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'Adolescence kicked in . . . and you need help again': A qualitative study of the experiences of parents of autistic teenagers with mental health difficulties or behaviours that challenge

Suzanne Mukherjee and Bryony Beresford

Abstract

Relatively little is known about the experiences of parents of autistic teenagers, with the existing research on this life stage principally about transition. This study sought to address this gap. It focused specifically on parents of autistic teenagers with mental health difficulties and/or behaviours that challenge (MHD/BC). The study design was qualitative and used in-depth interviews to collect data. Thirty-three parents of 31 teenagers (15–19 years) living in the United Kingdom were purposively sampled and recruited from an existing research cohort. A thematic analysis was undertaken, adopting the framework method. Parents typically reported the emergence of new MHD/BC, or existing difficulties becoming more severe, during the teenage years. At the same time, they described feeling de-skilled and uncertain about how best to support their child. Many parents also referred to deteriorations in their own physical and emotional health. Very few had accessed beneficial professional support during this period. Findings add weight to the case for increasing support to parents of autistic teenagers, and the need to work preventatively to reduce the risks of MHD/BC emerging or increasing in severity during the teenage years.

Lay abstract

Being a teenager can be challenging for any young person, and it is during this stage of life that most mental health difficulties (MHDs) emerge. The teenage years can be even more demanding for autistic young people who are known to experience more emotional distress and MHDs than their neurotypical peers. Parents are an important source of support for most children and young people, including those who are autistic. It therefore surprising that there is very little research on the experiences of parents of autistic teenagers. Most of the research that has been carried out is specifically about leaving school or moving from children's to adult services. The purpose of this research was to understand the experiences of parents of an autistic teenager with mental health difficulties or behaviours that challenge (MHD/BC). We interviewed 33 parents of 31 teenagers aged between 15 and 19 years. Most parents said their child experienced new or more severe MHD/BC during their teenage years. This was upsetting to witness and caused them a lot of worry. Many described not knowing how best to respond. Others said that their efforts to support their child were unsuccessful. The difficulties parents experienced had an impact on their day-to-day lives and many said their own physical and emotional health had worsened as a result. Very few parents had received help from mental health or social services. The findings highlight the importance of supporting parents of autistic teenagers, including intervening to support autistic teenagers.

Keywords
adolescents, family functioning and support, lived experience, mental health, parents, qualitative research

Introduction

As with any child, parents are a primary source of support and key influence on outcomes for autistic children and young people. It is therefore important that there is an

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awareness and understanding of parents' experiences and their potential support needs. However, to date, most research on this topic has focussed on the childhood years (Cheng et al., 2023; Colvert et al., 2021; Ooi et al., 2016). This is surprising given that adolescence, typically defined as spanning 10–19 years (Sawyer et al., 2018), is a life stage characterised by physical, cognitive, social and behavioural development and change (Jaworska & MacQueen, 2015; Mansfield et al., 2020). Such changes can be challenging for any young person to negotiate and resolve, increasing the risk of mental health difficulties (MHDs; Solmi et al., 2022). Indeed, it is during this period that most MHDs emerge (Sacco et al., 2022). Importantly, existing evidence suggests that being autistic further adds to the demands and challenges of adolescence, with higher rates of emotional distress and MHDs observed compared to neurotypical peers (e.g. Colvert et al., 2021; Hudson et al., 2019; Rydzewska et al., 2018; Tseng et al., 2020; Widnall et al., 2022). This increased risk has been attributed to autistic traits (e.g. differences or difficulties with communication, an intolerance to change or uncertainty), the co-occurrence of other neurodevelopmental disorders (e.g. attention-deficit hyperactivity disorder (ADHD)), struggles with acceptance of the autism diagnosis and how it relates to their identity, and external risk factors (e.g. bullying, social isolation and academic pressures) (Accardo et al., 2024; Horgan et al., 2022; Jenkinson et al., 2020; Mukherjee & Beresford, 2023; Toseeb et al., 2018, 2020).

However, despite evidence of the demands, challenges and risks adolescence may bring, little *specific* attention has been paid to parents' experiences during this period (Horgan et al., 2022; Warner et al., 2019). Furthermore, the research which has been carried out has focussed primarily on parents' experiences of planning for and supporting 'transition' (e.g. leaving school, moving to further/higher education or adult services, or supporting the move to more independent living) (Agarwal et al., 2022; Anderson et al., 2018; Hoffman & Kirby, 2022; Wolpe et al., 2023). The few studies which have explored the wider experience of being a parent of an autistic adolescent report both the emergence of new challenges and the persistence of struggles and difficulties encountered during childhood (Ho et al., 2018; Mount & Dillon, 2014). However, this body of work is very limited.

