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Disability Voices: Understanding the lives of disabled people in Cumbria

A report for Healthwatch Cumbria

Health and Society Knowledge Exchange
(HASKE)

April 2023

This report was produced by Dr Laura Snell, Dr Meghán Ward and Professor Tom Grimwood at Health and Society Knowledge Exchange (HASKE), University of Cumbria.

Executive summary

Context:

Between January and March 2023, Healthwatch Cumbria conducted the *Disability Voices: Understanding the lives of disabled people in Cumbria* project. The 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. 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 seven people providing comments about their experiences via Facebook.

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.
- 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.
 - 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.

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

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:

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

¹ For example, the new University of Cumbria campus at the Citadels, Carlisle and the redeveloped Carlisle Train Station, are two projects that need to be accessible to people of all disabilities.

² [Changing Places Toilets \(changing-places.org\)](http://changing-places.org)

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.

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1. Introduction

1.1 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.

1.2 Data collection

Healthwatch Cumbria conducted the Disability Voices project over a three-month period, from January to March 2023. In total, the 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 Disability Voices project, which resulted in 7 people providing comments about their experiences via Facebook.

The survey questions and focus group/case study questions were designed by Healthwatch Cumbria and were framed around six main topics: 'normal' day, barriers, quality of life, frustrations and worries, loneliness, and change.

1.3 Data analysis

The quantitative data collected through the online survey and demographic questions was analysed descriptively. As some of the focus group, case study and survey questions did not have a full response rate, the quantitative findings presented in this report are based on the actual number of responses.

In addition, a thematic analysis of the qualitative data was conducted using a template approach. The first stage of this involved open coding of the data for emerging themes. These were then aligned to the six broader headings used by Healthwatch Cumbria during data collection. For each of these headings, themes were organised into one of three categories: enabler, barrier or outcome. Enablers referred to those themes that enhanced a disabled person's life. Barriers referred to themes that were reported as having a negative impact on a disabled person's experience. Outcomes were the intended or unintended effects of the enablers and barriers. This template was used to enable the identification of potential connections across the three categories and highlight the key findings across the whole dataset.

HASKE's approach to data analysis was informed by the Social Model of Disability, which proposes that people with impairments and/or health conditions are disabled by the barriers in society that exclude or discriminate against them.³

³ <https://www.disabilityrightsuk.org/social-model-disability-language>

2. Findings 1: Demographic data for the Disability Voices project

This section of the report will present the demographic data for the Disability Voices project. As noted in section 1.3, some of the focus group, case study and survey questions did not have a full response rate and therefore, the findings presented in this chapter are based on the actual number of responses.

2.1 Data collection methods and locations for the Disability Voices project

The Disability Voices project data was collected from across Cumbria and involved 751 participants in a total of 54 focus groups, 202 case studies and 155 surveys. Figure 1 shows that most of the data collection engaged people living in postcode areas that are covered by the unitary authority area of Cumberland:

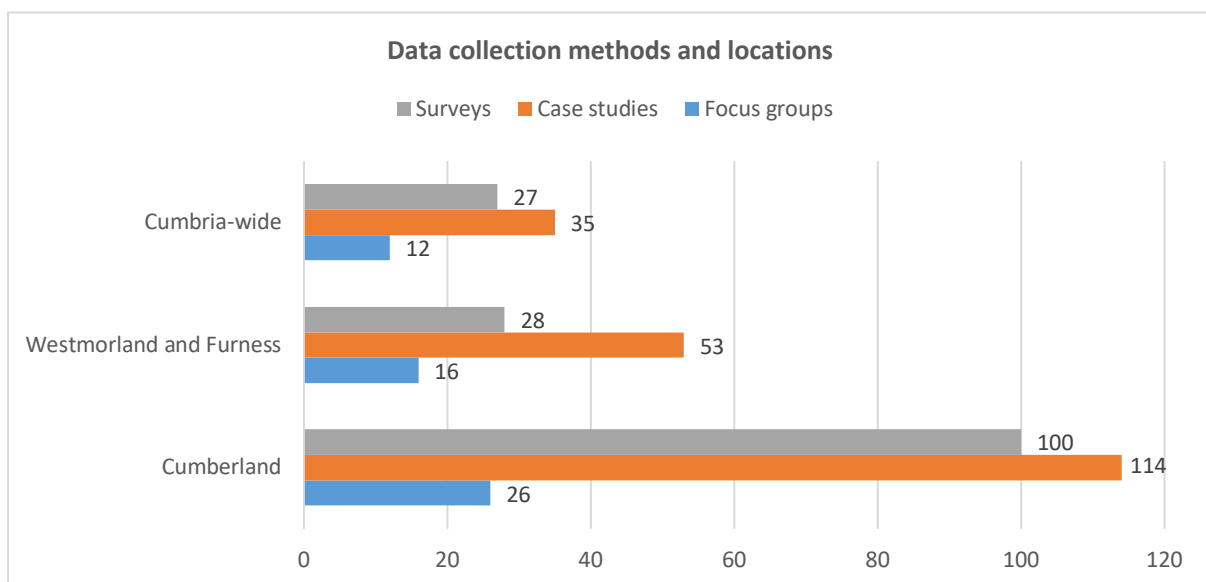


Figure 1: Summary of data collection methods and locations

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 (for example, participants living in postcode areas starting with CA4, CA7, CA12 or LA20). In addition, data collected from participants who access services within Cumbria but live outside the county, or data responses that did not contain the participant's postcode, have been analysed as part of the Cumbria-wide dataset.

2.2 Total number of participants involved in the Disability Voices project

Figure 2 shows the total number of participants recruited for the focus groups (n = 381), case studies (n = 215) and surveys (n = 155) across each data collection area. In addition, Healthwatch Cumbria posted the Disability Voices project on their Facebook page, which resulted in seven individuals providing comments about their experiences across Cumbria. As the comments were posted on Facebook, it was not possible to collect demographic information or specific details about their experiences; three of the comments mentioned the area where the individual lived and have been analysed with the relevant dataset, and the remaining four Facebook comments have been analysed as part of the Cumbria-wide dataset. In total, the Disability Voices project engaged with 758 people across Cumbria.

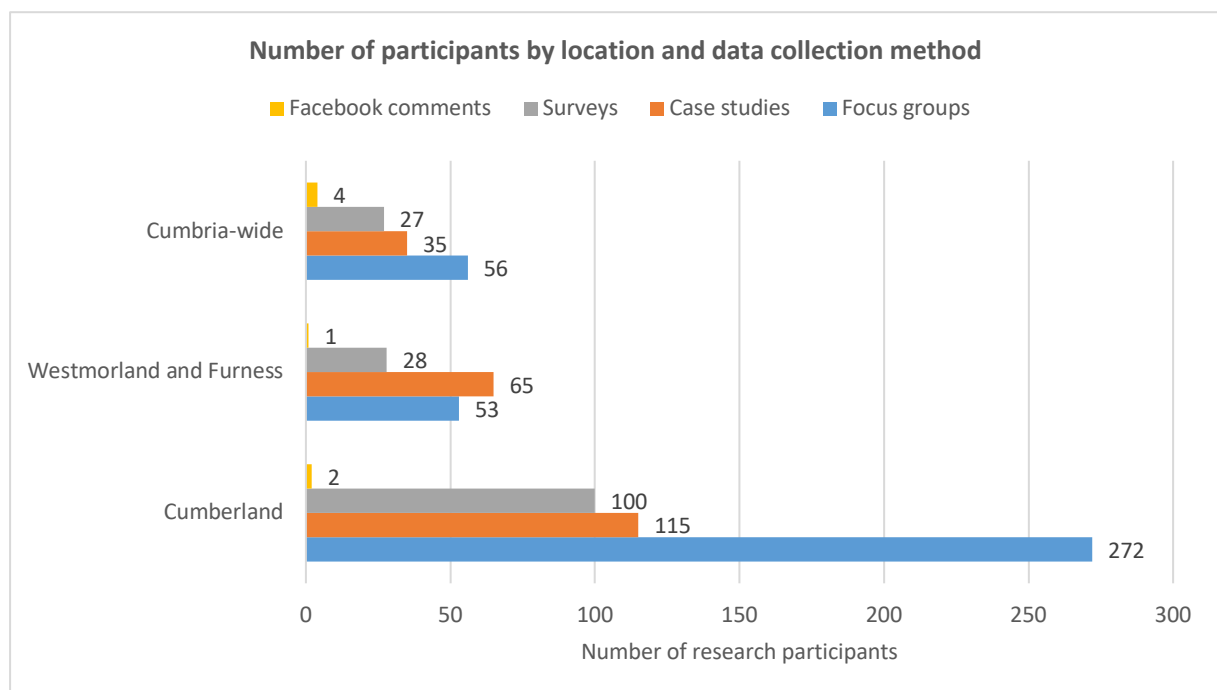


Figure 2: Number of research participants by data collection method and area

2.3 Focus group and case study participants

The data presented in this section relates to the 596 participants who were involved in the focus groups and case studies.

2.3.1 Age of participants

As shown in Figure 3, 21% of the focus group and case study participants were aged 65 and over (n = 114), 18% were in the age range 35 – 44 (n = 102), 17% were aged 18 – 24 (n = 95), 15% were aged 45 – 54 (n = 81), 15% were aged 55 – 64 (n = 81), and 14% were aged 25 – 34 (n = 76). Less than 1% of participants were under 18 years old or preferred not to include their age.

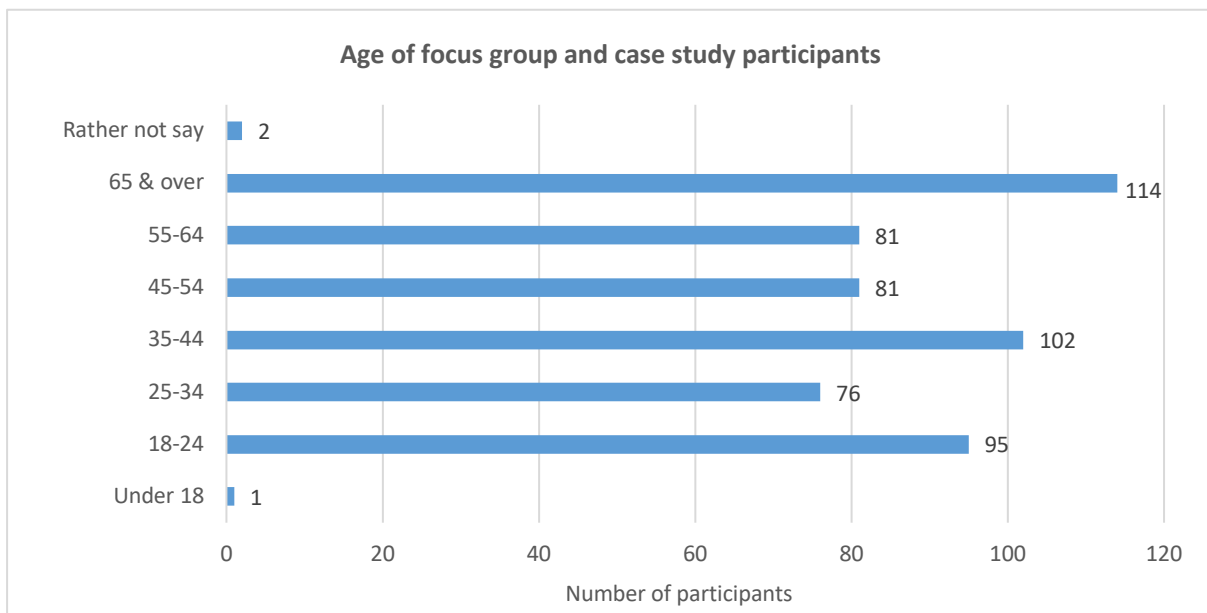


Figure 3: Age range of focus group and case study participants

2.3.2 Gender of participants

53% of the focus group and case study participants identified as female (n= 262), 47% as male (n = 234), and less than 1% identified as non-binary (n = 2), as depicted in Figure 4:

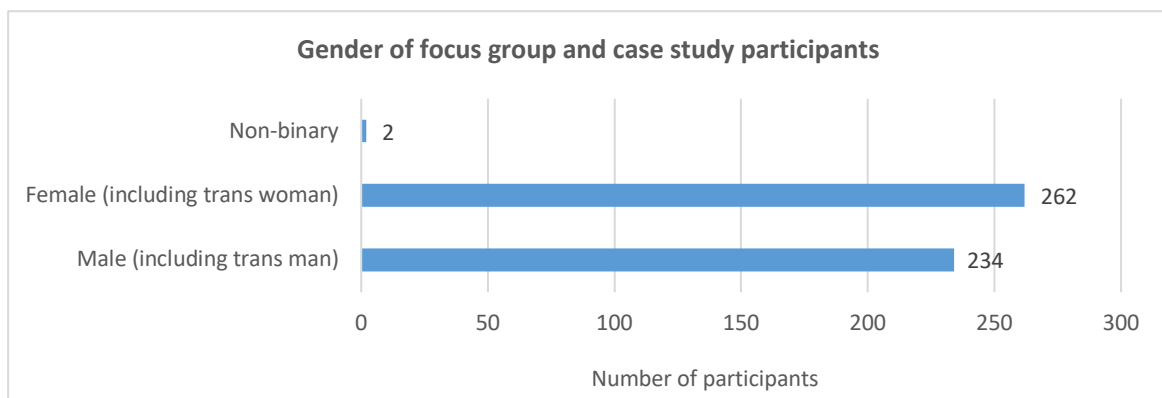


Figure 4: Gender of focus group and case study participants

2.3.3 Ethnicity of participants

96% of the focus group and case study participants identified as 'White British' (n = 522):

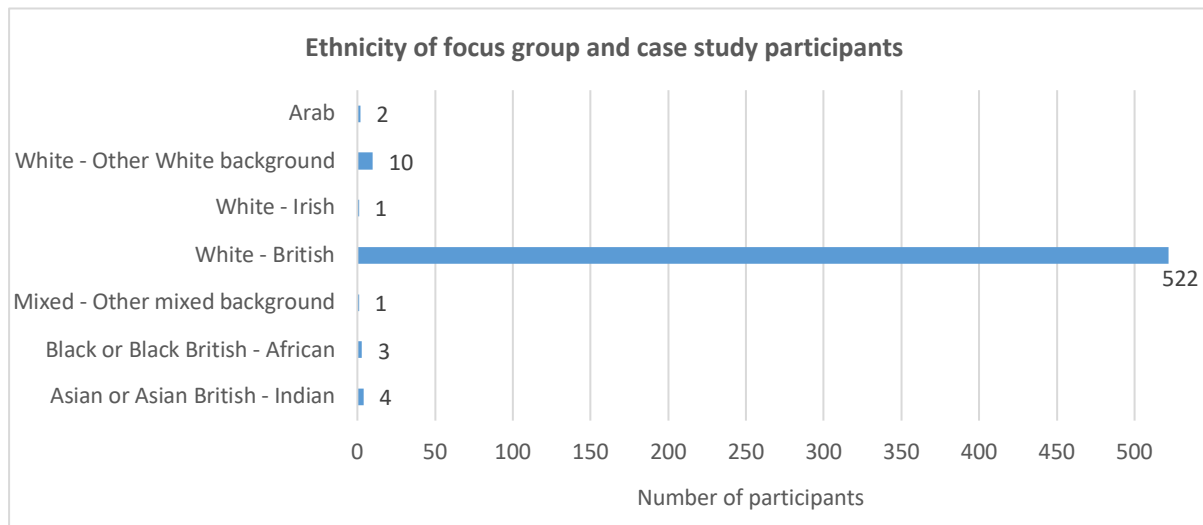


Figure 5: Ethnicity of focus group and case study participants

2.3.4 Employment status of participants

As shown in Figure 6, 23% of the participants were retired (n= 116), 22% were unable to work due to disability (n=114), 20% were in full time employment (n = 106), and 12% were in full time education (n = 63). Reasons for selecting 'other' included being a volunteer or being in part-time education.

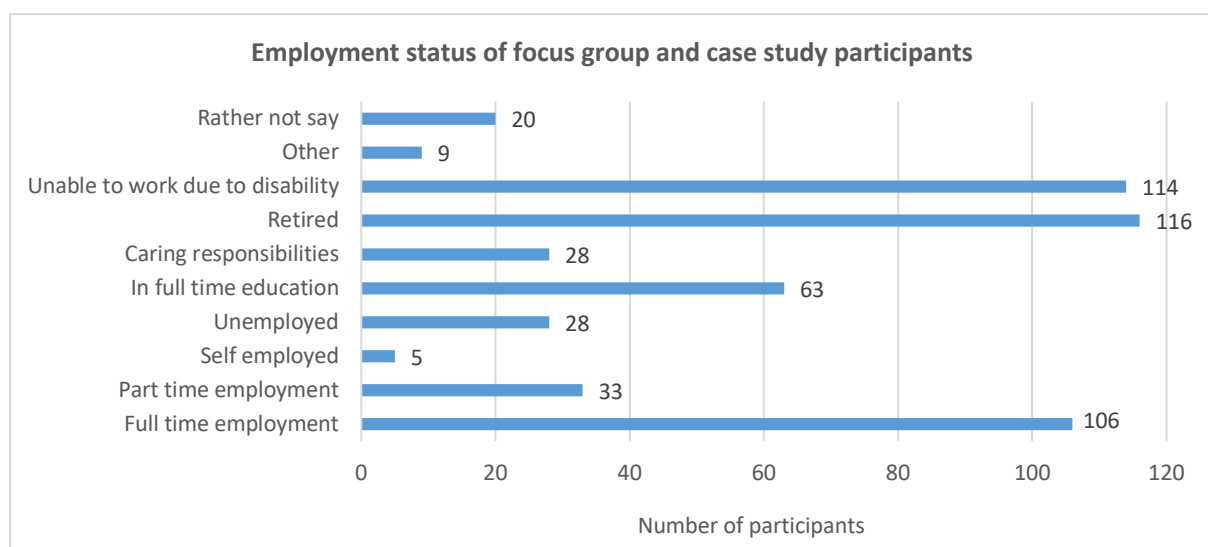


Figure 6: Employment status of focus group and case study participants

2.3.5 Disability status of participants

72% of the focus group and case study participants (n = 430) indicated that they had an impairment or health condition, and 38% were officially registered as ‘disabled’ (n = 162).

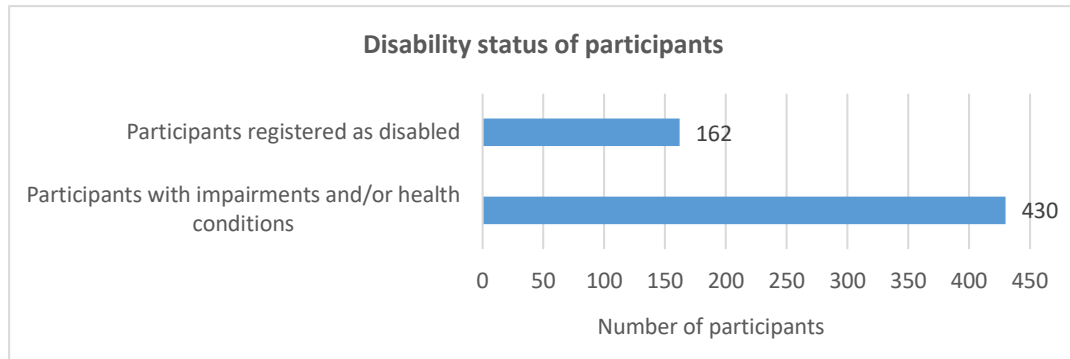


Figure 7: Disability status of focus group and case study participants

Figure 8 provides details about the focus group and case study participants’ impairments and health conditions:

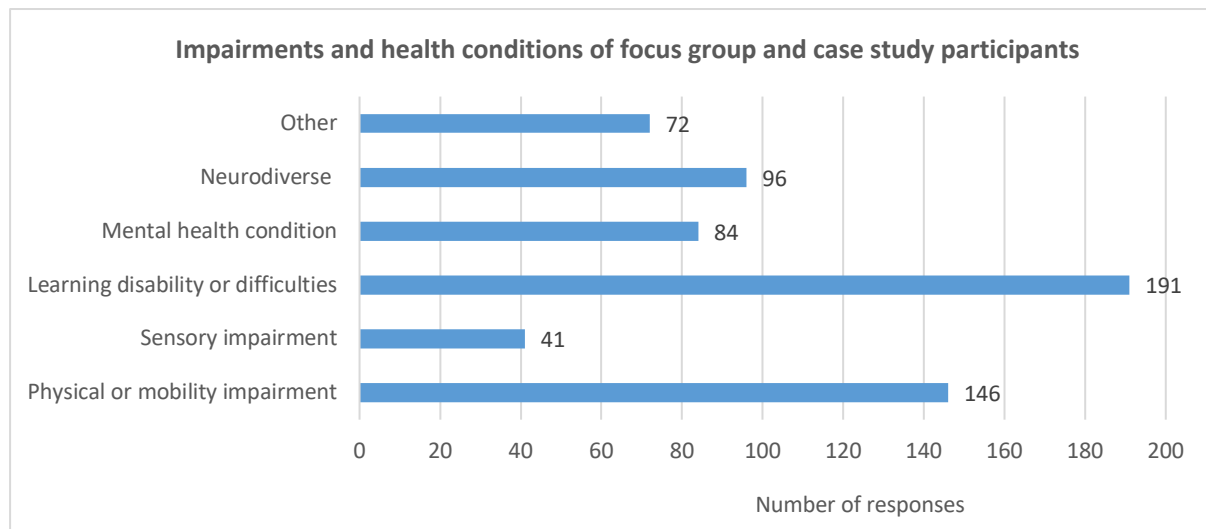


Figure 8: Impairments and health conditions of focus group and case study participants

Examples of ‘other’ impairments and health conditions included: type 2 diabetes, heart condition, cancer (e.g. breast, prostate, bone, blood), high blood pressure, brain tumour, fibromyalgia, scoliosis, stroke survivor, rheumatoid arthritis, pancreatitis, liver disease, epilepsy, asthma, and long Covid.

2.3.6 Carers and professionals working with disabled people

Out of the total number of focus group and case study participants, 21% were carers for disabled people (n=125) and 15% worked with disabled people (n= 91).

