



Life on hold

Neurodivergent people and healthcare experiences
November 2023

West Yorkshire

VOICE

Making a difference in health and care

healthwatch
working together in West Yorkshire

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Life on hold

Neurodivergent people and healthcare experiences

West Yorkshire Voice invited feedback from people with experience of neurodivergence to talk about some of the key issues in healthcare.

We offered a chance for neurodivergent people and carers to have their say about assessments and support services.

The [West Yorkshire Health and Care Partnership](#), who work to improve the health and well-being of local people, held a meeting to discuss neurodiversity.

It brought people from across West Yorkshire and Craven together. These were health and care professionals and partners from education, local councils, community groups, the voluntary sector, and people with experience.

People talked about the long waiting lists for attention deficit hyperactivity disorder (ADHD) and autism assessments, the problems this is causing, and how to do the best for all the people who need support.

A total of 27 people responded and participated in online and in-person meetings and completed a survey or interviews. Some attendees are also members of [West Yorkshire Voice](#).

West Yorkshire Voice will continue to listen to people and share what they tell us with decision-makers to make care better; in particular, improving assessments and healthcare services.



“I have been waiting for years.”



Assessments: The impacts of long waits and the process

People told us they feel it’s a ‘life on hold’ whilst waiting to access assessments and healthcare. It creates stress and impacts their mental health (including suicide, substance dependence, and vulnerability to abusers).

People struggle to manage many things, including life without support, financial consequences, education, lost opportunities, and unemployment.

Many also feel there are delays in gaining reasonable adjustments, and no access to medication, benefits, and services.

What other impacts are there?

- People told us the process of getting a diagnosis is complex and difficult to navigate, with professionals giving contradictory and confusing advice. [Right to Choose](#) is a pathway to access private assessment through the NHS. A Shared Care Agreement is an agreement between you, your GP, and your psychiatrist to enable care and treatment for ADHD to be shared between the psychiatrist and GP. People told us that Right to Choose and Shared Care Agreements are not properly understood or delivered. Privately funded diagnosis are often not accepted by the NHS.
- [‘Spiky profile’](#) is a visual representation of personal and work-related strengths and areas for development to promote inclusivity. People with a neurodivergence are more likely to perform highly in some areas, and lower in others, making their ‘skill profile’ look ‘spiky’. People shared that having a spiky profile is not understood by many professionals with assumptions made about people who have communication skills.
- People told us that processes aren’t often followed, breaching the [Care Act](#), [Equality Law](#) and the [NHS Constitution for England](#).
- People told us that professionals’ expectations of behaviours are still very gendered, disadvantaging many women, non-binary people, and some men.
- Masking is a behaviour or coping mechanism individuals may use to hide or conceal their true thoughts, feelings or difficulties. People told us that masking and the impacts of this are not understood.

- People shared their experiences of patient and parent blaming and negative attitudes. Neurodivergent parents told us about them and their children being blamed for behaviours which are autistic traits, like being called 'neurotic', children described as 'unruly and naughty', and parents being advised to stop children being hyper-focused.
- People said that some professionals were not reading notes or following guidelines.
- People said they were given contradictory information by professionals, for example being told to get a private diagnosis but it then not being accepted and refusing to prescribe medications.
- People told us there are barriers to accessing medication after diagnosis, people often face another long wait.



Solutions

What do you want to see happen?

People told us that they would like to see:

- An increase in the range of professionals who can assess and find ways to streamline the process.
- Better support for people who are waiting and more options for people who don't seek a diagnosis.
- Investment in better support will reduce costs in the long term.
- Better staff training and accountability when guidance is not followed.
- Schools to be better at individual support to help neurodivergent children.
- Professionals listening to parents and carers.
- Educating GPs about the Right to Choose and Shared Care processes.
- Prioritise and incentivise the training of people qualified to do the assessments.
- Offer peer support while people are waiting.
- Bespoke children's support.
- Parenting course on neurodivergent children and how to support them.
- Use autism pre-screening tools, which can then become a full assessment once criteria are determined. This would eliminate "unnecessary therapy" sessions in Child and Adolescent Mental Health Services.
- Develop an app for diagnosis and/or support.
- Use a human rights equality approach and social model of disability.



“From pillar to post – and back again.”



Services

What are your experiences?

They told us:

- Many people’s needs go unmet, with services offered unsuitable. Generalist services often reject neurodivergent people, with no alternatives.
- Advocates and care managers are needed to help people manage accessing services and systems like benefits, health and care and navigating the criminal justice system.
- Some had good experiences with individual health professionals.
- Mental health services do not understand neurodivergent people and the adaptations needed.
- Cognitive behavioural therapy is not good for many people.
- Disjointed lack of links between services.
- Lack of services and support contributes to suicide, mental health crisis and in some cases has contributed to people ending up in the criminal justice system.
- ‘One size fits all’ does not work for neurodivergent people.

- Being told that you are "unsuitable" for services and not recognising that services are "unsuitable" for neurodivergent people.
- Having to repeat their story (in one case, over 130 times), finding this re-traumatising, feeling disbelieved and rejected.
- Being told that you are either "too ill" or "not ill enough" for every service.

Want

What do you want from services?

People told us they want autistic-led services developed and delivered by people who have experience and third sector who can use peer-led methods.

In addition, they also told us:

- People want needs-based assessments.
- Services to be local.
- Person-centred services which support the whole person.
- Better support for parents.
- More suitable types of support for autistic parents.
- Services and professionals are held to account when things go wrong.
- Separate service for autistic people.
- Autism training for staff.
- Easier access to support with opportunities for earlier diagnosis.
- Access to mental health services, including children and young people.

- Seeking the opinions of those with experience, actively recruiting them into the decision-making teams.
- Strategies to help people recently diagnosed with autism and attention deficit hyperactivity disorder (ADHD).
- Remove rural barriers such as access to activities or clubs.
- Timely neurodiversity assessment following the [National Institute for Health and Care Excellence](#) requirements, timely social care assessments and understanding of neurodiverse needs.
- Access to attention deficit hyperactivity disorder (ADHD) coaches
- Timely access to talking therapy.
- Upskilling teachers to pick up on autistic and attention deficit hyperactivity disorder (ADHD) traits.
- Special educational needs coordinators are trained to carry out initial screening and/or be equipped to listen to parental concerns.

Additional information

Gaining feedback

What we heard mirrors the issues faced by people who have been in touch with their local Healthwatch organisations for support.

Issues for neurodivergent people have come through strongly in the feedback given to Healthwatch about mental health.

Further reading

- Healthwatch Calderdale wrote a report on [Child and Adolescent Mental Health Services](#).
- [Adult experiences of autism services](#) in Calderdale and Kirklees.
- A [mental health report](#) by Healthwatch Leeds also featured issues faced by neurodivergent people.
- Healthwatch North Yorkshire also found that neurodiverse people are facing issues when accessing mental health services, shown in this [report](#).
- An [insight report](#) by the Leeds Health & Care Partnership.

Right to Choose information - [S4nd](#) and [ADHUK](#).



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