

The autism diagnosis crisis

Research from Rt Hon Norman Lamb MP and the All Party Parliamentary Group on Autism uncovers stark regional variation and long waits for autism diagnosis

More information for supporters



About autism: 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 there are certain difficulties that everyone with autism shares, the condition affects them in different ways. Some autistic people are able to live independent lives with limited support, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK.¹

Introduction

New research from Norman Lamb MP has uncovered the shocking waits for an autism diagnosis faced by children and adults in England. Troubling waits have been raised by parliamentarians and the National Autistic Society as part of the charity's [Autism diagnosis crisis](#) campaign. This has secured vital new data collection on waiting times – something that has never happened before. These waiting times will be published next summer.

But measuring the waits is only one part of the solution. Leading work on diagnosis for the All Party Parliamentary Group on Autism (APPGA), Norman Lamb issued Freedom of Information (FOI) requests to every Clinical Commissioning Group (CCG) and health trust in England. 22 CCGs and 27 trusts provided responses between October and December 2017 (figures relate to the year 2016-2017). This briefing gives more information about these figures and what they mean.

A diagnosis postcode lottery

National guidelines state that people suspected of being autistic should start their diagnostic assessment within three months of being referred to the autism team. But the FOI responses highlight a postcode lottery in waiting times for a first appointment, with many parts of the country falling woefully short of the three-month target.

In 2016-17, 0% of adults in areas such as South Gloucestershire CCG, the Isle of Wight CCG or Cornwall Partnership NHS Foundation Trust were first seen within three months of referral (full results are shown at the end of this briefing). The target was met for only a fraction of adults in Southampton CCG (4.6%) and children in Northern, Eastern and Western Devon CCG (1.78% in the Virgin Care service) and Hambleton, Richmondshire and Whitby CCG (3%). Barnsley CCG reported that no adults or children were first seen within 3 months “unless required urgently”.

Berkshire Healthcare NHS Foundation Trust reported that children faced an average wait of 509 days for a first appointment, with a median wait of 574 days (1½ years). Long average waiting times were also reported by Northern, Eastern and Western Devon CCG in the CAMHS service provided by Virgin Care (271 days), as well as in Cumbria Partnership NHS Foundation Trust (253 days).

The longest waiting times for the start of assessment in 2016-17 were reported in:

- Berkshire Healthcare NHS Foundation Trust – 848 days for an adult and 799 days for a child (more than 2 years)
- South West Yorkshire Partnership NHS Foundation Trust – 528 days for an adult and 535 days for a child (1½ years)
- North Staffordshire Combined Healthcare NHS Trust – 428 days for an adult (more than 1 year) and 637 days for a child (almost 2 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.

What these figures mean

The figures uncovered by this research offer a snapshot of the waits that many autistic people and their families face getting a diagnosis. However, it is important to consider the following things when looking at the figures:

- This is not a complete national picture. Many areas did not submit responses to the FOI requests. Some that did respond were not able to provide figures as they did not collect the information. From April 2018, each health trust is required to collect the information that is needed to monitor diagnosis waiting times, but many will not have been collecting it before. When the new data is published in the Mental Health Services Data Set (MHSDS), we hope to have a national picture of diagnosis waiting times.
- Public bodies have a duty to respond to FOIs unless, for example, they would cost too much or take too much staff time to respond to. You can find out more about the FOIs [here](#).
- It is not possible to say what the average waiting time in the country is from these figures. Again, once the new figures are published next year, we hope to have this.
- But the responses we had to our requests underline just how different people's experiences can be – just because of where they live.
- There may be areas that are performing much better. Unfortunately, without a response to our FOI requests, we cannot be certain.
- Staff and clinicians in these diagnosis services work very hard and services are often overstretched. In order to bring down diagnosis waiting times, CCGs will need to make sure that diagnosis services have the staff and funding that they need to meet demand. If this demand cannot be met with existing local funding, then the Government needs to ensure that each CCG has the resources it needs.
- The responses at the end of this briefing also include some figures on the overall waiting time from being referred to getting a final diagnosis. There is not currently an established benchmark for how long this should take, unlike referral to first appointment which NICE states should be no longer than three months.

