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Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom

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Abstract

A sample of 1047 parents completed an online survey about their experiences and opinions regarding the process of attaining a diagnosis of autism spectrum disorder (ASD) for their children. Results revealed that parents usually waited a year from when they first had concerns about their child's development before they sought professional help. On average, there was a delay of around three and a half years from the point at which parents first approached a health professional with their concerns to the confirmation of an ASD diagnosis. Just over half of the parents surveyed were dissatisfied with the diagnostic process as a whole. Several factors predicted parents' overall levels of satisfaction with the diagnostic process, including: the time taken to receive a diagnosis; satisfaction with the information provided at diagnosis; the manner of the diagnosing professional; the stress associated with the diagnostic process; and satisfaction with post-diagnostic support. Post-diagnosis, the support (if any) that was provided to parents was deemed unsatisfactory, and this was highlighted as an area of particular concern amongst parents.

Keywords: autism, autism spectrum disorder (ASD), diagnosis, parent, survey, satisfaction, support

PARENT DIAGNOSIS SURVEY 2

Receiving a diagnosis of an autism spectrum disorder (ASD) has a major impact on an individual and his/her family (Howlin & Moore, 1997). This is often the key stage at which parents can access support for both themselves and their child (Mansell & Morris, 2004; Midence & O'Neill, 1999), and a positive diagnostic experience is associated with greater levels of acceptance, lower levels of stress, and more effective coping strategies (Woolley, Stein, Forrest & Baum, 1989). Delays in receiving a diagnosis can lead to low levels of parental satisfaction (Howlin & Moore, 1997) and can hinder the implementation of effective support or intervention strategies (Webb, Jones, Kelly & Dawson, 2014). Further, parents who experience a long diagnostic delay may lose confidence in the healthcare professionals involved, and are more likely to seek alternative treatments for their child that have poor empirical support (Harrington, Patrick, Edwards & Brand, 2006).

ASD affects approximately 1 in 100 individuals (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum, & Charman, 2006; Brugha, Cooper, McManus, Purdon, Smith, Scott, Spiers, & Tyrer, 2012), with recent estimates from the United States suggesting that this figure could be even higher (CDC, 2014; although see Mandell & Lecavalier, 2014). Given that this equates to over 700,000 people in the United Kingdom (UK), diagnosing the condition represents a significant public health issue. To date, there has only been one large-scale and comprehensive research study exploring parents' experiences and opinions on the routes to ASD diagnosis in the UK. Surveying almost 1300 parents who had a child with ASD, Howlin and Moore (1997) found that around half of families were 'not very' or 'not at all' satisfied with the diagnostic process. The average age at which a diagnosis was made was around five and a half years for children with autism, and 11 years for children with Asperger syndrome. This was despite parents first noting concerns regarding their child's development much earlier; at around one and a half years for children who later received a diagnosis of autism, and around two and a half years for children who later received a diagnosis of Asperger syndrome (Howlin & Asgharian, 1999). Parents typically opted to contact their General Practitioner (GP) or Health Visitor (HV)¹ to discuss initial concerns, which tended to be in response to atypical language development, worries regarding social development, and general behavioural problems. This tended to be when the child was around two years old, but slightly later (around three and a half years) in children with Asperger syndrome. However, parents were almost always referred to at least one other professional for the subsequent diagnosis (Howlin & Moore, 1997). Exploring parental experiences post-diagnosis, the support offered to families was very limited, with educational provision being viewed as the greatest benefit. Post-diagnostic support was found to be a source of particular dissatisfaction amongst parents.

Although these results should be considered within the context of wide regional variations, Howlin and Moore (1997) found that higher levels of satisfaction with the overall diagnostic process were associated with: (i) receiving a formal diagnosis at a young age; (ii) a shorter length of time between initial concerns being noted and the final diagnosis being received; and (iii) receiving a clear diagnostic label from professionals (opposed to a vague diagnostic term such as autistic 'features', 'traits' or 'tendencies'). Rather surprisingly, there was little evidence of a relationship between satisfaction with the diagnostic process and the amount of help received post-diagnosis, nor was parental satisfaction related to geographical area.

¹ In the UK, a HV is a trained nurse or midwife who has additional specialist qualifications in community health and health promotion. One of the roles of a HV is to provide support to parents and pre-school children.

