out to prove, what are often pre-existing, paradigms. The epistemological position described by Willig (2013) as "a branch of philosophy concerned with the theory of knowledge" (Pg. 4) is one of 'proving' that which is and can be known. Willig (2013) suggests that positivism can "even insulate the community from those socially important problems that are not reducible to the puzzle form, because they cannot be stated in terms of the conceptual and instrumental tools the paradigm supplies" (Pg. 37). The ontological position, described by Willig as "what is there to know" (2013, pg. 3), is one of truth, the 'reality of things' as something which can be discovered, studied, and proven. Lawson (2014) explains that "a traditional goal of ontology has been to explore a possibility of a system of classification that is exhaustive in the sense that everything (we know about) can be interpreted as a particular instance" (pg. 3). Historically, and currently, this can be seen in autism research journals which have been full of studies which set out to prove pre-existing paradigms and beliefs about the nature of autism and autistic people, for example research to prove extreme male brain theory (see Greenberg et al, 2018). The focus of the research has been to find order, give answers and to deliver reportable 'facts' about autism, autistic behaviour, treatment efficacy, prevention and cure.

From a positivist/realist epistemology, a researcher stands outside and looks at that which she is researching objectively. The research can be repeated with a belief that the same outcomes can or will be reached. Reality is viewed as "universal, objective and quantifiable", and "the

same for you as it is for me" (Darlastan-Jones, 2007, pg. 19). The belief is that research data 'will provide us with information about the world and how things really are" (Willig, 2013, pg.11) and the external world is "seen to exist independently of our representations of it" (Burr, 2015, P.26). Edley (2001), refers to this view of the world as 'the common-sense view'. Reality is seen as "both prior to and independent of representation" (pg. 435). In the case of autism, this would mean that autism pre-existed Kanner's naming of it and will continue independent of it. In the medical world it is this belief that has, potentially, added fuel to numerous theories and studies in the search for its aetiology and prevention and the treatment and cure of individuals defined and diagnosed as autistic.

Whilst I have worked in a diagnostic service my view of autism is not that of autism as a fixed medical fact, there to be identified and named. I have seen the diagnosis and 'diagnosing' of autism transmute significantly in the years I have practiced within CAMHS and neurodevelopmental services. What was once excluded from diagnosis is now part of it, terminology has been introduced and removed, our understanding about autism and girls has changed exponentially and there remain significant cultural differences in the perception about, awareness of, or existence of, autism. For me the fluid nature of the term autism is highlighted, it is metamorphic across time and context, making me embrace a more relativist and social constructionist epistemology.

Adopting a social constructionist stance invites researchers to question our "taken for granted ways of understanding the world and ourselves" (pg. 2 Burr 2015). It challenges the view that we have a "real world" and that we then "have accounts or descriptions of that world" that are "good, faithful and accurate" (pg. 434, Edley 2001). Willig (2013), explains that relativists "subscribe to the view that there is no such thing as pure experience and the aim of research ought to be an exploration of the ways in which cultural and discursive resources are used in order to construct different versions of the experience (for example autism) in a different context" (pg.11). Research is no longer about proving theories or finding one objective truth and is more about gaining a greater understanding of meanings created in a specific context, in a moment in time and history and through the eyes of that particular researcher. In the words of Berger and Luckman (1966, 1991), thought to be the founders of social constructionism, if reality is socially constructed 'the sociology of knowledge must analyse the process in which it occurs' (Loc. 175).

Social constructionism is described by Simon and Salter (2019) as 'the theory of theories' but a precise definition of social constructionism has led to much debate. In this respect discussions about 'what is social constructionism' holds some similarity to discussions about 'what is autism' as its boundaries, and what is social constructionist or not, are unclear. Edley

(2001) said that there is no 'unitary paradigm' that can be described as social constructionism and "no single description" that would adequately fit all those referred to as social constructionists. However, there is what Burr (2015) refers to as a 'family resemblance*'* in which "differently nuanced forms exist side by side" (Edley 2001, pg. 436). Taking a similar position Gergen explains that "not all those who work in a constructionist idiom would agree on a premise, and still others would entirely avoid freezing the dialogue" (pg. 48, 1994). In seeing benefits to a "momentary solidification of perspective" Gergen (1994) proposes the following suppositions:

1. *"The terms by which we account for the world and ourselves are not dictated by the stipulated objects of such accounts.*
2. *The terms and forms by which we achieve understanding of the world and ourselves are social artefacts, products of historically and culturally situated interchanges amongst people.*
3. *The degree to which a given account of world or self is sustained across time is not dependant on the objective validity of the account but on the vicissitudes of social process.*
4. *Language derives its significance in human affairs from the way in which it functions within patterns of relationship.*
5. *To appraise existing forms of discourse is to evaluate patterns of cultural life: such evaluations give voice to other cultural enclaves" (pg. 48 to pg. 53)*

Whilst a positivist position might accept the existence of autism as a taken for granted fact (even if it's diagnostic definitions and boundaries may change), a social constructionist viewpoint would see autism as something brought into being through communication. Burr (2015) describes social constructionism as a "critical stance towards taken for granted knowledge" which "invites us to be critical of the idea that our observations of the world unproblematically yield its nature to us, to challenge the view that conventional knowledge is based upon objective, unbiased observation of the world" (pg. 2). From this epistemological viewpoint, reality, and in this case autism, "cannot exist outside of discourse waiting for fair representation. Instead it is the product of discourse, both the subject and the result of what is talked about" (Edley, 2001, pg. 437). In the words of Gergen, "what we take to be knowledge-bearing propositions about the world are essentially the outcome of social relatedness" (1994, pg. 129). Rather than autism being understood as something 'discovered' and named by Kanner, it would be seen as something 'brought into being' by Kanner's naming of it, as well as by the social discourses and practices that ensued.

Gergen (1994) proposed that there is “no foundational description to be made about ‘out there’ as opposed to an ‘in here’ about experience or material” (pg. 72) and that social constructionism ontologically speaking, is ‘mute’. Research from a social constructionist perspective requires a change of focus where “we cease to be concerned with foundational issues of truth and objectivity. What we happen to call things on any given occasion is not a matter of fidelity to the world as it is. It is a matter of the particular relationships in which we are participating…. For the constructionist, concepts of truth and objectivity may largely be viewed in terms of social pragmatics” (pg. 130 1994).

This shift sees descriptions and labels as not “just about something” but also “doing something” (Potter quoted in Edley 2001). For the purpose of my research, this positions me as curious about what are we *‘doing’* when we are describing, diagnosing, and identifying someone as autistic. When an autism diagnosis is made what is created and brought into being, what are the pragmatics of that diagnosis, and what are the affordances and constraints.

Whilst for research purposes a social constructionist position fits with my epistemological view, what about my lived experience? If I adopt a social constructionist viewpoint, what relationship do I now have with autism if it is seen as something ‘created through discourse’ rather than ‘described by discourse’. As I said, we are a family of labels. Does this mean our experiences, the challenges I see my children experience are not objectively real?

How do I, as a researcher, clinician, and parent, respect the lived experience of autistic people whilst adopting an epistemological position which says that their diagnosis is nothing but a social construct? Is this a denial of their lived experience? Is it ethical to engage people in researching their experience and then to tell them their experience is not real? Research tells us that autistic people are more likely to die younger from physical health or mental health conditions, including suicide, than people who do not have a diagnosis of autism. In one study the average age of death for autistic people was 53.87 years, compared with 70.2 years for the neurotypical population (Bazian 2016). In another study autistic people were found to be 9 times more likely to die from suicide than those with no diagnosis (Spiers 2016, Hirvikoski et al. 2015). If autism is a label given to those who are ‘little more than socially awkward’ why are these people dying younger? Whilst we can argue a case for meaning being historically and culturally situated surely death, being no longer living and breathing, is form of reality, as is life itself.

I did consider Phenomenology as a research approach, with the phenomenon of ‘Autism’ and its diagnosis as the focus of research. Groenewald explains that a ‘researcher applying phenomenology is concerned with the lived experiences of the people’ (2004 pg. 44). Whilst

this fitted with my interest in exploring mothers experience of autism diagnosis the approach did not fit with my onto-epistemological approach due to the positioning of realities as 'pure phenomena' (Groenewald 2004). Phenomenology is less concerned with external factors such as 'social or cultural norms, traditions, or preconceived ideas about the experience' (Centre for Innovation in Research and Teaching) which was an area of particular interest for my research.

I understand the definition of autism, the boundaries of what is classed as autism and what is not, and the power given to those who can diagnose and those who cannot as products of multiple historical, social, and cultural discourses. However, I also see a type of reality connected to some of the physical and emotional markers that we currently define as autism. For example, one of the criteria for an autism diagnosis in DSM-V is 'Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment'. In my clinical practice and my lived experience as a parent, I have seen children who are significantly affected by labels in clothes, noises such as hairdryers, distressed by certain smells and who are unable to eat foods with certain textures. It is hard to see how this physical and emotional response to external physical stimuli, is solely the product of discourse. Yet in DSM-IV, and previous diagnostic manuals, reactivity to sensory input was not included in the diagnostic criteria for autism. Smells, clothing labels, noise, and sensory stimuli of all types differ across cultures and have also changed over time. The identification of these responses as 'outside the norm,' or the changes in the contexts or environments that provoke these responses, can also be understood as part of a social process. Similarly, reduced eye contact, defined diagnostically as 'abnormalities in eye contact' within DSM-V, has different meanings attributed across cultures. Whilst averting gaze is seen as an 'autistic' trait in many western cultures, in other cultures making eye contact can be "considered aggressive or intimidating and not a required human interaction" (Willingham 2012). The physical-emotional experience of an individual of finding discomfort in using eye contact may be the same in two cultural contexts, but the meaning given to that discomfort may differ greatly, which in turn may impact on the behaviors of that individual and the interpretation of those behaviours.

Social constructionism is in itself an epistemological oxymoron, denied by its own theory, as even in the words of Gergen social constructionism is also a social construct (1994). Nightingale and Cromby (2002) state that "constructionist claims regarding the social conventional nature of referentiality and objectivity are grounded in a flawed epistemology that whilst offering a thoroughgoing critique of naive realist and objectivist accounts of social and psychosocial reality, at best entails a limited and partial account, and at worst merely inverts the conceptual and theoretical problems it associates with these positions it critiques" (pg. 710). In summary, "to say there really is nothing outside talk implies one somehow knows that

to be the case, absolutely and for all time, which is precisely the assumption that the epistemic sense of social construction sets out to disturb" (Edley pg. 427, 2001). Using this viewpoint, if a person says there is no such thing as autism, that it is just a social construct, they are 'implying they know that to be the case' which in itself is in conflict with a social constructionist epistemology.

Whilst not supporting positivist/realist research positions, and holding the belief that much of our lived experiences, that which we take for granted in our everyday lives, is the product of social communication and discourse, I feel unable to commit fully to Gergen's view of social constructionism as ontologically mute. For the course of my research I found that I was, epistemologically speaking, in what is described by Pearce (1999) as a strange loop (see fig 2).

I found that stepping out of the epistemological loop I found myself in required me to reconsider Gergen's view of Social Constructionism as being ontologically mute. Edley (2001) writes about how it is possible to take a social constructionist ontological position, in which "the term social constructionism refers to the way that real phenomena, our perceptions and experiences, are brought into existence and take the particular form that they do because of the language that we share" (taken from Burr 2015, Pg. 105).

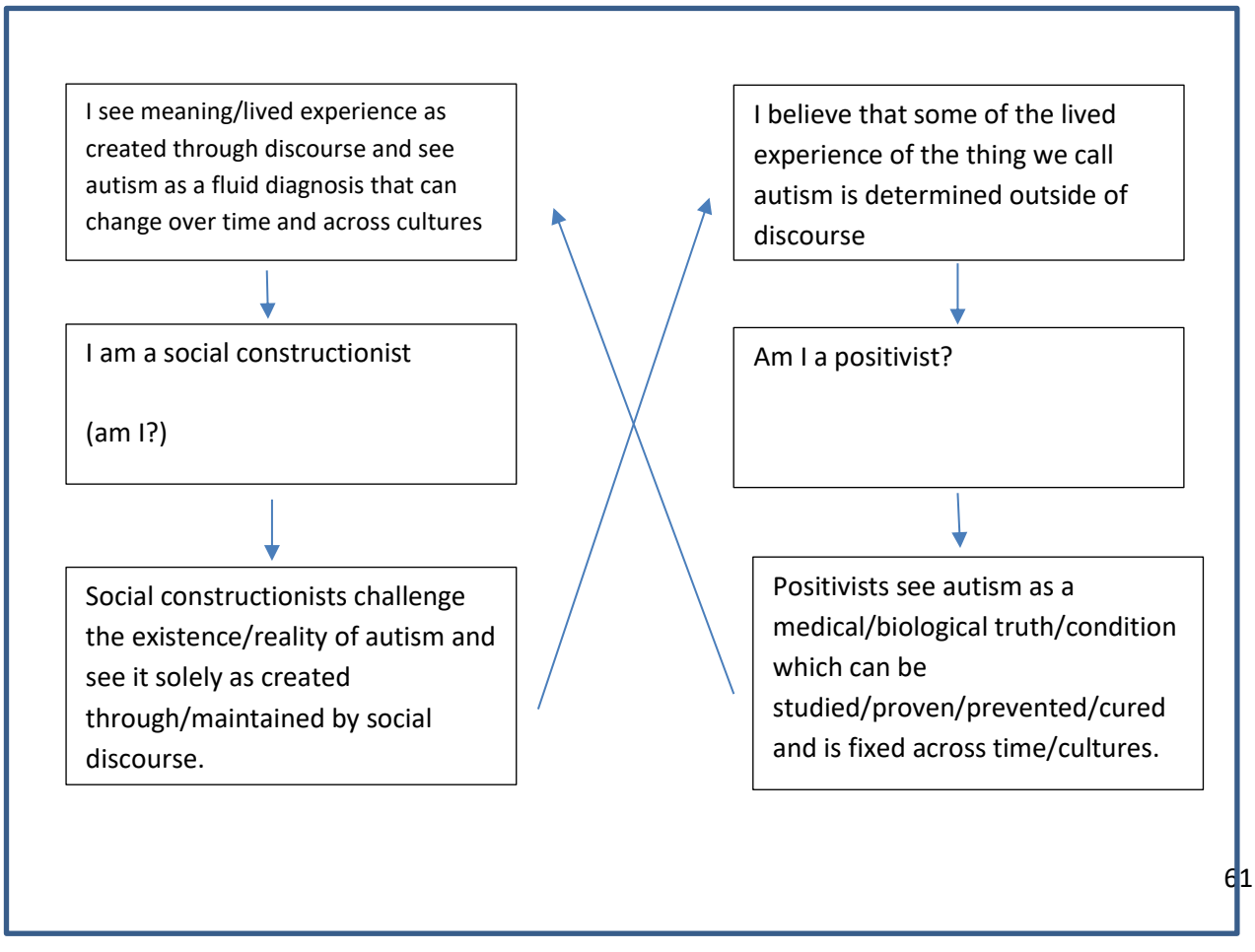


Fig 2: My epistemological Strange loop.

Both Edley (2001) and Nightingale & Cromby (2002) argue the case for social constructionist researchers taking an ontological position:

"Language is never a perfect mirror of materiality. But this need not entail that we consider it autonomous, transcendent, free-floating, and wholly self-referencing; instead language performs flawed, incomplete reference. However, this implies that constructionism, far from being ontologically mute, must in itself be an ontology. In other words, constructionism, as we present it here, has the potential to function as an explanatory framework within which we might examine the actual 'nature' of our world rather than the knowledge of such a world" (Nightingale and Cromby 2002. Pg. 705)

Edley (2001) uses the example of a social constructionist driving to Nottingham to illustrate this point. Whilst they will look at a map they will not suppose that it just "appears in the middle of the M1 motorway because it says so on the page and neither do they imagine that it somehow springs into existence at the moment it is mentioned. Social constructionism is much more subtle than this. Instead, a constructionist might point out that Nottingham is a city by virtue of a text (i.e. by royal decree) and its boundaries – where it begins and ends- are also a matter for negotiation and agreement. The argument is not, therefore Nottingham doesn't really exist, but that it does so as a socially constructed reality" (pg. 439). The same could be said of autism. The boundaries of what is inside and outside of the diagnostic criteria, the 'naming' of autism as a disorder, and the identification of this thing called autism as something different from the norm are socially constructed, whilst some of the experiences that are attributed to the label may not. Ontologically a social constructionist position does not dispute that someone is experiencing sensory discomfort from scratchy clothing or harsh strip lighting, however the attributing of this experience to a diagnosis of autism and 'outside of the norm' is a socially constructed reality.

This view is not new. In their early writings about the social construction of reality Berger and Luckman (1991) considered the dialectic relationship between biological factors and social factors. The same person, in terms of biology, born in a different time, different culture, into a different family system, may have very different life chances defined, in part, by their social realities and context:

"Biological factors limit the range of social possibilities open to any individual, but the social world, which is pre-existent to each individual, in its turn imposes on what is biologically

possible to the organism. The dialectic manifests itself in the mutual limitation of organism and society" (Berger and Luckman, 1991, loc 3222).

From an ontological perspective, reality, and our experiencing 'of' a reality, is co-constituted by language (Nightingale and Cromby 2002). It is "shaped and constrained by embodiment, materiality, socio-cultural institutions, interpersonal practices and their historical trajectories (all of these structured by, and reproducing structures of, power) such that language does not independently and thoroughly constitute our world. But within such constraints, language, in its objective materiality, discursively co-constitutes the realities we experience" (Nightingale and Cromby 2002, pg. 706). From a similar perspective Lawson argues that taking a social ontology approach invites us to question issues of power and democracy. It raises "questions of who should be taking decisions in the world of different identities where most of us are likely in some way (differentially) affected by actions taken by others" (2014, pg. 22). Our socially constructed realities are 'identity forming' (Berger and Luckman 1991) they are part of a circular process of whereby they are formed by society, internalised by the individual and are then reinforced externally by social expectations and roles. Berger and Luckman (1966,1991) highlight how some realities (such as autism as a disorder) are privileged over others, made within historical discourses and then become one of the many, present day objects of our social lives. There is "no fixed biological substratum determining the variability of socio-cultural formations" and "ways of becoming and being (are) as numerous as there are cultures" (loc. 967, Berger and Luckman 1991). Some of us have more power than others to influence these constructed realities, largely due to other social constructed realities that have informed our life chances, for a crude example a white, educated, self-employed middle class mother of an autistic child as opposed to an unemployed single mother from a minority ethnic group who had a poor education. Some of us may be constrained by the constructs of others who hold more power over us. Some of us will have more agency over some aspects of our social realities and less over others, and, as with autism, this may change across context and time.

I believe that taking an onto-epistemological position, one which Simon and Salter (2019 & 2020) define as 'transmaterial worlding', enables me to consider "the presence of power in relations and which realities have more influence over others" whilst not making separations between human life and "all else around us, whether man-made and/or naturally occurring" (Simon and Salter 2019, pg. 2). They propose an ethical-onto-epistemological position that promotes an awareness of the 'becoming of social realties', how they are formed and reformed in an interplay between the world (physical and neurological) and the world of discourse and communication. How do we come to know what we know about the 'realities' which shape our lives? Why are some stories are "promoted and sold in some contexts over others" (Simon and Salter 2020, pg. 86), such as medical discourses about impairments and diagnosis being

promoted above the celebration of difference and diversity. What are the socio-political and cultural power of these realities, who has the power to form or inform them, where do they create affordances and constraints, and how can they be resisted and/or reformed by those they impact on the most? This is a position also taken by Pearce (1989) who suggested that the "the characteristics of the material universe and the properties of mind are sufficiently different that any number of stories may be told that "adequately" account for the facts" (pg. 11). From this position I believe that I, as researcher, am able to explore the narratives and discourses that have brought autism, as we know it, into the social and political domain, whilst respecting the lived (including physical and psychological) experiences of those given the diagnosis of autism, 'autistic people', as well as those who love and care for them.

4.4: **Methodology**

Whilst it may not always have been 'visibly' present, my chosen methodology has informed all aspects of my research. It has been present in my thinking through the literature review, has guided my thinking in interviews, has informed the gathering of data, was the lens I used for my analysis and was the framework I used for the presentation of that analysis.

I wanted a methodology that would facilitate an exploration of the ways in which mothers of girl's experience diagnosis for their daughters, and how this is informed by family stories, cultural stories, and societal stories. I wanted the stories to hold centre stage. What stories did the mothers hold about autism and their daughters, what stories did they tell, what had influenced those stories and what sense of agency did they have in the development of those stories going forward. I was curious about how those stories might change and why, why some stories might be promoted over others, and where did they liberate or constrain them.

What was the 'meaning' and experience of the diagnosis and the 'diagnosing' and what affordances and constraints did the diagnosis bring? I was aware that waiting times and service provision may form part of the story, but this was not my main focus. I was interested in what narratives were held about autism, how this informed their lived experience of the diagnosis and what impact this had on their identity, their sense of agency and their relationship with daughters.

In his editorial Bolte (2014) reflected that there may be a 'perceived lack of need' to conduct qualitative research because the 'main objective of qualitative research is to gain deeper understanding of human behaviour and experiences' and many researchers and practitioners may feel they already have this from their clinical experience. If we did all take this position how would we hear the stories of those we wish to research and learn more about. Whilst the

last four years has seen an increase in in qualitative research, the majority of the earlier studies I read that did add comments and reflections from participants had done so 'in addition' to figures and percentages, rather than giving them centre stage. It was the numbers and percentages that were promoted to tell the stories, not the participants 'the people' themselves.

In order to address my research question and explore the stories held about autism, both in my literature review and by the mothers I interviewed, I used the Co-ordinated Management of Meaning (CMM) as a framework and methodological lens.

CMM is a social constructionist model which explores levels of meaning which inform any given moment in interaction or communication, such as societal stories or family stories.

Barnet Pearce coined the term 'Coordinated Management of Meaning' in 1973 when he said "communication is about meaning...but not just in a passive sense. Rather, we live in lives filled with meaning and one of our life challenges is to manage those meanings so that we can make our social worlds coherent and live with them in honour and respect. We are always and necessarily coordinating the way we manage meanings with other people. So (he) concluded, communication is about the coordinated management of meaning" (1999, pg. 7). Pearce explains that "CMM does not try to offer a set of propositions about the events and objects of the social world it is rather a set of concepts and tools focusing on the process by which those events and objects are made" (Pearce 2007, pg. 78). It gives "terms and diagrams and the like with which to think" rather than "a set of truth-claims to think about" (Pearce 1999 pg. 13) The use of CMM encourages practitioners and researchers to "look at the complexity of meanings" to "identify the unknown connections among things, and the multiple levels of meaning embedded in even such apparently mundane things" rather than trying to "get behind or beneath them to the facts" (Pearce 2007, pg. 96)

Whilst initially developed as a communication theory CMM is emerging as a research tool. Swords et al (2014) used CMM to explore the coordinated management of meaning of sex for male college students using a survey with open-ended questions about current sexual practices. They then used a thematic analysis of the narratives, first using "repetition, recurrence and forcefulness" and then re-engaging the data using "preliminary themes as conceptualised through a CMM theoretical lens"' (pg. 1386). They reported that "as a theory with practical applications CMM, analyses demonstrate how narratives can represent a crucial tool in understanding how individuals make sense of their sexual experiences" (pg. 1393). Something which I feel can also be applied for the experience of autism diagnosis.

CMM is based on the view that we "consist of a cluster of social conversations, and that these patterns of communication constitute the world as we know it" (Pearce 1989, pg. 11). Pearce invites us to be curious about things such as "beliefs, personalities, attitudes, power relationships, and social and economic structures as made not found... in reciprocated communicative action" (Pearce 2006). Pearce asserts that each of us is "born into patterns of pre-existing relationships that we did not choose and that will shape the way we live our lives in important ways" (2007, pg. 199) and "the forms of communication in which we participate either liberate or enslave us; they facilitate or subvert human values" (1989 pg. 11). It shifts the focus from 'truth' or 'observable facts' to how the 'meaning' and 'experiencing of' things is informed by, and co-ordinated in, communication. Within my study it facilitated curiosity about the 'diagnosing of autism' as a construct, exploring the potential affordances and constraints of autism as a description of the behaviours, challenges, and 'symptomology' of the daughters of the mothers interviewed. Burr (2015) suggests that whilst we use gender as the main division of the human race – 'men and women'- we could easily have used the division of 'tall and short'. This could potentially be connected to the observed divide between 'autistic' and 'neurotypical' behaviours.

The theory initially started as an "interpretive theory primarily focused on interpersonal communication" but has developed into a "practical theory that collaborates with practitioners to improve the patterns of communication that it describes and critiques" (Pearce 2004 pg. 37). In both my literature review and research I adopted CMM as a lens to view autism diagnosis and look at what is being communicated when a diagnosis of autism is given, what meanings are connected to the diagnosis, how have those meanings been made, not just for or by the individuals involved, but also for wider society and across time and context.
Citing Pearce; Rascon and Littlejohn (2017) propose that "in one form or another, all CMM research asks two questions:

1. What is being made?
2. How is this being made in communication?

(and that) CMM research can go a step further to ask:

3. How can participants make something that works better for them?" (pg. 15)

For the purpose of this study when I asked, 'what is being made?', I explored how the label of autism has been created (historically), how it has changed (in developing practices and understandings) and what does it mean when a diagnosis of autism is given.
When I looked at 'how is this being made in communication?' I explored about how the mothers perceive and experience autism through how it is talked about in society, services and families and how the diagnosis is communicated.

With regards to how can participants make something that works better for them? I considered how I as researcher (and participant researcher as a mother and clinician), and the mothers participating in my research can shape practice and services to 'work better' and be more coherent? I also considered how the diagnosis may or may not make something better for the mothers and their daughters who received the diagnosis.
When considering autism diagnosis and 'what is being made?' I considered the historical and cultural social construction of autism itself. To put this in context, to take an objectivist position one could say that in 1943 Kanner discovered Autism. Autism had always been there, but no one had observed, measured, and named it before. Research might question the specifics of autism, did Kanner get it right? Were there things he missed? Do we have more information about types of autism? Is autism more prevalent or is it just that we did not have all the facts to identify and diagnose everyone who is autistic before? If you were researching maternal experience of diagnosis you might ask questions about the impact of waiting times, the experience of getting the diagnosis and how having this diagnosis has helped you access support and information. You would have less interest in the values of diagnosis itself, why we diagnose autism, who diagnosis it and is it helpful.

If you take the perspective of autism as 'made not found' using CMM you may consider that rather than 'discovering' autism, Kanner made autism a 'thing' when he observed a certain set of behaviours and labelled them as 'autistic'. It is not to deny that those behaviours and/or experiences exist, but would question the meanings given to them, Why those specific behaviours were identified as autistic? Why then? Why were certain behaviours excluded? What meanings were given to those behaviours? What would the impact have been if certain behaviours had been excluded or included, and what if Kanner's work had never been published? Looking at Maternal experience of autism diagnosis, you might ask why mothers feel they should seek diagnosis for their child, what do they think it will change and why do they feel they need a diagnosis to bring about that change, do they feel obligated to seek diagnosis and what do they believe it means to be the parent of an autistic child in their family or in wider society.

So, what if autism had been 'discovered' or identified at a different time, by someone other than Kanner who had been observing a different set of subjects?
Kanner observed 11 children who presented with significant difficulties, all or most had language delay and learning difficulties, and the majority were male. What followed was an understanding of autism as a childhood disorder which was connected to learning difficulties and language delay and believed to be more prominent in boys. Research has largely focused on how to identify, prevent, treat or cure autism as it has been presented to the world by

psychiatrists as a disorder, something which should be removed or at least corrected, and diagnosis has to be by qualified medical professionals. What some now believe and/or understand is that autism is a lifelong 'condition' or way of seeing the world. Autistic people do not always have language delay, people identified as very intelligent can be autistic or people with average intelligence as well as people with learning difficulties. It is also believed that autistic girls have been under-identified, under-referred and under-diagnosed. Autistic people and advocates are now challenging the focus of research and arguing that it should be about improving quality of life, not prevention or cure and adults are identifying as autistic and not always seeing the need for an 'official' diagnosis.

4.4.1: *A telling and an un-telling of the autism story*

I would like to invite you to imagine how things might or could have been different if autism had been identified by someone else at a different time. Fitzgerald (2004) has suggested that historical figures such as Einstein, Marie Curie and Emily Dickenson may have been autistic. What if it was in connection with one of these great thinkers that autism had first been 'named' or 'identified'. Einstein was born in 1879. He is believed to have been a 'loner, and repeated sentences obsessively until he was 7 years old' (Muir 2003). He was also believed to struggle socially, had sensory sensitivity, and is described as presenting with a lot of behaviours that are currently understood to fit with a diagnosis of autism. Marie Curie and Emily Dickenson have also been retrospectively identified as showing signs of being on the autism spectrum.

What if, in the 1930's, prior to Kanner's work being published, someone had published research into similarities between great thinkers, scientists and poets. In their study, they may have found a common thread of a preference for solitude, some social communication difficulties, an ability for great thought and creativity and an ability to see the world slightly differently from the majority of the population. They may have used the word autistic to describe them due to the common thread of either difficulty socialising or finding socialising difficult (which whilst similar I would argue are not one and the same as one is observed and one is experienced).

Autism may then have then identified as gift rather than a disorder and it would not be understood as a male or childhood condition/disorder. It may not make it into the DSM or ICD manuals, you might not have it diagnosed by medical professionals but it may be identified in schools who would encourage and develop the skills of those who had it, or it would be identified by individuals about themselves. Research would not have gone on to predominately focus on how to prevent or cure autism. Scientists and researchers may however have focused on how to reproduce the 'autism gene' with many of the scientists proudly identifying

as autistic themselves. With the term autism taken, Kanner would have chosen a different term to describe the children in his work and at first, they may be seen as something quite separate to the likes of Einstein, Marie Curie or Emily Dickenson. The behaviours currently identified as 'autism' would still be the same, but the co-ordinated management of meanings given to those behaviours would be different.

Now, rather than having a growing neurodiversity movement advocating for the rights of autistic people and giving some autistic adults a voice, we might start to see shock stories in the press connecting autism (that everyone wanted to identify with) with the condition named by Kanner (which might be seen as a deficit or disorder and something very different).

I know the second story has not happened, but I would like you to consider the possibility that it could have happened. Both stories are about the same people and the same set of behaviours, they have just developed alternative meanings due to how the stories were told by different people at different times.

4.4.2: *The power of language*

CMM acts on the "assumption that language is fateful" and the stories we tell, or that are told about us, "prefigure and/or constitute the lives we lead" (Pearce 1999 pg. 42). Pearce (2007) describes how the "power of language cuts two ways". It "enables us to move into a world of purpose and meaning that we did not create". It " supports and sustains us in having identities, motives and opportunities for sophisticated lives beyond our capacity to create" but it also "programs us to fit predetermined niches within those societies, and prefigures problems as well as opportunities" (pg. 98, 2007). He suggests that "change can be brought about by a process of re-authoring our stories" (pg. 42, 2007). The power to change these stories varies across time, social context, and culture. Historically, with autism, psychiatrists and psychologists have had more power to change and create stories than those who are diagnosed or labelled by them (contextual force). We now see examples of the autistic community striving to re-author the story of autism from one of deficit and disorder to one of difference and different ability. Whilst historically the medical 'story' has had more power, the collective voice of the autistic community has become stronger and has gained more influence. Once defined, described and constrained by medical and deficit narratives about autism, the autistic community are redefining autism itself (implicative force).

CMM takes the position that the meaning of language "is not only its use but its effects. Utterances call forth or elicit responses from others and these responses join the original use to create and co-construct a pattern" (Pearce 1999 pg. 21). CMM also takes the position that "meaning is dependent on the context in which it is occurs, but communication acts are always in multiple contexts. While there may be any number of stories and these may be in any

pattern, we almost always find stories of personal identity, of relationships among the people involved in the communication event; of the episode itself; and of institutions, organisations or cultures involved" (Pearce 2004 pg. 39). If we consider an autism diagnosis this invites us to question what it might bring forth for those who receive it for themselves or their children, and how it is given new meaning with their own stories about autism and diagnosis, their lived experience and the responses and interactions of others, including what is said in society. The same diagnosis given by the same person about two children of the same age can mean very different things to those who receive them. For example, for one person the diagnosis may bring relief and an understanding of unique qualities that are to be celebrated, whilst for another it may be seen as a deficit and something they wish to hide or deny. Even for the same person, the diagnosis may mean different things at different times due to context, relationships, new events, or new information. CMM invites us to think about the different meanings from culture, society, family relationships and the moment of interaction itself, and how they inform any given moment. Whilst illustrated as a hierarchy in early models these levels of meaning are not seen as fixed as they will have different influence at different times. For example, if you are with family the influence of family scripts may be stronger, if you are with work colleague's stories from your work culture may have more influence. Burnham (2017) suggests playing around with the levels of the CMM hierarchical model. Additional levels of context can be added, such as 'stories about significant relationships' (see fig 3). The arrows, signifying implicative or contextual force, can also be shown in different sizes to show which levels have the most influence at any given time. The arrows can also jump across levels, indicating that they are not fixed but interchangeable dependant on context, relationships, and time.

A challenge is created when the stories or beliefs you hold contradict one another which can create confusion and impact on your ability to go on, something described by Pearce as a 'strange loop'. For a mother of an autistic child, this might be holding stories of autism and disability whilst also seeing the abilities and strengths of her daughter, or conflicting stories about what it means to be a 'good mother'. If the stories fit and complement each other this is described as a 'charmed loop'.

Pearce suggests that we don't just communicate differently, we also experience the world differently 'because' we communicate differently and that "we... come to believe the patterns to which we are born (as) natural and right" (1999 pg 10 & 25). With autism, a number of societies have come to believe there is a 'thing' called autism and that professionals have the power to diagnosis it or not. Whilst some question if a diagnosis has been made correctly about an individual by a clinician, or for example if there is a difference between males and females, few question why it is only medical professionals who can diagnose, why autism has been framed as a disorder and why we need to diagnosis it all.

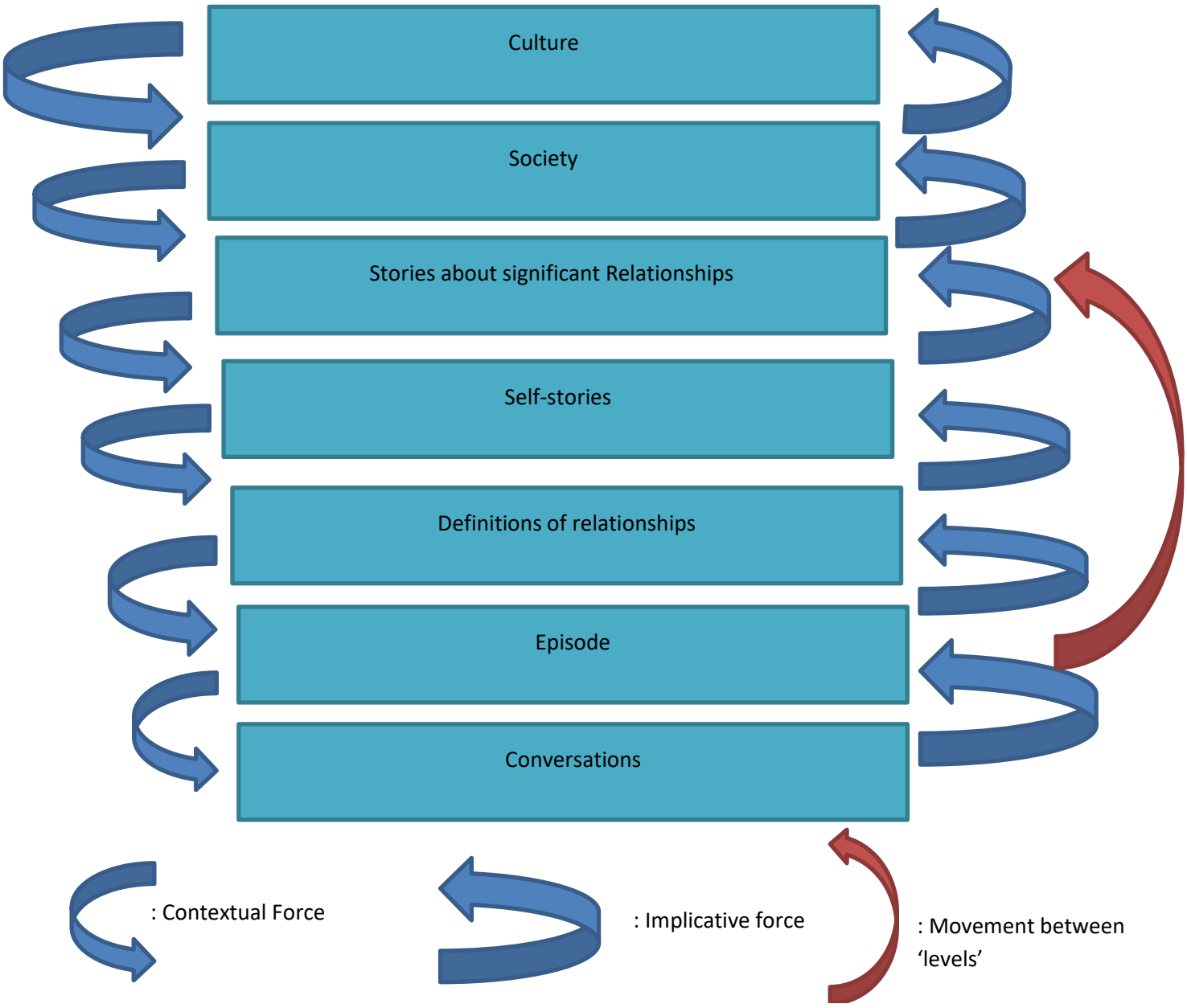


FIG 3: CMM hierarchical model adapted from Pearce (2004, 2007) and Burnham (2017)

CMM invites us to look at critical moments, 'bifurcations' or turning points "in which what happened or in which what might have happened determine the trajectory of the conversation (or event)" (Pearce, 2007, pg. 5). For autism, some of the critical moments might be the first-time autism is suggested, when a referral is made or the moment of diagnosis. Wasserman and Fisher-Yolanda (2017) state that "whilst each choice has consequences and sets the

stage for the next interaction" some moments are more critical than others. "All interactions have an afterlife, but critical moments have a bigger impact and longer afterlife". Each episode, such as the episode of diagnosis is entered into 'midstream' with conversations, stories and events that occurred before, and events, actions, and experiences to follow (pg. 16 & 66). Importantly Pearce highlights how "every naming is also a not naming" and "every affirmation is a denial of alternatives" (2007, pg.100). When we describe someone as autistic, what are we also 'not naming' them, whilst there may have been opportunities or benefits due to the diagnosis what potential alternatives have been denied?

CMM invited me to be curious about why a parent feels they 'ought' to seek a diagnosis for their child. Is it because they feel they have to in order to get the right support as suggested in Russell and Norwich's study (2012), or do they feel they have to because of societies expectations about seeking a diagnosis if something is 'wrong' or 'different'? Ultimately do they feel that this is something they had a choice over, or something in which they had no say? I have in the past spoken to practitioners who have considered it a safeguarding concern if a parent does not pursue a diagnosis for their 'potentially autistic' child. Pearce suggests that we often find ourselves in "overlapping, unravelling, unfinished webs of perceived oughtness" (Pearce 1999, 2004, 2007 & Wasserman and Fisher-Yolanda 2017) and uses the term 'deontic logic' and 'logical force' to describe this process. He explains *that* "researchers will listen carefully for descriptions of oughtness and use the concept of logical force to identify the participants' sense of what they must, must not, and may do" (2006, pg.17). For example, did the mothers believe that they had to seek a diagnosis for their daughters, did they feel they had a choice and what informed that perceived choice, or lack of it. I believe that the sense of agency or obligation felt by a mother when seeking diagnosis will have an impact on how they experience the process and subsequent diagnosis of their child. What was the context in which the decision to pursue diagnosis was made (contextual force), what was the influence of others (pre-figurative force), what did they hope the diagnosis would bring (practical force) and what did they want others to do in response to the diagnosis (implicative force) (Pearce 1999, 2004, 2007, Wasserman and Fisher- Yolanda 2017). If a mother feels she had a choice to seek the diagnosis and wanted it to bring about change for her child will she have a more positive experience of the process than a mother who feels they had to seek the diagnosis and felt the process was 'done to' them?

