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Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom

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Abstract

A total of 128 adults with high-functioning autism spectrum disorders (ASD) were surveyed concerning the process they went through to obtain their diagnosis and the subsequent support they received. Results suggested that routes to diagnosis were quite heterogeneous and overall levels of satisfaction with the diagnostic process were mixed; 40% of respondents were '*very/quite*' dissatisfied, whilst 47% were '*very/quite*' satisfied. The extent of delays, number of professionals seen, quality of information given at diagnosis and levels of post-diagnostic support predicted overall satisfaction with the diagnostic process. Important areas and suggestions for improvement were noted for all stages of the diagnostic pathway. Finally, respondents displayed above average levels of depressed mood and anxiety, with greater support being requested in this area.

Keywords diagnosis; survey; adults; depression; anxiety

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Receiving a diagnosis of an autism spectrum disorder (ASD) has a huge impact on the life of an individual and those close to them (Midence & O'Neill, 1999; Punshon, Skirrow, & Murphy, 2009) and a positive diagnostic experience can influence reactions to the news and subsequent coping strategies (Hasnat & Graves, 2000). Amongst adults with ASD, strong post-diagnostic support has been shown to improve quality of life (Renty & Roeyers, 2006), reduce levels of anxiety and depression (National Autistic Society, 2008) and decrease the use of high-cost acute hospital services (National Audit Office, 2009).

To date, studies have explored *parental* satisfaction with the process of getting an ASD diagnosis for their child. For example, Howlin and Moore (1997) surveyed nearly 1300 parents and found that 49% were not satisfied with the diagnostic process, with many parents experiencing lengthy and frustrating delays before receiving a diagnosis for their child. Further, the amount of support provided post-diagnosis was very limited. In a more recent survey on parental experiences of receiving an autism diagnosis, Crane and colleagues (in prep a) found that the situation remains a cause for concern: parents still report high (52%) levels of dissatisfaction with the overall diagnostic process; they are being referred to several different professionals for assessments; they face lengthy waits before receiving a formal ASD diagnosis for their child; and they do not tend to receive satisfactory information or access to services post-diagnosis. These difficulties remain particularly pronounced for parents of children who received a diagnosis of Asperger syndrome (Crane et al., in prep b; Howlin & Ashgarian, 1999); a label that is now subsumed under the broader category of 'autism spectrum disorder' in DSM-5 (American Psychiatric Association, 2013).

However, the current paper explores the experiences and concerns of adults who have received an ASD diagnosis themselves, which are likely to be different to the views of parents seeking a diagnosis for their child. Research suggests that the diagnostic process may be even more complex and lengthy for those at the high functioning end of the autism spectrum who are seeking a diagnosis in adulthood. First, they may experience longer delays in receiving a diagnosis due to the presentation of subtler autistic traits (Howlin & Asgharian, 1999; Oslejskova et., 2007). Second, they may be likely to see a higher number of professionals (Siklos & Kerns, 2007). Finally, they may have an increased risk of being misdiagnosed with mental health problems, schizophrenia or personality disorders (Dossetor, 2007; Punshon, et al., 2009; Wolff & McGuire, 1995).

Similarly the repercussions of, and reactions to, a diagnosis are likely to differ between parents and the individual receiving the diagnosis. Receiving an ASD diagnosis in adulthood may have a significant impact on an individual's life and developing sense of self; and, indeed, a range of reactions (both positive and negative) have been documented (Calzada, Pistrang, & Mandy, 2012). However, little is known about the psychological consequences of receving a diagnosis in adulthood. Given the increasing number of adults seeking diagnoses, this is an area in which more research is urgently needed (Huws & Jones, 2008).

It is also important to determine if support services are meeting people's needs post-diagnosis as, despite the fact that the majority of individuals with ASD are adults (Knapp, Romeo, & Beecham, 2007), service provision appears to *"diminish dramatically"* as individuals grow past adolescence (Howlin, 2008, p.407). Adequate support is especially important given that adults with high-functioning ASDs experience above average levels of mental health problems (Ghaziuddin & Zafar, 2008).

There have been a number of positive pieces of legislation from the UK Government centred on improving the lives of adults with ASD. 'The Autism Act' (UK Parliament, 2009) and the subsequent 'Strategy for Adults with Autism' (Department of Health, 2010) were pivotal in highlighting the need for better diagnostic provision and support for adults with ASD, who *"have often been badly let down by public services which have failed to recognise or respond to their needs"* (Department of Health, 2010, p.6). To ensure these promised improvements are as successful as possible, it is vital to involve adults with ASDs in service planning, and to discover if the key areas for improvement identified by the UK Government match areas identified by adults themselves.

Previous work looking at the opinions of adults with ASDs regarding diagnosis and support has been in the form of qualitative studies that focus in detail on just a handful of participants (Griffith, Totsika, Nash, & Hastings, 2012; Punshon, et al., 2009). Given the heterogeneity evident among adults with ASD, there is a need for a larger-scale survey looking at the experiences of diagnosis and subsequent support received amongst adults with high-functioning ASD. To date, there has been little discussion regarding the diagnostic experiences of these individuals and this is representative of a wider tendency to focus research into ASDs on young children (Howlin, 2008).