What needs to happen

These figures provide just a snapshot, and it is likely that many more examples of unacceptably long waits exist in England. The full scale of the problem will not be known until April 2019, when the NHS publishes waiting times for every area for the first time. Where there are excessive waiting times, commissioners must act and develop new services or add capacity to existing ones.

The last Health and Care Secretary, Jeremy Hunt, committed to look into how areas can be held to account on their diagnosis waiting times when quizzed by MPs on the Health Select Committee. This commitment was very welcome. We hope that the new Health Secretary, Matt Hancock MP, will take this opportunity to affirm his own commitment to tackle long autism diagnosis waits across England.

Norman Lamb, the APPGA and the National Autistic Society are calling for two crucial actions from the Government and NHS England:

- Urgent action to tackle the postcode lottery in waiting times for an autism assessment, establishing a formal structure to hold each area to account **from April 2019**, when national data will be available.
- To make sure that being seen quickly leads to a timely final autism diagnosis, to establish a **new waiting time standard from referral to diagnosis**, just like we see for other conditions. This will need to bring together autistic people, professionals and clinicians to identify an appropriate benchmark wait.

“These scandalous waiting times are happening despite clear evidence that early diagnosis and intervention can make a massive difference to people’s life chances. In many cases, a diagnosis is necessary for children to access vital support, including Education, Health and Care Plans (EHCPs).”

"We know there can be complex cases which require several follow-up appointments with different specialists, but there is no excuse for the widespread delays we are seeing all around the country.

"I welcome the fact that the Government is starting to collect data on waiting times between referral and the initial assessment, but it is not just about the first appointment. Getting the diagnosis is critical thing so that people with autism get the support and assistance they need.

"The Government has an obligation to set a maximum waiting time standard from referral to a final diagnosis of autism, as well as ensuring that data is published for each mental health trust and CCG so that local areas can be held to account for their performance against this target."

Rt Hon Norman Lamb MP, APPGA Member

Why getting an autism diagnosis is important

Diagnosis can be a critical milestone for people on the autism spectrum. It helps people take control of their lives by helping to unlock barriers to essential support and services, enabling families to better understand their child and provide newly diagnosed adults with an explanation for many years of feeling "different".

- 61% of people who responded to an NAS survey said they felt relieved to get a diagnosis
- 58% said that it led to getting new or more support.

Autism is not a mental health condition, but around 70% autistic children develop mental health problems, like anxiety and depression. Moreover, parents and autistic adults tell us that delays in getting diagnosed have led to the development of serious mental health problems, both for the individual and for the family. It is therefore important that people with suspected autism are able to access a timely diagnosis, wherever in the country they live and then appropriate support post-diagnosis.

We believe 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, when concerns are first raised.

In 2015, the National Autistic Society launched *Autism diagnosis crisis*, calling on Government and NHS England to take action to address long waits. Almost **12,000 people** signed our letter to the Health Secretary and the Chief Executive of NHS England.

"The last year and a half have been awful. It's been soul destroying seeing Edward struggling and not knowing why or how to help him. We felt helpless.

"We sought help when he was two and were referred for an autism assessment a year later. But we were then told that the waiting list was 18 months for a first appointment – and our own research suggested it could be even longer. We just couldn't face any more uncertainty and didn't want Edward starting school without a clear knowledge of his problems or the type of support he'd need. We were desperate and felt like the only option was to take out a loan seek a private assessment.

"We've heard that a private diagnosis isn't always accepted but, thankfully, things do seem to be improving for us. I finally feel like we're being listened to, we're now working with the local autism team and they're helping put things in place. It's just really disappointing that we had to resort to this to get here, just because our local services aren't up to scratch. It's not fair to put this additional pressure on families.

"I believe that Edward will need to go to a specialist school and we can now apply for an EHCP to make this possible. I imagine this will be another battle, as places are so limited, but it'll be worth it to get Edward the support he needs in school.

"Every book I read talks about the importance of getting children the right support from a young age, and equipping parents with the knowledge and skills they need. This will be impossible until we bring down waiting times."

