



Health and Adult Social Care Select Committee – 5th March 2024

AUTISM SERVICES COMMISSIONING FOR ADULTS

Local Context

In Hampshire there are just over 3,000 adults waiting for an assessment for Autism Spectrum Condition. Demand for services has increased by more than 300% since 2019 which places significant pressure on services to maintain waiting times. Due to recruitment challenges across the NHS nationally, the capacity we have in place within the NHS does not meet the level of demand. To mitigate this, additional non-NHS trust organisations have been commissioned to respond to waiting list initiatives. However demand continues to significantly outstrip funded provider capacity with average waiting times in Hampshire exceeding 2.5 years.

- Latest reports from Hampshire Autism assessment providers indicate circa 72% positive diagnostic rates for children in Hampshire and 60% for adults.
- Hampshire figures indicate 0.94% prevalence rate for the total registered population which is slightly under the estimated UK prevalence rate of just over 1%. However it is important to note that these figures do not include those who are undiagnosed.

National context

Nationally, regionally, and locally Autism Spectrum Condition (Autism) assessment and support services face significant capacity issues due to large waiting lists. Even before the Covid-19 pandemic, long waiting times for ADHD and ASC assessments were widely reported and acknowledged within the *NHS Long Term Plan* and *The national strategy for Autistic children, young people, and adults: 2021 to 2026*.

158,000 people were waiting for an autism assessment in England in December 2023 (National Autistic Society). Too many people are still waiting longer than 13 weeks between referral and first assessment as recommended by the National Institute for Health and Care Excellence (NICE).

Autistic people are at significantly greater risk of experiencing health inequalities than the neuro-typical population. They are more likely to experience major illnesses, including poor mental health and/or other co-morbid physical health conditions, face shorter healthy life expectancy and die earlier - average 16 years earlier than the general population. Autistic adults who do not have a learning disability are nine times more likely to die from suicide and Autistic children are 28 times more likely to think about or attempt suicide.

Patient Feedback

The Hampshire and Isle of Wight Integrated Care Board has worked closely with Hampshire County Council to develop the Hampshire Autism Strategy. As part of the strategy build, feedback was gathered from residents regarding their experiences of the current Autism assessment services and support pathways.

Key support needed for Autistic adults:

- Access to self-referrals for assessments and better focus on early, simple diagnosis processes.
- Less online and more face-to-face support required by Autistic people which has been even more difficult to access since the COVID pandemic.
- Ongoing and appropriate mental health support.
- Follow up sessions post assessment.

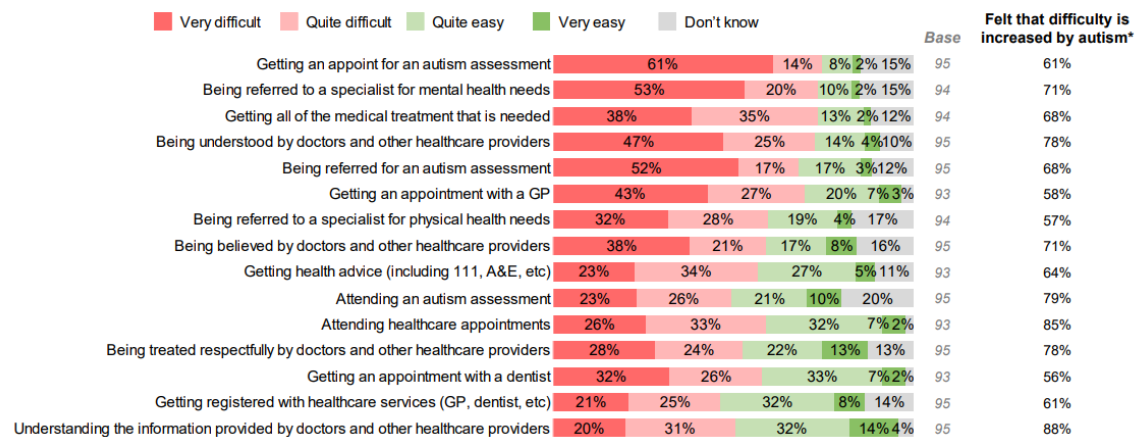
For Autistic adult respondents, the most important benefits of autism assessments given were to access support at work (74%), to confirm autism for a person they know (66%), and to protect them from discrimination (62%).

For those that had an autism assessment, 88% found them useful for the person being assessed, increasing to 93% of Autistic respondents which demonstrates there is a positive impact from receiving a diagnosis.

The process of access to assessments, however, was seen as 'quite or very difficult' by 78% of Autistic respondents. It was positive to see that 86% (89% for Autistic respondents) felt the assessments were of a good quality and similar figures around the level of detail within the assessment but clear there is more to be done to ensure access is not a barrier to assessment.

