



North West Regional Stakeholder Network Insight Report into the development of the National Disability Strategy

North West Regional Stakeholder Network Insight Report into the development of the National Disability Strategy, December 2020

Table of contents.....	2
Executive Summary.....	3
Introduction	4
Research Methods.....	5
Recommendations.....	6-9
Analysis of Results.....	10-25
Contact details	26
Appendices	27-76
<ul style="list-style-type: none">• Appendix 1: Data: Quantitative Survey Results• Appendix 2: Data - Qualitative Survey Results• Appendix 3: Data - Collective Responses from BSL users Focus Group• Appendix 4: Copy of Easy Read Survey• Appendix 5: List of RSN members	

Executive Summary

We (the North West Regional Stakeholder Network) welcome the opportunity to present our research to the Disability Unit, on the views of disabled people from across North West England.

The UN Convention on the Rights of Disabled People stipulates specifically that Governments must consider how new policies affect disabled people, and we're pleased to see Government taking this idea on board and engaging with disabled people before a Strategy is published rather than afterwards. Co-production with disabled people on something as significant as the National Strategy is vitally important to make sure that the Strategy supports disabled people to live independently within their local communities, with choice and control.

This research takes in the views of disabled people from across the region and gives a representative spread of age groups and areas across the North West. We have gathered both qualitative and quantitative data via online surveys, focus groups, and easy read paper surveys. 394 disabled people took part in the research.

Our network worked to agree recommendations which we then presented in our research, asking respondents to say whether they were the things that mattered to them.

On the basis of this research, we have a series of recommendations that we would like to see included in the strategy. These are detailed in the Recommendations section of this report on pages 6-9.

Whilst the results suggest that all of our proposed recommendations are important, four key themes stood out as being particularly significant in this region. These are:

- Advocacy - we want the government to make sure that everyone can get advocacy to help people say what matters to them in all areas of their life and to help them with processes that can be difficult to work through, for example in education, health and social care, benefits, housing and justice systems. (100% of respondents thought this was important)
- Health and Social Care – we want the Government to increase funding for health and social care to make sure that disabled people can live full lives (100% of respondents thought this was important)
- Benefits - we want the government to deliver a benefits system that is based on need, fully supports the right to live an independent life and supports the idea that a person is disabled by a world that doesn't meet their needs, not by their condition. The money people receive from benefits must be enough to live a full life. (100% of respondents thought this was important)
- Communication and Information – we want the Government to make sure all government information and communication is in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed. Going further, we want the government to legislate for protection for British Sign Language (BSL) as a distinct language of the UK, and with an associated culture. (97% of respondents said this was important to them, however in amongst British Sign Language users who took part in the research, that figure was 100%).

We look forward to seeing the completed Strategy, and to continuing to work closely with Government via the Disability Unit.

Introduction

The Disability Unit set up 9 Regional Stakeholder Networks to help it reach out to disabled people across England.

Each region in the network is tasked with:

- amplifying the voices of disabled people and disability organisations in their regions
- reporting back to the government on a range of issues including transport, housing and employment
- helping to develop the new National Strategy for Disabled People

Each region is led by a chair who is independent of government and was selected based on their understanding of disability issues specific to their regions, their expertise in disability policy and its effects at grassroots level.

Many of the chairs are disabled people, while others work in disabled people's organisations or organisations that support disabled people. Several hold voluntary roles which will help them tap into the issues and concerns of their local networks and reach more disabled people.

The chairs work with the Disability Unit to provide engagement opportunities for network members to share their views and experiences to help inform and drive future policy.

The North West Regional Stakeholder Network is currently made up of 29 members, who are disabled people and/or are supporting organisations. To view the list of current members, please refer to Appendix 5 of this report.

Our Network wanted to carry out some insight gathering across the region with disabled people, to understand what is important to people as part of the National Disability Strategy, that could be linked to the Government's five cross-cutting working groups to drive Departments to think about how to overcome issues/difficulties, as follows:-

1. Built environment (MHCLG, DfT, BEIS, DHSC, DCMS, DfE, Defra)
2. Assistive technology - DWP, DfE, BEIS, DCMS, NHS Innovation or NHS X, MHCLG
3. Transitions to adulthood and outcomes DWP, BEIS, DfE, DHSC
4. Mental health / loneliness / being part of a community DfT, DHSC, DCMS, MHCLG
5. Economic recovery and employment DWP, BEIS

Research Methods

We collected insight from disabled people across the North West using a plain English survey-monkey link and a paper based easy-read version. To view an example of the easy read survey, please see Appendix 4 of this report.

Using these methods allowed us to receive insight from a representative sample from across the Northwest. 394 surveys were completed. However, it is important to note that some of the survey responses were from supporting organisations that were able to complete the survey on behalf of their wider membership.

In addition to these two methods, we also held a focus group with British Sign Language (BSL) users from the North West, in recognition that written English would not be widely understood or utilised by this cohort.

The analysis of results takes into account the qualitative and quantitative data collected, and supports the recommendations made.

Within this report we use the words **‘disabled people’**, **‘we’**, **‘us’** and **‘our’** to mean people who identify as deaf or disabled people, people with lived experience of disability or long-term conditions, or their organisations.

Recommendations

On the basis of the research we have carried out across the Northwest, the following are our recommendations, aligned to each of the Government cross-cutting working groups and reflect what is most important to us, in this region, that we want to see reflected in the National Disability Strategy.

We recognise that this is a substantial list of recommendations, so we have highlighted in bold, the recommendations that were rated as most important to be included within the Strategy.

1. **Built environment** - How do we achieve a built environment that is fully designed for and accessible to all?

- 1.1 Make 20% of all housing owned by councils and housing associations accessible by 2025.
- 1.2 Make rules for building, that make sure new buildings or parts of buildings are accessible.
- 1.3 Publish national guidance requiring all streets to be designed to meet our needs as pedestrians, cyclists, and car users.
- 1.4 Make local authorities work with us to make sure the design of streets and town centres meets our needs
- 1.5 Provide funding to make all train and bus services and cycling affordable and accessible by 2025.

2. **Assistive technology** - How can we ensure disabled people's access to the assistive technology that's best for them alongside the support to use it (whether for learning, working or other aspects of daily life)? Website accessibility- How do we ensure public and private sector websites are accessible to disabled people?

- 2.1 Make sure that we can use computers and smart phones. Bring ideas led by us into future development.
- 2.2 Make sure Further Education funding goes towards improving our skills, in using computers and smart phones. Make sure we can do this in accessible, community places.

- 3. Transitions to adulthood and outcomes** - How do we ensure that public services support the transition to adulthood for disabled young people?
Parents/Families of disabled children - How do we ensure a positive step change in the support and advice available to the parents and families of disabled children?
- 3.1 Provide funding for care and educational support for us to ensure inclusion in mainstream schools.
 - 3.2 Include the Equality Act in the National Curriculum to teach young people about equality and diversity.
 - 3.3 **Increase funding for health and social care to make sure that we can live full lives**
 - 3.4 **Give us the right to independent living by law and make sure we are involved with planning what the law looks like.**
 - 3.5 **Make sure support services are not 'just' care but help us to learn Independent Living skills so that we can live a full life.**
 - 3.6 **Make sure Direct Payment policy is the same in all areas and that it supports real choice and control**

4. Mental health / loneliness / being part of a community - How do we ensure that every disabled person can get appropriate support if they have mental health worries or are lonely?

- 4.1 **Make sure everyone can get advocacy to help us say what matters to us in all areas of our life and to help us with processes that can be difficult to work through, for example in education, health and social care, benefits, housing and justice systems**
- 4.2 Provide funding to encourage and support us to stand for election as a Councillor or an MP
- 4.3 1 in 4 people in the UK is a disabled person. We want to see the same representation in politics.
- 4.4 Make all voting accessible by 2025
- 4.5 Give funding to Police Authorities to work with us to improve the identification of Disability Hate Crime.
- 4.6 Review how we report Disability Hate Crime and how understood and accessible 'third-party reporting centres' are.
- 4.7 Work with local Councils to improve our safety, to protect us from crime and harassment.
- 4.8 Make the United Nations (UN) International Convention on Rights for Persons with Disabilities part of UK law.
- 4.9 Enforce the Equality Act, make the Equality Act more important and extend the Equality Act to cover things you buy, like computers and furniture.
- 4.10 **Create a separate BSL Act to recognise that British Sign Language is a language in its own right**
- 4.11 **Make sure all Government information and communication is in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed.**
- 4.12 **Make sure all websites are accessible.**
- 4.13 Support and provide funding for local organisations led by disabled people, to make sure care and support services are delivered to meet our needs.

5. Economic recovery and employment - How do we ensure the full contribution of disabled people to the economic recovery?

- 5.1 Make sure the benefits system is fair, so we don't have to live on less money in the North West, compared to the South of England.**
- 5.2 Understand that levels of poverty in the North are much greater. The money we get from benefits must be enough to live a full life.**
- 5.3 Ensure there is a benefits system that is based on need, fully supports the right to live an independent life and supports the idea that we are disabled by a world that doesn't meet our needs, not by our condition.**
- 5.4 Provide a trusted employment support service that helps us to find and keep jobs. The service should be led by disabled people.
- 5.5 Work with us to review the Access to Work processes to ensure these are accessible, and implement timescales for responding to requests, so that more of us can get into paid work.
- 5.6 Extend Access to Work or provide new funding to cover job searching.
- 5.7 Extend Access to Work or provide new funding to cover wage subsidies where necessary to give employers some money towards our wages, in recognition that some of us take longer to carry out work tasks. This will help more of us get into paid work.
- 5.8 Make it so that all Employers have to have Disability Equality Training, run by disabled people.

Analysis of results

Against each of the recommendations above, our research asked disabled people to choose whether or not it was important to them and were then invited to say why they had given that answer.

To view the full survey and focus group results, please refer to Appendix 1, 2, and 3.

Some of the recommendations had more comments added than others, which correspond to the subjects that people most often rated as important to them. These were:

- Advocacy
- Benefits
- Health and social care
- Information and Communication

Advocacy

Respondents were asked if the following recommendation was important to them.

Make sure everyone can get advocacy to help people say what matters to them in all areas of their life and to help them with processes that can be difficult to work through, for example in education, health and social care, benefits, housing and justice systems.

100% said yes

0% said no

Respondents were then asked to comment, explaining why they gave their answer. Those who commented were overwhelmingly supportive of the need for advocacy, with one commenting:

“Without advocacy, how would my voice be heard”

Many also highlighted difficulties they face in participating in the complex systems around benefits, education and other decision making.

“Regulations and systems are complicated and difficult to understand without help. Sometimes decisions that are made on matters that affect me are unfair.”

The vast majority of respondents also raised concerns that advocacy is difficult to access, or they wouldn't know where to go to find it.

“It is very difficult to find advocacy services, and it is essential to me, I have difficulty understanding and speaking for myself a lot of the time”

Others also highlight the fact that only statutory advocacy is available to them

“we have lost lots of advocates, now only [statutory] advocacy is funded. More funding is required to hear the voice of people and their families.”

Benefits

Respondents were asked to consider two recommendations on benefits and say if they are important to them.

1. Make sure the benefits system is fair, so people don't have to live on less money in the North West, compared to the South of England. Understand that levels of poverty in the North are much greater.

95% said Yes

5% said No

2. A benefits system that is based on need, fully supports the right to live an independent life and supports the idea that a person is disabled by a world that doesn't meet their needs, not by their condition. The money you get from benefits must be enough to live a full life.

100 % said Yes

0% said No

In the comments against both recommendations, many respondents said that they felt the current benefits system only offers the bare minimum and focused on 'need not aspiration', with many also commenting that the system is overly punitive.

"The money given in benefits is not enough to live any good quality of life on. The benefits system treats people like they are committing fraud even before they have applied...government needs to understand that [it] is only a very small minority who take advantage of the benefits system."

A few respondents did however feel strongly that people shouldn't need to rely on benefits and should be supported in to work wherever possible,

Democracy

Respondents were asked to consider 2 recommendations and say if they were important to them:

- 1. Funding to encourage and support disabled people to stand for election as a councillor or an MP. 1 in 4 people in the UK is a disabled person. We want to see the same in politics.**

93% said Yes

7% said No

Respondents were asked to comment on why they had chosen their answer. There was overwhelming support for better access to public roles, with many passionately highlighting the importance of lived experience in decision making.

“One of the main problems in today’s politics is that the politicians are completely unaware of the problems that disabled people face you cannot know what a person experiences unless you walk in their shoes.”

“It should be recognised more widely the barriers which are still faced by many disabled individuals in society. Having more individuals with a disability in parliament and on the council would benefit everyone.”

However, many also recognised the barriers to participation, with many comments detailing basic issues of access as well as ongoing discrimination against disabled people.

“We need to find ways to include everybody without discrimination. Knocking down barriers through changing our physical environment, building architecture that considers everyone from the planning stage, people’s attitudes and the way we think about disabilities. Change is far too slow.”

Some respondents also questioned the capacity of some disabled people in being able to take up such roles.

“...we have to be realistic. As an example, I belong to an organisation helping those with learning disabilities. The constitution requires that a proportion of the service users serve on the management committee. Try as we can, this is very difficult to make work properly as mostly they have a narrow grasp of the issues affecting charities and their disability prevents better understanding.”

2. Make all voting accessible by 2025

95% said yes

5% said no

Respondents were asked to comment on why they had chosen their answer. The comments were overwhelmingly supportive of the idea, with many saying that postal voting had hugely improved access to voting for them.

However, many suggested postal voting was not enough and that there needed to be serious consideration of how online methods could work in the future.

“Voting needs to be modernised and done online so most people have access to the system without having to go outside.”

Digital Inclusion

Respondents were asked to consider two recommendations and were asked 'Is this important to you?'

- 1. Make sure that disabled people can use computers and smart phones. Bring ideas led by them into future development. Make sure that if we can't use technology there are still alternatives**

98% said Yes

2% said No

- 2. Make sure Further Education funding goes towards improving the skills of disabled people, in using computers and smart phones. Make sure we can do this in accessible, community places.**

100% said Yes

0% said No

Amongst the comments on both of these proposals there was overwhelming support for digital technology, with respondents commenting that that it is vitally important for disabled people to have the skills to use it because it is the future of communication, interaction with organisations and to prevent isolation.

"Technology is part of everyday life and [a person who has lived experience of disability or long-term conditions] should be able to access technology. [They] made need additional training or adaptive equipment."

Interestingly, none of the respondents talked about the importance of offering alternatives, instead focusing on the importance of training and education.

"It is self-evident that ICT knowledge gives greater access. However, it must be accompanied by help and training. Giving a disabled person a laptop and no help is a waste of money."

A few respondents talked about the fact that it is difficult to afford broadband and devices to access digital platforms with one commenting:

"How can I afford the cost of running a smart phone and a computer? I need both to even get my benefits and fill in forms - it's all a nightmare. So many people...can't work the new technology or afford to buy it."

Hate Crime

Respondents were given the following recommendation and then asked, 'Is this important to you?'

Give funding to Police Authorities to work with disabled people and their organisations to identify Disability Hate Crime. Review how disabled people report Disability Hate Crime and how accessible it is (these are sometimes called third party reporting centres). Work with the local council to improve the safety of disabled people, from crime and harassment.

97% said yes

3% said no

The overwhelming majority of comments shared personal experience of having been a victim of disability hate crime, with many saying that they feel the police do not understand the issue or how to support victims.

"I have found that [police officers] do not really understand this subject and I have been fobbed off on numerous occasions having made complaints. I do not believe that the Police are responsive or effective in tackling this subject, a lot of rhetoric but very little action"

Education

Respondents were asked to consider the following recommendation and asked, 'Is this important to you'.

Provide funding for care and educational support for every disabled child to ensure inclusion in mainstream schools. Include the Equality Act in the National curriculum to teach young people about equality and diversity.

97% said Yes

3% said No

The comments were overwhelmingly supportive of this recommendation, with many particularly focusing on the importance of education on equality.

"To break down prejudice and give all children an early understanding of the needs of disabled people and how to support and value all people."

Some queried whether mainstream schools are always the right setting, with one commenting:

"Whilst I support inclusion in mainstream schools, I know from my son's experience that he thrived in a special school."

Employment

Respondents were asked to consider three recommendations and were then asked, 'Is this important to you?'

- 1. Provide a trusted employment support service that helps disabled people, to find and keep jobs. The service should be led by disabled people.**

97% said Yes

3% said No

Respondents were asked to comment to say why they chose their answer. The majority highlighted that many disabled people want to work but lack support to do so. Many talked about the role of job centres, importance of properly trained staff, and the lack of support available in recent years.

"Job Centre [or other organisation] staff should be fully supportive and trained to understand the needs of disabled people including those with conditions such as Autistic Spectrum Disorder and ensure that they offer appropriate opportunities."

"... it shouldn't necessarily be led by disabled people; it should be led by the best persons irrespective of disability. It is surely about sustainability and not revolving doors."

"The Job Centre used to do this well. Due to austerity cuts they no longer do so, and it is left to individual charities to plug the gap."

- 2. Extend Access to Work funding or provide new funding to cover job searching and look at wage subsidies (government giving your employer some money towards your wages). This will help get more disabled people, into paid work.**

90% said Yes

10% said No

Respondents were asked to comment to say why they chose their answer. Many were supportive of Access to Work but highlighted that there are issues with the scheme and felt that it needed modernisation and improvement.

"The Access to Work Process needs to [be] more streamlined too. The few times I've accessed this service on behalf of others, I've found it very time consuming and difficult."

3. Make it so that employers have to have disability equality training, run by disabled people.

92% said Yes

8% said No

Respondents were then asked to comment to say why they gave their answer. The majority of comments were very supportive of the idea, highlighting the importance of employer understanding and knowledge of the law.

“Quite often the problem is that the employees are ignorant of the rules in the laws and the equality act as if they were properly aware that a lot of the problems would disappear.”

Many also commented on lived experiences as vital to bring training to life for employers.

“Training will be much better if provided by individuals with a lived experience. It is also always well received by employees.”

Equality

Respondents were asked to consider three recommendations and then asked, 'Is this important to you?'

1. Make the United Nations (UN) International Convention on Rights for Persons with Disabilities part of UK law.

92% said Yes

8% Said No

Respondents were then asked to comment to say why they chose their answer. Many respondents expressed surprise that the UNCRPD is not already part of UK law.

2. Make the Equality Act more important than all other laws.

55% said Yes

45% said No

Respondents were then asked to comment to say why they chose their answer. Many commented that more important than the Equality Act being more important, was that it was understood and obeyed in the first place.

"I want laws to be equally important. There's a difference for me between strengthening the provisions and widening the provisions of the Equality Act 2010, opposed to making it more important."

"Not a lot of people are aware it exists. It will only be understood when people are guided towards it."

