

SUPPORT SURROUNDING DIAGNOSIS

An Inquiry into Pre- and Post-
Support for the Autism
Diagnosis Pathway



Support Surrounding Diagnosis: An inquiry into pre- and post- support for the autism diagnosis pathway which meets the needs of the autism communities in the UK

About the Westminster Commission on Autism

The Commission was launched in recognition of the need to do more to work in strategic partnerships, taking action to improve quality of life for autistic people. All work carried out by the Commission is driven by the authentic voices of autistic people and their families/advocates.

The Commission produces recommendations for policy and practice based on the best available evidence, meeting regularly in the Houses of Parliament and holding time-limited inquiries on the model of select committees. These inquiries are intended to lead to positive improvements in policy and practice and add to the body of knowledge available to policy makers and practitioners.

The Commission calls for evidence submissions from autistic people, their families, charities, service providers, academics, health professionals, statutory bodies and others. Themes drawn from this evidence are used to produce recommendations in a written report for the attention of Government, NHS England, Clinical Commissioning Groups, NICE guidance, Royal Colleges, practice managers, Local Government and others. All work carried out by the Commission is aimed at creating a more 'autism-friendly' world to improve quality of life for autistic people.

About this report

The Westminster Commission on Autism (WCA) commissioned the Centre for Applied Autism Research (CAAR) at the University of Bath to survey the autistic and broader autism communities for their views concerning the support available during the autism diagnostic pathway in the UK.

Key issues from the survey were discussed by professionals and experts by experience from the autistic community in evidence sessions held in the Houses of Parliament. Recommendations are made for the dissemination of best practice for supporting the autistic community and the broader autism community through the autism diagnostic pathway.

The report was written by Dr Liz Smith, CAAR, with oversight and support from Prof Mark Brosnan, Dr Ailsa Russell and Dr Vanessa Lloyd-Esenkaya.

Acknowledgements

We would like to thank the steering group who guided this research and the members of the Commission who gave up their time to provide feedback and support throughout the process.

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Foreword

The period surrounding an autism diagnosis is often stressful and uncertain. For the sake of autistic individuals and their families, easy access to the right support is vital. Yet for many people, their needs are not met.

We believe this has to change; seeking a timely autism assessment and diagnosis should be a helpful process rather than a source of additional stress. And to make sure diagnosis and support are helpful, we must listen to what autistic people are telling us about what they need.



This inquiry was based around a survey of almost 600 members of the autism community, who took the time to share their experiences, frustrations and inspirations with us. This has been the starting point and driver of our research; the Commission believes that autism policy and practice will not work if it is not genuinely centred on autistic people's voices and those of their families.

From this consultation and our evidence sessions, five recommendations have emerged for how the diagnostic and support journey should be structured. We believe these guiding principles – which include clarity, consistency, needs/strengths-based support and identity-based assessment – would shape a system that puts autistic people first.

This report is not a criticism of the organisations working hard to offer support, many of whom do not receive the funding they need. Our recommendations instead suggest how support can be best organised to make it easily accessible to those who need it.

We need to get support right. If it is done well, it can vastly improve the health and wellbeing of autistic individuals and their families. If done wrong, we risk people being pushed into crisis. We ask that the Government continues their work to improve diagnosis pathways and listens to the voices of the autistic community who have highlighted the support they want and need.

A handwritten signature in black ink, which reads "Barry Sheerman". The signature is fluid and cursive, written in a professional style.

Barry Sheerman MP

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Terminology

ADHD	Attention Deficit/ Hyperactivity Disorder
ASD	Autism Spectrum Disorder
Autistic community	Individuals with a diagnosis of autism
Autism diagnostic pathway	The processes and procedures undertaken to assess autism
Autism hub	An integrated centre of resources to support the autistic and broader autism communities
Broader autism community	Family members, advocates, affiliated health and educational professionals
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
Child services	Under 18 years of age (Adult 18+)
EHCP	Education, Health and Care Plan
NICE	The National Institute for Health and Care Excellence
NHS	National Health Service
OFSTED	Office for Standards in Education, Children's Services and Skills
Pre-assessment	Before the formal autism assessment processes
Post-assessment	After the formal autism assessment processes
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
SEN support	The system by which schools should assess and provide support according to the needs of the child

In this report, we use the term 'autistic individuals', as some members of the autistic community have expressed a preference for identity first language [1, 2].

Executive Summary

Over the past decade, increased awareness and increases in funding have led to significant improvements in the support available to autistic people and their families. Progressive policies have broadened the availability and capacity of autism teams and integrated service provision and there are many examples of innovative and excellent practice. However, such success may have led to demand outstripping supply in respect of autism assessments. Over-stretched service providers need to make resources available to focus specifically upon the assessment of autism, the outcome of which can be a gateway to further support.

While the societal, funding and service contexts have changed considerably, the findings of the present survey of 585 members of the autistic and broader autism community match those of Howlin and Moore [3] from over a quarter of a century ago, namely 'that many parents continue to experience lengthy and often frustrating delays before they finally receive an autism diagnosis. Moreover, even when this process is completed, the amount of practical help subsequently provided is generally very limited.' If anything, there are greater levels of dissatisfaction and stress associated with the autism diagnostic pathway today than there were in previous years [4-6].

Our community survey identified eight key areas for improvement. Potential solutions to address these issues were explored by experts during a series of evidence sessions held at the House of Commons and via written evidence. Evidence was provided by experts who were autism-related professionals or experts by experience. Synthesising information from both sources produced a set of recommendations. These recommendations should be incorporated into Statutory Guidance for Local Authorities and NHS organisations to support the implementation of the national strategy for autistic children, young people and adults: 2021 to 2026.

What the autism community told us they wanted	Solutions discussed
<ul style="list-style-type: none">[1] Reduced waiting times for a diagnostic assessment[2] Clearer information on referral processes and how to access support services[3] Better support both before and after an autism assessment[4] Peer support[5] Contact with a 'key person' to help access services and navigate the system[6] Tailored support, rather than multiple generic resources[7] Support for the whole family, including parents and siblings[8] Access to ancillary services, particularly for mental health support	<ul style="list-style-type: none">[1] Make routes into diagnostic services easier to access and easier to understand[2] Create an alternative way for autistic adults to confirm their autistic identity[3] Closely connect services across the lifespan and link them to the third sector[4] Central point of contact facilitating an 'easy in, easy out' system for access support across the lifespan[5] Create access to peer support services for all[6] Increase funding and accountability to ensure that change happens

Recommendations in brief

Recommendation 1 – Needs/strengths-based assessment & support

Focus clinical diagnostic services on identifying needs (clinical, educational, health, social care) as well as strengths and aspirations of those presenting with suspected autism. Integrate diagnostic services with support services (both statutory and third sector), ensuring consistency across the lifespan.

Recommendation 2 – A single, accessible pathway

Have a single source of clear and accessible information succinctly detailing all aspects of the needs/strengths-based autism diagnostic pathway (possibly through autism hubs). There should be support from a 'key person' serving as a single point of contact throughout, including agreeing formal support.

Recommendation 3 – Identity-based assessment & support

Directly fund third sector peer support services to provide advice and guidance on non-clinical (e.g. self) diagnosis of autism and peer support for those with an autistic identity, as well as families/advocates.

Recommendation 4 – Pre-diagnostic support

Provide support before diagnosis (for those seeking needs/strengths-based assessment or identity-based assessment), which is integrated with needs/strengths-based post-diagnostic support services and peer support services (possibly through autism hubs).

Recommendation 5 – Fund and monitor

Ensure appropriate levels of funding for the implementation and monitoring of these recommendations to reduce pressure on diagnostic services and waiting times, as well as facilitating peer support and reducing dissatisfaction with existing provision and stress for autistic people and their families/advocates.

Next steps

Incorporate these recommendations into Statutory Guidance for Local Authorities and NHS organisations to support the implementation of the national strategy for autistic children, young people and adults: 2021 to 2026.

PART ONE

BACKGROUND



1.1 What is autism?

Autism is a neurodevelopmental condition characterised by difference that is lifelong, and which can affect people in a range of ways as they go through their lives. The definition of Autism Spectrum Disorder is typically impairment based, characterised by persistent difficulties with social communication and interaction across multiple contexts, combined with restricted and repetitive behaviours, interests or activities [7, 8]. Therefore, autism affects communication and impacts on how a person experiences the world around them [9]. Comprehensive clinical assessment seeks to understand an individual person's needs as well as their strengths and aspirations. Whilst strengths and needs are highly individualised, a range of strengths have been consistently associated with autism [10].

A recent survey of over 7 million school children in England indicates the prevalence of autism is approximately one in 57 (1.76%), with a male-to-female ratio of around 4:1 [11]. This is significantly higher than previously reported and would equate to around 1.2 million autistic individuals in the UK¹. Such estimates are based upon current rates of diagnosis amongst children. In recent decades there has been a recognition that autism is a neurodivergent condition not limited to those with Learning Disability. This, coupled with an expansion of diagnostic assessments for children and adults, has led to many more autistic people being identified at all ages. This would indicate there are a number of 'late-diagnosed' [12], as well as undiagnosed, autistic adults.

Autism can also co-occur with a range of other conditions such as Intellectual Disability (with an IQ of less than 70; 33% in the USA [13]), Learning Difficulties (18% in the UK [11]), or other developmental conditions, such as ADHD (28%) and mental health conditions, such as anxiety [20%: 14]. Access to services, such as appropriate mental health services, is therefore crucial when considering how to best support autistic individuals [e.g. 15, 16].

1.2 Statutory service provision

The Autism Act (2009) was the first condition-specific legislation to be introduced in England. The Act put a duty on the government to meet the needs of autistic adults by producing an autism strategy and statutory guidance for local authorities and NHS organisations [17]. *'Think Autism': an update to the government adult autism strategy* was published in 2014 (18a) with a governance refresh in 2018 [18b]), with the clear vision that adults on the autism spectrum can get a diagnosis and access support if they need it 'to live fulfilling and rewarding lives within a society that accepts and understands them.'

The national strategy for autistic children, young people and adults: 2021 to 2026 was updated in July 2021 for the purpose of improving the lives of autistic people and their families and carers in England. It extends the scope of the strategy from adults to children and young people for the first time, in recognition of the importance of ensuring that they are diagnosed and receive the right support as early as possible and across their lifetime. Six themes are identified, including 'Tackling health and care inequalities for autistic people'. The vision for this theme is: By the end of the strategy, we will have made demonstrable progress on reducing diagnosis waiting times and improving diagnostic

¹ 1.76% multiplied by UK population estimate of 67 million = 1,179,200, assuming rate is consistent across regions of the UK, age, etc.

pathways for children, young people and adults across the country. Autistic people will be able to access a high quality and timely diagnosis, as well as the support they need following diagnosis. We will have also made progress on improving early identification of autism, so more children and young people can get the support they need at an early age [19]. Supporting individuals on the autism spectrum (or with learning disabilities) is also one of the four clinical priority areas in the NHS long-term plan, to ensure better healthcare services for autistic people are provided [20].

In England and Wales, the National Institute for Health and Care Excellence (NICE) provides recommendations for the diagnosis and care management of autistic children, young people and adults. For children and young people under the age of 19 years, NICE recommendations were first published in 2011 and updated in 2017 [21].

These guidelines include recommendations such as starting the autism diagnostic assessment within three months of referral and incorporating the examination of potentially co-occurring neurodevelopmental or mental health conditions into the diagnostic assessment. Other recommendations within the guidelines include having a 'single point of referral' to co-ordinate access to the autism team throughout the diagnostic process, and a follow-up appointment six-weeks after a diagnosis [21].

Similarly, the guidelines for adults were first published in 2012 [22] with minor revisions in subsequent years. These guidelines include good practice for screening, assessment and interventions with the aim to reduce core difficulties and co-occurring conditions in autistic adults. For instance, the guidelines suggest that an autism evaluation should examine several features such as language and communication, physical or mental conditions, sensory problems, neurodevelopmental conditions (e.g., ADHD), disruptive and self-injurious behaviours and abuse by others.

Autistic children and young people will often require some form of additional support in school to meet their education and health needs. What this support might look like, however, varies considerably according to the needs of the individual. Children who require extra or different help to that provided as part of the school's usual curriculum are considered within the education system to have Special Educational Needs (SEN) [23].

In England, how these children and young people receive such support underwent significant reform in 2014/15, with the introduction of the Children and Families Act [24] and the Special Educational Needs and Disabilities (SEND) Code of Practice [23]. This reform placed a greater focus on the participation of children and families in decision-making processes and an increased focus on joined up working between the health, education and care sectors.

As part of this reform, Education, Health and Care Plans (EHCP) were introduced, replacing the existing 'Statement of Special Educational Needs' and placing a greater emphasis on the holistic needs of the individual, and better collaboration between education, health and care services. Recent figures from the Government's National Statistics [25] report that the most common primary need currently recorded on EHCPs is Autism, with 92,600 pupils (30% of pupils with an EHCP). Not all children with autism will require an EHCP, however, as the Code stipulates that "most children with SEN will have their needs met within school through 'SEN support' and effective teaching" [26].

1.3 Autism diagnostic pathways

Perspectives of autistic adults, parents and professionals about the autism diagnosis pathway fall under three themes [4, 5]. These indicate autism diagnostic pathways have a structure as follows:

PRE-DIAGNOSIS

Differences are identified and discussed with health or educational professionals
A referral is made for a formal diagnostic assessment

DIAGNOSIS

A screening process may be undertaken to triage people in or out of waiting lists
A diagnostic process is undertaken

POST-DIAGNOSIS

Post-diagnostic support is provided

1.4 Previous research on support for the autistic and broader autism communities

Concerns about an autism diagnosis are primarily raised by parents, but may also be flagged by health visitors, General Practitioners (GPs) or other practitioners, and education staff. The autism strategy recommends GPs refer individuals or families to a specialist autism team, who will conduct assessments (including questionnaires, interviews, or observations across home, school or work), and provide support (including information about autism and intervention options) [12].

Such specialist teams are not available everywhere, but access is increasing across the country [27]. Furthermore, GPs knowledge of autism has been found to be mixed [28], which may delay referral for assessment and there is a general issue around under-diagnosis in females, gender-fluid and non-binary people, and those from ethnic minorities [12].

Although NICE recommends that a diagnostic assessment for autism be started within 3 months of referral, Public Health England identified that this target is rarely met, with only 30% of under-18s meeting this target in the latest figures [29]. In addition, waiting times are increasing, almost doubling between 2016 and 2018 [30].

