


Disability Voices

**Understanding the lives
of people with disabilities
in Cumberland - 2023**





Healthwatch Cumberland and Healthwatch Westmorland and Furness would like to thank the Nuclear Decommissioning Authority who have generously funded this project.

Their support has enabled us to carry out this vital work on behalf our local communities and we are incredibly grateful.



Introduction



This is the easy read report.



You can get a copy of the full report from
info@healthwatchcumberland.co.uk
or phone 0300 303 8567.



The Easy Read in this report has been made by the team at Skills for People. They employ people with learning disabilities.



A team of people from the University of Cumbria, called the Health and Society Exchange (HESKE) wrote the report.



About this report



In 2023 Healthwatch collected the views of people with a disability across **Cumbria**, and their families and other people who support people with disabilities.



People gave their views in interviews, group meetings, on Facebook, and through surveys.



758 people gave their views. 498 of these people live in **Cumberland**. This report tells you what they found out.

healthwatch



Healthwatch makes sure that people who run health and care services listen to people who use them, to make services better.





“I always have to think about my [long term health] condition and how it will impact me, a flare up can happen quite suddenly so I always have to ‘be prepared’ which stops me being spontaneous and causes stress and anxiety.”

Survey respondent



People with disabilities told us about their lives



They told us:

- Everyone is different.
 - Our lives are different.
 - We like different things.
-



Some people with a disability need support from their family, friends or paid carers.



One in five people with disabilities said they need a lot of support.



Carers told us how they support people with disabilities



Carers help people get washed and dressed.
Carers help with cleaning and cooking.



Carers support people to go out and about.
Carers help people to sing together.



Carers help support someone when they're upset.



People with disabilities told us what makes a good life



They told us getting the bus to the shops, having a coffee and time for friends and fun is important.



They told us getting out in nature.



They told us listening to music makes a good life.





'Now that I've got my hearing dog, I don't stress as much about getting up in the morning. He's just brilliant. He's the best thing that ever happened to me. He's just a ray of sunshine in what's been a rough journey.'

Case study participant



People with disabilities told us what makes a good life



People understanding me and how my autism affects me.



Freedom to choose for myself, with help from an expert when I need it.



Support at work so I don't burn out.





“Not all buses/bus drivers advocate for the wheelchair users who require the allocated spaces. Not all taxis are wheel chair friendly. Train replacement services are not suitable for wheelchair users most of the time. There has been times when my daughter has been stranded at unmanned stations.”

Survey respondent



They told us what stops them having a good life



Lots of people said their life was worse than five years ago.



Since Covid it can be hard to get out and about. Some support services and charities have closed.



The cost of living means people cannot afford to live as they want.



Health staff seem to be too busy.



Carers told us



Carers often have little or no support.



Men who care for someone find it hard to find support.



Loneliness



Almost all people told us they feel lonely sometimes.
Nearly half feel lonely often.



Nearly everyone feels that they have fewer chances to be part of their community than other people.



People feel very tired.
People who are autistic can feel burn out.



There are lots of community and charity groups which help people get together. They help people to be less isolated but often people don't know about them.





“...most of the improvements in mine and [family member’s] daily lives are the result of my own initiatives and approaches and sheer tenacity.”

Case study participant



Mental Health



The problems people have made them feel worried and anxious.



People are very worried about bills and paying for food.



Carers worry about the future of people with a disability that they care for.

People with disabilities said these things affect them badly



Pain and tiredness.
Poor memory or foggy brain.
Feeling depressed or anxious.
Not being able to get out and about.





“I use to live in London but have lived in the west of Cumbria where there were lots of services. I was shocked when I came to live in Carlisle at the lack of services for disabled people, it is beginning to get better, but Covid has affected services.”

Case study participant



People said some things have got better

People said they had made changes in their lives.



Moving into a care home –
“now I can do more, as staff help me.”
Getting a hearing dog.
Getting a Blue Badge.
Buying a scooter.



There are local charities which help us.



About half the people told us they know their rights as a person with a disability.



Half said they do not know the rights or wanted to know more.





“I was at home prior to the pandemic, moved into the care home Sept 2021. Best decision I have made as now I can actually do more as the environment and staff can help me, that’s improved my quality of life.”

Case study participant



Being held back: From having a good life

Most people told us they are held back from having a good life.



