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Article: "Parenting an autistic child: Experiences of parents with significant autistic traits"

Abstract

Despite autism being highly heritable, this study is the first to investigate the experiences of parents of autistic children who have significant autistic traits themselves. Eight parents of autistic children with significant autistic traits themselves were interviewed regarding their parenting experiences. In line with what has previously been reported by parents of autistic children, participants described difficulties with parental mental health and navigating professional services. Novel participant experiences included the interaction between parental and child autistic traits helping and hindering their parenting; parents learning to manage their own autistic traits, and parents finding the home to be an accepting place of autism. The need for adequately funded, tailored and accessible services for these families is emphasised.

Parenting an Autistic Child: Experiences of Parents with Significant Autistic Traits

Parents of autistic children experience high levels of parenting stress and poorer mental health (Hayes & Watson, 2013; Scherer et al., 2019). Having an autistic child can also negatively impact on the parent-child relationship (Hoffman et al., 2009) and is associated with lower levels of marital satisfaction and higher divorce rates (Hartley et al., 2010; Gau et al., 2012). In addition, parents of autistic children experience social isolation and negative social judgement (Griffith et al., 2012), financial burden (Marsack-Topolewski & Church, 2019), and frequently report having difficulties navigating professional services (DePape & Lindsay, 2015). Despite these challenges, parents of autistic children also report positive parenting experiences such as enrichment, personal growth and joy (Phelps et al. 2009; Safe et al. 2012; Young et al., 2020).

Whilst a considerable body of research has explored the experiences of parents of autistic children, this research has not explored or separated out parental autistic traits. Little is therefore known about the lived experiences of parents of autistic children who are themselves autistic or have significant autistic traits. This is somewhat surprising given that sub-clinical threshold autistic traits are common in parents of autistic children (Rubenstein & Chawla, 2018) and as many as 18% of parents of autistic children obtain scores indicative of an autism diagnosis on screening measures (Lau et al., 2016).

The general parenting literature provides some information about parents with significant autistic traits' parenting experiences. Dissanayake et al. (2019) explored 58 parents with significant autistic traits' experiences of parenting typically developing children. Parents with significant autistic traits reported greater difficulties in the

domains of modelling and teaching positive behaviour, understanding their child's needs, controlling their own emotions, feeling connected to their child, and coping with the sensory demands of being a parent.

Many therapeutic interventions for autistic children rely on parents supporting their child to learn and maintain new social communication skills (e.g. Pickles et al., 2016). Autistic parents, as a result of their own social communication challenges, may find these interventions more difficult to learn and implement than neurotypical parents do. There is some preliminary evidence in support of this hypothesis. When following-up mothers who had taken part in an early, parent-mediated, social communication intervention for young autistic children, Parr et al. (2015) found that 6 mothers with a 'Broader Autism Phenotype' (BAP, which is characterised by milder autistic behaviours and traits) had lower total mother-child interaction scores 8 years after the intervention than 12 mothers without BAP. Furthermore, in a randomised controlled trial (RCT) where 136 autistic children were randomized to a waitlist control or Theory of Mind (ToM) intervention, parental autism had a significant impact on the acquisition of ToM skills in the children in the intervention group (de Veld et al., 2017).

In summary, the extant literature suggests that autistic parents and parents with significant autistic traits will experience additional challenges when parenting and providing social-communication interventions to their autistic child. In our own clinical practice (in UK diagnostic and intervention services for children with neurodevelopmental conditions) we have found that when parents of autistic children are also autistic or have significant autistic traits themselves, there can be a beneficial 'match' of autistic symptoms, leading to greater understanding and connection, and/or a 'mismatch' of autistic symptoms, leading to discord and tension. Furthermore, in our

experience, autistic parents and parents with significant autistic traits often have difficulties accessing support and feel misunderstood and judged negatively in relation to their parenting.

Although the initial research suggests that parents of autistic children who are themselves autistic or have significant autistic traits may experience unique challenges, no study has yet explored the lived experience of these parents. A holistic, qualitative understanding of the experiences of parents of autistic children who themselves have significant autistic traits is therefore vital in order to help develop future research into this area and effective intervention. The current study therefore asks the question “what are the parenting experiences of parents of autistic children who themselves have significant autistic traits?”

Method

Design

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was used to examine the lived experiences of parents of autistic children who have significant autistic traits themselves. IPA was chosen because it views participants as experts, demands researcher reflexivity and flexibility (Howard et al., 2019), and has been successfully used with individuals with ASD (e.g. Acker et al., 2018; Griffith et al., 2012). IPA provides rich, detailed accounts of participants' experiences, and develops an interpretative analysis to position these within a wider context (Larkin, et al., 2006). IPA's idiographic nature, focusing on a small number of participants, allows for exploration of individual differences, and for the lived experiences of participants.

