

RESEARCH REPORT

Date: October 2024

Training
Sensory Empathy Time
Communication Visible
Availability Accessibility Physical
Awareness
Hidden Disabilities
Community Support
Intervention Understanding
Education Explanations Providing
Adjustments Professionals

Neurodiversity



Contents

1. Introduction	2
1.1 About Us	2
2. Background – What is Neurodiversity	3
2.1 Why this subject?	3
2.2 Research	3
2.3 Methodology	6
3. Key Findings	7
4. Conclusion	20
5. Acknowledgements	21
6. Further Reading	21

Disclaimer

Please note: This report is based upon feedback provided to Healthwatch North Lincolnshire from members of the public and professionals. The findings are based upon individuals' perceptions, which are not verified for factual accuracy.

Quotes in the report are written as received, to ensure opinions are kept in context, as such there may be grammatical errors within quotes.

1 Introduction

1.1 About Us

We are the independent champion for people who use health and social care services. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

In summary Healthwatch is here to:

- Help people find out about local care.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.
- Encourage people running services to involve people in changes to care.

2 Background

What is Neurodiversity?

“Neurodiversity” is a popular term that’s used to describe differences in the way people’s brains work. The idea is that there’s no “correct” way for the brain to work. Instead, there is a wide range of ways that people perceive and respond to the world, and these differences are to be embraced and encouraged (Child Mind Institute, 2024). It is estimated that one in ten people in the UK are neurodiverse.

2.1 Why this subject?

Healthwatch North Lincolnshire received feedback that support with mental health for neurodiverse individuals was lacking in the local area. Services were difficult to source and waiting times for a diagnosis for autism were extremely long. This led to the Neurodiversity survey being produced and distributed to the local community to gain clarification if this was the case. It also gave the chance to give feedback around any other experiences.

2.2 Research

Healthwatch completed research on what was available locally to the Neurodiverse people of North Lincolnshire and what should be available. Our findings were as follows.

The pathway in North Lincolnshire for children up to eighteen years is through a referral to CAMHS. Children begin the transition to adult services when they are seventeen and a half years old. At eighteen, they then sit under adult services and require a referral from a GP to start the process of gaining a diagnosis. Due to there being no commissioned pathway for adults residing in North Lincolnshire, there isn’t a waiting list for a diagnosis

of autism due to the 'right to choose' offer. In England, patients have a legal right to choose who provides their healthcare, including who carries out an autism assessment. GPs should offer you the option to choose a service to carry out the assessment.

“I had to use a computer to have a video link consultation with a psychologist in Cambridge to get my autism diagnosis.”

Whilst carrying out this project we attempted to find out information about social groups that were advertised for neurodivergent adults. The information that we found was available to the public either on websites, Facebook pages and within newsletters. 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.

“The room isn't fit for purpose, no individual lights that can be dimmed.”

Our research found other surrounding areas such as Hull, North East Lincolnshire and Lincolnshire have dedicated hubs and Autism Community Support with Specialist Autism Navigators. These include Matthews Hub in Hull, Faraway in North East Lincolnshire and the virtual Autism Hub in Lincolnshire. Without this vital information and support in North Lincolnshire, Neurodiverse people are missing out.

“No where to walk in and access current information. I rely on other people telling me after they have tried things out!”

“I have been told there is no funding to help provide mental health support for neurodivergent people.”

The RDaSH 28 promises strategy endeavours to nurture partnerships with patients and citizens to support good health.

RDASH Promise 8 – Research, create and deliver 5 impactful changes to inequalities faced by our population in accessing and benefitting from our autism, learning disability and mental health services as part of our wider drive to tackle inequality (“the RDASH 5”).

However, there are currently no RDaSH commissioned autism specific services for adults in North Lincolnshire.

“It’s a continual fight, it’s never ending.”

“Not enough mental health support around for people. I haven’t seen anyone from this team.”

Healthwatch have spoken with the Integrated Care Board (ICB) and the Local Authority (North Lincolnshire Council) who are currently focusing on improving and developing a new strategy for local autism services. Their current autism strategy highlights the key areas they are targeting.

