

The autism diagnosis crisis: key information

About autism, a condition which affects 600,000 in England

“Had we had a diagnosis a lot sooner then we could have avoided the hideous condition of depression and all the misery and pain that entails.”

Helen, who was told “something wasn’t quite right” with her son’s development, when he was three. He received a diagnosis at almost 26.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people on the autism spectrum share certain difficulties, their condition will affect them in different ways. Some autistic people are able to live relatively independent lives but others may need a lifetime of specialist support. People on the spectrum may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.



Helen, mother of Chris, told us her story.

Prevalence studies show that more than 1 in 100 people have autism.¹ This means that in England there are an estimated 600,000 people on the autism spectrum. Not all of these 600,000 are diagnosed.

Diagnosis waiting times are causing families to spiral into crisis

The NICE Quality Standard on autism calls for waiting times between referral and initial appointment for assessment to be no longer than three months, but we know that this is not consistently being met across the country.²

Recent surveys indicate that people are waiting years for an autism diagnosis. On average, the wait for children is reportedly over three and a half years, while adults receive a diagnosis around five years after their concerns first emerge and two years after seeking professional help.³ Diagnosis delays mean people are experiencing avoidable mental health problems – falling into anxiety and depression from being left waiting.

We need national leadership on this critical issue.

“The diagnosis delay led to severe mental health issues for him, which cut him off from school and his peers. It also had a hugely negative impact on our family life.”

Jane, whose son Dan was diagnosed with autism at 15, after eight years.

¹ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al. (2012) *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care.

² NICE Quality Standard [QS51] on autism (2014), <https://www.nice.org.uk/guidance/qs51>.

³ <http://www.autismdiagnosis.info>

Why getting a diagnosis is important

Diagnosis helps people take control of their lives. It unlocks barriers to essential support and services, enabling families to better understand their child and providing an explanation for many years of feeling “different”.

Without a diagnosis, access to the right help is delayed or simply not available, meaning that many may develop mental health problems such as anxiety or depression. This has an impact on families, who are put under the additional strain of being left to look after loved ones without support, or even the understanding of what support could be available.

For children, parents tell us that without a diagnosis and full identification of need, they have struggled to get the right help for their son or daughter. Delays in getting the right help can have a negative impact on a child’s education and development.

- 69% of parents in The National Autistic Society’s survey said that their child’s educational progress has suffered because of a lack of timely support.
- Three quarters said that a lack of support has harmed their child’s social and communication skills.⁴

Autistic adults who have not received a diagnosis find it hard to get the support they need, to live the life they choose, including help with daily living and getting and keeping a job. In a survey The National Autistic Society has done, over half of local authorities told us that they thought it was more likely people would get help if they had a diagnosis.⁵

Being left without support can mean that people face social exclusion and anxiety, which can have negative effects on individuals’ mental health. Research suggests that 16 – 35% of autistic adults have a comorbid psychiatric disorder.⁶ While not all of these are attributable to not getting a diagnosis, getting a timely diagnosis and appropriate support as a result, will reduce these numbers.

“Although for many years I was able to function, my needs were never really met. I was suicidal. If I hadn’t been able to get a diagnosis I would have taken my own life... The diagnosis helped me reach a place of acceptance, which allowed me to stop obsessively trying to calculate where I was on the spectrum.”

Chris, who was diagnosed as an adult, after having to get a private referral.

Earlier autism diagnoses will improve outcomes and save money

NHS England has identified a £30 billion gap in funding for the health service by 2020. It proposes closing this gap through £22 billion savings and £8 billion additional funding committed by the Government in the Conservative manifesto.

This means that the NHS in England needs to find substantial savings, if it is going to meet its targets and provide care. In order to find these savings, and to improve people’s lives, preventing mental ill health has been included as a key priority in its plans.⁷

⁴ Reid, B (2011) *Great Expectations* NAS: London

⁵ Rosenblatt, M (2008) *I Exist: the message from adults with autism in England*. NAS: London

⁶ Royal College of Psychiatrists, *Good practice in the management of autism (Including Asperger Syndrome) in adults*, 2014, Royal College of Psychiatrists

⁷ NHS England (2014), *Five Year Forward View* (<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>)

When it was developing its guidance for health services, NICE said: “Investment in local autism services also contributes to: a reduction in GP appointment, fewer emergency admissions and less use of mental health services in times of crisis, including the use of inpatient psychiatric services.”⁸ The National Autistic Society believes that, by investing in autism diagnosis, the NHS could save money that is currently spent on mental health services that result from autistic people not getting the support they need, as they have not got a diagnosis.

As well as having negative consequences on someone’s life, acute services are also very expensive, with inpatient mental health care costing between £200 and £300 per day.

In other words, the annual cost of supporting two people with autism in a mental health ward would fund a specialist autism team serving an entire borough for a year.

Furthermore, identifying and supporting someone on the autism spectrum can save the wider public sector money. According to National Audit Office, identifying and supporting six per cent of adults with high-functioning autism and Asperger syndrome would save £38 million per year. An eight per cent identification rate would save £67 million per year.

Over the five years to 2020, this is a potential saving to the public purse of £337m.⁹

What can the NHS and Government do?

We are calling on NHS England to prioritise the reduction of autism diagnosis waiting times. We know that this will help the NHS reach its own goals of preventing mental illness.

To do this, the performance of local NHS bodies should be recorded, measured and used to improve services.

- NHS England should collect, publish and monitor key information on how long people are waiting for diagnosis, and how many people are known to their GP to have autism.
- NHS England should ensure that ‘waiting times standards’ on mental health currently in development reflect national guidance that no one waits longer than three months between referral and being seen for diagnosis.
- The Government must share in this commitment, ensuring that NHS England meets its aims. In order to do this, timely access to an autism diagnosis should be written into the Government’s Mandate to NHS England.

Reducing diagnosis waiting times is the right thing to do, and it will also save money. Decisive national action is needed now to make this happen. Autistic people have waited long enough, this can’t wait any longer.

⁸ NICE, *NICE support for commissioning for autism* (2014).

⁹ National Audit Office (2009), *Supporting adults with autism through adulthood*. London: NAO