

Empowering Voices: **Examining Healthcare Access for **Adults with** **Learning Disabilities and Autistic Adults in** **Southwark****

Healthwatch Southwark
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If you have any questions or comments on the report or any of the issues raised, please contact Ruman Kallar (Healthwatch Southwark Research & Projects Officer) at ruman@healthwatchsouthwark.org

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1. Executive Summary

This project examines the accessibility of healthcare services for adults with learning disabilities and autistic adults in Southwark. It was prompted by evidence that adults with learning disabilities face notably poorer health outcomes compared to adults who do not have a learning disability (Southwark Council 2018; Learning from Lives and Deaths 2021; Office of National Statistics 2022; Healthwatch England 2022).

The research involved a written survey capturing the experiences of service users, carers, and service providers regarding healthcare access across Southwark. We held three Café Conversations events to gather in-depth insights and collaboratively brainstorm solutions. In total, 104 individuals participated.

The people we spoke to did not believe there was consistent equity of access to local healthcare services. Our findings reveal widespread barriers to healthcare, particularly within mainstream services including GPs and A&E. The most common obstacles identified **include encounters with unkind or impatient staff, communication difficulties with healthcare professionals, and a lack of reasonable adjustments for individual needs**. These challenges appear to stem predominantly from healthcare staff's limited understanding of learning disabilities and autism, as well as inadequate practice systems to accommodate individual needs.

Moreover, the **absence of a centralised directory of services and information** for adults with learning disabilities and autistic adults in Southwark hinders coordinated healthcare provision and leaves service users and carers uncertain about where to access support.

In response to these findings, we worked with respondents to develop a set of recommendations for care providers. These include providing **training** on learning disabilities and autism for healthcare staff, facilitating **information-sharing** between services, and implementing changes to **practice systems** to ensure that reasonable adjustments are consistently made available. Further details are provided in section 4 of the report.

1.1. Key findings

Our findings indicate that the majority of respondents have experienced barriers to accessing healthcare services. These barriers include:

Staff-Related Issues

- Poor staff attitude towards service users and carers, e.g. being rude, dismissive, and patronising.
- Staff failing to support service users to communicate and understand during appointments, e.g. use of complex language, not giving service users enough time.
- Staff having little understanding of learning disabilities and autism.



Patient-Centred Issues

- Feelings of fear and anxiety towards healthcare services.
- Service users and carers are uninformed about health promotion initiatives and adjustments such as double appointments.
- Unsuitable and inaccessible locations for appointments, e.g. bright and noisy waiting rooms, no lifts.



Operational Issues

- Inconsistent implementation of reasonable adjustments within and across healthcare services.
- Limited options to contact services outside of appointments, telephones are not always answered, and the use of withheld numbers to contact patients is off-putting.
- Lack of flexibility for the date, time, location, and structure of appointments.
- Lack of aftercare or follow-up care for adults with learning disabilities and autistic adults; caused by poor co-ordination between care providers and the reduction of services from child to adult care.



- Diagnosis of a learning disability or autism is required to access specialist services and adjustments. Long waiting times and unclear pathways for diagnostic services.
- Excluding service users from being involved in and informed about their own care.
- Excluding carers from being involved in and informed about service users' care, particularly after transition to adult services.
- Frequent staff rotation disrupting care.

Social Factors

- Financial hardship adversely impacting health and causing service users to deprioritise healthcare.
- Social isolation adversely impacting health and making it harder for service users to access healthcare.
- Lack of provision for service users who do not have carers to support them.
- Lack of support for carers, e.g. respite services.
- Systemic racial and ethnic inequalities preventing people from accessing suitable services until crisis point.



1.2. Summary of Recommendations

This research makes a series of recommendations to improve healthcare access for adults with learning disabilities and autistic adults. The complete set of recommendations is contained in section 4 of this report. However, our recommendations can be summed into four core categories:



1. Training. Provide training about learning disabilities and autism to all patient-facing staff delivering healthcare services.



2. Sharing Information. Facilitate and promote sharing information about services and support available for adults with learning disabilities and autistic adults. This should include voluntary and community sector support, and adult social care.



3. Communications. Healthcare services should audit and improve the accessibility of their communications with service users and carers.



4. Operational Issues. Implement measures to deliver a consistent standard of care across healthcare services that adheres to the Accessible Information Act 2016.

2. Introduction

Adults with learning disabilities are known to have significantly poorer health outcomes compared to adults who do not have a learning disability (Southwark Council 2018; Learning from Lives and Deaths (LeDeR) 2021; Office of National Statistics, 2022). These outcomes are influenced by factors such as access to health and care services, a higher burden of disease, and social factors such as poverty and poor housing.

In recognition of this, improving healthcare services available for people with learning disabilities and autistic people has been identified as a priority area at the national and local level. Both the NHS Long Term Plan (NHS England 2022) and Southwark's Joint Strategic Needs Assessment on Learning Disabilities in Southwark (Southwark Council 2018) set out actions to understand and help healthcare professionals respond to people's needs.

This project aims to contribute to this work by gathering feedback from adults with learning disabilities and autistic adults, their carers and healthcare professionals who provide general and specialist services for this group, about their experiences of using and delivering healthcare services in Southwark.

This project sets out to identify the barriers to healthcare access for adults with learning disabilities and autistic adults, and co-produce targeted recommendations to make healthcare services more accessible to this group.

What is a learning disability?

NHS England (2019) defines a learning disability as "a lifelong condition; it is not an illness and cannot be cured. The term learning disability is used in relation to people who have the following characteristics:

- A significantly reduced ability to understand complex information or learn new skills.

- A reduced ability to cope independently.
- A condition which started before adulthood and has a lasting effect.”

What is autism?

National Autistic Society defines autism as “a lifelong developmental disability which affects how people communicate and interact with the world. Autism is a spectrum condition and affects people in different ways” (National Autistic Society 2024).

Autistic spectrum conditions are not classed as a learning disability in themselves; however, approximately 20–30% of people with a learning disability also have autism (NHS England 2019).

2.1. Background Research

National findings

The life expectancy of adults with learning disabilities and autistic adults is up to 20 years shorter than adults who do not have a learning disability and are not autistic (Healthwatch England 2019). Worse still, the life expectancy of people with a learning disability who are from ethnic minority backgrounds is just over half the life expectancy of their white counterparts (Race Equality Foundation 2023).

Mencap, a charity that supports people with a learning disability, argues that health inequalities experienced by people with learning disabilities are not inevitable, but are the result of “poor quality healthcare causing avoidable deaths” (2023).

Research identifies key challenges in accessing healthcare services, including timely identification of needs, accessing appropriate services, and quality interactions during consultations. Barriers include long waiting lists, short consultation slots, insufficient joint working between healthcare and social care services, limitations on carer participation, and inadequate

transport links (Mencap 2023; Care Quality Commission (CQC) 2022; Blair 2016; Sakellariou and Rotarou 2017).

While fewer studies focus on autistic individuals accessing healthcare, reports suggest failings in identifying autistic individuals who do not have learning disabilities and a lack of staff knowledge to provide suitable care (CQC 2022).

From an intersectional perspective, individuals from ethnic minority backgrounds with learning disabilities encounter additional problems such as language barriers, cultural insensitivity, and racial discrimination from healthcare providers (Race Equality Foundation 2023).

Recommendations to address these disparities include holding providers accountable for service standards, involving individuals with communication needs in service design, and implementing existing policies related to learning disabilities (Healthwatch Southwark 2022; Race Equality Foundation 2023).

Local findings

At the local level, Southwark's Joint Strategic Needs Assessment (JSNA) on Learning Disabilities revealed low uptake of seasonal flu immunisation and lower rates of cancer screening among individuals with learning disabilities (Southwark Council 2018). The JSNA recommended efforts to promote greater participation in annual health checks and emphasised the need for formal engagement with individuals with learning disabilities, carers, and service providers to improve service provision.

Additionally, a 'Have Your Say' event was held by Southwark's Health Ambassadors in August 2022, gathering feedback from 34 participants, including 17 service users with learning disabilities and/or autism (Advocacy in Greenwich 2022). The event highlighted several barriers to healthcare access, including digital exclusion, poor communication with patients, and overwhelming medical environments. However, deeper engagement with service users and carers is necessary to fully understand the issues identified during this event.