In the current study, a survey explored perceptions of the diagnostic process in the UK. It focused on initial concerns, the different professional groups seen, the time taken to get a diagnosis, the disclosure of diagnosis, and participants' reaction to their diagnosis. It investigated what support the individual with ASD was offered and what additional support they would have liked. Additionally it included two questionnaires to measure symptoms of depressed mood and anxiety. The aims of the study were: (1) To gain an overview of the common ways that ASDs present in high-functioning individuals (e.g., nature of initial concerns, who noted them), and the journey that these individuals go through in order to obtain a diagnosis; (2) To assess satisfaction levels with various aspects of the diagnostic process and subsequent support; (3) To discover if factors previously found to influence parental perceptions of the diagnostic process similarly influence adults' experiences; (4) To explore in more detail the postive and negatives aspects of people's experiences in order to determine other areas in which improvements would be beneficial; (5) To determine the specific areas in which people would like more support post-diagnosis; and (6) To investigate the prevalence of depression and anxiety amongst respondents to establish if there is a need for more mental health support.

Based on previous work regarding parents' experiences, five key factors were predicted to affect overall satisfaction with the diagnostic process:

(1) Time taken to get a diagnosis: Several studies have found that a quicker journey through the diagnostic process results in increased satisfaction (Howlin & Moore, 1997; Osbourne & Reed, 2008; Siklos & Kerns, 2007; Smith, Chung, & Vostanis, 1994). It was hypothesised that those who experienced fewer delays between first seeking help and receving a diagnosis would be more satisfied.

(2) Number of professionals seen: A more streamlined diagnostic pathway with fewer visits to different professionals (referrals) has been shown to lead to greater satisfaction (Howlin & Moore, 1997; Oslejskova, et al., 2007; Siklos & Kerns, 2007). It was postulated that satisfaction would be increased amongst those who had to see fewer different professionals prior to being diagnosed.

(3) The quality of information given at diagnosis: Research has shown that parents who are well-informed about the nature of ASDs, including how these may

affect their child and where they can go for help, are more likely to be satisfied with the care they receive (Hasnat & Graves, 2000; Mansell & Morris, 2004; Osbourne & Reed, 2008). It was predicted that overall satisfaction would be greatest amongst those who rated the provison of information at diagnosis highly.

(4) Manner of the professional disclosing the diagnosis: Brogan and Knussen (2003) found that the interaction between parents and the diagnosing professional was an important determinant of overall satisfaction. As such, overall satisfaction was predicted to be highest amongst those who rated the professional's manner during the disclosure visit positively.

(5) Support offered post-diagnosis: Having access to support services following diagnosis is very important to parents (Mansell & Morris, 2004; Siklos & Kerns, 2007). It was hypothesised that respondents who were satisfied with the help available to them would have higher overall ratings of satisfaction.

Method

Participants

The survey was aimed at individuals aged over 18 with an ASD diagnosis, who were able to remember being diagnosed (either in childhood or adulthood). The decision to enrol participants who were diagnosed at any age (opposed to only those who were diagnosed when aged 18 or over) was taken because it is difficult to establish a suitable age cut-off in the context of whether participants are recalling their own or their parents' perceptions, or whether the respondents are more directly involved in the process. Regardless of age at diagnosis, we do not know to what extent memory of diagnosis in adulthood is influenced by an accompanying parent or partner. However, all participants needed to be high functioning in order to take part in the study. Numerous organisations that the target population was likely to engage with were identified and contacted via email. The email outlined the aims of the study, gave the address of the website hosting the survey, and suggested ways they could help promote the project to relevant individuals. A follow-up email was sent two weeks later to thank them for their participation or to encourage them to promote the project if they had not already done so. The types of organisations contacted included support groups, social clubs, day services, supported living services, organisations offering employment training and advocacy, and specialised higher education centres. An advertisement was also placed in the National Autistic Society (UK) publication 'Communication', which reaches all members of the organisation. This wide range of organisations was approached in order to try and gather a diverse and representative sample of respondents. Information regarding the project was also posted on online support groups and forums in order to promote the project to the significant number of adults with high-functioning ASD who do not engage with any official support services.

Data collection ran from March 2012 to May 2013. A total of 38.3% of participants saw the survey advertised online, 22.7% heard about it through a support/social group, 8.6% heard about it via the National Autistic Society, 6.3% saw it mentioned in a newsletter, 6.3% heard about it via a friend or relative and 18% became aware of it through other organisations. All information was collected anonymously and the average completion time was 36 minutes.

A total of 134 adults completed the survey. However, during data screening, six cases were removed: two cases had not yet received an official ASD diagnosis, two respondents had a diagnosis of pathological demand avoidance - a condition that

is not recognised in DSM-5 (American Psychiatric Association, 2013); and two cases described their ages at various stages of the diagnostic processes inconsistently, making the process chronologically impossible. This resulted in a final sample of 128 adults (although only 120 of our sample (93.8%) also completed the questionnaires assessing levels of autistic traits, depressed mood and anxiety). Missing data were not reconstructed.

