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Experiences of Autism Diagnosis: Parental Experiences and Interpretations of the Process of Having a Child Diagnosed with Autism

Bernard Dive and Dr Casey Edmonds
BPP University

The experience of having a child diagnosed with ASD is known to be challenging for parents, and research on this has been increasing over the past decade. This study provides a thematic analysis of the lived experience of having a child diagnosed with ASD, based on interviews with seven parents (aged 35 to 52 years) of six children (aged 7 to 13) who had received a diagnosis of ASD within five years of starting primary school. Parents described the experience of having a child diagnosed with ASD as raising questions and issues in four interconnected areas of concern: “seeing the child”, “navigating the professional system”, “accommodating the needs of the child in balance with the needs of the whole family” and “helping the child find a way of being in the world”. For parents, receiving a diagnosis of ASD involved a challenge of “meaning” – a challenge of integrating the information about their child provided in the diagnosis with their sense of who their child is. Parents were particularly appreciative of professionals who assisted them with this task and who showed an appreciation of the unique qualities of their children. The experiences of these parents have implications for how professionals might communicate with parents and families, as well as how they can provide clear and definite information, address some core practical concerns of parents and families and at all times show an appreciation of the child.

Keywords: autism, ASD, diagnosis, parental experiences, thematic analysis

Introduction

“Autism Spectrum Disorder” (ASD), according to the ICD-11 “is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests” (11th ed.; ICD-11; World Health Organization, 2019). Many parents learn that their child is autistic via an encounter with the professional world, which provides a diagnosis. The encounter parents have with the professional world can be difficult. Survey data gathered in 1997 regarding parental experiences of the diagnostic process identified that around half were “not very” or “not at all” satisfied with the experience (Howlin & Moore, 1997), and a further survey in 2016 echoed these findings (Crane et al., 2016) with 52 per cent of parents in the UK being “quite dissatisfied” or “very dissatisfied” with the diagnostic process. Factors significantly related to satisfaction levels were: time taken to get a diagnosis; perceptions of the quality of information given at diagnosis; perceptions of the manner of the professional during the diagnosis; and perceptions of the support offered post-diagnosis. Whilst some parents express relief in getting a formal diagnosis of ASD (Osborne & Reed, 2008), others express concerns about “labelling” and the impact this may have on their child (Russell & Norwich, 2012).

Having a child diagnosed with autism is stressful for parents. One retrospective study, in which parents of children with ASD were asked to fill out the Impact of Events Scale-Revised (IES-R) to identify indicators of post-traumatic stress symptoms (PTSS), found PTSS in twenty per cent of parents (Casey et al., 2012). Aside from the stress that is involved in caring for, and supporting, a child with social communication difficulties (Lecavalier et al., 2006; Osborne & Reed, 2009), and the stress that can be involved in navigating the professional system to obtain a diagnosis (Goin-Kochel et al., 2006), there is the stress that is involved in making sense of a diagnosis (Rabba et al., 2019). A recent study — making use of data from interviews, subjected to thematic analysis — of how the diagnostic process is experienced by autistic adults, parents of autistic children, and professionals providing autism assessments, identified a number of core “barriers to satisfaction in the diagnostic process”. These barriers included “professionals’ tendency to focus on negatives, not positives”, a “lack of rapport” between professionals and those being served by them, and a “lack of clarity” in the communications of professionals. What is more, a concern was expressed, by professionals, and by those served by them, about a lack, in the UK, of “provision for post-diagnostic support” (Crane et al., 2018).

Dr Casey Edmonds is now at The Open University

This current study aims to explore further the lived experiences of parents navigating the diagnostic process — exploring the question "How do parents make sense of, and assimilate, an ASD diagnosis, in relation to their lived experience of their child?"

Method

Design

A qualitative design was used to explore how parents experience, and understand, the process of having a child diagnosed with autism. Semi-structured interviews were carried out with parents, either in person or via telephone or Skype, and were recorded and transcribed verbatim. Themes were identified through a "bottom up", inductive analysis to provide a Thematic Analysis (Braun & Clarke, 2006).

