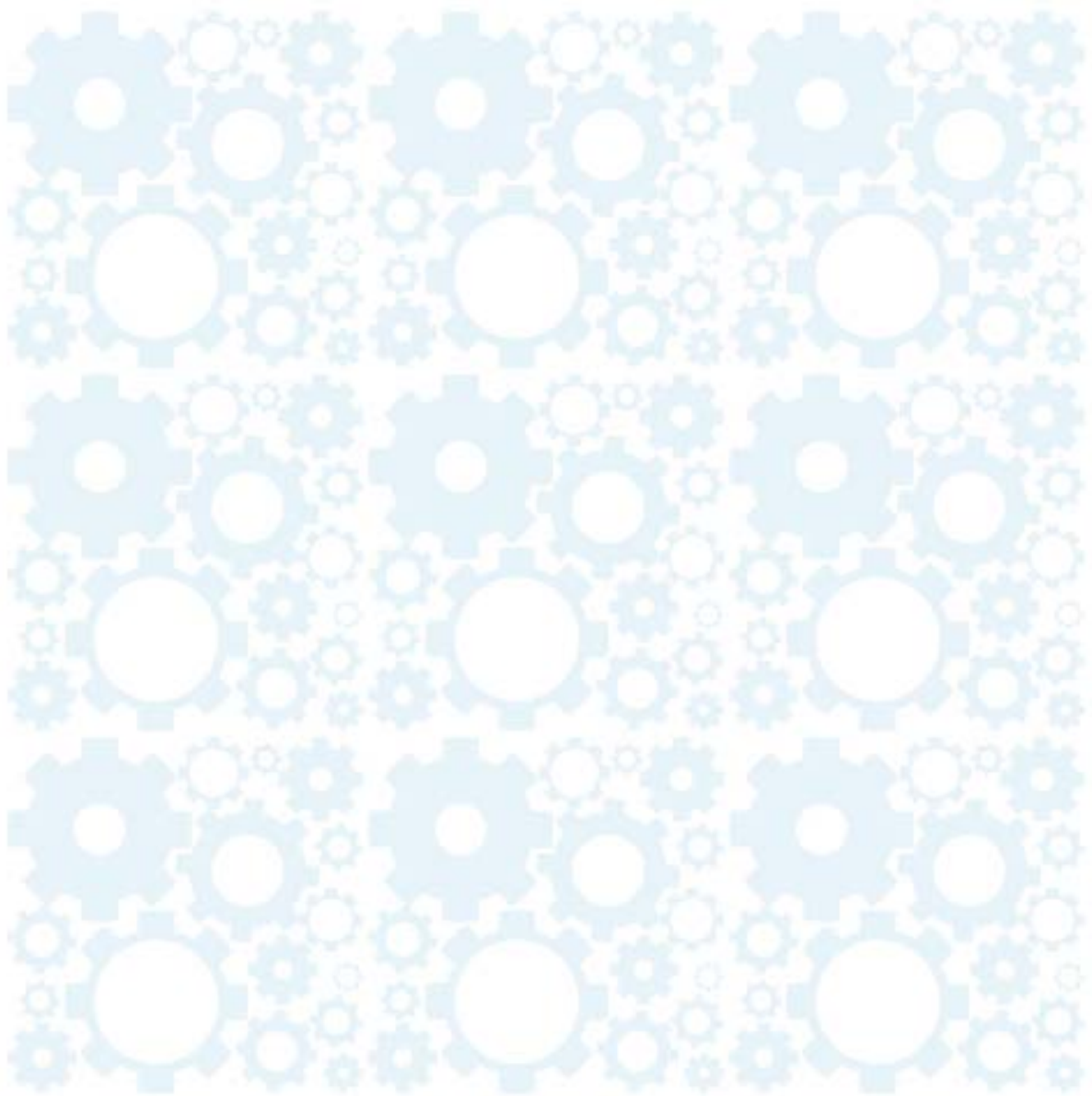


Children and young people with autism

Findings from the Healthwatch network



Executive summary

Around half a million people in England have an autistic spectrum condition. Early assessment, diagnosis and support can help people with autism and their families improve their quality of life. That's why it's vital that young people with autism and their families are able to access the support they need.¹

Since 2014, 33 local Healthwatch across the country have spoken to over 1,000 people to understand their experiences of using autism services and what improvements can be made.

The four most common issues that people have told local Healthwatch they want to see improve include:

1. Understanding and knowledge

- Some GP surgeries and schools found it difficult to spot the signs of autism consistently, suggesting the need for more awareness training. This would help improve the referral process for diagnosis.
- Parent carers felt that doctors did not listen to them when they said their child was experiencing problems.
- People said some GPs did not have a clear understanding of how the referral process works.

