Engagement and Insight - a focus on SEND services in Humber & North Yorkshire

July 2025

Humber and North Yorkshire
Health and Care Partnership

Key Themes

- Difficulty **accessing timely diagnosis and support**; long waiting times often result in a **deterioration in an individual's overall health and wellbeing**, especially their mental health, and that of their support network.
- A feeling amongst service users and their carers, that **health and care staff do not always have the appropriate awareness and understanding** of neurodiversity and SEND, and how this impacts a person's life.
- People often **feel stuck between multiple services**, being passed around trying to get a diagnosis and/or support, with organisations being slow to react and often only providing support once a situation has reached breaking point. **Communication between individual services, and public facing information, could be improved**.

When people had a **negative experience of accessing SEND services**, they often told Healthwatch of **multiple issues which impacted the experience**, and in some cases one issue led to another: for example, poor communication from a service, resulting in a longer waiting time.

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Why SEND?

- Since December 2024, several reports have been published by local Healthwatch organisations, focusing on Special Educational Needs & Disabilities (SEND) services across the HNY area. These have identified common areas of concern about services being provided.
- The reports are based on feedback Healthwatch have received from people who have had contact with SEND services in our region.
- Common ground includes difficulties accessing assessments for conditions such as Autism and ADHD (including long waiting times), a lack of awareness from health and care staff about neurodiversity, and poor communication between services and service users.
- This report focuses particularly on insight gathered by Healthwatch York and Healthwatch North Lincolnshire, whilst drawing in data and insight from the ICB’s own patient engagement and data channels.

Sources of insight

- Healthwatch North Lincolnshire ‘Neurodiversity report’, October 2024
- Healthwatch York – ‘Listening to Neuro-divergent families in York’, January 2025
- HNY ICB ‘We Need to Talk’ public & stakeholder engagement, Autumn 2024
- HNY ICB ‘NHS75’ engagement, Summer 2023; and ‘NHS111’.

Accessing support from services

We regularly hear of individuals having a great difficulty in accessing services that support people who are Neurodiverse. These challenges appear to be most prevalent for people who are on the waiting list to access an NHS commissioned service, to be assessed and receive a diagnosis for a condition such as Autism.

People tell us of the **frustration they face when trying to get an assessment**, the length of the waits that they're facing, and the negative impact that not being able to access the appropriate support (that comes with a formal diagnosis) has on, not only the person being diagnosed, but their family and close networks. **Parents report having to reduce their work hours, or leave employment completely**, to allow them to provide the support their child requires, and a lack of support from services has a significant impact on their mental health, as well as that of their other children.

It is apparent that delayed diagnosis of a neurodivergent condition has a significant, negative impact on not only the individual, but those closest to them, with many people identifying a deterioration in their mental health as a direct consequence of a delayed diagnosis.

In North Lincolnshire, people told Healthwatch that due to the lack of an adult assessment pathway in the local area, they have resorted to using **private organisations to enable an assessment of their needs and appropriate diagnosis**. At a time of financial pressures due to the cost of living, this will be an additional expense which some will be unable to afford. Respondents to the survey also report **having waited (and still waiting in some cases) several years for an assessment and diagnosis from the NHS**; often, people told of how they had resorted to using professionals outside of their local area, to get a diagnosis due to the length of wait they had been told they would face.

Healthwatch York found that long waiting times for a diagnosis are having a **negative impact on children's development**, as they're not able to access the additional support and services which become available once a diagnosis has been confirmed. Sometimes, people said that they felt **offers of help from organisations arrive too late**, with problems needing to have reached a certain level of severity before an intervention – by which point, there has been a significant deterioration in the health of both the person and their loved ones.

Accessing support from services

Whilst the issue of long waiting times for assessment and support is a significant trend throughout all these reports, there appears to be examples where this issue has been further compounded by the **lack of integration between services**, including NHS providers, Local Authority, and education settings.

People tell us of a **lack of joined up working between statutory organisations** such as schools, mental health, and children's social care, to effectively assess and meet the needs of individuals; examples have been given of individuals and their carers, going around in circles trying to get answers from providers, and needing to constantly chase up staff to ensure actions are undertaken.

However, people with a learning disability also tell us that **they value the care and support they receive from NHS services.**

People told Healthwatch York of experiences they have of multi-disciplinary meetings being held, but little agreement on a way forward to support the individual. In some cases, people told Healthwatch about how these **meetings seemed to be more focused on where funding would come from** to support an individual's care needs.