2.2. Aims

Our project aims to build upon and help deliver the recommendations identified in existing work. To achieve this, we set out to:

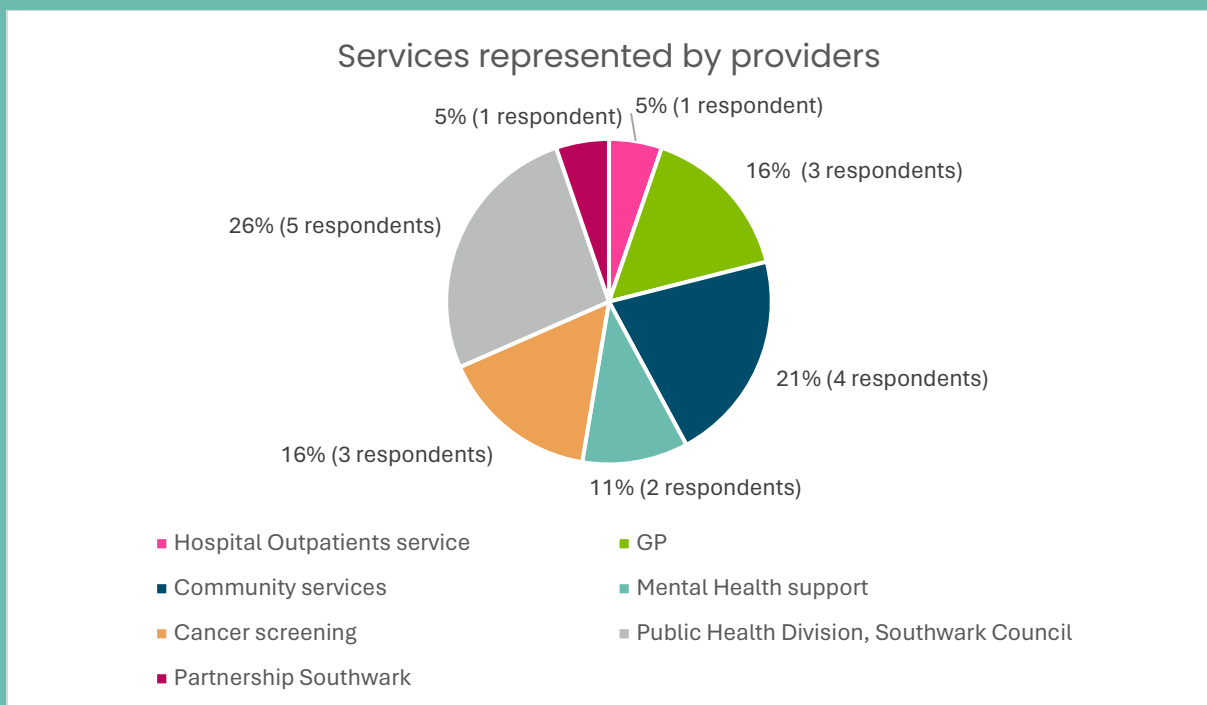
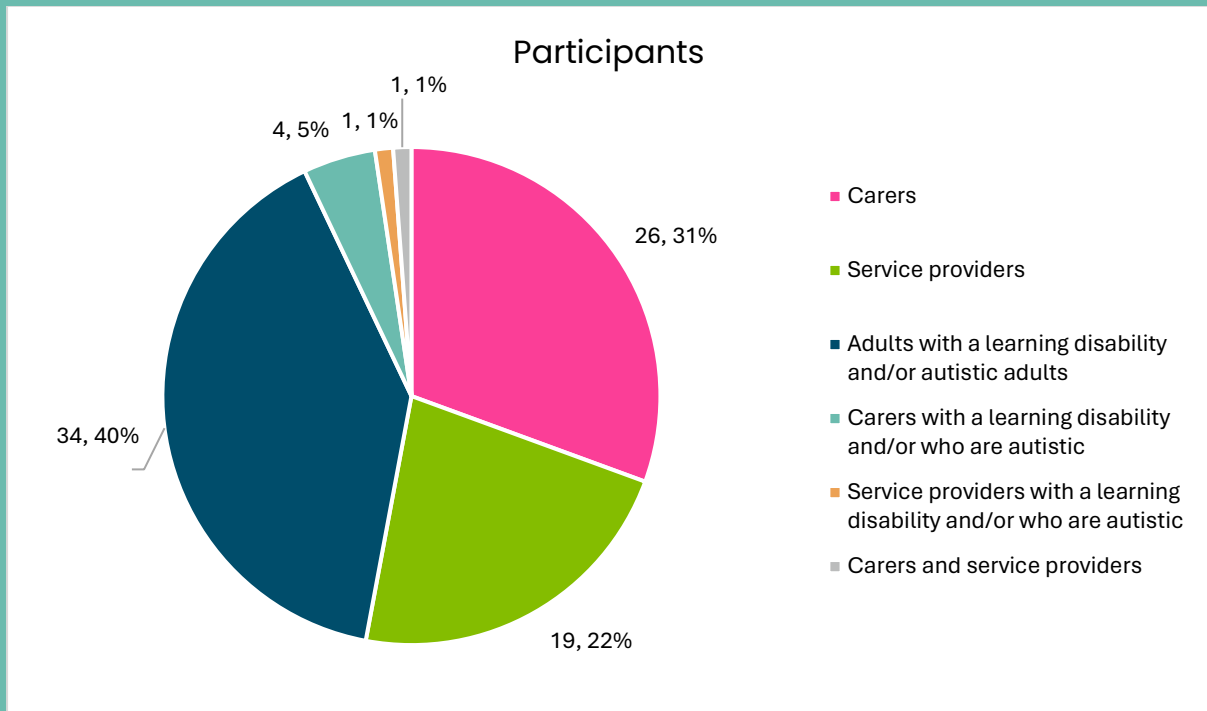


We prioritised the engagement of service users and carers from ethnic minority backgrounds, recognising the additional disparities in health outcomes between people with learning disabilities and autistic people from ethnic minority backgrounds and those from white ethnic backgrounds (Race Equality Foundation 2023).

2.3. Methodology

Between September 2023 and February 2024, we engaged with 104 participants through a survey and three Café Conversations events. Although we offered to hold individual interviews, none were requested.

Respondents included adults with learning disabilities and autistic adults (40% or 34 individuals), carers (31% or 26 individuals), and healthcare professionals who provide services for this group (22% or 19 individuals). Six respondents (7%) belonged to more than one of these categories. We aimed to include service providers, as this perspective has previously been underrepresented. Additionally, 66% of respondents (69 individuals) identified as being from ethnic minority backgrounds. We collaborated with voluntary and community sector organisations supporting adults with learning disabilities and autistic adults to reach our target groups effectively.



Survey

Our survey employed a branching structure tailored for three distinct participant groups (service users, carers, and service providers), with slightly different sets of questions to capture the different perspective of each group. Those identifying with multiple groups were directed along one survey branch and offered the opportunity to provide additional feedback directly. Bede House Day Centre piloted the survey draft with 20 service users to assess the accessibility and efficacy of the questions.¹

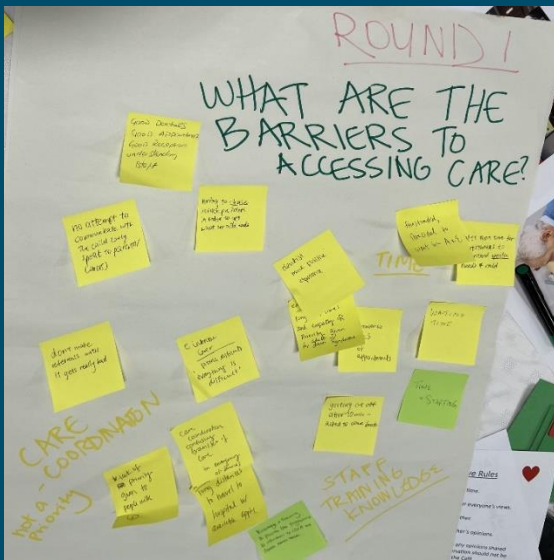
The final survey included a mix of closed and open questions to gather detailed personal experiences. It was distributed online and promoted by voluntary and community sector groups (VCS), Southwark Council, and care providers' internal and external communications. We also circulated physical copies at Bede House and Cherry Gardens Day Centres. We obtained 51 responses, yielding both quantitative and qualitative data. While this study relies predominantly on qualitative analysis for narrative capture, quantitative data is useful for identifying service usage patterns and feedback trends.

Café Conversations

We organised three events, utilising the World Café workshop methodology to facilitate deeper, richer engagement. Service users, carers, and providers were brought together to discuss three rounds of questions, culminating in an opportunity to brainstorm solutions for how to improve healthcare access. These events, facilitated by local voluntary and community sector groups- Autism Voice, Bede House Day Centre, and Cherry Gardens Day Centre- provided familiar settings for respondents. In total, 53 people attended these events.

¹ We followed guidance from Mencap (2023) and South East London Integrated Care System (2022) on involving people with a learning disability in research and consulted the project steering group for insight into appropriate methods and topics to include for this group, e.g. health promotion initiatives.

Photographs from Café Conversations.



2.4. Analysis

We used thematic analysis to process our qualitative data, focusing on how people described their experiences and what this revealed about healthcare services. We employed an inductive approach to let the data shape our themes.

Initially, we coded the data to describe expressed ideas, then grouped codes to form broader themes. These themes were reviewed across the dataset to ensure they provide comprehensive and accurate representations of recurring issues and key ideas.

2.5. Challenges

We received feedback from service providers that the project aims were too general to produce focused outcomes. Based on this feedback, we polled a shortlist of more specific topics that had been flagged as priority areas by providers. However, VCS groups and carers responded that it was difficult to choose one priority area, as service users experience barriers to accessing services across the entire healthcare system.

This presented a challenge, as the narrowing requested by service providers reflects the way that organisational improvements are actioned but does not align with community feedback about a whole-system issue.

The decision was made to maintain the project's broad focus to better understand service users' and carers' perspectives on improving access to healthcare services. This approach aligns with recommendations from Healthwatch England (2022) and Healthwatch Sheffield (2016) to establish a foundational understanding of the communication, information, and access needs for people with learning disabilities and autistic adults.

3. Findings

We asked service users and carers about their experiences of accessing healthcare services. **78%** of service users and carers (31 individuals) we spoke to said they have had at least one **good experience** with healthcare professionals. These experiences included kind and helpful staff, timely appointments, and good continuity of care.



“There is a national shortage for my treatment and the GP was fantastic in finding a solution. I was very anxious and catastrophising and assumed nothing would happen, but my GP was very attentive, kind, and took steps to remedy the situation including engaging with the local chemist.”

