healthwatch Walsall

The Experiences of Neuro-diverse People of Accessing and Using Healthcare

Report

July 2026

Engaging Communities Solutions

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Abbreviations

ADHD = Attention Deficit Hyperactivity Disorder

Introduction

Healthwatch Walsall is the independent voice of the public in health and social care in Walsall. We gather feedback from the public through engagement and projects and use that feedback to work with health and social care providers and commissioners to improve service delivery.

Background to undertaking this research

Healthwatch Walsall undertook this research following feedback from local neurodiverse service users about their experiences of accessing and using health services. Concerns were identified through a range of engagement activities, including face-to-face community engagement, discussions on local social media platforms and evidence gathered through the **Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR)** programme.

Feedback highlighted that some neurodiverse service users experience barriers when accessing both primary and secondary healthcare services. These included challenges in navigating services, communication, and the overall patient journey. Similar issues have also been identified nationally through the LeDeR programme, which is commissioned by NHS England to improve understanding of the experiences and outcomes of people with a learning disability and autistic people.

In light of this evidence, Healthwatch Walsall considered it important to build a local picture about neurodiverse service users experiences of accessing and using health services. The findings from this research will help identify where services are working well, highlight areas for improvement and provide evidence to support service development that better meets the needs of local people.

Methodology

This research used a mixed-methods approach, combining quantitative and qualitative research methods to provide both measurable findings and a deeper understanding of people's experiences.

Quantitative data was collected through a structured survey, while qualitative evidence was gathered through personal stories and focus groups. The qualitative element was particularly important in providing greater context, insight and depth to participants' experiences of accessing and using health services.

Survey responses were collected through face-to-face engagement with participants, as well as via the Healthwatch Walsall website and Facebook platform. Efforts were made to include participants from a range of demographic backgrounds to ensure a broad representation of experiences. All participants were residents of Walsall.

Ethical Considerations

Participation in the research was voluntary. All participants were informed that they could choose not to answer any question and were free to withdraw from the survey or leave a focus group at any stage without giving a reason.

Recognising that discussions about healthcare experiences can be sensitive, information about appropriate support services was made available to participants should they experience any distress during or after taking part in the research.

Who took part

Participants

Qualitative data was gathered through three focus groups comprising:

- Parents of teenage children living in Walsall.
- Members of a local neurodiversity social media group.
- Attendees of a Walsall community group.

Survey participants were recruited through a range of community engagement activities, including community groups, Healthwatch Walsall drop-in sessions and the Healthwatch Walsall website and social media platforms. This approach enabled a broad range of local people to share their experiences.

Participant Profile

The demographic profile of respondents was as follows:

- Participants ranged in age from 16 to 64 years, with the largest proportion aged between **25 and 49 years.**
- The largest ethnic group represented was **White: English, Welsh, Scottish, Northern Irish or British**, accounting for 70.7% of respondents.
- Most respondents identified as women (56.1%), while (36.6%) identified as men. A small number of respondents identified as transgender men and a further (2.4%) identified as non-binary. Although the numbers were relatively small, these groups were proportionately well represented within the sample when compared with national population estimates.
- Around half of respondents considered themselves to be disabled.

A full demographic breakdown of participants is provided in **Appendix 2 (Page 14)**.

Key Findings

The key findings from our work are:

1. Limited awareness and use of Hospital Passports.
2. Greater use of GP services than other primary care services.
3. Hospital services were the most commonly used secondary care service, while specialist services such as speech and language therapy and podiatry were used less frequently.
4. Nearly half of respondents who had experienced an inpatient hospital stay reported a poor experience.
5. Less than one-third of respondents felt that healthcare professionals explained their condition, treatment and follow-up care well.
6. Nearly three-quarters of respondents were not offered alternative methods or accessible materials to support communication and understanding.
7. Nearly two-thirds of respondents reported 'masking'* their traits when accessing and using health services.
8. Anxiety and sensory overload were the most commonly reported barriers to accessing and using healthcare services.