Several recent, often smaller-scale studies (both in the UK and abroad), have since explored parental perceptions of the ASD diagnostic process. Encouragingly, this research has found that the age at which ASDs are being diagnosed is slightly earlier than previously reported (e.g., Goin-Kochel, Mackintosh, & Myers, 2006; Latif & Williams, 2007; National Autistic Society, 2012; Siklos & Kerns, 2007). However, the average delay between parents first seeking help to the point at which a diagnosis is received is still two to three years (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Siklos & Kerns, 2007). Osborne and Reed (2008) reported that the majority of parents highlight the need for a quicker and easier route to diagnosis (see also National Autistic Society, 2012), with parents emphasising the lack of coherence regarding both the structure and the content of the diagnostic pathway. Indeed, parental dissatisfaction with the diagnostic process remains high, despite indications that the time taken to receive a diagnosis of ASD is becoming faster (Chamak et al., 2011; National Autistic Society, 2012). Overall, the diagnostic process is extremely stressful for parents, although levels of stress are reported to be lower for children more severely impaired by ASD (Siklos & Kerns, 2007). This is an interesting finding given that long-term stress has the opposite relationship with ASD severity (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001), but is likely due to the symptoms of ASD being more obvious in children more severely impaired by ASD (e.g., in cases where language fails to develop), thus expediting the diagnostic process.

Parents also continue to express dissatisfaction with the help and support they have been offered or have received following their child's diagnosis. Siklos and Kerns (2007) reported that 53% of their sample was dissatisfied with the help received; an even higher figure than the 35% reported by Howlin and Moore (1997). Parents of children with ASD are also less satisfied with post-diagnostic support than parents of children with other developmental disorders (Siklos & Kerns, 2006). In particular, the need for greater post-diagnostic information and support from professionals has been noted, with parents tending to revert to other sources (e.g., support groups, school) for help, advice and intervention (Mansell & Morris, 2004).

Since the collection of Howlin and Moore's (1997) survey data in 1993, the situation regarding the diagnosis of ASD (in the UK and abroad) has changed significantly (e.g., Matson & Kozlowski, 2011; Wing & Potter, 2002). ASD is now a more widely recognised disorder, by both parents and professionals. There has also been an increase in the numbers of children being referred to clinicians and subsequently receiving diagnoses, including those children who may have received a different diagnosis in the past (cf. Bishop, Whitehouse, Watt & Line, 2008). This has been, in part, aided by the increased use of "gold-standard" diagnostic tools such as the Autism Diagnostic Observation Schedule – General (Lord, Rutter, DiLavore & Risi, 1999) and the Autism Diagnostic Interview – Revised (Lord, Rutter & Le Couteur, 1994). Such tools are viewed favourably by clinicians (Rogers, Goddard, Hill, Henry & Crane, under review) and reduce the need for professionals to rely on clinical judgement alone. In view of these changes, it is timely to conduct an up-to-date investigation into parental experiences of receiving a diagnosis of ASD in the UK.

The aim of the current research, conducted in 2012-2013, was to survey over 1000 parents who have received a diagnosis of ASD for their children in the past 15 years (i.e., in the time since Howlin & Moore's original survey). Adapting and extending the original questionnaire used by Howlin and Moore (1997), the current sample of parents completed an online survey. The survey questioned respondents about: (i) initial concerns they had regarding their child's development; (ii) the

different professional groups seen during the diagnostic process; (iii) the time taken to get a formal diagnosis for the child; (iv) how the diagnosis was disclosed to them; and (v) their own reaction to their child's diagnosis. Parents were also asked about the support, if any, that they were offered post-diagnosis and what additional support they would have liked.

Based on previous work, six key factors were predicted to affect overall satisfaction with the diagnostic process:

(1) *Time taken to get a diagnosis*: Given that several studies have found that a faster and more streamlined journey through the diagnostic process resulted in increased levels of parental satisfaction (Howlin & Moore, 1997; Osbourne & Reed, 2008; Siklos & Kerns, 2007; Smith, Chung, & Vostanis, 1994), it was predicted that those who experienced fewer delays between first seeking help and receiving a diagnosis would be more satisfied with the process.

(2) *Age of child at diagnosis*: Howlin and Moore (1997) found that parental satisfaction was highest amongst those whose children were diagnosed during the preschool years. This is potentially linked to many of these children having a diagnosis of 'classic' autism. Children with 'high functioning autism' or Asperger syndrome' (who may present with subtler signs) tend to be diagnosed later. Their parents also report lengthier delays and find the diagnostic process particularly frustrating (Howlin & Asgharian, 1999). Therefore, it was predicted that overall satisfaction with the diagnostic process would be highest amongst parents of children diagnosed at an earlier age.

(3) *The quality of information given at diagnosis*: Parents who receive information about the nature of ASD, how it may affect their child, and where they can go for help, report higher levels of satisfaction with the care that they receive (Hasnat & Graves, 2000; Mansell & Morris, 2004; Osbourne & Reed, 2008). Therefore, it was predicted that overall satisfaction ratings would be greatest amongst the parents who rated the provision of information received at diagnosis highly.

(4) *Manner of the professional disclosing the diagnosis*: Overall levels of satisfaction were predicted to be highest amongst those who rated the professional's manner during the disclosure consultation favourably (cf. Brogan & Knussen, 2003).

