

My Voice Counts

The views of young people with autism about their experiences of health and care services



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About Us

We are an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

Our mission

We are a strong, independent, and effective champion for people that use health and social care services. We will continue to influence health and care services and seek to improve joined-up care for the people of Derbyshire.

Our vision

We want to see consumers of health and social care services being put centre stage so that service providers and commissioners listen to what they have to say and use their voices to shape, inform and influence service delivery and design.



Summary

Young people share their views on health and care services

This work was done to hear and share what young people with autism say about their experiences with health and care services.

Health and care services must listen to young people and give them the help they need. Young people will need care and support for many years, so it's important to know what matters to them.

We made links and built a relationship with a local school and sixth form. This was Alderwasley Hall School and Sixth Form and is part of the SENAD group. They support people with autism to live their lives to their full potential.

In March 2025, we heard from 15 young people with autism at Alderwasley Hall School and Sixth Form. They shared views on their local doctors (general practice), dentists, hospitals and opticians, as these were the health services they know, visit or use the most.

We worked with the staff and young people at the school to create a simple picture-based survey.

There was also the opportunity for the young people to share their experience of any other health or care service. They told us what they felt was good or not so good. They also told us what should be improved in the future.

Since 2020 and the COVID pandemic, Healthwatch Derbyshire had not been into local schools to hear the views from young people.

It is important that we engage with young people and listen to their views in a way that works for them, as this is a group of people that we don't often hear from.

The staff and young people helped to design the session, including the questions we asked. This made sure it was interesting to them.

The session was relaxed and gave young people a chance to talk and share their experiences with friends and classmates about using health and care services.

This led to many good conversations where people discussed health in a positive and supportive environment.

Some young people said they now felt more confident sharing their needs and concerns with services in the future.

Key information

- We heard from 15 young people between the ages of 15–20
- Eight were male and seven were female
- We heard from young people who lived across Derbyshire.

Key findings

- The main thing that the young people shared with us was that they did not feel listened to by health professionals, this included GPs. However, mostly they said this about getting help from mental health services, like Children and Adolescent Mental Health Services (CAMHS)
- They felt that services did not know enough about young people with autism and their needs. This makes services difficult to access and can lead to inequalities
- When given the option of what service to share their views about, most people mentioned CAMHS. All who shared feedback said it was not a good experience. They talked about not being listened to, long waits, and not being helped because they had autism.

Positive feedback

- The young people had many positive experiences to share about their dental care
- There were good practice examples given of dentists playing music, having a comfortable seat and clearly explaining what they were going to do before they did it
- Most reported positive experiences at opticians.

Areas for improvement

- There is a need to improve communication with young people with autism, as they want to be involved in their health care

- Young people want to be listened to
- Many felt they do not get the help they need with their mental health
- Young people are concerned about waiting for help and treatment. They want and need to be kept updated about what is happening. They feel that waiting times are too long
- There should be greater awareness of the needs of young people with autism and the adjustments that can be put in place to improve their experience. This will enable young people with autism to have control and responsibility for their long-term health and well-being.

Why did we do this project?

Our role is to listen to people who use health and social care services

It is important that we hear from a wide range of people from across Derbyshire, especially those whose voices are not always listened to and acted upon.

Since 2020 and the COVID pandemic, Healthwatch Derbyshire had not been into local schools to hear the views of young people.

It is important that we listen to their views in a way that works for them, as their voices can be seldom heard.

We had not heard directly from young people themselves. We wanted to address this gap in our knowledge and share the information with service providers and commissioners.

We want the information collected from local young people to be used to help plan future services that are more inclusive, ready to listen and provide appropriate adjustments.

Young people will then feel able to take control and responsibility for their health and have positive experiences of accessing health and care, help and support in the future.

How did we do it?

Engaging with a local school for young people with autism and communication difficulties.

We worked with school staff to help them learn about Healthwatch Derbyshire and to build trust. Together with staff and young people, we found the best way to listen to young people. The young people wanted to share their thoughts, but didn't want anyone to know who had said what.

All the feedback we took was anonymous. The young people were happy to share their age, gender and where in Derbyshire they lived. Being anonymous gave the young people the confidence to share their experiences.

With support and advice from staff and the young people, we devised a short picture-based survey. This would help students who needed communication support to complete it.

We asked the young people what it was like going to the doctors, dentists, hospitals and opticians. We asked about these services as they know about them and use them most often.

The young people were asked to select good, okay or bad. There were images representing these views to help with choosing. The young people were then given the option to explain their answer.

The young people were also asked if they wanted to share any good or bad experiences from any other health service. Finally, they were asked how they would like services to be improved.

We didn't want to take up the young people's learning time, so we held the session in the canteen area. This is where they felt comfortable in an environment they liked.

Staff were available to help the young people complete the survey if needed.

The session took place one morning. Small numbers of young people came to the canteen for a short time, so they did not feel overwhelmed.

Who did we hear from?

