

**CHALLENGES FACED BY PARENTS OF CHILDREN DIAGNOSED
WITH AUTISM SPECTRUM DISORDER**

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10 **SPECTRUM DISORDER**
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14 **ABSTRACT**
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17 spectrum disorder. This article reports on a qualitative interview study with 20 parents exploring
18 their experiences, challenges faced, and what has helped them to cope. A thematic analysis of the
19 data identified five core categories: Dealing with challenging behaviour; dealing with
20 judgements from others; lack of support; impact upon the family; coping and the importance of
21 appropriate support. The findings emphasise where the parents themselves believe they still
22 require additional support. It raises key strategies and resources that parents have found helpful.
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CHALLENGES FACED BY PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

INTRODUCTION

It is well recognised that raising a child or adult with a developmental disability confers exceptional care giving and contributes to higher levels of stress (Dyson, 1997). Caring for a child diagnosed with an Autism Spectrum Disorder has been shown to be especially stressful for carers due to the complexity of the symptoms that characterise ASD (Griffith & Hastings, 2010; Ingersoll and Hambrick, 2011). For example, in addition to having difficulties in social interactions and communication, children in the autism spectrum often exhibit behaviors that are disruptive and hard to manage. They display repetitive, non-functioning activities and interests, which present considerable challenges and distress for individuals with autism as well as their families, due to the individuals' intolerance of changes (Dunlap, Dylor and Koegel, 1983). This can leave parents feeling locked at home, as they fear taking their child out in public. These problematic behaviors are not only a major source of stress for parents (Lecavalier et al., 2006) but leave many parents feeling extremely isolated (Woodgate, Ateah & Secco, 2008).

Much of the previous research in the area of parent caregiver wellbeing has focused too readily on the challenges caused by the child's behavior, and the severity of the child's disability (e.g. Plant & Sanders, 2007). Despite the importance of these variables, this research has largely ignored the external factors contributing to parents stress, including environmental restrictions (Lollar, 2008). However, it is important to acknowledge that the parents also have to deal with many other co-occurring difficulties of having a child with ASD, such as financial and time burden of medical treatment, restrictions on social activities and changes to family goals and achievements (McCubbin, Cauble and Patterson, 1982; Lecavalier et al., 2006). Financial costs are high, with the total cost of raising a child with a disability estimated to be approximately three times greater than the cost incurred by raising a typically developing child (Järbrink, Fombonne & Knapp, 2003). This financial impact is exaggerated by the shortfall that exists between the costs of bringing up a child with severe disabilities and benefits received (Broach,

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3 2003). Furthermore, research suggests that there is insufficient support services for parents of
4 children with autism, which might help them cope with stress (Whitaker, 2002).
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9 Research is also heavily weighted towards exploration of maternal levels of stress (Pisula, 2007;
10 Tomanik, Harris & Hawkins, 2004) with relatively few that have addressed those of the father
11 (Hastings et al., 2005; Rimmerman, Turkel, & Crossman 2003). The few that exist seem to
12 suggest gender differences with regard to the impact of parenting a child diagnosed with ASD,
13 with mothers generally reporting more stress and depressive symptoms than fathers (Hastings et
14 al, 2005). Coping strategies used by mothers and fathers of children with autism also differ
15 (Gray, 2003). For example, fathers' primary coping strategy is thought to come from their work
16 outside the home whereas a mother appears to be linked to levels of social support.
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25 For virtually all parents, caring for a child is an experience full of triumphs and joy, as well as
26 challenges and stress (Myers et al., 2009). Many of these challenges they face are likely due to a
27 lack of necessary environmental supports (Resch, 2010). As the number of children diagnosed
28 with autism continues to rise, resources must be available to support parents of children with
29 autism and their families (Hall & Graff, 2011). Therefore knowing more about the experience of
30 parents is important in designing more specific interventions focused on reducing parenting
31 stress.
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40 With the aim of exploring parents subjective experiences of having a child diagnosed with
41 autism, a qualitative study was completed which explored parents experiences around current
42 stressors and factors that help them to cope. Qualitative research has been recognised as offering
43 a valuable approach to exploring meaning and subjective experiences, and capturing the
44 complexities of experience in-depth (Willig & Stainton-Rogers, 2008). We report here on results
45 of the study, focusing on the daily experiences of parents, and what challenges they face, as well
46 as what helps parents to cope with challenges and stresses. Given the lack of studies involving
47 fathers, an important feature of the current study was to also explore the experiences of both
48 fathers and mothers.
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METHOD