The average age of the participants at the time of the survey was 39.2 years (SD = 12.8, range 18-76) and the male to female ratio was 1.2:1[1]. As can be seen from Table 1, there is a Gaussian distribution of ages, with men being an average of 6.2 years older. Overall, 84.4% of respondents were diagnosed with Asperger syndrome, 7% with high-functioning autism and 6.3% with autism spectrum disorder. Responses were pooled across diagnostic categories due to the variable nature of the diagnostic criteria used to differentiate them, their recent merging in DSM-5 (American Psychiatric Association, 2000) and evidence that suggests that autism and Asperger syndrome are not functionally distinct (Howlin, 2003; Macintosh & Dissanayake, 2004; although see, for example, Ozonoff, South & Miller, 2000).

[place Table 1 about here]

To gain further insights into the nature of this sample, information concerning education, employment and living circumstances was obtained. As detailed in Table 2, the vast majority of respondents attended mainstream school, with around three-quarters (74.2%) gaining GCSEs and just under half (46.1%) gaining A-levels. Most adults (68%) were living independently, either alone or with their partner/children. We can therefore assume that the sample was generally high functioning. Despite this, 42.4% were not currently employed or studying.

Of the 120 respondents who completed the Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001), 103 (80.5%) scored above 32, which is indicative of clinically significant levels of autistic traits (range 0-49). This figure is consistent with the results of Baron-Cohen et al. (2001), and others (e.g., White, Hill, Winston, & Frith, 2006) who have used this tool with high functioning adults. There was no significant difference in total scores on the AQ between men (M= 39.06, SD 6.5) and women (M = 39.27, SD 8.6); $t(118) = -.153$, $p = .88$.

[place Table 2 about here]

Materials

Questionnaire

The survey was accessible online via a website designed specifically for the project. It was divided into a number of sections, as described below.

Information about the respondent: This section comprised closed-ended questions concerning age, gender, current living situation and educational history (including type of school attended, qualifications gained and whether participants were currently studying or employed). These questions were included to gain a snapshot of participants' lives and to assess the extent to which they were integrating into wider society.

Diagnostic process: Questions in this section were adapted from a questionnaire that explored the experiences of parents whose child had received an ASD diagnosis (Howlin & Moore, 1997). Closed-ended questions investigated: the

age at which concerns were first raised regarding an ASD; who raised these concerns; the nature of the concerns; the age at which professional help was sought; the professional(s) seen; the ages at, and outcomes of, further referrals; use of private healthcare; the final ASD diagnosis; and any additional diagnoses. In response to feedback from a pilot survey, a free text box was included after the questions regarding each referral, which allowed respondents to expand on their answers if they wished.

Disclosure of diagnosis: Several questions regarding the visit in which participants received their diagnosis were included as this visit is often vividly remembered and it has the potential to have a significant impact on the reaction to diagnosis (Brogan & Knussen, 2003). Consequently it is an area in which small, cost-effective changes could bring about large improvements. Questions were adapted from previous work examining the experiences of disclosure from the perspective of parents of children with a developmental disability (Brogan & Knussen, 2003; Hasnat & Graves, 2000). Closed-ended questions asked about: emotions when hearing the diagnosis; people that were was present; whether the individual was expecting their diagnosis; whether they agreed with it; and whether they were glad to receive it.

Support after diagnosis: Closed-ended questions explored: whether the respondent received a written report on their diagnosis and a follow-up appointment; which services they received information about; and which services they would have liked to have been offered access to.

Satisfaction with the diagnostic process: Respondents were asked to rate their overall satisfaction with the diagnostic process on a 5-point Likert scale, ranging from 'very dissatisfied' to 'very satisfied.' Using the same scale, they indicated their satisfaction with the manner of the diagnosing professional, the information they received at diagnosis, and support services. To supplement the quantitative satisfaction scores, free text boxes were included after each Likert scale that asked respondents what could have been done to improve their experience and to comment on any aspects they were particularly satisfied with.

Personality and mental health measures

Autism Spectrum Quotient (AQ; Baron-Cohen et al, 2001): This is a 50-item self-report questionnaire that was included to measure the extent of autistic personality traits in respondents (in five different areas: attention switching, attention to detail, communication, imagination and social skill), as no background clinical information was independently confirmed during the research process. A score of 32 or above is indicative of clinically significant levels of autistic traits (Baron-Cohen et al., 2001).

Beck Depression Inventory (BDI; Beck, Steer, & Carbin, 1988): The BDI includes 21 groups of statements relating to symptoms of depressed mood. Respondents indicated which statement in each group best described the way they have been feeling in the past week. Scores for each question were summed to give a total score that indicated severity of mood: minimal depression (score of 0-9), mild depression (score of 10-18), moderate depression (score of 19-29) and severe depression (score of 30–63). Although not specifically designed for an ASD sample, this tool has been used previously in research with adults with high-functioning ASD (e.g., Berthoz, Lalanne, Crane & Hill, 2013; Crane, Goddard, & Pring, 2013).

Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988): The BAI lists 21 symptoms of anxiety (e.g., inability to relax, difficulty in breathing) and respondents indicate the extent to which they have been bothered by each symptom in the past week on a 4-point scale ranging from '*not at all*' to '*severely*.' Again, scores in response to each statement were totalled to gain an overall score; with 0-7 representing minimal anxiety, 8-15 mild anxiety, 16-25 moderate anxiety and 26-63 severe anxiety. As before, this tool was designed for a typical sample but similar measures have been successfully used with adults with ASD (e.g., Berthoz et al., 2013).