Sarah, mum to Edward

What has been achieved so far

As a result of the National Autistic Society's campaign and its support from MPs across political parties, the Government committed to collecting vital data on autism diagnosis. Since then we have been working with the Department of Health and NHS Digital to make changes to the Mental Health Services Data Set (MHSDS) needed to measure waits. These changes have now been agreed to and data collection will begin in April 2018.

But this is only part of what needs to change. To drive down waiting times across the country, bringing them in line with NICE guidance, means holding areas accountable for their performance. We are calling on the Government and NHS England to develop a waiting time standard in the CCG Improvement and Assessment Framework that no one should wait longer than three months to be seen after being referred for an autism diagnosis. The former Health Secretary, Jeremy Hunt, suggested he will look into this, but we believe swift action is needed to end the *Autism diagnosis crisis*.

"It's completely unacceptable for autistic people and families to be waiting many months, even years, for a diagnosis - just because of where they live. This research highlights the scale of the crisis and the alarming variation across the country."

"Many autistic people and parents describe their diagnosis as life changing. It can explain why someone has always felt different, help unlock barriers to vital support and enable people to take control of their lives. But long waits are traumatic and pushing people into anxiety and depression. Autistic people and families are desperate for help and are breaking down under the strain."

"These shocking findings should act as a wake-up call for the Government and for local areas, which must act and develop better or new services. The Government has taken an important first step by starting to collect waiting times. But unless each area is held to account for bringing down their own waiting times, we won't see the vital improvements that autistic people and their families desperately need."

Mark Lever, Chief Executive of the National Autistic Society

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Clinical Commissioning Group responses

The table below consolidates the responses of 22 Clinical Commissioning Groups to requests for the following information under the Freedom of Information Act:

1. In your area, how many people who were referred for a diagnostic assessment had the assessment started within 3 months of their referral? Please provide this information as a number and as a percentage.
2. What was a) the median and b) the longest wait for the start of the diagnostic assessment?
3. Out of those who received a diagnosis of an autistic spectrum condition in 2016-17, what was the median time from referral to final diagnosis?
4. Out of those who received a diagnosis of an autistic spectrum condition in 2016-17, what was the longest time from referral to final diagnosis?
5. As of October 2017, what is the current waiting time from referral to the start of the diagnostic assessment?
6. As of October 2017, what is the expected waiting time from referral to a final diagnosis of autism?

| Assessment and diagnosis waiting times for people with possible autism in 2016-17 | Percentage of patients who started diagnostic assessment within 3 months of referral in 2016-17 | Median wait for start of assessment in 2016-17 | Longest wait for start of assessment in 2016-17 | Median wait from Referral-to-Diagnosis for people diagnosed with an autism spectrum condition in 2016-17 | Longest wait from Referral-to-Diagnosis for people diagnosed with an autism spectrum condition in 2016-17 | Current waiting time from Referral to Assessment as of October 2017 | Expected waiting time from Referral to Final Diagnosis as of October 2017 | Further Information |
|---|---|---|--|--|---|---|---|---|
| Vale of York CCG [Scarborough Hospital Assessment Team for Children & Young People] | Children & Young People: 100% (7 people) Adults: Not held ('The Tuke Centre York') | Children & Young People: 7 weeks Adults: Not held ('The Tuke Centre York') | Children & Young People: 12 weeks** Adults: Not held ('The Tuke Centre York') | Children & Young People: Not given Adults: Not held ('The Tuke Centre York') | Children & Young People: Not given Adults: Not held ('The Tuke Centre York') | Children & Young People: 9 weeks Adults: Not held ('The Tuke Centre York') | Children & Young People: Not given Adults: "At the last quarterly report from the Tuke Centre in June 2017, the duration between screening appointment and feedback was on average 195 days" | Data for adults not held by the CCG - may be held by 'The Tuke Centre York' ***The longest wait for the Scarborough Assessment Team was 12 weeks and for TEWV [Tees, Esk and Wear Valley NHS Trust] it was 61 weeks." |
| Hambleton, Richmondshire and Whitby CCG | Children: 3% Adults: 8% | Children: 21 weeks Adults: 7 weeks | Children: 45 weeks Adults: 8 weeks | Children: 35 weeks Adults: 19 weeks | Children: 57 weeks Adults: 33 weeks | Children: 37 weeks Adults: 37 weeks | Children: 37 weeks Adults: 37 weeks | |
| Stockport CCG | Not held | Not held | Not held | Not held | Not held | Not held | Children & Young People (5-18): 12 months | Direct queries to Stockport NHS Foundation Trust (under 5s in Stockport), Pennine Care NHS Foundation Trust (5 to 18 year-olds in Stockport), Sheffield Adult Autism and Neurodevelopmental Service (adults 18+) |
| Birmingham Cross City CCG | 16-18s: 50% Adults (19+): 26% | 16-18s: 129 days Adults (19+): 143 days | 16-18s: 228 days Adults (19+): 397 days | Not held | Not held | Not held | Not held | List of autism service providers provided in response: Birmingham Community Healthcare Trust, Danshell Healthcare Group, Specialist Mental Health Consultancy Ltd, Woodbourne Priory Hospital, Autism West Midlands, St Andrew's Healthcare |
| Castle Point & Rochford CCG | Not held | 6-7 weeks | 10 weeks | Not held | Not held | 6-10 weeks | Within 10 weeks | For some questions, CCG responded with information relevant to other questions. Therefore, data in the spreadsheet may not directly correspond with the CCG's responses to specific questions. |