Data was collected by means of individual interviews with 20 parents (14 mothers and 6 fathers). This represented the parents of a total of 14 children diagnosed with autism (8 children) or Aspergers (6 children). The ages of the children ranged from 4 to 14 years, with 2 children of adult age (26 and 29 years). Participants were recruited through convenience and snowball sampling from people known to one of the authors from their participation on previous projects and through advertising through parent support groups. Participants were recruited from towns and cities in the East of England, as well as in London.

Participants took part in individual interviews averaging approximately 45 to 60 minutes. Four interviews were shorter due to time constraints for parents who presented for interviews as a couple (but interviewed separately). Participants were informed about the purpose and aims of the project, the dissemination of findings, and their anonymity was assured. All participants gave their written signed consent to take part in the interview study. Semi-structured interviews were conducted by the first and last author (AL and PR). An interview schedule was drawn up, which was used as a guide for topics to cover in the interview. Core questions included:

1. As a parent of a child with autism, what makes things difficult or challenging for you?
2. What makes things easier?
3. What helps you cope with any challenges or difficulties you may face as a parent?

Issues raised by parents were explored further with the aid of probing and follow-up questions.

Interviews were recorded and transcribed verbatim. Transcripts were then analysed using the techniques of thematic analysis (Braun & Clarke, 2006), with the aid of NVivo software for analysing and managing data. Transcripts were first read in full so as to get an overall sense of data. Themes in the data were identified, informed in part by the focus of questions asked (for example 'challenges faced', 'support resources'), and from what emerged in the data. A list of codes was developed and structured according to themes and subthemes. This was applied to all 20 transcripts, and quotes from the transcripts were selected and assigned to codes. In reporting results, representative quotes are selected to illustrate findings. Data has been anonymized by removing references to people's names in order to protect confidentiality. The project was given ethical approval by the university's ethics panel.

RESULTS

The results are presented in terms of four core categories identified: Dealing with challenging behaviours; dealing with judgements from others; lack of support; impact upon the family; coping and the importance of appropriate support. There were few noticeable gender differences, with both mothers and fathers identifying similar challenges. Although there were some suggested gender differences with regards coping, as perceived by the parent being interviewed.

Dealing with challenging behaviours

Almost all of the participants (16 out of 20) cited childrens' challenging behaviours as being particularly stressful. Examples given included temper tantrums, repetitive behaviours and aggressive behaviour. Tantrums were described as often being unpredictable and difficult to manage. Ten parents cited changes to routine as being a particular challenge, as it resulted in the child's behaviour becoming more difficult, for example ending in tantrums. One mother described how stressful and difficult her son's obsessive and repetitive behaviours were and its impact on everyday life in terms of the limitations it places on any spontaneity.

if I don't get [him] on the bus for school, then [he] won't want to go the next day, and then we will have an obsession regarding that. "But I didn't go to school on Tuesday. So I don't go to school on Tuesdays!" It will become - Do you see what I mean? I HAVE to keep the routine. If I let the routine slide, we in trouble, all over again! (Participant 19)

Their childrens' difficulties with social interactions, was a problem consistently raised by several of the parents (11 out of 20). Their children who were diagnosed with autism found it difficult to relate to others, understand others, or even tolerate the presence of others. Parents described their child as a "loner" or "isolated", and expressed some concern, even sadness at this difficulty in socialising. For example one mother staid:

he's left primary school not really having anyone he's playing with anymore but you know, he's not that bothered. But I kind of worry that he's going to go here and children

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3 are going to start saying to him 'you're weird, you're odd' and he's going to start feeling
4 like there's something wrong with him (Participant 1)
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9 Some parents spoke about the exclusion faced by their child such that they were not invited to
10 birthday parties or other events. However this also interlinked with a negative impact upon the
11 parent's social life, as it could often be problematic for them to have guests in their home. For
12 example one mother stated:
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17 you don't have friends around because you have a son who cannot bear people in the
18 house. Whether they are family members, other family members, or very close friends,
19 other people don't come around because he will make a fuss. He will swear, he will
20 shout, he will get angry (Participant 13)
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26 This may render parents isolated, which was also expressed in how many parents felt
27 unsupported or lacking enough support from others (see below).
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31 **Dealing with judgements from others**