Results

Diagnostic process

Initial awareness of difficulties

In just under half of cases (44.5%) it was the respondent themselves who first raised the possibility they may have an ASD, whilst for others it was a parent (18%), other relative (3.9%), a healthcare professional (14.1%), partner (6.3%), friend (4.7%) or teacher (3.9%). A small proportion (4.7%) of the sample reported another individual in this category, or did not know the identity of this person. The average age at which these concerns first became apparent was 29.1 years (SD = 15.8 years; range = birth to 74 years). To discover more about these initial concerns, participants were asked to select from a list all the areas in which they had problems. The vast majority (85.2%) had concerns relating to social interaction, 68% had mental health difficulties and just under half (47.7%) displayed ritualistic or obsessive behaviour (see Table 3).

[place Table 3 about here]

First consultation

The average age at which respondents first sought professional help was 32.4 years (SD = 14.5, range = 2-74), which was on average 3.3 years after concerns emerged (SD = 7.5; range = 0 to 39 years). Just over half of respondents initially went to their General Practitioner (GP), with psychiatrists and psychologists being the second most common professional to visit (see Table 4 for further details). Just over a quarter of people received their ASD diagnosis at the initial visit, whilst 6.3% were given a different diagnosis. Half were either referred on to another professional or sent for tests, although 14.1% were told there was no problem (see Table 5 for further details).

[place Tables 4 and 5 about here]

First referral

After the initial visit, the remaining 94 individuals in our sample were referred to another professional, with over half visiting a psychiatrist, psychologist or other mental health worker. The average age of the sample at this visit was 33.3 years (SD 14.2 years, range 3-75). Of these 94 adults, 42.6% were given their ASD diagnosis at

this visit, 30.9% were referred on to another professional or sent for tests, and 10.6% were told that there was no problem (Table 5).

Subsequent referrals

54 people in the sample were sent for further referrals, with the majority being directed to psychiatrists, psychologists or other mental health professionals. Of these, nearly half (48.1%) received a diagnosis at the third referral, 20.4% got one at the fourth referral, 13% were diagnosed at the fifth referral and 18.5% had to attend six or more referrals before being diagnosed. 5.8% of this group received an additional diagnosis during these visits, most frequently anxiety or depression.

Final diagnosis

On average, respondents received a diagnosis 5.2 years after concerns first emerged and 2 years after seeking professional help. Encouragingly, there was a modest but significant relationship between the number of years since receiving a diagnosis and the time taken to receive a diagnosis, $r(109) = .23$, $p < 0.01$, illustrating that people diagnosed more recently experienced fewer delays. The average age at diagnosis was 34.4 years (standard deviation 13.6 years; range 8 – 75 years) and 28.9% of participants sought help privately (i.e., outside the UK's National Health Service) at some stage whilst trying to obtain their diagnosis.

Results demonstrated that 57.8% of respondents were expecting the diagnosis they received. A Mann-Whitney U test showed that those who were expecting their diagnosis were more satisfied with the manner of the disclosing professional (Mdn = 5) than those who were not expecting their diagnosis (Mdn = 4) ($U = 1437.5$, $z = -2.92$, $p < 0.01$). Generally, people responded positively to their diagnosis: 88.3% of respondents agreed with it and 85.9% were glad they received it.

When asked to select from a list of (both positive and negative) emotions that they felt on hearing their diagnosis, *'relief'* was by far the most common selection (71.9%). The next most common positive responses were *'satisfied'* (29.2%) and *'pleased'* (22.7%). However a significant proportion of participants experienced negative emotions when they received their diagnosis; 25% felt '*anxious*', 24.2% felt '*confuse*d', 17.2% felt '*upset*' and 12.5% felt '*angry*.'

Support services and mental health provision

Rather worryingly, 41.9% of respondents were offered no form of post-diagnostic support. The top three most frequently cited types of support that people would have liked were: counselling, social skills training and access to support groups (Table 6). According to scores on the Beck Depression Inventory, 23.4% of respondents expressed symptoms of low mood indicating moderate depression, and 18.8% had scores indicating severe depression. Similarly a significant proportion of people had elevated scores on the Beck Anxiety Inventory: 28.1% had scores suggesting moderate anxiety and 28.9% had scores suggesting severe anxiety. Almost a third (28.9%) of people said they were currently receiving help for symptoms of depression and anxiety, and around a fifth (21.9%) of people indicated they would like help with these symptoms. However, the overwhelming majority (78.6%) said they did not know where to go to access such support.

[place Table 6 about here]

Satisfaction with the diagnostic process

Satisfaction ratings concerning various aspects of the diagnostic process are presented in Table 7. Levels of overall satisfaction had a bimodal distribution, with 39.9% of respondents 'very' or 'quite' dissatisfied and 46.9% 'very' or 'quite' satisfied. There was no significant difference in overall satisfaction scores between those who had sought help privately (i.e., outside the UK's National Health Service) at some stage (Mdn = 2) and those who had not (Mdn = 3.5) (U = 1029, z = -1.57, p = .115). Satisfaction ratings concerning aspects of the visit in which participants received their diagnosis were higher than ratings for the process as whole. Both categories had a unimodal distribution of satisfaction scores, with 57.8% of respondents being satisfied with the information they received, and 71.1% being satisfied with the manner of the disclosing professional. Satisfaction with support was the area in which people expressed most discontent, with just 22.6% of people being satisfied with the support they received. None of these variables were related to the number of years since the diagnosis had been given (*ps > .10)* nor the age of the respondent since their diagnosis was made *(ps > .10)*.

