healthwatch
Lancashire

Disability Voices Phase 1 Report

June 2025

Contents

Acronyms

AIS - Accessible Information Standard
GP – General Practitioner
HTCS - NHS Healthcare Travel Costs Scheme
LCC – Lancashire County Council
NEPTS - Non-Emergency Patient Transport Services

Acknowledgements

Healthwatch Lancashire would like to thank everyone who shared their experience for this report. Also, we would like to thank everyone who contributed to our steering group:

- People First Self-Advocacy
- RNIB (Royal National Institute of Blind People
- Macular Society
- Lancashire and South Cumbria Integrated Care Board
- Lancashire County Council
- Volunteers with lived experience

Executive Summary

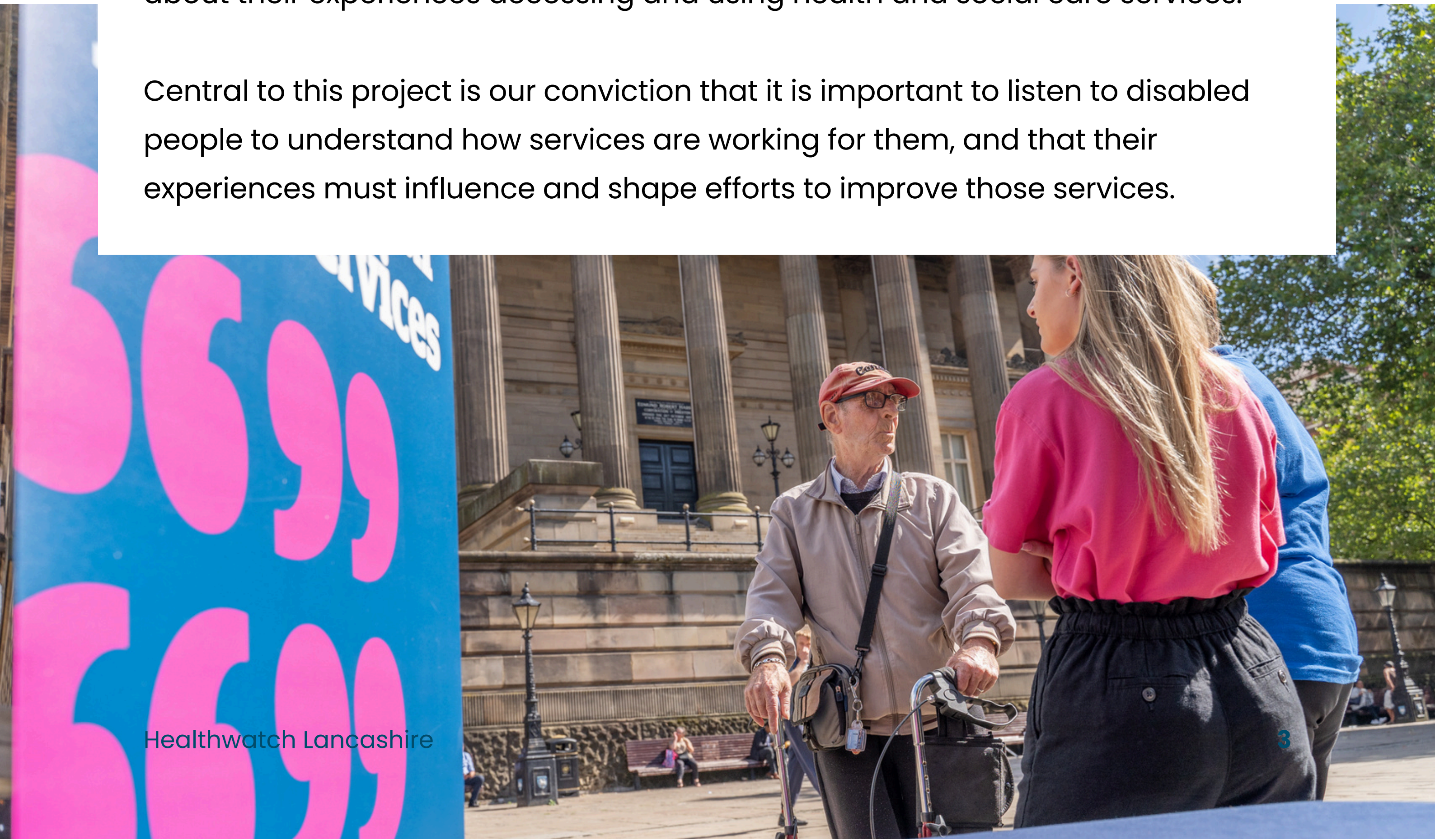
Between August and October 2024 Healthwatch Lancashire conducted engagement for the Disability Voices project, exploring the health and social care experiences of disabled people in our county.

The project followed a recent study of the same name by Healthwatch Cumberland and Healthwatch Westmorland and Furness, which found that access to health services and good healthcare was the biggest concern for disabled people in the region, and the area that they would like to see the most change.[1]

Read the full Cumbria report here

Building on these findings, we sought to hear from disabled people in Lancashire about their experiences accessing and using health and social care services.

Central to this project is our conviction that it is important to listen to disabled people to understand how services are working for them, and that their experiences must influence and shape efforts to improve those services.



Key Findings

Our report finds that while there is much that is working well, health and social care systems and services often fail to fully meet the needs of disabled people. When new systems are introduced or old systems are adapted without meaningful collaboration with the people they are intended to serve, they often overlook their specific needs. We strongly advocate for the inclusion of disabled people in all service development decisions.

Our main findings are as follows:

Most disabled people who participated in our survey were satisfied with the care they receive from health services: However, while quality of care was generally considered good, access to care remains a significant barrier for many.

Travel and transport pose considerable challenges: Limited public transport services, especially in rural areas, and high costs, create barriers to healthcare access. While NHS-assisted transport is essential for many, inconvenient pick-up times often result in long, uncomfortable waits in hospitals.

The Pharmacy First initiative may disadvantage disabled people: Accessibility issues at many pharmacies, such as steps and heavy doors, create barriers to inclusion in the Pharmacy First initiative for some disabled people.

Compliance with the Accessible Information Standard (AIS) is inconsistent: Despite the AIS being a legal requirement, many disabled people receive healthcare information in inaccessible formats, leading to difficulties in booking appointments and understanding medical information.

Poor continuity of care is common: Good continuity of care is crucial for disabled people, particularly those with complex conditions. However, many feel passed around healthcare services without consistent support from familiar healthcare professionals.

Understanding of some conditions is insufficient across services: People with complex health needs experience frustration due to a lack of awareness and medical expertise among healthcare professionals, leading to delayed or missed diagnoses.

Many disabled people feel patronised by services: People feel their voices are not always heard when discussing their healthcare, and are frustrated by the tendency of health professionals to talk to carers or family members instead of them.

Disabled people are generally satisfied with the support provided by social care services once they are in the system: However, getting into the system is difficult, with long waiting times and uncertainty often following applications for support.

Many disabled people are not informed of the types of social care they are entitled to: People are missing out on support from social care services due to a perception that they will be refused support, or because they do not know what they are entitled to.

1. Introduction

1.1 Methods

Our research involved a mixed methods approach which included an online survey, personal experience case studies gathered at engagement events and by phone, and public focus groups.

During this project we engaged with:

370

People

Our public engagement events for this project were primarily conducted at disability community groups across Lancashire. Consequently, most of the people we spoke to self-describe as disabled, even if they are not necessarily registered as disabled. We recognise that some people who are disabled according to the Equality Act are neither registered nor self-describe as disabled, and we were conscious to hear from these people at our general engagement events.

Our survey was available online, on paper copies, and in an easy-read format. It was designed to gather insights into the experiences of disabled people in Lancashire regarding health and social care services.

The engagement can be broken down into:

130 Survey responses

24 Personal experience case studies

15 Focus groups with **101** participants in total

The survey comprised of five key questions (along with demographic questions), with space provided for written comments. The questions were:

1. Tell us about your experiences with health services in Lancashire.

2. Tell us about your experiences with social care services in Lancashire.

3. Do Lancashire's health and social care services meet your needs?

4. Please rate your satisfaction with Lancashire's health services. [Responses were recorded using a five-point scale, ranging from 'Very satisfied' to 'Very unsatisfied'.]

5. Please rate your satisfaction with Lancashire's social care services. [This question also used a five-point scale, ranging from 'Very satisfied' to 'Very unsatisfied'.]

6. Is there anything else you would like to share about your quality of life as a disabled person in Lancashire?

These questions were used as the foundation for guiding discussions in our focus groups and personal experience case study interviews.

To analyse the data, we categorised responses into several broad themes and then into interrelated sub-themes. This approach enabled us to identify common patterns and key concerns, and explore positive and negative aspects of people's experiences.

By combining survey responses, focus group discussions, and case studies, we aimed to develop a comprehensive understanding of the challenges faced by disabled people in accessing health and social care services in Lancashire.

