Inclusion Gloucestershire Big Survey 24/25 Appendices

Appendix 1: Survey Questions

Survey Information

We would like you to take part in this study carried out by Inclusion Gloucestershire. Before you decide if you want to take part, it is important you understand why it is being done and what it will involve.

What is the aim of the research

We are doing this research because we are a Disabled People's User Led Organisation and we want to find ways to improve the lives of disabled people in Gloucestershire. We want to find out what is important to disabled people in the county at the moment and what issues they are facing.

This survey will help us to plan which areas of work we will do that will most improve the lives of disabled people. It will also give us evidence to tell other organisations how they can improve the lives of disabled people in Gloucestershire

We will also give people who complete the survey the chance to talk to us more about what matters to them and what they want to see change.

The results of this study will be made anonymous, analysed and put into a report and video on the Inclusion Gloucestershire website. They will be shared with people who have the power to make changes such as the NHS, Gloucestershire County Council and voluntary sector services.

Who can take part in the research?

You can take part in this research if you are:

- Over 18

- Living in Gloucestershire
- Disabled as per the definition in the Equality Act 2010 that is, you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities. This will include people who have visual impairments, hearing impairments, learning disabilities, autism, physical impairments, chronic illness, long term health condition etc. If you are not sure if your condition meets this definition, then get in touch on the details above.
- If you are a parent or carer of someone who meets the criteria above, you may complete this survey on their behalf

Do I have to take part?

You do not have to take part. It is up to you to decide whether to take part or not. You can decide to withdraw your consent at any point. If you want to take part, you will need to complete the agreement form in the next section

What might be the benefits to me of taking part?

There is unlikely to be much personal benefit to taking part. You will be contributing to a study which aims to provide evidence of changes that could improve life for disabled people in Gloucestershire.

What might be the risks to me of taking part?

We do not anticipate or foresee any significant risk to you in taking part in this study. We will take all possible steps to anonymise your data however, it is possible that someone who knows your situation well may be able to identify you from our report.

What will happen to my information?

All of your information will be kept securely. Any personal or identifying details will be anonymised.

How will you keep my details private?

Your details will be kept separate from your survey in a password protected file on a password protected computer, on a drive only able to be accessed by Inclusion Gloucestershire staff.

Where will the results be published?

A report will be written with our findings. An Easy Read version of the report will be produced as will an accessible summary video. These will be published on the Inclusion Gloucestershire website and via our social media pages. The findings will be shared in meetings across the county with people in positions of influence who can make the changes that the study shows need to be made. A copy of the report will be made available to all participants if they choose.

What if something goes wrong or I have any questions?

Please read this information carefully and if you have any questions contact Harriet Roberts, the Research Coordinator. You can either email her at research@inclusion-glos.org or phone 07517 994765.

In the first instance, use the contact details above. However, if you wish to pursue the matter further, please contact Debbie Worrall, Research and Health and Wellbeing Manager at research@inclusion-glos.org.

1. Please tell us about your disability. A disability is a 'physical or mental impairment that has a substantial and long-term adverse (negative) effect on your ability to carry out normal day-to-day activities'.
   If you have more than one disability, please say.

   ☐ ADHD
   ☐ Autism
   ☐ Chronic illness
   ☐ Hearing Impairment
   ☐ Learning Disability
   ☐ Mental Health Condition
   ☐ Neurological Condition
   ☐ Physical Impairment
   ☐ Sight Impairment
   ☐ Other
   ☐ No disability - sorry you cannot complete this survey.

2. Are you aged 18 or over?
    - ☐ Yes
    - ☐ No

3. Do you live in Gloucestershire?
    - ☐ Yes
    - ☐ Yes - Some of the year I spend in Gloucestershire as a student
    - ☐ No - sorry, you cannot complete this survey.

Agreeing to take part

4. I have read and understood the survey information section, or someone has explained it to me and I understand

☐ Yes
☐ No

5. I understand that taking part means I will do a survey]

☐ Yes
☐ No

6. I understand that I do not have to take part, and I can stop taking part at any time

☐ Yes
☐ No

7. I understand that my details will not be shared with anyone outside of the research team

☐ Yes
☐ No

8. I understand that my answers may be written in a report or on a video and shared with other people, but my name will not be used

☐ Yes
☐ No

9. I allow Inclusion Gloucestershire to safely store my survey feedback electronically so they can use this in more research in the future

☐ Yes

☐ No

Health Care

How do you feel about the health care you receive? This might include your GP, hospital or other physical health support

😃 I am very happy

😊 I am a little happy

😐 I am not sure
😟 I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Mental Health

How do you feel about the support you have for your mental health and well-being?

😃 I am very happy
😊 I am a little happy
😐 I am not sure
😟 I am not too happy
😔 I am not happy at all
😶 This does not apply to me
Please explain your answer

Social Care

If you get help from the social care team, how do you feel about your social care assessment or reviews of your support?

😃 I am very happy
😊 I am a little happy
😐 I am not sure
😟 I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Advocacy

How do you feel about getting advocacy support if you feel you need it? Advocacy is speaking up for yourself or asking other people to speak up for you

😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Finances

How do you feel about your finances? This might include the money you have coming in, bills or debts.
😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Housing

How do you feel about your housing?

😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Help to find work
How do you feel about getting support to find or maintain paid work or voluntary work?
😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Education
If you are at school, college or university, how do you feel about the support you are getting?
😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Leisure

How do you feel about accessing leisure activities?

😀 I am very happy

😊 I am a little happy

😐 I am not sure

☹️ I am not too happy

😔 I am not happy at all

😶 This does not apply to me

Please explain your answer

Social

How do you feel about being able to have regular contact with friends, family and other people who are important to you?

😀 I am very happy

😊 I am a little happy

😐 I am not sure

☹️ I am not too happy

😔 I am not happy at all

😶 This does not apply to me

Please explain your answer

Sexuality and Gender Identity

How do you feel about the services that meet your needs around sexuality or gender identity?

😀 I am very happy

😊 I am a little happy

😐 I am not sure

☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Concerns/ Complaints

How do you feel about sharing concerns, complaints or compliments with any of the organisations who support you?

😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Culture/ Religion

How do you feel about the services you receive meeting your cultural or religious needs?

😀 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Discrimination

Are you worried that you have been discriminated against in the last year? Discrimination is if you are treated differently because of who you are. This may be because you are disabled or because of your sexuality or because of your culture or religion. It may also be because of your age or your gender or because you are pregnant. It may also be because you are married or in a civil partnership

😔 I am very worried

☹️ I am a bit worried

😐 I am not sure

😊 I am not too worried

😀 I am not worried

😶 This does not apply to me

Please explain your answer

Accessible Information

How do you feel about getting the accessible information you need? This could be information from any organisations or services that you use e.g. councils, GP's, banks, leisure centres, buses etc.

😀 I am very happy

😊 I am a little happy

😐 I am not sure

☹️ I am not too happy

😔 I am not happy at all

😶 This does not apply to me

Please explain your answer

Access to services

How do you feel about the accessibility of services and facilities you use (for example councils, GP's, banks, leisure centres, buses etc?)

😃 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Personal safety

How do you feel about your safety when you are not in your home?

😃 I am very happy
😊 I am a little happy
😐 I am not sure
☹️ I am not too happy
😔 I am not happy at all
😶 This does not apply to me

Please explain your answer

Anything else?

Is there anything not covered here that is an important concern for you? For example: Access to exercise, using technology, support to learn new things, caring responsibilities, reasonable adjustments/support in work or something else.

What is the one thing that is causing you most concern at this time? Please tell us more about this and share your ideas about how Inclusion Gloucestershire might be able to help with this.

About you
We want to make sure this survey includes as many different people as possible, (it is optional)

What is your gender identity?

- ☐ Female
- ☐ Male
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ Other:

Do you identify as trans/transgender?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

What is your sexual orientation?

- ☐ Heterosexual
- ☐ Homosexual (Lesbian/Gay)
- ☐ Bisexual
- ☐ Prefer not to say

How old are you?

- ☐ Under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44

- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ Over 75
- ☐ Prefer not to say

Is English your first language?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

Please tell us your ethnicity

- ☐ Prefer not to say
- ☐ Arab
- ☐ Arab British
- ☐ Asian or Asian British- Indian
- ☐ Asian or Asian British- Pakistani
- ☐ Asian or Asian British- Bangladeshi
- ☐ Asian or Asian British- Chinese
- ☐ Asian or Asian British- Any other Asian background
- ☐ Black or Black British- Caribbean
- ☐ Black or Black British- African
- ☐ Black or Black British- Any other Black background
- ☐ Mixed- White and Black Caribbean
- ☐ Mixed- White and Black African
- ☐ Mixed- White and Asian
- ☐ Any other Mixed background
- ☐ White British
- ☐ White Irish
- ☐ Any other White background

Which area of Gloucestershire do you live in?

- ☐ Cheltenham
- ☐ Forest of Dean
- ☐ Gloucester
- ☐ Stroud
- ☐ Tewkesbury
- ☐ The Cotswolds
- ☐ Prefer not to say

Are you a member of Inclusion Gloucestershire?

- ☐ Yes
- ☐ No
- ☐ Not sure

Have you been using any of Inclusion Gloucestershire's services in the last 6 months? This might be the Inclusion hubs, drama group, advocacy support, speak up groups or MHELO (Mental Health Experience Led Opportunities).

- ☐ Yes
- ☐ No
- ☐ Not sure

Contact Information

Do we have permission to get in touch with you to talk about your answers in an interview or focus group?

- ☐ Yes, you have my permission (please fill in your contact details below)
- ☐ No, I don't want to be contacted

Would you like us to send you a copy of the report when it is completed?

- ☐ Yes
- ☐ No

Please tell us your full name (optional)

Please tell us your phone number (optional)

Please tell us your email address (optional)

Appendix 2: Easy Read Survey

INCLUSION GLOUCESTERSHIRE

BIGGER DREAMS ▶ BETTER LIVES ▶ BRIGHTER FUTURES

Big Survey 2024

Easy Read

Survey of Disabled People in Gloucestershire 2024

INCLUSION
GLOUCESTERSHIRE
BIGGER DREAMS ▶ BETTER LIVES ▶ BRIGHTER FUTURES

We want to know what is important to disabled people in Gloucestershire so we can help to make changes.

We are asking a lot of different people what they think.

We will write a report about what everyone tells us and put it on our website and social media.

We will not put your private information in our report. We will keep all your information safe.

If you feel you need help or information about the things in our survey you can get in touch, and we will try and help.

If you would like the survey in a different language.

Or if you would like help to fill in the survey.

You can e-mail us - research@inclusion-glos.org

Or call us on 07517994765

To answer the questions in the survey, put a tick or colour in the circle that best describes how you feel.

Section 1 is about your life and support.

1

How do you feel about getting help with your health? This could be your GP, hospital, or other health things.

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

2

How do you feel about getting help with your mental health or feelings?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

If you get help from social care, how do you feel about getting an assessment or review?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about getting help to speak up for yourself? This is called Advocacy.

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about things like paying your bills and having enough money?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about where you live?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about getting help to find and keep a job or be a volunteer?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

If you go to school, college or university now, how do you feel about the help you get?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about being able to go out to do things you enjoy?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about being able to see your friends, family or other people who are important to you?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about the services that meet your needs around sexuality or gender identity?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about telling the people who support you when things are going well and not so well?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about the services you receive meeting your cultural or religious needs?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

Are you worried that you have been treated differently or badly this year because of who you are, like your religion or disability or race or other things? This is called discrimination.

Very worried	A bit worried	Not sure	Not too worried	Not worried	This is not about me
○	○	○	○	○	○

Tell us more about your answer:

How do you feel about getting easy to understand information that you might need, for example from your GP, banks, buses, and other things?

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

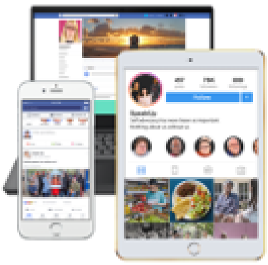
Tell us more about your answer:

How do you feel about accessing different places? This could be things like getting in and out, being able to understand signs, being too busy, or too bright or having hearing loops.

