

# Insight Report: Learning Disability and Neurodivergence

Understanding the experiences, needs and preferences of people with a learning disability, and / or neurodivergence, their carers / family / friends and staff

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## 1. What is the purpose of this report?

This paper summarises what we know about the learning disability and neurodivergent populations in Leeds. This includes the experiences, needs and preferences of:

- People with a learning disability, and / or neurodivergence.
- Their carers, family, and friends
- Staff working with people in health care services

Specifically, this report:

- Sets out sources of insight that relates to this population
- Summarises the key experience themes for this population
- Highlights gaps in understanding and areas for development
- Outlines next steps

This report is written by the [Leeds Health and Care Partnership](#) with the support of the [Leeds People's Voices Partnership](#). We have worked together (co-produced) with the key partners outlined in [Appendix A](#). It is intended to support organisations in Leeds to put people's voices at the heart of decision-making. It is a public document that will be of interest to third sector organisations, care services and people with a learning disability, and / or neurodivergence. The paper is a review of existing insight and is not an academic research study.

## 2. What do we mean by learning disability and neurodivergence?

Learning disability can be defined as:

"...a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people." (Mencap, 2022).

Neurodivergence can be defined as:

"...a word that describes someone who has a condition that affects how they think and process information and sensory input such as sound, light and smell. It is a broad term, used to describe the many and varying ways in which human brains are wired. This includes people who are: autistic, Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder (ADD), Dyslexic (words), Dyspraxic (movement), Dysphasic (language), Dyscalculic (numbers), or have Tourette's syndrome. (Leeds Autism AIM and Autistic UK, 2022).

It is to be noted that this is not 'neurodiversity' or to be 'neurodiverse'. Neurodiversity / being neurodiverse refers to everyone and the differences in their brain, it does not refer to people

who are specifically described above, who are called ‘neurodivergent’ or are considered to have ‘neurodivergence’.

Depending on a person’s need; they will have access to a range of health and care support.

It is our aspiration that, by 2030, Leeds will be a fair, open, and welcoming city. It will be a place where everyone has an equal chance to live their life successfully and realise their potential. Leeds will be a healthy and caring city for all ages, where people are supported by high-quality services to live full, active, and independent lives.

You can find out more about Leeds’ learning disability’s strategy by reading the ‘Being Me – Leeds Learning Disability Partnership Board Strategy 2018 – 2021 here:

<https://democracy.leeds.gov.uk/documents/s174420/LLDPB%20Being%20Me%20Appendix%201%20Strategy%20Document%20060418.pdf>

You can also read the Leeds Adult Autism Strategy 2017 – 2022 for more information on Leeds’ approach to supporting autistic adults:

<https://democracy.leeds.gov.uk/documents/s174420/LLDPB%20Being%20Me%20Appendix%201%20Strategy%20Document%20060418.pdf>

### **3. Outcomes for learning disability and neurodivergency in Leeds**

The Learning Disability and Neurodiversity Population Board brings together partners from across Leeds so that we can tailor better care and support for individuals and their carers, design more joined-up and sustainable health and care services and make better use of public resources.

The ambition of our learning disability and neurodivergence work in Leeds is that we will improve the lives of people with a learning disability or who are neurodivergent as well as the lives of their carers, family, and friends. The aim is for people in this population to experience health and care that reflects these statements:

- I live well, defined by what matters to me.
- I receive high-quality, accessible, person-centred care and support.
- I am included in all decisions about my life.

These are our identified outcomes. By setting these clear goals, that are focused on how services impact the people they serve, the board is better able to track whether we’re really doing the right thing for the people using these services. The full framework can be seen in [Appendix B](#).

#### 4. What are the key themes identified by the review?

The insight review highlighted a number of key themes:

- People told us that they value having **information** before their appointment so that they know what to expect.
- People told us that it is very important that their needs, preferences, and concerns are clearly and accurately outlined in their case notes (**clinical treatment and communication**)
- People told us that they need clear **information** about what services are available to them and when / how they can be used.
- People with a learning disability, neurodivergence, or both, and their carers / family, told us they want to see health and care services working better together so that they feel well-informed, and their care is well coordinated (**joint working**)
- People told us that it is important for them to have a choice about how they use the service and the types of treatments they receive. This might include the choice of having face-to-face appointments or spending longer with the clinician (**choice and person-centred**).
- People told us that staff behaviours, attitudes and competence have a big impact on their experience of using services (**workforce**).
- People told us that they felt staff often did not have a good understanding of learning disabilities and neurodivergence and that this made it more difficult to develop a trusting relationship (**workforce / person-centred care**).
- People tell us they want care closer to home and that their conditions can sometimes make it difficult to travel to appointments (**transport and travel, health inequality**).
- People told us that the attitudes, behaviours, and beliefs of the wider public had a significant impact on their wellbeing. This often led to people feeling misunderstood (**wider determinants**).
- People with sensory sensitivities noted that places like waiting rooms can be very challenging and adaptations or alternative waiting spaces can really help (**environment**).
- There are some potential **gaps** in our current insight including:
  - Feedback from people with a learning disability and/or neurodivergence who are accessing general health and care services in Leeds.
  - People who have a neurodivergent condition that isn't autism.
  - Staff working with people from this population.
  - Insight related to a wide range of health inequalities – feedback from people with a learning disability or neurodivergence who also experience other health inequalities.

This insight should be considered alongside city-wide cross-cutting themes available on the Leeds Health and Care Partnership website. It is important to note that the quality of the insight in Leeds is variable. While we work as a city to address this variation, we will include relevant national and international data on this population's people's experience of health care.

## 5. Insight review

We are committed to starting with what we already know about people's experience, needs and preferences. This section of the report outlines insight work undertaken over the last four years and highlights key themes as identified in [Appendix C](#).

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
Healthwatch Leeds	<p><b>How does it feel for me? – Emma and Adam's story</b></p> <p><a href="https://healthwatchleeds.co.uk/wp-content/uploads/2023/01/Emma-and-Adam-summary-report-FINAL-v2.pdf">https://healthwatchleeds.co.uk/wp-content/uploads/2023/01/Emma-and-Adam-summary-report-FINAL-v2.pdf</a></p>	2, one autistic female with identified mental health and physical health conditions and their carer	2023	<p>Healthwatch Leeds' 'how does it feel for me?' work, follows the journeys of people receiving health and care services in Leeds and regularly captures their experiences through videos. At the end of a year's involvement, this is then written into a summary report.</p> <ul style="list-style-type: none"> <li>• <b>Communication</b> – consistent, clear information is important prior to appointments and throughout the care pathway.</li> <li>• <b>Communication</b> – the first contact, including the 'hello, my name is' principles, is important; people need to know who is calling, and why.</li> <li>• <b>Information / communication</b> – co-produced patient / service user notes mean everyone is clear on actions and progress, and people feel involved and listened to.</li> <li>• <b>Person centred / workforce / involvement in care</b> - when someone is struggling and finding it difficult to articulate their needs, it is important that staff are considered when acting on someone's care and listening to what is being said (or not), including any communications by a carer.</li> <li>• <b>Satisfaction / resources / health inequality</b> – knowledgeable, trained and kind staff are important to people's experience of care.</li> <li>• <b>Joint working</b> – services across boundaries (e.g. Harrogate and Leeds) can have different access criteria, limited awareness of other services and</li> </ul>

