Disability Voices:
Understanding the lives of disabled people in Cumbria

A summary report for Healthwatch Cumbria

HASKE University of CUMBRIA

Full Report – April 2023

This is a summary report pulled together by Healthwatch Cumbria, from the full report. The full report was produced by Dr Laura Snell, Dr Meghánn Ward and Professor Tom Grimwood at Health and Society Knowledge Exchange (HASKE), University of Cumbria.

Overview:

Between January and March 2023, Healthwatch Cumbria conducted the Disability Voices: Understanding the lives of disabled people in Cumbria project.

This project aimed to capture the voices of disabled people across Cumbria in order to understand their experiences of everyday life, the barriers they encounter, their frustrations or worries, and what changes they feel are needed to improve their lives.

The original idea for this project was instigated by the Health Inequality Group and was based on the Marmot principles/recommendations. The Health Inequalities report, produced by the Health and Wellbeing Board, identified that: 'Further work needs to be undertaken with local organisations who support people with disabilities to gather information on what the local impact has been and develop appropriate actions.'

The data for the Disability Voices project was collected by Healthwatch Cumbria, who engaged with disabled people across Cumbria - these are people who self-describe as 'disabled' under the definition of a disabled person set out by the 2010 Equality Act, which means that they feel that their daily activities are limited significantly due to a mental or physical impairment.

In April 2023, Health and Society Knowledge Exchange (HASKE), at the University of Cumbria, was commissioned by Healthwatch Cumbria to undertake an analysis of the data collected for the Disability Voices project.

Methodology:

The Disability Voices project engaged **758** people across Cumbria, which included disabled people, their carers, and professionals working with disabled people. The data was collected through:

- **54** focus groups and **202** case study interviews, which recruited a total of **596** participants.

- An online survey, which had **155** responses.

- Social media posts about the project, which resulted in **7** people providing comments about their experiences via Facebook.

Findings were split into three sections:

- **Cumberland**

- **Westmorland and Furness**

- **Cumbria-wide**

The Cumbria-wide dataset includes data collected from participant's living in postcode areas that can come under either Cumberland Council or Westmorland and Furness Council, from participants who access services within Cumbria but live outside the county, or data responses that did not contain the participant's postcode.

The summary report focuses on the Cumberland, and Westmorland and Furness findings. However, the Cumbria-wide findings and more in-depth analysis of the other two sections can be found in the full report.

Conclusions:

The findings of the Disability Voices project were analysed and presented in three separate sections: Cumberland, Westmorland and Furness and Cumbria-wide.

The findings across all three datasets reported similar themes and experiences, which have provided a detailed insight into the lives of disabled people, their carers, and people working with disabled people in Cumbria.

The Disability Voices project captured many diverse accounts of 'normal life' for disabled people, and their carers, along with many shared experiences. For example, many disabled people described how their various impairments or health conditions can 'hold them back' - to some extent - when going about their daily lives.

Another commonality across the data was the barriers that disabled people encounter within society, which can restrict their access to health and social care services, education, employment, social activities, and impact on their interactions with other people. Examples of the barriers identified within the research include:

Physical barriers:

inaccessible buildings, high kerbs, uneven pavements, steps, stiles, a lack of lifts or escalators, no wheelchair access, and a lack of accessible public toilets.

Transportation barriers:

inaccessible public transport (buses, trains and taxis), limited bus services in rural areas, and limited parking facilities for disabled people across the county.

Organisational barriers:

inaccessible health or social care systems (e.g. booking GP appointments), long waiting times for medical appointments, lengthy paperwork for claiming financial support (e.g. PIP), and a lack of specialist neurological care within the county which results in disabled people travelling long distances for treatment in other areas.

Attitudinal barriers:

a lack of disability awareness within society, the stigma associated with some conditions (e.g. mental health and neurological conditions), and a lack of understanding about hidden impairments (such as neurodiversity, multiple sclerosis, or dementia).

Communication and information barriers:

a lack of accessible information about impairments/health conditions and the various support that disabled people are entitled to, and communication barriers due to a lack of understanding about neurodiverse conditions.