Very happy	A little happy	Not sure	Not too happy	Not happy at all	This is not about me
○	○	○	○	○	○

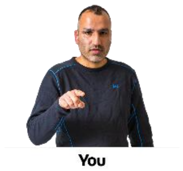
Tell us more about your answer:

	How do you feel about how safe you feel when you are not at home? Very happy ○ A little happy ○ Not sure ○ Not too happy ○ Not happy at all ○ This is not about me ○
Tell us more about your answer:	

18		Is there anything we haven't asked about that is worrying you?
		○ Exercise
		○ Technology
		○ Support to learn new things
		○ Looking after someone like your parent or child

	 ?	○ Getting reasonable adjustments in work ○ Something else
	Tell us more about your answer:	

19		Can you say here what you are worried about most?
		Can you tell us your ideas about how Inclusion Gloucestershire might be able to help you?
		Would you be happy for us to get in touch with you to find out more about your answers? Yes ○ If you tick yes, please fill out your contact details below. No ○



Section 2 These are questions about you.

We would like everyone to fill in these questions so we can find out what is worrying different people.

Please tick or colour the circle that best describes you.

○ Male
○ Female
○ Not male or female, this is called non-binary
○ Both male and female, this is called intersex
○ Not saying
○ Something else

Are you trans/transgender? This means you are a different gender than the one you were when you were born.

○ Yes
○ No
○ Not saying
○ Something else

Who do you prefer to have a romantic relationship with? This is called sexual orientation.

○ People of the opposite sex to you
○ People of the same sex as you
○ People of the same sex and different sex to you
○ Not saying
○ Something else

How old are you?

Under 18
18-24
25-34
35-44
Not saying
44-54
55-64
65-74
Over 75

Is English your first language?

○ Yes

○ No

○ Not saying

○ Something else

Please tell us which in this list best describes you.

○ Not saying

○ Arab

○ Arab British

○ Asian or Asian British - Indian

○ Asian or Asian British - Pakistani

○ Asian or Asian British - Bangladeshi

○ Asian or Asian British - Chinese

○ Asian or Asian British - Any other Asian background

○ Black or Black British - Caribbean

○ Black or Black British - African

○ Black or Black British -Any other Black background

○ Mixed - White and Black Caribbean

○ Mixed - White and Black African

○ Mixed - White and Asian

○ Any other Mixed background

○ White British

○ White Irish

○ Any other White background

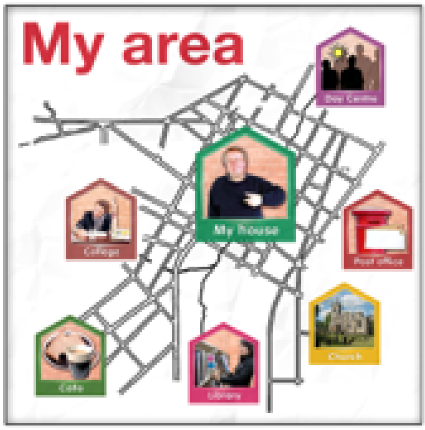
○ Something else

Please tick or colour all the circles that best describe you or things you have experienced.

- ○ Anxiety disorder
- ○ ADHD
- ○ Autism
- ○ Family/unpaid carer
- ○ Learning Disability
- ○ Mental health condition
- ○ Neurological condition
- ○ Physical impairment
- ○ Sensory impairment (Sight or hearing loss)
- ○ Sensory processing disorder
- ○ Not saying

Please tick or colour the circle in this list next to where you live in Gloucestershire.

- ○ Cheltenham
- ○ Forest of Dean
- ○ Gloucester
- ○ Stroud
- ○ Tewkesbury
- ○ The Cotswolds
- ○ Not saying
- ○ Somewhere else



Are you a member of Inclusion Gloucestershire?

- ○ Yes
- ○ No
- ○ Not sure
- ○ Not saying

Have you been using any of Inclusion Gloucestershire's services in the last 6 months? This might be the Inclusion hubs, drama group, advocacy support, speak up groups or MHELO (Mental Health Experience Led Opportunities).?

○ Yes

○ No

○ Not sure

○ Not saying

Thank you.

If you don't want to fill in section 3 you can send us your survey with your answers. Our address is at the end of the survey.

Section 3 your contact information.

We would like to be able to contact you, but you don't have to give your contact details to us if you don't want to.

If you do give us your information, we will only use it for four reasons:

1) to talk to you to find out more about your answers to this survey

2) to ask you to help us with other surveys or research

3) to write to you about how you can become a member of Inclusion Gloucestershire.

4) to send you a copy of the report.

We will keep your personal contact details safely for 4 years from the date the survey closes, so this will be until December 2028.

To find out more about how we keep information safe or to tell us you do not want us to keep your information please email research@inclusion-glos.org

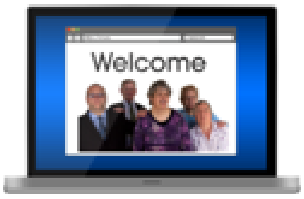
We will not share your personal details with other people or organisations.

Please tell us your full name.

Please tell us your address

Please tell us your phone number.

Please tell us your email address.



Please keep an eye on our website and social media as we will share information about what you have told us on these.

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

https://www.facebook.com/inclusionglos/

https://www.instagram.com/inclusiongloucestershire/

If you want to post your survey back to us,

please post your survey by
5pm on 31^{st} January 2025 to us at:

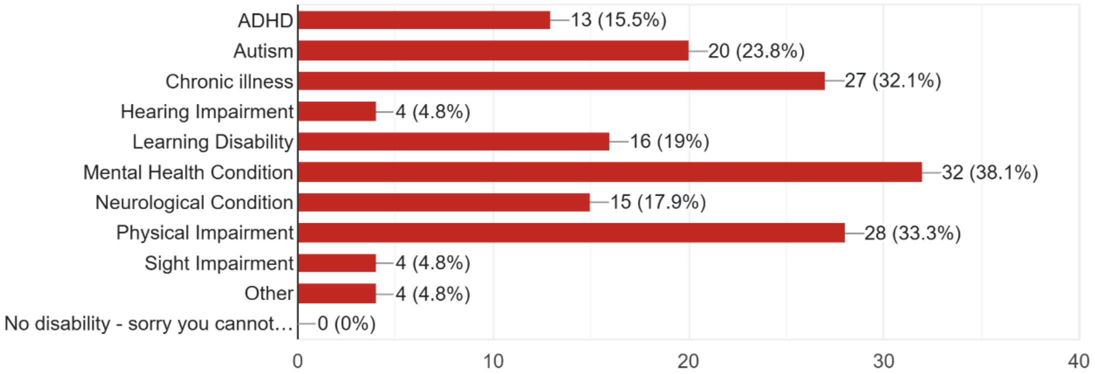
Inclusion Gloucestershire
Railway House
Bruton Way
Gloucester
GL1 1DG

Thank you for helping us with our survey

Appendix 3: Survey Responses

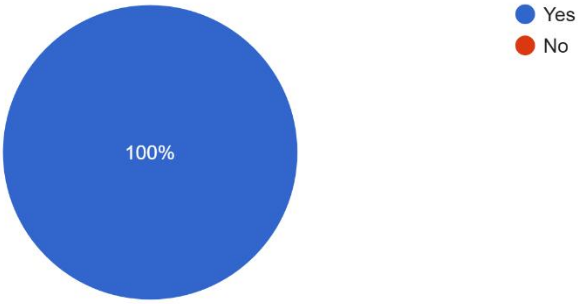
Please tell us about your disability. A disability is a 'physical or mental impairment that has a substantial and long-term adverse (negative) effect o...e than one disability, please select all that apply.

84 responses



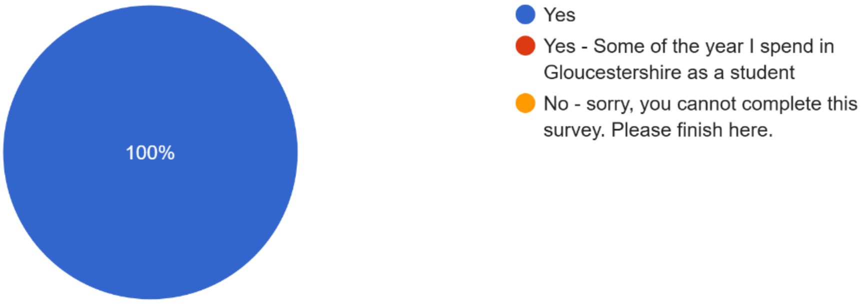
Are you aged 18 or over?

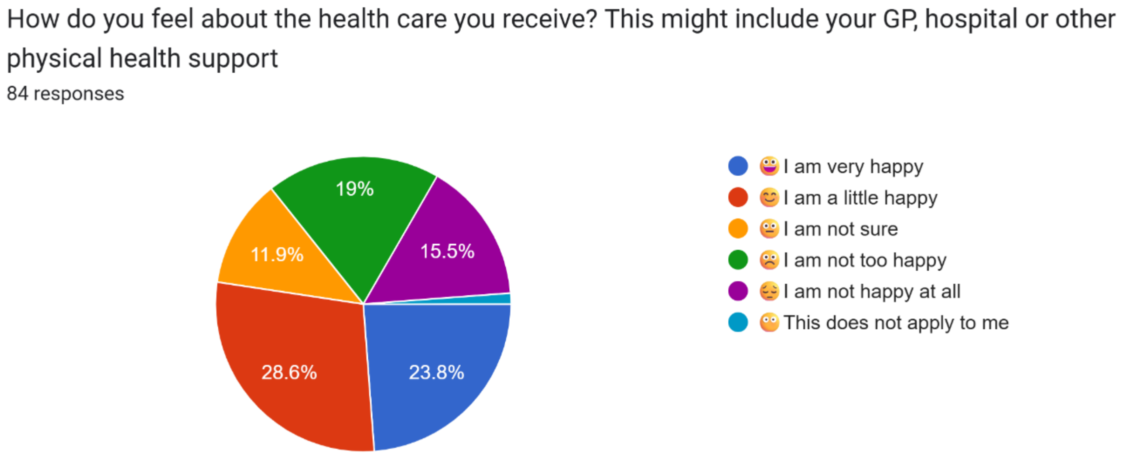
84 responses



Do you live in Gloucestershire?

84 responses





How do you feel about the health care you receive? This might include your GP, hospital or other physical health support

84 responses

Please explain your answer

72 responses

- On the whole I do not have to wait too long to see a GP although I know this is not the case at many surgeries (perhaps because I live in a rural area). I worked for the [Organisation] and their treatment of me on the whole has been very good. I did have a planned procedure cancelled last week because of us being in a Critical Incident position - luckily it has been rearranged for next week.
- Because even though there have been problems nothing has gone seriously wrong. And when it works it works reasonably well.
- Very difficult to get any medical help/therapy without distressing environments, lots of communication, executive function, time, energy.
- My doctor has gone on maternity and no replacement has been identified for me. I need the stability of one GP…not potluck when I call.
- I have had a real lack of support from my doctor/GP for my mental health struggles, long term eating disorder, and diagnosis of M.E.
- I have been referred to [Talking Therapy Service] on multiple occasions for depression and anxiety but am often told I'm not actually eligible for sessions due to my multiple issues meaning they cant offer what I need. No suggestions or alternative place to

go for help is given. On the occasions I have been offered some sessions I have found they come to an end before any lasting progress or improvement is actually made.

- I have had such terrible experiences from the local eating disorder unit I was referred to that I walked away in a worse condition and have am still now trying to self manage my illness alone for multiple years.
- I'm not too happy because there is so little understanding or acceptance of ME/CFS. Most health professionals ignore it if it bring it up. I imagine they don't want to talk about something they don't understand or don't believe in, but that doesn't help me. I am also not happy because there is no treatment available for ME/CFS so having it overlooked by health care professionals almost feels negligent.
- I have ME, POTS, FND, ADHD and more and find despite supposedly otherwise on [Service] websites etc, there is little or no treatment or support. I'm left to flail and rot.
- Never able to get appointment, get seen and discharged in 1 consultation or told I do not fit the criteria. GP doesn’t understand conditions or puts new problem down to existing condition rather than looking at other causes I am fed up of ringing for appointment to be told sorry all gone, ring back tomorrow morning why have an app and not allow people to make appointments.
- There are no avenues to diagnosis or support for my Ehlers Danlos syndrome or Mast Cell activation syndrome. GPs are stumped about how to either get a diagnosis or support me. The administration at my GPs mean I have been let down 4 times in the 2 years with referrals for appointments. I have completed forms which they have lost. Its been so challenging to get anywhere. It affects my mental health because at times it feels hopeless.
- I generally am able to get help fairly swiftly when needed
- Some GPs respond to consultations with unhelpful advice for example when I asked for a medication review as my chronic pain had been getting worse one GP sent a text advising to use talking therapies. After, I spoke to a different doctor and they were really helpful and accommodating! It can be impossible to get an appointment and if you’re running late you can’t call to let the

surgery know and so you are classed as not showing up and sent a message with the cost of an appointment. Doesn’t matter if you’re a minute late they mark you as not attended, however when waiting for your appointment the GP doctors are always running behind anyway

- Once medication is removed, there is no support or monitoring of my condition.
- Had bad experiences but also find that they can blame everything on your condition & solution offer strong painkillers which can then give you side effects so more things to put up with. Not enough knowledge of the condition at times.
- When I fell over and had an X-Ray they responded to it well
- They take a long time to get back to me
- Health care professionals have been great but they are under resourced and waiting lists are too long
- When I see my GP she's more confident with my health. She is very understandable, chatty, very slow and clear (when explaining things).
- Limited if any knowledge of M.E/CFS across different medical professions
- GP services are very poor, extremely difficult to get an appointment and filtered via reception staff. Hospital waiting list for 18 months.
- I can’t get in to see the GP before 30th Dec (a month). I don’t want to have to go to the new surgery that they are building. It'll be a long walk.
- My GP surgery is very good, and I always get to see someone quite quickly
- I have regular appointments with the specialist team and they are always contactable should I need them in between appointments.
- There is very little support and where there is it is crisis management
- GPs, Nurses etc are excellent but often there are delays getting to see Rheumatology Consultant or Team and if this involves a change in medication or something which needs to be dealt with it can be months before it is sorted.