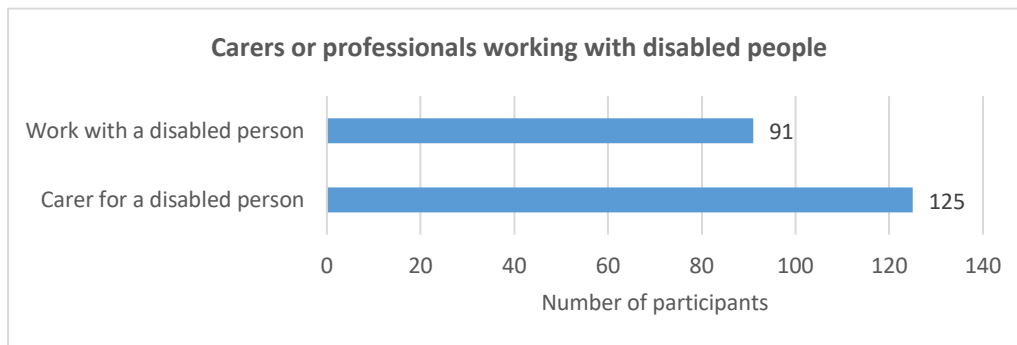


Figure 9: Focus group/case study participants who are carers or work with disabled people

2.4 Survey participants

This section contains the demographics for the 155 respondents who completed the online survey. The survey response rate was lower than anticipated for this project, which is an ongoing trend in health and social care research. Due to the low response rate, the survey responses presented in this report are not intended to be representative of all disabled people across Cumbria; however, many of the survey findings align with the focus group/case study data and provide a detailed insight into the lives and experiences of disabled people across the county.

2.4.1 Age of survey respondents

The data shows that most of the survey respondents were over 35 years old: 28% of the respondents were aged 35 – 44 years (n = 43), 26% were aged 45 – 54 years (n = 39), 19% were aged 55 – 64 (n = 28) and 9% were 65 and over (n = 14).

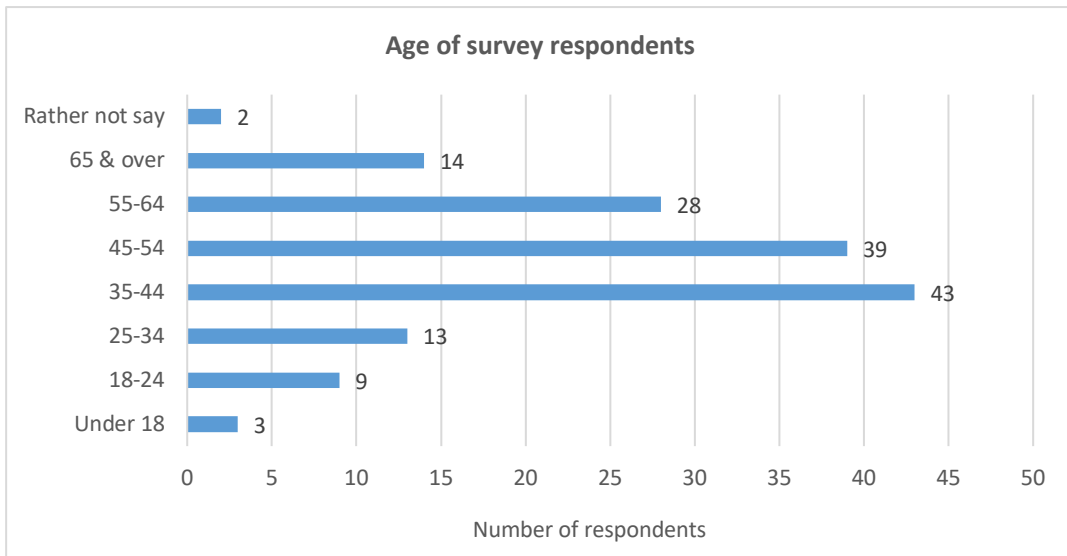


Figure 10: Age range of survey respondents

2.4.2 Gender of respondents

As shown in Figure 12, 83% of the survey respondents were female (n = 125), 15% were male (n = 23) and 2% indicated that they preferred not to disclose their gender (n = 3).

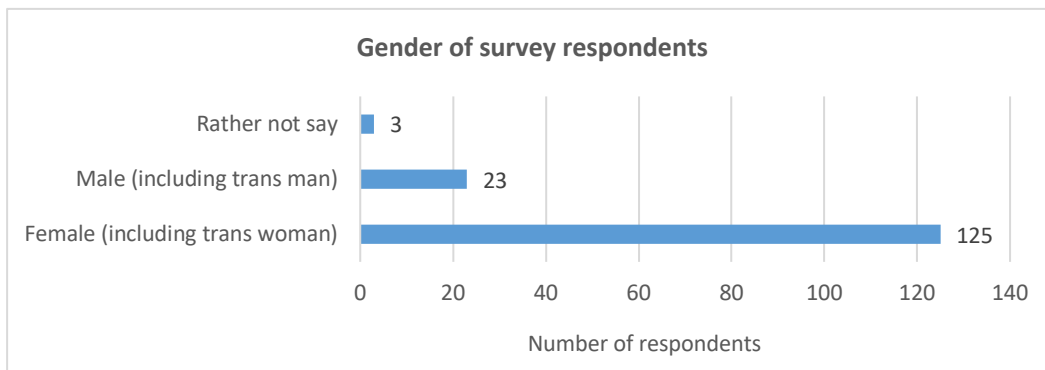


Figure 11: Gender of survey respondents

2.4.3 Ethnicity of respondents

Figure 13 shows that most of the survey respondents were 'White – British' (n = 135):

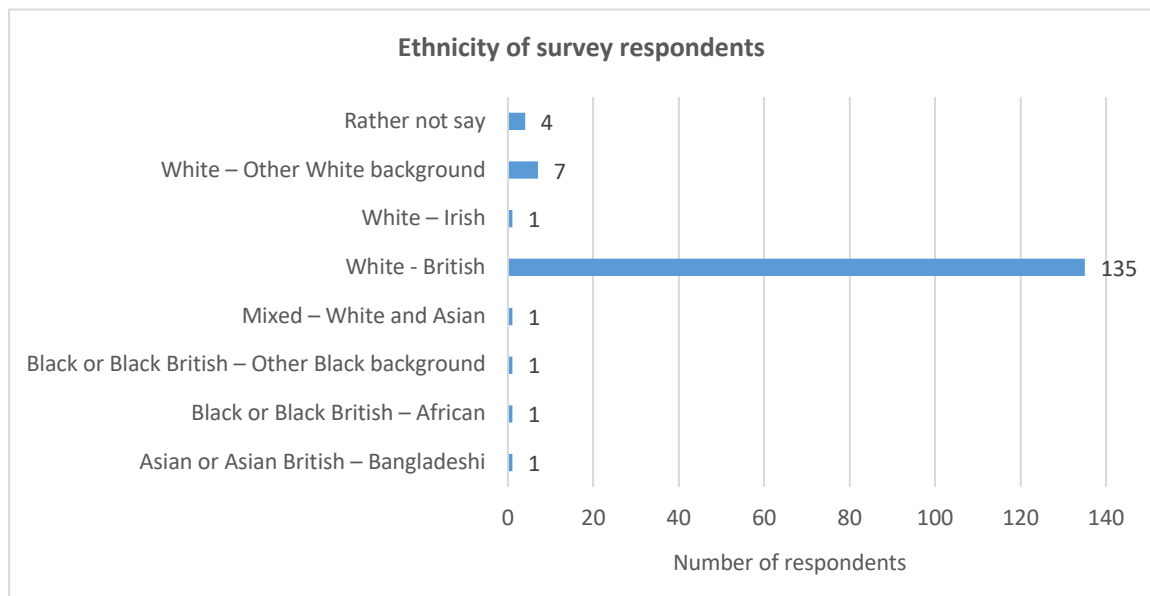


Figure 12: Ethnicity of survey respondents

2.4.4 Employment status of respondents

30% of the survey respondents were in full-time employment (n = 45), 26% were in part-time employment (n = 38), and 12% were unable to work due to their impairments or health conditions (n = 18).

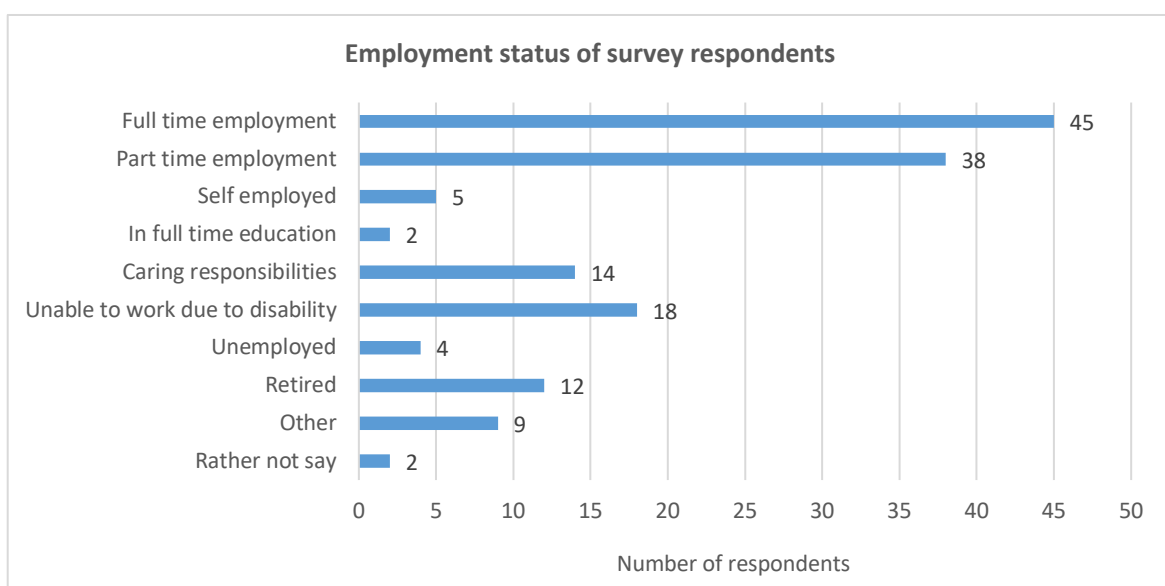


Figure 13: Employment status of survey respondents

Reasons for selecting ‘other’ included: being in part-time education or both full-time employment and full-time education, being on long term sick, being a stay-at-home parent, a day service user or a volunteer.

2.4.5 Disability status of survey respondents

Figure 16 shows that 61% of the total number of survey respondents identified themselves as someone with an impairment or health condition (n = 95). 92% of those who had impairments or health conditions indicated that they had a formal diagnosis (n = 87).

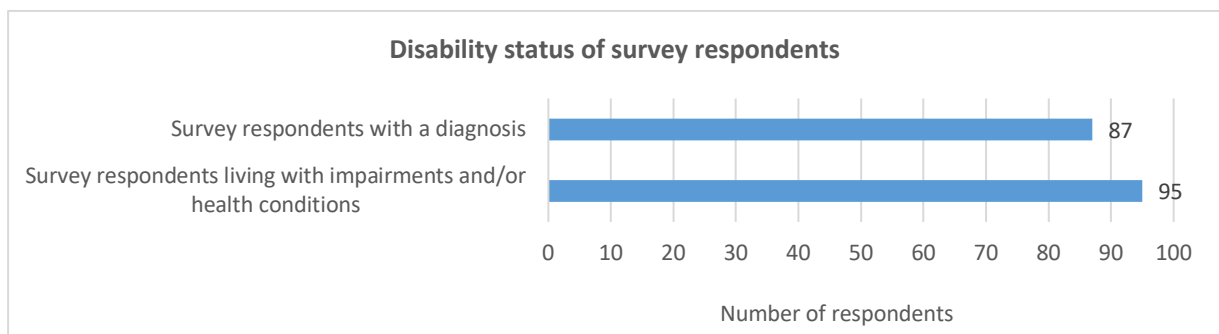


Figure 14: Disability status of survey respondents

Figure 17 provides details about the survey respondents’ impairments and health conditions:

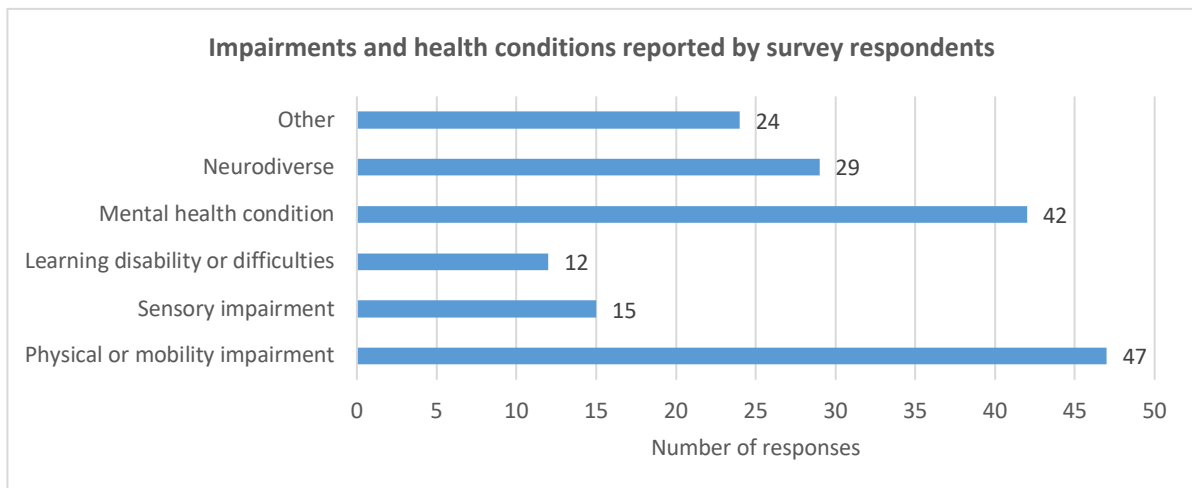


Figure 15: Survey respondents’ impairments and health conditions

Examples of ‘other’ impairments and health conditions included: brain injury, bipolar disorder, personality disorder, neurodivergent burnout, autoimmune conditions, dilated cardiomyopathy, peripheral neuropathy, fibromyalgia, osteoarthritis, nerve damage, myalgic encephalomyelitis

(ME/chronic fatigue syndrome), migraines, fatigue, Ménière’s disease, perimenopause, long Covid, pelvic inflammatory disease, and gastric issues.

2.4.6 Carers and professionals working with disabled people

Out of the total number of survey respondents, 48% were carers for disabled people (n=74) and 25% worked with disabled people (n= 39):

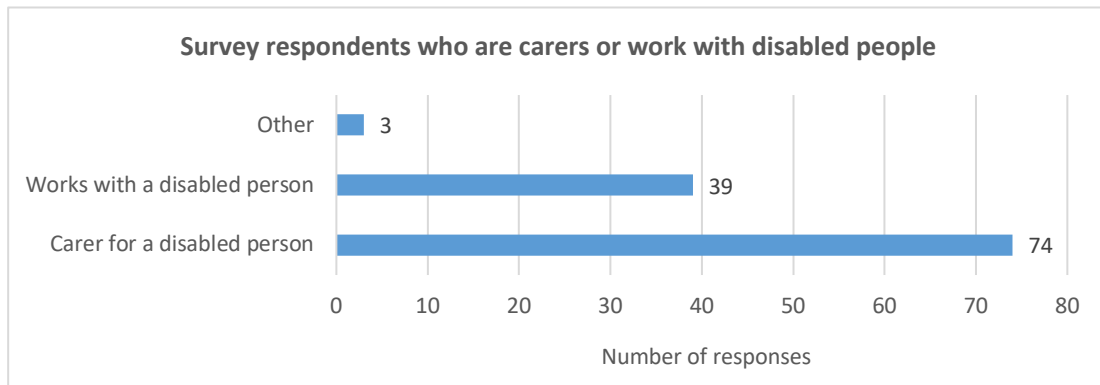


Figure 16: Survey respondents who are carers or professionals working with disabled people

3. Findings 2: Cumberland

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 two Facebook comments (as detailed in section 2 of this report).

3.1 'Normal life' for disabled people in Cumberland

The comments presented below provide an example of the wide variety of 'normal lives' described by the research participants across Cumberland:

'I don't have a 'normal' morning, I have to go with what my body is telling me, sometimes I feel ok sometimes I don't. On a good day I will get showered, dressed then have breakfast. I take medication twice a day. I don't get any support apart from my GP, my cardiologist, good friends and 1 local family member.' (Survey respondent)

'I have carers that support me getting up and ready for work and also throughout the day within work for toilet, transfers, lunch and within work.' (Survey respondent)

'Activity is dependent on my ability that day, sadly I can't predict a flare or pain.' (Survey respondent)

'I don't sleep well so seldom feel refreshed when I get up. My arms and legs are invariably stiff, so I take painkilling medication (mainly for nerve pain) with breakfast and leave in the car to start work at 9am. I have to allow more time to do things, particularly anything involving physical exertion. I am currently living with my partner, and we enjoy preparing meals together in the evening. Despite many limitations, I feel that I am living the best life I can under the circumstances.' (Case study participant)

'I get picked up by taxi for college. I am at college, where I have support. I get the taxi home again. At home I watch TV, play on the play station or kindle. My parents ask me to help with chores and assist me to do them. No medication.' (Survey respondent)

'I had a stroke in 2015. It gives me a physical weakness on my left side, it affects my arm and my leg. It was life changing. A typical day for me is working on my rehab. As well as physical activities, it's household tasks. I go to the gym as well and I do lots of exercise classes on Zoom.' (Case study participant)

'I clean, cook, go for a local walk, some light gardening in the summer. I do word games, I write poetry, read, listen to the radio, use social media as I am in a national support group for my illness and for the vulnerable so chat to folks on there...' (Survey respondent)

'I work until between 5 and 5:30. I like it, it keeps my mind busy, and the people are nice - though they don't know about my disability, and I mask it as best as I can so that I don't get treated any differently (though sometimes wonder if it would be easier if they knew).' (Survey respondent)

'I work full time and have a hidden disability. What would make my evening different to someone without such a condition is after work I have to arrange doc appointments, blood tests, hospital tests, picking up pills, change dressings, additional clothes/bedding washing, sometimes multiple showers, frequent toilet trips to check on stoma. All this with extreme fatigue brought on by my condition. I could be more open and share my condition with others and perhaps get some leniency, but it is personal and embarrassing so only my closest friends/family and colleagues know. Going out is a nightmare, I have to be careful where I eat, that there are toilet facilities near, public transport is poor, and I get fatigued...all this means I don't go out in the evening.' (Survey respondent)

Some of the participants described their typical day in their role as carers for disabled people:

'It can vary. The day can consist of domestic tasks, personal care, going out and doing activities and supporting in the community. The day can range from singing with someone when they are happy, reassuring them if they are having a bad day, or using strategies to manage behaviour that challenges. There are no normal days, as no two are the same.' (Survey respondent)

'My wife is an MS sufferer and I'm her carer... Following her diagnosis, I gave up work, there was a deterioration in her condition, and we weren't sure how it

was going to go, thankfully she's okay now. Getting her up the stairs and stuff has impacted on my health. The impact on our lifestyle has been seismic.' (Case study participant)

'Much the same as any other parent with a ten-year-old child. The main difference for us is that we have to monitor our son's blood glucose levels 24 hours a day, seven days a week. This often means sleepless nights and sometimes disrupted plans. Our son is autistic and feels settled and comfortable when things are predictable and "in order", so we try to keep to a routine as much as possible. Having these disabilities just means we have to plan ahead for everything and be prepared for any eventuality when leaving the house.'

(Survey respondent)

As shown in Figure 17, all disabled survey respondents from Cumberland indicated that their impairments and health conditions hold them back, to some extent, when going about their daily lives:

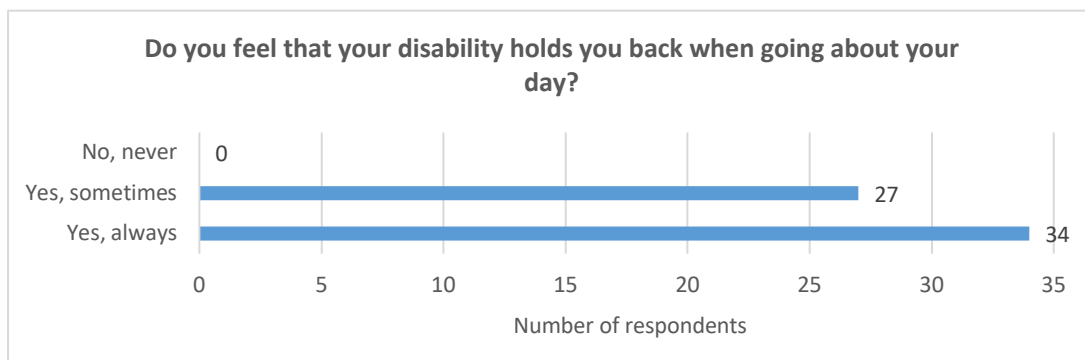


Figure 17: Disabled people's views about their impairments or health conditions holding them back (Cumberland)

The survey respondents explained how their impairments or health conditions can hold them back when going about their day:

'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)

‘Lack of independence, registered blind so can’t drive, public transport is terrible in Cumbria so I’m often late for work which holds me back in my career.’ (Survey respondent)

‘It [mental health condition and neurodiversity] affects my executive functioning and I experience choice paralysis, poor memory at times, time blindness, lack of concentration or hyperfocus, sensory overload, fatigue, etc. it’s difficult to manage normal everyday tasks that most other people don’t even have to think about.’ (Survey respondent)

‘It [sensory impairment] can be challenging in situations where I am talking with a group of people particularly face to face or if a person is wearing a facemask etc. I also have difficulties when using the phone and oftentimes this is the only way to get a medical appointment. I do rely on my family for situations like this. If I am using online services, I generally tend to be better but sometimes the English that is used can make it tricky. Also due to [my] concentration level I become tired more quickly than my hearing counterparts, so usually by 3 - 4pm in the afternoon I am exhausted.’ (Survey respondent)

‘My disability/long term health condition is hidden. It is not obvious to others and therefore I can be discriminated against completely unintentionally. I'm the one expected to give up my seat on the bus, I'm the one that should allow others to jump the toilet queue... [the] physical exhaustion that comes with my condition is not seen by others, they just think I'm lazy. So, it plays with my mental health.’ (Survey respondent)

Figure 18 shows that 37% of the survey respondents live fully independently and 18% rely heavily on support, which was often provided by a disabled person’s spouse, family, friends, or carers.

