



Appendix A

How Camden's Health and Care System supports Disabled residents



Background and inequalities data - Camden

In the 2021 Census almost 32,000 (15%) of Camden's residents defined themselves as Disabled, and for these residents there are some large inequalities with non-Disabled residents.

JOB



S 57% of the Disabled population are economically inactive compared to 15% of the non-disabled population.

HEALTH



31% of our Disabled residents say they are in 'bad or very bad health' compared to just 1% of the non-disabled population.

The number of Disabled people aged 18 years and over who contacted Adult Social Care between January 2023 and December 2024 identified themselves as having: 3918 Physical Disability; 249 Learning Disability; 120 Sensory Disability (d/Deaf people, hard of hearing and those who are blind or living with sight loss); 361 Mental Health; 246 memory or cognition.

Across Camden we know from the Census and other published data that there are at least 90 Camden residents who use British Sign Language as their first language and approximately 1,000 blind and partially sighted residents.

In a 2024 Adult Social Care survey, 61% of people with a Learning Disability felt 'very positive' and 22.2% felt 'positive' about the care they received.





Background and inequalities data - National

Cancer

d/Deaf people are more likely to be diagnosed at late stages of cancer. People living with an "intellectual or developmental disability" were 2·28 times more likely to die of breast cancer, 2·57 times more likely to die of colorectal cancer, and 1·38 times more likely to die of lung cancer than those without such a disability.

Cancer Research UK and The Lancet

Mortality

A review published in November 2023, found the median age of death was 63 for people with a Learning Disability and 55 for Autistic people with a Learning Disability. In the general population, the median age at death was 86 for females and 83 for males.

UK Parliament

Access to GP support

The Learning Disability Register is vital for people with a Learning Disability to receive important, life-saving annual health checks and reasonable adjustments. Yet around 75% of people with a Learning Disability are not registered.

UK Parliament

Wellbeing

Disabled people aged 16 to 64
years had poorer ratings than nonDisabled people on all four
personal wellbeing measures;
average anxiety levels were higher
for Disabled people at 4.6 out of
10, compared with 3.0 out of 10 for
non-Disabled people.

Office for National Statistics

Workforce

The proportion of NHS staff with a Disability who experienced harassment, bullying or abuse at work from managers (16%) was higher than staff who did not have a disability (9%). A higher proportion of staff with a Disability (28%) felt pressured to work when feeling unwell compared with staff who did not have a Disability (20%).

Care (Medital Registrission

People who are d/Deaf or have hearing loss are twice as likely to experience mental health problems compared to people without hearing loss. Evidence shows that the rate of depression amongst d/Deaf British Sign Language users is double that of the general

population. RNID





Theme 1 - the value placed on Disabled people's lives

The underlying theme is the value placed on Disabled peoples' lives. The recent vote in favour of assisted dying brings this into sharp focus. Although Camden Disability Action (CDA) recognises this is a difficult and delicate issue CDA believes that we cannot have a situation where assistance to die is easier to access than assistance to live. During the pandemic CDA's Camden members received do not attempt resuscitation notices - and were denied access to critical care.

Not valuing Disabled people's lives can often mean that those who are not getting the accessible services they need are also not part of co-production, consultation or engagement, as these are also not made accessible to them. So, the inequalities persist.



Across the board Disabled people's needs are **not adequately built into service design** and therefore anyone with access needs is more at risk of poorer health outcomes. For example, Michael reports on Camden Disabled Voices on his experience of someone with mobility impairments and chronic pain accessing the

GP: https://camdendisabledvoices.org/is-there-a-doctor-in-the-house

Research by the **King's fund** suggested that Health and Care services need to improve their understanding of how people's multiple identities shape their experiences, and embrace diversity of voices, opinions and challenges as an opportunity to think differently.

It is also important to include Disabled people in designing and planning health and care system responses. <a href="https://www.kingsfund.org.uk/insight-and-analysis/long-reads/new-partnership-disabled-people-analysis/long-reads/new-partnership-disabled-analysis/long-reads/new-partnership-disabled-analysis/long-reads/new-partnership-analysis/long-reads/new-partnership-analysis/long-reads/new-partnership-analysis/long-reads/new-partnership-analysis/long-reads/new-partnership-analysis/long-reads/new-partnership-analysis/long-reads/ne

There is a commitment in Adult Social Care to develop plans together. **Supporting People, Connecting Communities**, the Council's strategy for Living and Ageing Well notes, 'By making this commitment explicitly it lays down a challenge to Adult Social Care and our partners to properly harness the skills, knowledge and ideas of the people we work with by developing our plans with them. It will look at different approaches to ensure the voices of people with lived experience are heard.' Adult Social Care has committed to this by investing in a Co-production Lead, and developing a Coproduction Framework: https://camdencarechoices.camden.gov.uk/co-production-matters/asc-co-production-framework/