2. Defining and Understanding Disability

Under the Equality Act of 2010, a person is considered disabled if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities.[2]

Based on these criteria, the 2021 census estimated that 17.7 percent of the population of England and Wales is disabled.[3] Some organisations put the figure at over 20 percent. The Family Resources Survey, for example, which is run by the Department for Work and Pensions, estimates that 24 percent of the population is disabled.[4]

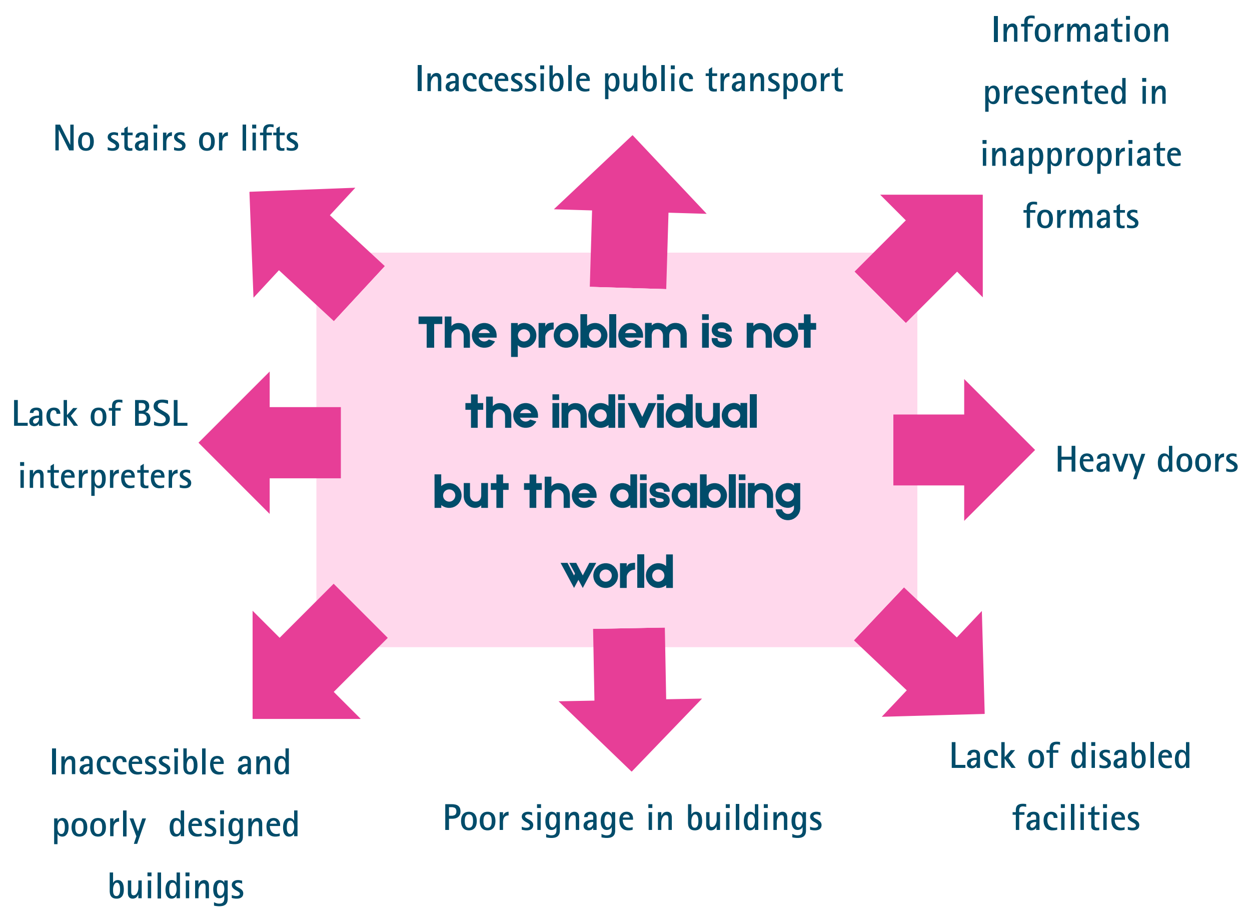
Among people aged 65 and over, the proportion is estimated at around 50 percent. Many people in this group may not personally identify as being disabled. Disability covers a broad spectrum of long-term conditions. Disabilities can be physical, mental, learning, sensory, and neurological. Some people have multiple disabilities.

Disability rates vary by region. According to the census, the North West has the second highest rate of disability in the country, at 19.8 percent, and the North of England more broadly has much higher rates of disability that the South.[5] In Lancashire, almost 240,000 people are classed as disabled.[6] These regional differences are important, as disability is a factor that contributes to poverty and ill health. People living in poorer areas spend on average more of their lives with disability. It is therefore vital that we understand the health and social care needs of disabled people in our region.

In this report we have adopted the social model of disability. This model says that people are disabled by barriers in society rather than by their impairment or difference.7

Barriers can be physical, such as buildings not having accessible entrances (e.g. steps, heavy doors etc.), lifts or toilets, or they can be attitudinal, such as assuming that disabled people are incapable of understanding things or performing certain activities.

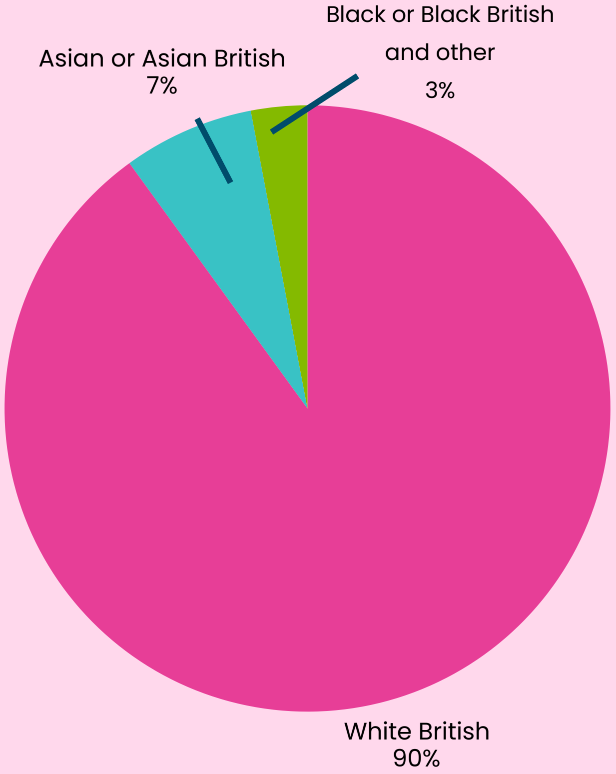
The Social Model of Disability



3. Demographic Information

This section of the report details the demographic data collected from people participating in this project.

Ethnicity



Gender

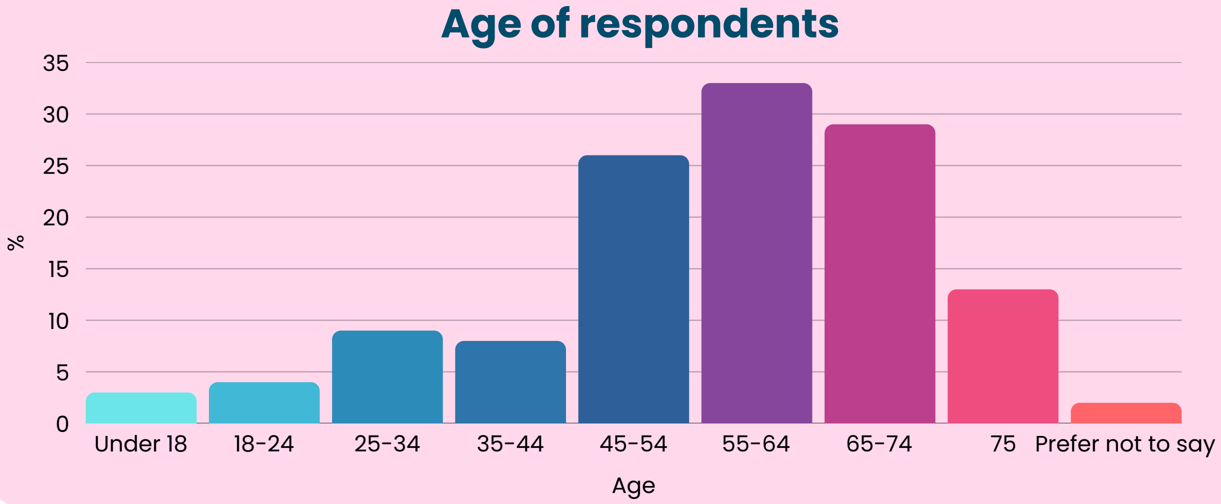
Female 58%

Male 39%

Non-binary 1%

Prefer not say 2%

Women made up 58% of respondents, which is consistent with national data showing that disability is more common among women. According to the Family Resources Survey, there are around 1.5 million more disabled women than men in England and Wales, a gap that becomes particularly pronounced in older age groups.[8]