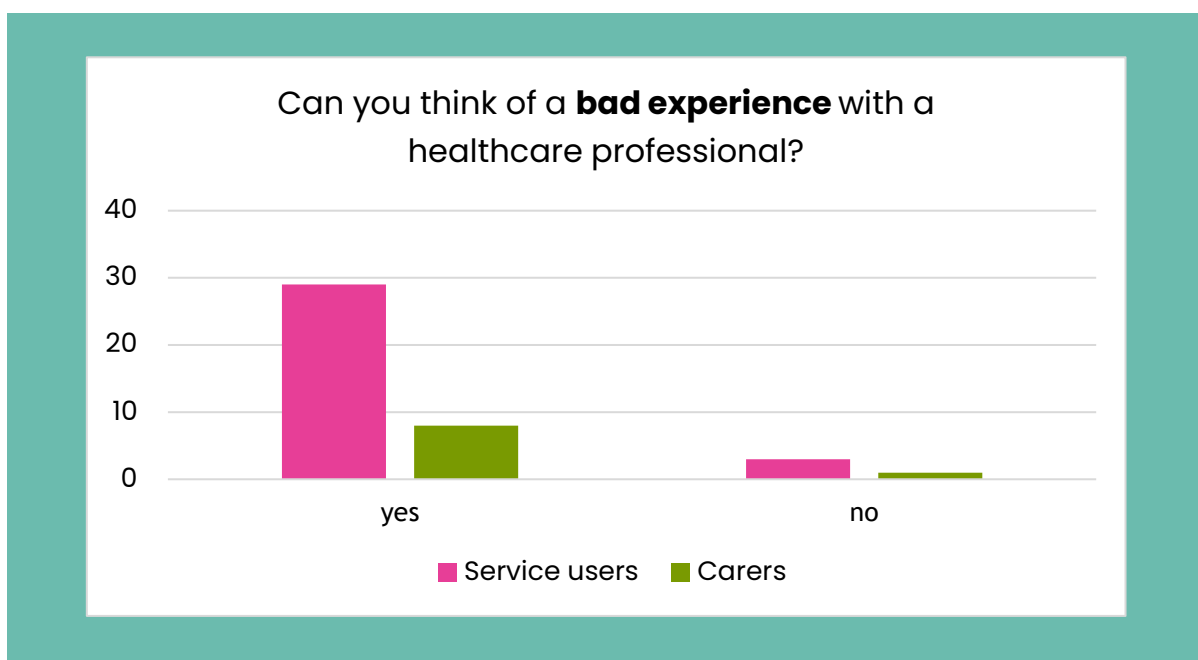


However, **90%** of service users and carers (37 individuals) said they have had at least one **bad experience** with healthcare professionals. The reasons given were wide-ranging, including rude staff, inaccessible buildings, and a lack of follow-up care.

“I’m constantly having bad experiences, constantly not being followed up with the specialist.”



“I’ve had too many to share, unfortunately. I expect the worst, perhaps a trauma response now. Sometimes when professionals know I’m autistic they treat me like a child or don’t expand upon my questions. Others previously have dismissed my concerns and not followed through for me – they say one thing, but subsequent actions do not match.”



We asked follow-up questions to understand what is currently working well for this group and to pinpoint areas that require improvement.

We grouped the barriers identified by respondents into four themes to make our findings more accessible to all audiences. However, we recognise that there is substantial overlap between themes.

Staff-Related Issues



3.1. Staff Attitude

Most of the feedback we received centred around the attitudes of healthcare staff, particularly how staff communicated with service users and carers, and made them feel.

Positive feedback included,



“My doctor is funny and likes football.”

“Our GP is very engaged and treats our daughter with care and respect.”

Respondents emphasised the importance of friendly conversation with healthcare professionals to facilitate access to healthcare; building rapport during appointments creates trust and can foster a positive association with healthcare services.



However, the volume of negative feedback we received regarding staff attitude was far greater, with service users and carers describing feeling ignored, rushed, and patronised when communicating with healthcare professionals. This feedback was regarding doctors, nurses and receptionists.

“When I was in hospital, they didn’t talk to me, I was left alone, and the nurses were horrible...I never want to go to hospital again.”



The sentiments expressed here recurred throughout our data, with several service users explaining that the feelings induced by negative interactions with healthcare professionals make them reluctant to return to services for support.

alone horrible dismissed confused
patronising frustrated
overwhelmed challenged
rude upset stressful
ashamed rushed misunderstood
lost ignored anxious

3.2. Communication During Appointments

Adults with learning disabilities and autistic adults often find it challenging to communicate with healthcare professionals during appointments, particularly in mainstream services. Barriers to communication include the use of complex language and medical jargon, and not being given enough time and support to understand.



"I didn't understand what was going on. The doctor didn't give me time to speak."



One carer said that staff did not explain why her son's medication was being changed and ignored her questions. She described feeling "like the staff were blaming me."

This can be particularly challenging for people with multiple disabilities, who may experience greater difficulty with communicating and understanding.



For example, a service user who has a learning disability and a hearing impairment said, "I've given up. They don't do anything for me, they don't listen to me because of my hearing."

Whilst two service providers said they find the use of visual communication methods such as Picture Exchange Communication System (PECS) or Makaton to be effective during appointments with adults with learning disabilities and autistic adults, they acknowledged that these methods are

not available in all services, particularly mainstream services such as primary care.

3.3. Staff Knowledge and Understanding

Service users and carers expressed concerns about the limited understanding that healthcare professionals' have of learning disabilities and autism, especially in primary care and emergency services. They felt this lack of understanding led to poor quality care, with instances of misdiagnosis and incorrect medication.

One carer felt that her autistic son had been overmedicated due to the inability of healthcare professionals to identify his needs and provide appropriate support. This aligns with the national STOMP campaign, aimed at stopping the overmedication of people with a learning disability, autism, or both with psychotropic medications.

“Staff do not recognise people with autism as their own person. They act like all autism is the same when it is not.”

“For any vaccines (my son) receives, there is no understanding on how to deal with learning disability.”



While **70%** of service providers (7 individuals) reported receiving sufficient training to support adults with learning disabilities and autistic adults, they acknowledged that the level of training provided differs across services.

“Yes (I have received sufficient training), but I work in a specialist service, I do not think that is the case for mainstream mental health or physical health services.”



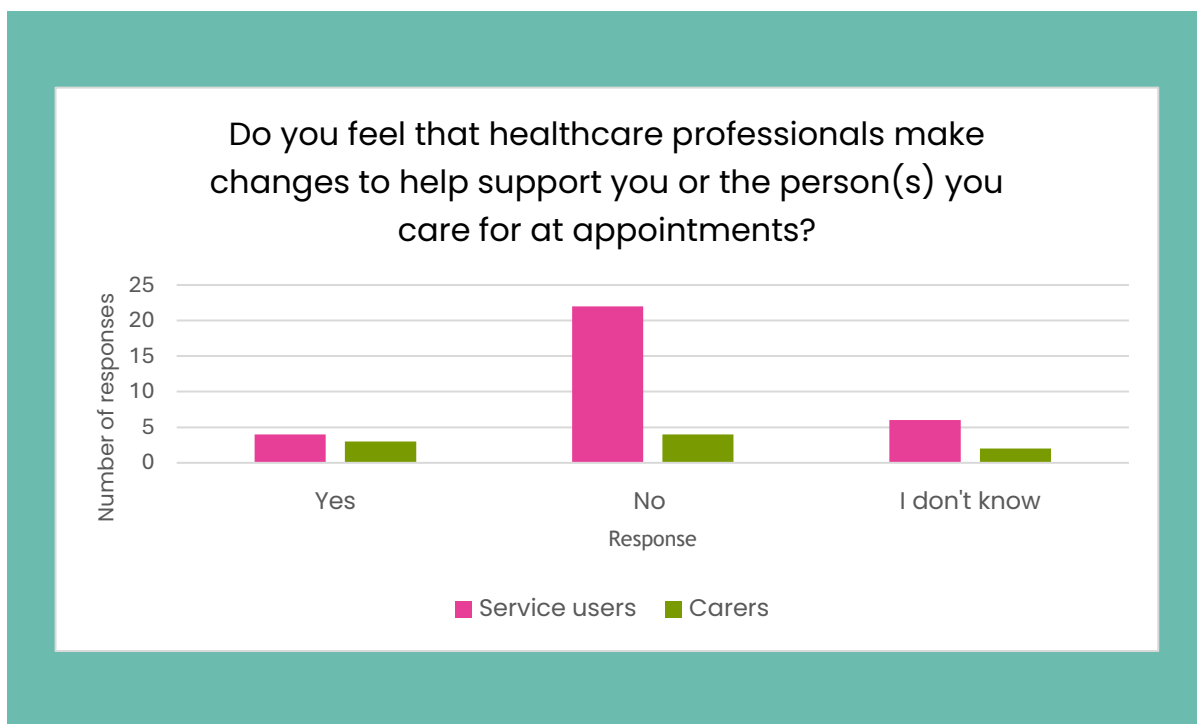
One response highlighted the value of lived experience in meeting the needs of this group,

“Yes, but I am autistic myself and my information is based on my own research and experiences which help me to understand the different support needs or services which may help autistic adults.”



3.4. Reasonable Adjustments

When we asked service users and carers if healthcare professionals made changes to support them or the person they care for during appointments, **63%** of respondents (26 individuals) said no.



Examples of positive experiences where professionals made adjustments for patients include:



“My GP is really good and has in the past offered additional resources like easy read leaflets.”



“They understood that I have a lot of anxiety around hospitals. Letting me take my dog to the appointment helped.”