Theme 1 – Questions to explore further

- Camden Healthwatch asked how a needs assessment could be conducted for residents experiencing a level of inequality or Disability?
- There is a need to ensure that Disabled people's voices are represented, and inclusion is meaningful, so they have the power to make the changes they want. A suggestion from a **resident** asked how the Council could consider Disabled people in all their strategies.
- Peer support may be an important way for Disabled people to enable change in services.
- Can we collect examples of interactions with health professionals where the template for diagnosis and treatment is based on a non-Disabled person.
- Camden Disability Action (CDA) receives a large number of requests to engage with Disabled people and it always comes as a surprise when CDA includes the costs of meeting Disabled peoples' access needs, such as easy read/British Sign Language (BSL)/Transport/Support workers. The costs of compensating people for their time with user involvement payments are also not always included at the outset but there seems to be increasing flexibility on that in CDA's experience. As a further point, to make the engagement meaningful and effective, a certain amount of pre work with participants can be helpful for example, empowering Disabled people to explore the engagement and coproduction through the Social Model of Disability. This too, adds additional costs which providers are not always able to meet. How can the best practice about the approach, and costs needed, for accessible engagement be showcased and shared?

Theme 2 – Accessible information

Communication is a key issue for many Disabled residents accessing health and social care services. This includes the lack of access to interpreters (e.g. for d/Deaf people), critical information, such as cancer screening tools and information given in hospitals, not being available in easy read or other accessible formats.

Camden residents also speak about not having joined up services and having to tell their story more than once.

There is also an indication that people have trouble navigating the health and care system and this led to a lack of awareness of support that is available.

23/24 **Camden Healthwatch** Annual Report noted a priority for the coming year as to 'Work with groups with disabilities and groups whose first language is not English to promote higher levels of cancer awareness and how important it is to listen to your body.'

Healthwatch conducted focus groups around cancer awareness with a focus on Disabled people. People spoke about having quite a worry about cancer and cancer symptoms and wondered if information or material could be more readily available in clearer/ easy read formats and to suit those with either visual and other sensory impairments, as well as those with learning disabilities.

Theme 2 – Questions to explore further

- There is a suggestion to undertake a review of cancer screening invitations, and the style of communication could be considered, as some residents felt that their invitations for certain screenings made them fearful and reluctant to attend on that basis.
- Camden Healthwatch also suggested a communications needs assessment could be developed to benefit Disabled residents and a desktop needs assessment for those who are at the apex of Disability inequality or exclusion. This would enable Camden Council to support Disabled residents further with positive outcomes.

Theme 3 – Social Model of Disability in practice

- The Council and Camden Disability Action believe in the **Social Model of Disability**. This model was developed over the last 40 years by Disabled people. It is a radically different understanding compared to the more traditional, medical view of disability.
- The Social Model states that people have impairments and long-term conditions. However, the oppression, exclusion and discrimination people with impairments face is not an inevitable consequence of having an impairment. It is caused instead by the way society is organised. People with impairments are 'disabled' by the barriers in society which exclude and discriminate.
- Put simply, disability is seen as something that is done (unnecessarily) by a society that does not include Disabled people.



An example of this in practice, and how accessibility to health services are compromised when services are outsourced.

Mik Scarlet, wheelchair user and Camden resident reports on his experience being referred for an MRI in an inaccessible building. https://camdendisabledvoices.org/inaccessible-health-clinic-leaves-mik-in-despair.

Research by the **King's Fund** also notes that 'Health and care services need to understand the broad diversity of Disabled people's identities and experiences identities and experiences, and adopt a social model approach to disability, understanding that people are disabled by barriers in society, rather than by impairments or health conditions.'

Having strong leadership and a confident and well-trained workforce is essential when supporting Disabled people who draw on health and care. This will ensure that health and care are developed and delivered by people with an embedded understanding of disability equality and through an equality lens. This includes taking a relational practice approach and making necessary reasonable adjustments. Recognising people's unique lived experience and the importance of this, so that Disabled people are empowered to make informed decisions about their care.

Also, noting the impact of any pressure across the health and care system to work at pace to deliver contract commitments or address people waiting for support which does not support inclusivity or help to address health inequality.