Recruitment and screening

Participants were recruited using purposive, homogenous sampling from an NHS Child and Adolescent Mental Health Service (CAMHS) and a charitable organisation supporting autistic children and adults. Both organizations provide support to the population of Oxfordshire, England. Three potential participants were approached by the final author (NV) in their role as a CAMHS clinician. NV had been working with all three parents for some time. Of these three parents, one already had an autism diagnosis and the other two parents had talked with NV (at length) about the possibility that they were on the autistic spectrum prior to recruitment. Nine potential participants were recruited via an existing support group for parents of children with a confirmed diagnosis of autism who themselves were autistic or believed they were autistic or had significant autistic traits. This was a voluntary group which parents

could choose to attend if they knew or believed they were autistic (they did not have to have a confirmed diagnosis of autism to attend the group).

All 12 potential participants were provided with an information sheet and completed the Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001). The AQ is a 50-item self-report questionnaire used to measure autistic traits (e.g. difficulties in social skills, attention to detail and communication) indicative of a diagnosis. It has good test-retest reliability and internal consistency (Baron-Cohen et al., 2001). A cut-off score of 32 is indicative of significant autistic traits and is highly predictive of a diagnosis of autism in both clinical and non-clinical populations (Woodbury-Smith et al., 2005; Ruzich et al., 2015). Researchers have found that the AQ represents a continuum of autistic traits, with higher scores on the AQ correlating with a greater severity of autism (Hoekstra et al., 2008).

Participants

Participants were all adults who scored 32 or above on the Autism Quotient (AQ; Baron-Cohen et al., 2001). Eight parents scored 32 or above on the AQ, with a range of 32-46 (see Table 1.), suggesting considerable variation in the level of impairment these parents experienced. Four parents were excluded from taking part in the study because they scored below 32 on the AQ. Of the eight eligible participants, 6 were recruited via the autistic charity and two via CAMHS. Participant demographic characteristics are provided in Table 1 [insert table 1.]. All participants were of white British or white Irish ethnicity. Three participants had a verbally confirmed ICD-10, DSM-IV, or DSM-V diagnosis of ASD, autism or Asperger's syndrome. Participants all had a child or children (aged up to 18 years) with a confirmed ICD-10, DSM-IV or

DSM-V diagnosis of Autism, Asperger's Syndrome, or ASD. This was confirmed by the recruiting services the children were accessing (i.e. CAMHS or ASD charity).

Interview Process

Verbal and written consent was obtained prior to each interview. Participants were informed that someone they trusted could join them for the interview. Confidentiality was explained, and participants were informed that they could withdraw their data up to two weeks post-interview. Participants completed a demographics questionnaire prior to the semi-structured interview. Interviews were carried out in participants' homes (n = 7) and a local NHS building (n = 1), audio recorded, and ranged in length from 54 to 87 minutes (M = 72.5 mins). Prior to beginning the interview, the interviewer established rapport with participants. The lead author, who was a Trainee Clinical Psychologist at the time of the interviews and did not have a clinical relationship with the participants, completed all interviews. The lead author received specialist guidance and supervision from an expert IPA practitioner. All interviews were transcribed verbatim. Participants were reimbursed £15 for their participation. Post interview, participants were, if appropriate and necessary, provided with information about additional support. All participants received an accessible summary of results.

Interview schedule development

A semi-structured interview schedule was developed by the authors, three of whom have significant professional experience of working with autistic parents and children. The semi structured interview schedule was developed through consulting the literature and liaising with other researchers who had previously used IPA with autistic people (e.g. Acker et al., 2018). A range of other stakeholders, including a parent of an

autistic child (i.e. a service user), professionals from an autism charity, and a specialist from a Neurodevelopmental Conditions CAMHS team were asked for their views on potential questions. The schedule included questions about each participant's family, being a parent, and the support they received. Broad but concrete questions were used flexibly, with prompts, to facilitate the participant sharing their experiences (see supplementary information for full semi-structured interview schedule). A pilot interview with an autistic parent did not lead to significant changes to the schedule. The pilot data was included in the analysis.

Data analysis

Semi-structured interviews were transcribed and analysed by the lead author using IPA (Smith et al., 2009; Larkin & Thompson, 2012). Transcripts were re-read multiple times and initial notes were made regarding the interview, any preconceptions (particularly those stemming from psychological theory and research and the author's professional experiences of working with autistic parents and children) and striking parts of the transcript, including content, tone and linguistics. Interpretations were clustered into emerging themes and summarised for each participant. Participants' themes were clustered and compared across accounts to produce subordinate and super-ordinate themes (see Table 2).

