

Accessing and using GP services in Newcastle

Understanding the reasonable adjustments made for autistic people and people with a learning disability.

About Healthwatch Newcastle

Healthwatch Newcastle is one of 152 independent not-for-profit Healthwatch services established in England under the Health and Social Care Act 2012.

We help children, young people and adults have a say about social care and health services in Newcastle. This includes every part of the community, including people who sometimes struggle to be heard.

We work to ensure that those who plan and run social care and health services listen to the people using their services and use this information to make improvements.

Healthwatch Newcastle would like to thank everyone who gave their time and expertise to assist with this report.

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1. Introduction

Healthwatch Newcastle (HWN) engaged with autistic people and people with a learning disability to understand their experiences accessing and using GP services in Newcastle. GP Practice Managers across Newcastle were invited to share information around their processes for requesting and implementing reasonable adjustments and their capacity to make requested adjustments.

Through the project, Healthwatch Newcastle wanted to understand what worked well and possible areas for improvement across three key areas:

- Levels of awareness of reasonable adjustments among autistic people and people with a learning disability.
- The types of reasonable adjustments autistic people and people with a learning disability wanted.
- The process for requesting reasonable adjustments and whether the requested adjustments could be implemented.

1.1. What are reasonable adjustments?

Legislation in England set forth in The Equality Act (2010)¹ stated that public service organisations must anticipate and prevent discrimination against people with a disability, including autistic people and people with a learning disability. Reasonable adjustments were recognised as a way of reducing and preventing disadvantage through changes to services. Any changes made, were expected to enable users with a disability to use a service to the same or similar standard to those without a disability. Changes could include:

- the time of day and duration in which the service could be accessed.
- alternative methods by which a user could interact with the service.
- the provision of clear, easy to read information.
- alterations to the physical environment.

Any adjustments requested should be reasonable. What is “Reasonable” depends on a number of different things including the practicality of the changes, the costs and resources needed to make changes, the disability a person may have, and the type and size of the organisation and the physical premises.

¹ Equality Act (2010). Adjustments for disabled persons. Available [here](#). Last Accessed: 22nd March 2023.

1.2. What is a learning disability?

A learning disability is a lifelong condition that affects the way in which people learn new things. Experiences and severity differ from person-to-person, however common characteristics include:

- A reduced ability to understand complicated information.
- A reduced ability to look after themselves or live independently.

Public Health England recognised learning disabilities to be a group of conditions that impacts “the way individuals develop in all core areas, and ultimately how they live their lives and access health care”². In addition, they recognised people with a learning disability were likely to have more health care needs than the general population.

In Newcastle, over 4,500 adults aged between 18 and 64 were believed to have a learning disability. This figure was expected to increase in the next ten years³.

1.3. What is autism?

Autism is a developmental disability that impacts how a person communicates and interacts with others and how they experience the world around them. Like a learning disability, autism is a lifelong condition. However, being autistic does not mean a person has a learning disability, nor does it mean that they have a mental health problem, although the conditions can co-exist.

Common characteristics include:

- Difficulties communicating and interacting with others.
- Difficulties understanding how other people think or feel.
- Finding certain situations overwhelming or stressful.
- Feeling anxious about unfamiliar situations.
- Taking longer to understand information.
- Repeating actions over and over.
- Consistency and routine.

In Newcastle, over 2,000 adults aged between 18 and 64 were believed to be autistic. Much like the anticipated increase in the diagnosis of learning disabilities, the number of people who were autistic was also anticipated to increase over the next ten years⁴.

² Public Health England. (2018). Learning disabilities: applying All Our Health. Available [Here](#). Last Accessed: 22nd March 2023.

³ Newcastle City Council. (2021). Newcastle Future Needs Assessment City Profile - Updated April 2021. Available [here](#). Last Accessed: 22nd March 2023.

⁴ Newcastle City Council. (2021). Newcastle Future Needs Assessment City Profile - Updated April 2021. Available [here](#). Last Accessed: 22nd March 2023.

The NHS recognised that they have a “crucial role” in helping autistic people and people with a learning disability lead longer, happier, and healthier lives and both conditions featured heavily in the NHS Long Term Plan⁵.

This report considered how GP practices, as gatekeepers to other services in the NHS, are supporting autistic people and people with a learning disability to access and use their services.

1.4. Methodology

Healthwatch developed a patient survey, along with an easy read version, to collect feedback from autistic people and people with a learning disability. GP Practice Managers were also invited to complete a Practice Manager survey.

The patient survey looked to understand awareness around reasonable adjustments and the types of requests made, and positives and areas for improvement. The Practice Manager survey focused on processes and the resources required to put reasonable adjustments in place. Both surveys were available in paper-based versions and accessible online.

Data collection ran between December 2022 and March 2023. HWN contacted several organisations who worked directly with autistic people and people with a learning disability to engage with patients in an environment that was already familiar to them.

Seventy-nine responses were received from autistic people and people with a learning disability with a formal diagnosis (60 respondents completed the easy read version of the survey and 19 completed the standard version). Five useable responses were received from people who indicated that they had not received a formal diagnosis (four completed the easy read version and one completed the standard version). Nine useable responses were received from GP Practice Managers.

Just over half of the respondents completed the survey by themselves (n=46, 55%) and 45% (n=38) completed the survey with support from someone else.

⁵ NHS. (2019). The NHS Long Term Plan. Available [Here](#). Last Accessed: 28th March 2023.

2. Respondent Demographics

Survey respondents most commonly indicated that they had a learning disability-only (n=35, 42%). Twenty-three respondents (27%) stated that they had both a learning disability and were autistic, and 21 (25%) were autistic-only.