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				<p>sometimes no access to patient records. This can make an already complicated system even harder to navigate.</p> <ul style="list-style-type: none"> <li>• <b>Joint working / satisfaction</b> – more joined up and coordinated services make a very positive difference to people’s care.</li> <li>• <b>Choice / satisfaction / person centred</b> – offering a choice of appointments can help people to engage better with their care.</li> </ul>
Care Opinion + NHS.UK	<p>Stories from Care Opinion with search team “Autism – Leeds”, “Learning disability – Leeds” and ADHD – Leeds”</p> <p><a href="https://www.careopinion.org.uk/">https://www.careopinion.org.uk/</a></p>	<p>12 stories relating to ‘autism’ tag</p> <p>2 stories relating to ‘ADHD’ tag</p> <p>0 stories relating to ‘learning disability’ tag</p>	<p>2016 - 2023</p>	<p>“Autism – Leeds” – 12 stories across all Leeds services (GPs, LYPFT, LADS)</p> <ul style="list-style-type: none"> <li>• <b>Satisfaction</b> - Fairly even split of positive and negative experiences.</li> <li>• <b>Workforce</b> – staff were mentioned in almost every story, notably in some having the biggest bearing on someone’s experience, both positively and negatively. People noted: <ul style="list-style-type: none"> <li>○ Negative – a lack of understanding / patience for people’s individual needs and what their condition might mean in how they present.</li> <li>○ Negative – the feeling of not being listened to / believed by staff had an impact</li> <li>○ Positive – a positive, kind and caring attitude, focused on the person can make even very difficult situations more manageable.</li> </ul> </li> <li>• <b>Clinical treatment</b> –some people reported that when in crisis, they were left without any help or understanding of where they would get help.</li> <li>• <b>Communication</b> – people told us they sometimes need extra time to process information or alternative ways to communicate, including written options due to some autistic people’s ‘mutism’.</li> <li>• <b>Communication</b> – some people mentioned note making, and inconsistencies between what was discussed and what was written in letters / notes.</li> </ul>

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				<p><b>“ADHD – Leeds” – 2 stories across all Leeds services (GPs, LYPFT)</b></p> <p><b>Satisfaction</b> – both stories reflected negative experiences, however, both noted positive experiences with staff.</p> <ul style="list-style-type: none"> <li>• <b>Resources</b> – difficulty in using the e-consult system was noted - it was hard to explain their difficulties using the categories in the system.</li> <li>• <b>Joint working / communication</b> – a poorly joined up experience with miscommunication and inconsistencies in reporting and planning was noted, leading to a feeling of being bounced between services.</li> </ul>
<p><b>NHS England</b></p>	<p><b>Supporting autistic people in primary care</b></p> <p><a href="https://soundcloud.com/nhsengland/supporting-autistic-people-in-primary-care?in=nhsengland/sets/primary-care-network">https://soundcloud.com/nhsengland/supporting-autistic-people-in-primary-care?in=nhsengland/sets/primary-care-network</a></p>	<p>N/A</p>	<p>2022</p>	<p>An NHS England podcast that explores autism and reasonable adjustments to support autistic people in primary care:</p> <ul style="list-style-type: none"> <li>• <b>Person centred / resources</b> – autistic people can get very anxious about attending health care appointments, needing help from a carer to attend.</li> <li>• <b>Communication / information</b> – providing clear and helpful information before and throughout an appointment can ease the anxiety of autistic people. For some, the fear of what might happen, and sensory overload might be enough to dissuade them from attending an appointment.</li> <li>• <b>Communication</b> – autistic people often struggle with a condition called ‘alexithymia’ meaning they can struggle to identify and describe emotions or what they are feeling, which can make communicating a problem difficult in appointments.</li> <li>• <b>Person centred / environment</b> – autistic people identified that a number of ‘reasonable adjustments’ can make attending GP appointments easier, including: <ul style="list-style-type: none"> <li>○ Longer / double appointments</li> </ul> </li> </ul>



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				<ul style="list-style-type: none"> <li>○ A quiet space separate from main waiting room</li> <li>○ Appointments at the start or end of the day (quieter waiting room)</li> <li>○ Opportunities to alter the environment (turn off / down lights)</li> <li>● <b>Choice</b> – people want the option of attending appointments face to face or digitally.</li> </ul>
Care Quality Commission (CQC)	<p><b>Experiences of being in hospital for people with learning disability and autistic people</b></p> <p><a href="https://www.cqc.org.uk/publication/experiences-being-hospital-people-learning-disability-and-autistic-people/report">https://www.cqc.org.uk/publication/experiences-being-hospital-people-learning-disability-and-autistic-people/report</a></p>	N/A	2022	<p>The CQC carried out a review focusing on what people experience when they need physical health care and treatment in hospital.</p> <ul style="list-style-type: none"> <li>● <b>Person centred / health inequality</b> – people said they found it difficult to access care because reasonable adjustments weren't always made.</li> <li>● <b>Communication / person centred / resources</b> - there is no 'one-size-fits-all' solution for communication. Providers need to make sure that staff have the tools and skills to enable them to communicate effectively to meet people's individual needs.</li> <li>● <b>Involvement in care</b> - people are not being fully involved in their care and treatment. In many cases, this is because there is not enough listening, communication, and involvement. Providers need to make sure that staff have enough time and skills to listen to people and their families so they understand and can meet people's individual needs.</li> <li>● <b>Health inequality</b> - equality characteristics, such as age, race and sexual orientation, risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about inequalities.</li> <li>● <b>Workforce / resources</b> - specialist practitioners and teams cannot hold sole responsibility for improving people's experiences of care. Providers</li> </ul>