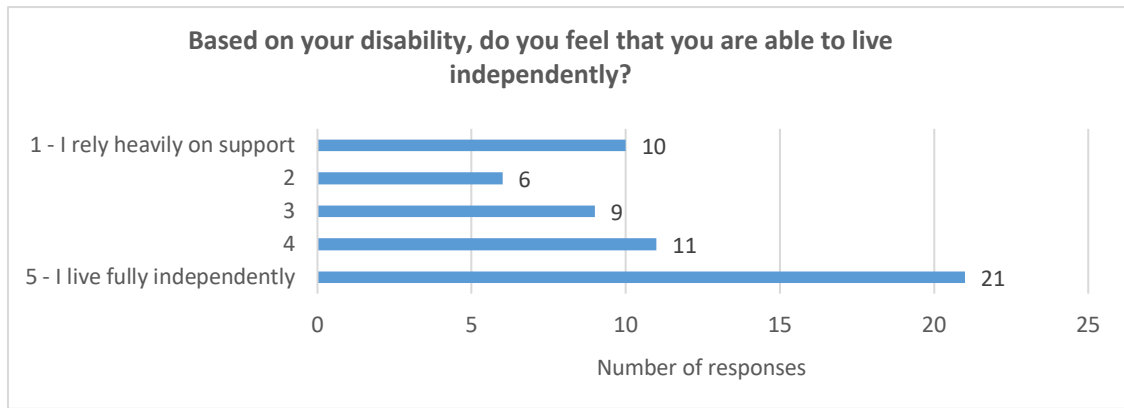


Figure 18: Disabled people's views about living independently in Cumberland

The survey findings show that just over half of disabled survey respondents (53%) from Cumberland either felt confident that they knew their rights as a disabled person or felt they 'know enough'. In contrast, just under half of disabled survey respondents (47%) felt that they did not know, or wanted to know more, about their rights as a disabled person, as depicted in Figure 19:

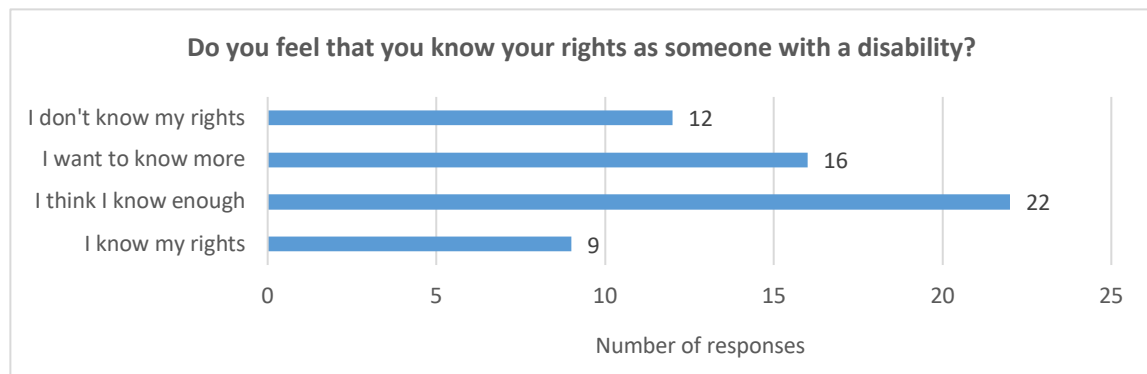


Figure 19: Disabled people's knowledge about their rights (Cumberland)

3.2 Challenges and barriers experienced by disabled people in Cumberland

3.2.1 Living a 'good life'

As shown in Figure 20, the majority of disabled survey respondents indicated that their impairments or health conditions hold them back from living what they consider to be a 'good life'. For example, the participants explained that various impairment effects (such as pain, fatigue, poor concentration, brain fog, poor memory, anxiety, depression, restricted mobility,

communication difficulties, emotional burnout and sleep deprivation, amongst others) can create challenges in their everyday lives.

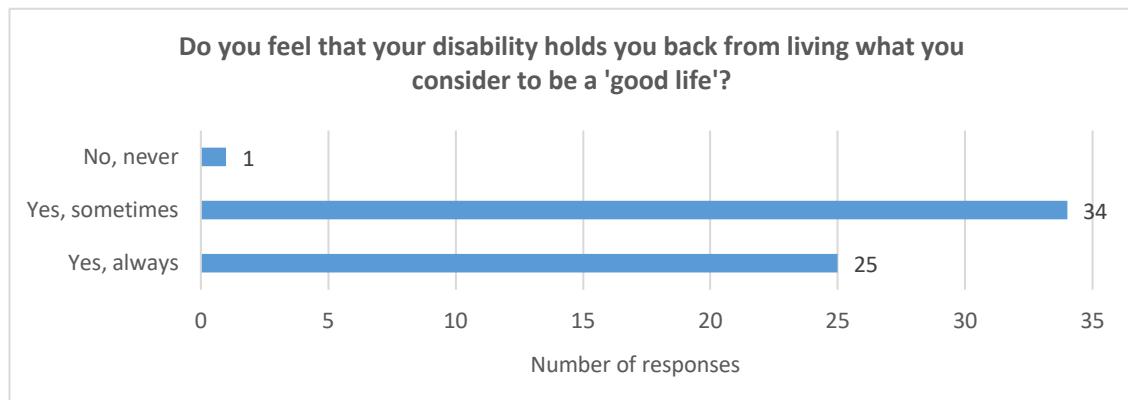


Figure 20: Disabled people's views about living a 'good life' (Cumberland)

Examples of what a 'good life' might look like for some disabled people included the following:

'Being able to go out & catch the bus to have a look around the shops or go for coffee. Going for a walk, something so simple but unattainable for the last 2 years...' (Survey respondent)

'Being understood and my sensory issues & neurodivergent traits being accommodated by others would improve my life significantly...' (Survey respondent)

'Doing what I do now but also being capable of exercise and not having to sleep/crash.' (Survey respondent)

'Freedom of choice in all things, with ability to ask for expert guidance if necessary.' (Survey respondent)

'You make the best of what you've got but a more inclusive, accessible and accepting society would make this life a lot better.' (Survey respondent)

'For me living a good life it would involve having sufficient support within my work environment such that I don't regularly end up burning out and so that it also meant that I had time to care for and look after myself and that there was time to build and maintain relationships with friends for a good social life and to have some time out for those activities which re-charge my batteries (getting

out into nature, spending time relaxing, going to music gigs, and socialising).’
(Survey respondent)

3.2.2 Barriers

The findings show that disabled people in Cumberland often experience barriers that exclude them from society or discriminate against them. These barriers can relate to the physical environment, transportation, organisational systems, the attitudes of others, communication and information, and technology.

Physical barriers

A key theme within the data was the physical barriers that many participants experienced across Cumberland, such as no wheelchair access, uneven pavements and high kerbs, stairs, no access to lifts or ramps, and a lack of accessible public toilets. For example:

‘Pavements so dangerous in my area as so uneven and not enough drop pavements.’ (Survey respondent)

‘I use a mobility scooter, but obstacles on the pavements, parked cars, shortage of dropped kerbs etc can hamper progress.’ (Case study participant)

‘Some places have a disabled toilet...but it's down two steps... The other thing is lift access.’ (Case study participant)

‘...if I get off the bus and need the toilet there isn't one anywhere near, in Whitehaven there isn't any toilets at all.’ (Case study participant)

Transportation Barriers

Many participants reported barriers with accessing public transport, particularly in rural areas where bus timetables can be limited:

‘In West Cumbria there just aren't buses to places. That's a barrier, lack of transport. There's a good bus service to Penrith but if you're out of that axis you're stuck. Buses are only every couple of hours, your day's gone. When something goes wrong and you're stuck somewhere, it's not good.’ (Case study participant)

‘My bus used to be every 7 minutes now it’s every 12, if it comes at all.’ (Survey respondent,)

‘There are only buses that go round my area twice a week, so I can't get over my anxiety going on buses...’ (Focus group participant)

‘Public transport. Issues with accessibility. Bus drivers have poor awareness of disabilities. If changes to timetable there is no warning. Due to rural living, it affects ability to and from appointments etc. Hard to get a bus pass since changed criteria and PIP framework. Living rurally with a specialist health condition, must travel to gain medical support...’ (Focus group participants)

The challenges of accessing public transport and taxis for wheelchair users were also noted:

‘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)

Some of the research participants explained that they would find it very difficult to get around Cumberland if they could not drive, or if they did not have someone else to drive them:

‘Public transport is so terrible that getting anywhere without driving (e.g. to visit far away family) is almost impossible. I have been stranded in Barrow train station due to delayed trains for over 2 hours in the freezing cold before. I left on the 17:40 train from Preston and walked through my front door at gone 11pm with painful Raynaud’s symptoms in my hands and sensory overwhelm. If a person doesn't drive, they will be entirely stuck and lonely.’ (Case study participant)

‘... my transport stopped when I left collage and now rely on my mum and dad to take me where I want to go.’ (Focus group participants)

In addition, it was suggested that a lack of disabled parking spaces can present a barrier across Cumberland, for example:

‘...[need] more disabled parking in and around Carlisle...’ (Case study participant)

‘Finding suitable wheelchair, friendly parking - my car has all suitable signage, but people don't pay attention and often don't leave enough room.’ (Case study participant)

Organisational barriers

Another key theme was the organisational barriers that disabled people, and their carers, experience within society. For example, navigating complex healthcare and social care systems, booking GP appointments, long waiting times, and referral processes that can involve travelling long distances for treatment:

‘It's very difficult getting in at the doctors.... That's the biggest barrier, getting in to see someone.’ (Survey respondent)

‘It depends on the disability but in the case of Parkinson's, it's degenerative, it's only going to get worse, so I've always got that in the back of our heads. There's probably more help available if you know where to ask for it but the way the NHS has been fragmented by this Government is that the GP's only the starting point, then you pivot. There's the ICC Co-ordination Hub, and the hub is awful, badly managed, full of misinformation and unprofessional.’ (Focus group participants)

‘GP not doing home visits for MH [mental health] needs. Secondary services have very long waiting lists, just for assessments and even longer for treatment. Social needs are not being addressed, so MH declines and social needs then decline further - cycle continues.’ (Case study participant)

‘Access to a GP not being able to phone early or use online forms, not being seen by experts in their condition, out of county referral, people being housed out of area so away from family/support.’ (Focus group participants)

‘The centralising of certain medical facilities means you have to go further for your care.’ (Case Study participant)

In particular, some participants reported a lack of specialist neurological care within Cumbria, which resulted in them travelling outside the county to receive treatment:

‘Poor neurology care, meaning [I] travel to Newcastle to access this.’ (Survey respondent,)

‘Absolutely appalling neurology service. I actually went private in the end. Here in Cumbria, it's tricky to get to speak to a consultant, it was nine to ten months...’ (Case study participant)

‘...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)

Another organisational barrier relates to the paperwork that disabled people and their carers need to complete in order to access financial support such as Personal Independence Payment (PIP) or Attendance Allowance. It was evident that the lengthy application forms were stress inducing for many people:

‘Anxiety surrounding PIP - every time renewal is due, I feel severe stress. The claim process is so difficult, broken trust as you get penalised for having a good day. No empathy from assessors, pressure of society on how we are meant to live, I feel like we are taught from an early age that we must "fit in the box" and a good life was a certain way.’ (Focus group participants)

‘...the Attendance Allowance form is 50 pages long and the questions focus mostly on physical capabilities, there is very little on it about mental capacity. There is too much bureaucracy and a need for outside agencies like Age UK to complete the forms for you because if you don't answer the questions well, you miss out on benefits you are entitled to.’ (Focus group participants)

‘A 50+ page form just to even apply for support for disabilities that affect your ability to complete forms etc is ironically cruel. I appreciate a great deal of it is

probably standardised by government, but you wouldn't believe the amount of paperwork that comes with being disabled and having a disabled child. It's a full-time job in itself.' (Survey respondent)

Attitudinal barriers

The findings show that disabled people in Cumberland experience attitudinal barriers due to a lack of understanding and disability awareness within society:

'I feel as though people with disabilities, especially those with learning disabilities are often misunderstood and underestimated. The lack of age-appropriate engagement from the public, because as soon as they realise somebody has a learning disability, they talk to them as though they are stupid, or speak to the support worker when the person is perfectly capable to speak for themselves.' (Survey respondent)

'I don't always feel that I am being listened to properly, even by NHS and Social Care professionals. The GP appointments system is difficult to access, and I am often brusquely treated or ignored by reception staff. People generally often have no concept of the problems I face on a daily basis and make snap judgements about me, sometimes poking fun at me.' (Case study participant)

'My hearing loss makes it difficult to be social because it can be tiring but also people are less likely to engage with me because they struggle to communicate with me, there is a lack of awareness.' (Survey respondent)

Some research participants have experienced attitudinal barriers, particularly regarding the stigma associated with mental health or neurological conditions such as dementia:

'Stigma surrounding mental illness in Cumbria is massive. There's no usable help. I get so frustrated that I have to explain myself all the time.' (Case study participant)

'The stigma around dementia means people seem to avoid us. It's as if people are frightened of it.' (Focus group participants)

Communication and information barriers

The findings also indicate that some disabled people, particularly those who are neurodiverse, often experience barriers relating to communication and information:

‘The colour of the font/background matters. There are not many places where considerations are made re. dyslexia. Studying and absorbing info is hard. Trying to process differently to everyone else, I think there needs to be more dictaphone options.’ (Case study participant)

‘I have ADHD... I can't manage the phone systems and internet that seem to be the way of communicating with many services these days, so I really struggle to make GP appointments, sort financial things out...’ (Survey respondent)

‘Communication difficulties - masking is the only way I can survive & it is exhausting. My ADHD medication keeps me chemically awake during the day so to speak so I function, but it's not a healthy or good way...’ (Survey respondent)

‘Different types of communication between neurodiverse and NT [neurotypical] means I feel misunderstood, rejected, unacceptable and criticised, needing to change. Yet I am rarely told what I have done that is against social rules, I am ghosted and passively ignored. Often people misinterpret my communication, and they project their insecurities onto me which I take very personally. I am desperate to fit in, but my manual is different to most peoples.’ (Survey respondent)

Technological barriers

Digital technology can be a barrier to accessing information and services for some disabled people, particularly those who are elderly or do not have access to smartphones or the internet:

‘Everything is online and I don't have internet/smartphone etc, so being penalised for that.’ (Case study participant)

‘When I want a GP appointment I have to go down in person as they don't answer the phone and I struggle with the internet.’ (Case study participant)

‘In my mother's case, not having a good enough understanding of new technology [was a barrier]. She didn't have broadband, she had sky but she used

to get the controllers mixed up sometimes. She had a mobile but it was just a basic one. She had an operation a few years ago because she had nerve damage so she couldn't feel her fingers which meant touch devices, she just couldn't use.' (Case study participant)

3.3 Quality of life for disabled people in Cumberland

The majority of disabled survey respondents rated their current quality of life as either 'good' or 'neither good nor poor', as shown in Figure 21:

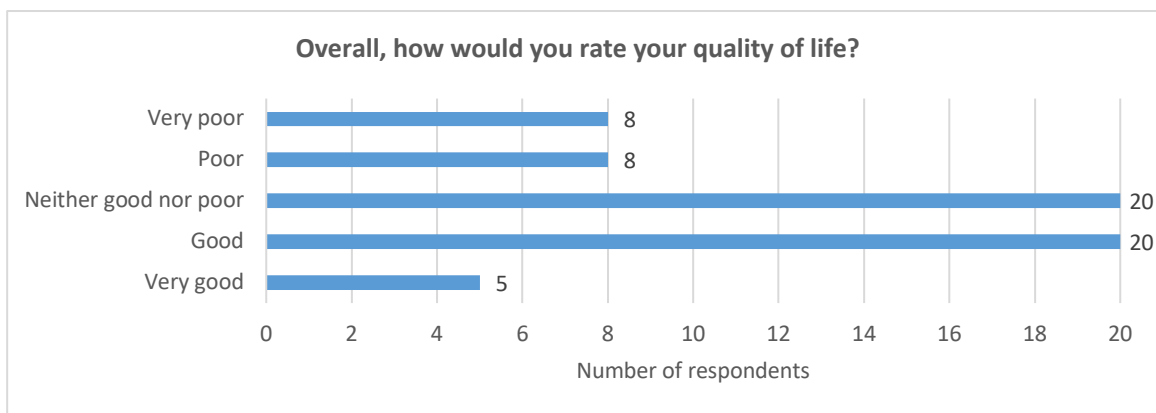


Figure 21: Overall quality of life for disabled people in Cumberland

However, most disabled survey respondents (69%) felt that their quality of life was worse than five years ago:

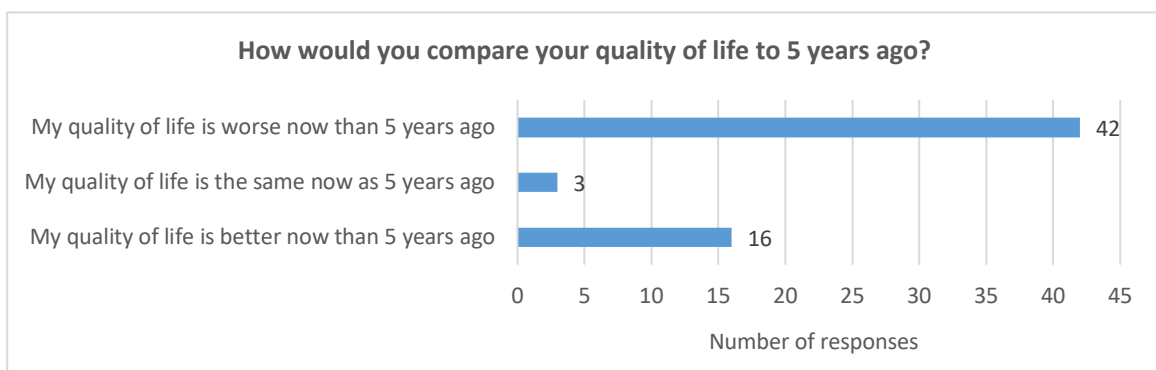


Figure 22: Quality of life for disabled people in Cumberland compared to five years ago

The survey for disabled people involved rating 16 statements about their quality of life, ranging from physical and mental health, to social, practical, and personal factors. Whilst the responses to home environment, food and clothing choices, and family relationships were rated more positively, responses to physical health, mental health, accessing services and socialising with friends were rated with more disagreement:

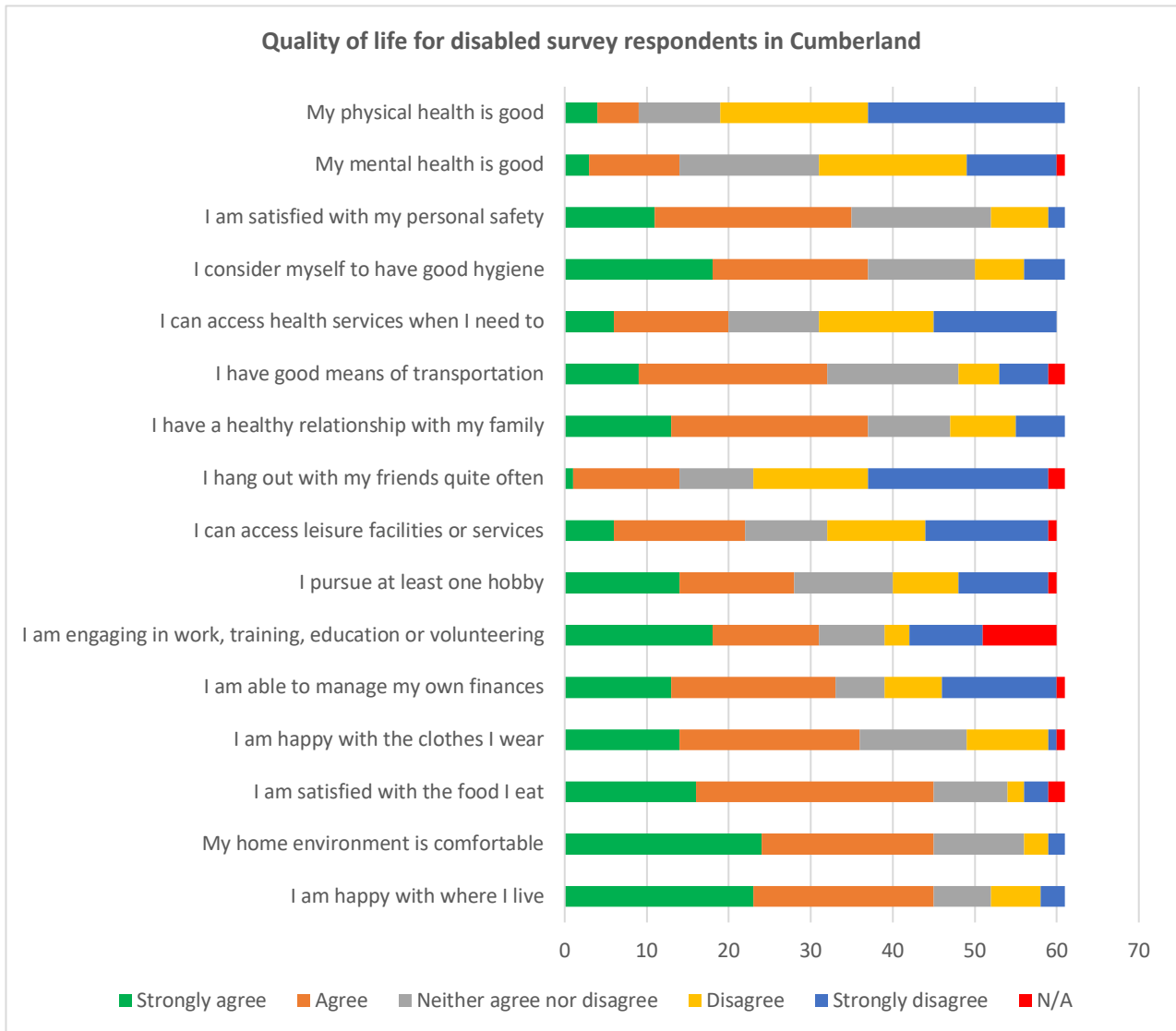


Figure 23: Quality of life for disabled people in Cumberland

3.3.1 Improvements in quality of life

The findings show that more awareness of disabilities, improvements in impairment effects, increased availability of services and flexible working have the potential to improve quality of life for some disabled people, and their carers, in recent years:

‘The vast majority of people do care, and you'll find disabilities are catered for. A lot has been done, we have the Equality and Diversity Act and Access to Work...’ (Case study participant)

‘Speaking personally, the medication for ADHD has almost banished my ‘fixations’, improved my memory and allowed me to focus and discipline myself a little better. Case study participant)

‘... the services available to the family are certainly better than they were 5 years ago when [child] had just got their diagnosis.’ (Case study participant)

‘My recent contact with Mental Health Services locally (GPs apart) has seen an improvement in the way they operate and offer support/listen to my parents. This applies particularly to NHS Crisis and Community Mental Health Teams. There seems to be more local charities devoted to supporting people with mental health and autistic disorders.’ (Case study participant)

‘Zoom has really helped, there's loads of things available thanks to Zoom (virtual appointments). It's the big positive that's come out of the pandemic. I think the pandemic has had an effect on the ability to meet physically with others in the area, but in the positive, we've got Zoom out of it.’ (Case study participant)

‘The ability to work from home reduces the stress of getting into work on time.’ (Survey respondent).

