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The “Aha Moment”: Exploring autism narratives as told by the mothers of autistic girls

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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 article explore the history of autism diagnosis, autism and girls and introduces my doctoral study, conducted from a social constructionist viewpoint, exploring the diagnostic journey of 12 mothers in the UK to identify the meanings attributed to their daughter’s diagnosis.

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Introduction

I have become increasingly curious about autism diagnosis over the years, both professionally and personally. In 2016 I combined this interest with my love of systemic and social constructionist thinking and began a journey as a doctoral researcher. At this time, I was working in an Autism Assessment Team as well as in a specialist CAMH service (child and adolescent mental health). This was the second time I had worked in a neurodevelopmental service. In my first post I had been able to focus on systemic and therapeutic interventions and I strove to avoid a role as a diagnostician. This second post, which I had started in 2012 as a consequence of a service redesign, required me to conduct autism assessments. It was not long after joining the service, and as my diagnostic experience developed, that the world of work and my own personal and family life became inextricably linked. I had begun to identify the behaviours required to make an autism diagnosis in my own children, both of whom later received a diagnosis of autism and ADHD. This led to an interest in autism and autism research, not just as an outsider looking in, but also as a parent and member of a neurodiverse family, researcher and subject of that research.

I would like to take this opportunity to share some of the findings from my doctoral research with you. However, I would also like to share a word of caution about the potential unintended consequences of such research. Pearce wrote that "every naming is also a not naming" and "every affirmation is a denial of alternatives" (2007, p. 100) and I am curious about the impact of what 'not naming' occurs as a consequence of any research which focuses on a particular group, such as my research focus on autistic girls.

The Autism Story – Made, Found or Both

Over time, and as my relationship with autism has evolved, my understanding of what autism is and what it means to be autistic has changed exponentially. The more I learn, the more I read or talk with others, the more I discover different autism stories, told or untold, suggested, disputed, advocated, or denied.

First defined as a "unique syndrome" by Kanner in 1943, it is now estimated that, in the Western world, between 1 and 2 children in 100 have a diagnosis of autism (National Autistic Society) with a Northern Ireland school census reporting numbers to be as high as 1 in 25 (2019/2020 school census).

Diagnosis is impairment and deficit based with the current needing to be observed for a diagnosis to 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.

As the scope and prevalence of autism has broadened, the ethics and construction of its use as a diagnosis has been questioned (Molloy and Vasil 2002, Timimi, Gardener and McCabe 2011, Hassall 2016). Some researchers argued against the benefits of diagnosing or naming someone as autistic if "the cause is not known, it doesn't predict outcome and there is no cure" (Latif 2016, p. 294). A view point challenged by Uselton (2020), a self-diagnosed adult, who said that whilst there is "no medication or treatment" an autism diagnosis can still facilitate "awareness and strategies for living a happy life".

If, as Pearce wrote, "every naming is also a not naming" (2007, p. 100), it could be argued that when we name a group of people or persons as "autistic" then by result we are naming another group of people "not-autistic", with the risk of the binary distinction: "not autistic = normal, autistic = not normal".

The concept of normality, which is required as a marker for behaviours to be described as "outside the norm", is itself 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" (p. 105). Mueller (2020) refers to the idealised "norm" being "unmarked and unnamed, only defined and created by its deviations" (p. 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.

Neurodiversity – A different autism story

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. Milton (2020) explains that neurodiversity 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" and that "all brains to a degree are unique" (p. 3). Whilst it is acknowledged that autism has its challenges, 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.

Ida (2020) claims that in celebrating difference, neurodiversity brings an ability to open up human potential and challenge "crude binaries of being normal, or not" (p. 80). As a concept it challenges ableism (discrimination in favour of people deemed as able bodied) and the view that disability makes someone less or "inferior" (Campbell 2020). It brings its own complexities as, whilst celebrating difference, it is important to be mindful of the challenges that come with being autistic or neurodivergent, both in modern society or in any given context and time. This point is 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 people's way, but it is true that disability can never be disentangled from its social context" (p. 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.