At the start of my study I believed that what some mothers or parents hope for from a diagnosis is a shared meaning and understanding of their child's challenges, strengths, and needs. In CMM terms shared meaning enables 'co-ordination' with others which allows us "to feel connection and receive social recognition" (Wasserman and Fisher-Yolanda, 2017). The

process in which we co-ordinate is informed by ‘coherence and mystery’. Pearce explains that “coherence directs our attention to the stories we tell that make our lives meaningful”’ and “mystery directs our attention to the fact that the universe is far bigger and subtler than any possible set of stories that we might develop. Whatever we think there’s more to it than that: it’s not a riddle to be solved but a mystery to explore” (2004. Pg.50). Importantly coherence helps inform us of what “episode (we) are in, what (we) should do next” and gives us “at least some idea of what to expect as a consequence of (our) actions” (Pearce 1999 pg. 32). Without coherence, we can experience confusion and ‘vertigo’. Due to the discomfort and unease experienced when we do not achieve coherence, it is thought that there is a drive ‘to know’ and our “impatience can result in an inability to manage the ambiguity of not knowing” (Wasserman and Fisher-Yolanda 2017, pg. 72). For parents of children suspected to be on the autism spectrum this may be the drive in seeking a quicker diagnosis (e.g. for those who go for a private assessment or make complaints about waiting times) in order for them to give meaning to their child’s behaviours, co-ordinate with others and create some coherence about what they feel they can, can’t and should do and what to expect from others, including their child. In part this will be informed by societies story that a diagnosis has to be made by a medical professional and that without it there is little (or at least less) that can be done.

CMM gives different tools or models for exploring the stories or meanings that inform and are informed by interactions in any given moment or over time. The serpentine model is described by Rascon and Littlejohn as being primarily used “as a conversation or episode analysis tool” and “particularly useful in depicting actions turn-by-turn” (2017 pg. 33). The model illustrates conversation and/or an interactional sequence over time. The model is largely used to look at moments of interaction between individuals in acts such as:

Act 1 - Person 1 – Want’s to connect with person 2 and ‘stops and says Hello’
Act 2- Person 2 - Is in a hurry and says ‘Hi’ whilst still walking.
Act 3- Person 1 – Looks embarrassed says ‘oh’ and looks back at person 2.
Act 4 – Person 2 – Carries on walking unaware.

In a serpentine model this may be shown as on the next page in Fig 4:

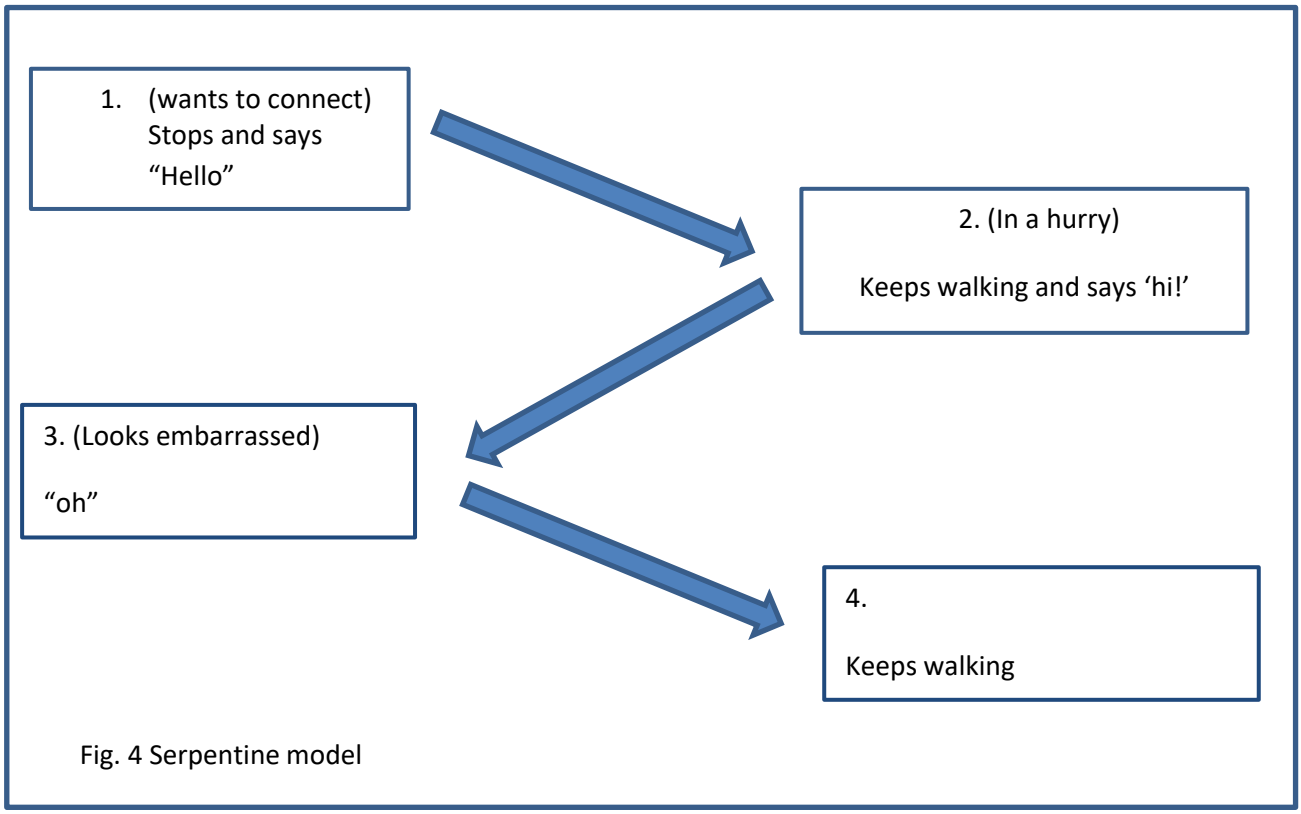


Fig. 4 Serpentine model

Whilst the model more traditionally looks at turn taking in an interaction Pearce has stated that CMM models are not fixed in how they are used. The serpentine model can be widened to look at different interactional sequences and could be useful in punctuating moments or stages in a diagnostic journey.

If the focus is on the process rather than an interaction between two people some of the stages could be as shown on the next page in Fig 5:

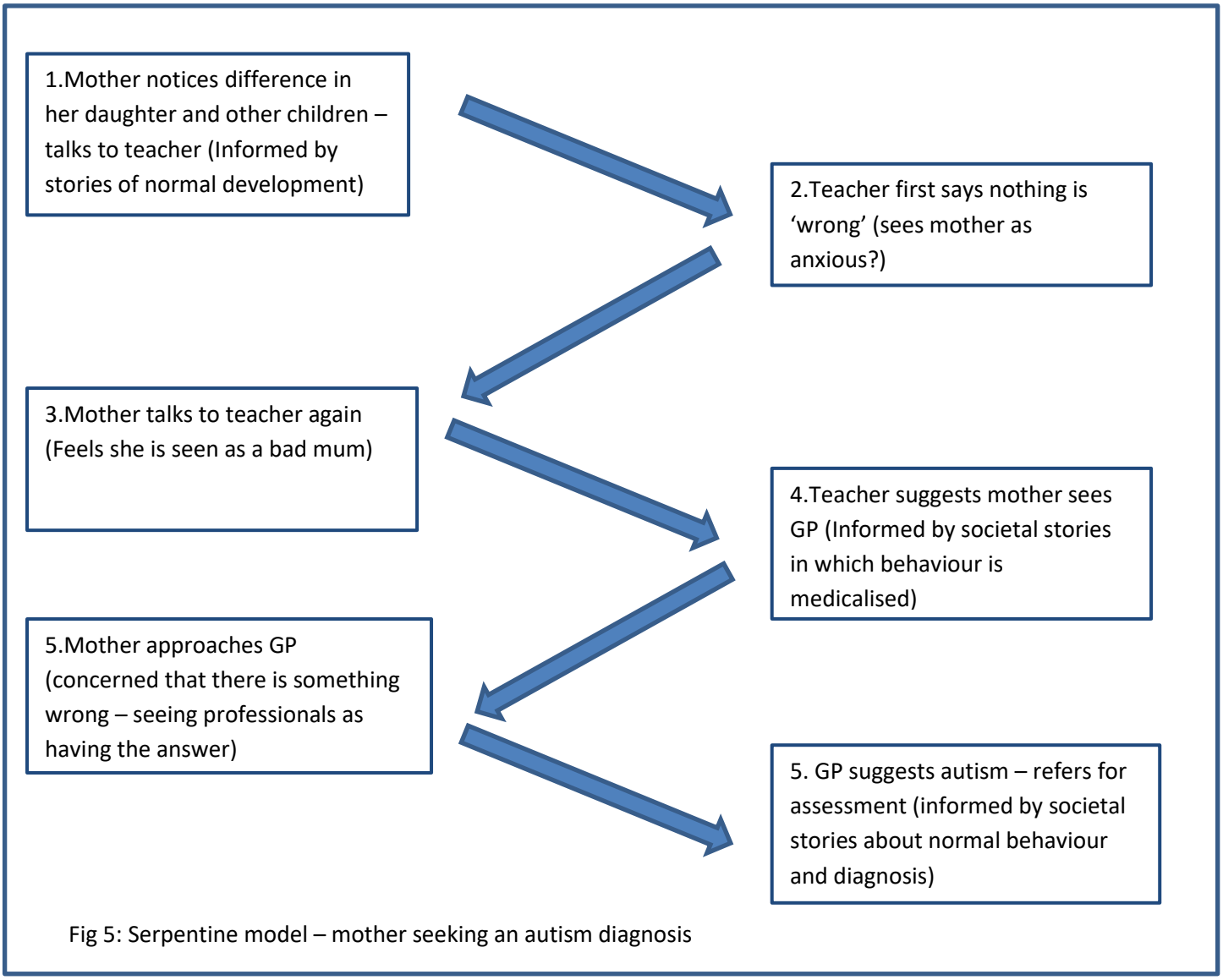


Fig 5: Serpentine model – mother seeking an autism diagnosis

The model may also be used to show how different mothers identify the stages in the process differently. One mother may include a conversation with another parent as important in the journey, where another might include reading a newspaper article or watching a program on the television. Pearce explains that "CMM researchers look at the sequence of actions and mark those points where something changed" (2004 pg. 13) and strive to be curious about the complexities at what is happening in each of these moments. For a mother seeking a diagnosis for a child, I believe there will be many stories which influence how she feels and acts. These may be stories about what it is to be a mother, stories she had about how her daughter would be and what relationship they would have, stories about autism and deficit, and stories about autism and diversity. Each turn in the serpentine model can be informed by multiple stories,

some of which will have more power than others. CMM invites us to be curious about these stories and offers the LUUUUTT model. “LUUUUTT is an acronym for 1) Stories **L**ived, 2) **U**nknown Stories, 3) **U**ntold Stories 4) **U**nheard Stories, 5) Untellable Stories 6 Stories **T**old, and 7) Story **T**elling” (Pearce 2007 pg. 212). For a mother this may include (but not be exclusive to) her lived story as a mother to a daughter, stories which she has not yet heard about her child’s diagnosis or autism (unknown), stories untold about how she feels about the diagnosis, unheard stories about strength and resilience, and the process in which she feels able to tell her story, including in my research. In any given moment, there are multiple layers of stories and multiple storytellers, many of whom may be absent or in the past, or even imagined in the future. “There will always be a tension between stories lived and stories told” (pg. 210, Pearce 2007) and these stories have an impact on what a mother feels she can, can’t, should and ‘ought’ to do. Pearce (2007) described this tension as “one of the powerful drivers fuelling the development of our relationships” and explained that “if the gap between our stories lived and stories told gets too great, we’ll need to do something, either by reauthoring our stories or changing our actions” (pg. 211). The challenge, as highlighted by Griffin (2014) is that whilst we can author and craft our own stories ‘to be coherent and consistent’ our stories also ‘interact with the actions and reactions of others’ and that can make them ‘messy’. I believe this to be the case with autism, as there are many people for mothers to coordinate with regarding an autism diagnosis, sought or given, for their daughters along with a multitude of historical, social and medical narratives. This can give rise to many conflicting stories, some useful, some not, and the mothers are subject to a lot of, what I refer to as, ‘oughtism’.

4.4.3*: ‘Oughtism’*

Pearce (1989, 2007) refers to how the ‘oughts’ that we experience impact on our actions, often without us thinking and questioning why we do what we do, or what makes us feel we should, can, can’t or have to do it. In my practice and experience Autism is surrounded by ‘Oughtisms’. The dictionary definition of ‘ought’ is to critically express ‘obligation, advisability or probability’. You ought to do something, you ought to act a certain way, you ought to feel a certain way, a certain thing ought to happen. The Merriam-Webster online dictionary definition of ‘ism’ is defined as ‘a distinctive doctrine, cause, or theory, an oppressive and especially discriminatory attitude or belief’ or ‘prejudice or discrimination on the basis of a (specified) attribute’. Therefore combined ‘Oughtism’ is ‘the practice of criticizing others, telling others how they should or shouldn’t be and questioning their actions or beliefs’ (Evans 2019, Simon, Evans et al 2020). For the mothers of autistic girls some of the oughtism’s experienced might be:

‘You ought to use more discipline’.
‘You ought to seek or you ought not to seek a diagnosis to explain your child’s behaviour’.
‘Your daughter ought to avoid eye contact if she is autistic’.
‘You ought to seek professional help’.
‘You ought to cope without professional help’.
‘You ought to feel ashamed of autism’.
‘You ought to feel proud of autism’.

When combined with the LUUUUT model there may be ‘oughtisms’ that are lived, that are unknown, that are untold, that are unheard, that are unseen and that are told either by the mother themselves or by those they interact with. This may be in actual terms or in the relationships they carry with them as memories or in thinking about the future. Oughtisms may also contradict with other oughtisms, they can change, develop or have more influence at different times, such as ‘you ought to seek diagnosis’ when talking with a GP, and ‘you ought not seek a diagnosis’ when talking with a family member or when worrying about stigma. When contradicting stories have equal power this may also create a sense of ‘stuckness’ and not knowing what steps to take e.g. ‘Am I a bad mum for seeking a diagnosis, or am I a bad mum for not seeking a diagnosis?’

The multiple layers of stories and oughtisms at play in any interaction or episode can be illustrated using the ‘Daisy Model’. The daisy model, “assumes that each event or object in the social world” such as autism “is a nexus of many conversations” (Pearce, 2007, pg. 179). Wasserman and Fisher-Yoshida (2017) describe how the model “highlights the various conversations and influences that relate to a person, episode or event”. It “helps to look at what conversations are considered or valued and what else might be helpful to consider to expand meaning” (pg. 92). From a research perspective ‘if researchers note that a particular event is deeply textured, they might use the daisy model as a way of differentiating the strength or salience of particular relationships or conversations’ (Pearce 2004 pg. 17). For a mother seeking a diagnosis for her daughter this might include family stories about diagnosis, behaviour or autism, stories from and about education, stories from the paper or the news about diagnosis or waiting times, stories about normal behaviour and girls, stories about other families who have a child with a diagnosis, and stories about how life was ‘meant to be’ as a mother.

Adopting CMM as a lens has facilitated an exploration of the stories about autism both in wider culture and popular fiction as well as the narratives shared by the mothers interviewed in the course of my research. It has also encouraged me to explore my own stories and to reflect on how they may have influenced me in all stages of my research. The literature review stage, the interview and data gathering stage and in the final analysis and presentation of my findings. In this way the methodology has informed and has been informed by the approach

(onto-epistemological) as well as the doing (method and technique) of my research and analysis.

Stating Dewey, Clandinin and Connelly (2000) say that “experience is both personal and social. Both the personal and the social are always present. People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context” (pg2).

Whilst conducting my research I was mindful of my own position as a researcher looking into a phenomenon that I am also part of, both as a mother who has been through the diagnostic process with my children, as a therapist that has worked with autistic children and their families, as a diagnostic clinician, and as a researcher. How was my experience informing the questions I asked, how I asked those questions and how I heard what was being told? And, how did the stories held about me by the participants influence what stories they told me, or how they told those stories. I became what Ellis describes as a “vital part of the narrative” of which the telling will “indicate something about how (the interviewee) locates themselves (or finds themselves positioned) in a social world” (Ellis 2004). CMM can help to examine this positioning, both in exploring the taken for granted knowledge of the interviewee and also by questioning my own interpretation of the story. Josselson warns novice researchers that one’s ideas about what participants will say can influence how stories are heard. To try to manage this she suggests researchers should be interviewed using their own questions prior to starting their research. Prior to starting the interviews, I completed a reflective piece of writing in which I answered the questions I was due to pose to the research participants. This enabled me to narrate, and to reflect on, my own story to reduce the chance I would “try to find it in others” (Josselson, 2013). I also utilised the daisy model to visualise some of the narratives that were informing me within the interviews (see Fig: 6)

In summary, CMM is a social constructionist model which explores levels of meaning which inform any given moment in interaction. This includes moments such as the moment of diagnosis, the interactions within a research interview or simply greeting someone in the street. CMM invites us to be curious about how meaning is made in co-ordination and communication with others and how, or why, some stories or meanings hold greater power than others. CMM proposes that we experience the world through our communications about it and within it, and the language we use or that is available to us is seen as fateful, it can ‘liberate us or enslave us’ (Pearce 1989). This can lead to ‘oughtisms’ which influence how we interpret our actions, the actions of others or our own actions as we believe they are seen through the eyes of others.

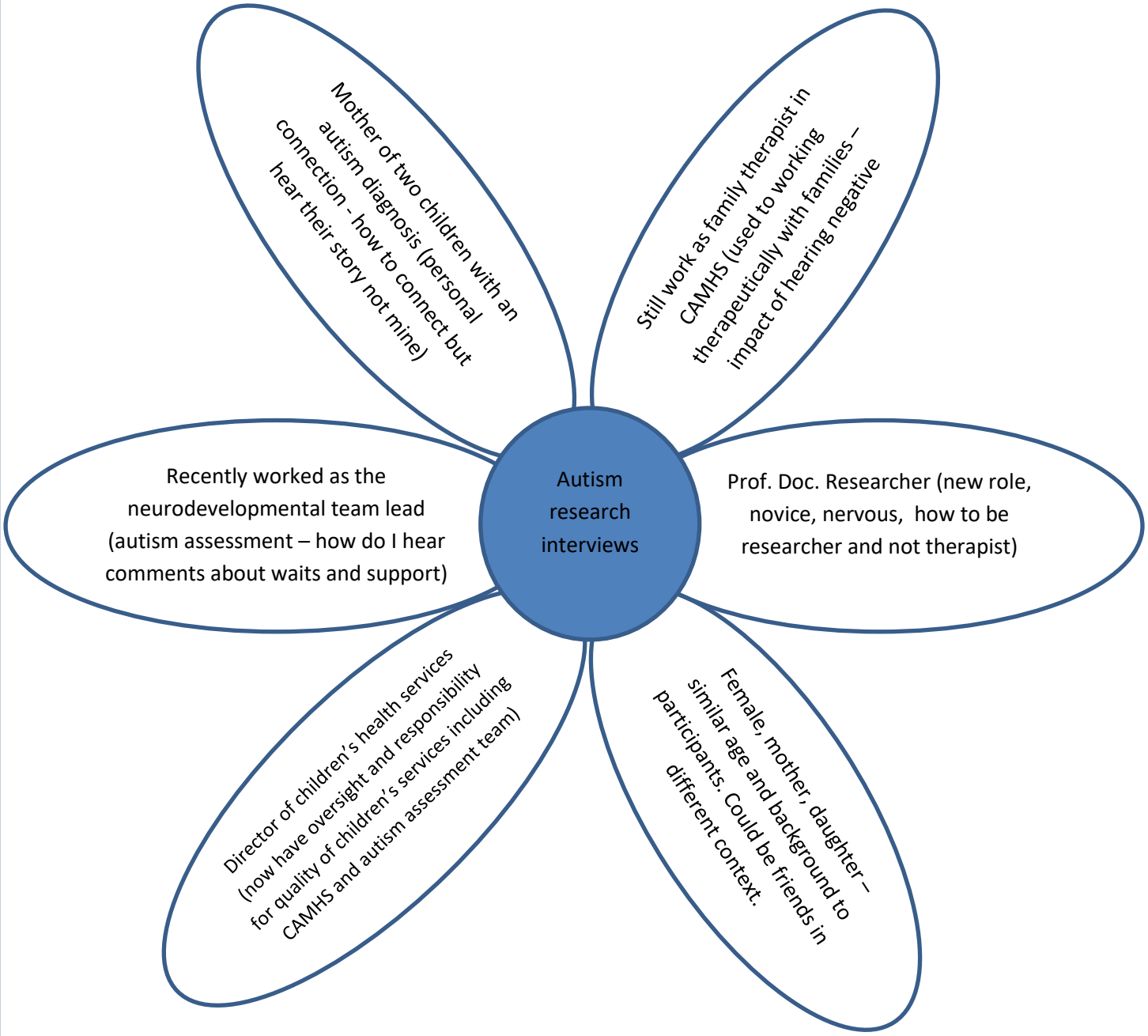


Fig 6: Daisy Model – reflections on my lived stories/narratives brought into the research

4.5: **Method**

Method refers to the 'act of doing' my research. This includes a consideration of how I recruited participants, the framework for the interviews and method of gathering, organising, reviewing, and analysing the data. Here I describe the visible, reportable and replicable part of my study.

4.5.1*: Recruitment and Recruitment Criteria*

For the purpose of this study I recruited mothers (biological, stepmothers or adoptive mothers) of autistic girls who attend, or who had attended mainstream school, and as such were less likely to have an identified significant learning disability and who were more likely to have functional language. Whilst I initially planned on interviewing the mothers of autistic girls who were not identified as autistic in their pre-school years, I did include the mothers of two girls, diagnosed whilst at primary school, where some concerns had been raised in an early years setting.

The reason for the above criteria is as follows:

- Age range of 6 – 17. Research suggests that girls diagnosed under 6 are more likely to have additional learning difficulties. *Whilst I did interview the mothers of two girls who were aged under 6 at the time of diagnosis, they were both in mainstream school and there were no additional learning difficulties identified.*
- First child diagnosed. Due to the focus of my research being perceived affordances and constraints of diagnosis prior to the assessment as well as the experienced affordances and constraints I aimed to interview mothers with no prior experience of having a child diagnosed with autism*. It transpired at interview that one of the mothers in the study had a son who was diagnosed prior to her daughter, even though he was younger. I chose to transcribe and include the interview as the data collected still appeared relevant.*
- Child at mainstream school. Girls at mainstream school are at increased risk of going longer before their diagnosis and are most likely to camouflage their symptoms which is an area of interest for my research.
- Able to use spoken language to communicate and no learning disability. Whilst it is was not possible to exclude any learning disability such as dyslexia my focus for the purpose of this research was girls where there was no severe learning disability and/or language disorder. This enabled the focus to be the pre-and-post assessment experience of autism diagnosis as opposed to a complex multi-faceted developmental disorder.

Mothers interviewed in the study were recruited via a local Autistic Girls Parenting Group using a flyer that was shared via the group email (see appendix 2). The Autistic Girls Group was established by a local parenting group in 2016 following a conference that the organisers had hosted regarding autistic women and girls in 2015. One organiser of the group has recently concluded a PHD researching the experience of autistic girls in education 'Missing: the autistic girls absent from mainstream secondary schools' (Moyse 2021). When I asked her about the history of the group she explained that it was set up because she and her colleagues had identified a gap in provision, with most existing groups focused on the experiences of autistic boys. She told me that she "knew from delivering workshops on autism, and (her own) research, that many autistic girls faced challenges being identified as autistic and being provided with appropriate support". She added that "it seemed reasonable that parents/carers of autistic girls may have felt isolated and frustrated, and that providing a place for them to meet, share experiences, learn from each other and realise they were not alone would be beneficial for all". The ethos of the group is based on "understanding, acceptance and appreciation".

In the last couple of years, the group has widened to include education and healthcare professionals to some of their events to encourage collaborative working. They have also organised events where the autistic girls have been given a platform to present their experiences of being autistic to their parents.

The pandemic has led to a change in the facilitation of the groups which have continued via an online platform. The organiser explains that prior to the pandemic and when the groups were organised 'in-person' they had developed into "a real community, with older members and new faces all supporting each other". Since going on-line there are approximately 150 people linked to the group via group emails and the monthly workshops.

The group is supported by a larger parenting led charity, set up in 2006 by the mother of a girl with additional needs who had experienced a lack of support. The charity offers a range of support groups, workshops, conferences, and more targeted parenting support. I know the charity well and have collaborated with them on a number of projects, workshops, and conferences, including the setting up and provision of pre-assessment workshops for autism and ADHD which have been funded by NHS commissioners. I have also, on occasion, accessed their support as parent.

I chose the group as the first source for recruitment due to the groups focus on the improving the lived experience of autistic girls and their parents, and the organisers interest and experience in research. When I approached her to ask if it was possible to distribute

recruitment flyers via the group, she was very supportive and the flyers were swiftly shared via the groups distribution list.

This was intended as the first stage of recruitment with a plan to open to other parenting and autism support networks. However, due to the high number of responses further recruitment was not necessary. Mothers who were interested in the study emailed me and I responded to arrange a time for an initial phone call. In the phone call I described the format and intentions of my study, shared some information about myself as researcher and gathered information about the mother and her daughter to establish suitability.

4.5.2: *Ethical considerations*

Ethical approval for this study was obtained from the Institute of Applied Social Research (IASR) Ethics Panel in March 2019. Due to my role within the NHS additional clarification was sought from the NHS Research Ethics Committee (see appendices 7&8). All research has been conducted within the guidelines of the application to the IASR Ethics Panel.

The names of all the participants and their daughters have been changed within this thesis and will not be included in any published material from the research. Some of the participants had situations which were unique in some way and might identify them, so this information has not been included. All the mothers participating in the study were contacted on the phone to discuss the nature of my study and my personal and professional reasons for studying autism diagnosis and girls. Within this call I also advised them of my professional role within the local CAMHS service, invited them to ask about my role, and checked that they were happy to continue. If they were happy to proceed, we booked a time for me to visit, or a time for me to call back and discuss further if they wanted more time to consider taking part. When interviews were arranged, I checked that there was a suitable place in which the interviews could take place where we would not be disturbed or overheard, especially by the daughters themselves.

When I first met with the mothers, they were asked to sign a consent form and were given a leaflet with further information about the research and the intentions of my research (see appendices 3&4). They were given time to read the information and to ask questions. Prior to starting the interviews, I was clear about my responsibility to pass on any safeguarding concerns highlighted within the interviews, whether this was about the participant, their child/children, or another family member.

In this context I was a researcher, but I have worked for many years as a therapist and was mindful of my role as researcher not therapist in the interviews. I was clear with participants

that I was interviewing them for research and as part of my Doctorate, not in my professional capacity, and that this would not impact on their rights to accessing local services if they were needed and appropriate. I felt this early and clear statement about my role had two benefits, one was to ensure the participants were made aware of their rights to services and the purpose of the interview, the other was to help me position myself as researcher rather than therapist.

The welfare of the participants and/or the welfare of their children and family members remained paramount within the research interviews. All were conducted with the plan to stop the interview if the mother/participant became overly distressed. The interview would then be rebooked or discontinued, whichever would be considered most appropriate and through discussion with the participant. Prior to interviews, and in a role play interview with one of my supervisors, the emotional impact of the interview was highlighted. With this in mind all interviews were conducted in the knowledge that the participants may become tearful at times and that the pace of the interview would need to be adjusted where appropriate to allow time for this.

I also had information about signposting for further support, within my organisation and other relevant community agencies in case it was needed. Participants were made aware that I have a supervisor and that the interview process and content would be discussed as part of the supervisory process. The study followed General Data Protection Regulation (GDPR) guidelines and all information has been stored on my computer which is password protected.

4.5.4*: Data Gathering*

All the mothers were interviewed using semi-structured qualitative one-to-one interviews. At the start of each interview demographic information was gathered and recorded, to include age of diagnosis for daughter, current age of daughter, the location of the diagnosis (private or NHS), waiting time for assessment, family composition, marital status of the mother, self-described ethnicity and culture, religion/spirituality, school information for daughter and mothers employment status (see appendix 5). This information was gathered due to the potential of themes being highlighted in conjunction with demographic information e.g. highlighting different themes for girls diagnosed later, or in connection with ethnicity or culture. It also gave transparency about the mothers recruited for the group, reducing the risk of generalising across all mothers of all autistic girls.

Whilst there had initially been six core questions, following a pilot interview two further questions were added. Whilst the pilot interview informed later interviews, the results from the pilot interview were not included in my final study due to the addition of these questions. Specific prompts were used for all questions, but I also responded with curiosity to the stories

told by the interviewees especially when they told them as if they are 'taken for granted'. This enabled me to be guided but not restricted by the questions and allowed a more collaborative interview with the participants, privileging what was important to them, rather than restricting responses to my planned questions.

I asked questions to expand on what had informed the development of their stories and how this may influence their experiencing of the diagnosis, and also used reflective listening and used the grammar of the participants to show I was listening to what was said and to encourage them to give a richer detail about their experiences.

1. **What did you understand about autism before your daughter's diagnosis?**
   Who or where did you get this understanding from?

The aim of this question was to explore 'stories told', personal, professional, family, cultural, that informed the mothers beliefs about autism prior to their daughters' diagnosis.

2. **Has your understanding about autism changed?**
   How?

The purpose of this question was to explore if, and how, the mothers had reauthored the stories they held about autism due to their lived experience following their daughter's diagnosis. I was curious to see how the meanings may have changed due to the 'bifurcation' point of the diagnosis.

3. **Could you please tell me a little about why you first sought an autism assessment for your daughter?**
   What or who led to you making this decision? Did you feel that you had a choice?

I added this question because I was curious about the contextual force which informed the mothers seeking a diagnosis. Did they feel they had an active choice to have their daughter assessed (practical force)? Was their decision influenced by others e.g. the school, family or a belief that support would only be available with a diagnosis (pre-figurative). Did they want others to respond in a certain way to the diagnosis (implicative force)?

4. **What did you think a diagnosis would help with?**
   Why?

As above, this was a question about perceived affordances/benefits, the practical force. As this question had the potential to be answered by the previous question it was only intended to be asked if needed.

5. **Before your daughter's assessment and diagnosis did you have any concerns about an autism diagnosis and what it might mean?**

   What made you think this?

The aim of this question was to explore perceived constraints and how this may have been informed by stories told, untold and untellable stories before the bifurcation point of the diagnosis.

6. **Once your daughter received a diagnosis of autism what difference did it make? Did it bring what you (and others) had hoped for? Has it brought any new challenges or difficulties?**

The aim of this question was to ask the mothers to reflect on the changes in their stories told about autism following the bifurcation point of the diagnosis and the new meanings attributed to autism following their lived experience. What were the experienced affordances and possible constraints of the diagnosis and what, if any, were the new stories told.

7. **Do you feel the diagnosis changed how you view your relationship with and/or how you related to your daughter?**

   Could you explain how?

   Has it changed how you feel viewed as a mother?

This question was added to explore the potential affordances and constraints of the diagnosis in terms of the relationship between the mother and her daughter. If 'meaning is use' (Wittgenstein 1953) and to know the meaning of something is to 'know how to go on', how were the mothers able to 'go on' in their relationships with their daughters when 'autism' has become a narrative within that relationship. What narratives did they feel others held about them as a mother and what impact did this have on the stories, they had about themselves.

8. **Is there anything that you know now that you wish you had known at the start of the process?**

   What advice would you give to mothers at the start of the process?

   What advice would you give to practitioners/professionals?

This question was very relevant for practice and involved the mothers themselves in shaping a message to other practitioners and researchers about what was important to share with others.

9. **Is there anything that I have not asked about that you think is important to know?**

   Was there anything in today's conversation that is new to you or that you have not thought about before?

These questions were intended to promote co-construction, to give the participants the agency to share any important messages or information that they felt might have been missed in the main body of the interview, and that they wanted included in the research. This question held the potential for eliciting themes not drawn from the interview questions.

Whilst the participants were interviewed as part of a research project and not entering into a therapeutic relationship, I was aware of a possibility that there would be some therapeutic and emotional elements to the conversation. The emotional element of the interviews was first highlighted to me in a role play with my supervisor, prior to conducting my study, which at times was experienced as emotional by both of us. This was then demonstrated in practice when a number of the mothers became emotional and tearful in the interviews. As well as inviting participants to reflect on the interview and giving insight into new or rediscovered stories told, asking if there was anything new or not previously thought about also gave space to reflect on the impact of the interview and if any further signposting or support may be helpful.

4.5.4: *Technique*

When interviewing participants, I was mindful of the types of questions I was asking, when I was asking them, and how I was asking them. Josselson (2013) suggests that the fewer the questions the better the interview as the aim is to hear the story as the interviewee wants to tell it, and to 'allow them to paint their picture'. Questions are used to 'orient inquiry' rather than 'specify a direction'. She described the use of a big Q question, which is the main research question or 'road map' and little q questions, which "orient the interviewee and engage him or her with your research interest, but must not colour the interview in a direction that does not fit the interviewees experience" (2013, pg. 43). This was a particularly important consideration for me as a mother of an autistic girl, as 'I was not researching me, but I am what I am researching'.

Some of the techniques which I used within the interviews included, the 'use of silence' to allow space and time for the mothers to tell their own stories as I was mindful that silence can mean thinking and engaging with the question and it was important not to fill that gap with more questions. I used clarification questions described by Josselson (2013) as questions which 'get the story straight' invite 'more detail' and 'check on meanings'. This type of questioning had the benefit of both checking meaning but also inviting the mothers to expand further. I also used empathic responses, such as reflective listening.

Examples from the interview transcripts are:

Clarifying meaning: *"What do you mean by struggles?"* (Participant 8)

Getting the story straight: *"..and you said that with (your husband) he started reading about things after the diagnosis. Did that help?"* (Participant 6)

Detailing the story: *"You mentioned that from the press and the media that you thought there would be a kind of, sort of, negative thing. Could you explain a bit more about that?"* (Participant 10)

Josselson highlights the importance of 'moving together' with an 'empathic attitude' within research interviews, with researchers having the challenge of holding onto 'two ropes'. The first is keeping the interview orientated towards the 'big Q' or conceptual research question, and the second is 'the rope of engagement with the participant'. If the hold on "either of the ropes feels tenuous or in danger, always let go of the conceptual question rope and hold onto the rope of your relationship with the interviewee" (2013, pg. 78). Taking this in mind I made sure to let the mothers tell me their story, even if it did not seem to connect. At times this led to new and rich information that I had not considered, and if there continued to be a disconnect with the research question I would wait for them to tell that part of their story before guiding them back with a further question or prompt.

I found that exploring my own stories before interviewing helped me to reflect on and in moments when I had the potential to overidentify with the mothers, taking note that identification 'can further an interview or can be intrusive' (Josselson 2013). Whilst I was careful to take an empathic stance and was aware of similarities in the mother's stories and my own, I was careful not to share this in the interviews and to look for difference. Josselson states that "empathy always involves some internal identification, a capacity to resonate with and therefore understand, but leaving space for difference. Identification on its own does not constitute an empathic response and may impede understanding the other person as other" (2013 pg. 99).

4.5.5*: Thematic analysis.*

Interviews were transcribed and then analysed using thematic analysis. Thematic analysis is a widely used qualitative research tool which Braun and Clarke describe as "flexible and useful" in part due to its "theoretical freedom" but "poorly demarcated and rarely acknowledged" with "no clear agreement about what (it) is and how you go about doing it" (2006, pg. 4, 5 & 6). Thematic analysis is a research method in which the researcher reviews data, such as interview transcripts or news articles, to identify 'patterns and themes' (Maquire and Delahunt 2017). Initially 'codes' are identified. Codes can be 'in-vivo' codes, where specific words, utterances or short phrases which appear meaningful and relevant are encoded. Within my study this included in-vivo codes such as '*borderline normal*' and '*autism*

that's nasty'. Codes can also be descriptive with a researcher identifying narratives, subject matter or emotions, potentially relating to whole paragraphs or sections, and which the researcher feels holds meaning. Within my study this included codes such as 'confusion' and 'understanding daughters' behaviour'.

One study can produce 100's of codes which may or may not be connected or related in some way. Codes can then be grouped into 'themes', or potentially discarded. Saldana (2016) explains that "just as a title represents and captures a book, film or poems primary content and essence, so does a code represent and capture a datums primary content and essence" (pg. 4). However, in the same way there could be more than one choice for a title for a book or play, there could also be more than one way in which a piece of data could be coded. The nature of thematic analysis means that there is no fixed way in which data will be analysed, codes identified, and themes formed. The same researcher may look at the same data and identify different codes at different times, and may group similar codes into different themes, either due to looking through a different methodological lens (Jackson and Bazeley 2019), due to a different research question or simply due to what holds interest on that day. It is 'not a precise science' and is an 'interpretive act' (Saldana 2016) which cannot be exactly replicated. Whilst acknowledging variations in themes are likely, if not certain, it is also important for researchers to show that their study is reliable and trustworthy.

Braun and Clarke (2006) defined 6 phases of thematic analysis, 'familiarising yourself with the data', 'generating initial codes', 'searching for themes', 'reviewing themes', 'defining and naming themes' and 'producing the report'. Nowell et al (2017) proposed combining these phases with the following criteria of "credibility, transferability, dependability, and confirmability" originally refined by Lincoln and Guba (1985) in order to "parallel the conventional quantitative assessment criteria of validity and reliability" (pg. 3). I found this combination useful whilst orientating myself within my study.

4.5.5.a*: Phase 1: Familiarising yourself with your data.*

Nowell et al (2017) and Braun and Clarke (2006) stress the importance of researchers familiarising themselves with their data. This includes immersing yourself thoroughly in the data prior to coding, taking field notes and considering and documenting 'pre-existing thoughts' (Nowel et al 2017). I found that keeping a journal was a useful way of reflecting on the data at different stages, this included thoughts directly after interviews, sometimes whilst still sat in my car, and notes taken when listening to and reviewing tapes. These early notes enabled me to reflect on potential themes and points of interest as well as my own reactions and interactions within the interviews. The following comments are entries from my journal after the first interview:

"*I am finding it hard as a research interviewer not to give advice and to share my own thoughts about how she (the interviewee) had less support due to having a private assessment"*
"I left not sure, did I get enough, did I prompt enough, and am I asking the right questions?" (Journal entries 08/08/19).

These entries helped me reflect on potential biases and the repositioning of myself as a researcher rather than a practitioner, as well as my interview technique. I was also able to discuss this in supervision and to hold these considerations in mind when transcribing the interview.

I found transcription to be an important yet time consuming way to familiarise myself with the data. In the following section I describe my approach to transcribing the recordings from my research interviews, my evolving relationship with, and understanding of transcription, and how this informed the ongoing interview process, including adaptations of both the questions and my questioning style. I believe this reflection on, and adaptation of, both the interview questions and my interviewing style was an intrinsic part of my research which in turn influenced the subsequent data collected and collated for analysis.

4.5.5.b*: Transcription as re-connection – listening to the clock that ticks, not driven by the ticking clock.*

Transcription is described as a process which is often ignored (Lapadat 1999, Davidson 2005) despite being an "integral process in the qualitative analysis of language data" (Lapadat 1999). Lapadat (1999), Green et al (1997), Hammersley (2010), Shelton and Flint (2019) and Davidson (2005) all advise researchers to think carefully prior to transcription about "whether, what and how to transcribe" (Lapadat 1999, pg. 212), so that they can "produce a transcript that enables research questions to be addressed through the application of an approach to transcription that is suited to the needs of a specific study" (pg. 42, Davidson 2005).

Lapadat (1999), Skukauskaite (2012) and Loubere (2017) advise that due to transcription facilitating a researcher 'seeing it' (Lapadat 1999) there is a prerequisite to be explicit and transparent about decisions made in the transcribing of interviews. Transcription is observed as "an analytic and interpretive process" which "must be undertaken in theoretically informed ways with a reflexive stance". Transparency is required to identify conditions for "socially constructed interpretations" and provides "the basis for warranting research claims in ways that are accountable both to the research participants and to the research community" (Skukaskaite 2012, pg. 26). How one chooses to 'do' the transcribing of interviews is a 'methodological choice' interviews are not captured as a "more authentic version of the truth" and the approach to transcribing will shape the "types of knowledge that are produced" (Loubere 2017, pg. 19).

As I began to conduct research interviews I had initially considered transcription as a functional task, one where I would be painstakingly recording what was said in my interviews so that I could collate the completed transcripts and then commence with 'actual' analysis. However, as I started to transcribe and explore more about the different approaches to transcription, I became increasingly mindful that this task was more than transforming and reproducing spoken word into written word. I became aware of transcription as an integral and creative part of the analytical process of a qualitative research project (Lapadat 1999, Green et al 1997, Shelton and Flint, 2019, and Davidson). It is more than the (albeit time consuming) 'reproduction' of recorded data into written data (Hammersely 2010) and not "merely a task to be completed", to get to the "good stuff" of analysis and writing (Shelton and Flint, 2019).
My journey with transcription began with reviewing and transcribing my pilot interview. My initial approach, at the pilot stage, was to transcribe the words, with comma's and full stops where I felt they fitted, but without additional information, such as pauses or comments on emotional presentations (as I interpreted them). This was informed by my intention to draw on the themes of 'what' was said, rather than analysing 'how' things were said or the specifics of the interaction between myself and the participants.