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33 Whilst many of the parents were in agreement that dealing with tantrums was often difficult to
34 manage, most parents regarded public tantrums and the reaction from others as being the most
35 difficult aspect of such challenging behaviour. Eleven parents commented on how the perceived
36 judgements from others were the most gruelling part rather than the behaviour per se. A common
37 perception from the parents was that others tended to judge their children as just "naughty"
38 children, and that they as parents were not effective in their parenting. For example one father
39 said:
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47 if you are out in a shop and something happens and he can have one of his turns, which
48 again is doesn't happen that often, but people look at you and think what are doing? What
49 kind of parent are you? (Participant 17)
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55 Most of these parents described how others would stare at them when their child is having what
56 was perceived as a tantrum, with parents describing feeling "embarrassed", "guilty", with
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3 everyone “staring as if you are doing something wrong and hurting your child” (participant 10).
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5 Importantly, it was not only cases of parents describing the perception of others but also the
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7 more concrete scenarios. For example, parents often discussed incidents or reported that others
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9 had expressed comments to them, describing others as “rude”. One mother stated how she finds
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11 herself “battling with public all the time” (participant 20).
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13 14 **Lack of support**

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16 Parents referred to their parenting responsibility as consuming of their time. Some parents
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18 expressed a sense of exhaustion, with little break. Three parents referred specifically to the
19
20 difficulty finding a child-minder to look after the child, as the child presented particular
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22 challenges that minders were not typically experienced or trained to deal with. This resulted in
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24 little respite for the parents. Grandparents were in some cases cited as a resource in this regards,
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26 where grandparents could be called on to assist or look after the child for a short period of time.
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28 However, this was not always the case and a number of parents described the lack of
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30 understanding from grandparents, who did not understand autism and regarded the child’s
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32 behaviour as a response to bad parenting. For example one mother stated:

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34 His [the child’s father] mum said there was nothing wrong with him he is just slow and
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36 he, and of many people, and even up to now say there is nothing wrong with him because
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38 they want to see some physical disability because you know he looks fine. But they are
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40 not there when he is having the tantrums or when he is having his mood swings and when
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42 he is going bonkers. (Participant 20)
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45 As with this comment, mothers tended to describe their own parents as more supportive or
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47 understanding than the parents-in-law.
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50 Parents also referred to the lack of resources or support from external organisations. This varied
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52 between parents, with some parents feeling well-supported by various organisations. Others felt
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54 unsupported. There were no clearly identifiable differences in parents’ experience of external
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56 support depending on location (London or towns in the East of England). A couple of parents
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58 attributed their experience of support to their socio-economic circumstances. However, whether
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3 there is a “post-code lottery” in terms of resources cannot be substantiated. Some parents
4 referred to lack of information about resources that are available. As one mother stated:
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8 we didn't have any information, we didn't know we could actually go for a statement
9 through the GP or anything. There is no, there's no information at all. You, it's all down
10 to you. (participant 6)
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16 The above parent had a child diagnosed with Asperger's and there was some indication that the
17 level of resources and support may vary according to severity of diagnosis with parents of
18 children diagnosed with autism possibly having more resources and support available to them
19 than parents of children diagnosed with Aspergers. For one single parent who was a working
20 mother, she felt that there was not enough support to help her with her son who was diagnosed
21 with autism while she was working. She took the decision in the end not to work, so that she
22 could spend the time taking care of her son.
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30 Parents also expressed deep concern about the dependency of their children on them for care.
31 This posed some anxiety for parents (12 out of 20), particularly for mothers, as they worried
32 about how their children will be able to cope when they are no longer alive or able to look after
33 them. For example a mother explains:
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38 as he gets older I do worry kind of what things will hold for him, you know. When you're
39 a little child, you know, people are understanding of you and what not, but as you get
40 older people, you know, perhaps wont be [pause] and, you know, as an adult or, you
41 know, in years to come, or when I'm gone or [his father is] gone do you know what I
42 mean? Yeah kind of, who'll be there to kind of protect him? (Participant 9)
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49 **Impact on family**