In addition, disabled people who reported an improvement in their independence - which in some cases was facilitated through appropriate support or equipment - tended to report a better quality of life, as shown in the following comments:

‘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 let me and can help me, that's improved my quality of life.’ (Case study participant,)

‘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)

'Having a blue badge has improved the quality of my life. It only took a week to get it, because [worker] from Forget-Me-Nots helped me complete the form.' (Case study participant)

'...Purchase of a mechanical scooter helps with the balance and coordination problems which are also part of my condition, and it also makes me feel more independent. I have acquired 2 dogs which give my mother and I a lot of pleasure. I look forward to Triple A (charity supporting autistic adults) fortnightly meetings. My mental health, confidence and self-esteem have all improved as a result of all these changes...' (Case study participant)

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 the local area:

'Any improvements in my own, children or husband's daily lives are the result of my own initiatives and approaches, but the emergence of local charities supporting Autism has been a recent game changer for us. Amongst other things, they run Fun Days and run courses.' (Case study participant)

'...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)

'It depends what the disability is, it depends how severely disabled you are. It's knowing what's out there and available to you. A lot of the older generation won't ask for help, the younger generation will and are more computer literate.' (Case study participant)

3.3.2 Decline in quality of life

Whilst the responses above indicate improvements in quality of life for some people, the findings also show that many research participants reported that their quality of life had become worse

over the past five years, which was often attributed to deteriorating impairments or health conditions, the negative impacts of the Covid pandemic, and the increasing cost of living:

‘The older I get the more difficult I find it to manage my condition. COVID hit my mental and physical wellbeing hard, I find it easier to stay in than go out. My condition does not allow for free prescriptions, and I need multiple medications - cost of living is rising and even with working there is going to be a point where I might have to choose shoes for the kids or my medicine. This decision should not be one happening in the western world, for someone willing to work full time. Working removes me from many benefit options and perhaps it is getting to the point I would be better off on benefits as opposed to being in work but the wages in Cumbria are very low but the cost of prescriptions/travel are the same country wide.’ (Survey respondent)

In the past five years, the effects of the Covid-19 pandemic have also impacted negatively on quality of life for some disabled people due to a reduction in services and an increase in organisational barriers and technological barriers:

‘...but following Covid there are less activities/providers that have re-opened.’
(Focus group participants)

‘I think there's been a massive decline because of Covid, there's not enough resources, people have lost their positions. My dad's going through a mental health crisis, but we've seen a psychiatrist twice in 12 months, they're just so stretched.’ (Case study participant)

‘Due to Covid, the young people who were struggling are now nearing crisis point. Although they're older, they've missed out on large chunks of the most formative years. This is concerning for any young person, but those who are neuro-diverse will be impacted significantly more.’ (Survey respondent)

It should be acknowledged that the finding about perceptions of quality of life being negatively affected by a deterioration in impairments/health conditions is not specific to the region of Cumberland, as this could be experienced by disabled people throughout the UK. However, many disabled people have reported a reduction in the availability of services and support across Cumberland, which has negatively impacted their quality of life in recent years:

'It's got worse. The Blind Society had Action for the Blind here five or six years ago, they've got [Carlisle Blind Society] here now, that's about it... I've got an autistic son as well, I'm a carer and I'm cared for, by my husband. When you get past 20, all the assistance drops off, if you ask any parent of a disabled child, they all say this. Past 25 they say, "well your education's finished". But you've still got to give them something to occupy themselves with.' (Case study participant)

'Not enough mental health services in Millom, everything is in Barrow, my daughter is constantly with me, so I don't get enough time to myself.' (Case study participant)

'Most definitely due to the termination of step down supported living services; five years ago people had services like The Acorn Centre then mental health residential care homes as a recovery pathway to move through in manageable stages after long stays in secure units; now people are facing a much bigger challenge going from secure units straight into their own flats - albeit with some support - which can be very overwhelming and for some an unfair and unfeasible task.' (Survey respondent)

'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)

Carers of disabled people also acknowledged a lack of support, recognition and respite provision:

'There's very little support for men who care for their wives. Lots of ladies' groups where I don't feel comfortable. I also don't feel recognised as a carer when I'm trying to manage my own appointments, etc. For example, when trying to get an appointment, it needs to be around her needs and doctors don't often care about you.' (Case study participant)

'There is an over reliance (expectation) of family to care for their loved ones with dementia. There is no 1:1 support for people and this puts a huge strain on carers who have little to no respite.' (Focus group participants)

Finally, a few of the research participants felt that disabled people with hidden impairments tend to be easily overlooked by society, which can impact negatively on their quality of life:

‘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)

‘Hidden disabilities are always forgotten... We tend to work, pay tax, contribute etc... but are hidden so get forgotten about.’ (Survey respondent)

3.4 Experiences of loneliness for disabled people in Cumberland

As illustrated in Figure 24, most disabled survey respondents reported feeling some level of loneliness, with almost half of them (45%) indicating that they ‘often’ felt lonely, followed by ‘some of the time’ (18%), ‘occasionally’ (16%), and ‘always’ (12%) respectively:

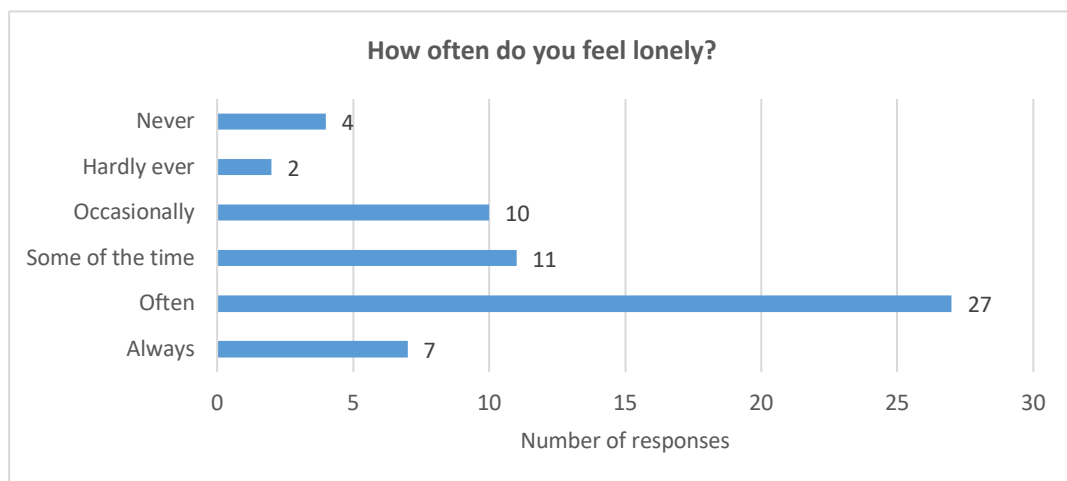


Figure 24: Feelings of loneliness amongst disabled people in Cumberland

Figure 25 shows that most disabled survey respondents (84%) felt that non-disabled people have more opportunities to feel part of their local communities than disabled people:

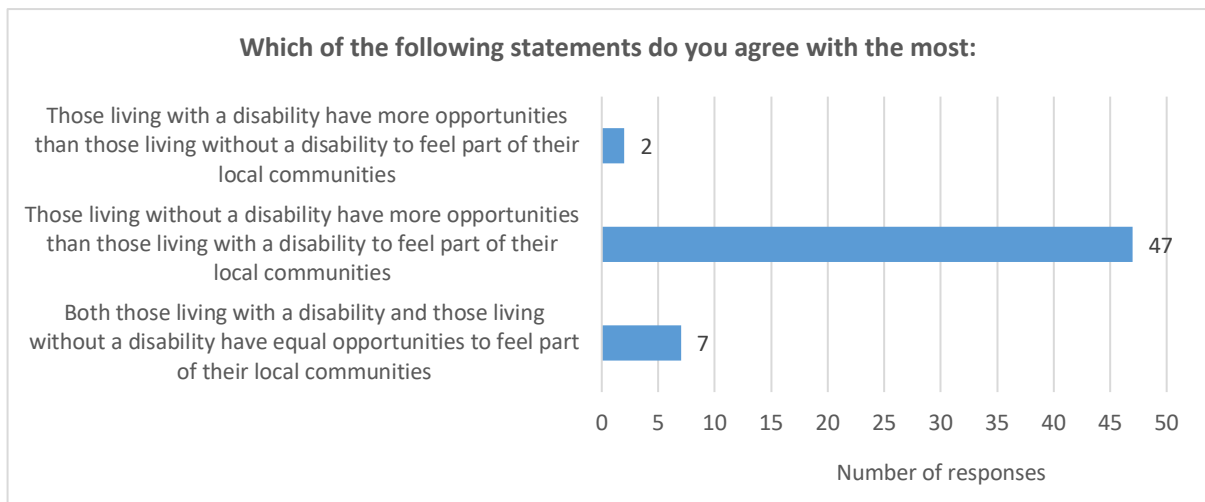


Figure 25: Disabled people's views about equal opportunities in Cumberland

According to the findings, the barriers reported in section 3.2.2. (particularly those barriers relating to accessing buildings and public transport) can prevent disabled people from having equal opportunity to access social activities and support groups within their local communities. In addition, some disabled participants emphasised that the effects of their impairments or health conditions can impact negatively on their social life:

‘Emotional burnout/exhaustion from masking leaves little energy for social interaction.’ (Survey respondent)

‘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)

‘If no disabled toilets or access to a restaurant or bar or no wheelchair taxis [1] have been unable to go. Have to plan around carers for toilets at times...’ (Survey respondent)

It was also suggested that there is a need to raise more awareness of the various social activities and support groups taking place in local communities, and this information needs to be shared in various formats – not just online – to ensure that people are not excluded by communication or technology barriers, as shown in this comment:

‘...I couldn't even tell you if there's a deaf group in Cumbria. If you're walking around certain buildings you see posters, but it's not publicised enough. If you haven't got Facebook, how are you supposed to get enough information? Not everybody is digitally aware... Being a deaf person, I'm very isolated in what I can and can't do. I also don't like being a burden to anyone either.’ (Case study participant)

The research participants in Cumberland provided examples of various activities, organisations and support groups that they had engaged with, such as: ADHD support group, Macular Society, Blind Society, Mencap, MIND, Age Concern, Positive Pals, People First, Carlisle Youth Zone, Forget Me Nots, Owl Group, Healthy Hopes, Invisible Illness Support Group, Fibromyalgia Support Group, Mencap, Triple A, Ewanrigg Community Centre, Together We Men's Mental Health Group, The Sands Centre, Keep Fit with Cake, Prism Arts, and Always Another Way, amongst others.

It was evident that being involved with these groups provided some disabled people with the opportunity to engage with others who understand their impairments/health conditions and their experiences of disability. This shared experience can reduce feelings of isolation or loneliness, and provide a sense of belonging for some disabled people:

‘Getting diagnosed with a condition (fibromyalgia) is very isolating which increases mental illness. Coming to this group [Invisible Illness Support Group] is the only place I can feel like myself.’ (Focus group participant)

‘... Getting the initial diagnosis of dementia is overwhelming and makes you feel so alone. Groups like this [Forget Me Nots] helps because you realise other people are going through the same stresses.’ (Focus group participants)

‘Support groups are good and beneficial to get together with others with disabilities. You can learn from others' experiences too...’ (Case study participant)

‘I don't feel lonely when I get to come and see my fantastic friends at Prism Arts and Mencap.’ (Focus group participant)

‘I can no longer work due to pain, without "Wecan" I would have nothing, it's like a second family.’ (Focus group participant)

‘Since COVID the digital world has opened up opportunities to people like me. I am computer literate so I'm ok... I am an active participant in an art group and a fibromyalgia support group but can only manage a short stint...’ (Case study participant)

3.5 Frustrations and worries voiced by disabled people in Cumberland

Many of the frustrations and worries reported by research participants align with the barriers and challenges detailed in section 3.2.2, such as the environmental barriers of inaccessible public transport, attitudinal barriers, and organisational barriers, all of which can limit access to services and support, and have a negative impact on a disabled person’s quality of life. For example:

‘There's been a big fumble around finding support. You have to be an expert on your own condition. If you don't have a doctor's note, people will not listen. It's very frustrating especially because it could take up to two years to get a referral. PIP is a massive frustration for anybody it is very humiliating... If a disability can't be seen, there still is that thing about 'are you disabled?’’ (Case study participant)

Some disabled people also worried about their finances, as shown in the following comments:

‘Finance is a big worry. My partner has fluctuating conditions and if she has to take time off work, there is worries about how they'll take it.’ (Case study participant)

‘My mental ill health and disability have impacted on my ability to earn a living because I have regularly become ill with the pressure of work. So, there is already the impact of disability on income...’ (Survey respondent)

‘I rely partially on Universal Credit as I cannot work a full-time job, so my income is limited.’ (Survey respondent)

In particular, the cost of living was reported to be a significant financial concern due to the increasing cost of utility bills and food:

‘Cost of living is another big worry - I worry about how people can afford all the rises in costs when wages and benefits don't change.’ (Survey respondent)

‘Cost of living - If I had no money the amount of washing, paying for prescriptions would be impossible, and affording a car.’ (Case study participant)

‘Gas prices are going up at the minute, if they put that up anymore, we'll be lucky to have enough money for food, people are going to be homeless.’ (Focus group participants)

Concerns were also expressed about the future, particularly for disabled people who were currently being cared for by family members:

‘My wife who has dementia... I worry if something happens to me as my wife can't use the phone and is completely reliant on me.’ (Focus group participant)

‘I worry about how my family would cope when I'm not around, particularly one of the [children], who struggles with life generally...’ (Case study participant)

‘The future - where to live, especially once [the] parent is no longer available, working life, income, social life, personal development, mental health, exceptionally poor care/supported living.’ (Focus group participants)

‘I worry about being left on my own, I don't drive so I would have to rely on public transport. Not enough support out there, cancer is an isolating illness, my husband doesn't want to talk about it.’ (Case study participant)

3.6 Changes suggested by disabled people in Cumberland

As illustrated in Figure 26, disabled people in Cumberland indicated that having better access to healthcare services and support would improve their lives the most, along with having more support with maintaining good living conditions, and a better social life:

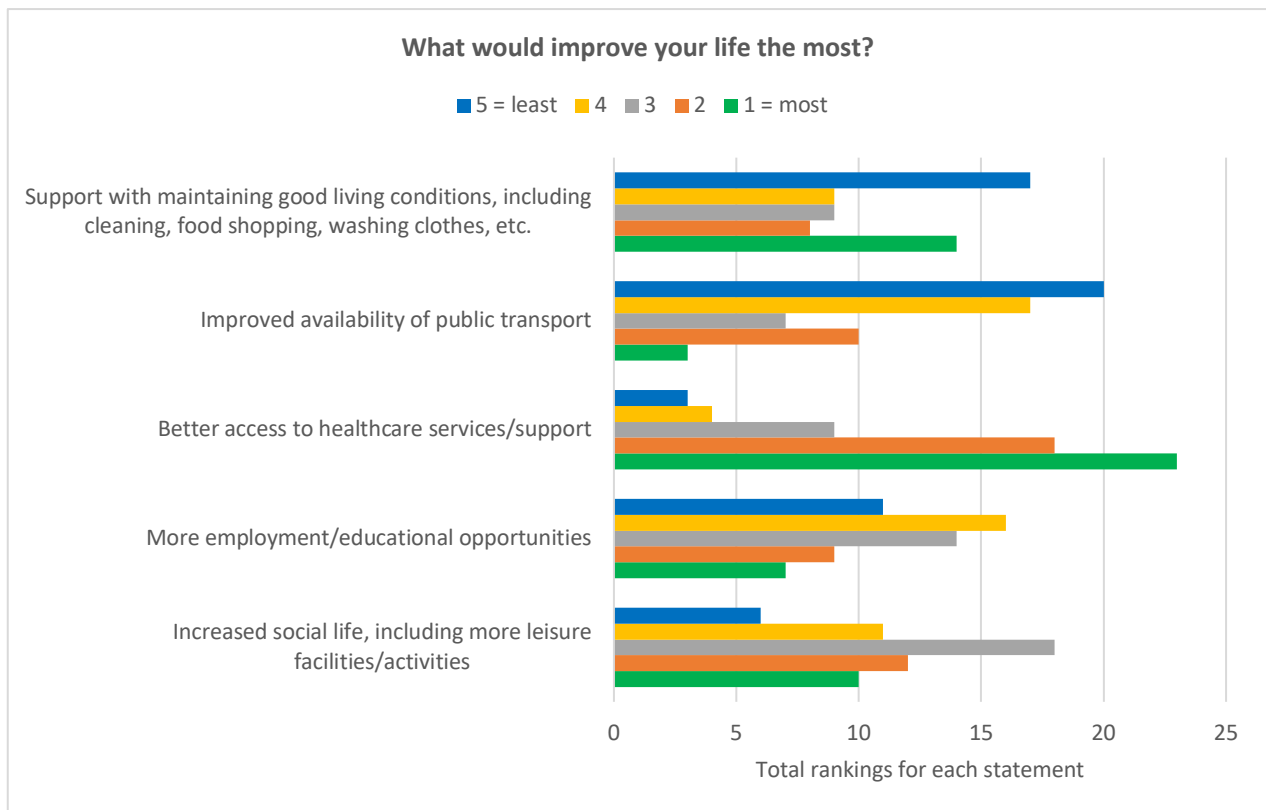


Figure 26: Disabled people's views about what would improve their lives (Cumberland)

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.

Comments from research participants provide further suggestions for change:

‘More understanding of hidden disabilities – starting at school perhaps.’ (Case study participant)

‘I think there needs to be more daytime activities available where individuals can learn skills and be part of something that gives them a sense of purpose and leads to them feeling more valued as well as being a potential source of social connection.’ (Survey respondent)

‘More information/signposting by health and social care professionals at an earlier stage, rather than being left to flounder in a complex system. Early intervention could make a difference to the eventual outcome in adulthood and help people lead a more fulfilling life...’ (Case study participant)

3.7 Recommending Cumbria as somewhere for disabled people to live

60% of disabled survey respondents from Cumberland would recommend Cumbria as somewhere for disabled people to live, whilst 40% disagreed with this statement.

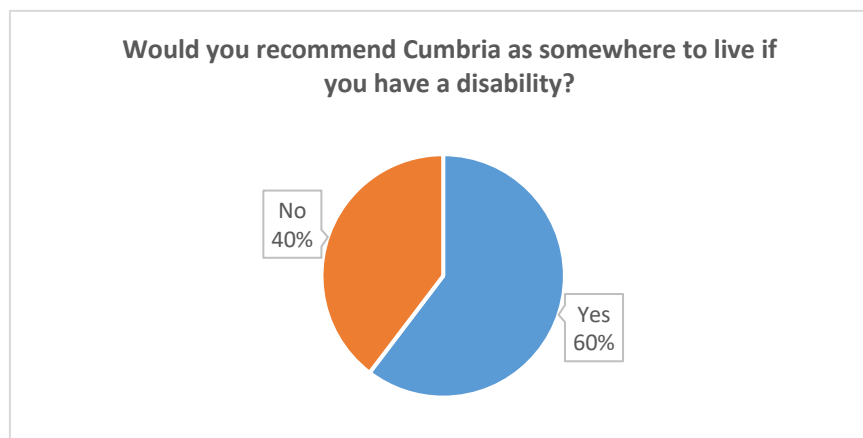


Figure 27: Disabled people's views about recommending Cumbria (Cumberland)

Comments included:

‘Cumbria has a lot going for it as an area to live, in particular the amazing natural beauty and the opportunities of getting into nature to improve wellbeing.’ (Survey respondent)

‘Because it is a lovely place to live, disabled or not.’ (Survey respondent)

‘Cumbria is no different to any other area. It is EDUCATION of the masses that needs to change. If done properly, through media, it can be a simple and straightforward task.’ (Survey respondent)

‘Question too broad. Depends on the disability. If you are mobility impaired, a place where walking is the main attraction is probably not an easy sell. If you're autistic, it's very good because it's quiet and there are many of us here. If you need to use public transport to get around, then no because it's not at all reliable and sporadically available in terms of location. I love Cumbria and never want to move away - but I can drive and have a job here.’ (Survey respondent)

‘I don't think anywhere in the UK is supportive of disability. But Cumbria seems to have a lot less investment than down south.’ (Survey respondent)

‘Quite isolated, not as much support as somewhere more populated.’ (Survey respondent)

4. Findings 3: Westmorland and Furness

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 one Facebook comment (as shown in section 2 of this report).