Five respondents stated that they had not received an official diagnosis of either autism or a learning disability. Despite answering “No” to “Has your GP told you (or your parent / carer) that you are autistic?”, answers to other questions suggested that a diagnosis had in fact been made. These respondents were therefore retained in the data set.

Figure 1: Autism and / or Learning Disability diagnosis of respondent group.



Source: Patient Survey (84 Responses)

Twenty-one of the respondents who had both a learning disability and autism, selected the same time category in the survey for both diagnoses⁶ when asked when they were diagnosed. Over half of these respondents (n=12, 57%) were diagnosed over four years ago. The data indicated that the remaining respondents received both diagnoses at the same time or within a short time window, with four diagnosed between one and three years ago. Five received both diagnoses within the past year (two were diagnosed between six and eleven months ago and three others were diagnosed in the last six months).

Two respondents reported that they received a diagnosis of both autism and a learning disability during different time categories, with an initial diagnosis four or more years ago and a second between one and three years ago.

Where a diagnosis of either autism-only or a learning disability-only was made, most respondents were diagnosed four or more years ago (autism, n=15, 71%; learning disability, n=26, 74%). The nine remaining respondents who had a learning disability-only were diagnosed within the past three years and six who were autistic-only were told during the same time period.

⁶ Either Less than six months ago, Between six and eleven months ago, Between one year and three years ago, More than four years ago.

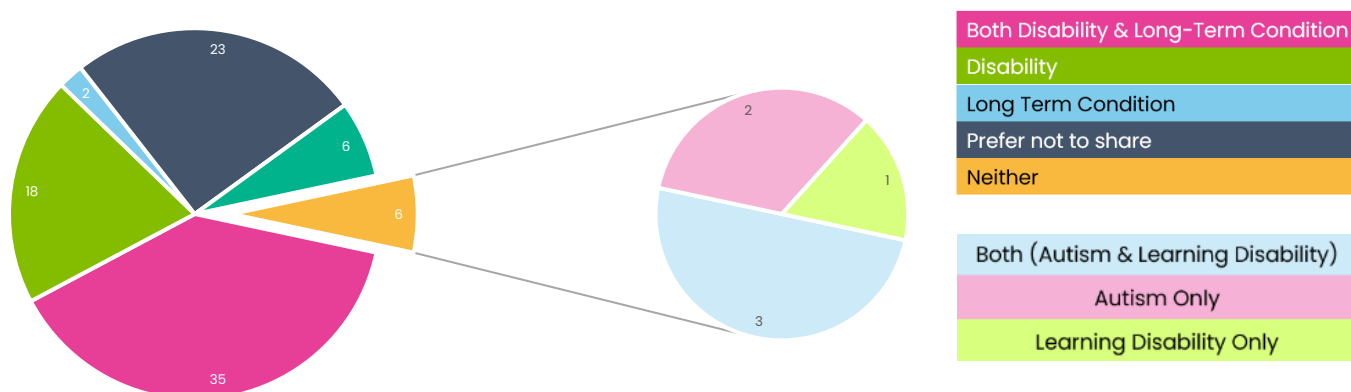
Figure 2: When were respondents diagnosed?



Most often respondents considered themselves to have a disability and a long-term condition (n=35, 42%). Just over one-fifth reported that they had a disability only (n=18, 21%) and two respondents reported that they had a long-term condition only.

Six respondents said that they did not consider themselves to have a disability nor a long-term condition. However, these respondents did state that they had received a formal diagnosis of autism (n=2), learning disability (n=1), or both (n=3) from their GP. Twenty-three respondents (27%) did not provide information about their disability and long-term condition status.

Figure 3: Do you consider yourself to have a long-term condition or a disability?



Source: Patient Survey (84 Responses)

2.1. GP Practice Demographics

The nine GP Practices who completed the survey reported that they had a combined total of over 1,300 patients registered who were autistic or had a learning disability. Numbers ranged from between 50 to 262 patients per practice.

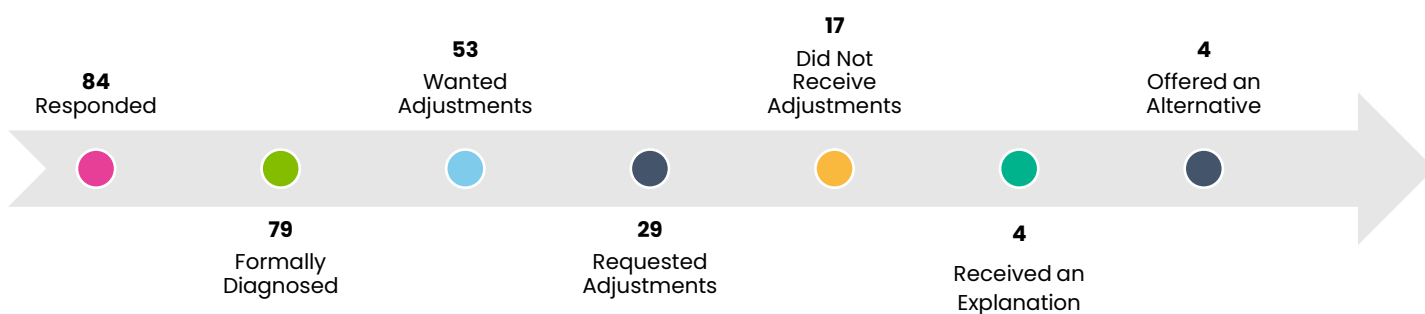
3. Main Findings

This report considered the different stages from awareness of reasonable adjustments through to implementation. Through each of the stages, the number of respondents who chose or who were able to provide information reduced.