(5) *Support offered post-diagnosis*: Having access to support services following diagnosis is very important to parents (Howlin & Moore, 1997; Mansell & Morris, 2004; Siklos & Kerns, 2007). Previous surveys have not explored the relationship between satisfaction with the overall diagnostic process and post-diagnostic support. This variable was considered in the current study with the prediction that these variables would be positively associated.

(6) *Stress during the diagnostic process*: Although parental stress has been examined in relation to caring for children with autism (e.g., Mori, Ujiie, Smith & Howlin, 2009), there has been little exploration of this variable in relation to diagnosis. This is despite Siklos and Kerns (2007) noting that 82% of parents found the diagnostic process to be stressful. It was predicted that higher levels of parental stress would be associated with lower levels of satisfaction with the overall diagnostic process.

Method

Participants

A total of 559 services providing information, support or assistance to parents of children with ASD were identified via the publically available directory of autism-related services provided by the National Autistic Society (UK). Services were

contacted via e-mail and given full information on the nature of the research, provided with an advertisement for volunteers, and asked to forward the information to their members and associates. An advertisement was also placed in the National Autistic Society (UK) publication 'Communication' (now called 'Your Autism'), which is mailed to all members of the organisation. Finally, details of the project were sent to existing databases of research participants at Goldsmiths, University of London.

Data collection ran from March 2012 to May 2013. All information was collected anonymously and the average time to complete the questionnaire was 26 minutes. Data screening identified 91 cases that needed to be excluded from the final sample: either the child's age at various stages of the diagnostic processes was described inconsistently, making the process chronologically impossible; the child had not yet received an official ASD diagnosis; or he/she had a primary diagnosis of pathological demand avoidance (a condition that is not recognised in DSM-IV-TR or DSM-5; American Psychiatric Association, 2000; 2013). A total of 1047 parents comprised the final sample and missing data were not reconstructed.

Ethical approval for the study was obtained by Research Ethics Committee within the Department of Psychology at Goldsmiths, University of London. All respondents gave their informed consent to participation online, prior to completing the survey.

Questionnaire

The questionnaire was administered online via a website specifically designed for the project. The questionnaire was constructed using a substantial proportion of items taken from Howlin and Moore's (1997) survey, as well as other research studies (e.g., Brogan & Knussen, 2003; Siklos & Kerns, 2007), but was adapted to also reflect conditions present in the current diagnostic manual at the time the survey was active, DSM-IV-TR (American Psychiatric Association, 2000). The questionnaire was divided into a number of sections, as described below:

Information about the parent: This section comprised questions concerning the parents' age, gender, ethnicity, and geographical location.

Information about the child: Parents were asked to provide their child's current age and gender, as well as the nature of their initial concerns (and the age at which these were first noted).

Diagnostic process: When parents first contacted a health professional, they were asked to indicate: the age of the child; who was seen; and what the outcome of the meeting was. Comparable information was collected for each subsequent referral until the point at which the final diagnosis was made.

Disclosure of diagnosis: When receiving their child's diagnosis, parents reported on: the people present; whether the diagnosis was expected; whether they agreed with it; their emotions at the time; and whether they were glad to receive the diagnosis.

Support after diagnosis: Parents were asked: whether they received a written report on their child's diagnosis and/or a follow-up appointment; which post-diagnostic services they received information about; and which services they would have liked to have been offered access to.

Satisfaction with the diagnostic process: Using 5-point Likert scales ('very dissatisfied' to 'very satisfied'), parents indicated their satisfaction with: the manner of the diagnosing professional; the information received at diagnosis; post-diagnostic support; and the overall diagnostic process.

Stress: A 4-point Likert scale was included to assess parents' levels of stress during the diagnostic process (1 = not at all stressful, 2 = not very stressful, 3 = quite stressful, 4 = very stressful).

Results

Information about the parents

The mean age of the parents at the time of the survey was 43.4 years (SD = 8.0), and 93% of respondents were female. A weakness of the sample was a lack of ethnic diversity, with 95% of parents describing themselves as white. Only 2% of parents in the final sample had a positive diagnosis of ASD themselves, although it was not established whether the parent that did not complete the survey (usually the father) had an ASD diagnosis. The sample was geographically diverse, with respondents from all regions of the UK (see Appendix for details).

Information about the children

The mean age of the children was 11.8 years (SD = 6.1): 1% <3 years; 83% aged 3-18; 15% > 18 years. The gender ratio of the sample (80% males, 18% females) was in line with the higher numbers of males than females diagnosed with ASD. Similar numbers of children had diagnoses of autism (40%) and Asperger syndrome (37%). Only 4% had a diagnosis of high functioning autism, with a further 13% receiving a general 'autism spectrum disorder' diagnosis. Small numbers of children received other diagnostic labels (e.g., PDD-NOS, Rett syndrome, autistic traits). For the purposes of these analyses, responses were pooled across diagnostic categories. This decision was made due to the lack of reliability concerning the diagnostic classification of Asperger syndrome (Sharma, Marks Woolfson, & Hunter, 2012), which limits the interpretability of the results. Further, this decision was influenced by the recent move towards a more generic 'autism spectrum disorder' diagnosis for those who would have previously been diagnosed with either autism or Asperger syndrome (American Psychiatric Association, 2013). Fairly high levels of comorbidity were observed across the sample, with 65% of children having one or more additional diagnoses. These included: learning disability (28%); behavioural disorder (19%); affective disorder (16%); physical health problem (11%); mental health condition (5%); or genetic condition (1%). A further co-occurring condition (e.g., developmental coordination disorder, pathological demand avoidance) was reported by 25% of the sample.