- Can feel rushed at doctors
- I have found everyone who is involved with my care to be very supportive in helping me anyway they can
- I was in hospital recently and the lady doctor was nice.
- You get limited help, then it stops and you are left to try and manage on your own.
- Healthcare seems to be mixed. The main problem for me is accessing GP appointments and continuity of care. You have to fill in an online form to speak to the GP and wait for the call back rather than booking in an appointment face to face. The phone appointments seem rushed and you can speak to a different person every time you make a request. This means continuity of care can get lost. Sometimes I have found that the GP's are looking for a quick fix to a problem rather than the cause. Waiting times for various treatments are incredibly long with no support offered in the interim.
- Keep changing doctor
- Long waiting lists (6 + years on waiting list for ADHD assessment, went private and had to wait 1+ year for medication)
- Same for my chronic condition, long wait times to have appointments at hospital and see specialists, or even a GP
- The specialist hospital healthcare I receive is great (but this is not in Gloucestershire). It is hard to get through to the GP - there is a portal to request appointments online but it is never open or working, which is frustrating
- They're doing the right thing at the right time
- I was discharged from the M.E. clinic because I was up fatigued too attend and I had emailed them to let them know. Their response was to state sorry but we have too many referrals to get through go back to your GP. Getting a GP appointment is impossible. Feeling left and isolated from support
- I'm looked after
- In the 2 years I have lived in [town] my support has slightly increased with regards to my physical disabilities although I have been waiting 18 months for a referral to a knee consultant. My GP service is awful and I haven't had a face to face appointment for

about 10 months. My diabetes nurses are very good but again I don't see them as often as I should due to them having too many patients. I had a physio appointment after a long wait and they said my condition was too bad to have physio as my knee needs replacing. I now have my first appointment with the Knee Consultant in March 2025 and am in pain daily. My back condition for which I am classed as disabled is treated under a Neurosurgeon in [City] so not this area and I have recently paid privately to have a breast reduction to assist my ongoing Spinal condition. I gave up on a mental health referral because it was taking so long and did have some private counselling sessions which have helped me a lot.

- They have been speedy at diagnosing and treating my cancer.
- Generally very good, but sometimes long waiting times for some services
- Autism support is in short supply for adults
- My physical conditions are looked after well but my neuro condition is just not understood by clinicians & i get fobbed off regularly when new specific symptoms arise. As a result, I get prescribed unsuitable treatments.
- Better care for people with long term conditions is needed
- Well because I've not had to stay in hospital at all. There is also easy access to staff here
- I think the GP does their best with little resources. They would like to be more engaged and thorough but can’t be due to their workload and lack of sufficient funding.
- I'm not sure I was properly attended to, I felt like I wasn't really given enough to attention
- GP is fantastic, and any interactions with the Ophthalmology Department have been very good.
- It’s patchy
- The support I receive from outpatients appointments at the hospital is generally really good. I’ve spent a lot of time in patient as well and for the most part people are understanding of my condition and of my needs.

- Accessing my GP is much more difficult, I used to have a named GP and a second doctor that I knew very well and they knew me which made things easy as they fully understood my condition and I did not have to explain myself, my condition or my needs at every appointment.
- Now if I want an appointment that is not an emergency. I have to wait 3 to 6 weeks and that's to see a doctor I don't know and who does not know about my condition, multiple times the doctors have asked me to explain my condition and how it works or they outright google it in front of me which does not give me any confidence in them.
- I used to request to see certain doctors but now I'm told that it's not an option even though I have extremely complex health conditions which could be better managed if I could consistently see one or two doctors (then others only at urgent/emergency appointments)
- I also struggle constantly with the pharmacy team at the doctor surgery; I take 23 regular medications plus several as required. Due to multiple admissions to hospital over the years and different amounts of medication being sent at home my medication not currently synchronised which means I'm ordering tablets multiple times across the course of the month rather than being able to order them all at the same time.
- The pharmacy have agreed that if synchronised then they will order all medication for me which would save a lot of stress and anxiety.
- Over the last 12 to 18 months I've been battling with the pharmacy team at the surgery, trying to get them to synchronise the medication but they keep telling me that it's not possible but they do not give me a justifiable reason. Several times I've been told that I'm taking too many medications and it would be a lot of work to synchronise them OR that its just not possible (no reason given).

  Once or twice I've been told that they have synchronised them as best they can but when I ask how many medications have been synchronised they named three medications out of 23 which is not helpful.

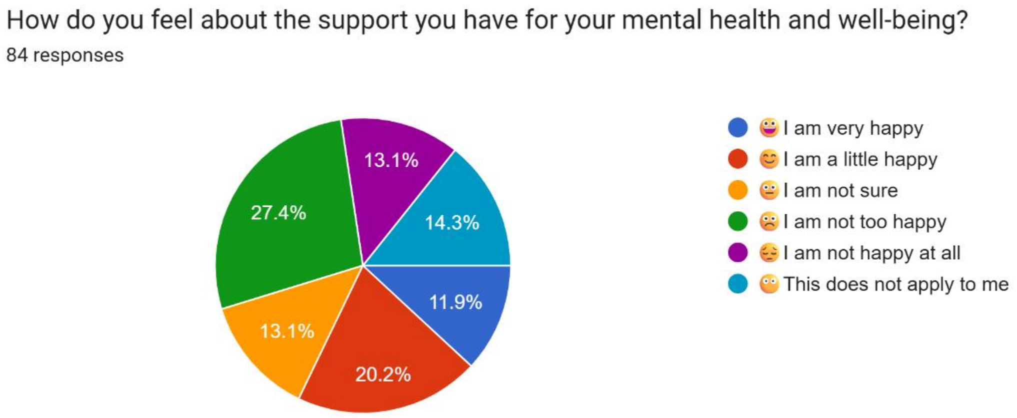
- Twice I’ve done the calculations for them and given them a table showing how much medication have in my stocks and how much they need to give me to make everything synchronised, I know I did not have to do this however I felt that if I did the work for them (because they were claiming it’s a lot of work and would take a long time) that they would synchronise my medication but they have not.
- It does not help that every time I ask how I can get everything synchronised I’m given different information which is very confusing and always leads me back at square one with them refusing to synchronise the medication
- I’ve spoken to my pharmacy about this a few times and they’ve told me that my GP surgery is the absolute worst in terms of communication and ensuring patient’s medication is ordered in timely manner
- Obviously not getting medication on time & the stress involved in keeping on top of my medication is not good for my physical or mental health
- All my treatment on the whole is great - although the waiting list for my procedure is very long
- At the moment, I am not receiving support.
- I'm in pain all the time and it makes me feel down. I had a hospital appointment but it was changed to one six months later on.
- Because my family help me
- I am not happy because I am not treated with respect
- With my current GP I’ve been able to improve my health, which includes barrets and pars defect, but I’ve also taken responsibility for my health but received great support.
- the GP is understanding. I had my covid and flu jab. I had to ring the doctor and tell them I had it at [service] and they were fine, if I need to get my inhalers at [service], as the doctors don't do it anymore.
- Very good, with nurses on site
- GPs don't have a clue, but my hospital specialists are good.
- Whilst I receive an excellent service from my GP surgery, I have had an appalling and traumatic experience with [Hospital] A&E

night staff (not day staff) which resulted in me having to be admitted and I am still recovering from. I was disbelieved, treated as a fraud, when I infatuated on a care plan being in place to safely discharge (I couldn't walk and live alone), I was threatened with the police, verbally and physically abused, ignored and medications placed out of reach. I am terrified of ending up there again and understand from others have had similar experiences with ME/Chronic Fatigue Syndrome, Long Covid, Functional Neurological Disorder.
- All the professionals always have empathy
- The way I gain access to a psychiatrist has changed so it's a little unclear who I sit under
- Things can always improve, it is easier not being in the home where I was previously, as before I would always have appointments made for me without being told, now I can do it alone when it suits me.
- I don't feel the doctor understands me or my health conditions
- I think the system is broken, [service] is in a sad state and I think more visual awareness training needs to be done with staff, I've noticed that some of the staff I have dealt with could do with more visual awareness training.
- Have no ongoing health care for any services apart from annual check from GP
- I'm probably more very happy than a little happy but I wouldn't say I was totally happy
- I have had issues with GP's receptionists and them making appointments without explaining why appointments are made, without explaining any more than "dr X requested it" then when I have anxiously explained that they shouldn't just make appointments and send me a text giving me no choice they have reported me to the doctor and I’ve ended up saying "I'm sorry I'm autistic you can't just make appointments with no regard for my routine"
- I had a nurse for preop a year ago who had no understanding of Autism and medicalised it, and despite my diagnosis being on the records at no point have I been referred to the Autism liaison nurse

- That said I had an operation in August, I and my step dad were very impressed with everything
- I prefer face to face appointments, not telephone appointments.
- I get help for my injections
- If I wasn't happy, I would tell them- the surgery treated me well and I was in and out
- When I’m able to be seen by them, they are good. But being able to get an appointment is difficult. What I dislike is that if your illness is invisible, they actually write on your notes “does not appear to have anything wrong “. That’s before they have taken a history or examined you!
- There has been a significant change over the last few years in regular appointments and preventative care offered for people living with long term conditions.
- Need more help understanding
- I had wisdom teeth out and I went to hospital and they were so nice they let me take my teddy bear.
- I feel like I receive little support for my chronic illness and am pretty much left to get on with it myself.
- Many different interactions with different levels of service providers, between the mental health system we have in place and doctor surgery’s every time I’ve felt let down and failed, it has left me in a predicament where as an adult I still struggle because I never got the help I needed when I needed it. A big fault was not being intercepted at an early age after it was clear by professionals involved, I most certainly was not ok. One service (I was 9/10 years old) was the only service I ever felt helped me it was a charity that was discontinued due to lack of funding.. there is no specified support for particular illnesses, so for a diagnosis of “borderline personality disorder” there generally isn’t hardly any support personally for this. There isn’t much if any support for adults that went through abuse as children so therefore we have children suffering their childhood being abused then adulthood ill because I didn’t have the support there when it was supposed to be. I have had many years under multiple different sectors of the mental health system and have been tossed from pillar to post, the only times I have felt fully listened to and supported was by 2

particular mental health workers who went above and beyond and showed their passion to help people like me. Unfortunately, again the inconsistency of support means I didn’t have those two helpful workers for very long. Over the years I have had over 20 mental health support workers or doctors etc.. it’s so hard living with this condition knowing we’re treated differently due to stigma or lack of awareness or lack of staff. It’s always an excuse as to why I haven’t received what I was due or needed at the time and I speak from my own personal experience and the experience of family and friends around me. Please we need to do better!

- It varies - the CLDT in [town] is great and I feel really supported, [Service] fund my care and they are very hard to reach and talk to someone. The GP is good with me and teams in the hospital vary about how much they know about reasonable adjustments.