The major factor leading to an increase in waiting times is the number of referrals. One study covering over 9 million patients from GP practices in England identified a 787% increase in the number of people diagnosed with autism between 1998 and 2018 [31]. Waiting around three and a half years from first approaching a health professional to receiving a diagnosis is reported by parents and a two-year wait is reported by adults seeking a diagnosis [5, 32a]. After the wait for a diagnosis, the subsequent provision of support is also a significant area of concern for individuals on the autism spectrum and their families. Waiting times reflect the phenomenal increase in demand for diagnostic assessment. It should be noted that this is in the context of far more diagnostic assessments being undertaken than ever before for people at all life stages. The increased availability of diagnostic assessments represents a significant improvement, especially for adults, and strategies are being developed to manage this increased demand [19, 20].

Parents reporting on the experience of advocating for their child and adults reporting on their own experience both consistently report low levels of satisfaction regarding the autism diagnostic process [3, 5, 6, 32a;b]. Crane and colleagues [5], for example, completed a large UK survey with over 1000 parents who had sought an autism diagnosis for their child and found 52% felt either 'very' or 'quite' dissatisfied with the diagnostic process.

Prior to this, Howlin and Moore [3] had also found similar levels (49%) of parental dissatisfaction and Jones and colleagues [6] found similar levels (40%) amongst adults seeking diagnosis. Factors that influenced satisfaction levels included:

- a) waiting times;
- b) quality of information given at diagnosis;
- c) the professional manner of those giving the diagnosis;
- d) stress levels during the diagnostic process.

Dissatisfaction has been reported with pre-diagnosis (e.g. accessing an autism diagnosis involved lengthy delays and unclear pathways; vague and inconsistent routes available for accessing an autism diagnosis), the diagnosis itself (e.g. mixed satisfaction with the diagnostic process; spaces in which the assessments were carried out, and the activities the patients were required to do during the assessment) and post-diagnosis (e.g. dissatisfaction with the nature and availability of post-diagnostic support; lack of appropriate support) [4-6]. This research has highlighted that there are undoubtedly ways to improve autism diagnosis pathways. This is important as people benefit from the diagnostic process and this research can inform strategies that are being developed to improve the diagnostic pathway [19, 20].

In addition to this dissatisfaction, the diagnostic pathway has also been highlighted as a particularly stressful time for families [5, 28, 33-38]. Myers and colleagues [35], for example found that 70% of parents reported finding the diagnostic pathway either 'very' or 'somewhat' stressful. Factors that influenced stress levels included:

- a) lengthy waiting times;
- b) insufficient time with professionals;
- c) not feeling listened to;
- d) and not feeling like a partner in the care of their child.

Similar issues have been raised across a number of other studies, and an increase in symptoms of anxiety and depression during this time has also been noted [39]. In addition, a recent review found that parents' initial concerns were often not acknowledged or minimised by frontline health professionals, increasing the difficulties faced during this time [33]. Despite these levels of stress, the diagnostic process is overwhelmingly beneficial, and strategies to reduce stress are being developed [19,20].

Suggestions for improving the diagnostic process have included a focus on positive aspects of autism and efforts to improve rapport and mutual respect (in relation to the expertise that individuals and families bring) [5]. Additionally, post-diagnostic support has been reported as inconsistent in terms of structure, content and quality [3-6, 40, 41], adding to feelings of dissatisfaction.

This research is reflected in a 10-year follow-up of the impact of the Autism Act, which highlighted deeply concerning levels of unmet need and insufficient services for autistic adults [42]. Challenges with providing diagnoses included making sure patients and their families understood the diagnosis, pitching information at the correct level and managing distress. Professionals also expressed dissatisfaction with post-diagnostic provision, especially onward and long-term support options [43]. Currently, Abrahamson et al. [44] are conducting a review of diagnostic pathways in Autism and Child & Adolescent Mental Health services in the UK, exploring how particular approaches may deliver high-quality and timely autism diagnostic services for children with possible autism.

1.5 Current inquiry aims

"There is some debate as to whether guidelines and recommendations truly lead to the delivery of good practice by agencies, and whether this professional view of 'best practice' is reflected in parental opinions of what they value to be 'good practice'" [36]. The autistic and broader autism communities provide valuable insights, based on lived and shared experience of autism which is vital in driving future developments of services and policy [45-47]. The aim of the current inquiry was to gain a better understanding of the support needs for individuals and families before, during, and after the autism diagnostic process, and to consider how such needs can be best met. This topic was decided in collaboration with the autistic community over a series of the Westminster Commission on Autism (WCA) meetings and a 'research seminar'. It also aligns with feedback from the autistic community in response to NHS England, which states that a key issue is 'to make the support before, during and after the assessment process better for autistic people and their families' [48].

The inquiry comprised two key elements. Firstly, an online survey was developed to gather the views of individuals/families regarding their experiences from the time at which initial concerns were first raised to twelve months post autism assessment. Secondly, the issues raised from the survey findings were then used to formulate questions, which were put to a range of stakeholders involved with policy making and clinical service provision during a series of Parliamentary evidence sessions. Findings from the survey and evidence sessions, taken together, were synthesised into a set of recommendations with the aim of facilitating positive improvements in policy and practice, and to add to the body of evidence available to policy makers and practitioners.

PART TWO

UK-WIDE SURVEY OF THE AUTISTIC AND BROADER AUTISM COMMUNITIES



2.1 Survey Methods

The survey was administered using Qualtrics XM, an online survey platform commonly used for academic research. Questions were developed based on the previous literature (see above) and input from an expert steering group comprising autistic self-advocates, parent-advocates, academics and clinicians (see Appendix A for full details). Ethical approval to carry out the survey was obtained from the Psychology Research Ethics Committee at the University of Bath.

Survey respondents were recruited via volunteer research databases at the University of Bath and Cambridge University, and autism-relevant online sources including Twitter and Facebook groups. Members of the Westminster Commission for Autism also shared the survey with their networks. Particular efforts were made to recruit respondents from black and ethnic minority backgrounds by targeting social media and online recruitment sources. Respondents gave informed consent, prior to completing the survey. All data was recorded anonymously.

The questionnaire is included in Appendix C and summary findings are presented in this report. Survey items included statements to which respondents indicated their level of agreement using a 5-point Likert scale. The two most positive responses on the Likert scale ('somewhat' and 'very much' agree) were grouped together for presentation in graphical format. The survey also included open format questions allowing respondents to give greater detail about their experiences and views. These were analysed using thematic analysis.

Three versions of the survey were developed to capture the views of:

- (i) adults who had experience of autism assessment (self-advocates),
- (ii) parents who had experience of an autism assessment for their child (parent advocates),
- (iii) family members or advocates of a person who had had an autism assessment as an adult.

Where the responses for the three groups did not significantly differ from each other the data is presented for all respondents together, reporting any adult/child differences where appropriate.

The online survey was open between 02.04.2021 and 05.05.2021. A total of 617 people accessed the survey. In total, 585 (95%) respondents completed more than just the demographics section and are included in the analysis.

2.2 Survey findings

Respondents

Of the 585 respondents included in the analysis, 248 were adult self-advocates, 301 were parent advocates and 36 were family members or advocates reporting on behalf of an adult who had experienced autism assessment. The demographics of these respondents are shown in Table 1:

Table 1 Demographics of respondents included in the survey analysis

	Parent report (n=301)	Adult self-report (n=248)	Family member (n=36)
Age			
Current age	11.1yrs (2-38yrs)	41.4yrs (17-72yrs)	34.0yrs (9-78yrs)
Age at referral	6.9yrs (1-19yrs)	36.5yrs (3-66yrs)	27.7yrs (2-67yrs)
Gender			
Male	214 (71.1%)	67 (27.3%)	21 (58.3%)
Female	80 (26.6%)	149 (60.8%)	10 (27.8%)
Non-binary / gender neutral	7 (2.3%)	25 (10.2%)	4 (11.1%)
Prefer not to say		4 (1.6%)	1 (2.8%)
Ethnicity			
White - British	256 (85.6%)	215 (89.2%)	33 (91.7%)
White - Irish	3 (1.0%)	4 (1.7%)	0
White - other background	12 (4.0%)	12 (5.0%)	0
White and Black Caribbean	4 (1.3%)	0	1 (2.8%)
White and Black African	3 (1.0%)	0	0
White and Asian	6 (2.0%)	1 (0.4%)	0
Any other mixed background	4 (1.3%)	2 (0.8%)	0
Indian	4 (1.3%)	1 (0.4%)	0
Pakistani	1 (0.3%)	0	1 (2.8%)
Bangladeshi	2 (0.7%)	0	1 (2.8%)
Black – African	1 (0.3%)	0	0
Black - Caribbean	0	1 (0.4%)	0
Any other ethnic group	3 (1.0%)	5 (2.1%)	0

Location of assessment

East England	9 (3.1%)	14 (5.8%)	3 (8.3%)
East Midlands England	29 (10.0%)	20 (8.2%)	1 (2.8%)
London	24 (8.3%)	12 (4.9%)	3 (8.3%)
North East England	7 (2.4%)	10 (4.1%)	0
North West England	24 (8.3%)	36 (14.8%)	5 (13.9%)
Northern Ireland	1 (0.3%)	3 (1.2%)	0
Scotland	4 (1.4%)	15 (6.2%)	1 (2.8%)
South East England	70 (24.1%)	54 (22.2%)	6 (16.7%)
South West England	62 (21.4%)	34 (14.0%)	11 (30.6%)
Wales	29 (10.0%)	18 (7.4%)	4 (11.1%)
West Midlands England	21 (7.2%)	15 (6.2%)	2 (5.6%)
Yorkshire and the Humber	10 (3.4%)	12 (4.9%)	0

Waiting times

The average length of time from first considering an autism assessment to getting a referral was 1 year 8 months for children and 3 years 6 months for adults. The average length of wait from referral to the start of the assessment was 1 year for the children and 11 months for adults. Thirty five percent of the children, and 45% of the adults were assessed within a single appointment. For those who did not have a single assessment the average duration of their assessment was 1 year for the children and 3 months for adults.

Many individuals and families expressed how difficult this waiting period was and how it had a considerable impact on the wellbeing of both the individual and their family. One parent told us:

“

My daughter has been through so much over the years, and basically wasted 2 years playing a waiting game it really does no good for people to go through all the mental and physical health impacts of waiting so long. – Parent of an autistic child

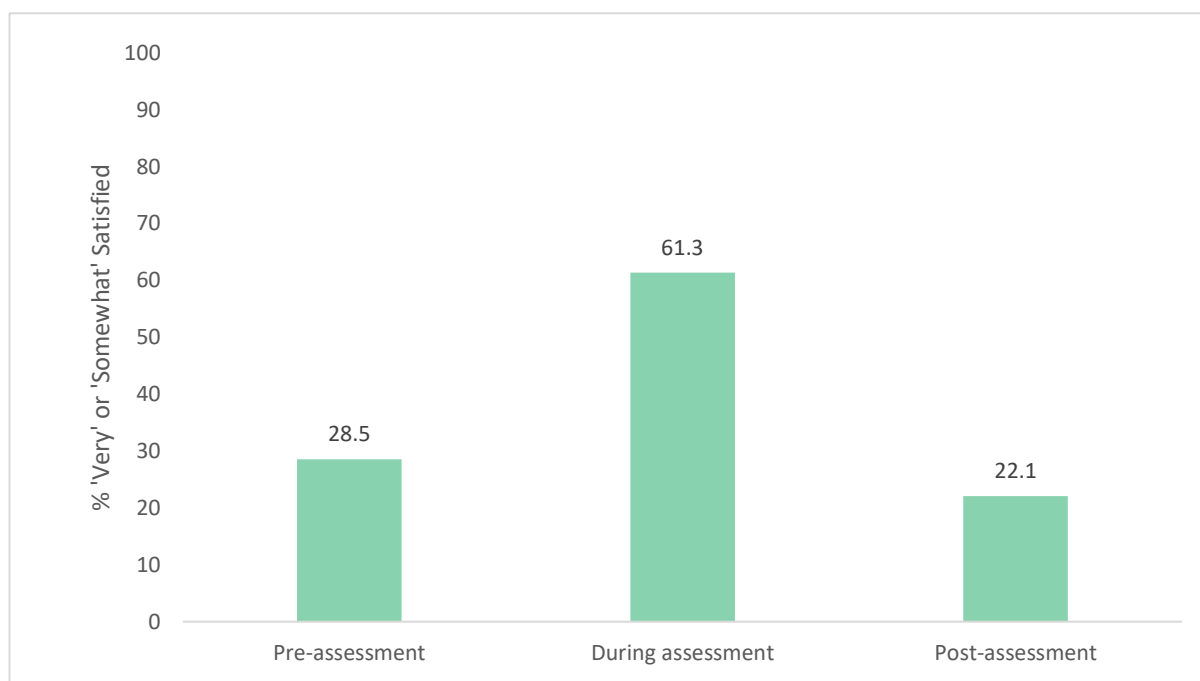
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Overall outcomes

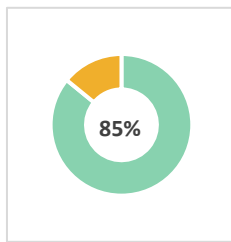
Most assessments (84.2%) were completed within the NHS. Of those that were independent of NHS services (15.8%), the main reason for choosing independent services related to NHS waiting times, with other reasons including wanting a second opinion, or being refused an assessment on the NHS. The majority of respondents (88.8%) received an autism diagnosis following their assessment.

Respondents were asked about their overall satisfaction with the pre-assessment, during the assessment and post-assessment phases. Respondents reported low levels of satisfaction during both the pre- (28.5%) and post-assessment (22.1%) phases with significantly higher satisfaction levels during the assessment (61.3%), see Figure 1.

Figure 1: Percentage of respondents who felt either 'very' or 'somewhat' satisfied during: a) the pre-assessment phase; b) during the assessment itself; c) the post-assessment phase

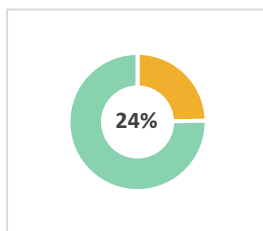


PRE-ASSESSMENT PHASE



High levels of stress: 85% of respondents reported that they found the time whilst seeking a diagnosis either 'quite' or 'very' **stressful**.

*“ It was one of the most stressful periods of my life, mainly because of watching my son struggle and having no clue how to help him, despite being very proactive in trying to get help.
Parent of an autistic child ”*



Low levels of support: 24% of respondents reported that they were either 'very' or 'somewhat' satisfied with the provision of **support** available to them (or their child) whilst waiting for the autism assessment.