2. Waiting times

- Waiting times for young people to get an appointment for a diagnosis assessment could vary between 10 weeks and more than three years. This means they are often left without the right help, as support is only available after a diagnosis.
- Long waiting times could cover a significant proportion of a child's school years and overlap the important transition from primary to secondary education.
- When people did get an appointment, the environment in waiting rooms for health and care services could be stressful. More work needs to be done to make waiting rooms autism-friendly.

3. Support for parent carers

- Parent carers felt they are not being offered the right support and information from the beginning.
- Families said they don't know where to seek help in a crisis.

4. Communication and coordination

- Parent carers found that there was limited communication between health and social care services.

¹ [*Department of Health, Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update, April 2014, p.4*](#)

- Some parent carers felt that appointments were not productive as they were often asked to repeat their child's patient history. This meant that there was less time spent discussing their child's diagnosis or treatment.
- Families need clearer information about local support groups and social care services available to them, and how to help young people prepare for the transition to adult services.

Key recommendation: Child and Adolescent Mental Health Services (CAMHS)

From what we have heard from people across England, there is a lack of consistency in the pathways for diagnosis and support for children and young people. Some young people are referred to CAMHS, whilst others go through neurological or learning disability services. Families have also told us that professionals can be unsure about which services are best placed to help young people with autism.

Many local Healthwatch have highlighted that there is currently no single unified service available to cover autism services. A single service could provide relief for the strain on CAMHS services and ensure healthcare professionals know where to send families for support and guidance.

Understanding the issue

In the last 30 years, there has been a 25-fold increase in autism diagnosis.² This has led to increased public awareness of the issue, as well as continued calls for greater support for those with autism spectrum disorders and their families.

Autism is described by the National Autistic Society as a “lifelong, developmental disability that affects how a person communicates with and relates to other people and how they experience the world around them”.³

While there are no clear figures for the overall number of children with autism, the most recent figures show that 57,200 children have a Statement of Special Educational Needs or Education, Health and Care Plan for an autistic spectrum condition that entitles them to support at school. Of this group 27,500 (48%) attend special schools.⁴

Positive steps have been taken by the Government to answer this demand. The Autism Act 2009 committed the Government to producing a strategy for adults with autism, and in 2010, the first autism strategy for England, *Fulfilling and rewarding lives*, was released. Actions in the strategy included guidance on making public services accessible for adults with autism, such as by improving buildings, public transport and communication, and the introduction of a clear, consistent pathway for diagnosis.

The strategy was updated in 2014. The update, *Think Autism*, set a renewed focus on three areas:

- Building communities that are aware of autism;
- Promoting innovation in service provision;
- Providing integrated care.

A progress report on the implementation of *Think Autism* was published in January 2016.

The National Institute for Health and Care Excellence (NICE) has published a range of guidance outlining how young people with autism should be treated.⁵ Despite the focus on this issue, the experiences young people and their families have shared with Healthwatch indicate that many areas still face issues with diagnosis, waiting times and support, both from medical professionals and within their wider communities.

² <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7172>

³ <http://www.autism.org.uk/about/what-is.aspx>

⁴ Pinney, Anne, *Understanding the needs of disabled children with complex needs or life-limiting conditions*, February 2017, pp. 11-12

⁵ <https://www.nice.org.uk/guidance/cg170>

What people said

In this section, we look at specific examples of what local Healthwatch heard from their communities about each area for improvement.

1. Understanding and knowledge

Local Healthwatch heard that young people struggle to receive a referral for diagnosis because GPs and schools do not always recognise the signs of autism or autism spectrum conditions. This means young people and their families can be left without the correct diagnosis or support for years.

[Healthwatch Derbyshire \(2015\)](#) interviewed 26 families with young people who have autism to understand their experiences before, during and after diagnosis.

They heard that:

- Schools need to be better equipped to recognise the signs of autism and know what to do.
- Some parents felt that young people did not receive the right support. This meant that they missed school, were bullied, isolated or even temporarily suspended because teachers could not deal with their child's behaviour.
- Parents often felt blamed for their child's bad behaviour as staff could not identify the signs of autism.
- Although many parents found their GP understanding, others were frustrated as they felt their GP was hesitant, or didn't know how to make an appropriate referral. In some cases, parents were told that a referral would be made to a paediatrician, but when this was followed up nothing had been done.
- Getting a diagnosis was important to parents because of the impact this would have on their child's future.