RDaSH are carrying out works at Great Oaks inpatient unit which provides care and treatment for adults living with mental health problems will involve adding two new bedrooms on Mulberry ward. There will also be improvements to patient areas including new multi faith spaces, new calm sensory spaces for patients and improved space for visitors and families. A crisis assessment centre will be created to provide care to those who are in a mental health crisis as an alternative to attending the emergency department.

2.3 Methodology

We produced a survey that was available online via the Healthwatch North Lincolnshire Website, via a scannable QR code and a printed paper version, which we also adapted to be available in easy read. Healthwatch Freepost envelopes were also provided to participants so that they could post back their completed surveys; this ensured people could remain anonymous if they wished to do so. Wherever possible, surveys were also handed out during regular engagement sessions at Scunthorpe General Hospital, Central Library, The Arc and at the Ironstone Centre. We also attended public events such as Pride Festival, Ongo Carnival and North Lindsey College freshers' day.

Engagement took place with the following organisations.

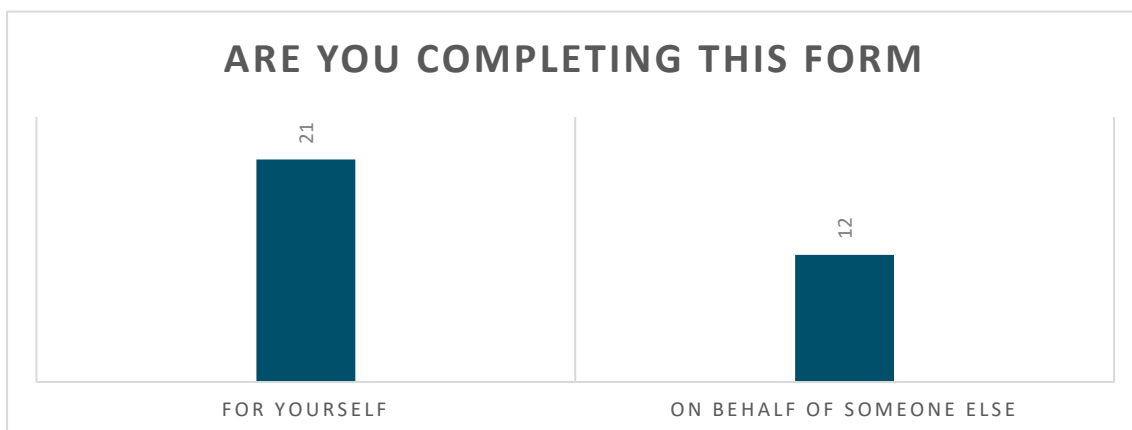
Mind	Cloverleaf	St Hughs School
Poplar Tree Avenue Supported Living	Enablement/Home First Team	Short Breaks Team
Elite Care Solutions	RDaSH LD Team	South Axholme School
Magic Moments	The Arc	UCNL
North Lincs Council Social Work Teams	North Lincs Parent Forum	Goodwins Healthcare
North Lincs Council HAT	Great Oaks	Options Group
North Lincs Council Peoples Voice	Carers Support Centre	MIND
Foresight	Social Prescribing Teams	Amber Gateway

We received a total of thirty-three survey responses. We have examined the results, and the key findings are provided in this report. Responses from the public and professional surveys have been analysed and highlighted over the following pages.

3. Key Findings:

Responses from the Public Survey:

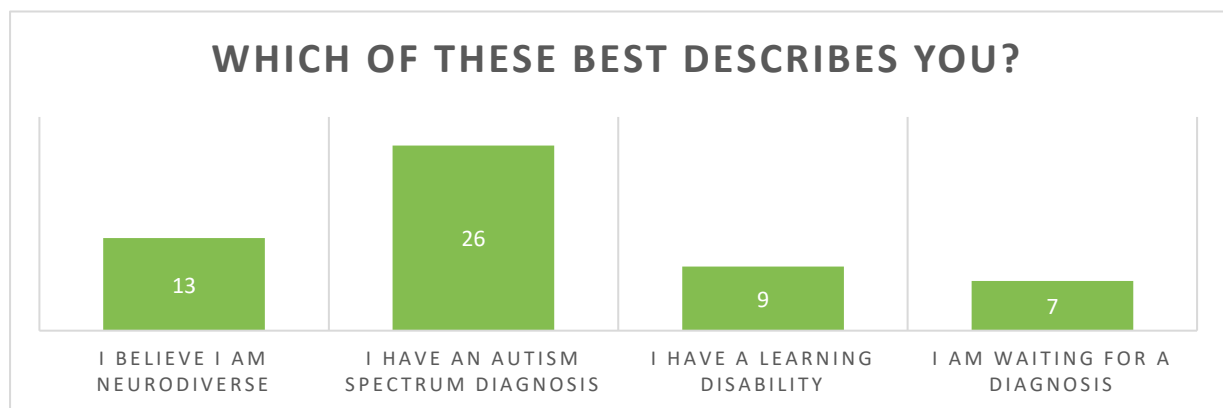
We asked people to state whether they were completing the survey: for themselves or on behalf of someone else.



The Initial diagnostics:

We asked this question to determine where individuals are in their journey for diagnosis and what conditions they have.

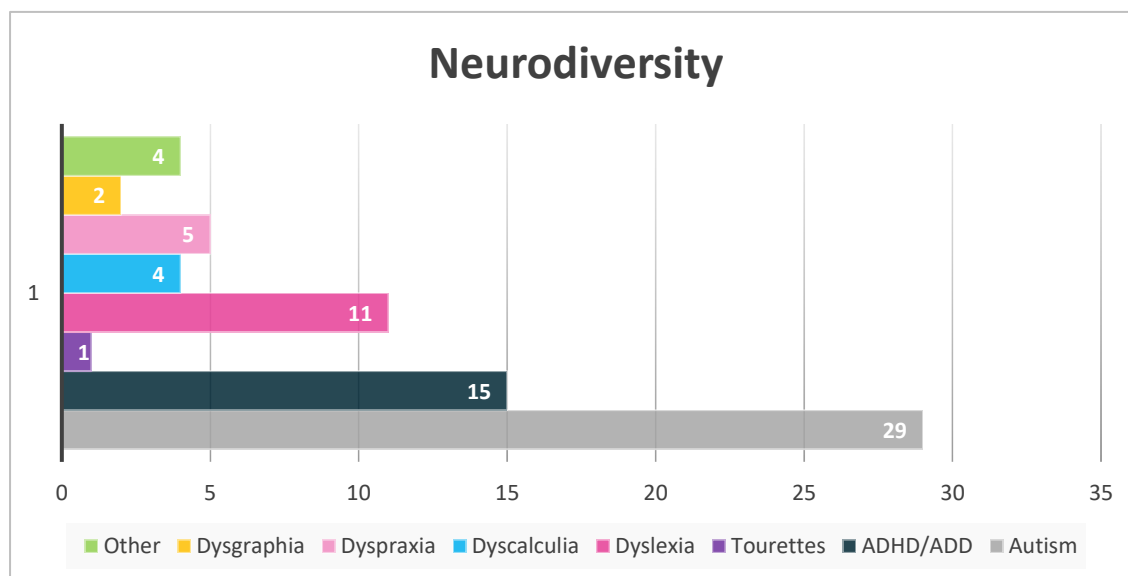
Most people who answered this question selected more than one answer. The most common theme was individuals stating they believe they are neurodiverse with another condition other than autism as well as having an autism diagnosis.



