



Inclusion Gloucestershire Survey

OCTOBER 2022

Headline Report

INCLUSION
GLOUCESTERSHIRE

BIGGER DREAMS ► BETTER LIVES ► BRIGHTER FUTURES

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Introduction

Inclusion Gloucestershire wanted to understand the areas of everyday life that are causing concern or worry for people in Gloucestershire who face disabling barriers.

We invited people who face disabling barriers to give us their opinions and experiences along with any ideas they have for improving things in 2021.

The top concern in 2021 was health. We decided to ask for people's opinions again in 2022 to see if anything has changed.

We asked family members or friends to give their views and paid staff members who support people who face disabling barriers.

We would like to thank everyone who has taken part, given us their thoughts and opinions. It is so important that we are able to share the reality for disabled people in Gloucestershire in 2022.



We would like to thank all our partners for their help in making the survey available to people!

How we found out what people think (Methodology)



A group of 4 people worked together to write a survey in a co-produced (joined up) way. This group involved staff members from Inclusion Gloucestershire with lived experience of disabling barriers.

The draft survey was then shared and tested with others with and without lived experience for comments, and changes were made.

The survey was open for 4 weeks in October 2022.

The survey was available online and in paper versions (See Appendices).

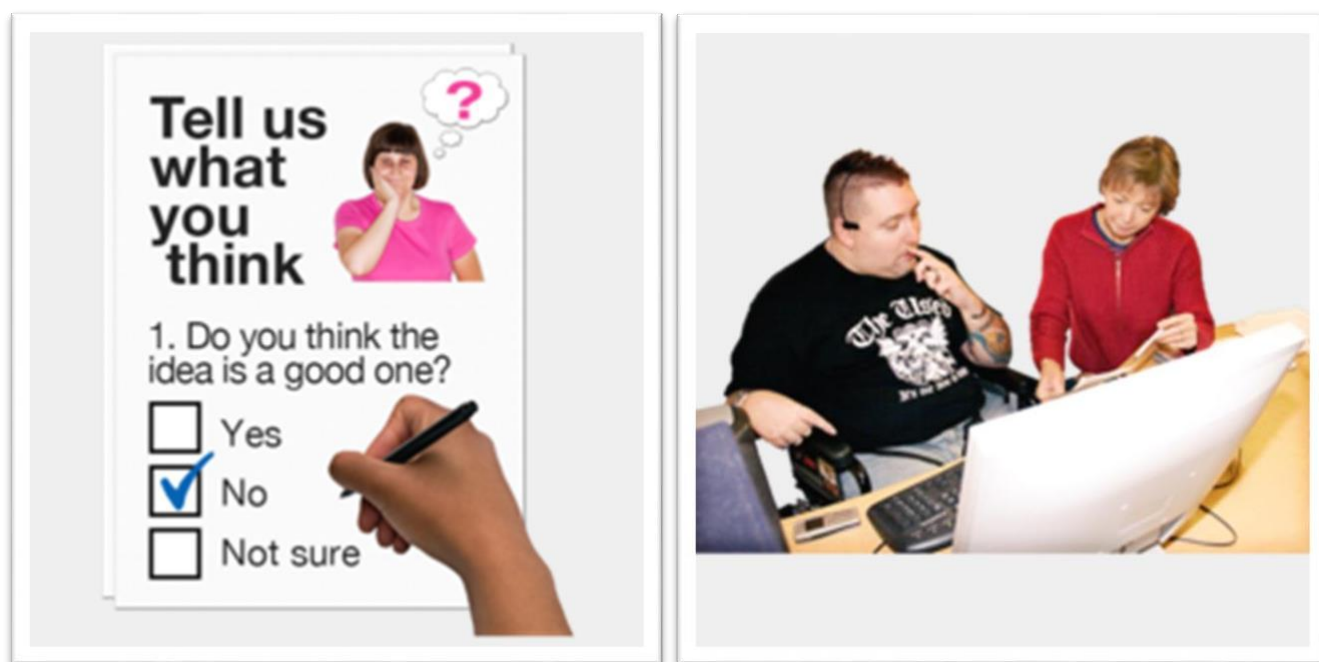
There was an easy read paper version (See Appendices).

Support was available to anyone on request to have help to fill out the survey on the phone or in person.

The electronic survey could be translated into several different languages on request and was available in a paper format also.

Information about the survey was shared throughout Gloucestershire in a few ways, including:

- Social media of Inclusion Gloucestershire, MHELO (Mental Health Experience Led Opportunities) and many of our partners.
- Direct mail outs to people known to us in Inclusion Gloucestershire.
- Direct mail out to partners in other voluntary sector organisations.
- Direct mail out to partners in local authorities and health organisations.
- Inclusion in various individual organisational newsletters and bulletins across the county.



We also met with people to get their responses in groups and one to one on a face-to-face basis through the Inclusion Gloucestershire Hubs in Gloucester, Cheltenham and the Forest of Dean, along with our Dramatic Change Drama group.