[Healthwatch Hampshire \(2015\)](#) worked in partnership with local organisations to raise awareness about the issues young people with autism face.

People told them that:

- GPs, receptionists and staff in schools need more awareness training, to promote a greater understanding of autism.
- Some professionals lacked empathy and misunderstood disruptive behaviour from young people with autism, leading to a delay in diagnosis. This meant that some families could not access the support they needed.
- As parents, they felt they were not being listened to early enough, even though they recognised the signs of autism in their child.
- The referral process for a diagnosis was not clear to them or to professionals.

[Healthwatch Croydon \(2016\)](#) spoke to parents and carers to find out if their children were receiving the right support and treatment. They heard that people's experiences at different GP practices varied considerably and some doctors had little awareness of autism. One parent was left feeling desperate, but was advised by their GP to 'go out and socialise'. Following this work, the

local Healthwatch recommended to their Clinical Commissioning Group (CCG) that all staff at GP surgeries should receive awareness training. The CCG's subsequent plan for local CAMHS included an additional 20% in funding, and contained steps to address GPs' awareness and understanding through training.

“We didn’t spot them and the teacher didn’t spot them and the teaching assistant didn’t spot them because there is not enough autism knowledge in education and I feel that needs addressing because there is more diagnosis now of autistic children.”

(From a parent discussing autism symptoms in schools, Healthwatch Derbyshire, 2015)

2. Waiting times

Reducing the time it takes for a referral

People told local Healthwatch that waiting times for treatment and diagnosis are too long. This means that young people can be left without the right help, as support is only available after a diagnosis. Some people have reported waiting more than a year to get a referral for their local autism team and longer for an assessment. [Healthwatch Bradford and District \(2017\)](#) found that people in the area usually wait 12 to 18 months for a diagnosis assessment.

People also felt that there was a significant variation in the time they had to wait depending on where they lived and to which service they had been referred. [Healthwatch Cheshire East \(2015\)](#) spoke to 200 parent carers over a five month period and heard that their main concern was lengthy delays in getting an appointment to confirm whether their children had autism. Not having a diagnosis had an impact on every part of a family's life - from everyday coping strategies to schooling.

They found that across Cheshire there were large variations in waiting times for treatment. In South Cheshire the autism diagnosis pathway does not involve CAMHS and most people are seen in less than ten weeks. However, in Eastern Cheshire where young people need to go through the CAMHS referral process, there have been incidents where people are waiting for over three years.

As a result of their engagement work, Healthwatch Cheshire East got in touch with the local Clinical Commissioning Group to help plan a better service based on what people want and need. Although the new approach is in the early stages, there is already a lot of positive feedback.

[Healthwatch Worcestershire \(2016\)](#) is currently working on understanding more about the levels of autism awareness in health services. This will include gathering feedback about a toolkit for professionals to help identify people's needs and provide better support.

Reducing waiting room times

People told local Healthwatch that many waiting rooms at health and care services do not cater for children and young people with autism and their families.

[Healthwatch Stockton-on-Tees \(2016\)](#) spoke to people about their experiences of visiting dental surgeries. They found that waiting rooms were often stressful for people with autism, but improvements could be made to help make visits easier. Suggestions included cutting down waiting times by scheduling people with autism for the first appointment of the day, or alternatively providing them with a separate waiting area.

This also worked well in other areas. One example is at Birmingham Children's Hospital, where [Healthwatch Dudley \(2016\)](#) received positive feedback from a family with an autistic child who were able to wait in a separate area before their appointment and seen quickly. This helped to reduce stress and anxiety for the family, and contrasted with their experience at another hospital in Dudley, where they were left waiting for hours.

[Healthwatch Islington \(2017\)](#) heard positive stories from local people about how some services in the area allow young people with autism to be seen first. This reduces stress for both children and their families as they don't need to wait long. However, some people also told them that they try not to visit their GP as it can be a difficult experience. Consistency and sharing good practice across all healthcare providers could greatly reduce stress and anxiety for young people with autism and parent carers.

[Healthwatch Bradford and District \(2017\)](#) have an ongoing project to understand the experiences of people of all ages affected by autism spectrum conditions. Their initial report identified that people often struggle to get a diagnosis assessment, which prevents them accessing the support they need. The report also noted the impact of resource pressures on the length of assessment waiting times. Following this work to highlight the impact of the delays in diagnosis, Bradford and Airedale Neurodevelopment Service (BANDS) has seen its budget increase by 45%. This investment by the CCG is expected to reduce the waiting time for assessment over the next 6 months and reopen the service to new referrals.