Please explain your answer:

61 responses

- I have received help from work as I had two sessions with different psychologists - one was great but the first one not so good. I have been trying to find a local place that does CBT or that I can go on a course about but this doesn’t seem to be available at this time.
- All the mental health support I get is from my mother; therefore I don't need any support from the [service].
- Very long wait times

- There is little support for lower support needs autistic people in Gloucestershire. I'm amazed no one ever checks on me considering the higher risks of self harm amongst the autistic community.
- See previous answer
- I am getting some mental health support, but it is such a battle to get it and my previous experience was so bad that I'm very wary about the support I'm going to get now. My experience of mental health professionals is that they lack in self-awareness, awareness of how institutionalised they are and they have a very narrow view of MH patients as lacking insight, lacking resilience, being dysregulated etc - there's no nuance or attempt to understand people as individuals.
- I had CBT with [service] including intensive but it didn't help. I needed ongoing counselling (which I was told I would have to access privately) and other forms of support not more and more CBT.
- Can't get any support or help fed up being assessed then dropped or palmed off with contact [helpline] or similar and crisis team say they are unable to help me so I'm left in limbo and scared
- There aren't services for people like me who care for a child/ children with SEND who have behaviour that challenges / are violent. Talk services won’t support me until "things calm down and you are able to complete the work / prep for sessions". I have been under the crisis team previously who helped but I was extremely vulnerable and was being beaten by my son and no one could help me with my mental health
- I recently accessed 1:1 CBT through (I think) [service]. It was very much a box ticking exercise and not very personal. As a result I’m not clear as to whether it really assisted.
- There feels like there’s no support for mental health. I haven’t had much interaction with a lot of services however I never hear good things about them. I tried CBT talking therapies, and although it was helpful to see a different perspective it wasn’t very impactful. Option to seek more support if CBT hadn’t helped but I felt like there was no point
- Again, pills offered other than talking therapy & understanding

- I got my family if I need help
- Health care professionals great but there is no long-term support. Resources need to be available for continued support
- I feel alone and neglected. I have to deal with my condition by myself.
- I do get a bit of anxiety. If I need to, I would talk to counsellor. When my nan goes, I'll be terrible. I try to keep positive. I would ask the GP or the MH clinic for help.
- I haven't found the crisis team very helpful at all
- There is none
- I have diagnosis of Rheumatoid Arthritis which can be very debilitating as is the side effects from the horrible chemo medication I am on to try to control it. I have to work full time as I have children to provide for and my ex-husband isn't involved, but it's hard. Really hard some days! Even my children don't get it as the disability is invisible and so they just think 'Mum is moaning again.' I also have Idiopathic Intracranial Hypertension which increases the pressure in my brain and this causes intense pain, fatigue, dizzy spells etc and can cause blindness, visual issues. Fortunately, having Covid has improved the frequency of the IIH episodes but I feel exhausted from fighting just to have a normal life every day, a normal life of working really hard, managing a team and running a home and being a sole parent. Nothing exciting or anything! This leaves no energy for fun things or anything beneficial mentally (as well as physically) as I'm just too exhausted. I try to get in nature with my dogs (if I'm physically able) as this helps my mental health but I really don't think that there is sufficient consideration or support for people with RA and their mental and emotional health which can be severely impacted by having this condition and being limited due to the nasty medication needed to manage it.
- Do see a counsellor
- In hospital I really struggled with feelings of despair and would have liked to have been able to talk to someone about my feeling. After leaving hospital I was signposted to people and activities that would help my mental health and my overall wellbeing.
- I get lonely. I've got no family. I live with my mum.

- I was doing ok with a new treatment then we ran out of sessions and no more could be offered.
- Support for mental health is mixed. I have received both good and bad support for mental health. The Crisis Team can be unreliable through their phone service. Mental Health nurses have little understanding about autism linked to mental health conditions which means that they do not understand the links. Note taking between the Recovery and Crisis services seems to be really good. I would say that the support services offered are not always accessible if you live on the border. I have had to explain to mental health staff the condition of PMDD, as many do not know what it means, it is also common for people on the autism spectrum. This is hard, as it has been difficult to manage and health workers do not know the best way to help. I had an amazing experience with a therapist from a Talking Therapies service, she offered me trauma therapy for PTSD. She made sure that the therapy was tailored to my needs and closed down my thought processes between each session. I wasn't given homework as such but thoughts to remind myself of through the week when things got difficult. I would say mental health care is definitely improving. There is also a gap in support for transitions between children's mental health services and adults. The lack of support can also make mental health conditions worse. It can be harder for an autistic person to adjust.
- I've not felt the need to, I could go through the GP if I wanted to.
- I have free access to mental health support through my employer, but I have not utilised it
- Just medication, it works
- Very good, I do dance on a Monday
- Being hard to get GP appointment I haven't been able to talk to anyone about it. When I spoke to a nurse she just replied "aww bless" and carried on.
- As said I no longer am on any Mental Health waiting list as I went privately and am now doing really well - my condition is physical
- I don’t think there is a lot of face-to-face support, especially when you’re unable to go out and about
- Sometimes the lack of access to counselling / talking therapy can contribute to low moods

- There is no support I am aware of.
- When I’ve needed support I've had to wait for it but the support has been good.
- The threshold for getting mental health care is too high. You have to be very depressed to get help when needed
- People ask me if I'm alright and take me out if I need to. They try to help but might not be able to immediately. There is counselling available but they don't actually help, they give you the tools to do it.
- I think some is there if needed, but I don't want to bother them if not absolutely necessary.
- I don't think my mental health is really considered
- I’ve been in out of mental health support service since I was 18. I’ve had multiple sets of talking and art therapy, I found that from the age of 18 to 25 there were more things in place and I was able to access Support more easily however after the age of 25 things just kind of filtered away and when I asked for support nothing was really given.
- Since the age of 26 (7years) I’ve been through the cycle with going through my GP to get support and be referred to [service] 4 times but have not actually been able to receive the support I need to fully manage my mental health.
- Due to my physical health condition and chaotic home life I’ve not been able to access the treatment I need for my mental health, for a long time I’ve been told I need CBT however actually getting this has been challenging, the first few times I went through the cycle. I was told that there were a group CBT sessions that I could be referred to however they did not do it in the end as they felt that my hearing impairment would mean I wasn’t able to interact with the group, they also felt that at the time I needed more 1:1 support before transitioning to a group however that was not available.
- On another cycle round the referral system, they did get authorisation to have one-to-one CBT but I was due to have an operation which would have a very long recovery time a few weeks into the course so I was told to come back when I was recovered, they were not able to keep my place open as I’ve had no idea how

long the recovery would be (we knew I would be in hospital for three weeks and the recovery would be many months).

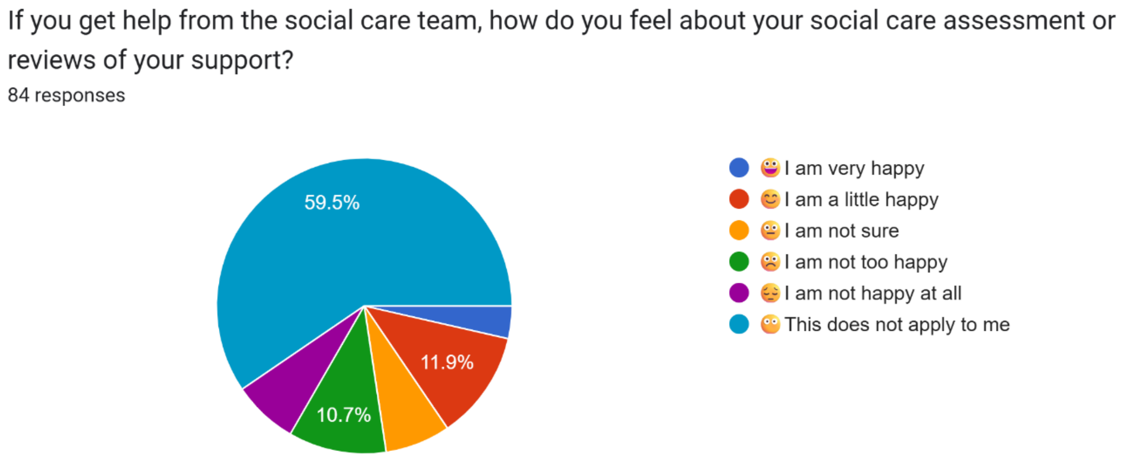
- In the past I've been also been told that I can't start CBT because life at home is too chaotic (I need staff awake with me 24 hours a day) getting a stable care team with consistent faces has been almost impossible, this was a massive problem. On top of Staffing issues I had to deal with multiple health diagnoses and their side effects, managing my home finances and the usual challenges that adults face in life…due to all of these things my life is never going to be 100% stable and consistent as there are just too many things to take into account. I did try to explain this to the person but they felt that it was not right to start CBT when there was so much chaos and uncertainty in my life, they told me to come back when things were a little bit more settled. Whilst I understand they think it's best to do these treatments when people are feeling safe and secure due to the above the reality that's never going to happen for me. Things have phases where they are slightly better but staffing is always a worry due to my complete dependence on other people. I feel some adjustments could have been made to accommodate my needs. About a year after being told I could not do CBT because of my care situation, I decided to try again however again we were not able to do the treatment, this time we were specifically looking at me feeling unsafe and anxious at night times, we were talking through what was kind of real risk and what was mentally feeling like a risk. I use breathing support at night and there are real risks involved with this, and if someone were not to notice me when I was sick there was a risk of death (whilst this is unlikely to happen it is still a risk). The therapist is working with me thought it was morally wrong to try and change my thinking to tell me that I was not at risk at night when there was this real risk hanging over me. They told me to look into talking therapies and gave me a list of organisations and sent me on my way. I did not follow through with looking at these agencies because I did not fully understand how these agencies worked, firstly I knew I would have to pay. My financial situation was not best but also, I did not know whether the people I was talking to were trained and skilled enough to deal with hearing the things that I wanted to talk about. I had heard that some agencies use people that have done a 1- or 2-day course on counselling and I felt this was not enough to deal with someone who has complex PTSD due to witnessing and being on the receiving ends of quite brutal treatment as child. On my last cycle round the system, I begged not to be transferred straight to [service] when I spoke to the doctor, they had recently employed a mental health care professional practice so I spoke to them, they seemed very understanding and knowledgeable. They felt that I possibly needed to change medication but they said that they felt I needed more than that as well, they were very understanding of the fact that [service] had failed me in the past and said that I possibly needed something that [service] could not provide, they said they were going to do an MDT meeting (which happened every week). After hearing nothing for three weeks, I rang the GP practice and was told that my note said to carry on with current course of treatment and review in 8 weeks. I was very confused as I've been on my current course of treatment for many years and I'd gone to the doctors because I felt things were getting worse so I don't know why they felt it was reasonable to just leave me and say they were going to review in 8 weeks. I asked for another appointment or for someone to speak to this mental health professional and let me know what was going on. They said they would call me back but I heard nothing and a couple of weeks later I received a letter from [service] saying I've been to referred to them and that there was a standard wait of several months before I would be seen. At first things seemed more promising it with [service] as they were standing that a lot of my problems stemmed from my situation and they were actively helping me to get this resolved, we were waiting to hear back from someone who was proving difficult to get hold of. I didn't hear anything for several months, when I rang again I was told the person I need to speak to was on leave, I rang again a few weeks later I was told my case have been closed and to go back to my GP. I did not bother going back to my GP until things were really bad because I knew what would happen, I've now been waiting always 11 weeks for a preliminary appointment with the GP.

- There is little support available it's not enough

- My GP is very supportive of my MH issues - my Employer isn’t
- I don't require mental health support.
- I don't get any help with my mental health unless I ring up the Crisis Team. They don't really help and I don't understand them all the time.
- Because my family help me with the correct medication
- I am happy because I have an understanding therapist
- While I’ve suffered a lot of pain, I did have a wobble and got upset, but the professional I saw understood the need to support me and my feelings which helped me to give a holistic representation and I felt accepted. If you have to give up work and accept benefits for financial support it’s hard to feel understood
- We have support at the [service] for mental health, they said I couldn’t go anymore because I don't have any MH problems anymore. My friends help me to be calmer and be less stressed.
- It is very difficult when people die here
- Very difficult to access the service, really long waiting list, counselling only available privately at huge expense.
- The treatment I have has is great when I get it but the waiting times are long and also treatment programmes end but I will always have my brain.
- Because I am autistic, there doesn't seem to be any mental health support for me
- I'm not sure where to go for support, and it's a long waiting list. I feel really low at the moment and I don't know where to go for help, if you go to GP you have to go onto a waiting list. When you get the call to say you're being spoken to you feel better by then.
- Have never been assessed for my mental health since leaving rehab in 2015
- I’m mainly self-supported and haven't called on health services for that
- My diabetic nurses are supportive
- I feel ok about it; I got help quite a while ago. They can help me with my mental health at my local surgery.
- I've had 1 or 2 problems before and they were really quick to get me help but I haven't used them in ages, if I needed more help,

then it would take longer. There are always people in the home that I can go to.

