

Perceptions and experiences of UK-based mothers of autistic daughters in relation to the potential affordances and constraints of an autism diagnosis

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Abstract

Whilst there is a growing body of research about autistic girls, much less is known about the experience of mothering an autistic girl, and the potential impact of the diagnosis. This study qualitatively explored the diagnostic journey of 12 mothers in the UK to identify the meanings attributed to their daughter's diagnosis. A thematic analysis was applied with themes examined through the lens of the CMM LUUUUTT model to further explore the stories lived and told by the mothers. Eighteen themes linked to perceived affordances, perceived constraints/constraints of perception, experienced affordances and experienced constraints. Participants highlighted the impact of autism myths and stereotypes which influenced identification, referral, diagnosis and ongoing support for the girls. Myths and stereotypes told about autism also played a significant role in the mothers lived experience of the diagnosis. An affordance of diagnosis was a new understanding about their daughters' needs, which led to new parenting styles, letting go of blame and resisting perceived societal 'oughtisms' about how parenting should be. Whilst the diagnosis was seen as relationally transformative, challenges were described in accessing emotional or educational support for their daughter's post-assessment.

KEYWORDS

autism, daughters, diagnosis, parenting, stigma

INTRODUCTION

The quality of all stages of the autism diagnostic journey is key for the well-being and support of autistic people and family members. However, autism research has long highlighted dissatisfaction with all stages of the assessment and diagnostic process, including delayed referrals, long and increasing waiting times, the experience of the

assessment process itself and the lack of post-diagnostic support (Crane et al., 2018; Crane et al., 2015; Jacobs et al., 2019; Russell, 2012; Smith-Young et al., 2020). Professionals' initial response can also prevent or slow down the process particularly if a passive or incorrect rejection of the assessment request is observed by the autistic person or parent/carer requesting support (Lockwood Estrin et al., 2020; Makino et al., 2021; Wei et al., 2021). Parents

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have reported not feeling heard (Boshoff, 2019) and feeling that they need to ‘build a case’ to professionals who are experienced as gatekeepers to their daughters’ referrals with a variation in how their concerns are acknowledged (O’Reilly et al., 2017, p. 69). Once a referral is made and the waiting time is finally concluded, parents have reported that the experience of the assessment itself can be overwhelming and isolating due to the focus on negative behaviours and the deficit-based language used (Jacobs et al., 2019; Potter, 2016). It has been suggested that more work could be done to prepare parents for these potential reactions to their child’s diagnosis (Legg & Tickle, 2019) which includes a range of mixed emotions including relief, shock and despair (Jacobs et al., 2019, Legg & Tickle, 2019, Potter, 2016; Smith-Young et al., 2020).

To receive a medical diagnosis of autism, an individual must meet two core criteria described in the DSM-5 TR (American Psychiatric Association [APA], 2022) and ICD-11 (World Health Organisation, 2019). As stated in the DSM-5 TR (APA, 2022), these include ‘persistent deficits across three areas of social communication and interaction including reciprocity, non-verbal communication, and developing and maintaining relationships’, and ‘two of four types of restrictive behaviours, including stereotyped behaviours, insistence on sameness, fixated/unusual interests and hyper or hyperactivity to sensory input’ (APA, 2022). The terminology used in diagnostic manuals is based on the medical model (i.e. deficits/impairments/disorder), and as such adopts deficit-based language which fails to reflect the many societal challenges and stigma faced by autistic people and their families (Almog et al., 2022; Farrugia, 2009; Nealy et al., 2012; Russell & Norwich, 2012). The neurodiversity movement (Botha et al., 2024) however, does reflect these challenges and has helped to produce a gradual shift in understanding about autism and what it means to be autistic through listening to the voices and experiences of autistic individuals. Whilst acknowledging the many difficulties autistic people may face, neurodiversity also celebrates difference and challenges ‘crude binaries of being normal, or not’ (Ida, 2020, p. 80). An awareness of neurodiversity has been identified as a positive factor in influencing how a parent will experience a diagnosis for their child (Kapp et al., 2013), including an ability to challenge societal stereotypes or ‘oughtisms’ (Evans, 2022; Evans et al., 2019; Simon, Evans et al., 2020) about what behaviours are correct or acceptable for them as parents or for their child. This in turn can have a positive impact on family relationships, particularly between a parent and their autistic child (Navot et al., 2017).