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				must make sure that all staff have up-to-date training and the right skills to care for people with a learning disability and autistic people.
NHS England	<p><b>Autism – My Story (a series of video case studies)</b></p> <p><b>Joe -</b> <a href="https://www.youtube.com/watch?v=MDkPO8VGMv8">https://www.youtube.com/watch?v=MDkPO8VGMv8</a></p> <p><b>Rosalind -</b> <a href="https://www.youtube.com/watch?v=pUw2tq3F3Lc">https://www.youtube.com/watch?v=pUw2tq3F3Lc</a></p> <p><b>Adrian -</b> <a href="https://www.youtube.com/watch?v=IO02QTF5eOw&amp;t=117s">https://www.youtube.com/watch?v=IO02QTF5eOw&amp;t=117s</a></p> <p><b>Amy -</b> <a href="https://www.youtube.com/watch?v=tpUY3ti9dJI&amp;t=9s">https://www.youtube.com/watch?v=tpUY3ti9dJI&amp;t=9s</a></p>	Four autistic people involved	2021	<p>NHS England case studies of autistic people, highlighting the difficulties they experience as well as what services / society can do to support autistic people.</p> <ul style="list-style-type: none"> <li>• <b>Communication / person centred</b> - it can be hard to process information at a fast pace.</li> <li>• <b>Communication</b> – it is important to explain rules and why they exist, how things work and what to expect for autistic people.</li> <li>• <b>Transport and travel / resources</b> – some people cannot travel independently and need support from a carer.</li> <li>• <b>Person centred</b> – autistic people need to work with people who will take the time to listen to and understand their needs.</li> <li>• <b>Wider determinants / timely care</b> – people identified that getting a diagnosis and subsequent support, particularly early on, made a big difference in understanding their autism and how it affects them.</li> <li>• <b>Wider determinants</b> – it can be difficult in different settings, such as a workplace, where people don't understand your needs / condition.</li> <li>• <b>Wider determinants</b> – greater public understanding is needed about people having different individual needs.</li> <li>• <b>Wider determinants</b> – people noted the difference it made for family to be open, honest and attentive to their differing needs.</li> <li>• <b>Health inequality / joint working</b> – other diagnoses (such as mental health conditions) should not overshadow someone's autistic needs.</li> </ul>



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West Yorkshire and Harrogate Health and Care Partnership	<p><b>Making health services better with people who are neurodiverse</b></p> <p><a href="https://www.wypartnership.co.uk/application/files/1516/4736/4357/Making_health_services_better_with_people_who_are_neurodiverse_October_2021.pdf">https://www.wypartnership.co.uk/application/files/1516/4736/4357/Making_health_services_better_with_people_who_are_neurodiverse_October_2021.pdf</a></p>	Worked with a number of neurodivergent children and young people and adults as well as their family and carers	2021	<p>The aim of this work was to explore and understand how to support the development of kinder, more compassionate, and effective health and care services with people who are neurodivergent.</p> <ul style="list-style-type: none"> <li>• <b>Communication</b> – neurodivergent people reported having anxiety about being ‘ill enough’ to access services (legitimacy anxiety). People said that when they are reassured, they could receive and relay information effectively about their condition.</li> <li>• <b>Person centred / workforce</b> – kindness from clinicians is effective in helping someone who is neurodivergent and anxious when accessing health and care services. This relates to communication, actions, and behaviours.</li> <li>• <b>Resources</b> – people said they wanted to be known and flagged on records as neurodivergent so that all staff (for example, reception team and doctors) know that additional support maybe needed.</li> <li>• <b>Choice</b> – face to face appointments were preferred to telephone appointments.</li> <li>• <b>Communication / information</b> – additional information that explains the appointment experience and how to make the most of appointments (including pre-appointment preparation) are useful. These can be done via videos or other visual aids.</li> <li>• <b>Workforce</b> – people spoke of anxiety with reception staff; that they were unsure that staff would be welcoming and friendly, and not feeling confident that any additional needs would be picked up and then catered to.</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<ul style="list-style-type: none"> <li>• <b>Wider determinants / COVID-19</b> – people noted the impact the COVID-19 pandemic has had on people’s understanding of the hidden disabilities’ lanyard, noting that some people only take it to mean exemption from mask wearing.</li> <li>• <b>Environment / information</b> – waiting areas can generate a lot of anxiety for neurodivergent people. <ul style="list-style-type: none"> <li>○ Clear information and knowledge about what to expect can help with this.</li> <li>○ Have clear updates on waiting times and instructions on when to check to ensure you haven’t been forgotten and other things (e.g. ask for the key if you need the toilet).</li> <li>○ Many people liked the electronic check-in screens.</li> <li>○ Suggestion for use of electronic call pads (like in restaurants).</li> <li>○ Access to distractions (including details on using Wi-Fi, access to fidget toys / books etc.).</li> <li>○ Where possible, facilitate a quiet room / more private waiting area.</li> </ul> </li> <li>• <b>Timely care</b> – a suggestion was that neurodivergent people could be given priority in a waiting room to assist with anxiety and help the person be at their best to engage in their care.</li> <li>• <b>Person-centred / communication / workforce</b> – people said that they often need ‘processing time’ to think about a question or conversation and answer, clinicians need to ensure they are not rushing neurodivergent people. Staff may need additional training / awareness for the best ways to communicate with neurodivergent people.</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<ul style="list-style-type: none"> <li>• <b>Involvement in care</b> – some people shared that they had opinions about their diagnosis / treatment and that the GP didn't listen and dismissed them. It is important for neurodivergent people to be believed.</li> <li>• <b>Involvement in service development</b> – people identified that there is an opportunity for neurodivergent people to share their learning and create resources to help others. People should also be involved in designing services so that they are designed for everyone, not just the majority.</li> </ul>
<b>Healthwatch Leeds</b>	<p>What can health and care providers do to play their part in addressing health inequalities?</p> <p><a href="https://healthwatchleeds.co.uk/wp-content/uploads/2021/07/Health-inequalities-report_FINAL.pdf">https://healthwatchleeds.co.uk/wp-content/uploads/2021/07/Health-inequalities-report_FINAL.pdf</a></p>	<p>Spoke with Leeds Autism AIM and People in Action</p>	<p>2021</p>	<p>Healthwatch Leeds spoke with a number of third sector organisations on what services can do to improve their offer for the people they work for.</p> <p><b>Autism</b></p> <ul style="list-style-type: none"> <li>• <b>Resource</b> - people may need support to get to a GP appointment – this can be a problem if there aren't family networks or access to support workers.</li> <li>• <b>Person centred</b> – people said that continuity of care is important, and that for autistic people, retaining information can be difficult. It was queried if it could be standard practice for GPs to put advice in writing so that people with autism can take it away. Also queried if priority access to the same GP be given to people with autism</li> <li>• <b>Health inequality</b> - not all people with autism are flagged or asked about autism when talking about reasonable adjustments on service's systems – autistic people might not know whether to tell someone about it.</li> <li>• <b>Person centred</b> – for autistic people, processing time can be slower. It was queried as to whether their appointment times be extended as a matter of practice, instead of leaving it up to the patient to book extended sessions.</li> </ul>