Kapp et al., (2013) found that an awareness of neurodiversity influences how parents experience diagnosis for their child. They found "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" (p. 61). Parents who were aware of neurodiversity were more likely to "endorse positive emotions about autism". Parents with less knowledge of neurodiversity 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" (p. 381).

Autism – power and diagnosis

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" (p. 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, p. 41). This perspective is supported by Williams (2020) who proposes "neuro-constructivism" in which "genes, brain, cognition and environment all interact multi-directionally" (p. 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 (p. 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. They say the grouping of impairments, such as in the diagnosis of autism, "are socially and culturally determined" (p. 16) and "different major groupings of impairments, because of their functional and presentational impacts, have differing individual and social implications" (p. 12). 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 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.

Autism and Girls – "Not different enough"

Historically, autism has been viewed as a male and Western condition or disorder. In 2009, studies reported that boys outnumbered girls 4:1 (Fombonne 2009), with a more recent systematic review of research suggesting a figure closer to 3:1 (Loomes, Hull and Mandy 2017).

A 2013 study found that when girls were given a diagnosis of autism, they were 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)

Baron-Cohen (2002) presented the "extreme male brain theory" to explain the reduced prevalence of autism diagnosis for cognitively able girls, suggesting that autism was an extreme form of maleness. He proposed a different ability in systemising and empathising between male and female brains, with males being better at systemising and females having better innate empathy skills, a difference he highlighted as more pronounced in autistic people. 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 saying that it is "comparable to the claim that, because on average men are taller than women, extremely tall women have extreme male height" (2018, p. 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 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, Gould 2017, Bargiela et al., 2016, Szalavitz 2016, Nasen 2016). Happe (2019) suggests that "what we think we know about autism from research is actually what we just know about male autism" (p. 12) which is also represented in "the media and popular conceptions of autism" (p. 11).

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".

In a study comparing parents' 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 study, 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” (p. 1367). Also, 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 at home (Anderson et al., 2020, Fattigh-Smith 2010, Hiller, Young and Weber 2014, Frazier et al., 2014), with no variation in age when parents first become concerned about their daughter (Begeer et al., 2012). This has 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.

One reason given for girls are not being picked up by teachers and referrers is that they are less likely to identify themselves by isolation from others and they will “mask or camouflage” autistic behaviours (Anderson et al., 2020, 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). 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 is believed to contribute 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).

Despite the potential to mask behaviours, 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, p. 9). The ability to mask and “blend in better” only extends to “looking normal” not “feeling normal” with the impact of “communication and unwritten social rules” still threatening her emotionally (Fattigh-Smith 2010, p. 55).

Studies focusing on the experiences of mothers to autistic girls identify “unique challenges” due to “female specific social pressures” (Fowler and O’Connor 2020, p. 2), “scepticism” (Navot et al., 2017, p. 538), and diagnostic delay (Fowler and O’Connor 2020, Navot et al., 2017). Anderson et al., (2020) found that the mothers they interviewed had an “early sense of something being different” about their daughters but “most did not arrive at autism as the explanation for this difference” (p. 1549), again highlighting the important role of professionals in raising autism as a possibility. Navot et al., (2017) found that even after delays in receiving a diagnosis for their daughters, the mothers of autistic girls were twice excluded due to “a sense of exclusion from the neurotypical population and male dominant ASD population”. However, studies have also highlighted many benefits to the diagnosis including the mother’s pride in their daughters (Fowler and O’Connor 2020), an increase in empathy and understanding (Anderson et al., 2020), and a re-shaping of maternal competence and the creation of a “different bond” (Navot et al., 2017).