This article reports a study that sought to add to this gap in the literature by investigating the lived experiences of parents of autistic teenagers and, specifically, those with a history of mental health difficulties and/or behaviours that challenge (MHD/BC) (for further information on these terms see Michaud & Fombonne, 2005; Wolkorte et al., 2019). The study was one component of a wider programme of research on improving the mental health outcomes of autistic adults by improving the way MHD/BC are identified and managed in childhood and adolescence (https://www.fundingawards.nihr.ac.uk/award/RP-PG-1211-20016).

The study had two core objectives. The primary objective was to elicit parents' 'theories' about their child's mental health trajectories, including the factors they believed influenced the development, or not, of MHD/BC (Findings reported elsewhere (Mukherjee & Beresford, 2023)). A second objective, and reported in this article, was to explore and understand the experiences of parents who reported their child was currently experiencing MHD/BC or had previously experienced them as a teenager. Here the research questions we sought to address were:

- What are parents' observations of their child's mental health and behaviour during adolescence, and compared to the childhood years?
- What are parents' experiences of supporting and responding to MHD/BC during adolescence?
- How do parents describe life with an autistic teenager who has MHD/BC?

Methods

Study design

A cross-sectional 'generic qualitative' design (Bradbury-Jones et al., 2017; Patton, 1990) was used, informed by phenomenological and narrative approaches. Generic qualitative studies take a pragmatic approach, with the objective being to generate the evidence needed to address the 'real-life' issue or challenge under investigation, rather than adhering strictly to a philosophical position or method of inquiry. The approach is common in applied health and social care research. The study was approved by an National Health Service (NHS) Research Ethics Committee (reference no: 18/WS/0204).

Sampling

The study's target sample was parents of ~35 autistic teenagers with a range of histories of MHD/BCs. Parents were recruited from a United Kingdom community cohort of autistic children ($n = 277$), born in two London districts between September 2000 and August 2004. They were recruited to the cohort between 4 and 8 years of age. The cohort was created to investigate mental health outcomes during childhood and adolescence (Hollocks et al., 2023; Salazar et al., 2015). At the time of sampling for this study, there had been three waves of data collection, including measures of intelligence quotient (IQ), mental health and behaviour. Wave I occurred at recruitment (4–9 years), Wave II 7 years later (11–15 years), and Wave III around 2 years after that (13–17 years). Most families ($n = 214/277$) had participated in all waves. Of these, 192 families had consented to be contacted about additional studies. These families formed the study's sampling pool. The Cohort Team shared an anonymised dataset, containing only data relevant to sampling, with the research team. This dataset excluded seven families known to the Cohort Team as currently facing significant difficulties.

A purposive sampling strategy ensured representation of children with and without learning difficulties (IQ </> 70), different genders and MHD/BC histories. MHD/BC histories were determined using scores (above or below clinical cut-off) on a global, parent-completed measure of MHD/BC (Waves 1 and 2: the Developmental Behaviour Checklist (Einfeld & Tonge, 1995); Wave 3: the Strengths and Difficulties Questionnaire (https://sdqinfo.org/)).

Recruitment

Recruitment was conducted in phases approximately 2 years after Wave 3 (September 2019–February 2020). The target sample was achieved after 126/185 families had been approached about taking part. To start, the Cohort Team phoned families to seek consent to post them a study recruitment pack. Almost all families (*n*=122) agreed. The pack included: invitation letter, study information sheet, 'expression of interest' (EoI) form (returned direct to the research team), and pre-paid reply envelope. On receiving an expression of interest (EOI) form, a researcher telephoned the parent. The call was used to answer parents' questions, provide further information and, if agreed, arrange an interview.

Parents of 41 families returned EoI form. Of these, 37 were contacted by the research team. The remaining four respondents, who were among the last to receive a study recruitment pack, were notified that they were not required because the target sample had been achieved. Of the 37 approached, 31 were recruited. In two instances, both parents wanted to take part and a joint interview conducted. Among those who responded but were not recruited (*n*=6), one declined, two were uncontactable, and four agreed to be interviewed but could not be contacted at the arranged time.

Data collection

In-depth interviews were conducted by one researcher (SM). Parents could choose to be interviewed by telephone (*n*=29, including 1 joint interview) or face to-face (*n*=2, including 1 joint interview). Informed consent was taken immediately prior to interview. For telephone interviews, the consent process was audio-recorded. For in-person interviews, written consent was secured.

