

Autistica Action Briefing: Adult Diagnosis Process

AUTISTICA

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about the adult diagnostic process. It was developed in collaboration with leading researchers and autistic people with experience of adult diagnosis as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. There is growing evidence around how to effectively diagnose autistic adults, but to make further progress, the unwarranted national variation between diagnostic pathways must be tackled.

www.autistica.org.uk/AutismStrategy

“The doctor dropped the bombshell that I ‘clearly have autistic traits’ but she could not give me a diagnosis because they needed ‘parental input’. She knew my parents were dead but had dragged me through a second appointment – I am 60 years old.”¹

What we know

“My diagnosis has been one of the best things ever to have happened in my life – liberating in so many ways and I am truly grateful.”

- **The process and service configuration for diagnosing autistic adults varies widely across the country.** Where services are available, they collect different information ahead of assessment, use different diagnostic tools, involve different groups of health professionals, and ultimately diagnose very different numbers of autistic adults.^{2,3,4}
- **Evidence for the effectiveness of existing diagnostic tools and screening measures in adults has been limited in the past,^{5,6} but an evidence base is beginning to emerge.^{7,8}** Some autistic adults report being assessed with tools designed for children which they found inappropriate.¹ Services should be flexible about who acts as an informant in the assessment of adults; insistence on parent-informants can lock out those whose parents are estranged or deceased.^{1,9}
- **Existing diagnostic tools can be ineffective in distinguishing autism from mental health conditions, sometimes resulting in misdiagnosis.^{6,9,10}** This is particularly problematic for the 8 in 10 autistic adults who experience co-occurring mental health problems,¹¹ as mental health difficulties are a leading reason for adults to seek an autism assessment.^{3,12,13}
- **There is growing consensus between clinicians and autistic adults around aspects of the diagnostic process that should change,** such as the need for expertise in mental health conditions and more effective standardised diagnostic tools.³ This creates an opportunity to build on best practice and develop more consistent pathways. Autistica are funding a programme of research at Newcastle University to improve adult diagnosis;¹⁴ two recent workshops stimulated discussion amongst autistic people, clinicians and policymakers and led to a list of consensus statements that could be implemented now.³

What we need to find out

Adult diagnosis is one of the **top research priorities of the autism community,¹⁵** yet up until now **little autism research has focused on it.^{16,17,18}** We know that in some areas, adults are having a positive experience of the diagnostic process.³ To ensure that this becomes the norm, we need to find out:

- How do rates of autism diagnosis in adults vary nationwide? Which autism diagnostic tools and screening processes are currently used in areas with different rates of diagnosis?
- Which diagnostic models are considered best practice with respect to cost-effectiveness and accuracy? Is there sufficient capacity to manage NHS referrals in all areas of the country?
- How do rates of diagnosis vary across different combinations of professionals used to diagnose autism in adults across the UK? Is there an optimal group of professionals for adult autism diagnosis?

“Diagnosis has been life-changing. I know where I fit, and why I don’t fit where I don’t. I’ve developed strong positive views about neurodiversity. It would be good if medics could understand how adult diagnosis can be so valuable.”¹

- What are the risks of further harm and distress being caused for adults throughout the autism diagnosis process? What are the benefits of the diagnostic process as an autistic adult? How can we ensure that the diagnostic process is a positive and constructive experience relevant to the current needs of the person?
- What diagnostic tools, or what adaptations to diagnostic tools, are effective in identifying autism in the presence of co-occurring mental health conditions? How can clinicians effectively screen for mental health conditions in the diagnostic pathway for autism?
- What is the clinical and cost-effectiveness of the various new adult diagnosis tools currently in development?^{7,8}

What we should do now

“My assessment was three hours and the report was cursory. Adults in different areas are assessed for longer. Could there be some standardisation across the UK?”¹

- While child diagnosis pathways are often poorly implemented in practice, for adults these pathways are often seriously underdeveloped, underfunded or non-existent. However, adult diagnosis is not mentioned in the NHS Long Term Plan¹⁹ despite autism being included as a clinical priority.²⁰

To reduce health inequalities, the NHS Long Term Plan workstream on autism should prioritise action to tackle unwarranted variation in processes and outcomes between diagnostic pathways.

- It is often unclear which services are commissioned to diagnose autistic adults with a learning disability, autistic adults without a learning disability and autistic adults (of either group) within local mental health services.

Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) should be able to demonstrate to NHS England that their commissioning arrangements explicitly resource appropriate services for each of these separate groups. Those arrangements should specify the responsibility of local Community Learning Disability Teams in diagnosing each group.

- Most adult autism diagnostic teams work in relative isolation. Establishing networks to help teams share information and compare approaches to complex cases (vignettes) could help reduce some variations in diagnostic approaches.

NHS England should work with the Royal College of Psychiatrists and other professional bodies to map and supplement existing networks on adult autism diagnosis across each region and relevant specialism. This must accompany, not replace, action at a national level to improve adult autism diagnosis.

- Changes to the Mental Health Services Data Set (MHSDS) last April means that more reliable statistics on autism diagnosis in NHS services can begin to be published from 2019.^{21,22} As it becomes more complete this dataset could help identify unwarranted variation in diagnostic rates and waiting times across the NHS.

NHS Digital should publish an annual analysis of the rates of autism diagnosis amongst adults, the rates of referral for autism diagnosis and the referral-to-assessment times recorded in the MHSDS. Where appropriate, figures should be published by age, gender, ethnicity, geographical location and commissioning area (including STP and ICS boundaries).

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