Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom

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Abstract

To date, research exploring experiences of diagnosing autism spectrum disorder (ASD) has largely focused on parental perspectives. In order to obtain a more complete account of the ASD diagnostic process, it is essential that the views and experiences of professionals are heard. In the current study, 116 multidisciplinary professionals involved in diagnosing ASD in the United Kingdom completed an online questionnaire exploring their experiences and opinions of three key areas of service: accessibility; the diagnostic process; and post-diagnostic support. Although professionals were largely satisfied with service accessibility, around 40% of services were failing to provide timely assessments. Standardised diagnostic tools were perceived as helpful and were used consistently, but concerns were raised about their validity in detecting atypical ASD presentations (e.g., females). Several challenges regarding giving ASD diagnoses were reported; these included making sure caregivers understood the diagnosis, pitching information at the correct level, and managing distress. Further, the practice of 'upgrading' to a diagnosis of ASD in uncertain or complex cases was reported by many, albeit infrequently, and reasons for this varied widely. Professionals expressed dissatisfaction with post-diagnostic provision, especially onward and long-term support options. They also felt that service improvements were required across populations and across the three key areas of service.

Keywords autism spectrum disorders; diagnosis; health services; professional development

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In the absence of biological markers, the diagnosis of Autism Spectrum Disorder (ASD) relies upon clinical judgments about behavioural markers (Filipek, Accardo, Ashwal et al., 2000; Gray, Msall & Msall, 2008). These behavioural markers include persistent difficulties with social communication and interaction, as well as the presence of restricted and repetitive behaviours, interests or activities (DSM-5; American Psychiatric Association, 2013). Current 'gold standard' practice involves a best-estimate clinical consensus diagnosis derived from integrating several sources of information including: a detailed developmental history from parents/carers; opinions of multi-agency and multidisciplinary professionals who know the individual; results of standardised assessments; observation of the individual in multiple settings; and diagnostic criteria (Baird, Charman, Baron-Cohen et al., 2000; Filipek et al., 2000; NICE, 2011; 2012).

Many aspects of diagnosing ASD create challenges for professionals (Lord & Corsello, 2005), leading to ongoing uncertainties regarding 'best practice' processes and procedures for diagnosis. Currently, diagnosis is more reliant on the expertise of professionals in interpreting the results of standardised observations and assessments (NICE, 2011; 2012), than on the results of any objective measure alone. Given the increasing pressure exerted on professionals to diagnose ASD as early as possible, in order to facilitate intervention (Braiden, Bothwell & Duffy, 2010), teams of professionals are relied upon to make difficult diagnostic decisions; balancing uncertainty regarding 'best practice' with individual patient need. The result has been inconsistent practice across services, with access to diagnosis varying according to the area in which the family live (NICE, 2011).

Parents have consistently reported frustration and dissatisfaction with ASD diagnostic services in the UK (Crane, Chester, Goddard, et al., 2015; Howlin & Moore, 1997; Mansell

& Morris, 2004; Midence & O'Neil, 1999). In particular, parents have highlighted significant delays between raising initial concerns and receiving a formal diagnosis of ASD (Crane et al., 2015), as well as having to exert substantial pressure for a referral to diagnostic services in the first place (Howlin & Moore, 1997). This is despite the fact that timely recognition and diagnosis of ASD enables access to autism-specific support services, which can result in more positive outcomes (NICE, 2011). Post-diagnosis, the limited support offered is an area of significant concern for both parents of children with ASD and adults with ASD (Crane et al., 2015; Jones, Goddard, Hill, et al., 2014).

Parents' perceptions of the diagnostic process are influenced by several characteristics of the diagnosing professional, including their inter-personal skills and the therapeutic partnerships that they develop with parents (Braiden et al., 2010; Mockett, Khan, & Theodosiou, 2011; Moh & Magiati, 2012). Further research has highlighted the value parents place on being consulted as a 'co-expert' on their child. As well as feeling heard and having transparent, honest communication with professionals, parents want to be involved in key decision making (Braiden et al., 2010; Moh & Magiati, 2012). Further, Brogan and Knussen (2003) reported that the disclosure of an ASD diagnosis need not be a negative experience for parents, highlighting the importance of not only *what* parents are told, but *how* they are told.

De Clercq and Peeters (2007) emphasised that whilst it is important to understand parents' views, as they are experts on their children, professionals are the experts on autism. Hence, to ensure the quality of ASD diagnoses, both elements of this expertise need to be elucidated and integrated. Although a few studies have assessed professionals' perspectives of the challenges that parents face when living with a child with ASD (e.g., Keenan, Dillenburger, Doherty, et al., 2010), there is little research on professionals' views of the diagnostic pathway. In one of the few studies on this topic, Moh and Magiati (2012) surveyed 17 professionals involved in ASD assessments in Singapore. All respondents reported using

diagnostic criteria and standardised tools to aid the diagnostic process, perceiving them to be very helpful. Professionals who were experienced in multi-disciplinary teams (MDTs) advocated this way of working, reporting that it was advantageous for a holistic assessment. However, constraints were acknowledged regarding time, obtaining enough information, conflicts of opinion, parent involvement and case complexity.