A topic guide ensured consistency and comprehensiveness of topics covered. The interview comprised three main sections:

1. Eliciting parents' views and perceptions of their child's MHD/BC from diagnosis through to the time of the interview.
2. Aspects of their child's mental health and behaviour they find particularly distressing or challenging, ways of managing and experiences of help-seeking, and the impact of these experiences and challenges on them and the family.
3. Parent's explanations or 'theories' about their child's mental health trajectory were elicited.

The data reported in this article draw on Sections 1 and 2 (see Supplementary File 1 for the interview topic guide). Interviews lasted 34 to 192 minutes (median 74 minutes). All were audio-recorded and transcribed verbatim.

Data analysis

A thematic analysis was undertaken adopting the framework method (Gale et al., 2013; Goldsmith, 2021; Miles et al., 2019; Spencer et al., 2014) (Supplementary File 2 provides a fuller account). This comprises: data familiarisation and immersion; development of an analytical/coding framework, including a priori and newly generated codes (Supplementary File 3); extracting coded data into a series of thematic charts in the form of summaries and verbatim quotes; and the creation of analytical notes based on scrutiny of the thematic charts. Data were compared *within* participant's accounts to explore changes over time, and *between* study participants to identify patterns and differences, and to explore whether the child's or families' characteristics (e.g. presence of LD, lone vs two parent families etc.) appeared to influence parents' experiences. Both researchers (SM, BB) worked on the analysis with SM leading on data extraction and creating analytical notes. These were refined and developed through an iterative process of discussion and revising. Visual displays (e.g. mind maps, timelines) (Wheeldon & Faubert, 2009) were used to support the analytical process (e.g. mapping different facets of parental experience, changes in parenting challenges, etc.).

Participatory methods

Two advisory groups supported the programme of research of which this study formed a part. One group comprised parents of autistic children (*n*=6), and the other, autistic adults (*n*=5). Group members were recruited via notices distributed by a national autism charity to its supporters. The groups met in-person 11 times over the course of the research programme, equivalent to approximately twice a year. An autism practitioner independent of the research team organised and facilitated meetings. For the study reported in this article, face-to-face meetings were used to fine-tune study objectives, critically review the interview topic guide, and advise on recruitment materials and processes. The researchers met again with both groups to discuss initial findings, including those presented in this article. Both groups agreed that parents' stories collected by this research were important and, typically, unheard. They also agreed that some findings – particularly parents' descriptions of the adverse impacts of living with an autistic teenager with MHD/BC – *may* be regarded as portraying autism negatively and privileging parents' voices over autistic young people themselves. However, both groups were unanimous that the researchers should seek to publish and present these particular findings, believing such evidence would help to build the case for improvements in the care and support provided to autistic teenagers and their parents.

Positionality statement

The researchers (SM, BB) are both academics who work on applied health research projects that seek to generate evidence relevant to policy, service development/delivery, or practice. Both have led/been involved in other studies on the care and support of autistic people across the life-course. Neither holds clinical or other professional qualification. Both are neurotypical and have experience of being parents of teenagers.

Data availability statement

Study data are to be archived with the University of York Research Data Service. Access to anonymised data may be granted following review by the corresponding author.

Findings

Sample characteristics

Almost all parents recruited to the study ($n=30/33$) reported their child was currently experiencing and/or had experienced MHD/BC during their teenage years. It was these parents' accounts that are the focus of this article (Data from all parents were used to address the study's other objective (Mukherjee & Beresford, 2023). These 30 parents (27 mothers, 3 fathers) represented 28 autistic teenagers. Sociodemographic information was collected from primary point of contact. In all but two cases, this was the mother. Fourteen identified themselves as White British, 10 as Black British and the remainder as another ethnicity. Most were married/co-habiting ($n=21$). None identified themselves as autistic.

The autistic teenagers (18 male, 10 female) were aged 15 to 19 years (median 17 years). Age at diagnosis ranged from 20 months to 8 years (median 42 months). Nine also had a learning disability. Almost all ($n=27$) were in full-time education and lived in the family home (or returned during university holidays). Most ($n=24$) had at least one sibling and six had at least one other sibling with an autism diagnosis. Five were under the care of Child and Adolescent Mental Health Services (CAMHS) or adult mental health services when the study was taking place.

Locating difficult experiences in a wider perspective

Many parents talked easily about their child in positive terms, describing their positive characteristics and strengths (e.g. loving, funny, intelligent, etc.) and, for some, pride in how their child had overcome the challenges they encountered in their day-to-day lives. At the same time, there were difficulties and struggles which, for many, increased when their child reached adolescence and through their teenage years. These are described in the following section, after which we go on to report parents' accounts of their experiences of parenting during the teenage years, the impacts of their child's MHD/BC on their everyday lives and well-being, and contacts with health and social care services over this period.