4.1 'Normal life' for disabled people in Westmorland and Furness

The comments presented below provide an example of the wide variety of 'normal lives' described by disabled people, and those who identify as carers, across Westmorland and Furness:

'I live in a bungalow, and I am largely able to look after myself and attend to my daily needs, but I do have a PA should I need extra help. On rising, I shower and get breakfast. I have bought equipment and have made many adaptations/alterations to enable me to carry out a range of domestic tasks. I work throughout the day, mainly at home, but can access my workplace if I need to be on the job. I have an adapted vehicle and a manual wheelchair which keeps my upper body muscles toned. My PA helps with shopping, cleaning and meal prep, although I can do this if necessary. I watch TV in the evenings and retire to bed between 10pm and 12am.' (Case study participant)

'Cooking, cleaning, childcare, working. I receive emotional support from family but very independent.' (Survey respondent)

'Work 4 days a week. Check on my mother every day. She is 80 and has Parkinson's. TV, listen to podcasts, read, embroidery, crochet. Hospital visits monthly or via phone call. Medication 7 times a day and with each meal too. I do some cooking but only if I have energy, my husband does the rest. I clean once per week, but my husband takes a share too. I often fall asleep on the sofa in the evening when I run out of energy. Some days I get everything that I want to do done, other days I take a quiet day and sit on the sofa. I need at least one sofa day a week, but often two.' (Survey respondent)

'Life is boring, come into the cafe in the market 4 days a week - been coming here for 20 years. Need social contact for company. We like to watch the world go by.' (Focus group participants)

‘I have to do a lot of juggling around of my commitments to see to the children and tend to my husband before the carers come. If [husband] needs the toilet between carer’s visit, I have to use the hoist myself, otherwise two carers have to do it. Fortunately, my employers have been very good, and I can base myself at home for some of my duties. [Husband] has communication difficulties, complicated by aphasia, apraxia and problems with sequencing. He also hears negative voices, can have between 5 and 15 epileptic episodes daily and can get very agitated at times. Caring for him can be very challenging and different carers have varying levels of success.’ (Case study participant)

‘My son has an undiagnosed mental health condition. He is currently waiting to go through autism assessment. He lives independently (to a point) in flats which has staff on hand. He is vulnerable and naive and has got in with a bad circle of friends with drug use. Normal day involves us (mum and dad) helping him financially by buying him food, paying his bills. We won't give him cash as we can't guarantee he'll spend it on food or bills etc. He gets frustrated and has aggressive outbursts and can break things. He needs lots of emotional support from us.’ (Case study participant)

As shown in Figure 28, all disabled survey respondents from Westmorland and Furness indicated that their impairments and health conditions hold them back to some degree when going about their daily lives:

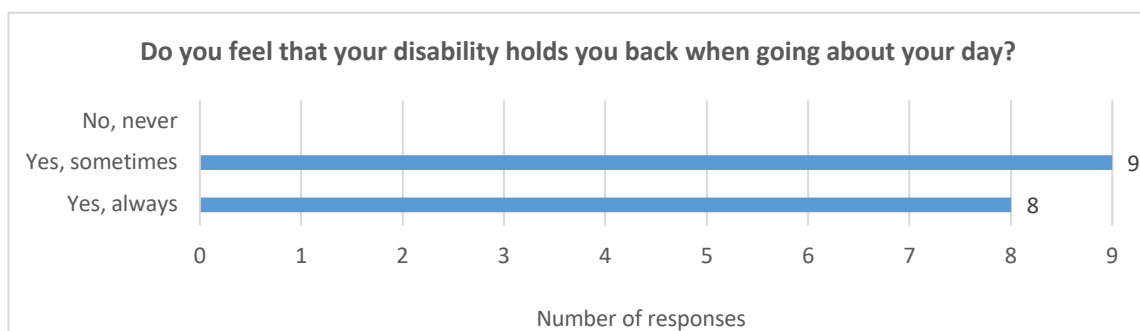


Figure 28: Disabled people’s views about their impairments or health conditions holding them back (Westmorland and Furness)

The survey respondents explained how the effects of their impairments or health conditions can hold them back:

‘Fatigue. Pain. Food issues. Planning and mental load’ (Survey respondent)

‘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)

‘Pain and lack of access to toilets when needed urgently, so when condition flares up, I don't go out.’ (Survey respondent)

Figure 29 depicts that 38% of disabled survey respondents live fully independently and 19% rely heavily on support. Three of the respondents indicated that family members (sibling and partner) cared for them; one disabled person was supported by a carer three times per day, and another respondent accessed care two to three times per week. One disabled person commented: “I prefer to use the title PA [Personal Assistant] as carer is medical model language” (Survey respondent).

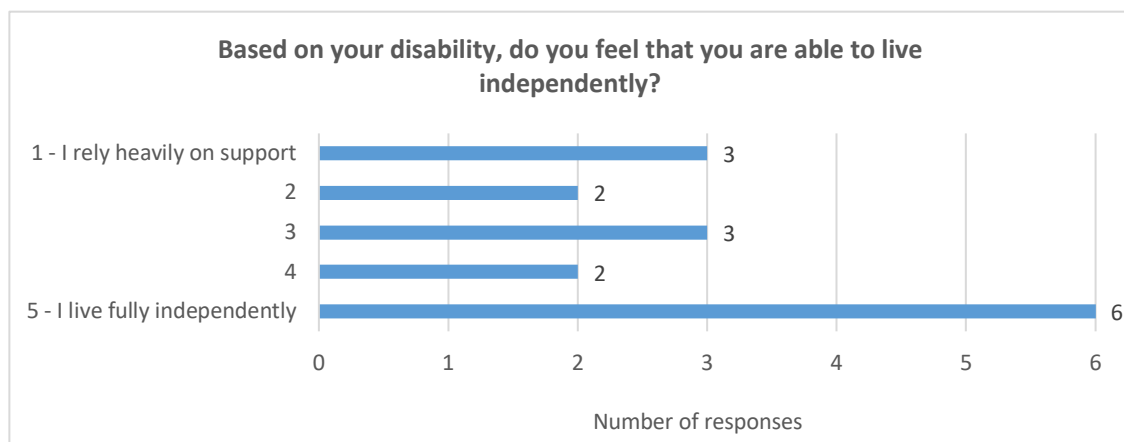


Figure 29: Disabled people's views about living independently in Westmorland and Furness

The survey findings show that 38% of disabled survey respondents from Westmorland and Furness felt confident that they knew their rights as a disabled person and 31% felt they ‘know enough’. In contrast, a quarter of disabled survey respondents (25%) felt that they wanted to ‘know more’, and 6% indicated they did ‘not know’ their rights, as shown in Figure 30:

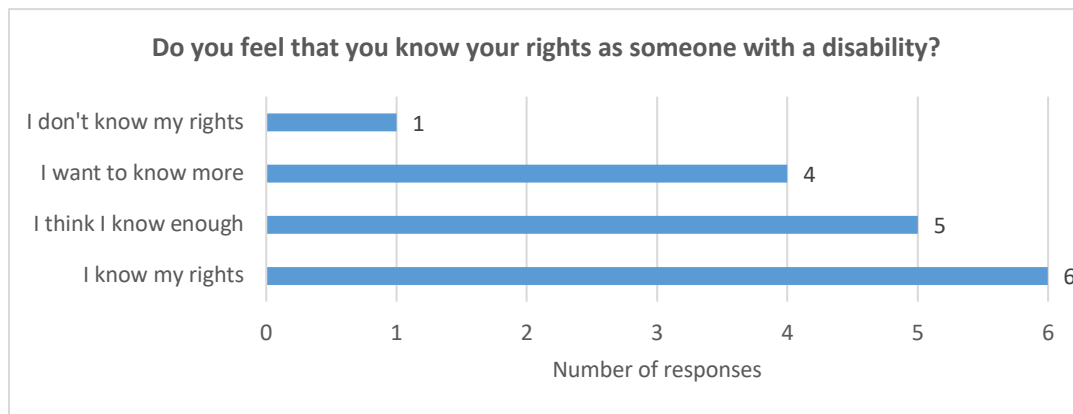


Figure 30: Disabled people's knowledge about their rights (Westmorland and Furness)

4.2 Challenges and barriers experienced by disabled people in Westmorland and Furness

4.2.1 Living a 'good life'

The majority of disabled survey respondents (71%) indicated that their impairments or health conditions sometimes hold them back from living what they consider to be a 'good life':

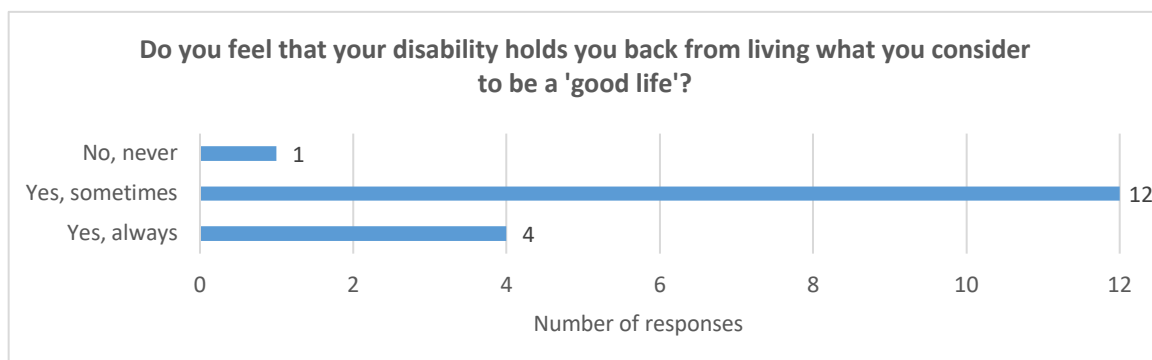


Figure 31: Disabled people's views about living a 'good life' (Westmorland and Furness)

It was evident that for some disabled people, the effects of their impairments or health conditions (for example: pain, exhaustion, difficulty with decision making or processing information, depression, anxiety, sensory overload) can impact significantly on how they go about their everyday lives. For example, this comment emphasises the need to plan ahead and be alert to potential risks:

‘Needing to plan everything in advance around treatments or being extra cautions due to Covid (as someone with a lung disease I am still at extra risk). Just having to do a risk assessment before I do anything takes the spontaneity out of life.’ (Survey respondent)

Examples of what a ‘good life’ might look like for some disabled people included the following:

‘Just being able to get into the independent shops in Kirkby, but many steps and no lifts or stair lifts.’ (Survey respondent)

‘Living the same "good life" as anyone else does! Working, shopping, going out with my cycling club, attending my weekly Italian class, spending quality time with my girlfriend and family, visiting friends, the occasional holiday.’ (Survey respondent)

‘Every day without pain and debilitating symptoms, freedom to work and socialise without pain and debilitating symptoms.’ (Survey respondent)

‘Living safely, with my basic needs managed, with enough left to have social connections. In an ideal world I would like to work.’ (Survey respondent)

‘Accessing facilities, [absence of] employment and social barriers, public transport access. There needs to be a real commitment of independent living and the breaking down of barriers for all disabled people.’ (Survey respondent)

4.2.2 Barriers

The findings demonstrate that disabled people in Westmorland and Furness often experience barriers that exclude them from society or discriminate against them. These barriers can relate to the physical environment, transportation, organisational systems, the attitudes of others, communication and information, and technology.

Physical barriers

A key theme within the data was the physical barriers that many participants experienced throughout Westmorland and Furness, such as: high kerbs, uneven pavements, inaccessible

buildings, a lack of lifts or escalators, no wheelchair access, and a lack of accessible public toilets, including those with hoists. Comments included:

‘Barrow isn't designed for wheelchair users. It's been a hell of a lesson for me. So, if in a wheelchair there's not as much opportunity for disabled people in this area.’ (Case study participant)

‘...poor access to buses and other transport, poor access on pavements/roads i.e. lack of dropped kerbs uneven pavements etc. Parking on pavements etc.’ (Survey respondent)

‘Lack of awareness for wheelchairs...many of the towns in south lakes are challenging for access. Only 3 hoist public toilets in the entire south lakes!’ (Survey respondent)

‘There are only 3 public toilets in Cumbria - all in the Lake District – with hoists, which [stroke survivor] needs, which limits our activities.’ (Case study participant)

‘...Kendal...there is less accessibility within the town, for example, Westmorland Shopping Centre has had the escalators stopped and two thirds of the lifts are broken. This is putting a barrier in place for people with mobility problems...’ (Focus group participants)

Some of the research participants also reported physical barriers when accessing facilities or services located within historical buildings, or in specific areas such as Barrow and Penrith:

‘Poor access to shops and most buildings, i.e. Barrow Town Hall as an example...’ (Survey respondent)

‘I live in Penrith and most shops don't cater for disabled people so how am I supposed to shop local?’ (Facebook comment)

‘The hardest thing is awareness of access to buildings, there's quite a lot of old architecture so some buildings are off limits, it is just the lack of understanding.’ (Case study participant)

Transportation barriers

Public transport was often identified as a barrier affecting a disabled person's independence and access to social activities and healthcare appointments. For example:

‘The accessibility of public transport - my wife can't go on the bus as it is too far for her to walk unaided with crutches, walker. She could go by wheelchair, but when we get to the bus nearly always the disabled section has a young mum using it with prams. The disabled section is a dual-purpose section for prams or wheelchairs. The trains are better, but the luggage racks aren't wide enough to put a walker on without it falling off also...’ (Case study participant)

Rural areas, such as Sedburgh, tend to have limited bus timetables as ‘only one bus is available for residents per day’ (Focus group participants). Although transport schemes such as Rural Wheels are available in some parts of Westmorland and Furness, it was noted that this service does not run in the evenings or on Sundays:

‘I live in Sedburgh, very isolated, not enough transport, politicians not interested in listening to people with learning disabilities. The transport situation is terrible... Rural Wheels relies on volunteers, only on 6pm Monday to Saturday.’ (Focus group participants)

When public transport is not an option, the cost of hiring a private taxi can be a barrier for some participants:

‘...not everyone can afford a taxi back and forward if they're not capable of getting a bus that day...’ (Focus group participant)

‘Transport, that's the main issue and taxis cost too much money because it's £30 one way from Sedburgh to Kendal.’ (Case study participant)

It was also noted that bus passes (which are available for disabled people and older people) have time restrictions which can be a barrier when travelling for healthcare appointments:

‘Use public transport for hospital appointments, bus pass only starts at 9.30am, but appointments can be earlier so then have to pay.’ (Focus group participants)

Organisational barriers

Another key theme within the findings related to the organisational barriers that disabled people and their carers often encounter when trying to navigate the healthcare or social care systems, for example, when trying to schedule appointments with their GP:

‘GP appointments are worse - you can't get past the receptionist.’ (Focus group participants)

‘I haven't talked to my GP about my worries as can't get in to see them...’ (Case study participant)

‘Longer GP appointments [needed] for people with long term complex problems and ideally being seen by the same GP more consistently...’ (Case study participant)

‘Accessing any form of healthcare (GP, hospitals, dentists) is a REAL challenge (noisy waiting rooms, not kept informed if services are running late, changes of plan, etc), which impacts on my ability to access routine healthcare services.’ (Survey respondent)

Long waiting times for hospital appointments and assessments for assistive equipment were also reported as barriers to accessing healthcare for some disabled people:

‘3 year wait for power wheelchair assessments.’ (Survey respondent)

‘... You have to use your own savings to pay for treatment because NHS waiting times are too long...’ (Case study participant)

Due to a lack of specialist healthcare services within Westmorland and Furness, there were several comments about research participants travelling long distances to attend medical appointments out of the area:

‘Appointments were out of area. Family had to support getting me to and from, which meant they had to take time off work etc to care for me.’ (Case study participant)

‘Some do get patient transport but if they couldn’t have that, or be given a lift by family, they would have to travel to Kendal for eye appointments... [participant] has to travel to Liverpool for her specialist appointments. Much too far away for them... and impossible to attend alone.’ (Focus group participants)

‘...I have to travel 3 hours for the bulk of my treatment. That costs a lot of time and money.’ (Survey respondent)

‘...It is a long way to travel if we need to get sorted for my heart - Blackpool - but not as far as we used to travel.’ (Case study participant)

Another organisational barrier related to the paperwork and application forms that must be submitted in order to claim financial support, such as Personal Independence Payment (PIP), which contain language that was described as ‘gobbledygook’ (Focus group participants). Further comments from the research participants included:

‘All the forms that need to be completed for benefits/getting a job are full of jargon words I don't understand.’ (Focus group participants)

‘...I don’t get any benefits as I wouldn’t know what I am entitled to and the forms look frightening, I did try once but couldn’t summon the energy.’ (Survey respondent)

‘Forms for PIP hard to complete and I have lost my allowance/support as I haven't been able to keep up with the paperwork.’ (Case study participant)

‘P.I.P personal independence payment – [I] did try to get enhanced mobility after [my] leg was removed, but I am over 65 so they wouldn't increase it. I get enhanced care and standard mobility.’ (Focus group participant)

In order to claim this type of financial support, a disabled person must have a formal diagnosis, which itself can take considerable time:

‘I am struggling to get a diagnosis for my autism. It has so far taken 2 years. Covid has slowed the process down. I can't claim PIP as I still don't have a diagnosis.... I need to rely on my parents to complete forms. Everywhere closes

at 5pm when my parents come home from work, so it's hard to speak to support services as I struggle to talk to strangers on the phone.' (Focus group participants)

In addition, the findings suggest that organisational barriers exist within the social care system due to a shortage of carers in rural areas, a lack of support for those who are caring for family members, and a lack of mental health support:

'Services seem to be less available since the pandemic, many people are still working from home and there is a definite shortage of carers, especially in Eden as it is so rural...'. (Focus group participant)

'...I feel [my daughter] falls through the cracks as we look after her. She deserves more involvement [from professionals].' (Case study participant)

'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)

'... There should be more onus on mental health support with social care in the community with a package for lower-level conditions before they are exacerbated into crises. If you're physically disabled, they try and patch you up but not if you are depressed or anxious.' (Case study participant)

Attitudinal barriers

Many disabled people have encountered attitudinal barriers due to a lack of disability awareness within society:

'The biggest challenges are social attitudes, employment opportunities as well as government policy. Society needs to embrace the social model of disability and reject the medical model.' (Survey respondent)

There is often a lack of understanding about hidden impairments, such as neurodiversity or multiple sclerosis, which are not immediately apparent and can fluctuate over time:

‘I don't look disabled. You get looks from people if you are parked somewhere in a disabled bay and it's a day not using your stick, they look at you and I've had people asking me if I should be parking there.’ (Case study participant)

‘I have a range of sensory issues relating to being autistic. So, I can become overloaded by crowded, noisy environments (shops, city centres, restaurants, public transport). On the other hand, at times I am fine coping with those. The unpredictability is one of the challenges. Getting employers to understand this is a challenge.’ (Survey respondent)

The attitudes of some healthcare professionals can be barriers to accessing treatment and support. During one of the case studies, a participant described their experience of acquiring multiple impairments and health conditions over several years - which included chronic fatigue syndrome, degenerative disc disease and spondylitis - and recalled being told by the GP that other people were ‘more deserving of his attention’, and that the participant should ‘get used to’ their situation.

Communication and information barriers

A small number of research participants indicated that they had encountered barriers to accessing information about their impairments/health conditions, the financial and employment support that disabled people are entitled to, and the process for registering for a ‘support dog’. As one case study participant commented, ‘if you don't know what's available, how can you ask for it?’ Further comments provided by the research participants included the following:

‘At the beginning of the diagnosis, you're assigned an MS [multiple sclerosis] nurse to give you information but I don't think there's enough information. Years ago in a doctor's waiting room, they would have a list of services, but they don't do things like that anymore...’ (Focus group participants)

‘...A lot of the things you can get, nobody tells you, you have to hear about it on the grapevine. I didn't know that you can get free car tax (for a mobility car), I'd been paying car tax for eight years, it could've been spent on something else.’ (Focus group participants)

‘...The necessary adaptations to her workplace have been made at the [employer's] expense – raised work surface, high backed, adjustable chair with

neck support, voice recognition computer software etc. She was unaware that the government's Access to Work programme could have provided her with a grant towards an ergonomic assessment and subsequent recommended equipment, thus possibly saving the [employer] at least part of the cost. She has also had her home adapted, and has purchased equipment, but purely on her own initiative, without the input of an occupational therapist.' (Case study participant)

Furthermore, communication barriers were experienced by research participants who are neurodiverse or have learning difficulties, particularly when trying to access medical appointments:

'It's harder to get a doctor's appointment now, so even though I need to see a doctor I don't try. As well as getting through on the phone I struggle to explain my problem to the receptionist who doesn't seem aware of the communication difficulties I have.' (Focus group participants)

'More face-to-face appointments with doctor's, people with LD/Autism require a multitude of senses in order to understand and communicate effectively. Lack of eye contact and exposure to body contact can lead to miscommunication.' (Focus group participants)

Technological barriers

The findings indicate that most research participants in Westmorland and Furness appeared to have adequate access to digital technology, such as computers and the internet. However, one small focus group felt there was a risk that disabled people living in rural areas could be digitally excluded:

'Rural communities could be less tech-savvy and have poor Wi-Fi access. Which could lead to them not knowing about what services are out there or being unable to refer themselves to necessary services.' (Focus group participants)

4.3 Quality of life for disabled people in Westmorland and Furness

The majority of disabled survey respondents (65%) rated their current quality of life as ‘good’, as shown in Figure 32:

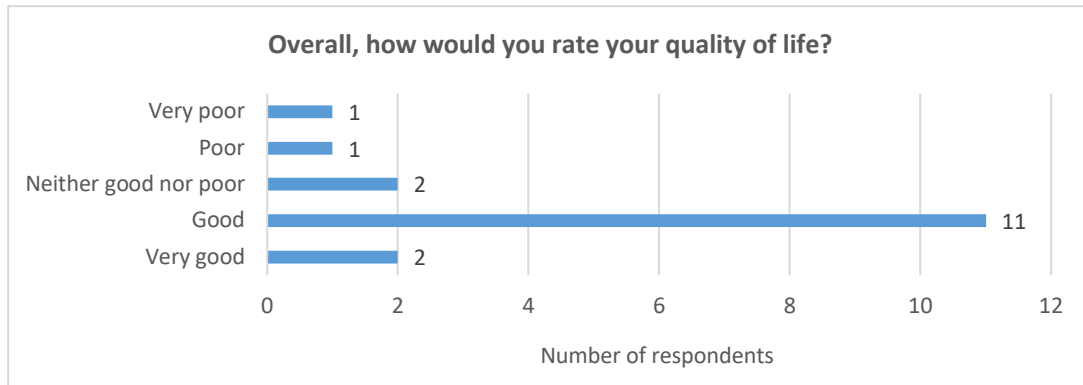


Figure 32: Overall quality of life for disabled people in Westmorland and Furness

However, just over half of disabled survey respondents (53%) felt that their quality of life was worse than five years ago, which was attributed to a deterioration in health, ageing, the increase in cost of living, and Brexit:

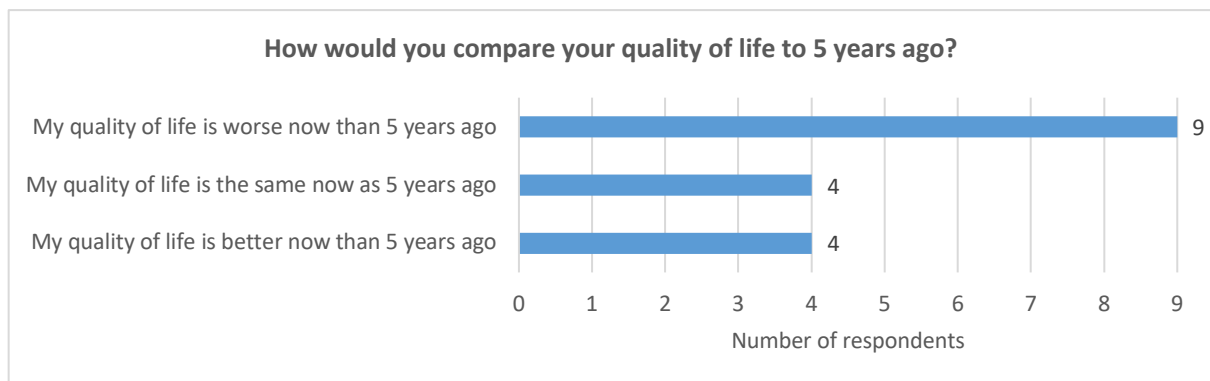


Figure 33: Quality of life for disabled people in Westmorland and Furness compared to five years ago

Figure 34 depicts disabled people’s ratings for 16 statements about their quality of life, ranging from physical and mental health, to social, practical, and personal factors. The strongest positive response was for the pursuit of at least one hobby, and other strong statements were about personal safety, good hygiene, satisfaction with place of residence, comfortable home environment, and self-management of finances. Healthy family relationships and a good means of transportation were also given strong levels of agreement. In contrast, the majority of disabled survey respondents indicated that their physical health was worse than their mental health.