3. Extend the Equality Act to cover things you buy, like computers and furniture.

63% said Yes

37% said No

Respondents were then asked to comment to say why they gave their answer. There were relatively few comments on this, and whilst some felt it would be helpful to have an extension to the act, most were unconvinced of how this would work in practice.

Health and Social Care

Respondents were asked to consider four recommendations and were then asked, 'Is this important to you?'

1. Increase funding for health and social care to make sure that people can live full lives

100% said Yes

0% said No

Respondents were then asked to comment to say why they gave their answer. The majority were supportive of improving health and social care, and highlighted the importance of social care to their lives and the varying levels of support

"Everyone deserves equal access to good, free high-quality high care provided in a timely manner which meets their individual needs."

2. Give disabled people/people with lived experience of disability and long-term conditions the right to independent living by law and make sure they are involved with planning what the law looks like.

90% said Yes

10% Said No

Respondents were then asked to comment to say why they gave their answer. Many commented that this was vitally important going forward, and particularly in the light of the Covid crisis, with one respondent commenting that:

"Unfortunately, disabled people's rights don't seem to be immediately taken into account [e.g. Coronavirus Act 2020]. It only seems after a hardship has taken place and campaigns then people will sometimes listen."

3. Make sure support services are not 'just' care, but help disabled people, to learn Independent Living skills so that they can live a full life.

100% said Yes

0% said No

Respondents were then asked to comment to say why they gave their answer. There was overwhelming support for this recommendation, with many people highlighting that giving people the tools to live independently is vitally important for their futures.

“Should be important to everyone. Empower disabled people and save money for everyone long-term.”

“This would take the anxiety of having to rely on others for support and empower people to become independent.”

4. Make sure Direct Payment policy is the same in all areas and that it supports real choice and control

90% said Yes

10% said No

Respondents were then asked to comment to say why they gave their answer.

Many comments focused on the fact that Direct Payment policy varies between local authorities too much, and that they feel this is unfair.

“Where you can live independently should not be a postcode lottery”

Other comments also stressed the need for there to be services available, otherwise there is no real choice

“[Giving] people real choice means having options. it is no use giving people money if there is not anything to buy!”

Housing

Respondents were asked to consider three recommendations and then asked, 'Is this important to you?'

1. Make sure all new homes that are built are accessible.

84% said Yes

16% said No

2. Make rules for building that make sure new buildings or parts of buildings are accessible.

93% said Yes

3% Said No

3. Make 20% of all housing owned by councils and housing associations accessible by 2025.

91% said Yes

9% said No

Respondents were then asked to comment to say why they had given their answer. There was strong support for all the proposals above in the comments given, with many expressing frustrations that this hasn't yet happened

"[There is] No reason why majority of buildings built cannot be accessible, we have the knowledge now so no need for excluding people"

Information

Respondents were given two recommendations to consider and then asked, 'Is this important to you?'

- 1. Make sure all government information and communication are in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed.**

97% said Yes

3% said No

- 2. Make sure all websites are accessible.**

94% said Yes

6% said No

Respondents were then asked to comment to say why they gave their answer. There was strong support for both of these recommendations, and many comments highlighted frustrations with lack of accessible formats from government, especially during the coronavirus crisis.

"It isn't any good developing systems to ensure that people with disabilities have a voice, plan their own lives, etc, if they cannot access information"

"A lot of government information is difficult to decipher, for example the covid 19 rules, even listening to the prime minister is not helpful, as he [doesn't speak clearly and uses confusing language] about what is and isn't allowed."

"Needs to be set out in ways that are easy to read and understand...no hidden meanings. Info should be accessible to all regardless of disabilities"

Respondents at our British Sign Language (BSL) focus group highlighted a complete lack of understanding of the separate cultural identity of BSL users, and that for deaf people the written word may not be fully accessible as BSL is constructed completely differently. In particular, there was strong support for proper legal protection for BSL as a language.

"BSL is an important language and sadly this government in England does not use BSL for example when doing Covid Press Conferences - this creates a sense of isolation and exclusion for hearing impaired and deaf people"

Street Environment

Respondents were asked to consider two recommendations and then asked 'Is this important to you?'

- 1. Publish national guidance requiring all streets to be designed to meet the needs of disabled pedestrians, cyclists and car users.**

93% said Yes

7% said No

- 2. Make local authorities work with disabled people to make sure the design of streets and town centres meets their needs.**

94% said Yes

6% said No

"Stop most parking on pavements - causes problems for wheelchair users, mobility scooters, visually impaired people and people with prams. More dropped kerbs and enforcement of parking on dropped kerbs. Stop inappropriate street furniture - e.g. A-boards. Create a licencing scheme for street furniture and enforce breaches.

Pause E-scooter rental trials until further safety trials can be undertaken. Reduce street clutter- e.g. overhanging trees, bins not put away, dog faeces, fly tipping, broken glass/litter."

Transport

Respondents were asked to consider the following recommendation and then asked, 'Is this important to you?'

Funding to make all train and bus services and cycling affordable and accessible by 2025.

89% said Yes

11% said no

Respondents were then asked to comment to say why they had given their answer.

There was strong support for this in the comments, with many saying that public transport is vital to their lives, and to access and equality for disabled people. Some suggested that simple actions could also help such as public transport operators making clearer which services and stations were accessible and which were not.

Voice

Respondents were asked to consider the following recommendations and then asked, 'Is this important to you?'

Support and provide funding for local organisations led by disabled people to make sure care and support services are delivered to meet their needs.

97% said Yes

3% said No

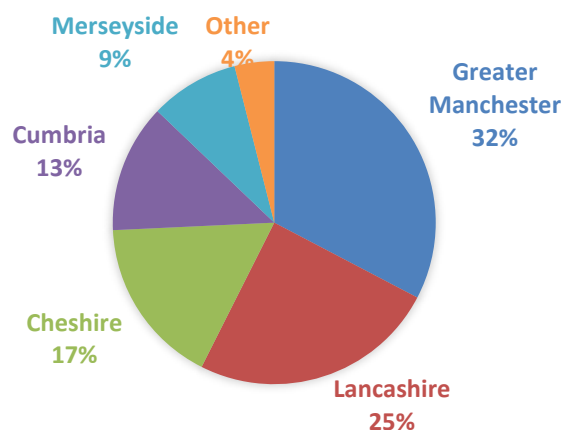
Respondents were then asked to comment to say why they had given their answer. There were a small number of comments, received, and all were supportive of the role of local organisations, with one commenting

"This is vital for those of us having difficulty securing any form care"

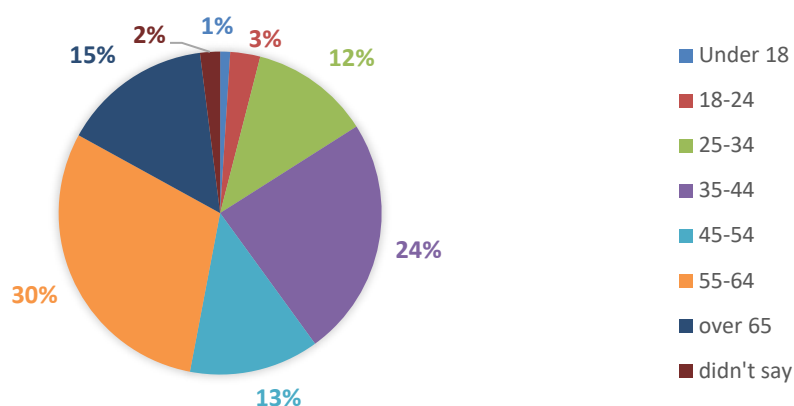
"Someone who knows what they are talking about is a very good idea"

Demographics

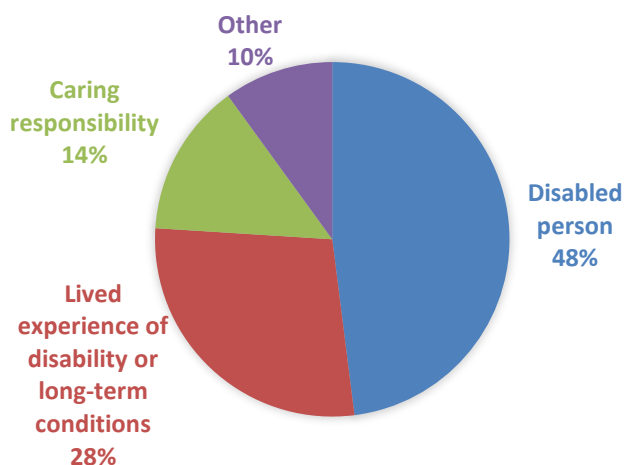
Respondents were asked to tell us where they live in the North West. There was a fairly even split across the Northwest in terms of responses, relative to the size of the locality.



Respondents were also asked to tell us their age range. The largest proportion respondents were 35-44 and 55-64; however, there were responses for all age ranges.



Respondents were then asked how they would describe themselves. The majority of respondents identified as disabled people.



Contact details

For further information, please contact:

Lynne Turnbull

North West Regional Stakeholder Chair

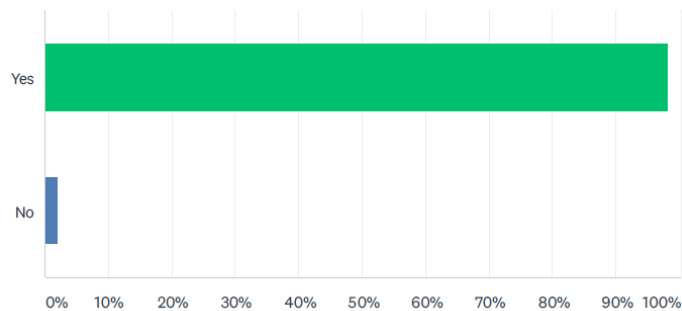
rsnnwest@gmail.com

07815897865

Appendix 1: Data – Quantitative Survey Results

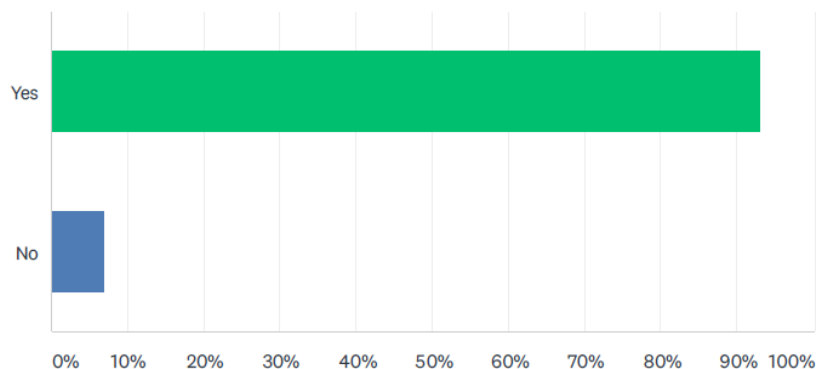
Q1 Advocacy: Make sure everyone can get advocacy to help people say what matters to them in all areas of their life and to help them with processes that can be difficult to work through, for example in education, health and social care, benefits, housing, and justice systems

Is this important to you?



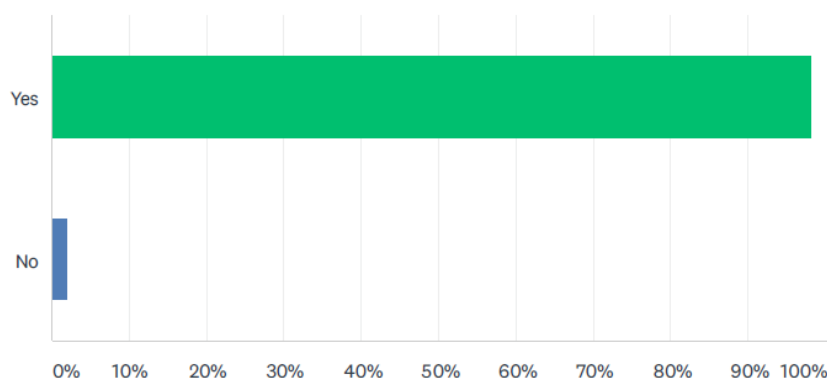
Q2 Benefits: Make sure the benefits system is fair, so people don't have to live on less money in the North West, compared to the South of England. Understand that levels of poverty in the North are much greater.

Is this important to you?



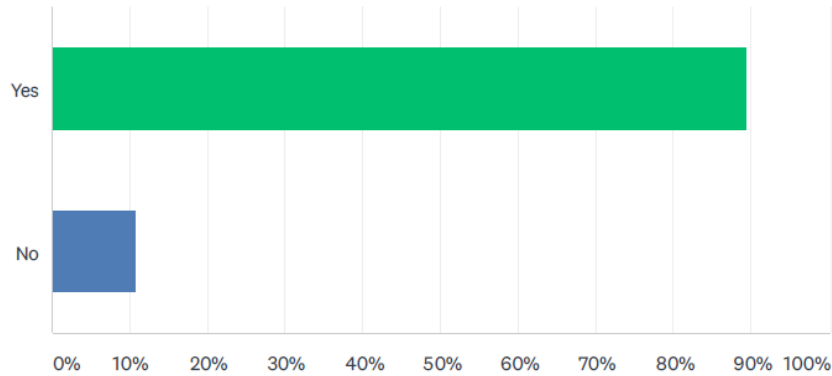
Q3 Benefits: A benefits system that is based on need, fully supports the right to live an independent life and supports the idea that a person is disabled by a world that doesn't meet their needs, not by their condition. The money you get from benefits must be enough to live a full life

Is this important to you?



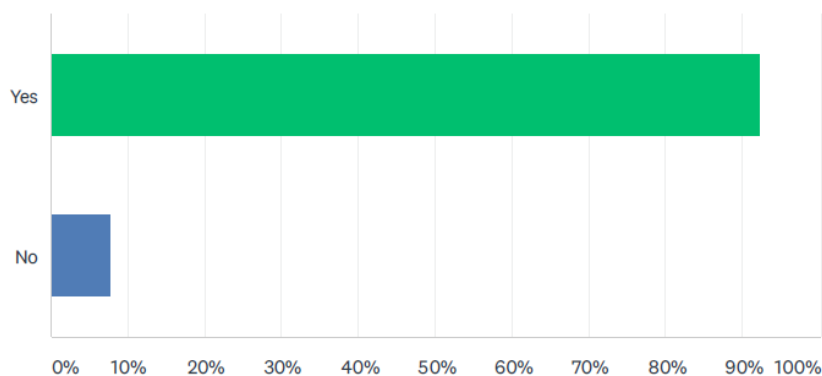
Q4 Democracy: Funding to encourage and support disabled people/people with lived experience of disability and long-term conditions to stand for election as a councillor or an MP. 1 in 4 people in the UK is a disabled person/ has lived experience of disability or long-term conditions. We want to see the same in politics.

Is this important to you?



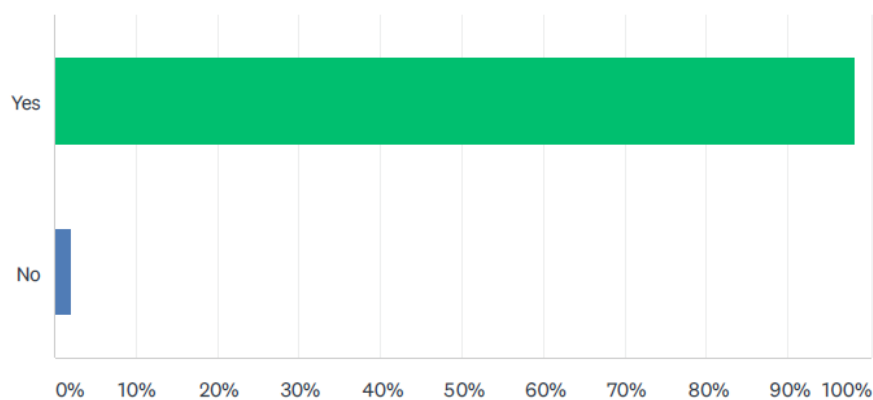
Q5 Democracy: Make all voting accessible by 2025

Is this important to you?



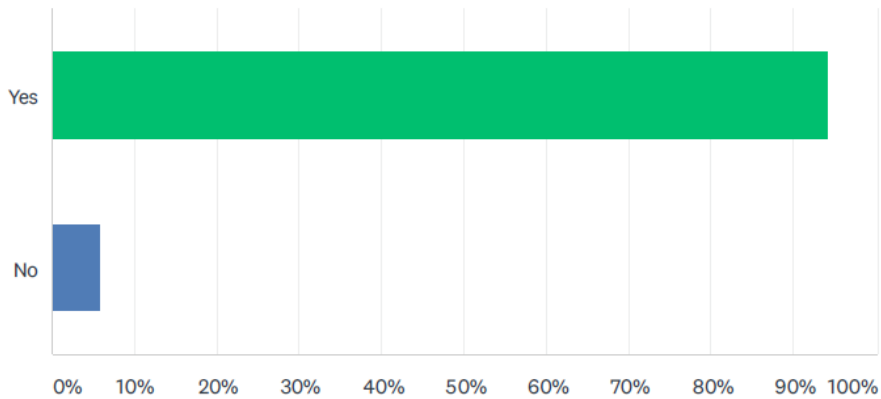
Q6 Digital Inclusion: Make sure that disabled people/people with lived experience of disability and long-term conditions can use computers and smart phones. Bring ideas led by them into future development and make sure that if we can't use technology there are still alternatives

Is this important to you?



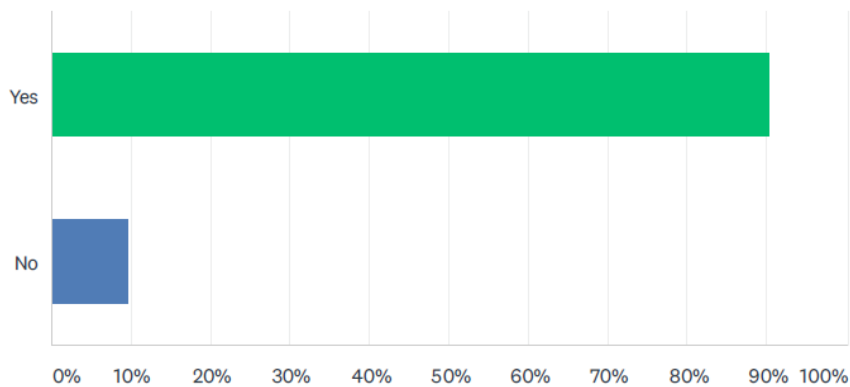
Q7 Digital Inclusion: Make sure Further Education funding goes towards improving the skills of disabled people/ people with lived experience of disability and long-term conditions, in using computers and smart phones. Make sure they can do this in accessible, community places.

Is this important to you?