Quality, rigor, and the researcher's reflexivity were ensured following Yardley's quality criteria (Yardley, 2000, 2017; Smith et al., 2009) through use of a reflective journal, 'bracketing' interviews with peer IPA researchers, and supervision with the co-authors and an independent IPA research expert which included ad-hoc credibility checks on analysis. Full parallel analysis was carried out on two transcripts by the lead author and co-author (OH). Parts of all other transcripts were randomly

selected for parallel analysis to ensure consistency of coding. Throughout analysis, themes were also discussed and re-analysed with the supervising co-authors and the independent IPA research expert, on multiple occasions.

As is integral to the epistemological stance of IPA, the co-authors were mindful of how their personal and professional experiences (such as being parents and their experiences of working closely with autistic parents and children in mental health settings) will have affected their interpretation of the data. Yardley's quality criteria (Yardley, 2000, 2017; Smith et al., 2009) were followed to ensure credibility, with checks including an audit trail, and parallel analysis with supervisors and an independent IPA research expert.

Researcher reflexivity is an integral part of the IPA process and involves highlighting one's own 'lens' from which to interpret the data in order to successfully engage with participants' experiences (Larkin & Thompson, 2012).

First author: 'My experience of working with individuals with autism and/or Intellectual Disability (ID) helped me to understand the difficulties these parents might have and to engage and support them in the interview process.'

Second author: 'Over the years I have worked as a Clinical Psychologist in NHS services for children and adults with neurodevelopmental difficulties (ASD, ID, ADHD) I have become aware of the additional challenges families have in accessing and engaging with services when both a parent (or parents) and child(ren) have neurodevelopmental difficulties.'

Third author: 'As a Clinical Psychologist working clinically in NHS ID services I have been especially interested in how this methodology can allow the voices of marginalised participants to be heard'.

Final author: ‘As a Consultant Child and Adolescent Psychiatrist working with children with neurodevelopmental conditions, I have had to become a strong advocate for parents who have difficulty finding the right language to access care and are often misunderstood and blamed by the agencies that are there to support them’.

Ethical considerations and approval

To avoid parents first becoming aware of the possibility that they were autistic whilst participating in this study, only parents who were already aware that they may be autistic were approached to take part in this study. We were also aware that the outcome of the AQ had the potential to be seen as diagnostic tool and to steer parents in a certain direction with regards to whether or not to seek out an autism diagnosis. Therefore, we made sure to highlight in the participation information sheet that a high number of symptoms on the AQ was not equivalent to an autism diagnosis, nor did a low score exclude autism. We encouraged participants to discuss any concerns they had about their AQ score with the researcher and made it clear that only a formal diagnostic service could either confirm or refute a diagnosis of autism. Whilst children of participants were not informed that their parents were taking part in this study, awareness of the need to protect the confidentiality of these children meant that special attention was paid to the anonymity of participants, including ensuring all quotes were fully anonymised, and that participants age range rather than specific ages were given.

Full NHS ethical approval was granted by an NHS Research Ethics Committee (ref: 17/SC/0577) and the Health Research Authority.

Results

[Insert Table 2 here]

1. The interaction of parents' and children's autistic traits both helps and hinders parent-child relationships

All participants spoke about having an understanding of their child and their child's needs, which was often described as an "*instinct*" (Tanya) or "*intune-ness*" (Sarah), suggesting a sense of effortlessness. Participants related this understanding of their child to their own autistic experiences:

"So, from my own experience of having been a child, and thought that way, and I'm looking at Charlie thinking the same way too. That kind of enabled me to connect a little bit because I kind of understood, firstly not to touch his stuff, but also to ask the sorts of questions. Because I knew what was going on in his head. A little bit about how he was dealing with all these patterns and stuff"
(Neil).

This highlights that Neil's own autistic traits helped him to connect with his son, understand his son's thinking and how best to react. Some participants reflected on how having similar traits to their child merged their sense of identities. When discussing a shared need for routine, Sarah said "*I don't know if it's him that drives it, or me that drives it...*". Some parents reported that their own experiences of the world enabled them to have a better understanding of their child's experiences compared to their partners. Tanya described her son as "*very rigid and I just got it. Like Richard will be like, 'But why?' And I'm like, 'Well I understand.'*". This was something Kate appeared to value: "*It's quite nice that I can understand her...that I can translate*", suggesting an exclusive connection with her daughter and a sense of purpose.

Alongside the aforementioned understanding and connection with their children, most parents also highlighted a “*clash*” (Sarah; Emily) with their children, particularly when the parent and child had differing needs related to their autistic traits and were “*pulling in opposite directions*” (Hilary). For example, Emily described an intolerance to her children’s touch and feelings of guilt surrounding this:

“...if we’re a bit close to each other, that’s difficult. We do our best.... but I think that’s where we probably struggle the most, because I struggle probably most with sensory difficulties. And so that’s our main kind of clash. I think other things I can kind of let go. Or let them do their own thing, and I’ll do my own thing. Umm...but when you’ve got somebody on you that you really don’t want on you. And it’s awful because they’re your children...”