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| Scarborough and Ryedale CCG | Adults: 16% Children: 73% | Adults: 8 days Children: 11 days | Adults: 37 days Children: 31 days | Adults: 15 days Children: 29 days | Adults: 54 days Children: 51 days | Adults: 30 days Children: 27 days | Adults: 29 days Children: 37 days | |
| Harrogate and Rural District CCG | Adults: 19% Children: 8% | Adults: 8 weeks Children: 20 weeks | Adults: 39 weeks Children: 32 weeks | Adults: 17 weeks Children: 21 weeks | Adults: 37 weeks Children: 33 weeks | Adults: 33 weeks Children: 32 weeks | Adults: 35 weeks Children: 39 weeks | |
| Dudley CCG | Adults: 100% (3 patients) Children and Young People: Not held | Not held | Not held | Not held | Not held | <6 weeks | Not held | |
| South Gloucestershire CCG [Figures for Adult service only] | 0% | 5 months | 6 months | 5 months | 6 months | 4 months | 4 months | A monthly monitoring of ASD waiting times for Children has been initiated but is still in its early stages, and the CCG is not yet confident of the data's accuracy |
| Milton Keynes CCG | 100% (since September 2016; 29 individuals)* | Not held | Not held | Not held | Not held | Not held | Not held | **"There are two cohorts of individual in Milton Keynes. The initial AADS service was a non-commissioned 'virtual service' that was run by clinicians in other services. This arrangement was under resourced and meant a backlog of referrals, the pathway then broke down meaning the waiting list became 'frozen' until a new pathway was put in place. Those on the waiting list pre the spot purchase arrangement... At the time of writing they had a longest wait of 3.5 years and a shortest wait of 1.5 years. This waiting list was frozen for some time and the CCG is now triaging individuals in order to refer for assessment, to understand if they have been diagnosed via another pathway." |
| Bath and North East Somerset CCG [Figures for 'Speech and Language Therapy' assessment] | 19% | 4 months | 6 months | Not held | 6 months | Preschool children: 4 months Primary school children: 6 months Secondary school children: 5 months | Approx. 8 months | |
| Camden CCG [Some data in relation to Children & Young People only] | CYP: 25% in 2016 (2016-17 data not held) | CYP: 13.5 weeks in 2016 (2016-17 data not held) | CYP: 32 weeks in 2016 (2016-17 data not held) | CYP: approx. 8-12 weeks in 2016 (2016-17 data not held) | CYP: approx. 16-24 weeks in 2016 (2016-17 data not held) | Not held | Not held | Information for adults held by Camden & Islington NHS Foundation Trust. 2016-17 data for children and young people held by Central and North West London NHS Foundation Trust |