How many people told us what they think? ***(Responses)***

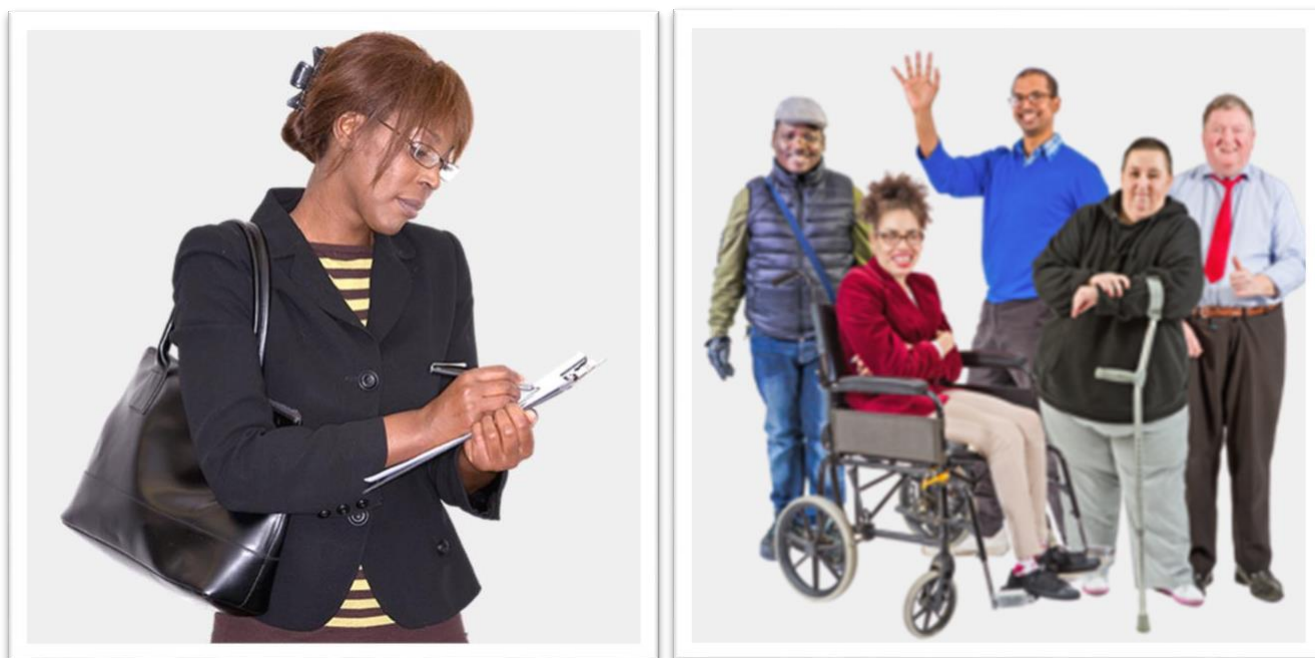
79 People Gave Us Their Views!

79 responses were received to the survey – 49 of these were online and 30 were paper copies of the easy read version.

No requests for the survey in an alternative language were received.

All responses did consent to be involved so have been included in the summary of results below.

Of the 79 responses, 34 people (43%) have given us their name and contact details for further contact, whilst 45 (57%) people preferred to be anonymous.



Who told us their ideas and opinions? (*Demographics*)

There is more detailed information in the appendix about who gave us their ideas and opinions (all Charts and data from survey). These can be found on our website:
<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>

Here is a summary:



- 61% identified themselves as female, 30% as male and 5% as non-binary
- 1% identified themselves as transgender.
- 3% identified themselves as lesbian / gay, 12 % as bisexual and 47% as heterosexual.
- The largest groups of people who gave us their ideas were in aged 25-34 and 45-54. The next largest group were aged 35-44, with just 12% of people in the 55-64 age group. People were generally younger than last year's research respondents.
- 96% used English as their first language, while 1% use dual languages
- 83% identified themselves as White British, 4% were from other white backgrounds, 3% were Asian or Asian British – Indian, 3% were Mixed – White and Black African
- 43% have lived experience of a mental health condition. 42% were people with learning disabilities and 35% have an anxiety disorder, 30% were Autistic, 24% have a physical impairment, 17% have sensory processing disorder, 16% have ADHD, 14% were family / unpaid carers, 14% had a neurological condition, 10% had a sensory impairment (sight or hearing loss)
- Many people had more than one “type” of lived experience.
- 35% live in Gloucester, 29% live in Stroud and 20% live in Cheltenham, but there are still many respondents who live in other areas in or near to Gloucestershire.
- 52% who gave their ideas are members of Inclusion Gloucestershire.
- 55% have not used Inclusion Gloucestershire's services in the last 6 months.

What areas of life are worrying people?

(Summary of Areas Causing Concern)

We asked people who gave us their ideas and opinions to tell us how worried they are about 23 areas of life.

We asked people to tell us if they were:

- Very worried,
- A little worried,
- Not sure,
- Not too worried,
- No worries **OR**
- Whether the area does not apply to them.



In most of our work we use a strengths-based approach but the reason that this survey used the negative concept of worries and concerns, was to reflect that people still face significant disabling barriers in society. We wanted to identify where there are issues and gaps so that something can be done to address them.

We have looked at which areas of life people were most worried about.

We have added together the scores of “very” or “a little worried” to give a combined score.

Areas People Worried About

The areas where people were “very” or “a little worried”, including the percentage of people are:

- 1. Finances – 71%**
- 2. Accessing health care – 64%**
- 3. Accessing support for mental health and well being – 54%**
- 4. Worry about housing – 52%**

5. Getting information and support with cost of living – 51%
6. Amount of exercise taken – 50%
7. Feeling safe when not in own home – 49%
8. Long Covid – 47%
9. Accessing leisure and social activities – 45%
10. Contact with friends, family, and other important people – 46%
11. Being discriminated against in the last year – 41%
12. Difficulties in accessing services and facilities – 41%



There were also several people who answered that they were not sure or not worried about the areas above.

There were a number of people for whom some of the questions did not apply.