Girls have been identified as experiencing longer delays in identification, referral and subsequent diagnosis

than their male counterparts (Gesi et al., 2021; Leedham et al., 2019; McCrossin, 2022; Wassell & Burke, 2022; Wayman, 2020). This delay is in spite of mothers having an early awareness that something is different about their daughters (Anderson et al., 2020). Once a diagnosis is given there can still be scepticism (Anderson et al., 2020; Navot et al., 2017) and disbelief from professionals (Anderson et al., 2020), or family members (Dallos, 2019). Whilst lack of support post diagnosis has been raised for all autistic children and their families (Jacobs et al., 2019; Potter, 2016; Weale, 2020) mothers of autistic girls can experience ‘a sense of exclusion from the neurotypical population and male dominant (autism) population’ (Navot et al., 2017) due to the male focus of information and support services. Mothers are vulnerable to experiencing blame, stigma and judgement, regarding their daughter’s difficulties (Anderson et al., 2020; Farrugia, 2009; Wayman, 2020), with their ability to parent questioned. Once a diagnosis is given research has highlighted a shift in parental narratives about what it means to be autistic from negative to celebratory ones (Fowler & O’Connor, 2020; Sanchez, 2019). New understandings informed by the diagnosis have been shown to have a transformative effect on mother–daughter relationships, as well as a positive impact on mothers’ own identities as a carers and advocates for their daughters (Anderson et al., 2020; Fowler & O’Connor, 2020; Navot et al., 2017). This benefit includes reauthoring their narratives about autism from negative to celebratory ones.

Educational staff and community providers have been identified as less likely to correctly identify autistic girls due to their perceptions about autism and an apparent limited knowledge about the presentation of autism for girls (Hill et al., 2020; Hiller et al., 2014; Lockwood Estrin et al., 2020). Whilst autistic girls’ behaviours may be less evident, or visible in school (Anderson et al., 2020), research has highlighted more aggressive and externalising behaviours in the home (Anderson et al., 2020; Hiller et al., 2014). This lack of knowledge about autism and girls, combined with behaviours being more apparent in the home environment can act as a barrier (Anderson et al., 2020; Fowler & O’Connor, 2020; Whitlock et al., 2020). Consequently, mothers’ reports of difficulties potentially lack corroboration from school and risk being 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.

Once a referral for an autism assessment is made, the assessment tools available to assessing clinicians have been identified as having a male bias (Evans et al., 2019; Haney, 2016). Autistic girls may also be susceptible to later or missed diagnosis because they score better on

TABLE 1 Participant characteristics.

Mothers pseudonym	Ethnicity	Marital status	Employment status	Daughters pseudonym	Private or NHS assessment	Age at diagnosis	Age at time of interview
Sarah	Indian	Separated	Self-employed	Rachel	NHS	5	8
Amy	W.UK	Married	Part-time	Liz	NHS	17	18
Caroline	W.UK	Married	Self-employed	Emily	Private	6	14
Diane	W.UK	Married	Part-time	Samantha	Private	7	13
Karen	W.UK	Married	Part-time	Helen	NHS	10	12
Victoria	W.UK	Married	Full-time	Danni	NHS	10	11
Sharon	W.UK	Married	Self-employed	Louise	NHS	17	18
Jennifer	W.UK	Married	Self-employed	Tanya	Private	10	13
Barbara	W.UK	Married	Part-time	Chloe	Private	7	10
Molly	French	Married	Self-employed	Jane	NHS	4	9
Laura	W.UK	Married	Self-employed	Fiona	NHS	8	14
Lindsey	W.UK	Married	Full-time mum	Pam	Private	10	12

reciprocity scales (Backer van Ommeren et al., 2016; McCrossin, 2022), present with a wider range, or more 'usual' range, of interests than autistic boys (Hull et al., 2020), are less likely to identify themselves by isolation from others and due to masking or camouflaging autistic behaviours (Hull et al., 2020; Wood-Downie et al., 2020). The ability to mask and 'blend in better' only extends to 'looking normal' but not 'feeling normal', with the impact of 'communication and unwritten social rules' still emotionally threatening (Fattigh-Smith, 2010, 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; Cassidy et al., 2019).