Please state your neurodiversity:

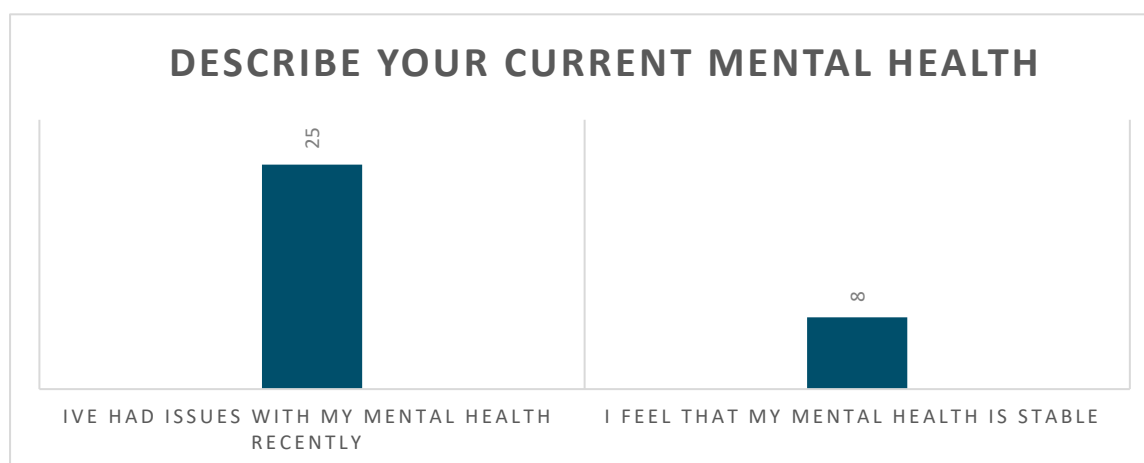
We asked individuals to state their neurodiversity to help us understand the prevalence of such conditions in the local area. Sixteen respondents stated they have one or more neurodiverse condition.

Getting a diagnosis:



Many of the responses received a diagnosis from different organisations, however most of those were out of area professionals. Some people commented that they had to seek out private Psychologists as there isn't an available adult assessment pathway in North Lincolnshire. The wait that people experienced varied from only several months to six years.

Describe your current mental health state:



The effects on people's mental health having to wait for a diagnosis:

We received a multitude of comments around how people's mental health was affected by having to wait for their diagnosis. Ten individuals stated their mental health did not change. People whose mental health declined shared these comments with us:

- "Yes, lots of stress and anxiety"
- "Yes, but in a positive way, less masking and accessing reasonable adjustments"
- "Big impact on mine and my parents' mental health"
- "The uncertainty gave me anxiety"
- "I have been under a lot of stress and struggle to get help and support"
- "I had mental health struggles prior to diagnosis which didn't improve"
- "Deterioration in anxiety having to wait years for face-to-face assessment"
- "No although my GP struggled to see that it is my physical health not my mental health"
- "My child is suffering terribly with his mental health"
- "I become distressed and annoyed when filling out forms as I cannot do it myself"
- "Finding out at age twenty-five was a shock and hard to take in"
- "I self-harmed and suicidal tendencies with some acted on, very low mood."
- "No, but only due to being able to access private, had I had to wait nearly three years I know it would have"
- "Was at crisis point and could not function in everyday life"
- "Yes, because I struggled a lot at school"
- "Yes, it caused my marriage to breakdown"
- "Yes, as I have PTSD and BPD - antidepressants don't work"
- "Yes, as my daughter was exhausted from lack of sleep and constant meltdowns, my mental strength was affected badly"
- "The absence of follow up support has most certainly impacted my mental health"

Facing barriers:

People told us:

- "Waiting list for CAMHS was far too long, I felt like no one was there for me."

- “The therapy I need is not available on the NHS.”
- “CAMHS have no understanding of autism. Paediatrician is sympathetic but CAMHS is the only choice for referral, and we have tried that several times and ended up in a worse situation each time, CAMHS is not fit for purpose.”
- “Constantly fighting and delays at every turn. Currently waiting for an independent funding request but it is dragging on.”
- “All of the family are struggling, and the GP isn’t helpful. My dad can’t cope and goes to bed all the time.”
- “It wasn’t understood by professionals why I struggled with some types of therapy.”
- “Lack of availability.”
- “Once a diagnosis is received, there is no further support offered.”
- “Not being listened to as a parent and lack of support for us and our child.”
- “No professionals listened. CAMHS referrals were declined as they said they couldn’t do anything once we had a diagnosis.”
- “Difficulty in getting a GP appointment.”
- “Passed around, no treatment offered.”
- “My doctor helped with medication but other than that I have had no support, had to wait two and a half years after being diagnosed with ADHD to be assessed for the medication.”
- “Health professionals are poorly trained about autism. Very few services are tailored or adjusted to take autism into account.”