Due to my own clinical observations and the growing body of research about a male bias in how autism presents, how it is identified, and how it is diagnosed, I chose to focus on the diagnosis of girls in my research. Having worked in a diagnostic pathway I was curious about how mothers experienced the diagnostic journey. With girls less likely to be identified by practitioners and teachers, and reports of challenging behaviours at home, I was curious about how mothers experienced the diagnostic journey. Did they feel their concerns were not taken seriously or that professionals saw them as exaggerating (which I suspected to be the case)? Did they feel their daughter's diagnoses were delayed and protracted and importantly, once given, did they feel that the diagnosis brought the understanding and support that they had hoped for?

Autism and Communication

As a systemic therapist I have always been interested and informed by the Co-ordinated Management of Meaning (CMM). Pearce (1999) said that "CMM acts on the assumption that language is fateful" and that the stories we tell, or that are told about us "prefigure and/or constitute the lives we lead" (p. 42). He said that 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 also "programs us to fit predetermined niches within those societies and prefigures problems as well as opportunities". He suggests that "change can be brought about by a process of re-authoring our stories" (Pearce, 2007, p. 11).

As a researcher I wanted to explore about 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). Did the diagnosis re-author the stories about the mothers and their daughters in a way which was useful and purposeful (opportunities), or did it bring problems (constraints)? Or did it bring with it both opportunities and constraints?

The mothers

Conducting semi-structured interviews, I met with 12 mothers, who had been recruited via a local Autistic Girls Parenting Group.

All the interviews were transcribed and reviewed via thematic analysis. First, I looked for general themes, and then I revisited the themes using CMM as a lens to look for stories, both lived and told, by the mothers, and how they represented the potential opportunities and constraints of their daughters' autism diagnosis, both perceived and experienced. (I would thoroughly recommend that any researcher completes transcription themselves as it was a way of reconnecting with the interviews and the precious stories so generously shared by the mothers in my study).

The mothers' stories

My review highlighted several themes. The themes identified a number of perceived and/or experienced affordances or constraints as experienced by the mothers informed by their lived experience, and also by their perceptions and their "perception of the perceptions" of others.

As I share the themes, which I have amalgamated for the purpose of this paper, it is important to be mindful that the attendance of the mothers at the Autistic Girls Parenting Group is likely to have had a significant impact on the themes highlighted in my study. The group was run and facilitated by adult autistic women and advocates, also mothers to autistic girls, who promoted a positive view about autism and who advocated strongly autistic women and girls.

Perceived Constraints - Myths and Stereotypes

Throughout the study I was struck by the power of societal myths and stereotypes about autism and how these influential “stories told” informed the lived experience of the mothers. Most of the mothers spoke with me about how, prior to the diagnosis of their daughters, they had understood autism as something which mostly affected boys. Rainman was often mentioned as something which informed their early understanding and there appeared to be a general belief at this early time that an autistic person would have learning difficulties and present with extreme and obvious behaviours or difficulties. For a few mothers there was also an earlier view, gained from society, that autism was something not nice or even nasty. Whilst there was an awareness that something was different with their daughters’ development or behaviour, the majority of the mothers had not considered autism as an explanation, or they had discounted it due to their daughters’ behaviours not fitting their understandings of what autism was and how it presents. These early views and understandings changed significantly for all of the mothers after their daughters’ diagnosis, as you will see in later themes.

The mothers spoke about their frustration when raising concerns about their daughters’ development. This included feeling professionals were “fobbing them off”. There was also a sense of blame, either due to the feeling that others were blaming them for poor parenting, or due to self-blame and questioning why they could not make things better. For the mothers of two girls, diagnosed at 17, there was also a deep sense of sadness and lost opportunity. Both girls had been diagnosed after extensive contact with Child and Adolescent Mental Health services and had experienced a number of educational, emotional, and mental health challenges. The mothers questioned if these challenges would have been as significant if their daughters had been diagnosed, with their needs better understood, much earlier. These early challenges in being heard, or having concerns recognised, suggested that professionals too had specific ideas about what autism was, or what it was not, and that it was not just the mothers whose views of autism were informed by certain myths and stereotypes about what it meant to be autistic.

