

Initial Study Results Summary

Getting an autism spectrum disorder diagnosis in adulthood, and the support or services received afterwards

The aims of this study were to identify ways to support the development of diagnostic pathways for people who may have an autism spectrum diagnosis in adulthood. We did this by (1) surveying people who have received a recent autism spectrum diagnosis as an adult, and relatives of adults, about the experience of the diagnostic process and (2) surveying clinicians in the UK National Health Service (NHS) about current services provided, the methods used in diagnosis, and their views on where there are gaps in services.

We started the surveys in early 2018; we had a fantastic response and are very grateful to everyone who took part. Below is a brief summary about the people who took part, and some of the information people gave us (much more detail will be available later in 2018).

The study is the largest ever undertaken in the UK. People from across the UK took part, giving us good geographical coverage. Half of the participants were women, and half were men. People from age 18 to 89 years took part; the average age was 42 years.

We found some people waited a long time for an assessment. Many people stated they wanted the diagnostic process to be '*shorter*'. Some people had found the assessment process difficult '*I didn't know what would happen*'. Others reported the diagnostic assessment had gone well for them '*the information I received in advance of the appointment was very helpful. It explained what would happen on the day and gave detailed instructions*'. One improvement suggested was that there should be '*much clearer information about the process - what questions to expect and how the diagnosis would be made*'.

People generally thought getting an autism diagnosis had been beneficial to them – for example one woman said '*it helped with self-acceptance and depression*'. However, not everyone was positive – some people said they had been '*excluded from getting services by having an autism diagnosis*.' Most people received a report after their diagnosis. However some people did not receive an adequate information pack or have the opportunity to discuss the impact of the diagnosis after their assessment.

Many people were concerned that there had been little support available following diagnosis. Participants also identified types of support that they thought would be useful - for example how to explain about their autism spectrum diagnosis to family, friends and employers and how to ask for reasonable adjustments at work. In addition people wanted support with how to cope with sensory issues, and autistic traits that may fluctuate over time. Some people were keen to connect with other people with an autism spectrum diagnosis. We hope the findings from this study will provide clinicians, NHS policymakers and service commissioners with evidence based information about:

- How NHS autism diagnostic services for adults should be improved
- The types of support that people diagnosed with autism during adulthood and their relatives wish to receive during and after diagnosis.
- The ways in which clinicians working in diagnostic pathways might best be supported in the context of limited NHS resources.

In a separate study, we also reviewed and published a summary of research evidence for the use of diagnostic tools as part of the diagnostic assessment. This built on findings from the NICE guideline for Autism in Adults (National Institute for Health and Care Excellence [Clinical Guideline 142]). We found that the diagnostic tools and particularly questionnaires being used may have many limitations in some settings. The review can be accessed via the following links: <https://doi.org/10.1177/1362361317748245> and <https://eprint.ncl.ac.uk/243274> (this is our Newcastle University open access manuscript version, so you can read the findings free of charge).

Next Steps

- We will complete analysis of the information given to us, and create a report describing the findings
- We will discuss the findings with NHS professionals, policymakers and commissioners of services, and people on the autism spectrum so they can improve clinical services

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