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				<ul style="list-style-type: none"> <li>• <b>Workforce / resources</b> – it was noted that there is a variation in receptionists’ awareness of autism.</li> <li>• <b>Environment</b> – it was fed back that a quiet waiting room would be preferable for autistic people due to sensory sensitivities.</li> <li>• <b>Workforce / health inequalities / resource</b> – it was fed back that doctors’ understanding of autism varies widely (with some people thinking doctors “don’t believe” in autism). Autism awareness training (including information on how some people respond to questions) would be beneficial.</li> <li>• <b>Choice / information</b> – people told us that e-Consult can be useful, as people don’t need to speak to the receptionist. However, a lot of the questions can be confusing. For example, it might ask what the problem is, then ask what the symptoms are. This can result in people with autism giving up. It would help if there was some guidance for each question.</li> </ul> <p><b>Learning disabilities</b></p> <ul style="list-style-type: none"> <li>• <b>Timely care / workforce</b> – people told us that medication reviews for people with learning disabilities don’t always happen.</li> <li>• <b>Satisfaction</b> – people told us that there was variation in the delivery of annual health checks for people with learning disabilities in terms of effectiveness and implementation.</li> <li>• <b>Joint working</b> - people told us that there needs to be more of a joined-up approach between health, individual, families, and support organisations.</li> <li>• <b>Information</b> – people fed back that accessible information should be readily available as needed.</li> <li>• <b>Involvement in service development</b> – people told us that services should be designed with people with learning disabilities in mind, involving</li> </ul>

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				them in service design would make a big difference to ensure that services are designed for them.
Healthwatch Leeds	<b>Supporting people to be more involved in their health and care</b>  <a href="https://healthwatchleeds.co.uk/reports-recommendations/2021/supporting-people-to-be-involved-in-their-health-report/">https://healthwatchleeds.co.uk/reports-recommendations/2021/supporting-people-to-be-involved-in-their-health-report/</a>	79 people –  Survey via focus groups with people who experience disproportionately low or inadequate health literacy including people with disabilities.	2021	Healthwatch Leeds worked in partnership with Leeds City Council (Public Health) and partners to find better ways to support individuals and their carers to understand the health information they receive about their care and treatment: <ul style="list-style-type: none"> <li>• <b>Person centred / communication</b> - a number of people told us they were not asked about their communication needs or that their preferred communication needs were not met.</li> <li>• <b>Involvement in care</b> - some people felt they could not ask questions at their appointment.</li> <li>• <b>Information</b> – people fed back on the tools provided as options, there was support for them, the most popular being 'It's OK to ask' (page 17).</li> </ul>
Healthtalk	<b>Learning disability and health stories</b>  <a href="https://healthtalk.org/Learning-disability-and-health/overview">https://healthtalk.org/Learning-disability-and-health/overview</a>	Nine people with learning disabilities	2019	Nine people with learning disabilities told their story about accessing health and care services through videos. Locations of care services are not identified. <ul style="list-style-type: none"> <li>• <b>Person centred / resources / environment</b> – one person (Gabrielle) spoke about safety and how a stay in hospital led her to be injured. This was due to the bath / shower not having the same safety features that she has at home (such as non-slip bathmats).</li> <li>• <b>Travel and transport / timely care / resources</b> – one person (Kristian) spoke about losing an appointment and having to wait four months for another one due to a lack of transportation to get to the appointment. The</li> </ul>

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				<p>person's mother had not been contacted so didn't know about the issue with transportation, as they could have driven.</p> <ul style="list-style-type: none"> <li>• <b>Communication / involvement in care / health inequality</b> – one person (Paul) spoke about difficulties with an ambulance crew as he was deaf and couldn't communicate with them. His wife told them about this, but they didn't listen, and it took a porter who knew the person to say the same thing, so the ambulance crew had to drive back to get it.</li> <li>• <b>Wider determinants / resources / information</b> – one person (Tracy) spoke about her diabetes and how she was unaware of the 'hidden sugars' in the ready meals she cooks as they are easier for her, which staff believe contributed to her diabetes. She says she wishes she had more information / support around this.</li> <li>• <b>Wider determinants / resource / timely care / health inequality</b> – one person (Nigel) spoke about the four months wait for special mobility shoes that he needed; he was told they would take four weeks. Had to wear slippers everywhere, including going out and on the bus. He reports being subject to bullying and getting weird looks and feeling silly and upset.</li> <li>• <b>Communication</b> – one person (Neal) spoke about when he was diagnosed with Type 1 diabetes and how the doctor didn't explain what diabetes was or where it came from to help him understand.</li> <li>• <b>Health inequality / person centred / resources</b> – one person (Kevin) spoke about an experience whilst he was staying in hospital and his dad was admitted to the same hospital. Kevin wanted to visit his dad on the ward, but the staff didn't believe that he was his father's son so wouldn't let him see his dad until his brother's wife told them. Kevin said that the staff need training on working with people with learning disabilities.</li> </ul>



Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<ul style="list-style-type: none"> <li>• <b>Health inequality / person centred</b> – one person (Andy) described an experience at Christmas where his brother, who also has a learning disability, had a fit and the paramedics assumed that Andy and his brother were drunk and didn't listen to Andy when he explained that they both had learning disabilities.</li> <li>• <b>Satisfaction / workforce</b> – one person (Pam) described a visit to hospital following an overdose where staff were rude and abrupt to her. She didn't like this so discharged herself, with a needle still in her hand. The police were called to bring her back to hospital and then she was allowed to go after they sorted the needle. Was supposed to see a psychiatrist but didn't.</li> </ul>
NHS Leeds CCG	<p><b>Urgent Treatment Centres – Autism Hub drop-in session</b></p> <p><a href="https://webarchive.nationalarchives.gov.uk/ukgwa/2020902102412/https://www.leedsccg.nhs.uk/get-involved/your-views/urgent-treatment-centres/">https://webarchive.nationalarchives.gov.uk/ukgwa/2020902102412/https://www.leedsccg.nhs.uk/get-involved/your-views/urgent-treatment-centres/</a></p>	Six people took part in the drop-in session	2019	<p>This engagement aimed to talk to people about the proposals to bring five Urgent Treatment Centres (UTCs) to Leeds. Part of this work involved reaching out to specific communities. One of the groups contacted was the Leeds Autism Hub who hosted a drop-in session.</p> <ul style="list-style-type: none"> <li>• <b>Information</b> – people told us about the need to communicate and raise awareness, specifically, about UTCs; what they are and what they are for, was highlighted as very important. A suggestion was made that we outline the process, perhaps using some real examples so people know exactly what will happen.</li> <li>• <b>Communication</b> - keeping patients in the loop when they are in services was identified as very important. When you are waiting for a long time, for example at A&amp;E, it can be difficult for people with autism to know what is going on and to worry that they have been missed or forgotten about. It's important to find a way to provide updates or keep people in the loop. A</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<p>poster at Leeds General Infirmary (LGI) that explains how A&amp;E works was identified as being very useful.</p> <ul style="list-style-type: none"> <li>• <b>Environment</b> - The waiting environment was mentioned as being an important element to consider. For people with autism, the environment can be very stressful / overwhelming due to the busyness, loud noises etc. This can add to an already stressful situation of needing urgent/emergency health care and might be so daunting to some that they might not go at all.</li> <li>• <b>Environment and information</b> - People told us that it is very difficult to go to A&amp;E, especially if you have autism:             <ul style="list-style-type: none"> <li>○ It's a very big and overwhelming environment</li> <li>○ A quiet waiting area for people who were more hyper-sensitive to certain things would be a great help – can this be considered for the new hospital and UTCs?</li> <li>○ It can be a scary experience, people with autism benefit from knowing what is going to happen and if there was a process clearly mapped out as to what is going to happen when you go to A&amp;E (or other services) it would be very helpful.</li> <li>○ Another person told us that it isn't clear what "you're supposed to do".</li> </ul> </li> <li>• <b>Communication</b> - people told us that differentiating between the terms 'urgent' and 'emergency' is very difficult. What's urgent and what's an emergency?</li> <li>• <b>Resources and workforce</b> - people told us that there needs to be reasonable adjustments for people with specific needs:</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<ul style="list-style-type: none"> <li>○ People told us that some places have the ‘flag’ come up that they have autism or other additional need but then don’t change their behaviours or are accommodating</li> <li>○ One example given was that the patient had explained they were autistic and the reception staff replied, “I can see that here” and then handed them a daunting looking survey with little instruction or explanation.</li> <li>○ People told us that they were subjected to poor attitudes and a lack of information as to what was happening regarding tests and diagnoses, with one staff member asking, “are we doing the scary one?” and “this is going to hurt you know?”, without any information about what they are testing for.</li> <li>○ It was fed back that some people have had staff who have not taken the time to listen or pay attention to what an autistic person is saying. This is distressing for them and not doing anything to help.</li> <li>● <b>Information</b> - one person commented that they were surprised that the Accessible Information Standard wasn’t being followed in this respect as they didn’t feel able to communicate as they were not being properly informed as to what is going on.</li> <li>● <b>Workforce</b> - people told us that staff need to be appropriately trained and to ask if people have specific needs or additional support, especially if it is flagged on the system.</li> <li>● <b>Person centred</b> - a person centred approach and awareness and understanding of mental health, autism, learning disability is needed so that delivery of information is in a way that is understandable.</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
				<ul style="list-style-type: none"> <li>• <b>Information</b> - Some people who are autistic might not go to A&amp;E unless they are told to as some people follow the rules and won't know / think to go there in an emergency unless it is expressly said.</li> <li>• <b>Communication</b> - an instructional video / DVD might be of benefit to people who may struggle to understand the changes.</li> </ul>
<p><b>Advances in Autism Journal</b></p>	<p><b>Are we good and are we safe? Measuring quality and assessing risk in an adult autism diagnostic service</b></p> <p><a href="https://www.leedsandyorkpft.nhs.uk/our-services/wp-content/uploads/sites/2/2018/01/Are-we-good-and-are-we-safe-Measuring-quality-and-assessing-risk-in-an-adult-autism-diagnostic-service.pdf">https://www.leedsandyorkpft.nhs.uk/our-services/wp-content/uploads/sites/2/2018/01/Are-we-good-and-are-we-safe-Measuring-quality-and-assessing-risk-in-an-adult-autism-diagnostic-service.pdf</a></p>	<p>164 users of the autism diagnostic services were invited to respond to the service evaluation</p>	<p>2017</p>	<p>The aim of the paper was to describe the approach taken to measure the quality of the service and accurately assess risk in autistic adults.</p> <ul style="list-style-type: none"> <li>• <b>Clinical treatment</b> – people told us that there was a lack of follow-up appointments after receiving a diagnosis of autism.</li> <li>• <b>Health inequality</b> – there were inconsistencies with additional support being accessed by people, post diagnosis.</li> </ul>
<p><b>NHS Leeds West CCG</b></p>	<p><b>Improving access to primary care for people with learning disabilities</b></p> <p><a href="https://webarchive.nationalarchives.gov.uk/ukgwa/2020902102656/https://www.leedsccg.nhs.uk/get-involved/your-">https://webarchive.nationalarchives.gov.uk/ukgwa/2020902102656/https://www.leedsccg.nhs.uk/get-involved/your-</a></p>	<p>232 people contributed to this engagement</p> <p>139 patients</p>	<p>2015</p>	<p>This engagement asked people with a learning disability, their carers and families, what their experiences were around accessing primary care services:</p> <ul style="list-style-type: none"> <li>• <b>Satisfaction</b> – people were generally happy with the service.</li> <li>• <b>Information</b> – people want to receive reminders of their appointments in accessible formats.</li> <li>• <b>Choice</b> – patients want it to be easier to make appointments at times that suit their needs.</li> </ul>

Source	Publication	No of participants and demographics	Date	Key themes relating to learning disability and neurodivergence experience
	<a href="#">views/improving-access-primary-care-people-learning-disabilities/</a>			<ul style="list-style-type: none"> <li>• <b>Communication</b> – information from clinicians was not always clearly explained.</li> <li>• <b>Timely care</b> – surgeries running late made patients anxious and stressed.</li> <li>• <b>Health inequality</b> – wheelchair access into waiting rooms can be a problem.</li> <li>• <b>Workforce</b> - GPs and staff should have more awareness of the needs of people with learning disabilities.</li> <li>• <b>Involvement in care</b> – some people felt that they were not being listened to. A number of people felt that GPs and staff didn't speak to them but spoke to their carer instead.</li> <li>• <b>Person centred</b> - a small number of patients felt that they would be more comfortable in their appointments if they were shown around the surgery.</li> <li>• <b>Person centred</b> - a few patients told us that sometimes due to their more complex needs home visits are sometimes more appropriate.</li> </ul>

### Additional Reading

- NHS England - Autism Research Strategy (2022): <https://www.england.nhs.uk/wp-content/uploads/2022/03/B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf>
- West Yorkshire and Harrogate Health and Care Partnership – Mental health, Learning Disability and Autism Strategy, 2019 – 2024: <https://www.england.nhs.uk/wp-content/uploads/2022/03/B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf>
- Right Conversation Right Time Guide: <https://www.altogetherbetter.org.uk/allresources/2018/9/7/right-conversation-at-the-right-time-appointment-guide>
- NHS Long Term Plan – Learning disability and autism: <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism/>

- Leeds Autism AIM - Making information accessible for neurodivergent people:  
<https://www.wypartnership.co.uk/application/files/3716/4735/6437/making-information-accessible-for-neurodivergent-people-final-v2-20.04.21.pdf>



## 6. Inequalities Review

We are committed to tackling health inequalities in Leeds. Understanding the experiences, needs and preferences of people with protected characteristics is essential in our work. This section of the report outlines our understanding of how care for people with a learning disability and who are / or are neurodivergent is experienced (as outlined in the Equality Act 2010 – [Appendix D](#)).