Adult Social Care have invested in a Workforce Strategy Lead, who is leading on induction and learning and development programmes. This will ensure that the social care workforce, including commissioned care providers, can grow, develop and progress their careers. The Adult Social Care workforce strategy has a strong focus on inequalities. It will ensure that its workforce has the tools it needs to support people who draw on services.

Theme 3 – Questions to explore further

- It is likely that traditional ideas of what Disability is (and what it isn't) are deeply entrenched. **Camden Disability Action** suggested that it would be interesting to know the level of Disability equality training in health and social care.
- They also suggested it would be interesting to know the number of Disabled people working in Camden's health and social care services.

Existing Services – Camden Disability Action

Camden's Disabled-led organisation, Camden Disability Action (CDA), believe in a radically inclusive world where people with differences are never Disabled by the society in which they live. Their missions, and reason for existing, is to enable the Disabled community and those most marginalised within it, to lead the way in building a Camden that works for everyone.

They provide information and powerful opportunities for Disabled people to lead the way in building a Camden that works for

everyone.





CDA run a range of leadership, engagement, coproduction and active citizen forums which campaign and coproduce accessible services. This includes the innovative Community Journalism project, where Disabled residents are trained to report on their own insights into experience of Camden, including the health and care system.

They also run social welfare law advice services, including a dedicated D/deaf Advice service with a D/deaf BSL speaking advisor.

CDA use the Greenwood Centre, where CDA are based, to empower our members to lead projects for change, including our Deaf Access Group, Deaf Social, IT hub. Craftivism group.

Website:

https://camdendisabilityaction.org.u

Existing Services – Camden Carers

It is well known that unpaid carers often neglect their own health and wellbeing needs focusing instead on the person/people they care for.

Quote from a carer supported by Camden Carers:

"It was really nice to speak to you last Wednesday. I don't speak to anyone generally about my life and health as I feel like I'm complaining about things. However, I do feel better after speaking to you and the team. I guess it's because there's a level of ucanstem Cagetschrelpsatesidents of Dynackert in obyesupporting unpaid carers providing vital help to those who couldn't manage without them.

Camden Carers offers a wide range of support that focuses on the carer. This support includes:

- Health and Lifestyle Checks
- Carers Conversations
- Counselling

Website dy learned to formation www.camdencs.org.uk/

Nationally, we know that unpaid carers face poorer health outcomes, as a result of their caring role. Carers UK 2023 State of Caring report found that:

- 54% of carers said their physical health had suffered
- 22% said that caring had caused them injuries
- 44% of carers said they had put off health treatment because of their caring role

14,605 carers were identified in the 2021 census. 5% of these carers describe themselves as long term unwell or Disabled.

From a health and care perspective, the main challenges and opportunities to consider include:

- How best to support carers to focus on their own wellbeing carers often say they are exhausted; they don't have time to take part in activities or focus on things like form filling.
- Making pathways to support easy for carers
- Joined up working across services; including carers in decision making and information about the person they care for
- Introduction and implementation of Triangle of Care

In July 2024, Camden launched the Carers Action Plan after 18 months of coproduction with carers and partners. The Plan outlines strategies to better support unpaid carers. It emphasises five principles and eleven action areas, addressing early identification, information, guidance and advice, effective partnerships, and accessible services. Information can be found:

https://carersactionplan.camden.gov.uk/

Existing Services – Age UK Camden Care Navigation & Social Prescribing Service

Age UK Camden's Care Navigation and Social Prescribing Service supported **618** people who identified as being Disabled in the financial year 2023/24 and **444** people in the current (2024/25) financial year.

A table showing the number of Disabled people supported between April 2023 and January 2025

Disability	Number of people supported
Dementia	152
Learning Disability	60
Physical Disability	777
Sensory Disability	50
Wheelchair user	23

Website:

https://www.ageuk.org.uk/camden/ourservices/care-navigation-and-socialprescribing/

From a health and care system perspective, the main challenges reported by people included:

- Inappropriate housing (council tenants and housing association tenants). People can no longer manage stairs in the block of flats they live in and wish to move however the process is long, often taking months and even years before a resolution. The situation impacts not only on physical but also on mental health.
- Long wait for occupational therapy visits and adaptations to be carried out.
- Carers arriving late and not spending long enough or the commissioned time with people.
- Lack of community transport to help people attend community centres and or other activities.
- Lack of one to one support in the home for those who are not able to leave their homes.
- Lack of face to face befriending.