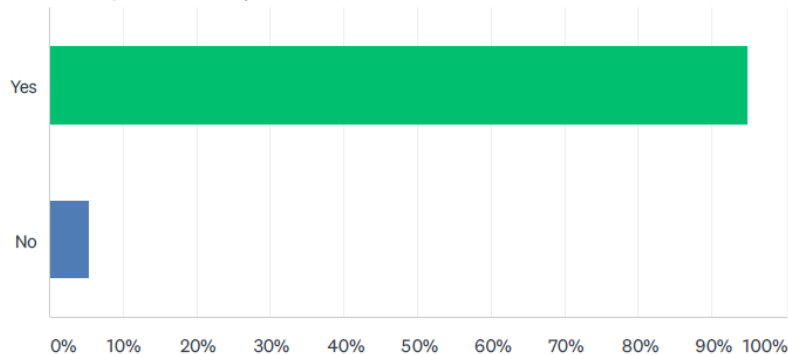
Q8 Disability Hate Crime and Harassment: Give funding to Police Authorities to work with disabled people and their organisations to identify Disability Hate Crime. Review how disabled people report Disability Hate Crime and how accessible it is (these are sometimes called third party reporting centres). Work with the local council to improve the safety of disabled people/people with lived experience of disability and long-term conditions, from crime and harassment.

Is this important to you?

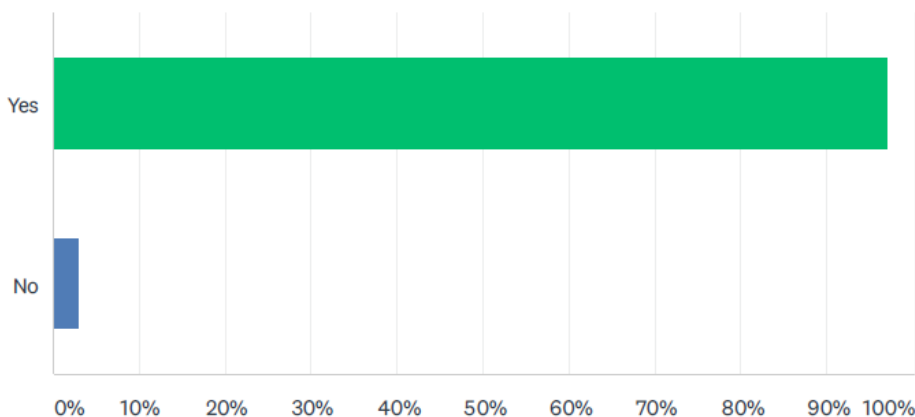


Q9 Education: Provide funding for care and educational support for every disabled child/child with lived experience of disability and long-term conditions to ensure inclusion in mainstream schools. Include the Equality Act in the National curriculum to teach young people about equality and diversity.

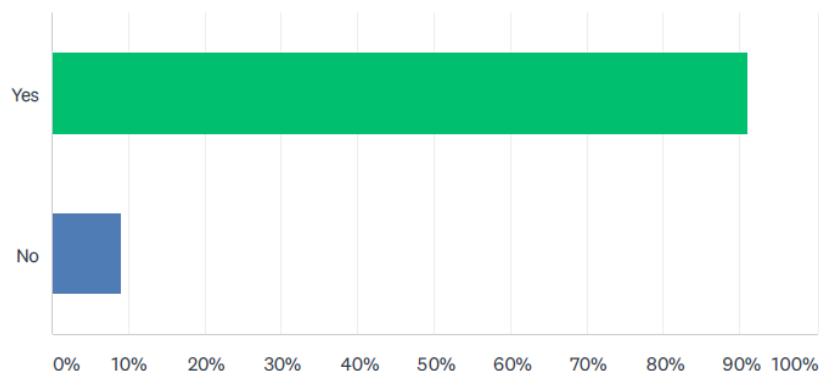
Is this important to you?



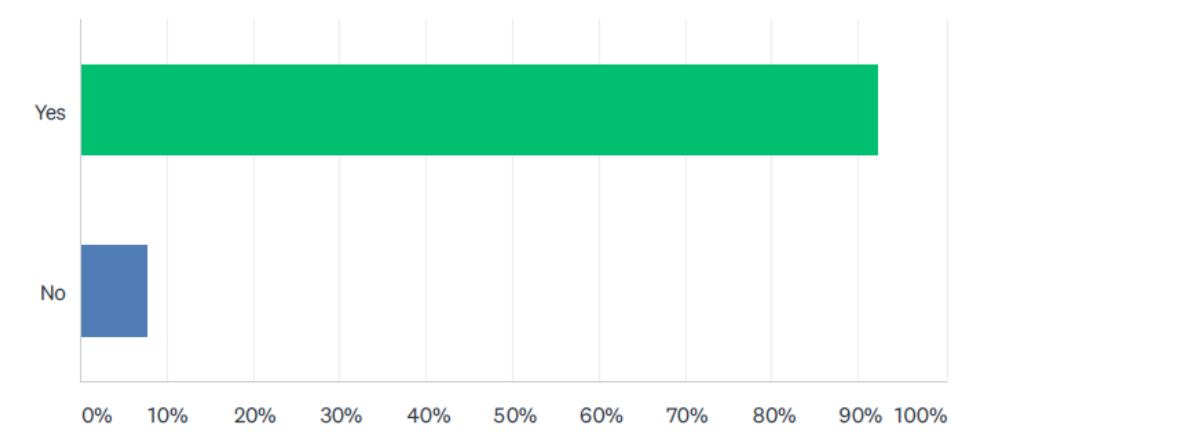
Q10 Employment: Provide a trusted employment support service that helps disabled people/people with lived experience of disability and long-term conditions, to find and keep jobs. The service should be led by people with lived experience of disability and long-term conditions. Is this important to you?



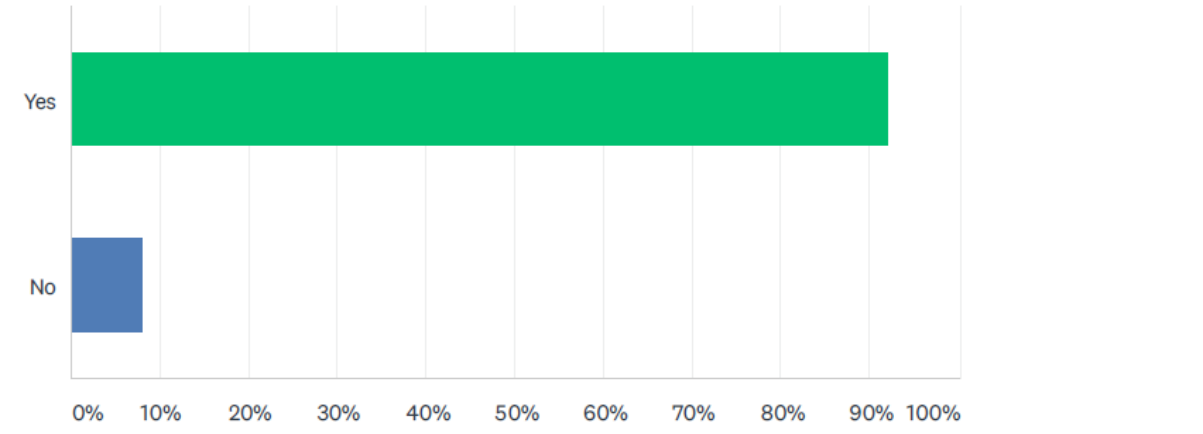
Q11 Employment: Extend Access to Work funding or provide new funding to cover job searching and look at wage subsidies (government giving your employer some money towards your wages). This will help get more disabled people/people with lived experience of disability and long-term conditions, into paid work. Is this important to you?



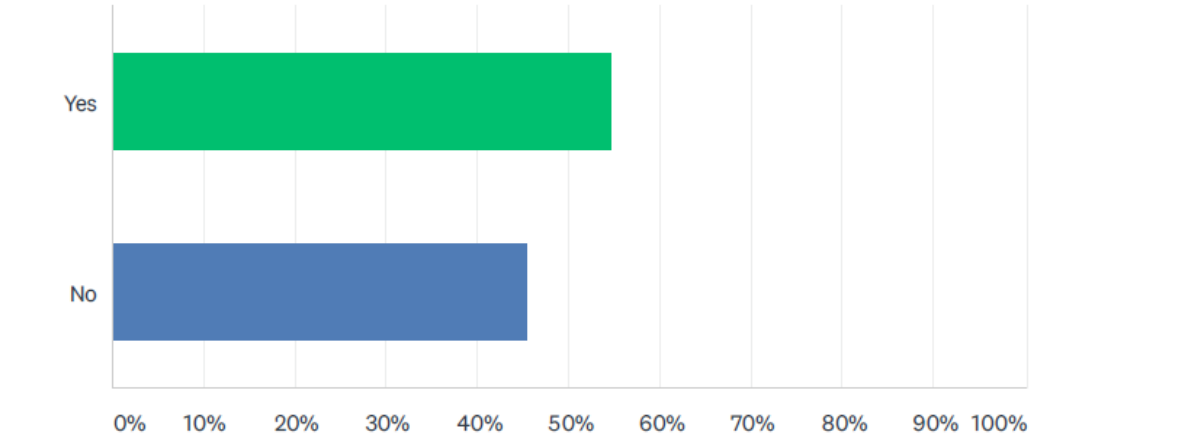
Q12 Employment: Make it so that employers have to have disability equality training, run by disabled people/people with lived experience of disability and long-term conditions. Is this important to you?



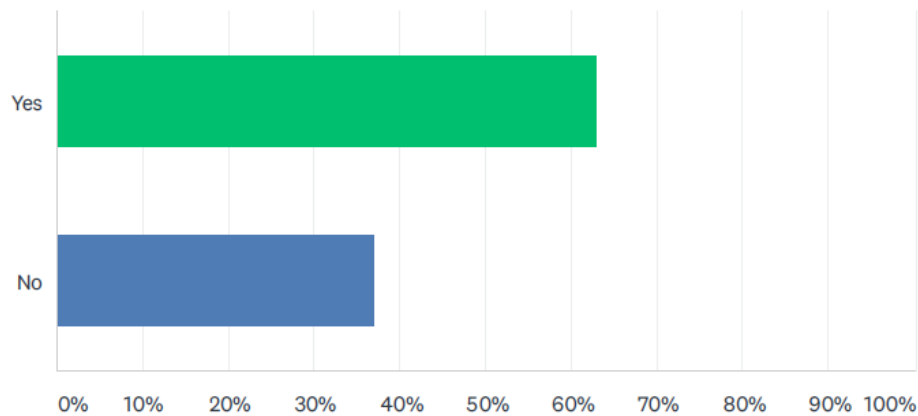
Q13 Equality: Make the United Nations (UN) International Convention on Rights for Persons with Disabilities part of UK law. Is this important to you?



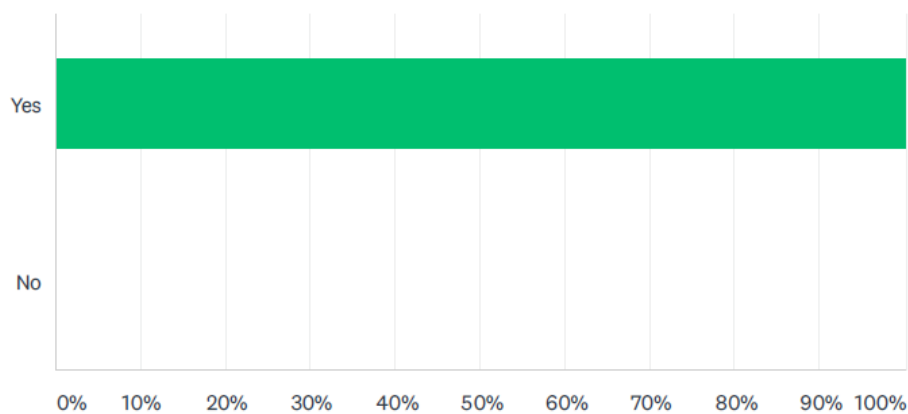
Q14 Equality: Make the Equality Act more important than all other laws. Is this important to you?



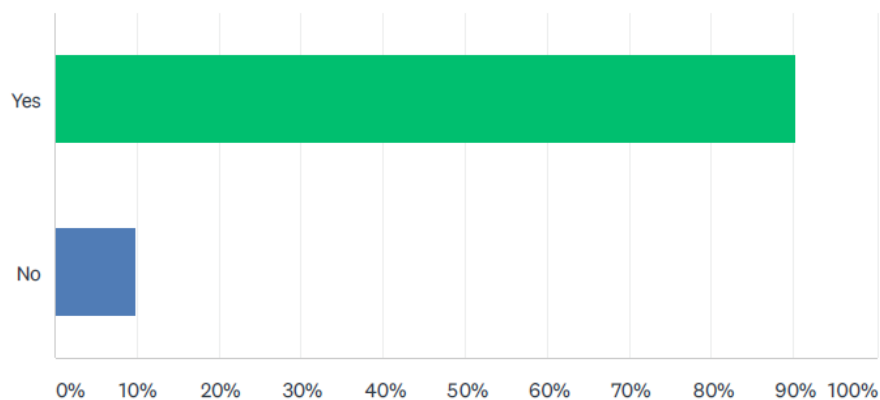
Q15 Equality: Extend the Equality Act to cover things you buy, like computers and furniture. Is this important to you?



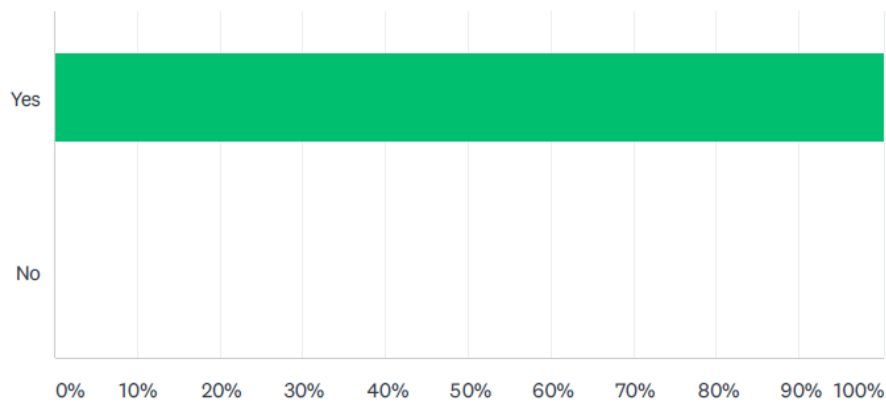
Q16 Health and Social Care: Increase funding for health and social care to make sure that people can live full lives. Is this important to you?



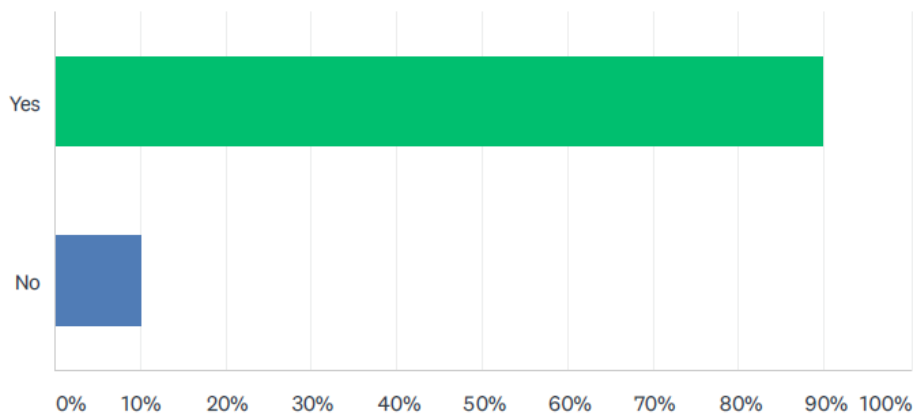
Q17 Health and Social Care: Give disabled people/people with lived experience of disability and long-term conditions the right to independent living by law and make sure they are involved with planning what the law looks like. Is this important to you?



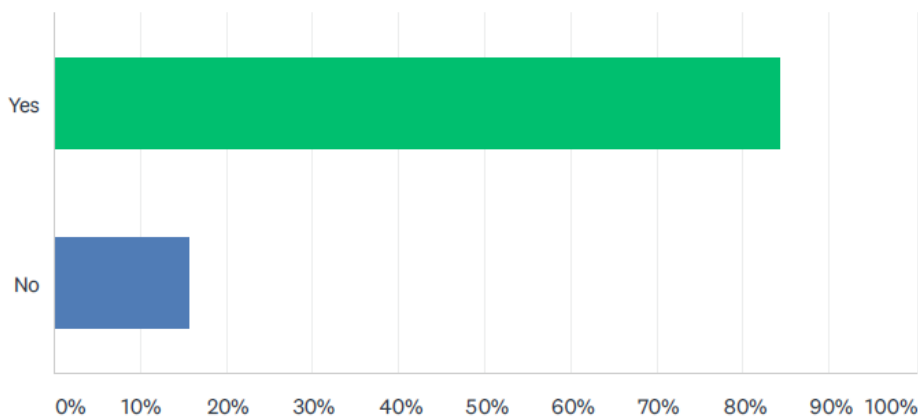
Q18 Health and Social Care: Make sure support services are not 'just' care, but help disabled people/ people with lived experience of disability and long term conditions, to learn Independent Living skills so that they can live a full life. Is this important to you?



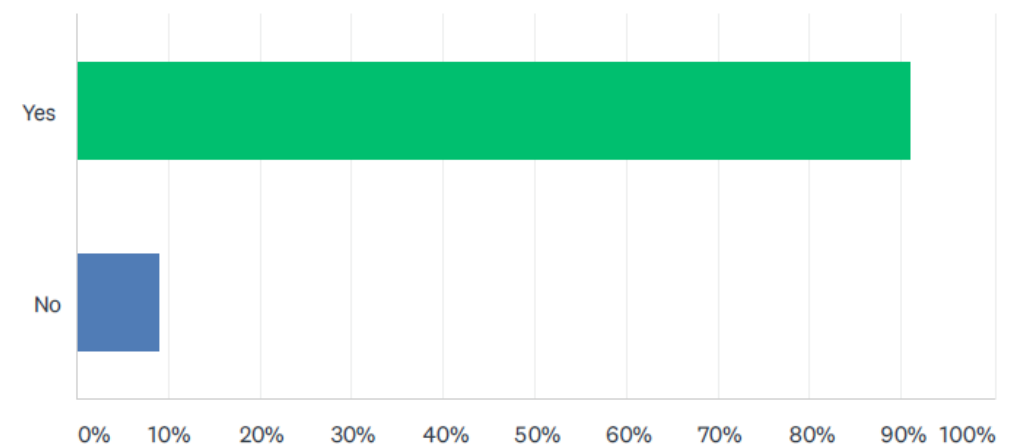
Q19 Health and Social Care Make Sure Direct Payment policy is the same in all areas and that it supports real choice and control. Is this important to you?