People told us:

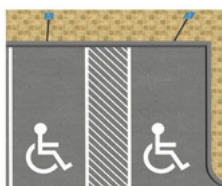
Many places make it difficult to get around.

- No wheelchair access.
- No ramps or lifts.
- Uneven pavements and kerbs.



No accessible toilets and changing spaces.

About public transport they told us :



- Poor service which does not meet our needs.
- Very few buses in rural areas.
- It is harder to get a bus pass these days.
- A lack of parking spaces. Some parking spaces don't leave room for a wheelchair.



Being held back: Getting health and care



People told us:
It is difficult to get an appointment with the doctor.



Doctors don't do home visits for mental health.



Booking appointments over the phone or by computer can be too difficult.



Being held back: Getting health and care



Long waiting lists for hospital appointments.



In Cumbria, there is a lack of **neurology** care. **Neurology** means treatment for brains, nerves and muscles.

Neurology



People told us they have to travel far for some care.



Being held back: Money to live on



People told us:
It is difficult to claim money like Personal Independence Payment (PIP) or Attendance Allowance.



The forms are long.
The questions are difficult.



It makes people anxious



Being held back: Technology



Many people find it hard to use computers and smart phones.
It is very hard for some some older people.



It makes it harder to make appointments with a doctor.





“...In the time we've been here, Cumbria and North Lancashire has not had a consultant neurologist for anyone with brain injuries/diseases.

I do feel in Cumbria, because we're very rural, we're at a disadvantage.”

Case study participant



Being held back: What others think

People with disabilities said that other people often do not treat them well.



People told us:

- We feel misunderstood.
- People treat people with learning difficulties as if they are stupid.
- Sometimes they talk to a supporter instead of the person.
- People talk about mental illness and dementia as something bad, to be ashamed of.



Being held back: Communication



Often people don't listen – even health and care staff.



Some people feel cut off due to hearing loss.



People have to explain mental illness.





Living in Cumbria

More than half the people said that Cumbria is a good place for people with a disability to live. There are things that could be better.



We asked people what would improve their life the most



People told us:
Make it easier to get health appointments.



More support for mental health.

More specialist services in Cumbria (e.g. neurology).



Better public transport.



We asked people what would improve their life the most



More public toilets and Changing Places.



More information about services and support groups which can help.



Teach people about people with disabilities.





“Hidden disabilities are just that, hidden so no one notices your needs, or much easier to brush under the carpet than seeing a physical disability.”

Survey respondent



What should happen in the future?

We used what people said to come up with a list of things that would help.



1. Involve people with disabilities.

This is the most important thing people said.

People need to be included whenever people are making decisions.



2. Think about people.

Everyone should think about how we make Cumbria better for people and their families.



3. Make it easier to get around.

Better pavements, steps, wheelchair access, public toilets and Changing Places, parking spaces and driving lessons.



What should happen in the future?



4. Make public transport better.

This means more public transport, better transport on evenings and at weekends, and make bus passes free all day.

Transport needs to be better for wheelchair users, and staff on public transport need to be trained better.



5. Make organisations better.

This means organisations need to make things easier for people to get the help they need.

This includes things like information, forms, appointments and buildings. It also means more help and more services.



What should happen in the future?



6. Change what people think about people with disabilities.

This means we need to tell people about the lives of people with a disability so they understand them and their needs better.

This includes training for health, care and education staff, disability awareness, and workshops for school children.



7. Communicate better.

This means better information for people with disabilities.



More ways to tell disabled people about services and things that can help them.



What should happen in the future?

8. Make sure technology does not get in the way.



This means making sure that people can get information, get help from services and have their say in ways that work for them. This includes using paper, speaking to someone, and getting help to use computers or phones.



9. Other things.

There are lots of other things that can be done to make the lives of people better. This includes more money, better plans, and more opportunities for people.





“What social life? Socialising is exhausting. I have nothing left after work for that by way of energy nor can I leave my son to socialise. Nor can he feasibly join me. I talk to my husband and people online sometimes. Online friends are easier.”

Survey respondent



Contact us

**Healthwatch Cumberland
The People First Conference Centre
Milbourne Street
CA2 5XB**

www.healthwatchcumberland.co.uk

Call us

0300 303 8567

Email us

info@healthwatchcumberland.co.uk