We are thankful to everyone who answered the questions. It helps us see if different groups of young people had different thoughts or experiences of health and care services.

Area

We heard from 15 young people. This included one person from Derby City and one person who does not live in Derbyshire. See the chart below:

Where did the young people live?	Number of young people:
Amber Valley	2
Bolsover	0
Chesterfield	1
Derby City	1
Derbyshire Dales	2
Erewash	0
High Peak	2
North East Derbyshire	1
Sheffield	1
South Derbyshire	5

Age

The young people told us their age, see the chart below:

How old were the young people?	Number of young people:
15 years old	4
16 years old	5
17 years old	3
18 years old	2
20 years old	1

Gender

The young people told us about their gender in their own words. Six said they were female, eight said they were male, and one person said they were a woman.

What did people tell us?

It's important to make sure young people with autism are heard, so their words can help tell their own stories.

General Practice (GP) experiences

Young people were asked what it was like at their doctor's surgery. Two people said it was good:



"Nice people and a friendly atmosphere when I am waiting." **Male, age 15, Derbyshire Dales**



Nine young people said it was okay:



"I am used to going now, but it was hard at first."
Female, age 18, Derbyshire Dales

"Sometimes the [check-in] machines do not work ...
prefer these." **Female, age 16, Amber Valley**



Four young people said it was bad:



"They did not help me with my mental health."
Male, age 17, High Peak

"They ignored my problems and do not listen to me.
There are also long waits." **Male, age 18, North-East
Derbyshire**

"It has a strange smell (sensory overload) They ask too
many questions, too quickly and do not listen to what I
say." **Female, age 15, Derbyshire Dales**

"No support for Autistic Selective Mutism people to
access appointments, i.e. no online booking options."
Female, age 20, South Derbyshire



Dentist experiences

The young people were asked what it was like at their dentist.

Ten young people said it was good. The reasons for this included:

- personalised care
- understanding and awareness of the needs of people with autism
- providing adjustments so people feel comfortable.



"James [dentist] is nice and understanding with my autism and anxiety." **Female, age 17, South Derbyshire**

"It is nice and chilled even when I am nervous."
Female, age 16, Amber Valley

"Check-up explained all." **Male, age 16, High Peak**

"Appointments with the same dentist each time.
Understanding of autistic needs." **Female, age 20, South Derbyshire**



Three young people said it was okay:



"They are okay and there's nice music playing." **Male, age 15, Derbyshire Dales**



Two young people said it was bad:



"I can't get a dentist and none on NHS." **Female, age 15, Derbyshire Dales**

"I don't like it when they stick their fingers in my mouth to look at my teeth." **Female, age 17, Amber Valley**



Hospital experiences

The young people were asked what it was like going to the hospital. A total of 14 young people answered this question.

One young person said it was good because Royal Derby Hospital saved their life several years ago.

13 young people said it was okay, and some shared their views about this. They included the following services:

Royal Derby Hospital



"The nurses did not understand sensory overload and what impact it has on me. Also, about food issues as I can only eat certain foods." **Female, age 15, Derbyshire Dales**



Kings Mill Hospital



"Hard to get hospital appointments. It was about period pain and suspected endometriosis. When I got there, it took hours to be seen as well." **Female, age 16, Amber Valley**



Chesterfield Royal Hospital



"I had to wait over six hours to be seen for an awful chest infection where I needed my lungs clearing." **Male, age 18, North-East Derbyshire**



Macclesfield Hospital



"They didn't know how to help me with my mental health ... because of my autism." **Male, age 17, High Peak**



Optician Experiences

We asked young people about what it was like at their opticians.

A total of 13 people answered this question and nine said it was good. The reasons for this included providing the equipment (glasses) that person needed, and how friendly staff were.



"Glasses that make me see." **Female, age 17, Amber Valley**

"I go regularly because I am short-sighted. They are good." **Male, age 16, Derby City**



Three young people said it was okay:



"I would prefer to not have glasses, but I know I need them." **Female, age 18**

"The staff are lovely. However, I do not like how close to me they have to get for testing and fitting glasses." **Female, age 17, South Derbyshire**



Other health or care experiences

The young people were asked to share good or bad experiences of any other health or care service they had used. Eight chose to answer this question.

Six young people mentioned CAMHS and support for their mental health. They all shared bad experiences. One person said 'nothing' was good and responded 'all' to the question of what was bad.

Further feedback included:



"I was treated like a child due to an autism diagnosis." **Male, age 17, High Peak**

"Was not helpful. They dispatched [discharged] me as they 'could not help'." **Female, age 16, Amber Valley**

"Long waiting list. Three years of waiting for CBT – never saw anyone as the person cancelled, then we got discharged. Always new staff, all ineffective, didn't read my notes, and offered no strategies or help whatsoever." **Female, age 20, South Derbyshire**





"Extremely long waiting list but I got my autism/ADHD diagnosis." **Male, age 16, South Derbyshire**

"I got taken off a waiting list after waiting for almost a year just to wait to be put back on the waiting list. I knew I wasn't meant to be taken off the list and nobody knew why I had been taken off the list.