Initial awareness of difficulties

It was usually the parents themselves who first noted problems with their child's development (96%). As illustrated in Table 1, these difficulties were in a range of areas, but most commonly related to impairments in socialisation, the presence of behavioural rigidity, and/or the displaying of behavioural problems. These behaviours were most commonly noted before the age of 5: 17% of parents noted problems in the first year; 34% by 2 years; and 33% between 2-5 years.

[place Table 1 about here]

First consultation

On average, parents first sought help when their child was 3.9 years (SD = 3.3). For 72% of parents, this was before their child's sixth birthday (7% < 1 year;

25% between 1-2 years; and 39% between 2-5 years). The remainder of the sample first sought help for their child during later childhood or adulthood. A range of professionals was seen at this first consultation, most commonly a GP or HV (see Table 2). When a diagnosis was not received (92%), the outcomes were mixed, but around half of parents were referred to another professional (see Table 3).

[place Tables 2 and 3 about here]

Final diagnosis

Taking the sample as a whole, the mean age of the children at the time of receiving a formal diagnosis was 7.5 years (SD = 5.0). This ranged from one to 40 years old: 11% < 3 years, 82% between 3-18, 4% > 18 years. On average, these diagnoses were made 4.3 years (SD = 4.2) prior to the completion of this survey. The average delay between concerns first being noted and the child receiving a diagnosis of an ASD was 4.6 years (SD = 4.4). The delay between the parent initially contacting a health professional and the child receiving a formal diagnosis was 3.6 years (SD = 4.1). In line with the results of Howlin and Asgharian (1999), children who had been given the diagnostic label 'Asperger syndrome' (M = 4.4 years, SD = 4.5) experienced a longer diagnostic delay than those given the diagnostic label 'autism' (M = 2.9, SD = 3.7). These children also tended to be diagnosed at a later age (Asperger M = 9.9 years, SD = 5.3; Autism M = 5.6 years, SD = 4.1)². The professional giving the diagnosis tended to be a Paediatrician (34%), Psychologist (21%), Child Psychiatrist (19%), or a Multidisciplinary team (9%). Other diagnosing professionals included Neurologists and Speech and Language Therapists, although many parents were unsure of this information.

Support services

Post-diagnosis, 85% of parents received a written report on their child's diagnosis, but only 56% received a follow-up appointment. Further, only 21% of parents received a direct offer of help/assistance during or following the diagnostic process. A slightly higher number (38%) were signposted to advice or help but, disappointingly, 35% of parents received no offers of help or assistance during or after the diagnostic process.

Satisfaction

Satisfaction with the diagnostic process was rated on a series of five-point scales, and these data are presented in Table 4. Satisfaction with the overall diagnostic process did not correlate with the number of years since the ASD diagnosis was given ($r = .04, p = .16$). However, longer delays between the final diagnosis being made and: (i) parents first having concerns about their child's development ($r = -.24, p < .001$); and (ii) seeking help ($r = -.25, p < .001$) were significantly associated with lower overall parental satisfaction. Dissatisfaction with the overall diagnostic process ($r = -.13, p < .001$) and post-diagnostic support ($r = -.16, p < .001$) increased somewhat in line with the age of the child.

² As previously noted, due to the lack of reliability regarding the diagnostic label 'Asperger syndrome' (e.g., Sharma et al., 2012), analyses of parental responses are pooled across groups. However, data concerning the delay parents experienced before receiving a diagnosis, as well as age at diagnosis, are presented here, purely to allow a comparison between the current sample and those surveyed by Howlin and Asgharian (1999).

[place Table 4 about here]

Stress during the diagnostic process

A total of 1012 parents rated the stress of the diagnostic process on a four-point scale: 56% = 'very' stressful, 28% = 'quite' stressful, 12% = 'not very' stressful, 2% = 'not at all' stressful. Stress was not correlated with the delay between first seeing a healthcare professional and receiving a diagnosis ($r = -.05, p = .09$), nor was it correlated with the age of the child ($r = -.03, p = .40$).