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|---|---|---|---|--|--|---|---|---|
| Hull CCG | Not held | Adults: Not held Children and Young People: 29.7 weeks (median wait on waiting list as at August 2017) | Adults: Not held Children and Young People: 69.7 weeks longest wait on waiting list as at August 2017) | Not held | Not held | Adults: Not held Children and Young People: 29.7 weeks (as at August 2017) | Adults: Not held Children and Young People: 69.7 weeks (as at August 2017) | Contact Humber NHS Foundation Trust |
| Southampton City CCG | Adults: 4.6% Children and Young People: 38% | Adults: 18 weeks Children: Not held | Adults: 26 weeks Children: Not held | Adults: 26 weeks Children: Not held | Adults: 34 weeks Children: Not held | Adults: 30 weeks Children: 6-18 months (as of August 2017) | Adults: 36 weeks Children: Not held | Contact Solent NHS Trust who provides the CAMHS service |
| Barnsley CCG | 0 people would commence assessment within 3 months of referral unless required urgently | Not held* | Not held* | Not held* | Not held* | Adults: Commissioned capacity already reached as of Nov 2017 - non-urgent referrals will not be seen before April 2018 Children - Under 5's: 9 months Children - Over 5's: 23 months | Not held* | *Data would need to be obtained from the South West Yorkshire NHS Trust |
| Medway CCG | Not held* | Not held* | Not held* | Not held* | Not held* | Children & Young People: 13-16 weeks Adults: 17 weeks as of Aug2017 | Children & Young People: Not held Adults: Not held | *Contact Sussex Partnership NHS Foundation Trust (Children and Young People) and Kent and Medway NHS and Social Care Partnership Trust (Adults) |
| Bury CCG [Adult figures only] | 95% | 11 weeks | 14 weeks | 47 weeks | 65 weeks | 12 weeks | 52 weeks | Contact Pennine Acute NHS Hospitals Trust and Pennine Care NHS Foundation Trust for Children and Young People figures |
| Oxfordshire CCG | Not held* | 61.5 days | 149 days | Not held* | Not held* | Not held* | Not held* | *Contact Oxford Health NHS Foundation Trust (Children and Adolescents) and Avon and Wiltshire Mental Health Partnership NHS Trust (Adults) |

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| Sheffield CCG [Adult figures only] | 9.3% | 104 days | 463 days | 106 days | 437 days | 39 weeks | Depending on complexity, diagnosis may be completed after 1 assessment session or it may involve an assessment by more than one professional and require multiple follow-up appointments. However, this would still take place relatively quickly and within 1 month on average. | For children and young people in Sheffield, contact NHS England |
| Isle of Wight CCG | 0% | 18 months* | 18 months* | Not held - each case varies differently | 18 months | Not held** | Not held** | **"This had been brought down from 18 months to approx. 6-8 weeks, but is now back to 18 months due to an unprecedented number of referrals since September and those on current list. It is expected that this will rapidly reduce as all referrals are filtered over the next months." ***"This is indeterminable at this point in time as this will be dependent upon the new service following review of all referrals, filtering, triage and prioritisation of cases." |
| Northern, Eastern and Western Devon CCG [Data for CAMHS service provided by Virgin Care Ltd] | 1.78% | 271 days | 571 days | 585 days | 1,288 days | 389 days [median waiting time from referral to initial assessment for those whose pathways ended on or after April 2013] | 580 days [median waiting time from referral to diagnosis for those whose pathways ended on or after April 2013] | The 2 providers of CAMHS services are Virgin Care Ltd and Livewell South West, covering the areas of Devon and Plymouth. Livewell Southwst cannot extract data in a way that enables the CCG to respond to these questions. The figures provided relate to the Virgin Care provided service. Significant progress has been made in improving the service, for instance as a result of introduction of Saturday and evening clinics and changes in working practices. At the time of responding, commissioners across Devon, including Plymouth and Torbay, are re-procuring children's mental health services and working to identify how to improve provision. The aim is for any changes in services and providers to be in place by April 2019. |