The placement of commas and full stops should not be interpreted as innocent when it comes to portraying different meanings, the meaning of an utterance can be changed significantly. This can be illustrated with the following example. 'A woman without her man is nothing', can be interpreted as meaning the woman is nothing if she does not have her man. By the addition of a colon and comma the meaning, whilst using the same words, can be transformed as follows, 'A woman: without her, man is nothing', now suggesting something quite the reverse of the initial statement (Gibson, 2020). Another example which has been used when providing autism training to practitioners is, 'I didn't say she stole the money' which can have 7 different meanings depending on how it is written (I will leave you to experiment with this!)

This first undertaking of transcribing enabled me to reflect on the process and content of the interview. How was I asking the questions? On what, and where, was I was focusing my attention to and asking for elaboration? Where was I moving to the next question when I could have shown more curiosity? I was able to review and reflect on the written transcript with my supervisors and to think about what other questions might help the interview process. This led to the addition of the following question and prompts following the pilot interview, and when I progressed to conducting the research interviews:

Q: Do you feel the diagnosis changed how you view your relationship and/or how you related with your daughter?

Prompt: Could you explain how?
Prompt: Has it changed how you feel viewed as a mother?
I added this question because the process of, listening to, and transcribing the recording, and then reviewing the transcription, highlighted to me that this was one of the aspects in the diagnostic process that I was particularly curious about and which connects with the main aims of my study. How had the diagnostic process potentially informed the relationship between the mother and daughter, and what, if any, had been the experience of the mother in terms of how she felt viewed as a mother in relation to the diagnosis of her daughter. Whilst this had not been included in my initial list of questions, I was curious to explore if it was a potential affordance in the diagnosis and I felt that the absence of this question meant that this aspect may be left unexplored.

Following my second interview, I transcribed before continuing further, and again discussed the content with my supervisors. Here I was asked to reflect on my own talk and interaction within the interview process when my supervisor asked "Why do you keep saying, 'thank you, that's helpful' when you have told me that you feel she had not answered your question?" This enabled me to review my own interactions in the interview and how I had at times closed down the conversation and the potential for more elaboration from the participant, rather than asking for her to expand or to reflect back to the question.
This continuous process of transcription and review allowed me to develop a different interviewing style and in my third interview I was holding onto key words, the use of the participants grammar and reflecting back their words for them to explain or expand further. At times I would repeat the initial question if I felt the participant had not interpreted it as I intended or if they had given little detail in their answers. As I interviewed, transcribed, and reflected I was aware of where my interests lay, to think about what I had not elaborated on and why, and to adapt my style prior to the next interview. Where did I notice questions elicited emotional responses? Where did I think my question may not have been heard as I had intended? Where did I wish I had asked more or allowed more time?
This ongoing process of interviewing and transcribing helped me to continue to reflect on the interviews, and my part in them, as they took place and evolved. My transcript was 'shaped by' what was known and came to be known by myself as researcher, and the data that is produced went on to 'shape what can be known' (Green et al, 1997) as I moved to the next stage of analysis. As I learnt more about my participants lives I reflected more about myself as researcher, and about how I may interpret and hear things due to my own lived experience as a mother of an autistic girl and as a practitioner from CAMHS with diagnostic and therapeutic experience. This encouraged me to reflect on where my lived experience may

influence my listening and what I transcribe. Was I at risk of transcribing what I wanted to hear, or omitting that which I didn't?

In likening the researcher's construction of a transcript to that of Frankenstein piecing together his monster with carefully chosen 'cuts and sutures' Shelton and Flint (2019) say that:

"We are always co-produced with our data – just as Frankenstein created the monster, the monster created Frankenstein. Similarly, even as we create transcriptions as (seemingly) static representations of research, they are dynamically and iteratively productive of inquiry, producing responses and engagements that entangle across spacetimes to make possible different understandings and readings of research encounters and experiences". (pg. 207)

Following my second interview I was asked about my omittance of signifiers for a pause in the conversation or descriptors about changes in emotion such as a laugh, or tearfulness. This enabled me to consider the purpose of the transcription. What data was I hoping to collect, and how did this all relate to my research question. If I was using discourse analysis then it would be necessary to include all the pauses, stutters and utterances but I am more interested in themes within the talk rather than the structure of the talk itself. I did however, once my attention was drawn to it, feel that the absence of pauses and some of the pattern of talk also meant that I lost the times when the participants had seemed to be thinking more about what was said, maybe connecting with something new or recalling something that might be significant. I then chose to add a sign for a short (.) or a long pause (..) and added if the participant had become tearful or laughed. This enhanced awareness of the talk of the participants also transferred to a further awareness of my own talk. Where was I pausing? Where was I stepping in too quickly or talking over the participant. Reflecting on my own interaction in one interview, in turn influenced the next, I found I was slowing down, more aware of my own talk, when not to talk, where I sounded compassionate, what I was showing the most interest in and when I was less interested and less likely to ask questions to encourage the participant to expand on what she had said.

Davidson suggests that by not making their decisions about transcription apparent, researchers allude to a "default position whereby transcript has been taken as transparent – positivist" (2005, pg. 41) From a more positivist stance transcription could be seen as a means to an end, the goal being to get the data of the interview into written format in order for analysis to begin. The talk would be seen as 'objectively represented', transcript will be written verbatim as "a one to one match with the spoken words and the spoken words are the sum of the observable event" (Lapadat 1999, Pg. 208).

Taking a more interpretivist stance towards transcription the transcript is understood as 're-presenting' (Green et al, 1997, Roberts 1997, Shelton and Flint, 2019) or constructing (Hammersley 2010) the data, not merely 'talk written down' (Green et al, 1997). In the same

way that ‘the map is not the territory’ (Korzybski 1933) the ‘transcript is not the interview’ but a re-presentation of the data which is constructed by me in the process of listening, interpreting and transcribing.

Whilst not recreating the interview in its exact form the process of transcribing the interviews myself did promote a re-connecting between myself and the recordings. Lapadat claims that “speech that is audiotaped can be listened to again and each listening evokes the original event” (1999 pg. 204.) Whilst I found the audiotape did evoke a revisiting of the event, it also enabled me to revisit from an observer position, as well as a participant, creating something new as well as a revisiting of something previously experienced. I found myself taken back to the place in which the interviews took place, the taste of the coffee I was offered, the sound of a clock ticking, a knock on a door and a break whilst it was answered, even the sounds of ducks as they landed in the river close-by. These sounds, as well as listening to the words and emotions of the participants re-connected me with the interviews, drawing me back across time and place. I was also able to hear myself as a researcher, how I interacted with the participants and how the conversations were emotional, filled with rich information and an important insight into the lived experiences of the mothers who were kind enough to give me their time and tell me these momentary co-constructions of their story. Stories which could have been constructed differently with a different researcher, with different questions, different interactions, and at a different time in their journey. This experience reminded me of why I was conducting my research and who I was conducting it for. These women shared their homes, their hospitality and their stories with me. They shared their time, their frustrations, their love of their daughters, their strengths and their desires for change. This is what reminded me that my research was real, that it mattered, and that it carries with it a responsibility of doing so with respect for their experiences. Their stories are precious and need to be looked after and shared with care and in a way that is useful to them and others like them.

Transcribing interviews was something which took me many weeks. At times I found it hard and frustrating, repeating one section of recording many times so I could check if I had heard something right, the task being to identify one word or utterance which may or may not hold an important meaning for my study. At other times I found myself re-connecting with the talk, transported back to the interview, a fly on the wall taking a meta-position to my own part within the interviews, hearing things which I may have missed in the moment of the interview itself, not just re-connecting but hearing it as if for the first time.

By taking an interpretivist stance to transcribing I became acutely aware that transcribing was more than a job to ‘get done’ before I started my analysis. I was able to reflect on my own

part within the interview process, I was able to develop my interview technique and I was afforded the opportunity to think about how best to facilitate the participants in telling their story. Most importantly I was able to re-connect with, as well as visit anew, the interviews themselves, to hear the emotion and passion of the participants and to be reminded of why I was conducting this research at all. To give a voice to the mothers of autistic girls, who the data might go on to suggest, have at times felt that their own voices have been silenced.

4.5.5.c: *Phase 2: Generating initial codes*

Throughout the process of transcribing I continued to write notes within my journal. I identified potential codes and what appeared to be emerging themes, and I read and re-read the newly written transcripts to look for similarities and differences in each of the women's accounts. I also began transcribing within the interview phase, to reflect on the development of the interviews, rather than waiting until all interview data was collected. I read and highlighted transcripts that had been completed, noting points of interest and I wrote potential codes on post it notes (see appendix 6) and began to order them in prospective groupings. This meant that there was no defined division between the 'familiarisation' stage and the 'initial code phase'. I familiarised myself with the data whilst considering potential codes, and in doing so further familiarised myself with the data. Saldana describes coding as a heuristic process where researchers "code their data both during and after collection as an analytic tactic, for coding is analysis" (pg. 9). The nature of coding is 'reverbative' and 'cyclical' (Saldana 2016), it is "an iterative and reflexive process that develops over time and involves a constant moving back and forward between phases" (Nowell et al 2017, pg.4).

When transcripts were completed, I utilised the computerised coding programme Nvivo. Nvivo facilitates coding and analysing data and also enabled me to keep a record of different stages of the coding, and thus create an audit trail. Nowell et al (2017) stress the importance of an audit trail in order to promote trustworthiness in qualitative research. Whilst the programme provides 'tools to assist' in the undertaking of the analysis it does not "supplant time-honoured ways of learning from data or diminish the role of the qualitative researcher in exploring and interpreting rich data" (Jackson and Bazeley 2019, pg. 8). To put it simply, the programme helped me to store and review the data, but it did not do the thinking for me. What it did offer was a useful way of reviewing, identifying, and storing codes, a tool to group and regroup codes into themes, and different techniques for visualising the emerging data with graphs and tables. Whilst the programme allows for memos and notes to be added when identifying codes I continued to write in my journal, reflecting on my 'reactions to the data', as well as 'what was going on in the data', a process advocated by Jackson and Bazeley (2019). This was a useful process as I was able to reflect on my personal responses to some of the codes, for example

how I felt when mothers talked about ‘grief’ at the point of diagnosis or about initial understanding of autism e.g. as ‘something nasty’.

Braun and Clarke (2006) describe two approaches to coding, ‘data driven’ and ‘theory driven’. Within this first round of coding I aimed to be data driven, coding any aspects of the interview that seemed relevant, interesting or to stick out in some way. At this stage I adopted both an ontological and epistemological approach to coding, highlighting codes which seemed to capture ‘lived experience,’ “what is it like being…?” (ontological) and codes which appeared to capture meaning “what does it mean to be…?” (epistemological) (Saldana 2016). Initial coding was eclectic, using a mixture of In vivo codes, process coding and values coding, this generic approach is encouraged by Saldana (2019) for early stages of research. Advice given by the mothers, for professionals or other mothers, was coded separately and labelled as advice, and also added to relevant emergent codes.

Following the recommendations of Jackson and Bazeley (2019) I initially coded two pieces of transcript, one of which stood out as ‘typical’ and one which ‘seemed particularly interesting’ and ‘rich in detail’ (pg. 66). This was an interesting approach which promoted curiosity about the data. I chose an interview with a mother whose daughter was diagnosed at 5 and an interview with a mother whose daughter was diagnosed at 17. There were differences in their stories, with the mother whose daughter was diagnosed at 17 talking more of lost opportunity and the impact of schooling without a diagnosis, however there were a lot of similarities in terms of early beliefs and the impact of diagnosis on their relationship with their daughters. When coding I considered ‘what was interesting, why it was interesting and why I was interested’ three steps as recommended by Jackson and Bazeley (2019) in reference to Richards (2009).

When coding I took the approach recommended by Braun and Clarke (2006) of coding “for as many potential themes/patterns as possible” (pg. 18). Some extracts were coded under more than one heading as it was not clear in the early stages what may be relevant at a later stage. This included some similar codes such as ‘better understanding of emotions’ and ‘better understanding of behaviour’, which at this stage had the potential for being merged together into one theme or being part of separate themes. Throughout the process of coding I still found that I was adding new codes with each transcript I reviewed, some which seemed unrelated or unique.

Once all of the interviews were coded I was able to use Nvivo to create a hierarchy chart of percentage of coverage for each code across the whole data set (see appendix 9) , and to create individual tables to highlight the most frequent codes per interview (see appendix 10). After first round coding the hierarchy chart showed ‘better understanding of needs’, ‘anxiety’, ‘diagnosis gave new understanding’ and ‘struggling at school’ as the most coded items.

After the first round of coding I created a data code and summary table with a summary and/or observation about each of the participants as well as the codes most mentioned, or that covered the biggest percentage of the interview (see appendix 11). This approach, recommended by Saldana (2016) enabled me to scan for early patterns, similarities and differences in the codes across the 12 interviews. Storing the data in this way, and at this stage, also provided me with a reference to see how much the overall themes from each of the interviewee's changed from first round coding to the final themes that I identified.

4.5.5.d: *Phase 3: Searching for themes*

Once I had completed initial coding for all 12 interviews, I focused my attention on the search for themes. As with the transition between the first and second phase of coding this was not a clear and defined step as I had been making mental notes, and notes within my journal about potential themes throughout the interview, transcription and first round coding process. Throughout all stages of coding and theming data I reflected, reviewed, revisited, and refined themes. Jackson and Bazeley (2019) highlight that "there is no need to see coding as unchangeable" and "there can never be a complete separation between codes and researchers, as they are engaged in an iterative process of mutual construction" (pg. 68, 69). The metaphor of 'sorting laundry' has been used to describe this stage of thematic analysis (Jackson and Bazeley 2019). In the way a jumble of laundry may be grouped according to colour or the recommended wash temperature to create some order, themes are created when codes are grouped together. Grouping can 'inductive', allowing the themes to be driven and informed by the data, or 'deductive' and driven by theory, analytic approach, or the research question (Braun and Clarke 2006, Nowell et al 2017). Using the laundry metaphor this might be deciding to do a 'hot' wash cycle, so looking for clothes that will fit together for a hot wash, or grouping clothes due to similarity and then choosing the type of wash cycle dependant on the biggest pile of sorted clothes. At this stage, whilst I was aware of CMM in my thinking, I took an inductive approach when I grouped the codes to develop themes, informed by the data.

I did not discard anything that I felt might not fit with the research question or CMM. This included the creation of some themes, such as 'girls parenting group' which were later split and merged into other themes, and also a collection of codes which did not appear to create a theme at all, or where only one or two codes were connected. Saldana (2016), Nowell et al (2017) and Jackson and Bazeley (2019) all advise researchers to keep and collate codes that do not appear to fit as they can then be reviewed and potentially included when themes are refined further.

I used pattern coding in this second round of coding. Pattern codes are described by Saldana as “explanatory or inferential codes, ones that identify an emergent theme, configuration, or explanation. They pull together a lot of material from first cycle coding into more meaningful and parsimonious units of analysis’ (pg. 236. 2016). Saldana adds that “several pattern codes can emerge from second cycle analysis of qualitative data. Each one may hold merit as a major theme to analyse and develop, but pattern codes are hunches, some pan out, others do not” (pg. 239). Utilizing Nvivo enabled me to create a new project book for second round coding so I was able to have a record of both first-round codes, and second round emerging themes. Alongside Nvivo I still used post it notes to draw and map out potential groups and themes. At this stage of coding the largest themes included ‘diagnosis informing new thinking about daughter’, ‘autism stereotypes pre-assessment’ and ‘changes in parenting and family relationships’. Comments about school were grouped into positive and negative, with negative being the largest of the two (see appendix 12).

Whilst notes and memos can be added to codes in Nvivo I still found a journal was the most flexible way to record thoughts, feelings, and observations, including potential links to CMM. This included the following entry in September 2019:

“Second round observations Changes in narratives, how much is informed by the (parenting) girls’ group? Most talked about the group, some talk about meeting adults, meeting other parents?”

4.5.5.e: *Phase 4 – Reviewing themes*

Nvivo allowed me to ‘aggregate’ codes together to form themes without losing the initial codes used. At this stage a number of themes and subthemes were similar with repeated data. This meant that some codes, for example codes about new understandings of behaviour, were repeated within a different theme with a similar description. In the next phase I began to revise those codes, and the newly created themes to refine them further (Braun and Clarke 2006, Nowell et al 2017).

I adopted an axial coding approach to consider the emerging themes in relation to the research question. “The axis of axial coding is category” (Saldana 2016, pg. 244). Here I began to group the emerging themes in accordance with the categories of ‘perceived constraints’, ‘perceived affordances’, ‘experienced constraints’ and ‘experienced affordances. A Nvivo hierarchy chart showed that ‘experienced affordances’ was the dominant theme, then ‘experienced constraints’, ‘perceived constraints’ and finally ‘perceived affordances’ (see appendix 13). This suggested at this stage that the mother’s had shared more stories and examples of experiencing their daughter’s diagnosis as an affordance, such as ‘a better

understanding of their behaviour' , but there were also a significant number of experienced constraints, such as 'feeling lost and unsupported after diagnosis.' Whilst Nvivo gave the ability to group or 'aggregate' the themes, and to show this in a hierarchy chart, following the advice of Nowell et al (2017) I also created a coding diagram to "visualise the themes and creatively think about how the parts fit together" (pg. 9) (see appendix 14). This visualisation helped me to reflect on potential ways in which the themes related. Some did appear to fit 'within' the defined contexts of perceived or experienced affordances and constraints, such as 'worry about stigma' as a perceived constraint, whilst some appeared to 'contextualise' other themes, such as 'myths and stereotypes' informing the worry about stigma. As well as helping me visualise the connections this approach enabled me to reflect on the suitability of the categories defined by the research question. It was at this stage I began to consider how I might redefine 'perceived constraints' as 'constraints of perception'.

This part of the process was long. After review, I refined the codes (Braun and Clarke 2006) in each subtheme individually to check that they still had a coherent relationship with the overall theme that they had become part of, or if they 'overlapped' with other codes (Nowell et al 2017). As I progressed in this stage of coding, I began to merge codes and themes together rather than aggregate them. By merging codes together in Nvivo, repeated codes are removed. The benefit of using the programme was that I was able to save the workbook with the coding at each stage to return to if necessary, so whilst codes were merged the steps were not lost. Some codes were removed and put into a 'spare' folder, some were moved to other themes, some were merged, and some were deleted due to repetition. I continued to reflect on which themes connected with the research question and what was informing these themes. By using the hierarchy chart on Nvivo I was able to visualise any changes in which themes contained the most data when codes were merged. The hierarchy chart showed a change in the dominance of the themes at this stage, and whilst experienced affordances remained the dominant theme, perceived constraints became the second largest 'main theme' instead of experienced constraints (see appendix 15). I continued to use the reflective journal to record thoughts as well as making notes on each theme using the Nvivo Programme.

As with all other stages in the process there was no definable moment when I moved from phase 4 to phase 5 of coding and I admit to some difficulty in considering exactly which part of the process to describe where. Braun and Clarke (2006) warn that "it is important not to get over-enthusiastic with endless coding" and that it is "impossible to provide clear guidelines on when to stop". They advise that "when the process of recoding is only fine tuning" it is important that you recognise this (pg. 21). Taking this advice and their recommendation that at the end of this phase "you should have a fairly good idea of what your themes are" (pg.21) I moved to defining and naming the themes.

4.5.5.f: *Phase 5 – Defining and naming themes.*

When I was happy with the themes as displayed in the thematic hierarchy I moved to 'defining and naming' the themes (Braun and Clarke 2006, Nowell et al 2017). Braun and Clarke advise that researchers 'identify the essence' of each of the themes and 'what aspect of the data each theme captures' (2006, pg.22). At this stage I carefully reviewed the individual codes within each of the themes and listed key words to look for similarity, repetition, and pattern. These were listed and highlighted in my journal (see appendix 16). This process was iterative as in the process of defining themes I found that I was still refining them, merging data and bringing themes together where I felt that they were illustrating the same thing, such as merging the 'daughters understanding of self' with 'diagnosis brought new understanding'.

I adapted and developed theme names at this stage so that they gave a 'sense of what the theme was about' (Braun and Clarke 2006, Nowell et al 2017). Where possible I named themes using 'Invivo' codes from the data, such as 'The Aha moment' for diagnosis bringing a new understanding. Braun and Clarke (2006) advise that researchers write a brief description of each theme, as well as a more detailed analysis. A brief description of each theme and how I felt it captured the essence of the data, was added, and stored in a code book via the Nvivo programme (see appendix 17), as well as a manualised code chart (see appendix 18) which showed any change in the nature of the themes for each participant. A more detailed analysis is illustrated in the following results section where I describe and illustrate each of the themes, and in more detail within my final analysis and discussion. I used LUUUUTT as a framework to analyse the stories lived and told within the themes and to explore how these stories may have influenced, and been influenced by, the mothers experiencing of their daughter's diagnosis.

Advice given by the mothers was grouped into three main themes: 'It doesn't have to be a lonely thing', 'read and learn all you can' and 'be more respectful'.

4.5.5.g: *Phase 6 - Producing the report.*

In the final phase, producing the report, I first give examples that capture the 'essence' (Braun and Clarke 2006) for each of the themes in a results section before illustrating the relationship between the themes, the data, and past research and literature in a discussion section. Nowell et all (2017) advise that "the final analysis should create an overall story about what the different themes reveal about the topic" (pg.11). To explore the overall story or stories within the themes, and to inform the discussion of my findings, I utilised the CMM LUUUUTT model as a lens for exploring stories lived and told by the mothers and how they were woven through the four overarching themes of perceived affordances, perceived constraints and constraints

of perception, experienced affordances, and experienced constraints. Rascon and Littlejohn (2017) describe the LUUUUTT storytelling model as “good for helping you understand the story dynamics of the social reality in which participants find themselves” (pg. 40). The stories we tell, or that are told about us, or that we ‘believe’ are told about us ‘pre-figure and/or constitute the lives we lead’ (Pearce 1999).

A CMM perspective assumes that we are all trying simultaneously:

- *“To act in such a way that we call into being those episodes that we want or need and preclude the enactment of those episodes we hate or fear;*
- *To tell ourselves stories that:*
  -Are coherent with each other; and,
  -Are consistent enough with the episodes in which we live to make them comprehensible” (2007 Pearce, pg. 211).

I believe that identifying ‘themes within the themes’, or ‘stories within the stories’ can tell us something about how the mothers I interviewed experienced the diagnostic process for their daughters. How did pre-existing ‘told’ stories, and current ‘lived’ stories, inform their decision to pursue diagnosis (contextual force). Did stories told by others (within wider society or within day to day relationships), or that they ‘believed’ were told about them by other others make them feel a diagnosis was necessary (pre-figurative force), what new stories did they hope the diagnosis would facilitate (practical force) and what part did they want others to play in reauthoring these new stories (implicative force). I was curious to explore if the diagnosis delivered what they had hoped for themselves and their daughters, did it fall short of expectations or did it bring new challenges they hadn’t anticipated? I also wanted to know how they felt the diagnosis influenced, or was influenced by, their co-ordination with others. Wittgenstein wrote that ‘meaning is use’ (1953) whilst Pearce (1999) referred to people experiencing ‘confusion and vertigo’ if stories are confused or conflicting. Did the diagnosis bring a meaning that is useful for the mothers to enable them to ‘know how to go on’, or did it bring ‘confusion and vertigo’, or did it bring both?

I was interested to see if there were tensions between ‘stories lived’ in the mother’s day to day interactions and in how they co-ordinated with others in relation to their daughters diagnosis, and the stories told about the diagnosis, both pre and post assessment. In particular I was curious to see how these stories informed both the perceived and experienced affordances and constraints of the diagnosis and if it was helpful to them in the living of their lives.

Before I continue I think it is important to note that the term ‘stories’ is used to describe how our lived experiences, or understandings about the world are talked about, or not talked about,

by us or by those we are in relation with. These stories, including many ‘oughtisms’, can and do influence how we live or feel we can live our lives. They can impact on our abilities to act, or not act, they can enable us, or they can disable us. The use of ‘story’ does not mean that I am suggesting the information shared by the mothers I interviewed is ‘made up’ or fabricated in anyway. Our lived and told stories are the social realties of our everyday lives. This distinction is important to make as the mothers have described how at they have felt their concerns were not heard or have been seen as exaggerated. I did not want the term story being misinterpreted as a claim that things are in any way less real or important as I think they are of great importance.

The information gathered in my study informed a number of possibilities and considerations for practice for therapists, diagnostic services, and policy makers. These considerations are included at the end of my paper as well as considerations for further research and possibilities for dissemination of ideas. Some of the strengths and limitations of the study are also included. Once my thesis was reaching its conclusion I shared a summary of the research findings, themes and recommendations with the participants of the study. Feedback was received from 4 of the mothers and their final thoughts are included at the end of my thesis.

In the next chapter I share the results and themes identified from the interviews, including information about the participants and the research interviews.

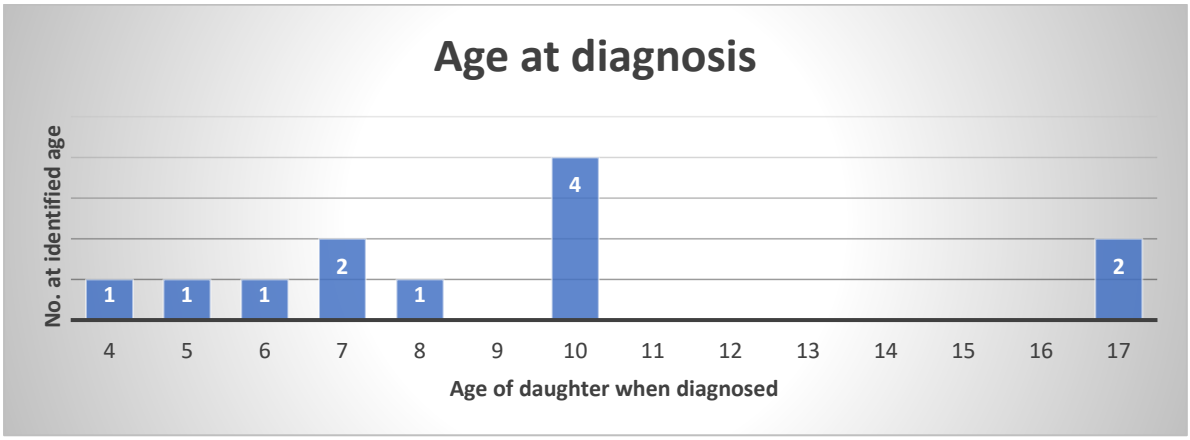
5: Results

In this chapter I share information about the research interviews, including a description about the participants, the age of their daughters, the age of their daughters at the time of their autism diagnosis, and the length of the interviews. I then describe the themes that I identified from the thematic analysis of interview data which are illustrated using experts from the transcribed interviews. Identifiable information such as names, school names and any unique characteristics have either been omitted or anonymised.

5.1: Participants

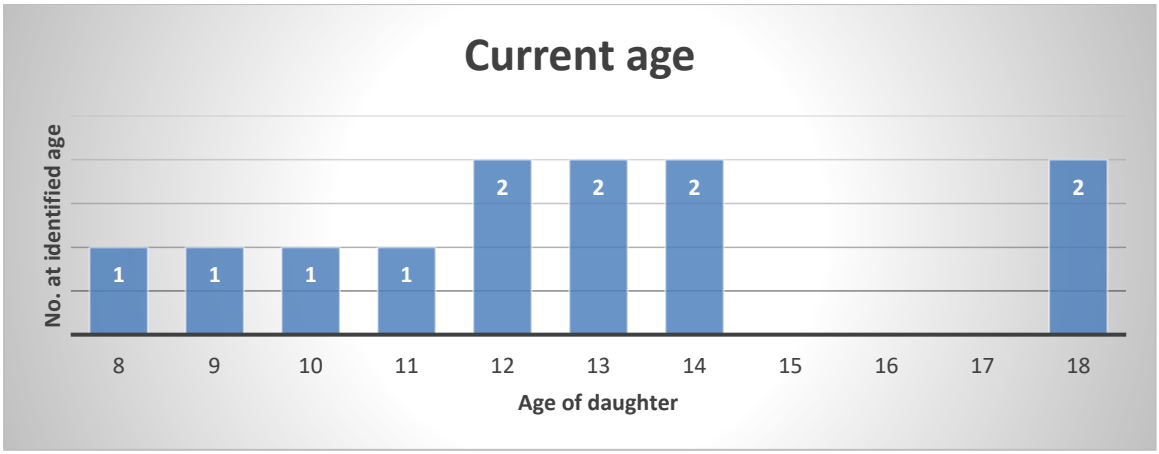
Seventeen mothers responded to the flyer and a total of twelve mothers were interviewed. Two mothers were excluded, one due to location (she lived in a different county to all the other mothers with the potential that local support services and resources would be different) and one due to the diagnosis being very recent (within a month). One mother cancelled prior to the interview due to family circumstances and two interviews were cancelled due to the COVID-19 lockdown.

The age at which the daughters were diagnosed ranged from 4 to 17 with an average age of 9.25 years (see table 1).



(Table 1)

The current age of the girls ranged from 8 to 18 (see table 2).



(Table 2)

The most recent diagnosis was approximately 1 year prior to the interview which related to three girls, including Liza and Louise who had both been diagnosed at 17. The longest time since diagnosis was 8 years, which was Emily, who was diagnosed at 6 and was 14 at the time of the interview.

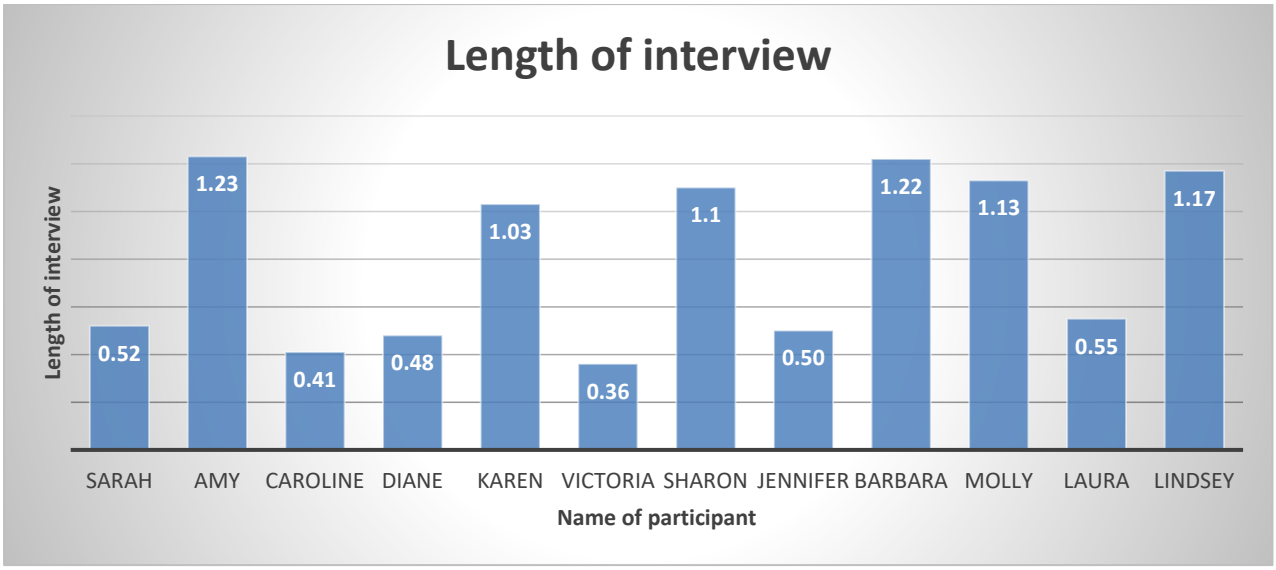
The 12 mothers interviewed were (names, unique characteristics and location specific details have been changed):

- Sarah, mother to Rachel now 8. Rachel was diagnosed at 5 by a private practitioner following the primary school raising suspicions that she may be autistic. Sarah was self-employed and lived separately from Rachels father. She had a son, 3 years older than Rachel, who was diagnosed with autism after Rachel's diagnosis.
- Amy, mother to Liza now 18. Liza was diagnosed at 17 by CAMHS after she had been in contact with the service due to self-harm, anxiety, and depression. Amy was married and had an older son who was at university. She was working part time and was also caring for her daughter who was no longer in education.
- Caroline, mother to Emily now 14. Emily was diagnosed at 6 by an NHS practitioner but the initial referral had been via private medical insurance. Caroline was married, had two daughters and was self-employed.
- Diane, mother to Samantha now aged 13. Samantha had been diagnosed at 7 by a private practitioner who also worked within the local CAMHS service. Diane was married and had a son; 5 years older than Samantha. She worked part time and was in post graduate training to be a therapist.
- Karen, mother to Helen now aged 12. Helen was diagnosed at 10 by CAMHS. Karen was married and Helen was the oldest of two daughters. Karen worked part time in a nursery.

- Victoria, mother to Danni now aged 11. Danni was diagnosed at 10 by CAMHS following a second referral and assessment and involvement with the local CAMHS anxiety pathway. Victoria was married with two children including Dannni's younger brother who received an autism diagnosis at the age of 4. Victoria worked as a teaching assistant.
- Sharon, mother to Louise now aged 18. Louise had been diagnosed at 17 by CAMHS following a period of suicidal behaviour, deliberate self-harm, depression and anxiety. Sharon was married with two daughters, aged 18 and 17, and she ran her own business.
- Jennifer, mother to Tanya now aged 13. Tanya was diagnosed at 10 by a private practitioner. Jennifer was married with two daughters aged 13 and 11. She was self-employed.
- Barbara, mother to Chloe aged 10. Chloe was diagnosed at 7 by a private practitioner and had a dual diagnosis of ADHD. Barbara was married with two daughters, including Chloe's younger sister. She worked part time.
- Molly, mother to Jane aged 9. Jane was diagnosed at 4 by the NHS after concerns were raised by the nursery and school. Molly was married with two daughters and was self-employed.
- Laura, mother to Fiona aged 14. Fiona was diagnosed at 8 by CAMHS following assessment and intervention for severe OCD. Laura was married with three children including Fiona's younger brother, who was given a diagnosis of autism after his sister. Laura was self-employed and also home educated Fiona.
- Lindsey, mother to Pam aged 12. Pam had additional physical health concerns and was diagnosed at 10 by a private practitioner due to Lindsey's concerns that something else was impacting on her ability to engage at school. Lindsey was married with three children, including Pam's youngest brother who received an autism diagnosis after his sister. Lindsey described herself as a fulltime parent and also home educated Pam.

All the mothers were white British, apart from Sarah who had an Indian background and Molly who had a French background. Only one mother, Sarah, was separated. Three of the mothers had given up work to be a full-time parent, whilst the other 9 mothers' either worked part time or ran their own businesses.

The interviews took place in the homes of all the participants with no other family members present. The time taken for the interviews ranged between 36.11 minutes (Victoria) and 1 hour 23 minutes (Amy) (see table 3).



(Table 3)

I had no cause to stop any of the interviews due to any of the mothers becoming overly distressed, but if this had happened the interview would have been stopped or paused as planned. The interview would then have been rebooked or discontinued whichever was most considered most appropriate after discussion with the participant. The interviews were emotional and there were times when the mothers became tearful. When this happened, I slowed the pace of the interview, gave them time, checked that they were ok to continue and made sure I brought a box of tissues!

5.2: **Identified Themes from interviews**

In this section I present the themes identified from the thematic analysis of the transcribed interviews in relation to the research question:

"How do mothers of autistic girls perceive and experience the potential affordances and constraints of diagnosis for their daughters?"

Several themes relevant to the research question were identified. It is noted that some of the themes could be identified as perceived and/or experienced affordances or constraints as the mothers lived experience may be informed by their perceptions, the perceptions of others or their perception of the perceptions of others. Two additional themes 'Emotional and Mental Health' and 'School Challenges (pre-assessment)' have been included because for many of the mother's they informed their perceptions of what the potential affordances of a diagnosis

might be. Whilst the themes can be grouped into headings specific to the research title (as in table 4) this does not reflect their chronology in relation to the diagnostic journey.

The identified themes are shown in table 4. Three additional themes about advice were identified, in response to the questions:

What advice would you give to mothers at the start of the process?
What advice would you give to practitioners/professionals?

This included advice to other mothers at the start of a diagnostic journey for their daughters, 'it doesn't have to be a lonely thing' and 'read and learn all you can' and advice to professionals, 'be more respectful'.

Contextual Themes	**No of Participants who contributed to theme**
• **Emotional and Mental Health**	**12**
• **School challenges** (pre-assessment)	**12**
Perceived Constraints (Constraints of perception)	
• **Autism as other**: Myths and Stereotypes	**12**
The two didn't join up	**11**
• **Borderline normal:** Professional not identifying autism	**11**
• **Worry**: Stigma, prejudice and the future	**11**
Perceived affordances	
• **Here she is again:** Feeling blamed on parenting	**10**
• **Seeking an understanding 'Something's going on'**	**12**
• **Hope - Seeking help and Support**	**11**
Experienced Constraints	
• **Confusion and Upset** (pre-diagnosis)	**10**
• **'Too-da-loo'** feeling lost and unsupported (post-diagnosis)	**11**
• **Diagnosis not accepted** or understood by others (post-diagnosis)	**9**
• **Support Challenges** (post-diagnosis)	**12**
Experienced Affordances	
• **The 'ah' moment** – bringing a new understanding	**12**
• **Evidence and validation** – to self and others	**11**
• **Diagnosis brought support**	**10**
• **'She owns it' - new and positive autism narratives**	**11**
• **Diagnosis informed parenting**	**12**
• **Diagnosis helped family relationships**	**11**

Table 4 – Themes identified in thematic analysis

5.2.1: *Emotional and Mental Health*

The theme 'emotional and mental health' captures the pre and post-diagnostic concerns raised by 11 of the mothers about the emotional and mental health of their daughters. These concerns ranged from managing temper tantrums and aggressive behaviour to anxiety, OCD, significant self-harm and attempted suicide. This theme informed the mothers concerns about their daughters, their desire for an understanding about what was going on for their daughters, and their experiences of seeking help. It connects with a number of themes including 'hope – seeking help and support' and the theme of 'seeking an understanding – something's going on', 'here she is again – feeling blamed' and 'diagnosis brought support'.

Eight of the mothers referred to their daughters exhibiting high levels of stress and/or anxiety. In the case of Lindsey's daughter this led to what she described as an inability to cope with everyday life:

'Pam just got so stressed that she started to not be able to cope with daily life, like she couldn't sleep, she couldn't eat, everything kind of regressed, she started to just be agitated' (Lindsey).

Both Amy and Sharon, whose daughters were diagnosed at 17, described significant emotional and mental health difficulties which had led to intervention from CAMHS.

Amy described how the search for help, prior to her daughter's diagnosis, led to appointments with 8 different practitioners before they met with someone who said they could help, and by this stage she was not communicating with them at all:

'So, in all of this time Liza was being... we were saying, ok you've got an appointment to see this person. And she was going great, someone's going to help me. No, we can't help you, you need to be referred to this. Great somebodies going to help me. We got to 8 before anybody was saying we can help.'

'…she was (..) told you will be on a waiting list for interventions and yet by this time Liza had stopped eating and drinking properly, was barricading herself in her room, or in the kitchen, she was slamming, throwing (.) she was not communicating with us at all' (Amy).

Sharon explained that whilst her daughter received a diagnosis and support for depression and anxiety, after a significant suicide attempt, things were not 'going away' which led her to question what else might be underlying:

'She, was diagnosed with depression and anxiety in January (in breath) 2018, after, I think I told you this, after a suicide attempt, um, which was planned for and very significant, um (.)

and then she was treated for depression and anxiety, but the anxiety didn't diminish. So, then you go 'ok, what's under, so what's underlying, so what's the root cause of this?' And it was really hard to unpick, and it was a mix of (.) GCSE's but a lot, a lot of social anxiety was still there. It wasn't going away (.) It just wasn't going away'.

Jennifer described how her daughter's emotional volatility had an impact on the whole family:

'*She was very emotionally volatile, and as we saw it then, and I can remember this huge frustration that the family were sort of being held to ransom emotionally. Um, and if we didn't do things her way, we'd have these, what I'd now call meltdowns' (Jennifer).*

Laura's daughter, Fiona, was first diagnosed with OCD prior to the possibility of autism being highlighted, which she explained was awful to see:

'When she was 7, she, she became quite unwell with OCD kind of out of the blue, and we were like 'woah' um, which is quite awful to see your 7 year old washing their hands, so much that, you know, their, their wrists have gone red from the hand washing and things, um, and that was kind of the crisis' (Laura).

Laura recalled how they had wanted help due to her daughter being so unwell:

'By that point we were just like, she was so poorly that actually we were just like 'please help us' really, um, because the, OCD was, was awful, at that point (Laura).

5.2.2: *School challenges: Pre-Assessment*

This theme reflects the difficulties or 'struggle' all 12 of the mother's described their daughter's experiencing at school prior to the assessment and diagnosis of autism, ranging from difficulties in attendance, peer group difficulties, or not reaching their potential.

Amy felt that her daughter, who was not diagnosed until 17, struggled with several challenges, but instead she was considered lazy at school:

'…all through primary school she struggled socially and with friendships, she kind of had a lack of motivation about things, she wasn't really that bothered about doing certain things and I think a lot of the teachers considered her lazy' (Amy).