This concern was also reflected in Sarah’s account: “*...sometimes I have to sort of step back and think, am I missing the fluffy stuff?*” She seemed to reproach herself for neglecting her children’s needs while at the same time her contemptuous use of the word “*fluffy*” seemed to excuse herself from this.

Participants spoke about the different ways they responded to the ‘clash’ with their child. Some parents highlighted the need to prioritise their child’s needs over their own. This is illustrated by Emily:

“It’s really difficult. Because as the parent, you have to put their needs first...And both of them in their own ways are pushing me. She’s such a crier and that really...I find that really difficult to process. And then if Edward’s shouting and all I’m really trying to do is...kind of calm myself...There’s sort of 3 people who really want their needs met. And they want me to solve it. And

they look to you, and actually all you want to do is sit in the corner going “No! [laughs] I can’t. I can’t do it!”

Some parents spoke of times when they were unable to accommodate their child’s need, as illustrated by Kylie’s reaction to her son’s challenging behaviour: “*I end up shouting at him...which makes it worse...which then makes me worse*”, suggesting an escalating cycle of difficulties.

2. The personal impact of being a parent with autistic traits

Six participants spoke about the positive aspects of parenting. Neil described parenting as “*a blessing. It’s the most amazing thing.*” Hilary illustrated: “*I am very glad I became a parent. Because it has changed me as a person. Most of it for the better...*”. Some highlighted learning skills which may not have come naturally to them, such as learning to “*chit chat*” (Sarah), or becoming less rigid. For example, Hilary described having to be “*more laissez-faire with things...my control aspects*”, using the example of wanting “*all this Lego sorted by shape and colour. All of these sets completely made up and neatly displayed*”, which was not possible with young children. She described how it took her “*longer to give up*” compared to other parents as a result of her autistic characteristics.

For six participants, having an autistic child led to the discovery of their own autistic traits and, they mostly felt this was a positive outcome. Tanya felt empowered and surprised:

“What struck me the most was the lady in [local autism charity] who was diagnosed in her 60s and the way she was talking...I just got chills. It was just like she was talking about my life. It was just the most amazing thing...we were

there to learn about Alfie... how to be good parents but it ended up being about all about me.”

Others experienced anger and injustice for their own childhood, and not getting the additional support they had needed as a child with additional needs. Neil shared:

“I have to say at the beginning I was incredibly angry. I had all of these issues of not being able to cope at school and not having any friends. Of really being very socially isolated from everybody, of being blamed by your teachers and parents. Frankly for being stupid [...] So, I would say at some point, it led to a tremendous self-realisation and truth historically.”

Neil’s improved understanding of his traits enabled him to start to address his difficulties and how these impacted on his family:

“One of the reasons I wanted to get the ASD diagnosis, is because you can have a lot of temper or a response to things that is disproportionate to the activity, which of course is distressing to everyone else [...] So you have to work on that.”

Kylie, on the other hand, expressed that *“because of the way I am, with my anger and flying off the handle, I don't know how I'm supposed to stop that. Maybe I need therapy myself. But then I don't believe in that.”* Here she seemed unable to manage her difficulties alone, which may in turn impact on her family.

Participants discussed the relentless nature of parenting having a negative impact on their own well-being, as illustrated by Kate: *“You just don't get 5 minutes to stop. And it gets you down. And you think why me? I just want a break”* and Emily: *“so I spend a lot of time at such a heightened level as well. Because I'm like...just gotta keep going.”* Kylie described: *“Sometimes I don't want to be a parent...Sometimes I wish I could get out and go away, just not bother with anything.”* This suggests

overwhelming feelings of wanting to escape yet being trapped by the responsibility of parenthood. Four parents felt that becoming a parent had impacted on their mental health or exacerbated existing mental health issues. Rosie described “*a bit of PTSD going on*” when her son met the same developmental obstacles that she had. Hilary described parenting to be “*not so great for my mental health. But that's a lot to do with what was already there in me*” and Kylie said “*I've had depression for years. I just can't bring myself to be happy about anything, you know. So that's hard, on top of looking after kids and Dylan being challenging.*”

Participants experienced the home as being “*chaotic and challenging*” (Hilary), where the family were “*on eggshells*” (Kylie). Parents used powerful imagery associated with war, depicting the difficulties of living with an autistic child. Tanya described her house “*like Beirut*” and “*a bit of a war zone.*” Sarah shared that living with her autistic son was “*like living with a dictator.*” Participants stressed that they felt “*trapped*” (Emily,) and “*like I was being held hostage in my own home*” (Tanya), suggesting physical and emotional entrapment.