More frequently, service users and carers reported mixed experiences, stating that the support they received differed depending on the healthcare professional or service they encountered.



“It depends. Sometimes they do (make changes), sometimes they don't. Most of the time they don't though.”



Referring to a lanyard used to indicate a hidden disability, “When my child had an accident and ended up in A&E, the flower lanyard and ‘I’m autistic’ badge meant nothing.”



Two individuals reported that despite requesting adjustments, none were made, “I have expressed during my x-ray that I prefer to have only one person in the room which the nurse said she would make a note of but I’ve yet to receive any accommodations following my autism diagnosis.”

Service providers noted that patients often struggle to access reasonable adjustments in non-specialist services, explaining that “mainstream services are not set up to offer reasonable adjustments.” For example, some GPs offer home visits whilst others do not due to lack of capacity.



“Not every surgery is the same, some are better prepared and aware of care needed.”

Patient-Centred Issues



3.5. Feelings and Anxiety

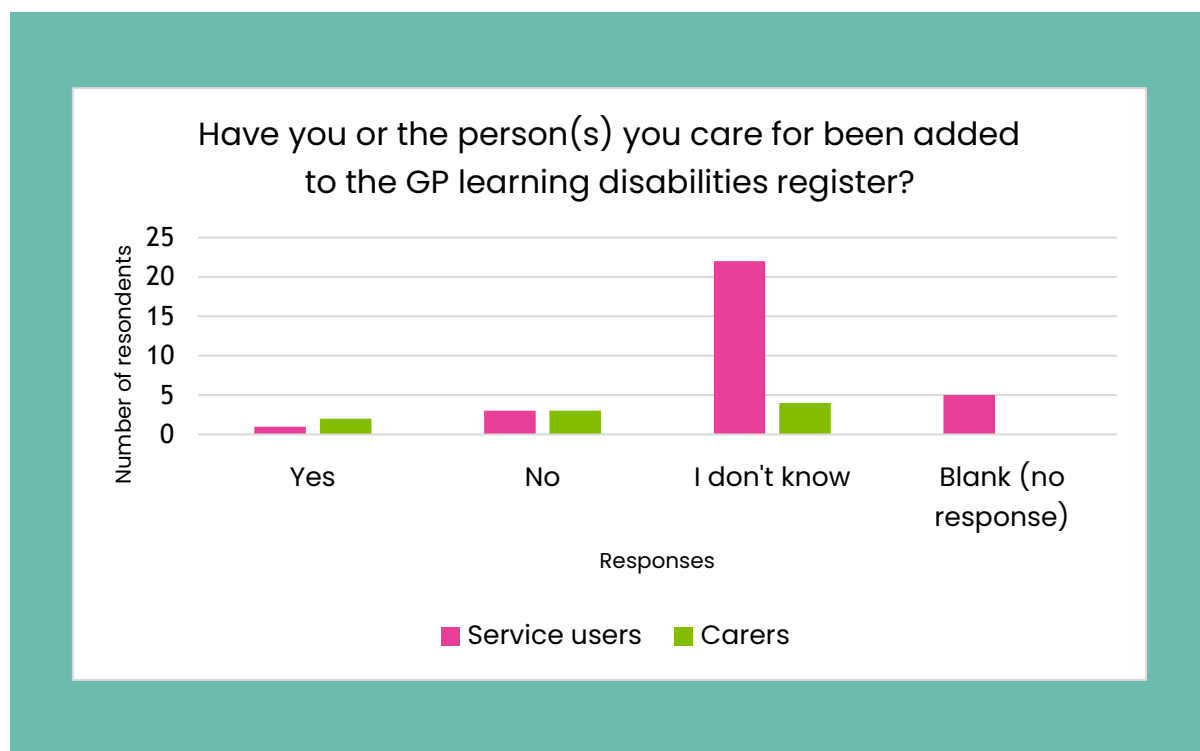
Many service users expressed fear and anxiety about accessing healthcare services, especially for routine procedures like dental checks or vaccinations. This can stem from past negative experiences, fear of pain, aversion to touch, and sensory sensitivities. As discussed, lack of communication from service providers intensifies these feelings. Dental appointments were specifically highlighted as challenging, despite the availability of specialised support from community dental services for people with learning disabilities and autistic people. Respondents described feeling overwhelmed and frightened during these appointments.

“The dentist is really scary. I don’t like to open my mouth... It’s scary.”



3.6. Service User and Carer Knowledge

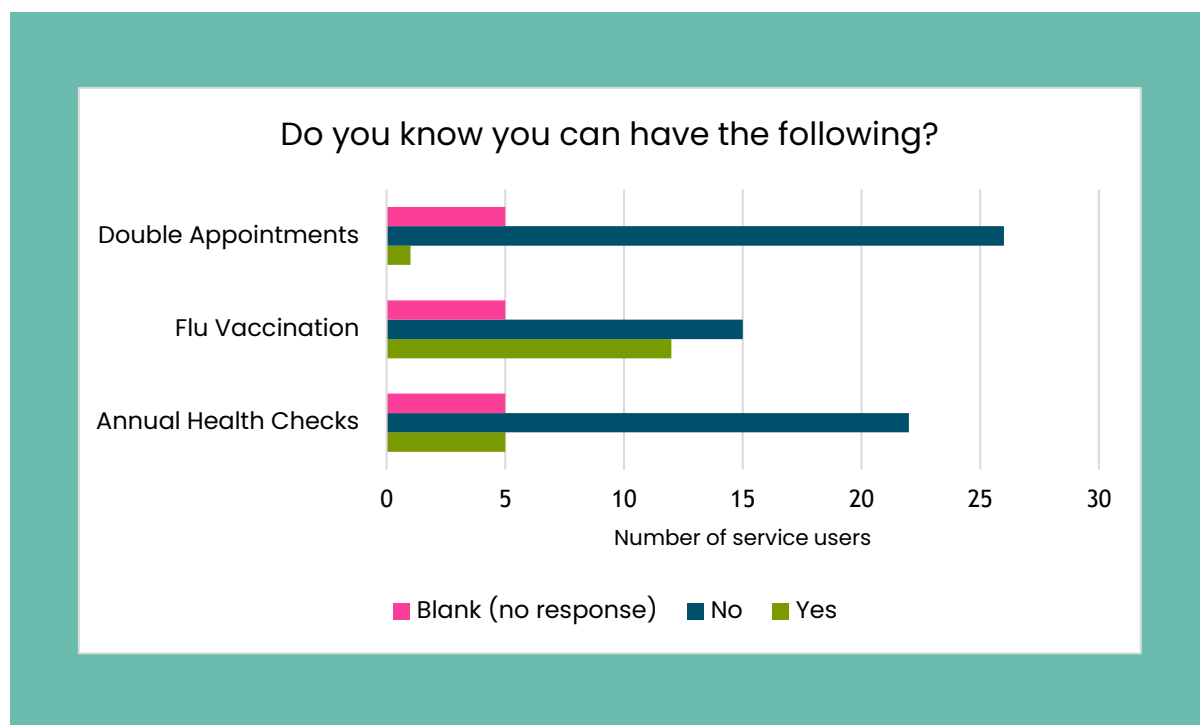
Despite national and local reports indicating increased uptake of health promotion initiatives for adults with learning disabilities and autistic adults (NHS Digital 2019; Southwark Council 2018), our findings revealed that many service users were unaware of these initiatives. For instance, individuals must be added to their GP Learning Disability Register to access initiatives like annual health checks and flu vaccinations, yet **65%** of service users and carers (26 individuals) did not know their registration status.²



Furthermore, when asked about entitlements such as double appointments, annual flu vaccinations, and health checks, a significant proportion of service users were unaware of their rights. For example, **81%** (26 individuals) were unaware of their entitlement to double appointments, despite time constraints being identified as a major barrier to healthcare access.

² This question was only asked to people with learning disabilities and people who care for someone with a learning disability, as autistic people who do not have a learning disability are not included on GP Learning Disability Registers.

Similarly, **69%** (22 individuals) did not know they were entitled to annual health checks, indicating a lack of information about the care they receive.³ This suggests that whilst measures are in place to improve access to healthcare services for people with learning disabilities, they are not widely understood by service users.



Service users and carers emphasised the need for clearer information about available services and adjustments, expressing frustration with the lack of accessible resources. While a local offer exists for young people with

³ Feedback we received on the quality of annual health checks was mixed, "Good experience. Consultant at Guy's & St Thomas's made sure to cover all areas of health in annual review."
"GP annual health checks are not great. They keep asking the same questions and irrelevant questions e.g. if my son smokes or drinks when he has severe disabilities! They have 20 years of notes in his files from many doctors, yet I have to sit for an hour answering questions about his health history."
However, as the majority of respondents did not know what the annual health check was, this feedback was limited.

special educational needs, there is no comprehensive equivalent for adults.⁴



“There should be more information in accessible formats, not just ‘go online’.”



“Services would be better if information was more transparent and accessible. More flyers, brochures etc. in easy read formats.”

3.7. Exclusion from Patient Care

Some service users felt uninformed and excluded from decision-making about their own care, as healthcare professionals only communicate with their carers, depriving them of independence and privacy.

“They speak about me, not to me.”



Conversely, some carers felt marginalised in decision-making about the health of the person they care for, despite their expertise relating to the individual's needs.

“Doctors need to listen more to what carers say, because while they are medical experts, we are the ones who live with them day-to-day and know them better.”



Thus, the extent to which carers should be involved in healthcare varies depending on the individual's needs and preferences, underscoring the importance of tailored care.