Technological barriers:

limited access to digital technology or internet services, particularly for elderly disabled people or those living in rural parts of Cumbria.

Conclusions:

The findings show that in the past five years, some disabled people have experienced improvements in their quality of life due to:

a reduction in physical barriers; improvements to impairments or health conditions; increased availability of services and more/adequate support; gaining more independence; increased confidence, and engagement in social activities. However, it must be noted that some disabled people, and their carers, emphasised that any improvements in quality of life were a result of self-advocacy and independent research to find out about services or support available in their local area.

Overall, disabled people indicated that having better access to healthcare services and support across Cumbria, and better social lives, would improve their lives.

In contrast, the findings show that many disabled people felt that their quality of life had declined in the past five years as a result of:

deteriorating impairments or health conditions; ageing; loss of independence; the impact of the Covid pandemic; a reduction in services and support within local communities; the increasing cost of living; and an increase in organisational and technological barriers.

Conclusions:

Experiences of loneliness were often attributed to the barriers identified above and the effects of a disabled person's impairment or health condition, which sometimes impacted on their social life.

A key theme throughout the data was that having access to a good support network (which might include family, friends, neighbours or community members), along with the opportunity to engage in a range of social activities, was a positive experience for many disabled people. In particular, being involved with support groups or activities with other disabled people can provide the opportunity to spend time with those who understand their impairments/health conditions and the disabling barriers they experience in wider society. This shared experience can reduce feelings of isolation or loneliness and provide a sense of belonging for some disabled people.

Disabled people expressed worries or frustrations about the various physical, transportation, organisational, attitudinal, communication and information, and technological barriers detailed above. In addition, concerns were raised about ageing, the possibility of worsening impairments or health conditions, loss of independence, the impact of the cost-of-living crisis, and the uncertainty of accessing support in the future.

It is relevant to note there is significant overlap in many of the themes presented in this research as each theme impacted on several aspects of a disabled person's life. As an example, the physical barriers associated with accessing public transport can exclude a disabled person from carrying out their daily activities, which can limit their independence, cause feelings of frustration and isolation, and impact negatively on their quality of life.

This research has shown that there is still work to be done across Cumbria to create a society which is fully inclusive for disabled people. In particular, the research participants suggested that the lives of disabled people could be improved through raising more awareness of their impairments and health conditions; improving access to information about the various support and services available within local communities; and tackling the physical, transportation, organisational, attitudinal, communication and information, and technological barriers that exist within society.

Cumberland Summary

The findings in this section present the voices and experiences of the 489 research participants living in Cumberland. This dataset included 114 case studies, 26 focus groups, 100 survey responses, and 2 Facebook comments.

Selection of Quotes:

"I always have to think about my [long term health] condition and how it will impact, 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)

"Transport around Cumbria has always been an issue as 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)

"...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've very rural, we're at a disadvantage."

(Case study participant)

Selection of Quotes:

"...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)

"I originally lived 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)

The research participants suggested that the following changes would improve the lives of disabled people in Cumberland:

- More disability awareness is needed, including more understanding of both visible and hidden impairments and health conditions.

- Organisational barriers can be addressed by improving access to healthcare appointments, providing more support for mental health services, more specialised services within the county (e.g. neurology services), and providing more support with claiming financial assistance (e.g. PIP application forms).

- The physical barriers that exclude disabled people from society need to be addressed, such as improving access to public transport and providing more public toilets across Cumberland.

- More information needs to be provided about healthcare services and support groups for disabled people and their carers, particularly at an early stage of diagnosis.

- The various social activities, support groups and services that are available in local communities across Cumberland need to be widely publicised to raise more awareness amongst disabled people and their carers.

Westmorland and Furness summary

The findings in this section present the voices and experiences of the **147** research participants living in Westmorland and Furness. This dataset included **53** case studies, **16** focus groups, **28** survey responses, and **1** Facebook comment.