***Masking refers to an autistic person's management of their social presentation to try and minimise or mask autistic traits from others.**

Survey Results

A total of **43 people** completed the survey. It should be noted that not all respondents answered every question; therefore, the number of responses may vary between survey questions.

Where respondents provided additional comments, these are reproduced in full in **Appendix 1**. To aid readability, a summary of the key themes identified from these comments is presented alongside the relevant survey question within the findings section.

Q1. Do you use primary care services.

Yes (34) 81.0%
No (8) 19.0%

If you answered Yes, tell which services you use (select all that apply).

Doctors (33) 94.3%
Dentists (24) 68.6%
Opticians/Audiology (20) 57.1%
Podiatry (foot care) (2) 5.7%

Q2. Do you use secondary care services?

Yes (28) 66.7%
No (14) 33.3%

If you answered Yes, tell which services you use (select all that apply)?

Hospital (25) 83.3%
Mental Health support (11) 36.7%
Speech & Language Therapy (2) 6.7%
Occupational Therapy (1) 3.3%

If you answered No, please tell us why not?

Themes identified from respondents' comments include:

- Anxiety and emotional barriers to accessing healthcare, including fear of attending appointments, fear of the unknown and feeling unable to face healthcare settings.
- Sensory sensitivities, with respondents describing healthcare environments, physical contact and busy waiting areas as overwhelming and contributing to avoidance of services.
- Communication and access barriers, including difficulties with telephone-based systems, repeatedly having to explain their needs and challenges communicating with healthcare professionals.
- Avoidance or limited use of healthcare services, with some respondents only accessing services when essential or delaying care altogether.
- Previous experiences influencing healthcare engagement, including negative past experiences and childhood experiences affecting confidence in accessing services.
- Difficulties accessing appropriate support, particularly in relation to mental health and therapy services.

Q. Were you given a choice of where you could be seen or where you could receive treatment?

No (23) 71.9%

Yes (9) 28.1%

Q. Have you ever had an overnight stay on a Hospital Ward?

No (25) 61.0%

Yes (16) 39.0%

If you have answered Yes, how was your hospital experience?

Very good (2) 10.0%
Good (1) 5.0%
OK (8) 40.0%
Poor (5) 25.0%
Very poor (4) 20.0%

Please explain a little about your hospital experience

Themes identified from respondents' comments include:

- **Anxiety and emotional barriers to accessing healthcare**, including fear of attending appointments, fear of the unknown and feeling unable to face healthcare settings.
- **Sensory sensitivities**, with respondents describing healthcare environments, physical contact and busy waiting areas as overwhelming and contributing to avoidance of services.
- **Communication and access barriers**, including difficulties with telephone-based systems, repeatedly having to explain their needs and challenges communicating with healthcare professionals.

- **Avoidance or limited use of healthcare services**, with some respondents only accessing services when essential or delaying care altogether.
- **Previous experiences influencing healthcare engagement**, including negative past experiences and childhood experiences affecting confidence in accessing services.
- **Difficulties accessing appropriate support**, particularly in relation to mental health and therapy services.

Q. Do you experience problems around booking systems?
No (17) 42.5%
Yes (13) 32.5%
Sometimes (10) 25.0%

If you answered Yes or Sometimes, which service does this happen in?
Both (16) 69.6%
Primary care services (6) 26.1%
Secondary care services (1) 4.3%

Q. Do medical professionals explain things in a way you can interpret and understand?
Yes (11) 28.2%
No (15) 38.5%
Sometimes (13) 33.3%

If you answered No or Sometimes, are alternative methods or materials offered?
Yes (5) 15.6%
No (23) 71.9%
Sometimes (4) 12.5%

Q. Do you "Mask" in any of the services?
Yes (24) 64.9%
No (5) 13.5%
Sometimes (8) 21.6%

If you answered Yes or Somewhat to the above masking question, please tell us which services?
Primary care services (8) 25.8%
Secondary care services (2) 6.5%
Both (23) 74.2%

Q. Do you find professionals underestimate your health issues because you are "Masking"
Yes (19) 52.8%
No (7) 19.4%
Sometimes (10) 27.8%

If you have answered Yes or Sometimes, please tell us how? or give an example?