Several of the mother's, including Jennifer, described how their daughter's ability was not matching up with what was seen at school:

'She'd be singing all the songs, but then you turned up to things and she was sort of, staring into space and it, there were just a whole lot of things that didn't quite add up. You know, and our perception of a child who'd got, plenty of ability was not, matching up with what was happening in a school environment (Jennifer).

Sharon noted how her daughter, also diagnosed at 18, was not thriving and had experienced years of bullying at school that continued to sixth form:

'She just wasn't thriving and she was bullied, a lot (.) erm, and she believed that in her first year of six year, first year at sixth form there, that she would, integrate socially and she would begin to socially thrive, but she didn't, and she was bullied, bullied but in a more insidious way' (Sharon).

Some of the mothers, including Lindsey, started home-schooling their daughter's due to ongoing difficulties with attendance and/or anxiety:

'So, she went and did the one lesson. Couldn't go anymore, tried to do just tutor time for a few weeks, couldn't go, um, by this time we saw a psychiatrist in London, because she really was like (..) I mean saying she couldn't go, she wasn't sitting there saying she couldn't go, we were like, she was too big to kind of like manhandle, not that we would do that anyway, but she was just, er, like she just (.) it was like trying to force somebody (..) in a burning building she just, could, not, go. It was just heart breaking to see the level of what she couldn't do' (Lindsey).

5.2.3: *Autism as other*

The theme 'Autism as other' captures the beliefs held by all 12 of the participants about autism prior to the assessment and diagnosis of their daughters, many of which were informed by the media and social stereotypes. For 11 of the mothers this meant that they did not, initially, consider autism as a possibility for their daughters. In all cases the mothers reported a change in their understanding about autism following their daughter's diagnosis, for 11 this included new and positive autism narratives, as illustrated in the later theme 'Neurodiversity – new and positive autism narratives'. The theme 'Autism as other' also connects the themes of 'confusion and upset', 'Too-da-loo' (feeling lost and unsupported)' and 'worry' (stigma, prejudice and the future).

5.2.3.a: *Autism as other – Myths and stereotypes*

Many of the mothers indicated that the topic of autism was something 'not talked about' in their family or in their social groups and was not seen as relevant to them prior to their daughter's

referral. What they did understand about autism was informed by the media, including the news, books and films.

Sarah explained:

"I think anything you see like TV, erm film, media, erm, never, not really spoken about I don't think I'd had many conversations with anyone about autism before it entered my family, erm the awareness wasn't really there". (Sarah)

For eight of the mothers the portrayal of autism in the film 'Rainman' was given as an early perception of what it meant to be autistic. Lindsey described the 'Rainman stereotype' and how, prior to her daughter's diagnosis, she had perceived autism as 'niche' that affected some people:

"*I think just the general media, and just like um, even like, so I went round all the mothers groups and everything, you know, with my children, and they went to pre-school and everything, I didn't even hear other parents talking about it. But I just picked, it was just whatever was in the ether I picked up. It might have been a news story, or, but I wasn't, it sounds awful as well, I wasn't super interested in it, because I thought like it was a niche thing that affected some people and that quite often they had learning difficulties, and that it was something that wasn't in my normal everyday life, .. I didn't understand the term neurodiversity had never heard of it, so I just kind of thought (.) didn't really affect us, and, you know (.) kind of like the sort of like Rainman stereotype, that some people who were savants and had great skills at some things that was, that was pretty much the limit of my understanding. That and the kind of like jokey things about people who weren't very good communicators being 'so autistic' but I didn't say that, but, that's what I heard round and about". (Lindsey)*

Through the media portrayal of autism, reading autism books aimed at parents, or their own work experience in health or schools, 11 of the mothers had previously considered autism to be something that typically only affected boys. For Karen this included a belief that autism had something to do with genetics and chromosomes:

"*I think I probably swallowed the myth about it being more of a boy thing, whereas that's being questioned now isn't it, that the numbers really could be, could be equal. It's kind of, might be, who knows, but it, the numbers were so different then, that, that you know, I thought oh, it must be something on your, you know, on your X, you know, Y chromosome or what. Do you know what I mean?" (Karen)*

All the mothers described their initial beliefs that, as well as being a predominantly a male condition, autism was 'visible' in some way, either due to learning difficulties, overtly unusual behaviour or in some cases savant skills.

"*So, I think if you had asked what I knew about autism, before we had any conversations about anybody around Chloe, I'd had said pretty much nothing other than they can be seen, typically boys, quietly rocking in the corner or screaming and shouting. That was pretty much as much as I knew." (Barbara)*

"So, those kinds of things that made them stand out, er, in a class of children. The two little boys that I worked with, they stood out, um, they weren't able to sit on a carpet and listen, they would just get up and wander off. They had their quirks about them, and they were both wonderful little boys but that's my impression of what classic autism was" (Amy)

"It's very much the kind of a, no eye contact, and um, you know fiddling with small parts of cars" (Laura)

Some of the mother's described a belief, either held themselves, or that they perceived to be held in society, of autism as something with negative connotations attached or as an insult. Lindsey recalled that prior to her daughter's diagnosis she had picked up the perception of autism as something nasty, whilst Barbara understood autism as 'not a good thing':

"I didn't give a lot of thought to it because I didn't see it, I thought, I didn't see it in my everyday (.) life, and so it was a bit, like, 'oh, he's got autism, oh that's nasty' (slight laugh) because I didn't really know but I didn't, I couldn't say hand on heart that I'd met (.) like what I would consider properly autistic people, and I think if I did I might have thought they would have been pretty disabled". (Lindsey)

"…my perception of all of that was generally negative comments about it, and negative perception, and whether that's my own perception, whether that's what I'd heard, what I'd said, I couldn't tell you. But my feeling was that autism was not a good thing. Um, and, perceived by other people as being not a good thing and therefore if you are autistic you come with a 'not a good thing label' as well, um, and that's not something (.) anyone would want their child to experience, that they come with a label that says 'you are not a good thing'. Or you bring with you issues". (Barbara)

Karen recalled a children's story that she had read to her daughter where autism had been used as an insult:

'It's hard, when, when you've been part of it for so long, then, you see it all with a very different perspective, and so, it's um, yeah, it's hard to see how (.) how the yeah (.) yeah, I don't know. I don't know. I did come across one children's book which had one of the characters using autistic as a, as an insult, that's so autistic or something.'

5.2.3.b: *Autism as other – 'The two didn't join up'.*

11 of the mothers interviewed described how their early understanding about autism, such as the belief it was something very visible, the link to the Rainman stereotype and the view of autism as a predominantly male condition, meant that they had not considered autism for their daughter. Sarah described how she '*knew there was something'* which led her to research about autism, but her daughter did not fit what she understood as the criteria, so she initially discounted it:

'*I think at first I was like yeah I'm sure there's something, but I don't think it's that. And it wasn't a denial thing it was because I didn't think she'd fit the typical criteria because she is you know very expressive, very loving and you know hugely um, empathy is very much the she can pick up on you know your feelings and very demonstrative and so, um, from what I started to read she just didn't quite fit.*' (Sarah)

Laura explained that she had worked with autistic adults with learning difficulties, but they had been very different to her daughter:

"So, it was when the community, care in the community, so we had quite a lot of people who, who need a lot of care and whatever. So, so that was my, my first experience of autism I suppose. But that was always tagged onto kind of severe learning disability and epilepsy, and so on and so forth. So that, is very different to the presentation of my daughter" (Laura)

As well as her lived experience through work, what she had read about autism also didn't fit with her daughter, due to the predominance of information about boys and descriptions of specific behaviours:

"…if you read lots of the stuff about autism or how your child might be autistic, that doesn't really, er, seem, it's very much boy dominated, well it seemed to be. It's very much the kind of a, no eye contact, and um, you know fiddling with small parts of cars. And the assessment as well is, you know, do they focus on tiny wheels or something. um, which obviously doesn't

seem relevant. So, lots of the, lots of the mainstream stuff that's been in existence, um, wouldn't have made me thought that my daughter was autistic" (Laura).

Diane and Amy also had prior experience of autism through work within schools, but they did not make a connection with this and their daughters:

"I am SEND governor at (local school) which is where Samantha was at school, and I was asked to be SEND governor before, while she was simply a (.) er, a slight, rather eccentrically behaved (..) small child. Um, (.) so I, but I did some research around it for that, so I, I'd kind of, kind of come across a little bit about (.) about um (.) autism in education (.) um but I didn't join the two up" (Diane).

For Amy, whose daughter received a later diagnosis aged 17, this led to a sense of self blame that she had not made the connection earlier:

"Before I was an admin assistant I worked 1:1 in the primary school and I actually worked with two little boys 1:1 who had autism, so I would say that my knowledge of autism was reasonable, it was certainly, it wasn't anything that I didn't know about. Um, the boys I worked with were obviously severe enough to need 1:1 support in school so how they presented and how I now think back to Liza there wasn't really any comparison because that, that, I, I rethink that I was working with autistic children, she gets an autism diagnosis at 17, and how did we not spot that, how did we not get that? (Amy)

For one mother, Molly, who had expressed the most distress at the initial stages of referral by the school, autism had just not crossed her mind:

"Not for one (.) minute did that cross my mind. I don't know whether other people would have, um, thought that (slight laugh) but I, I, no, it never, that just didn't occur to me" (Molly)

The possibility of autism was raised by a family member to Jennifer, and she described her initial response as being furious:

"...it was suggested to me by my dad's wife. As in, well she said, well of course Tanya comes across as autistic and I was, you know, furious at the time and didn't see it at all. Um, because I didn't really understand anything at all about autism". (Jennifer)

Karen did consider autism at an earlier stage, but this was after researching autism for a friend at church:

"I might not have said in my mind 'autism' but I was thinking there might be something, she hasn't got a friend at nursery, she didn't really, she was on her own little agenda at nursery, I knew that (.) but I thought no, let's let her kind of start school with a blank slate. So, I made a decision there based on something I thought there might be, and then Um (.) um, a friend at church, um, her two year old, so the same age as (Helen's sister) um she was, they were trying to work out was he just delayed or was he autistic and I went home and I looked at the NH, NAS website, because I thought I'm a teacher I'm supposed to know about these things, and as I read it I thought, oh (.) gosh this is Helen isn't it" (Karen).

5.2.4: *Borderline Normal – Professionals not identifying autism*

The theme 'borderline normal' encapsulates the experiences, shared by 11 of the mothers, of professionals telling them their daughters would either grow out of the challenges they were observing or that they were 'fine'. They described a feeling that they were either 'brushed' off by professionals when they raised their concerns or left to question themselves. For some this also led to a sense of sadness and lost opportunity.

Lindsey said her daughter Pam needed support for worries, despite being bright. She felt that when she has raised concerns about things 'not being right' that she was 'brushed off' and that her daughters needs were minimised.

'I feel looking back, because, Pam, even in infant school was in the head's job club at lunchtimes because she, she was having some one-to-one with a worry person, dealing with, she was worried, in school, so they obviously picked that up, but didn't pick anything else up, and I was going down quite often saying you know, um, 'things don't seem right, Pam's really bright but she's saying she can't, you know, she can't remember stuff, she can't do this, she can't do that'. It was just brushed off; I was just brushed off.'

'I feel everyone minimizes your needs and it's very reliant on you to draw the line and say 'this is absolutely beyond the pale' but because we were kind of like frogs in hot water' (Lindsey).

Several of the mothers described times when they were told their daughters were 'fine', would grow out of it or were just shy.

For Sharon this led to a feeling of confusion, due to the reports that her daughter was 'doing well' not fitting with what she was seeing:

'So I think the whole thing about when you've got a child whose got, you know is bright and able, it's very confusing, to get underneath that because the schools saying 'actually she's

doing really well,' and then you're going 'well she's obviously not because she doesn't want to go' and they're going 'yeah, but look'.

Karen described years of unexplained behaviour:

'…we fought through three years of school with, just, bizarre mis-behaviour. Unexplained behaviour.' (Karen)

When Molly's daughter Jane began primary school, she was already on the waiting list for an assessment following concerns raised by the nursery. Molly explained that after she was told Jane was doing brilliantly and that she could forget about her assessment Molly had thought 'that's that then'.

'*I was completely open with the teachers. They came to do the home pre-visit and I said this is what's happened, this is where we are, we've filled in these forms, um, and then she had the first term of school up to the parents evening, and the first parents evening, everything's fine, she's doing brilliantly. She's settling in well, she's, and I said, I remember saying to the teachers, well do you think we can forget all about that, the you know, the forms and er, going down the autism diagnosis thing. And I think, I think they said 'yes, I think as far as we're concerned we, we, you know, we haven't got any concerns' and so we left the first parents evening, and I thought 'oh, that's that then' (Molly).*

Victoria also described how the impact of other's saying her daughter is fine influenced her own thinking:

'…but the things is you've still got people saying 'oh no, well she's got eye contact and she talks, and she does, no, no, no'(..) So it's just a constant (.) it just seems such a battle to actually get there in the first place and you just need one person saying to you, oh no, no, that, no, she's fine, it's in your head' (Victoria)

She recalled noticing that Danni was looking or acting a bit different to her friends, but when she raised it, she was reassured that she was just shy:

'*So, I think I was sort of thinking (..) she was starting to look a bit different to her friends or acting a bit differently and her teacher turned around and said 'oh, no, no she's just shy'. So I sort (.) of put it on the back burner and didn't really (.) and then she changed to the junior school and then I did then start the process (.) um (.) when I look back actually she showed signs very young but I just didn't realise' (Victoria).*

Whereas Laura was told her daughter, Fiona, would grow out of it:

'*Yeah, um, well she was, when she was seven (.) almost at, right, she's an end of August baby. So she's very young in her year, so I think potentially, had she been a September or November child, they, school might have raised issues earlier but, but kind of right from the beginning they were very much kind of 'Oh she's very young, she's very..' and obviously now as a 14 year old, in many ways, in many ways she's starting to mature, but in other ways she's, she's still enjoying playing with Barbies' (Laura).*

Both Amy and Molly took their daughters to the GP and were told it was 'not autism' or that there was nothing to put forward for an assessment'.

'I took her to the GP and the, and my GP turned round, and she's lovely (laughs) she, she turned round to me and she said 'well, it's not autism' (laughs) of course, you know, and so I kind of, I, I, that might have influenced me quite a lot, early on, just that 'oh, it's not that' (Molly).

'I think we went to the GP and he said 'well I can't see anything that would make me think that she should be put forward for anything and the school aren't saying that she should be put forward for any sort of assessment, so we just decided privately to contact somebody and say will you come and do (..) a chat with us at home, would you come and see our daughter and see what you come up with…'(Amy).

When Amy did seek an assessment and support through a private practitioner in 2010, she was told that Liza was 'borderline normal'. Liza was later given a diagnosis of autism in 2019.

'…in 2010, but we did have this lady that came, we filled in some questionnaires, she did a conversation with us, she did a conversation with Liza at the time with us in the room and that's when she came up with her 'it's borderline normal'…' (Amy)

For Amy, the delay in her daughter finally getting her diagnosis made her question if she could have pushed or done things differently, leaving her with a sense of guilt and sadness:

'You *feel guilt (..) because we did get her assessed in 2010 (..) and maybe if we had done things differently, maybe if we had just, pushed (..) or wanted to go, I don't know, I don't know what we would have done differently but it would have been, you just guilt that 'what if?' 'What if?' The whole time. And it's sad' (Amy).*

5.2.5: *Worry about stigma and about the future*

This theme captures the worries that 11 of the mothers shared about the potential for their daughters to be labelled and judged due to the diagnosis of autism. This included concerns that their future and life chances might be limited in some way. Connections were made between the beliefs they held about autism prior to their daughter's diagnosis and the beliefs others in society may still see autism in the same way.

For Molly the worry was that people would make assumptions about her daughter Jane, and not bother to understand her:

'*I still worry about people making assumptions about her, that her, that this label becomes before her. That people see the label and then not, and they don't bother to understand her, to talk to her and meet her, and understand who she is and that they just see a label, and um, you know, especially people who may not be particularly well informed about autism. Um, and you know plenty of people are not, and I suppose I wasn't particularly either, and um (.) So, I don't like the idea that people meeting her may have preconceived ideas about what she might be like, and the way she might behave. I, I still don't like that' (Molly).*

Karen was concerned people may look at the diagnosis negatively and that this may come back to Helen*:*

Even though I don't look negatively on it and the family don't, and I know there will be people out there that don't (..) but I think there would be, would they feel negatively, would there be come back to Helen? (Karen)

Jennifer made a connection to her initial understandings of autism and the possibility that others may still see autism in the same way:

'I think there was a concern about what labelling would do. Um, and also I guess, um, I think we weren't entirely sure to, sort of how (.) public that label would be and therefore what that might mean for people making assumptions, um, because I think we'd probably clocked quite early on that given that we hadn't known anything much about autism in girls then why would anybody else, and, and therefore that a label might not be helpful because they then also might assume that she's, you know (.) stay in corners banging her head against the wall and, lining up, trains in alphabetical order or something' (Jennifer).

Barbara and Laura attributed some of their concerns to the media and social media portrayal of autism, including stories about potential work and emigration restrictions:

'I had, a preconceived idea that come from the press, from the media, that a child with a label generally is treated differently, and treated worse, than a child without an, an autism label' (Barbara).

'I know now there's people in various social media, I wasn't really on social media then, but now I know there's people kind of going 'ooh they might not be able to be in the police or they might not be able to do this, or emigrate to Aus, America', ffuf, not that I'd want her to anyway' (Laura).

When considering the impact of the label 'autism' Lindsey's concern was that it would influence the expectations of teachers:

'I just think once your child gets diagnosed with special needs that, that also means that in some teachers eyes they're not going too far and, I don't know They're on the special needs list, and then, and there's not an understanding that actually you can have autism and (..) be brilliant' (Lindsey)

Molly recalled a comment from a teacher, potentially intended to reassure her, that made her worry about the future:

'*I still remember in foundation stage two saying, I hope I don't, to the teacher who was really helpful to me, 'I hope I don't ever regret, you know, having accepting the..' and she said 'you won't whilst she's at school' but, in the back of my mind, of course what sticks in the back of my mind from that conversation is 'why did she say whilst she's at school? What will I regret later?' (Molly).*

For Sharon it was permanency of the diagnosis that led to concern:

'I knew once she had that diagnosis, she would never lose it. That made me really nervous' (Sharon).

For Amy the potential for Liza needing long term support, and the impact on herself as well as Liza, was hard to think about:

'She had a crash, we now realise she has ASD (..) she's got anxiety and depression, she's already had, she's had one spell in hospital, she's two years down the line her peer group have moved on, she knows her peer group have gone on. She has no (..) thoughts about where her future might lie, and she can't even think about that now, and now we can't think about that now either. We're stuck (voice emotional), *she's stuck, and you have this kind of*

impression of what your child's going to do because your told they're very bright and they're not going to have a problem going through GCSE's and A levels and go to university, and then something like this happens (Amy).

5.2.6: *Here she is again – Feeling blamed on parenting*

This theme reflects the view, of 10 of the mothers, that they were blamed by others for their daughter's difficulties, either due to poor parenting, or due to being over-protective or 'neurotic'. This led to a feeling that they were an inconvenience at school as well as some self-blame as they questioned why they could not make things better. A perceived affordance of diagnosis was that it would protect from blame and be evidence that concerns were justified.

Caroline and Molly felt that parenting is blamed and that it is always the mothers who are given a hard time:

'I think us mum's get given a really hard time especially having worked in the field professionally as well, I think there's sometimes an assumption that it's the parenting, it's the mother, it's the mother's insecurities, it's the mother's mental health and 'ra, ra, ra, ra' and you know and that's not always the case. There might be elements and pockets of that, but I don't think that's always the case' (Caroline).

'*That we hadn't got behaviour under control, that we were somehow, that there was a lack of discipline or something'(Molly)*

Karen believed that she was being blamed after an email suggesting she attend a parenting course, and considered herself a bit of an 'inconvenience':

'Helen started having, at the beginning of this year, kind of problems with her shirt feeling uncomfortable. The first time we've had anything like that, as far as I know, and um, and I thought, I don't think it's the shirt, I think it's um, being upset about things but I don't know what. And um, and I did get an email back from the Head of year who suggested it was 'all' to do with home, so 'ah, you need more structure at home' and it was one of those emails that make you think, 'mm, they're blaming us.'

'*I obviously, I was a bit of an, in, inconvenience to some extent because (..) well I just, yeah, I don't think (.) there, there was an awkwardness about the relationship but I don't know whether that was the, you know the kind of needed, needing extra help' (Karen).*

Lindsey (1) felt like a complete pain in the neck when raising difficulties with the school, whereas when Victoria (2) was asked about how she was seen by the school she said she thought she was seen as neurotic:

(1) 'I think before it just felt embarrassing, and, it, and the whole journey with school was so difficult that I just felt like a complete pain in their neck. Turning up there regularly, trying to say very politely 'my child's not coping with this, that and the other' or people, er, you know, er, accusing you' (Lindsey).

(2) 'And how about, um, (.) how you felt you might be seen by the school before the diagnosis? (Interviewer).

'Neurotic' (Victoria).

'Why neurotic?' (Interviewer).

'Oh. Because I'm there all the time. 'Oh, um can I just mention that. Can I mention this?' (.) You know when you can see people going 'oh God. Here she is again' (Victoria).

Some of the mother's, including Barbara, also experienced blame from their wider families:

'I realised that actually, my mum would often make comments that would make me think she didn't think I was doing a very good job with my children' (Barbara).

In some cases, the mother's experiences led to self-blame and a questioning of their own parenting capabilities:

'You know, I really want this world to be one that they can grow and thrive in and for them to grow and thrive in that world, and the fact that they can't, or aren't, no matter how much effort everyone's put in, fundamentally it comes back to me as a mum (tearful) I'm going to get really emotional, come back to me as a mum saying 'why can't I make it brilliant for my kid?' (Barbara).

'..you've got these children and you love them utterly and you want to do your absolute best by them, and you feel like you're doing everything you can, every day for them and then (.) oh, they can't go to school, and they're not doing well or they're not coping or they don't have friends like other children, and then you're like 'what have I done wrong' or that is what you think other people are thinking, and, I don't think they are, but I think, on some level it feels like a failure' (Lindsey).

5.2.7: *Seeking an understanding – Something's going on*

All 12 of the mothers described an awareness that their daughters were developing differently to their peers, either socially, emotionally or behaviourally. This brought them to question what was happening and to search for answers and understanding, which ultimately led to their daughter's diagnosis. For 7 of the mother's this included the feeling that 'something wasn't right' or 'something was going on'.

'Pam started to say things like the classroom's all too noisy, it's way too bright, I feel all stressed when I'm in there, um, it's too busy, um, um, I don't like the playground, I don't like going outside, there, I'm, I'm, I'm worried about the dining room, I can't eat my food in there. And so all these like complaints and I thought it was partly because she wasn't coping but then in my mind I thought, well something isn't, right' (Lindsey).

'Um, that was really at the point where we were saying something really isn't right. You know, our perception was that we had a very bright child and a very able one and she really wasn't doing very well at school at all' (Jennifer).

'So, we kind of knew that something wasn't quite right there, in terms of getting what was going on' (Barbara).

For Caroline, Victoria and Sharon, the differences became more apparent as their daughters got older:

'I know children develop at different rates so, um, but then you know as we started getting further into school, it's like' yeah, er, you know, I hm, I don't know' (Caroline).

'So, I guess her differences were beginning to become more apparent, you know you couldn't pass it off as a toddler tantrum anymore by the time she was 7' (Victoria).

'Um, but then I noticed it was creeping into other things which was her room and stuff like that. And then I also noticed some of the things that I thought she'd grow out of, which she has a real phobia about, that's things like smells of bananas and stuff like that, the smell of oranges, I noticed she wasn't growing out of them. So, it was the fact she wasn't growing out of things' (Sharon).

Difficulties in making friends, bullying and social behaviours were identified as the cause for

some of the mothers seeking a better understanding about their daughters. Amy described how Liza had always struggled to make and maintain friendships:

'So, in her primary school years um, Liza I suppose was that odd child. And she didn't (..) She didn't (..) she wasn't socially (...) um great, she wanted to have friends, she would make friends, but she would lose friends. A lot. So, there were a lot of friendship things going on. And that (sigh) kind of (..) hmm, became bullying, and sometimes just low level bullying but through, you know, the later years bullying, I mean some of the things it (..) (sigh) the, the bullying started and then her anger management (.) just didn't keep up and she had big anger management problems. And school, so the school were dealing with it with an anger management programme (inward breath) but there were a lot of children that knew that if they pushed her button she would go, she would go, and that became a sport for them' (Amy).

Diane said that her daughter Samantha had always appeared to be 'in her own world':

'She was in her own. She didn't respond, didn't always res, reliably respond to her name. She was difficult to transition from task to task (.) in a nursery kind of environment' (Diane).

Lindsey described how she was left wondering 'why' whilst Diane wondered what she was missing:

'I guess for us we were, 'why can't she go to school?' 'Why can't she cope?' 'Why is she falling apart?' (Lindsey)

'Um, I got to the point of saying to my parents, what are we doing, what are we missing, what are we doing wrong, because her behaviour was challenging '(Diane).

It was hoped that having some insight into their daughter's difficulties would enable the mothers to know what to do to support them. This led Barbara to seeking a private diagnosis:

'*So, then we thought the best thing we could was go and find a private diagnosis which would give us some insight into which challenge is greatest for her, and whether there's anything that could help her, should she need it. So, we went down that route, and we got the diagnosis, and we pretty much did nothing with it, other than 'ok, we've got a better understanding of Chloe let's see where go'. So, it was about insight I think for us' (Barbara).*

Whilst Lindsey and hoped a diagnosis help her with an understanding about her daughter as well as what to do:

'So, it wasn't necessarily the label I was after it was, assuming a label would lead me towards, 'and so this is what you can do about it' (Lindsey).

'We could get help for her (..) and understand her better, and for her to understand herself better, that's what I wanted from a diagnosis' 'We wanted things to change' (Lindsey)

5.2.8: *Seeking help and support*

This theme illustrates the hope the mothers had that an assessment would bring the affordance of help and support. For some there was a perception that the diagnosis would bring support at school, for others there was a belief that there would be more specialised support or support in the future.

Jennifer and Lindsey described an assumption that there would be support and treatment options that would make things easier:

'I think I just assumed that, that would be what happened. That, you know, I think in my head was quite a medical kind of model where if you, if you get a label or a diagnosis then that automatically follows on to what you do about it. Um, so I think probably what I was hoping for was some (.) er, some support, some expertise, some guidance, and that would help us live, live with this more effectively' (Jennifer)

'Yeah, I think I was definitely hoping that it would be, erm, you now a little bit in, if you get a diagnosis of cancer or something everybody talks you through your treatment options and the likely prognosis and, you know, you could do this or you could do that, and so on' (Lindsey).

For 6 of the mother's, including Sarah, Amy and Barbara, support at school and learning was a driver for the assessment, including projecting forward to secondary school:

'Um, for her in particular I thought with um, just us as parents, er hopefully um, supporting her in the right way and then for school, um, which hasn't come to light, yet, but we are still working on it, is for her to have the right support at school with her learning' (Sarah).

'Things can be put in place for her, in school, and that means she gets the help that she needs, and she can get, so even going out into the outside world into whatever we could get help for

her (..) and understand her better, and for her to understand herself better, that's what I wanted from a diagnosis' (Amy).

'We were thinking about what do we need to do for the future for Chloe where does it go, we'd heard that getting help further down the journey takes two to three years because of the wait lists, if we needed her to have help before she goes to secondary school' (Barbara)

Victoria saw no sense in not going for the assessment due to concerns that, without a diagnosis, Danni would not get help in the future if she needed it:

'I didn't see how it made sense if I thought she had it, to not go for it ,because, although she might be coping in that setting it mean she was going to cope further down the line and without having any sort of diagnosis it, she wouldn't get any help' (Danni).

When Laura's daughter became very unwell with OCD, she was just looking for help:

'by that point we were just like, she was so poorly that actually we were just like 'please help us' really, um, because the, OCD was, was awful, at that point' (Laura).

5.2.9: *Confusion and Upset – In the referral and assessment process*

The theme 'Confusion and Upset' encapsulate the negative experiences highlighted by 10 of the mothers about how they experienced the referral and assessment process for their daughters. This included how the possibility of autism was raised, the wait for the assessment and the focus on impairments in the diagnostic process.

Molly, whose daughter was one of the youngest at the time of diagnosis, shared how she had found the way autism was raised hurtful:

'*Lots of things that people said stick in my mind because they felt quite hurtful. Because she said, 'it's better to have a diagnosis, without, you know or 'it's better to go down this route without it other people might just think she's a nasty child' or something like that' (Molly).*

Caroline, whose daughter Emily was 6 at the time of diagnosis, explained she had not even been aware that the assessment she was attending was for autism:

'…it was like 'come along for a speech and language assessment' didn't necessarily (.) er, no autism wasn't mentioned at that point. Although maybe the consultant had been trying to lead me down that road when he said, 'ooh she doesn't give that much eye contact does she?' But at the time I was like 'there's nothing wrong with that' (laughs) (Caroline).

Due to concerns about waiting for a long time on the wrong list, Barbara sought a private assessment for Chloe:

'The danger being you start her on a pathway, you get to the end of it and they say no it's not that it's the other one, start again, and we're four years out rather than two years out. So, then we thought the best thing we could was go and find a private diagnosis' (Barbara).

Laura, whose son had subsequently got an autism diagnosis, said that she had felt in limbo when her daughter was on the waiting list, but she felt the support had now improved:

'You sit and wait for two years' with no input or whatever, um, and that was horrible. Um, so, the fact they're now doing lots of pre-assessment workshop for parents, I think, is a massive improvement, um, because you were just left in limbo going 'what the hell' you know, you've got to the point where, where things are going awry enough for you to get referred and put on the pathway, and then just be left in a total limbo is, is fairly horrendous, um, um (.) so having that early information would have been much, much, er really you know, gratefully received (Laura).

Whilst Amy felt that she had been ill informed:

'…*as a mother of a girl, at the proc.. um (.….) do I think that I, I do think that we were ill-informed? I don't think that there was overly much support for people going through the process' (Amy).*

Laura and Lindsey shared how they found the process of the diagnosis, and the content of the assessment report, negative due to the focus on impairments:

'*The process of diagnosis was not, er positive, because of how, um, the diagnostic interview is, um, which is (..) wholly focused on their difficulties and impairments and how it's stated and everything else, um, so that was more of a, going through that wasn't good' (Laura)*

'…it's a negative experience to be honest, you say everything that's wrong with your child or whatever, they ask everything that's wrong, and then they write it all up and then you read it all, and then you come out with a sort of sinking heart of 'oh my goodness look at this mess of poor shortfalls, we've got significantly affected in this area' you know (slight laugh) and you're just like, and then things like 'ability to make friends is limited' and all this kind of thing, and you're like 'oh, my goodness, this is pretty, pretty terrible' but then you go for a walk and

your like 'she's exactly the same person she was before I got this piece of paper and we actually didn't think (..) she was wrong before so why should we think that now'(Lindsey).

5.2.10: *'Too-da-loo' (Felt lost and unsupported following the diagnosis)*

The theme 'too-da-loo' captures the stories 11 of the mother's told about their initial feelings at the time of their daughter's diagnosis and immediately after. This included feeling overwhelmed, shocked and isolated. This experiencing of the diagnosis is likely to be informed by the myths and stereotypes they held about autism.

Barbara recalled having a weep mainly due to the statements made about her daughter:

'Um, from then on it was pretty much like 'too-da-loo' um, here's your piece of paper. Um, I do remember going to a pub on the way home from the hospital and having a little weep myself. Mainly from actually (.) um, reading the statements made about her by, and from school, and things like that, were actually quite upsetting, um (..) so yeah, and the actual kind of process is quite upsetting, (becomes a bit tearful) sorry, ridiculous, so many years ago'(Barbara).

Sarah felt grief and sadness, and that she had to process things on her own:

'If I am really honest, I don't think I had anyone really to talk to about it. I just had to process it on my own which was quite hard because I'd watch her playing, on the rare occasions that were in her way playing, and I just couldn't. It was hard because I just. Or, I'd buy her a toy, or a game and she couldn't get on with it, where her peers were playing in a more traditional way or whatever you know. And, I'd feel downhearted; my heart would sink a little. Yeah, there was quite a lot of sadness for a little while (Sarah).

Amy, Sharon and Jennifer described how they experienced the diagnosis as abrupt or they were left hanging:

'We *were kind of 'here you go, here's a load of bumph Liza will get used to the idea that she's autistic and it will all be fine because that will reduce her anxiety and actually, in actual fact, it's done nothing' (Amy).*

'.. so, we, we were given our diagnosis very abruptly and we were like 'whoa', whatever, well I was like that (husband) was 'yep, knew it!' I was like, 'I feel differently to you, I feel different to you' (laughs) It was like 'that's it, we're all sorted now' and I'm like, 'whoa this wall's going to hit us' and it did' (Sharon).

'So I think I was probably hoping that somebody would make it, that easy and, giving me information and, and advice um, and it was a bit of a shock when, um, it wasn't at all like that, you kind of got the label and were left hanging, that was it' (Jennifer).

When Molly first sought support, just after the diagnosis, she couldn't recognise her daughter in support group discussions and began to panic about what might happen:

'At the start when I, just after the diagnosis I didn't, um, I mean the very first workshop I signed up to, I just, I just wanted to cry all the time, because I could just hear.. I couldn't recognise Jane in anything, so it was awful because I felt I couldn't recognise her among children who didn't have a diagnosis, she wasn't, she was obviously not, you know her development obviously wasn't taking the same path as theirs, and then I didn't, I couldn't recognise her when I spoke to other parents of children with a diagnosis at that time, in the early, in the early stages, and they were talking about problems that we didn't have, and then I would panic because I'd think 'this is what's going to happen to us' (Molly).

5.2.11: *Diagnosis not accepted or understood by others*

This theme reflects the post diagnostic experiences, described by 9 of the mothers, of others not understanding or accepting their daughter's diagnosis. The most frequent references, made by 7 of the mothers, were about grandparents either questioning the diagnosis or demonstrating a lack of understanding about what it meant.

Caroline described how her father in law had said they were making a fuss:

'(His) dad, like, 'ugh, there's, there's nothing wrong'. You know (.) Just maybe we were making a bit of a fuss of it (Caroline).

For Jennifer there was a sense that her in law's saw her daughter as a 'naughty girl', whilst her father, who was a GP, questioned how they could get a cure:

'(Husband's parents) are a little bit, narrower and more old fashioned in some of their thinking and I think they still had elements of, you know, she's being a naughty girl, kind of thing so it's been quite interesting that you, you have to assume zero knowledge on everybody else's part' (Jennifer)

'So my dad is an ex GP, long retired now but you know he was a GP, so you might have expected him to have some understanding of autism, but it was quite interesting that er, his reaction when I told him about the diagnosis were 'right, so what are the treatments for it now?'

and, you know, 'how do you get a cure' basically was his, his, hi approach you know, very medicalised way of viewing it' (Jennifer).

Lindsey recalled another parent questioning the diagnosis of her daughter, implying it was a convenient category she had chosen for her:

'We were at piano lessons, and there was another parent there last week, we were talking about, I was talking about Pam and he was saying his daughter's had anxiety, and I was like, yeah Pam's is terrible and we were talking, about her sever anxiety and stuff, and um, I said 'but she did get diagnosed with autism' and he went 'ahh, everyone's getting diagnosed with that these days aren't they. These children they don't have, they don't have autism, are you sure she really has. I don't think they really have it. It's just a convenient category they're putting people in because everybody wants to label everything' (Lindsey).

When Molly told her friend about her daughter's diagnosis she was shocked at her response:

'I remember just after the diagnosis a friend (.) and her reaction just (..) and I said, I think I remember saying to her, I don't know whether did the, that, that, because I remember the diagnosis, I was very upset at the point, the point at which they told me and um, and she said to me 'you don't have to accept the diagnosis' and I found that also shocking, because I thought well how could I not' (Molly).

Lindsey felt the validity of the assessment and her daughter's diagnosis was questioned because she had paid for a private assessment:

'They try and throw in your face that you paid for it as if you bought it, as if these people are somehow, these medical professionals are somehow so, um, sort of (.) I don't know, um, um (.) like, like as if their professional conduct means nothing that they would just, a bought, a bought report is worth much less than a, so even now when I go to LA school meetings, they are 'that's a private report that one isn't it. That's a private psychiatrist that isn't it. And, it's like 'my goodness, we're seeing someone on Harley Street, like we're paying, you know, £290 a follow up appointment because we're so desperate to get help for our daughter' (Lindsey).

5.2.12: *She's not broken enough: Support Challenges (post diagnosis)*

All 12 of the mother's in the study described challenges with accessing support for their daughter, post diagnosis, across both education and mental health (CAMHS) contexts. Some

mothers described a sense that their daughter's needs were not seen as severe enough to warrant support, whilst for others it was a lack of available resources or the diagnosis itself that were a barrier. For one mother the concern was that the emphasis was on her daughter to change to fit in. Available support was also seen as boy focused.

Barbara and Sharon spoke about their daughter's diagnosis as a barrier to support:

'…..the fact that she has a diagnosis of ADHD and autism meant she didn't qualify for the study. So, we weren't able to access that help because she's, quotes 'not broken enough' (slight laugh) to get there. So, yes, yes it has been a block but that was a very specific block. I think it's more to do with the fact that there isn't anything' (Barbara)

'And, we went forth with the diagnosis, to these schools. Schools wanted to see us, so we saw two private schools. So, schools wanted to see of because of course Louise's GCSE results are ridiculously good. So, they, interview us, and the interview Louise, and they, do the showcasing that private schools do, and then they come back and go, two of them come back and said no, they can't cope' (Sharon).

Amy was told her daughter was 'not severe enough for an EHCP:

So now, I'm at the stage where I am thinking I really need to get this EHCP sorted, I need to start at it now. Because I've been asking every year at school, shall we do this, shall we start this and it's 'she's not severe enough, she's not severe enough, you're not going to get it'. Now I'm at the point, well I don't really care what anyone thinks now, I know that she's going to need it, and 'sod you' I'm going to do it myself.

Jennifer described how her daughter isn't 'on the school's radar':

'Tanya is, essentially high functioning and therefore just isn't really even on their radar at all, so you know, she's on their list but clearly most of her teachers (.) won't have, won't have done anything about that, we had a few, um (.) er, interactions with the school, things like, um you know she'd gone to sick bay to say she felt rubbish and the school had gone, yeah, yeah, alright, go back into class you'll be fine, um, anyway so I had to call the school and say, 'actually it's really important that you have it on her file that it's a MASSIVE big deal for her to ask for help and if she's asked you for help she REALLY needs it' (Jennifer).

Both Sarah and Karen stressed how the diagnosis itself did not bring all the answers or help that people might hope for:

'A diagnosis is not a silver bullet. It's not the answer. Don't wait, don't pin your hopes on diagnosis' (Sarah).

'…the diagnosis wasn't a magic, magic pill that would solve all our problems. Cos I think that's what I'd, what I'd thought that there'd perhaps be a program of, program of help or something, something might, might be offered to us they'd say 'ah well', you know cos in, that's what it is in medicine, normally isn't it 'here's the diagnosis and here's the' not the cure but 'here's what you need to do to help'. But I realised in that there was nothing. There was nothing almost specific that was gonna come. It's not that I regret getting the diagnosis because it does give a little bit of clout (.) um (.) umm (.) it kind of helps the schools realise that (.) they need to do something. I could see that all those things would be harder without the diagnosis. But, but has it really changed things, no not really' (Karen).

Diane described a lack of resource across the NHS, Policing and education:

'My perception is that CAMHS is grotesquely under resourced just like the all the rest of the NHS, and therefore everything is going back onto the schools, it's like knife crime. So, the police don't have any, the police don't have enough resources for knife crime, so the schools can do it, and it feels like the same thing (.) happening with (.) all sorts of (.) neurodiversity and mental health (.) without the resource, but the school don't have the resources either' Diane).