Exploring professionals' views and experiences of complex and uncertain cases, Skellern, Schulter, and McDowell (2005) questioned psychiatrists (n= 26) and paediatricians (n= 79) on whether they would specify an ASD diagnosis in situations of diagnostic uncertainty. Surprisingly, they found that 58% of surveyed clinicians would err on the side of a positive diagnosis when faced with some degree of doubt regarding whether a child or adult met the criteria for an ASD; a practice termed 'upgrading'. These professionals reported 'upgrading' to facilitate access to support - prioritising functional need above diagnostic aetiology - with the belief that they were fulfilling a fundamental role in advocating for patient need (Rushton, Felt, & Roberts, 2002; Skellern et al., 2005; although see Williams, Tuck, Helmer, et al., 2008). This practice raises concerns regarding the consistency of diagnostic labels, with Skellern et al. (2005) surmising that it may be more appropriate for the provision of services to be based on functional need rather than a categorical label.

To summarise, the limited research on professionals' perspectives of diagnosis has emphasised the complexities of categorising ASD based on assessments and judgements of a phenotypical profile that is not always typical. Professionals appear to be openly challenged by ASD diagnoses and aspire to a co-ordinated system in which multi-sources of opinion inform shared decision-making and planning. However, the surveys that have been conducted to date have been limited in terms of region and number of respondents, as well as in terms of diagnostic population (largely surveying professionals working in children's services). There

is ample justification for a wider and larger scale survey of the perceptions and experiences of professionals involved in ASD diagnosis.

Such a survey is particularly timely given the increased focus on the issue of ASD diagnosis in recent years. Improving the ASD diagnostic process was explicitly addressed in the Autism Act (UK Parliament, 2009), which was the first disability-specific law to be passed in the UK. It was also emphasised in the subsequent autism strategy for England (Department of Health, 2010), which provided statutory guidance concerning the autism diagnostic process. More specific recommendations regarding the recognition, referral, diagnosis and management of ASD have been outlined in the National Institute for Clinical Excellence (NICE) guidelines for children and young people (2011) and adults (2012). These guidelines sought to develop a more consistent approach to the diagnosis of ASD in the UK, through initiatives such as the development of specialist autism teams in each local area, as well as the creation of multi-agency strategy groups.

The broad aim of the current investigation was to conduct a review of diagnostic practice in the United Kingdom (UK) by exploring the experiences and perspectives of professionals involved in diagnosing ASD. The research was designed to complement the recommendations made in the NICE (2011; 2012) guidelines, to identify what aspects of the ASD diagnostic process are working well, and what areas are in need of improvement. Views were sought regarding three key stages of the diagnostic pathway: service accessibility; the diagnostic process; and post-diagnostic support. Specific research objectives were: (1) To identify areas of professionals' satisfaction/dissatisfaction with the diagnostic process; (2) To explore the challenges that professionals' faced when conducting ASD assessments (e.g., the extent of 'upgrading', and challenges with best practice delivery); and (3) To identify areas for improvement and service development.

Method

Participants

A heterogeneous sample of professionals from across the UK, who were clinically active in ASD diagnosis and assessment at the time of the survey, were invited to participate. To recruit the sample, details of assessment and diagnosis services were collated via the National Autistic Society online directory, and Internet searches were conducted for ASD diagnostic services. In total 300 services were catalogued and contacted. Additionally, approximately 3000 statutory and non-statutory ASD services listed in the UK's National Health Service (NHS) choices directory were contacted.

A total of 126 multidisciplinary professionals completed the full questionnaire but 10 professionals were excluded from the analysis as they were not clinically active at the time of the survey. This resulted in a final sample of 116. As illustrated in Table 1, the sample largely comprised psychologists, speech and language therapists, paediatricians and psychiatrists, along with other professionals such as nurses, teachers and occupational therapists. Although this represents a very broad range of professionals, not all of whom are able to personally provide a formal diagnostic label to individuals with ASD, all were actively involved in the ASD diagnostic process. The sample was also relatively experienced, with the majority (n = 66; 57%) having between two and ten years experience. Respondents also worked with individuals across a range of ages. Although the sample was geographically diverse (from all areas of the UK; see Appendix 1), there was a lack of ethnic diversity in our sample (90% of the respondents were White). Missing data were not reconstructed.

[place Table 1 about here]

Materials

Professionals completed an online questionnaire concerning the ASD service in which they were employed. The questionnaire was developed by: adapting items from parental surveys of the ASD diagnostic process (e.g., Howlin & Moore, 1997); utilising items from existing surveys of professionals who are involved in the ASD diagnostic process (e.g., Skellern et al., 2005); and developing novel items based on clinical experience (our team included an Assistant Psychologist [C.R.] and Chartered Clinical Psychologist [L.A.H.]).

The questionnaire was structured in sequential order, leading the respondent through the patient pathway. As well as requesting practitioner and service demographics, sections included: (1) service accessibility; (2) the diagnostic process; (3) post-diagnostic support; and (4) improving the patient pathway.