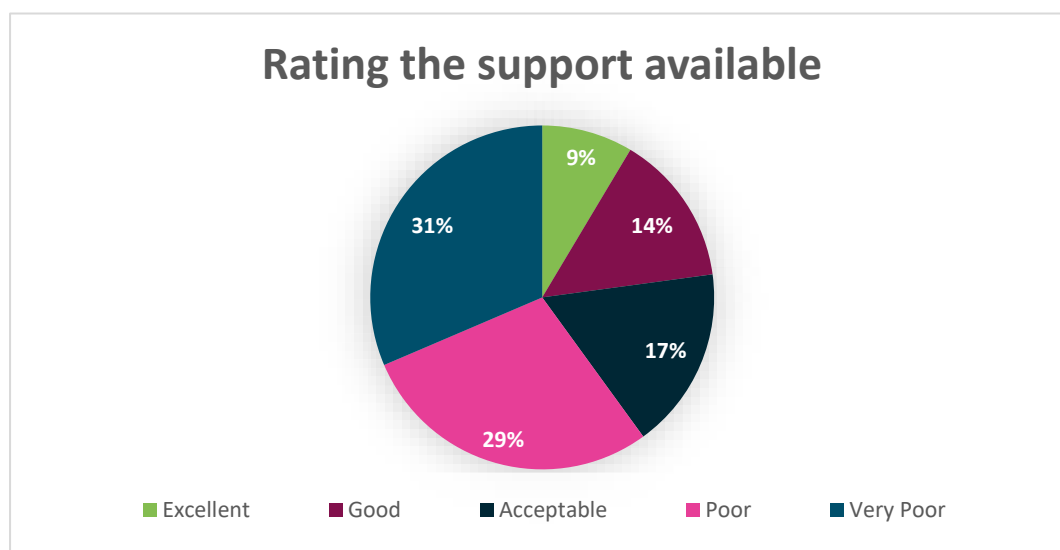
What support people are currently receiving and who provides it:

We have identified that many different services provide support however the feedback suggests that this support does not always meet the needs of the individual whilst others felt they needed to access private services.

- “Crisis team at Doncaster”
- “Had CBT but that only helped a little. The (EMDR) Eye Movement and Desensitisation and Reprocessing I had was brilliant, but it was only a few sessions paid for by my employer’s assistance Scheme. I can’t afford it privately. There’s no counselling available on the NHS either.”

- “Primary care counselling and secondary care counselling through the NHS. Also paid for private in the gap between as felt needed support, but on a waiting list for the secondary. I will probably have to pay privately again, which I am not sure if I have the money for.”
- “Social Prescriber. My last PA was a mental health nurse who had a lot of experience. Social services are not helpful, eight weeks wait for an urgent referral. Four hours of PA time taken with no valid reason.”
- “I have had to fight for all support, and it has been delayed over three years. Over two years without educational support. CAMHS only supported because Social Services involved.”
- “None.”
- “None, apart from the Occupational therapist support for my sibling, who is worse than me.”
- “Parental Interventional Courses. Not specific for need of the child.”
- “My mum does everything for me, she adapts things so that I can manage and cope with daily life.”
- “Not enough mental health support around for people. I haven’t seen anyone from this team.”
- “My own GP supported with medication for me, but other than that no support. I was diagnosed with ADHD and had to wait another two and a half years for an assessment for medication.”
- “For the first time in my life at age sixty-four. I have finally been able to begin accessing financial and housing support following autistic burnout. The burnout is a direct consequence of decades of struggling without support.”