Factors affecting overall satisfaction with the diagnostic process

A multiple regression analysis was used to test the hypothesis that variables previously found to correlate with parental diagnostic satisfaction would predict respondents' overall satisfaction with the diagnostic process³. Overall satisfaction with the diagnostic process, measured on a 5-point Likert scale, was used as the dependent variable, with the following six variables entered as predictor variables: (i) The time taken to get a diagnosis (from when parents first sought professional help to the point at which a diagnosis was given); (ii) The age of the child at diagnosis; (iii) The quality of information given at diagnosis; (iv) The manner of the professional disclosing the diagnosis; (v) The support offered post-diagnosis; and (vi) Stress during the diagnostic process. Using a forced entry method of multiple regression, a significant model emerged that predicted overall satisfaction with the diagnostic process ($F_{6, 903} = 144.90, p < 0.001$). With regards to the initial hypotheses, five of the six variables were significant (Table 5). The model had an adjusted R square of .49, meaning it explained 49% of the variance regarding overall satisfaction with the diagnostic process.

[place Table 5 about here]

Stress during the diagnostic process was the strongest predictor of overall satisfaction with the diagnostic process. This was followed by satisfaction with the support offered post-diagnosis and satisfaction with the manner of the professional disclosing the diagnosis.

Discussion

The aims of this research were to: (i) provide an overview of the journey that parents in the UK currently experience in order to receive a formal diagnosis of ASD for their child; (ii) identify key factors that influence parental experiences of the diagnostic process; and (iii) explore post-diagnostic support needs. By surveying over 1000 parents who experienced the ASD diagnostic process for their children (typically within the past five years), this study reflected the views and experiences of this group at all stages of the diagnostic process.

³ For the regression analysis, key statistical checks (e.g., Durbin–Watson, tolerance/variance inflation factor statistics, Cook's/Mahalanobis distances, standardised DF betas, plots of standardized residuals/predicted standardised values, standardised residuals and partial plots) were acceptable (Field, 2013). Although there was some indication of outlying cases (identified by high Mahalanobis distance values), omission of these cases did not affect the results of the regression and these cases were, therefore, retained. Likewise, although some variables were positively skewed (age of child at diagnosis; the delay between first contacting a healthcare professional to the point at which a final diagnosis was received), transformations applied to these data did not alter the findings of the regression. Therefore the original variables were utilised in the reported analyses.

A key finding from this survey was that parents typically encounter a delay of three and a half years between first contacting a healthcare professional and receiving a formal diagnosis of ASD for their child. Given that parents usually wait about a year after they first have concerns about their child before contacting a professional, this represents a delay of over four and a half years between parents' first noting concerns about their child's development and their child receiving a formal ASD diagnosis. Disappointingly, these findings indicate no great reduction in diagnostic delay from Howlin and Moore's (1997) survey (see also Howlin & Asgharian, 1999). It is likely that any potential reductions in diagnostic delay may have been masked by the higher incidence of children diagnosed with Asperger syndrome in the current sample. As also found by Howlin and Asgharian (1999), our sub-group of children with Asperger syndrome (which is likely to comprise a higher proportion of individuals who are more intellectually able) experienced a longer diagnostic delay than our subgroup with a diagnosis of autism. Although the diagnostic label of 'Asperger syndrome' has now been omitted from DSM-5 (American Psychiatric Association, 2013), it is important to investigate and address the lengthy and frustrating diagnostic delay experienced by those individuals who would have previously received a diagnosis of Asperger syndrome.

Levels of parental dissatisfaction with the overall diagnostic process were also similar to those reported by Howlin and Moore (1997). As previously mentioned, this 'lack of change' could be related to the high numbers of children with Asperger syndrome in the current sample. These children tend to be diagnosed at a later age, and their parents experience greater delays and higher levels of frustration than parents of children with autism (Howlin & Asgharian, 1999). Indeed, both the age of the child at the time of diagnosis and the length of diagnostic delay were negatively correlated with parental satisfaction with the overall diagnostic process. Length of diagnostic delay was also a significant predictor of overall satisfaction with the diagnostic process in the multiple regression analysis.

Although greater awareness of ASD in the general population may serve to raise expectations of the level of service expected by parents (potentially accounting for the high levels of dissatisfaction in our sample), no relationships were found between the satisfaction measures and number of years since diagnosis. This suggests that parents of children diagnosed many years ago expressed the same level of satisfaction, on average, as those diagnosed very recently. Clearly, more needs to be done to improve parental experiences and perceptions of the diagnostic process. Reducing the time taken from when parents first raise concerns about their child's development to the point at which they receive a diagnosis of ASD would be a major step towards improving parental experiences. However, it is important to acknowledge that, in some cases, clinicians are simply not able to provide a child with an accurate diagnostic label at an early stage and therefore reassessment after a specified time frame is necessary. Nevertheless, further research is needed to gain a better understanding of how services that assess children with suspected ASD in a prompt and timely manner are structured and organised. These can then serve as models of diagnostic best practice for other services in the UK.