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| Eastern Cheshire CCG [Children] | Not held | Not held | Not held | Not held | Not held | 18 months to 2 years* | Not held | Contact Cheshire & Wirral Partnership NHS Foundation Trust and Axia ASD Ltd *"NHS Eastern Cheshire CCG understands from local intelligence that the current waiting time from referral to the start of diagnostic assessment for autism in children in Eastern Cheshire is typically 18 months to 2 years." |
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Mental health trust responses

The table below consolidates the responses of 27 health trusts to requests for the following information under the Freedom of Information Act:

1. In your area, how many people who were referred for a diagnostic assessment had the assessment started within 3 months of their referral? Please provide this information as a number and as a percentage.
2. What was a) the median and b) the longest wait for the start of the diagnostic assessment?
3. Out of those who received a diagnosis of an autistic spectrum condition in 2016-17, what was the median time from referral to final diagnosis?
4. Out of those who received a diagnosis of an autistic spectrum condition in 2016-17, what was the longest time from referral to final diagnosis?
5. As of October 2017, what is the current waiting time from referral to the start of the diagnostic assessment?
6. As of October 2017, what is the expected waiting time from referral to a final diagnosis of autism?

| Assessment and diagnosis waiting times for people with possible autism in 2016-17 | % of patients who started diagnostic assessment within 3 months of referral in 2016-17 | Median wait for start of assessment in 2016-17 | Longest wait for start of assessment in 2016-17 | Median wait from Referral-to-Diagnosis for people diagnosed with an autism spectrum condition in 2016-17 | Longest wait from Referral-to-Diagnosis for people diagnosed with an autism spectrum condition in 2016-17 | Current waiting time from Referral to Assessment as of October 2017 | Expected waiting time from Referral to Final Diagnosis as of October 2017 | Further Information |
|---|--|--|---|--|---|---|---|---|
| North Staffordshire Combined Healthcare | Under 19s: 18.2% Adults: 8.2% | Under 19s: 266 days* Adults: 246 days | Under 19s: 637 days Adults: 428 days | Under 19s: 281 days Adults: 271 days | Under 19s: 330 days Adults: 531 days** | Under 19s: 46 days Adults: 54 days | 16 weeks | * Due to a change in the Trust's reporting system the final 9 weeks, CYP data for 2016/17 only records the longest wait for each week's cohort of patients rather than every individual wait. This has had a negative impact on the overall median figure for the year. ** Longest wait relates to one isolated case where the client was initially assessed and an outcome could not be determined due to their mental health at the time. They were re-assessed 6 months later when their mental health was stable. Excluding this client the longest wait would have been 348 days. |
| Berkshire Healthcare | Adults: 8.77% Children: 6.18% | Adults: 277 days Children: 574 days | Adults: 848 days Children: 799 days | Adults: 177 days Children: 567 days | Adults: 498 days Children: 799 days | Adults: 13.5 months Children 5+: 18 months Children <5: 12 months | Adults: 13.5 months** Children 5+: 18 months** Children <5: 12 months** | ** The diagnosis is given at the end of the first appointment for adults and for the majority of children and young people |
| Hertfordshire Partnership [Mid & West Essex ASD Assessment Service] | Mid Essex: 23.7% West Essex: 4.2% | Mid Essex: 5.3 months West Essex: 5 months | Mid Essex: 8.1 months West Essex: 6.8 months | Mid Essex: 7.7 months West Essex: 7.6 months | Mid Essex: 11.4 months West Essex: 10.1 months | Mid Essex: 2.1 months West Essex: 2.7 months | Mid Essex: within 3 months West Essex: within 3 months | In Hertfordshire and North East Essex, autism assessments are not co-ordinated as a separately funded and monitored service and are integrated within normal clinical work. It is not possible to identify assessments through the electronic patient record system used in these regions. |