Eighty-four useable responses were received in total. Of these, 79 respondents had received a formal diagnosis and 53 wanted reasonable adjustments to be made. Twenty-nine respondents stated that they had requested reasonable adjustments or that a family member requested adjustments on their behalf. Seventeen respondents reported that the adjustments had not been put in place. In only four instances, respondents received an explanation and alternatives were offered.

Further exploration of the numbers within each stage can be found in the findings section of this report.

Figure 4: Respondents Awareness



To understand general feelings towards using GP services, respondents were asked to consider their levels of agreement across four indicators. Indicators included the language used by GPs, whether they felt understood when visiting their GP, and their levels of comfort while in the waiting room and in the consulting room. In around half of all cases, the responses were positive.

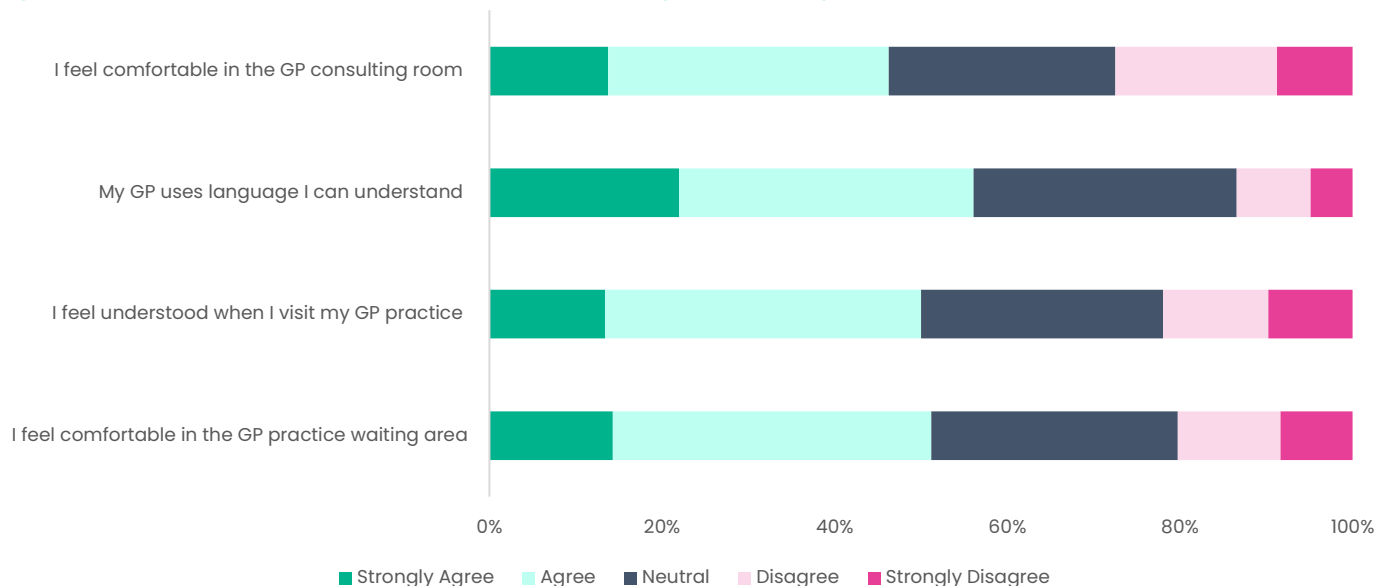
Some of the respondents explained their ratings. When speaking positively about their experiences in the GP practice, respondents reported positive feelings towards their GP including being made to feel at ease, feeling that their GP or another member of staff was kind to them, and that information was shared with them in a way they understood.

Across the indicators, **GPs use of easy-to-understand language was rated highest** with an average rating of 3.6 out of five. Forty-six respondents (55%) either “Strongly Agreed” or “Agreed” with the positively phrased statement. Despite being the highest rated, a rating of three-point-six would be considered “Neutral” in the “Strongly Agree” to “Strongly Disagree” scale.

Just over half of the respondents reported that they were **comfortable in the waiting room** (n=43), with an average rating of 3.4 out of five. When considered by diagnosis type, comfort levels in the waiting room were highlighted as an important issue for all groups. Seven of the

autistic-only respondents reported that they did not feel comfortable and an equal number of respondents with a learning disability-only felt the same. Five respondents who were both autistic and had a learning disability did not feel comfortable in the waiting room. However, it is not only those with a formal diagnosis who reported feelings of discomfort, three of the five respondents without a diagnosis “Disagreed” with the positively phrased statement. Respondents tended to find waiting rooms unsettling due to loud and conflicting noises (e.g., people talking, telephones ringing, the radio playing), the lights, a lack of fresh air, and ‘boring colourless’ walls. Some respondents highlighted that the longer they waited in the waiting area, the more uncomfortable they felt.

Figure 5: Please indicate the extent to which you agree or disagree with these statements



Source: Patient Survey (84 Responses)

When asked about their **comfort levels in the consulting room**, 44% (n=37) of respondents felt comfortable. This indicator achieved an average rating of 3.2 out of five. Where explanations were provided, one respondent reported a general dislike for GPs and another wanted longer appointment times to feel comfortable enough to discuss any health concerns.

Forty-nine percent of respondents felt that the **GP staff understood them** (n=41), with an average rating of 3.3 out of five. Respondents shared that they felt that they were treated differently by practice staff once they knew they were talking to an autistic person. A lack of continued care from the same GP within the practice was also a point of frustration for some respondents, when they felt that they had to repeat themselves each time and get used to a new person. Some respondents felt that they were burdening the system, that they were seen as aggressive as their frustration grew, or that practice staff were impatient with them.