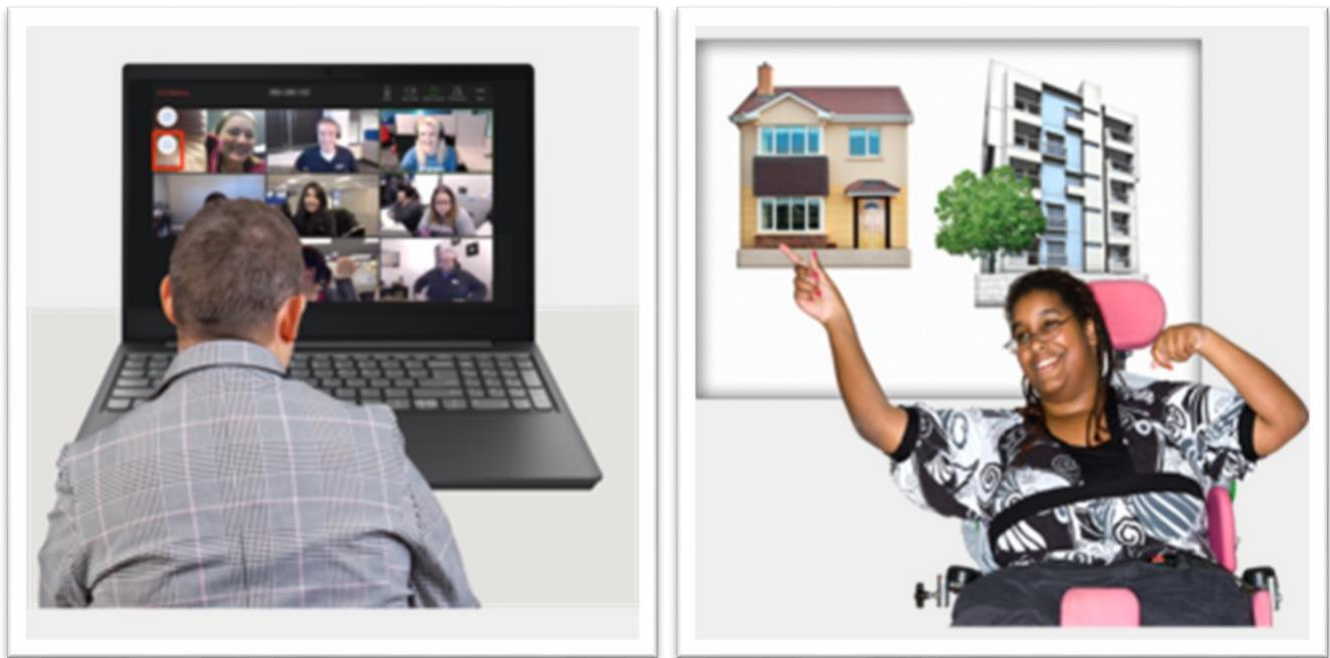
Generally more people were more worried about more areas of their lives than last year.

Areas People Were Not So Worried About

The areas where people were “not too worried” or had “no worries”, including the percentage of people, are:

1. Access to technology – 64%
2. Getting support to find ways to learn new things – 46%
3. Amount of exercise taken – 45%
4. Housing – 44%
5. Getting accessible information – 43%
6. Contact with friends, family, and other important people – 42%

7. Feeling safe when not in own home – 39%
8. Support getting paid work, unpaid work or volunteering – 37%
9. Difficulty accessing services and facilities – 36%
10. Being discriminated against in the last year – 36%
11. Sharing concerns, complaints or compliments with organisations who support people – 36%



Some of these areas were high areas of worry for many people and whilst also being low areas of worry for others. This shows how individual circumstances make a difference. For instance, one person may be very concerned about discrimination, while another person is not worried about discrimination at all. These areas may need particularly individualised support:

- **Amount of exercise taken**
- **Housing**
- **Contact with friends, family and other important people**
- **Difficulty accessing services and facilities**
- **Being discriminated against in the last year**

We will look in more detail at the areas that people were worried about in our next reports.



This year there was only one area that seemed to be causing little worry for most people who filled in our survey and this was access to technology.

Generally fewer people had little or no worries about fewer areas than last year.

We realise that our survey results don't represent all disabled people and that the number of people we heard from is relatively small.

Also, the survey did not reach as many people in certain groups as in others.

The results of this survey will be used alongside other data to influence key decision makers around Gloucestershire.

We explore the detailed answers people gave us later in this report.

We have used the information about the biggest worries to decide which areas we will look at first – see the next section called “What has this told us and what will we do next?”

Please note: where we have quoted people's comments directly, spelling may have been slightly altered to improve readability.

More information about what people said was worrying them

We have looked at all our questions and have grouped them into different areas. We will look in more detail at each of these areas over the next few months and give more information with ideas about things that could be done to make things better (detailed recommendations).

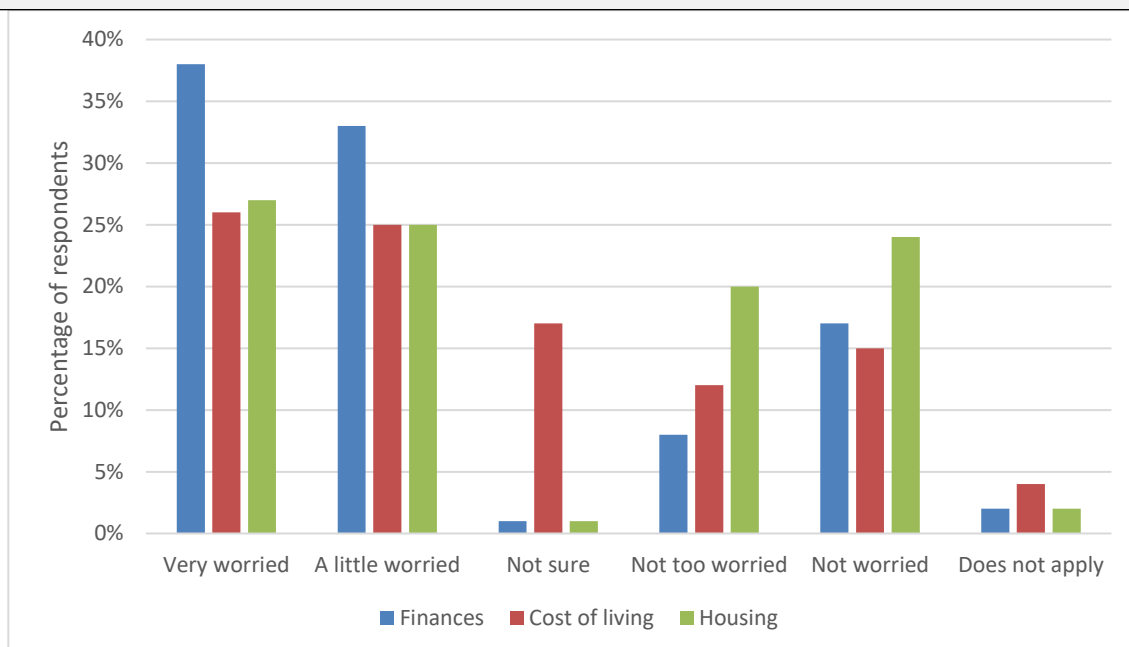
The top 5 areas that people have shown the most concern about are:

- **Finances – 71% were either very or a little worried**
- **Access to healthcare – 64% were either very or a little worried**
- **Accessing support for mental health – 54% were either very or a little worried**
- **Housing – 52% were either very or a little worried**
- **Cost of living – 51% were either very or a little worried**

Information about what people told us in each question are in the charts below along with some of the comments that people made.

