

Experiences from autistic people and people with learning disabilities: access to services



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Introduction

At the start of 2024, Healthwatch Brent met with the Brent Adult Social Care team to agree an engagement programme gathering perspectives from residents about their experiences with adult social care services. The aim of this engagement is to support Brent Council in understanding the real views and experiences of local residents, to support them in improving the service.

During the first phase of work, we spoke to people who have dementia and their carers. [That report can be viewed here.](#)

For the second phase of the project, we have met with people who have learning disabilities and people with autism to find out about their experiences of accessing care. In total, we spoke to **30 people** about their experiences, including people with lived experience, professionals and carers. This report gives the details of what they shared with us and pulls together some key themes and recommendations.

The experiences shared throughout the report focus on accessing support and services from a range of different agencies. While this report was commissioned by Adult Social Care to understand the community's perception of these services. The majority of individuals who contributed their experiences were not current Adult Social Care customers, however they did have experience of contacting the council to request a care needs assessment and were able to talk about their experience of attempting to access care.

Methodology

This work was carried out through a series of three engagement visits with local community organisations. We visited the Brent Play Association day centre, Brent Mencap's 'Disability, Rights and Politics' Group and the Autism Care Navigation focus group.

In total we heard from

- 11 people who have been diagnosed with autism or who are currently on the waiting list for an autism assessment
- 9 people who have learning disabilities
- 4 professionals
- 3 parents/guardians who were supporting people with learning disabilities
- 2 social workers with experience of working with autistic people and people with learning disabilities
- 1 care assessor

Visiting existing groups and communities meant that participants had a comfortable and familiar environment, which helped us to engage with people more effectively. It also meant that staff were able to help us collect feedback from people who had additional communication needs. This ensured that, wherever possible, people were able to share information about their experiences in their own words.

During the sessions we asked participants to share feedback about experiences of making a care needs assessment, barriers to accessing care, experiences with information and signposting, and what they felt would help to make services better. We also welcome participants to share additional feedback about any experiences that they felt were relevant.

The aim of this research is to share qualitative information about how residents feel when they are attempting to access adult social care, and to get feedback about what they feel could be improved as well as what is currently working well.

This engagement was initially intended to look at adult social care. However, the complexity of people's lives meant that their feedback often related to a wider set of services, including health services, community support and support from other parts of Brent Council. In order to present a full picture, we have shared the wider themes that emerged as well as specific feedback about adult social care.

Use of language

Throughout this report, we have used both person-first and identity-first language to refer to the groups that we spoke with. Many autistic people prefer to use identity-first language, and you can read more about this topic [here](#). We acknowledge that there is no universal consensus on whether person-first or

identity-first language should be used. Wherever possible, we aim to use the language that groups and individuals have told us that they prefer.

Image credit: Disability:IN

Key Findings

The majority of participants shared neutral or mixed feedback, expressing that although some aspects of the service do work (such as the quality of local community services and the attitudes of social workers), there are many areas of frustration. We have broken the findings into key themes that emerged throughout the focus group and interviews.

Contacting Brent Council/ making a care needs assessment

Many participants told us that accessing information about adult social care and other services could be challenging. Difficulties included finding the council website difficult to navigate, and not feeling that there is enough information about how to request a care needs assessment. One individual who attended our engagement session for autistic adults said:

“I have no idea how a care needs assessment is done. It would be good to have a flowchart about the process.”

A second person from the group told us that: “[It is] extremely difficult to communicate with the Council. The Council often only wants verbal communication. The Council blindly follows their rules when the rules do not fit or don’t make sense. They ignore personal circumstances.”

Understanding of individuals’ needs

A common theme which emerged when speaking with autistic people was that their individual circumstances and communication needs were not being taken into account. Speaking about the process of contacting the council to request a care needs assessment, one person told us that: “Autistic persons are not understood.”

Several people stated that there was too much emphasis on the need for phone communication, which could be a challenge for those in the group. One participant suggested that: “The council needs to think about diverse ways to access services. An online chat service might help when people are not up to speaking.”

Overall, we heard that there was a need for more flexibility in communication, and better training for staff on the diverse needs of different groups.