Whilst support had been offered to her daughter, Laura questioned why it was her daughter, now being home-schooled, that had to change and not the behaviour of those around her:

'She recommended this circle of friends idea, and I kind of looked into it a bit, and, and I just kind of thought, would I like that? And every ounce of my being screamed 'no'. So, I was kind of like 'actually I'm not, I'm not going to say yes this is a good idea for my daughter' um, and lots of these lots of like social skills things and, huh, stuff like that, um, are actually not very helpful, um, I don't think. And I think a lot more work, it feels a lot more work needs to be done around, and it's really difficult I know, around um other children not being shits!' (Laura)

5.2.13: *The 'Aha' moment- Diagnosis brought a new understanding*

A prevalent theme for the mothers, across all the interviews, was that of the diagnosis bringing a new understanding about their daughter's behaviours and experiences. This was informed by new information about sensory processing, executive functioning and masking and more awareness about autism and how it may present in girls. Statements such as 'like having

something lifted off your eyes', 'like a jigsaw piece just put in' and 'The Aha' moment were used to describe the effect of this new information about their daughters which led to more tolerance and understanding. This had a transformative impact on parenting and also on the family:

'...*as soon as Pam got diagnosed it was amazing because the family worker came around. She gave us this simple leaflet and it was basically like, very simple things like, er, autistic people would like to feel safe, and they want autonomy, and they need to feel that they have some control over their situation, and that just completely altered how we were dealing with Pam because we were like 'oh, we understand it so much..' It was like a jigsaw piece that was just put in'(Lindsey).*

'It was kind of like entering a new world, that had been there all the time, but you just hadn't (.) understood or seen it. So, it's kind of like having something lifted off your eyes and you were like 'oh my goodness' (slight laugh). So, for us as a family it was really positive and straight away we were like, ok, this is how we, this is like (.) fuelling your anxiety, it's part of the way of how we are operating as a family, so straight away we were like, we learnt so much'(Lindsey).

Sharon, whose daughter was diagnosed at 17, described the 'Aha moment', in terms of looking back and knowing how to respond:

'I think the main one is just to finally understand and go 'ahh'. The 'ah' moment the 'aha'. You know, it's said hindsight is a wonderful thing, oh yes. Now you can go all the way back and you can go 'ah' it's the 'aha' moment. It's just that, it's the understanding, and then because you have the understanding, your belief, it's because you have the understanding that you're more likely to be able to respond to things with patience, understanding and um, benefit. That's the belief.

Victoria felt that she understood her daughter more and was able to look at situations she may struggle with, which in turn enabled her to be calmer:

'*I can understand now the girl side of it (.) and um, just how different she is (..) she is, she's really highly anxious and it's um, just being able to look at situations and being able to work out if she is going to struggle with that and why. So, I think I understand her a lot more now' (Victoria).*

'*Yeah. I think I try and be much calmer. Because I don't want her, I don't want her to start escalating. Whereas if I didn't understand the reason behind her being like that I'd be 'for God's sake, why are you being like this?'(Victoria)*

Several of the mothers referred to working out triggers for behaviour, playing detective of pre-empting things. This included Caroline, Barbara and Sarah:

' I think we've had to do a lot of erm, (..) learning ourselves you know just um about, kind of almost being like, I've heard other people say this, about being a detective thinking 'right, hang on a minute, what's triggered that, what have I said, what smells have I introduced, what food have I introduced, you know, how could I have raised that bet..?' It's just constantly having to rethink, how you communicate whether it's communicating non-verbally or verbally, yeah. (Laughs) (Caroline)

'*So rather than making the assumptions that she's choosing to be naughty, or she's choosing not to listen, or she's choosing not to do what I've asked her to do or, or, m, m, my approach to her is different, and that's because I think I recognise that much of what she experiences comes from triggers that are around her and there are, they're not, choices and decisions she's making in her head' (Barbara).*

'It's looking at the why. It's always playing detective, constantly playing detective. Um, which is exhausting for them but also the neurotypicals in the family' (Sarah).

It was felt, by Amy and Diane, that this new understanding of behaviour enabled them to be more tolerant and more accepting of their daughters:

'*And it's, it's finding out about those things, those things that she can find out about herself (.)and we can put things in place (.) we can be more tolerant about things we might feel are a little bit odd but that, that's what she needs so that's fine' (Amy).*

'…because it stopped us assuming that we were terrible parents um, and it stopped us um (..) well, blaming Samantha, did we blame Samantha? I don't know, it's made it easier for us to accept Samantha as she is' (Diane).

For all the mother's there was a new understanding of autism itself, including how it can present differently in girls. For Molly and Jennifer this included a more nuanced understating of autism and the idea of masking:

'I think, I've maybe a more nuanced understanding of autism now, and, um (..) er (.) and that some of the days that it affects Jane can be quite subtle and they're not immediately obvious to anybody else who meets her but, they're there and she needs help with those things' (Molly).

'I think my understanding of autism and girls has (.) changed an awful lot and the idea of masking, um, being er, quite a significant feature of it and that , that in itself explains so much of (.) what we've, we've seen with Tanya. Um (.) yes, so I think, so I think the sort of the breadth of if it and also the, the, gender specific, er, presentation of it has changed a lot' (Jennifer).

8 of the mother's interviewed, including Sharon, referred to executive functioning and sensory processing as some of the biggest learning points that had informed a new understanding of their daughters:

'*And that's probably been the biggest learning, is about things like executive functioning, sensory overload, has probably been the biggest um (.) learning' (Sharon).*

Karen, who found groups helpful, felt she could have started attending sooner, pre-diagnosis:

'I think, I could have started going to these things sooner, erm, because they all accept people pre-diagnosis um, so perhaps I could have got through that bit and then found (the autistic girl's group) thing sooner. Which, that would have been good' (Karen).

5.2.14: *Evidence and validation*

The theme 'evidence and validation' captures the examples, given by 11 of the mothers, of where the diagnosis acted as validation, to themselves and others, about their daughter's needs. The experiencing of the diagnosis as something tangible and official enabled and empowered them to push for more support where they felt it was needed, and where they had perhaps felt they were not listened to before.

Laura described how she had got much better at asserting herself with the school, whereas Caroline felt it made the school take her more seriously:

'*I've you know, got much better at asserting myself with school, and um, and I think it allowed me yeah, to, to be, really on it for secondary school, because again everybody was going kind of 'whoa' secondary school transition, um, and going from again, it was a primary school with 45 children into a secondary school with a thousand. Um, so, I think (..) more supportive within the school environment, I think, of being able to go in and say 'right, my daughter is autistic' and da, da, da, da.' (Laura)*

'*I suppose there was an element of um (..) (laughs) It's a bit tricky! Erm (..) there was an element of me feeling like the school weren't necessarily taking us seriously so (..) er, in that respect I think yep, well we can go back to them now saying actually there is something going on here, this is what they've said. So, there was, there was, an element of that as well, um, sort of, people just taking us more seriously' (Caroline)*

Victoria felt that the official diagnosis meant that people could not 'fob her off' as easily:

'*Well, you've got the official diagnosis so (.) I think you know because that's there (.) it's not as easy, easy for people to fob you off. Because she has got a condition, so, if it's something that's reasonable they can't turn around and say, well no we're not doing that' (Victoria).*

For Barbara sharing the diagnosis with her mother helped her feel her daughter's challenges were not seen as a result of poor parenting:

'I think with the diagnosis, sharing it with my mum, and sharing with the 'why it's challenging for (N) in that situation because.' She's suddenly gone 'oh yeah, I get it. I get that. It's not because you haven't done a good job of parenting' (Barbara).

Jennifer said that the diagnosis stopped her assuming they were terrible parents, removed blame from her daughter and stopped her sister taking things personally:

'It stopped us assuming that we were terrible parents um, and it stopped us um (..) well, blaming Tanya, did we blame Tanya? I don't know, it's made it easier for us to accept Tanya as she is, um, and also to help (sister) understand (.) not to take it personally, I mean she does but you, you know at least there's some rational dialogue around it, um, so I think that, that definitely has helped, and I certainly, you know with hindsight I, I don't have any regrets at all that we went and got a diagnosis' (Jennifer).

5.2.15: *Diagnosis brought support*

In addition to an increase in understanding about their daughters, 10 of the mothers talked about ways in which the diagnosis had brought support. This included courses and groups which they had found helpful, access to books and information, support from other parents and support in school.

Molly described how support at school had made a huge difference for Jane whilst Diane felt it had got her daughter on the SENCO's radar:

'We just put in 6, 8 different points, um (.) and it made just a huge difference. I think we had her starting school 10 minutes later, so she didn't have to do that morning rush because the cloakroom was awful and it stressed her out, so she came in 10 minutes later than the others, um, and I've even got the list still of points that, um, the different things that we put into place, um, in place. So, at school lunch time we put something into place because she couldn't clear her own tray, she couldn't stand the smell of the food, er, the waste food bin and things like that' (Molly).

'It does still actually open up support at school um, because (.) I spoke to the SENCO quite recently and talked about who's on her, who's on her er, list of children with SEND and she said almost, almost, entirely based on diagnosis. So, actually the label, kind of at least made sure she was on the SENCO's radar' (Diane).

Jennifer found reading books, linking with charities and talking with other parents helped:

'I've read lots of books, um, I'm signed up to a couple of charities and get their newsletters and things so, we're getting um, you know, a fairly steady stream of, autism related information through, and of course I'm connected up with other parents so it's become much more part of everyday dialogue now to, talk to other parents and their experiences of, of, of kids on the spectrum' (Jennifer).

Laura said that the support she had hoped for came from a charity group but not from CAMHS, whilst Sharon had found CAMHS support helpful for her Louise:

'*What did I hope for (..) in a roundabout way but provided not by CAMHS, so provided very strongly by the (charity) group, um, who we were signposted to I think, um (…) so yes, I suppose' (Laura)*

'They did everything to try and get her back to school. But what they didn't do was address the insidious bullying, so anyway the CAMHS therapist, who was amazing and, initially (husband) and I said we may have to own the decision about what to do. So, what that school did was offered a third year, Louise could do less hours over a longer period. Um, and we thought that was the best option (..) but in the end after a lot of heart searching, we said actually it has to be Louise's decision (..) with what she wants to do, with the support of that therapist she made the decision not to go back to that school' (Sharon).

Amy also found the support from the charity group and talking with other people helpful:

'We've joined the (charity) girls group and that's been a great source of information for us and support for us, and realising that there's all these girls out there and they've all got similar or very different presentations or you know, routes to diagnosis or whatever. But that's just been really nice to hear other people's impressions and got lots of information' (Amy).

5.2.16: *'She owns it' – New and positive autism narratives*

All 12 of the mothers described a change from their early beliefs about autism as a male disorder or something 'not nice' as described in the theme 'autism as other – myths and stereotypes'. The theme 'she owns it' captures a significant shift in the narratives of 11 of the mothers away from autism as impairment and towards autism as something more positive. This included a celebration of their daughter's strengths, autism as a 'superpower' and an awareness that no two people with autism are the same.

For 9 of the mothers, including Jennifer, there was a new understanding about how no two people with autism are the same:

'I think I've, er, come to realise it's er, um, a much broader spectrum of, of, different attributes um, and that no two autistic people are the same' (Jennifer).

Molly described a change an acceptance of her daughter's diagnosis and an understanding that all children with autism are different:

'It's changed in every way um (..) um, in that I understand that Jane, um, I think it's, I do understand that Jane has autism, I know that sounds ridiculous to say that's a very basic fact, but I do understand that now, and I do see that, that is, that is right. Um, which I say that took me a while to understand that. And I do understand that, that is right, and I

understand how um, um (..) eh, I understand that (..) eh, that I suppose that all children with autism are different and that spectrum encompasses Jane and the way she is' (Molly).

When talking about her daughter Laura referred to her having many strengths and described how powerful it was to hear autistic women speaking, whilst Caroline appreciated her daughter's honesty, and Sharon saw her daughters 'neurodiversiveness' as enabling:

'She's got a great many strengths and, in different ways. So I think it's, yeah, kind of understanding the (..) the neurotypical and the, kind of autistic view of things and, and actually hearing other parents talk, but actually, particularly autistic women speaking, is really, really powerful, because they're normally by the time they're speaking to people about something they're actually um, at least coming across as being quite empowered, and um, and quite challenging to the, the status quo (Laura)

'Just, the way she comes out with things, just tells it like it is, you know that's what's brought us close together because we always try and celebrate that and we'll have, you know she'll have really honest conversations with me and I think that's really nice actually (Caroline)

'she's definitely got some neurodiversiveness that's enabling' (Sharon).

Lindsey said her daughter 'owns it' when referring to autism, that it is her 'super power' and that some of the things they find most fantastic about her are probably her autistic traits, but she also acknowledged that there are challenges due to society.

'We are happy. We're like Pam owns it, she's like 'yes I'm autistic' and so do we because we think it's a real like, she's amazing, do you know she, as a whole person she's amazing, like kind of autistic or not and I think the things that we find most fantastic about her probably are autistic traits' (Lindsey).

'We sort of talk about it as being a kind of super power, but also it comes with limitations because society isn't necessarily set up to accommodate you in, in everything you might need, so we see it completely differently now. I sort of see it in a much more neurotribe way, but that's not to undermine, like, the significant difficulties that you can face with it' (Lindsey).

5.2.17: *Diagnosis informed parenting*

The theme ‘diagnosis informed parenting’ encapsulates the descriptions, of all 12 mothers, about ways in which their daughter’s diagnosis had led to them adjusting their approach to parenting. This included the adoption of specific strategies, ‘shaking up the rules’ and giving themselves permission to do things differently.

All of the mothers described a change in their parenting style, for Molly this included putting a visual calendar in place, for Victoria it was being calmer, whilst for Barbara and Amy it was clearer language and making less demands:

‘We immediately started putting into place things like the, you know, the visual calendar and all those sorts of things that really did help her’ (Molly).

Yeah. I think I try and be much calmer. Because I don’t want her, I don’t want her to start escalating. Whereas if I didn’t understand the reason behind her being like that I’d be ‘for God’s sake, why are you being like this?’(Victoria)

‘I think the autism diagnosis made me change the language I use with Chloe. So, I simplified it, and she’s highly, highly articulate. So rather than saying to her Chloe, come on, let’s get your bag packed, have you got your thing, have you got your blah, have you got your blah, have you got your blah, right, let’s get it on your back, let’s get out the door, it’s ‘Chloe bag’ (..) and she’ll go, and she’ll, she’ll get her bag and I’ll say ‘have you checked’ (..) and then we’ll go ‘snack’, ‘water-bottle’, ‘homework’, so simple language which is easier for her to process’ (Barbara).

‘I try and be (.) clearer (.) slower, put less demands um, (..) I talk her through things so the whole, you know, when we were going on holiday, which she managed this year, she didn’t manage last year, (..) um tell, for her to be a part of ‘right this is what we are thinking, do you think that would be ok with you?’ and I’d, and I think that’s what, yeah, I think that’s what the ASD diagnosis did give me, I think in terms of what she needs, ASD wise’ (Amy)

Many of the mothers described how the diagnosis had given them permission not to conform to parenting norms, which included changing the rules and forging their own path:

‘I think less pressure to conform, as well, and maybe because there is an alternative (.) I suppose an alternative peer group for parents is quite useful, um because, you know, although the differences are quite subtle, there are loads of little things as a parent, and I know my friend who’s got a young son who’s autistic, and he’s saying the same’ (Laura).

'Well that's not how you treat a 12-year-old is it. It's not how you treat a 'typical' 12-year-old girl, but she's not a typical 12-year-old girl. So, actually the rules were off the table. It, yeah, it changes the rule, it changes the game, it changes the rules' (Diane).

'I've kind of tossed how parenting should be aside and think I'm quite happy to forge our own path, and it only really clashes when you meet people who don't agree' (Lindsey).

Caroline reflected on 'getting it so wrong' prior to the diagnosis, whilst Jennifer described how a removal of blame, through the diagnosis, had enabled her to be a better parent.

'We were inadvertently getting it 'so' wrong and inadvertently making matters worse because we didn't understand what was going on, we didn't, you know, we didn't understand why it was distressing her so much' (Caroline).

'We wore her the whole time in a baby-sling because it was the only way you could do anything and, um, and I just assumed (.) yeah that, that it was us that meant that, that was difficult so that was quite affirming, that was quite nice really to think 'oh, there's a label I can blame it on, and actually it's not just us' um so yeah, I think that, that did help a lot actually, and then probably because, I could feel better about myself as a parent, probably enabled me to then be, a better parent' (Jennifer).

5.2.18: *Diagnosis helped the family and family relationships*

The theme 'diagnosis helped family relationships' captures the ways in which 11 of the mother's described the diagnosis of their daughter's helping members of the family and family relationships in some way. This includes others in the family newly identifying as autistic, the impact on the mother/daughter relationship and/or an ability to talk about their daughters needs with the wider family in ways which were useful.

A number of the mothers spoke about siblings and family relatives who were subsequently diagnosed or self-identified as autistic following the diagnosis of their daughter. For Sarah this was her son whilst for Laura this was her 78-year-old father:

'So up until year 5/6 when he started to display severe changes in his behaviour that's when I then stepped in but by then I had more of an understanding of autism with my daughter. So, her diagnosis has actually helped the whole family hugely' (Sarah).

'When my daughter was diagnosed, we got some kind of big book about it, I don't know, um, and, um (.) let my parents read it as well, um, and from reading that my dad, who, and the family joke was 'he's autistic' for years, actually self-identified as being autistic at the age of 78 or something. And then, wrote us this big long letter saying actually, he'd never been happier in his life, um, then when he realised that he thinks he's autistic' (Laura).

A change in understanding about their daughter's needs and challenges following diagnosis also had a positive impact on mother/daughter relationships. For Diane this meant taking things less personally whilst Caroline said they had been brought closer together:

'Um (.) Makes me more (..) more conscious of how she responds to things (..) and more aware that whatever she might do to me, or say to me, erm, may be influenced by things that are well outside me, outside my control. Because otherwise you could take, I could take it really, really, personally' (Diane).

'It's brought us closer together because I'm constantly having that dialogue with her. 'Do you want to smell that, is that a good one, is that a bad one can you tell me how you feel'. So, yea, yeah' (Caroline).

For a some of the mothers, including Barbara and Jennifer, the diagnosis changed the parental relationship, whilst for Lindsey her daughter's diagnosis helped the whole family:

'I think (husband) *and I found it easier to talk to each other……He went to a dad's group, and heard the stories of the other dad's, it suddenly clicked in his head, 'ah, that's because' and 'ooh, if we do that differently that'll be…' (Barbara)*

'*I mean that's because my husband would very much fall into that category, but, I don't know, you asked about how relationships changed, it's changed my relationship with my husband because I'm pretty sure that he's, fairly far along aspects of the spectrum, um, so and that's a whole different conversation' (Jennifer).*

'For us as a family it was really positive and straight away we were like, ok, this is how we, this is like (.) fuelling your anxiety, it's part of the way of how we are operating as a family, so straight away we were like, we learnt so much' (Lindsey).

In some cases, the diagnosis also helped with extended family relationships. Victoria described how she can talk about her daughter's needs with extended family relationships and expectations:

'I think sort of especially family. Family need to understand (.) So it's like on, you know, Christmas or whatever she'll, she'll still be in her bedroom. 'Oh, why isn't Danni coming down?' Well she's, she's not comfortable down here. So, they might go up an see her' (Victoria).

5.2.19: *Advice given by the mothers*

Advice given by the mothers was grouped into three themes as follows:

It doesn't have to be a lonely thing: The mothers said that they would advise other mothers/parents to join groups, talk to other parents and also to make sure they talk to each other. They said it was helpful to know that they were not alone and to hear and share advice. Amy said how it is important to talk:

'Talk to as many people as you can. Get support from as many different places because (..) there is lots of things out there and there is information. It can be overwhelming and it's actually better sometimes just to talk to people.' (Amy)

Read and learn all you can: They wanted to encourage other mothers not to wait for an assessment or diagnosis and to read or learn all they can. Whilst they all spoke about the benefits of a diagnosis, they also said that you do not need to wait for a diagnosis to make changes, to learn about a child's experiences and to make their lives easier. Sarah said it is about trial and error:

'Don't wait, don't pin your hopes on diagnosis. If there is any suspicion just go out there and educate yourself. Start finding out, start (.) trying things. Because what you try with one person with autism might not work with another. You've just got to, it's trial and error until you find your way.' (Sarah)

Be more respectful: 11 of the mothers wanted professionals to be more aware of the emotional journey that mothers and parents can experience as they seek and/or receive a diagnosis of autism for their daughters. They wanted support and advice to be provided at all stages of the journey. This included not presuming knowledge that the mothers may not have, sharing useful and timely information and very importantly making time to listen to concerns. Jennifer wanted professionals to be aware of what a big deal diagnosis can be for a family:

'I think don't underestimate the extent to which this is a big deal for the family, um, and (.) how, um (.) how unfamiliar this is, even if they've grown up for however many years it is, with an autistic person in the household if they didn't know that, that person was autistic they don't know how to deal with it, they don't realise that necessarily, it's a life-long condition um, it, you know, just the extent of the newness and unfamiliarity of it and therefore what a big deal it is to cope with.'(Jennifer)

6. Discussion

In this study I explored how 12 mothers of autistic girls perceived and experienced the affordances and constraints of their daughter's diagnosis. The aim of the study was to explore the meanings that the mothers gave to the diagnosis and the stories about their lived experiences post diagnosis, with the following research question:

'How do mothers of autistic girls perceive and experience the potential affordances and constraints of diagnosis for their daughters?'

My intention was to get a better understanding about the perceptions first held by the mothers prior to their daughter's diagnosis, what hopes or fears they had about the diagnosis, and when given what difference the diagnosis made. As a researcher with diagnostic experience I wanted to know if the diagnosis brought the benefits they may have hoped for, or did it fail to live up to expectations. As a systemic practitioner/researcher I was curious to know if the diagnosis influenced mother-daughter, or wider family, relationships. Throughout my study I aimed to challenge ableist narratives, to give the mothers a voice and to gain a better understanding of their lived experience.

In Coordinated Management of Meaning (CMM) terms I was curious to know:

> What was being made? *(When the diagnosis was given)*
>
> How was this made in communication? *(Including the stories told about autism pre and post diagnosis and in the diagnostic process itself.)*
>
> How did/can the participants make something that works better for them? *(In the creation of new stories lived and told)*

As explained in chapter 4, to achieve this, I first completed a thematic analysis with emergent themes grouped into the four headings of perceived and experienced affordances and constraints. I then utilised the LUUUUTT model (Pearce1990, 2007, Griffin 2014) to highlight the stories 'lived and told', old and new, that informed the mother's experiencing of their daughter's diagnosis, including where these stories were useful and brought affordances or where they caused confusion, tension and constraints.

In this chapter, I present a quadrant diagram (see Figure 7) to illustrate the interrelatedness between the stories lived and told in relation to, and in relation with, the affordances and constraints of an autism diagnosis for girls. I also reflect on the strengths, limitations, and other possibilities for my study. Importantly, I share implications for practice, informed by the stories of the mothers themselves. Practice implications include implications for clinical

intervention (including systemic therapy), diagnostic pathways, service providers and policy makers as well as suggestions for further research.

This research makes connections with similar studies into the lived experience of the mothers of autistic girls. There is also new knowledge highlighted, in particular with regards to the affordances and constraints of the diagnosis itself. I believe the research findings give a valuable insight into the experience of the mothers prior to their daughter's being referred for an assessment, their experiencing of the assessment and diagnosis, and the subsequent impact of the diagnosis on their identity and in their relationships with their daughters.

6.1: **Perceived Affordances and Constraints, and Constraints of perception.**

Prior to their daughters' diagnostic assessments, the mothers who participated in this study perceived both affordances and constraints to the potential diagnosis. Constraints of perception were also identified which impacted on pre, and post, diagnostic experiences.

The mothers described how their lived experience prior to the diagnosis was that they were not coping in their roles as a mother, they were struggling to manage their daughter's behaviours and saw their daughters struggling at school, or at home. The 'practical force' driving the mothers was to gain a better understanding of their daughters and to get them the help they felt they needed. They could see their daughters developing differently to their peers but there was no immediate explanation as to why. This awareness of difference, with no clarity as to 'why' has been highlighted as source of frustration for parents (Lewis, Skirton and Jones 2010).

The mothers described telling others that something was not right and that they were missing something, but they experienced seeking help and support as a battle. This made them question themselves and left them with a lack of clarity about what was happening whilst they continued to advocate for their daughters and battle for support, expanding on the findings in the study by Fowler and O'Connor (2021) who described mothers rolling up their sleeves "to demand the best possible outcomes for their daughters" (2020, pg.9). As with previous studies, professionals appeared to have limited knowledge about the presentation of autism in girls which led to early challenges in identifying autism as a possibility which acted as a barrier to the mothers concerns being heard (Anderson et al 2020, Whitlock et al 2020, Fowler and O'Connor 2020, Hill et al 2020, Navot et al 2017, Bargiela et al 2016, Hiller, Young and Weber 2014). This challenge in getting concerns heard has been highlighted by Wei et al (2015) as an important contributor to diagnostic delays.

As seen in previous studies, diagnosis was seen as a means to access support (Crane et al 2015, Russell and Norwich 2012, Lewis, Skirton and Jones 2010, Siklos and Kerns 2007, Midence and O'Neil 1999, Howlin and Moore 1997, Howlin and Ashgarian 1997) and 'acquire certainty' Jacobs et al (2019). The finding highlighted that whilst a diagnosis was seen as a means to gain help and understanding, the label or diagnosis itself was not the mothers' main concern, it was more about what they hoped it would bring. This is illustrated in Lindsey's comment that what she really sought was the *'and this is what you can do about it'* element of the diagnosis for her daughter in the theme 'seeking an understanding'.

Initially the possibility of autism appeared to be an untellable story (a story that is forbidden or painful to tell) for some of the mothers. Consistent with the findings of Anderson et al (2020) the mothers did not "arrive at autism as the explanation" for their daughters appearing different to their peers. They were beginning to observe that there was something different and there may be a need for a diagnosis to get help, '*but not autism'*, '*not that'.* This experience of autism as *'untellable'* appeared to be informed by *'constraints of perception'* about what autism was, what it 'ought' to look like, and how others may perceive it. This was compounded by concern that a diagnosis would lead to stigma and prejudice from others, or that it may influence their future life choices. Similar concerns associated with stigma and the future have been highlighted by Nealy et al (2012) and Fowler and O'Connor (2020) and were a factor in parents resisting diagnosis for their children in past studies (Russell and Norwich 2012). This fear remained for the mothers following the diagnosis despite a considerable shift in their own understanding about autism and meant that whilst the diagnosis was seen as a means to bring support and help for their daughters, there was also a fear it may limit their life chances or hinder them.

A dominant story was one of feeling blamed and seen as responsible for their daughter's difficulties due to poor parenting. This was compounded by their daughter's difficulties often being more pronounced in the home whilst they were masking or camouflaging in school, as reported in previous studies and literature (Anderson 2020, Fattigh-Smith 2010, Hiller, Young and Weber 2014, Frazier et al 2014, Stewart 2012, Eaton 2017). In this sense, in addition to obtaining understanding and support, the act of seeking diagnosis was informed by both a 'pre-figured' and a 'practical force' influenced by the disbelief of others and driven by the desire not to be seen as 'bad parents of naughty children' as described by Farrugia (2009) and Anderson (2020).

Figure 7 shows the initial tensions between the perceived affordances of diagnosis and constraints of perception. Whilst most of the mothers saw diagnosis as a means of accessing help, they were clear that at first that they did not want a label for their daughters due to

concerns about stigma and stereotypes. This initially created some tension between seeing a diagnosis as an affordance 'a means to bring support needed' and a constraint 'something which may bring stigma and limitations' with the potential to create a 'strange loop'. A practical force, guiding the decision to actively seek diagnosis, was the belief that it was a necessity to gain support for their daughters both at school and for their emotional and mental health difficulties. There was also a belief that the diagnosis would counteract some of the scepticism and disbelief they experienced when raising their concerns, consistent with studies by Navot et al (2017) and Anderson et al (2020). At this stage the concern about potential constraints of diagnosis became outweighed by the perceived affordances, thus bringing the mothers out of the 'strange loop'. This process was also influenced by perceptions of what autism ought to look like and about how autism ought to present, informed by autism myths and stereotypes (stories told). In CMM terms the diagnosis, and the decision to attend an autism assessment for their daughters, is a critical moment 'bifurcation' or turning point for the mothers (Pearce 2007). This connects with the concept of a 'tipping point' between a parent defending their child's 'normal status' before they feel a diagnosis is necessary to get support (Russell and Norwich 2012).

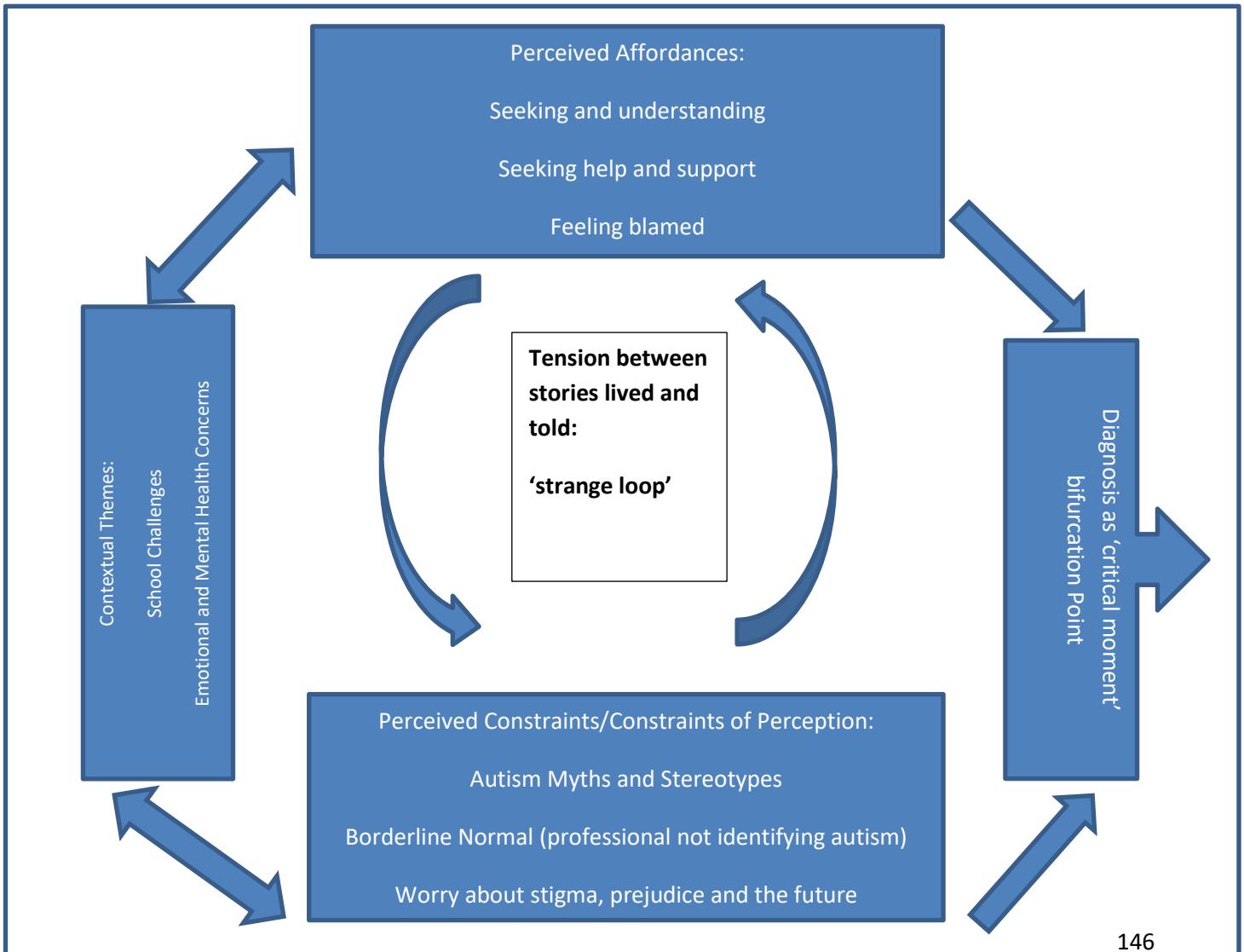


Fig. 7: Relationship between perceived affordances and constraints of perception/perception of constraints

6.2: **Experienced Affordances**

Writers have questioned the benefit, or affordance, of an autism diagnosis due to lack of agreement about aetiology, it's lifelong nature and a lack of cure (Chapman 2020, Dallos 2019, Latif 2016, Hassall 2016, Chown 2016, Timimi 2011, Timimi, Gardener and McCabe 2011, Molloy and Vasil 2002). In contrast to this view, the mothers in this study described a variety of significant experienced affordances related to their daughter's autism diagnosis, and consistent with the findings of Howlin and Moore (1997), Russell and Norwich (2012), Mansell and Morris (2004) 'just knowing' the diagnosis was in itself helpful. What this study highlighted is the transformational impact the diagnosis had on the stories told about the needs and behaviours of the daughters. Of particular benefit was an increased awareness about anxiety, sensory processing, and executive functioning. This was illustrated with descriptions such as 'having something lifted off your eyes' and the 'Aha moment'. The change in awareness about the needs of the daughters was accompanied by a change in understanding about autism itself, including an increased awareness that all autistic people are different, and autism is not just something that affects boys. The mothers also found new knowledge, or stories told, about masking or camouflaging helpful in understanding their daughters more, consistent with the findings of Fowler and O'Connor (2020) and Anderson et al (2020).

Stories shared by the mothers, about lived experience following the diagnosis, showed how new understandings about their daughter's behaviours and challenges had significantly informed new parenting styles. They described 'playing detective' and becoming more aware of their daughters triggers as well as becoming more tolerant and patient. This led to them shaking up the rules as they learnt to parent their daughters according to their individual needs, rather than focusing on what they had once thought they 'ought' to be doing. This letting go of 'oughtisms' resulted in less comparison with other parents and children, feeling less blame, and adapting new autism informed parenting strategies. A similar protective factor of an autism diagnosis against parental stigma and blame has been reported by Anderson et al (2020), Midence and O'Neil (1999), Farrugia (2009) and Gray (1993, 2002).

In contrast to the indication by Dallos (2019) that a diagnosis serves to remove an element of responsibility from the parents, the mothers in my study were far from passive recipients. Whilst the diagnosis did create some protection from experiencing blame, the mothers demonstrated that they were actively taking responsibility for making changes to support their daughter's wellbeing. Whilst autism was seen as an explanation for their daughter's difficulties, the study highlights how the diagnosis became an enabler, with problems predominantly seen as external due to schooling and/or environmental factors. This resulted in the view that it

was the external environment, including school and family relationships, that needed to change and not the daughters themselves.

As with mothers in the study conducted by Anderson et al (2020), the mothers in my study viewed the diagnosis as something tangible and official which enabled them to push for more support. When I reviewed the experienced affordances of diagnosis to look at 'story telling' I was struck by how the narrative seemed to shift from 'asking' others for support, or about what might be happening, to 'telling' others about their daughters needs and what might help them. The mothers described feeling more empowered and able to advocate for their daughters, and the participants who had previously had challenges with school support described feeling listened to where they had not been before. Similar findings were reported by Anderson et al (2020), Fowler and O'Connor (2020) and Eaton (2017). As seen in prior studies (Howlin and Moore 1997, Lewis, Skirton and Jones 2010) the hope that the diagnosis would bring support was (in part) met at school with some of the mothers describing new strategies being put in place, such as starting school 10 minutes early for one of the girls.

The majority of the mothers described attending groups and meeting other parents helpful. Of particular benefit was the autistic girl's group, run by the local charity that they had been recruited by, and where they were able to hear autistic adult women talk. The benefit of parent's groups and the role of parents in supporting each other has been well documented in previous research (Howlin and Moore 1997, Lewis-Skirton-Jones 2010, Taner and Walizer, Braiden eta al 2010, Fowler and O'connor 2020). As well as accessing groups, the diagnosis also led to the mothers reading more about autism which was described as helpful, particularly when reading material about autism and girls was accessed.

What this study highlighted was a significant shift in all the mothers' understandings about what autism is, about autism and girls, and a reauthoring of the stories and narratives about autism from negative ones, to stories about celebration. Where autism had previously been seen as a male condition, something with extreme and obvious atypical behaviours or even something 'nasty', it was now described as having a number of strengths, a 'superpower', and something to be celebrated. A development of pride in the mothers of autistic girls has been highlighted by Fowler and Connor (2020) whilst Sanchez (2018) observed a similar shift from mothers trying to cure or treat their autistic children to advocating for their needs in her review of the book 'Autism Mothers Speak Out' (Golding and Stacey 2018). There was an awareness that autism brought challenges, but the majority of the mothers referred to neurodiversity in some way. I believe this is in part due to the girls group they attended which celebrates neurodiversity and is run by empowered autistic women who share positive 'lived' stories

about autism. This supports the findings of Fowler and Connor (2020) who recommend groups specifically for the parents of autistic girls.

A number of the mothers shared stories about how their daughter's diagnosis helped family members and family relationships, including in the wider family. This included a touching story about how one of the girl's grandfathers had self-diagnosed following her diagnosis. This had answered a lifetime of questions for him about why he had found certain things difficult. For others, the diagnosis of their daughter led to the subsequent diagnosis of a sibling. The mothers also described a change in parental relationships and an ability to talk about their daughters needs with the wider family in ways which were useful. A positive bond or impact on the mother/daughter relationship was also described as seen in the mother-daughter study by Navot et al (2017). What was highlighted in this study was the impact of new narratives about their daughters needs and behaviours, which were informed by the diagnosis, and how these informed those positive changes in relationships.

The experienced affordances of diagnosis, and the complementary relationship between new stories lived and told in relation to those affordances can be seen in the following diagram (see fig 8).

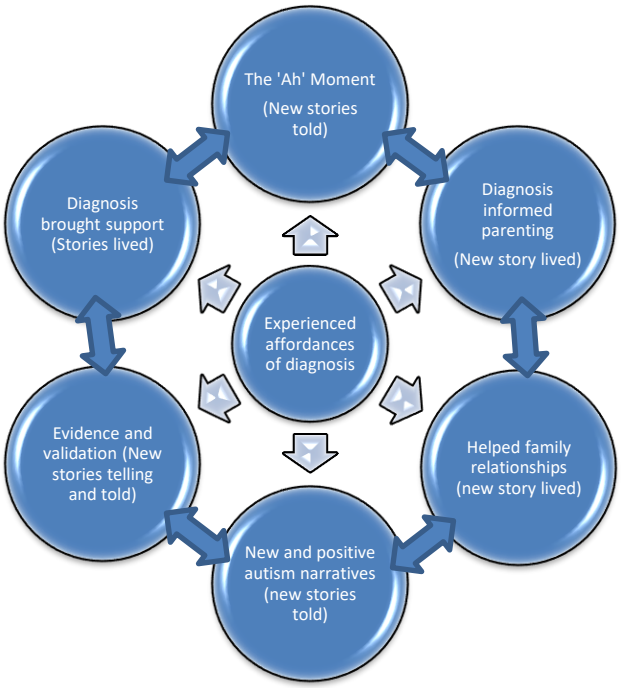


Fig 8: The experienced affordances of autism diagnosis for the mothers of girls.

6.3: **Experienced constraints**

Whilst the mothers described a number of experienced affordances from the diagnosis of their daughters, in particular an increased understanding about their needs, there were also a number of experienced constraints (see fig 9). As seen in other studies (Jacobs et al 2019, Potter 2016, Crane et al 2015, Siklos and Kerns 2007, Howlin and Ashgarian 1999, Howlin and Moore 1997, Piper and Howlin 1992) the wait for an assessment, and the assessment process itself, was a difficult time for the mothers. One mother described 'being in limbo' whilst waiting for an assessment for her daughter, whilst another spoke about being ill informed about the process. The wait for an NHS assessment had proved too long for a number of the mothers and they had obtained a private diagnosis for their daughters. For one mother the assessment of her daughter spanned over more than 7 years due to missed or miss-diagnosis. This protracted nature of assessments for girls has been highlighted by Stewart (2017), Navot et al (2017) and Rivet and Mason (2011). On a more positive note one of the mothers, who had since received a diagnosis for her son, said that she felt pre-assessment support had improved since her daughter's assessment due to the introduction of pre-assessment workshops and support.

The diagnostic experience was described as overwhelming, shocking, and isolating due to a focus on negative behaviours, impairment and deficit within the assessment, and a sense of being 'left hanging' once the diagnosis was given. These findings are consistent with numerous studies into parental experience of autism assessment and diagnosis (Jacobs et al 2019, Potter 2016, Crane et al 2015, Siklos and Kerns 2007, Howlin and Ashgarian 1999, Howlin and Moore 1997, Piper and Howlin 1992). This study expands on those findings by highlighting the impact of societal myths and stereotypes and 'stories told' about autism on the mothers' experiencing of the assessment and diagnostic process. Concerns about the future were shared, and consistent with studies by Navot et al (2017) and Nealy et al (2012) the mothers described concerns about the future 'with their hopes and dreams brought into question' (Nealy et al 2012). Again, this study highlighted the particular role that negative myths and stereotypes, and 'stories told' about autism, played in informing the mothers experiences. When support was accessed post assessment one mother described how the first groups she accessed were boy orientated, and as described in previous studies and literature (Navot et al 2017, Eaton 2017, Anderson et al 2020) Fowler and O'Connor (2020), there was a sense that her daughter did not fit with her peers, but she did not recognise her as autistic either.