3.8. Medical Environments

We received feedback indicating that the busy and unfamiliar environments of healthcare facilities can be distressing for adults with learning disabilities and autistic adults due to overstimulation. Respondents described feeling anxious and overwhelmed by loud noises, bright lights,

⁴ The Local Offer is provided by Southwark Information Advice and Support Team (SIAS) which offers a directory of services for young people aged 0-25 who have special educational needs, as well as advice on how to navigate SEND services for families of young people.

and crowded waiting areas. Additionally, the lack of privacy in waiting areas can be distressing for carers who feel conscious of disturbing other patients.

“I don’t like the ambulance sirens. They annoy me, they are really scary.”



“They made me wait for ages in a really busy area that was so anxiety provoking, and I was not allowed to make noise.”

Furthermore, individuals with co-existing physical disabilities highlighted additional challenges with accessing care due to a lack of wheelchair access in some facilities. This can lead to patients being seen in unsuitable locations, causing further distress and discomfort.

For example, one respondent described feeling “traumatised” after having their blood pressure checked in the hallway of their GP practice. “The check was not in a private, reasonable space.”



“There is no lift in my local GP surgery, only a stair lift which my son can’t access.”



Operational Issues



3.9. Communication Outside of Appointments

Service users and carers reported difficulties contacting healthcare services when needed, hindering appointment bookings, follow-ups, and access to patient records. Limited communication options, primarily by telephone, fail to accommodate diverse needs. Additionally, services using withheld telephone numbers and email addresses that discourage replies or are not clearly identifiable can be off-putting for service users and carers, making it “hard to trust” who is contacting them.

One service provider stated, “Many hospital departments do not allow booking via email or web form. They always seem to insist that one phones or expects a call back from a ‘private number’.”



Carers also shared that staff frequently do not answer phone calls and it can be difficult to find the correct telephone number for services.

“I can never get through to staff if I have a problem. I was meant to receive a call from the hospital but it didn’t happen, though I was waiting with my phone by my side all day. Then I received a missed call from a private number and no voicemail was left.”



3.10. Inflexible Appointments

Lack of flexibility around the times, locations, and structure of appointments poses a significant barrier for adults with learning disabilities and autistic adults seeking healthcare. Appointments scheduled during typical working hours can be challenging for carers to attend and disrupt the daily routines of service users, causing emotional distress.

For example, one service user expressed reluctance to go to the hospital because it meant missing activities at the day centre he attends. He suggested that having a nurse visit the day centre instead would be more convenient, allowing him to receive treatment without leaving his familiar environment and staying with his friends and day centre staff.



“It is important to be flexible and not disrupt routines with appointments. Make things convenient. Come to the community centre, spaces where people feel comfortable.”

Moreover, limitations on appointment duration and the number of issues that can be addressed per appointment further prevent access to healthcare, particularly with GPs. One respondent recounted waiting a year for an appointment where all their concerns had to be addressed in a single session.



“The appointment times are too short (to discuss everything), especially when you have to explain your problems to someone who isn’t familiar with your medical history.”

3.11. Poor Care Continuity

Several respondents reported a lack of follow-up or aftercare following appointments. This was attributed to poor communication within and between services, leading to uncertainty about who is responsible for patient care. For example, one service user described being referred to a community dental practice by their GP in 2019 but had not received any further communication.

Others highlighted issues with the support received post-diagnosis.

One service user described feeling abandoned, “They simply gave a diagnosis and that is it. No support for my child once he was diagnosed, especially (transitioning to adult services), there was no follow up care.”



Moreover, several service users faced challenges in accessing medication due to coordination issues between doctors and pharmacists. Problems with repeat prescriptions resulted in interruption to treatment, causing distress for those reliant on long-term medication.

Carers also noted a significant reduction in support for service users after they transition from child to adult services, despite service users’ needs remaining the same. With no Local Offer tailored for adults with learning disabilities and autistic adults, service users, carers, and service providers found it challenging to locate appropriate support from healthcare services and within the voluntary and community sector (VCS). Service providers echoed the need for a more personalised approach to the transition to adult care, emphasising the importance of addressing individual needs.

3.12. Diagnosis


Access to specialised services and reasonable adjustments often requires service users to meet eligibility criteria or “thresholds” such as having a formal diagnosis of a learning disability or autism.

Receiving a diagnosis can be challenging due to factors such as long waiting times to access diagnostic services, individual differences in

presentation, and reluctance to pursue or accept a diagnosis from service users and carers due to culture, belief, lack of information or stigmatisation.

There are also gendered implications to the requirement for diagnosis to access services, as women are less likely to be diagnosed with autism than men due to gender biases (Brickhill et al., 2023).

Without a diagnosis, service users are forced to seek support from services that are ill-suited to their needs, which can lead to poor treatment outcomes and negative experiences with healthcare interventions. This cycle may deter them from seeking healthcare again in the future.

 As highlighted by one individual's experience, "My autism was diagnosed very late and was a battle." Moreover, a service provider noted, "The referral pathway to access an ASD [autism spectrum disorder assessment] is particularly unclear in Southwark."

3.13. Staff Turnover

We received feedback indicating that consistent interaction with the same service providers significantly improves the experiences of adults with learning disabilities and autistic adults, and their carers, when accessing healthcare services, as it fosters trust and understanding between staff and patients.

One service user explained, "I like to see the same GP, my preferred GP accommodates me. I feel listened to and heard."



As mentioned previously, service users often find that the quality of care varies depending on the healthcare professional they encounter. Staff turnover during treatment can be distressing for adults with learning disabilities and autistic adults, as they may struggle to repeatedly explain their history and preferences to different healthcare professionals. This contributes to feeling overwhelmed and disenchanted about service providers, as patients are unable to build rapport with staff.

“It’s too confusing seeing different people every time. A lot of explaining to staff although they have notes on the system. It’s draining.”



Social Factors



Wider determinants of health including socioeconomic status, race, and ethnicity impact health outcomes for everyone. However, when combined with the additional challenges that adults with learning disabilities and autistic adults experience in their daily lives, these factors can severely limit their ability to access the healthcare they need.

3.14. Financial Hardship

Respondents noted that the inability to afford essentials negatively affects both their overall health and wellbeing, as well as their ability to access healthcare services.



“When there are other demands on daily life, health is deprioritised.”

3.15. Isolation

Individuals who lack local connections, such as friends, family, community support, or social care links may be less likely to engage with healthcare providers, despite being more likely to face mental health issues. Service users reiterated the importance of friends and family to their overall wellbeing and ability to access care.

3.16. Role of Carers

Service users explained that they rely on their carers to help them book, attend, and communicate during appointments, as well as providing emotional support and managing medication. This poses a significant challenge to those who do not have full-time carers or whose carers are disabled.

Case Study: Staff at a day centre shared that one of their clients, an individual who is non-verbal and has a physical disability, was sent home from A&E without receiving treatment. The individual's carer was too old (90 years of age) to go to the hospital and advocate on his behalf.

"He wouldn't cooperate when they (healthcare professionals) saw him, because he didn't understand what they wanted or why – so they sent him home. They wanted to do an X-Ray with him in his wheelchair... you can't do that. So, they just sent him home."



This case study highlights how multiple barriers intersect to prevent access to suitable healthcare. This individual was not provided with reasonable adjustments and did not have the support of a carer to advocate for him.

Carers also highlighted the need for better support for carers, as age and the demands of caregiving can diminish their capacity over time. As asked by one respondent, "who cares for carers?"

3.17. Racial Inequalities

There is an overrepresentation of young Black men (18-24) in Southwark Learning Disability services, particularly in crisis services such as the Intensive Support Team (IST) (Davonport et al., 2023). Service providers noted that Black men with learning disabilities tend to access mental health services at crisis point or via adverse pathways such as police intervention, indicating systemic barriers to accessing timely support. Reports suggest that apprehension or distrust in healthcare professionals, stemming from personal experiences or community mistreatment, contribute to these barriers for young Black men with learning disabilities (Devonport et al., 2022 cited in Davonport et al., 2023).

3. Recommendations

We asked respondents for suggestions on how to make healthcare services more accessible to adults with learning disabilities and autistic adults in Southwark. Based on their responses, as well as our own analysis of the findings, we have compiled a summary of targeted recommendations set out below.

We will share this with local stakeholders and work collaboratively to implement these recommendations.

Training

1. Provide and monitor the delivery of training for clinical and non-clinical healthcare staff about learning disabilities and autism. The Oliver McGowan Mandatory Training on Learning Disability and Autism should be prioritised as a baseline for all service providers. However, additional training such as guidance on Picture Exchange Communication System (PECS) or Makaton should also be considered if requested by staff or indicated in service user feedback.
2. Training should take an intersectional approach, acknowledging the overlap between learning disabilities, autism, physical and mental disabilities, as well as health inequalities between people with learning disabilities from ethnic minority backgrounds and those from white ethnic backgrounds.
3. Appoint an LDA Champion in each service who has completed or will receive additional training on learning disabilities and autism. The Champion should identify barriers and best practice within their service and represent learning disabilities and autism in patient experience and public participation groups. This could involve establishing a network of Champions across services to promote information-sharing.