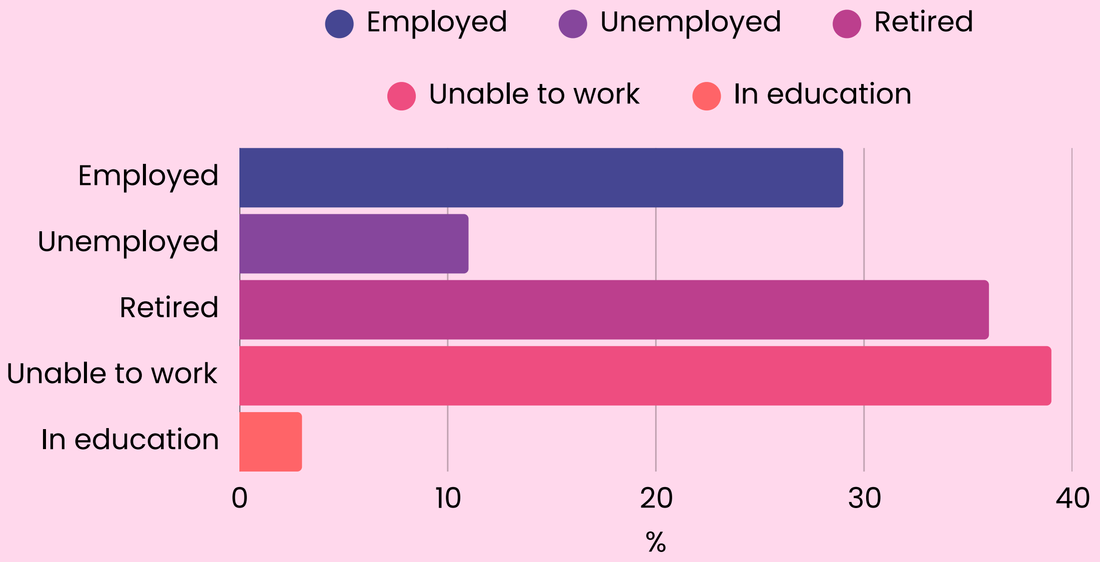
Eighty-three percent of respondents were registered as disabled. Most of our respondents were either retired (29%) or unable to work due to a disability (32%). Just over a quarter (28%) were in full- or part-time employment, while 9% were unemployed and 5% were in full-time education.

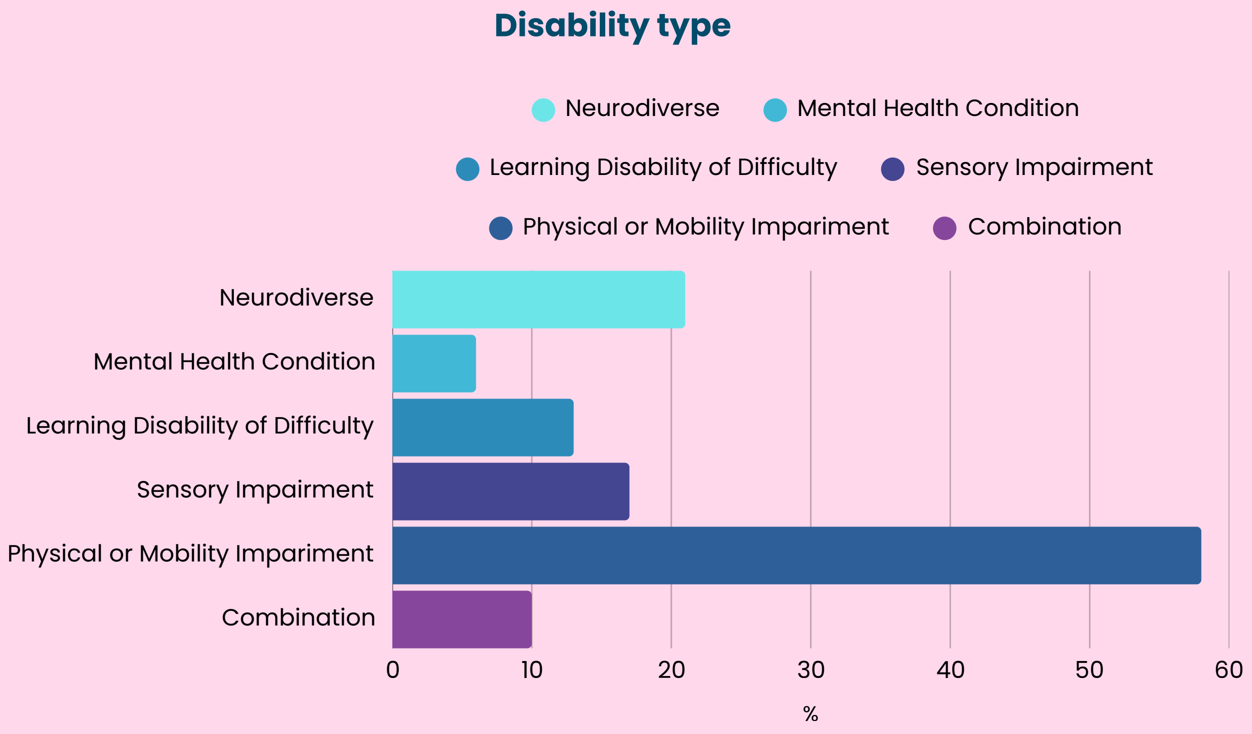
More than half of respondents reported having a physical or mobility impairment. Smaller proportions, ranging from 6 percent to 21 percent, had other types of disabilities, including mental health conditions, sensory impairments, neurological conditions, and learning disabilities. While 10% reported having multiple disabilities, this figure is likely an underestimation as the survey did not specifically ask respondents to list all types of disabilities they experience.

83%

of our survey participants were registered disabled

Employment of survey participants





Disability type

Disability Voices

We are exploring the experiences of disabled people in Lancashire

Tell us your story to help shape services.

Contact a member of our team to share your experience:

☎ 01524 239100
✉ info@healthwatchlancashire.co.uk

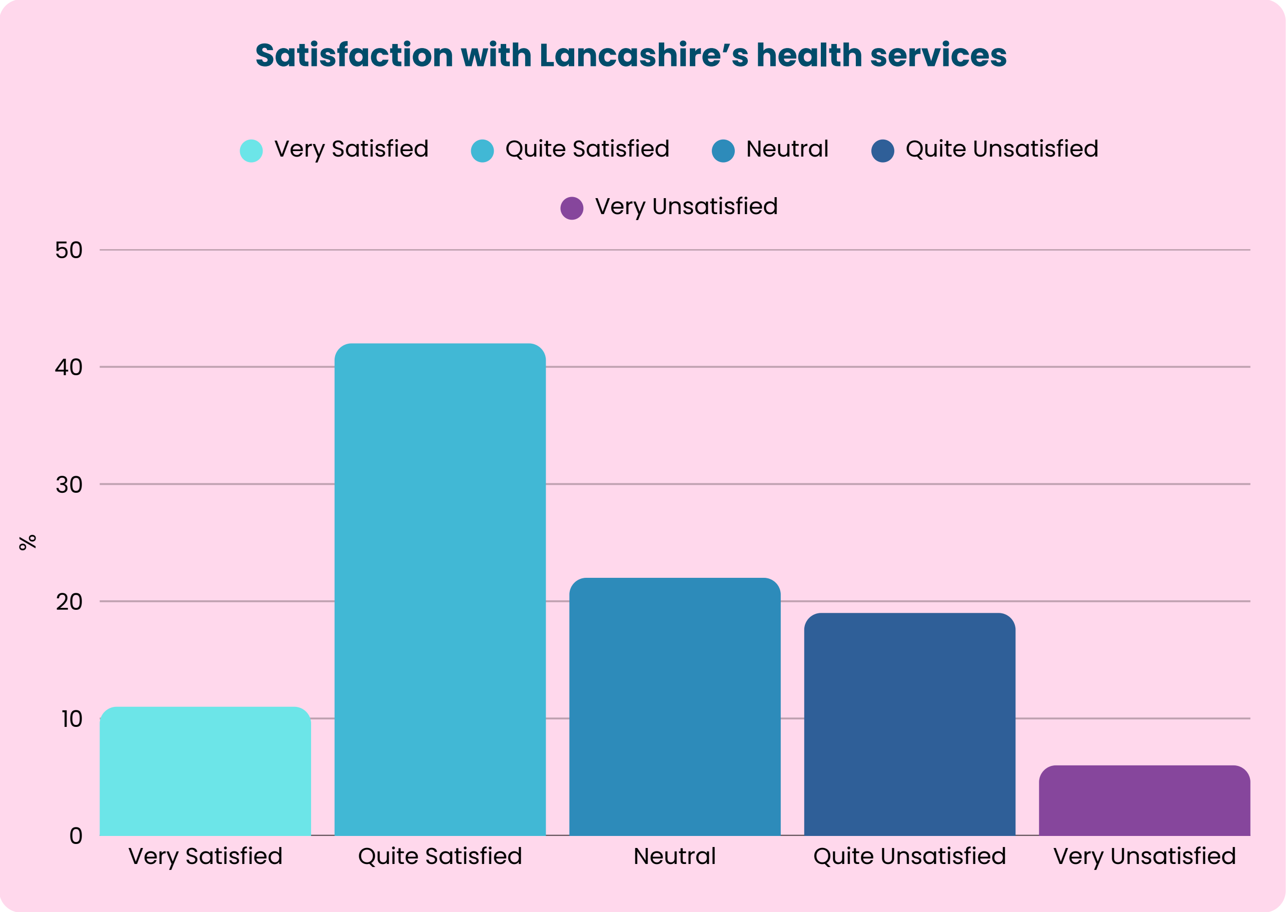
Or scan the QR code to access the survey

healthwatch
Lancashire

One of our Disability Voices posters.