Ways the Care Navigation and Social Prescribing Service support residents includes:

- Referring to organisations and services for benefit advice and checks, scam awareness and home safety checks (including such as Camden Disability Action; London Irish Centre; Age Uk Camden Information & Advice; WISH Plus).
- Liaising with care agencies when issues arise with carers.
- Referrals and liaising with Adult Social Care on care needs assessments and occupational therapy.
- Attaining grants such as Cost of Living/Household Support Fund and from other charities.
- Referring for Mental Health support such as Age UK Counselling/Listening place/Camden Crisis Sanctuary.
- Signmosting to local activities to ease social isolation

Existing Services – Camden Learning Disability Service Annual Health Checks

People with a Learning Disability have increased health risks compared to the general population. They also access health care less frequently.

A high annual health check take up supports people with Learning Disabilities to have their health needs identified and addressed early.

Anyone with a Learning Disability who is aged 14 or over, and is registered with a GP, is eligible to receive a free annual health check.

The Council recruited a Health Facilitator to focus on annual health checks. This is funded through the Health Inequalities Fund.

The purpose of this work is to:

- To Improve uptake and quality of annual health checks for people with a Learning Disability aged
 14+
- To mitigate the health inequalities as evidenced by research of Learning from lives and deaths People with a Learning Disability and autistic people (LeDeR) reports
- To improve the shared vision of reducing health inequalities across all partner agencies e.g. GP's, commissioned services, universal services and partnership work with the Camden Learning Disabilities Service
- To amplify the voice of people with a Learning Disability in the development and review of annual health check processes and protocols.

Last year there were focus groups on annual health checks. At these people with Learning Disabilities feedback on the annual health check process. From these discussions, things that were working well included: getting a phone call or text to book the health check; it makes people feel valued, involved and listened to. What was not working well included: once the health check is booked no appointment letter is sent – a letter would help people remember the appointment; not everyone was asked the same questions (for example about smoking, alcohol use and sexual health).

A video was produced to increase the uptake of annual health checks: https://vimeo.com/1035192115

- In the financial year 2023 to 2024, 87% Camden residents who have a Learning Disability received an annual health check from their GP practice.
- This is the highest uptake across North Central London.
- In the financial year 2022 to 2023, there was a 94.1% uptake.
- This was an increase from the year before which was only 61%.
 Website:

https://www.cldsinio.net/healthanget is

75%

Existing Services – Service Offers

Information and Advice: Camden Care Choices is the Council's website for adult care and support. It contains a wide variety of supportive information. There is specific information on this site for Learning Disability; Sensory Impairment and Physical Disability:

https://camdencarechoices.camden.gov.uk/disability/ It also contains directories of support services. The site has accessibility functions embedded. Some information is available in easy read (27 documents), and there are 4 British Sign Language videos on: 'what matters' Camden's approach to Adult Social Care; Camden's approach to safeguarding; How to contact Adult Social Care and what happens when you do; Support available for unpaid carers. Camden Learning Disability Service also have their own website: https://www.cldsinfo.net/

Advocacy: The Council commissions **Rethink** to provide a range of advocacy services to ensure that residents are able to have their voices heard, and so that their views and wishes are central to decisions about their health and care. This include decisions about serious medical treatment, changes of accommodation, safeguarding, being subject to a deprivation of liberty, care reviews, and to support making complaints about health or social care services.

Relational practice: Adult Social Care follow a 'what matters' approach. This is about focussing on what is most important to a person; recognising and building on strengths as individuals and within their networks; helping a person stay connected to their community; working with people to identify problems and intervene early. It aims to give people more choice and control over their care and support, involving people in the decisions that affect them. So people live healthy, active and independent lives for as long as possible, and to do the things that matter to them.

Reasonable adjustments: The NHS has made the commitment in their Long Term Plan to develop a Reasonable Adjustment Digital Flag capability. The flag is an immediate visible alert on people's health and care records; providing basic context and prompts for key adjustments. This is to provide amongst other things better positive interactions for Disabled people; reduce the need to repeat information; aid understanding of people; and reduce barriers and improve communication. Camden's Adult Social Care were an early adopter of this, starting in 2023, before the NHS rolled out plans for all health and social care staff who can access the National Care Record System: https://digital.nhs.uk/services/reasonable-adjustment-flag

Welfare Rights: Adult Social Care has a Welfare Rights Team that supports people who are over 18 and of any housing tenure. The qualifying criteria is that the person is elderly, has a long-term health condition or Disability which means they are unable to access other welfare advice services in the community. The Welfare Rights Team helps support people with benefits advice, helping with the claims process, helping to challenge incorrect decisions and represents people during the appeals process. They have recently employed new advisers to help with the managed migration to Universal Credit, particularly those on Income Related Employment Support Allowance, which impacts many people who draw on Adult Social Care