Participants

Seven participants were recruited via autism support groups, and via referrals from other participants and the research team. Six lived in London, one in the United Arab Emirates, six were of a white ethnic background (four British, one Polish, one South African) and one of an Arabic ethnic background; four were Christian, two Jewish and one Muslim. All participants had been educated to tertiary level (education level ranging from 6 to 8 — from BA level to PhD level). Participants were aged between 35 and 52 (mean = 41.4), and their children (five boys and one girl) were aged between 7 and 13 (mean = 9.8). The parents initially had concerns about the development of their children when they were aged between 18 months and 4 years, and the mean age of the children at diagnosis was 8 years old. Of the six children, four had additional diagnoses (three diagnoses of ADHD). In most cases, the mother was interviewed, and in one case, both the mother and father were separately interviewed. Parents were selected whose child had been diagnosed within five years of starting primary school, after starting primary school, so that the diagnosis, and its consequences, involved changes to established ways of doing things: a clear "before and after", which could be reflected on.

Materials and Procedure

Ethical approval for the study was granted by the Research Ethics Committee within the Department of Psychology at BPP University, UK. All participants gave written informed consent prior to participation. Interviews were conducted using an interview schedule to promote discussion about: the strengths and unique qualities of their child; the process by which their child was diagnosed; their experience of what was helpful, or unhelpful, in that process; their experience of the professionals they encountered in that process; their impressions of how their child was perceived or represented by those professionals; their sense of how much help they received in understanding ASD; their sense of what difference acquiring an understanding of ASD has made to them, in understanding their child, and in parenting their child; and their sense of what ASD means as they experience it in their family life. Parents were encouraged to reflect freely, and at will, on whatever aspects of the diagnostic process were meaningful to them. Interviews ranged in length from 45 to 90 minutes. Participants were informed of the aim of the study and that their anonymity would be preserved in the presentation of the results of the study. They were informed that they could withdraw from the study at any time.

The interview transcripts were, after multiple readings, analysed, and a number of recurrent topics were identified across the transcripts. As the researchers reflected on, and discussed, the topics, they gradually identified some common themes. Most of the topics could be subsumed under one theme only — though a few could be subsumed under more than one theme (for instance, the topic of "a child not fitting the ASD stereotype" could be relevant to the theme of "experiencing difficulties in recognising the signs of ASD in the child", and to the theme of "addressing denial or misunderstanding on the part of family members"). Through further reflection on, and discussion of, the emerging themes, and through further interrogation of the original transcripts, several superordinate themes emerged, which encompassed the core meanings, and core areas of concern that had been articulated.

Results

Four superordinate themes were identified: "seeing the child"; "navigating the professional world"; "accommodating the needs of the child in balance with the needs of the whole family"; and "helping the child find a way of being in the world". Each is presented below, with a table of associated themes, and each participant has been assigned a number from 1 to 7, with quotations attributed to each participant according to that number.

1. Seeing the Child

The process of obtaining a diagnosis of ASD for a child can be difficult for parents because it involves attending to "deficits". Some parents noted how the clinical interpretation of their child seemed focused on deficits; *"They don't really look at what... he's good at [laughs]"* (2). This parent found the reports to be *"accurate but distorted .... A lot of the things that were described I could probably recognise in, recognise in my son, but didn't necessarily ... see it as something that was wrong"* (2). The clinical interpretation of the characteristics of her son, and the language used, changed the meaning of these characteristics for this parent and labelled them as "wrong".

Table 1

Subthemes for Superordinate Theme "Seeing the Child"

Encountering clinical perceptions of the child
Feeling uncertainty about what ASD means, and for the future
Experiencing difficulties in recognizing the signs of ASD in the child
Undergoing the shock (or relief) of a diagnosis
Gradually assimilating the meaning of the diagnosis
Relating the ASD diagnosis to the reality of the unique qualities of the child

There was an appreciation by this parent for the professionals who seemed to recognise her son *"for who he was"* (2): she praised the psychiatrist who provided the diagnosis of ASD for *"recognising him for who he was and, and just putting a label on it but, but explaining why"* (2). The professional's ability to convey the diagnosis in a personal, chatty way, explaining how and why the "label" applied to the child, was appreciated.

One mother found reading reports about her son in the diagnostic process stressful, as the reports raised questions — like *"How would it develop in the future?"* — for which there were no *"answers back then"* (4).

All of the parents interviewed about their experiences of having a child diagnosed with ASD had felt, early on in the life of their child, that something was *"different"* about the development of their child (1, 4, 5, 7). Often an inchoate sense, on the part of parents, that something *"was different"* (7) would be developed by observations made by someone else, usually a professional (1, 3, 4, 6).