Themes from respondents' comments include:

- Masking symptoms leading to unmet healthcare needs, with respondents reporting that healthcare professionals underestimated the severity of their pain, illness or distress because they appeared calm or coped outwardly.
- Difficulties communicating health concerns, including challenges explaining symptoms, recalling medical histories and processing information during appointments.
- Anxiety, sensory overload and feeling overwhelmed, with respondents describing freezing during consultations, pretending to understand information and leaving appointments feeling confused or unsupported.
- Feeling misunderstood or not believed, with respondents reporting that their concerns were dismissed, attributed to anxiety or perceived as less serious because they masked their difficulties.
- Assumptions and stereotypes about autism and disability, including feeling patronised, having professionals assume a learning disability or making inaccurate judgements based on appearance or diagnosis.
- The emotional impact of masking, with respondents describing suppressing pain, distress and autistic traits in order to cope with appointments, often at the expense of receiving appropriate care.

Q. Do you feel that professionals listen to you?

Yes (11) 28.2%
No (12) 30.8%
Sometimes (16) 41.0%

Q. Do you have an up-to-date Hospital Passport?

Yes (10) 25.0% No (30) 75.0%

If you have answered No, why not?

Themes from respondents' comments include:

- Limited awareness of Hospital Passports, with many respondents reporting that they had not heard of a Hospital Passport or did not know what one was.
- Lack of opportunity to use a Hospital Passport, including respondents who had not required hospital care or who were diagnosed with autism after their most recent hospital admission.
- Potential missed opportunities to promote Hospital Passports, suggesting that awareness and uptake could be improved among autistic people accessing healthcare services.

Following completion of the survey, we then asked participants if there were any additional comments they wished to share that had not already been covered.

Themes from respondents' additional comments include:

- Lack of consistency and predictability in healthcare appointments, with unexpected changes to clinicians or appointment types causing uncertainty and increased anxiety.
- Need for support to communicate during appointments, with some respondents relying on parents or carers to explain symptoms and advocate on their behalf.
- Healthcare environments creating barriers to access, particularly urgent care settings, where noise, long waiting times and unpredictability were described as overwhelming.
- Autism not consistently recognised within healthcare records, including concerns that private autism diagnoses were not reflected in NHS records, potentially affecting the support and reasonable adjustments provided.
- Need for greater autism awareness and staff training, with respondents calling for improved understanding of neurodivergence among healthcare professionals.
- Masking and anxiety affecting healthcare interactions, with respondents describing concealing their difficulties or avoiding healthcare services altogether due to anxiety and sensory concerns.

Focus Group Feedback

Participants were recruited from three focus groups comprising parents of teenage children living in Walsall, members of a local neurodiversity social media group, and attendees of a Walsall community group.

A structured set of questions was used to guide the discussions and facilitate the collection of participants' feedback and experiences.

Q1. Do you use primary health care services?

Participants responded that many used opticians' services, except for one participant who although has a serious eye condition has not visited the opticians for many years.

Participants at one focus group, mostly all of them, used dental services, however in contrast for the two other groups dentists were a big issue and a service they avoided.

Reasons for not using primary health services were; close proximity of professionals, sensory issues, the 'unknown' but also included the attitudes of professionals. Participants feeling judged or even laughed at. This also extended to other people in waiting areas while awaiting to be seen.

The group of mothers with teenage children said they found it difficult to get their children to attend primary health care services.

One mother had encountered a bad response and poor support from their dentist who said they could refer to an autism approachable dentist but made her child attend the usual dentist first. Her child then, "huddled" in the corner of the room, the dentist approached them and cornered them, attempting to look in their mouth. This caused so much anxiety it is unlikely should a referral come through for a specialist dentist now, that they unlikely to attend".

Q2. Do you use secondary care services?