During the pre-assessment phase, most people experienced high levels of stress and low levels of support. Many respondents reported that finding information on how to seek an autism assessment was difficult (59%) and that this information could also be hard to understand (50%). One parent explained:

“ It was so complicated to know how to get the assessment. School Nurse, GP, [name of organisation], teachers, health visitors - all seemed to suggest they were not the one to refer. ”

Practical barriers, such as difficulties with childcare, transport (27%), and with financial costs (20%) were also noted by a significant minority. Nearly one quarter (24%) of those from an ethnic minority background agreed that ethnicity/cultural background contributed to difficulties in seeking an autism diagnosis, compared to 3% of White British respondents.

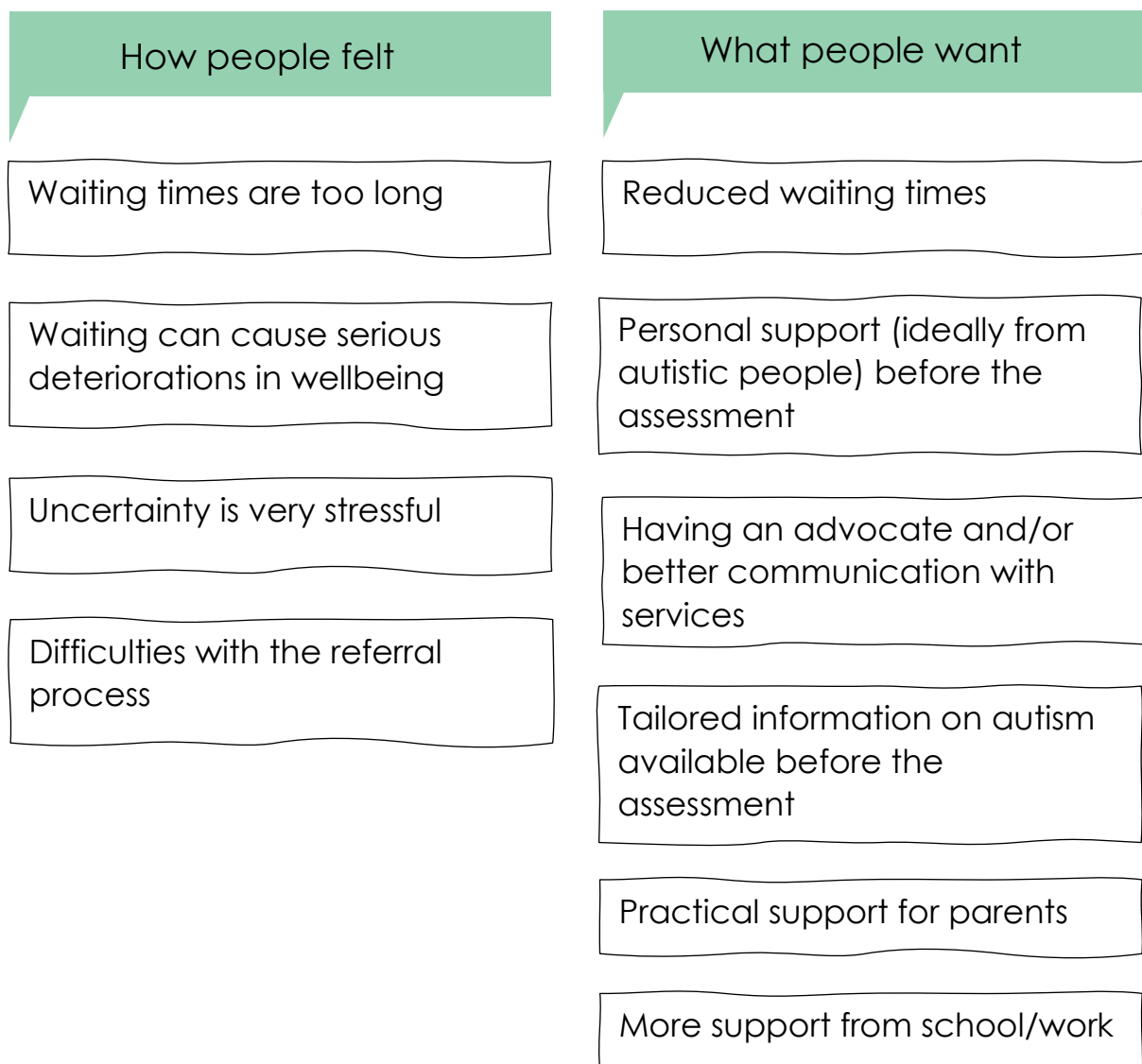
Being female was also considered to be an additional challenge to seeking an autism diagnosis for just over half (53%) of female respondents (compared to 4% of males who considered being male an additional challenge). This was also an issue for half (50%) of those who identified as non-binary/gender neutral.

Despite overall low levels of satisfaction during the pre-assessment phase, respondents generally held positive views of their relationships with the professionals involved during this time. Most people felt that their views had been respected (64%) and had been taken into account (70%) during the referral process.

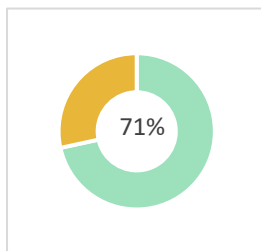
Overall, people reported having a good relationship with the people who they had spoken to during the pre-assessment phase (63%) and that the professionals had used language that had been easy to understand (77%). However, only a small percentage (34%) of respondents felt that this part of the process left them with a positive view of autism and many people (61%) felt that they did not have a clear understanding of what would happen next, during their assessment.

In response to open questions, respondents also reported on their feelings about the pre-assessment phase, as well as improvements they would like to see. These are reflected by the themes in Figure 2 below, examples of which are given in Appendix D.

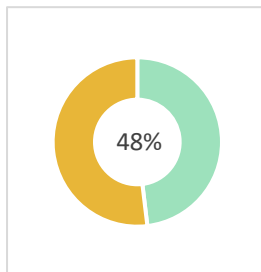
Figure 2: Themes from the open questions on the pre-assessment phase



DURING THE ASSESSMENT



Stress levels were high during the assessment period (71% found this time period either 'quite' or 'very' stressful), but levels were not as high when compared with the pre- and post- assessment phases.



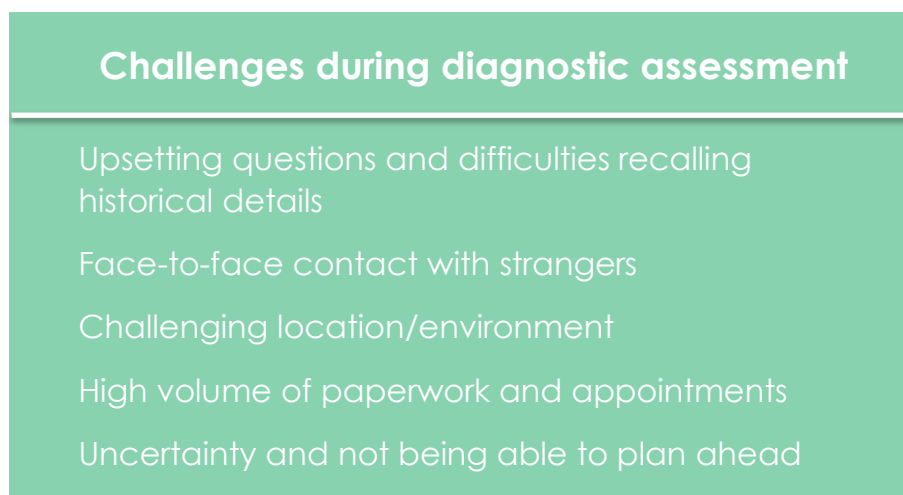
Nearly half (48%) of respondents felt either 'very' or 'quite' satisfied with the level of support provided during the assessment phase

Overall satisfaction ratings for the assessment itself were relatively positive, with 61% reporting to feel either 'somewhat' or 'very' satisfied. Relationships with professionals were also rated positively with 82% feeling that their views were respected and 78% reporting that their views had been taken into account. The majority (84%) felt that the professionals used language that was easy to understand and half (50%) felt that they were left with a positive view of autism.

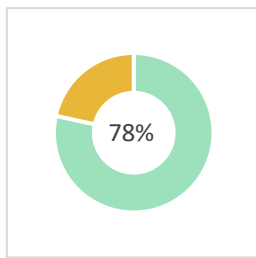
However, most (64%) felt that they did not have a clear understanding of what would happen next, after the assessment. The majority of people (96.7%) received a written letter or report following the assessment and most found the written report helpful (71.1%) and clear and easy to understand (79.9%).

In terms of challenges associated with the assessment itself five areas were raised within the open responses (see Figure 3 below), examples of which are illustrated in Appendix E.

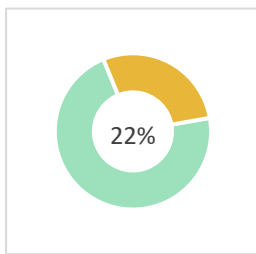
Figure 3: Challenges noted by respondents during the assessment phase



POST-ASSESSMENT PHASE



High levels of stress: 78% of respondents reported finding the post-assessment phase either 'quite' or 'very' **stressful**.



Low levels of support: Only 22% of respondents reported that they were either 'very' or 'somewhat' satisfied with the provision of post-diagnostic support.

“ *You realise you went through all that stress and anguish for an assessment and it makes no difference. Gives no benefits. No help.*
Autistic adult **”**

Similar to the pre-assessment phase, high levels of stress (slightly lower than at pre-assessment) and low levels of support (slightly worse than at pre-assessment) were reported. Most people also expressed difficulties with both finding (75%) and understanding (61%) the information on post-diagnostic support services. One parent told us:

“ *I had to do all the research myself to find out what support was available, how to get an EHCP, what ASD schools existed etc etc. I spent hours, days, weeks, on the phone and internet desperately trying to find help. We were really struggling. Most ended up at a dead end, but some led to support.*
Parent of an autistic child **”**

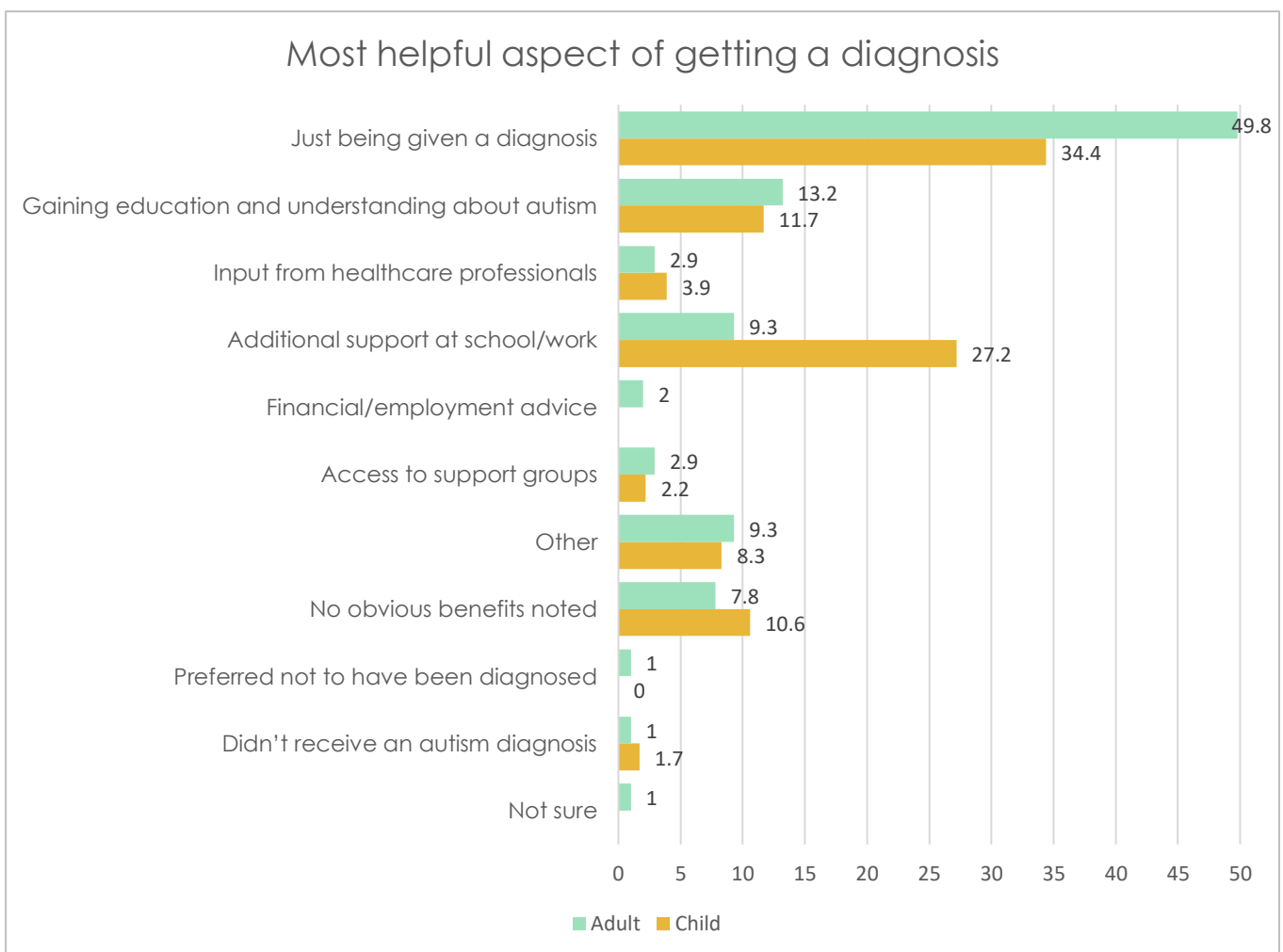
Some people also found financial costs (33%) and practical issues, relating to childcare, transport, work (37%) to be barriers to accessing support services. Challenges associated with ethnicity/cultural background and gender were a barrier to accessing support services for a minority of respondents (16% of those from an ethnic minority group; 26% of females).

Relationships with professionals involved during this time were more mixed for this post-assessment phase compared to before and during the assessment. Just over half (53%) of respondents reported having a good relationship with professionals involved with post-diagnostic services and a similar number felt that their views had been respected (51%) and taken into account (47%).

Only 30% of respondents felt that the post-assessment phase had left them with a positive view of autism, and only 21% felt that they had a clear understanding of what would happen next in terms of support.

Respondents were asked to endorse a set of items related to what was most helpful about accessing an autism diagnosis and the findings are shown below.

Figure 4: Most helpful aspect of getting a diagnosis



We asked respondents to indicate whether they had accessed a range of support services, and if so, had it been helpful. We also asked whether they would have liked to have been offered the support if it had not been available to them. The most popular responses are reported in Table 2.