Some parents (1, 4, 5) felt that they did not register all the signs of a difference in their child as early as they might have done, as they did not have opportunities to compare their child to other children. Some registered signs of a difference but were convinced by others that these were not significant (4). Some parents mentioned their concerns, early on, to professionals but were told that they were mistaken in having these concerns: *"Everybody told me I was wrong for years"* (7). For all the parents, it took some time to recognise that the signs of difference were, in fact, signs of ASD, or to get a formal diagnosis of ASD.

Sometimes, the difficulty was that the child being diagnosed had a comorbid condition which manifested itself more prominently than ASD (1, 3, 5, 6, 7). Many parents observed how, in certain respects, the signs of ASD in their child did not correspond to the *"stereotype"* of ASD (1, 3, 4, 5, 6). Some felt that this had posed an obstacle to obtaining a diagnosis of ASD (1, 6).

For almost all the parents (except one, 7) — even for those who had been of the opinion, prior to receiving a diagnosis, that their child had ASD — receiving a diagnosis of ASD was a *"shock"* (3, 4), or made a significant *"difference"* to their understanding (1, 2, 5).

One mother observed that, even though she had sensed that her son might have ASD, long before he had received a formal diagnosis, nevertheless, receiving the diagnosis had made a significant difference to her attitude. Her son was initially assessed at the age of six; she was informed that he had *"autistic traits"* but that, since he was *"functioning"* well, he did not need a diagnosis, and her reaction to this was *"relief"*.

> *I was relieved to — ah — not . . . not label him. Um, I think at, I think at six years old, it's, autism — I — actually al-, also in those days — I know we're only talking about eight years ago — but . . . I feel like there was more of a stigma. Even eight years ago. I do feel, you know . . . now I'm more happy to tell people he's got autism whereas then . . . I was relieved that he didn't have it, even though I knew he did. It was, it was like a . . . "Oh good we don't have to tell people then — that's fine, he doesn't have it" and I was happy to go with that, but deep down knew.* (5)

Although she *"knew"* in some sense *"deep down"* that her son had ASD, nevertheless, when he was assessed again at the age of eleven, and diagnosed with autism, she found that the diagnosis altered her attitude considerably; and this alteration in her attitude made her feel *"guilty"* for not having sufficiently registered the challenges her son had experienced owing to his ASD: she felt that she should not have needed to have been prompted by an *"arbitrary diagnosis"* to appreciate these challenges.

> *I felt guilty. I felt really guilty that I had known he'd had autism and had ignored it for five years. I felt really, really guilty that he'd had all these difficulties to deal with by himself, and he'd had to create his own coping mechanisms without me helping at all and I'd also felt guilty that I was blaming him for things that he . . . didn't know, and I, and I didn't, I didn't read about, I didn't do any, I was focused so much on ADHD, which I didn't know anything about at all — so I had to start from scratch with that — and I didn't read anything about autism . . . I didn't get . . . oh so much that was going on in his, in his mind — I didn't understand and I didn't make any effort to . . . and then this you*

> *know arbitrary private psychiatrist gives us an arbitrary diagnosis and suddenly I'm like "Ah, now I need to understand you". You know, and I did feel very, very — I did feel very guilty . . . I just was a little bit in denial about it.* (5)

One mother had to wait two years for a diagnosis, after being referred for a diagnosis by a professional who told her to *"assume"* her child was autistic (3). Even after that time, receiving the diagnosis was a *"blow"* (3).

> *You know it's like, that felt like a slap. Basically, a slap after a two-year wait, a two-year-plus wait. And then you're like "What now?" . . . Yeah it was still a blow. I mean when you, when you come out, um, you know it was very distressing. I had a good cry, for a, about a week.* (3)

For one mother — who had been convinced for several years that her child had ASD, and who had taken her child to be tested a couple of times before a diagnosis was arrived at — obtaining a diagnosis was a *"relief"* and a vindication.