Whilst the mothers described a challenge in being heard and accessing support, there was also a fear that any support received as a consequence to an autism diagnosis would be done so at a cost. The diagnosis, whilst seen as an enabler, was coupled with a worry that their daughter would experience prejudice and stigma, both in the present and in the future. I believe this is because, even when their early beliefs changed significantly, they were aware that the views of others would still be informed by the same myths and stereotypes that they once held, and that they could make incorrect assumptions about their daughters.

Perceived Affordances - The hope for answers

The mothers described an awareness that their daughters had been developing differently to their peers, either socially, emotionally, or behaviourally. They told me they had felt something “was not right” but they were not sure what that was.

It was this questioning about what was happening, and the search for answers, that ultimately led to the assessment and diagnosis for their daughters as well as a hope that they would receive some help and support. This included support at school, and a belief that there would be more specialised support available for their daughters as a consequence of a diagnosis.

Experienced Constraints - Feeling shocked and overwhelmed

The mothers told me they had experienced confusion and upset early in the diagnostic journey, due to the way in which professionals had raised the possibility of autism, the impact of waiting times, the focus on impairments and the language used in the diagnostic process.

After the long journey to assessment, and after a diagnosis was given, the mothers described feeling shocked, overwhelmed, and isolated. I believe this was, in part, informed by myths and stereotypes held about autism, the language and focus on impairments in assessment and the way in which the diagnosis shifted their views of what was and what might now be. I was also told that whilst they were making so many adjustments in their understandings of their daughters, they felt they were just left with a piece of paper and no one to talk to.

After the long, and sometimes protracted, journey to diagnosis the mothers still described battles in getting the support and acceptance they had hoped for. This included a lack of acceptance and understanding from family, friends, professionals, and other parents. The most frequent references, made by 7 of the mothers, were about grandparents questioning the diagnosis. This had a profound impact on their support systems, as it was often those they would turn to for support, such as their own mothers, who were questioning the validity of the diagnosis. This in turn made them feel their own parenting abilities were still being questioned. When accessing professional support, via services such as CAMHS, even if the diagnosis was accepted, some of the mothers described a sense that their daughters’ 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.

When support was available the mothers told me that much of it appeared to be boy focused. One mother even noted that when support was available for her daughter the emphasis seemed to be that her daughter should change in order to fit in. In other words, she needed to learn to be “less autistic”.

If I stopped here, you could easily question the benefit of an autism diagnosis, supporting the proposal by Latif (2016) that it brings little benefit. These themes, informed by societal stories, relationships with professionals, diagnostic narratives and relationships with others weave together to create a specific story. Whilst the mothers hoped the diagnosis may bring some help, support and understanding, the stories shared were ones of confusion. They focus on impairment, stigma, and stereotypes, lack of understanding, lack of support, and an overall sense of loss. Even when a diagnosis was given, it was questioned by people they loved. The mothers were left confused, and autism was even experienced as a barrier to accessing support. Why would anyone pursue such a thing if this is what it brings, especially if the diagnostic boundaries, relevance, and existence of autism as a “thing” is in question?

Experienced affordances - The Aha Moment!

For the mothers I spoke to, despite concerns, their experience of the assessment and diagnosis process and the perceived scepticism of others, there were experienced affordances to diagnosis. The most prevalent of all the themes was the new understanding that was brought about when they were told their daughters were autistic. This was described by one mother as the “ah – moment”:

> *“I think the main one is just to finally understand and go ‘ahh’. The ‘ah’ moment the ‘aha’…. 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…. you’re more likely to be able to respond to things with patience, understanding and.. benefit.” (Sharon).*

The mothers described a form of “new knowing” about their daughters, a new understanding of their needs and behaviours. Actions which once made no sense were now understood in the context of an autism diagnosis, such as sensory sensitivities, behaviours driven by social anxiety, a need for routine and a difficulty in managing change or new situations. This new knowing led to new forms of acting and being with their daughters. The mothers told me they had become more tolerant, understanding, and accepting of their daughter’s behaviours. Their daughters’ diagnosis had led them to adjust their approach to parenting. This included the adoption of specific strategies, “shaking up the rules”, less comparison with others and giving themselves permission to do things differently. They were no longer restricted by perceived societal “oughtisms”, the belief that you “ought to do something” or “you ought to act in a certain way” (Evans 2020, p. 63), about how parenting “ought to be”.