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51 Twelve parents spoke about the emotional impact that having a child diagnosed with autism has
52 had on them as parents, and as a family. Parents were careful to state love for their child, but it
53 was clear that in many cases there has been a difficult emotional impact on them as a family.
54 This was suggested by 4 mothers who reported having struggled with depression in the past, two
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3 of whom were diagnosed with post-natal depression, and one of whom who had felt suicidal
4 during a particularly difficult period in her life as a single mother. One couple spoke of
5 significant health problems that they attributed to stress.
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10 In describing their experiences, parents' responses emphasised the temporal nature of their
11 experience, using phrases that described on-going, 'never-ending' stress. In so doing, the parents
12 described feelings of desperation. One mother referred to her experience as a parent and how "it
13 consumes you" (participant 11). Parents used phrases such as "it is wearing" and "it is a
14 nightmare". Another mother said:
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21 I thought that there would be no end to it. I thought that I would have a breakdown
22 (participant 20)
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26 This mother, a single mother, described her time of despair when having to cope on her own with
27 a young child:
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32 I have been a total wreck crying everywhere. I have been walking down the road crying.
33 You know I used to dread the school holidays (Participant 20)
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37 As well as the impact on their well-being, parents described the impact on their self-esteem. For
38 example, one mother spoke about how at times she feels like a "failure as a parent" (participant
39 4). Another described how at times she feels "completely inadequate as a mum" (Participant 6).
40 Along with feelings of failure, some mothers also spoke of feelings of rejection and loss in
41 relation to their child. For example one mother said:
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48 it's difficult because he never wants to interact with you so you'll say to him: "shall we
49 go swimming?" – "no". "Shall we get the playdo out?" – "no". "Shall we do this?" –
50 "no". "Shall we do that?" – "no". "Shall we make a cake?" – "no". And he never wants to
51 do anything with you. So it makes you feel crap as a parent (participant 4)
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3 Another mother, more explicitly states how she feels like she “lost” her child at the age of 2
4 (when she started noticing changes in behaviour), and described her sense of loss at not being
5 able to hug her child who is unresponsive and sensitive to touch:
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10 sometime I do feel connected to [child’s name] quite well. And I know [he] wouldn’t be
11 able to cope without me, but, um, sometimes it’s really hard, because I would really like
12 to give [him] a proper hug, and I can’t do that.(Participant 19)
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18 Some parents also spoke of the sense of loneliness and isolation they felt. They described how
19 difficult it was to go out or socialise with others, due to their child’s challenging behaviours and
20 difficulties with social interactions. A mother of an adult child with autism spoke emotionally of
21 the isolation and desperation that they have experienced, with others having little understanding
22 of what their experiences have been. She described:
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28 You feel really really on your own as if that’s it, theres never going to be anything else.
29 You are going to get no help, no support. This is your life. Its (pause) I can only explain
30 it, its like being a beaten wife but you are not you are a beaten mum. That same thing. It’s
31 domestic abuse, its domestic violence. That same feeling, that stress. And you are
32 shattered and you are tired and you don’t want to get up again. And god forbid, there are
33 times when you wished you had not even had that child because of the strains it puts on
34 you (Participant 13)
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43 As well as the impact on themselves, thirteen parents also expressed concerned about any
44 possible negative impact on siblings. Parents were concerned that they, by necessity, were more
45 neglectful of their other children. They felt that the other children became jealous or upset about
46 this. For example a father stated:
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51 our children do get quite jealous the fact that [he] gets more attention and favouritism
52 than they do. He doesn’t get told off for doing certain things that they certainly would do,
53 but they won’t understand that he doesn’t understand (Participant 10)
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3 Some parents spoke about how in general the siblings have a reasonable relationship with the
4 child diagnosed with autism, and were understanding, even protective. However, other parents
5 spoke about how the other children are “embarrassed” about the behaviour of their brother or
6 sister. For example one parent described how her daughter was “embarrassed” and “mortified”
7 by her brother who was diagnosed with autism, she went on to say:
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14 she would be like standing away from us or she would be crying herself but I would say
15 to her ‘you know you have to understand that he has autism’ and you know she gets left
16 out as all the attention is always on him (Participant 20)
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20 21 **Coping and support**