Whilst previous studies have explored parental experience of autism diagnosis and waiting times (Crane et al., 2018; Crane et al., 2015; Jacobs et al., 2019; Legg & Tickle, 2019; Potter, 2016; Smith-Young et al., 2020), little is known about mothers' experiences and expectations in relation to the diagnostic process for their autistic daughters. To address this, the current study aimed to address the following research question: What are the experiences of mothers of autistic girls in relation to the affordances and constraints they perceive during the diagnostic journey? In this context, 'affordances' refers to the beneficial aspects that facilitate a smoother diagnostic process. For example, this could include clear communication or access to timely and accurate information. On the other hand, 'constraints' refer to the limitations or obstacles that may have made the diagnostic process more challenging. For example, systemic issues such as long waiting times as well as the negative impact from stigma.

METHOD

Participants and procedures

Mothers were purposefully sampled via a local Autistic Girls Parenting Group located in South East England. The Autistic Girls Group, established by a local parenting group in 2016, includes education and healthcare professionals, and the organisation of events where autistic girls are given a platform to present their experiences of being autistic to their parents. Twelve mothers were successfully recruited and interviewed (see Table 1). The mean age of diagnosis for the participants' daughters was 9.25 years ($SD = 13$ years). The mean age of the daughters at the time of the study interviews was 12.66 years ($SD = 10$ years). Participants were predominantly of White British ethnicity ($n = 10$), married ($n = 11$) and were self-employed ($n = 6$) or worked part time ($n = 4$). Please see Table 1 for a full breakdown of participant background characteristics. The mothers and their daughters have been given pseudonyms to protect anonymity.

Recruitment occurred via the dissemination of a flyer to the group's email (with permission). The eligibility criteria were mothers of girls who were diagnosed as autistic, who are verbal and who were attending or who had attended mainstream school. This criterion was chosen due to research suggesting that cognitively able girls take longer to be identified for referral and assessment (Ratto et al., 2017) which would likely have an impact on mothers' experiences. Mothers whose daughters had only recently been diagnosed were excluded due to the emotional nature of the diagnosis.

TABLE 2 Interview schedule.

Question number	Question	Prompts
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?	How?
3	Could you please tell me a little about why you first sought and autism assessment for your daughter?	What or who led to you making this decision? Did you feel that you had a choice?
4	What did you think a diagnosis would help with?	Why?
5	Before your daughter's assessment and diagnosis did you have any concerns about what it might mean?	What made you think this?
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?
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?
8	Is there anything you know now which you wish you'd 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?
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?

Data collection

Semi-structured one-to-one qualitative interviews were conducted face to face with all participants. Interviews were mutually agreed to be conducted in participants' homes to ensure participant comfort and confidentiality. Questions were not provided prior to the interviews, however the nature of the questions was discussed in a telephone call when the interviews were arranged. The interview schedule (see Table 2) was constructed on the basis of the relevant background literature, as described in Section 1. The schedule was further refined and finalised following a pilot interview conducted with an autistic mother of two autistic girls (the data from which is not included in the current study). This pilot interview allowed for the practical applicability and relevance of the interview questions, as informed by the literature, to be assessed and adjusted as necessary to better suit the study's objectives. Interviews took place between August 2019 and February 2020, and ranged from 36 to 83 min (mean duration = 61 min).

Ethics approval was obtained from the University of Bedfordshire Institute of Applied Social Research Ethics Panel in March 2019. The study followed General Data Protection Regulation (GDPR) ethical guidelines and principles (Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016). This included obtaining informed consent for participation, audio recording and publication via a Participant

Information Sheet and Consent Form. To safeguard the well-being of participants, a comprehensive distress protocol was established prior to the commencement of interviews. To ensure the well-being of participants, a comprehensive distress protocol was in place throughout the interview process. If a participant showed signs of emotional distress, the interviewer had the choice to pause or, if necessary, terminate the interview. Following any such interruption, a confidential discussion was held with the participant to assess their emotional state. Based on this dialogue, a decision was collaboratively reached to either reschedule the interview for a later time or discontinue it altogether, as deemed most appropriate for the participant's well-being.