Access to services was also an issue for some, which may have led to feelings of being misunderstood. Waiting lists and the need to call multiple times left one respondent feeling anxious. Another respondent felt that there was a lack of willingness by GP practices to put reasonable adjustments in place.

Figure 6: Felt understood when visited GP Practice and implementation of reasonable adjustments.

9/12 respondents who had reasonable adjustments felt understood when they visited their GP.



1/13 respondents who did not have reasonable adjustments (but did request them) felt understood when they visited their GP.



Where reasonable adjustments were made, respondents rated their experiences more positively. Sixty-seven percent of respondents who had reasonable adjustments made for them felt comfortable in the waiting room and the consulting room, and understood the language used by their GP. Seventy-five percent felt that their GP practice understood them.

In comparison, where reasonable adjustments were not made, only one respondent felt that their GP practice understood them. Just under one third of respondents (n=6) felt comfortable in the waiting room and in the consulting room, and six understood the language used by the GP.

Table 1: What works well and what could be better? – Main Findings

What works well?

- Where reasonable adjustments were made, almost all of the respondents felt understood when they visited their GP practice.
- Practices had specific members of staff that understood needs and who were able to provide support.

What could be better?

- Half of the respondents or fewer felt that their GP used language they understood or they themselves felt understood.
- Around half or fewer of the respondents reported that they felt comfortable in their GP waiting room and / or the GP consulting room.
- The respondent group indicated that there were poor levels of implementation of the reasonable adjustments that they had requested.

3.1. Awareness of Reasonable Adjustments

The ways in which GP Practices informed autistic people and people with a learning disability (or their parents / carers) that reasonable adjustments could be made varied. Practices said that information about the right to reasonable adjustments was actively shared with patients through email and online patient / provider communication software (i.e., Accrux) and passively shared via posters in the waiting room and through the practice website. Passive sharing of the information meant patients would need to notice and actively follow up on a poster in the waiting room or search for the information on the practice website.

Two practices stated that they had dedicated staff in the form of a Learning Disability Administrator and Care Coordinators. Another practice trained staff, both clinical and administrative, in the different ways patients interacted with the practice. It is unclear the types of training undertaken by staff across other practices in Newcastle. However, under the Health and Care Act (2022)⁷, regulated service providers must ensure that their staff receive training on learning disabilities and autism, as appropriate to their role.

Three practices highlighted the annual review as an opportunity to discuss reasonable adjustments with patients and / or their carer. However, 61% of respondents who had been formally diagnosed as autistic and / or having a learning disability reported that they either did not see or did not know if they saw their GP for an annual health check. The NHS Long Term Plan detailed the need for improvements in the uptake of annual health checks to ensure at least 75% of those who were eligible had a health check.

Two practices shared that their reasonable adjustments process either covered everyone or changes to appointments were automatically applied for eligible patients. One of these practices reported that when speaking to patients, either via email, face-to-face, or through the telephone, they invited patients to tell the practice what they needed. This practice highlighted that 'blanket policies' were not used and patients were considered on a case-by-case basis. Conversely, the information provided by the other practice suggested that all patients with a learning disability and / or autism were automatically given a longer appointment.

Despite the efforts detailed above, almost half of the respondents who had received a formal diagnosis (n=35, 44%) were unaware of their right to reasonable adjustments.

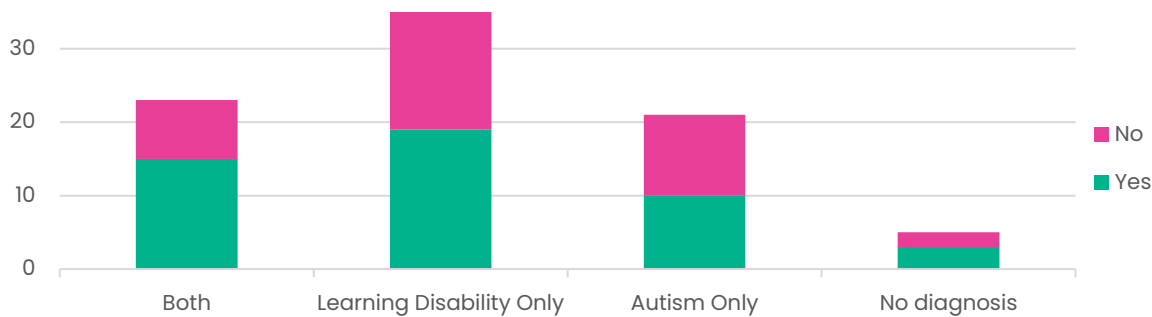
Proportionally speaking, respondents who had been diagnosed with both a learning disability and autism were more likely to be aware of their right to reasonable adjustments (n=15, 65%). Just over half of those diagnosed



⁷ Health and Care Act (2022). Disability and autism training. Available [here](#). Last Accessed: 22nd March 2023.

with a learning disability-only (n=19, 54%) were aware of their right to reasonable adjustments and less than half of autistic people were aware (n=10, 48%). Of the five respondents who had not been formally diagnosed, three were aware of people’s right to reasonable adjustments.

Figure 7: Awareness of right to reasonable adjustments by diagnosis



Source: Patient Survey (84 Responses)

The time in which a diagnosis was first received did not appear to impact awareness of reasonable adjustments among the respondent group. Twenty-eight of the respondents who received at least one diagnosis four or more years ago knew about reasonable adjustments, compared with 25 who received a diagnosis over four years ago and did not know. This was echoed throughout the different ‘time of diagnosis’ categories, where a maximum of two more respondents in each category indicated that they were aware of reasonable adjustments compared to those who were not aware.

