

Autistica Action Briefing: Access to Adult Diagnosis

AUTISTICA

Harper G, Smith E, Parr J, Wigham S, Douglas S, Stacey R, Ensum I, White M.

May 2019

Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about access to adult diagnosis. It was developed in collaboration with leading researchers and autistic people with experience of diagnosis in adulthood 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. Hundreds of thousands of autistic adults in the UK do not have a recorded diagnosis. This can cause serious challenges for those people and for the NHS. Public policy needs to ensure autistic adults can access recognition and support when they need it.

www.autistica.org.uk/AutismStrategy

"I was able to make so many improvements to my life after I understood I was autistic. I could have made them earlier and saved so much pain, time and money. Most of my mental health problems have been resolved now I have a better understanding of myself as an autistic person and had therapy which understood this." ¹

What we know

"I was unable to work, barely eating, and had recently cut myself again. Doctors told me I couldn't be autistic because I could speak and was 'high functioning'. I did not fit the image in their heads." ¹

- **Most autistic people are adults,² but most autistic adults are not diagnosed.**^{3,4,5,6} Receiving a diagnosis of autism can provide long-awaited answers and insight into a person's strengths and difficulties, enabling them and others to make adjustments to improve their well-being.^{7,8,9,10}
- Relatively few autistic adults are diagnosed, especially those in older age, because they largely grew up in a time when autism was rarely recognised. However, **adults seeking an autism diagnosis today continue to face a wide range of barriers to assessment**, including difficulties getting a referral to diagnosis services, inconsistent pathways, lengthy waiting times and a lack of information during the process.^{1,9,11,12,13,14,15}
- **Between two thirds and three quarters of adults wait longer than the recommended 12 weeks in NICE guidelines¹⁶ for an assessment, with one third waiting longer than 18 months.**¹¹ One study found that autistic adults wait an average of two years after first seeking professional help to receive an autism diagnosis.⁹ Another indicates that waiting times are still rising.¹¹ Although there is some evidence to suggest that adjustments to the referral and diagnosis process can reduce waiting times,¹⁷ efficiency savings alone will not enable diagnostic services to cope with rising demand.
- **Not every part of the country has a pathway for diagnosing autistic adults.** NHS.uk recognises that "*not all areas have a specialist autism assessment centre*" for adults¹⁸ and referral routes in over 4 in 10 local authorities are unclear or out of area, with some authorities having no pathway for diagnosing adults at all.¹⁹
- **People with co-occurring mental health conditions find it even harder to access diagnostic assessments for autism,** waiting longer on average to receive a diagnosis.^{11,20} This is a particular problem because almost 8 in 10 autistic adults will experience mental health problems,²¹ which are a leading reason for someone to seek an autism assessment.^{9,22}

"I could not get assessed by local autism services because being a mental health patient left me ineligible for assessment – mental health services were supposed to do it. But nobody had any knowledge about autism within this service"

What we need to find out

"I have a long history of mental health issues (including inpatient psychiatric care for an eating disorder). Not one professional suggested that I could be autistic." ¹

Adult diagnosis is a **top research priority for the autism community,**²³ yet historically **very little autism research has focused on adults,**^{24,25} with older adults being particularly excluded from research.²⁶ We know that autism diagnosis can bring a sense of relief and understanding^{1,9} and that many autistic adults have a positive experience of the diagnosis process.¹¹ To ensure that this is accessible to all autistic adults, we need to find out:

- Which service models for diagnosing autism in adults are most effective and sustainable? How does the variation in service models nationwide affect access to diagnosis?
- How can we improve the identification of autistic adults within mental health services and the criminal justice system?²⁷

- Do health professionals in primary and secondary care have the confidence and knowledge to identify potential autistic traits and make appropriate referrals?
- What are the most effective ways to support adults waiting for a diagnostic assessment, including mental health support? What is the most appropriate way to manage self-referrals?
- How can diagnostic teams sustainably support professionals in their local health, education, welfare or criminal justice systems to recognise when someone might be autistic and could benefit from a diagnostic assessment?
- How can we develop public health initiatives around autism diagnosis to reach under-represented groups?