- They think I must be ‘depressed’ because I am anxious, my anxiety is due to various aspects of my condition, eg I have IBS and Diverticulitis which makes me anxious when I’m socialising (always have to know where there is a toilet).
- I am rarely asked about my mental health regardless of having a long-term condition which does at times impact my mental health.
- I don't know if they believe me, they haven't believed me in the past.
- My GP surgery are quite good at prioritising when issues arise with my mental health.
- The support I have in place is family and friends when I turn to mental health services I’m still aware of major problems in the system. So as far as support goes I’ve had to make my own
- CLDT are really good


If you get help from the social care team, how do you feel about your social care assessment or reviews of your support?

84 responses

Please explain your answer

36 responses

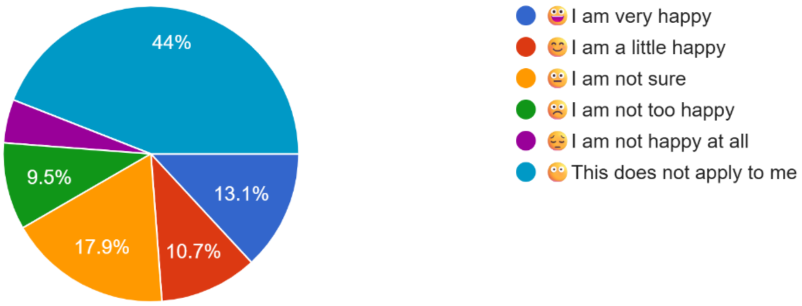
- I was assessed but they refused to give any support because I didn't meet their threshold.
- I don't have any support.
- I've had an assessment and getting a few grab rails etc, but I need more support. The support I need doesn't seem to be available as I am not so bad all of the time.
- Refuse to help me, say to use my PIP
- I do not have access to an adult social worker but need one. My child has support from [service] but staff turnover is so great that we are having to prove my sons condition and that we as a family meet the criteria and need for the respite even though we have been awarded previously. It makes me feel so vulnerable and triggers the past distress and trauma of having to fight to get this help in the first place. Also my child does not have the correct support he needs. He is a high needs child and social care do not have any support for overnights at the weekend for a child with his level of behaviour. So, we are left with care that isn't quite right for him, and allows us to just about manage, however if any of the placements / PA hours are missed it is both dangerous and detrimental to both mine and my child’s mental health. Social care does not provide anywhere near enough things for families like ours and it makes us feel ostracized from our own community or families with SEND.
- I've seen a social worker about my money, they can support me if I need help
- The system is very slow we had to be homeless to get support even though we knew there was going to be a problem months before problems arose, this is backwards and more costly in the long run for both the providers and the clients.
- My social worker is quite good. She writes notes down and goes through what I do. She doesn't rush things.
- I am happy with the support I have got from social care now, but it has been difficult to get there and I have had bad experiences with Adult Social Care in the past.
- Currently I have no one and no visits from anyone.
- They are sorting out stuff for me at the moment.

- This does not apply to me, but I am a social worker who conducts social care needs/assessments - and it is evident that there is a growing need for our services but less and less professionals in the occupation
- Haven't had one for a while but it was fine, just a lot of paperwork
- I don't talk to them a lot, I have more support from my family
- No regular contact, feels very impersonal and 'tick box'.
- No support offered by [service]
- I had a carers assessment but no actions were taken afterwards
- Haven't needed one, but they did come to see me last year to see if I did need one. The social worker would be there if it went bad
- It's not enough
- My care is funded due to requiring clinically trained staff for some areas of my- if applicable I can share my views about this
- I've got nobody. I'd like somebody like a carer even if its once a week. I've not had a social care assessment.
- I don't get help from social care
- I am happy because it easy to access
- I have a carer to help with cleaning and we go to Tesco’s to do shopping, it makes me very happy.
- They keep changing my social worker, so I don't have the same.
- I'm unable to get a grant for adaptations as I live in a static caravan, deemed not to be my main residence when I live there 365 days a year. I need a solid surface from my steroids to the road, was £150 over the £1k budget and not allowed to top-up, so received nothing. Cannot get a [service] electric wheelchair as steps to caravan.
- I don't qualify/ meet the criteria for help from social care or I have never been referred.
- It is difficult to get hold of them and then knowing what to do. I have been having problems with this recently due to my overhead hoist being broken and having long delays in getting a new one.
- I am very concerned about social care in this country because I've had to deal with it with members of my family, I'm concerned that if I did need to use it, it wouldn't be there.

- Not had my social care assessed since moving into independent living accommodation. My care is done by my mother who is now 74 and I have no back up plan in place if she is unwell.
- If I need to speak to them I know how to, I last spoke to them a year and a half ago. I want to be able to speak to the same person.
- What little social care I have received has been excellent; but it’s hard to find out what is available.
- If they are coming they don't tell me when and waiting does my head in, it happens a lot.
- I wish I had this kind of support.
- I think these assessments and reviews are necessary but maybe it could be less about what professionals think is best for us and more about individuals needs on a care plan
- Funded

How do you feel about getting advocacy support if you feel you need it? Advocacy is speaking up for yourself or asking other people to speak up for you.

84 responses



Please explain your answer

42 responses

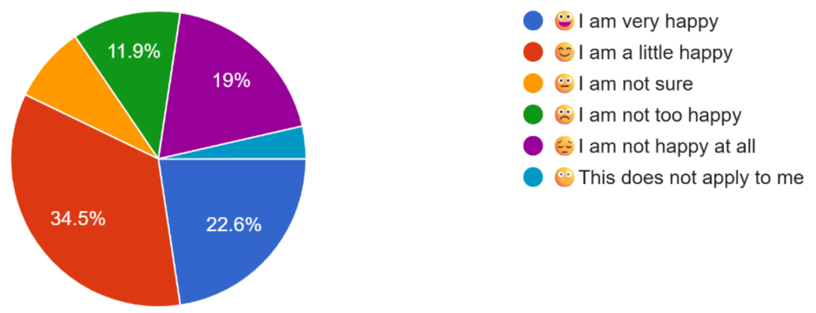
- I feel like my mum does a good job of it, but I wouldn't know how to go about asking someone else to do it.
- I didn't know it was available
- I wasn't aware this was a thing.

- I'm mostly able to advocate for myself but to what end? If the services and support aren't going to be offered, then no amount of advocacy will help.
- Don't even know where to get this support from
- I am currently looking for an advocate, but it has been very hard to find one.
- I find I can act as an advocate for others but struggle to advocate for myself. I wouldn’t trust staff to advocate for me but I would trust a couple of people I know personally
- I would use family; it is important that I have this.
- We need support with day-to-day admin, this is not available
- It's important to listen to the voice of people with learning disabilities and autism. My work helps with this, we discuss it a lot.
- I have a supportive family and I know that the advocacy service at [service] are there for support if needed.
- Fortunately, I have both my husband and sister who advocate for me
- I speak up for myself. I do my best.
- I have never been offered advocacy help.
- I work alongside advocates, so I am familiar with their role and remit.
- I don't understand what advocacy is- people need to be told more about this.
- I am unsure how I feel about advocacy it I'm honest
- I feel very comfortable with expressing my opinion when necessary
- I'm not aware of any
- I'm able to self-advocate thankfully
- I don't know how I feel about it
- I got support and applying for an advocate through work, this is for short term advocacy to support with a specific goal. My advocate is going to support me to access more longer term advocacy, to support me with situations with my ongoing care difficulties as they arise
- I don’t know how to get this help

- I think it is very good for patients who are anxious or nervous or just don’t know how to navigate their way through some of the processes involved
- I'm nervous to speak up for myself.
- My family help me
- It is not easily accessible
- I can talk for myself and have PA hours
- I am not good at asking for help.
- It is hugely draining and triggering having to self-advocate. No professional support. Have to rely on limited charitable support.
- Because of the LD partnership board being here for 12 years and because of all my colleagues.
- I sometimes feel I could do with it, but I wouldn't know how to access it.
- Similar to above question. My mother is my advocate, I am unable to read write or speak apart from phrases since my stroke in 2018. I do not know what I would do if my mother was taken ill. Nobody has suggested how I would get any practical day to day help if she wasn't here. (my mother is writing this for me)
- I use speak up groups
- My family advocate for me.
- I can speak up for myself, if I do need people to, I will ask.
- It is offered here at the home for some people but not everyone, so some people get left out.
- I’m rubbish at speaking up for myself and am not sure who can speak/ find things out for me.
- I don't have support to say what I want to say.
- I don't know how to go about getting that support.
- Luckily for me I am very outspoken (unfortunately leading to labels as “demanding and aggressive”) I feel like I can speak up for myself however I have not ever felt like I have had a professional advocate for me I’ve always had to advocate for myself.
- Family advocate for me

How do you feel about your finances? This might include the money you have coming in, bills or debts.

84 responses



Please explain your answer

63 responses

- I'm employed
- Through no fault of my own I had a wage reduction at work and everything just seems to be getting more and more expensive
- Scared and confused. I hate dealing with money so I have to have my mother deal with all that. But we seem to have enough to live on.
- I'm ok now but feel worried about the future and benefit assessments.
- I am in a difficult situation where I cannot work enough to earn the money I need to cover my outgoings (which aren't excessive) because my disability means I can only work limited hours and I can't manage a role that has more responsibility and therefore pays more. I have been turned down for PIP and I am not considered to have a low income so I'm not eligible for any other help. The DWP have assessed me to only need £900 a month to live on, which is extremely low. My only options are to sell my house (you need money to sell your house, and I also don't want to!) or work so many hours that I get so ill I cannot work at all!
- I get PIP and UC. I am unable to work although I'd love to. Simply getting washed and dressed is often too much for me, so a job is beyond me. To maintain my health at a level I feel it's worth staying alive, I need to pay for therapies and have food delivered. I

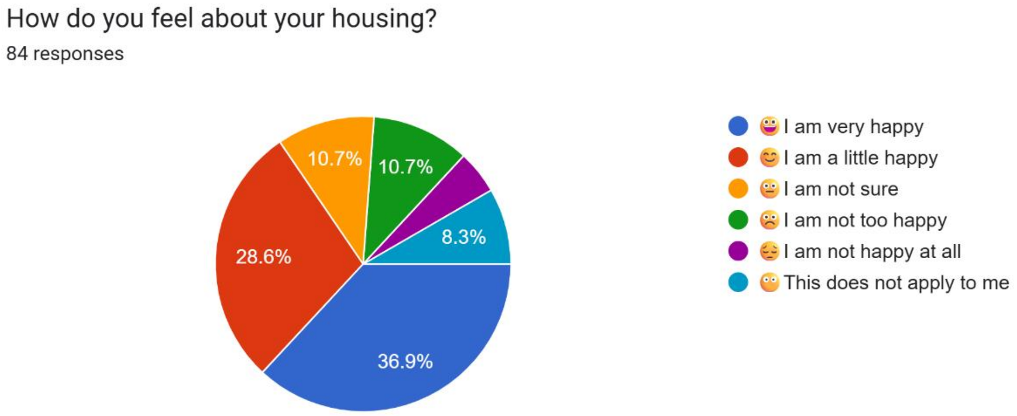
struggle to make ends meet. I can't maintain my home (I own it... it's a cheap house so I can't downsize) and I'm afraid to improve health wise as benefits could be taken away leaving me still unable to work but also unable to survive.

- Really struggling to cover what I need everything is so expensive and I can't afford extras and go without basics
- We are in financial distress as a family, and we frequently are unable to pay our bills. We hope this will change when the flat I own sells, but it is just about trying to keep going until then.
- I have to work part time which affects my ability to earn good money
- I have struggled financially for years, tried to apply for personal independence payments and was denied three times. Awaiting a tribunal. The assessment report I was sent was disgustingly dismissive and quite literally stated I must not experience difficulties with my diet and eating because I had no official diagnosis of an eating disorder. They said because I can drive and work I must not need support
- I have no issues with my finances - all care has been covered, which has been very useful otherwise I would not be able to afford it
- What I get from pip is minimal, I can't work so it doesn't cover that fact a proper wage
- Having a PA helps, and someone looks after my money so I have money to go shopping
- My family help me with it
- There is no transparency, it is impossible to make decisions because we do not know how it will affect our benefits, which makes getting off of benefits very hard
- At home I started doing bank transfers with help. Online banking is complicated. I have help with my budget especially if I go on holiday.
- Hard to find suitable work without discrimination and hard to achieve to health benefits for M.E/CFS
- I and my partner have enough to live on.
- My sister helps me with this.