4. Experiences of health Services

Our survey asked disabled people to rate their satisfaction with Lancashire's health services on and five-point scale, ranging from 'Very satisfied' to 'Very unsatisfied.'



The results show that a majority of respondents (53%) expressed some level of satisfaction with health services in Lancashire, with 11% stating they were 'very satisfied' and 42% reporting they were 'quite satisfied'.

This suggests that, for most survey participants, services are at least meeting their basic needs. However, a significant minority of respondents expressed dissatisfaction, with 19% stating they were 'unsatisfied' and 6% reporting that they were 'very unsatisfied.'

The qualitative data, gathered through our survey, focus groups, and case studies, reinforces this mixed picture. The evidence shows that there is a lot that is working well. Some people reported receiving excellent treatment and care. However, many disabled people were careful to distinguish between the good health care they received and the difficulties they experienced accessing services and information, with physical and communication barriers frequently cited.

Other people reported that healthcare services were not adequately meeting their health needs. This was particularly common among people with learning disabilities and neurological conditions, who frequently shared concerns about health professionals' limited understanding of their conditions.

They described being passed between services, feeling unheard, and experiencing lengthy waits for appointments. More broadly, many people highlighted cases where service providers failed to implement reasonable adjustments as required by the 2010 Equality Act.

Based on the feedback we gathered, we identified several major obstacles that disabled people encounter when engaging with healthcare services:

Transport and Accessibility

Communication, Inclusivity and Reasonable Adjustments

Continuity of care

Lack of awareness and medical expertise

4.1 Transport and Accessibility

The most persistent feedback we received highlighted the significant challenges disabled people face physically accessing NHS services. These difficulties were often linked to the journey itself, including the complexities of arranging assisted transport and the financial implications of relying on public transport.

Assisted transport services, such as the NHS Healthcare Travel Costs Scheme (HTCS) and the Non-Emergency Patient Transport Services (NEPTS) can be essential lifelines for disabled people. However, we heard that these services can be difficult to access and often fail to meet people's needs.

For example, while NEPTS supports people with 'significant mobility needs,' it is limited to hospital appointments, leaving gaps in support for travel to GP surgeries, dental practices, and pharmacies.

Additionally, many NEPTS users shared frustrating experiences, particularly with inconvenient pick-up times which left them having to arrange alternative transport or enduring long waits in uncomfortable waiting rooms.

> *Hospital transport is an issue as they pick you up so early and you have to wait around for your appointment. It feels quite lonely and isolating and you feel no one can support you.'*

> I had to have a follow up appointment to have a procedure done and I asked for some hospital transport, I was told I had to be at the hospital for 7am and the hospital transport said "oh no we only pick people up from 7:30am". I then had to ring around and find alternative ways of getting to the hospital.

My wife had an appointment at the hospital and the letter told us to arrive at 8am, but then we got a phone call the night before telling us not to get there until 11am. The thing they don't understand is I had booked hospital transport, so what was I supposed to do? They weren't happy that we turned up at 8am, but I had no choice…My wife has a physical disability and Alzheimer's, and I don't feel they understand what pressure I am under.

I go to Burnley for Chemotherapy once a month and it is a very costly affair. I try and get my family to come and take me which helps. I have used hospital transport, but it means I have to do a lot of waiting, and it isn't easy to book…With me living in Bacup it makes things hard. There's only one bus every two hours to Burnley and access to things isn't easy.

I have been in this wheelchair since I was young, and it has been a battle getting to my hospital appointments every time I have to go. I use the patient transport team which is a faff to get in touch with. I've had it where people at the hospital do it and its all sorted but sometimes it falls to me or my carer to make the arrangements. Because I live in Ribble Valley, I worry about getting to things on time and that's always at the back of my mind.

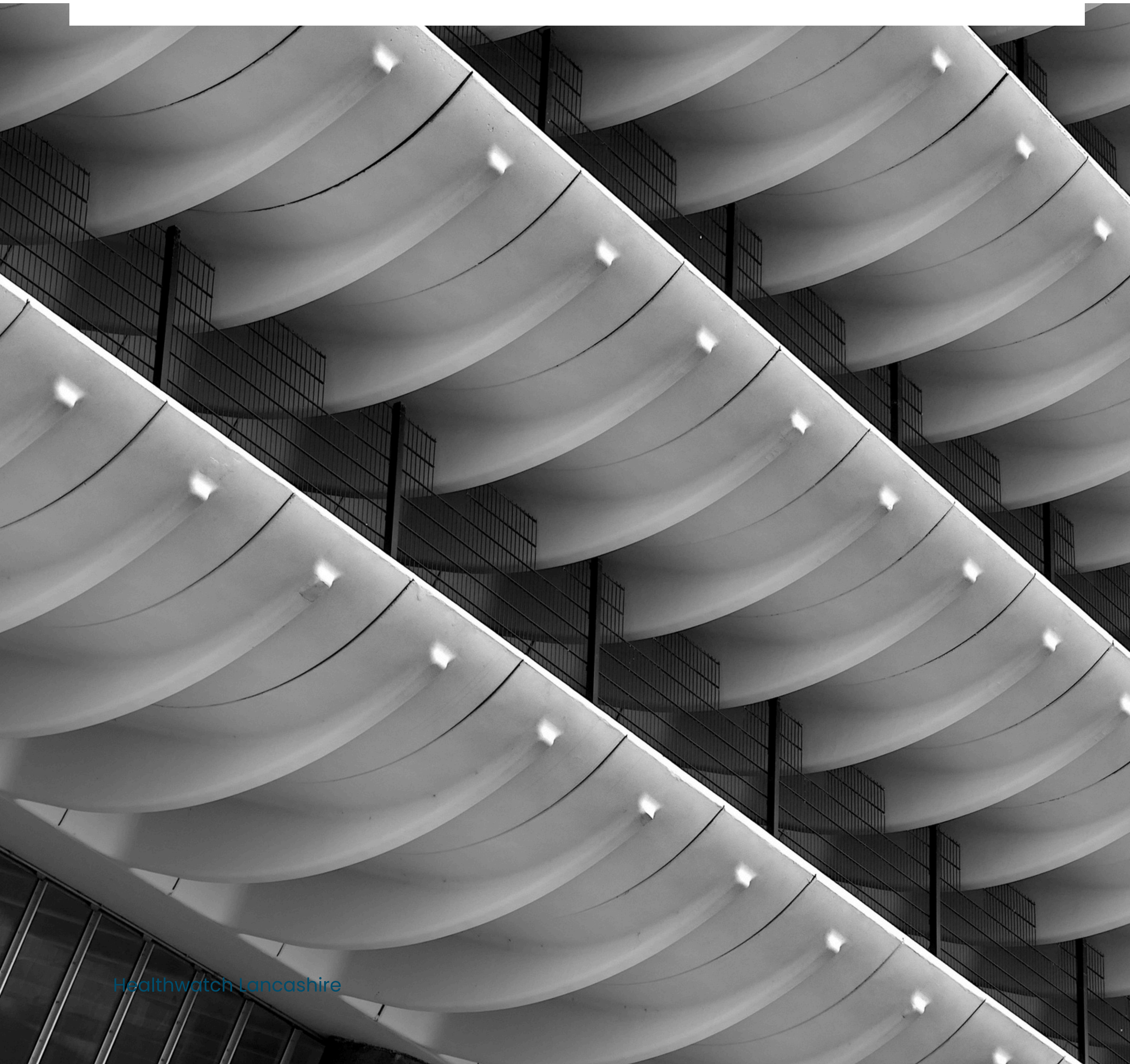
Disabled people who are ineligible for assisted transportation, or who choose to travel independently, often face expensive journeys to healthcare services. Costs for buses, taxis, and other transport options can add up quickly, placing significant financial strain on those already managing limited budgets. We heard that for people living in rural areas, the cost burden can be even greater due to limited transport options and longer travel distances.