What we should do now

“Waiting times for diagnosis are extremely lengthy. Almost makes you give up at the start. It is not clearly signposted, so difficult to even start the process.”¹

- Every English Autism Strategy has committed to improving diagnosis for autistic adults.^{28,29} In reality, funding and support for the specialist services needed to deliver adult diagnosis has fallen far short of these ambitions and of increasing demand.

The next Autism Strategy should explicitly commit to increasing the availability of specialist autism diagnostic services for adults.³⁰ The Department of Health and Social Care and NHS England should work closely to ensure that Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICs) recognise that commissioning effective adult diagnosis pathways is essential for tackling health inequalities and reducing inappropriate service use.

- The NHS Long Term Plan did not mention the challenges adults face in seeking an autism diagnosis,³¹ despite including autism amongst its key clinical priorities.³² Most autistic people are adults but most autistic adults are undiagnosed; increasing the number of diagnosed adults would be a significant step in tackling health inequalities.³³

The NHS Long Term Plan workstream on autism should prioritise action to identify optimal pathways for diagnosing autism in adulthood and address geographical disparities in access.

- Changes to the Mental Health Services Data Set (MHSDS) last April means that more reliable data is becoming available about autistic adults’ interactions with NHS services.^{34,35} This could help provide valuable insight into making diagnosis pathways more effective and efficient.

NHS Digital, NHS England and National Institute for Health Research should meet with the Department of Health’s autism data group to discuss commissioning an analysis using the MHSDS and other public datasets into the patterns of service use amongst adults who later receive an autism diagnosis.

- Rising demand can mean that people who seek an autism assessment are left on waiting lists for years without support or an estimate of when they will be seen.¹⁵

STPs and ICs should know whether local diagnostic services are resourced to provide adults on waiting lists with regular updates regarding their position and any support available.