(1) Service accessibility: Respondents were asked to estimate the current wait time for an initial appointment to start an assessment for ASD. Using a 5-point scale, professionals were also asked for their opinion on how easy patients found it to access the diagnostic service they worked in (1 = extremely difficult, 2 = difficult, 3 = neutral, 4 = easy, 5 = too easy), and how satisfied they were with the accessibility of their service (1 = very dissatisfied, 2 = dissatisfied, 3 = neutral, 4 = quite satisfied, 5 = very satisfied). Open-ended questions were included to allow respondents to elaborate on: (i) what they felt was working well; and (ii) the improvements they would recommend.

(2) The diagnostic process: Respondents were asked to select (from a list of options): (i) the standard components of an ASD assessment within their service; and (ii) the diagnostic and/or screening tools that they use to inform their decision

making. Respondents were asked to rate (on a 5-point Likert scale) how helpful they found using diagnostic tools (1 = very unhelpful, 2 = quite unhelpful, 3 = neutral, 4 = quite helpful, 5 = very helpful), and were offered the opportunity to elaborate on their opinions/practice in open ended responses. Professionals were asked which diagnostic criteria they used when making an ASD diagnosis (ICD-10 [World Health Organisation, 1992], DSM-IV [American Psychiatric Association, 2000][1], or other). Exploring the issue of diagnostic 'upgrading', respondents were asked to indicate (on a 5-point scale) whether they "ever made a positive diagnosis of ASD in the face of an unclear presentation or patients failing to meet criteria on diagnostic tools" (1 = never, 2 = very infrequently, 3 = quite infrequently, 4 = quite frequently, 5 = very frequently). If respondents responded with a 3, 4 or 5, they were asked to indicate their clinical reasoning for making these positive diagnoses (selecting from a series of options, but with the opportunity to provide additional explanations). Respondents were then asked to respond to a series of questions about the delivery of a diagnosis. Specifically, professionals were asked to select the top three most challenging aspects of delivering a diagnosis of ASD to a patient or their family. Although options were provided to respondents, the option to provide alternative challenges was offered.

(3) Post-diagnostic support: Respondents were asked whether (in line with NICE guidelines), patients were offered a follow-up appointment within six weeks of receiving a diagnosis (response options: yes or no). The nature of post-diagnostic support was explored by asking respondents to indicate (on a 5-point Likert scale) whether a number of post-diagnostic support options were provided to patients and/or their families (1 = never, 2 = rarely, 3 = sometimes, 4 = frequently, 5 =

[1] These were the diagnostic manuals in use at the time of the survey.

always). Professionals were asked how satisfied they were with the post-diagnostic support services they offered (1 = very dissatisfied, 2 = quite dissatisfied, 3 = neutral, 4 = quite satisfied, 5 = very satisfied). Free text boxes were provided to allow respondents to elaborate on their answers (reporting what worked well or what improvement they would recommend). Exploring post-diagnostic referral pathways, respondents were asked to rate (on a 5-point Likert scale) how satisfied they were with the availability or accessibility of these (1 = very dissatisfied, 2 = quite satisfied, 3 = neutral, 4 = quite satisfied, 5 = very satisfied). As before, respondents were able to explain (using open text-boxes) what they thought worked well or was in need of improvement in this regard.

(4) Improving the patient pathway: Focusing on the age groups most in need of service improvements, respondents were asked to rate (on a 5-point Likert scale) their satisfaction with the diagnostic services offered to patients of different ages (1 = very dissatisfied, 2 = quite dissatisfied, 3 = neutral, 4 = quite satisfied, 5 = very satisfied) and to select which age groups they felt service improvements were most needed in (providing justification for their selection, if they wished). To conclude the survey, respondents were offered the opportunity to add any additional comments or reflections on current practice in diagnosing ASD.

Procedure

Data collection ran from March 2012 to May 2013. A standard email invitation was sent to every identified service contact, outlining the nature of the project and providing a link to the online survey, along with a request that this invitation to be circulated to all appropriate multidisciplinary professionals. The questionnaire took approximately 40 minutes

to complete, although the time was reduced if the respondent did not expand on their answers to closed-ended questions. 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.

Results

Service accessibility

Although over half of services were meeting NICE (2011, 2012) guidelines and commencing assessments within three months of receiving a referral (n = 67; 58%), almost one fifth of those sampled (n = 21; 18%) reported a wait time of over 20 weeks, demonstrating variability in timely service provision (see Table 2).

Questioning professionals about how satisfied they were with service accessibility, over half of the respondents reported feeling satisfied (n = 68, 59%). Around a fifth of respondents (n = 25, 22%) expressed dissatisfaction, with the remaining 23 (20%) feeling 'neither satisfied nor dissatisfied'. A chi square analysis demonstrated that shorter waiting times were associated with higher levels of satisfaction, X^2 (4, N = 116) = 18.38, $p < .01$. Satisfaction levels as a function of waiting times are presented in Table 2.

[place Table 2 about here]

Satisfaction with service accessibility was also examined as a function of each age group that respondents worked with (note: age group categories were not mutually exclusive). As can be seen in Table 2, the majority of professionals were satisfied with service accessibility, and this pattern was fairly consistent across age groups (specifically, a higher percentage of professionals in each age group reported satisfaction – opposed to 'dissatisfaction' or a 'neutral' response – regarding waiting times).