Please note that we are aware that the terminology used in relation to the recognition of a person's identity may depend on the context of its use. Some people may define some terms differently to us. We have tried to use terminology that is generally accepted. Please do get in touch if you would like to discuss this further.

Protected Characteristic	Insight
Age	<p>People's age risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about equalities.</p> <p><b>(Experience of being in hospital for people with learning disability and autistic people, 2022)</b></p>
Disability	<p>Autistic people often experience 'alexithymia' which can make it difficult to identify and describe emotions, which can make communication in health and care settings difficult</p> <p><b>(Supporting autistic people in primary care, 2022).</b></p> <p>7 in 10 people with a learning disability have experiences of some kind of hate crime in the UK</p> <p><b>(Being Me Strategy, 2018)</b></p> <p>In Leeds, there are approximately 7,500 autistic people.</p> <p>Up to 30% of people with a learning disability are likely to be autistic as well.</p> <p>It is estimated that there are around 5,000 people in Leeds who are autistic and receive no social care or specialist health support.</p> <p><b>(Leeds Adult Autism Strategy, 2017)</b></p>
Gender (sex)	<p>At present, we have been unable to source any local evidence relating to gender (sex).</p>
Gender reassignment	<p>At present, we have been unable to source any local evidence relating to gender reassignment.</p>

Protected Characteristic	Insight
Marriage and civil partnership	At present, we have been unable to source any local evidence relating to marriage and civil partnership.
Pregnancy and maternity	At present, we have been unable to source any local evidence relating to pregnancy and maternity.
Race	<p>People’s race risked being overshadowed by a person’s learning disability or autism because staff lacked knowledge and understanding about equalities.</p> <p><b>(Experience of being in hospital for people with learning disability and autistic people, 2022)</b></p>
Religion or belief	At present, we have been unable to source any local evidence relating to religion or belief.
Sexual orientation	<p>People’s sexual orientation risked being overshadowed by a person’s learning disability or autism because staff lacked knowledge and understanding about equalities.</p> <p><b>(Experience of being in hospital for people with learning disability and autistic people, 2022)</b></p>
Homelessness	At present, we have been unable to source any local evidence relating to homelessness.
Deprivation	<p>65 of every 100 people with a learning disability would like a paid job, but only six in a 100 have one.</p> <p><b>Being Me Strategy (2018)</b></p>
Carers	<p>Carers have sometimes felt unheard or not involved in care or decisions. They have also reported feeling instances of feeling excluded.</p> <p><b>(How does it feel for me? – Emma and Adam’s story, 2023)</b></p>
Access to digital	<p>People have fed back about liking the option to have online or telephone type appointments as it saves from extra stressors such as travel.</p> <p><b>(How does it feel for me? – Emma and Adam’s story, 2023)</b></p> <p>Some people have found using online services, such as e-consult, difficult to use as the categories felt restrictive to what someone was trying to detail.</p> <p><b>(Care Opinion feedback, 2016-2023)</b></p>

<b>Protected Characteristic</b>	<b>Insight</b>
Served in the forces	At present, we have been unable to source any local evidence relating to serving in the forces.

## 7. Gaps and considerations

This section explores gaps in our current insight and suggests areas that may require further investigation. This does not mean that the insight isn't available, just that it isn't currently available to us to include in this report.

### Gaps identified in the report:

- Local feedback from service users of:
  - Leeds Autism Diagnostic Services (LADS)
  - Adult Attention Deficit Hyperactivity Disorder (ADHD) service
  - Community Learning Disability Team (CLDT)
  - Learning Disability Inpatient services
  - Learning disability specialist health planned care
- People with neurodivergent conditions that aren't autism (such as ADHD, Dyslexia (words), Dyspraxia (movement), Dysphasia (language), Dyscalculia (numbers) or Tourette's syndrome).
- People from diverse ethnic communities (told us we need to do more to work with them to develop services, in particular people whose first language is not English).
- People from areas of deprivation in the city.
- People from LGBTQIA+ communities, including people who are transgender.
- Experience from previous engagement work has identified working age people as one of the more difficult groups to involve due to being at work when engagement activities are often held, during the day, on weekdays.
- Experience from previous engagement work has identified that carers can find it difficult to be actively involved or spend time taking part in involvement activities due to their caring responsibilities.
- Considerations need to be made around ensuring offline stakeholders (people who do not / can't access the internet or technology) are engaged and effort is made to reach out locally, to where people are.
- Information connecting people's experiences with potential health inequalities linked to the protected characteristics (as outlined in the Equality Act, 2010).
- Feedback from staff working in learning disability and neurodivergence services.

### Additional gaps and considerations identified by stakeholders

- Can the correct language be used? I'm constantly seeing neurodivergence and neurodiverse being used interchangeably. They are not the same. Please start calling your workstream 'learning disability and neurodivergency.' Unless you actually mean 'everyone' when you keep referring to neurodiversity - both neurodivergent and neurotypical? There are so many online resources which explain the difference... why is the ICB using the incorrect terms? (**Leeds Bereavement Forum**).
- Feedback we've had from people with lived experience and speaking to other organisations like NAS and AIM is that that differentiation (neurodiversity vs. neurodivergence) is important to people, particularly with Autistic people who tend to use identity first language. This isn't the case for everybody but from anecdotal experience and discussions with our co-production group, that's my understanding of what people's general preferences are (**Touchstone**).

## **Next steps – What happens next?**

We would like to outline our next steps to demonstrate how this insight report will be used to improve learning disability and neurodivergence care in Leeds.

### **a. Add the report to the Leeds Health and Care Partnership website**

We will add the report to our website and use this platform to demonstrate how we are responding to the findings in the report: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/populations/ld-nd/>

### **b. Hold a workshop with key partners in the spring**

We will meet with key stakeholders in the spring to

- Describe our learning disability and neurodivergence work in Leeds
- Outline and agree the findings of this report
- Identify and agree additional gaps
- Plan involvement work to understand the gaps in our knowledge
- Co-produce an approach to involving the public in shaping health and care services for people with a learning disability and who are / or are neurodivergent in Leeds.

### **c. Explore how we feedback our response to this report**

We will work with partners to feedback to the public on how this insight is helping to shape local services.