Parents were also impacted by the challenges of managing the whole family with an autistic child. Tanya explained: “*the autism seems to dominate most things that we do as a family*”, suggesting lack of control and hopelessness. Parents described finding it difficult to find time for their other children, who often had their needs “*overlooked*” (Neil). Tanya recounted a powerful conversation with her daughter: “*So she has gone to sleep crying before and said, 'Mummy, why is our life so hard?' So that's really difficult.*”

3. Home is a rare place of acceptance of autistic traits for parents and children

Seven participants highlighted experiencing their family and home as being a place of acceptance, away from a judgemental society: *“this is our normal.”* (Hilary) Sarah said:

“It’s a very accepting family [...] I think it’s the acceptance because within these 4 walls we are just who we are. Flaws and all. And...I think it’s about being appreciated for who you are as a person.”

There is a sense that *“flaws”*, or perhaps difficulties relating to autism, are accepted, which people outside the family couldn’t do. Emily described:

“I don’t know how somebody would live with us [laughter]. And that’s quite nice, knowing that what we’ve got is ours. And...we’re all weird together.”

In contrast, most participants perceived the outside world as rejecting of being different, for both themselves as being *“unconventional”* parents (Rosie), and for their children. They discussed difficulties with the *“pressure to be, like, a certain kind of mother”* (Rosie) and to *“run with the pack”* (Sarah). Sarah described having *“almost like two worlds [...] There are things that...that are just parts of me that I don’t...share widely”*, suggesting she felt unable to act naturally outside her home. Participants were concerned about societal judgment of their children’s challenging behaviours. Kate noted: *“all the parents are looking at you like ‘Oh my God, she’s like...Year 1 and she’s doing that!’”* and that people *“blame you as a parent.”* Some participants isolated themselves from peers to protect their children: *“I don’t talk about how hard things are. Because I don’t want them to judge my son”* (Tanya).

4. Managing the complexities of professional services - struggling to be heard, believed and supported

Parents' experiences of professional services were similar to their experiences of society as unaccepting and isolating. All participants apart from Sarah felt like they were constantly being rejected from mental health, educational and social services:

“Help! And they're just like, “Well what do you want us to do?” I've spoken to social service. Again, there's just nothing.” (Kate).

This was often due to families' difficulties not being deemed severe enough. Parents described services instructing them to “*come to us when it's serious*” (Kate) which invalidated their distress. Tanya experienced the lack of help as feeling like they were “*marooned at sea much of the time.*”

Some parents described their own difficulties hindering their ability to access those services which were available. For example, Tanya highlighted how not being able to drive to unfamiliar places stopped her from accessing ASD support groups:

“I know some of these support groups are like in [local towns] and places like that I can't get myself to. So that's a barrier, a self-inflicted barrier, I guess. But not one that I can really overcome easily.”

Parents reported that professionals frequently failed to hear or validate the complexity of being in a family where both the parent and child have difficulties:

“There hasn't been anyone who's known exactly what to do. They're like, ‘Gosh! It's really hard isn't it? Anyway, see you in six months at the next meeting.’” (Emily).

Professionals often failed to acknowledge and provide space for the parental difficulties:

“And there's nobody checking in, going [...], ‘Are you doing ok? Are you doing fabulously? How about, you come in and just you and me, we have a

chat?’ They just go, [claps] ‘You’re doing brilliantly. Very well done. Next! Next person! Rosie is doing brilliantly. Next!’ (Rosie)

Participants discussed how they coped with a lack of support from professional services. Most participants spoke of the need to “*fight*” (Emily) services and be an “*ambassador*” (Rosie) for their child to receive adequate support, which was often fuelled by parents remembering their own inadequate support as a child:

“...I don’t want her to go through life as I have. I want her to be happy. I want her to have that support. I don’t want her to go under the radar” (Kate).

Many participants relied on their partners: “*if [my husband] is around obviously that helps because we sort of do the ‘divide and conquer’*” (Hilary). Most also found that the “*support we do have is from friends and family*” (Neil). Most parents found or created their own support and resources, which often felt like “*...I’m winging it. I’ve just figured out that’s something that works.*” (Emily) and:

“I’ll try other things which I’ve tried at work which I know have worked with other children. You know like visual timetables and different things. So I’ve got a toolkit.” (Sarah).

Neil’s wife “*set up ...her own social enterprise, geared up to supporting parents with autism.*” The self-agency displayed by Sarah and Neil was tied to existing resources, such as Sarah’s job and Neil’s academic background: “*We’re health literate parents. I will probably know more about autism than a very large number of people*” suggesting those without such resources may struggle to cope so well.