The diagnosis also acted as a form of validation, both to the mothers themselves and to others, about their daughters’ needs, even if it wasn’t accepted at times. They told me how the experience of the diagnosis as something tangible and official, enabled and empowered them to push for more support where it was needed, and where they had perhaps felt they were not listened to before. This included negotiations with their extended family about what to expect and how to be around their daughters.

The mothers’ understandings about autism also changed. Prior to their daughters’ diagnosis, it seemed that autism was seen as a “fault” within a person, something potentially shameful with negative connotations. They now told me of the many wonderful things about their daughters that they felt were part of them being autistic. These new positive autism narratives appeared, in part, to be informed by the support they had received from the autistic girls’ group which was run by autistic women. Autism was no longer seen as an internal problem to be fixed, the problem was now external to their daughters in a society that was not accepting of their differences and was not supportive of their needs.

Research Summary

I believe my research gave a useful insight into the lived experience of mothers of autistic girls. Constraints to diagnosis were fuelled by societal myths and stereotypes, variable levels of support and the negative focus of the diagnostic process. They did however share many affordances to diagnosis, most importantly due to a better understanding of their daughters’ needs and a reframing of their behaviours in the context of autism as well as a reframing of autism itself.

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 mothers 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, including 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.

All the mothers reported that the diagnosis brought support from others, including schools, however 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”.

What if he were a she and other stories - A cautionary tale

Before I conclude I’d like to raise a word of caution. Research such as mine can be useful, but it should be interpreted wisely. Yes, we have become more aware of how autism may present differently in girls, but we should also be careful not to create binary distinctions between “male autism” and “female autism”. As highlighted by Strang et al., (2020) “characteristics that have been associated with a “female” versus “male” version of autism are not isolated to one sex or gender” (p. 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 (p. 9).

If the study of “females and autism” leads to a theory about “female autism” and the development of “female” diagnostic tools, then this brings with it the risk of excluding autistic males, or non-binary or trans people, who camouflage and don’t fit with traditional autism stereotypes. A potential risk I saw lived out in practice when working in a diagnostic pathway. Our knowledge of “female” autism increased but we also saw boys who differed from the male autism stereotype and presented with similarities to autistic girls. When this occurred, I would ask my colleagues “What if he were a she?” With more awareness, understanding and fluidity about gender and identity for some we will also need to ask the question what if “they” were a she? If diagnostic tools and categories become separated and fixed to gender stereotypes this carries the risk of further missed or miss-diagnosis beyond that we have identified for autistic women and girls.

We must also be mindful of further identities within identities, or the multiple identities held by autistic people and/or autistic women. The influence of different identities will have varying influence at different times and within different contexts. In reference to intersectionality Saxe (2017) highlights those identities “interact with one another” (p. 154) in such a way that there is not one static overarching identity. Crenshaw (1989) introduced intersectionality as a way to consider the impact of black women not being male, but also not being white. For black women who are autistic there is the added complexity of not being neurotypical. The majority of the girls in my study were from a white middle class background but the mothers still highlighted significant challenges in the identification and diagnosis of autism, and in accessing further support once the diagnosis had been made. What challenges would the mothers and their daughters have faced if they were black or from minority ethnic backgrounds? What if they were from different social economic backgrounds? Myths and stereotypes about different social, economic and ethnic groups will also have a part to play in the identification, diagnosis and lived experience of autistic people and their families, not just myths and stereotypes about gender and autism itself.

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