Disabled people who drive to appointments themselves also face significant challenges. Some people told us of about the financial hardships occasioned by having to pay regular parking fees, as they were not eligible for a Blue Badge. Others who had a Blue Badge explained that disabled parking spaces are often full when they arrive for an appointment at hospital or GPs surgery, or are inconveniently located, meaning they had to walk long distances to the building. This problem was most pronounced at large hospitals, especially for people who use wheelchairs or struggle with mobility.

While transportation and financial concerns can affect all people, disabled people are often disproportionately impacted. Mobility limitations reduce their options for affordable and convenient travel, while additional expenses can create significant financial hardship. These challenges have been exacerbated by the rising cost of living and cuts to funding, making travel expenses an even greater burden.

A notable recent example is the decision by Lancashire County Council (LCC) to scrap the £1-per-journey rate for disabled people using a NoWcard before 9.30am on weekdays.[9] This scheme was introduced in 2011. The decision to discontinue the concession was made following a survey consultation, which saw 510 people take part. Of those who completed the survey, 81% disagreed with the proposal to end the subsidised fare.

It is worth noting that while LCC has scrapped the pre-9.30 cheaper fare, similar schemes remain in neighbouring local authority areas, such as Blackpool and Blackburn with Darwen. The decision has therefore made access to cheaper travel on public transport a postcode lottery.



In addition to travel challenges, disabled people also told us of the difficulties they have faced physically accessing some healthcare services, often due to barriers like steps, heavy doors, and a lack of accessible entry points. As one person told us,

> *I think it is very difficult in terms of accessibility. I was sent for a breast screening at one of those mobile buses. I arrived and they really hadn't thought about how I would get onto the bus. I have a physical condition which means that me walking upstairs is not going to happen.*

An important concern raised by several people is the challenge of physically accessing pharmacies at a time when the Pharmacy First initiative, introduced in January 2024, is encouraging people to go to their pharmacist before their GP.

> *The worst place for access is chemists, which often have large steps and heavy doors. And now that we're advised to see chemists first, it prevents access.*

> *[Access] could be better if they didn't just signpost people from reception (GP) to chemists, none of which are accessible in the local area.*

The Pharmacy First initiative allows patients to receive care and advice, including prescriptions, for seven common conditions directly from their pharmacy.[10] It is designed to reduce pressure on GP services and provide faster, more convenient access to treatment.

While this initiative has clear benefits, disabled people may be disproportionately disadvantaged if their local pharmacy is difficult to access. Unlike GP surgeries, which are often better equipped with ramps, automatic doors, and other accessibility features, some pharmacies have steep steps, heavy doors, and limited space, all of which can create significant access barriers for some disabled people.

4.2 Communication, inclusivity, and reasonable adjustments

Under the Accessible Information Standard (AIS), introduced in 2016, people in England have a legal right to receive information about their healthcare in a format they can understand.[11] The AIS is a reasonable adjustment that applies to all GPs, hospitals, and adult care providers. It is designed to support the needs of patients, service users, carers, and parents with a disability, impairment, or sensory loss.

> ***"I'm severe sight impaired. Some services are very good, with accessible information, and some services are not so good. When they are not so good, it can be really frustrating, and you can miss some really crucial medical information like appointments and test results. When it's really good, it makes you feel like you're included, and that you're independent, and it makes a real difference to how you feel about the health services."***

Despite AIS being a mandatory requirement, many disabled people told us that they often receive medical information in a format that they cannot access or understand.

We heard about people with visual impairments receiving letters or text messages about medical results or appointments, and people who are Deaf or hard-of-hearing being offered appointments over the phone. It is clear that there is considerable inconsistency in compliance with the AIS across services, with some services being very good and others poor. These findings align with studies by Healthwatch England and other organisations.[12]

The key communication problems reported to us include:

- Written information presented in standard formats that may be inaccessible for people with visual impairments, learning disabilities, or conditions affecting literacy.
- Insufficient provision of accessible formats such as Braille, large print, or easy-read versions of documents.
- Poor verbal communication practices.
- Difficulties booking appointments

> *I don't go to the doctors often, but they always used to phone me about medication reviews. Now they tell me to do things online. I can't use the app on my phone as I am blind. This is not helpful. I would rather do it over the phone, but they don't give me that option.*
>
> *Phone calls are not good for me as I struggle with my hearing, but the doctors insist on giving me a phone call appointment. The other day I was told the doctor would ring me after 12? What does this mean? I can't always hear my phone, and I can't have it in my hand for hours just waiting to be called. I feel there needs to be more in place for people who are hard of hearing.*

Face-to-face interactions pose challenges for some disabled people. We were told that healthcare professionals sometimes address carers or family members instead of speaking directly to them.

This not only undermines a person's autonomy, but can also lead to miscommunications or misunderstandings. Additionally, a number of people felt that some healthcare professionals speak too quickly, use complex terminology, or fail to explain information clearly, leaving people feeling confused and unsupported. As one patient explained:

> ***Some staff are not patient with me, and it is frustrating. I like people talking to me, but they talk to my carers instead of me. I have also got a problem with them talking in jargon as it is hard to understand.***

Another stated:

> ***I have autism and I am in a wheelchair, and I didn't feel they explained everything to me fully. My mum had to come in and help me, but I found it very scary as I had to stay in hospital by myself because they wouldn't let my mum stay with me.***

We also heard from young people at a Special Educational Needs and Disabilities (SEND) youth group, who expressed frustration at health professionals talking to parents instead of them about their conditions. This made them feel excluded from the conversation.

Some people also expressed frustrations at the lack of information provided to them by healthcare professionals after they were diagnosed with a condition. Many people feel like they were abandoned after receiving their diagnosis, and did not know who to speak to or where they could receive support.

The following case of a person who experienced physical disability as a result of Hepatic Encephalopathy (a brain dysfunction which can occur when the liver cannot remove toxins from blood) is one example:

> *I have to say that the love and care I received in hospital was amazing, [but] on leaving hospital I was totally unaware of what was going to become of me.I had no knowledge of how Hepatic Encephalopathy would change my life. I had to use a walking stick to get about. I was often off balance, [and] I had a terrible fall.*
>
> *The thing is, although I had some help from a friend…I felt life had come to a standstill. My business was gone, and I was in a great deal of debt. My doctor and Consultant were great, but I was a lost soul with no real knowledge of my conditions, how to deal with them, and what would become of me.*
>
> *I knew that I had to do something, and I came across The British Liver Trust on Google. I joined my first support group [and] at last I felt I wasn't alone. I learnt so much from the other people in the group and have continued to do so.*
>
> *I now carry a card in my wallet stating that I have HE and I also carry an HE Health Passport provided by the British Liver Trust. I should have been aware of these things when I left hospital. I should have also been notified of organisations like the British Liver Trust.*

Communication barriers and related access issues also impact appointment booking systems and processes, creating additional inclusion barriers for disabled people seeking healthcare.

We heard from many people about the difficulties they experience getting appointments at GPs surgeries due to the limited booking methods available. Many surgeries now encourage patients to use online apps to arrange appointments. While this system can be convenient for some, it poses challenges for others, particularly those with visual impairments, learning disabilities, or poor digital literacy.

Although the traditional option of booking by phone remains available in most cases, it is not always a viable alternative. Many surgeries operate a system where appointments are released in the early morning on a first-come, first-served basis. This can make it difficult for people who require extra time to process information, those who rely on assistance to make calls, or people with conditions that make phone conversations difficult or stressful. Booking in person is another potential option, but for many disabled people it is not a practical choice.