Table 2: What works well and what could be better?– Awareness

What works well?

- Different methods for raising awareness about rights to reasonable adjustments were used. Including email, when at appointments, through Accrux, via the practice website, and through waiting room posters.
- Legislation in 2022 was introduced to ensure staff received training around learning disabilities and autism, as appropriate for their role. Feedback from GP practices indicated at least some training was being done.

What could be better?

- There were poorer levels of awareness in people who were only autistic or only had a learning disability, when compared with respondents who were diagnosed with both. Nevertheless, awareness also needed to improve among those who were diagnosed with both.
- Methods for communication about reasonable adjustments either required a diagnosis (e.g., email or communication through Accrux) or active engagement from patients (e.g., visiting the practice website, or following up after having seen a poster in a waiting room).
- Reasonable adjustment awareness rates, even among those diagnosed four or more years ago, were poor among the respondent group.

3.2. What Reasonable Adjustments did People Want and Ask For?

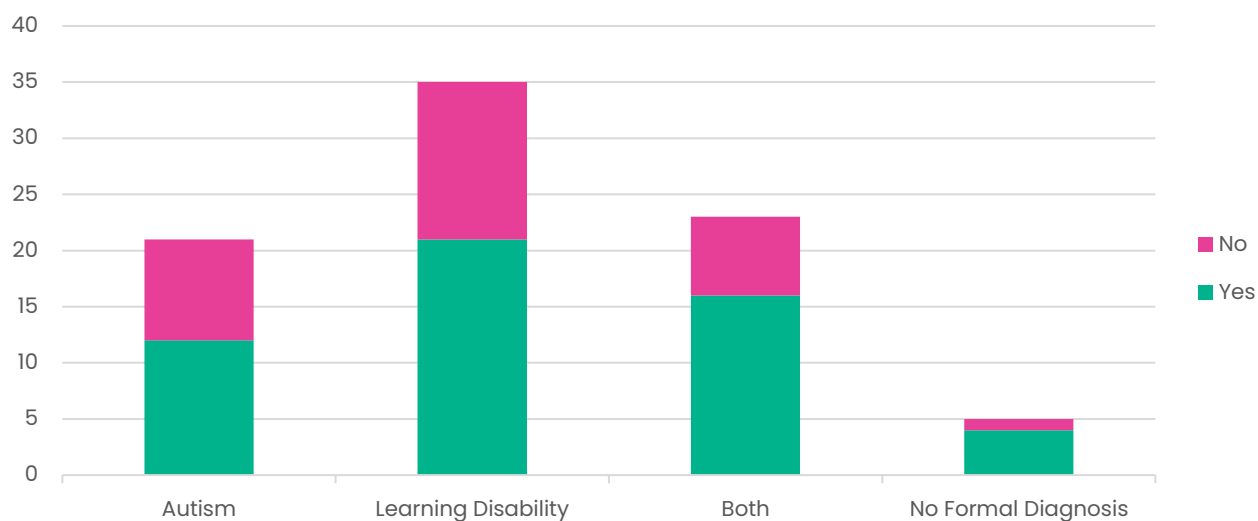
Most of the respondents (n=53, 63%) wanted reasonable adjustments to help them access their GP.

Seventy percent of respondents who were both autistic and had a learning disability, wanted reasonable adjustments to be made (n=16). Sixty percent of respondents with a learning disability-only wanted reasonable adjustments (n=21) and 57% of autistic-only respondents wanted reasonable adjustments (n=12).

Four of the five respondents who had not received a formal diagnosis also wanted reasonable adjustments.

Where respondents stated that they did not want reasonable adjustments to be made, they were asked to explain why. Most often these respondents stated that they were happy with the service they already received, that they liked that someone could accompany them to an appointment, that they were spoken to clearly, and that they felt GP appointments were easy to access.

Figure 8: Do you want reasonable adjustments to be made to help you access your GP?



Source: Patient Survey (84 Responses)

An open question was used to understand the adjustments wanted by autistic people and people with a learning disability in their own words. Eighteen respondents shared their views which tended to focus on communication & interaction, access to services, and the physical environment.

Communication and Interaction

- Respondents would have liked clearer communication and information. The adjustments respondents wanted included easy read and large text printed documents, as well as

memory aids such as confirmation or reminder letters or text messages, being able to write questions down, and permission to record the information discussed at appointments.

- When interacting with their GP practice, respondents wanted to feel like they were being listened to and to feel like that they were not having to repeat themselves each time they visited their GP. Some respondents wanted to prevent such repetition through less practical means such as the receipt of continuous care from the same GP.
- Some respondents also wanted to be able to have someone along to accompany them to an appointment. When accompanied to an appointment, one respondent stated that they were happy with the accompanying person to speak on their behalf, while another wanted to be spoken to directly. This demonstrated the need for personalised adjustments.

Access to Services

- Most often respondents wanted a variety of different appointment location options including through the telephone and face-to-face.
- Respondents also wanted to book appointments online due to feelings of discomfort when using the telephone.
- Once at the GP practice, respondents wanted shorter waiting times, longer appointments to allow adequate time to explain any issues they faced, and a greater understanding from their GP about how autism and / or learning disabilities may interact with other health conditions.