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23 There were few differences in fathers’ and mothers’ experiences of what they found to be key
24 challenges faced. Both mothers and fathers also mentioned similar factors that help them cope
25 (e.g. professional support). However there was some suggestion that fathers reacted differently to
26 their child’s problems and diagnosis than did the mothers. Many of the mothers reported that
27 they felt that their husband or the child’s father had difficulty coming to terms with the child’s
28 diagnosis; that they initially struggled with some denial. For example, one mother reported that
29 her husband at first “ignored it to a great degree” (participant 4); another mother reported that
30 she felt her husband “certainly went through denial” (participant 11). There was some
31 suggestion of this in terms of differences between fathers and mothers interviewed with regards
32 acceptance of the severity of their child’s difficulties. For example, most mothers spoke about
33 their concerns around their child’s future dependency needs, whereas most fathers (although
34 important to say that not all), expressed more hopes that their child will ‘grow out’ of their
35 difficulties. For example, one father, who self-reported as having ‘autism traits’, stated:
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48 I’m not as concerned about the future for [child’s name] as what I think what [wife] is
49 [pause] simply, when you know, when we, when he was diagnosed, if if I’ve turned out
50 alright then I don’t see a reason why he shouldn’t turn out alright.(participant 5)
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55 Four fathers stated that they felt that it was the mothers who experienced the most stress, because
56 they “spend more time with the children” (participant 10). This was also reflected in some of the
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3 mothers' comments that suggested that the fathers were less patient and tolerant of challenging
4 behaviours, as they were less consistently exposed to these. For example, one mother stated:
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9 I think he finds them quite stressful much much more than I do, just, just in their sort of
10 everyday behaviours and stuff, I mean he's much more likely to get into rows with G or
11 just find J just really annoying, you know, his noises and fidgeting and hovering and all
12 the things he does you know which I can kind of blank him out (Participant 1)
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18 Some parents spoke about how the challenges became easier to deal with over time, as parents
19 learnt how to respond to challenging behaviours or the severity of challenging behaviours
20 (particularly tantrums) diminished as the child got older. Parents also spoke of how their
21 experiences with their child was not always challenging and there were equally moments that
22 were rewarding and uplifting, for example when their child achieved something or a milestone
23 was reached.
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30 Nine parents spoke about how the support of other parents of children diagnosed with autism
31 was an important and valued source of support. Given that so many parents found the
32 judgements and lack of understanding from others difficult, other parents who are experiencing
33 similar issues, provided a source of understanding, support and advice. For example a father
34 stated:
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40 it's a relief to see that there are other people and until you get to that point when you are
41 with other people in your situation who you can talk to about the same sort of things; and
42 that understand, you know, what difficulties you have (Participant 10)
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48 What parents found particularly helpful, is that ideas and strategies for coping and dealing with
49 challenges could be shared. Parents also made comparisons to the children of other parents.
50 Seven parents commented on how they felt fortunate that their child was not "as disabled" or "as
51 bad" as other children with more severe disabilities. Some parents for example commented on
52 how their child was affectionate and enjoyed cuddles, which they felt fortunate about when
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3 comparing to children diagnosed with autism who do not like to be touched or cuddled. One
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5 mother commented:

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8 those woman who have a child who is so badly developmentally delayed, and it goes on
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10 for the rest of their life, I don't know. It must tear them to shreds. I mean I can be proud
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12 of the things that [daughter] has accomplished. And when she does get something, that
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14 can be good. But when your child is so developmentally delayed that your whole life – I
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16 can have a bit of life to myself. I am conscious how lucky I am (Participant 11)

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19 This can be considered as a strategy for coping, as the comparison to others helps create a sense
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21 that the difficulties and challenges faced are not as bad as could be.
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25 Nine participants talked about organisations and professionals who had been very helpful and
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27 supportive. Parents who tended to describe schools as unsupportive or lacking in understanding
28
29 tended to refer to previous “mainstream” schools, who may not have had an understanding or
30
31 expertise of educating children diagnosed with autism. Once the parents had managed to get their
32
33 child into a school that had learning support for learners with special education needs, they felt
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35 that the school was an invaluable source of support. Parents described such schools as “brilliant”
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37 and “fantastic”. Some parents also mentioned organisations such as the National Autistic
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39 Society, Mencap and Mind as very helpful source of information and support. Parents also
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41 described professionals, such as psychologists and paediatricians as very helpful.