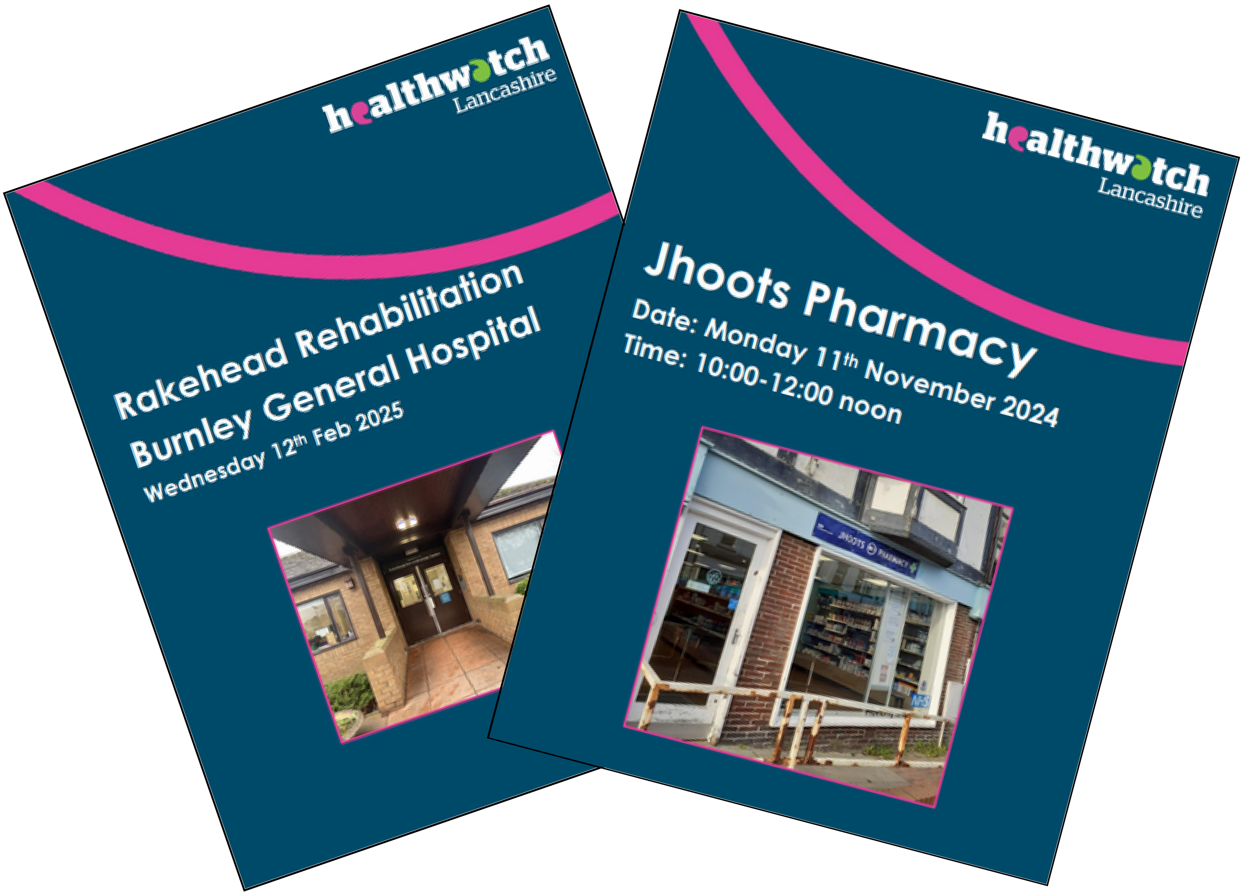
There is no one-size-fits-all solution to appointment booking. To ensure equal access, GP surgeries and other healthcare providers should offer a variety of booking methods to meet different needs. Many are doing this, but there is a lack of consistency across the sector. Staff should be trained to proactively offer reasonable adjustments and assist people in accessing the system that works best for them.

In addition to communication barriers, the physical environment can present further obstacles to inclusion. This includes factors such as poor signage and uncomfortable waiting rooms:

> “*[Waiting rooms] are not really geared up for neurodivergent nor people with chronic illness where noise, brightness and people crammed together are commonplace. About the only quiet waiting room I’ve found is one of the ones my GP operates (they have two sites but the first is nearly always quiet). Between TVs, kids, talking information stands and reception areas — they’re universally hard to sit in. In the waiting area for an x-ray, I chose to sit in the corridor as it was less bright, cooler and much quieter as the actual waiting room was the size of a shoebox and full.*”

At Healthwatch Lancashire we have undertaken an in-depth exploration of physical access to NHS services across the county, including GPs surgeries, hospitals and pharmacies, through our Enter and View programme. We conduct several Enter and View visits to health and social care providers each month. Our findings add further weight to the evidence we received from disabled people.

As our published Enter and View reports show, in some healthcare settings signage is inadequate, making it difficult for people to navigate the premises independently. This is particularly problematic for people with visual impairments and learning disabilities. Seating arrangements in waiting areas are not always appropriate for disabled people, especially those who might find standard seating uncomfortable. Some lack sufficient space for wheelchair users.



healthwatch Lancashire

Rakehead Rehabilitation
Burnley General Hospital
Wednesday 12th Feb 2025

healthwatch Lancashire

Jhoots Pharmacy
Date: Monday 11th November 2024
Time: 10:00-12:00 noon

Our reports also show that some waiting areas are unsuitable for people with complex neurological conditions such as autism, epilepsy, or sensory conditions, to whom bright lighting, excessive noise, and crowded spaces can exacerbate anxiety and distress. In some cases, GP surgeries rely on visual or audio prompts to signal when it's someone's time to see the doctor, which people with sensory conditions can miss.

When exploring the availability of separate rooms for people who require privacy or a quieter environment, we found considerable variation. A number of services have dedicated quiet spaces, while others do not. In some instances, staff informed us that they could make a separate room available upon request. However, this option is not always communicated to people. As a result, people who would benefit from these spaces often remain unaware that they exist.

4.3 Continuity of care

Research shows that most people prefer to see a consistent healthcare professional or a team of professionals who they are familiar with and who know their condition. This is known as continuity of care. The benefits of good continuity of care are clear; better patient outcomes, and reduced healthcare inefficiencies.[13] For disabled people, this is a significant priority, especially for those with complex conditions that are not necessarily well understood, and who often need ongoing support and care.

Yet, too often disabled people feel like they are passed around services, and have to repeatedly explain their conditions to healthcare professionals who they do not know, and who are not aware of or experts in their condition. While people can request to see a regular healthcare professional at their registered GP surgery, those who choose to do so often face long waits, limiting access to care.

Positively, we heard some good examples of continuous care. One individual shared their experience with Myalgic Encephalomyelitis (ME), a long-term condition that had been misunderstood by doctors in the past, noting that things only improved when they found the right doctor who they were able to establish a consistent care relationship with:

> *I've had a disability for over 40 years. I was diagnosed as having Myalgic encephalomyelitis or ME which was just fobbed off by drs back in the 80's who said it was a mental health condition. As time has gone by, I've seen a steady decline in my health and abilities. I now walk with a stick and am severely limited in what I can do. I've found that my issues changed when I found the right dr who understood that my condition is not just "in my head" and they understood different ways to cope with it. They've helped me on my journey where I am still relatively fit and able to do things. Not like I used to but they've helped me adapt to how I need to listen to my body and respond accordingly.*

Other people told us about good experiences of continuous care at their GP practices:

> *I find the local surgery, Irwell Medical, are really good at making sure my needs are being met. I have allocated staff for different issues, which makes things easier for me. I know I can ring, and I'll be given a slot with the right person who knows my history and what I need.*

> *The doctors here are really good with me. I've known them a long time. What I like is how they listen to me and take their time when I struggle walking around. My wife is a carer for me, and they always talk with her but make sure to include me in the chat."*

We found that poor continuity of care often arises when individuals are forced to navigate a healthcare system involving multiple providers across various services. Many people we spoke to described the exhausting experience of having to repeatedly explain their medical history, symptoms, or treatment needs to different professionals.

This lack of joined-up care not only leads to avoidable delays and unnecessary repeat tests, but also causes significant emotional distress. Over time, these experiences erode trust in the healthcare system and leave people feeling uncertain about the quality and consistency of the care they receive. One cancer patient shared their frustration:

> *I have a lot of appointments that I need to go to at Preston, Burnley and the Christie as part of my treatment for Cancer. I have found it a nightmare that they never talk to each other about how things are going with my condition. It has resulted in me nearly having two tests which involved radiation which would have made me very ill. It's like the left hand doesn't know what the right hand is doing, and it's made worse by the fact that I have to visit so many different hospitals in the area. It would be better if everything I needed was all with Lancashire instead of Lancashire and Manchester trusts. They just don't speak to each other and that's dangerous.*

Such cases were not uncommon. We heard from others who received conflicting advice, or were left chasing their medical records between services. The consequences of this disjointed system are not just inconvenient, they can be dangerous, particularly for people with complex or long-term health needs who rely on coordinated care to manage their conditions effectively.

Another person receiving episodic care for a complex neurological condition described their deep frustration at having to repeatedly re-explain their symptoms to healthcare professionals who were unfamiliar with, or did not fully understand, the nature of their condition. They told us that each new appointment felt like starting from the beginning, often with clinicians who lacked the specialist knowledge needed to properly interpret or respond to their symptoms. This not only delayed effective care but also left them feeling unseen and unheard. They told us that what they needed most was continuity; a consistent relationship with a healthcare professional who understood their condition and could track changes over time.

This is a national problem. A recent investigation by the Health Services Safety Investigations Body (HSSIB) found that poorly coordinated care, caused by an overly complex and fragmented healthcare system, was having serious consequences for people living with long-term conditions. The report revealed that patients were often left feeling abandoned and confused as they struggled to navigate disconnected services and inconsistent communication between healthcare professionals. As a result, many experienced increased levels of distress, delays in treatment, and a worsening of their health.[14]

4.4 Lack of awarness and medical expertise

> “I have had a mixture of good and bad experiences with the health system. The bad experiences are mainly because some doctors and social workers do not seem to know how to deal with someone with complex mental health needs. My current GP has been very sympathetic, and has been good with me recently, but I find it very hard to always see them when I get an appointment. The surgery is not willing to make reasonable adjustments, and communication has been very poor. They make me feel like an inconvenience.”

