

Report highlights need for greater support for individuals awaiting autism diagnostic assessment

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[A new report](#) published today authored by leading autism experts and members of the autistic community argues that much greater support is

needed to help individuals and their families navigate the long and often complex process of receiving a diagnosis of autism.

The Westminster Commission on Autism, convened by Barry Sheerman MP which drew on evidence from the Centre for Applied Autism Research at the University of Bath, calls on government to improve [support](#) for individuals waiting for an [autism](#) diagnosis, and to listen to the voices of the autistic community in implementing its core recommendations.

Over the past decade, increased awareness and funding have led to significant improvements in the number of people accessing autism diagnostic services. However, demand is outstripping supply, resulting in long waiting times and limited resources to provide the support needed by [autistic people](#).

Three stages make up an autism diagnosis pathway:

- A pre-diagnosis phase, where an individual's differences are identified and discussed with professionals (such as clinicians or GPs, and / or for children with specialist teachers).
- A diagnosis phase, which involves an evaluation of whether the individual meets the diagnostic criteria for autism.
- Post-diagnosis, where additional support that is needed can be provided including at home, in schools or workplaces.

While there is considerable variation across different regions of the UK, currently, in the pre-diagnosis phase, the time it takes to reach a decision about whether an autism assessment is appropriate lasts an average of one year eight months for children and three years, six months for adults. Once a referral is made for an autism assessment, individuals wait a further 11 to 12 months for the assessment.

Drawing on evidence from 585 members of the autistic community, today's Westminster Commission report suggests that long waiting times are leading to stress and dissatisfaction for individuals and their families. The report reveals distinct challenges at all stages of diagnosis:

- Pre-assessment: 85% found the time awaiting a diagnosis to be stressful, and only 24% felt satisfied with the support available.
- During the assessment: 71% reported stress, but more people, 48%, felt supported.
- Post-assessment: 78% reported stress, and only 22% suggested they felt satisfied with support.

As parents of autistic children who were part of the Commission explained:

"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. My daughter has been through so much over the years, and basically wasted two 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."

The authors of the Westminster Commission on Autism report now call for consideration of how funding via third sector organizations can enable members of the autistic community to provide meaningful peer support to others who are seeking an autism diagnosis. The report also argues that improved information provision, via a single source of clear and accessible information, could help to avoid current challenges families face with piecemeal communications, or, at times, information overload.

Barry Sheerman MP, chair of the Westminster Commission on Autism, said: "After the Commission's two previous successful reports, I am

delighted for the Commission to release its third report on such an important subject. This report is an inquiry into support pre and post the autism diagnosis pathway, based on a survey of almost 600 members of the autism community. We are so grateful that this many people took part in the research, as autism policy and practice cannot work if it is not centered on autistic people's voices. Our report launch will mark the beginning of the Commission's work to highlight what we can and should do to get support right."

Professor Mark Brosnan, Director of the Centre for Applied Autism Research at the University of Bath, explained: "The investment in autism diagnostic services has reaped multiple benefits, but the survey from the autistic community shows that there is an ever-increasing demand being placed upon these resources. Until waiting times can be dramatically reduced, support is urgently needed for those waiting for a diagnostic assessment. The report also highlights the subsequent need for support after the assessment."

Lead researcher on the project, Dr. Ailsa Russell, added: "The same diagnostic assessment pathway may not be optimal for all. It is possible that for some adults with fewer support needs who are seeking a diagnostic assessment, a peer-based, information with support service might be enormously helpful, allowing individuals to form their own decisions about the usefulness of an autism diagnostic assessment, and enabling those with higher support needs to access NHS services more rapidly."

With the publication of their report today, the report is calling for the recommendations to be incorporated into the recently-published Statutory Guidance for Local Authorities and NHS organizations around the national strategy for autistic children, young people, and adults (2021–2026).

The research undertaken for this report was funded by the John and Lorna Wing Foundation, a charitable foundation which funds research into all aspects of autism and ensures the results are published. Funding was also provided by Professor Michael Lewis MBE, of Riverston International, for a print run of the report.

The report estimates that there are 1.2 million autistic people in the UK. Around 66,000 people are diagnosed each year. For young people, autism assessments typically involve specialists observing their development and undertaking language, play and communication assessments, whilst for adults it typically involves a clinical consultation and [assessment](#).

More information: Support Surrounding Diagnosis: An Inquiry into Pre- and Post Support for the Autism Diagnosis Pathway.
www.bath.ac.uk/publications/re...unding-diagnosis.pdf

Provided by University of Bath

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