One constraint from the diagnosis was a lack of awareness from others about autism and in particular about autistic girls. Whilst the diagnosis did bring some additional support, the

mothers faced challenges and ‘scepticism’ with others not accepting the diagnosis, or not understanding what it meant for their daughters to be autistic, consistent with the findings of Anderson (2020), Fowler and O’Connor (2020), Eaton (2017), Navot et al (2017) and Stewart (2017). This continued scepticism came from schools, family and friends, with grandparents in particular questioning the diagnosis, not understanding what it might mean, or suggesting they were ‘making a fuss’. A tension between stories told by parents and grandparents is highlighted as an additional cause of anxiety by Dallos (2019). One mother also described how, when she had told another parent that her daughter was autistic, she received the response ‘ah everyone’s getting diagnosed with that these days’. This apparent lack of understanding about autism and girls also led to the mothers feeling their daughters were seen as ‘not broken enough’ to receive support due to camouflaging and the hidden nature of their challenges at school. As with other studies this led to a view that not enough help was given post diagnosis, either immediately after diagnosis or in terms of ongoing support (Nealy et al 2012, Weale 2020, Jacobs et al 2019, Siklos and Kerns 2007, Braiden et al 2010, Mansell and Morris 2004, Potter 2020). One mother explained that when support was offered, the emphasis was on her daughter changing to fit in rather than those around her adapting to her needs.

Whilst the autism diagnosis was seen as a way to access some support (*you ought to get a diagnosis if you want support*) and did bring a new understanding about difficulties, the mothers stated how it was ‘not a silver bullet’ and ‘not a magic pill’, because the needs and challenges experienced by the girls pre assessment remained post diagnosis. This fits with the advice of Jacob (2020) that diagnosis ‘should not be a goal in itself’ and the findings reported by Lewis, Skirton and Jones (2010) that even with a diagnosis ‘families still face similar challenges, uncertainties and joys’.

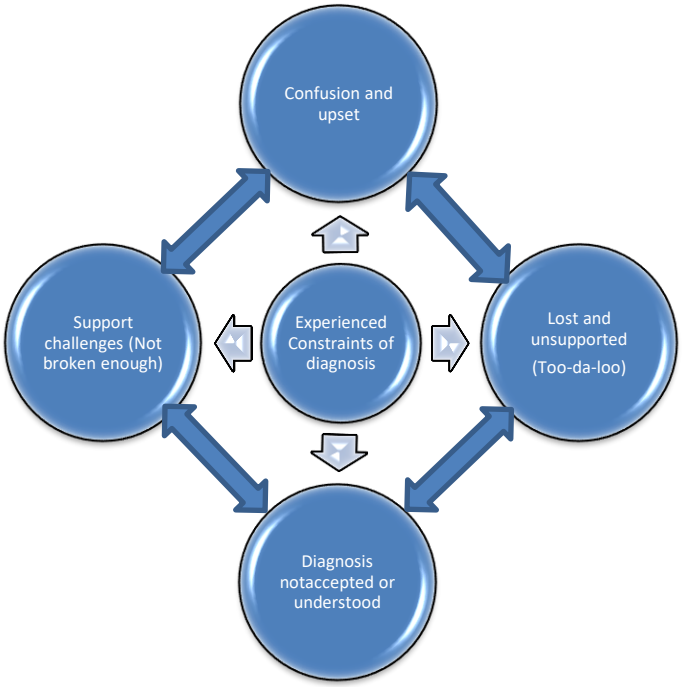


Fig 9 The experienced constraints of autism diagnosis for the mothers of girls

6.4: **Perceived, and Experienced, Affordances and Constraints (and Constraints of Perception)**

Whilst diagnosis brought many affordances, there was a tension between stories lived and told with regards to support, the acceptance of the diagnosis from others, and with regards to the potential implications of the diagnosis due to autism myths, stereotypes and perceived stigma. This interrelationship is shown in fig 10 in which the tensions between the affordances and constraints are shown. Related themes are colour coded to illustrate their connection.

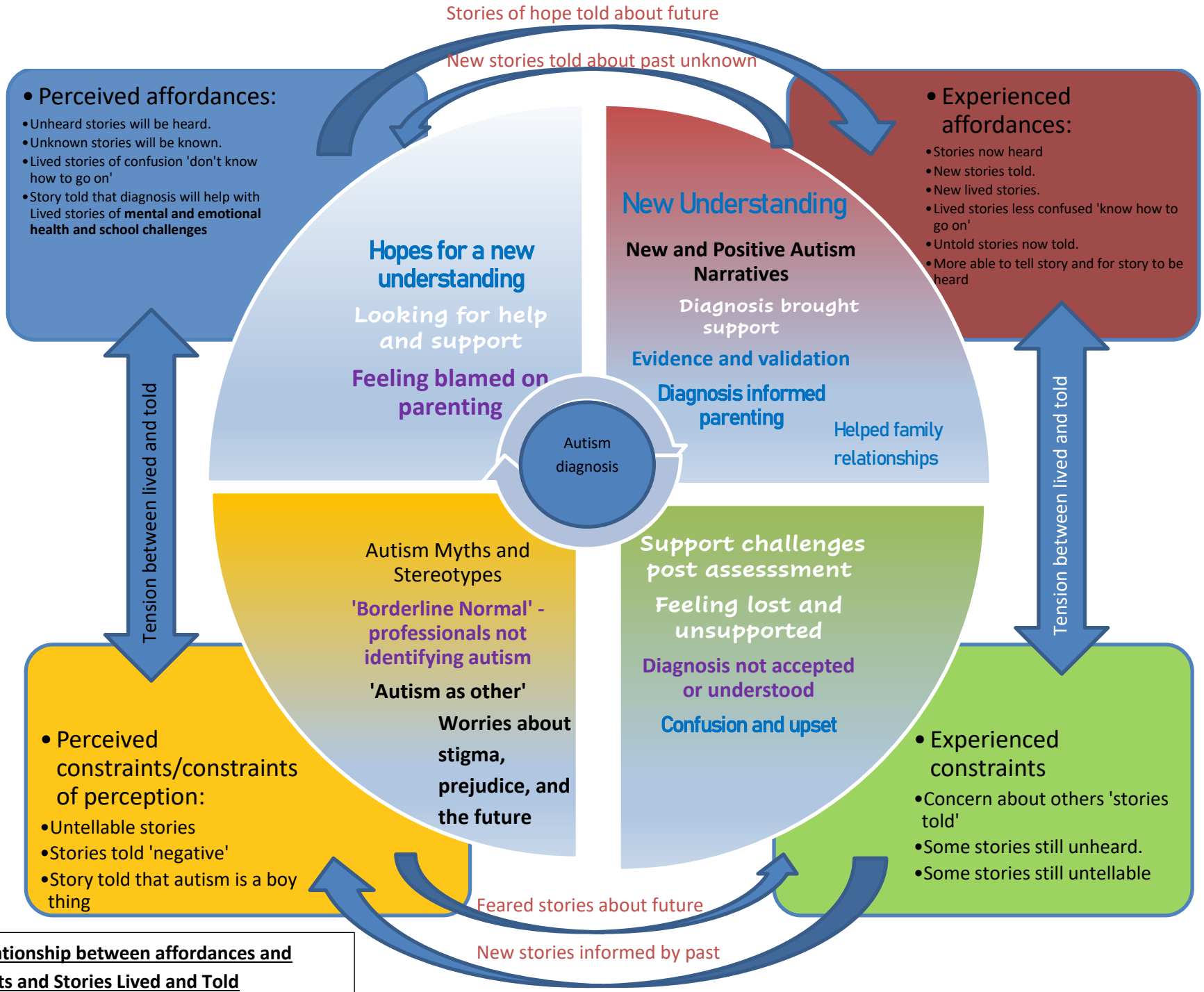


Fig 1: Relationship between affordances and Constraints and Stories Lived and Told

7. Final thoughts

7.1: Practice implications

This study has highlighted key practice implications and considerations across a number of contexts. I have ordered these implications across the following contexts of therapy and clinical practice, diagnostic services, local commissioners, charity and service providers, and policy and strategy makers. The relationship between these different levels of implications for practice is shown below in Fig 11 using the CMM hierarchical model:

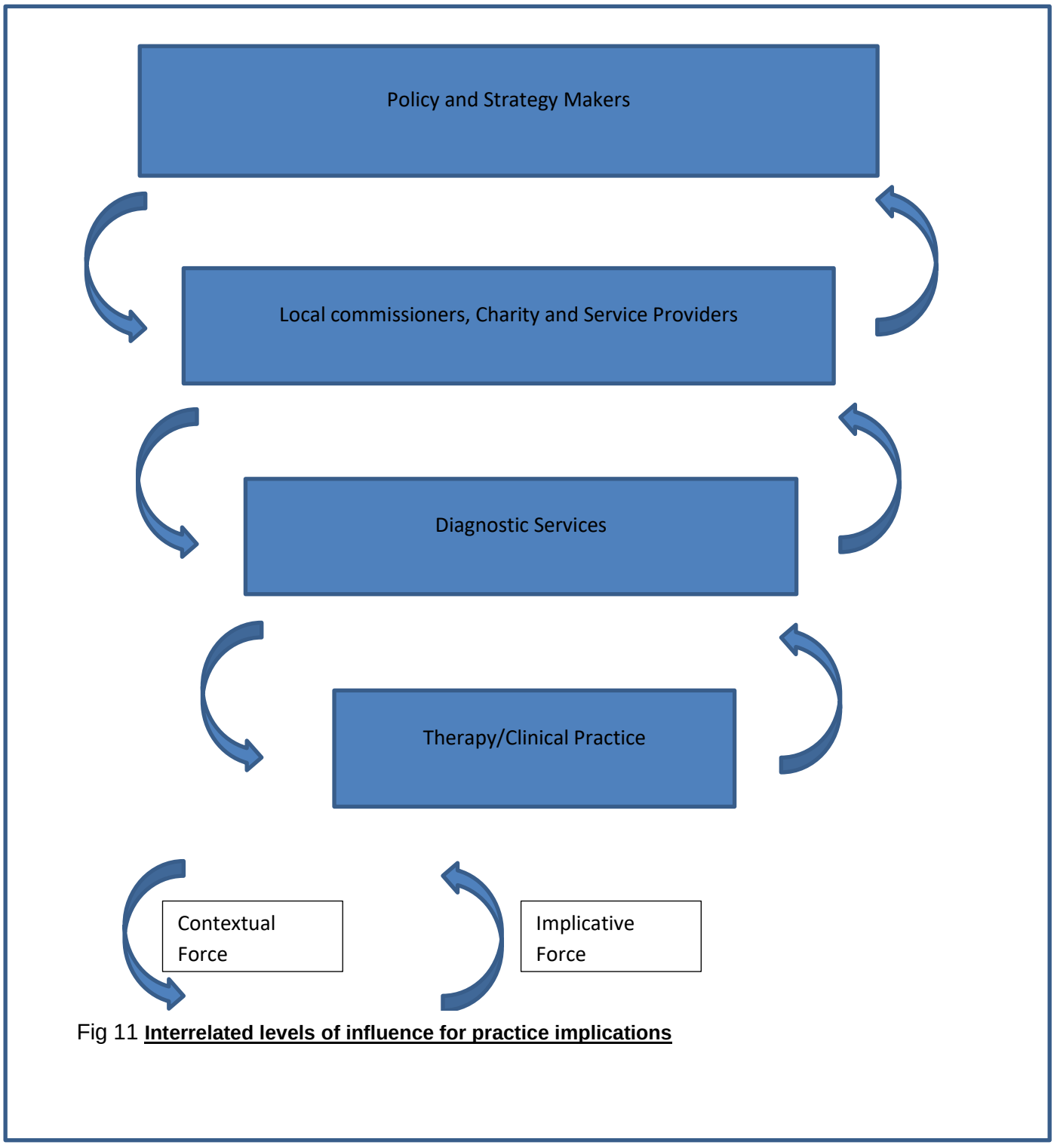


Fig 11 **Interrelated levels of influence for practice implications**

The theme, and interrelatedness, within and between these implications is the influence of how autism is 'talked about' (stories told) by and within services and society, and how the mothers are 'talked with' or 'talked to' about autism. I believe the way in which autism and neurodiversity is talked about within strategies and polices has a contextual force or impact on the lived experience of autistic people and their families, including the experiencing of diagnosis, in maintaining or challenging societal 'oughtisms'. The way in which individuals and smaller groups talk about autism and neurodiversity can in turn have an implicative force, or impact, on informing how services are provided and how policies are written and developed, as is seen with the neurodiversity movement. These considerations and implications for policy, service provision, and practice are highlighted below:

- Implications for Strategy and Policy Makers.

  The stories shared by the mothers in my study highlighted the power of language, including myths and stereotypes, about autism. Health and social care strategies can develop and promote the culture and ethos of services and healthcare communities. There is a need for comprehensive neurodiversity strategies which embrace and celebrate the many strengths of our neurodiverse population, as well as facilitating appropriate supports where needed. Where there has previously been an emphasis on the autistic or neurodiverse individual to be the one to change or adapt, strategies and policies should look at how they promote inclusivity and break down barriers to services. This might be achieved by policy makers asking themselves the following questions, which have been adapted from the 7 questions recommended for autism research by Bottema-Beutel et al (2020). These questions are not limited to autism and neurodiversity specific policies and question 1 in particular should be asked in the design and development of all health and social care strategies.

  1. *Does this policy act to include autistic and neurodiverse individuals in a way that is equitable and fair to that of others?*

  2. *Would I feel confident to explain this policy, and how it includes them and supports them, to an autistic person?*

  3. *Does the language and terminology used in this policy suggest that autistic people are inherently inferior to non-autistic people, or assert that they lack something fundamental to being human?*

4. *Does the language and terminology used in this policy maintain historical myths, stereotypes and 'oughtisms' about autism and neurodiversity?*

5. *Does the language and terminology used within this policy/strategy unnecessarily medicalize autism when describing educational, healthcare or staffing supports?*

6. *Have autistic people and their families been consulted with to in the development and review of this strategy/policy and have their comments been actively used to inform the final product?*

7. *Does the language or terminology used in this policy unnecessarily ''other'' autistic people, in a way that limits their access or perceived rights to an equality of care?*

- Implication for Local Commissioners, Charities and Service Providers

  Mothers within the study described a number of opportunities brought about by the diagnosis. The main theme was a new understanding about their daughters which enabled them to think differently about behaviours, identify triggers and challenges for their daughters and adapt their parenting strategies. This was largely connected to new understandings about sensory processing, social challenges, and executive functioning rather than 'autism' as a diagnosis itself. This led to a more supportive and understanding relationship with less blame, both self-blame for not managing as a parent and blame to their daughters about their behaviour.

  Due to long waiting times for assessment and the potential significance of this shift in understanding it is important that service providers create opportunities for new understanding that are not dependant on diagnosis itself. This could be in the form of pre-assessment support, workshops and information about sensory processing, executive functioning and adapted parenting strategies that would be beneficial regardless of diagnosis. This could facilitate the notion and benefits of 'becoming a detective' mentioned by a number of the mothers, regardless of the wait for assessment and diagnostic outcome.

  The majority of the mothers described delays in professionals identifying autism pre-assessment, and additional challenges in their needs being understood post assessment. In addition to the availability of pre-assessment training and support for mothers/parents, it is vital that autism training is available and compulsory for schools,

GP's and other front-line health and local authority staff. Training would include information about the different presentations of autism, anxiety, camouflaging (in males, female and non-binary children and young people), sensory processing and executive functioning.

- Implications for Diagnostic Services

  All the mothers in the study found the diagnostic process emotional and upsetting, in particular the deficit focus of the questions and the language used within assessment. Diagnostic practitioners need to be aware of the emotional impact of having a daughter referred for an autism assessment, how the negative focus of the assessment itself can add distress to this, and how culturally held myths and stereotypes can create additional confusion and distress if they are not challenged at an early stage. Early information and support may act to alleviate some of this distress, especially in the form of girl focused parents' groups and information. Practitioners should be aware that information and groups that are focused on the predominantly male presentation of autism, or a deficit model, can lead to additional confusion and/or distress.

  Whilst the focus of autism diagnosis is deficit and impairment, practitioners can improve the diagnostic experience by including strength-based questions. The diagnostic report is a lifelong document and it is important that practitioners should consider language and terminology used and how the parents and child/young person will experience reading the report.

  The constraints described by mothers included unfulfilled hopes and promises with regards to post diagnostic support and fears for the future. Practitioners should prepare mothers for the possibilities that the diagnosis may not bring all the support and change that they hope for. There should be opportunities for open dialogue about what may or may not be achieved through a diagnosis, within both the pre and post assessment phase. As mothers within the study spoke about the benefits of talking with other parents and/or adults with a diagnosis this may be achieved through assessment groups and workshops where they can openly talk with others and hear their lived experience of autism and autism diagnosis. This includes an opportunity to discuss fears about potential stigma for their daughters in the future.

- Implications for Clinical Practice

  Prior to their daughter's diagnosis, the mothers in this study held believes about autism as a male condition that was linked with significant learning difficulties and challenging

behaviour. This disconnect between their beliefs about autism and their experiencing of their daughters, along with the deficit focus of the assessment itself led to confusion and upset in the assessment process.

When working therapeutically with mothers, practitioners should be aware of the many stories, lived and told, that may have influenced how they experienced the diagnosis, and how this may have impacted on how they see their daughters and their relationship with them. This can be explored using the LUUUTT model.

Mothers in the study largely reported a positive impact of the diagnosis in terms of their understanding of their daughters which in turn had positive implications for their relationship and parenting practices. However, it was noted that different members of the family may have different experiences of the diagnosis, and at different times. This includes siblings, fathers, and grandparents as well as the daughters themselves. The narratives about autism also changed over time with initial stories focusing largely on a deficit model, with autism as something wrong with the individual, to neurodiversity narratives where autism has a number of strengths and challenges are largely external and in society.

Therapists working with families may find it helpful to explore the different narratives held in the family, and in society, about the impact autism and the diagnosis of autism has on family relationships, as well as how the narratives held by mothers may have changed over time. This can be facilitated by the CMM and the Daisy model.

7.2: **Additional observations and suggestions for future research**

There were a number of findings in this study I would have liked to explore further, and which are suggestions for future research.

More than one of the mothers described a lack of clarity about how and when to tell their daughters about their diagnosis, even though some time had passed since their assessments. This, in part, appeared informed by residual stories about autism as something 'wrong' or negative and a concern about the impact of disclosing the diagnosis to their daughters. I would be interested in knowing what prevents a parent from telling their child about their diagnosis. What pre-figured or informed their decision not to tell, and what are their concerns about the outcome if and when they do. An awareness of what informs their decision could help services to support parents in disclosing the diagnosis in a positive way to their children, which has been shown to have better outcomes for their wellbeing (Riccio et al 2020).

All the mothers recruited for my study had attended a parenting group especially delivered to the parents of autistic girls. Their change in narratives and 'stories about' autism was particularly interesting to me, and I feel some of this was informed by their attendance at the groups and by hearing empowered autistic women talking. I would be interested in researching the impact of this group further, including a comparison study conducting interviews with mothers who have not attended such groups.

In attending the Autistic Girls Group all the mothers had demonstrated an awareness of the support available to them and the ability to access such support via the group. The group is run and facilitated by autistic women and advocates who are able to demonstrate a level of personal and professional success and who share positive stories about what it means to be autistic. This is likely to have impacted the 'she owns it' theme as the mothers would have been part of those conversations and influenced by the ethos of the group where the positives of autism are promoted. This may not be the case for mothers who have not been able to attend groups, or who have attended groups that are clinically run that may have a different ethos, such as a medical deficit approach with more focus on changing behaviours rather than acceptance. It is possible that, had I interviewed a more diverse group of participants, that the themes would have been similar which would have added more weight to the outcome of this study as it would show the presence of those themes across different class, cultures and socio-economic backgrounds. It may also have highlighted core themes which were present alongside variations e.g., the majority experiencing a sense of loss and confusion following diagnosis but only a minority experiencing a sense of validation. It is also likely that a more diverse group would have resulted in different themes being highlighted and reduced the risk of the voices from a dominant group being heard above those whose voices were absent. For example, the majority of the mothers worked in professional roles and were able to advocate for their daughters in meetings and in negotiating healthcare. This had potential to influence the themes of the study in a number of ways. They had high expectations of the support that should be provided for their daughters and if it was not provided in a timely way by the NHS some of the mothers demonstrated the financial means to access private assessments and support. Interviewing mothers less able to advocate for their daughters due to additional forms of discrimination or stigma, such as racial prejudice or lack of reasonable adjustments for learning difficulties, or who are unable to access private assessments and healthcare, is likely to inform different themes in terms of the affordances and constraints of an autism diagnosis. Further research into the experience of mothers from different class, ethnic and cultural backgrounds, and who had not accessed such supports, would be beneficial in exploring if the change in narratives and 'stories told' about autism were specific to this group due to the support they had received or due to potential privileges they experienced due to class, culture,

and education. This could be facilitated by recruiting from other places, such as schools in deprived areas, via GP surgeries, the Local Authority or specific community groups.

The vast majority of research about parents of autistic children includes mothers with small percentages participants being fathers, and in general my experience of parenting groups is that they are attended by mothers. Navot et al (2017) spoke about mothers of autistic girls being 'twice excluded' from the autistic population and the neurotypical population, but it is possible that fathers of autistic girls are 'thrice excluded' due to maternal focus of research and support. An experience which my husband has shared with me! I would like to repeat this study with fathers to see where their experiences and stories told are similar, and where they differ from the mothers of autistic girls.

An area which interested me in the research data was the variation in the stories shared by two of the mothers whose daughters had been the youngest when diagnosed and the two mothers whose daughters were diagnosed late at 17. The mothers of the younger girls described more upset and confusion in the assessment process, with a greater sense of loss at the time of the diagnosis as they adjusted to this new understanding of their daughters. The older girls had both had significant issues with depression, anxiety and self-harm before their assessment and diagnosis. The loss described by their mothers was not a loss of their hopes for their daughters 'looking forward' but a sense of loss 'looking back'. They described lost opportunities for support and understanding due to the unknown nature of their daughter's challenges. Whilst the diagnosis did bring a new understanding for their difficulties, and enabled the mothers to adapt their parenting and support in ways that were helpful, the sense was that there were opportunities lost for support at school and in their daughters emotional development and awareness of self.

7.3: **Strengths and Limitations**

This study had both strengths and limitations, which were as follows:

- Flexible and in-depth semi-structured interviews were conducted with 12 mothers of girls of a variety of ages, with a rigorous process for reviewing data and creating and analysing themes, guided by the recommendations of Braun and Clarke (2006) and Nowell et al (2017), which has all been well documented. Themes were initially developed from the data rather than guided by the research question, which allowed the mothers voices to be heard on 'matters that matter' for them.
- Whilst there have been studies on diagnostic experience, and there have been a growing number of studies looking at the experience of mothering an autistic daughter,

this study is the first to look specifically at the impact of the diagnosis, and diagnostic experience, for the mothers of autistic girls.

- Research questions influence data collected, analysis and research outcomes, which in turn influence policy and practice. By asking about both the affordances and constraints of diagnosis this study gives a more balanced view of the lived experience of diagnosis for the mothers of autistic girls.
- The study covers a wide range of ages of diagnosis, from 4 to 17, similar in range to previous 'mother daughter' studies (Anderson 2020, Fowler and O'connor 2020, Navot et al 2017). This allowed for some comparison of the experience between earlier and later diagnosis which I have recommended as an area for further research.
- This is the first study identified to use CMM and the LUUUUTT model (Pearce 1999, 2007, Griffin 2014, Rascon and Littlejohn 2017), to explore 'lived and told' stories of the mothers of autistic girls, including potential tensions within those stories. It gives a useful insight into the lived experience of the diagnosis for their daughters, the impact of 'oughtisms', and how autism narratives both inform, and are informed by the mothers lived experience.
- Data collection stopped at 12 interviews when more had been intended. This was an ethical decision at the start of the Coronavirus pandemic. Due to all other interviews being face to face I did not transfer to on-line interviews at this stage. However, similar studies have had less participants with Navot et al (2017) interviewing 11 mothers, and Anderson et al (2020) interviewing 10 mothers.
- There was some diversity of the participants within the study, but this was limited with the majority being white, middle class, married and employed, and with all of the mothers being recruited via the same parents' group. In any publication of findings, it will be important to acknowledge that the research findings, and stories of these mothers, will not represent the lived experience of all mothers of all autistic girls. There are mothers who do not feel able to attend support groups, either due to accessibility of the group, or due to the resources required to access them (including ability to travel, finances, IT, childcare etc). There will also be mothers who do attend the groups but do not feel fully accepted or represented, or who do not feel able to respond to additional requests for involvement in research interviews. This brings with it the potential for those mothers of autistic girls being missed or misrepresented from the research outcomes. Autism is viewed, and conceptualised, differently across different socio-cultural groups, as highlighted in the studies by McCabe (2007), Tait et al (2015) and Decoteau (2017) who explored autism diagnosis in China, Hong Kong and for Somalian families, respectively, and the homogeneity of the participant group did not

allow for an in-depth exploration of the likely variations due to cultural, ethnic or class backgrounds. The consideration of how this influenced the data gathered has been included in recommendations for further research (see page 159). Whilst this was a limitation to the research, it did also highlight how this group of mostly white, well-educated and able mothers found communicating with professionals about their daughters challenging, in spite of the affordances of their class and education. This challenge, despite the privileged position of the mothers, is something which more than one of them commented on.

- I believe that my own personal, professional, public, and private stories and experiences brought both affordances and constraints within this research, both protecting from, and contributing to, different elements of researcher and participant bias. Shah states that it is difficult for a researcher to be "detached completely" from qualitative research due to its subjective nature (2019), and there are potentials for both participant and researcher bias. This includes the probability of a social desirability bias, with participants giving answers they believe may be socially acceptable or required by the researcher and which may be different from their true feelings or experience, thus impacting on the outcomes of the study. In turn the researcher may unconsciously look for answers that support their own theories or hypotheses. Ultimately the biggest element of power in influencing outcomes rests with the researcher and the research interview is not an "open dominance free dialogue between equal partners, but a specific form of conversation, which the interviewer controls in accord with his (or her) research interests" (Kvale 2002, pg. 13).

  As highlighted in Wakefield's study (1998), research outcomes have profound consequences on real people's lives. Research 'about' people creates public stories by which those people come to be known as 'other', rather than, as Ndlovu-Gatheni (2017) puts it, what it "means to be known by others". The dominant voice is the one of the individuals who are "capable of controlling research" and who set the "research Agenda" (Ndege and Onyango 2021)

    - Researcher Bias: As a mother of an autistic daughter, researching the experience of autistic mothers, I believe the likelihood of me 'othering' the research participants was reduced as I held a both-and position of researcher and of that which was being researched. However, I am aware that my position as researcher still created an element of someone 'looking in' from the outside. The mothers were aware I was the mother of an autistic girl, potentially seeing me as 'one of them', which may have enabled them to feel more able to talk about their lived experience. However, this brought with it the risk of me looking to confirm or validate my own lived experiences or discounting experiences I

either did not recognise, agree with, or want to identify with. To reflect on how my lived experience, personal and professional, may influence me within the interview process, I used a daisy diagram to explore my different relations with and in the research, and first looked at how I would answer the research questions as recommended by Josselson (2013). Whilst I conducted the interviews, I completed a reflexive journal, which I added to after conducting or transcribing each interview, and then discussed in supervision which served as a forum for me to explore the 'GrRRAAACCEEESSSS' (Burnham and Nolte 2020) and the influence of my own lived experience, identities and selfhood as a researcher, therapist, mother, etc and the interrelationship with that which was being researched.

    - Participant bias: There are a number of potentials for participant bias influencing the outcome of the study due to the recruitment and self-selected nature of the participant group, as well as their knowledge of me as a Professional Doctorate student and senior clinician in the NHS. I was careful not to reference my own experience, personally or professionally, in the interviews. I spoke to the mothers about my personal connection with the research in the recruitment phase and assured them that their access to services etc would not be influenced by our conversation. I encouraged all the mothers to feel that they could say anything about the services I work for, however there would have been some impact due to my connection with CAMHS (child and Adolescent Mental Health Services). For instance, one mother had also seen me present at a conference, which she referred to in her interview, and it is likely that she and other participants may have either intentionally, or unintentionally, edited or withheld some information within the interviews.

- All the mothers in the study wanted to, and felt able to, respond to my flyer. This suggests an element of confidence in talking to professionals, or others, about their daughters, and perhaps the belief that their story may be heard and make a difference for autistic girls and their mothers. Crocket et al (2004) suggest that researchers, like therapists, respond to more than the voices present in the interviews themselves. There are also the voices of those not immediately present, such as supervisors, editors, peer reviewers etc. The ethical question is about which of those voices or audiences are given 'what degree of attention'. I believe there is also the risk of voices not being present in the interviews and data collection, such as the potential voices of those with a different ethnic or cultural background. This brings with it the 'unseen danger' of generalisations due to "what was not seen and not reported in the study"

(Milner, 2007, pg. 392). In order to recruit from marginalised groups, or individuals who feel less able or confident to put themselves forward as participants researchers such as myself, may need to adopt different recruitment techniques, such as visiting schools, doctors' surgeries, and visiting community settings or engaging trusted community leaders in the initial development of flyers and research protocols.

- The daughter's stories were largely absent from the study, apart from occasions in which some of the mothers referenced how their daughters experienced their diagnosis. This absence does not allow for a more in depth understanding of the influence of the diagnosis on the mother-daughter relationship, or the impact of the diagnosis for the daughters themselves.
- I believe focus on mothers in this study had both strengths and limitations. The study did not conflate the views of mothers and fathers by combining 'parent' views 'without distinction and analysis by gender' as warned by Cheuk and Lashewicz (2015). However, fathers are underrepresented in research (Flippin and Crais 2011) and more than one of the mothers commented on her husband's experience of the diagnosis and how this would have been a useful area to study. This absence may have been mitigated against, in part, by the inclusion of a question about how the mother's believed the fathers experienced the diagnosis. Additionally, a similar question regarding sibling's experience of the diagnosis would have given insight into how the mother's viewed the impact of their daughter's diagnosis on their other children.
- Whilst I believe the main focus of my study, the experience of diagnosis for the mothers of autistic girls, has significant value across various practice contexts, there is also the risk that it reinforces a binary view of autism, with girls and boys having distinct types. Whilst camouflaging may (currently) be identified as more prevalent in girls it is also present in autistic boys. The awareness of girls 'going under the radar' (Nasen 2016) is gathering pace, but there is emerging awareness that there are some 'lost boys' and that what has become known as a female presentation for autism is 'not isolated to one sex or gender' (Strang et al 2020). The risk of identifying types of autism by gender brings with it the increased risk of clinicians developing diagnostic tools specifically targeting males or females. This brings significant challenges for either males who camouflage and present with what has become known as female type autism, or people who are non-binary, fluid or transgendered and do not fit within traditional 'male-female' boxes. If a diagnostic tool is gender specific a male who presents with 'female type' autism who only has access to a 'male specific' assessment may not get a diagnosis which brings a range of consequences. There would also be the decision of which assessment someone should be referred for. This risk was highlighted by a

potential study participant (who had to pull out for personal reasons) whose son, biologically born female, had been diagnosed when he was younger and at that time was still assigned as female.

- Parenting an autistic child has many joys, as well as challenges, regardless of gender, ability, and presentation. Whilst the mothers in this study shared how their fears prior to diagnosis were not realised, some mothers will parent children who present with the extreme and atypical presentations of autism that concerned them. These children still have many strengths and much to give and it is important that the outcomes of this study are read in that context.

7.4: **Dissemination ideas**

As this is a Professional Doctorate there are a number of potentials and opportunities for dissemination of this work, both clinically and academically.

As an NHS Clinical Director, and due to my current Neurodiversity role, I have the opportunity to share my research finding in a number of clinical and strategic forums. This includes my involvement with NHS England where I am involved with the National Autism Steering Group and sit as a member of the workstream focused on improving quality of mental health treatment and support for autistic people. Within our NHS Trust I am also able to draw on my research, from both the literature review and my research findings, to inform the development and delivery of the Neurodiversity Strategy, and to inform various policies and training within the trust, such as ensuring autism awareness is an integral part of all training and service development.

As a CAMHS professional I have already been able to share my research findings with the local CAMHS service. In particular the importance of language and increasing awareness about sensory processing, executive functioning and masking which clinicians reported they found very useful.

Academically I have been able to present at three systemic practice and autism conferences over the course of my study with the most recent being this July (2021). I gave two presentations, one with regards to the social construction of autism and neurodiversity, and informed by my literature review, titled ‘Autism untold – a telling and an un-telling of the autism story’, and the second, titled ‘Borderline normal’ which shared the findings of my research (see publications page iv).

I have had two publications regarding 'oughtism' and connected to my study, prior to completing my thesis. Publications include 'Oughtism and oughtistic narratives in the lives of autism people and their families' (Evans 2019) and Autism and Family Systemic Therapy (Simon, Evans et al 2020) (see bibliography pages 177 and 193, and publications page iv).

On completing my thesis there are opportunities for dissemination of my research across autism and systemic psychotherapy journals including the SAGE Autism Journal and The Journal of Family Therapy.

Due to collaboration with a number of autistic females/researchers there is also opportunity to write and publish a book, or book chapter, on autism and girls.

Importantly, I have also had the opportunity to disseminate my research in a presentation to the Autistic Girls Group from where the participants from my study were recruited. In addition to this, following on from a discussion about my husband's view that fathers of autistic girls are 'thrice excluded' he also presented at the group the month before me.

7.5: **Participant feedback**

"I very much feel that my views and experiences are reflected in your findings. Specifically, being faced with myths of how I continue to respectfully seek understanding (particularly at school) to respond to and meet my daughter's needs. In addition, the opportunity afforded by diagnosis of greater transparency regarding the challenges of operating 'everyday' has helped the immediate family make significant adjustments within our home, and push for more support thereby moving away from the concept of 'borderline normal'. Tweaks aren't sufficient. Therefore, the theme of being the pushy parent is still very much still present in my life, and I'm working on not being bothered by it." (Sharon – mother to Louise. Diagnosed at 17)

Whilst twelve mothers of autistic girls were interviewed as part of this study, due to my own lived experience, thirteen mothers took part. For my final thoughts I would like to share the feedback given by participants and how their experiences connect with my own experience as a mother to two autistic children. When the main body of my thesis was complete, I contacted all the mothers interviewed to ask if they would like to know more about my findings and to ask for feedback. This was to ensure that they agreed with the themes that I had drawn from the data, that they felt their experiences were being appropriately portrayed, and to check they were happy with the messages that would be shared from the research that they had participated in. Eight of the mothers replied and asked for a summary to be shared with them which was sent via email (see appendix 20). From those 8 mothers four replied. Three gave written feedback and one mother met with me on-line to discuss her feedback. Feedback was

guided by the following questions: *Do you feel that your views and experiences are represented in the study outcomes and in what way? Is there anything that you disagree with or that you feel does not represent your views? Is there anything that you think is missing? Is there anything new that surprises or interests you in the study outcomes? What do you think the most important message is from the research?*

Do you feel that your views and experiences are represented in the study outcomes and in what way? When asked if their views were represented in the study, all four of the mothers said that they were. They all commented on the similarities between their experience and the themes identified in the study. Three of the mothers expressed some surprise at the similarity between their experience and the experience of the other mothers. They said this meant they felt less alone. I too made a number of connections with the stories shared by the mothers. Perhaps in the process of the research I felt less alone too.

Is there anything that you disagree with or that you feel does not represent your views? None of the mothers felt that the themes and outcomes of the study misrepresented their views, but there were some variations. One mother, who fed back verbally, did feel that she had been less influenced by myths and stereotypes prior to her daughter's diagnosis than the other mothers. She did however have some concerns that the clinicians who saw and assessed her daughter would not give a diagnosis due to her not fitting a typical autism profile. Another mother, whose daughter was young at diagnosis, said she had not experienced some of the of mental health challenges described in the first theme.

Is there anything that you think is missing? In response to this question one of the mothers said that she felt the level of support available and/or needed for her daughters was not clear. Two of the mothers picked up on situations in which their daughter's needs had been overlooked due to them not fitting with a general understanding about what autism ought to look like. One of the mothers felt that more emphasis should be given to the journey made between the 'aha moment' and seeing beyond 'dawning' and 'moving through a journey of acceptance'. She said that for her part of this journey has been seeing her daughter's autism as part of her identity versus an 'add on'. I connect with all the comments made here. I have often felt that my daughters need for support is overlooked due to masking and her challenges not being overt within the school environment, sometimes with serious consequences. I also see autism as part of who she is, part of her identity and selfhood, not as a 'thing' which can be attached, removed, changed or corrected.

Is there anything new that surprises or interests you in the study outcomes? There was surprise for the mothers that their experiences were so similar. What is interesting about this is that they felt this way even though they all attended the same autism and girls' group. For me this highlights the importance of sharing this research so that mothers (and hopefully fathers) can understand that others are on a similar journey to their own.

What do you think the most important message is from the research? For all four of the mothers it was important that the outcomes of this study are shared and disseminated. For one mother, an important message from the research was how the diagnosis helped her to adapt her parenting. This is something I also connect with. I have let go of many parental oughtisms and threw out the rule book many years ago. Yes, this does protect me from feeling blame, but more importantly it stopped me from blaming my children when they didn't respond to traditional parenting techniques.

The mothers shared that an important message from the research was the need for professionals to have a greater understanding of autism and girls. This included challenging myths and stereotypes so that parents and professionals can be more aware of the different presentation of autism in girls and so they can see beyond the view that 'they are not broken enough'. Additionally, the importance of listening to mothers' concerns was also highlighted. I have had the privilege of my professional role when talking with schools about my children, but it has in no way been easy. As one of the mothers in this study said, if it is difficult for me with all the benefits of my professional background, class, and education how difficult must it be for others without such advantages?

8: **Summary**

"I can recognise my experience in many of the themes, including the journey to a greater understanding of autism, the confusion and upset at diagnosis (and in some parts of the referral process), and the fact that diagnosis has enabled us to adapt our parenting"
(Research feedback from Caroline. Mother to Emily, diagnosed at 6, now 14).

This study gives a valuable insight into the affordances and constraints of diagnosis, as perceived and experienced by 12 mothers of autistic girls. It highlights the powerful impact of societal myths and stereotypes about autism, in particular in delaying early identification and in the experiencing of the assessment and diagnostic process. Whilst the mothers were aware of their daughter's challenges, they did not make connections between what they saw and autism due to stories told about autism as a male condition, something visibly different, or even something 'nasty'. I believe this view of autism influenced the mothers in seeking a diagnosis, and informed their experiencing of the diagnosis and assessment, due to stereotypes first making them discount autism and then fuelling their fears about what a diagnosis of autism might mean. The impact of these negative stereotypes made the diagnosis itself an incredibly emotional experience. Perceptions about what autism was, both for the mothers and with professionals, meant that there was an element of 'confusion and vertigo' (Pearce 1989) with some confusion about 'how to go on'.

In answer to 'what was made' by the diagnosis, most significantly it was the new stories told about their daughters. The diagnosis facilitated new awareness about autism and girls, sensory processing, executive functioning and camouflaging. The biggest and most transformational gain was this new awareness which informed a change in expectations, tolerance, and understanding. The mothers let go of blame, either self-blame, blaming their daughters for their behaviour, or concerns about blame from others. They adopted new parenting strategies informed by what they felt their daughters needed rather than previous parental 'oughtisms'. This significantly transformed their parenting and ultimately their relationships with their daughters. These new understandings and changes in relationships reduced uncertainty and enabled them to 'know how to go on'. They felt more able to advocate for their daughters needs at school and saw the diagnosis as something official and tangible that meant others had to listen.

Whilst the mother's described a significant shift in their understanding about autism, girls, and neurodiversity, they experienced challenges with others understanding or accepting the diagnosis of their daughters, this included professionals, wider family, friends, and other

parents. Grandparents in particular appeared to struggle with accepting or understanding the diagnosis, with the mothers feeling their parenting was still held to account.

Whilst all reported that the diagnosis did bring support from others, including schools, the amount of support was questioned which led to tensions between the stories lived and told. The mothers felt that their daughters were not seen as ‘broken enough’ to receive the level of support they believed their daughters both needed and deserved, which left some of the hopes for the diagnosis unfulfilled and a caution to other mothers that the diagnosis itself is not a ‘magic pill’ or a ‘silver bullet’.

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10: **Appendices**

Appendix 1

Blog: Working in autism diagnosis, a frontline experience (3 October 2018)



Mairi Evans works in a children's autism diagnosis service in Berkshire, South East England. In this blog, she explains how a growth in public awareness of autism in recent years has led to increased demand for autism assessments – and how her team are trying to meet this need, reduce pressure on families and ultimately bring waiting times down. Without investment from central government, her service and many others will continue to find it difficult to meet demand. This is why the National Autistic Society is campaigning for the Government and NHS England to make sure that every area has the staff and funding it needs to drive down waiting times and improve support for autistic people and families before and after diagnosis. This is part of a series of blogs the National Autistic Society is planning to publish to highlight the autism diagnosis crisis.