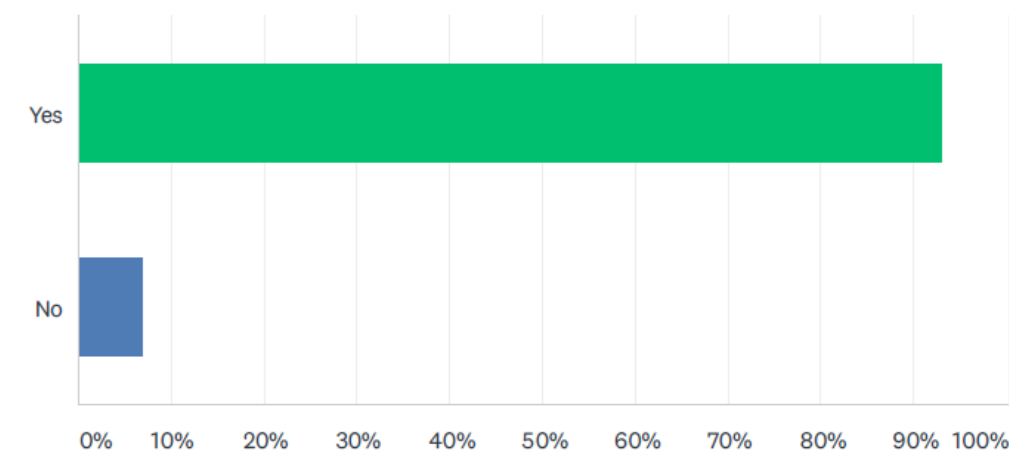
Q20 Housing: Make sure all new homes that are built are accessible. Is this important to you?



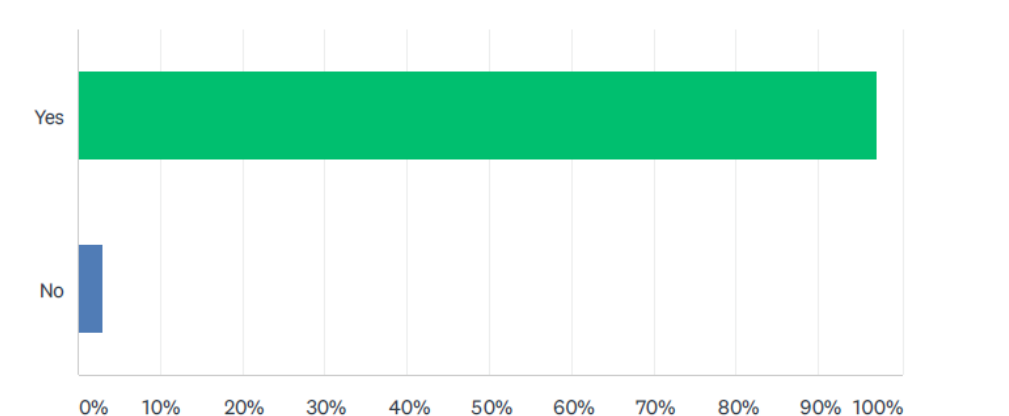
Q21 Housing: Make 20% of all housing owned by councils and housing associations accessible by 2025. Is this important to you?



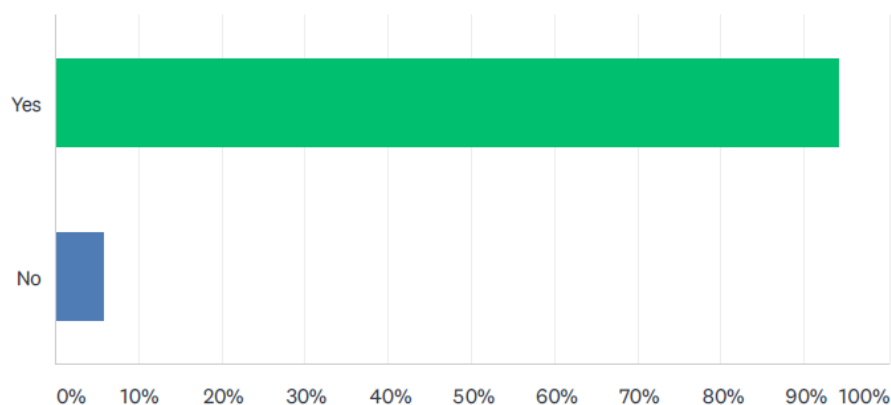
Q22 Housing: Make rules for building that make sure new buildings or parts of buildings are accessible. Is this important to you?



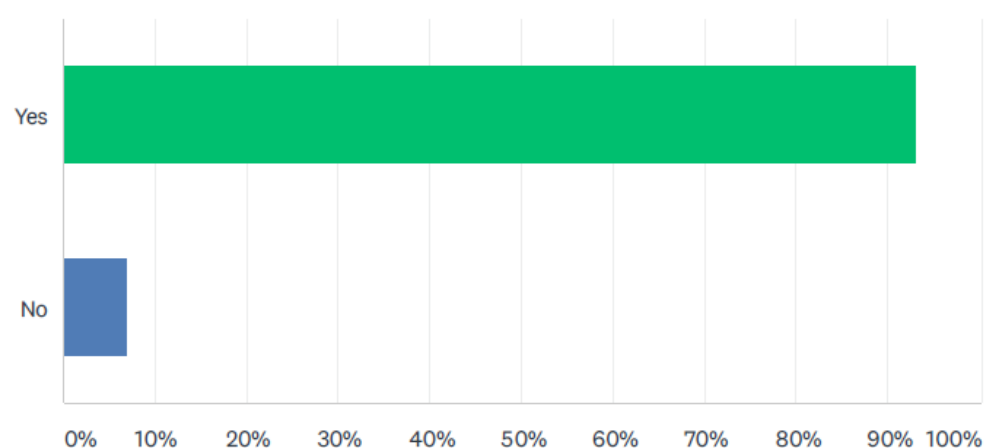
Q23 Information: Make sure all government information and communication are in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed. Is this important to you?



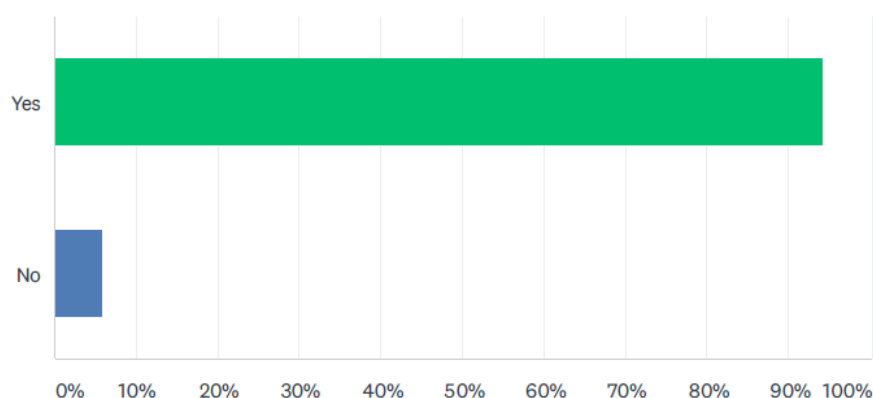
Q24 Information: Make sure all websites are accessible Is this important to you?



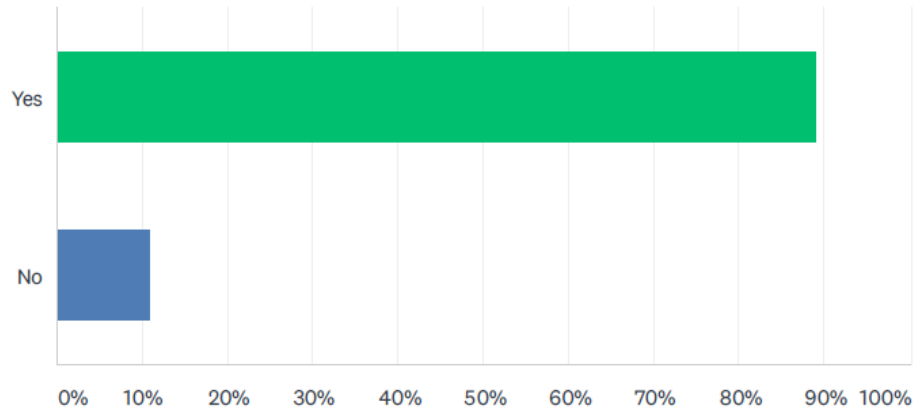
Q25 Street Environment: Publish national guidance requiring all streets to be designed to meet the needs of pedestrians, cyclists and car users with lived experience of disability and long-term conditions. Is this important to you?



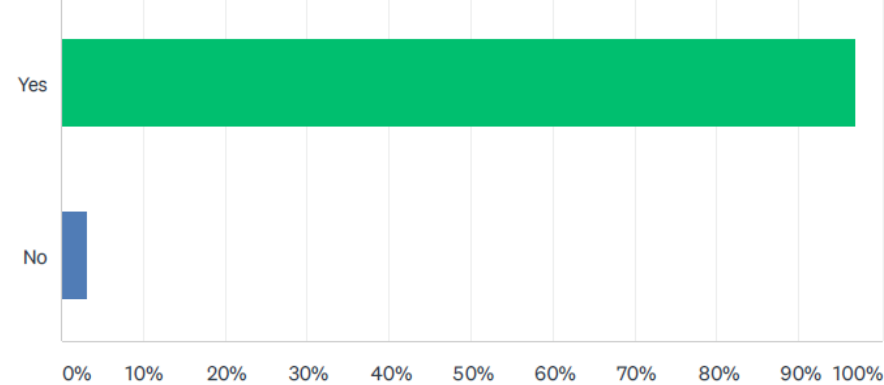
Q26 Street Environment: Make local authorities work with disabled people/people with lived experience of disability and long-term conditions to make sure the design of streets and town centres meets their needs Is this important to you?



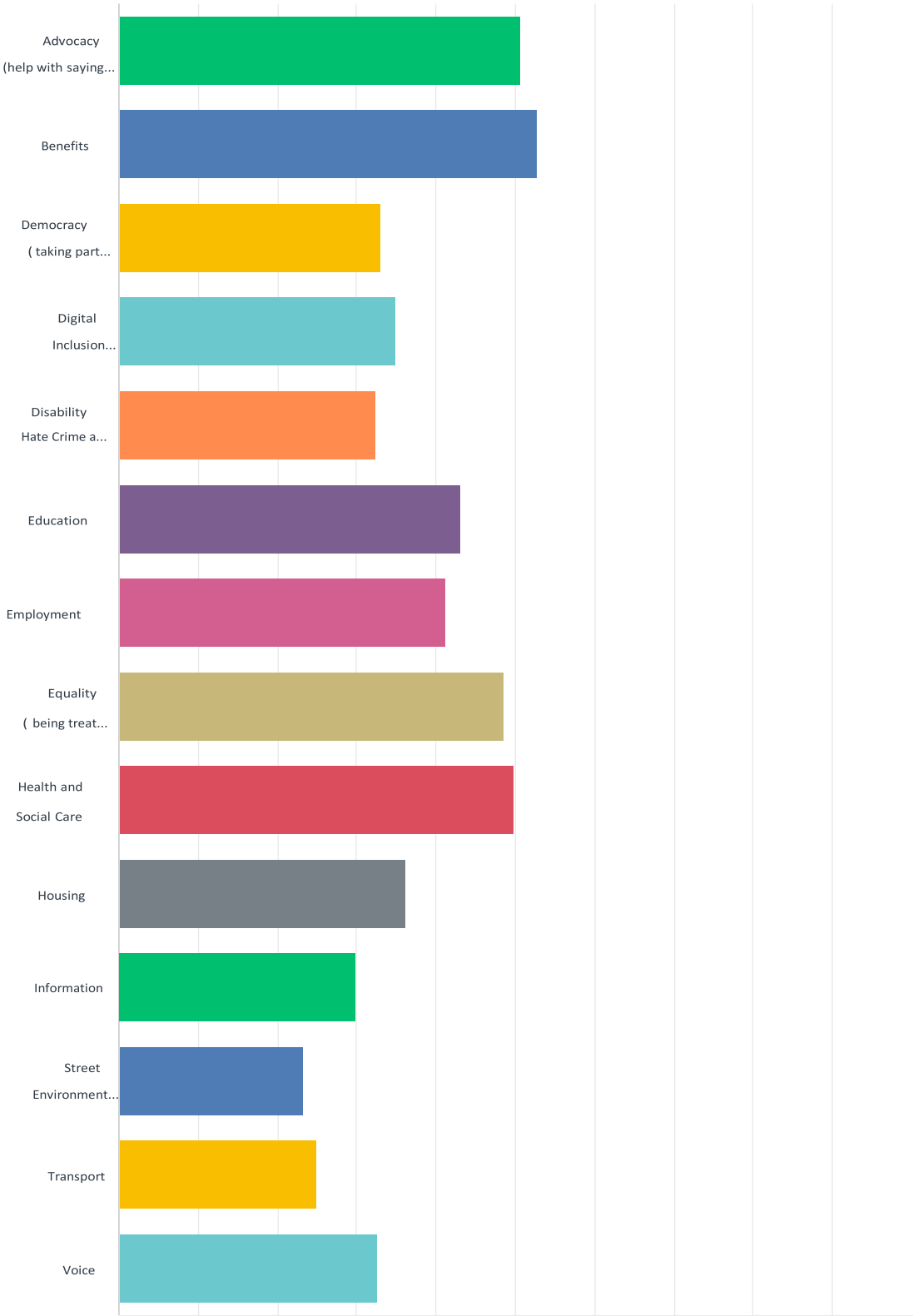
Q27 Transport: Provide funding to make all train and bus services and cycling affordable and accessible by 2025. Is this important to you?



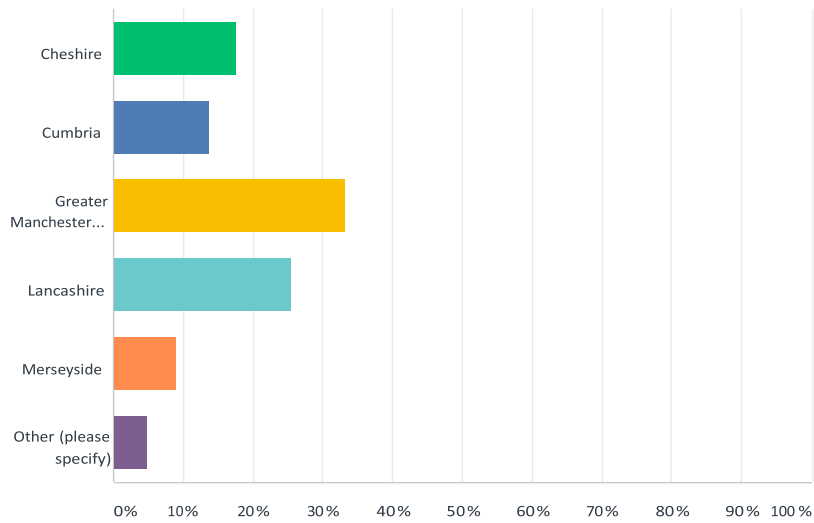
Q28 Voice: Support and provide funding for local organisations led by disabled people/people with lived experienced of long-term conditions to make sure care and support services are delivered to meet their needs. Is this important to you?



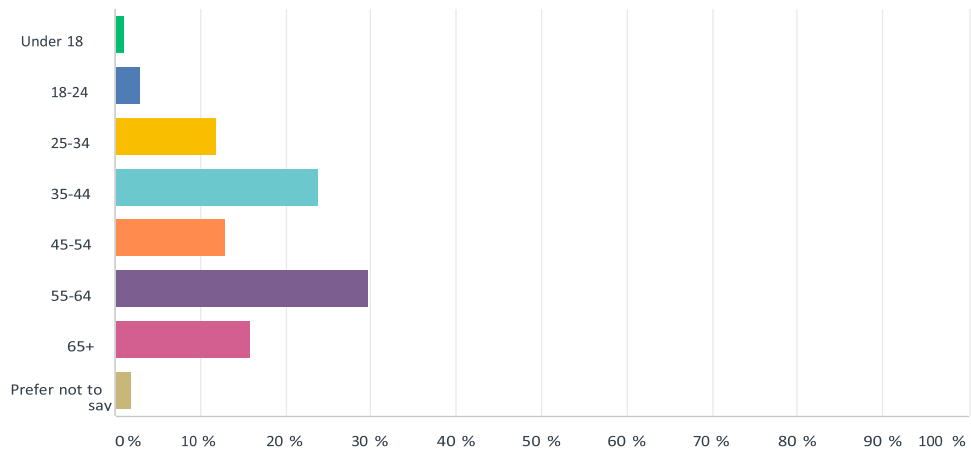
Q29 Please put the themes you have looked at above into the order that is most important to you, with the most important first.



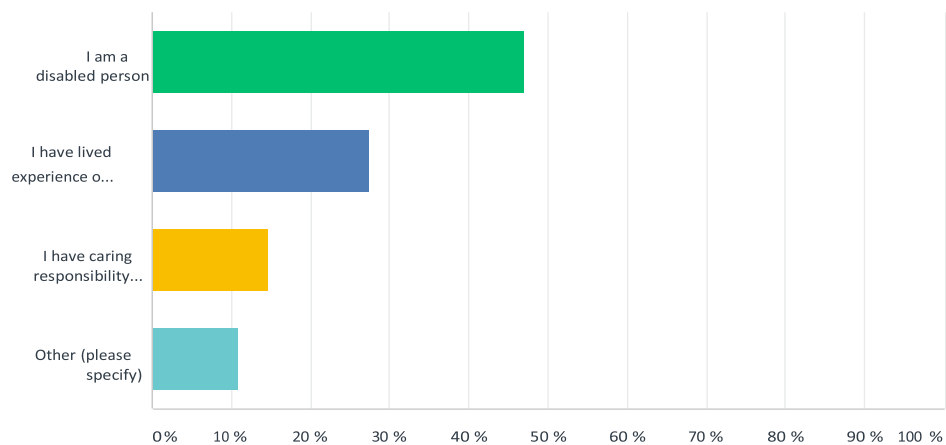
Q30 Where do you live?



Q31 What is your age?



Q32 How would you describe yourself?



Appendix 2: Data – Qualitative Survey Results

Q1 Advocacy: Make sure everyone can get advocacy to help people say what matters to them in all areas of their life and to help them with processes that can be difficult to work through, for example in education, health and social care, benefits, housing and justice systems. Is this important to you?