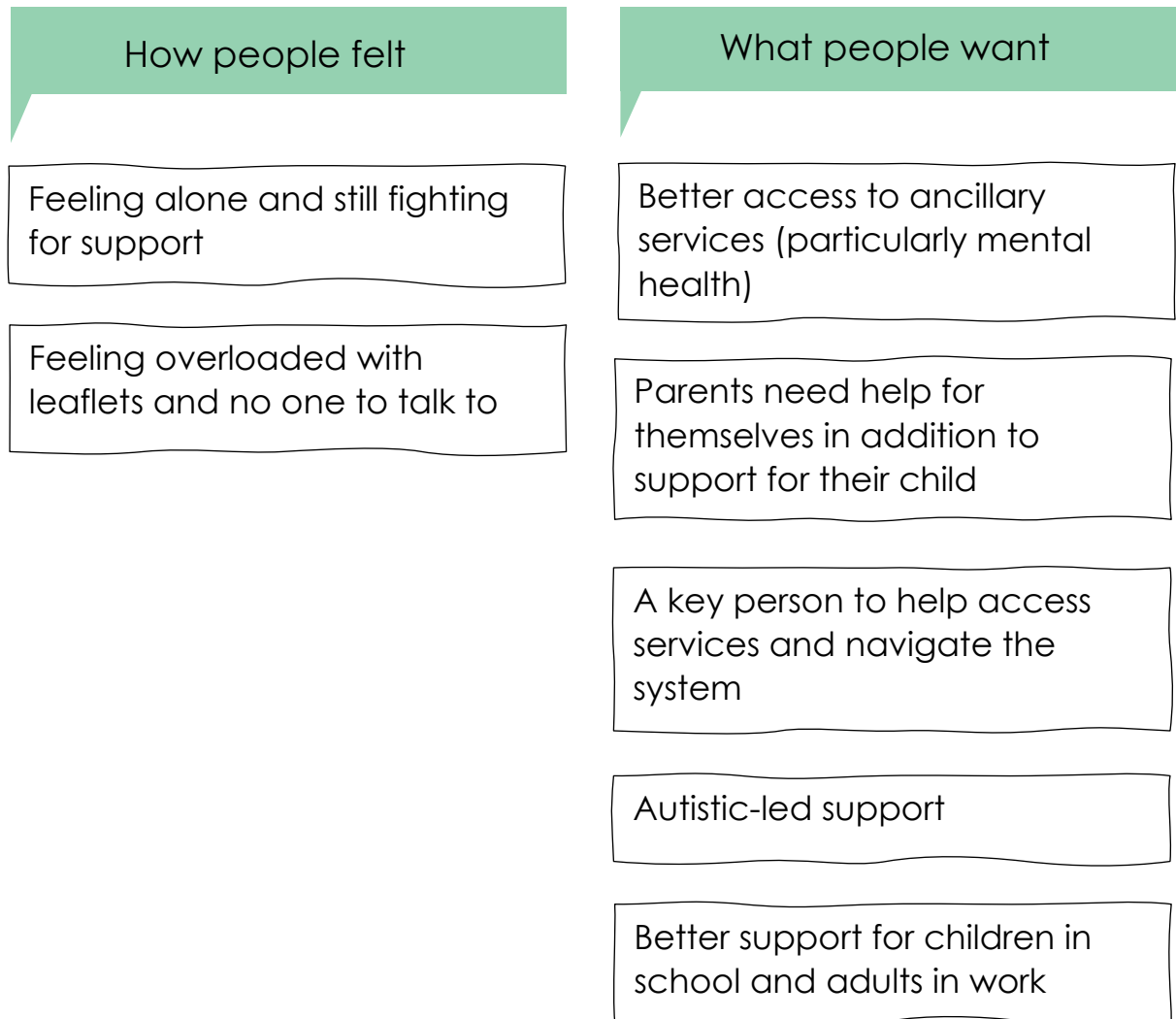
Table 2: Top 5 post-diagnostic support needs

Parent/Child (% accessed & helpful)	Adult (% accessed and helpful)
1. Additional support in pre/school or employment (48.1%)	1. Written information about autism (34.4%)
2. Education, Health and Care Plan (EHCP) or Statement (39.9%)	2. Additional support with education or employment (19.1%)
3. Help with school placements (e.g. access to a specialist unit) (29.8%)	3. Contact with a charity (18.3%)
4. Explanation of child's problems (29.1%)	4. Face-to-face support groups (14.6%)
5. Help with monetary benefits (28.3%)	5. Input or intervention from an autism specific support service (14.4%)

Parent/Child (% not available but would have liked)	Adult (% not available but would have liked)
1. Support/counselling for parent(s)/carer(s) (77.7%)	1. Input or intervention from an autism specific support service (59.1%)
2. Family therapy (67.9%)	2. Input from mental health services (53.4%)
3. Practical help for managing my child at home (61.7%)	3. Online autism support groups (50.5%)
4. Face-to-face support groups (53.6%)	4. Additional support in pre/school or employment (49.0%)
5. Input or intervention from an autism specific support service (53.4%)	5. Face-to-face support groups (46.9%)

The open questions were asked again for the post-assessment phase and were themed in Figure 5 below (examples are provided in Appendix F).

Figure 5: Themes from the open questions on the post-assessment phase



2.3 Summary

Overall, interaction with professionals was positive and there was relatively greater satisfaction with the assessment phase itself, compared to the pre- and post- assessment phase. The stress and lack of support associated with both the pre-assessment and post-assessment phases were the key areas of concern. It is important to note that originally there was only a requirement to fund an assessment phase of a diagnostic pathway.

In terms of waiting times, Crane and colleagues [5] noted how waiting times for autism diagnostic services had doubled between their work and that of Howlin and Moore [3], twenty years previously. This survey suggests that waiting times are still increasing, continuing this deeply concerning trend – reflective of the huge increase in referrals.

The current survey finds both the time whilst seeking an assessment, and the year after the assessment to be highly stressful and deeply unsatisfying for the autistic and broader autism communities. During these times individuals and families spoke of great uncertainties and frustrations.

Overall, for the time surrounding an autism assessment (pre-, during and post-) the autistic and broader autism community told us that they wanted:

Table 3: Key points raised from the survey findings

1. Reduced waiting times for a diagnostic assessment	Current waiting times were reported to be a major contributing factor to the high levels of stress and dissatisfaction surrounding the autism diagnostic process
2. Clearer information on referral processes and how to access support services	Information on the referral process was both difficult to find and hard to understand. This was the same for accessing support services
3. Better support both before and after an autism assessment	Individuals and families need better support both before and after the diagnostic process
4. Peer support	Access to peer support throughout the whole process was seen to be particularly beneficial
5. Contact with a 'key person' to help access services and navigate the system	Contact with a 'real person' to help with communication with services was seen as helpful (a named single point of referral)
6. Tailored support, rather than multiple generic resources	The need for tailored support, rather than signposting to multiple generic resources, was consistently identified as a key priority
7. Support for the whole family, including parents and siblings	Parents expressed a need for additional support for their own emotional needs and for the whole family, including siblings
8. Access to ancillary services, particularly for mental health support	Accessing ancillary services, particularly those for mental health was identified as being more difficult with an autism diagnosis

Limitations

A number of limitations are worth noting when considering the findings of our survey. Firstly, the self-selected sample means that the views captured are likely to represent those who have engaged with some form of autism-related support services or research, and who have access to the internet. This means that results may not be representative of all autistic people, but rather the thoughts and experiences of this population.

Secondly, most adult respondents were female, which is uncommon for the autistic population, but consistent with previous surveys of autistic adults [40, 49]. It may however, mean that the views of adult autistic males are underrepresented in our findings.

We had a relatively small number of respondents from an ethnic minority (n=75, 13%), though this represents the proportion of ethnic minorities in the UK (13%: [50]). Similarly, the numbers were small for X gender (n=36, 6%) though this proportion is reflected in other online surveys of the autistic community (6.7%: [49]) and higher than the general population [51]. It is likely that there are specific issues for different minority groups, and these will need to be considered in more detail for each group in future work.

PART THREE

GATHERING EVIDENCE FROM PRACTITIONERS, RESEARCHERS AND ADVOCATES



3.1 Methods

Initial findings from the survey were discussed extensively with both the steering group and WCA members in order to generate questions for use during the parliamentary evidence sessions (see Appendix G for full details). These questions were drawn from the findings of the survey and focused on the following two key issues:

Issue 1: Pre-assessment phase (i.e. time when seeking an autism assessment, before the actual assessment)

- I. How can stress and uncertainty for those seeking diagnosis, and for their families/advocates, be reduced?
- II. What pre-diagnostic support can be provided to those seeking diagnosis and their families/advocates?
- III. How can best practice be identified and shared across regions?

Issue 2: Post-assessment phase (defined for the purpose of this inquiry as the first year after the autism assessment)

- I. How can access to ancillary services (e.g. mental health) be facilitated and integrated into post-diagnostic support?
- II. What post-diagnostic support can be needs/strengths-based rather than dependent upon receiving a diagnosis?
- III. How can best practice be identified and shared across regions?

The questions for the evidence sessions were kept purposefully broad because they acted as starting points for an open discussion. The purpose of gathering evidence was to learn the real-world context underlying the difficulties currently faced by the autistic community (raised in the survey), and to encourage experts to give their ideas on how support for autistic communities can be improved.

Experts (professionals and by experience) were approached to give evidence and offered the opportunity to do this either via attending one of the three oral evidence sessions at the House of Commons, or by submitting written evidence. Eleven witnesses gave oral evidence and five submitted their evidence in writing (see appendix A for full details).

The oral evidence sessions were carried out over three parliamentary sessions. The first focussed on those with primary experience with adult services, the second on children's services, and the third on autism advocates (experts by experience) and third sector organisations. Each evidence session was chaired by an expert in the field, including experts by experience. Panel members from the WCA also attended the evidence sessions (see Appendix A for full details).

All three sessions were recorded and transcribed for the purpose of analysis. Two researchers observed the sessions and independently reviewed the transcripts and written evidence to synthesise the overarching themes present in the evidence.

3.2 Findings from the evidence gathering

Experts gave their views on the ways support could be improved to meet people's needs and reduce stress on the autism diagnostic pathway. Examples of organisations and services who were taking positive steps in the right direction were also sought. Discussions during the oral evidence sessions were loosely structured around the questions posed, with flexibility to explore relevant issues as they arose. The written and verbal evidence given by experts has been synthesised in Appendix H.

Experts made many suggestions for ways to improve support for the autistic community which fell under six key ideas (see Table 4). There was significant overlap between the ideas for improving support during the pre and post diagnostic phases, with an emphasis on needing joined up provision over the whole diagnostic pathway.

Additionally, some of the experts expressed the view that autism was an identity, making no distinction between the pre- and post- diagnostic phase as they felt that being given a professional diagnosis of autism makes no difference to whether someone requires support. For these reasons, the findings we present do not differentiate between a pre- and post- diagnostic phase of autism diagnosis. For further details into these six key ideas, see Appendix I.

Table 4: Overview of key ideas for improving support for autistic people which came out of evidence sessions

Make routes into diagnostic services easier to access and easier to understand	Provide clearer information for all age groups on how to get a diagnostic assessment. Make it possible for people to have informal conversations about the diagnostic process early-on, so they can decide if it is what they want to do. Allow adults to self-refer to autism diagnostic services.
Create an alternative way for autistic adults to confirm their autistic identity	Make it possible for autistic adults who feel they do not need or want a clinical diagnosis of autism to reach a valid confirmation of their autistic identity through discussions with autistic peers.
Closely connect services across the lifespan and link them to the third sector	Connect social care, medical, health, education, employment, and citizens' advice services, and community organisations more closely. All services require autism-led autism awareness training. Enable services to work together to improve the utility of reports, such as Education and Health Care Plans (EHCPs).

<p>Central point of contact facilitating an 'easy in, easy out' system for access support across the lifespan</p>	<p>Create a central point of contact who can provide guidance, at any time, on accessing support based on needs. Create a physical facility (e.g. community hubs) with knowledgeable professionals to help link up with services/organisations to meet current needs in the community to do all of these things. Make it possible for people to access each service at multiple time points, including during the pre-diagnostic phase.</p>
<p>Create access to peer support services for all</p>	<p>Give individuals and families access to autistic peer support organisations to explore identity and gain advice about coping strategies or services that can help (regardless of whether they have a clinical diagnosis).</p>
<p>Increase funding and accountability to ensure that change happens</p>	<p>Provide more funding for diagnostic and support services to reduce significant and increasing regional inequalities. Use legislation and strict monitoring with a grading system to make statutory services accountable for meeting the needs of autistic people throughout the lifespan. Improve auditing, inspections, performance indicators and implications for poor performance, via the Audit Commission, to make Local Authorities accountable for supporting children, including those without an EHCP, within education.</p>

PART FOUR

RECOMMENDATIONS



4.1 Five key recommendations

The following section makes five key recommendations for improving support for the autistic and broader autism communities across the diagnostic pathway. These recommendations address the issues that the autistic and broader autism communities currently have with the autism diagnostic process, which results in high levels of stress, uncertainty, and dissatisfaction.

The recommendations also take account of the context behind the current problems with the autism diagnostic process, as discussed in the evidence sessions. The recommendations draw together the improvements that the autistic community want to see happen, as shown from the survey findings, and the solutions that evidence gives for improving support for the autistic community, as discussed in the evidence session.

Recommendation 1 – Needs/strengths-based assessment & support

Focus clinical diagnostic services on identifying needs (clinical, educational, health, social care) as well as strengths and aspirations of those presenting with suspected autism. Integrate diagnostic services with support services (both statutory and third sector), ensuring consistency across the lifespan.

Recommendation 2 – A single, accessible pathway

Have a single source of clear and accessible information succinctly detailing all aspects of the needs/strengths-based autism diagnostic pathway (possibly through autism hubs). There should be support from a 'key person' serving as a single point of contact throughout, including agreeing formal support.

Recommendation 3 – Identity-based assessment & support

Directly fund third sector peer support services to provide advice and guidance on non-clinical (e.g. self) diagnosis of autism and peer support for those with an autistic identity, as well as families/advocates.

Recommendation 4 – Pre-diagnostic support

Provide support before diagnosis (for those seeking needs/strengths-based assessment or identity-based assessment), which is integrated with needs/strengths-based post-diagnostic support services and peer support services (possibly through autism hubs).

Recommendation 5 – Fund and monitor

Ensure appropriate levels of funding for the implementation and monitoring of these recommendations to reduce pressure on diagnostic services and waiting times, as well as facilitating peer support and reducing dissatisfaction with existing provision and stress for autistic people and their families/advocates.