Discussion

This qualitative study was conducted to explore the lived parenting experiences of parents of autistic children who themselves have significant autistic traits.

Participants' accounts revealed novel and important insights into the parenting experiences related to parental ASD traits, and also drew parallels with the parenting experiences of other parents of autistic children. Four themes emerged: (1) The interaction of parents' and children's autistic traits both helps and hinders parent-child relationships, (2) The personal impact of being a parent with autistic traits, (3) Home is a rare place of acceptance of autistic traits for parents and children, (4) Managing the complexities of professional services - struggling to be heard, believed and supported.

The first theme spoke to how parents, through their own experiences of having autistic traits, could better understand their child's autistic needs and adapt their parenting accordingly, often in a way that their neurotypical partners could not. This understanding seemed to be most prominent around their child's need for routine and order which tended to mirror their own needs. The words and phrases that parents used to describe this experience included: "instinct", "in-tuneness", and "thinking the same way" indicated how easily this understanding of their child came to them. This experience has not previously been described in the autism parenting literature and suggests that (some) parents with autistic traits may have a capacity to instinctively understand their autistic children in a way that neurotypical parents do not. The first theme also spoke to the significant difficulties parents experienced when their own autistic needs 'clashed' with their child's needs, which has not been previously highlighted in the ASD parenting literature. This was particularly striking in the areas of sensory sensitivity and emotional responsiveness. Emotional responsiveness, alongside behavioural control, is a very important aspect of parenting and includes

parenting behaviours that express warmth, sensitivity and approval towards the child (Johnston et al., 2012). The language used by participants concerning their emotional responsiveness was powerful (e.g. “am I missing the fluffy stuff?”) and illustrated how parents’ emotional needs interacted with those of their child, which impacted on their ability to provide effective support (e.g. “all you want to do is sit in a corner going ‘No I can’t do it’” and “I end up shouting at him...which makes it worse...which then makes me worse”). This mirrors some ADHD literature, where parents with ADHD have been shown to struggle more than parents without ADHD to be consistent and positive when parenting their child with ADHD (Friedrich et al., 2017).

Within the second theme, parents described the positive and negative personal impact of being a parent with autistic traits. The positive personal impact of parenting a child with ASD, such as finding personal strength and increased compassion, has previously been reported (e.g. Young et al., 2020). For the parents in our study, however, the positive personal impact often related to gaining skills which were possibly more challenging to them because of their increased ASD traits. For example, being a parent forced participants into situations they may have previously avoided and gave them opportunities to learn social skills and become more flexible. One parent spoke of learning to engage in social “chit chat”, others described having to learn to deal with change and becoming “more laissez-faire with things”. Furthermore, the point of their child’s diagnosis was often the moment parents realised they may themselves be autistic and this helped them enormously in putting their own difficult experiences, both as a child and now as an adult, into perspective. The words parents chose illustrated how profound this new understanding was for them: “a tremendous self-realization and historical truth”, “I got the chills”, “the most amazing thing” and “it ended up being all about me”.

Regarding the negative personal impact of parenting an autistic child, parents described the relentlessness, chaos, lack of control and constant need to adapt to their child needs. This was exhausting, impacted on their mental health, and could lead to a feeling of a total loss of control and safety at times. The extent of these feelings is depicted in their choice of words: “Like Beirut”, “a war zone”, “a hostage” and “trapped”. These experiences are commonly shared by all parents who look after children with ASD, where feelings of being overwhelmed and exhausted, and increased rates of mental health difficulties have often been described (e.g. DePape & Lindsay, 2015; Scherer et al., 2019). Further to this, however, parents in this study were deeply affected by having to bear witness to their child having similarly difficult childhood experiences to their own. This made parents feel “incredibly angry” and some experienced “a bit of PTSD”. The information provided by the parents in this second theme is important as it suggests that having an autistic child may help autistic adults to develop their self-awareness, reduce unhelpful avoidance and to practice and develop social skills and tolerance/flexibility. It also reminds us that parenting an autistic child (or children) brings many additional challenges to adults with autism who already have an existent increased risk of developing mental health difficulties (Russell et al., 2014). Given that parental wellbeing impacts the wellbeing of autistic children (Zhou et al., 2014), further research to explore this and the factors impacting on parenting stress (e.g. clashes in autistic symptoms) is urgently needed in this group of parents.