Parents' descriptions of changes in mental health and behaviour

Parents' accounts of their child's early and middle childhood included descriptions of behaviours they had found challenging or episodes of significant emotional distress (i.e. meltdowns). Reference to, or labelling, their child as having an MHD was unusual and, if mentioned, was framed as 'anxiety' or a related term. Most parents also described these difficulties becoming less troubling as they and others (e.g. child's school) learnt how to support their child. However, their descriptions of their child's teenage years differed. The majority reported that issues with their child's mental health or behaviour had become more severe.

> I always thought of him as my happiest child. If something went wrong then, yes, he would get upset, but it didn't go on for ages, and it was usually fairly easy to see what was wrong. Whereas now I do feel like that he's often cross and grumpy and I can't always tell why. . . . [*Recently]* he's sometimes says things like 'I, sometimes I worry I won't be able to control my anger'. (ID 743)

Over half described the teenage years as the most difficult and wearing time they had experienced to date.

> So I would say from diagnosis at junior school she kind of got on quite well. She discovered walking holidays and things, and we used to do that. And she loved nature and being outside [*but*] of course she didn't like busy places and loud places. So that was kind of quite a good time, I suppose. Then adolescence kicked in and then that's when I think you need help again. (ID 326)

Specifically, a greater diversity of (sometimes severe) MHDs were described including anxiety, depression, suicidal ideation or attempts, eating disorders and obsessional compulsive disorders.

> He worries a lot now, more than what he used to. He's constantly worrying about things. [*In comparing to how child was when younger*], . . . it's constant, rather than an outburst of behaviour I'd say it's more depression and anxiety. (ID 6)

> The meltdowns are non-existent now. There's not a physical meltdown, but it's internal[*ised*]. She cries, but she's not able to say why she's crying. It's not physical now, it's not overly obvious now, it's internalized. (ID 162)

Furthermore, parents' descriptions of meltdowns changed from being focused on times when the child injured themselves to situations involving harm to others or damage to property.

Parents also reported newly emerging behaviours they found difficult and upsetting to witness, were unsure how to respond to, and/or where efforts to reduce these behaviours had proved unsuccessful. These included non-accidental self-harm (i.e. cutting, stabbing), severe addiction to video games (manifest in refusing to stop to eat, sleep or wash), controlling behaviour within the home (e.g. insistence that lights never switched on, windows needing to be kept open), viewing/posting sexual content online, viewing violent content online, and criminal/ behaviours (e.g. stealing). Alongside these emergent issues, many parents also described behaviours which, in the past, had not particularly concerned them but now caused them significant worry and unease. This was particularly the case for social withdrawal (e.g. reluctance/refusal to leave bedroom or home).

> He doesn't really like going out so much now. He doesn't like people so much, even people he knows he'll just go and run into the bedroom now instead of like coming and chatting to them. So that's a big thing now that's changed since he was younger. (ID 68)

In addition were accounts of situations where previously a child had complied with instructions, or welcomed their assistance or involvement, but now resisted or challenged such interventions. Some parents described this being manifest as verbal or, more unusually, physical aggression.

Struggles with parenting during the teenage years

Parents consistently reported that the changes described above had left them feeling de-skilled and uncertain about how they should parent their child. This was not something they had anticipated, and it contrasted strongly with their accounts of early and middle childhood where almost all described reaching a state of feeling confident and competent as a parent. A number of different, and sometimes inter-related, factors appeared to contribute to this.

Existing strategies no longer appropriate or effective. As noted earlier, parents typically described a process of learning 'what worked' for their child in the time following diagnosis, and this had led to relatively settled and straightforward period. However, this changed during late childhood and the early teenage years. Crucially, many parents said they had not been able to identify alternative strategies and ways of supporting their child that 'worked' for them and their child.

> They [positive behaviour management strategies] worked for a good few years, up until about four years ago. Now it just feels like we're fighting a losing battle cos we're still using the same techniques but they're not working anymore. (ID 449)

Parents also observed that some strategies they had used in the past were no longer feasible, or appropriate. A common example parents gave was that the option to pick up their child in order to remove them from a stressful situation, or overcome a refusal to do something, was no longer possible.