Given the increased recognition of ASD and the associated information now available concerning the disorder (e.g., in the public domain, provided by charities), it was expected that parental satisfaction with the support offered to them following diagnosis would be higher than that found in Howlin and Moore's (1997) survey. Instead, quite the opposite trend was seen: the proportion of the current sample dissatisfied with post-diagnostic information (61%) was markedly higher than the

35% noted by Howlin and Moore (1997). Further, levels of satisfaction with post-diagnostic support were a strong predictor of parental satisfaction with the overall diagnostic process. This finding is mirrored in recent work looking at perceptions of diagnosis amongst adults with ASD. Here, post-diagnostic support was also identified as a significant area of concern (Jones, Goddard, Hill, Henry, & Crane, 2014). This result could be related to higher expectations of service provision from the autism community, particularly from those who had favourable opinions of the diagnostic process itself: *“After the very considerate diagnostic process and level of care, we were left in the dark. We were given no information...a few leaflets”* (quote from the mother of a 12-year-old boy, diagnosed with autism at the age of 2). Nevertheless, it is important (and disappointing) to note that nearly 40% of parents received no post-diagnostic support at all, and less than a quarter of parents were provided with a direct offer of help or assistance following their child’s diagnosis. Participants who had support offered directly to them following diagnosis were, perhaps unsurprisingly, more satisfied than those who had no offers of support. Further, many parents reported that they valued help and support that was tailored to the specific needs of their child, opposed to more generic information on ASD: *“None of it was appropriate or geared to our needs - it seemed to be organised for the professionals’ convenience”* (quote from the mother of an 8-year-old boy, diagnosed with autism at the age of 3). Therefore, a simple (and cost-effective) suggestion for healthcare professionals to improve parental satisfaction is to directly offer tailored links to relevant support services (e.g., instigating a referral to a local service, arranging a follow-up appointment with a speech and language therapist), rather than merely signposting parents towards generic services or omitting to mention the range of services that can potentially support parents.

Exploring the key predictors of parental satisfaction with the overall diagnostic process, the stress of the diagnostic process was found to play a key role. Here, many parents cited the long wait times as the key cause of their stress: *“The time waiting for screening and diagnoses was a year - a long time spent wondering what could be wrong”* (quote from the father of a 15-year-old boy, diagnosed with Asperger syndrome at the age of 10). For others, it was the mere realisation that their child had a lifelong developmental disorder: *“I was terrified about what autism might mean for my son - I thought the future looked very bleak - we were heartbroken”* (quote from the mother of an 11-year-old boy, diagnosed with Asperger syndrome at the age of 6). Parenting a child with an ASD can be a highly stressful experience that may increase a parent’s vulnerability to depression and anxiety (Hayes & Watson, 2013). It is, therefore, important that parents are supported as fully as possible. The current study suggests that the diagnostic process itself can represent an added stressor to parents and that there are key variables that impact on the extent to which the experience of receiving a diagnosis is satisfactory. In particular, early access to a streamlined diagnostic service that provides information and access to ongoing support networks is likely to result in a more positive experience. This may, in turn, facilitate a parent’s adjustment to their child’s diagnosis.

Satisfaction with the manner of the diagnosing professional was also a significant predictor of overall satisfaction with the diagnostic process. In the present survey, 66% of parents were satisfied with the way in which the diagnosing professional conducted themselves. This is in accordance with the results of a recent survey of adults with ASD, in which the clinician’s manner was reported to be one of the most positive aspects of the diagnostic process (Jones et al., 2014). Parents who were dissatisfied with the manner of the diagnosing professional cited a number of

examples of bad practice (e.g., communicating the diagnosis with the child present in the room; providing the diagnostic label for the first time in writing or on the phone; or not fully appreciating that, for some, the diagnosis was unexpected). Nevertheless, many more examples of good practice were noted (e.g., handling the diagnosis in a thoughtful and sensitive manner; clearly explaining the diagnosis to the parent; consulting with the parents as co-experts; and demonstrating a high degree of knowledge and empathy).

Finally, it is important to address the limitations of the current research. First, the findings that can be extrapolated from a survey of this kind are dependent upon the respondents that complete the survey. Examination of participant demographics illustrates that the views presented in this survey largely represent those of mothers, and there was very little ethnic diversity in the sample (few non-white respondents completed the survey). It is important for future research to sample the views of black and minority ethnic parents who have sought a diagnosis for their child, as these parents may have qualitatively different experiences of the diagnostic process. It was also not possible to establish whether parents had more than one child with an ASD diagnosis. If so, the diagnostic process for subsequent children might have been more positive. For example, parents with prior experience of the ASD diagnostic process may be more informed and confident about the key signs of ASD: *“I had previously had my son diagnosed and the manner of the professionals was awful, this was so much improved and I felt my opinions mattered this time”* (quote from the mother of a 6-year-old girl, diagnosed with autism at the age of 5). A further limitation of the sample was that the numbers of parents who took part from different areas in the UK was small, so it was not possible to reliably analyse regional variations. It is acknowledged that there are several areas of excellent practice in the UK, and also areas where improvements could be made, but it is hoped that a range of views were reflected in the results. Also, an issue with any self-selecting sample is that it is not possible to establish if the experiences of those who completed the survey were different to those of non-respondents. It is plausible that those who had particularly good or bad experiences when seeking a diagnosis for their child preferentially completed this survey. Nevertheless, with a sample of over 1000 parents, it is likely that these opinions may be balanced across the findings, and that the results offer important insights into current experiences of the autism diagnostic process.