> *I literally walked into her office, exhausted as you can imagine from fighting for ten, more than ten years, no, a decade of fighting to get this diagnosis. Erm, she — I said to her "Do you think I'm climbing up the wrong tree?" and she did this test, she said "No, you're absolutely right" and it was like the best day of my life. So where you would think that it would be the worst day of a parent's life to get a diagnosis, for me it was the best thing ever. Because now people were going to listen to me . . . It was such a huge relief. Because I was no longer — like a — I knew people thought I was over the top, that I was making it up.* (7)

Several parents observed that it took time for them to take in, or to accept the diagnosis (1, 3, 4), and a couple of parents observed that they felt that parents would benefit from *"counselling"* after receiving a diagnosis (3, 4) or a more *"personalised"* (2) explanation of what ASD is.

For the parents of children with ASD, "seeing their child" involves seeing those features of the behaviour of their child that seem to manifest ASD, and relating these to other features of their behaviour or character. Several parents observed that their children had strengths that did not fit the stereotype of children with ASD — such as humour (1, 2, 5, 6) or empathy (1, 2, 4, 5, 7). A couple of parents saw the intellectual capacities of their children as implicated with ASD, and as involving a coincidence of *"strength"* and *"weakness"* (4, 6). One mother connected the way in which her son *"doesn't . . . particularly relate to one person more than another"* to a *"moral"* strength: a tendency to regard *"everybody"* as being of equal worth and importance (5).

> *He feels like everybody's pain in the entire world, um, and is interested in what's going on all around the world and wants to affect all sorts of people — he doesn't distinguish between any sorts of people — he doesn't even particularly relate to one person more than another — um, doesn't really distinguish between his younger five-year-old brother and his headmaster, he's just "A human is a human."* (5)

Another mother saw an enchanting otherness in her son: *"He's got these magical qualities"* (7).

Some parents considered that the knowledge of ASD that they had acquired was somewhat peripheral to their sense of who their child was (2). Others regarded the ASD of their child as a difference to embrace.

> *The funny thing is I'm worried about it and I wouldn't change it at the same time because it makes him like really special and, you know it's a struggle and yeah I'm like at the moment I'm embracing that he's different and I want him to embrace that and you know value that for you know who he is.* (4)

For other parents, their knowledge of ASD complemented, without radically altering, their sense of who their child was.

> *The textbook helps me to paint a fuller picture that I didn't know during his childhood but it's more, ah — it adds, it adds, it doesn't . . . form, if that makes sense. Like, he is, he is him before the diagnosis he was given.* (5)

2. Navigating the Professional World

For some parents, an initial awareness of a difference in their child became stronger when their child attended nursery school — partly because they observed, or were alerted to, how their children differed from other children, and partly because their children struggled with peer relationships (4,3).

> *Almost from the beginning like had had problems with, ah, other children — definitely — every other day I'd come to nursery, and he was like, he was like — he hit somebody because someone came into his space and took his toys, you know . . . At home, it was different, yeah, but in nursery . . . and there was these two teachers which I owe the diagnosis to . . . After three months they come to me, and they think — they*

Table 2

Subthemes for Superordinate Theme "Navigating the Professional World"

Finding a way into, or being guided into, the professional world
Recognising differences in the child through his or her early experiences of nursery or school
Noticing strengths or limitations in "specialist" perceptions of the child
Noticing strengths or limitations in professional communication
Valuing professional support, and support from peers, in making sense of, and adjusting to, a diagnosis

> *didn't tell me it's autism but there is … so they told me it might be helpful to just get him diagnosed.* (4)

For several of the parents in this study (2, 3, 4) nursery school teachers initiated the first assessments of their children (by speech and language therapists, occupational therapists, psychologists) whilst for other parents their child's school was their primary link to the wider world of professional care services. Some parents engaged directly with the care *"system"* (1, 7), which they felt to be an onerous task in itself (1) or even a *"fight"* (3). One parent, though, was *"impressed"* at how effectively the system had coordinated different *"specialists"* and an array of *"resources"* in diagnosing their child (5).

While many parents felt that most of the professionals they encountered had been sensitive in engaging with their children, others felt that some had been insufficiently *"flexible"*. One parent was of the view that the *"not at all flexible"* (1) way in which a particular psychologist carried out a test on her child, meant that the psychologist formed a false picture of her child and *"completely misinterpreted"* certain things (1). The specialist focus of certain professionals could seem, to some, to result in those professionals not registering a fuller, more complex reality; one parent commented that *"Every doctor has their targets"* (3).