Most adult participants said they do not visit hospitals including accident and emergency, saying they had not needed to or if did they avoided attending. Some reasons for this were staff not understanding or participants feeling judged, or patronised. Neuro typical people said they pick up very easily on body language, they also said they masked but were very anxious under the surface.

Parents of teenage children reported that they currently supported their children to attend hospital appointments. However, many expressed concern that, as their children become more independent and transition into adulthood, they may be less likely to access healthcare services independently.

To help reduce anxiety and make appointments more manageable, parents described carefully planning in advance. This included bringing items and using strategies tailored to their child's individual needs, such as comfort hoodies, noise-cancelling headphones, tablets and other self-regulation or sensory support aids.

Q3. Have you ever had an overnight stay on a hospital ward?

One participant described feeling particularly anxious during a hospital stay, attributing this to being separated from familiar surroundings and, in particular, from their cat, which they identified as a significant source of comfort. Other participants shared similar views, explaining that although they were advised to bring only essential items to hospital, they considered personal belongings such as tablets to be essential. These items enabled them to access familiar programmes and other resources that helped them to self-regulate and manage anxiety.

Parent of teenage child reported that their child's hospital admission had been a generally positive experience. However, they felt this was largely because their child had been cared for on a children's ward, where staff were perceived to have a greater understanding of the needs of autistic young people and were better able to provide appropriate support.

Q4. Do you have any problems, anxieties or worries around booking systems?

Most participants reported no significant difficulties when booking appointments. However, some described telephone booking as challenging because of the uncertainty surrounding the conversation, including not knowing what questions they might be asked or how to respond. In contrast, online booking systems were generally viewed more positively, with participants describing them as a more accessible and preferable method of arranging appointments.

Q5. Do medical professionals explain things in a way you can understand? If not, are alternative methods offered such as pictorial, easy read or audio?

Across all focus groups, participants identified communication during appointments as a significant challenge. Many reported that healthcare professionals used medical jargon and spoke too quickly, without allowing sufficient time for information to be processed. As a result, participants often thought of questions only after the appointment had ended and found it difficult to obtain the information or clarification they needed.

Participants also described how heightened anxiety during appointments affected their ability to understand and retain information. Many explained that they entered a "fight or flight" response, with their primary focus being to leave the healthcare environment and return to a place where they felt safe. Several participants said that the effort involved in masking their autistic traits further reduced their ability to process what was being discussed. Consequently, many left appointments without fully understanding the information they had been given and later relied on internet searches to answer unanswered questions.

Participants felt that providing information in alternative formats would help improve understanding and support informed decision-making. Suggested adjustments included easy-to-read written information, patient information leaflets, flowcharts explaining care pathways, and a personalised written or emailed summary of their diagnosis, treatment plan and agreed next steps following each appointment. One participant with dyslexia also highlighted that colour-coded information would improve accessibility and make written information easier to understand.

Q6. Do you "mask"? And does this cause you any difficulties in using healthcare services?

Many participants reported that they masked their autistic traits during healthcare appointments. They explained that, because they appeared to understand and process the information being provided, healthcare professionals often assumed that no additional support was required. In reality, many participants said they had not fully understood or retained much of what had been discussed, with the effort of masking and managing anxiety significantly affecting their ability to process information during the consultation.

Additional Comments and Experiences

The following comments and case studies have been collated from experiences previously shared with Healthwatch Walsall through its community engagement activities. They provide further insight into the lived experiences of neurodiverse people when accessing and using health and care services and complement the findings from the survey and focus groups.

- Due to sensory issues, and fear of close contact., this has impacted upon their use of primary health services such as dentistry and opticians, as well as a reluctance to seek a GP or get hospital care. Sensory issues such as lighting, smells, sounds all compound the experience as senses are hypersensitive in neuro diverse people. In addition, close proximity for examinations are difficult. Other issues include: hospital stays unfamiliarity and the 'unknown', routines and timings, food options, even different beds and sheets can cause issues for neuro diverse people.

- Service user who is autistic, does get very anxious about blood tests due to senses and fear of needles. They wonder if there are things that can make these process easier. Such as possible gels that numb pain of injections, staff training to be aware of sensory issues, and support that stops people even attending these appointments.