Data analysis

Interviews were transcribed verbatim from audio recordings and then analysed using thematic analysis (via NVivo 12). This process, following the recommendations of Braun and Clarke (2006) and Nowell et al. (2017), involved the following steps: (1) data familiarisation; (2) coding; (3) initial theme generation; (4) theme review; (5) theme definition/naming; and (6) writing of results. In line with this, themes were initially developed from the data inductively so to allow for mothers' voices to be heard on 'matters that matter' for them. The analysis was then conducted using the 'LUUUUTT' model

TABLE 3 Identified main and sub-themes.

Main and sub-themes	No. of participants who contributed to theme
Main themes	
Perceived constraints (constraints of perception)	
• Autism as other: Myths and Stereotypes	12
• Autism as other: 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	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 'Aha' moment – diagnosis 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
Other	
• Emotional and mental health	12
• School challenges (pre-assessment)	12
• Advice to other mothers and service providers	12

(Pearce, 2007) 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 assessment and subsequent diagnosis. LUUUUTT is an acronym for (1) Staories Lived, (2) Unknown Stories, (3) Untold Stories, (4) Unheard Stories, (5) Untellable Stories, (6) Staories Told, and (7) Staories Telling (Pearce, 2007). LUUUUTT sits within Co-ordinated Management of Meaning (CMM), a social constructionist framework and methodological lens described by Pearce (1989, 2004, 2006, 2007). To utilise the LUUUUTT model as lens for analysis, initial data and the themes generated in NVivo were reviewed in detail to identify the stories within that data and what influence they had on the mother's lived experience of their daughter's diagnosis. This included lived experience such as changes in their actions and day to day lives as a consequence of the diagnosis, or the

impact of stories told such as myths about autism and what it means to be autistic.

Several steps were taken to maximise trustworthiness of the social validity of the interview schedule and analysis. These included obtaining retrospective feedback from the participants to ensure the accurate capture of their experiences. This involved inviting all participants to review and comment on the analysis and findings. Eight mothers agreed to participate, with four of them subsequently providing in-depth feedback that confirmed the accurate representation of their views and experiences. Additionally, a randomly selected sample of transcripts ($n = 6$) was independently reviewed by a second coder, which resulted in similar interpretations. Any initial conflicting points of interpretation were resolved through a consensus-building process, which entailed joint review and discussion of the conflicting points of interpretation until agreement was reached. The team adopted a

reflexive approach to ensure that any personal biases and assumptions were reflected upon and appropriately managed through debriefing and discussion. An audit trail of all research activities was also produced.

Community involvement

A pilot interview was conducted with a mother, herself also autistic, of an autistic daughter, in order to gain feedback about the suitability, relevance and clarity of the questions and overall approach. Additionally, the relevance of the research question and the suitability of the approach were discussed with a group of senior members from the London Autism Group Charity, comprising autistic adults of different genders and autistic parents of autistic children. Their collective feedback affirmed the importance of the study's focus and approach, and no significant changes were suggested. This consultation with the charity provided a broader perspective and ensured that the study design was informed by the experiences and insights of the autistic community. Two of the co-authors are also parents of autistic children, further enriching the study with lived experiences and varied perspectives.

RESULTS

Five main themes were identified (see Table 3). This included 'perceived constraints', 'perceived affordances', 'experienced constraints', 'experienced affordances' and 'other'.

Main theme 1: Perceived constraints

Autism as other – Myths and stereotypes

Many participants indicated that the topic of autism was something 'not talked about' in their family or social groups and it was not seen as relevant to them prior to their daughter's referral. What they did understand about autism was informed by the media that fuelled stereotypes, including the news, books and films.

...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.
(Lindsey)

All participants 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 or overtly unusual behaviour.

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)

Participants also described a belief, either held themselves, or that they perceived to be held in society, of autism as something with negative connotations attached.