> *They don't look at your child holistically — ever. That's the thing. So you go to a speech therapist because you've got some concerns and, yes, they will do something, and then, you tick a box. But I wish they would have said, "You know what. Normally, children that have got speech issues … it could be indicative of … " you know.* (1)

One mother kept returning to the phrase *"ticking the box"* (1) to contrast a form of engagement that was orderly, systematic, but perhaps somewhat superficial, with a form of engagement that was more "holistic" and more attuned to realities that could not be neatly classified. Her son was diagnosed with ASD only after a lengthy process of engaging with a variety of different specialists — *"Everybody kind of puts you onto someone"* (1). For her, realizing her son had ASD changed her view of the difficulties he was experiencing. She characterised this change as a transition from a sense that she might be able to *"tick a box"* in overcoming the challenges of her son.

> *I'd noticed things were getting better, so I think, in a way, I was just hoping I could just tick a box, and then all of a sudden you kind of, you've got another diagnosis, and you kind of think "well this one is actually for life" [laughs] — it's not one you're going to outgrow. So I think it was just like "Awrrr", you know, "not something else we have to deal with". Yeah, yeah. So I think it could have been like a, I don't know, perhaps it was a … [pause] an element of denial on, on my part. Only because we'd done so much, over the years, and then perhaps I was hoping that it wasn't?* (1)

She contrasts a piecemeal focus on particular issues — which could be *"tick"[ed]* off, one by one — with a *"diagnosis"* that is concerned with a whole *"life"*.

Parents particularly appreciated the insights of professionals where they felt that the professionals had registered things about their child that they had not (2, 4). Many parents appreciated professionals who were clear and definite in conveying information, but some found *"professional"* directness could be too abrupt.

> *Maybe, he's used to it? So for him, it was, like, normal. It was like, it was like — she has a cold. [laughs] She doesn't have a cold — you just dropped a bomb on me … I think it may be, some doctors maybe they seem a bit … you know, maybe it's that kind of … maybe he's used to it, but for me, I'm like — "whoah … ASD?" I mean come on … They were professional. But I think they're only just starting to realise that it is a kind of blow, you know.* (3)

All the parents who, in post-diagnosis follow-up meetings, had received assistance in making sense of the diagnosis of ASD, valued this assistance (2, 3, 4). Several parents recognised that, in addressing many of the challenges and tasks that were made apparent to them when their child was diagnosed with ASD, they could only ask so much of professionals.

> *I guess the main question is like "What do we do for the rest of our lives?" [laughs] We can't — no doctor can answer that, you know.* (3)

Some parents observed that, in the process of navigating the care *"system"*, they had particularly appreciated getting opportunities to meet other parents of children with ASD: to get understanding (1) and to get practical *"tips"* (3).

For all the parents, having a child diagnosed with ASD prompted a process of self-education — an attempt to gain a fuller knowledge of ASD from various sources. While all the parents sought to gain a fuller knowledge of ASD, some felt that reading too much about it could be counter-productive.

> *[I] don't want it to become this massive deal. He's just who he is . . . To be honest, I think I would only look for strategies to help with particular issues rather than just reading very generally about it.* (2)

3. Accommodating the Needs of the Child in Balance with the Needs of the Whole Family

Table 3

Subthemes for Superordinate Theme "Accommodating the Needs of the Child in Balance With the Needs of the Whole Family"

Addressing denial or misunderstanding on the part of family members
Nurturing harmonious relationships between the child with ASD and his or her siblings
Ensuring the needs of all family members are met in a balanced way

Some parents found that family members (1, 3, 4, 7) or spouses (3) took a while to accept that their children had ASD, and several found that family members were prone to misinterpret the behaviour of their children, failing to appreciate how certain aspects of that behaviour were due to ASD.

> *My brother completely misinterprets all of [my son's] mannerisms. Completely, you know. "He likes being the centre of attention", you know, because of the way he talks. And he reckons that, you know, he shows off because he likes, you know, he flaps around, and I'm like . . . ! . . .* (1)

One parent found that imparting general information about ASD to family members could be helpful.