## Appendix A: Key partners

It is essential that we work with key partners when we produce insight reports. This helps us capture a true reflection of people's experience and assures us that our approach to insight is robust. To create this insight report on learning disability and neurodivergence, we are working with the following key stakeholders:

### Board members

Name	Organisation
Jez Coram	Forum Central (Third sector rep)
Caroline Baria	Leeds City Council - Adults and Health
Max Naismith	Leeds City Council - Adults and Health
Steph Lawrence	Leeds Community Healthcare NHS Trust
Mo Drake	Leeds Community Healthcare NHS Trust
	Leeds Teaching Hospitals NHS Trust
Mark Dodd	Leeds and York Partnership NHS Foundation Trust
Sam Browning	NHS West Yorkshire ICB in Leeds
Eddie Devine	NHS West Yorkshire ICB in Leeds
	Primary Care
Caron Walker	Public Health

### Third sector and public representatives

Name	Organisations
	Advonet
	Affinity Trust
Katty Keyhani	Alzheimer's Society
Iain Anderson	Age UK Leeds
	Artlink West Yorkshire
	Asha Neighbourhood Project
	Aspire Community Benefit Society
	Avalon
	BARCA
	Barnados
	Battle Scars
	Better Action for Families
	Better Leeds Communities
	BHA
	Big Issue North
	Black Health Initiative
Claire Turner	Carers Leeds
Sharon Brooks	Care & Repair Leeds
	CATCH
	Catholic Care
	Ciaran Bingham Foundation Trust
	Citizen's Advice Leeds



	Community Integrated Care
	Community Links
	Connect in the North
	Creative Support
	Dark Horse Theatre
	DIAL Leeds
	Dimensions
	DREAM Leeds
	Emmaus
	Equine Pathways UK
	FDM (For Disability Mobility)
Karl Witty	Forum Central
Sarah Wilson	Forum Central
	GIPSIL
	Groundwork Leeds
	Hamara Centre
	Haqooq
	Health for All
	Healthwatch Leeds
	Hft
	Homelife
	Inspire North
Nicola Smith	ICB project support
	ICB Volunteer
	Leeds Autism Services
	Leeds Black Elders Association (LBEA)
	Leeds Citizens
	Leeds Mencap
James Woodhead	Leeds Neighbourhood Networks Scheme
	Leeds Involving People
	Leeds Islamic Centre
	Leeds Jewish Welfare Board
Ali Kaye	Leeds Older People's Forum
	Leeds Society for Deaf and Blind
	Leeds University Union Neurodivergent Society
	Leeds Weekend Care Association
	Leeds Women's Aid
	Leep1
	Lighthouse Futures Trust
	Linking Leeds
Rachel Ainscough	Local Care Partnerships Development Team
Kim Adams	Local Care Partnerships Development Team
	Meanwood Valley Urban Farm
	Mind
	Mindmate
	Mind Matters Society – Leeds Universities Unions
	Mind the Gap
	Mindwell

Nicolas Allen	NHS West Yorkshire ICB in Leeds
Amy Rebane	NIHR Leeds Biomedical Research Centre
	PAFRAS
	Paperworks
	People in Action
	People Matters
	Pluss
	Project 52
	Purple Patch Arts
	Pyramid
	Real Life Options
	Right Choices
	Scope
	Sikh Mental Health and Wellbeing
	Slate
	SNAPS
	SOLACE
	Space2
	Specialist Autism Services
	St. Anne's Community Services
	St. John of God Hospitaller Services
	Stop Hate UK
	Swarthmore Education Centre
	The Conservation Volunteers
	Thera Trust
	Together Women
	Touchstone
	Turning Lives Around
	United Response
	University of Leeds Student Counselling and Wellbeing Service
	West Yorkshire Community Chaplaincy Project
	The Wilf Ward Family Trust
	William Merritt Centre
	Women's Health Matters
	Women's Lives Leeds
	Voluntary Action Leeds
	YAMSEN (Yorkshire Association for Music and Special Educational Needs)
	Yorkshire MESMAC
	Young Lives Leeds

## Networks and partnerships

Contact	Group
	Alliance of Experts by Experience
	Leeds Asylum Seekers Support Network
Francesca Wood	Leeds Health and Care Partnership Third Sector Reference Group
Hannah Davies	People's Voices Partnership
	Service User Network



## Appendix B: Learning disability and neurodiversity Outcomes Framework

Learning Disability and Neurodiversity Population Outcome Framework		
Link to Healthy Leeds Plan Strategic Indicators		
Health Outcome Ambitions	System Activity Metrics	Quality Experience Measures
Improve healthy life expectancy Reduce premature mortality for those with LD and SMI	Increase expenditure on the 3 <sup>rd</sup> Sector Increase proportion of people being cared for in primary and community services	Improve the experience of those using: <ul style="list-style-type: none"> <li>- Primary care services</li> <li>- Community services</li> <li>- Hospital services</li> </ul> Person centred co-ordinated care experience P3C-EQ
Outcome	Outcome Measure	Process Measure
<b>1 I live well, defined by what matters to me</b>	Increase the life/healthy life expectancy for people living with a learning disability and/or Neurodivergence	Number of people in paid/employment, training, apprentices, internships, higher education (inc. T-Levels) <b>include sick notes – long term sickness</b> % people <b>in settled accommodation</b> % people with <b>goal setting personal plans in place and attainment rates</b> Number of people presenting in a crisis Peer led reviews e.g. Number of good lives leaders or results/feedback from good lives leaders work Reduction in suicide rates for people living with a learning disability and/or neurodivergence TCP rate
<b>2 I receive high quality, accessible person-centred care and support</b>	Reduced experience of death from condition amenable to health intervention Reduced premature mortality	Number of people registered with their GP as having a learning disability and/or Neurodivergence Providers adherence to learning disability standard implementation/reasonable adjustments standard – <b>how?</b> Increase in the number of annual health checks completed Increase in screening rates Increase in vaccination rates Access/service utilisation (poor access to long covid clinics) Increase number in Care and treatment reviews Health related quality of life measure Green Light Toolkit Timely access to diagnostic services – ADHD/autism assessment wait times – <b>incl medication waiting lists</b> Staff training to support people with LD/N – <b>training people to identify</b> Transition measure (EHCP?) ASC assessments % Access to mental health services Diagnostic services – LADS and others for each condition – is in place and successful
<b>3 I am included in all decisions made about my life</b>	Shared decision making person reported experience measure	# completed patient led health action plan # of people with a personal health budget Advocacy measure

## Learning disability and neurodiversity population outcomes framework

Link to Healthy Leeds Plan strategic indicators:

- **Health outcome ambitions**
  - Improve healthy life expectancy
  - Reduce premature mortality for those with LD Sector and SMI
- **System activity metrics**
  - Increase expenditure on the third sector
  - Increase the proportion of people being cared for in primary and community services
  - Reduce the rate of growth in non-elective bed days and A&E attendances.
- **Quality experiences measures**
  - Improve the experience of those using:
    - Primary care services
    - Community services
    - Hospital services
  - Person-centred co-ordinated experience.