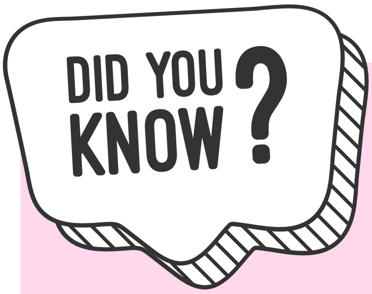
A broader issue closely tied to continuity of care is a lack of awareness and expertise among some healthcare professionals. Disabled people with learning disabilities, mental health conditions, and neurological conditions shared similar concerns with us. They feel their health concerns are often ignored, leading to delayed diagnosis or missed diagnosis. Some reported that they feel health professionals make judgements about their condition from visual appearance alone. We heard from a person diagnosed with M.E. and fibromyalgia, who, like so many others, have felt frustrated and that they are not being taken seriously:

> “*[I had] a lot of tests which brought up diagnoses of some of the other conditions often found with ME, such as IBS, allergies, etc., but everything was always considered separately and as my weight increased once I was ill and immobile, they would then just bring it back to that all the time as if my weight was why I was ill. Despite trying to lose weight and usually making myself more ill, I’ve remained a similar size over the whole of that time, in better times and worse and so the comments I have had from health professionals has remained the same for the last 30 years…Along with a lack of acknowledgement of my condition and constant belittling of my symptoms, I have felt totally worthless in the eyes of healthcare.*”

Disability in Focus: Macular Degeneration

Macular Society
Beating Macular Disease

During our research we visited Macular Society support groups in Chorley, Preston, Morecambe and Burnley. Macular disease is a term which refers to a range of conditions affecting the retina of the eye and impact vision. Its most common form is Age-Related Macular Degeneration (AMD), which affects 700,000 people in the UK.[15] It mainly affects people aged over 60, but can occur sooner.



700,000 people in the UK are affected by Macular degeneration. The condition mostly affects people aged over 60, but it can occur sooner.

Our meetings with macular groups revealed several key themes which reflects the wider issues experienced by disabled people trying to access healthcare. They were:

Gaps in Healthcare Awareness and Training

Healthcare professionals across different settings lack sufficient training and awareness when it comes to supporting people with MD, including GPs and opticians. Patients noted that while their visual impairment is recorded in their medical records, it is not always considered. GPs require more training to better understand and accommodate visual impairments. There is minimal information provided by opticians on how to live with MD. Additionally, written communications from opticians should be more accessible, such as using large-print formats.

Barriers in NHS Communications and Accessibility

Many aspects of NHS communication and hospital environments present significant challenges for people with MD. Letters for eye clinic appointments are often not in large print, making them inaccessible to those with visual impairments. Similarly, being asked to complete forms at appointments without assistance is a barrier, with some people reporting dismissive responses when they express difficulty. People are frequently handed leaflets that they cannot read due to their visual impairment, making these materials ineffective.

Moving screens are difficult to follow, and the lack of audio announcements means people may struggle to know when they are being called. Systems requiring patients to take a ticket and watch for their number are not accessible for those with MD. Overhead signs in hospital corridors are challenging to read, often leading to navigation difficulties. Eye clinic signage, in particular, should be clearer and more accessible. Additionally, vague directions such as "go to walk-in" without specifying a location add to frustration.

Challenges with Appointments and Treatment Access

Several issues make attending macular services difficult for MD patients:

- Appointment Timing & Location: Early morning appointments, such as those in Kendal at 8 AM, can be challenging due to limited public transport options - especially for people unfamiliar with the area.
- Portacabins & Mobile Units: These temporary facilities pose accessibility challenges:
    - Steps are difficult to navigate, particularly when made of reflective metal surfaces that can be blinding in sunlight.
    - Steep steps and sudden transitions from dimly lit interiors to bright outdoor light can be disorienting, as MD makes eyes highly light-sensitive.
    - Requests for yellow-painted steps to improve visibility have been denied.

Lack of Guidance and Support Post-Diagnosis

Receiving a diagnosis of macular degeneration (MD) often comes with little to no guidance on how to live with the condition. Many people reported feeling abandoned after their diagnosis, left to navigate the challenges on their own. Despite the presence of Eye Clinic Liaison Officers (ECLO) at hospitals like Royal Lancaster and Royal Preston, people were not always directed to them. There is also a general lack of signposting to local support groups or organisations such as The Macular Society.

Lack of Local Support Services

There is a noticeable gap in support services across some regions, particularly in East Lancashire, where organisations such as Galloways are not available.

Treatment Delays and Their Impact

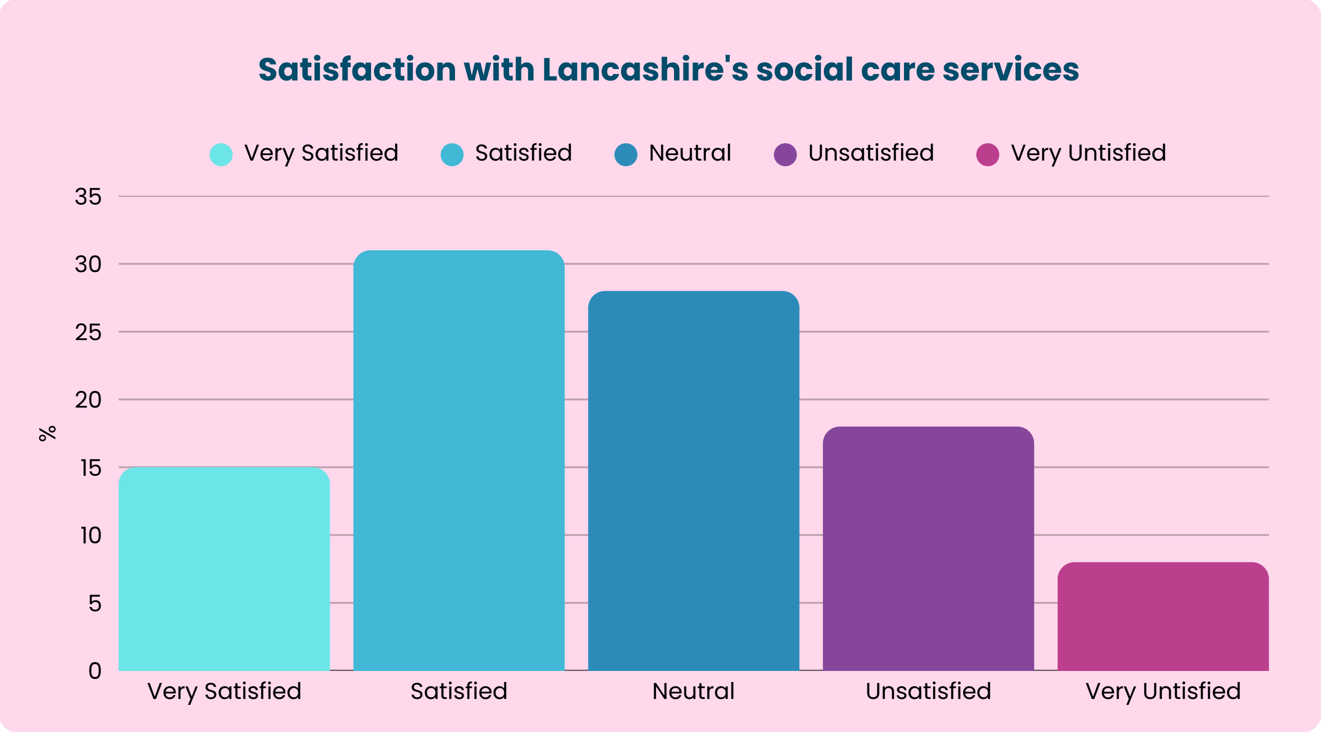
Many people experience delays in receiving treatment, which can result in further deterioration of eyesight. These delays also contribute to significant stress and anxiety, exacerbating the challenges of living with MD.

5. Experiences of social care services

Health and social care services play a vital interconnected role in supporting the overall wellbeing of disabled people. As such, we sought feedback from disabled people to better understand their experiences with social care and related services.

Social care encompasses a broad range of services designed to support people with disabilities or physical and mental health conditions to live independently. This support takes various forms, including care and support in people's homes, day centres, and care homes. It includes reablement services to help people regain independence, home adaptations to enhance mobility, and support and advice for carers.[16]

Social care is organised and funded by local authorities, who are responsible for assessing a person's needs, although services are often provided by for-profit organisations. Unlike NHS healthcare, social care is not free. People who receive publicly funded social care are means tested to determine whether – and how much - they must contribute to any assistance they receive. People with assets over £23,250 are not entitled to financial assistance for social care.[17]



Our survey results revealed that many participants are satisfied with social care services. Forty-six percent of respondents reported being either ‘Very satisfied’ (15) or ‘Satisfied’ (31%). A further 28% of respondents selected 'Neutral'; this group mainly consisted of people who have had little or no engagement with social care services. Meanwhile, 26% of respondents reported negative experiences, with 18% feeling 'Unsatisfied' and 8% 'Very unsatisfied'.