> *When my parents arrived I had a little book there waiting for them, because they very, kind of, you know, think I'm spoiling him a bit much, and . . . and so I've tried to educate them.* (1)

For most parents, the primary challenge, in ensuring that the life of the family was as balanced and tranquil as possible, was that of nurturing harmonious relationships between their child with ASD and the siblings of that child. Several parents observed that they had found establishing suitable methods of *"discipline"* for their children with ASD difficult (3, 4, 6). Some parents observed that their child with ASD struggled to respond to the playful overtures of siblings (1, 4). One parent observed that his son — whose ability to *"empathise"* was somewhat limited by his ASD — could be *"hurtful"* to his siblings, and this could be difficult for them to understand.

> *It's very difficult to understand someone that doesn't understand you . . . It's very difficult for them to understand and accept that someone who is exceptionally intelligent in all other elements of life cannot understand how certain comments that are totally obvious to even an eight-year-old or maybe even a six-year-old — just to him, he just doesn't get it.* (6)

All the parents observed that they needed to sometimes mediate between their child with ASD and his or her siblings. All commented that they made considerable efforts to ensure that they were being fair and to attend to the needs of all of their children. One mother felt that the life of the family had become somewhat too centred on the needs of her son with ASD.

> *Sometimes I almost find like we, that we're planets that revolve around him. You know, because everything that we do, whether that's going on holiday, the choice of restaurant, all revolves around [him], and um, and I often hadn't thought about that, and I had [his brother] saying "Do you realise, whatever we do we have to consider [him]?" and I thought "Yeah, you've got a point", you know.* (1)

Her appreciation of this point led her to arrange for her family to receive family therapy.

4. Helping the Child Find a Way of Being in the World

For many parents, having their child diagnosed with ASD presents the question *"What do we do for the rest of our lives?"* (3). It raises questions about the future. For the parents of children diagnosed at a young age, it raises questions about how their children will develop. How severe can they expect the "deficits" associated with ASD to be, in the case of

Table 4

Subthemes for Superordinate Theme "Helping the Child Find a Way of Being in the World"

Thinking about the future of the child with ASD
Helping the child cope with the mainstream school setting
Helping the child develop peer relationships and social skills, in accord with the inclinations of the child towards sociability
Supporting the child in understanding ASD and in forming a positive self-image

their child (2, 4)? For the parents of older, secondary-school-age children, the question of the future was often associated with questions about what careers might suit their children (1, 7).

All of the children were in mainstream schools — three in primary schools and three in secondary schools. All of the children in primary school had some dedicated one-to-one "support" provided by the state; one of the children in secondary school had one-to-one support. All of the parents whose children were receiving one-to-one assistance found the schools "supportive" (2, 3, 4, 7). One observed that the support her son had received had been very beneficial: *"A month of work with [the assistant] and he was a different boy"* (4).

The mother of a child in a mainstream secondary school, without one-to-one support, observed that the school was somewhat *"militant"* about discipline but that *"he loves the rules"* (1). While the *"pressure"* was helping her son to *"focus"*, it was, equally, evoking in him some *"anxiety"* (1), which she was trying to allay. Several parents felt that their children had considerable innate intelligence, but that conventional forms of schooling were not well suited to bringing out that intelligence (1, 4, 5, 6). One parent had arranged for her child to obtain additional vocational qualifications, alongside conventional GCSEs (7).

Even more than the academic side of the school experience, parents were concerned with the social aspects of the school experience. For their children, *"finding a way of being in the world"* involved finding a way of being with, and forming relationships with, others. All the parents were conscious that their children were encountering challenges in their peer relationships. The parents of secondary-school-age children were particularly conscious of this: as one parent observed,

> *There is so much, um, depth to the increasing complexity of social interaction that happens at this particular time of life.* (6)

Some parents set out to provide their children with additional social opportunities, to help them develop their social competencies.

> *OK, there's this youth club, they have, like, sessions, kind of like, after school sessions . . . One of the days I came to pick her up they told me she'd made a friend all by herself, so I was like [laughs] "OK thank you God" . . . At the end of the day, with autism, the main issue is the social one.* (3)

Some parents *"coach"* their children in forms of social interaction, day to day.

> *Every single thing he knows or hears or does, every type of social action, interaction, has to be taught to him, and that is exhausting. And you never stop [laughs] because every, like I said, every day there's something new.* (7)

Most parents observed an instinct or inclination towards sociability in their children (1, 2, 3, 4, 5, 7). One father observed that it required careful thought to work out how much social interaction his son needed.