Next steps

Incorporate these recommendations into Statutory Guidance for Local Authorities and NHS organisations to support the implementation of the national strategy for autistic children, young people and adults: 2021 to 2026.

4.2 Conclusions

Over the past decade, increased awareness and increases in funding have led to significant improvements in the support available to autistic people and their families. Progressive policies have broadened the availability and capacity of autism teams and integrated service provision and there are many examples of innovative and excellent practice (autism hubs, reasonable adjustments). However, such success may have led to demand outstripping supply in respect of autism assessments. Over-stretched service providers need to make resources available to focus specifically upon the assessment of autism, the outcome of which can be a gateway to further support.

Overall, the autistic and broader autism communities report high levels of stress and dissatisfaction with the current autism diagnostic pathway, particularly before and after the assessment itself. There is a sense of being left unsupported and autism-related services being isolated from much-needed ancillary services (such as mental health). There is also a strong desire for peer-support, for the autistic community themselves to support those exploring an autistic identity.

The recommendations above are based on focusing clinical diagnostic services upon needs/strengths-based assessments for autism and funding the autistic community to develop identity-based support. This distinction between clinical and peer support is highlighted by the comment from the third evidence session: 'you don't go to a doctor to find out if you are gay'. Directly funding peer support groups can enable the autistic community to develop self-identification support and could reduce pressure on clinical services, enabling them to focus on those with clinical, educational, health, and social care needs, as well as strengths and aspirations, which could potentially reduce waiting times.

Ideally this distinction in support will be co-ordinated (possibly through autism hubs) to ensure that good quality assessments outline the strengths, needs and aspirations of each individual person. Some people who think they are autistic may not meet the criteria (through either pathway), and autism hubs could consider how to support those who are not autistic but feel they have traits or sensitivities similar in some ways to autism.

The recommendations are for two distinct and complementary pathways, focussed on meeting the needs of the heterogeneous autistic community. A focus upon needs/strengths rather than labels would be facilitated by two distinct and complementary pathways, in a manner which supports autistic identity.

The National Autistic Society ran a campaign to highlight how autistic people can be overwhelmed by 'Too Much Information'. Paradoxically, there is too much information about autism and its diagnosis, with a multitude of contradictory information appearing across a plethora of internet sites. A single, accessible source of information is desired, ideally through 'autism hubs'. Single points of contact, with *human* support and guidance, which can facilitate access to tailored support and resources (rather than generic internet sites) would greatly reduce stress and increase satisfaction. This support needs to be available before diagnosis to address deterioration of health and behaviour while on waiting lists.

As ever, securing funding and mechanisms to ensure compliance, are key mechanisms for delivering these improvements. There are currently examples of good practice (such as autism hubs), however these have been achieved via ad hoc, short-term or piecemeal pots of funding. The positive perceptions of assessment are consistent with focussed resources relating to meeting needs and high levels of community satisfaction – this needs to be extended to pre- and post- support.

A coherent, long-term strategy to fund these recommendations would enable both professional services and the autistic community to best meet the needs of the autistic and broader autism communities. Statutory guidance for local authorities and NHS bodies to support the implementation of the national autism strategy (2021 to 2026) that incorporates the recommendations within this report will facilitate the integration of what the autistic and broader autism community want with what statutory services provide.

These recommendations are supported by more detailed recommendations made by the experts (professional and by experience), listed in Appendix I.

Appendix A: Contributors to the report

Members of the Westminster Commission on Autism:

Barry Sheerman MP (Chair)

Dr Anna Remington, Director of the Centre for Research in Autism and Education and Associate Professor at UCL

Dr Carole Buckley, Clinical Champion for Autism at the Royal College of General Practitioners

Chris Pienaar, CEO of Derbyshire Autism services

Cindy-Lee Watts, Trustee of the Giving Tree Foundation

Craig Kennady, Autism campaigner

Dr Damian Milton, Senior Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent

Professor Eddie Chaplin, Professor of Mental Health in Neurodevelopmental Disorders at London South Bank University

Professor Emily Simonoff, Professor of Child and Adolescent Psychiatry at KCL

Erica Craig, Head of Speech and Language Therapy for the Hesley Group

Fran Botley, SENCO

Dr Gemma Williams, postdoctoral researcher in autism

Helen Ellis, Autism public speaker

Hilary Fertig, Employment Autism

Dr Ian Davidson, National clinical lead GIRFT Crisis and Acute Mental Health; Consultant Psychiatrist at Cheshire and Wirral Partnership; former RCPsych Autism Champion

Jane Howson, CEO of Autism East Midlands

Jonathan Andrews, solicitor and Equality Improvement Champion

Katherine Hewlitt, CEO of AchieveAbility

Professor Michael Lewis, MBE, Executive Chairman, Riverston International.

Dr Michael Sills, consultant paediatrician

Dr Michael White, GP and member of Hampshire Autism Partnership board

Professor Nicola Martin, Professor of Social Justice and Inclusive Education at London South Bank University

Dame Stephanie Shirley, The Shirley Foundation

Professor Richard Mills, Research Fellow in the Department of Psychology at the University of Bath

Dr Ross Cooper, Chair of Trustees of AchieveAbility

Centre of Applied Autism Research (CAAR – University of Bath) team members:

Professor Mark Brosnan, Director of CAAR

Dr Ailsa Russell, Deputy Director of CAAR (Clinical)

Dr Liz Smith, Research Fellow / Educational Psychologist

Dr Vanessa Lloyd-Esenkaya, Research Associate

Steering group members:

Dr Kate Cooper, Research Fellow at the University of Bath, Clinical Psychologist

Dr Laura Crane, Associate Professor and Deputy Director of the Centre for Research in Autism and Education (CRAE) at UCL

Professor Nicola Martin, Professor of Social Justice and Inclusive Education at London South Bank University
Craig Kennady, Autism campaigner
Helen Elis, Autism public speaker
Dr Damian Milton, Lecturer at Tizard Centre at the University of Kent
Dr Ian Davidson, National clinical lead GIRFT Crisis and Acute Mental Health; Consultant Psychiatrist at Cheshire and Wirral Partnership; former RCPsych Autism Champion
Sarah O'Brien, autistic adult
Caroline Tchighianoff, parent advocate

Contributors to evidence sessions:

Oral evidence session 1: Adult services

Chair: Helen Ellis

Panellists: Dr Ross Cooper, Dr Michael White

Witnesses:

Dr Ian Davidson, National clinical lead GIRFT Crisis and Acute Mental Health; Consultant Psychiatrist at Cheshire and Wirral Partnership; former RCPsych Autism Champion

Dr Conor Davidson, Clinical lead for Leeds Autism Diagnostic Service; RCPsych Autism Champion

Dr Steven Stagg, Senior lecturer at Anglia Ruskin University

Chris Pienaar, CEO Derbyshire Autism Services

Oral evidence session 2: Children's services

Chair: Dr Laura Crane

Panellists: Cindy Lee Watts, Jane Howson, Fran Botley

Witnesses:

Vivian Hill, Programme Director DEdPsy at Institute of Education, UCL

Professor Sara Ryan, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University

Emily Frith, Children's Commissioner Office

Oral evidence session 3: Autism-led and advocacy

Chair: Dr Michael White

Panellists: Craig Kennady, Jonathan Andrews, Gemma Williams

Witnesses:

Caroline Hearst, AutAngel

Helen Ellis, National Autistic Society

Emma Dalmayne, Autistic Inclusive Meets

Jenn Layton, Doctoral Autism Researcher

Written evidence

Welsh Government

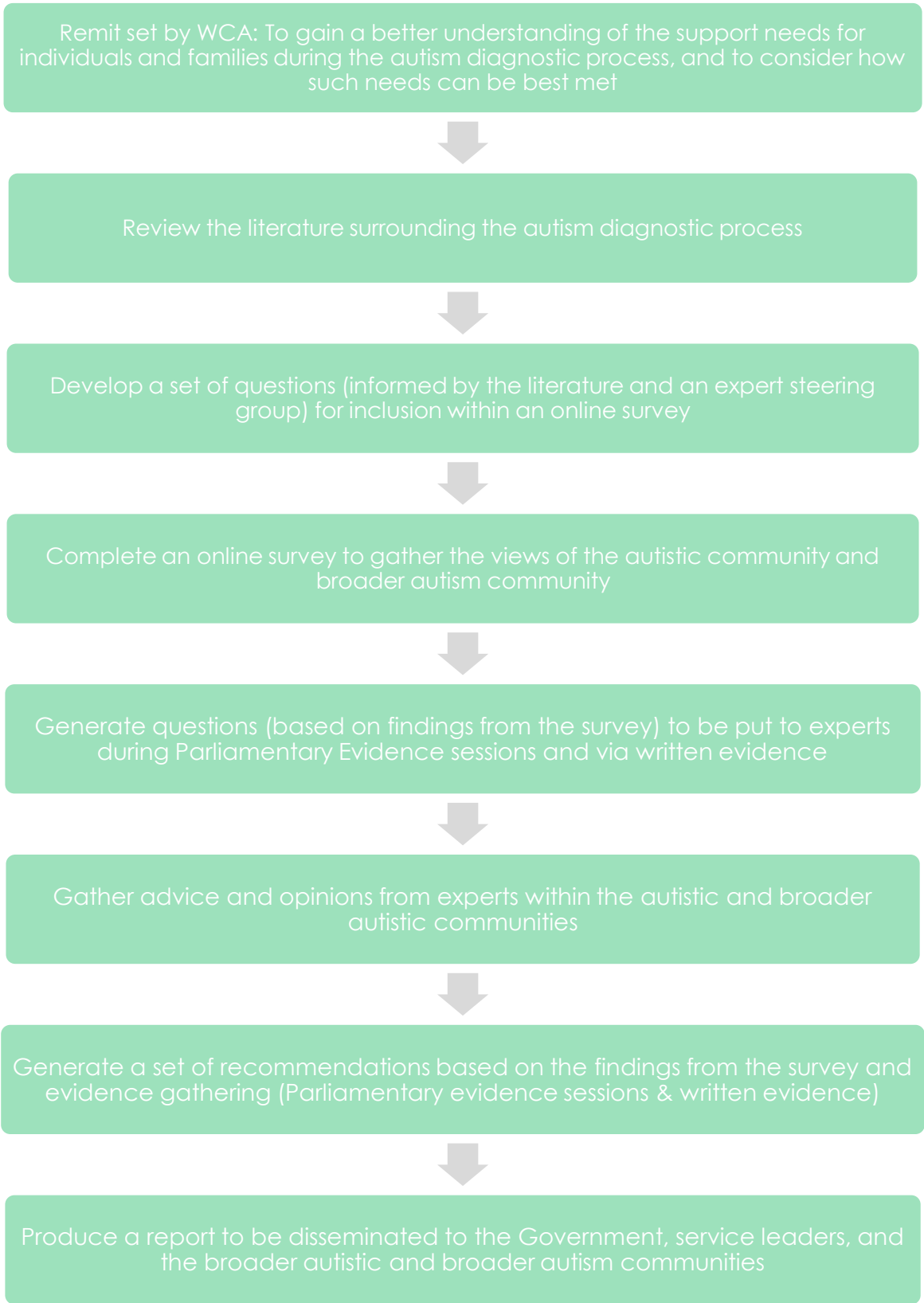
Care Quality Commission

Ambitious about Autism

Professor Michael Lewis

Autism Voice

Appendix B: Inquiry Process



Appendix C: Copy of questionnaire

Below is the parent version of the survey. The wording was amended for adults and family members.

SECTION 1: ABOUT YOU

What is your relationship to the person who has had the autism assessment:
(*mother, father, carer, other family member, other, please write:*)

Does anyone else in the family have a diagnosis of an autism spectrum disorder?
Yes/No If yes, please write the relationship(s) to the child in question

Where were you living at the time of your child's autism assessment?
Channel Islands, East England, East Midlands England, London, North East England, North West England, Northern Ireland, Scotland, South East England, South West England, Wales West Midlands England, Yorkshire and the Humber North

SECTION 1B: ABOUT YOUR CHILD

Child's age NOW

Child's gender
(*male, female, identifies as (please state): _____*)

What is your child's ethnic group? Please choose the option that best describes his/her ethnic background
White – British, White – Irish, Traveller of Irish heritage, Any other white background, Gypsy / Roma, White and Black Caribbean, White and Black African, White and Asia, Any other mixed background, Indian, Pakistani, Bangladeshi, Any other Asian background, Black Caribbean, Black – African, Any other Black background, Chinese, Any other ethnic group

SECTION 2: YOUR EXPERIENCE BEFORE YOUR CHILD'S AUTISM ASSESSMENT

This is about the period from when you first noticed differences in your child's behaviour or development, to the point when a request for an autism assessment was made. If your child has had more than one autism assessment please consider the time up to the request for the most recent assessment.

How old was your child when you first noticed differences in their behaviour and/or development?

How old was your child when someone first suggested seeking an autism assessment?

Who did you discuss the possibility of seeking an autism assessment with? (please click on all that apply)
(*your partner, another family member, friend/colleague/other parent, teacher of member of staff at pre/school, Social Worker/Social Care, Health Visitor, family doctor/GP, Paediatrician, child and adolescent psychiatrist or member of CAMHS, Speech and Language Therapist (SALT), educational psychologist (EP), Clinical Psychologist, Occupational Therapist (OT), other*)

Has your child had more than one formal autism assessment?

Yes, please give a brief reason (e.g. second opinion). You can write more in the comments section later in the survey if you wish, No

Who made the (most recent) referral for the autism assessment?

Self referral - child's parent/carer, Teacher or member of staff at my child's school/nursery, Social Worker / Social Care, Health visitor, Family doctor/GP, Paediatrician, Psychiatrist or mental health service (e.g. CAMHS), Speech and Language Therapist (SALT), Educational Psychologist (EP), Clinical Psychologist, Occupational Therapist (OT), Not sure, Other

Was this a private referral (not through the NHS)?

Yes, please give reason (e.g. waiting times, second opinion) / No

How old was your child when the (most recent) referral for an autism assessment was made?