...my perception of all of that was generally negative comments about it, (...) my feeling was that autism was not a good thing (...) a 'not a good thing label'. (Barbara)

Autism as other – 'The two didn't join up'

Whilst participants described '*knowing there was something*' they did not consider autism as a possibility at first, and information gathered from early research did not fit with how they viewed their daughters.

...it wasn't a denial thing, it was because I didn't think she'd fit the typical criteria (...) from what I started to read she just didn't quite fit. (Sarah)

Borderline 'Normal' – Professionals not identifying autism

Participants shared that education and health professionals were of the view that their daughters would grow out of the challenges, that they were 'fine' or that they were 'borderline normal'. Participants felt 'brushed' off and left to question themselves. For some, this also led to a sense of sadness and lost opportunity:

I was (.) often saying (.) 'things don't seem right, Pam's really bright but (...) 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. (Lindsey)

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'. (Sharon)

For some mothers, this included their GP discounting autism and not referring their daughters on for an assessment. Another participant sought an assessment through a private practitioner in 2010. She was told that her daughter, Liza, was 'borderline normal' and it was another 10 years before Liza was diagnosed in 2019:

...in 2010, but we did have this lady that came, (.) she did a conversation with us, she did a conversation with Liza (...) that's when she came up with her 'it's borderline normal'. (Amy)

Worry: Stigma, prejudice and the future

Many participants feared that a diagnosis may lead their daughters to being negatively labelled which may damage that their futures. Connections were made between the beliefs they held about autism prior to diagnosis and a belief that others may see autism in the same way.

I still worry about people making assumptions about her (.) that this label becomes before her. That people see the label and then (.) don't bother to understand her. (Molly)

For one participant, it was the 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)

Main theme 2: Experienced constraints

Confusion and upset (pre-diagnosis)

Participants highlighted negative experiences with how the possibility of autism was raised, the wait for the assessment and the focus on impairments during diagnosis:

You sit and wait for two years with no input or whatever, and that was horrible. The process of diagnosis was not positive, because of how the diagnostic interview is which is wholly focused on their difficulties and impairments. (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. (Lindsey)

'Too-da-loo' – Feeling lost and unsupported (post-diagnosis)

Participants felt overwhelmed, shocked and isolated immediately after diagnosis with a sense of being left hanging. This was influenced by the impairment focus of assessments and pre-existing myths, stereotypes and 'stories' held about autism:

From then on it was pretty much like 'too-da-loo' um, here's your piece of paper. I do remember having a little weep myself. Mainly from reading the statements made about her by, and from school, and things like that, were actually quite upsetting. (Barbara)

You kind of got the label and were left hanging, that was it. (Jennifer)

Diagnosis not accepted or understood by others (post-diagnosis)

Following assessment, many found that others did not understand or accept their daughter's diagnosis, this included other parents, professionals and extended family members, particularly grandparents:

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

(He said) these children they don't have (.) autism (...) It's just a convenient category they're putting people in because everybody wants to label everything. (Lindsey)

Support challenges (post-diagnosis)

Challenges with accessing support for their daughter, post-diagnosis, and across education and mental health contexts were described. Some felt 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 were a barrier:



We weren't able to access that help because she's 'not broken enough'. (Barbara)

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

Main theme 3: Perceived affordances

Here she is again – Feeling blamed on parenting

Participants also felt blamed by others for their daughter's difficulties, either due to poor parenting, or being over-protective. A perceived affordance of diagnosis was that it would protect from blame and validation of their concerns.

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. (Caroline)

This led to a feeling that they were seen as an inconvenience at school as well as self-blame as they questioned why they could not make things better:

I did get an email back from the Head of year who suggested it was 'all' to do with home (...) it was one of those emails that make you think, 'mm, they're blaming us'. (Karen)

Some participants 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)

Seeking an understanding

Participants described an awareness that their daughters were developing differently to their peers which brought them to search for answers:

'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 (.) it's too busy (.) I don't like the playground, I don't like

going outside...In my mind I thought, well something isn't, right'. (Lindsey)

For some, the differences became more apparent as their daughters got older:

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)

Hope – Seeking help and support

Participants hoped that an assessment would bring the affordance of help and support including a belief that there would be more specialised support.