More information about these areas will be in our next reports.

Finances and home



Context

When we asked some of the people who had said they were not too worried or not worried at all about finances, we found that they often had no financial responsibilities. When we approached parents and carers who did have responsibility for finances, we found that they were either very worried or a little worried, so even though 71% is very high, the total number of people we estimate are worried about finances relating to people with disabling barriers is closer to 90%.

Some of the things that people have told us:

Finances



Housing



Other comments regarding finances and housing

"I am worried about getting more funding to pay carers as their prices are going up, along with the cost of living."

"[I am worried about] the cost of everything"

"[I am worried about] money and housing difficulties"

"[I am worried about] debts and finances due to disabilities"

"[I am worried about the] cost of heating and food"

"[I am worried about] energy bills and bedroom tax" (Context: see case study on next page)

"[I am worried about] care staff not paid enough so [it is] hard to get people"

"Cost of living: I work full time, [I am a] single female [whose] children have grown up and left. [I only have] one income coming in"

"I worry about making sure I have enough food"

"I have ADHD & can't manage forms or finances well. I cannot understand the benefits system"

"I can't do money. I need someone to help with that."

"Finances are a constant worry. Everything is getting more expensive and I am already struggling to afford the things I need. I will have to decide between heating and eating"

"...I can't afford private therapies as I'm only on UC [universal credit]; even in the LCWRA [limited capability for work related activity] group the money isn't enough to cover the appropriate types of healthcare. So money is a big challenge and is stopping me from moving forward. I also need support in applying for PIP. I am also concerned about affording winter fuel bills and other essentials..."

"...there are no buses between my home and town - and I often can't manage the walk there and back. But can't afford to get taxis very often and it's not practical to rely on lifts that often....so having a bus service from Stroud going up Slad Lane would be a major lifeline. Or enough money to cover taxis..."

Case study

What follows are more in depth comments from one of the research respondents who gave an overview of how the cost of living increases impact their life in ways that are different to a person who does not face disabling barriers:

“Cost of energy

I have:

- 3 hoists that have to be plugged in at all times
- ventilator that I have to wear all night
- electric bed with air mattress plugged in at all times
- wheelchair that has to be charged each night
- reclining arm chair that has to be charged
- life link that has to be plugged in at all times
- amazon echo that helps me access my home - this is in 2 rooms and they have to be plugged in.
- I use laundry facilities more regularly "normal" person would due to continence needs
- I have a specialist toilet washes and dries me which is plug-in time.

Cost of water

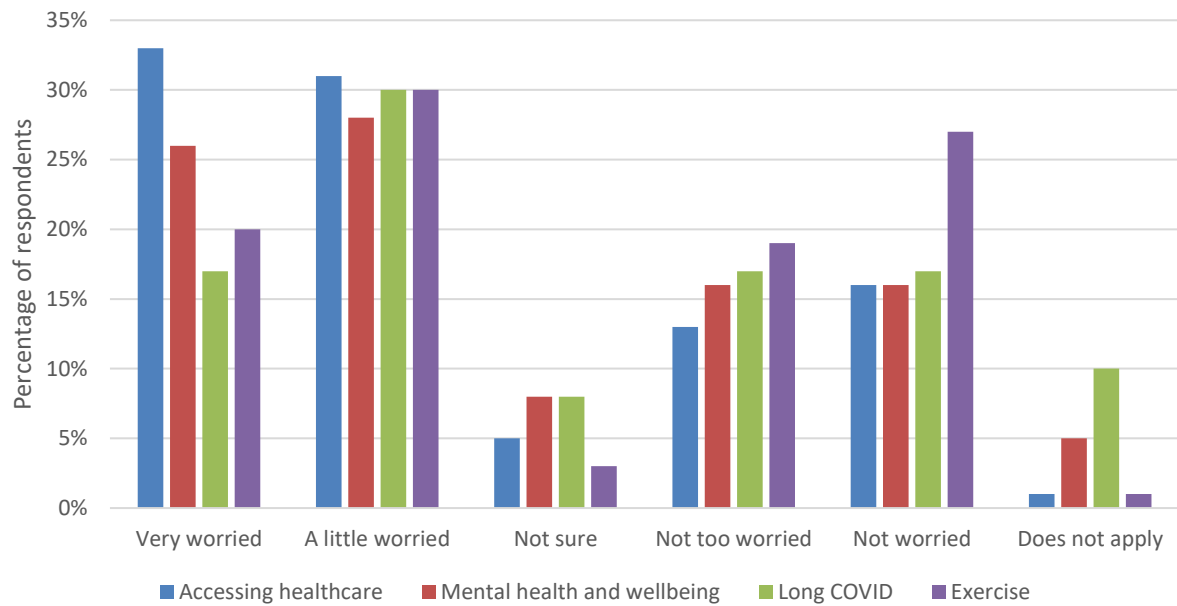
- I spend longer in the shower than the "normal" person would as it takes longer to wash myself
- I use the washing machine very regularly
- The toilet uses extra water as it washes me

Other costs

- I have to buy my own syringes
- I have to buy my own sheets for the commode
- I have to pay a bedroom tax for a room that I keep all my medicines in as it is too complicated to apply for the waver

All of these costs and more are to be paid before I’ve actually started living my life.”