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| Sussex Partnership [East Sussex and Brighton & Hove Adult services] | 11% | 28 weeks | 77 weeks | 25 weeks | 96 weeks | 8 to 12 months depending on complexity and need | 10 to 14 months* | Not provided for CAMHS and West Sussex Services Patients are open on average 2 months while they are in the process of being diagnosed |
| Northumberland, Tyne and Wear [Adult service referrals] | 6% | 223 days | 357 days | Not held | Not held | 195 days | Not held | CYP data is fragmented across CYPs service and we are therefore unable to disaggregate ASD data within the appropriate limit |
| South West London and St. George's | Adults: 45% CAMHS: 44% | Adults: 15.6 weeks CAMHS: 15.1 weeks | Adults: 45 weeks CAMHS: 48 weeks | Adults: 45 weeks* CAMHS: 48 weeks* | Adults: 45 weeks* CAMHS: 48 weeks* | Adults: 14 weeks CAMHS: 20 weeks ('longest waiters') | Adults: 14 weeks CAMHS: 20 weeks** | * Median/longest wait for start of the diagnostic assessment is the best estimate - date stamps attached to diagnoses are often not of clinical importance, and diagnoses are often reached at the first assessment appointment ** The team have successfully been reducing the number of long waiters, with the longest wait currently standing at just over 17 weeks (24/11/2017) |
| 2gether [Adults - data for Under 19s not available] | 84% (16% did not complete their questionnaires) | Not held | Not held | Not held | 9 months | 5 months | 6 months | |
| North East London [Adult Diagnostic Service in Waltham Forest only] | 23% | 112 days | 1 year (still waiting) | 160 days | 337 days | 3 months | 3 months | In the children and young people services in Essex (EWMHS) and London, services are not commissioned to provide a stand-alone, specific autism diagnostic service and therefore we do not have these figures. In adult services only Waltham Forest commissions a specific Adult diagnostic service. |
| Central and North West London | Adults: 0% Children: 59% | Adults: 18 months Children: 73 days | Adults: 24 months Children: 9 months | Adults: 18 months Children: 81 days | Adults: 24 months Children: 8.5 months | Adults: 24 months Children: 49 days | Not held | |
| Sheffield Health and Care | 9.30% | 104 days | 463 days | 106 days | 437 days | Not held | Not held | |

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| Oxford Health | Aylesbury Vale: 0% Chiltern: 2.76% Oxon: 41.6% | Aylesbury Vale: 35 weeks Chiltern: 28 weeks Oxon: 14 weeks | Aylesbury Vale: 46 weeks Chiltern: 45 weeks Oxon: 31 weeks | Aylesbury Vale: 32 weeks Chiltern: 30 weeks Oxon: 16 weeks | Aylesbury Vale: 46 weeks Chiltern: 44 weeks Oxon: 31 weeks | Aylesbury Vale: 1 year Chiltern: 1 year Oxon: Service not operating | Aylesbury Vale: 1 year Chiltern: 1 year Oxon: Service not operating | |
| Avon and Wiltshire [Bristol Autism Spectrum Service] | 28% | 5 months | 13 months | 5 months | 13 months | 5.75 months | 6 months | |
| Greater Manchester [Specialist autism service for adults in Bolton CCG, Manchester Health and Care Commissioning and Trafford CCG] | Trafford: 1 person Manchester: 0 people Bolton: 0 people | Trafford: 40 weeks Manchester: 49 weeks Bolton: 39 weeks | Trafford: 54 weeks Manchester: 68 weeks Bolton: 67 weeks | Trafford: 29 weeks Manchester: 29 weeks Bolton: 32 weeks | Trafford: 51 weeks Manchester: 45 weeks Bolton: 52 weeks | Trafford: 42 weeks Manchester: 63 weeks Bolton: 52 weeks | Trafford: 40 weeks Manchester: N/A* Bolton: 37 weeks | |
| Worcestershire Health and Care [Children and Young People's Service for Under 19s] | 96% | 22 days | 151 days | 264 days | 526 days | 90 days | 106 days | |
| Coventry and Warwickshire Partnership | Not provided | Not provided | Children: 168 weeks | Not provided | Not provided | Adults: 19.5 weeks Children: 33 weeks | Varies based on clinical need | |
| Nottinghamshire Healthcare | Adult: 100% Children: 83.3% | Adult: 46 days Children: 1.5 months | Adult: 160 days Children: 5 months | Not held | Not held | Adult: 12 weeks maximum Children: 83.3% | Adult: based on complexity Children: 8-9 months | Trust provided data for its two divisions: Local Partnerships (Community based care) and Forensic Services (Low, medium and high secure services). The spreadsheet data refers to Local Partnerships data only. |
| Essex Partnership [Adult service for over 18s] | Not held | Not held | Not held | 3.4 months | 19.7 months | Not held | Not held | The Trust is unable to provide this information because it does not maintain records of patients referred because they are not referred into a specific service. We are only able to identify those patients who have received a diagnosis of autism. |
| Leeds and York Partnership | 97% | 6 weeks | 35 weeks (due to technical issue with electronic system) | 21 weeks | 75 weeks (complex case) | 6 weeks | Approx. 26 weeks | |