42 **DISCUSSION AND CONCLUSION**

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46 Participants spoke at length about the various challenges they faced being a parent of a child with
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48 autism. The majority alluded to how stressful the child's challenging behaviour was for them.
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50 The challenges were described as ‘never-ending’, which had significant impact on the parents’
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52 sense of well-being and ability to cope. The challenging behaviours mostly included tantrums as
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54 a result of the child's difficulty coping with changes to routine. However, it was raised that
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56 potentially the most difficult part for them was in fact the social implications of their child's
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58 behaviour, both their child's lack of social responsiveness and its impact on them socially. Many
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3 described feeling extremely isolated mirroring that found in previous studies (Woodgate et al.,
4 2008). Importantly, whilst parents appeared to have learnt ways to deal with or just accept
5 challenging behaviour, it was the lack of understanding and even judgements from others that
6 often proved the most difficult for parents. This left them feeling judged as ‘bad’ parents or
7 feeling like a failure.
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14 Social support has long been cited as a contributing factor in counteracting the negative
15 outcomes of stress. Social support develops from the relationships and interactions between the
16 individual, family, peer group, and larger social systems (Boyd, 2002). Indeed, our findings
17 showed that parents who were coping better had support from extended families and had more
18 positive experiences with schools. This however was not consistent as many parents expressed
19 great difficulty in finding adequate support, as there seemed to be few resources that parents
20 could draw on where people were understanding or trained to deal with the challenging
21 behaviours of their child. Despite the increase in number of children diagnosed with ASD who
22 are included in mainstream educational settings, teachers and other professionals do not always
23 understand fully the impact that living with a child diagnosed with ASD has on parents and
24 families (Dillenburger et al., 2004). Parents argue that educational and social service supports
25 are not efficient and that they are forced to rely largely on support from within the family or from
26 friends (Dillenburger et al., 2010).
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39 A couple of parents attributed their experience of support to their socio-economic circumstances.
40 However, whether there is a “post-code lottery” in terms of resources cannot be substantiated.
41 There was also some indication that the level of resources and support may vary according to
42 severity of diagnosis with parents of children diagnosed with autism possibly having more
43 resources and support available to them than parents of children diagnosed with Aspergers, This
44 is important as previous research has reported that parents with children with more severe
45 behavior problems to be the most vulnerable (Barker et al., 2010). Yet, parents with children
46 with high functioning autism appear to be at high a risk from stress and more research needs to
47 address whether they are a group largely being neglected.
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3 An important source of support appeared to be the contact with other parents of children with
4 autism. Through this contact, parents could compare with the experiences of other parents and
5 learn from their successes. This contact also allowed them the opportunity to compare their child
6 to the child of other parents, and in some cases make a downward comparison that made them
7 feel more fortunate. The use of social comparison as a means of coping was also found in a
8 recent study of parents of children with Duchenne Muscular Dystrophy (Hodges and Dibb,
9 2010). Previous studies have also highlighted the benefits support groups can be to parents, such
10 as the offloading of negative emotions, for sharing common experiences, and in obtaining
11 specific information about care and treatment (e.g. Bennett & De Luca, 1997; Smith, Gabard,
12 Dale, & Drucker, 1994). However, even when such networks exist, lack of available time, travel
13 difficulties and childcare constraints can make it difficult for parents to seek and receive such
14 support (Burke & Cigno, 1996). Whilst social network groups have proved to be popular (Huws,
15 Jones & Ingledeu, 2001), parents should not have to be reliant on the internet to gain valuable
16 information and support.
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30 Although a weakness of qualitative studies is its limited generalizeability, the findings do allow
31 us to get a subjective account of parents' experiences, and how they cope with stresses, which
32 can be an indication of shared experiences. This is supported by findings from other research that
33 establishes the stressful nature of caring for a child with autism (e.g. Ingersoll and Hambrick,
34 2011). The lack of understanding and support of the lay public, extended family, and even some
35 professionals seem a key stressful component of the challenging behaviour.
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