I think in my head was quite a medical kind of model where if you get a label or a diagnosis then that automatically follows on to what you do about it. (Jennifer)

School-based support and a better understanding of needs were also drivers for assessment:

Things can be put in place for her, in school, and that means she gets the help that she needs (...) and understand her better, and for her to understand herself better, that's what I wanted from a diagnosis. (Amy)

Main theme 4: Experienced affordances

The 'aha' moment – Diagnosis bringing a new understanding

For many, the diagnosis brought new understandings about their daughters, including sensory processing, executive functioning and masking in girls, which facilitated greater familial tolerance and understanding:

Now you can go all the way back and you can go 'ah', it's the 'aha' moment...because you have the understanding [so] you're more likely to be able to respond to things with patience, understanding. (Sharon)

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)

Evidence and validation – To self and others

The diagnosis also acted as validation, to themselves and others, about their daughters' needs given they now possessed something tangible and official:

I've [now] got much better at asserting myself with school...of being able to go in and say 'right, my daughter is autistic'. (Laura)

Well, you've got the official diagnosis...so because that's there, it's not as easy for people to fob you off. (Victoria)

The diagnosis also helped reduce self-blame:

It stopped us assuming that we were terrible parents. It [also] made it easier for us to accept Tanya as she is and to help her sister understand not to take it personally. (Jennifer)

Diagnosis brought support

For some, the diagnosis brought support including helpful courses and groups, access to information and support from school and other parents:

So, actually the label, kind of at least made sure she was on the SENCO's radar. (Diane)

I've read lots of books, I'm signed up to a couple of charities and get their newsletters and things so, we're getting a fairly steady stream of information...And of course I'm connected up with other parents. (Jennifer)

Laura said she received support from a charity but not from CAMHS, whilst Sharon had found CAMHS support helpful:

What did I hope for was not provided for by CAMHS, but provided very strongly by the charity group we were signposted to. (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. (Sharon)

'She owns it' – New and positive autism narratives

This theme captures the significant shift in the narratives of many participants away from autism as impairment and towards something more positive:

[My understanding] changed in every way. I suppose that all children with autism are different and that spectrum encompasses Jane and the way she is. (Molly)

Autism and neurodiversity was seen as enabling with many strengths, and that challenges stemmed from society and not within their daughters:

We sort of talk about it as being a kind of superpower...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. (Lindsey)

Diagnosis informed parenting

All participants described a change in their parenting style including giving themselves permission to do things differently:

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

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

Diagnosis helped the family and family relationships

Participants described the diagnosis as helping family relationships. This included others in the family being 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.

The family joked that [dad] was autistic for years. And then [afterwards, he] wrote us this long letter saying he'd never been

happier in his life, because then when he realised that he's autistic. (Laura)

'It's brought us closer together because I'm constantly having that dialogue with her. (Caroline)

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. (Barbara)

Main theme 5: Other

Emotional and mental health

Participants raised concerns about the emotional and mental health of their daughters throughout the diagnostic journey. These concerns informed the mothers desire to understand and help their daughters:

She was diagnosed with depression and anxiety...after a suicide attempt. She was then treated for depression and anxiety...So, then you go 'ok...what's underlying, so what's the root cause of this? (Sharon)

School challenges (pre-assessment)

All participants described struggles at school for their daughters pre-assessment including difficulties in attendance and peer group difficulties:

I think a lot of the teachers considered her lazy. (Amy)

She was too big to kind of like manhandle, it was like trying to force somebody into a burning building. She just, could, not, go [to school]. It was just heart breaking to see. (Lindsey)

Advice to other mothers and service providers

Participants had two key areas of advice for other mothers in similar situations. First, they felt other mothers/parents should join groups to connect with other parents so to feel less alone and to hear and share advice:

Talk to as many people as you can. There's lots of things out there and information. It can be overwhelming and it's better sometimes just to talk to people. (Amy)

Second, they encouraged other mothers not to wait for an assessment or diagnosis to read or learn about autism, so positive changes can come made sooner:

Don't wait, don't pin your hopes on diagnosis. If there is any suspicion just go out there and educate yourself. You've just got to, it's trial and error until you find your way. (Sarah)