Sharing Information

4. Facilitate or join events about learning disabilities and autism to promote information-sharing across services and sectors, including social care and the voluntary and community sector (VCS). Similar “information day” events should be held for the public in accessible spaces.
5. Specialist learning disability and autism services should liaise with mainstream services to share learnings and help implement adjustments. This could be through direct training or learning resources.
6. Implement a centralised system across services to record gaps in provision. For example, if a patient cannot access home visits at their GP, the case could be flagged for the primary care network to refer that patient to another GP within the network.
7. Promote and encourage carers to access carer’s support and request a Carer’s Assessment under the Care Act 2014.
8. Southwark Council should expand the Local Offer and Southwark Information and Advice Support Team (SIAS) to include services for adults over 25 with learning disabilities and autistic adults.⁵

Communications

9. Carry out a self-audit of service information and contact details to ensure they are up to date and accessible to service users both on and offline, in accordance with the five mandatory actions set out in the Accessible Information Standard 2016.
10. Offer multiple methods of communication for patients to contact services e.g. email/website and telephone. Services should avoid using withheld telephone number systems to contact patients.
11. Provide information about health promotion initiatives, adjustments and support such as companion services that are available to

⁵ The Local Offer is provided by Southwark Council’s Information Advice and Support Team (SIAS) which offers a directory of services and up-to-date information for young people aged 0-25 who have special educational needs and disabilities (SEND), as well as advice on how to navigate SEND services for families of young people. [Southwark Information Advice and Support Team \(SIAS\) – Southwark Council](#)

service users and carers both online and in hard copies such as leaflets. Liaise with VCS groups to ensure that these resources reach service users and carers, and that resources about VCS support are available at healthcare sites.

12. Establish a standard easy read format to ensure consistency in the appearance of information across documents and services.

Operational Issues

13. Configure services to recognise the overlap between learning disabilities and autism, as well as learning disabilities and physical disabilities. This could involve a duty for providers to collaborate on an individual's care and share interventions across services.
14. Register with NHS England for connection to the DAPB4019: Reasonable Adjustments Digital Flag asset to ensure that reasonable adjustments are known across services in line with the Equality Act 2010.
15. Improve staff continuity and handovers to streamline referrals. Staff should be encouraged to read case notes ahead of appointments to ensure that adjustments are made.
16. Conduct an NHS Equality Delivery System (EDS2) review of areas that are utilised by patients, where service users, carers, and VCS groups can review and recommend improvements.
17. Provide suitable patient environments that are accessible to people with physical disabilities and reduce the impact of sensory sensitivities, e.g. a quiet waiting area. Home visits and visits to day centres should be facilitated where possible to reduce disruption to routine.
18. Health and adult social care services should collect feedback from service users and carers to evaluate quality against the Accessible Information Standard 2016. This could involve facilitating focus groups, which would serve a double function of preventing social isolation and potentially encouraging more people to access support before crisis point.

19. Conduct an equality impact assessment (EIA) to identify disparities and mitigate discrimination for service users, particularly adults with learning disabilities and autistic adults who are from ethnic minority backgrounds. Develop an EIA action plan to improve equality of access while ensuring compliance with duties under the Equality Act 2010.

Findings and Recommendations chart

Key:

- Staff-related Issues
- Patient-centred Issues
- Operational Issues
- Social Factors

| Barrier | Recommendation(s) |
|---------------------------------------|---------------------|
| Staff Attitude | 1, 2 |
| Communication During Appointments | 1, 2, 3 |
| Staff Knowledge and Understanding | 1, 2, 3, 4, 5, 8 |
| Reasonable Adjustments | 1, 5, 6, 14, 15, 16 |
| Feelings and Anxiety | 1 |
| Service User and Carer Knowledge | 4, 8, 11, 12 |
| Exclusion from Patient Care | 1, 2 |
| Medical Environments | 17, 18 |
| Communication Outside of Appointments | 9, 10 |
| Inflexible Appointments | 13, 18 |
| Poor Care Continuity | 6 |
| Diagnosis | 6, 16 |
| Staff Turnover | 16 |
| Financial Hardship | 11 |
| Isolation | 11, 18 |
| Role of Carers | 7, 11 |
| Racial Inequalities | 18, 19 |

4. Conclusion

In conclusion, this report provides further evidence of the barriers that prevent adults with learning disabilities and autistic adults from accessing healthcare. Our findings align with and expand upon existing research that identifies a link between poorer health outcomes and a lack of suitable healthcare provision for individuals from these groups (Mencap 2023; CQC 2022; Blair 2016; Sakellariou and Rotarou 2017; Healthwatch England 2022). For example, our respondents corroborate Healthwatch England's findings that the statutory duty to meet the information and communication needs of service users with learning disabilities is being compromised (Healthwatch England 2022).

However, we also offer an alternative perspective to Southwark Council's (2018) reporting that the uptake of annual health checks in Southwark is increasing in line with the national picture. Our findings suggests that service users are not aware whether they are receiving health checks, indicating a need to move beyond the current means of impact evaluation which monitors the number of health checks performed, rather than the quality of health checks experienced by patients.

We worked with service users, carers, and service providers to develop recommendations that promote a comprehensive, intersectional approach to achieving equitable access to healthcare for adults with learning disabilities and autistic adults. We encourage providers and partners to work together to form responses and action plans, as many of the issues highlighted are system-wide.

5.1. Limitations and Opportunities for Future Research

This report prioritises in-depth engagement with a small number of respondents to generate quality feedback from historically

underrepresented groups. Future research should therefore expand upon the number of respondents and explore the views of men, as they remain underrepresented within this study.

Furthermore, research into the quality of health promotion initiatives such as annual health checks would offer valuable insights into how these initiatives are perceived and utilised by individuals, and could inform strategies to enhance their effectiveness.

A similar analysis of adult social care services would be useful to understand the broader support needs of adults with learning disabilities and autistic adults, and enable policymakers and service providers to develop joined-up support systems.

5.2. Next Steps

We will present this report back to the community and to key stakeholders including:

- Partnership Southwark Strategic Board Meeting
- Partnership Southwark/ Southwark Council Engagement Advisory Group
- Southwark Council Health and Wellbeing Board
- Southwark Council Health Scrutiny Committee
- King's College Hospital, Guy's & St Thomas' and South London & Maudsley – including trust liaison meetings
- King's Community and Health Research Board
- SEL ICB LDA Collaboration Meeting
- Southeast London Healthwatch Staff Network
- Southwark Adult Social Care
- Southwark Primary Care Network
- Local Dental Committee (Southwark)

In addition to presenting the report, healthcare providers will be asked to provide formal responses to the report and its recommendations. The report and providers' responses will be available to view on Healthwatch Southwark's website.

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Appendices

Appendix 1- Equalities Data

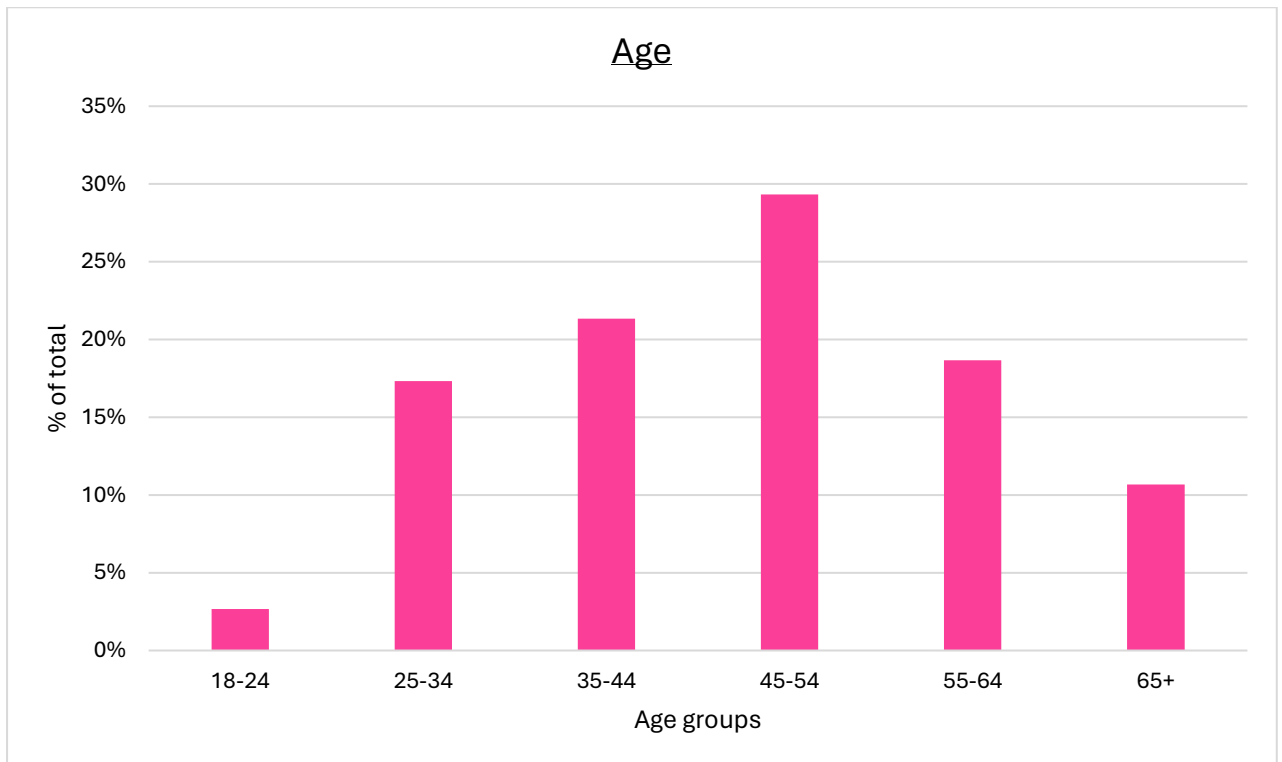
Ethnicity

| Ethnicity | % of total |
|--|------------|
| Arab/ Arab British | 1% |
| Asian/ Asian British - Bangladeshi | 1% |
| Asian/ Asian British - Japanese | 1% |
| Asian/ Asian British - Pakistani | 4% |
| Asian/ Asian British- Chinese | 2% |
| Black - other | 1% |
| Black/ Black British - African | 23% |
| Black/ Black British - Caribbean | 20% |
| Mixed - Black African and White | 1% |
| Mixed - Black Caribbean and White | 4% |
| Other - Kurdish | 4% |
| Other | 4% |
| Prefer not to say | 1% |
| White British/ English/ Scottish/ Welsh/ Northern Irish | 32% |
| White European | 1% |
| White Traveller/ Irish Traveller/ Gypsy | 1% |