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|---|---------------------------------|---|---|---|---|--|--|---|
| Northamptonshire Healthcare | 30% | 29 weeks | Not provided | Not held | Not held | 12 weeks | Not held | |
| South West Yorkshire Partnership | Adults: 8.6% CAMHS: 5.1% | Adults: 199 days CAMHS: 201 days | Adults: 528 days CAMHS: 535 days | Adults: 978 days CAMHS: not held | Adults: 1,285 days CAMHS: not held | Adults Wakefield: 2 months Adults Barnsley: 11 months Adults Kirklees & Calderdale: 15 mts CAMHS: approx. 2 years | Adults Wakefield: 3 months Adults Barnsley: 12 months Adults Kirklees & Calderdale: 16 mts CAMHS: approx. 2 years 1 month | |
| Cornwall Partnership | 0% | Not held | Not held | 627 days | 1,070 days | Not held | 24 months | |
| Cumbria Partnership | Adult: 11% Children: 0% | Adult: 190 days Children: 253 days | Adult: 364 days Children: 304 days | Not held | Not held | 6.5 weeks | 12 weeks | |
| Somerset Partnership | Adult: 100%* Children: 100%* | Adult: 5 days* Children: 4 weeks* | Adult: 7 weeks* Children: 10 weeks* | Adult: 11 weeks* Children: 17.5 weeks* | Adult: 208 weeks* Children: 196 weeks* | Not held | Not held | * All wait times are for patients who received an autism diagnosis during the year, not those referred for assessment |
| Devon Partnership | 3.2% | Started assessment as of 31st October: 271 days Not yet started assessment: 392 days | Started assessment as of 31st October: 603 days Not yet started assessment: 531 days | 308 days* | 466 days | South Devon and Torbay CCG: 103 days** New Devon: 420 days** | Not provided | * Figures based on patients who were referred in 2016-17 and have received the outcome of their assessment (not necessarily a diagnosis of an autism spectrum condition) ** Waiting time is dependent on CCG, due to differences in funding and staffing levels. |

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|--|--|---|---|-----------------|-----------------|--|------------------|---|
| Kent and Medway Partnership | 3.37% | 4 months | 8 months | Not applicable* | Not applicable* | Not applicable** | Not applicable** | *Only 6 patients who were referred to the Autism service in the period have an autism spectrum condition recorded on their record. The diagnosis was not as a result of the referral or any subsequent assessment if one took place. The diagnosis was either before the referral, or no assessment to place. ** The Autism service was ceased by KMPT in January 2017 and all patients, assessed and awaiting assessment were transferred to an external provider |
| Southern Health [Adult service only] | Adult: 17.1% YP (approaching age 18): 11.1% | Adult: 126 days YP (approaching age 18): 165 days | Adult: 182 days YP (approaching age 18): 208 days | Not provided | 238 days | 6-7 months | Not provided | |
| Rotherham, Doncaster and South Humber | North Lincs CAMHS: 88.6% | North Lincs CAMHS: 8-9 weeks | North Lincs CAMHS: 16-17 weeks | Not held | Not held | North Lincs CAMHS: waits range from under 10 weeks to 17 weeks | Not held | Data only provided for North Lincolnshire CAMHS ASD service. Rotherham CAMHS Service collates data on referral to assessment completion not assessment start. Adult ASD is not commissioned by Trust. |
| Bradford District Care | Not provided - exceeds cost limit | | | | | | | |