The diagnostic process

Professionals were asked to select (from a list of options) the standard components of an ASD assessment within their service. As illustrated in Table 3, a range of options were utilised, most commonly: interviews with the patient and their families; the gathering of prior medical, social and behavioural information; and communication with external agencies (e.g., teachers, social services).

[place Table 3 about here]

Most respondents reported standardised assessment/diagnostic tools to be 'very' (n = 28; 24%) or 'quite' (n = 59; 51%) helpful. A neutral response ('neither satisfied nor dissatisfied') was given by 23 respondents (20%) and just 4 (3%) reported that they were 'quite unhelpful'. The most frequently used assessment/diagnostic tools were the Autism Diagnostic Observation Schedule (ADOS-G), Diagnostic Interview for Social and Communication Disorders (DISCO), Social Communication Questionnaire (SCQ), Autism Diagnostic Interview – Revised (ADI-R) and Gilliam Autism Rating Scale (GARS). Full details are provided in Table 4.

[place Table 4 about here]

Questioning respondents on the criteria[2] they used when making an ASD diagnosis, 68 (59%) relied on ICD-10 (World Health Organisation, 1992) criteria, whilst 32 (28%) utilised DSM-IV (American Psychiatric Association, 2000) criteria. The remaining 16 (14%) reported using other criteria (e.g., Ehlers & Gillberg 1993; Gillberg & Gillberg, 1989) or, more commonly, ICD-10 and DSM-IV criteria in combination.

Professionals' views were sought regarding how they responded when faced with diagnostic uncertainty and to estimate the frequency with which they practiced 'upgrading' (providing an ASD diagnosis in situations involving some degree of doubt regarding whether the child or adult fully met the criteria for an ASD). Although 37 (32%) reported that they would 'never' upgrade a diagnosis, the majority of surveyed professionals acknowledged that they practiced upgrading to some extent: 'very infrequently' (n = 37; 32%); 'quite infrequently' (n = 27; 23%); 'quite frequently' (n = 12; 10%); and 'very frequently' (n = 2; 2%).

Exploring the clinical reasoning for making these positive diagnoses, the 78 professionals who reported upgrading diagnoses selected the following (from a range of options) as justifications for their decisions: enabling individuals to meet criteria for social/health care funding or support (n = 17; 22%); enabling individuals to get a statement of Special Educational Needs (n = 8; 10%); pressure to meet targets (n = 1; 1%); or differing opinions amongst colleagues in a team (n = 32; 41%). Note that many professionals felt that their reasoning did not fit into any of these categories and did not select an option; justifications for these decisions are explored in Table 9 (which presents a qualitative analysis of responses to open-ended questions).

[2] Specifically, the diagnostic manuals in use at the time of the survey.

Finally, professionals were asked to rank (from a range of options) the top three most challenging aspects of delivering an ASD diagnosis. The most frequent challenges reported (selected as rank one, two or three) were: (1) Ensuring caregivers understood the diagnosis and why it was given; (2) Pitching information at the correct level; and (3) Managing distress. Full data are presented in Table 5.

[place Table 5 about here]

Post-diagnostic support

Less than half of those surveyed (n = 51; 44%) reported that they were meeting NICE (2011; 2012) guidelines and offering a post-diagnostic follow-up session within six weeks of the formal diagnosis.

Exploring the types of post-diagnostic support that services offered to patients and their families (which respondents selected from a list of commonly offered services), three areas of support were more frequently selected by respondents than others: 96 (83%) always or frequently provided information leaflets; 95 (82%) always or frequently provided information about support groups; and 89 (77%) always or frequently liaised with other services (e.g., school, employer) to provide support. Full details are presented in Table 6.

[place Table 6 about here]

Questioning professionals about their satisfaction with in-service post-diagnostic provision, 54 (47%) were satisfied, whereas 35 (31%) were dissatisfied (the remaining 26 respondents were 'neither satisfied nor dissatisfied'). Regarding the availability of onward referral services, again, results were mixed. Professionals most frequently reported feeling

dissatisfied (n = 47; 40%), but many were either satisfied (n = 31; 27%) or 'neither satisfied nor dissatisfied' (n = 37; 32%)

Improving the patient pathway

Professionals were asked to select the age group[s] that they believed most needed ASD diagnostic service improvements. Although the majority of services appeared to require improvement, professionals most frequently selected services for primary school age children and young adults. Services for preschool children, secondary school age children, and adults were also consistently identified for service improvements, with services for older adults least in need of improvement (see Table 7).

[place Table 7 about here]

Throughout the survey, respondents were given opportunities to elaborate on their responses to closed questions and to provide additional comments. Responses to these open questions were analysed qualitatively, using a thematic analysis approach (Braun & Clarke, 2006). This involved identifying overarching themes within the data, which were assimilated and accommodated as they emerged. A particular focus was on identifying themes specific to ASD diagnosis (i.e., rather than generic problems with the UK's National Health Service), as well as identifying solutions and best-practice examples. Analyses were jointly conducted by two of the authors (L.C. and L.G.), with C.R. also independently coding the data. After the two analyses were merged, findings were reviewed and discrepancies resolved before key themes relating to each of the three key areas of service (accessibility, the diagnostic process, and post-diagnostic support) were identified. These are presented in Table 8, along with brief explanations of the themes and sample quotes.