- Booking appointments at GP he has found better since he can book online, as using the telephone was problematic. The unknown of what the person at the other end of the line may as caused intense anxiety and prevented him using GP services. Now he can write online he is more likely to request help.

- Autistic inpatient last year in hospital for surgery. They do however emphasise how important the hospital passport is. This can be helpful to parties' communication with each other. They were fortunate in obtaining a single room on the ward. They experienced some staff were more informed following mandatory 'Oliver Mc Gowen' training but other although must have undertaken were not au fait with it.

- Services for neurodiverse people in dental care can be positive. One particular dentist practice allow visits beforehand, showing equipment, pictures, videos of treatment and what is going to happen. Advance notice of any instruments going to his mouth etc. It is unclear how many dental services got to such lengths.

Conclusion

This research has identified that many autistic and neurodiverse people in Walsall continue to experience significant barriers when accessing and using health services. While participants generally recognised the clinical care they received as positive, their experiences were frequently affected by communication difficulties, anxiety, sensory challenges and a lack of reasonable adjustments.

The findings demonstrate that barriers exist throughout the patient journey, from booking appointments through to receiving information about diagnosis, treatment and follow-up care. Participants described healthcare environments that were often overwhelming, appointment systems that did not always meet their communication needs and consultations where information was delivered too quickly or in inaccessible formats. Consequently, many left appointments without fully understanding what had been discussed or what would happen next.

A consistent finding throughout the research was the impact of **masking**. Nearly two-thirds of survey respondents reported masking their autistic traits when accessing healthcare. Participants explained that this often led healthcare professionals to underestimate the severity of their symptoms, anxiety or support needs, resulting in individuals feeling unheard, misunderstood or not taken seriously. The findings suggest that healthcare professionals cannot rely solely on outward presentation when assessing an autistic person's needs.

Communication emerged as one of the most significant themes across the survey, focus groups and case studies. Participants consistently highlighted the need for healthcare professionals to use clear, jargon-free language, allow sufficient time for information to be processed and routinely provide information in accessible formats. Many respondents felt that relatively simple adjustments, such as written summaries, visual information, personalised care plans or emailed follow-up information, would substantially improve their understanding and confidence in managing their healthcare.

The research also identified low awareness and use of Hospital Passports, despite their potential to support communication and enable reasonable adjustments. Increasing awareness among both patients and healthcare professionals could help ensure that individual needs are recognised and addressed more consistently across services.

Anxiety and sensory overload were frequently cited as reasons for delaying or avoiding healthcare altogether. Busy waiting areas, unfamiliar environments, unpredictable appointments and telephone-based systems were all identified as barriers. Parents of autistic young people also expressed concern about the transition to adulthood, fearing that their children may become less likely to access healthcare independently without appropriate support.

Overall, the findings suggest that many of the barriers experienced by autistic and neurodiverse people are not related to clinical treatment itself, but to the way services are designed and delivered. Many of the improvements identified by participants are practical, low-cost and achievable, including improving staff understanding of autism, making

reasonable adjustments routinely available, providing accessible information and adopting more flexible approaches to communication.

Addressing these issues has the potential to improve patient experience, increase confidence in health services and reduce inequalities in access and outcomes for autistic and neurodiverse people across Walsall.

Recommendations

Based on the findings of this research, Healthwatch Walsall recommends the following actions to improve the accessibility and experience of healthcare services for autistic and neurodiverse people.

1. Improve autism awareness and understanding across health services
Healthcare providers should ensure that all patient-facing staff receive autism awareness training that goes beyond basic awareness. Training should focus on understanding the impact of anxiety, sensory sensitivities, communication differences, masking and the need for reasonable adjustments throughout the patient journey.

2. Routinely identify and record communication and reasonable adjustment needs
All healthcare providers should routinely ask patients whether they require any communication support or reasonable adjustments and ensure these are recorded consistently within patient records. This information should be visible to all relevant staff to reduce the need for patients to repeatedly explain their needs.