Physical Environment

- Several respondents shared their feelings of discomfort while physically attending an appointment at their GP Practice, particularly while in the waiting area. One respondent reported that due to feelings of discomfort entering the practice, that they wanted to wait in the car park. However, they reported that they were informed that this was not possible.
- Creating a relaxing environment, without noise, crowds, and a lack of fresh air were identified as important by the respondent group.

The waiting area is a NIGHTMARE for autistic people. The last time I was there, there was a telly AND a radio on, phones ringing, beeping noises, a tannoy service calling patient names, doors slamming, staff chatting and laughing quite boisterously and bright lighting. I almost left. I won't go back there

Everything [is] fine apart from one time during a procedure the GP didn't explain things properly and wasn't as kind as she was the time before. It confused me and upset me as I thought I'd done something wrong.

Telephone call appointments, clearer information, ability to book appointments online and access to same GP for continuous care purposes

GP Practices were asked about the types of reasonable adjustments they had already put in place for their autistic patients and their patients with a learning disability. All practices reported that they put at least one type of reasonable adjustment in place. These adjustments often echoed the requests listed above by the patient respondent group.

Most often adjustments focused on the flexibility of appointments including longer appointments, out of hours appointments, and advanced appointments. Practices also highlighted the variety of ways in which patients could interact with their service including through face-to-face appointments, telephone, video, home visits, and online appointments.

In terms of interacting with patients, three practices stated that they would interact with parents / carers, as appropriate and necessary. Specific staff members were also made available to patients, including a wellbeing team where team members could accompany patients to appointments when additional support was required, one-to-one support from a Care Coordinator, and continuity of care through a single learning disability GP lead.

Efforts to make the physical environment in the practice more comfortable were also highlighted by a couple of practices including the use of a small quiet waiting area, the option to wait outside, and the option to turn the lights off during the appointment.

3.2.1. Asking for Reasonable Adjustments

Of the 53 respondents who wanted reasonable adjustments, just under half had asked their GP (n=26, 49%). Three additional respondents indicated that a relative had requested adjustments on their behalf.

Where adjustments were not requested, respondents were asked why and 19 responses were received. Almost half (n=9) did not know that reasonable adjustments were available. Answers to previous questions indicated that an additional six respondents may not have requested adjustments because they did not know that they could.

Five respondents reported that the difficulties they faced prevented them from requesting reasonable adjustments. Such barriers included struggling to express their needs, struggling to talk to strangers, and fears over not being taken seriously.

I don't see the point [in asking for reasonable adjustments] as I have severe mental health issues with no hope. No one wants to help or understand what I'm saying

[I] often feel like we are requesting the impossible in the tone & nature of response. Currently my Parent manages my difficulties in accessing the environment, etc & advocates in my behalf as I am Non Verbal but often even then, it's an impossible task.

I am afraid of not being taken seriously about my health. This has already happened numerous times, and is always worse when GPs are aware of my diagnosis.

Four respondents felt that requesting reasonable adjustments would be a ‘pointless’ exercise as they would not be listened to. Two respondents were aware of their right to reasonable adjustments but felt that they had not yet needed any changes to be made to help them access services.

Table 3: What works well and what could be better?- Asking for reasonable adjustments

| |
|--|
| <p>What works well?</p> <ul style="list-style-type: none"> Relatives / Carers able to act on behalf of patient to request reasonable adjustments. |
| <p>What could be better?</p> <ul style="list-style-type: none"> Reported high drop off for those who wanted reasonable adjustments compared with those who actually asked for adjustments. Barriers around communicating needs and a perceived lack of empathy and understanding from practice staff. |

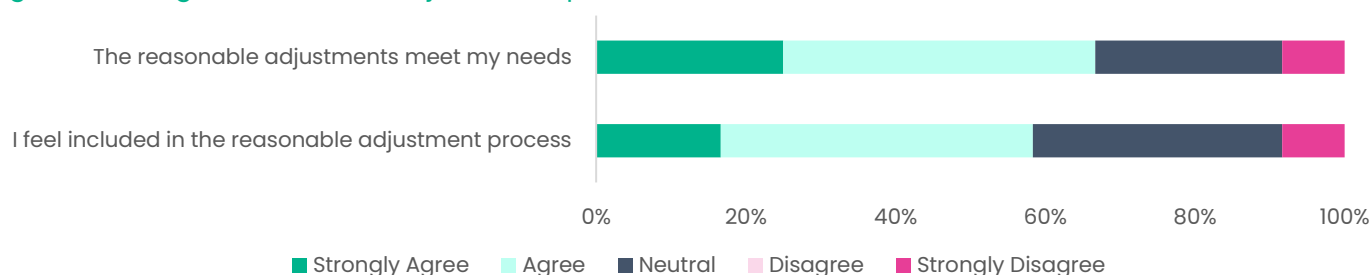
3.4. Implementing Reasonable Adjustments

Of the twenty-nine respondents who wanted reasonable adjustments and requested them, 12 (41%) reported that the adjustments had been made by their GP practice. Of these respondents five were both autistic and had a learning disability, seven had a learning disability-only, and none were autistic-only.

Overall, when reasonable adjustments were put in place, the feedback was positive. Seven of the respondents felt included in the reasonable adjustments process and eight felt that the adjustments met their needs. Where positive feedback was provided, respondents particularly liked that the process was explained and easy to understand and that they had time to talk. One respondent wanted ear plugs and highlighted the calming effect the reasonable adjustment had on them.

One respondent “Strongly Disagreed” with both statements, but when asked to explain, no explanation was provided. However, based upon other responses, this respondent, with a learning disability, may have been dissatisfied with the accessibility of the written information provided by their GP practice and wanted to feel understood.