- I have enough coming with my benefits to manage but I worry about losing them
- I work full time
- Cold temperatures equals severe pain for me. I have Rheumatoid Arthritis and it is important for me to be warm as cold temperatures make my joints hurt considerably more. However, I am struggling to have the heating on more than an hour or two a day as the utility bills are now so expensive. My joint electric and gas bill has increased by £114 pcm to £310 pcm in less than 2 years. My salary has not increased by this much and with the general cost of living increases, supermarket hikes and running a car etc it is very worrying. I have no debts other than my credit card which I pay off each month, however my boiler broke down over Christmas and it is just about working now with a temporary fix but I know I will need a new boiler. I have no idea how I will afford this. I have an intense job, I work long hours and for flexibility I work 3 days a week from home and 2 in the office to enable me to conduct the school run in my lunch hour. This convenience may have to be forfeited as I can't heat my home to work in it!
- Initially I was unaware as a self-employed person that I could claim benefit so being ill was a real worry. Now that I receive all the benefits available, I feel ok about my finances.
- Mum pays the bills and I have my own money.
- I manage ok.
- All is good, I don't have any problems in this area.
- I'm responsible for budgeting.
- Not the best salary as a social worker
- My dad sorts my benefits out and my sister helps too
- I am doing okay but can't afford luxurious things like taking therapy
- I have help with my benefits
- I am on Universal Credit and PIP with the mobility award so for now I get my housing and C Tax paid for and PIP helps with having a car and my general living although living alone is hard with Utility Bills and the cost of living as it is.

- I know my sick pay will run out and put me under financial pressure. The PIP system doesn’t pay enough and takes a long time to come together
- I am financially secure at the current time
- I'm ok day to day but worry about big bills such as replacing my powered wheelchair when it wears out
- No concerns recently, my only concerns are my phone and transport bills. It takes the pressure off living in a home like this.
- My finances aren't so good
- I feel I manage my finances well. My brother supports me with this when I am ill or in hospital
- I’m moving to universal credit and scared
- Because I ended up having a pay cut as a result of going off sick with MH issues
- Clearer understanding of ESA, savings and winter fuel allowance.
- Someone is supposed to be helping me work this out.
- I have enough money to meet my needs
- I am able to afford my daily need with the help of my family members
- My rent comes out my bank the only thing I have to pay is my electric. I have 20 pounds for spending.
- I don't have to worry about most bills here. I pay for my own telephone bills and people help support this
- I worry that my daughter will have to pay for my care.
- I am really struggling to afford to live, with no prospect of being able to work again. Traumatic applying for benefits, was successfully supported by [service]. Having to go to tribunal to secure PIP enhanced care. Very worried about what changes will be made to benefits to get people back to work. My condition is severely limiting.
- I don't normally pay bills, my parents do.
- I am unsure if the finances I share with my husband are fair
- I'm responsible for budgeting
- My partner can't work, but because we are a couple they only get a small amount of benefit.

- I understand money and I have direct debits set up. But again, if my mother was not here I would not be able to fill out forms for benefits reviews or set up or change a direct debit even though I understand what they are and how much I pay.
- I live within my means. I’m lucky to have a job, every one worries about money but I’m reasonably secure
- My family help with my finances.
- [Service] pay for my bills
- I’m a born worrier, so am always anxious about finance and who might be the person to approach for help.
- I worry about being able to stay in work and being able to earn a decent wage, if access to healthcare services are severely cut or no longer available in future.
- [Service] look after my money, I have enough money.
- I find it very difficult to understand bills and finances and often find myself in debt with companies because of it.
- Because of my mental health condition, I don’t have a concept of money I don’t realise bills need to be paid as it’s not the forefront of my mind I’m frivolous and don’t trust myself around money at all. I ensure my husband is in control of finances and bills as I have these issues however, I don’t have any independence around this! Also have asked for help numerous times around my struggles at understanding money and it never got anywhere
- Because I don't pay towards my care my budget balances mostly and my parents help


How do you feel about your housing?

84 responses

Please explain your answer

60 responses

- I like where we live - we just need some help but getting trades people (who are reliable) is darn near impossible!
- I like it, it's a nice house, and the family owns it outright, so I feel secure and it is accessible enough right now.
- I'm ok now but worried about long term
- I own my home but would like to move but find the prospect overwhelming
- I am lucky to be able to live with my parents so feel happy to have a comfortable housing situation. However, I am also really unhappy to be in my 30s and not have a more independent housing situation. I am also aware that it is unlikely I will ever be able to do so.
- I want to move to somewhere more suitable, but the cost of a suitable property is outside my price range.
- I like my place but it's isolated and nothing to do and I can't find a suitable place to swap
- We have been so lucky to get a bungalow in my local area. It is just what we need and we are happy here. We could not get a hone based on my sons disabilities and we only moved to silver when my PIP was awarded. This feels really unfair when all services working with a family with SEND say the accommodation

is totally unsuitable, but the [service] won’t take their opinions into account.

- I rent a one-bedroom flat and struggle for money constantly, I’m not able to live with parents or in a house share. I like my flat and like living independently however it is expensive
- I get help from my family
- We have been provided with social housing which is better than our rented property
- I live in a small property and my mental health sometimes requires me to be alone which I can’t afford.
- My cat likes playing in the fields near by. I do my own cooking. In the future I might do supported living.
- The housing is good though the service from the [service] is very variable.
- I live in the same house I’ve been in since I was a boy with my brother
- I live in a 2 bed ground floor flat which I'm happy with
- I am happy now but have just had a long battle with the [service] around making some structural changes to the property (at my own expense). I live in a Shared Ownership property.
- My house meets current needs but is unlikely to meet future ones
- My house was built in the 1970's. It is cold, draughty and doesn't retain any heat. There is no loft insulation or cavity wall insulation, and I have asked for a grant to install these, still waiting weeks on for a response. It desperately needs insulation as it is only warm if it is above 5 degrees outside and I keep the heating on constantly - something I can't afford to do. Because I have 3 children and (before she passed away) I had my Mum living with us, I needed a big enough house to accommodate us all, so size wise it's big but it is in no way efficient at all. I would love to downsize but my adult children are not likely to move out anytime soon - my daughter has a diagnosis of ASD and an executive function age of around 3-4 years so may not ever live independently so I feel stuck somewhere I'm not sure is right for me/us.
- I live in a lovely, rented property.
- I'm alright, it's quiet.

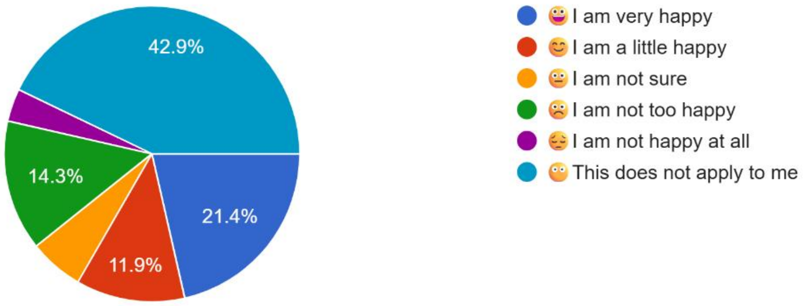
- I am ok with my housing.
- Living at home with parents, looking to move in with partner in 2025/26, It can be hard for a disabled person to get onto the property ladder, especially if they do not work full time.
- Things could always be better
- Difficult to answer in my current housing situation
- I am lucky enough to own my house and have adapted it as needed (mostly funded by me but with some input from the OT). I feel very lucky to have stable housing that meets my needs. I also have gadgets that help me, like robot vacuum cleaner and mop
- Private renting however myself and my husband are close to being able to buy
- I am very fortunate that my Parents own my flat
- I have a mortgage with my husband
- I live in a care home which is appropriate to needs
- I moved into a bungalow a while back & it is great
- Some rooms have a lot of space, some don't. Things will get fixed reasonably fast
- I think I'm trying to survive
- I live in [town] and love the area and my home is comfortable and accessible for me
- I have a ground floor flat through [service], they are generally good and responsive if I need anything in terms of repairs.
- My only issues are that I have to pay communal charges in relation to the cleaning of the block of flats and waste disposal even though I do not use these services. I have to pay this because I am technically part of the block of flats even though my flat is isolated underneath the block, I have tried a few times to explain that I do not use these services however I’ve always been told I have to pay as I’m part of the block. I also have to pay bedroom tax on the second bedroom which is used for medical storage, even though I was told by my occupational therapist when I was looking for flats and when I moved in that I would not have to pay this. I’ve tried several times over the years that I’ve lived in this property to get this changed, but I’m always told that it is just something I have to pay. My partner managed to go through the courts and get an

agreement saying he does not have to pay bedroom tax due to medical storage reasons and his housing association supported him with this. [Service] are unwilling/unable to support me with this.
- I hate where I live, I get hassle off neighbours, landlord keeps threatening legal action and it’s isolating here. Makes my mental health worse but I can’t move been trying over a year
- I live with my husband (and carer) and we own our house so very happy
- I am fortunate to own my own property.
- I'm alright where I live, I've been there a long time.
- I live with my mum and stepdad in a nice house
- I’m happy because I don’t bother with the neighbours and I keep myself to myself.
- I am very cold!
- My static caravan is not very accessible, and energy costs are high. Because I own it, I am low priority for social housing.
- I want my independence back. We are still looking for a house.
- Alot of things need fixing in the house I don't seem to be well enough to do it or/and don't have the time or money. My husband has the money but is saving it and doesn't have the time to fix things in the house.
- Problems with my hoist are an issue
- [Service] is ok but it's constantly trying to get them to do anything, but they are constantly short of money. I'm waiting for something to be repaired and it makes me stressed as I have to keep contacting them and getting them to sort it out.
- I have had issues recently with heating again if my mother was not here I would have idea how to report a fault. My bathroom needs modernising
- I live in social housing and I have been here for 10 years.
- I live with family.
- Ok about that, they help me. I have the odd argument with people there.
- Things could be quicker when fixing things, as they take longer than expected.
- I live in my own home

- I worry about my house being fit for purpose in future should my health deteriorate, and I require more equipment for me to be able to get around.
- No support was given to find new house when my landlord served notice
- I live in my own flat.
- No answer
- We have a ground floor flat with two bedrooms. [Service] would not take in to account my stepson staying with us every other weekend and our daughter not being able to share a room with him.
- I'm happy now, however only since living in this property. For 6 years I suffered abuse and bullying from neighbouring families, at numerous properties. [Service] was such a let down, we had parts taken off our car making it unsafe to drive we had our windows smashed they tried to break into my property whilst I was in it, they set fire to my car whilst we was in bed, then as I moved on, [Service] then moved said neighbours to my street in an entirely different town which then became a bigger issue as the abuse continued after I fought for myself tooth and nail. I've lived in numerous temporary accommodations due to the council not being able to offer the support I so badly needed. I was also left on the phone whilst a member from Stroud council spoke about me to a colleague. I've nothing but disgust for [services] at how they treat occupants with mental health. It's astonishing to me that this day and age people still experience these problems it's sad!! My children haven't been able to settle moving from [different towns].
- They haven't felt settled until now and my eldest child is 13. So, for 13 years I have constantly battled to make sure my kids have a safe home but because of my mental health issues affecting other people there weren't safe and neither was I. We weren't protected by anyone no one helped us we had to help ourselves.
- I own half my own home with a [service] owning the other half

How do you feel about getting support to find or maintain paid work or voluntary work?

