

# Autism Assessment in the UK: Closing the Gap

A Policy Contribution from the Autism Alliance



**The UK has a crisis in autism assessment. In England, as of March 2023 over 157,000 people of all ages were waiting for an assessment, of which 84% have waited longer than the 13 weeks recommended by NICE<sup>1</sup>. The number of people awaiting assessment in Scotland, Northern Ireland and Wales is also high; and at their longest, waits for assessment can stretch into years.**

This can have a devastating effect on families, and on the life chances of autistic people. Autistic people experience some of the greatest inequalities of any group, with poorer outcomes across education, health, employment and justice<sup>1</sup>, and being unable to secure a diagnosis can prevent access to a wide range of crucial adaptations and services that allow autistic people to live happier, healthier, longer lives.

Demand for assessment has grown exponentially, with the number of people diagnosed as autistic increasing by 787% between 1998 and 2018<sup>3</sup>.



This is partly due to improvements in the assessment process, but also due to increased awareness of autism across society. Awareness is now almost universal, partly supported by greater visibility of autism in the media. Alongside this, recent estimates of autism prevalence based on data from 2018 suggest that as well as the 463,500 people in England who have had an autism diagnosis, between 435,700 and 1,197,300 people may be autistic and undiagnosed<sup>4</sup>; and the proportion of older people, who are less likely to seek assessment but are deciding to be assessed, is also increasing. Against this backdrop, it is vital that the autism assessment process can meet demand, both now and in the future.

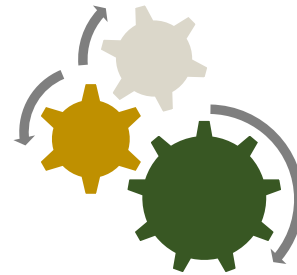


As well as an overriding social case to meet demand for autism assessment, there is a **significant economic case**. An autism diagnosis means that the system of education, health, and care should work more efficiently to meet an individual's needs, because those needs are known, and clinically diagnosed. Failing to meet autistic people's needs for help and support not only holds back lives, but increases cost, whether in education, health or social care. The total cost associated with autism across the UK economy has been estimated at £32 billion<sup>5</sup>.

Alongside action to close the gap in assessment, there is also a strong case for greater investment in **pre- and post-diagnostic services** for children, young people and adults, and their families. Evidence shows beneficial effects of this support on parental stress levels and children's participation in daily life<sup>6</sup>; and evaluation of post-diagnostic support has shown a range of positive impacts for autistic adults, particularly in mental health, self-confidence, reduced social isolation and better quality of life<sup>7</sup>. However, access to this support for families varies widely, and many families and individuals do not get the support they need<sup>8</sup>. It is vital that there is access to such services on a mainstream basis.

In April 2023 NHS England published a **National Framework and Operational Guidance** for all age autism assessment<sup>9</sup>, supporting Integrated Care Systems as they commission assessment services. This is welcome and important guidance, and should support higher quality and greater consistency of approach. But it is clear that capacity in the system is far outstripped by current demand<sup>10</sup>, which shows no signs of slowing. National and local gaps in the health workforce<sup>11</sup>, the result of years of austerity, have left the assessment system unable to cope, and the degree of variance in local healthcare budgets and design of assessment systems means that too often there can be a postcode lottery in access to assessment, in waiting times, and in the quality of the assessment process.

We can meet demand for assessment by increasing capacity and efficiency



Enabling the autism assessment system in the UK to meet demand can be achieved in two ways: by increasing the **capacity** of the system, or by increasing system **efficiency**. These are not mutually exclusive, and can be taken forward together.

Increasing the capacity of the system means employing more clinical specialists. This could be achieved by training new specialists, or redeploying existing specialists to the assessment pathway. The former approach has a significant lead-in time, and the latter approach would have a significant opportunity cost in services to patients across the NHS. On balance, an accelerated training programme to boost the assessment workforce would be the most advisable option. Better workforce planning is vital. For example, NHS England is carrying out a workforce mapping and planning exercise which will help Integrated Care Systems develop their own plans for the specialist workforce delivering assessment, and this should be the basis for a national approach to capacity building informed by known and expected demand for autism assessment services.