Selection of Quotes:

❝Exhaustion is constant and made worse by the poor infrastructure in the locality. Constantly having to work out what I have to do to work around poor pavements, thresholds and limited building access, parking for wheelchair users is adding to the burden of mobility solutions. Public transport is simply not accessible.❞

(Survey respondent)

❝Longer GP appointments [needed] for people with long term complex problems and ideally being seen by the same GP more consistently....❞

(Survey respondent)

❝...I have to travel 3 hours for the bulk of my treatment. That costs a lot of time and money.❞

(Case study participant)

Selection of Quotes:

"There is too much expectancy for the people to be cared for by family who have a disability which puts a strain on family members who need to work full-time due to the cost of living going up."

(Case study participant)

"I am frustrated over losing independence. Independence is so valuable; I hate feeling dependent on anyone. When it's forced on you, it's so dispiriting."

(Case study participant)

The research participants suggested that the following changes would improve the lives of disabled people in Westmorland and Furness:

- Physical barriers need to be addressed, particularly in areas such as Barrow.

- Transportation barriers need to be addressed, particularly in rural areas where services can be limited.

- Organisational barriers need to be acknowledged, such as the challenges encountered when seeking support from local GP services.

- More disability awareness training should be provided to all sectors across the region.

- More training should be provided for teachers in schools about disability awareness, specifically neurodiversity.

- More information should be provided to raise awareness of the various services, support groups and activities available for disabled people in Westmorland and Furness; this information should be publicised widely and made available in different formats (not just online).

Recommendations:

Based on the findings presented in this report, the following two principal can be made:

1. Ensure that disabled people are part of and have a voice within the decision-making process at both strategic and operational level in the health and social care system.

2. Everyone should continually self-reflect and question why disabled people are facing so many barriers and what can be done to make an inclusive society, as it is evident that all organisations and members of society could be doing more to support those living with a disability in Cumbria.

Furthermore, the report highlighted the barriers that disabled people encounter within society, which can restrict their access to health and social care services, education, employment, social activities, and their interactions with other people.

Therefore, the recommendations have been focused on reducing these barriers (and apply to both Cumberland and Westmorland and Furness):

3. Reduce physical barriers:

a) For any new infrastructure developments, local authorities, developers and organisations should establish a steering group of people with lived experience to ensure people are involved in the process and able to provide feedback on the physical accessibility of the proposed plans1.

b) Organisations should undertake regular audits focused on physical accessibility of all spaces and buildings which they are responsible for to identify improvements that need to be made (this is particularly important with historical buildings and areas).

c) Organisations should actively invest and address issues with inaccessible buildings and spaces (such as, high kerbs, uneven pavements, steps, stiles, a lack of lifts or escalators, no wheelchair access).

d) Increase the availability of accessible public toilets across the county. This includes opening times and accessibility of access.

e) Increase the number of Changing Places2 available as there needs to be enough room to accommodate for those people who require support from their carer when using these spaces.

4. Reduce transportation barriers:

a) Local authorities to complete a gap analysis to identify where there are specific gaps with the public transport (buses, trains and taxis) offer, especially in rural areas.

b) Expand the timetable of transport schemes, such as Rural Wheels, so that they are also available to people in the evenings and weekends.

c) Free all-hours public transport passes, such as bus passes, for those with a disability.

d) Ensure all public transport vehicles are accessible for wheelchair users and those running the service have the appropriate training.

e) Increase the number of parking facilities for disabled people across the county.

f) Work with driving schools to have a scheme where disabled people (or their parents and carers) can sign up to receive a letter on their 17th birthday from their local driving school which shares their disability support offer and what grants are available.

5. Reduce organisational barriers:

a) Address issues with accessing to healthcare appointments, such as difficulty with booking appointments, reducing waiting times for appointments and assistive equipment, and providing more support for mental health services.

b) Reduce the amount of paperwork required to claim financial assistance (such as, PIP application forms).

c) Provide a range of support with official paperwork (such as, PIP application forms), for example, talking it through over the phone, arranging for drop-in support sessions, or the creation of easy-read myth busters/cheat sheets

and step-by-step guides that would take someone through the process.

d) Have medical, employment and benefit forms in easy read (reduce acronyms and 'jargon' language), also consideration to be given to what fonts, text size and colours that are used.

e) Employers to provide necessary support to those with disabilities when completing job applications.

f) Increase specialist care available in the local area, or NHS to provide better practical support to those who have to travel long distance for treatment in other areas.