> When he was little you can move him. . . . And then he gets to an age where now you can't even get him in the car . . . it was easier when he was little. (ID 277)

Uncertainty in how to respond to newly emerging MHDs. Parents described not knowing how to respond to their child's newly emerging MHDs. This was felt particularly keenly when these difficulties risked the child coming to significant harm (e.g. serious self-harm, suicidal thoughts)

> I genuinely don't know what I should be saying . . . I don't know what I should encourage, what I shouldn't encourage. I mean with the self-harming in particular, I Googled it and I read about it and all that kind of thing, but ultimately I was, and still am, very worried about doing the wrong thing and making things worse. So no, I think actually what I feel is monumentally out of my depth. (ID 743)

Avoidance of confrontation due to fears of escalation or injury. Some parents reported that their child's increasing size and strength made them fearful of doing anything which could result in a conflict with the child or the child being aggressive. This often led to them to avoiding confrontations which, in turn, rendered parents feeling they had less control over what happened in the home (e.g. noise and light levels), or no longer felt able to talk to their child about things that concerned them (e.g. amount of time spent video gaming).

> He's always obsessed with something [*video games*]. So at the moment it's FIFA and there won't be any boundaries with that one, unless the wi-fi lead is taken out. If we do stop him he will get aggressive . . . So, you know, I think my husband's sort of given up completely. (ID 735)

Negotiating developmental changes in autonomy. One parent, whose child did not have LD, explicitly attributed some of the challenges they were experiencing to the consequences of their child's growing autonomy. They described the difficulties of knowing how best to resolve their child's desire for greater autonomy with their concern about the risks that brought because of their child's vulnerabilities.

> He doesn't want me to take him out, but he wants to go out. He's not patient with other people because he doesn't always understand what's going on, so it's a big safeguarding thing . . . luckily there's only been a couple of incidents but for me they're bad enough for me to worry. (ID 266)

Other parents' accounts also revealed struggles with identifying the situations or areas of their child's life in which they should be involved or have a say, and those where they needed to step back. This could be a source of tension or conflict.

Adverse changes in the parent–child relationship. Several parents attributed new or increased difficulties or uncertainties with parenting to adverse changes in the nature of the relationship between them and their child. They described a previously warm relationship being lost and/or their child becoming verbally abusive or aggressive towards them. Sometimes parents directly attributed this deterioration in their relationship to the sorts of conflicts described earlier in this section. However, other parents had not been able to identify an explanation for it. Either way, as well as being difficult to come to terms with, parents said it made it harder for them to support their child.

> There's all the swearing thing that goes on and the moods, the way that he spoke to his father and I . . . [*a*] disrespectful way . . . that's not how we brought him up. I found that really hard. (ID 266)

Impacts of MHD/BC on daily life

Parents were asked about the impact their child's MHD/BC had on their and their families' day-to-day life. We describe key themes below before moving on to report how these experiences impacted parents' health and well-being.

Increasingly confined to the family home. Many parents of children with LD reported feeling unable to leave their child alone in the house, or were very uneasy doing this, due to fears for their safety. Alongside this, some described feeling less able to go out with their child both because there was limited public tolerance for certain behaviours (e.g. meltdowns) over a certain age, and concerns that their child's behaviour may worry members of the public. Others explained that their child was unwilling to go out. The consequence of both these situations was a decrease in the time parents spent outside the family home.

> He won't go out at all, he doesn't go on holiday, he doesn't want to go anywhere, and because he doesn't go out I can't go anywhere either because he hasn't got a sense of danger. (ID 6)

> . . . so it's got worse because other people are much more aware and wary. . . it's just not worth taking him out because it's just so much hassle. . . [ID 68]

Living with the threat of violence. Some of the teenagers represented in the study had been physically violent (e.g. hitting, biting, pushing to ground) towards a/their parent, with this sometimes causing an injury which took time to heal. Where this had happened, parents said the threat of physical violence was a constant presence in their lives. Alongside this were instances of accidental injury. Their child's increased physical size and strength heightened this perceived threat, or the seriousness of the injury sustained.

> The challenge of having a teenager, as opposed to a small child, is that it hurts: he comes across like he's going through puberty and also the terrible twos mixed in together. So it's quite a difficult mix that. (ID 462)

Among mothers, many described an increased sense of fear and vulnerability because, or at times when, they were the only adult at home.

> If I feel that she's getting herself worked up and I am on my own the only place I can go that I can lock the door is the bathroom . . . but even then, the last time that happened she broke the door hitting her head on it. I go through a mental checklist, and I retreat there. I get my phone, I get a little stool, a blanket, whatever, cos I could be there for hours . . . and it's frightening, I'm frightened, I fear for my safety. (ID 158).

Deteriorating relationships between siblings. While relationships between siblings during the childhood years were typically presented as positive and benefitting their autistic child, some described deteriorations in these relationships during the teenage years. This added to the strain of everyday family life.