1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018. 2 Knapp M, et al. (2007) The economic consequences of Autism in the UK. Foundation for People with Learning Disabilities. <[bit.ly/2ZHVu1Z](#)> 3 Brugha T, et al. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. Arch Gen Psychiatry.68(5), 459-65. <[ncbi.nlm.nih.gov/pubmed/21536975](#)> 4 Brugha T, et al. (2016). Epidemiology of autism in adults across age groups and ability levels. Br J Psychiatry 209(6),498-503. <[ncbi.nlm.nih.gov/pubmed/27388569](#)> 5 Public Health England (2019). Psychotropic drugs and people with learning disabilities or autism: results. <[bit.ly/2Uti4GY](#)> 6 Public Health England (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. <[bit.ly/2Fdklh9](#)> 7 Powell T and Acker L (2015) Adults’ Experience of an Asperger Syndrome Diagnosis: Analysis of Its Emotional Meaning and Effect on Participants’ Lives. Focus on Autism and Other Developmental Disabilities 31(1), 72-80. <[journals.sagepub.com/doi/abs/10.1177/1088357615588516](#)> 8 Baron-Cohen S (2017). Editorial Perspective: Neurodiversity – a revolutionary concept for autism and psychiatry. Journal of Child Psychology and Psychiatry 58(6), 744-747. <[bit.ly/2IME2zx](#)> 9 Jones L, et al. (2014) Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. J Autism Dev Disord 44(12), 3033-3044. <[bit.ly/2W7eC2t](#)> 10 National Autistic Taskforce (2019). An independent guide to quality care for autistic people. <[nationalautisticstaskforce.org.uk/an-independent-guide-to-quality-care-for-autistic-people/](#)> 11 Wigham S, et al (manuscript in preparation). Improving diagnostic and post diagnostic services for autistic adults. Evidence from autistic people, relatives and UK diagnostic teams. <[autistica.org.uk/our-research/research-projects/better-diagnosis-of-autism-in-adults](#)> 12 Rutherford M, et al. (2016) Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children. Research in Autism Spectrum Disorders 31, 53-65 <[sciencedirect.com/science/article/pii/S1750946716300733](#)> 13 McKenzie K, et al. (2015) Factors influencing waiting times for diagnosis of autism spectrum disorder in children and adults. Res Dev Disabil 45-46, 300-306. <[ncbi.nlm.nih.gov/pubmed/26280693](#)> 14 Rogers CL, et al. (2016) Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom. Autism 20(7), 820-31. <[bit.ly/2FRpPOM](#)> 15 Crane L, et al. (2019) Understanding psychiatrists’ knowledge, attitudes and experiences in identifying and supporting their patients on the autism spectrum: online survey. BJPsych Open 5, e33, 1-8. <[bit.ly/2UJhMfr](#)> 16 NICE Clinical Guideline [CG142] Autism spectrum disorder in adults: diagnosis and management. <[nice.org.uk/guidance/cg142/chapter/1-Guidance](#)> 17 Rutherford M, et al. (2018) Implementation of a Practice Development Model to Reduce the Wait for Autism Spectrum Diagnosis in Adults. J Autism Dev Disord 48(8), 2677-2691. <[ncbi.nlm.nih.gov/pmc/articles/PMC6061014/](#)> 18 NHS Health A-Z: Autistic adults. Page last updated 2019. <[nhs.uk/conditions/autism/adults/](#)> Found on 29/04/2019. 19 Public Health England (2017). Autism Self-Assessment Exercise 2016: Detailed report and thematic analyses. <[bit.ly/2Thsp8s](#)> 20 Ashwood KL, et al. (2016) Predicting the diagnosis of autism in adults using the Autism-Spectrum Quotient (AQ) questionnaire. Psychological Medicine 46(12), 2595-2604. <[ncbi.nlm.nih.gov/pmc/articles/PMC4988267/](#)> 21 Lever A & Geurts H (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. J Autism Dev Disord 46(6), 1916-1930. <[ncbi.nlm.nih.gov/pmc/articles/PMC4860203/](#)> 22 Geurts H and Jansen M (2012). A retrospective chart study: the pathway to a diagnosis for adults referred for ASD assessment. Autism 16(3), 299-305. <[ncbi.nlm.nih.gov/pubmed/21949003](#)> 23 Autistica (2016). Your questions: shaping future autism research. Available: <[autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf](#)> 24 Murphy CM, et al. (2016) Autism spectrum disorder in adults: diagnosis, management, and health services development. Neuropsychiatric disease and treatment. 12, 1669. <[ncbi.nlm.nih.gov/pmc/articles/PMC4940003/](#)> 25 Pellicano E, et al. (2013) A future made together: Shaping autism research in the UK. London: Institute of Education. <[issuu.com/crae.ioe/docs/a_future_made_together_ioe_pdf](#)> 26 Autistica (2019). A review of the autism research funding landscape in the United Kingdom. <[autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf](#)> 27 Tromans S, et al. (2018). The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review. Clin Pract Epidemiol Ment Health 14, 177-187 <[ncbi.nlm.nih.gov/pubmed/30197663](#)> 28 DHSC (2015). ‘Think Autism’: an update to the government adult autism strategy. <[bit.ly/1eef55P](#)> 29 DH (2010). ‘Fulfilling and rewarding lives’ The strategy for adults with autism in England (2010). <[bit.ly/2USWwOG](#)> 30 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <[bit.ly/2RPoolZ](#)> 31 NHS (2019). The NHS Long Term Plan. <[longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf](#)> 32 Dunhill L (2018) Learning disabilities and autism added to long-term plan clinical priorities. Health Service Journal. <[bit.ly/2WHtHYf](#)> 33 Autistica (2018). Global Summit on Autism throughout the Lifespan: Physical Health & Wellbeing. <[autistica.org.uk/downloads/files/Ageing-Summit-Report.pdf](#)> 34 Hansard (2017). Minister of State for Health responding to a debate on autism diagnosis, 13th September 2017. <[bit.ly/2GtUNn](#)> 35 Minister of State for Care (2019). Written Answer to Parliamentary Question 208401. <[bit.ly/2SrsUx9](#)>