Please rate the following statements **based on your experience during the time you were seeking an autism assessment for your child**

It was difficult to find information about how to get an autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, I was referred directly by another service (e.g. Health/Education))

It was difficult to understand the information about how to get an autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, I was referred directly by another service (e.g. Health/Education))

My child's ethnicity / cultural background contributed to difficulties in seek an autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

My child's sex or gender identity contributed to difficulties in seeking an autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

There were practical barriers, for example difficulties with transport, childcare, taking time off work
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

Financial cost was a barrier to seeking an autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

Please give details of these, or any other factors, that made seeking an autism assessment for your child more difficult:

Please rate the following statements **based on your experience with the people who were involved in discussions about seeking an autism assessment for your child**

My views as a parent/carer were respected
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

My views as a parent/carer were taken into account
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

I had a good relationship with the people I spoke with during this phase of the process
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

The people I spoke with used language that was easy to understand
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

This part of the process left me with a positive view of autism
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

I had a clear understanding of what would happen in the next part of the process (the assessment)
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

Overall, how stressful did you find this period (whilst you were seeking an autism assessment for your child).
Very stressful, Quite stressful, Not very stressful, Not at all stressful

What made this period particularly stressful for you? (This question was only displayed if answered 'very' or 'quite' stressful to previous question)

Was there anything that helped to make this period less stressful? If so, please tell us about it here

Overall, how satisfied were you with the help/support offered during this time (whilst you were seeking an autism assessment for your child?
(*Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied*)

Please tell us about the help/support that you received during the time when you were seeking an autism assessment for you child, If there was anything that helped to make you feel supported, or that you would have liked please include it here.

Overall, how satisfied were you with this part of the process?
(*Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied*)

Comments: If you would like to make any additional comments on your experience during the time before your child's autism assessment, please write them here. If your child has had a previous autism assessment you can also use this space to tell us about this experience:

SECTION 3: YOUR EXPERIENCES DURING THE AUTISM ASSESSMENT *This is about the period from when a request for an autism assessment was made to when the outcome/diagnosis was given. If your child has had more than one autism assessment please comment on the most recent.*

What year did your child's (most recent) autism assessment start? (e.g. 2019)

After your child was referred for an autism assessment, how long did you wait before you had a face-to-face appointment with a member of the autism assessment team? (This may have been in person or by a video call)

What was the outcome of the autism assessment?
Diagnosis of Autism or Autism Spectrum Disorder, Diagnosis of Asperger's syndrome, Diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Diagnosis of something other than autism, please state, No diagnosis, Other, please state:

How long was the assessment period (from the time of your first appointment to the appointment when you were told the outcome/diagnosis)?
Single assessment, ___months, ___ years

Has your child been formally diagnosed with any other conditions alongside autism?
Please click on all that apply

Yes, a physical disability (including epilepsy and hearing or vision impairment), Yes, a specific learning disability (e.g. dyslexia), Yes, a general learning (intellectual) disability (LD), Yes, a genetic condition (including Fragile X syndrome), Yes, a behavioural condition (including ADHD, conduct disorder, Tourette syndrome), Yes, an emotional disorder (i.e. depression or anxiety), Yes, a mental health condition (including bipolar disorder, OCD, schizophrenia), Yes, a sensory impairment, Yes, any other condition, None of the above, Other, please state

Did you receive a written report/letter after your child's assessment?

Yes, No, Not sure

Please rate the following statements **based on your experience during your child's autism assessment.**

The information in my child's report/letter was clear and easy to understand
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, I didn't get a report/letter after my child's assessment)

My child's report/letter was helpful.
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, I didn't get a report/letter after my child's assessment)

My child's ethnicity / cultural background impacted on the autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

My child's sex or gender identity impacted on the autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

There were practical barriers, for example difficulties with transport, childcare, needing to take time off work
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

Please give details of these, or any other factors, that made the autism assessment more difficult for you or your child:

Please rate the following statements based on your experience with the professionals involved during your child's autism assessment

My views as a parent/carer were respected
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

My views as a parent/carer were taken into account
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

I had a good relationship with the professionals during this phase of the process
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

The professionals used language that was easy to understand
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

This part of the process left me with a positive view of autism
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

I had a clear understanding of what would happen next, in terms of support for my child after the autism assessment
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

Overall, how stressful did you find this period (during your child's autism assessment)?
Very stressful, Quite stressful, Not very stressful, Not at all stressful

What made this period particularly stressful for you?

Was there anything that helped to make this period less stressful? If so, please tell us about it here

Overall, how satisfied were you with the help/support offered during this time of your child's autism assessment?
(Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied)

Please tell us about the help/support that you received during the time of your child's autism assessment, If there was anything that helped to make you feel supported, or that you would have liked please include it here.

Overall, how satisfied were you with this part of the process (the assessment itself)?
(Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied)

Comments: If you would like to make any additional comments on your experience during the time of your child's autism assessment, please write them here:

SECTION 4: YOUR EXPERIENCE DURING THE FIRST YEAR AFTER YOUR CHILD'S AUTISM

ASSESSMENT *This section is about your experience during the first year after your child's autism assessment. If the assessment was completed less than a year ago and there are any questions you feel you cannot answer please just leave them blank.*

Did you have a follow-up appointment within 6 weeks of the assessment ending?
Yes, No, Not sure

What was the most helpful aspect of receiving an autism diagnosis?
NA – my child didn't receive an autism diagnosis after the autism assessment, Just being given a diagnosis, Gaining education and understanding about autism, Input from healthcare professionals, Additional support at pre/school, Financial/employment advice , Access to support groups, No obvious benefits noted, Would prefer not to have a diagnosis, Other:

What sort of help/support were you offered in the first year after your child's autism assessment?

	Would have liked but not offered	Offered but not taken up	Provided and helpful	Provided but not helpful	Not applicable
Education, Health and Care Plan (EHCP) or Statement of Special Educational Needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Additional support (individual or small group) at pre/school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with pre/school provision (e.g. access to a specialist unit or special school)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practical help for managing my child at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Face-to-face support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online autism support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Input from Speech and Language therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Input from mental health services (e.g. CAMHS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Input or intervention from an autism specific support service (e.g. earlybird parenting course)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal support/counselling (for parent(s)/carer(s))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact with a charity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explanation of child's problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informal support from family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informal support from friends/colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with monetary benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with medical problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Had any of this help/support been offered to you or your child BEFORE your child's autism assessment? (Please click all that apply)

Education, Health and Care Plan (EHCP) or Statement of Special Educational Needs, Additional support (individual or small group) at pre/school, Help with pre/school provision (e.g. access to a specialist unit or special school), Practical help for managing my child at home, Face-to-face support groups, Online autism support groups, Input from Speech and Language therapy, Input from mental health services (e.g. CAMHS), Input or intervention from an autism specific support service (e.g. earlybird parenting course), Personal support/counselling, Family therapy, Contact with a charity, Informal support from family members, Informal support from friends/colleagues, Help with monetary benefits, Help with medical problems, Respite care, Other)

Please rate the following statements based on your experience during the first year after your child's autism assessment

It was difficult to find information on accessing services
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

It was difficult to understand the information about the different services
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

My child's ethnicity/cultural background contributed to difficulties in accessing support services
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

My child's gender, or gender identity, contributed to difficulties in accessing support services
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

There were practical barriers, for example difficulties with transport, childcare, times of sessions, difficulties with work arrangements
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

Financial cost was a barrier to accessing support services
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree, prefer not to say / no response)

Please give details of these, or any other factors, that made the period after your child's autism assessment more difficult:

Please rate the following statements based on your experience with the professionals involved during the first year after your child's autism assessment

My views as a parent/carer were respected
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

My views as a parent/carer were taken into account
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

I had a good relationship with the professionals during this phase

(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

The professionals used language that was easy to understand
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

This part of the process left me with a positive view of autism
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

I had a clear understanding of what would happen next in terms of the available support for my child
(strongly agree, somewhat agree, either agree nor disagree, somewhat disagree, strongly disagree)

Overall, how stressful did you find this period (during the first year after your child's autism assessment)?
(Very stressful, Quite stressful, Not very stressful, Not at all stressful)

What made this period particularly stressful for you?

Was there anything that helped to make this period less stressful? If so, please tell us about it here

Overall, how satisfied were you with the help/support offered during this time?
(Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied)

Please tell us about the help/support that you received during the first year after your child's autism assessment, If there was anything that helped you/your child to feel supported, or that you would have liked please include it here.

Overall, how satisfied were you with this part of the process (during the first year after your child's autism diagnosis)?
(Very satisfied, Quite satisfied, Neither satisfied nor dissatisfied, Quite dissatisfied, Very dissatisfied)

Comments: If you would like to make any additional comments on your experience during the first year after your child's autism assessment, please write them here:

Comments: If you have anything else you would like to tell us please write it here. Suggestions on how the diagnostic process could be improved, or what could have been done to help make things easier for you and/or your child during the diagnostic process are especially welcomed.

Appendix D: Survey findings – comments on the pre-assessment phase

HOW PEOPLE FELT

Waiting times are still too long

The period whilst waiting for an assessment was reported to be extremely stressful. With reported waiting times of 1 year on average, and significantly longer for some, this had a considerable impact on the wellbeing/mental state of both parents and the individual waiting for the assessment (child and adult).

“My daughter has been through so much over the years, and basically wasted 2 years playing a waiting game it really does no good for people to go through all the mental and physical health impacts of waiting so long.” Parent of an autistic child

“I often thought I had been forgotten about, it seemed to take so long.”
Autistic adult

Uncertainty is very stressful

All the uncertainty and ‘not knowing’ during the waiting period added to stress levels, particularly for the adult. Two areas were highlighted, firstly regarding the assessment process itself, and secondly regarding identity and the future post assessment.

“The unknown I suppose was the most stressful thing - I didn't know what to expect and what it would mean going forward.” Parent of an autistic child

“I hated not knowing. I felt like I was on the verge of discovering something really unique about myself that could explain almost every struggle I'd had my entire life (and this is HUGE) but I wasn't sure. The uncertainty was overwhelming and added to the decades of feeling invalidated and dismissed.” Autistic adult

Deterioration in wellbeing

Parents often noted a deterioration in their wellbeing and mental state during the pre-assessment phase, which for some also impacted significantly on their ability to work and/or look after other siblings. Similar concerns were raised regarding the child's mental state and an escalation in externalising behaviours, sometimes resulting in school exclusions, was also noted.

"The waiting in between made me ill - I couldn't sleep and was depressed." Parent of an autistic child

"It was one of the most stressful periods of my life, mainly because of watching my son struggle and having no clue how to help him, despite being very proactive in trying to get help." Parent of an autistic child

"Child's challenges increased exponentially over the timeline of diagnosis and schools won't allocate sufficient resource without diagnosis due to levels of demand." Parent of an autistic child

Difficulties with referral process

A range of difficulties with the referral process were noted. People felt that the **pathways to referral were often unclear**, with services not knowing who or how to refer. This resulted in a feeling of going 'round in circles', with everyone 'suggesting they were not the one to refer'.

Another issued raised was with difficulties in **co-ordinating information/paperwork** between the different services and the added stress that was caused by having to arrange/chase up appointments and complete **lots of paperwork**. Particular difficulties were also noted for families who move frequently (e.g. military families) and for those who start on a waiting list within children's services but then reach the age cut off before the time of their assessment

"It was so complicated to know how to get the assessment. School Nurse, GP, Sirona Health, teachers, Health visitors - all seemed to suggest they were not the one to refer" Parent of an autistic child

Some respondent's also raised concerns about feeling that their **voice was not being taken seriously**, and/or **not feeling listened to** by the professionals. In addition, a number felt that it took reaching crisis point to be taken seriously (either in order to get a referral, or during the waiting period before the assessment)

"Nursery would not start process as he wasn't on their 'watch list' no matter how many times they had to talk to me about his behaviour and how many times I went to them with concerns." Parent of an autistic child

Certain **child characteristics** were highlighted as being associated with additional challenges during the pre-assessment phase. Being female, being intelligent and able to mask behaviours, not presenting with challenging behaviours in school and having more complex needs (not clear if autism or another neurodevelopmental disorder). Difficulties with **comorbidities** were also noted for adults

"The Mental Health Team said I could only be treated with one condition at a time so had choose between ongoing treatment for depression & getting help with my autism." Autistic adult

WHAT PEOPLE WANT

Personal Support (ideally from autistic people)

Support groups (face-to-face and online) were often seen as being particularly valuable at this time, with adults specifically wanting support/contact with other people who have been diagnosed as an adult. However, it was noted that not all adults felt like they needed any additional support, and not everyone liked groups.

“Access to an autistic-led group. Meeting another human like you is quite a profound experience and can be supportive at what tends otherwise to be a lonely time, full of self-doubt.” Autistic adult

“I am a very independent person capable of doing my own research and I am not emotionally needy, so I did not require any support.” Autistic adult

Having an advocate and/or better communication with services

Suggestions for helping to reduce stress levels focussed primarily on better communication with services, with regular updates, during the waiting period. People wanted information on what would happen next, what the appointments would involve, who would be at the appointments, and when they would be. A number of people suggested that having an advocate to help explain the referral/assessment procedure and support with arranging appointments, filling in forms, chasing things up would have been helpful.

“Better updates on your place in the assessment queue and preparation for the assessment itself would have been welcome, e.g. I was surprised to be presented with quite a complicated questionnaire by the Clinical Occupational Therapist at my initial interview. Couldn't they have let me know about that in advance? Would I need to involve my family or is that optional? Questions like that.” Autistic adult

“Having someone to explain the process, having someone to help fill forms in and deal with telephone calls, chasing things up etc. Maybe like a factual picture book of the whole process. Also, it would be handy if they got in touch with you to support you. Also, someone to help with the next steps after being diagnosed.” Autistic Adult

Information on autism

Many people commented how finding out more information on autism helped them during the pre-assessment phase. This was seen as particularly helpful for the adults.

“I wish professionals had given me information and resources about neurodiversity or where I can hear from autistic adults, or some inkling that autism is valuable and positive.” Autistic adult

Practical support for parents

Parents expressed a need for more practical support for their child and family during this time. It was also noted that some services allowed access to courses/workshops without a diagnosis, and this was felt to have been particularly helpful.

"I have 2 other children and was very stressed trying to help my son navigate his world while also being a parent to my other children."
Parent of an autistic child

Support from (pre)school/work

Some respondents felt well supported by (pre)school/work during the waiting period whilst others did not. This was associated with either reducing or adding to the stress felt during this period.

"School head and staff were great. Via a CAF we had school nurse, EP and local council behaviour support team supporting us and they were all great." Parent of an autistic child

"Work offered me reasonable adjustments BEFORE I received a diagnosis based on my own suspicions and this made me feel supported and secure in my employment." Autistic adult

Appendix E: Survey findings – comments on the assessment phase

Upsetting questions and difficulties recalling historical details

Some respondents reported difficulties with trying to remember historical details, particularly relating to early child development. Also, some found the personal nature of some of the questions upsetting.