Figure 9: Rating of reasonable adjustments process



Source: Patient Survey (12 Responses)

Fourteen respondents reported that the reasonable adjustments they had requested had not been made by their GP. Five of these respondents had a learning disability, five were autistic, and three were both autistic and had a learning disability. One of the respondents had not received a formal diagnosis, however, they did refer to themselves as an “Autistic person”. This respondent emailed their GP Practice with the request to make appointments using a method other than the telephone. They reported that the practice then proceeded to call them back.

In most cases, adjustments that some respondents reported had not been put in place were similar to those that had been put in place for other respondents.

Where adjustments weren’t made, four respondents stated that their GP explained to them (or their parent / carer) why the reasonable adjustments were not possible. Reasons included that the GP practice lacked the capacity to fulfil the request, that their GP Practice felt that the request was “Not appropriate”, or they were told “This is how we do it”.

Despite this, feedback from GP Practices suggested that they were putting reasonable adjustments in place and that they were keen to make improvements to better support their autistic patients and patients with a learning disability. One practice had appointed a Link Worker specifically for patients with autism and / or a learning disability, and another said that they welcomed any ideas on how services could be improved.

Three quote boxes are arranged horizontally. Each box has a teal border and a circular icon with orange quotation marks at the top left. The text inside each box is teal.

- We are passionate about improving the identification of people with a learning disability & autistic people... we appointed a Link Worker for people with a learning disability and autism, which we felt was the next step in improving access.
- Any ideas that could be shared with us would be welcomed as to how we make our services better for people with learning disabilities and / or autism.
- Our reasonable adjustments are not just specific for patients with autism or a learning disability, they are for all patients

GP Practices were asked if they had difficulties putting any reasonable adjustments in place. Five practices stated that there were no issues.

Two practices highlighted issues relating to access. One spoke in general terms and another spoke specifically about the challenges around accommodating out-of-hours appointments. However, they did specify that these requests could normally be accommodated. Another practice also stated that they overcame the difficulties they faced when implementing reasonable adjustments, but no further information as to what these difficulties were was provided. One practice highlighted that there were issues around non-attendance when appointments had been specifically arranged.

Table 4: What works well and what could be better?- Implementing reasonable adjustments

What works well?

- Where reasonable adjustments were put in place, they largely met the needs of those who requested them.
- Often, patients felt included in the reasonable adjustments process.
- GP practices had already made efforts to improve access and service for their autistic patients and patients with a learning disability. Practices were keen to further improve.

What could be better?

- All autistic-only respondents reported that not all of the reasonable adjustments they had requested had been put in place.
- There were poor levels of follow up to explain to patients why the reasonable adjustment they requested had not been accepted.
- Alternative adjustments were rarely offered to the respondent group when the requested adjustments could not be put in place.

4. Conclusion and Recommendations

Between December 2022 and March 2023, a total of 84 people participated in a survey to share their awareness of reasonable adjustments and their experiences accessing and using their GP practice. Seventy-nine of the respondents were formally diagnosed with either a learning disability, autism, or both.

In addition, nine GP practices shared information about their processes and their capacity to make reasonable adjustments through the completion of the Practice Survey.

- Generally, where reasonable adjustments were made, patients felt more understood by their GP practice. However, improvements were required to help with patient understanding of language and their levels of comfort while visiting their GP, both while waiting for the appointment and once in the consulting room.
- Although different methods were used by GP practices to raise awareness of reasonable adjustments, patient awareness was poor among all diagnoses. It was particularly poor among respondents with one diagnosis only.
- Respondents indicated that they particularly wanted reasonable adjustments in three areas which included Communication & Interaction, Access to Services, and Changes to the Physical Environment. Several of the Practice Managers detailed many of the same reasonable adjustments when asked what they had already put in place.
- Although most of the respondents reported that they wanted reasonable adjustments, only around half had actually requested them. Respondents highlighted barriers that deterred them from asking for reasonable adjustments which included personal issues around communication. They expressed their worries around staff attitudes and empathy.
- Based upon feedback from respondents, the levels of implementation of reasonable adjustments should improve to better meet the needs of autistic patients and patients with a learning disability. Where adjustments could not be made, explanations behind why decisions were made were not always forthcoming and alternatives were rarely offered. Where adjustments were made, feedback was mostly positive. Respondents often felt included in the reasonable adjustments process and felt that the adjustments met their needs.

Analysis of the feedback from both patients and GP Practice Managers identified a number of potential actions, which could improve the experiences of autistic patients and patients with a learning disability when accessing and using their GP practice.

- Raise awareness of reasonable adjustments among all patients by creating a culture where by anyone who needs reasonable adjustments in order to access the service are able to do so. Patients should be made aware of what “Reasonable” means at the initial point of contact, and GP practices should be proactive in offering reasonable adjustments to their patients. By being proactive GP practices may be able to remove the barriers for patients who would have otherwise been unaware of reasonable adjustments or felt they were not able to ask.
- Reach out to autistic patients and patients with a learning disability to promote the uptake of annual health checks. Ensure patients are aware of the importance of these health checks and that GP practices use annual health checks as an opportunity to understand any reasonable adjustments the patient may want.
- Maintain a record of a patients preferred contact method and ensure that the method is used when any information is communicated.
- Where reasonable adjustments are not possible, this should be clearly communicated to patients in a way they understand. If alternatives are possible, these should also be shared with patients and the offer to implement alternatives should be made.

5. Acknowledgements

We would like to acknowledge and say thanks to the following organisations for their contribution and support to complete this piece of work.