84 responses



Please explain your answer

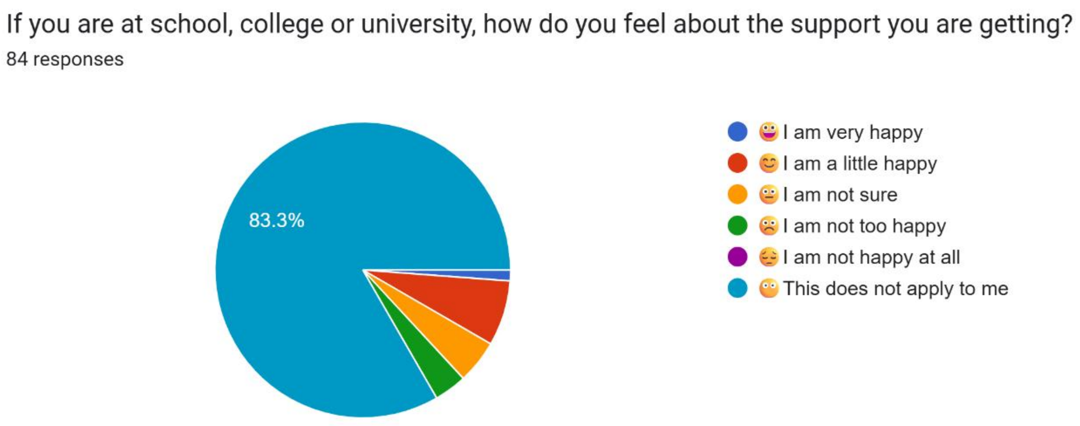
46 responses

- I don't know how to answer this question as no amount of support would make me able to do actual work.
- I am a director of a local charity and put as much into it as I am able.
- Signed off for life from working
- I am still waiting for [service] to get back to us for support for me. My health conditions are such that I have had to step down from my position and change my workload. I have to get support from my colleagues to complete my emails etc. It makes me feel like a burden and has affected my confidence in my abilities. I feel distressed that I cannot do what I used to do and feel I could with support with administrative tasks and physical support at meetings. So the wait for support has greatly impacted me.
- I am in full time employment
- I feel there would be nothing I could do as chronic pain & fibromyalgia won't allow me to stand or sit for long. Tiredness & anxiety makes me less able to concentrate also
- I help out in the home with the coffee mornings. I have been supported in the home but not outside of the home.

- There’s no support at all!
- If I wanted to leave my job I would go to the [service] for help or my carers can help. Job websites are not easy to find or suitable for people with learning disabilities.
- The guy in the [service] was very informative about what information I needed to provide and places I could contact to get help with access to work. As for work I found that by myself
- Again I have no help in this area.
- I find that I don't need support however in the past when I have needed it I was offered an Employ Autism Scheme through [service]and my University where by they sourced an apprenticeship for me.
- I found everything myself, I do voluntary work but it's not been easy.
- I feel this is an easy area for me to maintain
- I am in work
- I am in full time paid employment and my work are amazing at putting in reasonable adjustments
- There is no additional support outside of the home. In the home I help with the post which is good.
- I get no support at all - no one has ever checked from the DWP - although I have done Voluntary work for the last 2 years I am now searching myself for a part time job - but there aren't many around.
- I have a supportive employer
- I am retired on ill health grounds but work part time and voluntarily which I enjoy and this helps with mental health and wellbeing. I would not feel comfortable if I had to rely on works income to meet my day-to-day needs
- I get great support from [service]
- I have done work before but there is no one to take me there, I was doing office work and sometimes I couldn't go as it was reliant on other people, as I can't always go on my own.
- It's not easy but I find it a bit interesting so I can't say
- I’ve been employed with [organisation] since 2019, I work as an expert by experience at the [organisation] and do some voluntary work with the [organisation].

- My employers are great & support me to work on various projects as well as offering opportunities to work in either paid or voluntary positions on other teams as well as letting us know of other organisations that have opportunities that we may be interested in.
- If anything changes with my health or needs, they are really accommodating and ensure that anything that needs to be put in place is done quickly and efficiently.
- The University are often offering experts by experience the chance to do tasks related to certain courses or the opportunity to be involved in interviewing potential students who are looking to gain a place on any of the health and social care related courses, sometimes these opportunities are sometimes in a voluntary capacity and other times they are paid. I have a good relationship with the [specific team] and I’ve done some guest lecturing on their course and have some more coming up which is really exciting.
- I am on permitted work
- My dad supports me with this
- Lack of employment because of my health condition
- a volunteer at [organisation] and the [organisation]. I’ve been finding jobs to do without asking.
- I do voluntary work around the house, helping with the tea towels.
- I am unable to work in any capacity.
- I have a job and I help other people to work too. I give help and advice.
- I have a job but promotion or getting another job is difficult
- Everything that I'm doing, I have found and done myself. There is not enough information on how working will impact your benefits. I worked for [organisation] doing paid work and the support could have been better.
- My work helps me maintain my job
- I was working, but then I lost my job. I have been doing something volunteering and I don't think I can get into paid work. I am quite concerned about this, it's hard for visually impaired people to find work.
- I have no use right arm and slight limp right leg. Unable to read or write and limited speech.

- I'm in long term paid employment - a job I found for myself.
- Family help with this.
- I’ve got work at [organisation]
- Not always well supported, for example when I previously worked with [organisation]
- I’m retired
- I'm aware of several organisations providing support with this but from past experience the help offered was pitched at one level......and wasn't pitched for people from a range of backgrounds/abilities.
- No answer
- I mainly work freelance and am lucky that the non-freelance work I have is through a company who is very understanding when it comes to my medical needs.
- I’d love to do anything like this I’m here for the experiences
- My care team help me deliver leaflets 4 times a year around where I live and we go out for a meal with the money


If you are at school, college or university, how do you feel about the support you are getting?

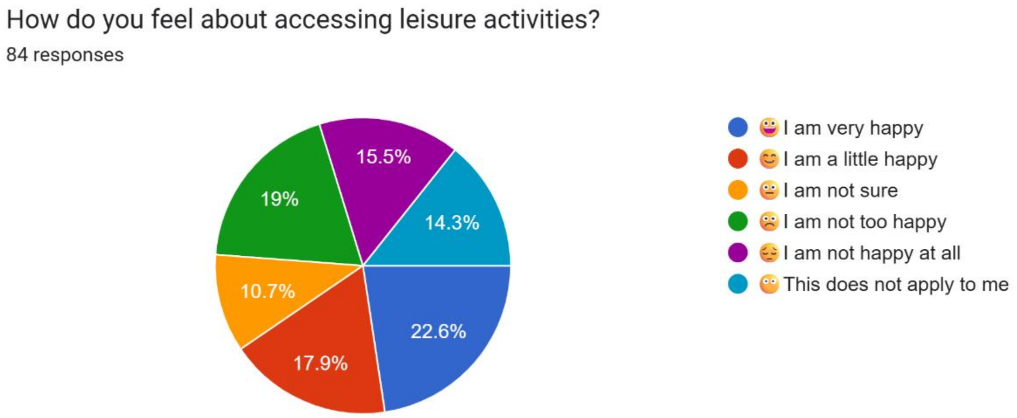
84 responses

Please explain your answer

12 responses

- I was home educated from childhood so I have continued learning independently.
- Na

- I'm unsure what support I need/would be beneficial, I'm also not sure what support is on offer. I get extended time for exams because of my adhd but I don't ever need that extra time
- I work and I study, there is theoretical support for students, but there is a lack of understanding of impacts of a disability
- Not applicable
- I used to do a photography course at the star college which was really good and accessible.
- Not recently, not been available.
- I am doing a course through [service] in Gloucestershire, they are currently working with me to try and figure out how best to support me and make sure I can complete the assignments with this little stress as possible.
- I don't go to school, college or university anymore
- It is accessible but I get discriminated from people
- Too old
- No answer


How do you feel about accessing leisure activities?

84 responses

Please explain your answer

51 responses

- There is nothing that I both want to do and can do. I used to go to a hydrotherapy pool in [town] but it is too far away so we stopped because it was too painful spending that much time in the car. There are no hydrotherapy pools in Gloucestershire that we can use.

- I hardly leave my house except for work
- I struggle with this due to energy. I don't really have the ability to do anything other that work.
- The cost of accessing leisure activities is prohibitive
- Very little around me and the time it takes to travel where there are things are too long for me, I tire easily and my pain is unpredictable also expensive to do or go to any social events
- I cannot access my hobbies or leisure activities in my spare time due to ADHD burnout, long covid / chronic fatigue and flare ups of my other conditions. To live I need to make sure I rest, but this means a lot of the time I am alone at home almost on bed rest.
- I used to pay for the gym and enjoy swimming, however I can’t afford this anymore
- I go to town on my own. I get the bus. My carer would help if I go to the cinema. I go to the cafe on my own.
- Not always physically accessible for my interests
- I have access to all that I need.
- I have had to suspend my gym membership since my Rheumatoid Arthritis diagnosis as I can no longer run (or sometimes walk!) so going to the gym is out. I would like to swim but don't have the energy to get undressed and showered and changed each time. I am determined to do more things for me this year if I can, but with children and a limited budget it is always hard to engage in leisure activities physically, mentally and financially.
- I was referred to [art service] which was brilliant but don't know of any other leisure activities available to me. Obviously, anything that incurs a cost while on benefits is difficult to join
- I go on the bus on my own.
- No help with this at all.
- I don't feel confident at all, or know where to begin. I can get tired really easily. There doesn't seem to be many leisure activities suitable for me in my area.
- Transport around here is a big big issue, the bus only hold 1 wheelchair per bus and they are so infrequent. There are not many wheelchair taxis, and when they are available they are so expensive. There is no room for spontaneity, you have to plan

everything in advance into the day. You have to get off the bus at the wrong stop just to be able to get off the bus.

- Lack of good leisure facilities in the Gloucestershire area that aren’t expensive
- The biggest barrier is attitudes and misconceptions, e.g. being denied entry to pubs and clubs because I am mistaken for being drunk
- I can't afford added luxuries and my chronic illness is getting to the point that I can't do anything after work or the weekends as my priority is resting
- It is difficult without support and there isn't any funding for it.
- I don't use the local ones available and pay to go to a local hotel where I go swimming - well I used to - I haven't been for a few months due to having had surgery and will be going again soon.
- I rely on my husband for lifts, so I can’t socialise without him and it impact my independence. I’m anxious about something happening to me when I am on my own
- I find it very frustrating relying on other people because I can no longer do things for myself that I used to take for granted. I feel all spontaneity has been taken away from me and I have minimal control.
- Nothing autism friendly near me
- Some are ok - eg theatres, days out, country home visits but sports related activities are not for me due my conditions.
- It's easier to do so
- I do not participate in leisure activities very often for multiple reasons: I have very few friends and do not like going out to places that are busy.
- I occasionally go out to eat with my partner (who is also a wheelchair user) and most places are willing to move tables and chairs around to accommodate us. I find that a lot of places have tables that are not wheelchair accessible due to lips or table legs underneath, this can be frustrating, especially if we’ve booked a table and there are not any alternatives around (I find most places have matching tables, so we do not have the option of just switching to a different table). In these situations, we make do as

best we can, in these past I've tried to speak to staff or managers about accessible seating but it never made any difference And ended up taking a lot of energy. Now my partner & I stick to the same few places if eating out.

- Finding toilets that are fully accessible can be an issue as I have a reasonably large electric wheelchair & and I require support from another person. In most places there is simply not enough space for me to turn around in the space so I have to either reverse in or out which can be tricky. There is often barely enough space for the person supporting me to move around my wheelchair and do what is required. Often and there are extra bins or baby changing units taking up space making accessibility difficult for me/us.
- I've noticed in many toilets the emergency pull cords are damaged, tied up or are not the required length. The level of hygiene in may public toilets is also off putting.
- I have to consider toilets when planning leisure activities as many toilets that are described as accessible are not for me purely because of the size and amount of space around my wheelchair, I often make a visit ahead of my planned activity to check out the toilets. If the toilet is not accessible for me or I don't know if it is then I may choose not to go. Or I'd have to know that there is another accessible toilet nearby.
- Finding sensory friendly leisure activities that are interest in me is difficult, indeed finding anywhere that is sensory friendly can be difficult. I've tried a few times to find somewhere for a work social that is sensory friendly but have been unable to find anywhere. There are places to eat where music levels are low so that's not too bad but finding an actual activity that is sensory friendly for adults in Gloucestershire is challenging.
- Cost can be an issue, if going out with a PA, I'm expected to pay for them to access the activity as well. Sometimes there are discounted or free PA tickets but not always.
- Transport can be very challenging for wheelchair users.
- Buses do have designated wheelchair spaces but only one, if there is a bus route where multiple wheelchairs live you often have to wait for a second (or third) bus to come if the first one has already on it which is frustrating and time-consuming, it means you can be

late for an activity or miss it completely because you have spent so long waiting for a bus. Busses can also challenging because the space for wheelchair is not very big (they are designed for manual wheelchair users)it can be difficult to get on especially if the bus Is busy, there are push chairs or people using other forms of walking aids as you have to get them to move or get off to enable you to fit on. I sometimes have to be quite firm & forward with some bus drivers (and other passengers) as they will just tell you there is no space and you'll have to wait, because it's easier then trying to get people to move around, I can be quite firm with drivers and let them know of my rights, but other people are not as confident in doing that as I am.