Alongside access to pre- and post-diagnostic support for families and individuals, a more efficient assessment system can be achieved through:

- ✓ **A better distribution of clinical specialists** across the assessment pathway, so that wasted time and bottlenecks are minimised - for example, grouping psychologists together to consider batches of cases.
- ✓ **A more consistent implementation of the assessment pathway** across local health and care systems, aiding performance management and providing a stronger platform for sharing best practice to improve performance.
- ✓ **A more co-ordinated model of planning and delivering assessments** at a national level, making use of economies of scale and the opportunities to move resource around to meet geographical spikes in demand.
- ✓ **More use of appropriate technology in the assessment process**, subject to rigorous research on effectiveness and quality: including AI tools to aid screening, and digitisation of the pathway process to reduce the time taken to complete an assessment.

Increased awareness of autism will naturally lead to more questions from parents/carers about diagnosis, and inevitably some less reliable, and potentially harmful information will be shared. In this context, it is also important to ensure that there is sufficient, accurate, evidence-based information available and accessible to families at the earliest opportunity, including as part of pre-diagnostic support, so they are able to make more informed choices.



## Insight from Autism Alliance Members

The Autism Alliance ran a workshop for specialist autism charities on the assessment system and the potential for reform. Charities shared their insight on the challenges and opportunities for assessment. These include:

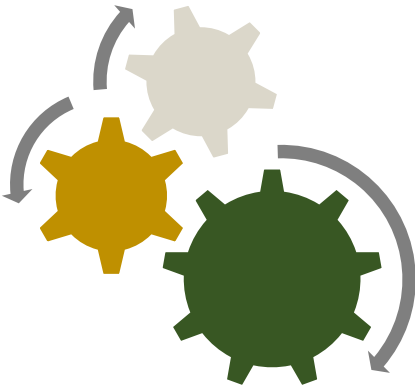
- ✓ **Better use of physical spaces in communities** to support clearing the backlog in assessments - for example, community halls, charity meeting rooms, and local societies. These could be part of a time-limited, concerted drive to close the assessment gap, reflecting (in part) the approach taken to accelerate the rollout of Covid-19 vaccines.
- ✓ **The opportunity to commission delivery of end-to-end assessment through not for profit specialist autism organisations.** For example, Autism Initiatives delivered an autism assessment project in Scotland, covering all stages of the assessment pathway, and has piloted post-diagnostic support for autistic adults in Scotland<sup>12</sup>.
- ✓ **The opportunity to digitise more elements of the assessment pathway** to increase efficiency. For example, Great Ormond Street Hospital has experimented with greater use of video evidence shared amongst specialists to reduce the length of time taken to assess<sup>13</sup>.
- ✓ **The importance of understanding why demand continues to rise**, and the process of decision making by families and individuals in seeking autism assessment, an area which is under-researched. This could help provide better information to support choices, and improve the forecasting of demand for assessment. It might also point to other parts of the system in which improvements could support the process of planning for timely autism assessment – for example, a lack of the right support at school, which can cause needs to escalate.

Source: Autism Alliance Member Workshop, June 2023



- ✓ **Linked to this, the opportunity to provide better information and more support to families pre-diagnosis**, delivered particularly through local charities that have strong reach into their communities, potentially on a statutory footing. This support should be co-produced, and where possible delivered through a peer-led model. It would aim to reduce anxiety, increase confidence and resilience and help families make informed choices about services and support. Examples of this support already exist, for example the model commissioned by the North East and North Cumbria NHS in England and delivered by not for profit organisation Daisy Chain<sup>14</sup>.
- ✓ **The opportunity to link the assessment model to other system-level interventions** that could support better outcomes for autistic people - for example, the Autism Research Passport being explored by Autistica and University College London, providing an easier way to support autistic people to engage with crucial research projects in ways that recognise and meet their needs<sup>15</sup>.