Mairi: I oversee two combined services that provide autism and ADHD assessments for children and young people up to 18. I am a social worker and family therapist by background and have worked in Children and Adolescent Mental Health Services (CAMHS) for almost 20 years. When I started, autism was seen as rare, affecting a small percentage of children who would often have profound learning and language difficulties and need specialist education or care. I have found over this time that my awareness of - and relationship with - autism has changed greatly, as has the awareness of autism in the services and communities I have worked with.
I joined Berkshire's new Autism Assessment Team in 2012 and took the role of Clinical Lead in the assessment team two years later. Since then, I've seen the diagnostic process from both sides: as a parent and a professional.

Referrals to the Autism Assessment Team have more than doubled since it was created in 2012, with well in excess of 1,000 children and young people referred every year. Our understanding of autism, and what autism is, has changed greatly since I first started work in CAMHS. As clinicians, we are now aware that we had already had years of experience supporting autistic children. But many of them were undiagnosed, which was potentially leading to the self-harm, depression or anxiety that brought them for therapy at CAMHS in the first place. There has also been an increase in adults being diagnosed. And advocates such as Carly Jones MBE are highlighting the impact of being diagnosed, how valuable autistic people are to our communities and the importance of the right support.

Increased awareness of autism is a great thing. But it also means an increase in referrals as parents seek clarification about their child's needs. Parents seek a diagnosis in the hope that they can access the right support both at home and at school and reduce daily struggles experienced by their children and family.

Journey to diagnosis

The journey for parents is emotional and often very difficult, from when they consider that there may be something 'different' about their child, to the decision to go for assessment and the moment of diagnosis. The journey doesn't end after diagnosis as they support their child to learn what it means to be autistic, educate their family and fight to ensure that they and their child have the support they need to have a happy and fulfilled life. While the diagnosis is a vital part of the process, it is only part of the process - and not the beginning, or the end. It is not surprising then that research has highlighted a lot of dissatisfaction in the diagnostic process (Crane et al 2015, Siklos and Kerns 2007, Howlin and Moore 1997), due to the waiting times and the emotional rollercoaster that is experienced along the way.

Services like ours are continuously trying to balance the need to see as many children as we can in the fastest time possible, with the need to develop and improve the process and quality of our assessments. This is coupled with the increase in demand and a backdrop of on-going financial pressures and cuts within the NHS.

We want to create a situation where parents and carers feel supported and informed before their child's assessment, listened to within the assessment itself, and supported once the diagnosis is made. We also want autism to be understood as a difference not a disorder - for parents, carers and young people to be able to understand their strengths and abilities, as well as how to manage the challenges. We also know that a diagnosis may give an understanding of need but it will not change the level of need or the level of support that is required once a diagnosis is made.

The changes our service is making

We have worked very closely with commissioners, local agencies and groups and autistic people, their families and carers to find ways to provide support throughout the diagnostic process, as well as before and after assessment. Support should be led by someone's needs, not whether they have a diagnosis. We do not think it is right that parents or carers should be told that there will be no support for their child until a diagnosis is made, or that there is nothing that they can do while their child is on the waiting list.

We also know that there is only so much money given to commissioners. And if they increase the money they are giving us to reduce the wait for assessments this means less money elsewhere (for example eating disorder services or locality CAMHS teams).

Lots of researchers have discovered that parents' experiences of diagnosis are more positive if they are involved in groups, where they can meet others in similar situations and have access to information, advice and support without having to wait for their child's assessment. So, we have taken a number of steps to help during this time:

- In 2014 we developed pre-assessment support groups with two local charities, Autism Berkshire and Parenting Special Children. These groups are now funded by the local Clinical Commissioning Groups (CCGs) and provided by three groups: Autism Berkshire, Parenting Special Children and The Autism Group.
- These local charity groups have also opened up their parenting programmes to parents/carers who are waiting for their child to be assessed, again supported by local commissioners. They invite families waiting for assessments to activities and events such as trampoline clubs and family fun days.
- We have built positive relationships with other agencies and have attended and presented at SENCO groups, Educational Psychology groups and parent forums to raise awareness of autism. We recently co-hosted a successful all-age autism conference with NHS England which had presentations by experts-by-experience and professionals, again with the aim raising awareness of autism and neurodiversity.
- We have created a YouTube film of the assessment process to help children, young people and their carers know what to expect when they come for an assessment.

- We have an online resource for children and young people with a range of information and advice about autism, ADHD and issues such as sensory processing difficulties.
- Our team provide a helpline three afternoons a week for people waiting for an assessment so they can help, advise and signpost when needed. We also have a letter which can be given to schools to promote needs-led support rather than waiting for a diagnosis to be made.
- Something which I am particularly proud of is SHaRON Jupiter. SHaRON stands for Support, Hope and Resources Online and provides an online support service where parents or carers can stay in touch with us and offer support and advice to each other before, during or after a diagnosis.

Once a diagnosis is made we are working to make it as positive as possible so that parents can be helped to celebrate their child's differences and get support in managing where their child is challenged. In order to gain some insight into different experiences of the diagnosis process, we have invited parents, carers and young people to talk to the team about what helped them and what they would have liked to be different when a diagnosis was made. And we are also working with local schools to promote autism awareness. We hope to improve awareness of autism regardless of diagnosis, and to work collaboratively with our education colleagues to think about the needs and challenges for our young people in the school environment.

Conclusion

We know we have a long way to go to get it right every time but we are doing all we can, despite the increase in demand and scarce resources.

We want to see children quicker and to continue improving all aspects of the assessment process to support parents, carers and children and young people with this important and emotional journey. In order to do this it is important is that we are all working together across all services (NHS, education, social care and charity organisations), with commissioners and with families and experts by experience.

Appendix 2

Volunteers Wanted for a Research Study

How do mothers of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters?

Are you a mother of a girl who is between the age of 6 and 18 and who has been given a diagnosis of autism? If so I would like to invite you to take part in my research study.

The purpose of my research: My name is Mairi Wickens. I am currently a student in a professional doctorate programme at Bedfordshire University. I have personal and professional experience of autism diagnosis and have a specific interest in exploring how to support parents and carers whilst they are waiting for an autism assessment for their child and also once a diagnosis is given. I aim to learn more about the experience of mothers' pre-assessment, including what they hope the diagnosis will bring, and what their experience of diagnosis for their daughters is once it has been given. My hope is that information from my research will help inform the support and information given to mother's pre-assessment so it can be the most useful and helpful, and also to prepare them for diagnosis when it is given and to look at how services and professionals can work together in the best possible way post diagnosis to support mothers and ultimately their daughters.

Eligibility criteria: I would like to invite mothers of girls who have been given an autism diagnosis, who are verbal and who are attending or who have attended mainstream school. I have specifically chosen mothers of girls who fit this criteria as research suggests that girls take longer to be identified for referral and assessment and I believe this may have an impact on how mother's experience the assessment process for their daughters.

What are the expected benefits of taking part in this study? It is not expected that this research will have a direct impact on the care and support you are currently receiving for your daughter. My intention and hope is that the information gathered in the study will inform practitioners about how to support mothers of girls who are seeking or who have received a diagnosis of autism and therefore improve future information and support provided.

What will happen if I take part? I will arrange to meet you to ask you a set of questions regarding your daughter's diagnosis, including your beliefs about autism pre-and post-assessment, your hopes about what the diagnosis would bring, and how you experienced the diagnosis and the impact that the diagnosis has had for you and your daughter. The interview is expected to last between one and two hours and I will meet you in your home or at a location of your choice.

What should I do if I would like to take part?

If you would like to take part in my study, or if you have further questions, please contact me either by email at (EMAIL ADDRESS) or by telephone (Telephone no)

Appendix 3

Participant Consent Form

Study Title: How do mothers of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters?

Name of researcher: Mairi Wickens
Professional Doctorate in Systemic Practice.
Student ID Number:

I confirm that I have read and understood the information leaflet about the above research project dated …../…../….. The information has been fully explained to me and I have been able to ask questions which have been answered to my satisfaction.	**Yes** ☐	**No** ☐
I understand that my participation in this research is voluntary and that I am free to withdraw at any time up until (give date) when the data is due to be collated and anonymised for inclusion in the final project submission. I understand that I don't have to give a reason for opting out and that it is my choice and right to do so and that I can withdraw consent by emailing (GIVE EMAIL).	**Yes** ☐	**No** ☐
I have been assured that information about me will be kept private and confidential and that recordings will be deleted once this research has been completed and the final submission has been confirmed, unless I have given consent for information to be stored for the purpose of future research (see below).	**Yes** ☐	**No** ☐
I give my permission for information collected about me to be stored or electronically processed for the purpose of related studies or other studies in the future but only if the research is approved by a Research Ethics Committee.	**Yes** ☐	**No** ☐
I agree to being quoted directly in relevant journal articles and publications if my name is not published and a made-up name (pseudonym) is used.	**Yes** ☐	**No** ☐

I give my permission for information collected about me to be stored or electronically processed for the purpose of this research.		
I have been made aware that whilst the information gathered in this study will remain confidential, there are exceptions when confidentiality may have to be broken due to safeguarding concerns. I have been advised that if this was to happen it would be with my knowledge and only if considered absolutely necessary.		
I have been given a copy of the Information Leaflet and this completed consent form for my records.		

Participant Name (Block Capitals)	Participant Signature	Date

To be completed by the Researcher:

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand I have invited them to ask questions on any aspect of the study that concerned them.

Name (Block Capitals)	Qualifications	Signature	Date

Appendix 4
Research information leaflet.

Study Title:
How do mothers of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters?

Are you a mother of a girl who is between the age of 6 and 18 and who has been given a diagnosis of autism? If so I would like to invite you to take part in my research study. The following information will explain why I am conducting the study, what I am studying and how I intend to gather and use the information from my study. If you have any questions or if anything is not clear please feel free to ask more questions so you can decide if you would like to take part or not.

My name is Mairi Wickens. I am currently a student in a professional doctorate programme at Bedfordshire University. My research supervisors are Chris Papadopoulos and John Burnham. I have personal and professional experience of autism diagnosis and have a specific interest in exploring how to support parents and carers whilst they are waiting for an autism assessment for their child and also once a diagnosis is given. In my research I am focusing on the experience of mothers of girls both pre assessment and post diagnosis. Before you take part in my study it is important that you understand what the research is for and what you will be asked to do.

The purpose of my study: I hope to learn more about what mothers believe the diagnosis will bring and what their experience of diagnosis is once it has been given. I would like to learn more so that we can inform the support and information given to mother's pre-assessment so it can be the most useful and helpful, and also to prepare them for diagnosis when it is given. I would also like to learn more about mother's experiences post diagnosis so we can improve the information given at the time of diagnosis and look at how services and professionals can work together in the best possible way to support mothers and ultimately their daughters.

I would like to invite mothers of girls who have been given an autism diagnosis, who are verbal and who are attending or who have attended mainstream school. I have specifically chosen mothers of girls who fit this criteria as research suggests that girls take longer to be identified for referral and assessment and I believe this may have an impact on how mother's experience the assessment process for their daughters.

Do I have to take part? Participation in this research is entirely voluntary and it is up to you to decide if you would like to take part or not. I will go through the information about the study with you and you are free to ask questions if the information is not clear or if there are other things you would like to clarify. I will then ask you to sign a consent form. You are free to withdraw your consent at any time prior to me collating and anonymising the data for my final submission, you do not have to give any reason for wanting to withdraw consent.

What will happen if I take part?
I will arrange to meet you to ask you a set of questions regarding your daughter's diagnosis, including your beliefs about autism pre-and post-assessment, your hopes about what the diagnosis would bring, and how you experienced the diagnosis and the impact that the diagnosis has had for you and your daughter.

The interview is expected to last between one and two hours and I will meet you in your home or at a location of your choice.

There will be one interview unless we are unable to complete the initial interview and agree to rearrange another time to complete it.

What if there is a problem? If you have concerns about any aspect of my study please let me know. If you feel unable to raise your concerns directly with me you can contact my supervisor Chris Papadopoulos (CONTACT DETAILS) or the Research Graduate School at Bedfordshire University (CONTACT DETAILS).

Will my involvement in the study be confidential? All recordings and data from our interviews will be securely stored on an encrypted memory stick and password protected computer that only I have access to. Recordings will be deleted once the research is completed unless you give additional written consent for the information to be stored for future research and/or training. Interview content will be discussed with my supervisors and course tutors as part of my research. Any information used in the final write up of the study will be anonymised.
The only instance in which I would not be able to keep information confidential is if I hear something that make me concerned that you or someone you have spoken about is at risk of significant harm. In the unlikely event of this happening I would talk with you about what my concerns are and why and would contact the relevant services with your knowledge.

What are the expected benefits of taking part in this study? It is not expected that this research will have a direct impact on the care and support you are currently receiving for your daughter. My intention and hope is that the information gathered in the study will inform my research project. Your contribution will inform practitioners about how to support mothers of girls who are seeking or who have received a diagnosis of autism and therefore improve future information and support.

How do mothers of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters?

Interview Schedule

Participant number: Date of Interview:

Age of Diagnosis for daughter: Where diagnosed:

Waiting time from referral to assessment: Who by:

1st/2nd/3rd assessment:

Genogram/Family Composition/marital status (Include family history of diagnosis (including self-identification) and related conditions, who is in family, who is in the home, include current ages)

Self-defined ethnicity/culture: 1st Language:

Religion/spirituality:

School information for daughter (mainstream, private, home ed etc):

Employment status of mother/carers:

Appendix 5

1. What did you understand about autism before your daughter's diagnosis?

Who or where did you get this understanding from?

2. Has your understanding about autism changed?

3. Could you please tell me about why you first sought an autism assessment for your daughter?

What or who led to you making this decision? Did you feel that you had a choice?

3. What did you think a diagnosis would help with?

Why?

4. Before your daughter's assessment and diagnosis did you have any concerns about an autism diagnosis and what it might mean?

What made you think this?

5. Once your daughter received a diagnosis of autism what difference did it make?

Did it bring what you (and others) had hoped for? Has it brought any new challenges or difficulties?

6. Do you feel the diagnosis changed how you view your relationship and/or how you related with your daughter?

Could you explain how?

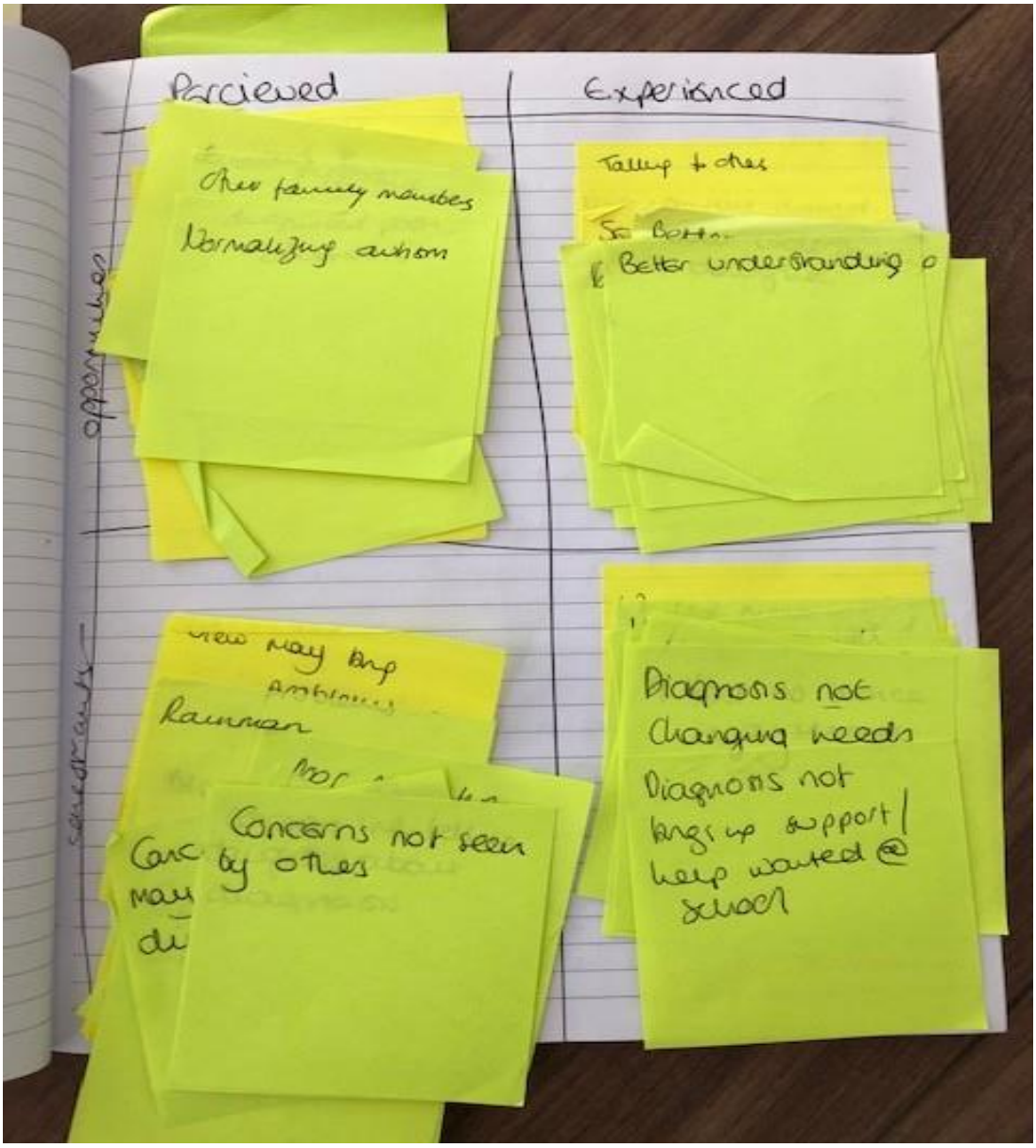
7. Is there anything that you now know that you wish you had known at the start of the process?

What advice would you give to mothers at the start of the process?

8. What advice would you give to practitioners/professionals?

Is there anything that I have not asked about that you think it is important for me to know?

Appendix 6


Parcieved
Experienced
Other family members
Normalizing autism
Better understanding
Diagnosis not
Changing needs
Diagnosis not
bringing support/
help wanted @
school
Concerns not seen
by others

Appendix 7



University of Bedfordshire

FAO Mairi Wickens Dear Mairi

Institute of Applied Social Research Dept of Applied Social Studies Park Square Luton LU1 3JU

20 March 2019

Re: IASR RIEP Application: IASR_08/17 Project Title: How do mothers of autistic girls perceive and experience the potential affordances and constraints of diagnosis for their daughters?

The Ethics Committee of the Institute of Applied Social Research has considered your application and are happy to inform you that the proposed research project has been approved.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

If the proposed work involves users or providers of any local authority service (this includes some education, pre-school and care establishments) you will additionally need approval from the relevant Local Authority.

If the project involves users of providers of health services approval will also be required from the relevant NHS Research Ethics Committee.

In all cases **it is your responsibility to ensure that you are in possession of proof of all necessary authorisations before any fieldwork commences**.

Yours sincerely

Dr Lisa Bostock IASR Staff and PGR Ethics Co-ordinator

Appendix 8
ENQUIRY TO QUERIES LINE

Dear Mairi,

Your query was reviewed by our Queries Line Advisers.

RE: How do the mothers' of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters

Thank you for your email seeking additional clarity on whether your project should be classified as research and whether it requires ethical review by a NHS Research Ethics Committee (REC).

You provided the following information:

- A summary outlining your proposal
- An explanation of which questions you have difficulty in answering and why

Based on the information you have provided, our decision is that the project is **considered to be research but does not require review by an NHS Research Ethics Committee.**

In giving this decision our advisors agreed that the project outline provided describes a qualitative piece of research but that it does not require NHS REC review as participants will be recruited from outside the NHS.

This decision is in line with:

- The harmonised UK-wide edition of the Governance Arrangements for Research Ethics Committees (GAfREC), (updated April 2012);
- UK Policy Framework for Health and Social Care Research (2017)
- The National Research Ethics Service (NRES) guidance "Defining Research"and the algorithm *Does my project require review by a Research Ethics Committee?*

This decision should not be interpreted as giving a form of ethical approval or endorsement to your project on behalf the HRA. However, it may be provided to a journal or other body as evidence if required.

You should also be aware that:

- This response only covers whether your project is classified as research and whether it requires review by an NHS REC. You are strongly advised to consider other approvals that may be required for your project.
- All types of study involving human participants should be conducted in accordance with basic ethical principles, such as informed consent and respect for the confidentiality of participants. Also, in processing identifiable data there are legal requirements under the Data Protection Act 1998. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation.

Regards
Queries Line
REF 478/60/88/81

The Queries Line is an email-based service that provides advice from HRA senior management, including operations managers based in our regional offices throughout England. Providing your query in an email helps us to quickly direct your enquiry to the most appropriate member of our team who can provide you with an accurate written response. It also enables us to monitor the quality and timeliness of the advice given by the HRA to ensure we can give you the best service possible, as well as use queries to continue to improve and to develop our processes.

Health Research Authority

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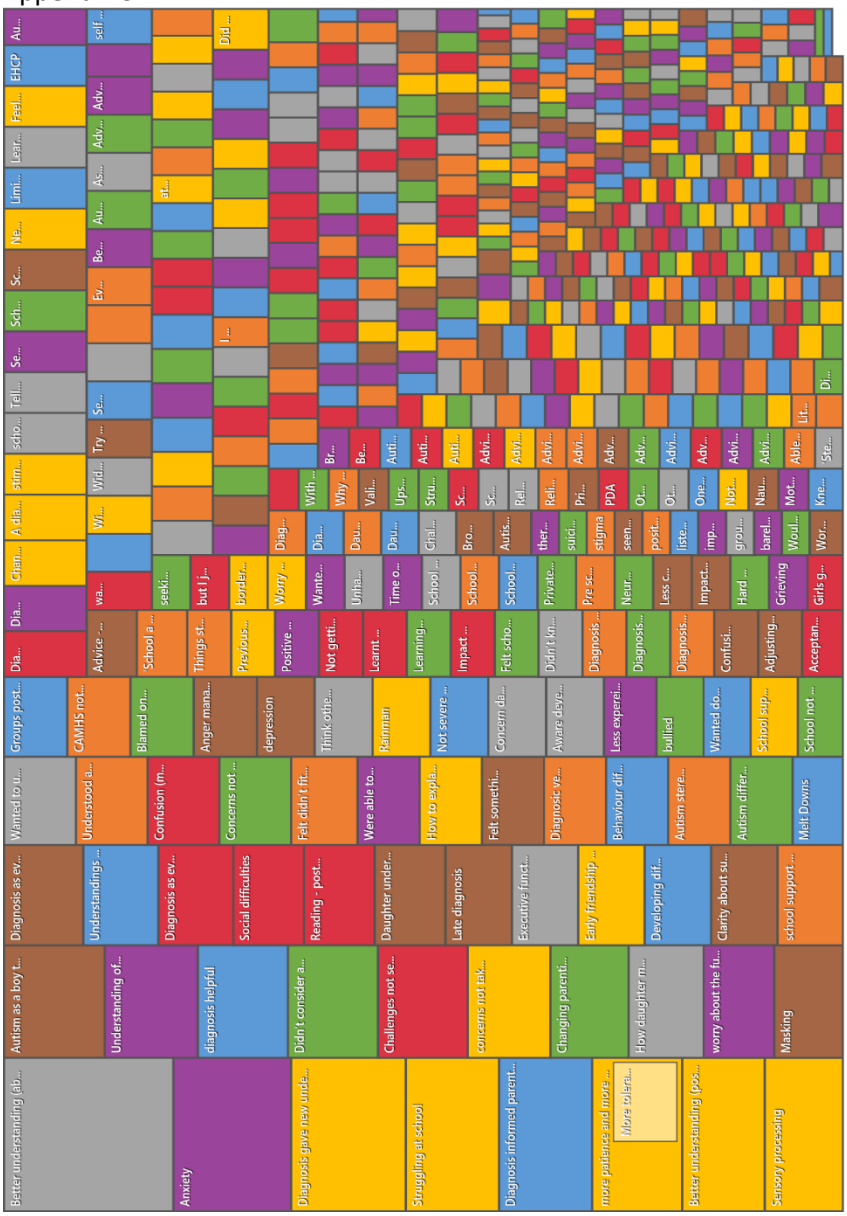
E. hra.queries@nhs.net **W.** www.hra.nhs.uk

Appendix 9


Better understanding (ab...
Anxiety
Diagnosis gave new unde...
Struggling at school
Diagnosis informed parent...
more patience and more ...
More tolera...
Better understanding (pos...
Sensory processing
Autism as a boy t...
Understanding of...
diagnosis helpful
Didn't consider a...
Challenges not se...
concerns not tak...
Changing parenti...
How daughter m...
worry about the fu...
Masking
Diagnosis as ev...
Understandings ...
Diagnosis as ev...
Social difficulties
Reading - post...
Daughter under...
Late diagnosis
Executive funct...
Early friendship ...
Developing dif...
Clarity about su...
school support ...
Wanted to u...
Understood a...
Confusion (m...
Concerns not ...
Felt didn't fit...
Were able to ...
How to expla...
Felt somethi...
Diagnosic ve...
Behaviour dif...
Autism stere...
Autism differ...
Melt Downs
Groups post...
CAMHS not...
Blamed on...
Anger mana...
depression
Think othe...
Rainman
Not severe ...
Concern da...
Aware deve...
Less experei...
bullied
Wanted do...
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EHCP
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Advice -...
School a ...
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Learnt ...
Learning...
Impact ...
Felt scho...
Didn't kn...
Diagnosis ...
Diagnosis...
Diagnosis...
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Dia...
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Ups...
Stru...
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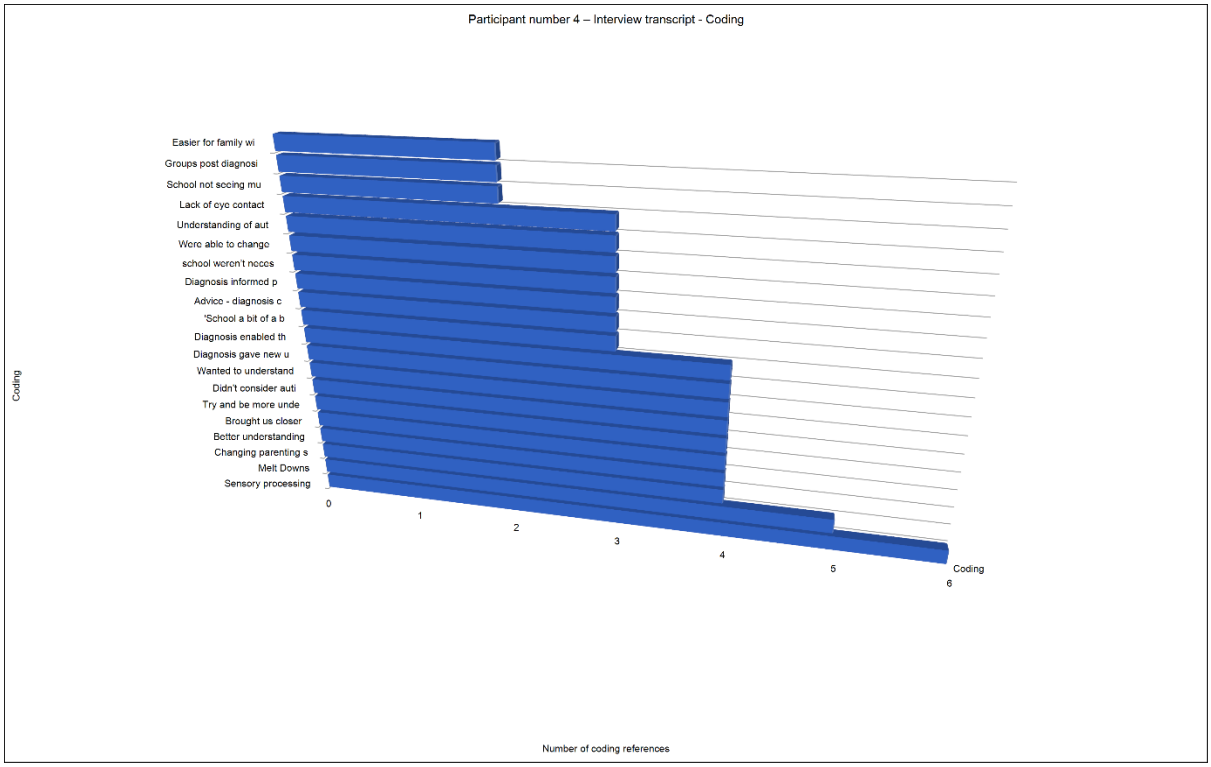
Appendix 10


Participant number 4 – Interview transcript - Coding
Coding
Easier for family wi
Groups post diagnosi
School not seeing mu
Lack of eye contact
Understanding of aut
Were able to change
school weren't neces
Diagnosis informed p
Advice - diagnosis c
'School a bit of a b
Diagnosis enabled th
Diagnosis gave new u
Wanted to understand
Didn't consider auti
Try and be more unde
Brought us closer
Better understanding
Changing parenting s
Melt Downs
Sensory processing
0
1
2
3
4
5
6
Coding
Number of coding references

Appendix 11

Code Chart – First Round Coding

Participant	Observation Summary	Most mentioned primary Codes (First Round Coding)	Biggest percentage - first round codes.
2	Living separately from children's father. Spiritual, massage, healing. **Daughter diagnosed at primary school, identified by teachers.** Felt primary school supportive. Older son later diagnosed. Had seen me give a talk prior to the interview. Presented as very independent.	• Not to wait for assessment/diagnosis to learn and change parenting approach. • Stimming behaviours. • Awareness her daughter was developing differently. • Limited understanding of autism pre-assessment • Understanding of autism changed post assessment. • Concern daughter may be judged due to label. • Wanted to understand behaviour challenges. • Diagnosis gave a better understanding of needs. • Has adjusted way of life. • Sensory processing.	• Give parents space to talk • Don't wait for diagnosis to learn • School supportive • Stimming • Melt downs • Sensory processing • Diagnosis gave new understanding of behaviours • Concern daughter may be judged • Better understanding about needs. • Telling daughter about diagnosis.
3	**Late diagnosis at 17 after contact with CAMHS** and significant mental health concerns. Not attending school as dropped out in senior year. Mother very tearful and emotional in interview. Had brought paperwork from meetings and interviews. Sense of loss.	• Anger management. • Anxiety. • Masking. • Late diagnosis. • Early friendship concerns. • Depression. • Autism as a boy thing. • Concerns not validated. • Concerns not taken seriously. • Struggling at school. • Diagnosis gave new understanding. • More tolerant.	• Anger management • Early friendship concerns • Late diagnosis • Depression • Autism as a boy thing • Anxiety • Masking • Concerns not taken seriously • CAMHS not helping
4	Didn't know was going for an autism assessment. Daughter had been referred to Paediatrician and SLT, then diagnosis given as part of	• Sensory processing. • Melt downs. • Changing parenting styles. • Better understanding. • Brought us closer. • Try to be more understanding.	• Melt downs • Sensory processing • Were able to change parenting behaviours • Diagnosis gave new

	overall developmental assessment, so no time to prepare. Diagnosis given at 6. Mother works in health Talked from knowledgeable position	• Didn't consider autism. • Wanted to understand. • Diagnosis gave new understanding. • Diagnosis enabled them to help daughter.	understanding of behaviour • Understanding of autism changed post diagnosis • Wanted to understand behaviour challenges • Diagnosis enabled them to help daughter • Better understanding about needs
5	Daughter diagnosed at 7 by privately by local CAMHS clinician. Now 11. Mother is training as a therapist and very interested in the research itself. Presented as very open. Has had a lot of contact with the primary school as a governor and has an interest in SEND.	• Better understanding (about needs) • Better understanding (post diagnosis) • Diagnosis gave new understanding. • Changing parenting style. • Social difficulties. • Reading (post diagnosis) • Didn't fit with early understanding about autism. • Didn't fit with early research. • Behaviour different/unusual. • Confusion (messages from professionals) • Changed mother daughter relationship. • Think others in the family may be autistic.	• Better understanding (about needs) • Better understanding (post diagnosis) • Think others in the family might be autistic • Diagnosis gave new understanding of behaviour • Changed mother daughter relationship • Anxiety • Helped with clubs outside of school • Processing
6	Daughter diagnosed by CAMHS at 10 (now 12) after a two year wait. Mum had read a lot prior to assessment and talks about knowing a lot prior to the diagnosis. Supports a boy with a diagnosis at a nursery.	• Diagnosis as evidence to school. • A diagnosis is not a silver bullet. • School support (post) • Diagnosis as evidence of challenges. • Impact on sibling. • Diagnosis informed parenting.	• Diagnosis as evidence to school • Diagnosis as evidence of challenges • Impact on sibling • Diagnosis informed parenting approach

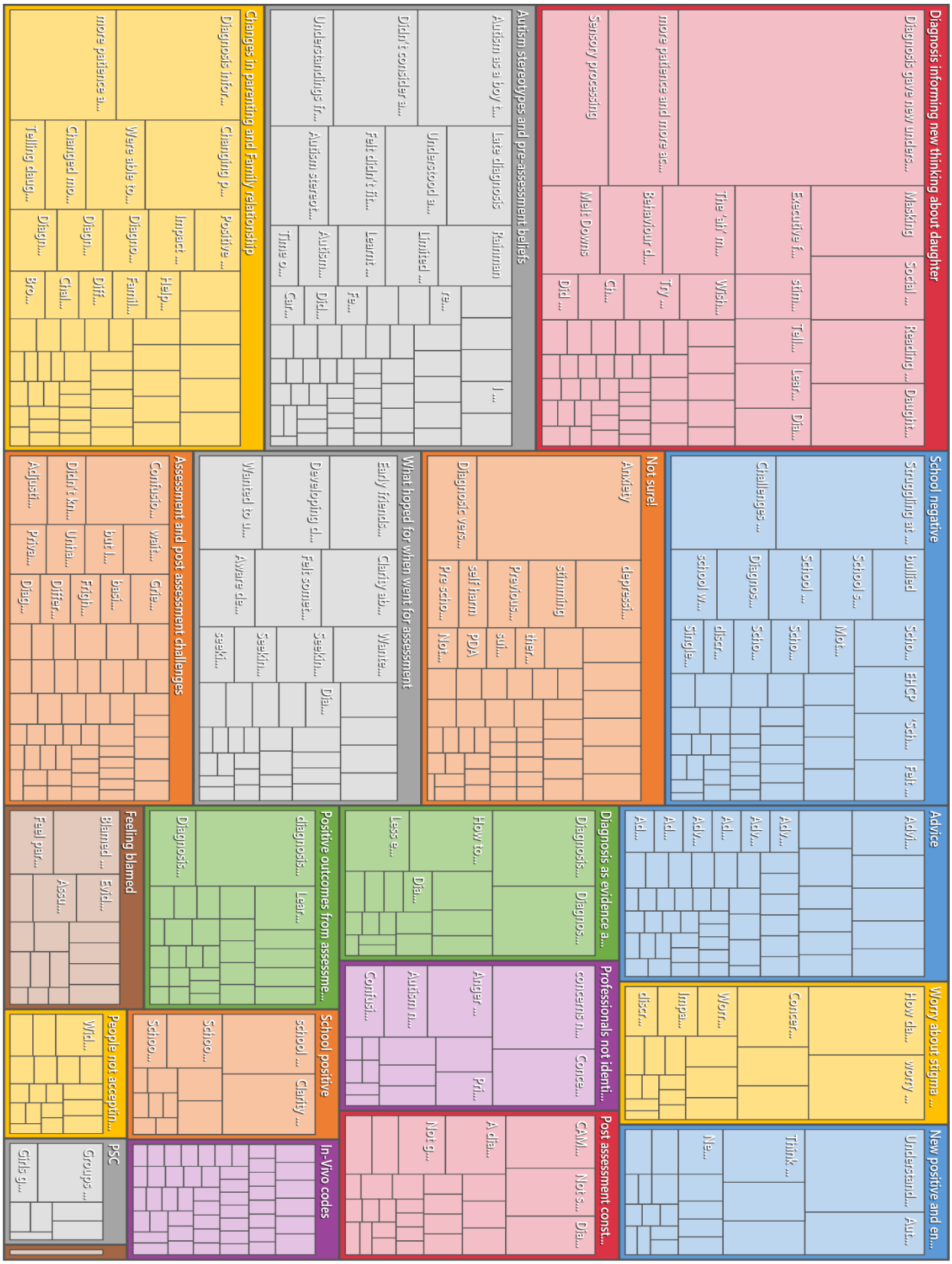
	Some challenges in getting school to provide support.	• Understandings from media. • Daughter understands herself better. • How daughter may be seen in society due to label.	• Daughter understand herself better • School support post • How daughter may be seen by society due to label
7	Daughter diagnosed at 11 in second assessment. Had waited 19 months for first assessment and was then re-referred via CAMHS A&D. Younger brother diagnosed with autism at 4 (before she was) and is very different to her. Mother presented as frustrated with the system, angry at school and angry at CAMHS for delays in support and not listening to her.	• Better understanding about needs. • Anxiety. • Diagnosis as evidence of challenges. • Autism as a boy thing. • Concerns not validating by others. • Diagnosis helped others understand. • How to explain behaviour. • Courses before diagnosis. • Diagnosis as evidence to school. • Were able to change parenting behaviours. • Masking.	• Better understanding about needs • Anxiety • Diagnosis as evidence of challenges • Changed mother daughter relationship • Concerns not validated by others • Mother empowered by diagnosis • Were able to change parenting behaviours
8	Daughter diagnosed at 17 (now 18) privately following involvement with CAMHS and overdose. Has one younger sister. Family attended Family Therapy and mother accessed private therapy. Very interested in systems due to own career in business systems.	• Better understanding about needs • Executive functioning • Sensory processing • Challenges not seen in school • Diagnosis informed parenting • Social anxiety • Anxiety • Discrimination (perceived and experienced) • Family Therapy • Able to change environment • Positive change in family relationships	• Better understanding about needs • Sensory processing • Executive functioning • Anxiety • Challenges not seen in school • Diagnosis informed parenting approach • Discrimination (perceived)
9	Daughter diagnosed privately at 10, confirmed by NHS at 12. Now 13. Attended	• Struggling at school • School not helpful • Adjusting review of future relationship with daughter	• Think others in family may be autistic • School not helpful

	mainstream school and now at private school. Autism initially seen as a loss – now 'sees it all over the place'.	• How to explain behaviour • Worry about the future • Grieving • Challenges not seen in school • Worry more • Melt downs • Was hoping the assessment would lead to answers • Hope • Understanding of autism changed • Wanted diagnosis to bring support • Felt something not right • Wanted diagnosis so would know what to do • Diagnosis as evidence of challenges	• Parents need support with wellbeing • Struggling at school • Adjusting view of future relationship • Worry more • Worry about the future • Impacts significant in the home
10	Daughter diagnosed at 6 by private clinic (now 10). Has dual diagnosis of ADHD. One younger sister. Mother very positive about autism and diversity and self-assured/confident in her role as a mother. Works part time.	• Better understanding about needs • Not severe enough for support • Wanted to understand behaviour challenges • Not getting support wanted with mental health • Wanted diagnosis so would know what to do • Daughter understands herself better • Changing parenting style post diagnosis • Struggling at school	• Better understanding about needs • Not getting support wanted with mental health • Changing parenting style post diagnosis • Not severe enough for support • Diagnosis informed parenting approach • Wanted diagnosis do would know what to do • Better understanding (post diagnosis) • Excluded from support due to diagnosis • Daughter understands herself better