Healthcare



Concerns and comments that people have told us:

"... the healthcare industry...doctors writing off legitimate symptoms of an illness as being healthy because they can't be bothered to prove that they are unhealthy."

"My mental health and lack of support for physical health"

"The fact that my stomach has been hurting since last October and very little seems to be getting done about it."

"The end of the mental health support I get and challenging my PIP application outcome"

"Begging for help from various avenues and not getting any."



Other comments regarding healthcare, mental health, long COVID and exercise

"I was previously ignored by the NHS when I complained of pain. Now I have lost some of my sight because they ignored me."

"I am very concerned about mental health services. I am worried if I have another crisis that I will not be able to access support and I will end up not existing. I am fine now, but I know the state mental health services are in."

"I would like access to a gym to lose weight"

"...eating disorders for autism...[it is] hard to find someone trained. Well impossible so far even my doctor can't. I can be referred to eating disorder clinic but no trained therapists for eating disorders with autism which would have to be managed differently as brain works differently in healing."

"Happy with the help"

"I have PTSD [post traumatic stress disorder] and chronic fatigue syndrome including hypersensitivity to sounds, light, smells and movement. Being in busy spaces feels overwhelming, especially if there is a lot of background noise and bright light.

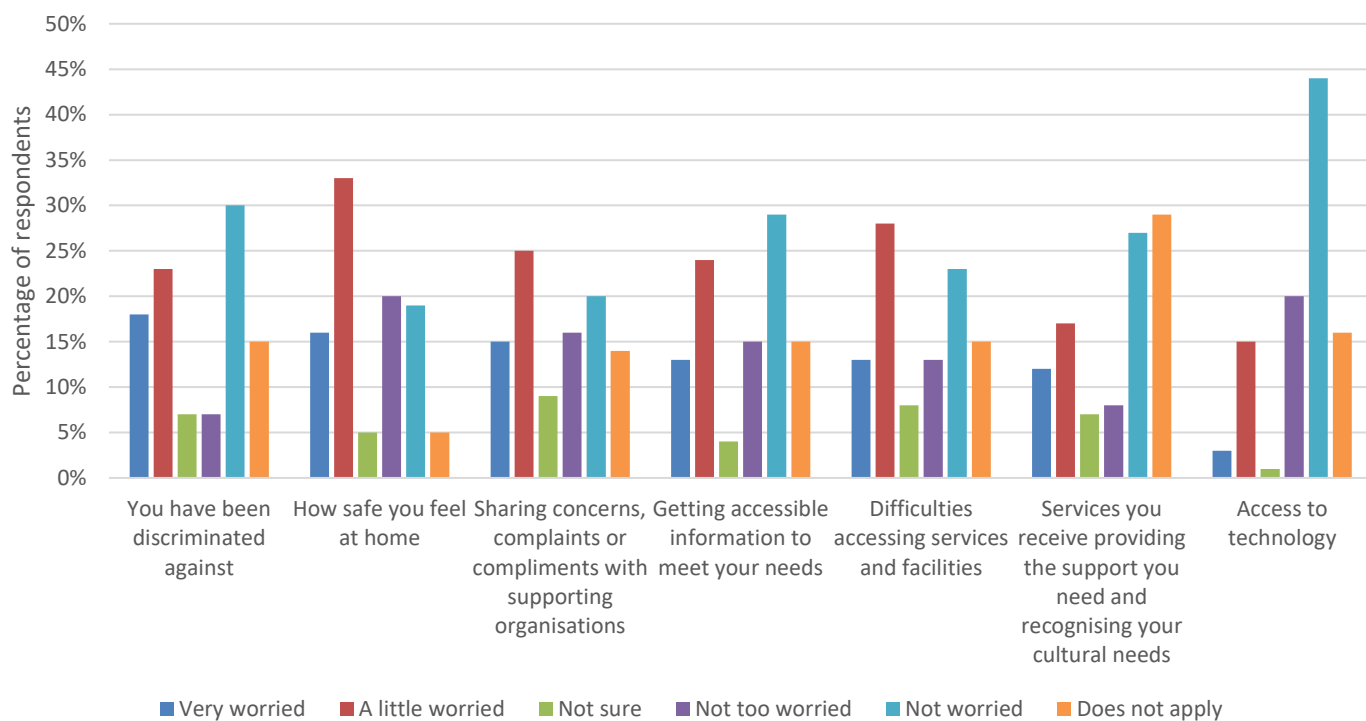
I find it extremely scary and uncomfortable to be in confined spaces e.g. supermarket aisles, buses, most buildings, so for these reasons and others, it's really difficult for me to access/spend any length of time in many places of work, leisure, commerce or essential public services without quickly becoming overwhelmed and going into nervous system meltdown.

So doing basic essential tasks like shopping, visiting my GP, volunteering, going to college and seeing friends become extremely difficult. The meltdown episodes are physically, mentally, and emotionally exhausting, painful, very hard on the body and can knacker me out for a few days. So it feels like there are limited public places to go during wet or cold winter weather which feels very isolating and is worsening my depression.

But I can manage the panic attacks, fits, brain fog, pain, dissociation, mood swings and syncope better if I get the right support.

I don't currently have any mental health support and I'm really worried about being able to access services due to high demand on Mental Health services, and trauma-recovery therapy is key to my health recovery and to be able to start leading a normal life again. I can't afford private therapies as I'm only on Universal Credit..."

Choice, control, and other important areas



Concerns and comments that people have told us:

"I am deaf in one ear and have bad eyesight. It makes it hard to do things."

"People being horrible at [named place]"

"Access to NHS treatment and education without discrimination"

"[I am worried about] NHS accessibility"



Further comments relating to choice, control and other important areas

“We have experienced racist abuse since moving to Gloucestershire last year. It is logged with police. I am scared of taking my child out. I want to move to somewhere different where I don't feel scared.”