## Case Study: Autism Initiatives – delivering an autism assessment service



[Autism Initiatives](#) is a charity supporting autistic people of all ages, across the North West of England, Wales, Scotland and the Isle of Man. The charity delivers an **autism assessment service** to a number of Health and Social Care Partnerships in Scotland, and is on the recognised autism assessment pathway. The service works with people aged over 16, and is run by a team of autistic and non-autistic staff who oversee data gathering and the administration of standardised tools (ADOS-2 and ADI-R).

The service takes a neuro-affirming approach to diagnosis – a key aim is that the process of assessment in itself is therapeutic, whatever the outcome. Referral to first contact is within two weeks but usually takes place within a few days. Referral to first assessment appointment averages 28 days, and from first appointment to feedback meeting (where the outcome of the assessment is given and a discussion of ‘next steps’ occurs) averages 43 days.

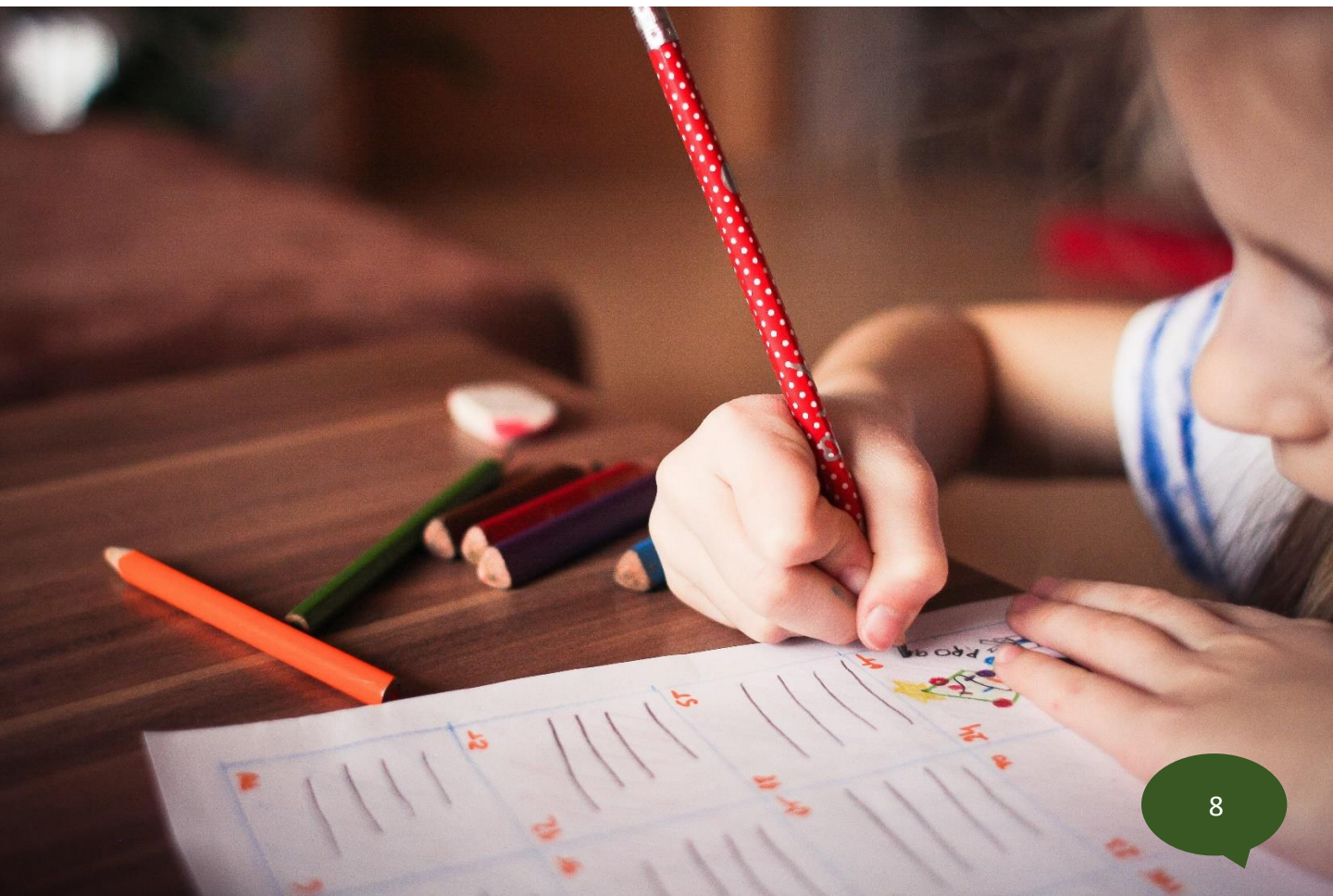
Everyone who receives a positive diagnosis, is able to access a wide range of post-diagnostic support. The service is not time limited, acknowledging that some people may not want to engage soon after diagnosis, and people completing the process are able to access the charity’s One Stop Service at any future point.