[place Table 8 about here]

Discussion

Surveying 116 professionals involved in ASD diagnosis in the UK, the aim of the current study was to identify the experiences and perspectives of this professional group regarding three key areas of service: accessibility; diagnostic provision; and post-diagnostic support. Suggestions for areas of improvement were also sought. This represents the most comprehensive survey of its kind across the UK and the findings have important implications at a service level and at an individual clinician level. Ensuring best clinical practice when encountering children or adults with suspected ASD is especially important given the recent prevalence estimates suggesting that ASD affects as many as 1 in 68 individuals (Centers for Disease Control and Prevention, 2014; although see Mandell & Lecavalier, 2014).

First, professionals were asked for their views on the accessibility of the service that they worked in. Although the majority of professionals estimated that services were providing timely access to an ASD assessment, around 40% of services were failing to meet recent NICE guidelines (2011; 2012) to commence assessment within 12 weeks of referral. The fact that 60% of professionals were satisfied with service accessibility appears high considering the significant frustration and dissatisfaction expressed by those in the autism community regarding access to diagnostic assessments (Howlin & Moore, 1997; Mansell & Morris, 2004; Midence & O'Neil, 1999). These results also appear inconsistent with previous research demonstrating that professionals perceive significant difficulties for parents accessing services (Keenan et al., 2010). Several factors could account for this apparent discrepancy. First, in the current study, professionals were asked about how accessible their *own* service was and they may have interpreted and estimated this from the point at which the

child or adult received a referral to their service (from another practitioner) to the time that they had an initial appointment within the service. Professionals, therefore, may not have responded to this question with respect to the entire journey that parents and adults experience from the moment that they first seek help to the point at which they encounter a diagnostic service (which is often a lengthy process with many other referrals being common before this point: Crane et al., 2015; Howlin & Moore, 1997). Secondly, professionals may have considered service accessibility within the context of improvements compared to past service accessibility and availability of diagnostic services. Thirdly, given the funding cuts that many services are experiencing (regarding resource and staff reductions, for example), respondents may have the view that service accessibility is perhaps better than it could be. It is also possible that sample bias may have played a role, with professionals from 'better' (i.e., more efficient or more autism-oriented) services opting to participate in this survey. Nevertheless, it is important to stress that surveyed professionals in the current sample did consider service accessibility as an area requiring improvement.

The thematic analysis highlighted that professionals believe that improvements to service accessibility were needed in several different areas, including: the need to improve knowledge and training (particularly for professionals who refer individuals to services); the need for clear and open referral pathways into services; and the need to reduce the time taken to access first appointments within services. These points reiterate recommendations made in the NICE (2011; 2012) guidelines and also echo the views of both parents (Crane et al., 2015) and adults (Jones et al., 2014) who have experienced the ASD diagnostic process. Given the relatively short length of time since the publication of the NICE guidelines, it is important for future research to assess the degree to which services have been able to implement these recommendations, and to determine how successful these attempts have been. Recent evaluations have been conducted in Scotland, with respect to their equivalent guidelines for

diagnosing ASD – Scottish Intercollegiate Guidelines Network 98 (SIGN 98) (McKenzie, Forsyth, O'Hare et al., 2015).

Once patients are able to access a diagnostic service, it is widely accepted that professionals need to make clinical decisions that are highly complex and, until recently, were made more difficult by a lack of standard practices. The current results highlighted that, in terms of the diagnostic process, professionals were largely applying 'gold standard' assessments, in accordance with NICE (2011; 2012) guidelines, and the majority perceived these to be helpful. Yet, the variety of tools applied, as well as the range of components comprising a 'standard' diagnostic assessment, reinforced the subjective and variable nature of the ASD diagnostic process (Matson & Sipes, 2010; Lord & Corsello, 2005).

A rather surprising result from this survey was that 76% of professionals acknowledged 'upgrading' diagnoses of ASD to some degree; erring on the side of a positive diagnosis when faced with some degree of doubt regarding whether a child or adult met the criteria for an ASD. Although only 10% indicated that upgrading was part of their standard practice, this was a slightly higher figure than that reported by Skellern et al. (2005) in their survey of upgrading practices in Australia. However, it should be noted that our definition of upgrading was slightly different: whereas Skellern et al. referred to upgrading as giving a positive diagnosis in uncertain cases (e.g., to facilitate access to support), it was operationalised here as providing a positive diagnosis 'in the face of an unclear presentation or patients failing to meet criteria on diagnostic tools'. Respondents cited a variety of reasons for engaging in upgrading. Although a minority justified their decision in terms of it being in the 'best interests' of the patient and their families (e.g., to facilitate access to support), the qualitative analysis highlighted that respondents often 'upgraded' a diagnosis when patients failed to meet cut-offs on standardised tools (as is often the case in those with atypical presentations, e.g., women and girls). In such cases, the diagnosing professional or multi-

disciplinary team felt that the individual was genuinely on the autism spectrum and that a diagnosis would be appropriate. Consequently, the extent to which these incidences were not, in fact, diagnostic decisions in the presence of uncertainty (i.e., Skellern et al.'s definition of upgrading), but a genuine exercise in clinical judgment remains unclear. Nevertheless, the question of 'upgrading' revealed a debate amongst professionals regarding the adherence to tools versus dependence on clinical judgement.