“The whole finding people and having to meet people to talk about me was hugely stressful” Autistic adult

“The process itself wasn't stressful but trying to remember every bit of 15 years of your child's life from when he was born to that day was the stressful part I have 3 children and remembering ever integrate detail over 15 years was particularly difficult.” Parent of an autistic child

“Meeting/ talking to new people about the difficulties in your life.” Autistic adult

Face-to-face contact with strangers

Adults reported finding all the face-to-face contact with strangers particularly stressful. Suggestions to help with this included using video calls with observer not on screen, encouraging the use of written notes and providing an email option, rather than relying solely on phone calls for communication.

“I would find it hard completing assessment with 2 people I did not know. Because of this the OT completed assessment on video call when another person was in the room and sat off the screen.” Autistic adult

Challenging location/environment

Parents reported difficulties with trying to occupy/look after their child whilst trying to have important conversations with the professionals. The environment also impacted on stress levels, with small rooms (especially with multiple professionals) and crowded waiting areas being particularly problematic. Having the assessment in a familiar environment, with familiar adults was felt to reduce stress levels. Practical difficulties, including travel, childcare and work were raised.

“Appointments appeared crowded and in a sensory environment designed to cause distress and meltdowns” Parent of an autistic child

“Trying to listen and talk to the consultant while also watching my son on my own. He is very active and having another adult (his dad) with me would have been extremely helpful.” Parent of an autistic child

High volume of paperwork and appointments

Some parents reported feeling overwhelmed by the volume of paperwork and number of appointments they were required to attend. This was less of an issue for the adults.

“The amount of appointments, number of people of unknown role present in each appointment and the manner of the psychologist were so incredibly upsetting it triggered meltdowns and reluctance to attend by the child.” Parent of an autistic child

Uncertainty and feeling unprepared

Some adults reported difficulties associated with not know what might happen at the assessment and not being able to prepare.

“I never knew what was happening from one appointment to the next so I couldn’t prepare myself. Had I have known, I would’ve had all my family and her dads family history (medical) to hand.” Autistic adult

Appendix F: Survey findings – comments on the post-assessment phase

HOW PEOPLE FELT

Feeling alone and still fighting for access to support “I was left with a label and no help in life”

Many people reported receiving little or no support following their diagnosis and a general feeling of being “left to get on with it”. This is consistent with the findings from the latest APPGA report that found only 4% of autistic adults and families felt fully supported during the 12 months after their diagnosis [42].

There was also a sense of disappointment in the realisation that the autism diagnosis did not necessarily mean that they received any more help or support. Given the high levels of stress and anxiety leading up to the diagnosis (throughout the pre-assessment and assessment phases) this was a particularly tough realisation.

Parents felt that they had ongoing battles to get help and support for their child in school and adults reported difficulties trying to get support at work. The availability of post diagnostic support services was reported to vary according to location, with difficulties being raised for those living on county borders. Also, the adults told us that services were often aimed at children and families, rather than autistic adults.

“You realise you went through all that stress and anguish for an assessment and it makes no difference. Gives no benefits. No help.”
Autistic adult

“I found it very strange that we were given the diagnosis and that was it. There is no follow-up, no support, no help in any way and no guidance as to what to do with it. We are just left, knowing that we're not crazy and our child does have difficulties but that's it.” Parent of an autistic child

Feeling overloaded with information and no one to talk to

After the diagnosis many people reported receiving a lot of written information or ‘leaflets’ with signposting to various potential support services, but no actual help. This was felt to be overwhelming and gave a sense of having to try to navigate through the system alone, without anyone to talk things through with

Sometimes the information given was not relevant or appropriate and/or out of date. Other times people reported receiving no information on the type of help they might need or how to access it. People often reported having to ‘do all the research myself to find out what support was available’ and how time consuming and hard work this was.

Parents, in particular, reported that the amount of information, appointments, and parenting courses resulted in additional pressures to their already stretched resources.

"I had to do all the research myself to find out what support was available, how to get an EHCP, what ASD schools existed etc etc. I spent hours, days, weeks, on the phone and internet desperately trying to find help. We were really struggling. Most ended up at a dead-end, but some led to support." Parent of an autistic child

"The amount of information was stressful and suddenly there was more information I had to get through." Parent of an autistic child

"I was given a leaflet and one follow up telephone call. Even as a well educated person I found it difficult to pick out what would be useful to me. As such I have not accessed any post diagnostic support as it was information overload." Autistic adult

WHAT PEOPLE WANT

Better access to ancillary services (particularly mental health) with an autism diagnosis

A key issue raised was around access to ancillary services, particularly for mental health. A number of adults reported that they actually lost their mental health support after receiving their autism diagnosis as they were told that being *"discharged because they were not commissioned to provide services for autistic people."* Parents also expressed a desire for better connected services within education.

"I was on a waiting list for NHS talking therapy when I got my diagnosis, but the offer was withdrawn when my diagnosis was confirmed. The service that I had been referred to were angry with me as they felt that I had tricked them into accepting me on the waiting list by not telling that I planned to seek an autism diagnosis (I didn't decide to seek a diagnosis until after they had assessed me), and told me that there was now "no point" in offering me talking therapy as any issues I had were autism-related and therefore incurable." Autistic adult

"The local mental health services cut off support as they said as i'm autistic it was too complex for them to deal with, they still do this." Autistic adult

"Losing all the mental health support because they said I should be supported by the autism team." Autistic adult

Parents need help for themselves in addition to support for their child

Eighty percent of parents reported wanting some form of support (e.g. personal counselling) for themselves in addition to the support required for their child. For almost all of these parents (97.5%) this had not been something that had not been available to them. They also told us about the impact that the whole diagnosis process had on their wellbeing and ability to work.

“We were broken from what had happened with his school before the diagnosis. I had a breakdown. I never returned to work. I am a single parent who was in a senior management role.” Parent of an autistic child

Autistic-led support

Support from local groups and charities were generally recognised as being particularly helpful. The benefits of meeting and getting support from other autistic people, or parents of autistic children (rather than neurotypical professionals) was also highlighted. It should be noted however, that for some people a group setting was not helpful.

“Without the support from the local charities I would have been at a complete loss- there was no further info or support from CAMHS.” Parent of an autistic child

A key person to help access services and navigate the system

Several people said that they would have preferred to have someone (like an advocate or mentor) to explain what support was available and how to access it, rather than just being given a set of leaflets.

“The fact that we were only signposted to the services rather than supported directly, which would have helped us to make sense of the landscape better.” Parent of an autistic child

Better support for children’s education and adults in the workplace

Parents wanted better support from schools and local authorities and adults wanted better support in the workplace. For parents, a key issue was getting appropriate additional support for their child in school. Benefits from getting an Education Health and Care Plan (EHPC) were noted but for some parents they were told that their child did not need this, and that subsequently no additional funding would be available.

For adults, a key issue was regarding support/reasonable adjustments at work. A number of people reported concerns regarding losing their job or being discriminated against if they disclose their diagnosis when applying for a new job. Being able to disclose at work and benefit from ‘Access to Work’ measures were seen as particularly helpful in reducing stress associated with work and employment.

“More understanding from schools and local authority. Not having to find everything out by myself.” Parent of an autistic child

“Disclosing at work and Access to Work measures helped a great deal to stabilise my employment situation and made me feel less vulnerable”
Autistic adult

Appendix G: Question development for evidence gathering sessions

From the output from the survey, the steering group discussed two overarching questions, that were made up of a series of sub-questions:

How could services demonstrate that a local region's autism diagnostic pathway is inclusive, accessible and autism friendly for families, children and adults?

- 1A) Given the heterogeneity of autism, how can the diagnostic pathway be 'autism-friendly' and how can this be evaluated?
- 1B) How can the knowledge and expertise of the clinical assessment team be spread across the service more widely (e.g. receptionists. Oliver McGowan Training?)?
- 1C) Can people be treated 'as if' autistic throughout the diagnostic process?
- 1D) How can inequalities in access to diagnostic pathways best be addressed? (gender, ethnicity, digital poverty, not having an assertive/well educated parent/advocate).
- 1E) How can stress and uncertainty for those seeking diagnosis and their families/advocates be reduced throughout the diagnostic pathway?
- 1F) How can expectations of the diagnostic pathway (and beyond) be most effectively managed?
- 1G) How can a positive view of autism be developed throughout the diagnostic pathway?
- 1H) How can best practice be identified and shared between local regions?

How can needs-led assessment and individually tailored support be implemented by health, education, and social care throughout the duration of the autism assessment process i.e. including waiting list period?

- 2A) Given the heterogeneity of autism, how can we ensure that support meets the needs of the individual and how can this be evaluated?
- 2B) To what extent is an autism diagnosis a gateway to autism-specific support, for example, autism post-diagnostic support?
- 2C) How flexible can access to support be, for example including those who identify as autistic?
- 2D) How can differential diagnostic processes best be integrated (for example access to mental health services can be suspended whilst waiting for an autism diagnostic pathway)?

2E) How can access to mental health services be made easier both during and after an autism diagnosis?

2F) To what extent can diagnostic support be targeted at family members/ advocates of the person seeking diagnosis?

2G) An excess of signposting leaflets and web-based resources can lead to information overload, and can be difficult to understand. How can an integrated, accessible source of information be developed? To what extent can this be supported by a key professional to respond to specific questions?

2H) Post COVID-19, how can digital resources be included within a 'blended' provision?

2I) How can peer-support offered by members of the autism community effectively be integrated into the diagnostic pathway?

The WCA reflected upon both the data from the online survey and the potential questions. These reflections were integrated to propose the following structure for the evidence giving sessions, to inform future recommendations:

There are TWO key phases to address:

- 1) Pre-assessment support (i.e. during the time from first considering an autism assessment to the diagnosis),
- 2) Post-assessment support (i.e. during the year after the autism diagnosis).

Three categories of expert will be invited to give evidence:

- 1) Formal (clinical leads, policy makers) providers of support for adults;
- 2) Formal (clinical leads, policy makers) providers of support for children;
- 3) Informal (autistic leads, autistic charities) of peer support.

During the evidence sessions (or in a written submission), experts will be asked to address two key issues:

A) How can stress and uncertainty for those seeking diagnosis and their families/advocates be reduced? What pre-diagnostic support can be provided to those seeking diagnosis and their families/advocates? How can best practice be identified and shared across regions?

B) How can access to ancillary services (e.g. mental health) be facilitated and integrated into post-diagnostic support? What post-diagnostic support can be needs-based rather than dependent upon receiving a diagnosis? How can best practice be identified and shared across regions?

Appendix H: Experts' ideas for improving support for the autistic and broader autism communities

The ideas that experts gave for improving support for the autistic community were synthesised into six key themes which are described in detail here:

[1] Make routes into diagnostic services easier to access and easier to understand

In line with findings from the survey, experts told us that the routes to diagnostic services and support services for autism are complicated and difficult to navigate, creating additional stress and tension for individuals and families.

Often, individuals and families are unsure of the process involved in diagnosing autism and have questions about whether the diagnosis is right for them. However, there is rarely a person available who can answer questions. Much of the information available on accessing diagnostic services is targeted at parents, which creates barriers for adults searching for diagnostic services for themselves.

In addition, the information available online on routes to diagnostic services is text-heavy, which reduces accessibility, particularly for those where English is not a first language and those with learning difficulties. The current system also relies upon an individual (self or parent/carer) to convince professionals of their need for a referral, which can create additional stress and requires a high level of assertiveness and ability.

Experts told us that diagnostic services need to be made easier to navigate. A clear pathway for referral needs to be created, which includes an option for self-referral. A simplification to the routes into diagnosis will help to reduce stress at the beginning of the autism diagnostic process. Currently, in England, different areas adopt their own 'local care pathways' (as recommended by NICE). This means however, that there is considerable variation in pathways across the country, adding to confusions regarding referral routes and how to access services.

Experts provided examples of organisations that are trying to make diagnostic services easier to navigate, which could be replicated elsewhere. For example, Ambitious about Autism (a UK charity for children and young people with autism) has co-produced a toolkit with parents and professionals called the Right from the Start toolkit [52], which is given to families at the beginning of the diagnostic process and one aim is to help parents to navigate the diagnostic process.

At the Leeds Autism Diagnostic Service adult patients are given the opportunity to self-refer themselves for an autism diagnostic assessment, which has helped patients to access diagnostic services more easily and has not resulted in overwhelming demand on diagnostic services as some feared:

"Our fear with allowing self-referral was that there be a kind of massive rise in the number of referrals coming through, but that doesn't seem to be borne out and I don't think that's been the case in Wales, either. So that's something certainly that, [according to] feedback from service users, they find positive." Dr Conor Davidson

Nevertheless, self-referral is not an option for adults everywhere in the UK and more work needs to be done to simplify routes to autism diagnosis for all age ranges. The presence of third sector community "hubs", which pool resources, information, and support for autistic people, is another way to facilitate routes to referral into autism diagnostic services. These hubs currently exist in pockets of the country, for example in Cheshire, Wirral and Leeds. They work well for helping individuals to understand how they can access diagnostic services for autism and to learn more about what the diagnostic process would involve, with an opportunity to ask questions.

[2] Create an alternative way for autistic adults to confirm their autistic identity

Evidence givers explained that viewing autism as a 'medical disorder' can be stigmatising, which may prevent some people from accessing services. Many autistic people view autism as an identity and a difference, rather than a medical condition. point of a diagnostic assessment is not a diagnostic label. Anyone can self-label and many do. A label is technically not necessary under SEND rules nor under Equalities Act. So whilst labels are convenient, they are not the prime purpose of properly conducted diagnostic assessments. A number of our experts expressed the view that it should not therefore be necessary to have a diagnostic label to confirm an identity:

"I call myself an autistic person because I very much see that is part of my identity, as opposed necessarily being a medical label that is not fully part of you. It's part of me in the same way that as it would be to have a different sexuality, for example, or gender or race. " Jonathan Andrews.

They raised the point that, if you are autistic it should not be necessary to go through a medical process to be told you fit the criteria for autism:

"I think, diagnosis as a process is largely unhelpful. It's a rubber stamp. I mean, I know that some people want it because it confirms...it's proof that they are really autistic as compared to that they're imagining that they are autistic, but I would compare it myself to the fact that being gay used to be in the DSM and it's been removed because it's not a psychiatric condition. Nobody even thinks that autism to psychiatric condition, so why is it even in the DSM." Caroline Hearst

These experts agreed that the main benefit of the clinical diagnosis of autism is that it can provide access to support, but this should not be an essential criterion since services should be based on needs, rather than a diagnosis:

“There is a real focus in society on getting the diagnosis, whereas actually it is merely a professional identification, which is the only (usually) validated way of accessing services.” Jenn Layton Annable

Experts explained that the lengthy diagnostic process and the deficit view of autism is a barrier to many autistic people from seeking a diagnosis, therefore society should recognise alternative forms of confirmation of an autistic identity as being valid.