Eligibility for support

Professionals working with people who have learning disabilities told us that many of the people they work with are not deemed to be eligible for support from the Council. Through their experience of working with residents, they had

found that there was a gap for people with lower-level needs who still required support for some of their day-to-day tasks. All the professionals we spoke to agreed that there should be better information and advice given to those who are not eligible, to ensure that they can offer alternative support.

Information and signposting

Lack of information and signposting was found to be a concern across all of the people that we spoke to. Both Mencap and Brent Play Association expressed that there had been a lack of signposting referrals from the Council into their services, despite many residents potentially benefiting from the services they could offer. In particular, the groups would have expected to see referrals from the Council for people who were not eligible for care act support, but still could benefit from a social group.

Commenting on the lack of information provided by the council, one parent told us: "My son's friend's mother informed me about the place. That's how a lot of parents know about the centre, word of mouth."

A participant at the autism focus group told us: "more signposting is needed to organisations that are waiting to help."

When speaking with professionals involved in adult social care, we heard that signposting is given where appropriate, including to Brent Start and the Shaw Trust (for education and employment training), to inclusion projects run by the disability team and to the floating day centre.

Experiences after receiving a care needs assessment

Three of the people we spoke to were already receiving support from Brent Council, while the others were either going through the process of a care needs assessment or had requested an assessment but been told they weren't eligible.

Two of them had been receiving support since childhood, and one had been through the process of a care needs assessment following their diagnosis of autism.

They shared positive or mixed feedback about the quality of the services that they had received, as illustrated by the stories below. The names and some minor details have been changed to protect the anonymity of participants.

Zak's story

Zak is a young man who was put in touch with Brent Council for a care needs assessment as an adult, after receiving a diagnosis of autism.

At first, it was a slow process. The council took a long time to find out what support Zak would be entitled to and share the information with him.

However, eventually, they were able to find a supported living environment that is suitable for his needs. Zak can go out independently but has support available when he needs it.

Zak told us that he is very happy with the arrangement, now that care is in place. There isn't anything that he would change.

Maria's story

Maria is a young woman with learning disabilities. She receives help from a support worker and has done for many years. Maria finds it very helpful when she is able to meet with her support worker and get assistance with different tasks.

However, the process also has challenges. Maria finds it difficult when her support worker leaves and she is introduced to someone new. It is not always easy to communicate, and sometimes the support worker cancels and reschedules appointments. Maria and her support worker meet monthly, but she believes they should be meeting more frequently.

Gaps between meetings and cancellations mean that issues can pile up. Maria often has to go to her friend for help, because she can't wait until the next meeting with her support worker.

Nigel's story

Nigel is an older adult who has lived in Brent all his life. He has been accessing services through the council for many decades, and has had a lot of good experiences with carers. Visits from carers have allowed him to continue living at home, maintain his independence and manage his own and manage his own health needs. Nigel feels that the carers who visit always know what they're doing.

Unfortunately, wider support from the Council has not been so good. Nigel feels that contacting Brent Council is difficult, and he has often felt like he is "fighting for little scraps of help." He has experienced many different improvement processes from the Council, but never seen much change as a result. Nigel also attends the disability forum, but doesn't feel that it is very collaborative. He said: "they tell us what they want to talk about, it's not based on what we need to know. It's not information that we want, and it doesn't help at all."

The adult social care professionals we spoke to talked about adjustments that can be made to help support people through the care needs assessment, such as involving family members. They also noted that there can sometimes be a challenge in providing the level of consistency that clients would like.

One social worker told us: "There are clients with autism and for this group, they like consistency and routine. However professionals can come and go, so the team can't always provide consistent carers which can make the clients with autism feel unsettled."

Similarly, a second social worker noted that: “People like to be comforted with the fact that there is a named worker on their case. However sometimes there can be a different caseworker or they move on from the case.”

The length of time taken to carry out assessments also came up in our conversations with professionals. The care assessor we spoke to told us that: “Some clients have asked if the review can be quicker. However the referral to other partners and agencies can be out of our hands. The Disability Team does everything they can to reassure and update clients.” This was echoed by the social workers, who acknowledged that the process can be lengthy, but noted the importance of ensuring that an assessment is thorough and that all relevant agencies are involved.

