

Petitions Committee: ADHD and ASD (autism) assessment waiting times

Activity

The Petitions Committee ran an online survey to ask petitioners for their views on assessment waiting times for ADHD and ASD (autism).

The survey was sent to people who signed the following petitions:

- e-petition [597804](#), 'Review management of ADHD assessments and increase funding', closed April 2022.
- e-petition [589677](#), 'Create an emergency fund for ASD (autism) & ADHD assessments', closed December 2021.

We have summarised the key themes below and illustrated them with relevant statistics and quotes from respondents.

Response

There were 7,340 responses to the Committee's survey.

Methodology

Committee staff manually reviewed hundreds of individual comments and answers, using both subject searches and randomised selection. Survey questions which produced statistical results have also been analysed.

Notes

We asked about the experience of people who had a diagnosis of ADHD or ASD (autism), were waiting for assessment, or suspected they had ADHD or ASD (autism) but had not been referred for assessment.

We also asked about the experience of parents and guardians of children who have or may have ADHD and/or ASD (autism), and for the views of other respondents on the adequacy of assessment waiting times.

ADHD assessments

The vast majority of respondents felt waiting times for ADHD assessments were inadequate, and almost two thirds of people awaiting assessments had considered paying for this privately

- Of the respondents who answered questions about ADHD assessments, **82%** said that they strongly disagreed that current waiting times for ADHD assessment were adequate.
- **63%** of respondents who were waiting for an ADHD assessment or suspected they may have ADHD said they had considered paying for private healthcare for a quicker assessment.

Most respondents who had a diagnosis of ADHD had paid for this privately, and most people who received an assessment through the NHS had to wait over a year

Of the respondents who have a diagnosis of ADHD:

- **48%** received a diagnosis through private healthcare, and **35%** received a diagnosis through the NHS.
- **18%** received their diagnosis when they were under 25, **32%** between the ages of 25 and 34, **33%** between the ages of 35 and 44, and **17%** when they were 45 or over.
- **27%** waited between 6 months to 1 year for an NHS assessment, **27%** waited between 1 and 2 years, and **14%** waited between 2 and 3 years.

Most respondents who were on the waiting list for an ADHD assessment were going through the NHS

Of the respondents who were waiting for an ADHD assessment:

- **86%** were waiting for an NHS assessment.
- **7%** were waiting for a private assessment.

Of the respondents who were waiting for an NHS ADHD assessment:

- **27%** had been waiting between 1 and 6 months, **26%** had been waiting between 6 months to 1 year, **24%** had been waiting between 1 and 2 years and **10%** had been waiting between 2 and 3 years.

Respondents identified various barriers to being referred for an assessment, including the lack of an assessment service in their area, and their GP not supporting a referral

Of the respondents who had visited a GP to ask for an ADHD assessment, but had not been referred:

- **28%** said their GP did not think an assessment was the best course of action.
- **16%** were not referred because there is no ADHD assessment service in their area.
- **42%** gave other reasons such as long waiting times or not being taken seriously by their GP. Some respondents said they were asked to fill out forms to get on the waiting list which they found difficult. Some respondents said they were asked to choose between being referred for an ADHD or an ASD (autism) assessment.

Most children with a diagnosis of ADHD received this through the NHS, but the majority had to wait over a year for their assessment

Of the parents and guardians with a child with an ADHD diagnosis:

- **56%** said their child received a diagnosis through the NHS, and **37%** said their child received a diagnosis through private healthcare.
- **17%** said their child had to wait between 6 months to 1 year for an assessment, **28%** said their child had to wait between 1 and 2 years, **21%** said their child had to wait between 2 and 3 years, and **7%** said their child had waited over 5 years.
- **30%** of parents who had at least one child with a diagnosis of or suspected ADHD told us they had multiple children with a diagnosis of or suspected ADHD.

Most children who were waiting for an ADHD assessment were going through the NHS

Of the children who were waiting for an ADHD assessment:

- **91%** were waiting for an NHS assessment.
- **6%** were waiting for a private assessment.

Of the children who were waiting for an NHS ADHD assessment:

- **18%** had been waiting between 1 and 6 months, **22%** had been waiting between 6 months and 1 year, **30%** had been waiting between 1 and 2 years and **14%** had been waiting between 2 and 3 years.

The parents and guardians of children with suspected ADHD highlighted several challenges to having their child referred for an assessment, including the difficulty of getting enough evidence for a referral

Of the respondents who had visited a GP to ask for an ADHD assessment for their child but had not been referred:

- **26%** said their GP did not think an assessment was the best course of action.
- **7%** said they weren't sure why their child had not been referred.
- **60%** gave other reasons that their child had not been referred for assessment. Many parents and guardians said that their GP had told them referrals must come from the child's school. Parents and guardians said they are struggling to obtain evidence from school about their child's symptoms. Other respondents were told that their child is too young to be referred for assessment.