Comments:

1. I still face shame and stigma in accessing goods, services, advice and information.
2. It is very difficult to find advocacy services, and it is essential to me, I have difficulty understanding and speaking for myself a lot of the time
3. I feel many people can get bullied in meetings. Be taken often by health professionals, CCG's and local authorities down the wrong path due to agendas back at the office including budgets and lack of resources. I have witnesses as an advocate many times. The adv. is able to give impartial advice.
4. The way the UK systems work are VERY difficult to understand and follow especially if you have problems speaking to people or filling in forms. The worse part is understanding what they are asking you - it is so difficult to speak to a person too. I have many disabled friends who need this type of help and someone to speak for them is vital to them getting the correct treatment and advice. Also the correct monies they need to live.
5. My son has learning difficulties and as an older parent, it is important that "when I'm gone" there will be an advocacy service to help him.
6. As a disabled vulnerable person that has encountered some major life changing events i have always found advocacy difficult to obtain,i believe it is under resourced. I also do not think advocacy is fully understood by the general public and what it covers. Legal representation for vulnerable people in low and modest incomes is almost impossible to get including: a. Employment Tribunals b DWP cases & appeals c Mental Health
7. I am at a loss as to how I may be able to access some practical home help and both emotional and parenting support. I need this type of help/care to enable me to meet the needs of my children and to continue being the best parent that I am able to be. My social care assessment requests are being passed between adult social care and children's social care. Then back to adults again.. and so on and so forth. Children's services will step on and remove my children from the home when/if my children are thought to be high risk. Adult social care won't help because it's help within the home & family/parenting support that I require and not personal care. I am at a loss and I'm genuinely frightened as to what the future holds for my children and I.
8. Isolated people need support
9. Some people are not always confident to speak up. They need as much information as they can get and to be made aware that they will not be judged, intimidated or coerced into any situation. Access to help needs to be easy for everyone.
10. Having access to support is always helpful. Though this is still not available to individuals with unseen disabilities or are not known to services as they do not met the criteria. Also trying to find help is not easy.
11. Everyone should enjoy as full a quality of life as possible regardless of disability or level of ability
12. Because people need support particularly under the stress of covid
13. To ensure people have equal opportunities, regardless of their situation.
14. I cared for my mother for 7 years she had dementia and I had to act as her advocate. Some one needs to be there for you.
15. Dyslexia is massively under supported in all areas of life.
16. I can't always be well enough to keep up with any official process
17. Living with an invisible disability I struggle at times to seek the support I require.

18. Life is complicated these days. Its all internet based. It will get easier as the younger generation gets older because they have grown up with it. For those who did not grow up with it, like me, it takes a lot to get my head around it and then keep my head around it. Help with advocacy is valuable in this situation.
19. All disabled people should have detailed person centred life maps so they have full control over all their lives, this requires skilled advocates who are continually improving their skills in this
20. My mam became very ill and sadly died in June 2020. Some of the issues she faced were about her choices and not being listened to. Had she not had family to support her she would have died in hospital and not at home where she wanted to be. Hospital was a very bleak and yes boring experience for mam. No stimulation, no one to talk to. Busy hospital staff with barely any time to spare accept for essential stuff like medication etc. She became depressed. My mam was misdiagnosed with sciatica when in actual fact she had kidney cancer and a fracture on her first vertebrae. She then developed a urine infection which turned to urosepsis which was also missed by her GP. The cancer and fracture were diagnosed in hospital when she was admitted to hospital with urosepsis. And all this happened even with family intervening and phoning the gp but we felt that nobody listened to mam or us. So what chance do people have who don't have family support? Will the excuse be Covid - 19? Seems to us as a family like neglect and dereliction of duty... Where was their duty of care when we were ringing our gp to make a house call because my mam was screaming and crying with pain and all they did was treat her symptoms by increasing the dosage of her pain medication, sending out physios and community practitioner instead of attending themselves, making telephone calls to 'check on her' well they can't have asked the right questions because my mam suffered greatly. I fear for our communities right now.
21. Regulations and systems are complicated and difficult to understand without help. Sometimes decisions that are made on matters that affect me are unfair.
22. Everyone has a voice and has the right to be heard
23. All of those system can be very intimidating and difficult to navigate, an advocate would be reassuring.
24. Without advocacy how would my voice be heard. Mean important elements of my life such as education and health social care benefits housing and justice system would not be reflective.
25. Too often we assume that people can express themselves but they can't
26. No voice = no choice. We have been abandoned by social workers/chc workers and LD nurse during the pandemic. We are feeling very alone.
27. we have lost lots of advocates, now only legal advocacy is funded. More funding is required to hear the voice of people and their families
28. My line Managers support in the Civil Service with Reasonable Adjustments, when other Managers in the section were trying to deprive me of them
29. Because when I was on Benefits got myself into a few messes and my dad and a community house nurse who use to come round and see me got on the phone a few times and helped me to sort this out
30. The benefit system is horrendous to navigate, with very unhelpful benefit staff who don't listen and don't see or recognize hidden disabilities. Reception staff in healthcare settings are a barrier to me accessing healthcare as they don't understand the communication differences with autistic people. Again hidden disabilities. Advocacy is important as trying to navigate these areas often leads to autistic meltdowns, so I completely avoid these settings.

Q2 Benefits: Make sure the benefits system is fair so people don't have to live on less money in the North West, compared to the South of England. Understand that levels of poverty in the North are much greater. Is this important to you?

1. It is not fair that some people loose out based on where they live , costs of living such as utilities cost the same regardless of where you live
2. I would like to think that the UK government believes all disabled people should have the same standard of living and opportunities. So clearly their should be equity in the giving of benefits.
3. This is really a big problem, when there is little help with paying to items such as wrists supports which I need to wear very day, they cost £32 for each hand. How can you afford this on such low benefits and living cost as so high.
4. My son has benefits and Direct Payments. The benefit system seems to work well for him; Direct Payments vary from area to area and social worker to social worker.
5. Because this is one aspect of British Society that is not regulated or governed adequately I believe. I think this question is rather limited in terms of it's objective ! The obvious answer is yes there should be parity, but I feel a lot of the Benefits system is unfair including assessments and savings limits.
6. Thankfully, I haven't had any major issues when applying and being approved for any relevant benefits
7. People need to also be given information on budgeting, food choices, being economical and understanding the worth of money. Poverty in general needs its own agenda in the way of help available again without judgement. Situations for anyone can change rapidly so the people today that can afford need to also be made aware that a good situation can turn bad so to just be kind
8. Benefits should be easier to continue once the person has met the qualifying criteria. The PIP system is still geared towards physical disabilities, questions are loaded and trying to qualify for the mobility component if you have an unseen disability is impossible.
9. The north is the forgotten 'meat in the sandwich'. The Government is more aware of and amenable towards Scotland because of the threat of them getting independence and the consequential breakup of the Union, and the South is where most of the Government's supporters live. We don't count!
10. Because there is a north south divide with less money being spent in the north per head of population
11. There's terrible poverty in the south I lived there for 3 years and costs are much higher
12. I personally don't claim any benefits but I know many people who struggle to get funding they desperately need
13. Due to people not wanting to appear needy, and want to appear as if they can cope OK, much poverty is hidden away from friends and family. Older generations have more of a coping strategy and in northerners this is more pronounced than in southerners. Younger generations are more likely to feel that can access benefits and understand them.
14. The complete disregard and look at respect the people in the north of England is very obvious and it is time that the voice was heard.
15. And far more, complete rethink of all benefits including wheelchair services Motabilitybasic income?
16. Disabled people often rely on benefits or have a low income. Disabled people are more likely to be in poverty compared to non-disabled people.
17. We have had personal experience of the benefit system and it is not easy to use or to identify what you eligible for. Furthermore, it is not consistent, especially in Cumbria we are one of the highest regions of poverty!!
18. It is difficult to live on the benefits that are given. Living in deprived areas can cause a negative knock on effect to people's physical and mental wellbeing causing extra strain on the NHS and other voluntary services.
19. I see this very clearly when applying for job roles. If you live within London you receive a higher wage to compensate for the higher living costs. The question is a little bit unclear but I believe you're asking if I feel benefits are important to me? Without my PIP not built for a car that is suitable for my disability. The remaining money I have helped to support the wider household bills as my disability limits my employment.

20. Probably generally true but every town has its poor districts and sometimes it is even harder if the rest of the area is well off
21. We live in rural Cumbria. Getting to any services (if they exist) is expensive of support time and money.
22. Across the North there is lots of poor people and less employment, also seems to be more people with learning disability and or autism ?
23. High southern cost's should not be supplemented. That just adds to higher cost's in the south
24. Because everyone throughout the whole of the country is of equal importance and should have the same amount of money

Q3 Benefits: A benefits system that is based on need, fully supports the right to live an independent life and supports the idea that a person is disabled by a world that doesn't meet their needs, not by their condition. The money you get from benefits must be enough to live a full life. Is this important to you?

1. Because I want to live a full life in spite of my disability
2. As someone that suffers with a disability thinking of my future needs and financial stability is important.
3. I could do with extra support but have been told this will cost quite a lot of money, they are not taking into account my medical conditions so I would have to pay the full cost myself which I would struggle to afford
4. Yes, but I also think people should be as independent as possible and not rely on benefits when they can work. I am paralysed from the neck down and run my own business.
5. You can hardly afford to buy the types of food and heat your home on benefits especially if you're disabled and need the heating on a lot. Staying warm is a nightmare. Getting help with jobs in the home - there is no money spare to get a man in etc.
6. To ensure equity and reduce stress.
7. My son deserves to live life well on the benefits he receives.
8. I do not think this question has been thought out-how do we define a full life? One person's needs might be totally different to another, isn't this about aspirations?
9. Although I struggle financially at times, I know many others who are far worse off than me.
10. Very important. In my own situation this last 9 months my mobility and pain has got very much worse. It has affected my ability to go to work, get out of bed easily, bathing becomes a problem, what are normal tasks around the house once were easy are now hard. Things have had to be neglected due to my disability. Therefore I found myself depending on others to assist i.e. with housework, gardening, helping sometimes with clothing that I couldn't manage some days. The extra financial help does assist in getting help to avoid further problems especially of mental illness and depression taking over. This obviously puts more strain on the health service. Preventing a situation getting worse can actually prevent higher costs in healthcare further down the line.
11. Previous funds issued for life and made it difficult for others looking to access benefits. Certain groups do not see the hardship of the younger disabled people.
12. Using the social model instead of the medical model to assess my needs looks at what is wrong with the world and not with me.
13. I am able bodied. Others less fortunate in that regard shouldn't be disadvantaged financially too
14. I have pensions but most don't
15. I can't function in society at all without help.
16. Disability is relative. Mine is minor and has little impact on my life. A friend is blind and finds that roadblocks and mountains to climb affect her every day, when claiming benefits, despite using sophisticated software to access them. A "full life" is also relative. One person's idea of a full life is quite different to another's. Instead of "full life" I would prefer that benefits were available to all disabled people to live in a warm, comfortable

environment, to have good and adequate food and sufficient social interactions to suit their needs.

17. The social model of disability is what everybody gives lip service to and everybody agrees but when it comes to practical things in the current climate they are reverting to the medical model through the back door it is desperately important that we look at the social model not the medical model .
18. Most people dread retirement and the thought of living off the state pension. Which is often considerably less than their earnings when employed. Some are fortunate enough to have extra pensions to top these up but not all.
19. This is very important. Not all disabled people can work. It can be difficult to live an independent life with just benefits as an income. Benefits have not kept up with inflation.
20. How can you live a life if your not earning or getting enough to get the basics...
21. The money given in benefits is not enough to live any good quality of life on. The benefits system treats people like they are committing fraud even before they have applied. Government needs to understand that is only a very small minority who take advantage of the benefits system. Most people would prefer not to be ill or disabled and able to work. They need to understand that when you have money things are cheaper in general, for example with a good credit score you can get a normal gas and electric meter with a reasonable tariff. If you have moved into council housing and the tenant before had a bad credit score and had a payment card meter then gas and electric cost a fortune.
22. It is important to not only provide for yourself but also your household, unfortunately, the benefits system does not allow me to live a full life, does support areas of my life to enable me to gain employment. Unfortunately do feel disabled people are still seen as lesser workers than their nondisabled counterparts.
23. Unfortunately where money is concerned fraud is prevalent which impacts on the genuinely disabled. 1 in 8 people in Great Britain claim to be severely disabled which means much less for those in real need.
24. Relevant for both the person on benefits and low waged care workers
25. Benefits only meet some peoples needs , and definitely not wishes, aspirations. Some local authority thresholds for support is linked to diagnosis and effects benefits to can claim. particularly this is an obstacle for autistic people who's needs are not recognised !
26. For the most severely disabled there money should be in line with average earnings + housing and Care
27. A lot of people with learning disabilities and Autism or NOT on Benefits because they are Lazy its because they can't find paid work like people without PLUS a lot of them do voluntary work a GOOD LONG hard days work WITHOUT being paid so deserve enough money to pay the bills
28. Very important! I have additional costs as the world isn't made for me. Why do I have to financially suffer? Having to navigate the PIP system every 3 years as PIP say my autism may get better! Never ever has somebody's autism got better! If anything it gets worse, due to mental stress of people not understanding me. How can I get them to listen?

Q4 Democracy: Funding to encourage and support disabled people/people with lived experience of disability and long term conditions to stand for election as a councillor or an MP. 1 in 4 people in the UK is a disabled person/has lived experience of disability or long term conditions. We want to see the same in politics. Is this important to you?

1. I think people with disability's need to be seen as equal and capable to raise the profile and inspire those who are disabled that they don't have to be limited.
2. This would be an amazing thing, one because the person would have a first hand experience of what it's like to live with a disability so would not just guess at people's

- needs. And secondly it would give hope that disabled people have voices to be heard, and people will listen
3. Yes, disabled people are massively under represented in positions of decision-making and power in the UK.
 4. I'm too old to do this, but I know many younger people who would be great
 5. Because everyone deserves to be involved in the democratic process. Disabled people are under-represented and their views/experiences can help towards creating a fairer society
 6. A disabled person or a person who has lived experience of disability or long term conditions has a lot to offer and with encouragement this can be recognised and others can benefit from the experiences.
 7. Many people with serious mental health condition who become incarcerated in hospital I doubt are encouraged to vote in a responsive or effective manner. Should also be encouraged to become Non-Executive Directors of Public Bodies such as the NHS
 8. No one should be discriminated against.
 9. It should be recognised more widely the barriers which are still faced by many disabled individuals in society. Having more individuals with a disability in parliament and on the council would benefit everyone.
 10. Again, I am an elected councillor, and everyone should have that opportunity regardless of physical ability
 11. Representation
 12. All the equalities matter it creates a balanced society
 13. I've lost all faith in this version of the democratic system
 14. Yes, it is important but we have to be realistic. As an example I belong to an organisation helping those with learning disabilities. The constitution requires that a proportion of the service users serve on the management committee. Try as we can, this is very difficult to make work properly as mostly they have a narrow grasp of the issues affecting charities and their disability prevents better understanding.
 15. One of the main problems in today's politics is that the politicians are completely unaware of the problems that disabled people face you cannot know what a person experiences unless you walk in their shoes .
 16. I work with and support disabled people and see the barriers they face in their daily lives. They like any like minded able bodied person are able to make positive contributions to our society. We need to find ways to include everybody without discrimination. Knocking down barriers through changing our physical environment, building architecture that considers everyone from the planning stage, people's attitudes and the way we think about disabilities. Change is far too slow
 17. Many people who make policies don't understand the issues disabled people face.
 18. to get their views heard in parliament
 19. People who are not disabled cannot possibly understand the difficulties that this can cause. A disabled representative may have more to say about real life experience than someone who doesn't comprehend the difficulties.
 20. Having more people with lived experience of disability championing the voices of other disabled people will hopefully help society to become more inclusive.
 21. Seems like tokenism to me - by all means support people who want to go down that road
 22. They might actually understand the issues
 23. People with lived experience should represent local people
 24. Support yes but not additional funding
 25. Because I think people with learning disabilities and Autism should have a say in how to run the country from there point of view
 26. We are under represented and often have people who have no experience of our lives speaking for us. This is wrong.

Q5 Democracy: Make all voting accessible by 2025Is this important to you?

1. Inaccessible voting is voting denied
2. I have a sensory disability. Polling stations aren't made for me.
3. Should be done sooner
4. Clear information on what each candidate stands for, as majority of the time I don't understand and have to get advice from others. Also my mum is house bound but would like to vote, the only way to do it is through the post, if her carers forget to post the letter she can't have a vote
5. It is important that everyone can be involved in, and understand the democratic process and who represents them and why. Having worked in the election process for forty years I am amazed how many people do not understand the election processes and who they are voting for and what type of elections they are voting in (e.g. local, national and previously European elections).
6. A disabled person or a person who has lived experience of disability or long term conditions has the right to vote. However it is important that all the pre-voting information is made clear to him/her and it is easily understood.
7. I vote via post
8. everyone deserves a vote
9. Everyone should be able to vote. It should not have a bearing on if you are a disabled or non disabled person. Your view should be heard.
10. With Covid still prevalent, all voting should be postal or on line. Covid should be the catalyst to make that a permanent arrangement
11. I have mobility issues
12. Much of the this has improved with Postal Voting
13. Everyone should have the right to vote. It's the only power in society most people have. Accessibility is fundamental.
14. Very important everyone has the right to vote, so everyone should be able to access their polling station easily or with reasonable adjustments in place.
15. Because you are disabled you don't get a vote? Really ? I didn't know! Voting should be possible on line for all.
16. The way to move things forward through the ballot box .
17. Earlier
18. We are all people and have the same rights we should all be able to exercise those rights or surely we are being discriminated against. Alot of the people I support suffer from extreme fatigue at times and /or are w/c users So at times they will suffer from bouts of fatigue and have been unable to fill their postal vote in on time and posted late or had no support to get to a polling station as they can't drive a car or had nobody available to take them to a polling station.
19. EVERYONE should be able to vote.
20. As someone who was bedbound for 2 year it would have been impossible to go to a post box and vote or to a polling station. Voting needs to be modernised and done online so most people have access to the system without having to go outside.
21. This one is a massive area that needs developing, people with a disability or long-term health condition or impairment sometimes don't have access to information in accessible formats. This is vitally important to allow people to express themselves.
22. Prefer the Australian system where you are fined £165 if you don't vote. People died to get the vote
23. everyone has the right to vote
24. Fully mobile
25. I am glad I have voted because it means if the Government is not living up to their expectations I can complain plus if everybody can vote why can't people with learning disabilities and autism ???

Q6 Digital Inclusion: Make sure that disabled people/people with lived experience of disability and long term conditions can use computers and smart phones. Bring ideas led by them into future development. Make sure that if we can't use technology there are still alternatives. Is this important to you?