> *[Knowing he has ASD] makes it more . . . It makes it easier to accept that he will choose to . . . um . . . remove himself or not involve himself in social situations, because it's difficult for him . . . It's like, well actually, if he has autism, does he, does he want to be with other people? should he be with other people? and does he need to be with other people as much as someone who doesn't have autism? . . . We don't want him to feel lonely. But in my opinion, he is — he will always be less likely to feel lonely I think than other people because I think that his mind works differently. Um, and then to know you know actually in, let's say, a work environment or a, you know, in the context of this and that, you know, to what extent does he need to learn um social interaction, to have exposure with social interactions.* (6)

One mother — who had observed that the friendships of her son tended to centre around common interests or "passions" — was trying to help him to develop, with one of his friends, a deeper friendship, involving more mutual confidences.

> *[His friend, who is dyspraxic] talks about his vulnerabilities, there's a great connection with*

> *[my son]. [My son] has never told him anything about himself, which is hilarious . . . so I said to [my son] "I think you actually need to tell [your friend] about this, [about the fact that you have ASD] because I think this would be a great thing for the two of you to share." but he's like "No no no." [laughs].* (1)

All the parents wanted their children to entertain positive images of themselves and did not want their children to feel diminished by knowing that they had ASD. The parents of the children in primary school had not yet disclosed to their children that they had ASD (2, 3, 4); all were waiting for a time when their children were, in their view, capable of taking this in, without feeling diminished. The parents of the children in secondary school had all thought carefully about how to disclose to their children that they had ASD. One mother felt she had *"waited too long"* before having an initial conversation with her son and that the conversation had *"confused"* him (1), but she had, since that initial conversation, made use of various sources of information to help him form a positive sense of what his ASD meant.

> *I found an amazing book . . . Heroes Like Me . . . all these people that were, you know, that were on the spectrum and have left their mark, you know.* (1)

Another mother noted how she put a *"positive spin"* on her explanations of what ASD was.

> *I talk about it as though it's a real, he's really lucky to have it — that's, that's the spin I put on it. He is different. I don't want him . . . I need him to know somehow that he has this thing, but I don't want him to think of it as a disability.* (7)

Discussion

The current study shows some of the ways in which parents make sense of, and assimilate, an ASD diagnosis in relation to their lived experience of their child. All but one of the parents interviewed for the present study found it a "shock" to have their child diagnosed with autism, even when they already suspected, or had been told to assume, that their child had ASD. On receiving the diagnosis, the parents then engaged in a sense-making activity, to understand more about what ASD is and to relate this to their knowledge of their child. This involved sorting through what, in "textbook" accounts of autism, seemed pertinent to their child, and this could evoke anxiety — *"How would it develop in the future?"* (4) — and it could evoke guilt — *"I felt really, really guilty that he'd had all these difficulties to deal with by himself"* (5). Most parents found that, with regard to their understanding of their child, *"the textbook . . . adds, it doesn't . . . form"* (5). Some parents appreciated the clarity and definiteness of the communications they had received from professionals; some felt that a focus on the clear and definite could be at odds with a more "holistic" understanding. Parents particularly appreciated any support they received from professionals in this sense-making activity (whether in the disclosure of the diagnosis or in a post-diagnosis follow-up session): *"recognising him for who he was and, and just putting a label on it but, but explaining why"* (2).

This study supports and extends the core finding of Howlin and Moore (1997) and Crane et al. (2016) — that many parents are dissatisfied with the diagnostic process — by providing an in-depth exploration of how parents experience this process. The study confirms the findings of Crane et al. (2018) that parents can find the "manner" of some professionals too aloof (even while recognising, equally, that professional clarity is valuable) and that parents feel the need for more post-diagnostic support. Additionally, this study supported the finding of Casey et al. (2012) that the diagnostic process is often stressful.