6. Reduce attitudinal barriers:

a) A large campaign around raising disability awareness and reducing the attached stigma, including more understanding of both visible and hidden impairments and health conditions, as well as highlighting the disabling barriers that are created within society. This is particularly relevant for hidden impairments (such as neurodiverse conditions like autism, sensory impairment like deafness and invisible pain conditions like fibromyalgia). It should be done via a variety of formats, including TV adverts, billboards, posters and social media.

b) All organisations (including, health professionals and teachers) to provide staff disability awareness training, which is at least partly (if not fully) delivered by someone with lived experience.

c) Schools to do workshops with their students focusing on raising disability awareness and reducing the attached stigma. Looking into the challenges people living with a wide range of disabilities face and what they can do to help make society more inclusive.

7. Reduce communication and information barriers:

a) Use a wider range of communication methods to share information, such as but not limited to, TV adverts, billboards, radio, posters, word-of-mouth, apps, social media, leaflets.

b) Improve access to information about and better promote the 'rights' a disabled person has.

c) Create a 'one-stop shop' resource that is widely advertised and promoted, that is regularly updated and provides information and advice about accessing healthcare, social care, and financial support, and signposts people to a range of local support groups, in a variety of accessible formats.

d) Voluntary, Community, Faith and Social Enterprise organisations should explore effective mechanisms for sharing information and raising awareness of the range of services and support groups (including specific impairment groups and inclusive activities for both disabled children and adults) that already exist within local communities throughout Cumbria, to enable them to signpost better.

e) More information/signposting by health and social care professionals, especially at the early stages of diagnosis/treatment.

f) Documents should be made available in an easy-read format which takes into consideration colours, text size and fonts.

g) Creation of a map which shows where accessible parking, toilets and changing facilities are throughout Cumbria.

h) A series of campaigns to share information and promote key support services on a wide scale, such as benefit support and access to work schemes. This could be in the form of easy read fact sheets (in both digital and physical formats).

i) Healthwatch to widely share the report and outcomes of the Disability Voices project (in various, accessible formats) with disabled and non-disabled people throughout Cumbria.

8. Reduce technological barriers:

a) Always offer a non-digital alternative, such as letter, leaflet, or a paper form.

b) Complete a 'digitally excluded' gap analysis to identify which areas in Cumbria would benefit the most from support, funding and training.

c) Better advertise and promote 'how to use technology' classes, support drop-ins and digital libraries.

d) Organisations to give equipment they no longer need to those living with disabilities free of charge (providing second-hand equipment).

9. Other suggestions to reduce barriers faced by people living with a disability:

a) Increase financial support for those living with a disability in relation to the 'cost-of-living' crisis.

b) Provide more support with 'planning ahead', especially with long-term care plans. This includes the transition points those living with a disability face at 18, 21 and 25 in relation to medical services, as well as those who may need to consider the possibility of their carers passing away.

c) Increase the support made available to unpaid carers, including respite, as well as both financial and practical support.

d) A wider variety of activities (daytime and evening) made available where people living with disabilities can learn a range of skills, including key life-skills, to give them a sense of purpose and feeling valued as well as being a potential source of social interaction.

e) Support those living with a disability to be able to volunteer, providing funding to organisations who have volunteers to help with any additional support/equipment that needs to be in place.

f) Supermarkets and shopping centres, offer magnifying glasses (to help those who are visually impaired) and sensory packs at customer service desks.

Finally, it is recommended that the following questions could be used by organisations and service providers to help review their current service, improve accessibility, and identify some of the barriers experienced by disabled people across Cumbria:

How can you increase disability awareness within your organisation/service, and improve understanding of both visible and hidden impairments and health conditions?

How do you raise awareness of your services to disabled people, and their carers? Think about the formats used (e.g. online resources, or paper-based materials such as leaflets/posters), the language (e.g. jargon or plain English), and how do you disseminate the information within local communities.

Can you identify any organisational barriers when accessing your service? (E.g. think about the process for booking appointments, times of appointments, or completing paperwork in order to access services or support).