1. Equality
2. I am pushed to online chats all of the time. The language used by customer service agents isn't made for autistic people, they don't give enough information. The chats get disconnected as its taking me time to process the information and they think I've left the chat
3. It's not always easy to learn how to use computers and technology, also if you don't have internet access or the correct equipment it's impossible
4. I literally pay my mortgage because of digital inclusion. It would help so many people add value to the system by being taxpayers living with disabilities
5. How can I afford the cost of running a smart phone and a computer??? I need both to even get my benefits and fill in forms - it's all a nightmare. So many people of my age (68 years old) can't work the new technology or afford to buy it.
6. To increase inclusivity in the wider society and breakdown isolation.
7. Technology is part of every day life and a disabled person or a person who has lived experience of disability or long term conditions should be able to access technology. He/she made need additional training or adaptive equipment.
8. Because it has provided me to access to the outside world and makes
9. Quite often, being able to access and appropriately use a computer or similar device, is the only connection that many vulnerable, disabled people have with the outside world.
10. Workplace adjustments can make life so much easier and less stressful for the person. No disabled person wants to stand out, want to be treated differently. A little compassion and kindness as well as understanding is all that we want. Agile working policies can assist too as we all still want to feel valued in our workplace even if our health status has changed.
11. Everyone requires a voice and so should be supported in the best possible way for this to happen.
12. I am bipolar, currently computers and backlight can be an issue for me as it can make me go high. I have just been a student, and it was terribly intense moving online. Zoom programmes and programmes like zoom are terrible for someone with bipolar. There is a 'lag' and I almost went high from the experience.
13. IT is the medium that makes us all equal, more than any other
14. Equal access
15. There still are a lot with no internet access but also being able to keep up with the changes
16. It's important that disabled people aren't left behind
17. Everything is technology based now; but though this can bring benefits for many for some people with disability it can bring issues and isolate especially if technology is not compatible, for example screen reader technology not being able to read a webpage as it's not formatted correctly so a blind person can't be read what is on screen
18. It is self evident that ICT knowledge gives greater access. However, it must be accompanied by help and training. Giving a disabled person a laptop and no help is a waste of money
19. Stop getting lip service to accessibility and do something about it .
20. Very important, we live in the digital age. Many of the people I support have used WhatsApp messenger etc to make video calls or sent messages and kept in touch with each other this way. Of course it is still challenging for many of our older clients who will not use technology or for the less able. Take the complicated out of it and ask for their input on how to make it more accessible. For example instead of having to install an app for say an audio reader for sight impaired make it an existing feature on the tablet or laptop. Making it more accessible and cheaper if it is an app you pay for

21. Disabled people are at risk of missing out and being further excluded as more services involve computers.
22. This is important to enable people with disabilities to access the outside world when maybe physically they cannot. It is important to allow people to have employment opportunities that can be done from home.
23. We are living in a fast-changing society which embraces and empowers the use of technology. With this technology needs to be accessible in all ways, for example, people living with a disability impairment long-term health condition are linked to low social-economic groups as well where technology and access to technology is not always available.
24. My wife was paralysed from the neck down and requiring ventilator support - the computer that she could talk to made life bearable
25. Make technology that reads out loud for all documents and simple ways of accessing website, and information through search bars. provide internet access free for all
26. There is already enough support in the community
27. I think its important because it helps prevent loneliness mental health and depression

Q7 Digital Inclusion: Make sure Further Education funding goes towards improving the skills of disabled people/ people with lived experience of disability and long term conditions, in using computers and smart phones. Make sure they can do this in accessible, community places. Is this important to you?

1. it needs to be accessible to all as everything seems to be geared towards using internet
2. As above
3. Yes in local buildings, but make sure they are fit for people with sensory disabilities
4. This is vital for the future - it would make such a difference to me if I could do everything young people do knower days on their equipment, disabled people need access and help to understand
5. To ensure disabled people can play an active part in society on an equal part with other people, with an necessary support they may deem necessary.
6. All people should have the right to up skill in whatever skill or to whatever level is appropriate.
7. It helps me feel less isolated.
8. All areas need to be looked at. Any help is worthwhile.
9. Having been excluded to higher education due to a disability when there was an original acceptance is very disheartening. It has now given a negative view on what can happen in the education system. Even after a challenge nothing happened and there was no access facilitated to the course. Very disappointed. This also goes to being discriminated as you also required to have LD to access a course on a supported internship.
10. People with disabilities deserve equal opportunities and help to achieve their goals
11. My son is not accessing education and struggles meeting new people
12. Without my laptop and phone I would be totally isolated from everyone.
13. Great if you have an accessible venue but how will they get there. Disabled transport can be very expensive and also limited in some areas so why can't all taxis or mini busses be wc accessible. For example if there are no accessible taxi vehicles in their local area they may have to hire a taxi from further afield making it alot more expensive
14. Disabled people are at risk of missing out and being further excluded as more services involve computers.
15. This is important as for assaults giving disabled people highlighted in the point previous this needs to go hand-in-hand with fully accessible infrastructure.
16. In my contact with Universities great strides have been made in this direction
17. Much needed
18. make sure people have support to use equipment, community hubs where equipment can be accessed and help to use them
19. Accessibility (sic) should already be in place

Q8 Disability Hate Crime and Harassment Give funding to Police Authorities to work with disabled people and their organisations to identify Disability Hate Crime. Review how disabled people report Disability Hate Crime and how accessible it is (these are sometimes called third party reporting centres). Work with the local council to improve the safety of disabled people/people with lived experience of disability and long term conditions, from crime and harassment. Is this important to you?

1. I have and am still experiencing hate crime , I have reported to police several times but didn't know how to word it, police have had no interest in helping. It should be suggested if it sounds like it could be a hate crime so the victim doesn't have to know all the terms. They need to offer support to stamp it out
2. Yes, but the police don't understand hidden disabilities like autism and they think we are being difficult, then we get told its not a crime as they don't want to waste their time
3. This is common sense, any type of HC needs to be eradicated from our society
4. The charity I volunteer for used to have this funding to help people in Chester it has been removed and yet people still come to us, in a terrible state needing help immediately.
5. To increase ensure Police/CPS have full training, awareness and understanding of the needs of disabled people and how to respond appropriately to individual needs.
6. A disabled person or a person who has lived experience of disability or long term conditions can be easy targets. He/she needs to know how to deal with hate crime and report it, knowing that the case will be dealt with.
7. I have found that PCO's do not really understand this subject and i have been fobbed off on numerous occasions having made complaints. I do not believe that the Police are responsive or effective in tackling this subject, a lot of rhetoric but very little action. Racial bias is also becoming a big issue i believe but there appears to e very |
8. Having parked in a disabled bay, I displayed my badge and made my way round to the passenger door to unbuckle my new-born babies car seat. At this point, a woman parked in the bay next to me, began verbally abusing me and accused me of using a disabled bay without being entitled. I told her she should take a look at my dashboard. My badge was displayed there. She then reversed her large 4x4 vehicle out of the bag, threatened to run me over and then actually attempted to run me over whilst I had my new-born in a baby sling. I was thrown to the floor and she drove away. I reported this to the police immediately and to staff at Morrisons as this was where I was parked. Neither were helpful and seemingly, requesting and viewing Morrisons CCTV footage of the carpark was simply too difficult a task to carry out and no further action was taken.
9. I have had experience of criticism and judgement because I look well. That doesn't mean that I am. The continuum of health and illness would denote that most people are not 100% well. Just because I don't look ill does not mean that I am 100% well. Also some disabilities affect people only on some days i.e. arthritic conditions, pain, anxiety. Other people are not qualified to judge or be unkind. Yes I think there should be more of a drive within local councils, posters, tv adverts so that the ignorant can learn.
10. Nothing to add as I have no experience.
11. Having worked for a Police Authority, they need more funding in many different areas. Whilst this is important to me, I fear the Police will not get that extra funding in my lifetime
12. I have come across cases of this where local councillors involvement solved a neglected problem
13. There is still much stigma around disability in certain areas of the NW. Better awareness needs to happen to improve this. The police can't tackle this alone.
14. The UK is not bad on this. I have seen far worse examples in other countries where disabled people are physically attacked, ostracised, and hidden to the point of death.
15. It's a recent as last week we had people give a list of we've got to realise that hate crime and they listed gender colour race religion what was the one thing they missed out disability we have got to stop being invisible

16. Most people with disabilities are extremely vulnerable and are most often in receipt of community services such as care packages funded by their local council. In these cases surely the care provider has a duty of care to ensure they support reporting of such crimes. Also put the Bobby back on the streets, make it less complicated. I've heard talk of having Covid Marshall's on our streets... Same principle
17. There seems to be greater emphasis on BAME issues. Disabled people's needs are not a priority.
18. Once had my back set on fire and I think that was a hate crime it was a HORRIBLE experience to go through and NEEDS STAMPING OUT

Q9 Education Provide funding for care and educational support for every disabled child/child with lived experience of disability and long-term conditions to ensure inclusion in mainstream schools. Include the Equality Act in the National curriculum to teach young people about equality and diversity. Is this important to you?

1. Teach from an early age people will hopefully listen and take on board
2. Every child must be given the same opportunity even if it cost more, that disabled person could be the person who cures cancer or Covid given the opportunity.
3. VITAL
4. There is too much bullying because schools aren't inclusive
5. To break down prejudice and give all children an early understanding of the needs of disabled people and how to support and value all people.
6. This is a tricky one. Whilst I support inclusion in mainstream schools, I know from my son's experience that he thrived in a special school. It's vital that inclusion in a mainstream school is done well and that the student feels comfortable, safe and secure. I do know disabled people who have enjoyed the relative quiet of a special school, the fact that because it is usually a small school, everyone is known with all staff working together.
7. But also Human Rights
8. Most definitely. Teach people young. Disability is not something to be ashamed of or hidden away. We don't want to be patronized either. Just to be as normal as the next person.
9. Everyone should have sufficient support in education to reach their potential. Unfortunately, this is not always the case due to fighting for funding support.
10. Young people need to be taught about all aspects of equality and diversity
11. Definitely! I've been to appeal now for my sons funding on 2 occasions... medical profession support this claim, education don't... it's just a circle we go round and round in and in the middle is my son who have fallen now out of mainstream education.
12. This happens in my local schools. They do it well.
13. Children should be made aware of the quality and it's very important that they don't have to wait 2 to 3 years before diagnosis .
14. Yes we hear a lot of talk about inclusivity of ethnic minorities, equality etc... Which is taught in our schools.... More of the same to include disability awareness taught from early years
15. I think that people should have a choice of which school to go to some people may benefit more from going to mainstream schools others may benefit more from going to special schools

Q10 Employment: Provide a trusted employment support service that helps disabled people/people with lived experience of disability and long term conditions, to find and keep jobs. The service should be led by people with lived experience of disability and long term conditions. Is this important to you?

1. People who understand the needs of disabled people is worth more than qualifications as they have lived it themselves .

2. Again common sense
3. I was in a desperate situation with work and needed help.. I was referred to Routes to Work and promised all of the support in the world. When it came to it nobody contacted me or returned my calls and emails.
4. I was forced to give up a very good job and career in 1998, due to the discrimination of my employer - I took them to tribunal and won. Couldn't get another job, I'm sure they gave me a poor reference and that effected my mental health which contributed to heart attack and problems that eventually forced me out of the job market. The whole tribunal experience was harrowing for me as I had to do it all myself as I couldn't afford legal help.
5. Job Centre etc. staff should be fully supportive and trained to understand the needs of disabled people including those with conditions such as Autistic Spectrum Disorder and ensure that they offer appropriate opportunities.
6. On leaving school / college, a disabled person or a person who has lived experience of disability or long term conditions can be left feeling "what next?" My son was fortunate in that a support worker / PA helped him to find volunteer work and supported him in the early stages, but this case is in the minority.
7. But it shouldn't necessarily be led by disabled people, it should be led by the best persons irrespective of disability. It is surely about sustainability and not revolving doors. To many private contractors basking for contractors with very little scrutiny or audit i believe. Important to support and promote the IPS model including the investment in employment link workers Job Centres need to really put the Plus factor into the support they provide.
8. Most definitely. In my place of work I can pick out the empathetic and compassionate people. Yes I can give a first hand account of what it is like but that is not to say that someone cant learn.
9. Looking for work and being unsuccessful for over 6 years is very disillusioning. Being on various employment schemes leading to nothing - only free unpaid volunteering is not a route to employment. There should be a requirement from the government that larger employers require to take on an support disabled individuals. How do you gain experience if no one gives you a chance to show your skills. Application forms are a nightmare. Interviews even worse - what answer do they really want. Give people a chance. Limited higher level apprenticeship - oh sorry you do not qualify.
10. This should have been provided long ago
11. I lost a job when the employer found out about my disability Trades union support also poor
12. A whole new approach is needed. Thousands of people stuck at home with useful skills wasted!
13. The Job Centre used to do this well. Due to austerity cuts they no longer do so and it is left to individual charities to plug the gaps.
14. The story of we know what's best for you is so annoying that people do not know what is best all they have to do is listen and learn
15. Many disabled people can work and be good workers but are not given the chance by employers. They also don't get enough help to move into work.
16. This is imperative, currently it feels as though government representatives are very out of touch with what people are physically and mentally capable of when living with a disability.
17. As we move through the tough times and unfortunate we see more job losses, feel disabled people will be at a further disadvantage. Someone who accesses the scope scheme found this useful in realigning my job areas linked to my skills and how to articulate them. However, the second part of the question in helping to support people in keeping jobs would have been very useful for me. For somebody who struggles with confidence, this service would be something I would feel could support me retaining my job and potentially progressing.

18. Having managed in the public and private sector unfortunately it is probably not achievable where the costs of adaptation are many times the value of the job. Could only work with large employers in the public sector.
19. Don't force disabled people to do work unnecessarily
20. Do more job share opportunity, and help develop jobs for people
21. I am now off benefits and earning a proper wage when I came off people started looking at me as someone who was adding to the community rather than a scrounger also am in a job I love

Q11 Employment: Extend Access to Work funding or provide new funding to cover job searching and look at wage subsidies (government giving your employer some money towards your wages). This will help get more disabled people/people with lived experience of disability and long term conditions, into paid work. Is this important to you?

1. Very important so that disabled people don't feel like a burden or a drain on resource.
2. But not sure about paying employer to have you is suitable
3. We are still human and have to live. This is degrading
4. Even volunteers should get access to work, volunteering is the steppingstone I think it is disgraceful how I did not get support in my early formative years living with a disability just because I wasn't earning a wage. I could've been paying tax much sooner and contributing to society if given the support earlier whilst a volunteer.
5. This is normally the only way disabled people can get into work, especially young people with no experience.
6. To enable disabled people to contribute fully in society and be valued members of society.
7. Anything that gives additional support would be welcomed.
8. This is a good suggestion.
9. Employers and HR like to collect the Disability Confident logos and work hard to make sure they have the evidence. Though on the ground there are no entry level opportunities - look at who they talking about long term employees who may have developed a disability. What is the age range of the disabled employees. Is Access to work supporting younger individuals or just the ones who can work the system of support in the work place?
10. My only reservation is where will the money come from
11. Poverty is a big issue for disabled people
12. I still think the old Remploy scheme was better
13. The Access to Work Process needs to come more streamlined too. The few times I've accessed this service on behalf of others, I've found it very time consuming and difficult sadly
14. Having the right equipment at work makes all of the difference between being employed and not.
15. Phil support package for employers to retain or actively support the employment of disabled people could help. Fear is disabled people might be used to attract this funding for businesses not leading to meaningful purposeful jobs. A review of the access to work funding understanding its relevance importance would be highly useful with a working group of people both with and without disabilities also with them with not in employment along with business leads again both who employ disabled people and don't would be very useful working group.
16. Probably post COVID & Brexit it is unachievable in the face of large scale unemployment
17. Access and support to be able to work is very patchy
18. Because what takes someone without Learning Disabilities or Autism about 15 minutes could take someone with about an hour So it's helping the employer to keep them on

Q12 Employment: Make it so that employers have to have disability equality training, run by disabled people/people with lived experience of disability and long term conditions. Is this important to you?

1. Sometimes its an awkward subject and not everyone is comfortable having discussions. Having a benchmark that's understood by all parties would be helpful
2. They should be trained and follow through with the advice, so everyone is treated equally
3. I have been bullied in every work place by staff and managers of all levels, making me very apprehensive to ever work again
4. Absolutely vital, and not just something online people with lived experience should provide the training
5. VITAL
6. To reduce discrimination and unconscious bias and enable employers to cascade training and good practice down throughout the workplace so that employees, the public and clients feel more confident in the workplace.
7. Who better to run training than those with experience, for whatever reason?
8. Including mental health first aid training.
9. I imagine this would be very helpful and informative
10. Most definitely. Maybe this way they will understand better. No one wants discrimination in the workplace but it is still there even though people don't think they are behaving that way. More training is needed.
11. Training will be much better if provided by individuals with a lived experience. It is also always well received by employees.
12. Should have happened long ago
13. To make the training relevant
14. But not all disabilities are the same
15. You cannot force culture on people. It has to be learned. Understanding of and empathy with disability is a cultural issue.
16. Quite often the problem is that the employees are ignorant of the rules in the laws and the equality act as if they were properly aware that a lot of the problems would disappear
17. Disabled people are best placed to explain about the challenges of living with a disability.
18. Often employers don't understand why disabled employees may need adaptations.
19. The more awareness the better, feel this should be more around full equality.
20. Seen many examples of this and it ticks a box but does not lead to long term changes
21. Important for those that can do meaningful employment
22. not just e-learning, roll out programmes of equality advisors in big organisations, peer roles
23. Because people like us have lived experience so we know what good and bad support feels like

Q13 Equality: Make the United Nations (UN) International Convention on Rights for Persons with Disabilities part of UK law. The International Convention on Rights for Persons with Disabilities Is this important to you?

1. Yes everyone should be treated with the same respect as everyone else, regardless of who they are. I believe that some of these could be improved upon significantly such as accessing services and receiving help. It should not always have to be a diagnosed disability too, as some are only picked up on later in life, for example my own was only diagnosed at 30. It should be if someone is struggling and needs help that is given
2. Definitely
3. It should be in place NOW - why is it not??????????????
4. To reduce discrimination and unconscious bias throughout the country and raise the profile of disabled peoples right, needs and issues.
5. No experience, however with a son with learning difficulties, it is important.

6. Steps in the right direction is always good. Highlighting disability, especially hidden disability too.
7. We need all the legislation available.
8. Should have happened long ago
9. People with mental health issues are discriminated against and human rights denied under mental health act
10. In theory it sounds good but I've never read it and don't know how it works in practice
11. We should not be out of step on this.
12. We are one of the very few countries that have not made it into law but it is to our disgrace that that's the case
13. The UK Government should ensure disabled people's rights are upheld, with legal protection.
14. As we move away from the protection of EU this could be potentially hard times for people living with a disability impairment long-term health condition. The government now has full rights to implement any law changes they need to and as we have seen with covert 19 disabled people unfortunate have been left behind.
15. Protection
16. its law- but its being breached all of the time by schools and employers
17. Because people with learning disabilities and autism have as many rights as people without

Q14 Equality: Make the Equality Act more important than all other laws. Is this important to you?