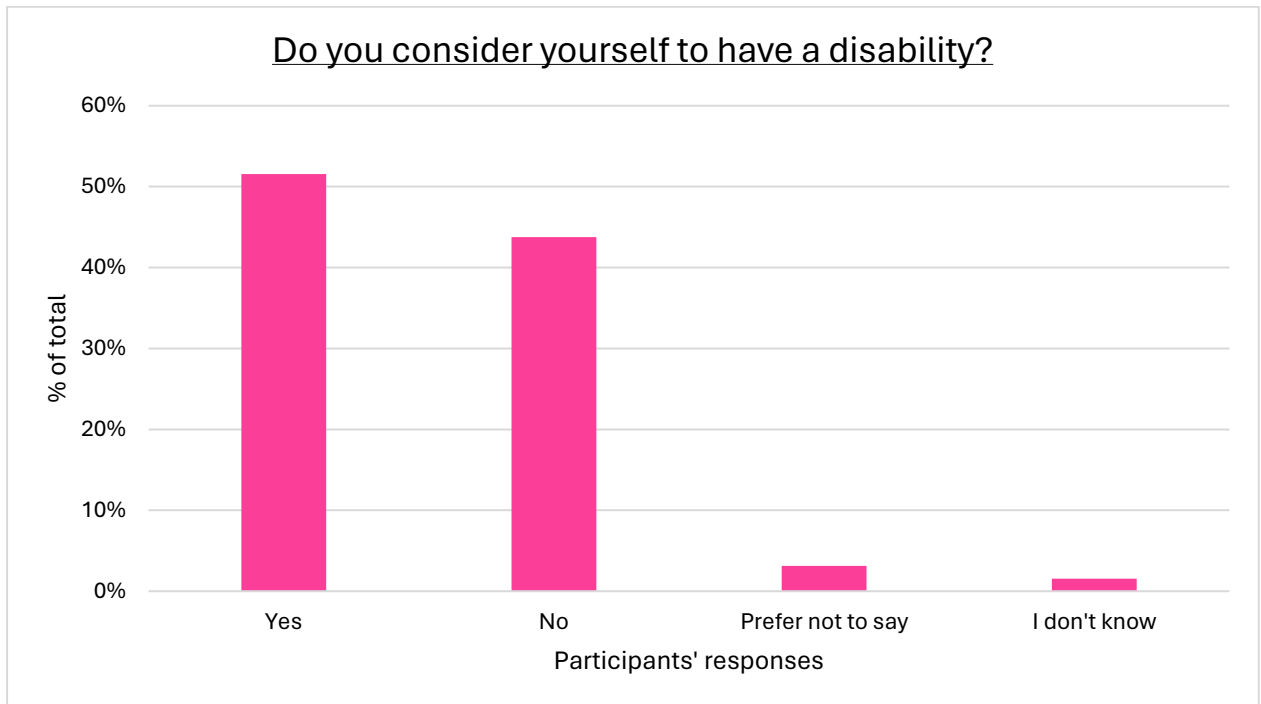
Gender



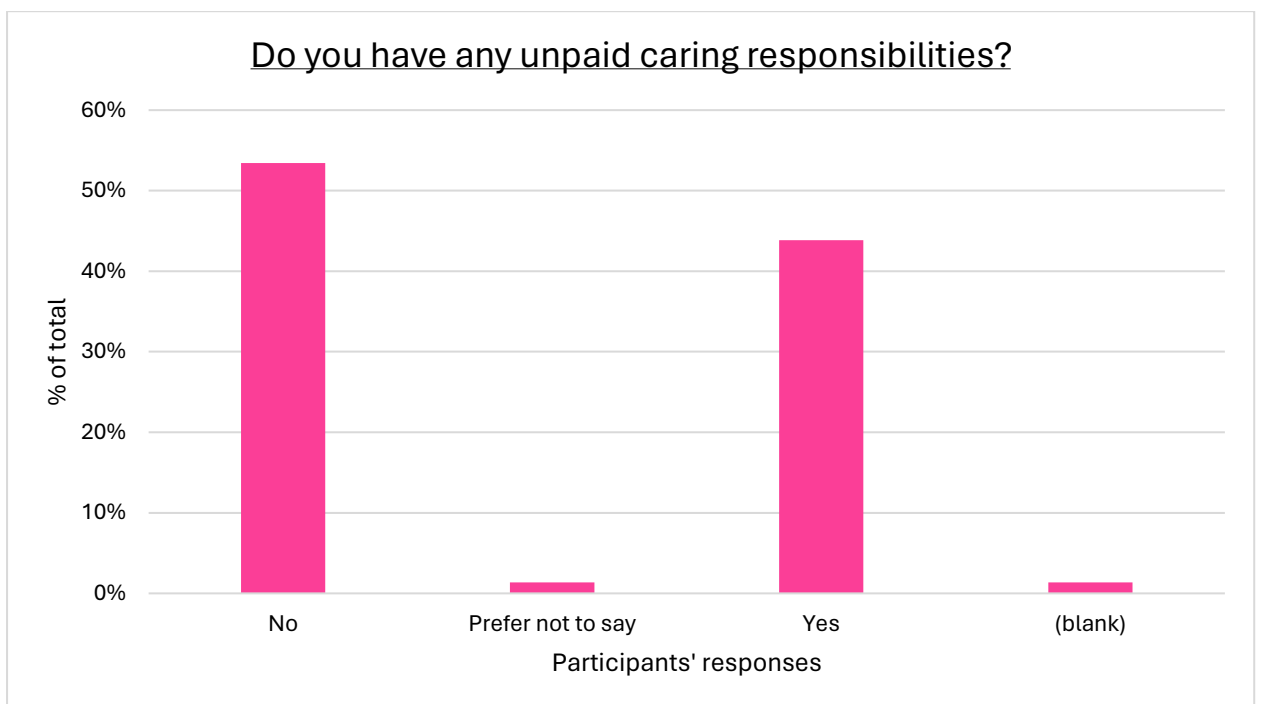
Age



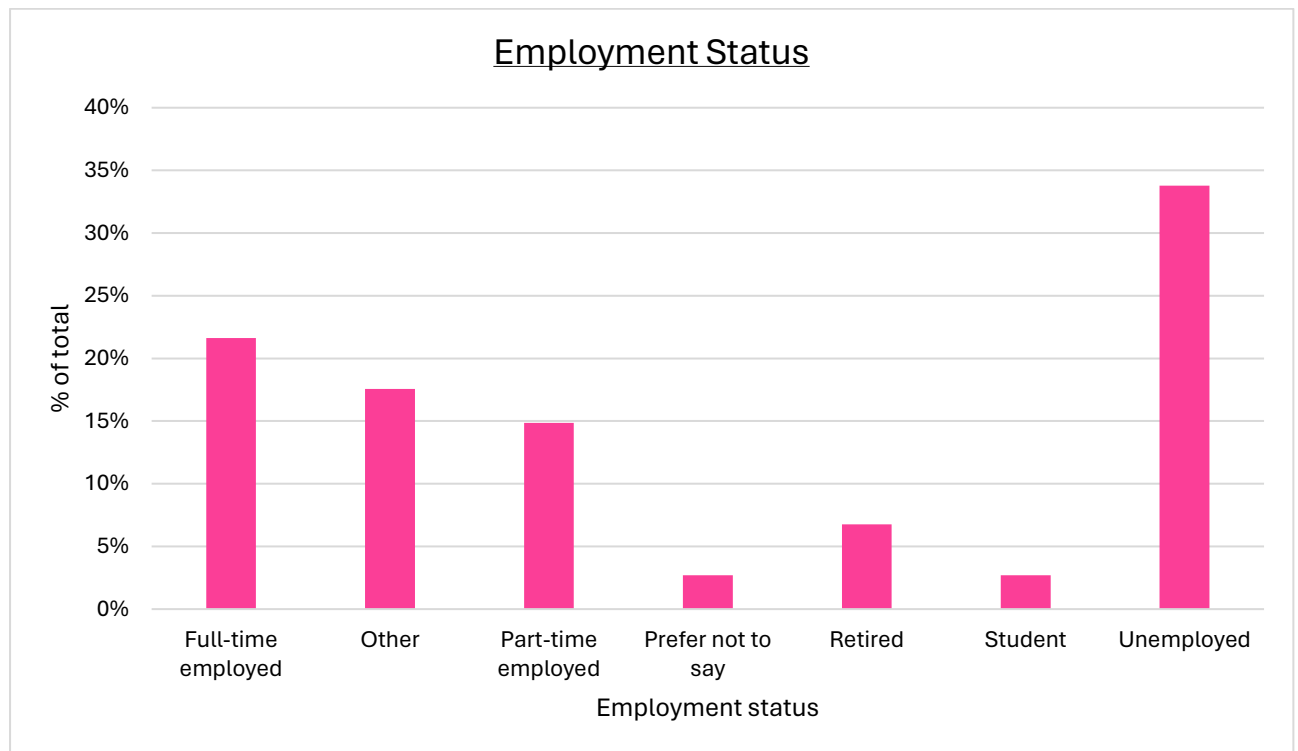
Disability



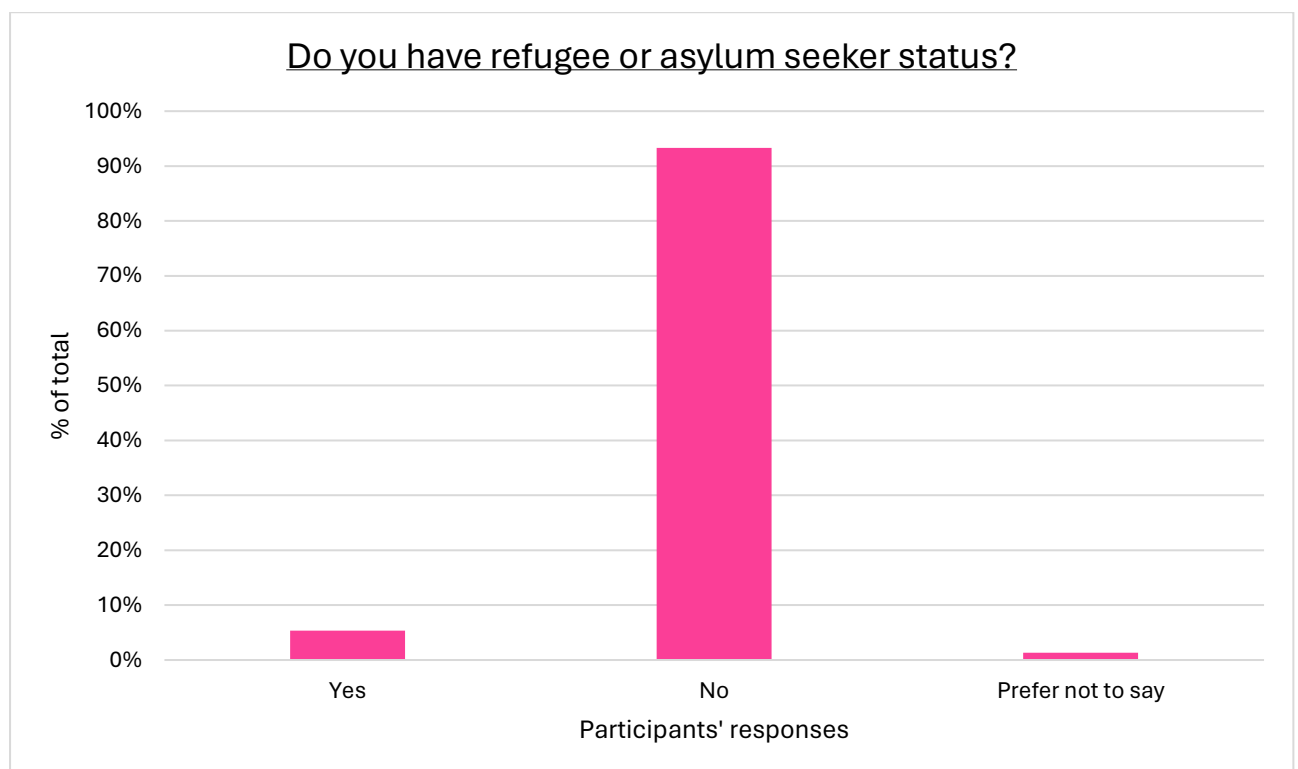
Carer status



Employment Status



Refugee or Asylum Seeker Status



Appendix 2- Survey



Start

Healthwatch Southwark is your independent health and social care champion. We listen to local people about what matters to them and help decision-makers understand what they need to do to make things better so everyone finds healthcare services easier to use.

We are carrying out research to understand what changes need to be made to improve healthcare access for adults with learning disabilities and autistic adults.

If you would prefer to speak to us on the phone or in-person, please contact ruman@healthwatchsouthwark.org or 07599653479

We will make sure that your data is confidential and treated securely. Please refer to our [Privacy Statement here](#).

1. Tell us who you are

We know that some people might fit into more than one of these groups. For example, you may be a carer who has a learning disability. If this describes you, please select one group and write the other in the comments box.

For example, select 'I am a carer' and write below 'I am a carer with a learning disability'

- I am an adult with a learning disability and/or autism
- I am a carer
- I am a service provider

Comments



Service Users

These questions are for adults with a learning disability and/or autism.

2. Are you autistic?



Yes



No



I don't know

3. Do you have a learning disability?



Yes



No



I don't know



4. Have you been added to your **GP learning disabilities register**?

The GP learning disability register is a list of all the people with a learning disability that your GP looks after. It helps GPs know what support people need.



Yes



No

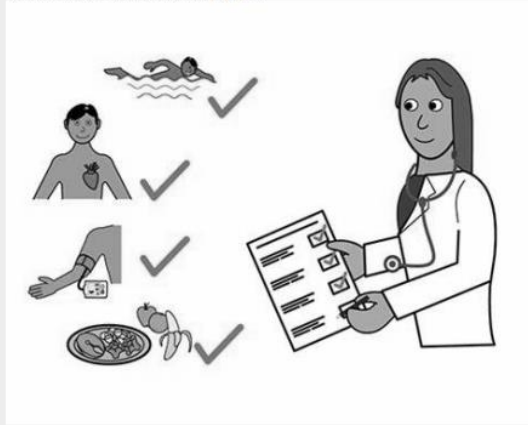


I don't know

5. Do you know you can have the following?

Yes No

Annual Health Check (once a year)



Annual Flu Vaccination

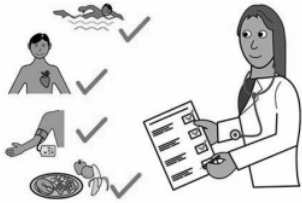


Double-Appointments (when the doctor gives you extra time during an appointment)



6. Have you had an **annual health check** in the past 12 months?

Annual health checks gives people who are on their GP learning disabilities register an appointment with a doctor once a year to talk about anything that is worrying them.



 Yes

 No

 I don't know

7. Can you think of a **good** experience with healthcare professionals? For example, at the GP, dentist or hospital?



Yes

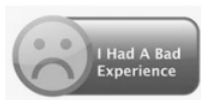


No

If yes, what made it good?

8. Can you think of a **bad** experience with healthcare professionals?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or the hospital.



Yes



No

If yes, what made it bad?

9. Do you feel that healthcare professionals **make changes to help support you** at appointments?

For example, does your GP give you easy read leaflets, more time, or see you first?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or the hospital.



Yes



No



I don't know

Any other comments (optional)

10. What should healthcare professionals do to **make it easier** for you to get help?

For example, should they use pictures to help you understand what they mean?

Healthcare professionals are people doctors, nurses and receptionists at the GP and hospital.



