

Resident views on adult social care: people with dementia and their carers



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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 local 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.

This work will be separated into multiple phases, reaching out to different groups who may make use of adult social care services. For the first phase of engagement, we have been reaching out to people who have dementia and their carers. In total, we heard from 42 people, and this report highlights their experiences and the things that they would like Brent's adult social care team to reflect on. We would like to express our thanks to Brent Community Action on Dementia and Ashford Place for supporting this project.

Methodology

In order to carry out this work, our team have carried out visits to local Dementia services such as the Brent Memory Cafes, and to relevant carer's groups. During our visits we have caried out informal interviews, encouraging people to speak to us about the aspects of adult social care that they have experienced. We have also guided the conversations so that people are encouraged to share information on particular topics such as:

- The quality of service received when contacting the Brent Customer Care team
- How easy it has been to access a care needs assessment or a carer's assessment

- How quickly after the assessment residents were able to access care
- The quality of care received once services were put in place.

We also conducted a focus group with unpaid carers who support people with dementia, and conducted interviews with four professionals who run dementia services.

One limitation of this work was that some people with dementia found it difficult to engage with the research, however carers were able to fill in the gaps while also offering up their own perspectives. In total we heard from:

- 20 unpaid carers through our focus group
- 8 service users through engagement visits
- 10 unpaid carers through engagement visits
- 4 professionals

Some residents were also reluctant to participate in this work due to the feeling that their feedback may not be acted upon. In particular, residents and community leaders cited the fact that previous engagement work on this topic has been carried out by other agencies, but not led to change. We acknowledged this concern while also reiterating the engagement from Brent Council and their commitment to making changes based on the feedback provided.

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's Customer Care Team

Six of the carers we spoke to throughout our engagement shared their experiences of speaking with the customer care team, and they all felt that this experience could have been improved. In particular, they noted the following challenges:

- Long waiting times on the phone
- Lack of support for people with hearing loss to be able to manage the conversation
- Abrupt manner and lack of compassion from staff

One individual who had been supporting her Aunt to access services told us: "there was no personal element to the case and the two of [us] were just treated

as numbers, not people. [We] felt as if she was annoying the staff member who picked up the call, although [we] did nothing wrong."

- Difficulty having to speak to multiple people who ask you to repeat yourself
- The need for more proactive signposting, particularly to support the carers' needs.

One individual told us that she had to find out the details of Brent Carers Centre and the memory cafes for herself. She said: "The customer advisor had no knowledge or information about mental health or signposting to local groups."

Receiving a care needs assessment

All 20 participants of our carers focus group agreed that they had to chase up the social care team before anything happened to progress their case. They told us that it feels like chasing the team is an expected part of the process, and if you don't then nothing happens.

This view was shared by one of the cares we spoke to at a memory café. They told us that this made it difficult, as due to her job and caring for her mother simultaneously, it is hard to find time to chase up the enquiry.

However, for some individuals the process had been smoother. We spoke to another carer at a memory café who told us that she had been able to easily phone the Council and request a needs assessment which was then carried out promptly.

Some other carers told us that accessing the care needs assessment itself had been simple, and they felt supported by the council. However, after the assessment had taken place they struggled to receive any follow-up information, and hadn't been able to get the accommodations they needed.

Overall, the feedback suggests that the technical ability of the individual to make calls or use the website, as well as the capacity to chase up the social care team if needed, effects how quickly residents are able to receive an assessment.

Receiving care after a care needs assessment

As mentioned above, several carers told us that they had received a care needs assessment, but not been able to get the care or support they were eligible for due to delays in the process.

One individual stated that they have recently had contact with adult social care, and initially felt quite supported. They had somebody visit the home to make an assessment, and spoke about the various adaptations that might be made for their mother. They were contacted afterwards with some information about direct payments. However, since then it has all gone quiet, and nothing further has happened. They waited several weeks, and then tried to contact the social worker. They haven't been able to speak to them, and nobody has been able to give them any information about what happens next.

A second individual spoke about how her mother's assessment has been difficult because so many different people and teams have been involved. As with the previous story, an assessment has taken place – but there has been no follow-

up. The assessment has included contact from housing and a GP/social prescriber as well as from the adult social care team. But they feel that no one person has taken ownership. This has also been distressing for the individual who needs support, as she has dementia and is confused by the contact with lots of different people. In this case, the individual has been waiting for years to resolve the issue.

Once care was received, people spoke highly of the quality of care they received whether from paid carers or social workers. Our engagement with this group didn't find any concerns about the quality of care itself, however we noted substantial difficulties for some people to access care.

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. The language needs to be slow, clear, patient, jargon free and they also should be a good listener. They should be trained in diversity and cultures as people are fluent in different languages and upbringings can vary.

- Service users would like communication to be slow, clear and jargon free
- There should be an emphasis on empathetic listening and maintaining a calm and patient approach throughout calls
- Residents suggested that team members should be trained in diversity and the needs of different cultures

There should be a clear escalation process available for people who have not had their case progressed quickly enough.