The third theme of home being an “accepting” place away from the outside world has positive aspects and has not been previously reported in the ASD parenting literature. Phrases that depict these positives are “we’re all weird together”, “accepting family” and “appreciated for who you are”. The more troubling side to this theme was

that the home was used as a place to hide away from a world which was perceived as highly blaming of these parents and highly judgemental of their children's behaviour. Statements such as "all the parents are looking at you" and "I don't talk about how hard things are because I don't want them to judge...." depict how isolating these experiences can be. Whilst feeling judged, blamed and isolated is a common experience for parents of autistic children (Ooi et al., 2016), the lack of a social support system is likely to even more exaggerated in this group of parents, given that social isolation is already commonly reported by adults with autism (e.g. Punshon et al., 2009). Therefore, it is perhaps unsurprising that parents in our study sought and found acceptance in their home. These findings are in line with previous research which has found that autistic people find acceptance with other autistic individuals (Punshon et al., 2009; MacLeod & Johnston, 2007). It is important for professionals and other parents to understand that, although home-life is an accepting place, it is likely that parents with high traits of autism may have additional difficulties seeking refuge elsewhere, given their common experience of social isolation, stigma and rejection.

The final theme, parents finding it difficult to find support through professional services, is an extremely important one and will hopefully be able to inform future service planning and delivery. As has previously been described by parents with autistic children (see DePape & Lindsay, 2015 for review), parents in the current study described having difficulty accessing suitable treatment for their children and a sense of helplessness, using language such as being "*marooned at sea much of the time.*" In addition, participants reported that some of their own traits, caused further difficulties in accessing services for their children. Parents in the current study described having to find and develop their own support networks and having to "fight" to access the

services they needed. This was easier for some parents than others, depending on the resources available to them. These experiences mirror the experience of other parents of children with autism who developed their own coping strategies to manage caregiving and access to services (DePape & Lindsay, 2015) and the challenges they experienced depended on factors such as socioeconomic status and professional background (Young et al, 2020). When parents were able to access treatment services, they experienced unsatisfactory communication with professionals, in line with the experience of other parents of autistic children (Wilson & Peterson, 2018). For example, parents felt that professionals did not accurately reflect their experiences, such as complimenting parents on how “brilliantly” they were doing while they were struggling to cope on a day-to-day basis. This is mirrored in the physical health literature where individuals with ASD have been shown to be at a greater disadvantage when trying to access physical healthcare service due to difficulties in areas such as communication, sensory sensitivities and cognitive processing which is measurable in much poorer physical health care outcomes (see Mason et al., 2019 for review). This last theme provides crucial information for government funding bodies and the further fine tuning of support services for autistic children and their families.

There are a number of limitations of the current study. First, the use of a screening tool (the AQ) to identify participants raises ethical considerations and limitations; some parents did not have a diagnosis of autism and therefore may not be representative of adults who meet a diagnostic threshold of autism. However, the cut-off was chosen due to its high sensitivity and specificity and some researchers now describe cut-offs as arbitrary, conceptualising autism dimensionally rather than categorically (e.g. Happé and Frith, 2020). Secondly, IPA calls for a homogenous sample, and consequently seven out of eight participants were women, all were White

British or White Irish, and none had ID, despite the high co-morbidity of autism and ID (Baird et al., 2006). The bias towards recruiting mothers is likely to reflect their greater care-giving roles with autistic children (Gray, 2003) and sheds light on the experience of women with significant autistic traits, an area which is under-researched. Whilst qualitative research is not concerned with generalisability, this means that the findings do not speak to fathers' experiences, and may miss gender-specific parenting experiences (Lau et al., 2016). Finally, given that challenging behaviour commonly contributes to parenting stress in parents of autistic children (Ooi et al., 2016), the current research is limited by not having explored the extent of participant's children's challenging behaviour.

Implications

Given that research in this area is in its infancy, further research is required to understand this population of parents and how best to support them. Quantitative research as well as further qualitative research is needed to extend the current findings and should include autistic fathers, autistic parents with comorbid intellectual disabilities, and parents of autistic children with a formal diagnosis of autism. Future research might directly compare the parenting experiences of autistic and neurotypical parents of autistic children, the process and mechanisms of parent-child interactions in families where both a child and parent are autistic, and the impact of targeted autism interventions on the parent and family which take into account parental autism as a moderating factor (e.g. de Veld et al., 2017; Parr et al., 2015). It will also be important to gather information on autistic and neurotypical children's experiences of being parented by an autistic parent.