3. Improve communication during consultations
Healthcare professionals should:

- use clear, jargon-free language;
- allow additional processing time before expecting a response;
- regularly check understanding rather than assuming comprehension; and
- encourage patients to ask questions before the consultation ends.

4. Provide information in accessible formats
Patients should routinely be offered information in formats that meet their individual needs. This may include:

- easy-read information;
- visual guides and flowcharts;
- written or emailed summaries of consultations;
- treatment plans and follow-up arrangements; and
- alternative formats where required, including larger print or colour-coded information.

5. Increase awareness and use of Hospital Passports
Healthcare organisations should promote the use of Hospital Passports among autistic patients and ensure staff understand how to use the information they contain to provide personalised care and reasonable adjustments.

6. Offer more flexible appointment and communication options
Where clinically appropriate, services should reduce reliance on telephone communication by offering alternative methods such as online booking, email, secure messaging and text-based communication. Appointment information should be clear, timely and include advance notification of any changes wherever possible.

7. Improve the sensory environment within healthcare settings
Healthcare providers should review outpatient departments, waiting areas and urgent care settings to identify opportunities to reduce sensory overload. This may include providing quieter waiting spaces, allowing patients to wait elsewhere until called, reducing unnecessary noise where possible and enabling patients to use sensory aids throughout their appointment.

8. Recognise the impact of masking
Healthcare professionals should be aware that autistic people may appear calm, confident or compliant while experiencing significant anxiety or distress. Staff should avoid relying solely on outward presentation when assessing a person's needs and should actively explore whether additional support or reasonable adjustments are required.

9. Strengthen support during transition to adult services
Health and care services should work together to ensure autistic young people receive appropriate support as they move from children to adult services. This should include planning for increasing independence while ensuring reasonable adjustments remain in place.

10. Continue to involve autistic people in service improvement
NHS organisations should work in partnership with autistic people, their families and organisations such as Healthwatch Walsall to co-produce service improvements. People with lived experience should be involved in designing, implementing and evaluating changes to ensure services are accessible and responsive to local needs.

These recommendations are directly supported by the evidence in our research and align with national policy, including the Autism Act 2009, the NHS England Learning from Lives and Deaths (LeDeR) programme, the NHS Accessible Information Standard, and the legal duty to make reasonable adjustments under the Equality Act 2010. Together, they focus on practical improvements that are achievable and proportionate while addressing the key barriers identified by participants.

APPENDIX 1

Service User Comments

For transparency, all comments provided by respondents are reproduced in full below under the relevant survey question.

Do you use secondary care services
If you answered No, please tell us why not?

Of the **14** respondents who reported that they did not access secondary healthcare services, the following comments were provided.

- 'Currently cannot find a form of therapy that helps me'.
- 'I attempted to get therapy, but they tried to get me to self-refer and I am not comfortable with phone calls'.
- 'There is no current need for me to use secondary care'.
- 'Because they are still remembering as a child'.
- 'Not used for years but now use a private dentist'.
- 'Sensory issues, Anxiety, unknown'.
- 'I hate having to explain if ongoing issue. If A&E try not to go there. Lights, seats, children crying, and smells'.
- 'I have not left my house since I was 17'.
- 'I do not like people to touch me. Find process explaining and talking to people too much'.
- 'Just cannot face it'.
- 'Sensory issues and fear of close contact. Had an accident wanted to go to a safe place. Fear of the unknown'.
- 'Only use doctor for diabetes medication'.

If you have answered Yes, how was your hospital experience?
Please explain a little about your hospital experience

- 'I was admitted for a kidney infection, I found that the nurses were very kind, but the doctors were lacklustre and dismissive'.
- 'My baby was in Neonatal Intensive Care Unit (NICU) and I was on the maternity ward without them. This was a terrible experience. I also gave birth on the ward because I wasn't listened to when I said the baby was coming. Also, they had to be resuscitated, and I was left naked on the ward in front of mothers and visitors including men. The crash team resuscitated my child in front of everyone. The baby then stopped breathing after 12 hours and I was accused of smothering the baby, but the real issue was that the baby was supposed to have checks and wasn't'.
- 'I couldn't eat the food they were serving it was disgusting'.
- 'Midwives were horrible post birth me as a first-time parent. Very dehumanising'.