ASD (autism) assessments

The vast majority of respondents felt waiting times for ASD (autism) assessments were inadequate, and almost half of people awaiting assessments had considered paying for this privately

Of the respondents who answered questions about ASD (autism):

- **80%** said that they strongly disagreed that current waiting times for NHS ASD (autism) assessment were adequate.
- **49%** of respondents who were waiting for an ASD (autism) assessment or suspected they may have ASD (autism) said they had considered paying for private healthcare for a quicker assessment.

Most people who had received a diagnosis of ASD (autism) received this through the NHS, but almost a third of respondents paid to get this privately

Of the respondents who have a diagnosis of ASD (autism):

- **56%** received a diagnosis through the NHS, and **34%** received a diagnosis through private healthcare.
- **22%** waited between 6 months to 1 year for an NHS assessment, **28%** waited between 1 and 2 years, and **20%** waited between 2 and 3 years.

- **33%** received a diagnosis when they were under 25, **22%** between the ages of 25 and 34, **27%** between the ages of 35 and 44 and **18%** when they were over 44 years old.

Most respondents who were on the waiting list for an ASD (autism) assessment were going through the NHS

Of the respondents who are waiting for an ASD (autism) assessment:

- **86%** were waiting for an NHS assessment.
- **6%** were waiting for a private assessment.

Of the respondents who were waiting for an NHS ASD (autism) assessment:

- **14%** have been waiting between 1 and 6 months, **23%** have been waiting between 6 months to 1 year, **29%** have been waiting between 1 and 2 years and **14%** have been waiting between 2 and 3 years.

A third of respondents who had asked their GP to refer them for an ASD (autism) assessment said they were not referred for an assessment because their GP did not think this was the best course of action

Of the respondents who had visited a GP to ask for an ASD (autism) assessment, but had not been referred:

- **33%** said their GP did not think an assessment was the best course of action.
- **16%** said they decided not to go ahead with a referral.
- **42%** gave other reasons such as long waiting times and not being taken seriously by their GP. Some respondents said their GP did not think their symptoms were severe enough. Some respondents said they were asked to choose between being referred for an ASD (autism) or ADHD assessment.

Most children with a diagnosis of ASD (autism) received this through the NHS, but over two thirds had to wait over a year to be assessed.

Of the parents and guardians with a child with an ASD (autism) diagnosis

- **74%** said their child received a diagnosis through the NHS, and **21%** said their child received a diagnosis through private healthcare

- **15%** said their child had to wait between 6 months and 1 year for an NHS assessment, **30%** said their child had to wait between 1 and 2 years, **23%** said their child had to wait between 2 and 3 years, **11%** said their child had been waiting between 3 and 4 years, and **9%** said their child had waited over 5 years.
- **30%** of parents who had at least one child with a diagnosis of or suspected ASD (autism) told us they had multiple children with a diagnosis of or suspected ASD (autism).

Most children who were waiting for an ASD (autism) assessment were going through the NHS

Of the children who were waiting for an ASD (autism) assessment:

- **93%** were waiting for an NHS assessment.
- **4%** were waiting for a private assessment.

Of the children who were waiting for an NHS ASD (autism) assessment:

- **16%** had been waiting between 1 and 6 months, **20%** had been waiting between 6 months and 1 year, **29%** had been waiting between 1 and 2 years and **18%** had been waiting between 2 and 3 years.

The parents and guardians of children with suspected ASD (autism) highlighted several challenges to having their child referred for an assessment, including GPs thinking their child was too young for a referral

Of the respondents who had visited a GP to ask for an ASD (autism) assessment for their child or children, but had not been referred:

- **26%** said their GP did not think an assessment was the best course of action.
- **12%** said they weren't sure why their child had not been referred.
- **57%** gave other reasons that their child had not been referred for assessment. Many parents and guardians said their GP had told them referrals must come from the child's school. Other respondents were told that their child didn't have enough symptoms to meet the criteria for ASD (autism). Other respondents were told that their child is too young to be referred for assessment.

Respondents said that long waiting times can lead to poor mental health in individuals waiting for assessment

- Respondent with a child with suspected ASD (autism): "My daughter has been waiting almost 4.5 years for an NHS ASD assessment. In this time, she has spent 1.5 years out of school, 6 months being unable to leave the house, had no social life, had severe anxiety, is depressed and had suicidal feelings."
- Respondent with a diagnosis of ASD (autism): "At the time of my referral [...] I was extremely burned out and distressed. I was in mental health crisis but I now know that I was masking the distress [...] It is extremely unsafe to delay clinical assessments for people in mental health crisis. [...] I was not provided any help and support while I waited."
- Respondent who suspects they may have ADHD: "The younger the diagnosis the better the chance the person and their family have of understanding and accepting the difference in neurology so that the person has the best chances in life. [...] A young person's mental health can be severely impacted by a delay in assessment."