Post-diagnosis, the support offered to service users has previously been reported as an area of extreme dissatisfaction amongst both parents and adults with ASD (Crane et al., 2015; Jones et al., 2014). Professionals' perspectives were, therefore, sought regarding in-service and onward referral support availability. Whilst half of the professionals surveyed were satisfied with in-service support, and a range of post-diagnostic support options were provided to individuals and their families, less than half reported having the provision to offer six week post-diagnostic follow-up support sessions (as recommended by NICE, 2011; 2012). Therefore, clinical guidelines appear to outline expectations of provision that hard-pressed services may be unable to fulfil (McClure, Mackay, Mamdani, et al., 2010). Elaborating on these findings, responses to open-ended questions highlighted that professionals felt the need to: streamline post-diagnostic support options; ensure the availability of long-term support; and to ensure that the post-diagnostic support needs of under-served groups (e.g., women and girls; adults without learning disabilities) were not overlooked.

In relation to the populations that respondents felt were most in need of service improvements, services for primary school aged children and young adults were most frequently selected (although it should be noted that the majority of all services were seen to be in need of improvement). Rather surprisingly, and in contrast to the priorities of the autism community (Pellicano, Dinsmore, & Charman, 2014), services for older adults were

identified as least in need of improvement. This may stem from respondents' lack of awareness of need (or greater awareness of need in the areas in which they worked), with the majority of our respondents working in child services. Alternatively, the finding may be related to the belief that if you are able to navigate through life without being identified as on the autism spectrum until later in life, there is no substantial clinical need to necessitate a diagnosis of ASD.

Finally, it is important to acknowledge that there are limitations to the self-report design, and online survey methods used in this study. Whilst questionnaires are advantageous for collecting data from a large sample of people on their personal perspectives, in line with the aim of this research, a questionnaire is limited in its capacity to reveal in-depth information (although responses to open-ended questions were encouraged). Moreover, whilst an advantage of an online questionnaire is its anonymity and confidentiality, the disadvantage is that it is not possible to validate the accuracy of responses, for example, qualifications, experience and practice areas of the participating professionals.

It is also acknowledged that the representativeness of the sample was affected by several factors: 90% of respondents were White; a disproportionate distribution of respondents worked in London and the South East; there was an over-representation of psychologists relative to other professionals; and respondents were predominantly working in child/adolescent services (NB. it is difficult to assess the extent to which this figure reflects an under-representation of professionals diagnosing adults, or under-provision of adult services). Nevertheless, the current study provides important insights into the views and experiences of professionals currently involved in diagnosing ASD in the UK, and highlights important areas for improvements in service accessibility, diagnosis, and post-diagnostic support.

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Tables

Table 1: Participant demographics

		N (%)
Profession	Psychologist	38 (33%)
	Speech and language therapist	22 (19%)
	Paediatricians	21 (18%)
	Psychiatrists	15 (13%)
	Nurses	7 (6%)
	Specialist teachers	6 (5%)
	Other (e.g., occupational therapists)	13 (11%)
Sector	NHS	92 (79%)
	Education	15 (13%)
	Local authority	11 (9.5%)
	Private	15 (13%)
	Charitable organisation	1 (1%)
	Other	2 (2%)
Age groups worked with	Aged 4 years and under	70 (60%)
	Aged 5-11 years	86 (74%)
	Aged 12-17 years	75 (65%)
	Aged 18-24 years	38 (33%)
	Aged 25-64 years	32 (28%)
	Aged 65 years and over	14 (12%)
Length of experience	One year or less	7 (6%)
	Two years or less	10 (9%)

	Five years or less	23 (20%)
	Ten years or less	33 (28%)
	15 years or less	18 (15.5%)
	20 years or less	13 (11%)
	Over 20 years	12 (10%)
Highest qualification	Research or Clinical Doctorate (e.g., PhD or DClinPsy)	22 (20%)
	Medical Doctorate (MD)	10 (9%)
	Masters	33 (28%)
	Degree	26 (22%)
	Diploma	3 (3%)
Ethnicity	White	102 (88%)
	Asian	7 (6%)
	Black	3 (3%)
	Mixed	2 (2%)
	Other/not stated	2 (2%)

Table 2: Respondents' satisfaction with service accessibility as a function of estimates of the wait time for the first initial assessment appointment within their service, and age group (n = 116).