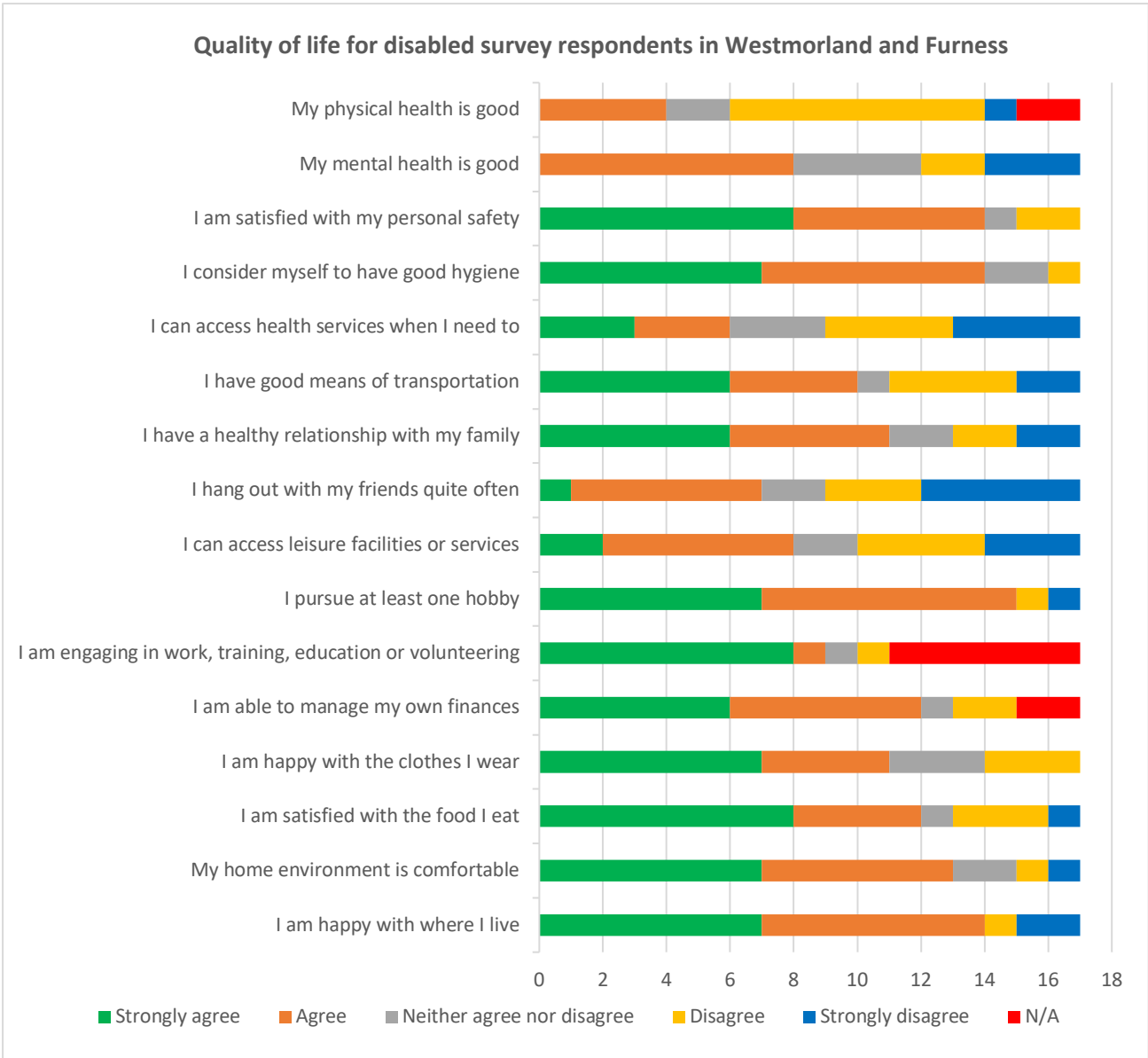


Figure 34: Quality of life for disabled people in Westmorland and Furness

4.3.1 Improvements in quality of life

The findings show that some disabled people felt their quality of life had improved in the past five years due to gaining more independence, being able to engage with people again post-Covid-19, being well supported, and living in an area that they like:

‘...I used to share a flat with someone and now I have my own flat, so I am fully independent now. I was scared at first but now I am happy.’ (Survey respondent)

‘Life better now Covid gone, can see each other and go to clubs.’ (Focus group participants)

‘...her quality of life is quite good, we all put our lives into her. At year 6 she went to a special school and now loves it. She liked being home for most of Covid. Going to more clubs would top it off for her.’ (Case study participant)

‘Yes, life is better now, we used to live in London. Cumbria has fresh air, clean water, safer area. There are less social activities but you can’t have everything.’ (Focus group participants)

In addition, being employed, and living and working in a supportive environment can have a positive impact on perceptions of quality of life:

‘...I am fortunate that I am intelligent and articulate, so I have managed to carve out a career for myself and I am aware of my rights and entitlements, but many are not so fortunate.’ (Case study participant)

‘Employer now is much more supportive and aware of my needs, whereas previously I had to leave a job due to my needs.’ (Focus group participants)

‘The support from PIP, family, partner and having my own home and job has improved my life from when I lived in London. The job and life I lived there was too fast paced and stressful. I was very unhealthy.’ (Survey respondent)

Some of the research participants also noted that experiencing less pain – either through medication or because of surgery – had enhanced their quality of life:

‘I have new medication that has improved some aspects of my life a lot. But now my liver is becoming an issue. It isn’t all good’ (Survey respondent,)

‘Think it’s improved for me – get out and about more now than before... I was finally scanned and kept in hospital at Preston and operated on 2 days later. Then I had a long journey for recovery and convalescence and now today I make [the] most of things. So, I’m in less pain now, so that’s a relief. Life may not be perfect but has improved. However, I don’t have any stamina anymore and am very forgetful and will lose track of my conversations.’ (Case study participant)

4.3.2 Decline in quality of life

Whilst the previous section demonstrated improvements in quality of life for some people, many research participants also reported a decline in their quality of life in the last five years due to factors such as ageing, a deterioration in health, the impact of the Covid pandemic, and loss of independence:

‘Age is catching up and the cancer is slowing me down.’ (Survey respondent)

‘Life now worse - 5 years ago I wasn't as disabled. My health has deteriorated and now getting arthritis, which is genetic.’ (Case study participant)

‘Worse than 5 years ago, I had more resilience 5 years ago, all that has gone, now have less mental capacity to move on if have setbacks.’ (Case study participant)

‘Definitely since Covid - worse. Became isolated due to lockdowns and lost my mobility to what it was. My memory got worse too as not mixing with people. Also, my meds give me memory problems now too.’ (Case study participant)

‘My friend's quality of life is much reduced due to his over-reliance on his wife. This was made worse through Covid as he was not able to go to groups through the MS society.’ (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)

It should be acknowledged that the findings about perceptions of quality of life being negatively affected by ageing and a deterioration in health are not specific to the region of Westmorland and Furness, as this could be experienced by disabled people throughout the UK. However, within the last five years, some research participants felt that access to support services and group activities had declined within their local communities, which has impacted negatively on their quality of life, as demonstrated in the following comments:

‘Nothing around Barrow for people with Autism (only food, charity and coffee shops)...’ (Focus Group participants)

‘Getting the support me and my husband need has got harder. I think 5 years ago I would not have needed to go private.’ (Case study participant)

‘Much worse than before Covid. Lots of places that ran social activities closed during Covid and haven't reopened. I miss not going to as many places as I did.’ (Case study participant)

It was also evident that the increasing cost of living was causing a decline in quality of life for some disabled people:

‘Cost of living has risen significantly in those 5 years, but my income has not.’ (Survey respondent)

‘Cost of living affecting me... on a bad day if I’ve had a seizure, I need a taxi to get home but can't afford it. I can't use the bus on these days.’ (Case study participant)

‘Cost of living means I have to prioritise - keep warm at all costs.’ (Case study participant)

‘... Leisure activities are now deemed a luxury due to the cost-of-living crisis, but the consequence is that people living with mental health issues are less social/active...’ (Focus group participants)

4.4 Experiences of loneliness for disabled people in Westmorland and Furness

As illustrated in Figure 35, disabled survey respondents indicated different levels of experienced loneliness, with most feeling lonely ‘occasionally’ (35%), ‘some of the time’ (24%) or ‘often’ (18%):

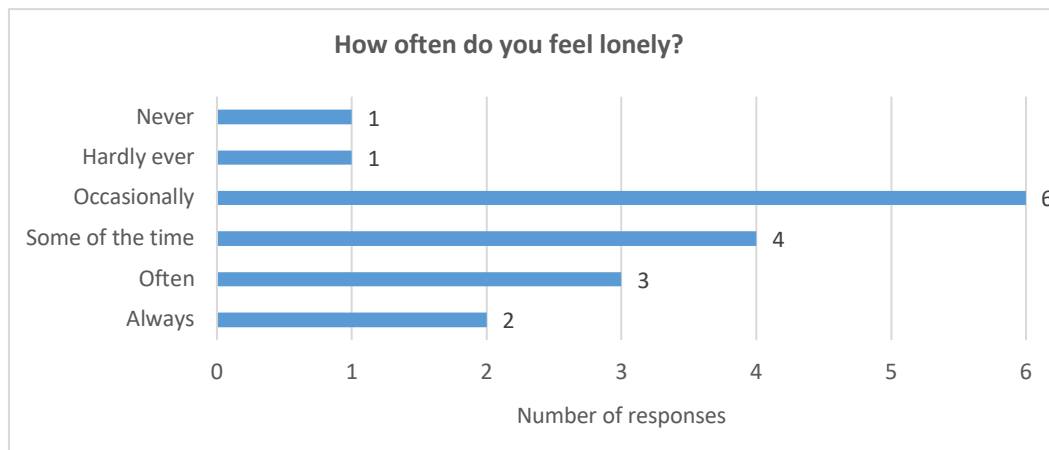


Figure 35: Feelings of loneliness amongst disabled people in Westmorland and Furness

The majority of disabled survey respondents (88%) felt that non-disabled people have more opportunities to feel part of their local communities than disabled people, as depicted in Figure 36:

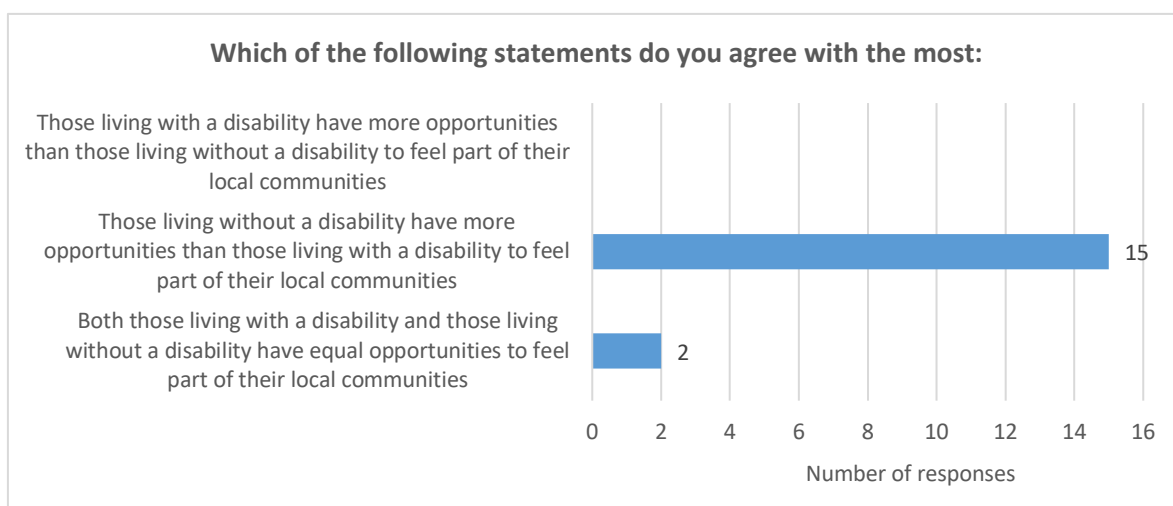


Figure 36: Disabled people's views about equal opportunities in Westmorland and Furness

The findings indicate that some of the barriers reported in section 4.2.2 - specifically, physical and transportation barriers - can restrict opportunities to travel or access activities across Westmorland and Furness, as noted in this comment:

‘Yesterday we should have had a group meeting [People First Self Advocacy] at the Space to Create building in Kendal but I couldn't get transport to take me there.’ (Case study participant)

It was also suggested that some disabled people living in very rural areas might be isolated from their local communities and family/friends due to technological barriers:

‘I've got people who live in the sticks, and they don't see anyone from one day to the next. The trouble is, now they're changing the phones to Wi-Fi phones. If the Wi-Fi goes down or the power goes off, that's it. Some people like the peace and quiet but a lot of these people, their daughters and sons have moved away or to the other end of the county, so they've got nobody to turn to.’ (Case study participant)

The various effects of disabled people’s impairments and health conditions (such as pain, fatigue, depression and anxiety, amongst others) can impact on their social life and how they engage with others:

‘You don't have that luxury of being spontaneous [living with MS], you can be exhausted just to get ready and then when you get there, to have the energy to socialise, it's hard.’ (Focus group participant)

‘Just last weekend, I was too tired / overloaded to attend a close friend's 60th birthday party. I'd have loved to attend and see lots of old friends, but simply too exhausted. Also, I often experience "organisational overload", and simply can't manage to find the impetus to get myself out of the house and socialise. I easily make excuses for not attending events/activities.’ (Survey respondent)

‘Very lonely and isolated, I don't feel I get left out with my Alzheimer’s, I feel it’s just me limiting myself.’ (Case study participant)

‘Post Covid, I am more likely to do something online than face to face as I am still at greater risk. That has a negative impact on mental health.’ (Survey respondent)

For some disabled people, experiencing feelings of isolation or loneliness can exacerbate the effects of their impairment or health condition, which can then impact negatively on their social lives:

‘Due to the isolation, I have found that I am overthinking, and my anxiety did increase. It has impacted my personal life significantly and made me aware of how important my health/mobility is.’ (Case study participant)

In addition, those who have caring responsibilities can sometimes become isolated from their local communities and social circles:

‘I don't see anyone anymore and don't go out. My husband's Parkinson's disease makes me a full-time carer. Physically I am not able to go out with him, pushing the wheelchair is too much for me. I tried it yesterday and nearly wasn't able to get home, it drained me for the whole day. This and my cancer treatment is wiping me out.’ (Case study participant)

The research participants in Westmorland and Furness provided examples of the various activities, organisations or support groups that they had engaged with in their local communities, such as: Age UK, Barrow Disability Centre, Different Strokes support group, Stroke Club, Sign and Song, Hub Club, People First Self Advocacy, Happy Hooves Riding Centre, Vision Support, Back Up and the MS Society, amongst others.

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, meant that individuals were less likely to experience feelings of loneliness or isolation:

‘Not lonely, have family round me and good husband and come out to coffee mornings with him like today.’ (Case study participant)

‘I don't feel lonely as I have my husband and we see our family lots. They ensure they make time for us. Would be different if people didn't have family around.’ (Case study participant)

‘Don't feel lonely... We have good friends and neighbourhood... we volunteer at groups and have good support network.’ (Focus group participants)

4.5 Frustrations and worries voiced by disabled people in Westmorland and Furness

The research participants expressed various frustrations and worries, some of which aligned with the themes presented in section 4.2.2 relating to transportation barriers and organisational barriers when accessing healthcare and financial support. For example, the parents of a neurodiverse child stated:

‘Frustrating that we need to ‘fight’ for a label in order to get kids the support they need. We had to pay privately for our children’s diagnosis as there were no resources/support locally.’ (Case study participant)

Other worries or frustrations shared by research participants typically related to ageing, the possibility of worsening impairments or health conditions, and accessing appropriate support:

‘Getting older and more infirm, and the effects of government policy which might not prioritise assistance for the disabled. Portraying benefit recipients as shirkers or scroungers regrettably doesn’t help many, but at least I have a highly visible disability. I wonder whether I will continue to get support.’ (Case study participant)

‘Have anxiety and depression due to everything. Not being able to see is frustrating. I count my blessings as have a husband and now in touch with vision support that helps.’ (Case study participant)

Both disabled people and carers voiced their concerns about the future of care provision, as shown in the following comments:

‘I worry about my wife, once I die - she has friends and she is a lovely woman, but she doesn’t drive, and her dementia is getting worse.’ (Survey respondent)

‘Who will support me, and when, if I no longer have my parents.’ (Survey respondent)

‘Where will he live when he grows up/ will he be able to go to college. Will he be close to home? Currently 70 miles away.’ (Survey respondent)

Worries about financial pressures - specifically the cost of living - were also expressed by some disabled people, which can impact on quality of life as previously noted in section 4.3:

‘Money is top of our list for this. We live on PIP x 2, carers allowance x 2, and wife is on state pension. That's it. Worried about cost of living and our income.’
(Case study participant)

‘Also worry about my bills, gas and electric so dear, and food.’ (Case study participant)

‘Cost of living worries me; I’m worried of going on the sick as sick pay is rubbish and I’m on my final warning for taking time off due to disabilities.’ (Case study participant)

4.6 Changes suggested by disabled people in Westmorland and Furness

As shown in Figure 37, disabled people in Westmorland and Furness indicated that having an increased social life would improve their life the most, followed by, better access to healthcare services and support, improved availability of public transport and more employment/educational opportunities:

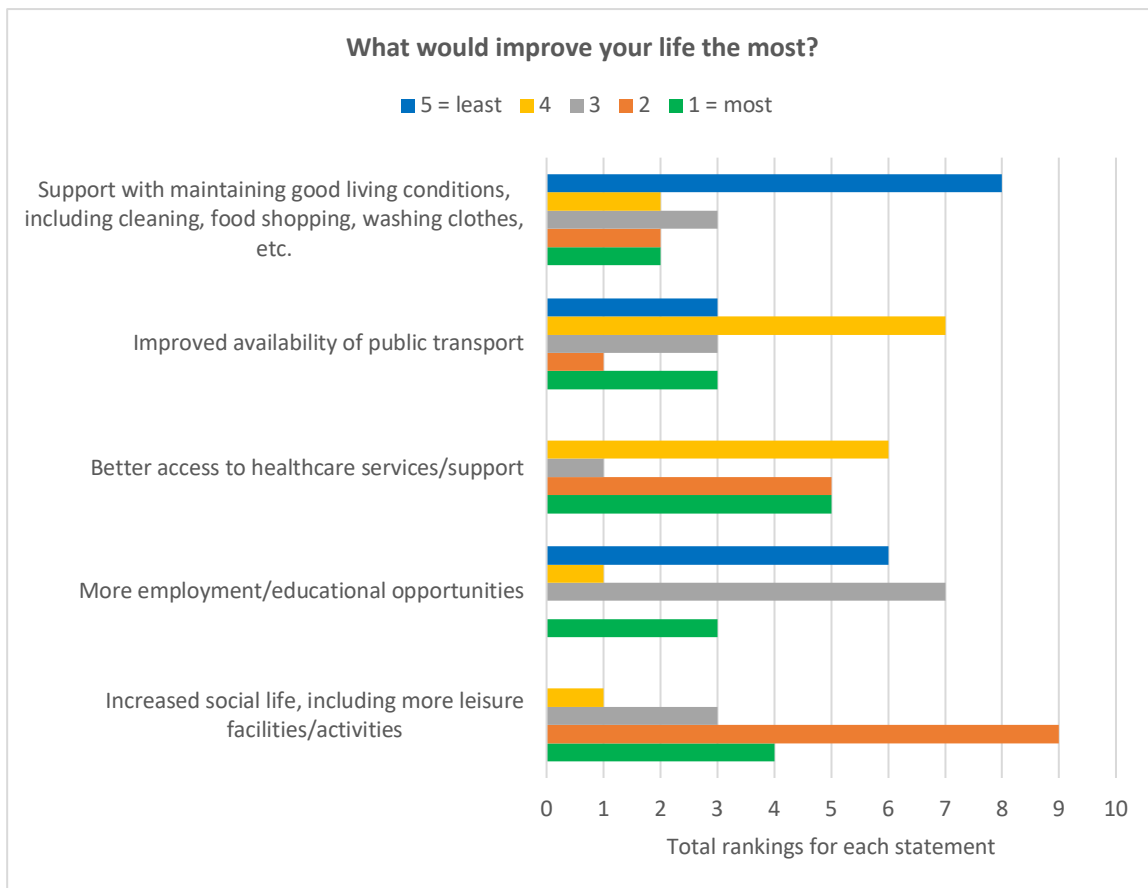


Figure 37: Disabled people's views about what would improve their lives (Westmorland and Furness)

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).

Comments from research participants provide further suggestions for change:

‘A one-stop shop is needed in rural area[s] with all sorts of general information, advice services etc. I live in Askam and if people turned up together on a pop up thing, then local people could find out about all sorts.’ (Case study participant).

‘A more inclusive society as a whole - not just those services directly working with people with disabilities but also 'mainstream' businesses and areas...’ (Survey respondent)

‘Progress is being made but disabled people need to be consulted and involved in changes which public bodies wish to make. There needs to be more user involvement in decision making.’ (Survey respondent)

4.7 Recommending Cumbria as somewhere for disabled people to live

62% of disabled survey respondents from Westmorland and Furness would recommend Cumbria as somewhere for disabled people to live, whilst 38% disagreed.