“[I am worried about the] very real lack of accessible buildings, steps into shops, cafes etc. When inside, what facilities are on offer, toilets etc, [may not be suitable with] tables too close together. Parking often taken up by cars without blue badge, especially in the evening. Public transport very very poor. [I do not like] being talked down to as if because I use wheelchair etc [People think] I must have an intellectual impairment.”

“[I am worried about] being able to travel to places I need to get to, e.g. buses are unreliable and require multiple changes”

“[I am worried about] discrimination, inequalities in health & social care, being kept in hospital against my will. People not working in my best interests & not consulting me.”

“Not being able to register with a local GP since moving because they only sent a list of reasonable adjustments they would offer and did not listen to or understand what myself and my daughter (who I am a full time carer for) need to access services.”

“I feel like if I was a business man who was doing business things whose time was worth £100 or £1000 per hour, I wouldn't have been put on so many waiting lists.”

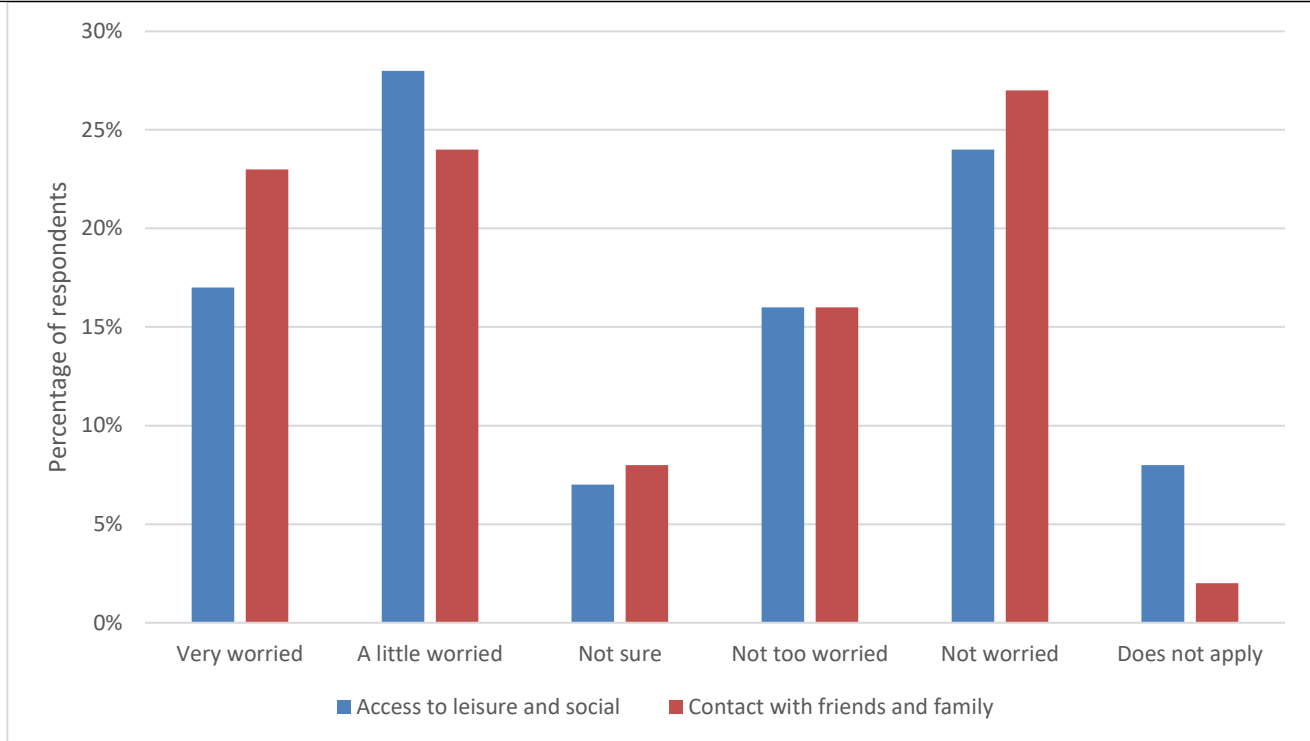
“GPs are inaccessible as an autistic person.”

“No access to therapy for autism locally, [which is] important to have if [you have a] late diagnosis.”

“Happy with the help”

“About accessing my local town - I live about a mile out of town - partly due to the bloody housing crisis meaning I couldn't find anywhere affordable in a practical location - but also because being in a quiet rural hamlet is actually much better for my shattered nervous system. But there are no buses between my home and town - and I often can't manage the walk there and back. But can't afford to get taxis very often and it's not practical to rely on lifts that often....so having a bus service from Stroud going up Slad Lane would be a major lifeline. Or enough money to cover taxis (but hardly good for pollution levels.)”

Leisure and Social



Concerns and comments that people have told us:

"I'm worried about going out"

"[I would benefit from] More groups in the Forest of Dean"

"[I'm worried about] Isolation [and] loneliness."



Further comments relating to leisure and social activities and particular concerns that people had

“My parents who are very important to me and provide a lot of support are growing older. I am scared about their mortality. Counselling could help.”

“[Concerns include...] Isolation, no work and inability to go places lack of public transport and cost of companion service”

“[I am worried about] not having a relationship and not having friends and x turning up here”

“[I worry about] probably getting older and I worry about death sometimes”

“I don’t worry, I’m happy coming to drama”

“[I] worry about how Dad died and about suicide. Struggling with Borderline Personality Disorder. Worrying about diabetes and death.”

“[I worry that there is] no respite for lone parents with disabled children. I need help and can't get it“

“I want more things to do”

“I have nice people in my life.”