[place Table 7 about here]

Factors affecting satisfaction

As can be seen in Table 8, all five variables hypothesised to affect perceptions of the diagnostic experience correlated with overall satisfaction at the 0.01 significance level. Two outliers, who experienced a delay of 10 and 30 years, respectively, before obtaining a diagnosis, were excluded from the analysis to prevent them biasing the output.

[place Table 8 about here]

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. Rating of overall satisfaction, measured on a 5-point Likert scale, was used as the dependent variable, with the following five variables entered as predictor variables: (1) Time taken to get a diagnosis, (2) The number of professionals seen, (3) The quality of information given at diagnosis, (4) The manner of the diagnosing professional, (5) The level of post-diagnostic support. [Note that key statistical checks (e.g. Durbin–Watson, tolerance/variance inflation factor (VIF) statistics, Cook's/Mahalanobis distances, standardised DF betas, plots of standardized residuals/predicted standardised values, standardised residuals and partial plots) suggested the absence of multicollinearity. Two outlying cases (time to diagnosis of 10 and 30 years, respectively) were identified and excluded, leaving a sample size of 126 (Field, 2013)]

Using a forced entry method of multiple regression, a significant model emerged that predicted overall satisfaction ($F_{5, 120.} = 10.68$, $p = <.001$). With regards to the initial hypothesis, four of the five variables hypothesised to affect satisfaction with the diagnostic process were found to be significant (Table 9). The model had an

adjusted R square of .279, meaning it explained 27.9% of the variance in satisfaction scores with a Cohen's f^2 of 0.39, indicating a large effect size (Cohen, 1988).

[place Table 9 about here]

Respondents' perception of the quality of information given to them at diagnosis was the most significant predictor of overall satisfaction. The length of time taken to get a diagnosis was the second most influential factor in the model. This variable, and the number of different professionals seen, had negative beta coefficients: as the number of referrals and the length of delays increased, overall satisfaction decreased. Satisfaction with the diagnosing professional's manner was the only factor not found to significantly predict overall satisfaction. As can be seen in Table 8, scores relating to satisfaction with the diagnosing professional's manner were quite highly correlated with scores relating to the quality of information received at diagnosis. This may explain why the former variable did not make a significant *independent* contribution to the variance, despite correlating with overall satisfaction.

Discussion

The current investigation aimed to: (1) provide an overview of the journey that individuals with high-functioning ASD experience in order to receive a formal diagnosis, (2) identify key factors that influenced their experiences, and (3) explore post-diagnostic support needs. By surveying over 100 adults with a diagnosis of ASD, this study provided the unique perspective of a group of adults with ASD regarding key issues that influenced their experiences, to help develop recommendations for improving services in the future.

The survey questioned respondents about the features that first alerted them to the possibility they may have an ASD, providing insights into how the condition frequently manifests in high-functioning adults. The majority of people experienced difficulties with social interaction (85.2%) and had concerns about their mental health (68%). This mirrors the findings of Geurts and Jansen (2011) who found that the most common initial reasons for adults with ASDs to seek help were social problems, mood disturbance and anxious feelings. It is also interesting to note the wide range of ages at which people (or their parents) first sought help, from two to 74 years old, illustrating the extremely heterogeneous nature of ASDs and the importance of clinicians being open-minded to the possibility of an undiagnosed ASD in anyone presenting with the features listed in Table 3.

On average, respondents received a diagnosis 5.2 years after concerns first emerged and 2 years after seeking professional help. The average age at diagnosis ranged from eight to 75 years, with a mean age of 34.4 years. This is very similar to findings from other studies looking at adults with late diagnosed ASDs, where the mean age at diagnosis was 31 years (Geurts & Jansen, 2011) and 34.1 years (Lehnhardt, et al., 2012). Many respondents wished that they had received their diagnosis earlier in life and this is a sentiment echoed in other qualitative work looking at the experiences of people with high-functioning ASDs (Jones, Zahl, & Huws, 2001). Indeed, the vast majority of respondents in this survey (89.8%) attended mainstream school, where acknowledgement of their condition and additional support would probably have been advantageous. In support of this, a report by the National

Autistic Society (2001) found a strong correlation between early diagnosis and satisfaction at school amongst people with high-functioning ASD.

The majority of the sample (71.2%) had received their diagnoses within the past five years, and therefore these figures are reflective of the current waiting times for adults to receive an ASD diagnosis in the UK. Hopefully, given the increasing awareness of the disorder (in clinicians, as well as the general public), the delay between first concerns/first seeking help and receiving a diagnosis may reduce in the future. Indeed, there was a positive indication that the situation may be improving as further inspection of the data revealed that there was a small but significant relationship between the number of years since receiving a diagnosis and the time taken to get a diagnosis, with people who were diagnosed more recently experiencing fewer delays. This is in accordance with a recent report from the National Autistic Society (2012), which found improvements in waiting times for adults accessing a diagnosis.