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Carers

These questions are intended for people who regularly look after one or more adults with a learning disability and/or autism.

11. Has the person(s) you care for been added to the **GP learning disabilities register**?

The GP learning disability register is a list of all the people with a learning disability that your GP looks after. It helps GPs know what support people need.



Yes



No



I don't know

12. Has the person(s) you care for had an **annual health check** in the last year?

Annual health checks give people who have a learning disability an appointment with a doctor once a year to talk about anything that is worrying them.

 Yes

 No

 I don't know

If no, why has this not taken place?

13. Can you think of a **good** experience with a healthcare professional?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or hospital.

 Yes

 No

If yes, what made it good?

14. Can you think of a **bad** experience with a healthcare professional?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or hospital.



Yes



No

If yes, what made it bad?

15. Have you experienced **barriers or challenges** when accessing healthcare services for the person you care for? For example: staff communication, loud waiting rooms.



Yes



No



I don't know

If yes, can you describe these barriers or challenges?

16. Do you feel healthcare professionals **make sufficient changes** to support the needs of the person you care for during appointments?

For example, does the GP provide easy to read leaflets, longer appointments, or see you first.

 Yes

 No

 I don't know

Any other comments (optional)

17. If you are experiencing issues with the health of the person you care for, **do you know where to go to access the right help?**

For example, do you know how to book a hearing test or get their feet checked?

 Yes

 No

 Sometimes

Any other comments (optional)

18. If you could change something about the healthcare services in Southwark to better support the person you care for, **what would you change?**



Service Providers

These questions are intended for staff who deliver healthcare services for adults with learning disabilities and autistic adults.

19. What type of healthcare service do you work for?

- GP
- Hospital Inpatients service
- Hospital Outpatients service
- Dentist
- Mental Health support
- Accident and Emergency Care
- Community services
- Other (please specify)

20. How would you describe the **quality of care** that adults with learning disabilities and autistic adults experience within your service?

Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes.

- Very good
- Good
- Neither good nor bad
- Bad
- Very bad

Please give a reason for your choice (optional)

21. What do you think are the **most significant barriers** to accessing healthcare for adults with learning disabilities and autistic adults?

22. Do you think you are provided with **sufficient training and resources** to support adults with learning disabilities and autistic adults?

- Yes
- No
- I don't know

Please give a reason for your choice (optional)

23. Do you have any suggestions to **make services more accessible** for adults with learning disabilities and autistic adults?

For example, changing the type of communications used.




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