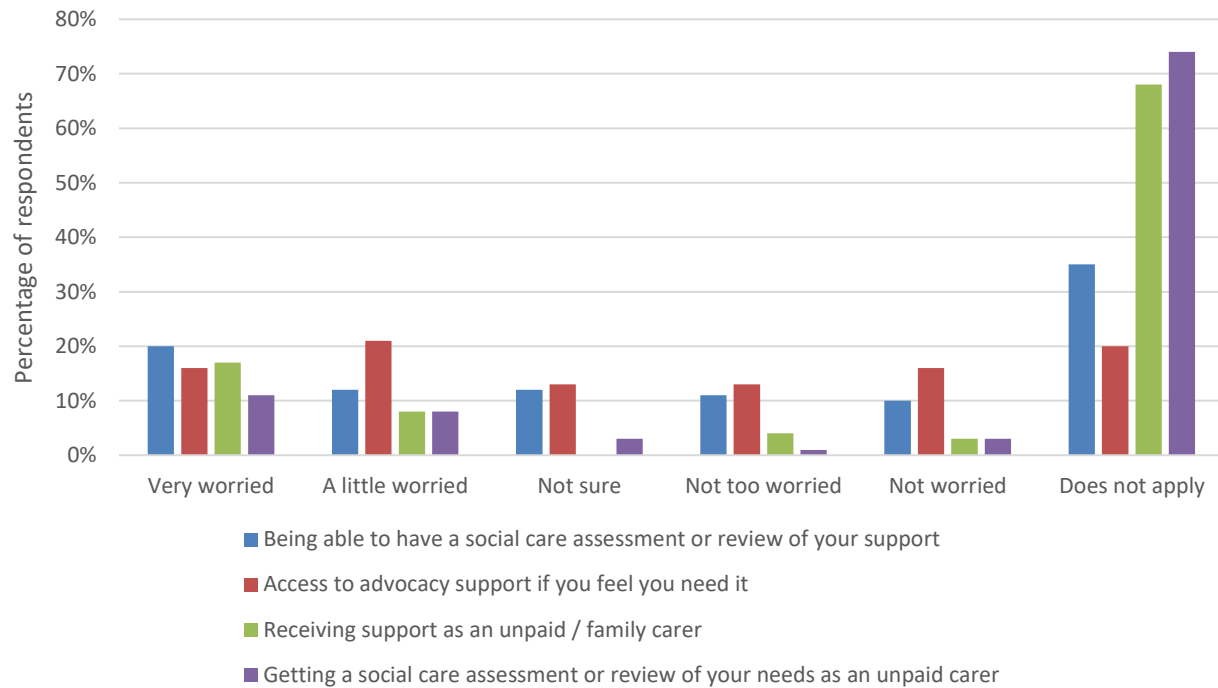
“I would like to meet friends more often. People my own age. I used to go to the Stroud Hub and it was easier when I was at college, but I'm not now. I would like a flight simulator club!”

“Sometimes people need a chat”

“[I would like] Regular chats and conversations and emotional support”

“One final thing that would make a huge difference to my recovery, the ability to access peopled spaces, and would massively improve my quality of life would be being granted approval for a therapy/support animal. Which I don’t think is currently enabled for many disabled people in the UK, with the exception of a few conditions”

Social Care and Advocacy



Some of the things that people have told us about social care and advocacy:

Social Care Assessment and Review

“I am worried about how many autistic adults without a learning disability fall through the gaps and the difficulty accessing mental health services and social care services because we don’t meet the criteria”

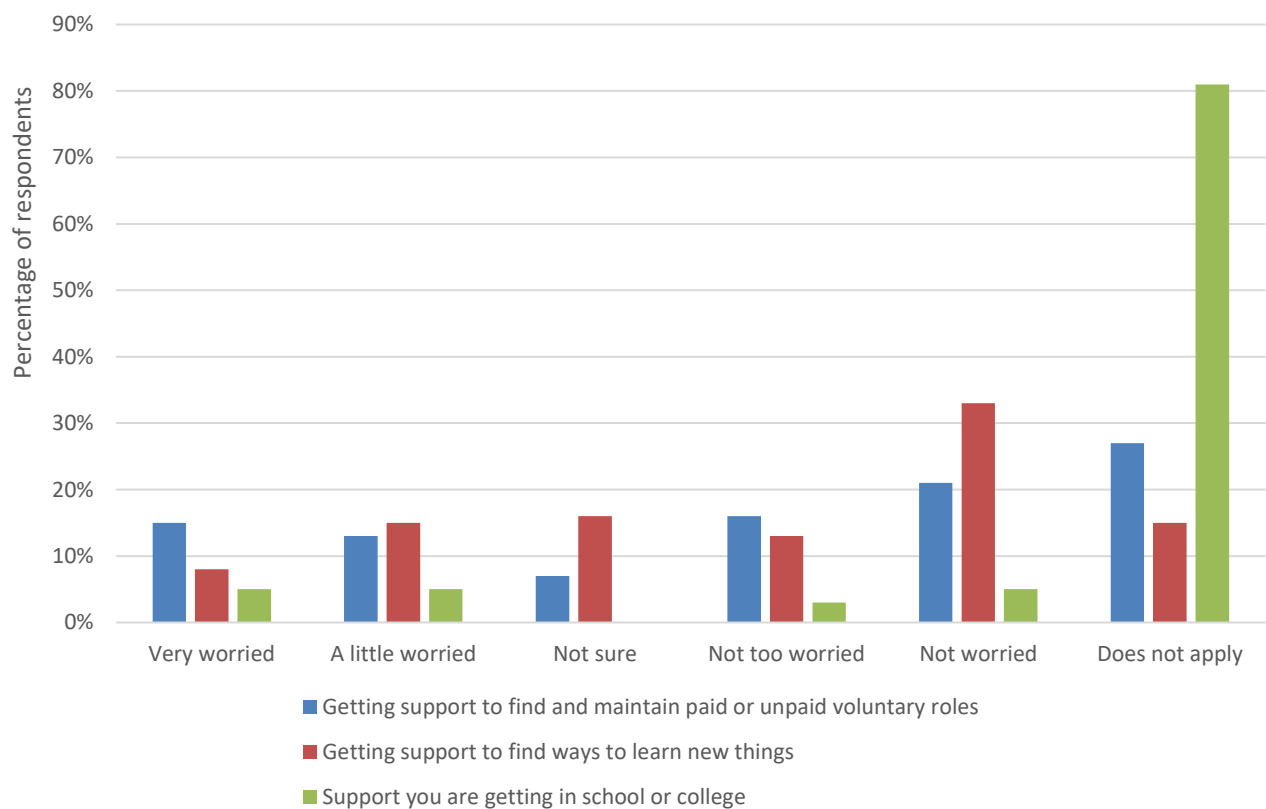


Advocacy



“There is support but you sometimes need support to access the support”

Work and Education



Some of the concerns and comments that people have told us about work and education:

Work

"[I am worried about] isolation, no work and inability to go places."