Rating the level of support available:



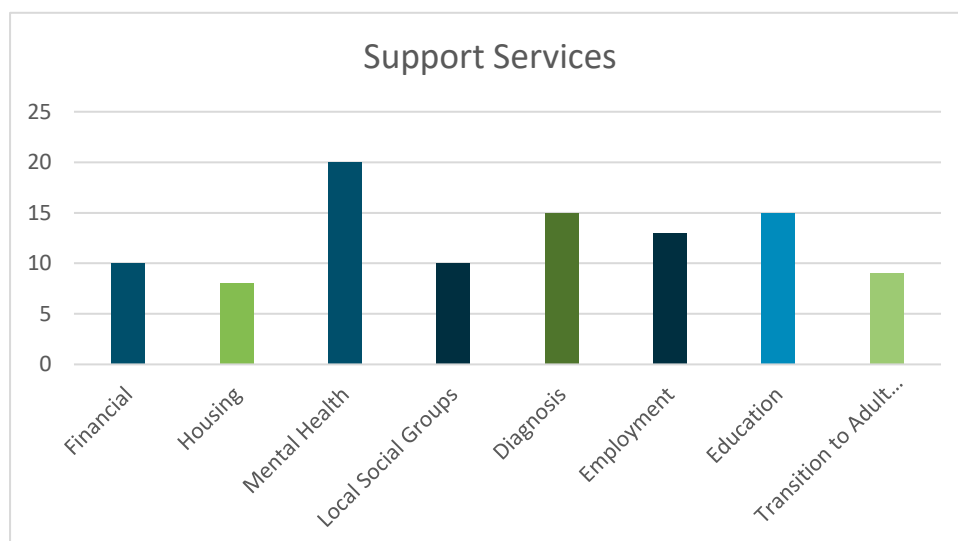
Giving more information on the support rating:

We were told:

- “Staff and my family support me to achieve my goals and show me how to live independently.”
- “Waiting lists are too long.”
- “What is available does not meet my needs.”
- “There is nothing for a highly intelligent yet sensory anxious sixteen-year-old.”
- “It is a continual fight, it’s never ending.”
- “There are no autism specific support services for adults without a learning disability in North Lincolnshire.”
- “No support offered.”
- “CAMHS weren’t very helpful.”
- “The help from school is very good.”
- “The support wasn’t very helpful as no one knew what they were doing.”
- “There isn’t anything available to adults without learning difficulties. You receive the assessment report and that is it.”
- “Have been going round in circles between agencies for years. Earlier face to face assessment from CAMHS is needed.”
- “It’s more about advice than support. Where is our support? Professionals need educating.”

Support people would like to see:

We asked people to specify what support they feel they would benefit from the most:



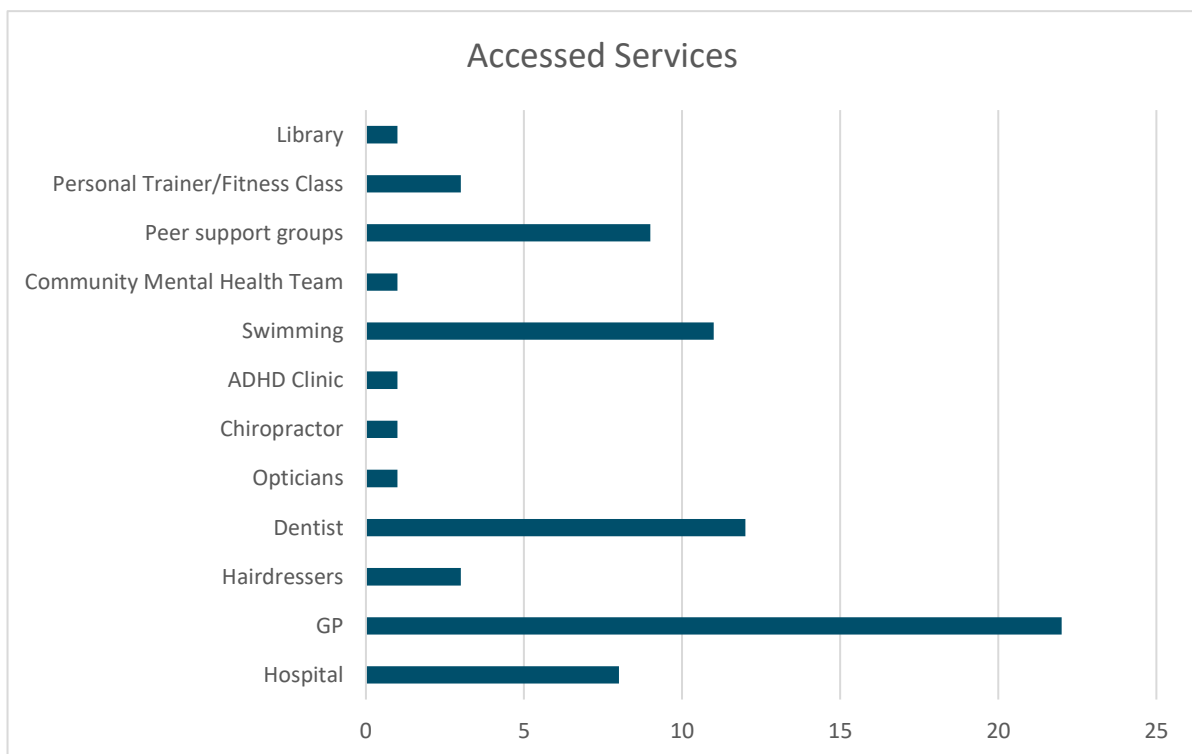
Why would this support help you:

- "Would help with confidence building and finding things which may be available to me."
- "I have a lot of problems with my employer making adjustments for my needs. Alongside that I need specialist counselling and mental health care which takes my neurodiversity into consideration."
- "I need help to become more independent."
- "Its what they need and should be entitled to full time efficient education that is suitable to their ability and SEN needs."
- "There should be post diagnosis support to process the emotions associated with receiving a late diagnosis and to provide information for the future regarding reasonable adjustments etc."
- "Being diagnosed at forty-seven means looking back at a life of trauma, knowing now why everything has been so difficult. Having the opportunity to talk through some of this trauma would have been helpful."
- "I am going to Senior school in September and I am not allowed to have my fidgets that keep me calm. I need a diagnosis and EHCP

before they will let me have them but no one will do this for me, my mum and dad need support with this.”

- “I believe it would make things easier on me as I’ve been struggling with getting a diagnosis, finances and my mental health.”
- “Just to understand what difficulties the diagnosis identifies.”
- “Additional financial support would help due to not being able to work full time.”
- “This would enable my child to learn better and be ready for challenges he may face in the future.”
- “Financial support would be great as they say I am not eligible for Personal Independence Payment. I am supported so much by my mum as I struggle to work twenty-two hours. Mental health support as the charge for private counselling is fifty pounds an hour.”
- “We wouldn’t get to crisis point if people listened and implemented support strategies.”
- “My carers don’t want to listen – no continuity of care.”

Health, wellbeing & leisure facilities accessed in North Lincolnshire:



Some responses we received stated that neurodiverse individuals do not

access any local facilities due to struggles with anxiety, places not being fit for purpose, too loud/bright or being too busy.

Improvements:

We asked individuals if there was any way their experience of accessing services could be improved:

- "All need to be aware of sensory needs."
 - "Better support for services like the Community dentist."
 - "Staff should be fully trained so they understand not all autistic adults have a learning disability."
 - "Assisting people with understanding what has been said to them – communication barriers."
 - "Accessibility."
 - "In general having a better understanding of autism and how this affects people in every day tasks."
-
- "Medical professionals need more education."
 - "Earlier intervention and quicker access to support."
 - "Education of staff – Day to day reasonable adjustments. Quieter gym sessions that are limited in numbers."
 - "There needs to be better communication between organisations."
 - "More understanding and empathy for those with autism and hidden disabilities."
 - "Everything always comes down to availability of PA hours, I can't go swimming or have help with getting dressed."
 - "More trained GP's."
 - "Training and awareness of not only healthcare staff but reception and administration staff too. Understanding that disability can exist without it being something that is visible or physical."
 - "Providing autism friendly access systems such as dimmed lighting, quieter places, ample time and explanations of things."