 Many people told us that they had needed to spend time chasing up their case, either before the care needs assessment or after it had taken place. This can be difficult for those who are already time-poor due to caring commitments. A clear point of contact for escalating cases would help make it easier for people to follow up when needed.

Once a care needs assessment takes place there should be a single, named individual who takes ownership for the case.

 Many of the challenges that carers had faced was due to it being unclear which council team was responsible for progressing a case. Having a named contact who is responsible for moving things forward would help give service users and carers clarity, and bring efficiency to the process.

Response from Brent Adult Social Care

We shared our findings with Claudia Brown, Brent's Director Adult Social Services (DASS), and received the following response:

"Thank you for conducting this engagement exercise and gathering valuable feedback from our customers regarding adult social care for individuals with dementia. Your efforts are crucial in helping us understand the needs and concerns of our residents.

"The report has highlighted several key areas for improvement in Brent, including long waiting times, the responsiveness of our service, particularly in relation to phone communications, and the additional support required for people with hearing loss. This feedback is essential as it underscores the need to enhance our communication and responsiveness to better serve our community.

"Brent is committed to this journey of improvement. We have already initiated a new structure aimed at refining the processes and pathways for customers accessing our services, with the goal of having these improvements in place by October. We are actively working with our teams to ensure that telephone lines are reliable, and that staff respond promptly to calls.

"Additionally, we are currently undertaking a project to develop and enhance our sensory services. The feedback from this report will significantly contribute to the new design and delivery of these services to our community.

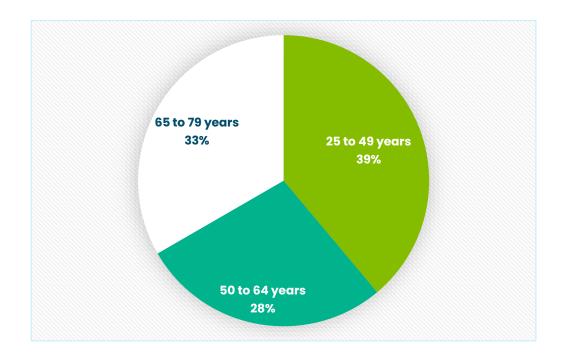
"We fully accept Healthwatch's recommendations and will integrate them into the ongoing changes we are developing. These recommendations will play a crucial role in shaping our service enhancements.

"Thank you once again for your feedback. We look forward to continuing our collaboration with Healthwatch and our customers to improve the delivery of our services."

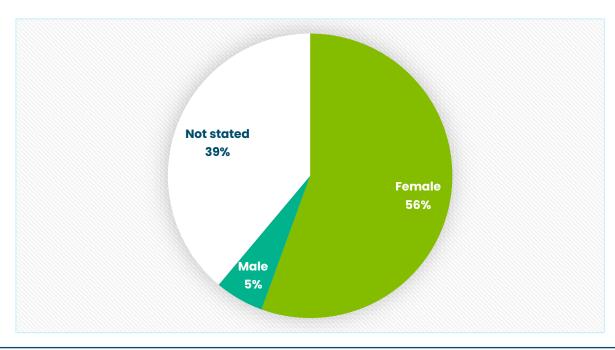
Demographic information

We did not collect demographic information for our focus group attendees, however the charts below show a breakdown of demographics for those who engaged with us during our outreach visits.

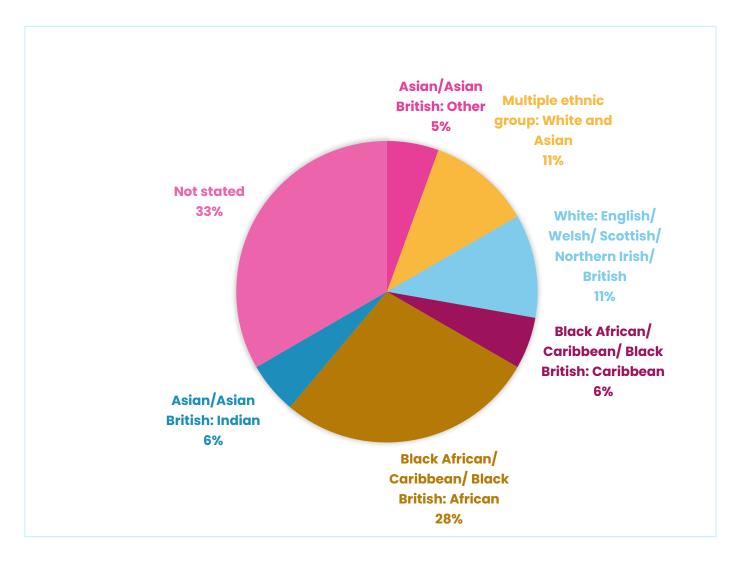
Age



Gender



Ethnicity



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