References

- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM-IV-TR)*. Washington, D.C
- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders – 5 (DSM-5)*. Washington, D.C
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368(9531), 210-215
- Bishop, D.V.M., Whitehouse, A.J.O., Watt, H.J., & Line, E.A. (2008). Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder. *Developmental Medicine and Child Neurology*, 50(5), 341-345. doi: 10.1111/j.1469-8749.2008.02057.x
- Bowler, D. M. (2007). *Autism Spectrum Disorders: Psychological Theory and Research*. West Sussex: John Wiley & Sons Ltd.
- Brogan, C., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder. *Autism*, 7 (1), 31-46. doi: 10.1177/1362361303007001004
- Brugha, T., Cooper, S.A., McManus, S., Purdon, S., Smith, J., Scott, F.J., Spiers, N. and Tyrer, F. (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*, The NHS Information Centre. Retrieved September 4, 2012 from <http://www.ic.nhs.uk/pubs/autism11>
- CDC (2014). Prevalence of autism spectrum disorders among children aged 8 years: autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries* 63(2): 1–22
- Chamak, B., Bonniau, B., Oudaya, L. & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, 15 (1), 83-97. doi: 10.1177/1362361309354756
- Dunn, M. E., Burbine, T., Bowers, C. A. and Tantleff-Dunn, S. (2001). Moderators of Stress in Parents of Children with Autism. *Community Mental Health Journal*, 37 (1), 39-52. doi: 10.1023/A:1026592305436
- Jones, L., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (2014). Experiences of Receiving an Autism Spectrum Disorder Diagnosis: A Survey of Adults in the United Kingdom. *Journal of Autism and Developmental Disorders*, 44(12), 3033-3044. doi: 10.1007/s10803-014-2161-3
- Goin-Kochel, R. P., Mackintosh, V. H and Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, 10 (5), 439-451. doi: 10.1177/1362361306066601
- Harrington, J. W., Patrick, P. A., Edwards, K. S. and Brand, D. A. (2006). Parental beliefs about autism: Implications for the treating physician. *Autism*, 10 (5), 452-462. doi: 10.1177/1362361306066609
- Hasnat, M., & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Paediatrics and Child Health*, 36 (1), 32-35. doi: 10.1046/j.1440-1754.2000.00463.x
- Hayes, S.A. & Watson, S.L. (2013). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629-643. doi: 10.1007/s10803-012-1604-y

- Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. *Developmental Medicine and Child Neurology*, 41 (12), 834-839. doi: 10.1111/j.1469-8749.1999.tb00550.x
- Howlin, P., & Moore, A. (1997). Diagnosis in Autism : A Survey of Over 1200 Patients in the UK. *Autism*, 1 (2), 135-162. doi: 10.1177/1362361397012003
- Keen, D., & Ward, S. (2004). Autistic spectrum disorder: A child population profile. *Autism*, 8(1), 39-48. doi: 10.1177/1362361304040637
- Latif, A. H. A. and Williams, W. R. (2007). Diagnostic trends in autistic spectrum disorders in the South Wales valleys. *Autism*, 11 (6), 479-387. doi: 10.1177/1362361307083256
- Lord, C., Rutter, M., & Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659-685. doi: 10.1007/BF02172145
- Lord, C., Rutter, M., DiLavore, P. S., & Risi, S. (1999). *The ADOS-G (Autism Diagnostic Observation Schedule - Generic)*. Los Angeles: Western Psychological Services.
- Mandell, D.S., & Lecavalier, L. (2014). Should we believe the Centers for Disease Control and Prevention's autism spectrum disorder prevalence estimates? *Autism*, 18(5), 482-484. doi: 10.1177/1362361314538131
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8 (4), 387-407. doi: 10.1177/1362361304045213
- Matson, J.L., & Kozlowski, A.M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 418-425. doi: 10.1016/j.rasd.2010.06.004
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, 3 (3), 273-285. doi: 10.1177/1362361399003003005
- Mori, K., Ujiie, T., Smith, A., & Howlin, P. (2009). Parental stress associated with caring for children with Asperger's syndrome or autism. *Pediatrics International*, 51(3), 364-370. doi: 10.1111/j.1442-200X.2008.02728.x
- National Autistic Society. (2012). *The way we are: autism in 2012*. London: The National Autistic Society.
- Osbourne, L., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12 (3), 309-324. doi: 10.1177/1362361307089517
- Oslejskova, H., Kontrova, I., Foralova, R., Dusek, L., & Nemethova, D. (2007). The course of diagnosis in autistic patients: the delay between recognition of the first symptoms by parents and correct diagnosis. *Neuroendocrinology Letters*, 26(8), 895-900.
- Rogers, C.L., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (under review). Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom
- Sharma, S., Marks Woolfson, L., & Hunter, S.C. (2012). Confusion and inconsistency in diagnosis of Asperger syndrome: a review of studies from 1981 to 2010. *Autism*, 16(5), 465-486 doi: 10.1177/1362361311411935
- Siklos, S., & Kerns, K. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, 28 (1), 9-22. doi: 10.1016/j.ridd.2005.09.003
- Smith, B., Chung, M., & Vostanis, P. (1994). The Path to Care in Autism: Is it Better Now? *Journal of Autism and Developmental Disorders*, 24 (5), 551-563. doi: 10.1007/BF02172137