Services supporting autistic children should consider the novel findings and implications of this study and incorporate them into service planning and delivery. Better knowledge and understanding of the unique experiences of parents of autistic children who themselves have significant autistic traits will lead to improvements in the quality of support such families receive from professionals working in healthcare, social care and educational settings. Potential adaptations in specialist healthcare settings (such as CAMHS) that could be made at assessment and during treatment include:

1. Routinely asking and discussing with parents whether they consider themselves to have autistic traits, and whether they believe that these interact with their child's needs and difficulties. Developing a formulation so that their unique strengths and difficulties can then be shared with other professionals involved in their children's care will be vital. This document could be used to encourage and direct 'reasonable adjustments' to such families' support.
2. Encouraging parents who believe that they may be autistic to seek diagnosis, if appropriate, and supporting them to identify and access local services.
3. Routinely screening for, and addressing, mental health difficulties in parents of autistic children, particularly those with clear/obvious autistic traits.
4. Tailoring post-diagnostic parent psycho-social support to the social communication and sensory needs of parents with significant autistic traits and consider smaller autism-friendly post-diagnostic groups.
5. Looking at providing (extra) respite for families in which both a child and parent have significant autistic traits as they may have less access to natural social support than other families.

6. Developing specific interventions to support parents with autistic traits to adapt and change their behaviour in order to support their child, given that these parents may find adapting and changing more challenging than other parents.
7. Providing further education and training to staff working in mental health, social care and education services. This could include information on the hereditary nature of autism and how autistic parents and parents with significant autistic traits will have social communication difficulties, a need for sameness and sensory needs that could impact on their functioning and relationships with professionals.
8. Carrying out local analyses of the time and resources that are needed to provide adequate support to families in where both child(ren) and parent(s) have significant autistic traits.

Conclusion

In line with the experiences of other parents of autistic children, parents with significant autistic traits found parenting to be both enriching and challenging, and found services very challenging to navigate. Although caution must be taken when drawing direct comparisons with this existing research, given that parental ASD traits were not accounted for, it suggests that parents with autistic traits share common experiences with other parents of children with autism. However, the current study also provides insights into the unique experiences of these parents. For example, parental traits exacerbated some existing challenges, such as when the traits of both child and parent clashed, or navigating services due to their additional needs. On the other hand, parents experienced novel positive aspects of being a parent with autistic traits, such as having an enhanced relationship with their autistic children through

shared or similar experiences, or having the opportunities to learn social skills and become more flexible. It is clear that further research and adequately funded, tailored and accessible services for families in which parents of autistic children are autistic or have a high level of autistic traits is vital.

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Table 1.
Participants demographic information

Participant						Child with ASD		
Name ^a	Gender	Age range	AQ score ^b	ASD Diagnosis	Co-morbid diagnoses ^c	Name ^a	Gender	Age range
Kate	Female	26-30	39	No	Yes	Zoe	Female	5-6
Emily	Female	26-30	45	Yes	Yes	Edward	Male	7-8
Sarah	Female	46-50	38	No	No	Jay	Male	9-10
Tanya	Female	41-45	39	No	No	Alfie	Male	7-8
Hilary	Female	41-45	46	Yes	Yes	Lizzie, Rachel	Female Female	11-12 7-8
Kylie	Female	31-35	32	No	Yes	Dylan	Male	11-12
Neil	Male	46-50	37	Yes	No	Charlie	Male	7-8
Rosie	Female	41-45	34	No	Yes	Kip	Male	15-16

Note: ASD = Autism Spectrum Disorder

^a Names have been anonymised and a pseudonym used

^b All participants met cut-off criteria of 32

^c Details regarding comorbid diagnoses (including ADHD and mental health disorders) have been removed to ensure confidentiality.

Table 2.

Superordinate and subordinate themes and endorsement by participants

Superordinate and subordinate themes	Total	Kate	Emily	Sarah	Tanya	Hilary	Kylie	Neil	Rosie
1. The interaction of parents' and children's autistic traits both helps and hinders parent-child relationships									
1a. Being 'in tune' with their child with ASD	8	*	*	*	*	*	*	*	*
1b. A 'clash' between parent and child	7		*	*	*	*	*	*	*
1c. After the 'clash': Being an accommodating parent	8	*	*	*	*	*	*	*	*
2. The personal impact of being a parent with autistic traits									
2a. Parenting changes you for the better	6		*	*	*	*		*	*
2b. Parenting enables self-reflection	7	*	*		*	*	*	*	*
2c. Negative impact of being a parent	7	*	*		*	*	*	*	*
2d. Managing the 'war zone' with a child with ASD	8	*	*	*	*	*	*	*	*
3. Home is a rare place of acceptance of autistic traits for parents and children									
3a. 'This is our normal'	7	*	*	*	*	*		*	*
3b. The outside world is threatening	6	*	*	*	*			*	*

4. Managing the complexities of professional services - struggling to be heard, believed and supported

4a. Crying out for help and being rejected	7	*	*		*	*	*	*	*
4b. Failure to be heard	6	*	*		*	*	*		*
4c. 'Winging it' and 'fighting': Coping with a lack of support	8	*	*	*	*	*	*	*	*

Note. * = endorsed by participant