Health-related activities – While the most difficult activities were seen to be getting an appointment for an autism assessment or a mental health referral, autism was said to have the most impact on people's ability to understand information provided to them and attend healthcare appointments

How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



Patient Feedback

Better support for mental health

"The length of time of getting an assessment causes anxiety in itself and not knowing when the appointment will be"

"Autistic people, especially those classed as "high functioning" often mask their discomfort and difficulties in order to "pass" as neurotypical. this leads to internalised feelings of being an outcast/wrong/inadequate which often leads to cripplingly low self-esteem and high risks of self-harm and suicide"

Shorter waiting times

"I have been waiting for a CAMHS assessment for mental health (linked to autism) and have waited 9 months so far with no expected appointment date"

"Increase the number of autism assessments to reduce the waiting time from being referred to being assessed"

"The waiting list for an autism assessment appointment is on average two years. Due to the pandemic I waited almost five"

Better trained staff to deal with autism

"Doctors should have more autism awareness and more understanding when we struggle to communicate"

"NHS staff have little understanding of the complexity of severe autism. They regularly expect me to restrain my son so they can examine him etc which is distressing"

"Training on how to explain medical terms to autistic people"

More empathy or understanding from service providers

"I sometimes find the language used can be quite derogatory"

"Many doctors and dentists are very kind to me. But before I was diagnosed with autism, i was referred to psychiatrists who had a poor understanding of autism: when I spoke of my suspicion that I could be autistic, he rapidly replied that it's not possible because I don't flap my hands!"

Greater focus of the importance of autism assessments

"Diagnoses is key to help and support a person who has autism"

"Assessment definitely means the school gives more support"

"We are...finding the money to try and get [my daughter] a private diagnosis in order for her to get the understanding and support she needs to get through secondary [school]"

Greater availability of, or access to, services

"Please increase the number of NHS dentists. Many autistic people rely on NHS healthcare and do not have dentists as there are no NHS dentists taking new patients"

"The individuals i work with really struggle to be heard and to get any support from health as services are so stretched"

"[There should be] doctors and other specialists who are specifically ring fenced for the care of the autistic."



Transformation Plan and Next Steps

To address the challenges outlined above, we will be establishing a new, co-designed, all age transformed pathway model to meet ongoing demand for ADHD and Autism Spectrum condition. The model will be needs led, inclusive and will offer support, assessment, and guidance as appropriate as well as meet aspirations of the national and South-East Region Autism Strategy.

We want to ensure that we involve all stakeholders in the improvement journey including people with lived experience. While waiting times are unlikely to significantly reduce in the short term we will endeavour to make changes as quickly as possible. The transformation and procurement of an end to end pathway which meets the needs of a very complex cohort of patients will take time to complete and as workstreams develop, patients should benefit from incremental improvement, cumulating in a fully redesigned service from 2026.

Workstream 1: Transformed Service Model – Maintain provision and patient safety		
Actions	Progress	
Stablise current contract arrangements to ensure no gaps in service	Services successfully procured. The Owl Centre will deliver Autism Assessment services from 1st April 2024 for adults living in Hampshire.	
Secure funding for short term capacity to clear or reduce current waiting lists	Funding identified to support 445 additional autism assessments for 18-25 year olds.	
Using the opportunity of a new NHS Fusion organisation, review the assessment pathway and identify opportunities to streamline, define proportionality and anchor to pre and post diagnostic pathways.	An all age Autism and ADHD Improvement Group has been set up to oversee transformation. Subgroups are: <ul style="list-style-type: none"> • Clinical Reference Group • Children’s Group • Adults Group • Transition Group 	
Facilitate the smooth delivery of triage, assessment, diagnosis and prescribing services as well as signposting/referrals onto other services	Clinical Reference Group leading on a pathway review	
Ensure reassuring and safe transition/discharge	Clinical Reference Group leading on a pathway review	
Provide the infrastructure required to maintain safe and equitable shared care which match national policy and are agreed with Primary Care	ICB Shared Care Policy due to be launched 1 st April 2024	
Workstream 2: Transformed Service Model - Future Proof Services		
Actions	Progress	
Collate and maintain data sets to build a true, dynamic understanding of demand across the ICS	Performance Dashboard in development. To be launched 1st April 2024. The dashboard will be used to inform internal and external reporting requests to promote systematic awareness	
Using the opportunity of a new Fusion provider, assess the harm and costs of waiting to individuals and system to anchor change	Clinical Reference Group leading on a pathway review	

Design a long-term assessment offer that fully meets current and projected demand and which is response and proportionate to need	Clinical Reference Group leading on a pathway review	
Map the end-to-end pathway (early intervention to crisis) to identify areas of good practice, gaps, and areas of risk	Clinical Reference Group leading on a pathway review	
Codesign support services which meet need and offer evidence-based intervention at the right time - non diagnosis reliant	People with Lived Experience are listed as equal attendees for the oversight group and subgroups	
Workstream 3: Transformed Service Model - System Dependencies (Multi-agency)		
Actions	Progress	
Understand and implement change alongside those people with lived experience as Subject Matter Experts	People with lived experience and experts by experience have roles on our oversight groups and leading on our do-design work	
Enable access to innovative models of needs-led and accessible support / alternative pathways for individuals across every stage of need, including evidence-based psycho-social interventions	Clinical Reference Group leading on a pathway review	
Identify and remove barriers to support and services which are historically reliant on a diagnosis to access support across the health, education and social care system	All Age Autism and ADHD Improvement Group includes system wide partners and agencies	
Develop collaborative partnerships (example strategies) for action on local systemic change, to ensure consistency across the ICS	All Ages Autism and ADHD Improvement Group includes system wide partners and agencies	