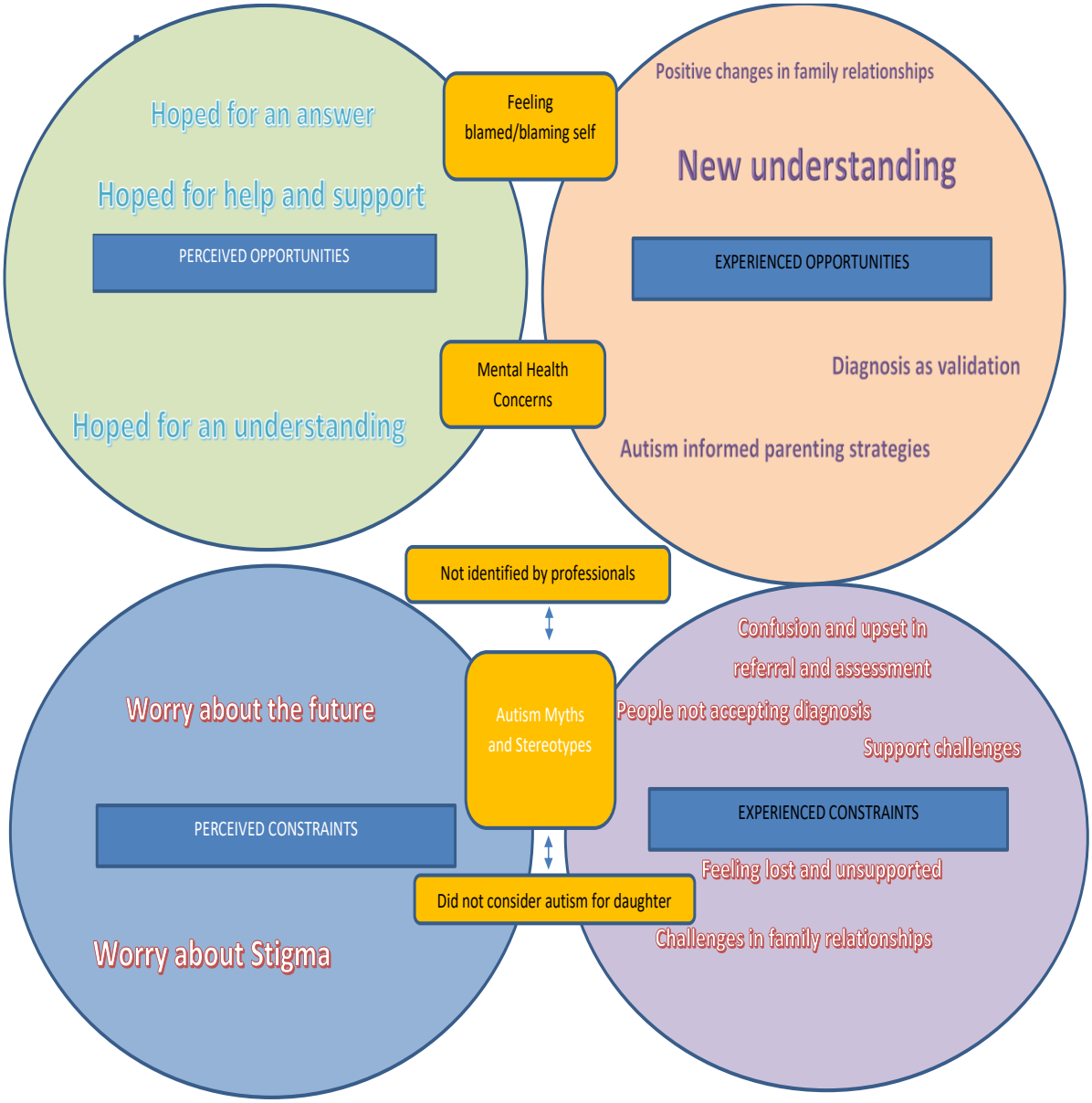
11	Daughter diagnosed at 4 (now 9) by a CAMHS paediatrician. Has a younger sister aged 5. Mother had not been concerned about her daughter being different and was upset with how it had been raised by the school/nursery. Still seeming very upset/emotional about this. Had been pregnant at the time. Shocked by references staff made to disability allowance and long term needs.	• Confusion (messages from professionals) • Worry about the future • Didn't consider autism for daughter • Diagnosis gave new understanding of behaviour • Diagnosis helpful • Better understanding about needs • "but I just felt like um (..) there's no problem here. • Unhappy with how it was raised • Didn't know what to expect from diagnosis • School support (post) • How daughter might be seen by society due to label	• Worry about the future • Confusion (messages from professionals) • Didn't consider autism for daughter. • Diagnosis helpful • Diagnosis gave new understanding of behaviour • School support • Better understanding about needs • How daughter might be seen by society due to label • Unhappy with how it was raised • Frightened and upset at diagnosis • This is a big deal for families
12	Daughter diagnosed at 9 by CAMHS, had been seen since 7 for OCD. Has two younger brothers, one with autism diagnosis. Daughter home educated. Mother talked very positively about neurodiversity and the celebration of difference. Her own father has self-diagnosed since her daughter was diagnosed and wrote a wonderful letter about how it had helped him understand himself so much better.	• More patience and more acceptance • Less comparing with other parents and children • Neurodiversity • Early friendship concerns • Waiting list • Struggling at school • OCD • Felt something not right	• Neurodiversity • Less comparing with other parents and children • More patience and more understanding • Early friendship concerns • Less experienced stigma • Waiting list • Struggling at school • Felt something not right • OCD • Felt didn't fit with early understanding about autism

			• Why should daughter be the one to change. • Pre assessment groups helpful
13	Daughter diagnosed at 10 privately. Oldest of 3. Has two younger brothers, one of whom has since been diagnosed. Mother gave up work to care for children. Daughter now home schooled. Daughter has a health condition which seems to have led to challenges being attributed to this and delaying autism referral and assessment. Mother feeling school and others see her as making a fuss.	• Anxiety • Concerns not taken seriously • Struggling at school • Diagnosis gave new understanding of behaviour • Better understanding (post diagnosis) • Feel parenting is judged by others • Diagnosis informed parenting approach • Blamed on parenting • Autism not identified by professionals • Diagnosis helpful • Autism stereotypes • EHCP	• Concerns not taken seriously • Struggling at school • Anxiety • Diagnosis gave new understanding of behaviour • Better understanding (post diagnosis) • Autism not identified by professionals • Feel parenting is judged by others. • EHCP • Blamed on parenting • Didn't consider autism for daughter

Appendix 12 Hierarchy Chart – Second round coding



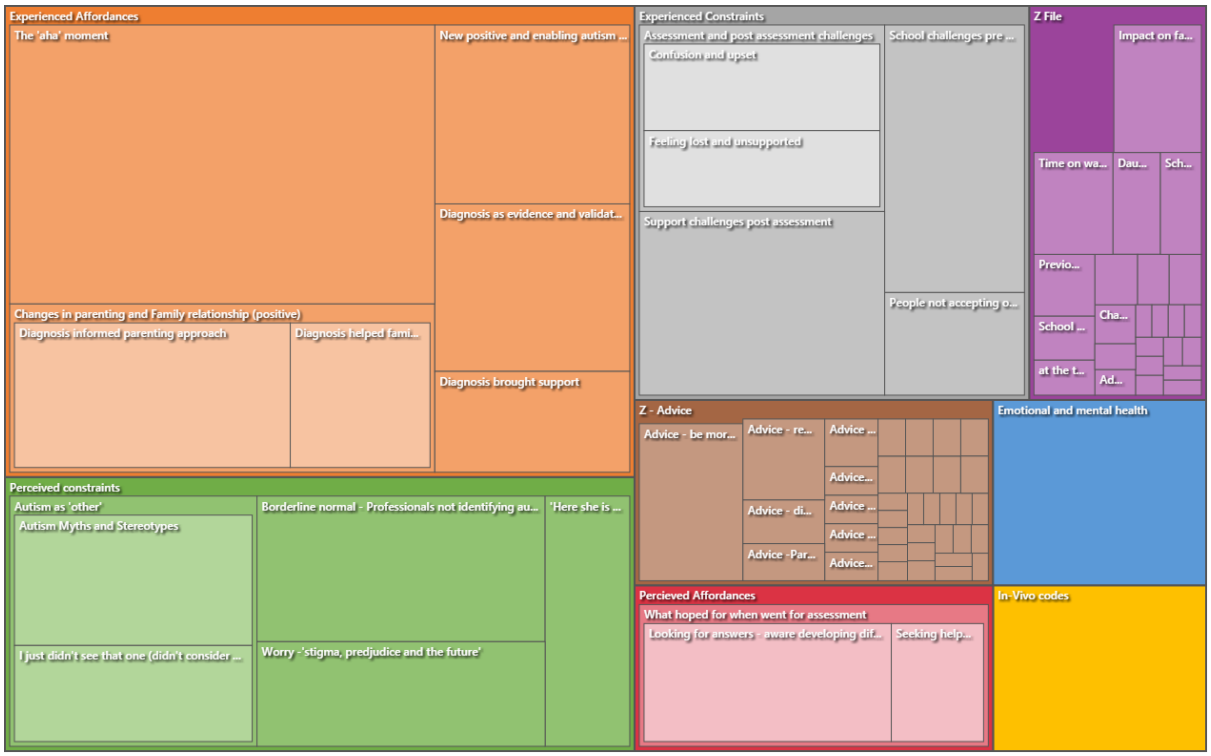
Appendix:13


Hoped for an answer
Hoped for help and support
PERCEIVED OPPORTUNITIES
Hoped for an understanding
Feeling blamed/blaming self
Mental Health Concerns
Positive changes in family relationships
New understanding
EXPERIENCED OPPORTUNITIES
Diagnosis as validation
Autism informed parenting strategies
Not identified by professionals
Autism Myths and Stereotypes
Did not consider autism for daughter
Worry about the future
PERCEIVED CONSTRAINTS
Worry about Stigma
Confusion and upset in referral and assessment
People not accepting diagnosis
Support challenges
EXPERIENCED CONSTRAINTS
Feeling lost and unsupported
Challenges in family relationships

Appendix:14


Experienced Affordances
Diagnosis gave new understanding of behaviour
Looking ba...
Daughters ...
New positive and enabling a...
Diagnosis as evidence and v...
Changes in parenting and Family relationship (positive)
Diagnosis informed parenting approach
Diagnosis helped family rel...
Changed mother daughter ...
Diagnosis brought support
Perceived constraints
Autism stereotypes and pre-assessment bel...
Early beliefs and stereotypes (not fitting ...
Worry about stigma and future
Concern daughter may...
worry about th...
Percieved Affordances
What hoped for when went ...
Awareness developing dif...
Seeking an...
Seeking he...
Professionals not identifying - ...
Blamed on parenting
School challenges pre assessment
Struggling at school
Challenges not seen in ...
Z File
Time on wa...
Dau...
School ...
at...
Previo...
School ...
Emotional and men...
Experienced Constraints
Assessment and post assessment challenges
Feeling lost &or unsupported after diagnosis
Confusion and upset in referral and assess...
Support challenges post assessment
Impact o...
People...
Z - Advice
Advice - be m...
Advice - ...
Advice - ...
Advice -P...
Adv...
Advi...
In-Vivo codes

Appendix:15


Experienced Affordances
The 'aha' moment
New positive and enabling autism ...
Diagnosis as evidence and validat...
Changes in parenting and Family relationship (positive)
Diagnosis informed parenting approach
Diagnosis helped fami...
Diagnosis brought support
Experienced Constraints
Assessment and post assessment challenges
Confusion and upset
Feeling lost and unsupported
School challenges pre ...
Support challenges post assessment
People not accepting o...
Z File
Impact on fa...
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Advice ...
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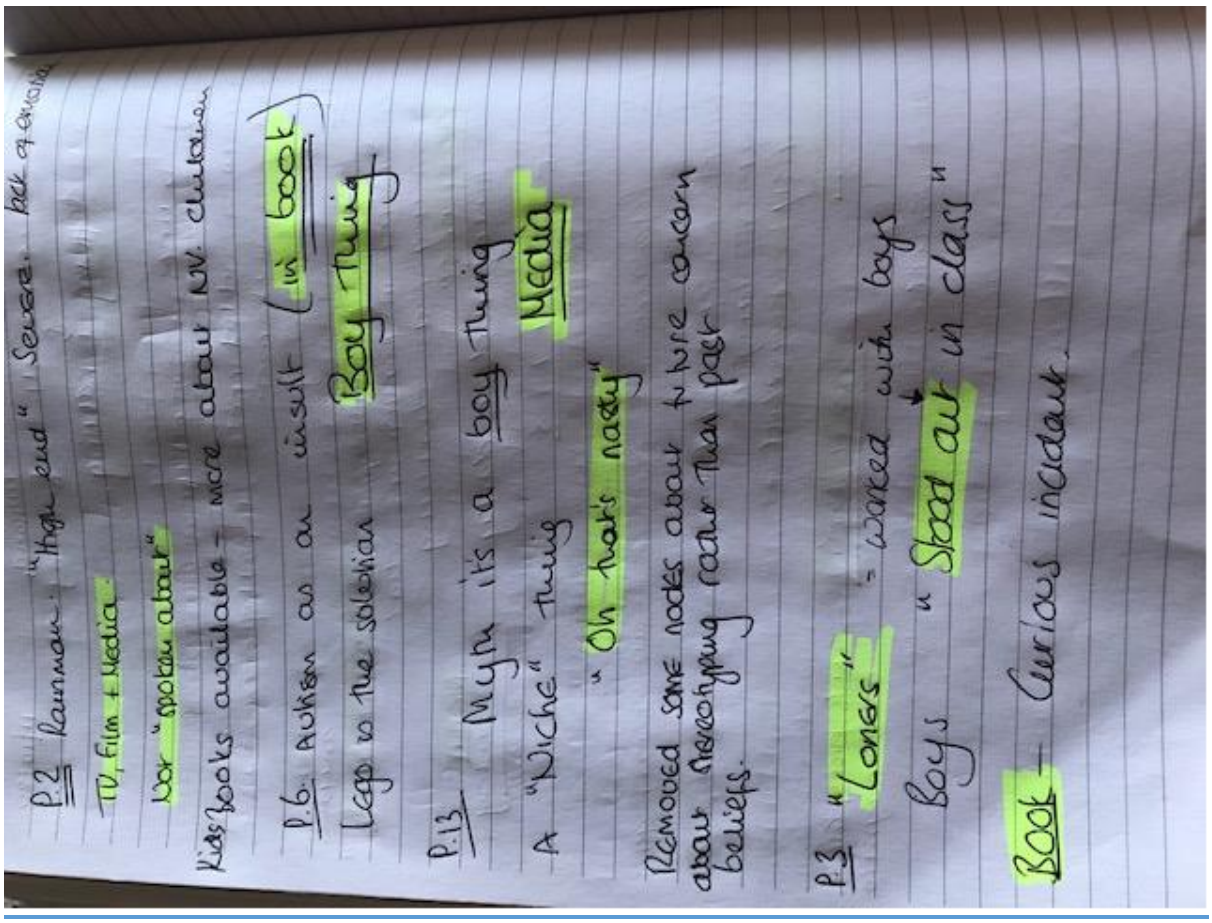
Advice - di...
Advice ...
Advice ...
Advice -Par...
Advice...
Emotional and mental health
Perceived constraints
Autism as 'other'
Autism Myths and Stereotypes
I just didn't see that one (didn't consider ...
Borderline normal - Professionals not identifying au...
Worry -'stigma, predjudice and the future'
'Here she is ...
Percieved Affordances
What hoped for when went for assessment
Looking for answers - aware developing dif...
Seeking help...
In-Vivo codes

Appendix 16 reflective journal – refining themes



Appendix 17 – Code Book

Code Book

Nodes

Name	Description
Emotional and mental health	Collated concerns about daughters anxiety, self harm, OCD, suicidal ideation and behavioural issues.
Experienced Affordances	
Changes in parenting and Family relationship (positive)	Collated nodes about how diagnosis informed a change in parenting and/or family relationships (affordances)
Diagnosis helped family relationships	Relationships within the home as well as with wider family including some who went on to have diagnosis of autism as a result of daughters diagnosis.
Diagnosis informed parenting approach	Changes in parenting informed by diagnosis. Mother empowered by diagnosis. Diagnosis has made different parenting 'permissible'. Looking back would have parented differently if knew.
Diagnosis as evidence and validation to self and others	Diagnosis as a way to show others that difficulties are there even if not observed by all, or to give an explanation of why there are certain behaviours (so not naughty etc) Also, diagnosis as a means to explain challenges to others or to negotiate relationships.
Diagnosis brought support	(Lnks with perceived affordance) Support at school, groups and in talking with other parents that they feel has been informed and enabled by the diagnosis.
New positive and enabling autism narratives	Narratives that differ greatly to first understanding of autism as bad and something that looked a certain way, just affected boys, limiting - to more enabling narratives, seeing strengths and possibilities and seeing challenges as outside the person in society not inside the person (society wrong not their daughter)
The 'aha' moment	Behaviours interpreted differently post diagnosis 'meaning is use' Past behaviours making sense when reflected on through lens of autism. New meanings given to behaviours that may once have been seen as naughty or challenging leading to more tolerance and acceptance.
Experienced Constraints	
Assessment and post assessment challenges	References to how assessment was experienced and feelings directly after diagnosis given - positive experiences post assessment coded elsewhere

Name	Description
Confusion and upset	How autism was raised, how assessment conducted. Male focused. Feeling confused and unsupported. Lack of understanding about what autism is as well as questions about how it was raised as well as the feeling that the process of getting the diagnosis was not a positive one due to negative language.
Feeling lost and unsupported	References to grief etc at time of diagnosis which appear to be informed by past view of autism as 'bad'. Feeling left without support at time of diagnosis 'not knowing how to go on'.
People not accepting or understanding diagnosis (seen as making it up)	Family, school, strangers, friends - Could be acceptance in terms of believing it is autism - so denying validity of diagnosis, but also questioning benefit or even existence of autism as a 'thing'.
School challenges pre assessment	Daughter struggling, school not identifying concerns raised by mother, 'masking' and identified needs. Mother's feeling they are seen as a pain/making it up. .
Support challenges post assessment	Narratives about support not being provided in spite of diagnosis (perceived affordance - more support - expereinced constraint - lack of resources and or understanding or agreement in needs) Not being sever enough School/CAMHS/EHCP other
In-Vivo codes	Good quotes to use'
Perceived constraints	
Autism as 'other'	Autism myths and stereotypes not fitting with view of daughter, seeming to be male focused, linking with learning disability and negative connotations.
Autism Myths and Stereotypes	Early beliefs about autism informed by media/literature that do not fit with perceptions of daughter and /or her difficulties and which are mostly negative. Autism seen as a 'bad' thing, something that other people have, something to be avoided, feared not talked about. Not fitting with narratives about daughter and not something that could be positive or helpful.
I just didn't see that one (didn't consider autism for daughter)	Due to how autism was portrayed and how they understood autism they had not connected autism as somethig that would describe their daughter or challenges/strengths that they had.
Borderline normal - Professionals not identifying autism	Told not autism, she'll grow out of it.

Name	Description
'Here she is again' - Blamed on parenting	Either self-blame, perceived blame or experienced blame about responsibility for 'creating' or not managing behaviours due to parenting (or lack of parenting) prior to diagnosis. Sense of failing, getting it wrong.
Worry -'stigma, prejudice and the future'	Worry about future career, life prospects and concern people will pass judgement if read about diagnosis rather than getting to know their daughter.
Perceived Affordances	
What hoped for when went for assessment	
Looking for answers - aware developing differently	Feeing something not right, assessment as way to clarify
Seeking help and support	Perceived opportunity - belief that assessment would bring support

Appendix 18

Code Chart – Final coding

Participant	Observation Summary	Most mentioned primary Codes (First Round Coding)	Biggest percentage - first round codes.
2	Living separately from children's father. Spiritual, massage, healing. **Daughter diagnosed at primary school, identified by teachers.** Felt primary school supportive. Older son later diagnosed. Had seen me give a talk prior to the interview. Presented as very independent.	• The 'aha' moment • New and enabling autism narratives • Looking for answers • Autism myths and stereotypes • Support challenges post assessment	• The 'Aha' moment. • Advice - be respectful • Looking for answers • Support challenges post assessment • New and enabling parenting narratives
3	**Late diagnosis at 17 after contact with CAMHS** and significant mental health concerns. Not attending school as dropped out in senior year. Mother very tearful and emotional in interview. Had brought paperwork from meetings and interviews. Sense of loss.	• The 'aha' moment • Borderline normal • Emotional and mental health • Support challenges pre assessment • Autism myths and stereotypes	• The 'aha' moment • Borderline normal • Emotional and mental health • Support challenges post assessment • Autism myths and stereotypes
4	Didn't know was going for an autism assessment. Daughter had been referred to Paediatrician and SLT, then diagnosis given as part of overall developmental assessment, so no time to prepare. Diagnosis given at 6. Mother works in health	• The 'aha' moment • Diagnosis informed parenting • Autism myths and stereotypes • Here she is again • Diagnosis helped family	• The 'aha' moment • Diagnosis informed parenting • Looking for answers • New and enabling autism narratives • Diagnosis helped family

	Talked from knowledgeable position.		
5	Daughter diagnosed at 7 by privately by local CAMHS clinician. Now 11. Mother is training as a therapist and very interested in the research itself. Presented as very open. Has had a lot of contact with the primary school as a governor and has an interest in SEND.	• The 'aha' moment • Borderline normal • Looking for answers • Diagnosis informed parenting • Diagnosis helped family	• The 'aha' moment • Borderline normal • Diagnosis brought support • Diagnosis helped family • Diagnosis informed parenting
6	Daughter diagnosed by CAMHS at 10 (now 12) after a two year wait. Mum had read a lot prior to assessment and talks about knowing a lot prior to the diagnosis. Supports a boy with a diagnosis at a nursery. Some challenges in getting school to provide support.	• Diagnosis as evidence • The 'aha' moment • Autism myths and stereotypes • Worry about stigma • Diagnosis brought support	• Diagnosis as evidence and validation • The 'aha' moment • Diagnosis brought support • Worry about stigma • Impact on family relationships
7	Daughter diagnosed at 11 in second assessment. Had waited 19 months for first assessment and was then re-referred via CAMHS A&D. Younger brother diagnosed with autism at 4 (before she was) and is very different to her. Mother presented as frustrated with the system, angry at school and angry at CAMHS for delays in support and not listening to her.	• The 'aha' moment • Diagnosis as evidence • Borderline normal • Diagnosis informed parenting • Support challenges post assessment	• The 'aha' moment • Diagnosis as evidence • Diagnosis informed parenting • Emotional and mental health • Borderline normal

8	Daughter diagnosed at 17 (now 18) privately following involvement with CAMHS and overdose. Has one younger sister. Family attended Family Therapy and mother accessed private therapy. Very interested in systems due to own career in business systems.	• The 'aha' moment • Diagnosis informed parenting • Support challenges post assessment • Support challenges pre-assessment • Emotional and mental health	• The 'aha' moment • Diagnosis informed parenting • Support challenges post assessment • Emotional and mental health • Impact on family relationships
9	Daughter diagnosed privately at 10, confirmed by NHS at 12. Now 13. Attended mainstream school and now at private school. Autism initially seen as a loss – now 'sees it all over the place'.	• The 'aha' moment • Support challenges post assessment • Diagnosis as evidence • New and enabling autism narratives • Diagnosis informed parenting	• The 'aha' moment • Worry about stigma • Diagnosis informed parenting • Support challenges post assessment • Diagnosis as evidence
10	Daughter diagnosed at 6 by private clinic (now 10). Has dual diagnosis of ADHD. One younger sister. Mother very positive about autism and diversity and self-assured/confident in her role as a mother. Works part time.	• The 'aha' moment • Looking for answers • Support challenges • New and enabling autism narratives • Here she is again	• The 'aha' moment • Support challenges post assessment • Diagnosis informed parenting • Looking for answers • New and enabling autism narratives
11	Daughter diagnosed at 4 (now 9) by a CAMHS paediatrician. Has a younger sister aged 5. Mother had not been concerned about her daughter being different and was upset with how it had been raised by the school/nursery. Still seeming very upset/emotional about this. Had been	• I just didn't see that coming • Confusion and upset • The 'aha' moment • Worry about stigma • Feeling lost and unsupported	• I just didn't see that coming • Confusion and upset • Worry about stigma • The 'aha' moment • Feeling lost and unsupported

	pregnant at the time. Shocked by references staff made to disability allowance and long term needs.		
12	Daughter diagnosed at 9 by CAMHS, had been seen since 7 for OCD. Has two younger brothers, one with autism diagnosis. Daughter home educated. Mother talked very positively about neurodiversity and the celebration of difference. Her own father has self-diagnosed since her daughter was diagnosed and wrote a wonderful letter about how it had helped him understand himself so much better.	• New and enabling autism narratives • Diagnosis informed parenting • The 'aha' moment • Confusion and upset at assessment/diagnosis • Looking for answers	• New and enabling autism narratives • Diagnosis informed parenting • The 'aha' moment • Looking for answers • Confusion and upset at assessment/diagnostic process
13	Daughter diagnosed at 10 privately. Oldest of 3. Has two younger brothers, one of whom has since been diagnosed. Mother gave up work to care for children. Daughter now home schooled. Daughter has a health condition which seems to have led to challenges being attributed to this and delaying autism referral and assessment. Mother feeling school and others see her as making a fuss.	• Support challenges post assessment • The 'aha' moment • School challenges pre-assessment • Emotional and mental health • Borderline normal	• The 'aha' moment • School challenges pre assessment • Support challenges post assessment • Borderline normal • Emotional and mental health

Appendix 19

Research Feedback for Participants

It is now some time since I met with you for the purpose of my research. I want to thank you again for your time and for being kind enough to share you experience with me. I really appreciated how open everyone was and how I was made to feel welcome within your homes. I am now reaching the final stages of my research and thesis and would like to share this summary of my research findings with you. I would be very grateful for your views.

As you may recall my research question was:

How do mothers of autistic girls perceive and experience the affordances and constraints of diagnosis for their daughters?

Aims: My aim was to learn more about your experience pre-assessment, including what you hoped the diagnosis would bring, and what your experience of that diagnosis was once it was given for your daughter. Did it bring what you hoped for and did it bring affordances as well as constraints. My hope is that information from this research will help inform the support and information given to mother's pre-assessment so it can be the most useful and helpful, and also better prepare them for diagnosis if it is given. I would also like to make recommendations about how services and professionals can work together in the best possible way post diagnosis to support mothers and ultimately their daughters.

Who took part: A total of 12 mothers took part in my study. I had intended to complete more interviews but had to change my plans due to the Coronavirus pandemic.

What I did after we met: I transcribed all of the interviews and used a program called Nvivo to assist me in reviewing each interview closely to look for themes. To do this I initially highlighted anything that seemed important or relevant (which was most of what was said!) in each of the interviews rather than being led by my research question. I then grouped all similar comments or statements together to create themes. This process created 18 themes which I then grouped together under the headings of perceived affordances, perceived constraints/constraints of perception, experienced affordances, and experienced constraints, in relation to diagnosis. Two themes, emotional and mental health, and school challenges (pre-assessment) did not fit within the headings about diagnosis. I felt these themes were very important and created a context for a lot of the other themes, so I kept them under the heading of contextual themes. Once I had grouped the themes I reviewed them all to look at how autism was talked about and understood, pre and post assessment (stories told) , and the influence this has had on day to day life for you and for your daughter (stories lived).

I have created a table of the themes with a description of each of them below. The last column shows how many of you made comments related to the theme:

Contextual Themes	Description of content	No:
Emotional and Mental Health	All 12 of you told me that your daughters had experienced some form of emotional or mental health difficulties or challenges. This included anxiety, OCD, depression, self-harm, or suicidal thoughts. For most of your daughters these concerns informed the decision to seek an assessment for autism. Whilst there were some improvements following diagnosis, it was noted that most of these concerns remained post-diagnosis particularly anxiety.	**12**
School challenges (pre-assessment)	You all described a difficulty or 'struggle' with school prior to your daughter's assessment. Some of the girls struggled to attend, a number experienced peer group difficulties and it was felt that they were not thriving or reaching their full potential.	**12**
Perceived Constraints (Constraints of perception)		
Autism as other: Myths and Stereotypes	For all of you, before your daughter's diagnosis, autism was understood as something which mostly affected boys. Most of you referred to Rainman as something which informed your early understanding. The general belief at this early time was that an autistic person would have learning difficulties and present with extreme and obvious behaviours or difficulties. For some of you there was also a view, gained from society, that autism was something not nice or even nasty. This view has changed significantly for all of you as you will see in later themes.	**12**
Autism as other: The two didn't join up	Whilst you had an awareness that something was different with your daughter's development or behaviour, 11 of you said that you did not consider autism at first, or you had discounted it. This was due to the idea that autism was a male condition with significant social and communication difficulties, learning difficulties and/or observed behaviours.	**11**
Borderline normal: Professionals not identifying autism	11 of you described how professionals had not identified, or had been late to identify, autism for your daughter. For some of you this included professionals such as GP's excluding autism as a possibility. This led to some of you feeling 'brushed off' or 'fobbed off' and also led to frustration, and a sense of sadness and lost opportunity.	**11**
Worry: Stigma, prejudice and the future	For 11 of you the consideration of autism brought worry and concern that your daughter may experience prejudice or stigma and that it might impact on their opportunities in the future. This concern was driven by your initial beliefs	**11**

	about autism. Even though all of your beliefs about autism began to change significantly you were concerned that the views of others would still be informed by myths and stereotypes about what it means to be autistic, and that they would make incorrect assumptions about your daughters.	
Perceived affordances		
Seeking an understanding: 'Something's going on'	All 12 of you described an awareness that your daughters were developing differently to their peers, either socially, emotionally, or behaviourally. For 7 of you this included the feeling that 'something wasn't right' or 'something was going on'. This questioning about was happening, and your search for answers and an understanding, is what ultimately led to the assessment and diagnosis for your daughters.	**12**
Hope - Seeking help and Support	For 11 of you there was a hope that a diagnosis would bring help and support. This included support at school, and a belief that there would be more specialised support available for your daughters as a consequence of a diagnosis, now and in the future.	**11**
Here she is again: Feeling blamed on parenting	Before the diagnosis, most of you felt that you were blamed by others for your daughter's difficulties, either due to poor parenting, or due to being over-protective or 'neurotic'. This led to some of you feeling that you were an inconvenience at school. There was also self-blame for some of you as you questioned why you could not make things better.	**10**
Experienced Constraints		
Confusion and Upset (pre-diagnosis)	The theme 'Confusion and Upset' encapsulate the negative experiences highlighted by 10 of you about how you experienced the referral and assessment process for your daughter. This included how the possibility of autism was raised, the wait for the assessment, and the focus on impairments and the language used in the diagnostic process.	**10**
'Too-da-loo' feeling lost and unsupported (post-diagnosis)	11 of you described feeling overwhelmed, shocked, and isolated directly after your daughter's diagnosis. I believe this was, in part, informed by the myths and stereotypes held about autism as well as the language and focus of the assessment itself. You also described a sense that you were just left with a piece of paper with no one to talk to about how you felt.	**11**

Diagnosis not accepted or understood by others (post-diagnosis)	After your daughter's diagnosis 9 of you experienced challenges with others not accepting or understanding the diagnosis. This included family, friends, professionals, and other parents. The most frequent references, made by 7 of you, were about grandparents either questioning the diagnosis or demonstrating a lack of understanding about what it meant.	**9**
She's not broken enough: Support Challenges (post-diagnosis)	All 12 of you described challenges with accessing support for your daughter, post diagnosis, across both education and mental health (CAMHS) contexts. Some of you described a sense that your daughter's needs were not seen as severe enough to warrant support, whilst for others it was a lack of available resources or the diagnosis itself that was a barrier. Available support was also seen as boy focused and one of you raised a concern that the emphasis was on your daughter to be the one to change to fit in.	**12**
Experienced Affordances		
The 'ah' moment – bringing a new understanding	The most recurrent theme in all the interviews was that the diagnosis brought you a new understanding about your daughter's behaviours and experiences. This was informed by new information about sensory processing, executive functioning and masking and more awareness about autism and how it may present in girls. Statements such as 'like having something lifted off your eyes', 'like a jigsaw piece just put in' and 'The Ah' moment were used to describe the impact of this new information about your daughters which led to more tolerance and understanding of your daughters.	**12**
Evidence and validation – to self and others	For 11 of you the diagnosis acted as validation, both to you and to others, about your daughter's needs. The experiencing of the diagnosis as something tangible and official, enabled and empowered you to push for more support where you felt it was needed, and where you had perhaps felt you were not listened to before.	**11**
Diagnosis brought support	In addition to an increase in understanding about your daughter, 10 of you talked about ways in which the diagnosis had brought support. This included courses and groups which you had found helpful, access to books and information, support from other parents and support in school. A number of you mentioned how helpful the autistic girls group had been.	**10**

'She owns it' - new and positive autism narratives	One thing that stuck out was the how all of you described a change from your early beliefs about autism as a male disorder or something 'not nice'. There was a significant shift away from an understanding of autism as impairment and towards autism as something more positive. This included a celebration of your daughter's strengths, autism as a 'superpower' and an awareness that no two people with autism are the same. You also talked about problems being in services and society, rather than something within your daughters.	**11**
Diagnosis informed parenting	You all talked about ways in which your daughter's diagnosis had led to you adjusting your approach to parenting. This included the adoption of specific strategies, 'shaking up the rules', less comparison with others and giving yourself permission to do things differently.	**12**
Diagnosis helped the family and family relationships	There were different ways in which the diagnosis of your daughter helped with family relationships in some way. This included the subsequent diagnosis of siblings, others in the wider family newly identifying as autistic and an ability to talk about your daughters needs with the wider family in ways which were useful. For a number of you the diagnosis also had a positive impact on your relationship with your daughter due to a better understanding about how she experiences the world.	**11**

A summary of my observations: As mothers you all described a combination of affordances and constraints in relation to the diagnosis of your daughters. Some of the experiences that you shared reinforced experiences that have been highlighted in other studies regarding mothers of girls. This includes the challenges in having your daughter's autism recognised, confusion and upset in the diagnostic process, challenges with accessing support, and concerns about stigma. As this study focused on the impact of the diagnosis on lived experience there are a few things which we can share that have not been highlighted before. This includes the significant impact of societal myths and stereotypes or 'stories' about autism on the initial identifying of autism and on the experience of the assessment and diagnosis. What really struck me was how much your understandings about autism changed after your daughters received their diagnosis. You spoke with passion about your daughters and all their strengths and highlighted that much of the problem is external to them in services and society, not 'within' them. Another thing that you highlighted was the benefit diagnosis had in helping you to understand your daughters more and how this enabled you to be more understanding and tolerant. A new awareness of sensory processing, masking and executive functioning was of particular benefit. You described how

you had changed you parenting to fit with what your daughters needed and were less influenced by traditional views about how parenting 'ought' to be.

Your advice to parents and professionals: You gave some excellent advice for other mothers/parents and professionals. The two themes for advice for mothers/parents were:

It doesn't have to be a lonely thing: You advised mothers/parents to join groups, talk to other parents and also to make sure they talk to each other. You said it is helpful to know that you are not alone and to hear and share advice.

Read and learn all you can: You wanted to encourage mother's not to wait for an assessment or diagnosis and to read all they can or learn all they can. Whilst you all spoke about the benefits of a diagnosis you also said that you do not need to wait for a diagnosis to make changes, to learn about your child's experiences and to make their lives easier.

Be more respectful: You wanted professionals to be more aware of the emotional journey experienced mothers in all stages of assessment and diagnosis and to provide appropriate support. This includes not presuming knowledge that the mothers may not have, sharing useful and timely information and very importantly making time to listen to concerns.

Recommendations for practice from research: There are a number of potential recommendations for services and clinicians. These include:

- More information and support to be made available with regards to girls and autism.
- Professionals need more training and awareness about the different presentations of autism, in boys and girls (but also boys who camouflage).
- It is important that professionals listen to mothers and acknowledge their concerns and their experiences even if they are about behaviour which cannot be easily 'observed' in school.
- Information and support should be made readily available for parent's pre-assessment particularly advice about camouflaging, sensory processing, executive functioning and relevant parenting strategies.

Ideas for future research: You all shared so much with me and there were lots of things that I would have liked to have included or to have explored further. These included your experience of telling your daughters about the diagnosis, what influence the autistic girls group had on your experience of the diagnosis, the experience of fathers, and the variation in your experience if you had a daughter who was diagnosed at a young age or at a much older age.

It would be very helpful to have your feedback on the themes and information that I have shared. I hope that you feel our conversations and your experience is represented and would like to hear your views before I submit my final thesis. I have written some questions as guidance for feedback. This can be via email, via the phone, via an online meeting or a

combination of them all. Whilst the questions are to give guidance please feel free to give any feedback that you feel it is important for me to have.

- Do you feel that your views and experience are represented in the study outcomes and in what way?
- Is there anything that you disagree with or that you feel does not represent your views?
- Is there anything that you think is missing?
- Is there anything new that surprises or interests you in the study outcomes?
- What do you think the most important message is from the research?

Thank you again for your time and support with my study.

Mairi

Appendix 20

Feedback 1:

Thank you for sending your thesis summary through; it was very interesting to read and I'm happy to pass on my feedback.

I actually felt quite emotional reading it as I spent the whole time saying, "Yes, that's it, that's right, that's exactly how it was, how I felt." So the answer to your first question is yes, I do feel my views and experiences are represented and are described in a way that I was probably not able to clearly articulate in the interview. Thank you for being able to decipher our stories and experiences into common themes.

There wasn't anything that I disagreed with or felt did not represent my views.

The thing that really surprised me was how many of the group talked about the same themes/issues as part of their own experiences – the vast majority for all themes. This was a really interesting thing to see and showed me that my own story/experience was not unique; that in fact there are many other families who have been through the same experience and felt the way I did. I know there are many families with girls who have been diagnosed from being part of the PSC group, but seeing that data made me feel like I am not alone in how I felt. It made me feel validated and to feel that understanding and support is out there.

The research did make me feel extremely sad to see that the vast majority of our girls had emotional and mental health difficulties, challenges in school, difficulties getting a diagnosis, parental blaming, confusion and upset in the diagnostic process then feeling unsupported as parents and accessing support for the girls – all negative life experiences. It brought home to me just how important it is for research like this to be done and made available to professionals and society as a whole. Only by clearly showing the negative experiences families go through, can people, hopefully, learn from them and change their practice to improve the experiences for families in the future.

I think there are probably two important messages from the research. The first I have explained above – to expose and hopefully change the negative experiences of girls pre and post assessment for Autism. The second is how families are learning more about the positives of Autism in girls. Hopefully this and further research can be used to educate not only professional but also society to try to dispel the myths many of us had regarding Autism, especially as the number of girls being diagnosed is increasing. Wouldn't it be great to see girls being identified and supported at a much earlier age, with no stigma attached, before they mask and spiral down to poor mental health.

I hope this feedback has been helpful.
Good luck with your thesis and I'll look forward to your presentation in June.

Feedback 2:

Research feedback

Do you feel that your views and experiences are represented in the study outcomes and in what way?

I can recognise my experience in many of the themes, including the journey to a greater understanding of autism, the confusion and upset at diagnosis (and in some parts of the referral process), and the fact that diagnosis has enabled us to adapt our parenting.

Is there anything that you disagree with or that you feel does not represent your views?

Not really, but perhaps because my daughter was so young at referral and diagnosis, the kind of mental health challenges described in the first theme don't represent our experience so far.

Is there anything that you think is missing?

In the support challenges section ('She's not broken enough'), I wonder whether other parents were very clear about the level and nature of support they felt their daughters needed. This section does represent my experience in that I have sometimes been told that 'she's not the worst' in the class. In fact, my daughter mentioned to me a few weeks ago that a teacher said she was 'not very autistic'. However, I sometimes feel unsure myself about the level of support that is either desirable or possible at school. I remember being told at diagnosis and at a later assessment at school that 'she will learn' and I feel sure that this is true. However, it isn't always clear what the best route to learning is and I think it is constantly changing.

Is there anything new that surprises or interests you in the study outcomes?

I was interested to see that my experiences on a number of themes were similar to the other participants.

Sometimes when I speak to other parents, I feel that they understood that their child was autistic and then fought for the diagnosis. For me, it wasn't clear that my daughter was autistic or that a diagnosis would be a positive outcome. I feel slightly relieved that this has been the case for other parents in the pre-assessment phase too!

I was also interested in the idea of the mother's emotional journey because I realise that actually it is a journey, and it takes time to move from a general idea of what autism is to an understanding of autism as it relates to your own child. It could be difficult for professionals to know where a parent might be on that journey.

What do you think the most important message is from the research?

Diagnosis helps parents to tailor their parenting to suit the child (and influence others).

Feedback 3:

Good afternoon Mairi
Thank you for inviting my reflections on your findings. My comments are below
Yes, I very much feel that my views and experiences are reflected in your findings. Specifically, being faced with myths of how I continue to respectfully seek understanding (particularly at school) to respond to and meet my daughter's needs. In addition, the opportunity afforded by diagnosis of greater transparency regarding the challenges of operating ' everyday' has helped the immediate family make significant adjustments within our home, and push for more support thereby moving away from the concept of ' borderline normal'. Tweaks aren't sufficient. Therefore the theme of being the pushy parent is still very much still present in my life, and I'm working on not being bothered by it.

I continue to worry, as my daughter tries to navigate through a final year of A level study, now being constantly tested, coupled with an immensely uncertain world and a question whether she will cope at University / away from home. Despite her abilities, she is questioning whether University is a place where she will be able to function.

What's missing?
Nothing for me. Rather a question of emphasis based on my own experience. For me this would be within the ' ah ha' moment and seeing beyond 'dawning' , moving from through a journey of acceptance which you also reflect in your key findings. My own journey of seeing my daughter's autism as central part of her identity versus an ' add on' has been imperative to my own full acceptance and one that I find myself having to advocate more as she continues to ' mask' in most environments.

Most important message for me
Thank you for asking this because this research supports my hope that our daughters will increasingly meet understanding and acceptance. The most important message for me in relation to Diagnosis of girls with autism is seeing beyond the ' not broken enough' to warrant acknowledgement and therefore significant support or adjustment. For me masking and high functioning within academic environments, unfortunately diminish understanding of the level of support required and therefore impact on opportunity to offer the value and strength of difference, in addition to being an enabler of mental wellbeing..

Thank you once again for seeking to understand my experience to inform your research .