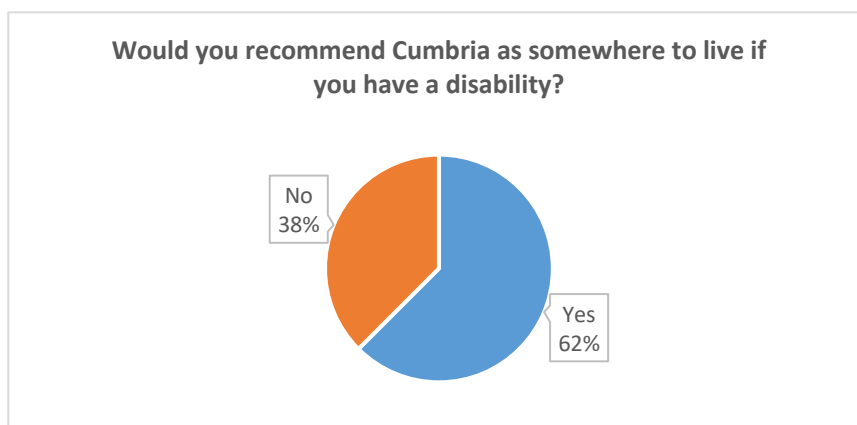


Figure 38: Disabled people's views about recommending Cumbria (Westmorland and Furness)

Comments included:

‘Because for me, the people are lovely and kind, my family are here, and people look out for each other. We just need more funding to take our transport links up to where they were about 20 years ago.’ (Survey respondent)

‘Other areas of the UK that I have lived in offer more meaningful support, particularly to people with "hidden disabilities".’ (Survey respondent)

‘...there needs to be a step change in support, Cumbria needs to adopt the social model of disability and embrace this model to drive forward opportunities for disabled people.’ (Survey respondent)

5. Findings 4: Cumbria-wide

This section presents the voices and experiences of 122 participants living across Cumbria. This dataset includes participants that live in postcode areas that come under either Cumberland Council or Westmorland and Furness Council; participants who access services within Cumbria but live outside the county; or data responses that did not contain the participant's postcode. The Cumbria-wide dataset included 35 case studies, 12 focus groups, 27 survey responses, and four Facebook comments (as detailed in section 2 of this report).

The Cumbria-wide findings displayed in this section align with the themes already presented for Cumberland (section 3), and Westmorland and Furness (section 4), and will therefore provide further insight into the lives of disabled people across the county.

5.1 'Normal life' for disabled people in Cumbria

The comments presented below provide an example of the wide variety of 'normal lives' described by disabled people across Cumbria:

'My day has to involve minimum movement and is evenly paced. I get up early to feed the dog, have coffee and, if I feel up to it, take my dog for a short walk using my mobility scooter. I then go back to bed. I get up again at varying times, often mid-afternoon, then prepare a snack. I seldom spend more than 10-15 minutes on chores. My son phones or visits daily. I prepare a ready meal early evening and watch TV for 1-2 hours before going to bed early, usually exhausted. Sometimes I listen to calming music for a short period.' (Case study participant)

'Impossible to have regular activities due to unpredictable and fluctuating symptoms and no help or support.' (Survey respondent)

'...I'm independent but need to pace myself and consider how much energy I'll have for the rest of the day's activities and whether I'll trigger a migraine etc. Shower every day but don't wash hair etc. Medication timing and having to remember alongside the rest of the family's needs etc. Can't walk the dog so have to rely on other members of family. Can't walk son to school so drive everywhere.' (Survey respondent)

'Woken up by alarm/parent/carer. I make my breakfast with a little bit of help. My dad drives me to group as the bus doesn't get me there on time... I need help getting into the building and I need to use the 'dropped curb' in case I fall.' (Case study participant)

Some of the research participants described their typical day in their role as carers or parents of disabled people:

'A normal day for me, who cares for someone with a disability, is helping them to communicate and access day to day tasks that someone without a disability may find easy.' (Survey respondent)

'No such thing! Get up. Make sure everything is ready for school. Breakfast, cuppa, hot choc, teeth, face, hair, suitable clothing, shoes, packed lunch, message school to update how evening/ morning is going. Reassurance about anything. Keep look out for taxi and make sure a countdown to him getting transport. Home from school. Make sure we have enough bread for snack, if not have to go to shop. Talk about day, unpack school bag. Read. Sort dinner. Supervise shower/hair wash. Empty dishwasher, tidy, Hoover laundry. Finally sit down about 8pm.' (Survey respondent)

'Bloody hard work. Almost impossible to get respite care. Social life non-existent.' (Survey respondent)

'It's like living with the disability yourself. Helping, supporting, and doing things for the person as they are unable to do it or need encouragement.' (Survey respondent)

As depicted in Figure 39, all disabled survey respondents felt that their disability holds them back, to some extent, when going about their daily lives:

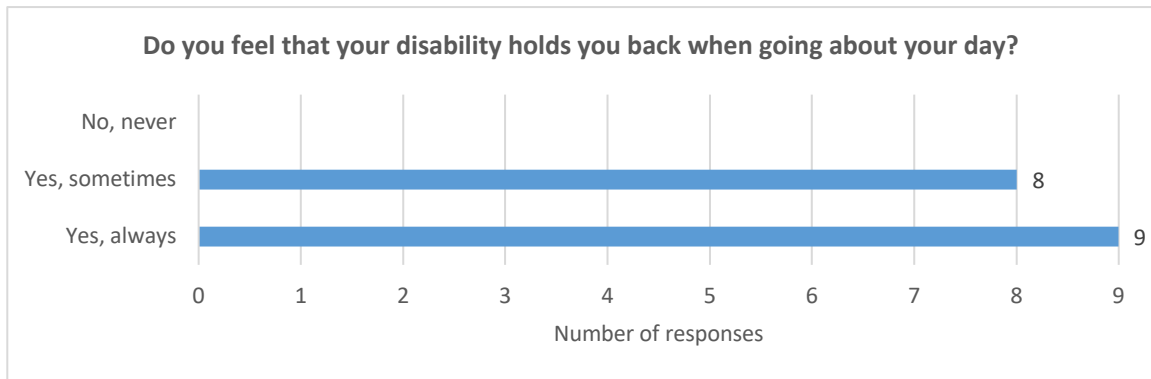


Figure 39: Disabled people's views about their impairments or health conditions holding them back (Cumbria-wide)

The survey respondents explained how their impairments or health conditions hold them back when going about their day:

'It stops me working, spending time with my family, exercising etc.' (Survey respondent)

'Chronic fatigue and breathlessness mean I spend more than 70 % of the day in bed.' (Survey respondent)

'It's mostly to do with other people not understanding. It also takes me longer to process things.' (Survey respondent)

'Access issues when out and about as a wheelchair user. Also, difficulty managing to look after myself at home with my disability.' (Survey respondent)

Figure 40 shows that 69% of disabled survey respondents live fully or somewhat independently, and the remaining 31% rely on some level of support. One survey respondent commented: 'I would consider my wife to be my 'informal' carer.'

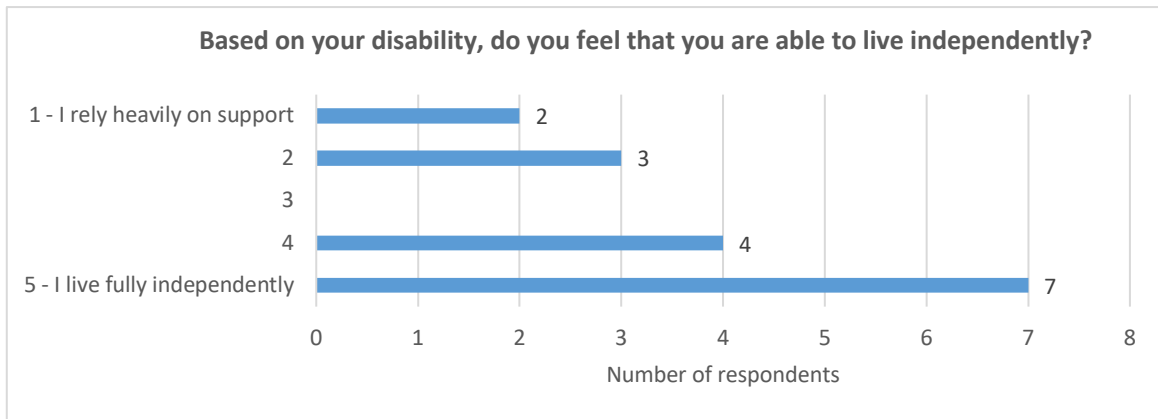


Figure 40: Disabled people’s views about living independently in Cumbria

The survey findings also show that most of the Cumbria-wide disabled survey respondents (71%) indicated that they either ‘know’ or ‘know enough’ about their rights as a disabled person; the remaining 29% indicated that they ‘don’t know’ their rights or ‘want to know more’, as illustrated in Figure 41.

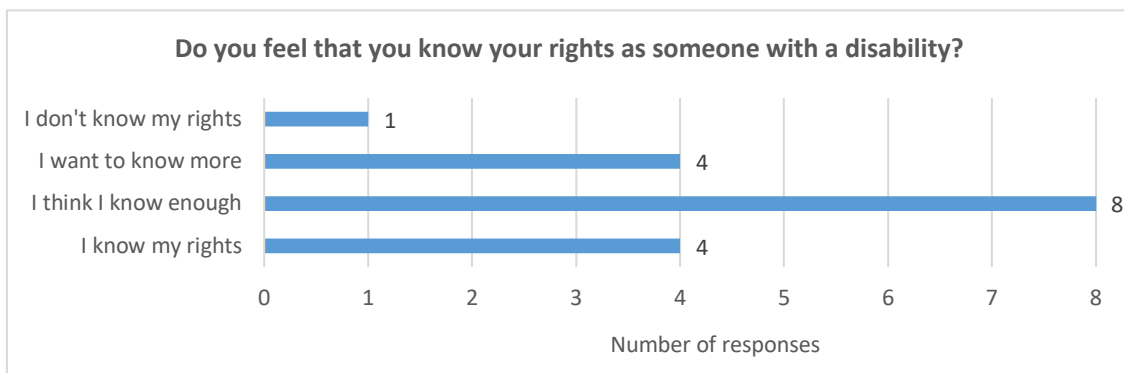


Figure 41: Disabled people’s knowledge about their rights (Cumbria-wide)

5.2 Challenges and barriers experienced by disabled people in Cumbria

5.2.1 Living a ‘good life’

As depicted in Figure 42, the majority of disabled survey respondents indicated that their impairments or health conditions hold them back, to some extent, from living what they consider to be a ‘good life’:

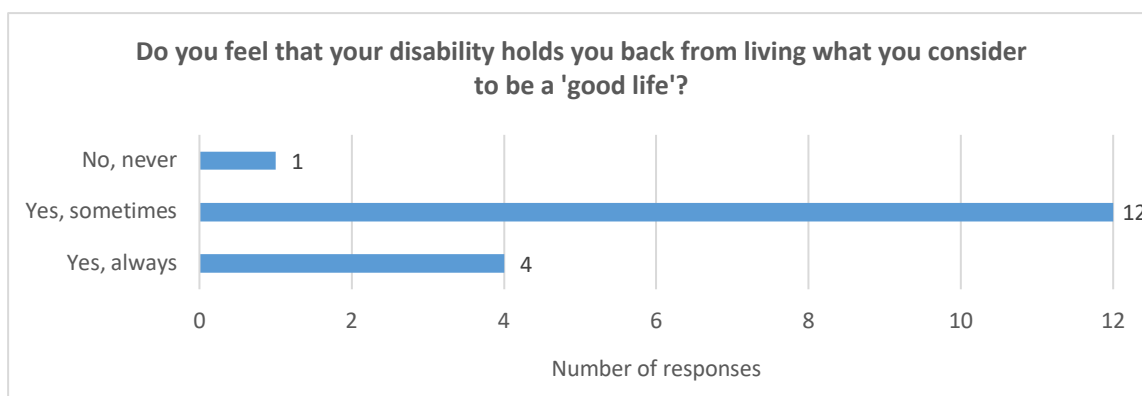


Figure 42: Disabled people's views about living a 'good life' (Cumbria-wide)

Examples of what a 'good life' might look like for some disabled people included the following:

'I encounter so many barriers due to the restrictions imposed by my health problems. A good life would be pain and allergy free.' (Case study participant)

'No pain, no brain fog, lost weight. Being able to concentrate on conversations.' (Survey respondent)

'Not being limited - maintaining relationships, being able to do things with my social group automatically without having to consider whether I'll manage. Spending time with family and friends.' (Survey respondent)

'Independence. But really, I am lucky to have the support of my wife and family. I wish the invisible barriers would disappear.' (Survey respondent)

'Stable working conditions. Weekend social activities. More independence (move in with partner and away from parental home).' (Survey respondent)

'I have always been an optimist and feel that barriers in life are there to be overcome as I want to set a positive example for my children. Reality dictates that there is much I am unable to do because of fatigue and exhaustion. I feel that in many ways I am leading as 'good' a life as possible in adverse circumstances. I never feel sorry for myself, and don't 'advertise' the fact that I am disabled.' (Case study participant)

5.2.2 Barriers

This section presents sample comments, from both disabled people and their carers, that indicate the disabling barriers experienced across Cumbria. A larger quantity of comments was provided in relation to transportation, organisational and attitudinal barriers.

Physical barriers:

‘Better accessibility into places, there's a lot of old buildings [in Cumbria] and they can't always guarantee they can change the buildings.’ (Case study participant)

‘Lack of yellow on black signage/step markers, if I didn't have a carer I would struggle.’ (Case study participant)

‘... Every movement has to be thought about. Steps, stiles, gates, kerbs, heavy doors, inaccessible toilets etc etc...’ (Survey respondent)

Transportation barriers:

‘Lack of accessible public transport. Lack of accessible toilets, with hoists, though there is one at Windermere but the accessible path to the lake isn't connected to the disabled parking. Seriously, I'm not making this up. Parking is always a problem. Many people do not respect disabled parking spaces.’ (Survey respondent)

‘Poor transport, buses, trains and taxis [which means] relying on parents.’ (Focus group participants)

‘Transport, you get buses every half hour in Maryport, that's okay. But in Workington, if you want to get up to Moorclose, the buses are regular but then they knock off at 9pm, and in Cockermouth that's the same’. (Case study participant)

‘I walk with a rollator walker and when I get on a bus for instance... I tend to sit on the seats allocated for disabled folk like me. So why do mums with prams feel that because I have a rollator walker, I should give them the space to park their prams even if I had got on the bus first. I'm sorry my walker is not a fashion

accessory. And I find that a lot of the shops when I go down the aisles are too narrow so keep knocking things over, so in the end I avoid it.” (Facebook comment)

Organisational barriers:

‘Systems and forms are over complicated.’ (Survey respondent)

‘... don’t even get me started on the fact that because my PIP 4 years ago had only awarded me 4 points for the moving around bit, I am not entitled to a disabled bus pass even though I can barely walk most days...’ (Facebook comment)

‘The only thing that stops me is my hearing, it's six months to wait to see if you can get a hearing aid, it's crazy. Mostly it's the time waiting for the doctors.’ (Case study participant)

‘Carlisle hospital is nowhere near as good as West Cumberland Hospital.’ (Focus group participants)

‘I contracted Covid during lock-down and continuing breathlessness, brain fog and difficulty in regulating body temperature suggest it may have developed into long Covid, which is being clinically investigated at the moment. Making GP or hospital appointments is stressful and attending them is physically exhausting, which exacerbates my symptoms. Attending appointments at Carlisle hospital is particularly challenging and involves a long walk. If kept waiting I need to be able to lay (not sit) down, which means I need to take appropriate resting equipment with me. This is generally not well received by clinical or reception staff.’ (Case study participant)

Attitudinal barriers:

‘The main barriers are a lack of understandability from the general public.’ (Focus group participants)

‘People perceiving me as weird.’ (Survey respondent)

'People not understanding what you're going through and then thinking you're making up your condition.' (Survey respondent)

'People need to understand me and my needs. People try to make me fit into what they think is right for me, this happened a lot at school and college. I am happy now that education has finished.' (Case study participant)

'You do a lot of the time feel like a second-class citizen. I used to go into Costa with my husband in a wheelchair and I would say 'you order' and they would speak to me, that's the attitude that you're a lesser person...' (Case study participant)

'I don't live in Cumbria but have... spent a lot of time in Carlisle for over 6 years. A large issue I face is with transport. This may seem like a menial issue, however I have faced many uncomfortable encounters at the station taxi... Alongside my autism I also have hyper-mobility and can experience (varying) pain in my joints... Because I appear 'young and able' a few (not all) taxi drivers at the rank had refused me for the short fare or during some journeys I have faced uncomfortable questions, been accused of laziness, been made to feel like I was impacting their earnings and day wage. I used to just say I was running late/train had been delayed. However, I now (due to my autism and anxiety) do not feel able to approach the taxi rank for my work commute, which (although is such a small issue in the perspective of things) means I often arrive to work in pain after the walk and feeling frustrated that my work could have been made easier...' (Survey respondent)

Communication and information barriers:

'From my experience, no help, no information. Not everyone communicates the same. Lack of knowledge from professionals & understanding.' (Survey respondent)

'I wear hearing aids, and this makes it difficult to communicate with people. I don't wear them for work, as it's a noisy environment. This impacts on my daily life as it makes me feel isolated.' (Case study participant)

Technological barriers:

‘Specialist equipment hard to access/know what equipment I need. I’m not online so have no way of finding information.’ (Case study participant)

‘Old people not being able to do online banking due to not having computers or mobile phones.’ (Case study participant)

5.3 Quality of life for disabled people in Cumbria

Figure 43 illustrates that 47% of disabled survey respondents rated their quality of life as ‘neither good nor poor’, and 35% rated their quality of life as either ‘good’ or ‘very good’:

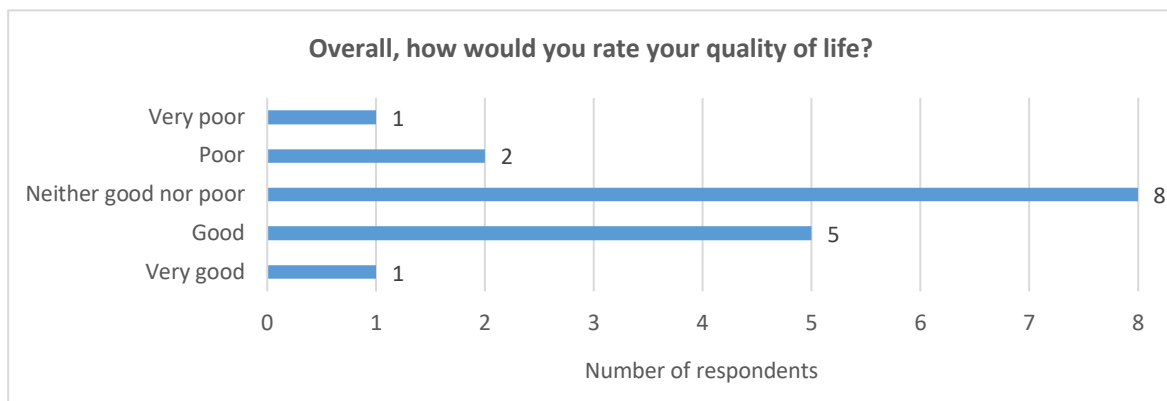


Figure 43: Overall quality of life for disabled people in Cumbria

The majority of disabled survey respondents (71%) indicated that their quality of life was worse than five years ago, as shown in Figure 44:

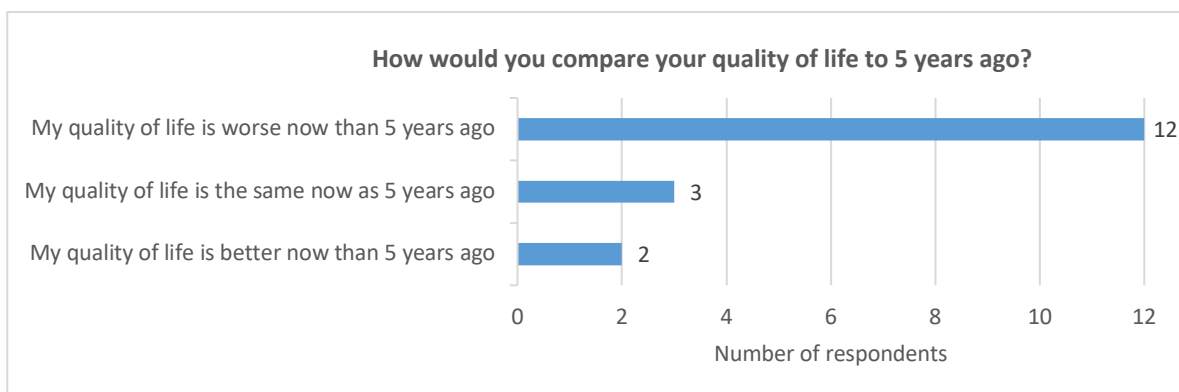


Figure 44: Quality of life for disabled people in Cumbria compared to five years ago

Figure 45 depicts disabled people’s ratings for 16 statements about their quality of life, ranging from physical and mental health, to social, practical, and personal factors. Personal aspects of life such as a comfortable home environment, being happy with where they live, and the management of own finances were viewed positively by disabled people. In contrast, responses to both physical and mental health, socialising with friends, and accessing health services or leisure facilities received very mixed responses.