- Webb, S.J., Jones, E.J.H., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International Journal of Speech and Language Pathology*, *16*(1), 36-42. doi: 10.3109/17549507.2013.861018
- Wing, L., & Potter, D. (2002). The Epidemiology of Autistic Spectrum Disorders: Is The Prevalence Rising? *Mental Retardation and Developmental Disabilities Research Reviews*, *8*, 151-161
- Woolley, H., Stein, A., Forrest, G.C., & Baum, J.D. (1989). Imparting the diagnosis of life threatening illness in children. *British Medical Journal*, *298*, 1623-6

Tables

Table 1: Nature of initial concerns

Area in which difficulties experienced	%
Delay in starting to talk	46
Delay in other milestones (e.g., walking)	26
Social development (e.g., relating to people in the normal way)	82
Rituals/obsessions/dislike of change/object attachments	63
Failure to develop normal pretend play	48
Behaviour problems (e.g., hyperactivity, tantrums)	64
Schooling	44
Medical problems (e.g., epilepsy)	9
Hearing problems	16
Sensory sensitivity	52
Sleep problems	44
No worries until a professional raised concerns	4

Table 2. Professionals seen at first consultation and subsequent referrals (n = 1048)

Professional seen	When first sought help (%)	At first referral (%)	At second referral (%)	At third referral (%)
GP	44	--	--	
Health visitor	47	8	3	1
Paediatrician	20	56	29	13
Speech & Language therapist	7	32	20	8
Psychiatrist	5	15	13	8
Psychologist (clinical)	8	16	12	8
Psychologist (educational)	--	19	15	8
Neurologist	2	3	2	1
Teacher	20	6	5	2
Nurse	3	1	1	.2
Social worker	2	3	2	1
Portage worker	--	4	3	1
Audiologist	1	12	5	2
Child and Adolescent Mental Health Services	--	2	1	1

Table 3: Outcomes (%) at each stage of the diagnostic process (categories not mutually exclusive)

	Diagnosis given	Referred to another professional	Asked to take child for further tests	Told there was no problem	Come back if problems persisted	Other (e.g., different diagnosis given)
When first sought help (n = 1048)	8	53	13	30	8	17
At first referral (n = 1044)	37	28	16	8	5	24
At second referral (n = 688)	40	20	14	5	5	25
At third referral (n = 429)	41	13	13	4	4	26

Table 4. Satisfaction scores (%) relating to different aspects of the diagnostic process (n = 1014)

	Very dissatisfied	Quite dissatisfied	Neither satisfied nor dissatisfied	Quite satisfied	Very satisfied	Mean (SD)
The overall diagnostic process	32	20	13	25	10	2.62 (1.41)
The information given at diagnosis	14	19	19	31	17	3.16 (1.31)
The manner of the professional disclosing the diagnosis	9	11	13	32	34	3.70 (1.29)
The support offered post- diagnosis	36	25	15	18	5	2.31 (1.27)

Table 5. Results of multiple regression analysis of variables hypothesised to predict overall satisfaction

Predictor Variable	B	SE B	β	<i>p</i>
Time taken to get a diagnosis	-.04	.01	-.12	.001
Age of child at diagnosis	-.01	.01	-.04	.25
Satisfaction with the quality of information given at diagnosis	.12	.04	.12	.001
Satisfaction with the manner of the professional disclosing the diagnosis	.26	.04	.24	<.001
Satisfaction with the support offered post-diagnosis	.28	.03	.25	<.001
Stress of the diagnostic process	-.38	.03	-.30	<.001

B = unstandardised beta coefficient, SE B = standard error, β = standardised beta coefficient

Appendix: Geographical spread of the respondents

<u>Location in UK at the start of diagnostic process</u>	<u>%</u>
Channel Islands	.3
East of England	5
East Midlands	9
London	11
North East England	3
North West England	8
Northern Ireland	2
Scotland	6
South East England	27
South West England	10
Wales	3
West Midlands	9
Yorkshire and Humber	7