Once the respondents had been recognised as potentially having an ASD, the ease with which they obtained a referral varied widely. This may go some way to explain the bimodal distribution of overall satisfaction scores: both the length of time between first visit and diagnosis, and the number of professionals seen were significant predictors of satisfaction. Clearer diagnostic pathways (from first contact with a professional, through the assessments and diagnosis, to the provision of post-diagnostic support) could lead to improvements in both of these areas. Encouragingly, the Department of Health (2010) identified clear, consistent pathways for diagnosis as a key area for improvement, with recent guidelines from the National Institute of Clinical Excellent (NICE, 2012) recommending the formation of local autism multi-agency strategy groups to develop and maintain care pathways. Importantly, these groups should include representatives from a wide range of services, including mental health, learning disability (i.e., an IQ below 70) and adult services, alongside individuals with ASD. Interestingly, a number of respondents remarked on the importance of involving people with ASD in service planning. This finding supports work by Hurlbutt and Chalmers (2002, p103), who found that *"high-functioning adults with autism want to be considered experts in the field of autism and want to be consulted on issues related to autism"* (see also Milton, Pellicano & Mills, 2012).

In terms of the initial contact made with a professional, the responses to the open-ended questions confirmed the need for training amongst frontline healthcare professionals (particularly GPs and mental health teams) on the ways in which ASDs may present in high-functioning individuals. Many respondents noted that when they initially broached the topic of ASD, they were met with a lack of understanding of the condition. Professionals displayed narrow and stereotyped views of ASD and the range of ways that ASD could manifest in adults at the higher end of the spectrum (who may have developed coping strategies to compensate for difficulties). Indeed, increased understanding of ASD amongst healthcare professionals was a major potential area for improvement noted by respondents, and also the first and fundamental step of the UK Government's strategy outlining how to improve the lives of adults with autism (Department of Health, 2010, p7).

Following the initial visit to a health professional, a recurring theme in respondents' comments was that the diagnostic process lacked structure, with professionals being unsure of the appropriate referral pathway and individuals feeling that they were being passed from pillar to post. This was often due to the fact that people did not fit the criteria for referral to either mental health or learning disability teams. Frequently, participants had to research services themselves to ensure they got

a referral. For various people, the trigger to seek diagnosis was a crisis of some sort (e.g., a relationship breakdown or losing their job) and the lack of a clear referral pathway caused delays at a time when they were feeling particularly vulnerable. Having some continuity of care in being able to see the same professional in the same building helped a number of people.

It was commendable that the majority of participants (71.1%) were happy with how the diagnosing professional communicated with them. A number of people commented on the importance of the clinician taking a positive approach to the disclosure of diagnosis. For some it was a revelation to meet someone who understood their behaviour and could offer them new insights into themselves (e.g., *"Coming across someone for the first time in my life who understood how I think and who spoke to me in a way that was crystal clear*" – quote from a 36-year-old man diagnosed with Asperger syndrome).

Parental surveys concerning ASD diagnosis (e.g., Crane et al., in prep a and b; Howlin & Moore, 1997) highlight the lack of available post-diagnostic support as a major concern in relation to the diagnostic process, and this finding was mirrored in the current survey of adults with ASD. This was the area in which respondents expressed greatest dissatisfaction with just 21.4% feeling satisfied with the help they were offered. This figure is consistent with the National Autistic Society's (2012) finding that only 28% of adults with an ASD received good information about where to go for help. Although over half of participants (57.8%) in the current survey reported being satisfied with the information they received following their diagnosis, there is still a lot room for improvement (e.g., having written information to take away such as basic information about the condition, contact details of local support groups and a suggested reading list). Further, receiving a diagnosis was a difficult experience for a number of people, and being left without any formal support after receiving such potentially life-changing information led some people to feel alone and unsure about the future. Although diagnosis should be complemented with a needs assessment, only 16% of adults with ASDs are offered a community care assessment (National Autistic Society, 2001). The proportion of people offered one in this survey was even lower (just 3.1%), with a large proportion of participants (41.9%) offered no form of support whatsoever. This means that the vast majority of people were unknown to services and had to find the help they required independently. Many people commented that having a follow-up appointment could help alleviate some of this distress. Additionally, numerous people felt there was not enough time for them process all the information they had been given at diagnosis and would have valued a follow-up appointment to discuss the implications of the diagnosis.

Griffith et al. (2012) found that adults with high-functioning autism desired flexible support, as their needs fluctuated in response to life-events and over time. ASDs affect no two people in the same way, so it is important to tailor support to each person's needs, allowing them to live their lives as fully and independently as possible. The UK Government's Autism Strategy also describes the need to personalise support services and give people *"choice and control to build the right package of care based on needs"* (Department of Health, 2010, p19).

High levels of depressed mood and anxiety were noted in this group. Although the tools used in this study (the BDI and BAI) only assess levels of depressed mood and anxiety over the past two weeks, these results corroborate other studies that have found people with ASDs to have higher than average levels of mental health problems (Balfe & Tantam, 2010; Bellini, 2004; Ghaziuddin & Zafar, 2008). Frequently these other mental health conditions were undiagnosed, illustrating the need for better

mental health support for a group that is "*among the most vulnerable and socially excluded in our society*" (National Autistic Society, 2001, p9). The Autism Strategy (Department of Health, 2010) advocates that high-functioning adults should access mainstream services for their needs, yet several respondents commented that there is a need for mental health support geared specifically towards people on the autism spectrum.