1. I want laws to be equally important. There's a difference for me between strengthening the provisions and widening the provisions of the Equality Act 2010, opposed to making it more important.
2. I have to highlight it to services on a near enough weekly basis. And when they do become aware of it. They don't adhere to it, I have had this within my employment with the NHS. Within shops, banks, councils. My experience of this is truly horrendous
3. Yes everyone should be treated as fair and equal as possible. Why should someone through no fault of their own be treated like a second class citizen?
4. Everyone one is equal, we are no different just because we can't do everything so called normal people can - I am a person remember that
5. Because equality should underpin all areas of law.
6. I don't feel it should be more important, but should have equal standing with other key acts.
7. They should make the Human Rights Act the most important it underpins everything we need.
8. Not a lot of people are aware it exists. It will only be understood when people are guided towards it.
9. Equality is very difficult to prove.
10. All laws should be of equal importance
11. It should guide other laws
12. The reality is that we are not all equal and we never will be. Equality is essential in many parts of our lives but not in all parts.
13. If you can't bring it into law what is the point it has got to be in law. This is for the benefit of the justice system to be able to enforce the law for the people that it affects
14. Isn't it already?
15. Everybody is important regardless of age, gender, race etc
16. So nobody is left behind.
17. Definitely feel that people should be penalised further for the equality act breaches. I also feel a full detailed policy for each aspect of the country for example employment education training have certain policy laws they need to implement.
18. Think all law should be important otherwise we pick and choose and it is divisive

19. Protection

Q15 Equality: Extend the Equality Act to cover things you buy, like computers and furniture. Is this important to you?

1. Yes the item needs to be fit for use, and that means for everyone. I have a friend who bought what she was told was an accessible bed, she tried it and it was not fit for her needs, she has had to make her condition worse by sleeping in a chair as she cannot get in and out of the bed, the company is refusing to help. The features of items should be explained in clear English that's easy to understand and should be allowed to try items are fit for purpose before being talked into buying product. Not talking down to people if they don't understand, this is a sales tactic but is wholly unfair to people with disabilities, and pressurises you into buying useless items.
2. I run the access group for Greater Manchester, so many things which suit Disable people also suit so many other people inclusively in society
3. VITAL
4. Definitely! Why do we have to conform to the "norm" services should be made to adapt as a reasonable adjustment
5. To ensure all people have access to all accessible issues.
6. I would have to see
7. It is not always easy to obtain the correct items when viewed online, then the return of the item may be an issue.
8. I don't understand what this is getting at
9. I don't really know
10. This can get silly. If every computer had to be adapted for use by the blind, before it is sold, the costs would be astronomic.
11. Think it's important that there are alternatives available for people but I don't think every computer should have to be fully accessible
12. That isn't problem. Should be a right for anyone to start action
13. Some of these tings are necessities rather than a want.
14. Yes, I feel there should be further support covering other elements under the equality act. Back to advocacy and the voice of people living with a disability impairment long-term health condition, how can the equality act cover this to support people to the most independent life they can.
15. Do not think this is possible
16. Make people realise disabled people are consumers too
17. Internet access, support equipment

Q16 Health and Social Care: Increase funding for health and social care to make sure that people can live full lives. Is this important to you?

1. Support for disabled people can be difficult to obtain and sometimes the funding doesn't go far enough to provide adequate level of support
2. Services are cut and cut, there is no funding. Benefits are so difficult to obtain and they aren't increased in line with the cost of living. Having to pay for private care and help is the only way to get help sometimes
3. Need some extra help but hard to find, the only option appears to be something I couldn't afford
4. Without funding I would not be able to contribute, I run a international business
5. I'm getting tired doing this so it's VITAL
6. Everyone deserves equal access to good, free high quality high care provided in a timely manner which meets their individual needs.
7. I have been instrumental in setting up the northwest care co-op, especially the Chester co-op. Living life to the full is one of our mantras.

8. I believe it is about the effective use of the funding that is provided-i believe there is a lot of wastage, it is about accountability & good governance. Just throwing money at the subject isn't the only answer.
9. Please see my answer and comments for question 1.
10. With rigid research and led by health professionals and people with experience of living with a disability. Assessments by government officials, clerical officers etc. just does not work.
11. Unless you are in server need of support there is nothing out there. Providing low level support and prevent a crisis. Lives can so easily be lost when there is no where to turn.
12. Absolutely
13. Living on low income is difficult
14. Disabled people should not feel themselves a burden on their families
15. After child protection, food and shelter, helping disabled people live full lives should be a priority
16. Any rise in funding will help so many families struggling right now
17. Again a "full" life for one is not the same as a "full" life for another, disabled or not.
18. I work with people who have a wide range of disabilities and during this pandemic have seen the impact of lockdown and social distancing on individuals. In the beginning they were happy to be locked down and shielded, it made them feel safe but now after speaking with some they don't care as much because they now need to get out for their mental health. One gentleman has not been able to get out of his house since March 2020. He has a care package in place, the carers assist him to wash dress, take medication on time and get in and out of bed and make meals. They do not take him out as it is not part of his care package or they feel it is unsafe for him. He has the capacity to make his own decisions and wants to go out for a walk. He has no family in his local area to help with this. He is desperate to get back to his day services and get out of his house. Adult social care commissioning teams have control of this and have told him he is unlikely to return to day services until next year. Will there be a service to go to by then?
19. So many people are left without adequate care because of lack of funding. Even getting the right diagnosis can take much longer than it should. So people cannot access the support they require.
20. Not only does the funding need to increase the fair access to care threshold needs to be re-addressed and how can people live either independently or with minimal support within their local community settings better. This could be via technology-based interventions.
21. Unfortunately support varies sometimes depending on the pet project of the Prime Minister. Like other areas of society there are corrupt organisations targeting vulnerable people and the MPs etc just will not do anything
22. The service has virtually disappeared for us. We are list and alone
23. make health and social care free for people
24. It is important to have someone who is NOT a close friend or family to discuss issues with to help prevent us from being detained

Q17 Health and Social Care: Give disabled people/people with lived experience of disability and long term conditions the right to independent living by law and make sure they are involved with planning what the law looks like. Is this important to you?

1. Unfortunately disabled people's rights don't seem to be immediately taken into account (ex.coronavirus laws) It only seems after a hardship has taken place and campaigns then people will sometimes listen. It's silly people with no experience of disabilities guessing how things would affect people, if it's the people who it would affect having a say in the beginning it saves time, money and resources and the hope of getting things done correctly the first time around
2. Absolute no brainer, of course this should be the case

3. VITAL
4. Because disabled people have the lived experience, their views matter and should always be considered and incorporated into planning laws affecting their lives.
5. The Care Co-op encourages individuals, with support, to plan their lives. Planning what the law looks like should be part of that.
6. Very important
7. Because they know how it feels
8. Ensure disabled people are listened to at all times.
9. Unfortunately, there is no requirement at present that a minimum percentage of MP's should be registered disabled so the second part is not currently possible
10. Some would not be capable dementia for instance
11. Yes, but must be a right and not an expectation. Someone I know with cerebral palsy was told he had to go into independent living. Reluctantly he did so, was very lonely, and finished up in hospital with severe burns incurred in the kitchen.
12. Do we not have an MP for this.... They may need some training too
13. People should be fully involved with all decisions made about them.
14. The above is important but making sure it is an informed decision health and life is not put at risk. However, making sure people live as independently as possible.
15. Possibly going to far at one - baby steps may be better to ensure a positive outcome
16. Who wouldn't want at least some control over their life choices?
17. everyone has the right to be as independent as possible

Q18 Health and Social Care: Make sure support services are not 'just' care, but help disabled people/people with lived experience of disability and long term conditions, to learn Independent Living skills so that they can live a full life. Is this important to you?

1. These skills are important to live a fuller life, without them it's a struggle. It should be mandatory classes in schools to be honest, and certainly if people are struggling, should be an ongoing thing that people can dip in and out of when they need help on a certain topic
2. It is not about people existing, it is about them living
3. VITAL - provide me with support and money
4. Because disabled people have the lived experience, their views matter and should always be considered and incorporated into care affecting their lives.
5. The Care Co-op encourages individuals, with support, to plan their lives and develop Independent Living Skills. I am a Trustee of an organisation that works with children, young people and adults with disabilities. Learning and developing independent living skills is a key part of our organisation.
6. This is one aspect of support that I have tried repeatedly to access but to no avail
7. need that extra help, and not just financial
8. We just wish to be like all non disabled people and have a meaning full live. Having to prove you are disabled to gain access to services - employment social care is very demeaning. The same desires and ambitions- relationship - home - children - employment - socialising etc.
9. Absolutely
10. My son is now 18 and needs ongoing support with benefits education etc
11. Independence should be the aim Disabled persons often outlive their carers
12. Should be important to everyone. Empower disabled people and save money for everyone long-term
13. Better to teach a person how to manage their disability and their life, than do it for them.
14. These services have been cut and no funding. How are people supposed to live independent if they don't have the skills. Mental Health difficulties then arise from not being independent or being able to access help, putting further strain on service that aren't available

15. This would take the anxiety of having to rely on others for support and empower people to become independent.
16. Within my work and volunteer capacity, this is an area I have been pushing for a number of years and understanding that health and social care covers not just the care element how can people be both physical and emotionally active to support their meaningful lives.
17. Again been thwarted in the LD area by firms set up to exploit people with LD (e.g. Supportive Housing LLP) that the Inland Revenue etc will not tackle
18. Stop using care thresholds for an excuse not to support people.
19. Because it effects us NOTHING about us WITHOUT us
20. Because if were NOT taught independent living skills all that will happen is our independence will get worse

Q19 Health and Social Care Make sure Direct Payment policy is the same in all areas and that it supports real choice and control. Is this important to you?

1. It's not fair that some areas have much better services in terms of information support and funding and others don't. Not clearly explained or much help as far as I can tell in Manchester and Trafford area
2. Of course this should be the case, again absolute common sense why treat people differently because they live in a different place?
3. VITAL
4. Too many things are decided for us, by people with no lived experience
5. To encourage independence.
6. This is so important. We are noticing the variations in Direct Payments within authorities. The Care Co-op is advocating choice and control.
7. Because i do not understand it, it is to complex in terms of who can claim and how you access payments. I just give up!
8. It does give independence but I sometimes think it can be abused.
9. Unfortunately, again you have to qualify and this does not apply for me. Some get things and others do not it is again more towards LD and physical disabilities.
10. Not sure what this refers to
11. Don't understand
12. I don't understand what this refers to
13. I had assumed it was the same in all areas.
14. Where are you can live independently should not be a postcode lottery
15. Real choice and control is important however need to understand sometimes direct payments have been used in really flexible and innovative ways supporting the person's life.
16. Proper wage for complex care jobs
17. Give people real choice , means having options. it is no use giving people money if there is not anything to buy !
18. Because everyone all over the country is of the same importance
19. This is way to difficult for an autistic person to navigate

Q20 Housing: Make sure all new homes that are built are accessible. Is this important to you?

1. Or at least with the ability to make it easily accessible, suppose it's not always possible to make all homes accessible and maybe cost? Not sure how it works to be honest. I have noticed that homes that are supposed to be accessible are in fact not, another case of a non disabled person guessing what people's needs are. For example my mother's wheelchair adapted flat, had small steps to come in and out, the space was not wide enough to manoeuvre wheelchair around safely and things were out of her reach whilst in the chair

2. I don't agree with this, I think a greater percentage of homes should be built accessibly not everybody
3. VITAL
4. To help all people live independent lives regardless of ages and disability. This will save considerable expense to undertake renovations later and allow people to remain in their own homes should they become disabled or house bound.
5. I don't feel that all new homes should be accessible, but certainly more than 50% of them.
6. It has to be this way these days as it undermines the disabled person if they cannot have room, access stairs, place for wheelchair and other equipment, garden spaces with ramps for wellbeing.
7. How good this would be - a home of my own.
8. Absolutely
9. Obvious improvement
10. Better for everyone
11. Not applicable to me directly but I know people in new-builds. I also a couple of years ago visited a new build facility with a friend in a wheelchair and all entrance points had steps!!! We could not believe it.
12. Again, this is over the top. If every new house had to have wheelchair ramps, lift to the upper floors, blind touch pads, etc, the costs would be astronomic.
13. Is the case in many other European countries or in fact indeed other countries in the world and it is just as easy when you build houses to make them accessible as not for example wider doors
14. I've seen the limits this places on a person when people cannot access all rooms in their own homes or get on and out of their front doors or gardens without risk to themselves Being unable to get washed because bathrooms are not suitable, unable to make a suitable meal or snack. Sleeping on the sofa because they can't get upstairs
15. Future proof the needs of an ageing society.
16. As we are an ageing population accessible homes for all would support people both with and without disabilities living more independent for longer.
17. Probably better to target a % which is achievable
18. Makes sense
19. this is extremely important, and with a little thought doable

Q21 Housing: Make 20% of all housing owned by councils and housing associations accessible by 2025. Is this important to you?

1. Minimum, it's difficult to find accessible housing due to costs and availability. This would allow more people to live independently
2. Yes, this is more proportionate and realistic and therefore affective
3. VITAL
4. To help all people live independent lives regardless of ages and disability. This will save considerable expense to undertake renovations later and allow people to remain in their own homes should they become disabled or house bound.
5. There is a need for more housing generally
6. How easy is the target and what is the buy in?
7. Too low a percentage!
8. Equalities
9. Not applicable to me directly
10. But the percentage must reflect local disability percentages, which are not the same across the country.
11. Time to put lip service into action
12. Make all housing the same
13. Future proof the needs of an ageing society.

14. I understand a 20% increase in five years is a lot however people work towards targets and the aspirations should be for higher than this.

Q22 Housing: Make rules for building that make sure new buildings or parts of buildings are accessible. Is this important to you?

1. No reason why majority of buildings built cannot be accessible, we have the knowledge now so no need for excluding people.
2. Yes as the previous answers demo. I have a proportionate and balanced view on this
3. VITAL
4. To help all people live independent lives regardless of ages and disability. This will save considerable expense to undertake renovations later and allow people to remain in their own homes should they become disabled or house bound.
5. If buildings are to be community buildings then all new builds need to be accessible.
6. see previous answer
7. Can this actually happen?
8. Very important
9. Including ease of egress in case of fire
10. But see my comments above about costs and percentages.
11. Future proof the needs of an ageing society.
12. Unfortunately, I think the building regulations don't suffice and feel more scrutiny needs to take place. Not just meeting the minimum requirements.
13. recognise the needs of people with complex needs, and need for additional staff too

Q23 Information: Make sure all government information and communication is in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed. Is this important to you?

1. A lot of government information is difficult to decipher, for example the COVID-19 rules, even listening to the prime minister is not helpful, as he seems to flap about and not speak clearly what is and isn't allowed. Needs to be set out in ways that are easy to read and understand, no loopholes or hidden meanings. Info should be accessible to all regardless of disabilities
2. Absolutely common sense, one size can fit all why make it complicated when it can be easy to read with easy read etc
3. VITAL
4. BSL is an important language and sadly this government in England does not use BSL for example when doing Covid Press Conferences - this creates a sense of isolation and exclusion for hearing impaired and deaf people. Plain text documents should also be available; do not publish changes to documents as text in an image. Consult with service users and relevant charities/interest groups.
5. It isn't any good developing systems to ensure that people with disabilities have a voice, plan their own lives, etc, if they cannot access information.
6. I often miss signs because they are either small or insignificant or in the wrong place hidden away
7. Basic accessibly and a human right.
8. Absolutely
9. The government messages are not accessible for autistic people. Too long, too confusing, too many words
10. Though a lot of legal stuff is incomprehensible to highly educated people who are not lawyers
11. Not applicable to myself but I have many friends and colleagues who would benefit from this
12. We are a lot better at this than we used to be. Progress must be continued.
13. Communication is key in all of life to make everything accessible

14. Accessible info is crucial to enable disabled people to access relevant services.
15. Somebody who is dyslexic, plain simple English helps me to understand.
16. Have to make sure that we do not waste money e.g. every Government document is produced in Welsh and is read by only one Plaid Cymru MP
17. Many forms are a disaster area for comprehension.
18. Make software that can turn documents into easy read, or read allowed on all documents
19. Because weather people have learning disabilities and Autism or not we need to know what's going on it's important to have different formats because everyone has different abilities and strengths

Q24 Information: Make sure all websites are accessible Is this important to you?

1. What would be the reason to exclude people?
2. VITAL
3. See above.
4. So much information is now available on the internet, we need to have accessible sites. All (with support, if necessary) can then access them.
5. that is a given
6. Removal of non essential adverts - no overload of images - sound would good for describing the item. Plain language.
7. I thought they were
8. Very difficult to find things on many sites
9. My blind friend says many websites miss a balloon tag over pictures. i.e. when you rest the cursor over an image, words appear that say "image of abc". She can hear this on her laptop.
10. Again communication and accessibility in all areas of life that we take for granted as an able bodied person
11. Future proof the needs of an ageing society.
12. don't need to say much about this if the information is accessible it's accessible for all.
13. stop making finding information difficult 20 clicks on the local offer !
14. Because weather we have learning disabilities Autism or not we need to know what's going on

Q25 Street Environment: Publish national guidance requiring all streets to be designed to meet the needs of pedestrians, cyclists and car users with lived experience of disability and long term conditions. Is this important to you?

1. It's scary for people who have a disability to try and navigate the pavements, blind and visually impaired people cannot always judge what's in front of them and the electric cars are so quiet you cannot always hear them if driver not paying attention you can be easily knocked down (have witnessed a friend very nearly been ran over few times due to this) Also pushing or manoeuvring a wheelchair up and down pavements is not easy , sometimes having to walk in busy roads due to traffic being on pavements. There are a lot of silly people who have no regard for pedestrians it should be made illegal to drive up pavements, without good reason. I have had it a few times cars driving up behind or in front to get to the shops near me, it's really intimidating and scary, I can't judge what to do and end up freezing in street. I'd also mention my friend who is blind recently had her cane ran over by a taxi driver on a pedestrian area shared by cars, this is unacceptable obviously not all drivers can be trusted so it should be a clear area for vehicles separate, and also keep pavements and markers
2. VITAL
3. Stop most parking on pavements - causes problems for wheelchair users, mobility scooters, visually impaired people and people with prams. More dropped kerbs and enforcement of parking on dropped kerbs. Stop inappropriate street furniture - e.g. A boards. Create a licencing scheme for street furniture and enforce breaches. Pause E scooter rental trials until further safety trials can be undertaken. Reduce street clutter-

e.g. overhanging trees, bins not put away, dog faeces, fly tipping, broken glass/litter. See guide dogs website guidedogs.org.uk/campaigns

4. It's important for people to feel safe on the streets with regards to traffic.
5. And public spaces free from dog fouling and free from A boards etc.
6. Because it avoids restrictions that can make life difficult
7. Difficult to change in most cases due to the narrow street around already.
8. Fine in theory. Pavements today though are unofficial car parks, cycle lanes and littered with sandwich boards and other street furniture, especially in retail areas.
9. But roads and pavements are showing the signs of 10 years of Tory rule
10. Again we must guard against blanket legislation. My street is narrow. Some houses do not have parking spaces. Cars park half on the road and half on the footpath. This makes it difficult for disabled people. Banning parking on the footpath would make the street inaccessible to ambulances and fire engines . Which is worse? If your question said all "new" streets to be designed to meet the needs etc I would have agreed with it
11. Don't think you'll be able to make all streets accessible but I think there should be national guidance relating to the streets that are accessible
12. The physical environment is as important as everything else. If it's not right for you then you can't access it. Big barrier
13. I personally don't feel I can comment on this too much as the area I live in due to its natural line features is not fully accessible, so I don't use the streets in the above way. However, city centres could be more inclusive supporting a full pedestrian infrastructure
14. Probably a distraction from more important issues

Q26 Street Environment: Make local authorities work with disabled people/people with lived experience of disability and long term conditions to make sure the design of streets and town centres meets their needs Is this important to you?