Participants also wanted professionals to be more mindful of the emotional journey parents experience during diagnostic process, and that compassionate support should be provided at all stages:

Don't underestimate the extent to which this is a big deal for the family...Just the extent of the newness and unfamiliarity of it and therefore what a big deal it is to cope with. (Jennifer)

DISCUSSION

The findings of this study revealed a range of experiences related to perceived affordances and constraints at the pre- and post-diagnostic stages for the mothers of autistic girls. Participants described 'not coping' and lacking in clarity over why their daughters were developing differently to their peers, resulting in frustration and confusion. Assessment and diagnosis were seen as a means to resolving this, as well as to access help and support. However, whilst the participants sought an assessment to gain some clarity and support, they described a battle in having their concerns heard with professionals' perceptions about autism, and, in particular autism and girls, acting as a barrier to referral. These early challenges and barriers are consistent with the finding of previous research (Anderson et al., 2020; Fowler & O'Connor, 2020; Whitlock et al., 2020). These findings draw attention to the importance of increasing referring professionals' knowledge about autism, and in particular autism and girls.

Findings highlighted a tension between viewing a diagnosis as a means of gaining support (a perceived affordance) and fearing that a diagnosis may bring stigma (a perceived constraint). This fear, also identified by others (Almog et al., 2022; Nealy et al., 2012; Russell &

Norwich, 2012), remained for mothers' post-diagnosis despite positive shifts in their own understanding about autism. Linked with this were the experiences of feeling blamed and seen as responsible for their daughter's difficulties. This was compounded by their daughter's difficulties often being more pronounced in the home and masked in school. For some, these experiences motivated mothers to seek diagnosis so not to be seen as 'bad parents of naughty children' (Farrugia, 2009).

Participants also described a variety of experienced affordances related to the diagnosis. 'Just knowing' the diagnosis was in itself helpful; however, more significantly, it had a transformational impact on the narratives and perceptions surrounding their daughters' needs and behaviours. Of particular benefit was an increased awareness about anxiety, sensory processing and executive functioning, as well as their daughters' need to mask. This accompanied a change in their understanding of autism itself, including an increased awareness of neurodiversity. Similar to Fowler and O'Connor (2020) and Sanchez (2019), improved understanding led to mothers reauthoring their narratives about autism from negative to celebratory ones. These new understandings led to new parenting styles. This included mothers 'shaking up the rules' as they learnt to parent their daughters according to their individual needs and moving away from focusing on what they 'ought' to be doing. This letting go of 'oughtisms' (Evans, 2022; Evans et al., 2019; Simon, Evans et al., 2020) resulted in less comparison with other parents and children, feeling less blame, and adapting new autism informed parenting strategies. The diagnosis also informed new narratives which shifted from 'asking' others for support, to 'telling' others about their daughters. Mothers described feeling more empowered and feeling to than before, and for some the diagnosis led to some positive new actions taken by schools. Consistent with Navot et al. (2017), the diagnosis also helped family relationships, including more open communication about their daughters' needs. This is likely to be important in further reducing familial stigma and gaining additional psychosocial support for mothers (and daughters).

A variety of constraints were also experienced. Mothers expressed that the diagnosis was 'not a silver bullet' as many challenges encountered during pre-assessment remained post-diagnosis. The prolonged wait for an assessment, coupled with the often-ambiguous assessment process, posed significant challenges, prompting some to pursue a private diagnosis. This protracted nature of assessments for girls has been previously highlighted (Wassell & Burke, 2022). Consistent with previous studies (Jacobs et al., 2019; Potter, 2016), the diagnostic experience was described as overwhelming, shocking and isolating due to a focus on negative

behaviours, impairment and deficit, and a sense of being 'left hanging' once the diagnosis was given.

There was also disappointment of the continued scepticism from others not accepting a diagnosis. These experiences came from schools, family and friends, with grandparents in particular challenging the diagnosis. Dallos (2019) has previously highlighted the tension between stories told by parents and grandparents as an additional cause of anxiety for families. Some participants sensed that their daughters were seen as 'not broken enough' to receive support due to masking and the hidden nature of their challenges. As with other studies, this led to a view that not enough help was given post-diagnosis (Jacobs et al., 2019; Potter, 2016; Weale, 2020). The type of support offered was also problematic; for example, one participant explained the support's emphasis was on her daughter changing to fit in rather than those around her adapting to her needs.