In summary, these findings have provided an important insight into the diagnostic experiences of adults with ASDs in the UK. However, it is important to note that this research was completed prior to the introduction of DSM-5 (American Psychiatric Association, 2013). The vast majority of our sample (84%) had received a diagnosis of Asperger syndrome, which has been omitted from DSM-5 and incorporated into the broader 'Autism Spectrum Disorder' category. The official guidance states that *"Anyone diagnosed with one of the four pervasive developmental disorders (PDD) from DSM-IV should still meet the criteria for ASD in DSM-5 or another, more accurate DSM-5 diagnosis"* (dsm5.org). In view of this, it is unlikely that the sample of adults who participated in this research would not have met diagnostic criteria for ASD using DSM-5 guidelines. Yet it remains to be seen whether the participants that completed our surveys would have viewed their diagnoses similarly if they received a diagnosis of ASD, opposed to Asperger syndrome; the latter often being views as part of a personal identity (e.g., Buxbaum & Baron-Cohen, 2013).

Finally, it is important to acknowledge the limitations of the current investigation. First, findings cannot be generalised to lower-functioning individuals with ASD, or be considered representative of all high-functioning individuals. Indeed, the proportion of adults in this survey who reported living independently and with partners/children is higher than previous research (e.g., Roux, Shattuck, Cooper, Anderson, Wagner & Narendorf, 2013), suggesting our sample were among the most independent of higher functioning adults. Further, there is no way of knowing if the views of respondents are the same as those of non-respondents (people may be more likely to participate if they have had a particularly good or bad experience). Related to this, the study was largely promoted through support services (so a significant number of people not engaged with these services were not reached) and the survey was only open to people who had been diagnosed (meaning the experiences of those who had been through the diagnostic process and were unable to get a diagnosis were not represented). Second, this survey has examined the experiences and issues associated with receiving a diagnosis of ASD in the UK. Although similar issues may apply outside the UK, it is important to assess this empirically - hopefully the current research may encourage those in other countries to conduct similar work to identify similarities and differences in adults' experiences, and to share examples of best practice. Third, retrospective reports are prone to error and there was no way to verify the respondents' diagnosis or clinical history. This issue regarding accuracy is especially pertinent given that the youngest participant was diagnosed at the age of eight. Nevertheless, recent research (e.g., Goddard, et al., 2014) has shown that while children with ASD (who were as young as eight) have less specific memories compared to typically developing children, they nonetheless are quite able to recall personally experienced events; impairments are subtle and not particularly age dependent. Further, several studies have demonstrated that individuals with ASD are no more likely to confabulate than their peers (e.g., Maras, Memon, Lambrechts & Bowler, 2013; McCrory, Henry & Happé, 2007), so there is no reason to suspect their account as a whole. Fourth, findings regarding the prevalence of depressed mood and

anxiety should be interpreted with caution, as the scales used were not designed for people with ASDs. Therefore the validity of questions and cut-off points may be different amongst this group; e.g., people with ASDs often have high trait anxiety as part of their condition, which may not be pathological (Tantam, 2000). Related to this, factors other than the specific diagnosis (e.g., pre-existing mental health conditions, family chaos, medical complications) may have played a role in how respondents experienced and viewed the diagnostic process and it is important to consider these when assessing the results (e.g., satisfaction levels). Despite these limitations, the current findings are encouragingly similar to those of other smaller qualitative studies (Griffith, et al., 2011; Punshon, et al., 2009; Renty & Roeyers, 2006), provide a valuable insight into the diagnostic experiences of a subset of adults with ASD in the UK, and underscore the need for timely diagnosis and treatment for adults with high functioning ASDs.

Footnotes

[1] This is lower than expected, based on previous research showing ASDs are 3-4 times more common in males (Chakrabati & Fombonne, 2001). However other research looking at high-functioning adults has found the gender ratio to be slightly reduced (Baron-Cohen & Wheelwright, 2004; Griffith, et al., 2012). This may be because more high-functioning women are diagnosed later in life, as girls tend to be more effective at developing coping strategies to mask their ASDs (Ashton-Smith & Gould, 2011). It may also reflect the fact that more women engage in the support services through which the survey was advertised.

[2] GCSE refers to General Certificate of Secondary Education and are qualifications studied for by 14-16 year olds, just before finishing compulsory education in the UK. A Level refers to Advanced Level, which is a qualification gained in the UK, typically by studying a restricted number of subjects more intensively for a two year period (usually at the age of 16-18). It is often used to gain entry to University level courses.