- 'They did not give us a room with a bed and said that the doctors would see me in the morning and they did not, we waited until late afternoon'.
- 'I had my own room, and I felt listened to by staff'.
- 'Ward was very loud and checks were unpredictable, very little communication from nurses'.
- 'The mental health team failed to recognise the issues I was facing. They seemed dismissing'.
- 'When I stayed it was a real mixed bag. I had some nurses who were lovely and comforting, but then my name was written wrong above my bed even though I'd ask them to correct it. They also kept changing their mind on how long I was staying'.
- 'This was during by labour and delivery experience. Whilst on the induction ward, I was treated well and everything met my sensory needs and communication was clear and effective however on the postdelivery ward nobody explained anything to me, they made my partner go home and I had a catheter that had been tied to the bed rail and my other hand was attached to a drip. I was extremely uncomfortable, struggled to move and was in a position in which I could not pick up my baby'.
- 'Wanted to be home'.
- 'Received good care but can only go with parent support. Think if I have to go alone, I would be very stressed and anxiety increased. The problem then is that they tend to talk to parent. Although educated to a master's level. Feels they see them as stupid'. 'Terrifying. Wanted to be in a safe place. Feel everything intensely'.
- 'A&E was awful due to sensory overload. One staff saw hospital passport, which said provide a private room and no hospital gowns. Family bought in own food in.
- 'Found it traumatic, the gowns, not knowing when people (nurses/doctors/porters) turn up and do things, take you places, caused anxiety. Didn't like lights, loud at night. Food wasn't what ordered but previous persons order'

Q. Do you find professionals underestimate your health issues because you are "Masking"
If you have answered Yes or Sometimes, please tell us how? or give an example?

Of the **17** respondents who said they do or sometimes "mask", the following comments were provided.

- 'I would try and put on a brave face even when I'm in pain. Been in pain for 40 years very good at masking it'.
- 'I am still struggling with chronic UTI symptoms, and I feel like I've reported these issues so many times. And because I tend to mask my most common tells of pain (stimming, rocking) and I feel that makes me be taken not seriously or sent away with medication that I have established does not help me'.
- 'I guess they just wouldn't know the truth and severity of the issues at hand, and it would just bottle up'.
- 'They mistake my composure as a lack of urgency or seriousness'.
- 'I have autism, so I get anxiety'.

- 'I can't explain how i feel properly which makes them underestimate when something is wrong'.
- 'Consultant once said when I said I was stupid. Oh, before you came in, I was expecting you to be disabled from the notes'.
- 'I find that medical professionals often assume I have a learning disability due to my diagnoses, and as a result, dumb things down for me'.
- which I find frustrating and patronising'.
- 'I cannot always remember timelines of my illness and feel that they think I am lying or withholding information'.
- 'They don't recognise symptoms'.
- 'It's hard to know what their reasons might be. It could be down to gender or the type of condition and symptoms you're experiencing'.
- 'I feel like they sometimes don't take me seriously because of my anxiety'.
- 'I feel as though I cannot communicate my problems effectively because I am not comfortable enough to do so and even though I can understand what is being said to me I do not always process and therefore exit appointments feeling overwhelmed and as though it was a waste of my time'.
- 'I pretend to understand information when really I don't take in a word'.
- 'They underestimate my anxiety and sensory issues. Probably think I am well when not, because I try to appear happier than feeling'.
- 'I freeze'.
- 'Because I act confident. Understanding of what they are explaining but feels just like a jumble of words. Pretend I OK, just want to get out and get home'.

Q. Do you have an up-to-date Hospital Passport?
If you have answered No, why not?

- 'What's the hospital passport?'.
- 'Don't know what that is'.
- 'I was not diagnosed with Autism at the time of my last hospital stay'.
- I do not know what that is and I barely go to hospital even though I should be going for scans haven't had one since I was thirteen though'.