1. The local environment is for everyone in that area, it's unfair that certain groups be excluded from using areas.
2. Again absolute common sense which will suit everybody not just disabled people
3. VITAL
4. See above.
5. The whole package - being involved in planning their lives, living life well, having a good education, finding employment (paid or voluntary) - should include having a say in designing and developing town centres and streets.
6. Could work. Sitting behind a desk wont have all the answers. It needs the lived in experience.
7. would be very useful - as long as it is not another tick the box- we consulted with but took nothing on board.
8. Should already be happening
9. Proper consultation
10. I have visual disturbances and photosensitivity. That yellow/white and black safety tape people put on step edges etc makes it Harder for me to see... Harder for me to see the edge!
11. Most definitelyspeak to those who know best!! Why do councils not do this. It frustrates me.
12. Again, I would have replied "yes" if your question said "new" streets.
13. For all the reasons stated. Its obvious. All curbs should be dropped, the number of times I've had to push someone in a wc on A main road because the next dropped curb is a hundred yards away is unreal. Or the pavement is too narrow for a larger wheelchair. Most shopping centres have automatic doors but still have steps up to the next floor or escalators that are not suitable for wc users or people with poor mobility that use walking aids such as trolleys or sticks. Lifts can be small and cramped and scary to use for some
14. It is important that street designers to take into account the needs of disabled people because they have a different perspective than able people.

15. Again goes back to the voice of disabled people why would you not have them on your working groups. Or even the voice of the local disabled People's network supporting.
16. Already happens in Lancashire
17. All planning should ensure accessibility. offer free electric equipment to help get up banks

Q27 Transport: Funding to make all train and bus services and cycling affordable and accessible by 2025. Is this important to you?

1. It is very difficult to use any of these things at the moment, hard to work out tickets and how to get to places, don't feel safe, and is far too crowded. Have witnessed a few times wheelchair users being left behind or verbally abused as they have took up space from someone with a fold up pram! They need more often services and clearer info on prices and routes. If you need to do something special like for example in London it should be clearly stated at the beginning of journey at stops. Cycling does not seem like a safe thing to do on roads, they should make different routes just for cycles
2. I love public transport, it should be fully accessible
3. VITAL
4. To allow all people independent barrier-less, access to all modes of transport.
5. Opens up new opportunities and prevents isolation
6. Transport is expensive and more free national pass should be considered - again not all qualify unless you have a mobility component in PIP.
7. Absolutely
8. Affordable for all!
9. Again beware of blanket legislation. It would be better to get train and bus providers to advertise which services were affordable and accessible and which were not.
10. So many times the counsellors are taking away from disabled people the different concessions that they can gain and this needs to be stopped
11. Absolutely crucial... Its all about accessibility
12. Much of this should have happened already but still hasn't.
13. I don't really use the above transport methods.
14. Not realistic
15. my word that will be a task, train fees are ridiculous !

Q28 Voice Support and provide funding for local organisations led by disabled people/people with lived experienced of long term conditions to make sure care and support services are delivered to meet their needs. Is this important to you?

1. Someone who knows what they are talking about is a very good idea
2. VITAL
3. Allowing disabled people to live the life they choose.
4. I hope my answers throughout and the fact that I've instigated the creation of a Care Co-op implies that I am keen for my son, and others, to live full lives and that will involve having a voice in organisations.
5. Because mine have not been et over the past 30 years I believe I have become one of the "Forgotten Generation"!
6. This is vital for those of us having difficulty securing any form care.
7. So that they feel listened to, included, involved
8. Our local group is always having to submit bids for funding and so may not be able to continue.
9. Absolutely
10. I would encourage Disabled people to become politically active
11. But caution is required. Those who pay the pipers calls the tunes.
12. An advocacy group has a stronger voice than someone trying to do it on their own

Appendix 3: Data – Collective Response from BSL Focus Group

1 Advocacy:

Make sure everyone can get advocacy to help people say what matters to them in all areas of their life and to help them with processes that can be difficult to work through, for example in education, health and social care, benefits, housing and justice systems

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Important for younger people to give them confidence, once they've received advocacy, they can then feel confident to move on.**
- **Manchester deaf centre has BSL trained advocates, they discuss the problem and then go onto support them deal with the issue. Comes down to communication yet again. Even the Citizens Advice have a barrier to communication. The hearing community also put barriers up which is where equality and diversity training for all would help.**
- **Attendee works in Preston as a link worker for deaf and people who are harder of hearing, he also trains equality and diversity, supporting people during the COVID-19 outbreak. People kept in the dark about what's happening as a result they become isolated and lonely. Also, he gives support and advice using BSL and text, various other platforms used to give support for finance and health anything as long as linked to COVID-19.**

2 Benefits:

Make sure the benefits system is fair, so people don't have to live on less money in the North West, compared to the South of England. Understand that levels of poverty in the North are much greater.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Attendees agreed equality for North or South should be equal, the deaf community aren't always aware of equality.**
- **Benefit forms and information for deaf people should be in more than just English, should be BSL, with information on how to book an interpreter – barrier is communication.**

- **Information isn't given to people, nor where to find out what is available. Older deaf community don't understand how to get benefits, communication and technology is there, but nobody uses it. This also would link back to advocacy - how to use and access equipment.**

3 Benefits:

A benefits system that is based on need, fully supports the right to live an independent life and supports the idea that a person is disabled by a world that doesn't meet their needs, not by their condition.

The money you get from benefits must be enough to live a full life

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Important that Deaf people have enough money to live well**

4 Democracy:

Funding to encourage and support disabled people/people with lived experience of disability and long term conditions to stand for election as a councillor or an MP

1 in 4 people in the UK is a disabled person/has lived experience of disability or long term conditions. We want to see the same in politics.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Important that people understand the Deaf community and Deaf culture to represent us.**
- **One attendee wanted to be an MP for the Green party, she applied but couldn't get access to work. The benefits normally given for work, you don't get if you want to be a councillor or MP etc.**

5 Democracy:

Make all voting accessible by 2025

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **All agree.**

- **Announcements made on tv but again no sign language. If wanting to vote (pre-COVID-19) there are no interpreters, the deaf community will then not vote, or some have been known to vote what their parents voted for or even by colour! How are deaf people supposed to understand the manifestos which all are written in English. Wales and Scotland interpret but not England - why?**

6 Digital Inclusion:

Make sure that disabled people/people with lived experience of disability and long-term conditions can use computers and smart phones. Bring ideas led by them into future development.

Make sure that if we can't use technology there are still alternatives

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **All agree.**
- **Elderly people struggle at best, deaf older people become totally out of the picture.**
- **Seems to be lot of reliance on phones, visiting a GP is difficult some use minicomms but there is a need for additional options. Most surgeries have a screen they could have a recorded BSL interpreter, use email (but that can be problematic if you first language is BSL). Obviously training for GPs or an advocate within the surgery to interpret to allow face to face (when we can post COVID-19)**
- **Depends on the device, table, pc, phone their understanding of third party.**
- **One attendee had to receive special permission to enable her to email her surgery to book a visit to her GP.**
- **Ensure people are trained to use smart phones and computers, there should be money to buy someone a smart phone or computer who can't afford one if things are being done digitally.**

7 Digital Inclusion:

Make sure Further Education funding goes towards improving the skills of disabled people/ people with lived experience of disability and long-term conditions, in using computers and smart phones. Make sure they can do this in accessible, community places.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **All agree.**

8 Disability Hate Crime and Harassment

Give funding to Police Authorities to work with disabled people and their organisations to identify Disability Hate Crime. Review how disabled people report Disability Hate Crime and how accessible it is (these are sometimes called third party reporting centres).

Work with the local council to improve the safety of disabled people/people with lived experience of disability and long term conditions, from crime and harassment.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Attendee was a victim of hate crime and wanted to work with police and help them understand that deaf people face hate crime on regular basis. There needs to be interpreters to report to, stress and wellbeing is increased leaving people to give up. Their confidence is knocked, and they feel 'why bother'.**
- **Manchester deaf centre does have a representative to report hate crime and then go onto liaise with the police. Good practice needs to be in every county.**
- **Reporting hate crime is too much hassle, reported before and nothing happens. If there was good access more would be reported. Another link into Advocacy.**
- **Community meetings with police or other groups aren't attended by deaf people. There is no way to put point across, deaf people don't bother going because these meetings are not accessible without an interpreter. There is no point, hearing people don't bother or care. Educating people that plain English isn't enough, need BSL also.**

9 Education

Provide funding for care and educational support for every disabled child/child with lived experience of disability and long-term conditions to ensure inclusion in mainstream schools.

Include the Equality Act in the National Curriculum to teach young people about equality and diversity.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Government are looking at skills and apprenticeships, but a lot of people don't realise they need to have level 2 English, this should also be the case for BSL i.e. level 2.**
- **Children are affected by having their reading age fall behind their peers, resulting in lower grades which could have been prevented if offered an interpreter. BSL should have the same prevalence as a preferred language.**
- **Most deaf schools are now closed due to funding, much worse for children these days. Where do deaf children go for the same education... deaf children aren't as important it seems.**
- **Education at a deaf school is good but they don't teach English to be able to proceed in a career. It's impossible to apply for a job when they all ask for level 2 English, suggest level 2 English is equivalent to level 2 BSL.**
- **BSL should be taught in schools**

10 Employment:

Provide a trusted employment support service that helps disabled people/people with lived experience of disability and long-term conditions, to find and keep jobs.

The service should be led by people with lived experience of disability and long-term conditions.

Is this important to you? Y/N

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **It's hard to complete job applications, difficulty is also some employers don't know how to work with deaf/disabled to people. One attendee had to give deaf awareness training at his own college as they didn't know how to communicate and work with him – all done whilst waiting for access to work. Access to work wanted to know what he did in his role, but he couldn't tell them as he hadn't started and was unable to communicate this to employers.**
- **Deaf Awareness, Equality and Diversity training should be made compulsory irrespective of the role.**

11 Employment:

Extend Access to Work funding or provide new funding to cover job searching and look at wage subsidies (government giving your employer some money towards your wages). This will help get more disabled people/people with lived experience of disability and long-term conditions,

into paid work.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

12 Employment:

Make it so that employers have to have disability equality training, run by disabled people/people with lived experience of disability and long-term conditions.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

13 Equality:

Make the United Nations (UN) [International Convention on Rights for Persons with Disabilities](#) part of UK law.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Communication, information and health and safety, equality act has to look at the word 'reasonable' it's unclear. Scotland campaigned for BSL to be included as a language. Deaf people have their own culture and ethnicity.**
- **Must have a BSL Act to make it law and not "would be nice to have".**
- **Historically the Government kept a percentage of how many deaf persons were in work, not sure if this is still being done, but communication has to be adjusted. BSL Act definitely needed to make sure recognition by the world that it is a different language, like they have in Scotland.**

14 Equality:

Make the Equality Act more important than all other laws.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

15 Equality:

Extend the Equality Act to cover things you buy, like computers and furniture.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **To make sure things are accessible to Deaf people without it costing more**

16 Health and Social Care:

Increase funding for health and social care to make sure that people can live full lives

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Concerns about older deaf people having to live in a care home or in nursing homes. Often deaf older people in these settings become very lonely and isolated and depressed. They then go downhill rapidly.**
- **Need a supply of support staff of a good standard that can communicate in BSL.**

17 Health and Social Care:

Give disabled people/people with lived experience of disability and long term conditions the right to independent living by law and make sure they are involved with planning what the law looks like.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Recognised that if they need assistance in the future it was important that people were able to live independently and that people could communicate in BSL**

18 Health and Social Care:

Make sure support services are not 'just' care, but help disabled people/people with lived experience of disability and long term conditions, to learn Independent Living skills so that they can live a full life.

Is this important to you? Y/N

Please tell us why you gave your answer and/or what your experiences of this issue is:

19 Health and Social Care:

Make sure Direct Payment policy is the same in all areas and that it supports real choice and control

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

20 Housing:

Make sure all new homes that are built are accessible.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Flashing light doorbell /smoke alarm etc.**
- **An attendee attempted to buy a new build, tried to ask questions of the people who built it, they allowed them to look around but there was no accessible information.**

21 Housing:

Make 20% of all housing owned by councils and housing associations accessible by 2025.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **See above**

22 Housing:

Make rules for building that make sure new buildings or parts of buildings are accessible.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **See above**

23 Information:

Make sure all government information and communication are in plain English, so that it is easy to understand, with easy read, British Sign Language, large print, audio, and braille available if needed.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Information from Government is really poor**
- **Not accessible to Deaf people as all in English and not in BSL**
- **People do not understand the information**
- **Must have a BSL Act to make it law that information is in BSL**
- **Discussed Coronavirus briefings and lack of BSL interpreter on stage with speakers, it was felt to be useless if you are watching catch up video there is no BSL available.**
- **Subtitles are in English so hard to follow.**
- **On attendee gave example that it leaves people thinking that they can do things in Lockdown that they can't but don't understand the information being given. It makes them feel like they don't matter.**

24 Information:

Make sure all websites are accessible

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **BSL on all websites would be the preference, so they understand what services are available.**

25 Street Environment:

Publish national guidance requiring all streets to be designed to meet the needs of pedestrians, cyclists and car users with lived experience of disability and long-term conditions.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Once the sun starts setting deaf people rely on signs, but as some councils are switching off street lighting to save money, this causes poor communication. Also need to remember that**

some deaf people have difficulty with balance which will also be affected by poor lighting.

26 Street Environment:

Make local authorities work with disabled people/people with lived experience of disability and long-term conditions to make sure the design of streets and town centres meets their needs

Is this important to you? **No**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **The attendees didn't feel this was a relevant to perhaps those with physical impairments or visual impairment.**

27 Transport:

Funding to make all train and bus services and cycling affordable and accessible by 2025.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Would help if drivers and conductors learn BSL.**
- **There are bus permits that allow users to get off and on a bus whenever and wherever, they shouldn't then be asked where they got on and where they are getting off the bus – it's irrelevant and communicating this is hopeless, bus companies should at least know what this kind of pass looks like.**
- **When a train stops for some reason it is usually verbally announced to passengers leaving deaf passengers in the dark as to why, this also happens when they have to deviate passed a station (possibly theirs) with no idea why a deaf person then has to try to make themselves understood with other passengers or ask them to write it down. Simple display would be great.**
- **Bus station delays/changes etc are also announced verbally, some have screens which don't always work. A real-time App would be a good.**
- **Deaf people in airports rely on screens otherwise they wouldn't know where to go at what time.**
- **An attendee was fined once because her train stopped to transfer so she missed her train (several times) ended up somewhere that wasn't on her ticket and received a fine because she missed the announcement. Couldn't tell people she was deaf as they don't pay attention.**

- **There are badges, cards, and lanyards but not everyone wants to be identifiable. One attendee created badges that say 'I can lip read' particularly useful during the pandemic, another was asking people to remove a mask to allow them to lipread. Without such items, deaf people are ignored, or people give up because they don't understand.**

28 Voice:

Support and provide funding for local organisations led by disabled people/people with lived experienced of long term conditions to make sure care and support services are delivered to meet their needs.

Is this important to you? **Yes**

Please tell us why you gave your answer and/or what your experiences of this issue is:

- **Better to have local services.**
- **Skills are important have to understand the deaf communities' culture, ensure people that deliver services are employed by better skill base.**
- **Be careful with positive discrimination.**

29 (Rate of importance)

Please put the themes you have looked at above into the order that is most important to you, with the most important first.

1 Information (communication)

2 Advocacy

3 Education (informal education also)

Remainder were in no particular order.

- Benefits
- Democracy
- Digital Inclusion
- Disability Hate Crime and Harassment
- Employment
- Equality
- Health and Social Care
- Housing
- Street Environment
- Transport
- Voice

30 Where do you live?

Cheshire

Lancashire

Cumbria

Merseyside

Greater Manchester

Other -

31 What is your age?

Under 18

18 - 24

25 - 34

35 - 44

45 - 54

55 - 64

65+

Prefer not to say

32 How would you describe yourself?

I am disabled person

I have experience of disability and long-term conditions

I have caring responsibilities

Other -

Appendix 4: Copy of Easy Read Survey

Easy Read Survey



Easy Read National
Strategy Questionnaire

Appendix 5: List of North West Regional Stakeholder Members

Lynne	Chair of North West Regional Stakeholder Network
Tom	Activity Alliance
Abigail	Individual
Melanie	Disability Equality (NW) Ltd
Minna	Sign How Ltd
Paula	Barclays Bank
Sally	University Hospital of Morecambe Bay trust
Yvonne	Multiple Sclerosis Society
Denise	Disability Association Carlisle & Eden (DaCE)
Mark	Individual and BAE Systems
Claire	Ability Consultancy (NW)
Colin	Cheshire East Council
Caroline	Individual
Daniel	Fighting Minds C.I.C.
Keith	Dial West Cheshire
Susan	Integrate (Preston & Chorley) Ltd
Catherine	Individual
Lynda	Chester Adult Phab Social Club
Julie	Together Trust
Anne	West Cheshire Access group
Jonathan	Dyspraxia Foundation
Pauline	TSSA Disability Working Group
Jess	Disability Positive
Michele	Breakthrough UK
Rob	East Cheshire Mental Health Forum
Ali	Together Trust
Marie	ENabled UK (employee disability network for BAE Systems)
Nick	Thorpe Whyman and Briggs Ltd and Argonaut Property Investments Ltd
Cat	Personal Independence Payment Professionals (PIPPS)
Janet	ICANN – Independent Community Advocacy Network North
Kate	Individual
Hilaria	WSH BME Network
Huw	British Association for Supported Employment (BASE)