> They [*siblings*] become frustrated because he's swearing at me. So then they step in and then they can actually get a little bit physical now with each other, like they're both angry. (ID 25)

There were also descriptions of siblings increasingly avoiding being in the company of their brother or sister. Indeed, in a couple of cases this had led to a sibling moving away from the family home earlier than might have been expected.

> Part of the reason why she [daughter] moved out of the house was because [*autistic son*] will fight with her . . . He will drag her down the stairs, he will pull her hair, he will scratch her, he may even spit at her and everything, you know, and over something as trivial as you shouted. (ID 6)

Strained and constrained by inadequate finances. Many parents described the chronic strain of living with inadequate financial resources, attributing this, at least in part, to their child's MHD/BC. Some, for example, had had to stop working or reduce working hours. Many had, over the years, paid for private mental health professionals/services or education support. Some also reported further financial costs during the teenage years because their child's increased strength and size caused greater damage during physical outbursts (e.g. damaged doors, walls), or meant possessions (e.g. computers) were more likely to get broken during moments of anger or frustration.

> We're not financially well off. We're not comfortable. We've been sitting, unfortunately, on benefits for years. It's not an easy life to be on benefits, especially when you have a disabled child . . . It is a strain trying to replace things and buy things that would help him. He's a very fussy eater, that all costs more money. (ID 462)

Living in an environment controlled by the child. A small number of parents reported their child controlled the lighting, temperature and/or noise levels in shared spaces in the family home. Their accounts included descriptions of living rooms having to remain unlit, not being able to watch TV if the child was present, and their child insisting on windows or external doors being left open. They attributed this to the child's sensory sensitivities. None attempted to challenge this due to fears (based on previous experiences) of how the child would react. All described this as a highly constrained and stressful existence. Alongside this could be the physical discomfort of being in rooms which were too warm or too cold, fears about security or how they would manage heating costs.

> Part of the temperature control thing is he likes to turn it [*heating*] off and open the windows. It's just a constant, we go round and round in circles. It doesn't sound like anything but when you're thinking about environment, heating bills, you know, keeping your house safe, to name but a few, it is actually very, very stressful. (ID 449)

The toll on parents

Impacts on emotional and physical well-being. A wide range of physical and emotional consequences of being the parent of an autistic teenager with MHD/BC were identified from parents' accounts. These included physical exhaustion, weight loss, panic attacks, depression, suicidal thoughts and struggles with alcohol. Some reported they had begun their child's teenage years feeling physically and/or emotionally exhausted because of the stresses and strains of the diagnosis and the childhood years.

> Sometimes it just becomes overwhelming and like brings me down as well. (ID 39)

> Back then and even now, having an autistic child, for me, it can be mentally, physically and financially draining. (ID 462)

For others, deteriorations in their physical and mental health/well-being had begun, or significantly increased in severity, during the teenage years. This had resulted in a number seeking help from their general practitioner (GP), albeit reluctantly. This typically resulted in anti-depressant/anti-anxiety medication being prescribed. While helpful in some cases, it was regarded as inadequate because it did not change their situation.

> They need to start looking [after us], because for me and my husband to be able to care for [child], we have to be healthy and happy. How are we supposed to care for them if we're not healthy and happy? (ID 462)

Some described feeling disappointed in themselves for needing medication.

> After the October incident [*requiring police intervention*] I went to the doctors and I just said 'I think I'm really anxious. . . . I don't think I am, I know I am'. And they put me on a low dosage of something, anti-anxiety, and it just helps me get to sleep because I just knew that I wasn't right in myself . . . I was really sad cos I was always quite proud that I hadn't done anything like that. (ID 449)

Feeling they can no longer cope. Some of those we interviewed spoke openly about wondering how long they would be able to continue having their child at home, with a sense of deep pessimism about their situation improving.

> I think we are coping but coping in the sense that we have not broken down. We've not gone mad . . . yes, we are keeping going. But it's difficult because it's like, how long does this go on for? What's next for our son? We can't continue like this. (ID 89)

Indeed, for three of the families who took part in our study, the stage had been reached where they had or were requesting their local authority find their child a permanent placement in a residential school or college.

Two families had been successful in making the case for this. One family regarded this as the best option for them and their child. For the other family, feelings were more mixed and a strong sense of guilt was expressed for (potentially) putting their needs over their child's.

> I feel guilty that I can't look after her and at the same time there are days I, I hate her. . . .Hate's the wrong, is a horrid word . . . but there are times I do not like her and I'm frightened of her. And yet you hear so many horror stories about what happens in social care and she's the prime candidate to be abused because of all her behaviours. So I'm scared of the future for her. (ID 158).