Respondents spoke of borrowing money and going into debt to get private ASD (autism) and ADHD assessments for themselves or their children

- Respondent with a child with suspected ASD (autism) and ADHD: "We have had to borrow money in desperation to pay for a private assessment for ASD and ADHD. She is now also prescribed anti-depressants privately. The cost is extortionate and we can't afford any more [...] She has been failed by the system."
- Respondent waiting for an ASD (autism) assessment: "The NHS waiting list [where I live] is 4 years [...] I borrowed to go private in July 22. I have had to borrow more money to access medication as my GP has refused shared care despite a trail of symptoms and misdiagnosis from childhood on my records."
- Respondent waiting for an ADHD assessment: "My GP stated that adult ADHD diagnosis is not a priority and therefore he cannot refer me at this time. ADHD impacts every area of my life and treatment could drastically improve things for me. I have now taken out a bank loan, getting into debt I really cannot afford, to seek private care."

Respondents who believe they have ASD (autism) or ADHD said they were put off seeking an assessment by the long NHS waiting times

- Respondent who suspects they have ADHD: "The wait times are ridiculous. My partner has only just received a diagnosis after first going to the NHS about it in May last year. It's unacceptable. It put me off getting an assessment."
- Respondent who suspects they have ADHD: "the waiting times for adults in my area put me off asking. My child is 14 months into a waiting list with no time yet set for an assessment."
- Respondent who suspects they have ASD (autism): "the wait times and stress it causes are too much for me."

Respondents said there were particular difficulties receiving an ASD (autism) or ADHD assessment for women

- Parent of children with ASD (autism): "The process of getting my daughters diagnosed was much more lengthy and difficult than my son. It was difficult to get school, in particular, to recognise their needs and difficulties as I think that ASD is still poorly understood, very much so in girls."

- Respondent waiting for an ADHD assessment: It is “notoriously difficult to get a diagnosis as a woman, we tend to have the inattentive ADHD subtype which is incredibly difficult to spot compared to the hyperactivity subtype. Too many people still believe “only boys can get it” or “only children get it” that it’s nearly impossible.”
- Respondent with a diagnosis of ADHD: “Women mask autism most of our lives to fit in - so by the time we realise everything messed up in our lives is due to undiagnosed autism, we are frequently over the age of 30. I talk to women just like me who are still waiting in their 40’s and 50’s, receiving zero support, suffering yet another lost job and endless mental health issues.”
- Parent of a child with a diagnosis of ASD (autism): “Diagnosis is essential to making sure a young person receives the right support in school. A delay of 2 years is outrageous and totally unacceptable as this means that a young person is unsupported and misses a huge amount of their education.”
- Parent of children with a diagnosis of ASD (autism): “Eldest was being thrown out of school, so had to go private to prove his neurodivergence to get the right support for him. If I had waited on NHS he would have been excluded from school.”

Some parents of children who have a diagnosis of or suspected ASD (autism) said that support and assessment waiting times had worsened over time

Some parents of children who are waiting for an ASD (autism) or ADHD assessment said that long waiting times had impacted their child’s or children’s education

- Parent of a child with a diagnosis of ASD (autism): Waiting times are “too long and negativity impacting on children’s education, their self-esteem and understanding of where they fit in the community and wider world, this creates anxiety for their future.”
- Respondent with one child with a diagnosis of ASD (autism) and another who is waiting for an ASD (autism) assessment: “My first was diagnosed 10 years ago and the process was most certainly quicker than it is now [...] My 9 year old is struggling with anxiety and other issues related to her autism and yet is not expected to be seen for potentially another 4 years of which there is no help she can get in the meantime to support her.”

- Respondent with one child with a diagnosis of ASD (autism) and another who is waiting for an ASD (autism) assessment: "My eldest son was diagnosed appropriately 8 years ago, our experience then was very different to our current experience of referring and accessing assessment now [...] My eldest son, once diagnosed, was offered support as a child (approximately 8 years ago) however this support ceased upon reaching adult services. [...] I expect less support for my youngest son who is currently awaiting assessment. The referral process has changed locally which added to the stress. Having two autistic children is hard when support is denied due to "awaiting diagnosis" and we as parents, are left to muddle through and do the best to ensure our children thrive, rather than merely survive, living in a world that is designed for a neurotypical person."