"Some of the therapists did not listen to my problems and interrupted me. Eventually I did get some therapy that sorted out a lot of my mental problems and had some very good therapists." **Male, age 18, North-East Derbyshire**



Two young people said they had used an orthodontist and indicated that this was good.

Improving services in the future

Nine people wrote down how they would like health and care services to be improved in the future. These are their own words:



"Not have to wait to see an OT [occupational therapist] SLT [speech language therapist], or clinical psychologist." **Female, age 17, Amber Valley**

"Updates on waiting lists. Shorter waiting times. Therapists to listen and not interrupt." **Male, age 18, North-East Derbyshire**

"More funding to the NHS, more appointments and less waits. Less pricey dental and optician charges." **Female, age 16, Amber Valley**

"More funding to the NHS and making surgeries actually have enough staff to be run properly." **Male, Age 16, South Derbyshire**





"More access to doctors especially after school in the evening. Seeing the same GP and more time (10mins is a rush).

"Less forcing us to see PAs [physician associates] instead of doctors. Also, systems that let autistic people book appointments easily." **Female, age 20, South Derbyshire**

"Educate people who are meant to be educated about autism." **Male, age 17, High Peak**

"Understand autism. Help people who have food issues to do with their autism (understand, not ignore or chastise when they are in hospital), help picky eater patients." **Female, age 17, Derbyshire Dales**

"I would like to be more independent for my healthcare, but it is all done for me. I want to do some things for myself." **Female, Age 17, South Derbyshire**



The main areas young people felt would improve health and care services were:



Waiting times to be shorter



More funding for the NHS



Better access to services



More independence, being in control of their own care



More awareness and understanding of autism for people who work in health and care. This would make services more accessible.

Recommendations

The Derbyshire health and care system to listen to young people, understand them and act, because they are the patients and the workers of the future.

- Autism training for all staff and awareness raising of the needs of young people with autism. This will improve people's experience
- Effective communication so that the young people understand why they may be waiting for care and treatment, and help, and support are offered whilst waiting
- Provide reasonable adjustments to enable young people with autism to access services and fully benefit from the treatment, that services offer
- Offer different communication methods and information in more accessible formats such as easy read
- Work with young people with autism and their recognised support organisations to continue to improve their experience.

What has happened so far?


The report has been shared with the staff and young people at Alderwasley Hall School and Sixth Form.

It has also been shared with commissioners and providers, and their response is included in the section below.

What is happening next?

A poster will be produced to display at Alderwasley Hall School showcasing the young people's feedback, and highlighting how it has made a difference.

Response from Children and Young People's Mental Health Commissioning team:

 "I want to say a big thank you to the young people at Alderwasley Hall School and Sixth Form for sharing their thoughts and experiences.

"I've listened carefully to what you said – especially about how hard it can be to get help with your mental health, and how sometimes it feels like people don't understand autism or don't listen properly.

"We know this isn't okay, and we're working to make things better. Right now, we're talking to lots of people to learn more about what it's like for children and young people with autism when they try to get mental health support. This report is really helpful and will be used to make sure future services are better and more supportive.

We're also making sure that staff get better training about autism, that waiting times are shorter, and that young people are treated with kindness and respect. Your voices are helping us make real changes – and I'm really grateful for that."



Helen O'Higgins

**Head of Children and Young People's Mental Health
Commissioning, NHS Derby and Derbyshire Integrated Care
Board/Joined Up Care Derbyshire**

Thank you

Healthwatch Derbyshire would like to thank the staff and students at Alderwasley School and Sixth Form for co-designing the engagement and survey, and for allowing us to come to the school to listen to the young people and share their stories about health and care services.

Thank you to the 15 young people for taking the time to complete the survey.

Thank you to the commissioners and providers for reading and responding to the report. Thank you for listening to young people with autism and working to make things better for them now and in the future.

It's important to create a space where people feel safe to share their thoughts and where services are simple to access and helpful for what they need.

Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all young people with autism within Derbyshire but nevertheless offer useful insight.

It is important to note that the engagement was carried out within a specific time frame and therefore only provides a snapshot of people's views as shared with Healthwatch.

They are the genuine thoughts, feelings, and issues the young people shared with Healthwatch Derbyshire. The data should be used in conjunction with, and to complement, other sources of data that are available.


Healthwatch Derbyshire,
Suite 14,
Riverside Business Centre,
Foundry Lane,
Milford,
Belper,
Derbyshire
DE65 0RN

www.healthwatchderbyshire.co.uk
t: 01773 880786
e: enquiries@healthwatchderbyshire.co.uk

 @HWDerbyshire

 /HealthwatchDerbyshire

 Healthwatch Derbyshire

 hwderbyshire

 @hwderbyshire.bsky.social