Getting through the door

The qualitative responses from our survey, along with our focus group and case study interviews, provide a deeper insight into these findings. The evidence indicates that most people are satisfied with the care and support provided by social services once they are in the system. Many of those who were unsatisfied had either been refused support of were still waiting for a response to their application for support.

Positive experiences included:

Swift implementation of housing adjustments

Good, timely support from social workers

The positive impact of adult social care support groups, such as day centres, in enhancing social engagement and overall wellbeing.

> *We have had assessments from social services in order to have adaptions made to our house. This was a while ago, but it was quite quick, and things were put in place to get things sorted such as handrails, ramps and wider doors for his wheelchair.*

> *I had an assessment of my needs earlier this year and have a small care package. My social care worker also arranged for grab rails and a trolley to help me in the house. She referred me to occupational therapy who referred me for a Disabled Facility Grant to convert my bathroom to an accessible shower room. She also referred me to Welfare Rights for help with disability benefits.*

> *[My son] has carer support, which is funded by Lancashire County Council. It is helpful as they take him out and about and they have him most days whilst I work.*

Conversely, those who expressed dissatisfaction often reported difficulties accessing services in the first place. Key concerns included:

- Lengthy waiting lists for assistance, leaving people without the necessary support
- Poor experiences with the quality of care and support received

The data suggests that satisfaction rates depend, in part, on the type of assistance commissioned by social services at the local level. For example, many people told us about the excellent support they have received from social workers, whereas others described poor experiences.

It appears that satisfaction might be lower where services rely on agency workers who have limited knowledge of a person's needs and frequently change, although this is inconclusive. In any case, just as people expressed a preference for seeing the same medical professional for continuity of care, disabled people expressed a clear preference for working with the same social worker over time. Consistency in care providers was seen as crucial for building trust, ensuring needs were properly understood, and improving the overall quality of support.

> *I feel that the only time I am taken seriously by social workers is when [my advocate is] present. Unfortunately, my advocate has been away on holiday lately, and I've had to meet with social care workers on my own. It's obvious that they haven't properly read my case notes, and they don't seem to have any idea about how autism affects people. They talk to me like I am a child [which] feels patronising…In my experience there needs to be more awareness of how to treat people with autism by social workers.*

> *I had a carers assessment, and the social workers kept changing and there was no consistency at all with the system. Instead of coming out and speaking with me they would go to my husband and ask what he thinks, but he didn't have the capacity to do things like that, which is why I was registered as his carer. But they took his word for it and said that he is fine and didn't need a carer even though he was in a wheelchair and unable to dress, wash or feed himself.*

It is clear that many people face significant struggles getting the social care support they need. Home adaptations, for instance, are often subject to extensive delays. One person described the difficulties they faced obtaining essential bathroom adaptations, which resulted in them spending a considerable sum paying for the work themselves:

> *I had to get a bathroom installed on the lower floor of our house for myself and my husband as we have limited mobility. I put the application in with the council and we were told that there would be at least a 12-month wait for the application to be considered and approved, and even then the chances of being approved despite our conditions were slim. I ended up making the decision to spend almost £10,000 of our savings on getting facilities installed downstairs.*

Another person described their struggles with delays to occupational therapy assessments:

> I have had assessments by occupational therapy for my condition which I found to be unhelpful as the advice took a lot of choice away from me. I have contacted the council, and it has taken them six months to get in touch with me for an assessment to see about getting some adaptations made to my home. I am unsure how I can make this process faster.

During our research, we heard from a person whose experience highlights many challenges faced by some people in social housing. This person, a male in his 60s, urgently needs a social worker to help resolve serious issues with his housing association-owned flat, including severe black mould which he told us is affecting his health. His advocate described the mould as ***'the worst I have ever seen.'***

He has tried to seek support from the Learning Disability and Autism Team at Lancashire County Council, but they were unable to assist him because his medical records list him as having a learning 'difficulty' rather than a 'disability.' He then sought help from Advocacy Focus, who are contracted by Lancashire County Council, but they could not assist him directly as they do not handle housing issues. Recently, with help from an advocate, he submitted a complaint to his housing association, which has led to some progress. However, his housing problems remain unresolved, and his flat is still mouldy.

Awareness of social care options and eligibility

A recent study by Healthwatch England found that of 1,504 working-age disabled adults who took part in a poll, 28 per cent had never accessed social care or related support despite potentially being eligible.[18] This represented more than 1 in 4 of those polled.

You can read the full Healthwatch England report here:

Missing millions: Exploring unmet social care need for disabled adults

The reasons they had not received social care were:

- They didn't think they could get any support (65%)
- They didn't know where to go for support (34%)
- They were unable to afford to pay for care or contributions (26%)
- They found it too difficult to get support from councils or the NHS (14%)
- Their local service closed (2%).

Our research closely aligns with these findings. In particular, during the course of our conversations with people it became clear that many were not aware of what social care support services were available to them.

> *I think what's needed is better support for people, so they know what they need and what is available to them. I think what would help me most is to know what support I can get.*

Some people had tried to get support in the past but found the process too difficult and stopped trying. Others did not try to get support because they assumed they would be turned down. Many people need urgent support but simply do not know where to turn.

We heard from a woman whose husband has been diagnosed a life-changing terminal illness:

> *I could do with finding out more about what is available to me as I really do not know what to do in order to look after myself or find out what [my husband] is entitled to in terms of support that is on offer with carers, district nurses or whatever. My husband has lost all of his mobility due to the condition and it has been difficult, for us both, coming to grips with the fact that he is now disabled. There has been some support put in place but it has taken 4 months to get the house adapted to let him move around. We were given the diagnosis at the start of the year, and it has taken 8 months to get him a wheelchair to allow him to move around again. That is 8 months of his life he can't afford to waste.*

Too many disabled people who could benefit from social care support are missing out due to a lack of awareness, difficulty navigating the system, and financial barriers. Delays in accessing essential equipment and adaptations leave people struggling unnecessarily. To address this, there must be clearer information, proactive outreach, and streamlined processes to ensure that those in need can easily find and access the support they are entitled to.

Information on adult social social care support services provided by Lancashire County Council, including eligibility criteria, can be found here:

Lancashire Gov - Health and Social Care & Adult Social Care

Conclusion

This study has found that while there are many aspects of health and social care services that are functioning effectively for disabled people, significant challenges persist.

For many disabled people, physically accessing services remains a major barrier, particularly regarding transport. Poor communication, a lack of accessible information, inconsistent and often ineffective continuity of care across services, and a feeling of being ignored or patronised, can contribute to negative experiences, delays in diagnosis, and poorer health outcomes.

We found that there is a pressing need for clearer information about the social care system and the range of options available to people. Many people report confusion about what support exists, how to access it, and who is eligible.

Health and social care are deeply interconnected, as they have direct implications on people's wellbeing and quality of life. Efforts to improve these systems must meaningfully involve disabled people in the process to ensure they are relevant, effective, and inclusive.

Next steps

This study has provided a broad overview of the current landscape of health and social care as experienced by disabled people. Building on these findings, the next phase of our work will involve a more focused exploration of transport and access to serivices; issues that emerged as central to the experiences and barriers we have identified.

Recomendations

Transport & Accessibility	• Local authorities should actively identify areas with poor public transport connections to key healthcare services, including hospitals, GP surgeries, dental practices, and pharmacies. • Assess the potential to reinstate the pre-9.30am NoWcard concession fare in Lancashire, ensuring that any public consultation is accessible and inclusive from the outset. • Conduct a feasibility study on introducing a transport service similar to the Non-Emergency Patient Transport Service (NEPTS) for disabled people who need to access non-hospital healthcare, such as GP surgeries and pharmacies. • Ensure that all pharmacies participating in the Pharmacy First initiative meet minimum accessibility standards, so disabled people can use these services without barriers.
Communication, inclusivity & reasonable adjustments	• Integrated Care Boards (ICBs) should regularly conduct AIS spot-checks across GP surgeries, hospitals, and adult care providers. • Ensure all healthcare information is available in multiple formats, including easy-read, to maximise accessibility. • Healthcare providers should offer and promote a range of appointment booking methods including telephone, online (via accessible platforms), in-person, and assisted options (e.g., through carers or advocates). • Providers should proactively offer reasonable adjustments.

Continuity of care	NHS England with ICBs should explore the potential of introducing a personal, portable patient care plan that can be easily accessed and shared across providers by patients and care coordinators.
Awareness & Expertise	All healthcare providers should receive regular disability awareness training and refresher training to staff. Emphasise to healthcare professionals the importance of speaking to disabled people, rather than to their carers and family members.
Social care	Local authorities should launch a targeted campaign to raise awareness of social care services and eligibility. Make all information on social care accessible to people in easy read and other formats to enhance inclusion.

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