		Satisfied	Neutral	Dissatisfied	Total N (% of total sample)
Wait time	12 weeks or less	49 (73%)	11 (16%)	7 (10%)	67 (58%)
	12-20 weeks	13 (46%)	7 (25%)	8 (29%)	28 (24%)
	More than 20 weeks	6 (28%)	5 (24%)	10 (48%)	21 (18%)
Age group	Under 4 years	43 (61%)	15 (21%)	12 (17%)	70 (60%)
	5-11 years	49 (57%)	19 (22%)	18 (21%)	86 (74%)
	12-17 years	40 (53%)	18 (24%)	17 (23%)	75 (65%)
	18-24 years	22 (58%)	6 (16%)	10 (26%)	38 (33%)
	25-64 years	20 (62.5%)	4 (12.5%)	8 (25%)	32 (28%)
	Over 65 years	6 (43%)	3 (21%)	5 (36%)	14 (12%)

Table 3: Standard components of an ASD diagnostic assessment within respondents' services

Component of ASD assessment	N (%)
Interview with family/carers	110 (95%)
Medical, social and behavioural history gathering	102 (88%)
Multi-agency communication (teachers, social services)	98 (84.5%)
Interview with patient	93 (82%)
Observation in home/school/work environment	76 (65.5%)
Specialist communication assessment	70 (60%)
Physical examination	47 (40.5%)
Dedicated play assessment	43 (37%)
Specialist cognitive assessment	37 (32%)
Other	34 (29%)

Table 4. Assessment tools (screening or diagnostic) used by the responding professionals

Tool	Reference	N (%)
Autism Diagnostic Observation Schedule (ADOS-G)	Lord, Rutter, DiLavore, et al. (1999)	73 (63%)
Diagnostic Interview for Social and Communication Disorders (DISCO)	Leekham, Libby, Wing, et al. (2002)	38 (33%)
Social Communication Questionnaire (SCQ)	Rutter, Bailey & Lord (2003)	33 (28%)
Autism Diagnostic Interview – Revised (ADI-R)	Lord, Rutter & Couteur (1994)	31 (27%)
Gilliam Autism Rating Scale (GARS)	Gilliam (1995)	24 (21%)
Childhood Autism Rating Scale (CARS)	Schopler, Van Bourgondien, Wellman & Love (2010)	21 (18%)
Autism Screening Questionnaire (ASQ)	Ehlers, Gillberg & Wing (1999)	20 (17%)
Checklist for Autism in Toddlers (CHAT or M-CHAT)	Baron-Cohen, Wheelwright, Cox, et al. (2000); Robins, Fein, Barton, et al. (2001)	19 (16%)
Developmental, Dimensional and Diagnostic Interview (3di)	Skuse, Warrington, Bishop, et al. (2004)	10 (9%)
Children's Communication Checklist – Second edition (CCC-2)	Bishop (2003)	7 (6%)
Social Responsiveness Scale – Second edition (SRS-2)	Constantino & Gruber (2012)	6 (5%)
Do not use tools	n/a	5 (4%)

Table 5. Top three challenges of delivering the diagnosis

Challenges	Rank 1 (N)	Rank 2 (N)	Rank 3 (N)	Total (N)
Ensuring caregivers understood the diagnosis and why it was given	35	22	13	70
Pitching technical/medical information at the right level	20	25	11	56
Managing family/carer distress	16	13	26	55
The amount of information	16	19	19	54
Having enough time to answer questions.	10	10	13	33
Pacing information	7	4	8	19
Managing patient distress	2	8	4	14
Knowing when it is appropriate to introduce information leaflets and support services	0	4	8	12
Having enough information to answer questions	2	2	2	6
Maintaining an empathic approach.	1	2	2	5
Other (please specify)	4	3	1	8

Table 6. The frequency with which post-diagnostic support options were offered to service users and their families

	Never	Rarely	Sometimes	Frequently	Always
Information on support groups	1 (1%)	4 (3%)	10 (9%)	20 (17%)	75 (65%)
Information leaflets	0 (0%)	3 (3%)	11 (9.5%)	22 (19%)	74 (64%)
Liaison with other services (e.g., school or employer)	0 (0%)	2 (2%)	19 (16%)	37 (32%)	52 (45%)
Education/support group for parents	22 (19%)	10 (9%)	14 (12%)	25 (22%)	30 (26%)
Information on housing/benefits and other appropriate services	13 (11%)	20 (17%)	28 (24%)	16 (14%)	24 (21%)
Education/support group for patient	32 (28%)	11 (9.5%)	21 (18%)	20 (17%)	11 (9.5%)
Post-diagnostic counselling	46 (40%)	18 (15.5%)	21 (18%)	8 (7%)	6 (5%)
Employment support	56 (48%)	22 (19%)	9 (8%)	1 (1%)	5 (4%)
Other	0 (0%)	1 (1%)	4 (3%)	7 (6%)	6 (5%)

Table 7. Services in need of improvement, with respect to the age of service users (note: categories are not mutually exclusive)

Age group	N (% of total sample)
Age 4 years and under	44 (38%)
Age 5-11 years	51 (44%)
Age 12-17 years	48 (41%)
Age 18-24 years	51 (44%)
Age 25-64 years	40 (34.5%)
Age 65 years and over	14 (12%)