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Table 1. Participant Characteristics (n = 128)[a]

		Males (n = 70)	Females (n = 58)
Age at time of survey (%)	18-24	9.4	27.7
	25-34	17.2	31.9
	35-44	32.8	19.1
	45-54	25.0	8.5
	55-64	14.1	8.5
	65+	1.6	4.3
Diagnosis (%)	Asperger syndrome	84.3	84.5
	Autism	7.1	6.9
	Autism Spectrum Disorder	7.1	5.2
	Other[b]	1.4	3.4
AQ score		39.06 (SD = 6.94)	39.27 (SD = 8.64)

[a] Data missing in 17 cases: 6 male and 11 female
[b] Other includes autistic traits, uncertain of exact diagnosis given

Table 2. Education, employment and living circumstances (N = 128)

		%
Place of education	Mainstream school	89.9
	Specialist school	5.5
	Specialist unit in a mainstream school	2.3
	Other[a]	2.4
Qualifications (categories not mutually exclusive)	GCSEs (typically at age 14-16)	74.2
	A-levels (typically at age 16-18)	46.1
	First degree	36.7
	Post-graduate degree	14.1
	No qualifications	5.5
Current day activity (categories not mutually exclusive)	Student	17.2
	Working part-time	12.5
	Working full-time	20.3
	Voluntary work	7.8
	Self-employed	5.5
	No work or school	42.2
Current living circumstances	At home with partner and/or child(ren)	38.3
	At home alone	29.7
	At home with parent(s)	23.4
	In supported housing	2.3
	At home with friends	1.6
	Other[b]	4.7

[a] Other includes home school and a pupil referral unit
[b] Other includes university accommodation, combination of alone/with children, between addresses

Table 3. Nature of initial concerns (n = 128)

	%
Social interaction or relationship concerns	85.2
Mental health difficulties	68.0
Ritualistic/obsessive behaviour	47.7
Sensory sensitivity	36.7
Motor or co-ordination difficulties	22.7
Altered sleeping patterns	21.9
Learning difficulties	14.1
Concerns about speech or hearing	13.3
Medical conditions	6.3
Other[a]	20.3

[a] Other includes diagnosis of a relative, social phobia, hallucinations, literal thinking, difficulties multi-tasking, suggestion of ASD from another healthcare professional.

Table 4. Professionals seen at first visit and subsequent referrals (N = 128)

Professional seen	First visit % (N = 128)	First referral % (N = 94)	Subsequent referrals % (N= 54)
General Practitioner	53.8	11.7	13.5
Psychiatrist	14.1	21.1	27.9
Psychologist	13.3	18.8	26.9
Other mental health professional	7.8	14.1	12.5
Speech therapist	-	-	3.8
Paediatrician	1.6	0.8	-
Combination	-	4.7	5.8
Other[a]	9.4	2.3	9.6

[a] Other includes support team at university/work, ASD specialist, occupational therapist

Table 5. Outcomes at initial visit and subsequent referrals (N = 128)

What happened	First visit % (N = 128)	First referral % (N = 94)	Subsequent referrals % (N = 54)
ASD Diagnosed	26.6	42.6	46.2
Other condition diagnosed	6.3	11.7	5.8
Referred on	50.0	25.5	19.2
Sent for tests	2.3	0.0	5.7
Told no problem	14.1	10.6	6.7
Other[a]	0.8	9.6	16.3

N.B: Where more than one outcome was selected, e.g., "ASD diagnosed and sent for tests" only the most significant outcome was recorded, e.g., "ASD diagnosed."

[a] Other includes applying for funding for further investigation, being told to return if problems persisted, being offered therapy or counselling.

Table 6. Type of post-diagnostic help wanted, compared to help offered (N = 128)

Type of service	% who would have liked to access service	% offered service
Counselling	44.5	21.7
Social skills training	36.7	7.8
Support groups	35.9	21.9
Support at school/work	34.4	12.4
Financial advice	29.7	13
Input from healthcare professionals	22.7	7.8
Community care assessment	20.3	3.1
Housing advice	16.4	1.6

Table 7. Satisfaction scores relating to different aspects of the diagnostic process[a] (N = 128)

	Very dissatisfied (%)	Quite dissatisfied (%)	Quite satisfied (%)	Very satisfied (%)
Overall diagnostic process	14.1	25.8	30.5	16.4
Information given at diagnosis	10.2	14.8	35.9	21.9
Manner of diagnosing professional	3.1	7.8	21.1	50.0
Post-diagnostic support	28.9	25.0	11.7	10.9

[a] Participants who were 'neither satisfied nor dissatisfied' have been excluded from the table, for purposes of simplification, but make the total up to 100%.

Table 8. Correlation matrix of overall satisfaction and the five predictor variables (N = 126)

	OS	TTD	NPS	SI	SPM	SS
OS	1					
TTD	-.263**	1				
NPS	-.239**	.414**	1			
SI	.410**	.015	.018	1		
SPM	.315**	.093	.008	.649**	1	
SS	.312**	.005	-.063	.396**	.298**	1

** Correlation is significant at the 0.01 level (1-tailed)

OS = Overall satisfaction, TTD = Time to diagnosis, NPS = Number of professionals seen, SI = Satisfaction with information given, SPM = Satisfaction with professional's manner, SS= Satisfaction with support

Table 9. Results of multiple regression analysis of variables hypothesised to predict overall satisfaction (N = 126)

Predictor Variable	B	SE B	β	*p*
Time to diagnosis	-0.13	0.05	-.24	.005
Number of professionals seen	-0.15	0.07	-.17	.040
Satisfaction with information	0.31	0.11	.29	.007
Satisfaction with support	0.18	0.09	.17	.042
Satisfaction with professional's manner	0.10	0.12	.09	.387

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