

Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder



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It is estimated that there are around 700,000 people in the UK, including one in 100 children, with a diagnosis of ASD (autism spectrum disorder).^{1,2} Five times as many boys as girls have a diagnosed condition.³ Many go undiagnosed for a variety of reasons, for example, the way that ASD can present, and therefore it has been suggested the true scale may be much larger.⁴ While support is mainly provided by the education system – 70% of children on the autism spectrum are educated in mainstream schools, with the remaining number largely receiving specialist provision or home schooling⁵ – doctors routinely see patients with the characteristics of ASD, such as persistent difficulties with social communication and interaction.

In recent years the policy response has started to reflect the scale of these issues and has led to a greater awareness and focus on ASD. In 2008 Wales became the first country in the UK to set out a national strategy for meeting the needs of individuals on the autism spectrum.⁶ Since then each of the nations across the UK have developed similar strategies. More recently in 2019, the NHS England long-term plan set out a renewed focus on autism and learning disabilities including improving the understanding of the needs of people with learning disabilities and autism and piloting the introduction of a specific health check for people on the autism spectrum.

Understanding the variation in waiting times to start a diagnostic assessment

While there is much to be admired in the range of national strategies that have been developed, the mechanisms for delivering these ambitions are failing to meet the level of demand. This is laid bare in performance against waiting time targets across the UK.

There are three key elements to achieving a timely autism diagnosis:

1. the wait for first appointment (from referral);
2. the duration of assessment; and
3. the wait from completing an assessment to receiving a final diagnosis.

Across the UK, the different national strategies set out targets for when a diagnostic assessment should commence (the first element) (Figure 1). However, the complexity of individual conditions can make it difficult to put a time on how long the duration of assessment (the second element) should take, and previous strategies have declined to do so. For example, diagnosis is based on an individual child's behaviour at a specific point in time and measured against average age expectations, and therefore can vary widely. Given the knock-on effect the time it takes to carry out an assessment has on final diagnosis waiting times (the third element), there is also no target currently set for this either.

There is currently no consistent and formal collection of data on performance against waiting time targets for a first appointment. From April 2019, data is available for England, which will give a sense of how long children and young people are waiting to start a diagnostic assessment.

Figure 1 – Waiting time targets to start diagnostic assessment across the UK

	Waiting time targets to start assessment	Average waiting time to start assessment	Longest reported waiting time to start assessment
Wales	26 weeks ⁷	No available data.	No available data.
Northern Ireland	13 weeks ⁸	No available data.	No available data.
England	3 months ⁹	16 weeks (2016) ¹⁰	799 days (2017) ¹¹
Scotland	No official target.	331 days (2014) ¹²	1,942 days (2014) ¹³

The most comprehensive data that is available on waiting times for initial diagnostic assessment is a range of FOI (freedom of information) requests that have been published across each of the UK nations. The most complete picture is available following FOI requests of CCGs (clinical commissioning groups) and Trusts in England, by the All Party Parliamentary Group for Autism and Norman Lamb MP, which were collected in 2017 and published in July 2018.¹⁴

The FOI data show that targets for starting diagnostic assessment are consistently being missed. For example, in England, less than 10% of children had their diagnostic assessment started within the three-month target.¹⁵ PHE (Public Health England) analysis found that in 2016, 22% of local authorities met the target.¹⁶ Similarly in Wales, only three out of seven health boards met their national target of 26 weeks,¹⁷ while in Scotland in 2014, 74% of cases took longer 119 days – the target set out in the 2003 National Autism Plan for Children for having an initial referral to sharing a diagnosis.¹⁸ The FOI data that is available also show that both average and the longest waiting time for assessment are badly failing children and young people [Figure 1].

Understanding the health harms of a delayed diagnosis

The potential impacts of a delayed diagnosis on a child's development are alarming and conversely the benefits of an early diagnosis are wide-ranging.^{19,20} For example, a delayed diagnosis can impact on access to education. On a personal level, a delayed diagnosis denies a child or young person the opportunity to understand the factors that are causing them to respond in a specific way. For families this can create undue stress, with their child's response to the world often misinterpreted as poor behavioural issues.

Secondly, a delayed diagnosis may lead to mental health conditions going undiagnosed. While not always related, it is estimated that around 70% of people on the autism spectrum also have a co-occurring mental health condition.²¹ For example, 42% of children with autism also have an anxiety disorder, compared to just 3% of children without autism.²² A failure to recognise and understand related conditions will delay access to early intervention or prevention services.

Finally, delayed waiting times are associated with increased financial costs, caused by, for example, failing to address the link between ASD and associated mental health conditions. PHE estimate that the total cost of supporting children with ASD in the UK is around 3.1 billion annually.²³ The National Autistic Society have estimated that investing in ASD diagnosis would lead to cost savings for the NHS of up to £337 million over five years, from reduced spending on mental health services.²⁴ This is important for the future sustainability of the NHS, particularly given the funding pressure the BMA and others have highlighted CAMHS (child and adolescent mental health services) are facing.²⁵

Improving waiting times for diagnosis

While it is clear that there is significant variation in average and longest waiting times from referral to beginning a diagnostic assessment across the UK, it is difficult to conclusively say what is driving this. Focus groups conducted as part of the 2014 Scottish assessment concluded that a range of factors drove high waiting times, including:

- inefficient working and communication between different agencies;
- high patient non-attendance rates at appointments; and
- inappropriate referrals for diagnosis and ineffective care pathways.²⁶

The research by Norman Lamb MP and the APPGA (All Party Parliamentary Group for Autism) suggested the solution to bringing down diagnosis times in England was ensuring services had the necessary staff levels and funding to meet the rising levels of demand. Each of these individual factors is likely to play some part in poor waiting time performance, and therefore a wide-ranging approach is needed to address these factors, reduce variation across the country and deliver a comprehensive service that provides effective support for children and young people.

In order to begin to address these inconsistencies, and following the lead of the government in England, all nations across the UK should commit to recording and publishing data on waiting times to begin diagnostic assessment, as well as completed assessment and commencement of support if identified. However, this is only a first step. The announcement by the Government of a forthcoming new autism strategy in England is an important opportunity to develop our approach to supporting those on the autism spectrum. It is vital that this renewed focus on ASD and the collection of better, more comprehensive data, is then used as the springboard for a wide-ranging approach to better support those on the autism spectrum in each of the UK nations, including action on the following key issues:

- local areas should be held to account for meeting average waiting time targets for starting a diagnostic assessment; and
- adequate funding should be provided to support local areas to deliver joined-up health and educational support to ensure no child or young-person is waiting longer than three months for initial diagnostic assessment, and national standards on autism care are met.

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BMA 20190189