"I have ADHD and want to be in full time accessible work that recognises and appropriately remunerates for my skill, education and experience."



Education

"I'm worried about getting enough support for my additional needs at school"

"[I would like to get] access to education without discrimination"



What has this told us and what will we do next? *(Conclusions and Recommendations)*

Who did we not reach with the research?

Some people were less likely to have been reached by or filled in the survey, including:

- Those who identify as male
- Those who identified themselves as transgender
- Those who don't identify themselves as heterosexual
- Young people under the age of 18, those between 18 and 24, and over 65
- People for whom English is not their first language
- People who identify themselves as from ethnic groups other than White English
- Those who are not members of Inclusion Gloucestershire
- Those who are already using our services
- People with lived experience of sight or hearing loss



Recommendations for expanding our reach

Inclusion Gloucestershire is committed to working with people from a diverse range of backgrounds and with diverse lived experiences. As a result we have secured funding to take on a Research Coordinator to work alongside the Delivery Director, so that we will be able to increase our reach and support more volunteers. This will mean we will be able to do more research with more people.

We will do this in a few different ways including:

- 1) Making sure that information about our research and Inclusion Gloucestershire is available in accessible formats, including easy read.
- 2) Share this information widely, both in person and using the internet.
- 3) Contact people who gave us their contact details, to let them know how to join Inclusion Gloucestershire and about our services.
- 4) Review the accessibility of our website.
- 5) Make sure that we are sharing marketing and information with groups that we know are under-represented in our services.
- 6) Build wider and stronger partnerships with organisations and groups who are more connected with people we did not reach through our survey.
- 7) Review our current membership information and make sure that we are effectively communicating with people who are already members of Inclusion Gloucestershire.
- 8) Review our internal policies, procedures and processes to make sure we are welcoming to a diverse range of people who could be interested in volunteering or paid work with Inclusion Gloucestershire. This will help us to reach more diverse communities with our work.

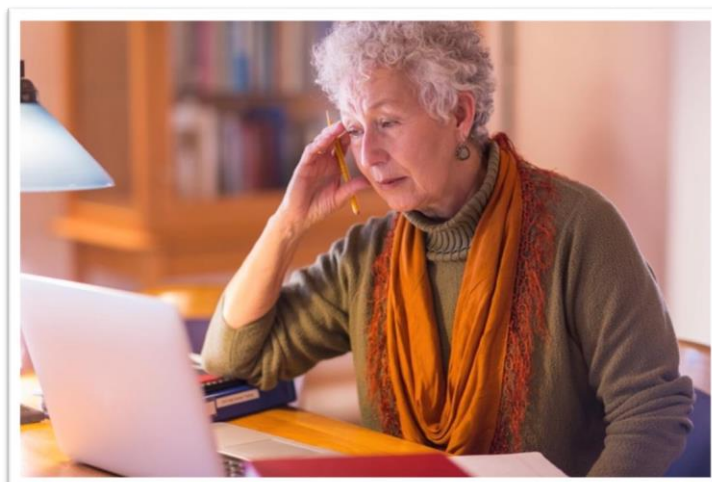


What areas of life are people worried about?

Clearly finances are the main concern that people are most worried about at the moment.

The comments that people have shared highlight how finances impacts every other area of their lives, from their food and heating, to their contact with friends and family. It means that the quality of people's lives are being significantly affected by having less available money, resulting from the increase in costs of living.

The comments also show how finances are adversely impacting disabled people more because of costs associated with their disabilities. This double discrimination, combined with the ongoing worry, is making day to day life very difficult for a high number of disabled people, their families and carers.



Recommendations relating to worries:

1. Review current resources, information and advice that is available to disabled people to support them with finances and cost of living, from Inclusion Gloucestershire and other organisations that support this area
2. Review current resources that are available to disabled people relating to healthcare, mental health support and housing
3. Compile a list of resources that are most helpful and up to date, or reference a particular website if this already exists
4. Share this report directly with those people who took part and wanted to hear the results, along with the appropriate supporting resources, and raise awareness with other disabled people via:
 - Our website and social media
 - Partnership and strategic organisations
 - Our own database of contacts
 - Events and opportunities over the next 6 -12 months
5. Raise awareness of the research findings with key decision makers in statutory organisations, including health and social care and relevant Partnership Boards, so they understand the context that disabled people are currently in
6. Work with other Disabled People's Organisations at a regional and national level to ensure that local and national government is listening to the concerns and priorities of disabled people; and collectively holding government to account on acting upon this
7. Review current projects within Inclusion Gloucestershire, such as mental health, advocacy and volunteering, to find out if it is possible to expand services to meet changes in needs
8. Explore developing new projects to meet specific demands, such as specialist peer mentoring to support newly diagnosed neurodivergent adults

9. Identify current partnership and new potential partnerships that can develop work in these areas to support disabled people's concerns
10. Review the concerns of disabled people in a year to develop work in line with their needs
11. Review this report when we are developing Inclusion Gloucestershire's 3-year strategy, including around diversifying our reach, strengthening the voice of disabled people, using our research to drive change, and raising awareness of current disabling barriers.



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Find out more about us at: www.inclusiongloucestershire.co.uk

Appendices on our website

These can be found on our website:

<https://www.inclusiongloucestershire.co.uk/research-strategy-and-partnerships/>

- Survey Questions
- Easy Read Survey Questions
- Charts and data from the survey