Whilst not directly categorised as either an affordance or constraint of the diagnosis, the sub-themes of Emotional and Mental Health, along with School Challenges (pre-assessment), emerged from study's findings. These themes seemed to contextually shape the participants journey towards seeking a diagnosis, aiding in understanding their daughters' challenges, accessing needed support, reflecting their lived experiences as carers, interacting with professionals, and ultimately, their relationship with their daughters.

The findings carry implications for diagnostic services. As all participants found the diagnostic process emotional and upsetting, practitioners must be mindful and sensitive of such emotional impact. The negative focus of an assessment and the subsequent diagnostic report can add distress to this, and culturally held myths and stereotypes can create additional confusion and distress if they are not appropriately challenged at an early stage. Early information and support, including an introduction to neurodiversity and a neuro-affirmative approach to parenting may act to alleviate some of this distress, especially in the form of girl-focused parent groups and information. For the mothers in this study, the new understandings about their daughters had a transformative effect which changed their approach to parenting, their identities as a parent and their relationships with their daughters. What was shared is that their new understandings, linked to an awareness of sensory processing, executive functioning, and anxiety presentations, could have been accessed prior to the diagnosis, and they gave the message to other mothers 'not to wait'. This indicates the benefits of support and information being provided prior to assessment and diagnosis, especially in the light of the long waiting times for assessment currently experienced in the United Kingdom.



Practitioners should also prepare mothers that the diagnosis may not bring all the support and change that they envisage. Therefore, opportunities for open dialogue about this should be sought across the assessment period. Assessment groups and workshops, where parents can openly talk with others about experiences including any fears about stigma, may be useful. Practitioners may also find benefit from using the LUUUUTT model in understanding the significance of the many stories, lived and told by parents, and how this may have influenced parents' relationship with their daughters. Practitioners should explore different and potentially conflicting narratives held across the family unit, and in the socio-cultural settings the family are located, about the impact autism and the diagnosis of autism has on family relationships. This will include pre-existing myths, stereotypes and traditional medical explanations that might lead to a negative interpretation of the diagnosis, as well as more positive neuro-affirmative understandings of autism and what it means to be autistic.

Several study limitations should be noted. First, the majority of participants were white, middle class, married and employed, with all of the mothers being recruited via the same parent group. Autism is viewed, and conceptualised, differently across different socio-cultural contexts, and therefore the homogeneity of the sample lacks an in-depth exploration of experiences that intersect with differing cultural, ethnic or class backgrounds. Second, the participants only represent those mothers who were able and willing to attend support groups, and who had consequently heard the positive and neuro-affirmative stories shared by the autistic adult females running the groups. The narratives and experiences of mothers who experience significant stigma and/or distress that prevent them from accessing such support and hearing such stories are missing from this study. A similar study including these mothers would be helpful in identifying potential differences in post diagnosis experiences, especially potential differences in post diagnostic autism narratives and understandings.

In conclusion, outcomes of this study provide valuable insight into the affordances and constraints of the process of receiving an autism diagnosis, as perceived and experienced by mothers of autistic girls. To our knowledge, this is the first study to use CMM and the LUUUUTT model (Griffin, 2014; Pearce, 1999, 2007; Rascon & Littlejohn, 2017) to explore 'lived and told' stories of mothers of autistic girls, including potential tensions within those stories. Outcomes contribute to understanding 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. With increased referrals, long waiting lists and diagnostic delays (Russell, 2012), this understanding is vital if service

providers are to adapt and improve services in all stages of the assessment and diagnostic process, particularly for autistic girls who are especially vulnerable for missed, late and poorer quality diagnosis.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

ETHICS APPROVAL

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the University of Bedfordshire Institute of Applied Social Research Ethics Panel in March 2019.

INFORMED CONSENT

We obtained informed consent from all participants before they participated in the study.

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