## Case Study: Ambitious about Autism – online peer support post- diagnosis

[Ambitious about Autism](#) is a national charity for autistic children and young people, providing education services and campaigning for change. The charity has created an **online peer support course** for young people aged 16-25 who have received an autism diagnosis, called Understanding You, Discovering You, to help them understand autism, explore their identity, and develop goals.

The course was co-designed by autistic young people, and a participant on the course said 'it made me feel more confident in my diagnosis'. The charity has also commissioned University College London (Centre for Research in Autism and Education) to deliver research exploring inequalities in access to post-diagnostic support for autistic young people, and solutions to address these; as well as evaluating the impact of the Understanding You, Discovering you online course.





## Recommendations for Governments and the NHS

### **Governments across the UK could:**

- ✓ Provide funding to the NHS to boost workforce capacity in the assessment system, and work with health leaders to mobilise a short term tactical response to close the current gap in assessment. These responses should be informed by the most up to date data on demand for assessment, and in England should draw on the workforce mapping and planning exercise being led by NHS England.
- ✓ Invest in better early support for families to reduce anxiety, increase confidence and resilience and support informed choices.
- ✓ Create a statutory requirement for local health services to commission pre-diagnostic support for families on the assessment pathway, in line with the requirement already in place in Northern Ireland as part of the Autism (Amendment) Act (Northern Ireland) 2022.

### **The NHS could:**

- ✓ Work with Governments to ensure better planning of the specialist workforce that supports autism assessment, both at a national and local level, with additional Government investment in the workforce.
- ✓ Co-produce information and guidance for parents/carers on the benefits and potential disadvantages of seeking autism assessment/diagnosis, to inform their decisions.
- ✓ Commission pre- and post-diagnostic support as a fundamental part of the assessment pathway, available consistently across the UK.
- ✓ Commission research to better understand why demand for autism assessment continues to rise, the detail of families' journeys to reach the start of the assessment pathway, and why decisions are taken to seek assessment.
- ✓ Commission additional pilots with a number of local health services to explore more efficient models of autism assessment that maintain quality.
- ✓ Accelerate research into the role of technology, including AI, in supporting autism assessment by co-investing with health businesses and universities and co-producing with autistic people and their families.

The Autism Alliance would be pleased to engage with Governments, the NHS, local health services, charities, think tanks and others with a stake in autism assessment, to discuss the ideas and proposals in this policy contribution, and to support continuing work to ensure timely access to specialist assessment for individuals and families across the UK.

The Autism Alliance has published 'Real Change for Autistic People and their Families', a policy framework to inform party Manifestos before the next General Election. This is available at: <https://www.autism-alliance.org.uk/real-change>

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The Autism Alliance represents autism charities across the UK. Together, we are campaigning for real change for autistic children, young people and adults. There have been successive Government strategies for autism, but although there has been some progress, we are not seeing better outcomes or reduced inequalities for autistic people. To deliver real change, the Autism Alliance has developed a framework for reform to inform party Manifestos in the lead in to the next General Election.

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