[3] Closely connect services across the lifespan and link them to the third sector

Experts told us that social care, medical, health, education (including university services), employment, citizens advice, and third sector organisations, such as those in the community that provide peer support, need to be better connected:

“I was just reflecting about how children and families are having to navigate these really different systems that we've set up for childhood. So there's that kind of early years system, everything to do with midwifery and your health visitors and maybe family hubs if you're lucky. And then you've got your SEND system in the education world, but then the local authority element of that, and then Children Social Care which is different again, but they might be dealing with short breaks. And then you've got the medical community paediatrics and your GPs – none of this is knitted together for the family and the family is having to do all of that joining up the system for them, unless you've got a really forward thinking local area that is getting it right, but in so many cases it's not.” Emily Frith

Diagnostic services do not always provide direct access to support services, meaning individuals or families must source relevant services on their own. Mental health services are particularly difficult to access due to current service pressures, with some autistic people reporting being excluded from services when professionals feel that their services are not suitable for an autistic profile.

During the children's evidence session, a particular focus was on the link between health services and Special Educational Needs (SEN) provision in school. Experts explained that diagnostic reports rarely make specific educational recommendations to support children at school because education representatives (e.g. Educational Psychologists) are not usually involved in the diagnostic assessments. This makes implementing relevant support in schools particularly difficult.

A higher level of collaboration among different services would ensure autistic people are put in contact with services who can help them when they require support. Greater collaboration could also make it easier to share knowledge and skills, resulting in higher

levels of autism awareness in different sectors. This knowledge-sharing could also support health professionals to make recommendations which have greater utility.

For example, experts told us that EHCPs do not always lead to improvements in educational support for young people with autism, which may be partly due to health and social care professionals not attending the EHCP reviews, to advise on changes to meet the individual's needs at school. Increased collaboration of health, education, and social care professionals would make it easier for educators to have a better wholistic understanding of how best to meet the needs of the children and young people in their care.

The importance of good collaboration between services is not a new concept and is recognised within the NICE guidelines for both children and adults. For adults NICE recommends establishing 'Specialist Autism Teams' - a multidisciplinary service responsible for co-ordinating and delivering care and support. However, currently only 18 such teams exist [27]. In Wales, the Welsh Government funds a National Autistic Team (NAT), which oversees the Integrated Autism Service (IAS), connecting Health Boards to Local Authorities with an aim to make it easier for individuals to access diagnostic and support services.

[4] Central point of contact facilitating an 'easy in, easy out' system for access support across the lifespan

Experts explained a need for creating a central point of contact that is available beyond the initial phase of the autism diagnostic process. The presence of a central community hub could help people after a diagnostic assessment in finding appropriate support in a timely manner, even when their needs change:

"What you need to access will be unique to you. If you want some employment advice support, they will link you with an employment person. If you want some educational support, they will link you with educational people. It's not that everything should be delivered through the hub, it's not that the hub is the end all and be all. But it's a single point of access and that continuity." Ian Davidson

The knowledge that this service is available could reduce stress and anxiety:

"You need a service that you are able to access at multiple time points with an easy in, easy out system. Knowing that you can come back at any time and that someone will be there to help reduces the anxiety and can mean that they don't actually need to actually use the service." Conor Davidson

Experts explained that support needs to be made available "at the point of awareness" (Caroline Hearst). Therefore, as soon as individuals become aware of their support needs, they must be able to find services to meet these needs. For this to happen, individuals need to be made aware of the range of services that are on offer, such as

Social Care, Occupational Therapy, and Speech and Language Therapy services, and those relating to education, employment, housing, benefits, the needs of the family, and end of life care.

Experts explained that individuals should also be able to access services which meet their interests, and these could exist in the third sector. These could include activities led by autistic people which encourage individuals to participate in their special interests and make meaningful contacts with people in their local community. Experts agreed that these ancillary services should be delivered based on need, not diagnosis. This would reduce stress for individuals and families as it would overcome the requirement to fight for access to support.

Experts also suggested that individuals or families be given resources at the beginning of the autism journey, even before entering a waiting list for a diagnostic assessment, which outline the support that is available and how to access these services. A short, informal conversation at the start of the process could also be used to identify the individual's interests, to connect them to activities in the local community which they may enjoy participating in. Individuals and families could then refer to these resources later when they need support. This could prevent autistic people from reaching a crisis point before they access services,

"Often autistic people are reaching these points of crisis because they their needs aren't being met, and that might be their sensory needs or their housing needs...." Gemma Williams

[5] Create access to peer support services for all

The importance of peer support was emphasised consistently throughout the evidence gathered. Evidence givers explained that peer support is needed to help autistic people to better understand their experiences, gain self-acceptance, and learn about coping strategies and reasonable adjustments.

Statutory services rarely provide peer support services and third sector peer support services are underfunded. Our experts explained that the outcome of an autism diagnostic assessment can result in a reframing of one's identity and support to explore this identity is crucial, but rarely provided by statutory services.

"The actual thing that the child needs is to meet other autistic kids and realise that there's nothing wrong with them. It's the world that's not designed for us at the moment." Emma Dalmayne

Non-autistic people working in statutory services tend to support autistic people, but they may not have a good understanding of the experiences of autistic people. Autistic people are rarely invited/paid to lead support programmes, but this should be built into services.

Experts explained that peer support is a powerful way for individuals who are diagnosed with autism or self-identify as autistic to make sense of their identity. By speaking with

others who have had similar experiences this facilitated gaining a positive view of autism, helping to identify their own needs, and to cope with the challenges that some autistic people experience, such as “shut down” and “meltdown”. Experts explained that peer support could improve their wellbeing:

“It’s little things like knowing that they care about me, hearing them say that they are struggling too but also what they are doing to cope. We can share our feelings and advice in a safe space full of honesty, kindness and support. Thanks to the participation team I’m making it through this when I didn’t think I could.” Quote from a young person given by Ambitious about Autism

Access to peer support services should be made available to everyone who enters autism diagnostic services and everyone who self-identifies as being autistic. Peer support should also be available to families. As Emma Dalmayne explains:

“I would recommend that anyone who thinks that they are autistic or that their child might be, to seek out autistic adults and seek out other parents to have a chat to about it because it’s very ostracizing. It’s very lonely.”

A diagnosis of autism can have a significant emotional impact on families who were previously unaware that their child is autistic. The presence of peer support can help families to make sense of autism, and to gain advice, for example to learn ways to help their children cope.

There are numerous examples around the country where peer-support groups are working well. For example, AutAngel, an autistic-led community interest company, runs peer support groups including structured courses where people can gain an understanding of autism and how specific aspects of autism impact them. There are also online peer support services, including Autistic Inclusive Meets and sessions hosted by the Scottish Women’s Autism Network.

One of the advantages of online peer support groups is that they have the potential to reach marginalised groups. For example, Autistic Inclusive Meets created an online initiative called Iggy’s Initiative, which specifically supports trans and LGBTQI young people and adults, who face barriers accessing services for autism. Peer support groups can also reach people who may be reluctant to access statutory services where autism is medicalised because this contributes to a social stigma.

Currently, access to peer-support is not guaranteed. Some statutory services link in with third sector organisations who provide peer-support, but a requirement to provide peer support services is not built into the diagnostic pathway for autism. Furthermore, peer-support groups might not exist in the local area, and those that do exist frequently rely on voluntary support and struggle to gain funding.

[6] Increase funding and accountability to ensure that change happens

Evidence givers highlighted that the lack of funding, together with increases in demand, has had serious implications on waiting times and service provision. Over time, such funding restrictions have resulted in a lower skilled workforce (e.g. autism 'screening' completed by 'early years assessors', rather than paediatricians), less early intervention, a lack of continuity in support services (due to short term funding), and a reliance on the ability to 'fight' for resources, which feeds inequalities.

Service provision is often decided at a local level and therefore is subject to different priorities and regional variations. This can create a 'postcode lottery' situation regarding the amount and quality of the support services available.

The value of autistic-led provision and peer support was consistently highlighted. However, statutory services are not required to deliver community or peer support sessions for those on the autistic pathway, therefore there is no accountability for services to meet the needs of autistic people relating to self-acceptance and participation in activities for their wellbeing.

There is also no accountability for (government-funded) organisations to support autistic-led organisations. Local authorities and Clinical Commissioning Groups (CCGs) are also not held accountable for providing the services that families need. Local authorities can choose which statutory services they wish to fund, and which they do not.

Experts stated that more funding is necessary to increase capacity for diagnostic and support services. Furthermore, there needs to be greater equality in the funding allocated to services supporting autistic people around the UK, to reduce regional differences in the quantity and quality of services.

It was also stated that central government should create a standard level of service for statutory services to provide, which could help in the process of holding statutory services accountable to meeting the needs of the autistic community. If this does not happen, the inequality in services delivered to autistic people around the UK is going to become worse, as illustrated by Ian Davidson:

"The patches [of high quality of service provision] are getting bigger and stronger, and I think what we have to do is stop telling people what bad looks like, because we know what bad looks like. We've got start telling people what good looks like and then asking them why they're not able to deliver good."

The Welsh Government explained:

"a responsibility to report on how autistic people are being supported in services will help drive improvements for people with autism, particularly if we embed into our regulatory approach the improvements for how we listen to people with lived experience and

their families and how we use this information in our monitoring, inspection and rating of services”.

With regards to support in schools It was highlighted that the onus of accountability should be placed on the Local Authority, with a need for better auditing, more rigorous inspections (e.g. with CCG and OFSTED), clear performance indicators and meaningful implications for poor performance.

“We need to put the onus for making this provision on the local authority and make the local authority accountable through the Audit Commission. If you don't have structures to monitor, evaluate and report, then local authorities...

Some will do absolutely nothing, some will do a little bit, and others will do a lot, so we will continue to have the post code lottery that we currently have. It's actually just saying: this is the process. A little bit like the education, health and care plans. They've got a time frame. You have to report on it and local authorities don't like it if they don't hit their performance indicators.

It's just generalizing that process to thinking about the diagnostic and the post diagnostic process. Not necessarily just for children with autism, but for all children... but certainly for this particular group, I think it's key.
Vivian Hill

Accountability for the support that should be given at a school level without an EHCP (SEN support) was noted to be of particular importance, especially as many parents are told that a diagnosis of autism does not necessarily require an EHCP for their child.

“It's that SEND support level in particular, before anyone needs to go down the route of an EHCP, that really needs to be [held to account]. We need better accountability for what local areas, schools, local authorities and CCG's have to do as part of that, I think.” Emily Frith

Ultimately, “if we don't make local authorities accountable and responsible, nothing's going to change and will be having this conversation every year for the next 20 years.” Vivian Hill

Appendix I: Detailed Recommendations

1. Needs-based assessment and support pathway

1a. Access to services should be needs-led, meaning individuals can access the services they require even without a diagnosis of autism.

1b. Statutory services need to be joined together and must link in with the third sector. Professionals within each service must share their knowledge with one another. This is particularly important for ensuring that recommendations within diagnostic reports translate to educational support for children and young people. Statutory services must link in with the third sector and make individuals entering their services aware of organisations that can support their wellbeing, such as peer support groups and special interests groups. The value of these services must also be fully recognised, meaning such services should receive adequate funding to sustain increasing demand.

1c. Make individuals and families aware of the ancillary services that exist, including Social Care, Occupational Therapy, and Speech and Language Therapy services, and those relating to education, employment, housing, benefits, the needs of the family, and end of life care, at the earliest point in the autism journey, before entering waiting lists for diagnostic services.

1d. Clinical guidance should be made which requires clinicians to record an individual's specific strengths and needs during the autism diagnostic assessment, to make clinicians accountable for creating diagnostic reports that have utility.

2. Single, accessible pathway

2a. Organisational points of contact should be made available to everyone who wants more information about accessing an autism diagnosis. Human contact is essential. The point of contact must be a person who understands the processes involved in autism diagnosis and the services that are available, who can be contacted at any stage before, during, or after the diagnostic process and who can facilitate informal verbal discussion and information giving, which goes further than providing leaflets or digital resources. The roll-out of community 'hubs' across the UK could facilitate this. A consistent name of 'hub' for such a facility should be agreed upon to make national guidelines clear.

2b. Guidance available through central NHS information resources about how to access a diagnostic assessment for autism should be reviewed in partnership with autistic people. A review of the terminology and language used will be needed, to ensure a balanced account of autism is given, with the view that autism is a lifelong difference. Wherever possible terminology should be consistent across the country.

3. Identity-based assessment and support

- 3a. Everyone on the autistic journey must have access to peer support services, and these services should be made aware to people before entering the diagnostic system.
- 3b. Statutory services should offer their own peer support services, or should financially support the third sector organisations that they are linked in with who provide peer support services.

4. Pre-diagnostic support

- 4a. Support services need to be accessible to everyone who identifies as autistic despite not yet having a diagnosis, if they are on a waiting list or if they do not wish to be diagnosed, and those who, against expectations, do not meet criteria for autism.

5. Fund and monitor:

- 5a. Current funding for autism diagnostic and support services needs to be reviewed to ensure equality and equity across the regions.
- 5b. Additional funding is required to increase the capacity of diagnostic and support services in order to reduce waiting lists.
- 5c. Longer term funding is needed to develop and maintain central contact points (e.g. community hubs) across the country, ensuring the continuity in service provision.
- 5d. The value of peer support groups needs to be taken seriously. A requirement to provide peer support should be built into the diagnostic pathway for autism. Also, where this type of support is provided by third sector organisations this should be funded accordingly.
- 5e. The next published statutory guidance for the national autism strategy (2021 to 2016) should be developed which requires local commissioners to provide a pathway of diagnosis that includes a universal minimum data set of pre and post diagnostic support that can be readily audited across different Local Authorities and NHS organisations, to ensure the same essential services are made available throughout the whole country.
- 5f. NHS England, the Department for Education and the Department for Social Care should provide clear advice to Local Authorities on the standards they must adhere to regarding meeting the needs of autistic children and young people.
- 5g. Local Authorities and NHS organisations should be made accountable through better auditing and data analytics (e.g. linking health and social care records), more rigorous inspections (e.g. with CQC and OFSTED), clear performance indicators and meaningful implications for poor performance.

5h. Schools, sixth form colleges, further education and higher education establishments need to be held accountable for the support that should be given (SEN support) without an EHCP.

5i. The same level of accountability is needed for Local Authority schools and academy trusts.

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