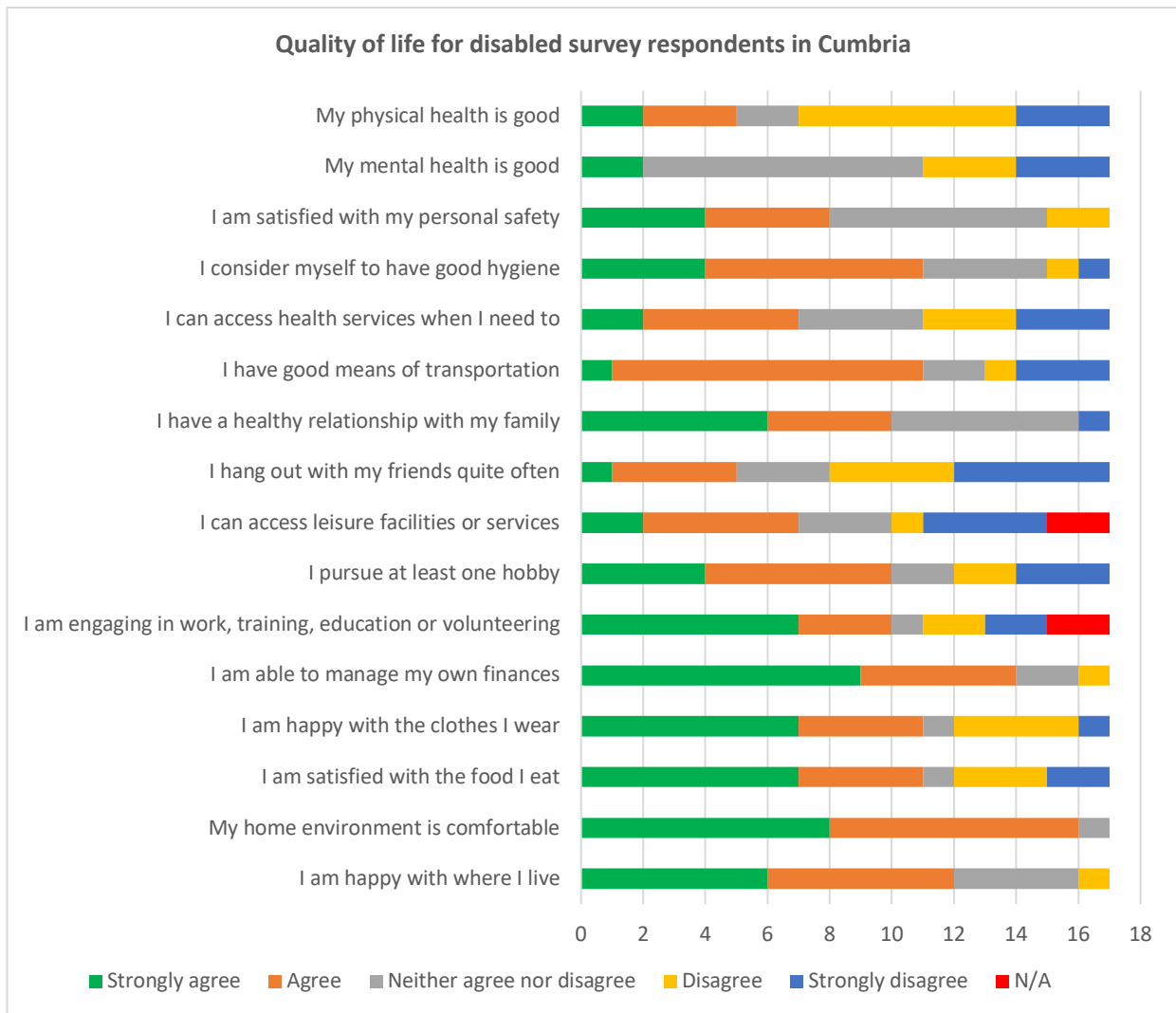


Figure 45: Quality of life for disabled people in Cumbria

5.3.1 Improvements in quality of life

The research participants indicated that improvements in their quality of life during the past five years could be attributed to: a reduction in physical barriers, improvements to impairments or health conditions, receiving a diagnosis, increased confidence, reasonable adjustments being made in the workplace, and engagement in social activities. For example:

'I purchased a mobility scooter recently which has improved my life. There are more dropped kerbs and equipment, and adaptations seem to be more readily available these days to enable people in both home, outdoor and work environments.' (Case study participant)

'Times have got better - greater awareness - improvements in facilities e.g. lowering the kerb at the hospital.' (Focus group participants)

'... there is no cure for this condition, but my vision has improved following the reattachment of a detached retina (again caused by Marfan's muscle weakening effect).' (Case study participant)

'I didn't have a diagnosis five years ago and I just thought I was weird. It helped me make sense of things.' (Focus group participant)

'Through reasonable adjustments I have been able to move from part time to full time work, so less of a financial strain.' (Survey respondent)

'My life is now better than it was - my confidence has improved, no bullying anymore. I'm more outgoing, keeping busy with swimming and horse riding makes me happy and I never used to be able to do those things.' (Focus group participants)

5.3.2 Decline in quality of life

The research participants provided the following reasons for a decline in their quality of life in the past five years: organisational barriers (e.g. long waiting lists), worsening impairments or health conditions, loss of independence, and a lack of support services. For example:

'Harder now for people with disabilities as the waiting lists are so long to be seen/reviewed. People have lost confidence in the NHS because they are so over-stretched now. People's conditions are getting worse as they are waiting longer to be seen.' (Case study participant)

'Since having a catheter my quality of life has worsened, fatigued (tiredness) - no energy to enjoy my life to the fullest, my partner who has cancer does most

of the driving as I am a less confident driver, so we now don't get away in the motor home. This is isolating for me.' (Case study participant)

'5 years ago, I was much more independent. I wasn't in pain all the time and had more energy. '(Case study participant)

'My quality of life is poor now. I used to be much more independent. I am no longer able to drive. I have less contact with the outside world now.' (Case study participant)

'Quality of life worse - constant worry - lack of independence, have to rely on my wife to help me get dressed and do basic everyday tasks.' (Focus group participants)

'I became ill in 2016. Since then, it has been a completely different life. I can no longer work (I loved my job), no longer have access to the countryside (was always out and about), cannot ride my motorcycle.... and so on.' (Survey respondent)

'On the whole quality of life is worse than 5 years ago. There are less activities now, there are less respite places, not all activities started back up after Covid. Money does not go as far. Transport is far worse. Lack of support staff and carers.' (Focus group participants)

'5 years ago [my child] was 16 and still availing off children services. It appears that there are fewer services for [my child] than there are for his peers with learning disabilities. He seems to fall through the gap. (Survey respondent)

'Cutbacks in health and social care services mean that there is no support available now so I'm housebound and struggling to cope or eat healthy as I cannot prepare or cook meals.' (Survey respondent)

5.4 Experiences of loneliness for disabled people in Cumbria

As illustrated in Figure 46, disabled survey respondents experienced different levels of loneliness, with most indicating that they feel lonely 'often' (29%) or 'some of the time' (24%) or 'occasionally' (18%). 18% of disabled survey respondents also indicated that they 'hardly ever' feel lonely:

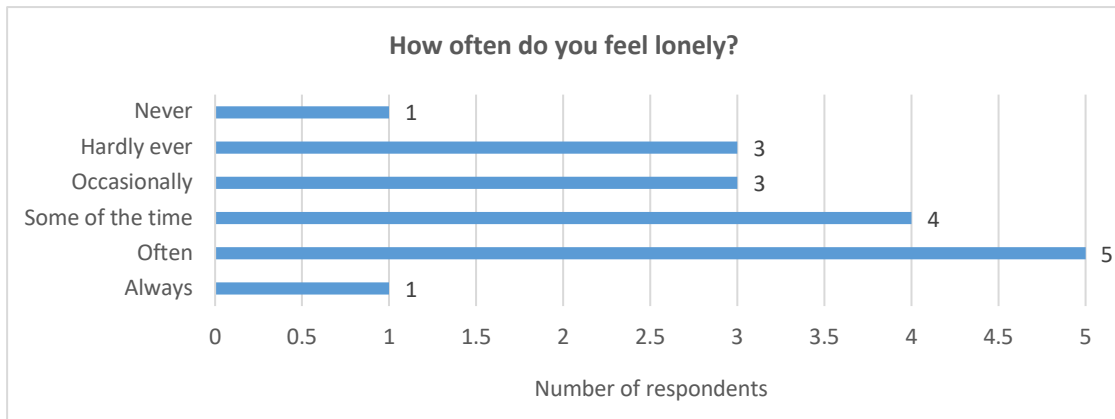


Figure 46: Feelings of loneliness amongst disabled people in Cumbria

Research participants shared their experiences of feeling lonely and isolated:

‘Missed out a lot, being a spectator. Sport, adventures, holidays that I wouldn’t be able to take part in. Have taken part in as normal a life as possible for me.’
(Survey respondent)

‘Loss of hearing causes you to become inward. Loss of confidence. Don’t go out as much and see friends.’ (Survey respondent)

‘Living rurally increases isolation. I’m no longer an active member of the community and that has changed my whole quality of life.’ (Focus group participants)

‘People living rurally feel less a part of the community due to reduced transport links. Logistically this is isolated, this is compounded for people with mental health issues as I am sensitive to the corruption in the world, and I don’t like going out, unless it is for essential things as it increases my anxiety’. (Case study participant)

The majority of disabled survey respondents (71%) felt that non-disabled people have more opportunities to feel part of their local communities than disabled people, as depicted in Figure 47:

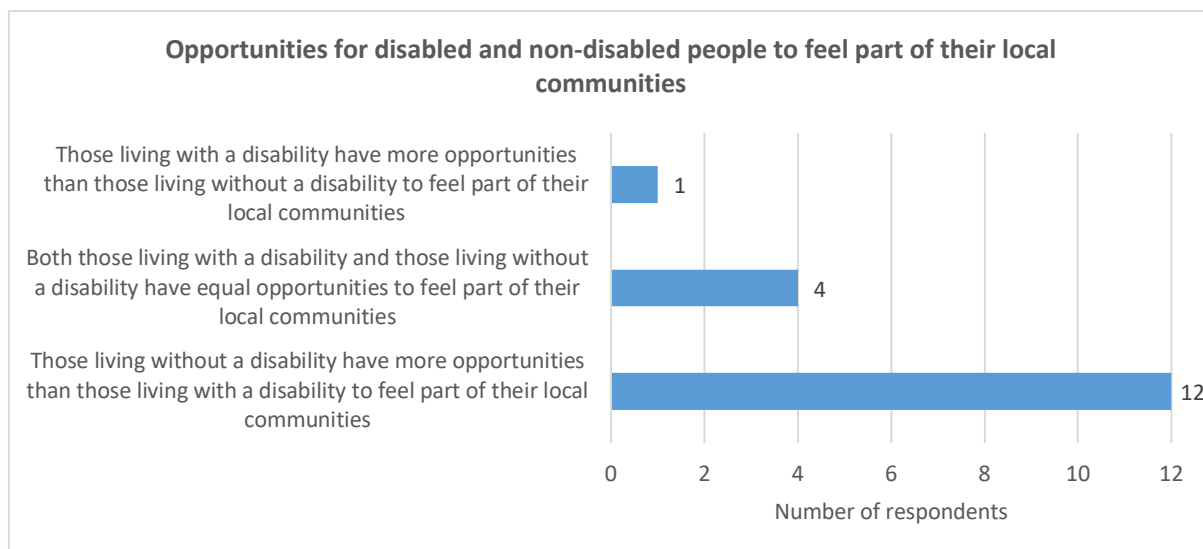


Figure 47: Disabled people's views about equal opportunities in Cumbria

The following comments support the view that disabled people having less opportunities to feel involved in their local communities:

'No, definitely not equal to non-disabled people. If I didn't have my family organising things for me and transporting me, I would never leave the house.'
(Case study participant)

'I would say that people living with a disability have less of an opportunity to feel a part of the community. However, this has improved massively over the last couple of years, I just feel it could improve more!' (Survey respondent)

The research participants provided examples of the various groups and organisations they had engaged with across Cumbria, which included: Men in Sheds, Positive Pals, Prime Arts, Macular Disease Society, Triple A, Heathlands, Two's Company, Harraby Community Centre, and Mencap. Some comments about disabled people's awareness of - and engagement with - local support groups and activities included:

'I don't know anyone else who has Fibromyalgia, and I don't know about any support groups or where I can be around people who understand.' (Case study participant)

'I think there's a couple of things run for disabled people but if you didn't know about them...I don't think they're very well signposted.' (Case study participant)

‘I am not lonely when I go to groups.’ (Focus group participants)

‘Coming to Heathlands is good for me, I get to meet lots of new people and see my friends...’ (Focus group participants)

‘I like coming to Prism Arts as nobody here judges me and I have friends here.’
(Case study participant)

5.5 Frustrations and worries voiced by disabled people in Cumbria

The research participants expressed worries or frustration about: worsening impairments or health conditions, loss of independence, future access to health and social care services, financial concerns, lack of support in rural areas, attitudinal barriers and lack of understanding about hidden impairments, and organisational and technological barriers. Examples of their comments are included below:

‘Every day is hard now. Feel more pain and becoming less able and motivated as I get older. Feel concern about how much worse things might get. (Survey respondent)

‘Worry about condition worsening, not being able to afford care/medication I might need.’ (Case study participant)

‘My condition stops me doing the things that I loved doing, such as gardening, which was a hobby of mine. I worry about my continuing ability to cope and to live independently, and what the future holds.’ (Case study participant)

‘The biggest frustration is not having things to look forward to. I am mainly housebound and rely on others to visit me. I used to be independent and a very social person. I worry about being a burden.’ (Case study participant)

‘I worry about my long-term financial security. Fears about later life and lack the of health and social care support to enable me to live well.’ (Survey respondent)

‘Lack of health and social care services for people with chronic illness and disability directly results in a deterioration in a person's health and wellbeing.’
(Survey respondent)

‘Frustrations include lack of support in rural areas, if I didn't drive my life would be completely different. It is also frustrating that people don't understand what it is like to have an invisible health condition.’ (Case study participant)

There is a lack of understanding around people with dyslexia, people will spell things out but say it really fast.’ (Case study participant)

‘I don't know how someone would take it if I told them I was autistic, so I don't tell anyone’ (Focus group participant)

‘The issue is the expense of the hearing aids...’(Case study participant)

‘So many different specialists cover the range of conditions I have – not much interconnection/liaison between them in my experience.’ (Case study participant)

5.6 Changes suggested by disabled people across Cumbria

As shown in Figure 48, disabled survey respondents indicated that having better access to healthcare services/support, and better social lives, would improve their lives the most. This is consistent with responses shown in section 5.3, where service access and socialising with friends were rated low for current perceptions of quality of life:

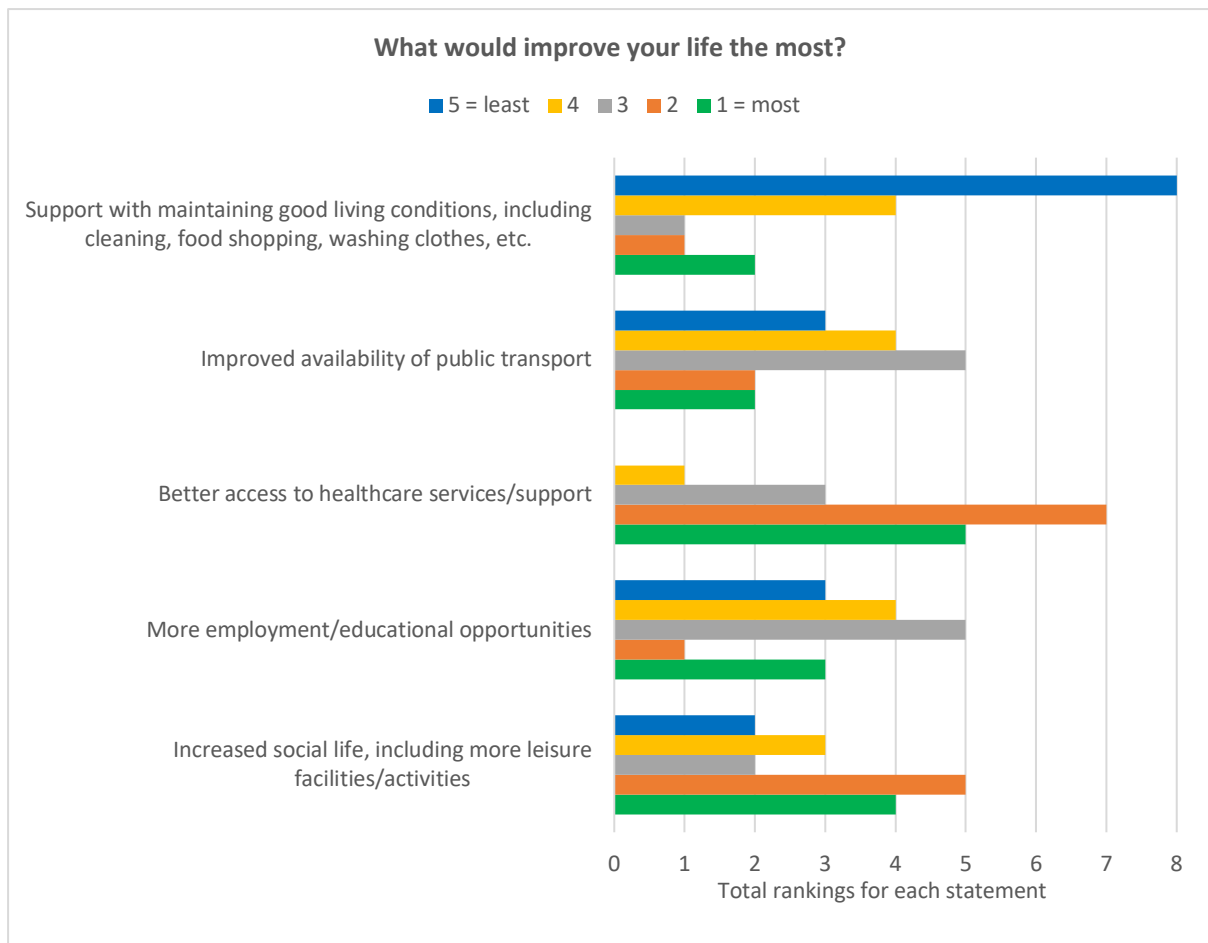


Figure 48: Disabled people's views about what would improve their lives (Cumbria-wide)

The research participants' suggestions for changes that could improve the lives of disabled people reiterated those already presented in sections 3.6 and 4.6 of this report, with a particular emphasis on the need to address the physical, transportation, organisational, attitudinal, communication and information, and technological barriers that exist within society. Comments from research participants provide further suggestions for change:

'Greater access to the outdoors. More designated Blue Badge spaces. More disabled toilets. Less stiles, kissing gates etc.' (Survey respondent)

'Improved transportation and access to facilities. Accessible support...' (Survey respondent)

'Much better understanding of those with disabilities... understanding that although two with the same disability may not look the same. Better support...' (Survey respondent)

‘More awareness across society re: invisible illness/disabilities.’ (Case study participant)

‘Services need to be publicised more, most of it is word of mouth.’ (Case study participant)

‘A one-stop shop with all the support, GP, carers, mental health services, social groups need to work together.’ (Case study participant)

5.7 Recommending Cumbria as somewhere for disabled people to live

Similar to the findings presented in sections 3.7 and 4.7 of this report, 53% of disabled survey respondents would recommend Cumbria as somewhere for disabled people to live, whilst 47% disagreed with this statement:

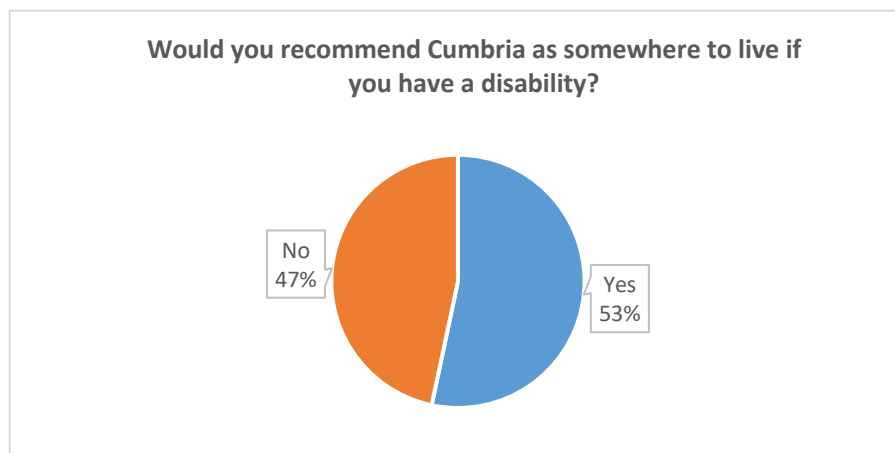


Figure 49: Disabled people's views about recommending Cumbria (Cumbria-wide)

Some comments from different perspectives included:

‘Information about support or services is very hard to navigate.’ (Survey respondent)

‘It's rubbish. Exclusion from inaccessible places and no support available for health and social care due to cutbacks so people are left to rot.’ (Survey respondent)

‘... The quality of life you can attempt to access in the natural environment here in Cumbria compared to an urban environment is better, even if the services and health care may not be. There are pockets of fantastic practice, but you have to properly search for them. Very much depends on your individual disability.’

(Survey respondent)

6. Conclusions and Recommendations

6.1 Conclusions

The *Disability Voices: Understanding the lives of disabled people in Cumbria* project aimed to capture the voices of disabled people 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.

In summary:

- The Disability Voices project engaged a total of 758 disabled people, carers, and professionals working with disabled people across Cumbria. The data collection involved a total of 54 focus groups, 202 case studies and 155 surveys, along with seven comments collected through social media.
 - Cumberland was the largest dataset with a total of 489 research participants, and involved 114 case studies, 26 focus groups, 100 survey responses, and two Facebook comments.
 - The Westmorland and Furness dataset had a total of 147 research participants, and involved 53 case studies, 16 focus groups, 28 survey responses, and one Facebook comment.
 - The Cumbria-wide dataset had a total of 122 participants, and included 35 case studies, 12 focus groups, 27 survey responses, and four Facebook comments.
- 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 the following:

- 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.
- 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.
 - 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.

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

6.2 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 plans⁴.
- 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 Places⁵ available as there needs to be enough room to

⁴ For example, the new University of Cumbria campus at the Citadels, Carlisle and the redeveloped Carlisle Train Station, are two projects that need to be accessible to people of all disabilities.

⁵ [Changing Places Toilets \(changing-places.org\)](http://changing-places.org)

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?

6.3 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 data shows that many responses display frustration or anxiety around the lack of awareness of such conditions. Future research could explore existing policies in key services, as well as attitudes within service delivery to hidden impairments, in order to

identify specific changes to practice that would have a positive effect in reducing frustration and/or anxiety.

- *The impact of the cost-of-living crisis on disabled people's lives.* Within the data, participants noted that the cost of living was a barrier to them living a good life. However, very few went into details on the nature of this barrier: e.g. whether rising costs in specific areas were particularly impactful. Further work could examine whether more work can be done in alleviating the impact of the cost-of-living crisis in those areas, to inform targeted support in Cumbria⁶.
- *The physical and transportation barriers experienced by disabled people across the county.* Research that mapped out the main routes of travel and 'black spots' for disabled people within the county would enable local authorities to better understand the areas to invest in.
- *Disabled people's experiences with technology.* Providing insights into the impact of the recent digital shift as a consequence of the Covid-19 pandemic, as well as the impact of living in rural areas.
- *Disabled people's experiences of accessing health services throughout Cumbria.* While many of the participant views reflected broader issues in health delivery that affect the whole population (such as increased waiting times), they also pointed to a number of localised solutions that could be pursued through further research at the level of General Practice Surgery; for example, whether access to autism-friendly waiting rooms might be possible.
- *Disabled people's access to, and experience of, education and/or training across Cumbria.* As above, it would be beneficial to explore specific education or training pathways and what can be done in terms of policy, delivery and communications to enhance the experience of people with disabilities in the region.
- *Disabled people's experiences of employment across Cumbria.* While a significant number of respondents were in full-time employment, the data produced less detailed accounts of these experiences. A more focused study on what good employment looks like for people with disabilities could link in with the studies suggested above to create a roadmap for employers.
- *The role and experiences of carers for disabled people - both those in professional caring roles and those in unpaid caring roles.*

⁶ The councils (Cumberland and Westmorland and Furness) could potentially undertake this research. They could survey the population for people in need, and use their contacts with community organisations to refer people to support.

- *The benefits of engaging in social activities and groups alongside other disabled people.* An increasing amount of research is looking at the different forms of social activities available to disabled people, and a review of the available data on this to ascertain what works well and for whom would be beneficial.

6.4 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.

Both new 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.