Outcome	Outcome measure	Process measure
1. I live well, defined Increase the by what matters life/healthy life to me	<ul style="list-style-type: none"> <li>• Increase the life / healthy life expectancy for this population</li> </ul>	<ul style="list-style-type: none"> <li>• Number of people in paid / employment, training, apprentices, internships, higher education (inc. T-Levels) link to CYP re education</li> <li>• Personal goal setting and attainment</li> <li>• Reduction in people presenting in a crisis</li> <li>• Peer led reviews e.g. good lives leaders</li> <li>• Access to mental health services</li> <li>• Reduction in suicide rates for this population</li> <li>• TCP - people get to stay in area</li> <li>• Universal credits/other support services</li> <li>• Third sector qualitative feedback / living well survey results e.g. Chapeltown CAB 1/4ly data</li> </ul>
2. I receive high quality, accessible, person-centred support	<ul style="list-style-type: none"> <li>• Reduced experience of death from condition amenable to health intervention</li> <li>• Reduced premature mortality</li> </ul>	<ul style="list-style-type: none"> <li>• Number of people registered with their GP as having a learning disability and/or Neurodivergence</li> <li>• Providers adherence to learning disability standard implementation/reasonable adjustments standard – how?</li> <li>• Increase in the number of annual health checks completed</li> <li>• Increase in screening rates</li> <li>• Increase in vaccination rates</li> <li>• Access/service utilisation (poor access to long covid clinics)</li> <li>• Increase number in Care and treatment reviews</li> <li>• Health related quality of life measure</li> <li>• Green Light Toolkit</li> </ul>

Outcome	Outcome measure	Process measure
		<ul style="list-style-type: none"> <li>• Timely access to diagnostic services – ADHD / autism assessment wait times – including medication waiting lists</li> <li>• Staff training to support people with LD/N – training people to identify</li> <li>• Transition measure (EHCP?)</li> <li>• ASC assessments</li> <li>• % Access to mental health services</li> <li>• Diagnostic services – LADS and others for each condition – is in place and successful</li> </ul>
3. I am included in all decisions made about my life	<ul style="list-style-type: none"> <li>• Shared decision-making person reported experience measure</li> <li>• DNACPR</li> </ul>	<ul style="list-style-type: none"> <li>• Number of completed patient led health action plan</li> <li>• Number of people with a personal health budget</li> <li>• Advocacy measure</li> <li>• Universal credits/other support services</li> <li>• DNACPR</li> <li>• MHCA adherence</li> </ul>

## Appendix C: Involvement themes

The table below outlines key themes used in our involvement and insight work. The list is not exhaustive and additional themes may be identified in specific populations.

Theme	Description	Examples
<b>Choice</b>	Being able to choose how, where and when people access care. Being able to choose whether to access services in person or digitally	People report wanting to access the service as a walk-in patient. People report not being able to see the GP of their choice
<b>Clinical treatment</b>	Services provide high quality clinical care	People told us their pain was managed well
<b>Communication</b>	Clear communication and explanation from professionals about services, conditions and treatment.	People report that they're treatment was explained in a way that they understood
<b>Covid-19</b>	Services that are mindful of the impact of Covid-19	People report the service not being accessible during the pandemic
<b>Environment</b>	Services are provided in a place that is easy to access, private, clean and safe and is a way that is environmentally friendly and reduces pollution	People report that the waiting area was dirty
<b>Health inequality</b>	Services are provided in a way that meet the needs of communities who experience the greatest health inequalities.	Older people report not being able to access the service digitally
<b>Information</b>	Provision of accessible information about conditions and services (leaflets, posters, digital)	People report that the leaflet about their service was complicated and used terms they did not understand
<b>Involvement in care</b>	Involvement of people in individual care planning and decision-making.	People told us they were not asked about their needs and preferences
<b>Involvement in service development</b>	Involvement of people in service development. Having the opportunity to share views about services and staff.	People told us that they were given an opportunity to feedback about the service using the friends and family test
<b>Joint working</b>	Care is coordinated and delivered within and between services in a seamless and integrated way	People report that their GP was not aware that they had been admitted to hospital
<b>Person centred</b>	Receiving individual care that doesn't make assumptions about people's needs. Being treated with dignity, respect, care, empathy and compassion. Respecting people's choices, views and decisions	People report that their relative died in the place they wanted



<b>Resources</b>	Staff, patients and their carers/family/friends have the resources and support they need	Family reported that adaptations to the house took a long time to be made
<b>Satisfaction</b>	Services are generally satisfactory	Most people told us that they were very happy with the service.
<b>Timely care</b>	Provision of care and appointments in a timely manner	People report waiting a long time to get an appointment
<b>Workforce</b>	Confidence that there are enough of the right staff to deliver high quality, timely care	People raised concerns that the ward was busy because there were not enough staff
<b>Transport and travel</b>	Services are provided in a place that is easy to access by car and public transport. Services are located in a place where it is easy to park.	People report poor local transport links People report good access to parking
<b>Wider determinants</b>	Services and professionals are sensitive to the wider determinants of health such as housing	People told us that their housing had a negative impact on their breathing

## Appendix D: Protected characteristics (Equality and Human Rights Commission 2016)

1. **Age** - Where this is referred to, it refers to a person belonging to a particular age (for example 32 year olds) or range of ages (for example 18 to 30 year olds).
2. **Disability** - A person has a disability if she or he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.
3. **Gender (Sex)** - A man or a woman.
4. **Gender reassignment** - The process of transitioning from one gender to another.
5. **Marriage and civil partnership** - Marriage is no longer restricted to a union between a man and a woman but now includes a marriage between a same-sex couple. [1] Same-sex couples can also have their relationships legally recognised as 'civil partnerships'. Civil partners must not be treated less favourably than married couples (except where permitted by the Equality Act).
6. **Pregnancy and maternity** - Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.
7. **Race** - Refers to the protected characteristic of Race. It refers to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.
8. **Religion or belief** - Religion has the meaning usually given to it but belief includes religious and philosophical beliefs including lack of belief (such as Atheism). Generally, a belief should affect your life choices or the way you live for it to be included in the definition.
9. **Sexual orientation** - Whether a person's sexual attraction is towards their own sex, the opposite sex or to both sexes.

### Other characteristics

Other protected characteristics identified by the ICB in Leeds include:

- **Homelessness** – anyone without their own home
- **Deprivation** – anyone lacking material benefits considered to be basic necessities in a society
- **Carers** - anyone who cares, unpaid, for a family member or friend who due to illness, disability, a mental health problem or an addiction
- **Access to digital** – anyone lacking the digital access and skills which are essential to enabling people to fully participate in an increasingly digital society
- **Served in the forces** – anyone who has served in the UK armed forces