CAMHS and autism services

From what we have heard from people across England, there is a lack of consistency in the pathways for diagnosis and support. Some young people are referred to CAMHS, whilst others go through neurological or learning disability services. Families have also told us that professionals are also unsure about which services are best placed to help young people with autism.

Many local Healthwatch heard that the main issue is that there is no unified service currently available to cover autism services. A single service could provide relief for the strain on CAMHS services and ensure healthcare professionals know where to send families for support and guidance.

The 2017 Lenehan Review into specialist services for children with learning disabilities and autism spectrum conditions, *These are our children*, found that there was often a lack of clarity around the roles and responsibilities of schools, GPs and CAMHS professionals, leading to children with autism falling through the gaps.

This lack of support was worsened by some social care services adopting an ‘access at diagnosis’ approach. This led to people who were facing long waits or difficulties in diagnosis being unable to access the support that they needed.⁶

The review highlights that some CAMHS feel unable to offer children and young people with learning disabilities or autism support, as they feel that the range of interventions they are able to provide are not suited to these children and young people’s needs. This shows the necessity for this group to have access to a separate care and diagnosis pathway.

Although most of the families that [Healthwatch Derbyshire](#) spoke to had dealt with CAMHS, there was a lack of consistency between the care young people received in different parts of the county. Parents also told them they were confused by the services CAMHS offered, and felt that a booklet with information on what to expect, the role of clinicians, coping strategies and support groups would help.

Following this work, Healthwatch Derbyshire received a number of positive responses from local services, including Chesterfield Royal Hospital. Since June 2015, the hospital has continued to work with families affected by autism. It now offers a more joined up service between GPs, hospital staff and social care workers. This has helped families to understand what is happening and who is responsible throughout their child’s care.

[Healthwatch Worcestershire \(2015\)](#) spoke to 40 parent carers about their experiences of using the Umbrella Pathway. This provides an assessment process, arrangements for diagnosis and care plans for children and young people with neuro-developmental disorders, including autistic spectrum conditions and Attention Deficit Hyperactivity Disorder (ADHD).

Issues that were identified by parents included:

- Professionals not always having the knowledge and understanding to make initial referrals for treatment and diagnosis.
- Delays and miscommunication about referrals.
- Once people were within the pathway there were delays causing long waiting times for diagnosis.
- A lack of clear information about how the referral and diagnosis pathway works, as well as who to speak to about any queries.

Healthwatch Worcestershire also carried out a CAMHS survey where some parents raised concerns about knowledge and understanding of autism amongst professionals. This included CAMHS lacking specialist knowledge in helping children and young people with autism and mental health support needs.

Waiting times for CAMHS can be too long, leaving young people and their families without the support they need. As [Healthwatch Bradford and District \(2017\)](#) highlight, people with autistic spectrum conditions often fall between the gaps between services. People told them that there

⁶ [Lenehan, Dame Christine. These are our children \(Department of Health, 2017\), p.16](#)

was no up-to-date information available on care pathways or support, online or in person, for people with autistic spectrum conditions who were not in mental health or learning disability services.

[Healthwatch Croydon](#) also heard similar stories from people, who felt they needed a single point of contact who could help them to understand the pathway process.

3. Support for parent carers

Local Healthwatch often heard from families about the lack of support available to them.

[Healthwatch Cornwall \(2014\)](#) conducted a review to find out how well services in the area work for people with autism. They heard that:

- People were frustrated by the lack of support available - 45% of the negative feedback was about this.
- Parent carers wanted better crisis support and training.
- After a diagnosis, families and parent carers felt there was a lack of general information about where to find support.
- People were not aware of their entitlements to financial support as parent carers.

To deal with some of these common issues, [Healthwatch Cheshire East \(2015\)](#) helped to make families feel less isolated by setting up an informal support group, linking families with similar issues together.

[Healthwatch West Sussex \(2016\)](#) conducted a survey with 104 members of Autism Support Crawley to help improve services for children with autism. They heard that nearly seven out of ten people felt their GPs did nothing to support their needs as parent carers. Following this piece of work, a local service involved in the survey created an action plan to address these issues.

Using the views people shared, the project team made a number of recommendations for achievable ways GP services could change to better support patients and parent carers. These included:

- Training for staff to understand how to work with families.
 - Visual resources that parent carers can use to help prepare their child for an appointment. However, these should not include photos of staff in case they are not present on the day.
 - Support, including regular check-ups and flu jabs, for parent carers.
 - Better notes on files that help identify when patients are autistic.
 - Doctors listening more to parents and carers as they know their children best.
 - Staff having a better understanding of referral pathways to help patients.
-

“We are our daughters’ carers and we need support - at the moment the floor is literally giving way and we will be needing temporary respite living... the social worker is also critical of GPs and says ‘they have no knowledge,’ so is there an issue

of trust between the services. Anyway, we as a family have been given very little knowledge, advice, understanding and professional support.”