Support from services during the teenage years

Despite the often multiple challenges parents faced, a dominant theme across parents' accounts was the absence of any, or any adequate, professional support for them and their child during the teenage years. This was often contrasted with the support they received *as parents* following diagnosis (Indeed, around half of those we interviewed said they had had no contact with statutory mental health services after the immediate post-diagnosis period). Crucially, they believed this absence of involvement, or effective intervention, increased the risk that MHD/BC would escalate.

> It just seems like there's a little bit of a black hole. Like there's just, suddenly you've gone from being watched by a paediatrician to then nothing . . . You would think that with that diagnosis there would be something that is actually joining the dots all the way through. (ID 430)

Barriers to accessing professional supports. A number of barriers to professional support and involvement were identified in parents' accounts. First, some parents described feeling they were not listened to and that their concerns had been brushed off as 'normal' for autistic teenagers, or not sufficiently severe to warrant professional involvement. Others reported contacts with services had been superficial, with a failure to explore the challenges they were facing and assumptions made that they were coping.

> So the generalised anxiety, the sensory problems . . . it's all there. But because she's not 'at risk', it's not considered to be a problem . . . Why does it have to get to the point where a child is slashing their wrists or cutting themselves to get attention, to get help? (ID162)

> I think the issues with us is they come to a nice house, see a nice car parked outside, [*They think*] 'Oh the house looks nice so they must be all right'. [*and*] not asking the questions that we know need to be asked, things like 'Have they replaced all the doors cos they've been kicked in?'. Just because it looks all right on the surface it doesn't mean it is all right at all. They need to listen to what people are actually saying. (ID 449)

Alongside a potential lack of professional recognition of a family's need for support, parents accounts revealed that child-centred factors could affect service involvement. Specifically, among parents whose children did not also have LD, most said their child's feelings about being autistic were, or became, entirely negative at some stage during the teenage years. For some, this had led to a refusal to engage with, or accept, support. As well as being a (further) point of friction between parent and child, it could also leave mental health concerns unaddressed and parents feeling isolated.

> Now that [*child*] is older, he is now in denial of his autism. He says '. . . there's nothing wrong with me and I don't want to hear that word [*autism*], even if I have to open my brain and scrape that word out of my brain I will do it'. In his new school he doesn't want me to tell anybody that he's autistic and he keeps saying that I go to the schools and talk to professionals and people about him because I want to destroy him. (ID 277)

In addition, in one or two cases, support had been withdrawn because professionals making home visits deemed the child's behaviour as too risky.

> He can be very, very [*aggressive and*] abusive, and because of that the social worker has not come anymore. (ID 277)

The final barrier to accessing statutory mental health services was a child's refusal to engage, or disengaging rapidly, and services making little effort to facilitate engagement.

> CAMHS said 'There is nothing we can do'. [*They*] said to me point blank, 'I have to be frank with you, there's nothing we can do for [*son*] if he doesn't want to cooperate and come to appointments. We can't come to him at home so he has to come here, and if he's not coming there's nothing we can do'. (ID 277)

Discussion

Given the historic exclusion of autistic people's voices from research, and the need to move away from a deficit-centred perspective (Pellicano & den Houting, 2022), it can be difficult to justify a continued focus on parental experience. However, there is a clear argument for paying attention to and supporting parents of autistic children because of the central role they play in their children's lives and outcomes (Fazel & Soneson, 2023; Foster et al., 2016). The case for this is particularly strong given these parents are at increased risk of experiencing parenting stress and poor mental and physical health outcomes compared to parents of neurotypical children (DePape & Lindsay, 2015; Lee & Barger, 2024; Ooi et al., 2016; Schnabel et al., 2019; Tint & Weiss, 2015; Zhang et al., 2023). Furthermore, there do remain aspects of the parental experience which have received little attention, including parents of autistic teenagers with MHD/BC. This article offers a contribution to our understanding of the lives and perspectives of this population.

The parents who took part in this study typically conveyed the teenage years as a period of turbulence, strain, apprehension and conflict. Parents attributed this to the emergence of new behaviours and mental health issues they found concerning, challenging and distressing. While recognising that the teenage years can be a challenging time for any parent (Sosnowy et al., 2017), these findings align with other research which report greater risk and increased severity of MHD/BC for autistic teenagers (Colvert et al., 2022; Hudson et al., 2019; Rydzewska et al., 2018; Tseng et al., 2020; Widnall et al., 2022). Parents described themselves as both being unprepared for these changes and finding that existing ways of parenting and supporting their child were no longer helpful.