Healthwatch York found that **access to appropriate services at school during transitions between education providers can be challenging.** "Some schools are still not considering the needs of neurodivergent children at times of transition."

They also identified that **some education settings support the transition period well,** but then 'do not maintain support beyond transition and fail to see the signs when a child begins to struggle.'

"We had a long meeting - three hours - with adult, child social worker and an NHS nurse in our home just to decide who and where the money was going to come from for XXX's social care support."

A parent story from "Listening to Neurodivergent Families in York"

Communication

A common topic reported to Healthwatch through their surveys and conversations is that communication is a major issue hindering access to SEND services. These communication issues appear to exist **across multiple areas of service delivery**, including **communication with patients** and people on waiting lists, the publication of **outdated public facing information** about support groups, and poor communication **between service providers about individual's care**. The knock-on impact of these poor lines of communication is that service users and their carers are not always clear on what actions are being taken by organisations, how their case is progressing, and what they need to do.

Examples were given of parents contacting services for support during a crisis, only to be told that no one could speak to them due to the time of day or not answering the phone at all. **We also heard of people ringing a service to get an update on their case, only to be told that their case had been closed and that they couldn't provide them with any assistance**.

Issues regarding communication between service provider and individuals are not limited to SEND services; The Kings Fund published a report in February 2025 'Lost in the system: the need for better admin' which reported that **communications now makes up 17% of NHS complaints**, and that 'importantly, a **poor experience of admin also made people less likely to seek care** now and in the future.'

Healthwatch North Lincolnshire investigated what information is available online, in newsletters and social media groups about social groups in the area for neurodivergent adults.

They said that "***Unfortunately, we found it difficult to find up to date information for support services within the community. When using the information available, we found support groups that were no longer running, we attended groups that had been cancelled upon arrival, and groups that had no one to facilitate the actual group. We also found venues that were being used to host the groups had not considered some peoples sensory needs***."

Communication

There were examples reported to Healthwatch York, where cases had been closed by a provider, but the individual and their support network at home had not been informed of this.

"…to be informed his case had been closed. Neither (client name) nor ourselves had ever been informed of this. This was appalling communication and caused stress, anxiety and extra work for disabled young people and their families" A personal story from a parent, "Listening to Neurodivergent Families in York."

As one of their key findings, Healthwatch York identified that 'parent experiences are also worsened by poor administration and poor communication from services.'

"…..called the CAMHS crisis line. I didn't get through, nobody answered. I waited and waited, but nobody picked up the phone."

A personal story from a parent, "Listening to Neurodivergent Families in York."

"One lady said she went to hospital, and she was having a rhythmic spasm and that many clinicians around her didn't understand what that was and despite the fact the lady was explaining herself, and that if they contact somebody in Grimsby Hospital who normally deals with her care, they would be able to explain the treatment they needed. But they didn't listen to her. And this theme of not listening to the patient came up frequently with this cohort."

Heard at a learning disability discussion group, as part of "We Need to Talk."

Awareness amongst healthcare staff of neurodiversity

Some people feel that there needs to be a **better level of training and understanding amongst health and care staff**, of conditions such as Autism, and how people who are neurodiverse communicate with others. Healthwatch North Lincolnshire found that in services that do not specialise in neurodiversity, such as General Practice, **patients feel there needs to be a better awareness of these conditions**.

Some people who responded to 'We Need to Talk' also told us that there needs to be **better training around Autism for NHS staff**, and we heard through our NHS111 engagement last year, that people feel there needs to be better awareness within NHS111 of Autism – examples were given of the operator asking to speak to a child who is non-verbal. They also felt **that NHS111 is not set up for people who are non-verbal or whom have communication difficulties**, and that staff who are taking calls, need to be understanding that people who are neurodiverse can sometimes speak more bluntly. We also heard that some of the **questions which are asked by 111, can be too probing or detailed for children to answer.**

Feedback also referenced the physical aspects of a service and how they could be modified to improve access to people who are neurodiverse; for example, such as providing an area with dimmed lighting, and quieter spaces where the footfall is lower.

"Health professionals are poorly trained about Autism. Very few services are tailored or adjusted to take autism into account"

Respondent to the North Lincolnshire Neurodiversity report

"Train staff properly to be inclusive of diverse demographics such as those with autism and those with gender variance"

Respondent to the 'We Need to Talk' survey

"Training and awareness of not only healthcare staff but reception and administration staff too."

"Staff should be fully trained so they understand not all autistic adults have a learning disability."

Respondents to the North Lincolnshire Neurodiversity report

Charlotte's story

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