(Parent speaking to Healthwatch Croydon, 2016)

4. Poor communication and coordination

Parent carers found that there was often limited communication and coordination between health and social care services.

Healthwatch Derbyshire spoke to families and parent carers to understand their experiences of using autism referral pathways. People said that poor communication and a lack of coordination between services were significant issues.

They recommended that:

- Parents and carers need clearer information about local support groups, advice regarding benefits and how to help young people prepare for the transition to adult services.
- Agencies and professionals should have a coordinated approach and share information, so that parents do not have to repeat information.
- People would benefit from having a named contact who they could speak to about any issues.
- More information is needed to explain what the autism pathway is and the role of clinicians.

Since their report was published, Healthwatch Derbyshire have continued to work with the local council to address these issues in the new upcoming autism pathway. They have also received a number of positive responses from local service providers.

Chesterfield Royal Hospital has also used the recommendations to make changes, including:

- Offering patients leaflets for different audiences to explain what is happening and when.
- Ensuring parents only need to tell their story once.
- Consistency in assessments, whether they happen in CAMHS or Paediatrics.

Healthwatch Wiltshire (2017) heard mixed views of CAMHS in their local area. People were positive about staff that managed expectations, supported families and had good knowledge of the process. However, others told Healthwatch that although CAMHS is a good service, it is understaffed. People also said that there was not enough information available in different formats, such as booklets and leaflets.

“There is a lack of consistency in seeing the same person so we had to repeat the patient history each time, causing a delay in diagnosis.”

(Parent speaking to Healthwatch Lincolnshire, 2014)

Conclusion

From what people have told local Healthwatch, it is clear that in many areas a number of steps need to be taken in order for services and professionals to fully meet the needs of young people with autism and their families.

While local Healthwatch heard about examples of caring and supportive services, good practice in diagnosis and high quality support for parent carers, it was not available consistently. Most strikingly, the stark difference in waiting times between those needing referral to CAMHS for diagnosis and those who have access to a separate autism diagnosis pathway highlights the importance of ensuring all children with autism are assessed and diagnosed in a timely and consistent manner. This is especially important when considering how a lack of diagnosis affects them and their families personally, educationally and developmentally. Given the importance of development in early childhood, children need support from a young age to grow into successful adults. Waiting times of more than three years for diagnosis, with further potential waits for support to be put in place, can cover a significant proportion of a child's school years and overlap the important transition from primary to secondary education.

Creating a supportive and aware environment is not just a matter of ensuring those with diagnosed autism spectrum conditions are given the support that they need. Children and parent carers would all benefit from schools, GPs and other professionals working together to raise and reinforce awareness of autism spectrum conditions, and where possible undertake awareness training.

Support can also come from online communities and local support groups, something that a number of local Healthwatch have helped to establish. Better signposting to existing resources would help to reassure people that they are not alone.

Local Healthwatch have identified a number of areas where health professionals, schools and local authorities have worked effectively together to support young people with autism and their families. We hope that these findings will help contribute to the existing body of good practice, and ensure that autism services work for everyone.

Thank you

Thank you to everyone who shared their experiences and ideas with Healthwatch about young people with autism.

Special thanks go to the following Healthwatch whose work has informed this briefing:

Bedford Borough, Bradford and District, Bromley, Calderdale, Cheshire East, Cheshire West and Chester, Cornwall, County Durham, Croydon, Darlington, Derbyshire, Dudley, Hampshire, Hillingdon, Isle of Wight, Islington, Kent, Lancashire, Lewisham, Lincolnshire, Milton Keynes, North Somerset, North Tyneside, Northamptonshire, Slough, Southend, Stockton-on-Tees, Stoke-on-Trent, Thurrock, Trafford, West Sussex, Wiltshire and Worcestershire.

For more information on autism spectrum conditions visit:

- [Autism-connect.org.uk](https://autism-connect.org.uk)
- [Autism.org.uk](https://autism.org.uk)

About us

We are the independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

A local Healthwatch exists in every area of England. We support them to find out what people want from health and care services and to advocate for services that work for local communities. Local Healthwatch also act as our eyes and ears on the ground, telling us what people think about local health and social care services. We use the information the network shares with us and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.



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