(There were a further sixteen comments indicating that the respondents did not know what a hospital passport was).

Additional comments received following completion of the survey

- 'You have an appointment to say one doctor expecting to say that doctor and you turn up and it's not the doctor you're expecting or it's a pharmacist to review your medication'.
- 'I feel sometimes that it's easier to have my parent with me to explain how I feel because when I try to, I forget what happens and it seems like I'm making it up, obviously when I'm at doctors' appointments my parent explains that I'm still under investigation but it's clear that I have some signs as I obsess over the
- little things even when it's health related.

- 'Often my GP will text after I make a referral telling me to go to urgent care. When they do this, I cannot seek any other support so need to sit in urgent care for (on average) 6 hours for a simple illness, I tend to get a few ear infections due to wearing ear defenders a lot. Urgent care is horrible; it is noisy and unpredictable'.
- 'I have a private diagnosis therefore it is not on my NHS record'.
- 'There needs to be more training in place for supporting neurodiverse patients'.
- 'Just never go since I was a child'.
- 'Because I mask. I stress about saying what my anxieties are sensory issues'.

APPENDIX 2

Demographics Participant Profile

Although a total of **43** people completed the survey some people may not have answered demographic questions, so the totals may vary. The demographic profile of respondents was as follows:

Gender

Response	Number	Percentage
Female	23	56.1%
Male	15	36.6%
Transgender Male	2	4.9%
Non-Binary	2	2.4%

Most respondents identified as **female (56.1%)**, with just over one-third identifying as **male (36.6%)**.

Age

Response	Number	Percentage
16-17	10	23.8%
18-24	11	26.2%
25-49	18	42.9%
50-64	3	7.1%

The largest proportion of respondents (42.9%) were aged **25–49 years**.

Disability or Long-Term Health Condition

Response	Number	Percentage
Yes	21	51.2%
No	20	48.8%

Around **half** of respondents considered themselves to have a disability or long-term physical health condition.

Nuerodivergent Conditions*

Condition	Number	Percentage
Autism	27	65.9%
ADHD	15	36.6%
Dyslexia	10	24.4%
Aspergers	6	14.6%
Other	5	12.2%

*Respondents were able to select more than one neurodivergent condition; therefore, percentages total more than 100%.

Ethnicity

Ethnicity	Number	Percentage
White English, Welsh, Scottish, NI or British - White	29	70.7%
Mixed or other multiple ethnic groups	3	7.3%
White Irish	2	4.9%
White Other	2	4.9%
Asian or Asian British – Pakistani	2	4.9%
Asian or Asian British – Indian	1	2.4%
Asian or Asian British – Other	1	2.4%
Mixed – White and Asian	1	2.4%

The majority of respondents identified as White: English, Welsh, Scottish, Northern Irish or British (70.7%).

Support Links (For advice and support)

Autism West Midlands: https://www.autismwestmidlands.org.uk/

National Autistic Society: https://www.autism.org.uk/

Neurodiversity Support Group Facebook: Various

Dyslexia Action: https://dyslexiaaction.org.uk/

Tourettes Action : https://www.tourettes-action.org.uk/

ADHD UK : https://adhduk.co.uk/

healthwatch Walsall

Share your Walsall Health and Social Care services experiences by getting in touch by using our services review platform "Have Your Say" on our website. Link: https://tinyurl.com/3778j3ps

How to contact us

Tel: 0800 470 1660

Email: info@healthwatchwalsall.co.uk

Find us and our reports on our Social Media platforms

Facebook: @HealthwatchWSL
X (Twitter): @HWWalsall
Instagram: healthwatchwsl
YouTube: Healthwatch Walsall 2020

Committed to quality

We are committed to the quality of our information. Every three years we perform an in depth audit so that we can be certain of this.

Engaging Communities Solutions

The contract to provide Healthwatch Walsall is held by Engaging Communities Solutions C.I.C.