Few parents in the study identified statutory services (mental health, social work/social care) as being involved or playing an effectual role in supporting them and/or their child during this period. The lack of involvement by statutory mental health services is, perhaps, unsurprising given chronic under-investment in children and young people's mental health services in the United Kingdom (Children's Comissioner's Office, 2023). However, it could be argued that it is also a consequence of approaches to supporting of autistic children and their families, which is characterised by child and parent-directed interventions in the post-diagnostic period, after which the child and family are discharged (Ishler et al., 2022; Laxman et al., 2019; Płatos & Pisula, 2019; Semovski et al., 2022). This model of care has persisted despite repeated calls for a lifelong model of care and support, both for those diagnosed with autism and their families (Green et al., 2022; Matson et al., 2009).

Our findings support this call. They also make the case for parent support interventions, such as parenting programmes, *specific* to the adolescent years because of the new and unique challenges and demands this life-stage brings which, as our and other studies have shown, parents feel ill-prepared to cope with (Ho et al., 2018; Mount & Dillon, 2014). While there may be local initiatives developing parenting programmes for parents of autistic teenagers (e.g.https://mft.nhs.uk/rmch/clinical-service-for-children-with-disabilities) but, to our knowledge, none have been subject to independent evaluation, and there is limited information available on their development and content (Rutherford et al., 2019). This is in sharp contrast to the investment there has been over many years in developing, evaluating and supporting access to parenting programmes for parents of newly diagnosed autistic children (Deb et al., 2020; Ratliff-Black & Therrien, 2020). The fact that most autistic teenagers and their families are not visible to mental health services may partly account for this. A wider lack of recognition or attention to the support needs of parents of adolescents is likely to also have contributed to this situation (Burke et al., 2021).

While we make the case for investing in the development and evaluation of adolescence-specific parenting programmes, such programmes should be regarded as just one element of the support available to parents of autistic teenagers. The often significant difficulties of everyday life, and the physical, mental and emotional strain and exhaustion described, highlight the need for a preventive and holistic approach to supporting parents during this phase of their child's life. Alongside this needs to be earlier access to mental health support for autistic teenagers themselves. However, our findings suggest that increasing provision *per se* will not be sufficient given parents' accounts of their teenage child refusing to engage with mental health services, or rapidly disengaging. In addition, there is a need to consult with autistic teenagers as to what services need to do to be accessible and attractive to young people. At present very little is known about this, and our findings lend support to the call for this to be prioritised in future research (Adams & Young, 2021; Albaum et al., 2023).

Finally, within many parents' descriptions of their lives were experiences, or fears, of verbal, psychological and/or physical aggression or violence. The notion of child-to-parent violence (CPV) is not a comfortable one, partly explaining the limited research on this topic more generally (Rutter, 2023). However, the argument is made that its relational and familial nature mean it should be understood and treated differently to the broader literature on childhood aggression. Current evidence points to mid-adolescence, MHDs and neurodevelopmental difference being 'correlative' (as opposed to causal) factors in CPV. That is, they are factors over-represented in the population with a history of CPV (Calvete et al., 2020; Holt, 2023; Holt & Iain, 2022; Rutter, 2023). Our findings, within the context of this wider body of evidence, suggest this is something which needs to be further explored and better understood, including the implications this has for professional training and practice.

Study limitations

This research focused on understanding the experiences of parents of autistic teenagers with MHD/BC. Purposive sampling from an existing community cohort ensured the participants represented a diversity of autistic teenagers with MHD/BC (e.g. gender, with/without LD, a range of MHD/BC trajectories). The recruited sample included lone and two parent families. However, fathers were under-represented. In addition, while the Cohort Study reports good retention over the different waves of data collection, it is possible that families with the most difficult, chaotic and stressful lives are among those more likely to have been lost at follow-up timepoints. We also note that a few of Cohort Study families were not approached about this study due to the Cohort Team's concerns about a parent's or wider family's well-being. It is possible, therefore, that parents under most strain are not represented in the study sample. In terms of directions for future research, as well as seeking to hear the views and experiences of fathers and extending the minority groups represented, a longitudinal study would generate more complete understanding of parents' experiences over time.

Conclusion

This UK-based study sought to explore and understand the lived experiences of parents of autistic teenagers with MHD/BC, a relatively neglected group – both by research and services. Overall, parents felt ill-equipped and unsupported and many described lives which could, at times, be tense and fraught. This had taken its toll on parents' emotional and physical health. Findings support the case for increasing adolescence-specific support to parents and ensuring timely access to mental health services which teenagers want to engage with and are effective.

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Supplemental material

Supplemental material for this article is available online.

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