Does your organisation/service provide information in different formats (e.g. in paper format as well as online) and in accessible, plain English?

Can you identify any physical access barriers when using your organisation or service and how can you remove or reduce these? (E.g. think about the physical environment such as raised kerbs, uneven pavements, stairs, no access to lifts or ramps, no wheelchair access to buildings).

How do you ensure people know they have a right to reasonable adjustments and these are being made?

How can you provide more accessible public toilets including facilities with hoists?

Can you identify any transportation barriers for people? (E.g. limited bus service in rural areas, inaccessible public transport, availability of disabled parking spaces).

To what extent would any of the above benefit from joint working with other organisations, employers or authorities? What would need to happen for this joint working to happen?

Suggestions for further research

The Disability Voices project has captured the experiences of many disabled people, as well as those working with and caring for people living with a disability, across Cumbria. This lays the foundation for more detailed and granular research with specific sampling and participants.

Based on the findings of this report, it is recommended that further research could explore the following topics:

- The experiences of disabled people with 'hidden' impairments and health conditions.

- The impact of the cost-of-living crisis on disabled people's lives.

- The physical and transportation barriers experienced by disabled people across the county.

- Disabled people's experiences with technology.

- Disabled people's experiences of accessing health services throughout Cumbria.

- Disabled people's access to, and experience of, education and/ or training across Cumbria.

- Disabled people's experiences of employment across Cumbria.

- The role and experiences of carers for disabled people.

- The benefits of engaging in social activities and groups alongside other disabled people.

Healthwatch Next Steps

As a result of Cumbria undertaking a Local Government Reorganisation, from the 1st April 2023, Healthwatch Cumbria became Healthwatch Cumberland and Healthwatch Westmorland and Furness, commissioned by the two new local authorities.

But both of these Healthwatch are committed to continuing this Disability Voices work that was started together, to keep raising the voice of those living with a disability in Cumbria.

This includes, doing the following next steps:

- **Share the Disability Voices Report**

  Healthwatch will share the report and outcomes of the Disability Voices project widely (in various, accessible formats) with both disabled and non-disabled people throughout Cumbria. This will ensure that disabled people's voices are heard within the wider community, and will also provide disabled people, and their carers, with an opportunity to learn about the value of shared experiences and the various groups/activities currently available.

Healthwatch will also share the report with the following:

- North East and North Cumbria Integrated Care Board and appropriate committees

- North East and North Cumbria Integrated Care Partnership

- Lancashire and South Cumbria Integrated Care Board and appropriate committees

- Lancashire and South Cumbria Integrated Care Partnership

- Cumberland Health and Wellbeing Board and appropriate committees

- Westmorland and Furness Health and Wellbeing Board and appropriate committees

- **Disability Voices further research**

  Healthwatch will conduct more focused project work to further

explore the experiences of people living with a disability in Cumbria. Healthwatch Cumberland will start by investigating the impact of technology, while Healthwatch Westmorland and Furness will look into the accessibility of health services, both through the lens of disability.

In addition, as the Disability Voices project captured lots of rich data about the lives of disabled people across Cumbria, the original dataset could be reanalysed with a specific focus on cross-cutting issues for certain groups of disabled people (e.g. people with physical impairments, mental health conditions, neurodiversity, sensory impairment, or learning difficulties). This is a piece of work that Healthwatch Cumberland and Healthwatch Westmorland and Furness will complete in their respective areas.

- **Disability Voices Collaborative**

  To make wide and significant positive change, organisations and individuals need to work together. Healthwatch will work with local voluntary, community, faith and social enterprise organisations and support groups who are active within the health and social care sector, to explore ways in which we could all work together to champion the voice of disabled people. This could be a space to drive change, share good practice, discuss progress and developments, create solutions and address any new issues as a collaborative.

  Healthwatch will begin by facilitating a series of online workshops to bring organisations and groups together, to discuss next steps, involvement and communication. The organisations and groups who have been involved in the Disability Voices project will be invited to the collaboration, as well as individuals with lived experience.

Contact Healthwatch at info@healthwatchcumberland.co.uk or info@healthwatchwestfurn.co.uk to get involved.