Other Comments

Below are some comments Healthwatch North Lincolnshire have received from the public during our general engagements:

- “There is no pre or post diagnosis support for autism/ADHD when you are an adult. There should be a ‘starter pack’ once you receive a diagnosis.”
- “There is nothing in Scunthorpe, I cannot describe what it’s like being autistic but it’s very unsupported in every way.”
- “Mathews Hub had funding from North Lincolnshire Council for pre and post diagnosis support and assessments. North Lincolnshire Council never employed anyone for the role in two years even though the funding was available.”
- “GP – always having to explain repeatedly. The talking shop try to make reasonable adjustments such as going into a spare room and dimming the lights.”
- “Please can more services be commissioned for neurodivergent people as we are consistently finding a lack of support in social care.”

- “No services understand autism. I asked for a Disability Liaison Nurse and was told there isn’t one. I found it to be a different experience at Hull Royal Infirmary and would rather pay the sixty-pound taxi fare to go to Hull than be seen at Scunthorpe General Hospital.”
- “Autism seems to be a grey area. I used to access Alvingham Road but there is nothing I am comfortable with doing now that has gone.”
- “I would like to see further support after a diagnosis. I am now labelled as autistic but then what? There has been nothing, so I am left with this feeling, I don’t know if it was harder knowing or not knowing.”
- “Lack of detailed communication between health professionals.”
- “Talking Shop could not support my needs and suggested Mind as an alternative. Sadly, they were unable to provide longer courses of support or therapy.”
- Parent had expressed concerns regarding the Community Mental Health team. Their child has just turned eighteen and had no transition from CAMHS to adult services for their ADHD. Melatonin had also been stopped as it is not licensed for adults to use.
- Individual explained there is no help for autistic people. They have been turned away three times when asking for mental health support through RDaSH and their GP. They have been told there is no funding to help provide mental health support for neurodivergent people.



This image was shared with us through an autism group we attended. This person expressed the concerns of the group in a visual way through this drawing, explaining current struggles and where improvements should be made.

Demographics:

We gathered demographic data, and we found that the most common age range of responses was 25-49 and mostly woman completed our survey with fewer responses from men.

4. Conclusion

There is a lack of mental health support for neurodiverse people in North Lincolnshire, this includes those who are awaiting a diagnosis, and those who are already diagnosed. There is a lack of commissioned services for Neurodiverse people in North Lincolnshire. This has had a significant impact on their daily living experiences.

Healthwatch Recommendations:

- Healthwatch recommend a service is commissioned for the people of North Lincolnshire in one place that is easily accessible for all, with a dedicated workforce that specialise in neurodiversity. This service should provide signposting, financial support, housing advice, a safe place to meet, education and employment support.
- The Talking Shop or a similar service should be commissioned to provide a mental health support service to support neurodiverse people with complex needs in North Lincolnshire.
- Healthwatch recommend the All-Age Autism Delivery Group consider the information gathered in this report is considered when developing the 2026 Autism Plan.

- Service providers should ensure that websites are monitored and updated regularly. Information shared about groups that are taking place should be correct, promoted regularly and further in advance. More notice should be given where possible if groups are cancelled.
- Environmental and sensory factors such as lighting and footfall should be considered when organisations and service providers are setting up social groups. Thought should be given to renting rooms from other organisations that offer better facilities.

5. Acknowledgements

We would like to thank all organisation involved for distributing the survey and everyone who took part in the survey and provided us with information for the project.

6. Further Reading

- North Lincolnshire Council – [Autism plan 2022-2026](#)
- NHS England – [Meeting the needs of autistic adults in mental health services](#)
- HM Government – [The national strategy for autistic children, young people and adults: 2021 – 2026](#)
- [NICE Guidelines for ADHD](#)
- [NICE guidelines for autism spectrum disorders in adults](#)
- [Right to Choose Information](#)
- [National Autistic Society – The Autism Act, 10 years on](#)