The analysis of the lived experiences of parents in this study highlights ways in which professionals can assist parents to recognise the characteristics of their children that manifest ASD, without, thereby, seeming to label those characteristics as in some way *"wrong"* (as one parent put it). Parents particularly valued the insights of those professionals who seemed to recognise and appreciate their child in his or her uniqueness. Abbott et al. (2013) found that parents feel better supported when clinicians assessing their child exhibit empathy and a sense of the positive characteristics of their child, and, in this regard, for clinicians to recognise the individuality of a child is to show regard for the worth of that child — a sense that the individuality of the child is worth attending to. Maynard and Turowetz (2022) have suggested that, in diagnostic reports, "instantiation stories" — which recount in detail particular events that occurred in the assessment — as contrasted with "tendency stories" — which construe particular events as expressions of patterns — can afford opportunities for recognising the strengths and competencies of individuals with ASD. Parents appreciated, equally, clear and definite information about what ASD is and why their children met the threshold for a diagnosis. Professionals can help parents, it would seem, when disclosing a diagnosis, or when providing post-diagnostic support, by providing clear and definite information, while relating this to, and showing an appreciation of, the unique personhood of the child in relation to whom this information is being provided.

The post-diagnostic support provided by clinicians could be oriented towards addressing some of the core practical concerns of parents — around balancing the needs of their child with ASD with the needs of the whole family and around helping their child find a place in the world: clinicians could exhibit an awareness of these concerns, and a willingness to engage with parents, as they begin exploring these concerns. As one parent observed, *"The main question is like 'What do we do for the rest of our lives?'"* (3), and while this parent recognised that *"no doctor can answer that"*, clinicians providing a diagnosis can show an awareness of this "question" and can engage with parents as they begin to address this question. Carlsson et al. (2016) found that the parents of children with ASD expected interventions to begin directly upon diagnosis and then felt they had to "fight" to obtain support. If ASD, as a lifelong condition, provokes the question "What do we do for the rest of our lives?", there is, equally, the question "What is to be done, here and now?" All of the parents who were trying to "navigate the professional world", without support, whether to get a child assessed for ASD or to secure support for a child with a diagnosis of ASD, found this experience challenging. Parents who have a child diagnosed with ASD would, evidently, appreciate guidance not only in ascertaining what ASD means, or could mean, for their child and their family, but in ascertaining what forms of support are suitable for, and available for, their child. Osborne and Reed (2008) found that the majority of parents wanted information on what professional help was available to them immediately after diagnosis (even if they recognised they might not be able to assimilate all of it at once); Carlsson et al. (2016) suggested that a "case coordinator" would be beneficial during the diagnostic process, and, in light of the desire for post-diagnostic guidance expressed by the parents whose views were sought in this study, support from a "case coordinator" after diagnosis seems something that would be equally beneficial.

The key strength of this study is that it provides an in-depth exploration of the lived experiences of parents as they reflect on their experiences of having their child diagnosed with ASD and the ways in which they make sense of the diagnostic process. It highlights ways clinicians, when providing a diagnosis, can assist parents in making sense of it (which will, in turn, assist parents in supporting their child). This study however has limitations. As most of the parents interviewed lived in the UK, their experiences relate to a particular health system; therefore, further research could look at these experiences in different countries. All parents had tertiary educational qualifications, and none had any difficulty making sense of the "professional" communications they had received — whether written reports or conversations with professionals; therefore, getting more insight into the experiences of parents of different educational levels would be worthwhile. At the time they were interviewed, all the parents had accepted the diagnosis of ASD that their child had received. More insight into the experiences of parents who are reluctant to have their children assessed for ASD or reluctant to accept a diagnosis of ASD (Russell & Norwich, 2012) would be worthwhile. Most of the parents interviewed observed that it took time to assimilate and to make sense of the diagnosis, so a longitudinal qualitative study of the experiences of parents in having a child diagnosed with ASD, interviewing parents in the period before and after the diagnosis, would be beneficial. Finally, while six mothers were interviewed for this study, only one father was interviewed; getting more insight into the experiences of fathers would, evidently, be worthwhile.

This study has highlighted the emotions, and the questions, that parents address in having a child diagnosed with ASD. Many clinicians will, in practice, be aware of these emotions, and questions, and it is evident that clinicians, in disclosing a diagnosis or in providing post-diagnostic support, can assist parents in the sense-making that they engage in, after receiving a diagnosis. One thing that it might be helpful for clinicians to be mindful of is the way in which a diagnosis of ASD can elicit, for parents, questions about who their child is. All of the parents interviewed for this study were concerned, in different ways, to recognise how those features of their children which, in their view, were connected to ASD, were, equally, bound up with what made their children who they were — *"I'm worried about it and I wouldn't change it at the same time because it makes him like really special"* (4).

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