Funding for community services

While not directly related to adult social care provision several of the professionals we spoke to felt that funding cuts and a lack of funding for community services was a key concern. They described a deterioration in the quality of services over the time that they have worked in Brent.

One individual told us: “Years ago, Brent was known as having the best youth centres in the country. Even better than the ones in places such as Manchester. Now most of them have shut down. There should be more places for young people.”

We also heard that a lack of funding meant that there were not enough community services to support people who do not meet eligibility for adult social care. This included a lack of non-statutory advocacy services, closures to day centres and the need for more employment support specifically tailored towards at people with learning disabilities. These concerns related to both adult and children’s services.

Development of an autism strategy for Brent

Throughout this engagement, we have seen a number of positive steps taken to ensure more support is available for autistic adults living in Brent, and to improved joined-up working between the different service providers. This includes the development of an autism strategy for the borough, and the relaunch of the Autism Partnership Board. Healthwatch welcomes this activity, and will play an ongoing role in its development.

Recommendations

The recommendations below are based on suggestions from those we spoke to as to what would be most helpful in improving their experiences.

Customer care team members should receive enhanced training to ensure that they're able to meet the specific needs of different client groups. In particular, staff should receive training about how to support autistic people.

- Residents felt that customer care staff did not have knowledge or understanding of the needs of autistic people
- They also felt that staff would benefit from more training about different communication styles, to allow them to support people more effectively

A range of different communication methods should be available to allow people to contact Brent Council in the way that suits them. This might include better support for email communication or a web chat function.

- A number of people we spoke to did not feel comfortable using telephone communications. However, they felt that this was the only option for receiving support, or that they were pushed to use phone communication rather than other methods.

Consideration needs to be given to how the council can better support people who are not eligible for support under the care act. This should include better information and signposting. Council staff should have an up-to-date directory of services that they can use to offer clear signposting to services.

- Individuals that we spoke to felt they did not receive enough information about services in the community that may be able to help them. For the services they did access, most had received information through word of mouth.
- Community professionals that we spoke to noted the lack of referrals received from Brent Council, despite offering services that may be able to help people currently experiencing unmet need.
- The conversations we had with social workers showed that advice and signposting given to people who have been allocated a social worker is of a high standard.

Response from Brent Adult Social Care

Thank you for the feedback provided in relation to the experiences of individuals with autism and learning disabilities in adult social care. We appreciate the time taken by everyone who participated in sharing their views.

It is important to note that the feedback provided comes from a very small cohort of 30 people that included both residents parents/guardians and professionals, while the population of individuals with learning disabilities and autism that are currently receiving support from adult social care exceeds 700. As such, the views expressed in the report represent a small proportion of our overall population, some of whom are not current adult social care customers.

There are always opportunities for us to improve, and we are particularly mindful of the need to continue improving the way we engage with and support individuals with autism. We are actively working on this, and I'm pleased to inform you that we have recently recruited an Autism Lead within our adult social care service. This individual is leading the development of policies and pathways to improve how we interact with and support autistic individuals.

Additionally, we have a dedicated multidisciplinary Learning Disabilities team that works closely with various health and social care professionals to ensure that individuals with learning disabilities receive regular health checks and the care they need.

We want to assure everyone that Adult Social Care is on an improvement Journey and have made significant progress in a number of areas in recent years and we continue to progress in the following:

- Development of our website to ensure information is accessible in various formats, such as Easy Read and multiple languages.
- Improvements to our "front door" services to create a smoother and more supportive first point of contact.

While we are proud of these developments, we are committed to ongoing progress. We will be relaunching our Disability Forum, and aim for it to be co-chaired by a person with lived experience to ensure that the forum is customer-led and reflects the voices and needs of the people we serve.

We recognise the value of the feedback provided in the report and will integrate it into our ongoing improvement projects to ensure that changes are meaningful and impactful. Our ultimate goal is to ensure that all customers, whether new to Adult Social Care or long-standing, have a positive experience when engaging with our services.

Thank you again for your contributions and partnership as we continue this journey of improvement.