- NECS
- Northeast and North Cumbria Integrated Care Board
- Skills4People
- North East Autism Society
- GP Practices in Newcastle
- Atypical Support CIC
- Your Voice Counts
- Friends Action North East
- RNIB
- Arcadea
- Disability North
- Arts Connect
- Journey Enterprises
- Quadrant Leisure CIC

6. ICB Statement



North East and
North Cumbria

16/06/2023

RE: Accessing and using GP services in Newcastle

Dear Natasha,

Thank you for sharing this draft report with NHS North East and North Cumbria Integrated Care Board (ICB), which provides the perspectives of local autistic people and people with a learning disability regarding their experiences of accessing and using GP services.

As the statutory NHS body responsible for commissioning these services, we are committed to ensuring that autistic people and those with a learning disability are not disadvantaged and can access services easily.

It is valuable to hear feedback from 84 people (of which, 79 are autistic or have a learning disability) and nine GP practices based in Newcastle, who estimate they have a combined total of over 13,000 patients who are autistic, have a learning disability or both.


It's positive to hear that around half of respondents reported being made to feel at ease by staff and that information was shared in a way that they understood, but we acknowledge that others felt this was not the case for their experience and that we need to ensure they are supported in future.

We also recognise that there was a correlation between reasonable adjustments being made for patients and them having a positive experience, with a similar trend occurring with patients not having adjustments made and consequently having a negative experience.

The report identifies a need for awareness raising about reasonable adjustments, to ensure people are supported to understand what they are, and how to request them. We would be keen to work in partnership with Healthwatch Newcastle as to how this, and other recommendations, can be achieved.

An initial response to the recommendations made in the report is available below:

| Recommendation | NENC ICB Response |
|---|--|
| <p>Raise awareness of reasonable adjustments among all patients by creating a culture whereby anyone who needs reasonable adjustments in order to access the service are able to do so. Patients should be made aware of what "Reasonable" means at the initial point of contact, and GP practices should be proactive in offering reasonable adjustments to their patients. By being proactive GP practices may be able to remove the barriers for patients who would have otherwise been unaware of reasonable adjustments or felt they were not able to ask.</p> | <p>We are currently looking to introduce a reasonable adjustment flag as part of a patient's record, the testing of this and its eventual roll out will help address the issues raised in the report.</p> <p>There is currently no national solution that alerts the practice to whether there is a reasonable adjustment request for a patient.</p> <p>This is in development and we will work with our practices to ensure that it is taken up when available.</p> <p>In the meantime, practices can and do use alert messages on the local electronic patient record to capture reasonable adjustments e.g. double appointment needed, needs late appointments to avoid noisy waiting room etc.</p> <p>All Newcastle practices/PCNs have commissioning link workers who can raise and re-emphasise these opportunities to offer and record reasonable adjustments.</p> <p>Practices will be encouraged to review their processes for promoting requests for reasonable adjustments as part of help and support for the Learning Disability Health Check as well as completing tier 1 level 1 of the Oliver McGowan training. We should also explore ways of capturing and flagging reasonable adjustments at new patient registrations.</p> |
| <p>Reach out to autistic patients and patients with learning disabilities to promote the uptake of annual health checks. Ensure patients are aware of the importance of these health checks and that GP practices use annual health checks as an opportunity to understand any</p> | <p>There is already a comprehensive and rigorous approach to supporting people with a learning disability access annual health checks and health action plans. In the year 22/23 Newcastle ICB exceeded the national target of 75% of people on GP Registers having an annual health, by achieving 82%. Work will continue to</p> |

| | |
|---|--|
| <p>reasonable adjustments the patient may want.</p>  | <p>understand how even greater reasonable adjustment might increase this figure. The ICB is in the early stages of developing its approach to autistic people and access to annual health checks. A key element of their introduction will be understanding what reasonable adjustments are required.</p> |
| <p>Maintain a record of a patients preferred contact method and ensure that the method is used when any information is communicated.</p> | <p>Practices will have their own methods for recording requests and ensuring that staff are aware of a request and how to fulfil it.</p> |
| <p>Where reasonable adjustments are not possible, this should be clearly communicated to patients in a way they understand. If alternatives are possible, these should also be shared with patients and the offer to implement alternatives should be made.</p> | <p>We will continue to encourage practices to both promote and be open to requests from any patient to discuss reasonable adjustments – and remind practices that where they are not able to be met, patients should be told the reason why, and a discussion had as to finding a suitable alternative solution.</p> |

Thank you again for sharing this report with us, we look forward to working in collaboration with you to improve service accessibility for local autistic people and people with a learning disability.

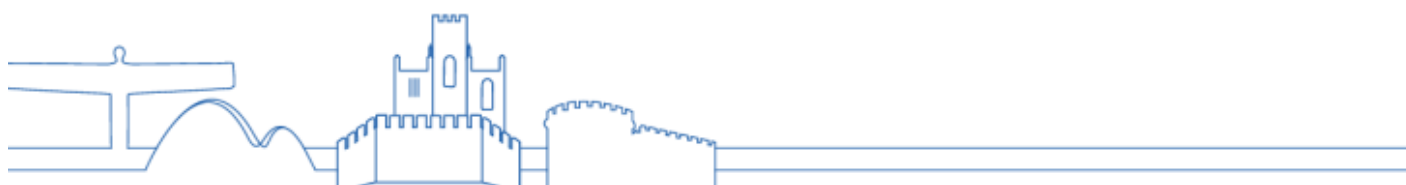
Kind regards,



Joe Corrigan

Director of Place (Newcastle)

NHS North East and North Cumbria Integrated Care Board



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