Table 8. Qualitative responses

Service area	Theme	Explanation	Example quotes
Accessibility	ASD Referral pathways	A clear process with open referral pathways is needed to improve service accessibility	"We take referrals from a wide range of sources - GPs, teachers, parents etc. We respond quickly and systematically to referrals with screening questionnaires and make informed decisions about arranging assessment appointments" "We have a well designed diagnostic pathway with a single point of referral and an experienced multi-professional team"
Accessibility (and also diagnostic process)	Increasing Knowledge of ASD	Lack of training and a shortage of trained staff (particularly in relation to those referring to services) hinders the accessibility of services	"There is a lack of professional knowledge in the area of Autism...they struggle to pick up the soft signs and red flags before the age of 3 ½" "A robust referrals process [is needed] supported by training of professionals in recognition, referral and diagnosis"
	Reducing wait times	Efforts need to be made to reduce the time taken to access a service, as well as reducing the entire time taken to complete the ASD diagnostic process	"...the wait is too long due to over referral and underfunding - 20 weeks is unacceptable" "People get referred in but the time gap to diagnosis is too long - there are significant delays in accessing the required assessments and then for the case to be discussed. It is a lack of capacity within the services to meet demand"
Diagnostic Process	Good communication	Professionals need to communicate the realities (positive and negative) of the ASD diagnosis with the individual and their parents openly and effectively	"Professionals need to respect the parents and believe their descriptions of their child. This is a lifelong 'disability' and needs time and openness and honesty when delivering often devastating news" "...ability to deliver information in a compassionate way, ability to pick up vibes of parents and bring them along in the diagnostic process"
	Wider ASD Knowledge	Diagnosing professionals need to have wider knowledge of ASD (e.g., of more subtle presentations)	"A clear understanding of all aspects of Autism, Asperger Syndrome in all contexts and at all ages (e.g. different presentation for girls, risk for later mental health difficulties, sensory issues, challenging behaviour, ASD style of working and challenges for schools etc). Most Health professionals - and especially CAMHS [Child and Adolescent Mental Health Services] colleagues do not understand the more subtle presentations"
	Multi-disciplinary (MD) teams	As recommended in NICE (2011; 2012) guidelines, multi-disciplinary working was advocated	"...practical and observational assessments by parents, teachers and others are an essential part, alongside clinical assessments, of a reliable diagnostic process. Their involvement in the process also sets a context within which post-diagnostic support can proceed meaningfully" "We have a good multidisciplinary pathway which allows parents time to talk to professionals and find out about ASD prior to diagnosis"
	Upgrading: meeting the needs of the child and family	In cases of diagnostic uncertainty, the needs of the child and family must be met	"diagnosis...as a gateway for services which are helpful…on balance a false positive diagnosis is better than a false negative one" "If there is differing opinion in the MDT and the child without a diagnosis is excluded from support (Early Bird, local authority autism support team) then a

			pragmatic decision is made in the best interest of the child"
	Upgrading: weaknesses of diagnostic tools	Weakness of existing diagnostic tools, especially in detecting ASD in those with atypical presentations (e.g., girls/women)	"Girls do not fit the picture presented in most of the diagnostic tools. There is an urgent need for help to diagnose this group" "The tools often aren't subtle enough. There is no tool that can provide a better assessment than an experienced team of professionals"
Post diagnostic support	Availability of in-service support	Despite some pockets of good practice, in-service support appears to be particularly lacking for those receiving a diagnosis of ASD	"Sadly many families are given a diagnosis and that is it! There needs to be a 'one stop shop' that shares with families all the information (education, social services and benefits, work possibilities, support groups etc.) that parents can access...this should not be at a cost to parents" "I think there should be more provision as standard. All national guidelines concern diagnosis. There is very little to compel commissioners to provide something to parents/individuals post diagnosis"
	Availability of long-term support	Professionals express a desire to offer long-term support, but this is not possible for many services	"We would like to provide ongoing treatment and support but we are not commissioned to do this" "[there needs to be] ongoing support acknowledging that this is a life time condition and like any chronic condition may require episodes of crisis and ongoing support"
	Streamlining of support services	Professionals felt services were fragmented and disjointed and that services needed to work together to provide the best possible support for an individual and their family	"Other services exist but it's hard to know when to tell families about them. Some families do not attend the group and we presume may not access other services. Key worker or similar would be an ideal way to support families and signpost to other services"
	Specialist provision	There is a need for specialist provision for individuals with ASD and their families, including under-served groups, e.g., adults without learning disabilities	"There are no specialist ASD services for this group. Other services (including special needs education, speech and language therapy, LD nursing) have little or no ASD awareness or training. The general philosophy in local education and social work services is that we should move away from 'specialist' services towards more inclusive services, so ASD voluntary agencies cannot access any local funding" "...there is only voluntary sector help available to do the longer-term advice/mentoring sort of work, and being aware that there is very little support for adults without significant LD"

Appendix: Geographical spread of the respondents

	N (%)
Channel Islands	1 (1%)
East of England	4 (3%)
East Midlands	3 (3%)
North West England	17 (15%)
Northern Ireland	4 (3%)
Scotland	17 (15%)
London and the South East England	40 (35%)
South West England	10 (9%)
Wales	1 (1%)
West Midlands	6 (5%)
Yorkshire and Humber	13 (11%)