- Taxis are convenient, however they are very expensive and often this is an issue for disabled people as there is no space in the budget to allow for such luxuries . There are also not very many wheelchair accessible taxis, not many taxi firms actually have wheelchair accessible vehicles available, the ones that do often and have limited times available as the wheelchair taxis are used for school runs meaning you often cannot get it transported at certain times. I know a private wheelchair taxi driver so I'm quite lucky because he has a lot of availability and he is very flexible however he's only one person and it took me years to find him, if he's not available I can struggle to find someone else.
- Community transport schemes are great as they are often much cheaper than taxis however, they still come at a cost, they are also very limited unavailability and only work on weekdays so this can be an issue. Another issue with community transport schemes is you have to pre-book, some of them you can give 24 hours notice (if they have availability) but others need more notice.
- Struggles to find transport can impact on accessing the activities, especially if you spontaneously you would like to go out, as people do
- There is nothing here for people especially disable
- It would be useful to have information on accessible GYMS
- If I had somebody with me I would go out, but I wouldn't go out by myself.
- I feel I am independent to go out with my friends

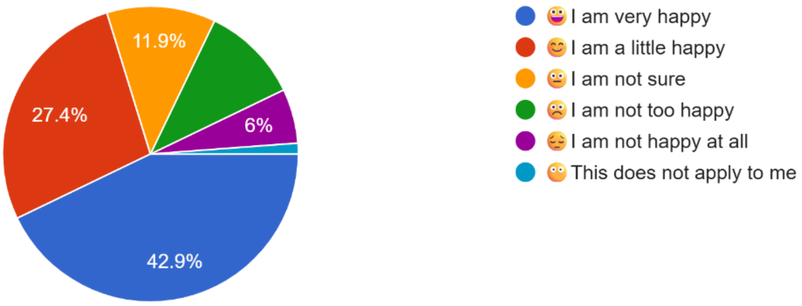
- I am able to access a gym in town due to having a car
- I go swimming, I cycle everywhere. I get the bus to football with my friends. I get to do things I want to do.
- It is very daunting finding social activities.
- I have to run a car as public transport provision is infrequent. Limited accessibility to outdoor leisure except where hard surfacing. Limited accessible toilets at many. Accessible seating at performance venues is often restricted viewing. Some are excellent.
- When I have access to the car I can get to the gym.
- It's always a 50/50 chance with buses if I miss one it makes more sense to walk as there so infrequent. I go to the cinema all the time out in town, anything that is free is fine. It's so hard to get a wheelchair taxi, the DLA doesn't cover this. I can't go to the leisure centre as I wouldn't know where it is, I would have to consider money for not just the lesson, but the transport, having a carer with me.
- I cannot afford this
- It's quite difficult because blind people are not always accepted. There's always a big issue around health and safety, sometimes this puts barriers up. It's very difficult for us to access activities.
- My mother has found leisure activities I can attend and takes me to them as unable to drive
- it’s difficult to access late night or Sunday activities because of public transport, also there is a lack of activities for Neurodiverse LGBTQIA intersection
- I could probably do them but no one has taken me out for a while, no one has taken me out since May this year.
- I'm lucky I've got a PA as I get to go out with a group or on my own. It would be hard if I didn't have my PA as there's not enough funding to support this.
- As a retired person, it’s not easy to find leisure activities I can afford
- More often than not a gym membership/payment is required to be able to access a leisure space that I feel comfortable to go to and

isn't overcrowded, but even then, they can't cater for all my access requirements.

- No groups to join to do leisure activities with disability
- I go shopping.
- No answer
- I don't really have time or energy for leisure activities.
- It used to be terrible to try and find access to these activity’s however I do think it’s got better this day in age you can access more i.e. through the internet or contact through the phone
- There are not things that would suit me like an adult soft play or somewhere I could just run around safely.

How do you feel about being able to have regular contact with friends, family and other people who are important to you?

84 responses



Please explain your answer

51 responses

- Everybody is digital these days so it is easy to keep in touch
- I have enough social contact now but a very small social circle and online only. If something should happen to my three friends I would have nobody but my mother.
- I have no friends and little family
- I'm often too exhausted for social activities. I don't have friends as I can't maintain relationships.
- I struggle with social engagement
- My work role means I have weekly contact with peers. I can only see friends and family during school hours as my child's needs are

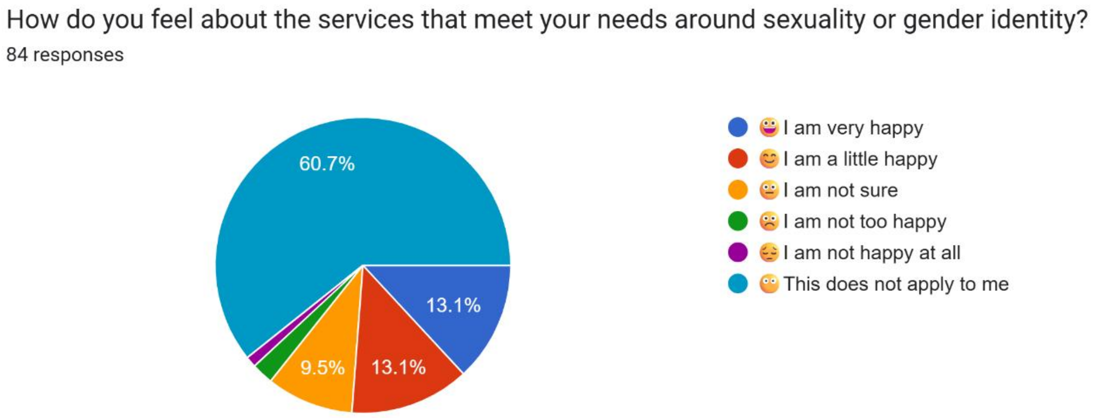
so great that he requires my full attention at all times. I cannot see my family that is further afield because I do not have the option of having enough care for my child who is on a 2:1 ratio at all times. I cannot drive there and back within the hours of respite I have. I am also too tired after a long journey that I need a significant rest before I travel back again.

- I usually feel there’s not enough time to fit in socialising between work, uni and keeping my flat clean etc
- It's important to see family & to get out but find there’s more & more you can't do anymore which has a big effect on your mental health & family commitments
- I have my iPad and I have regular contact with my family.
- I can phone or text them
- This can be very expensive
- I have social anxiety and I need more time to get to use to a new face. I mask most of the time so that I could live a normal life.
- I can see my nan when I want to after work or at the weekends. Sometimes I stay overnight.
- I have local friends
- I get to see my sister every week, she comes first.
- I have good contact with family and friends I go to church and bingo locally
- I have very close friends who, although not local, are always at the end of the phone and we are able to meet as much as possible.
- I am fortunate to have a few good friends who are very supportive of me and are flexible enough to consider my limitations due to my Rheumatoid Arthritis but I have lost a lot of friends because I cannot always join in with group activities. I haven't had a relationship for many years as there is not the time, energy or money to do so. This makes me sad but have to conserve my energy to be able to work and provide for my children.
- I have a very good social network online but I do miss the face to face interaction with people
- I get to see them at the hub.
- I do have people but find the social side very hard due to my autism.

- I am really close to my family and they are a great support as well as my boyfriend however, I find that I don't have many close friends. This has been a recurring theme throughout my life. It takes time to really be open with those around you and for me to feel like I am able to be myself. In the past socialising has felt like a chore.
- I speak to my mum and sister daily as well as my husband being an amazing support. However, I have no friends and socially I struggle with my energy levels
- I talk with my sister
- I do see my family when I can and I do have friends that I see at meetings I go to because I am in recovery from addiction - 2 and half years clean and sober so attend AA and Na meetings where I see people.
- It helps the feeling of normality
- I feel I have lost contact with friends and family because they have to come to me because of the issues of transport and accessibility.
- No friends, little family
- I have a good circle of understanding friends & my family are supportive
- Regular contact via phone and iPad. If I use my iPad I'm assisted as I can't do it on my own.
- I am cool with this
- I do not really have much contact with family but this is my choice.
- I do not really have many friends, the few friends that I do have do not live locally or also have chronic health conditions so are not really able to get about anymore, I would like to meet more people outside of work however I don’t really like the idea you’re going to day centres or clubs. I’m also not very good at talking to others due to anxiety and hearing impairment
- If I had more friends, I would be able to meet them regularly as I have the right care support to do this
- Friends are important to me and we keep in touch by texts, virtual calls and emails. I like the ITV advert about talking to friends but should mention families to keep in touch too.

- I love being with my friends at the Hub, its the only place I get to see them.
- I see them all of the time
- I get discriminated and disrespect
- I have a good circle of friends, I am also able to gain social support from my Buddist practice, chanting as a Member is very important to my holistic life and health
- I call my mum in the mornings. I call my friend, I go to football with friends and have a laugh.
- I use my iPad, iPhone and Alexa to help with this
- It can be exhausting.
- My condition restricts my ability to care for my kids, take part in social activities/meet people. Rely a lot on social media, facetime. Access to public transport is very restricting.
- I get in contact with old school and college friends on Facebook.
- I do not have time for this. If I do have time, I don't have the money to see people.
- My mother speaks to or sees me every day. She takes me to visit my children once fortnight. My sister comes to visit about once a month. I do activities with people but they do not help facilitate me getting to them I again rely on my mother. I would not be able to get on a bus to pursue my interests or see my children who live miles away.
- I can text my mum whenever I need to
- I'm quite introverted and suffer from anxiety.
- A lot of my socialising wouldn't be able to take place without the use of my car. If my health were to deteriorate and I could no longer afford to keep my car or be able to physically drive my car, I don't believe public transport would be able to replace it.
- My dad is coming home for Christmas so I will see him.
- Not being able to walk far means that I would have to take two buses to get to the train station.
- It very much varies on a day-to-day basis. Due to my personality disorder some days I need everyone around me sometimes I need to be alone, so it varies

- My house is really close to my family and where I went to school



How do you feel about the services that meet your needs around sexuality or gender identity?
84 responses

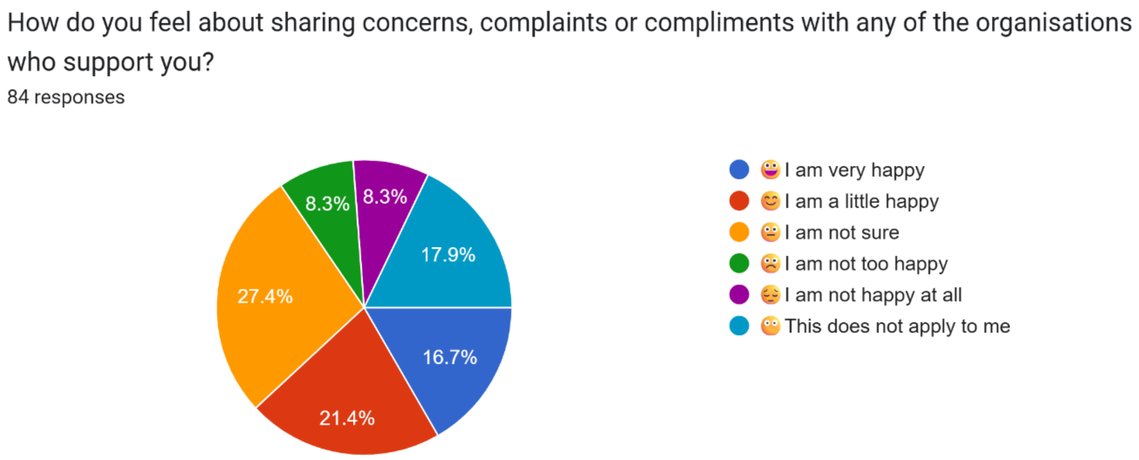
Please explain your answer

17 responses

- I'm not aware of any
- Na
- Not accessed
- I am supported with relationships
- Not applicable
- There is some chance to express that, but it is a difficult conversation to have.
- I don't receive services around this but am happy in my relationship
- Never had any problems
- I am happy and confident with my sexuality and gender identity
- I am happy around my sexuality and gender identity. I am a little unhappy about the difficulties I have with building and maintaining relationships.
- There is support to get out and find them, I feel comfortable to talk to staff about relationships.
- I feel I can be myself
- No answer
- I think I’m very reliant on myself and friends for support around my gender and sexuality. Gloucestershire pride is getting better.

- Pride have a few quieter activities and support groups but nothing specifically for Autistic people and I’m very nervous to engage with them
- There's a very good understanding here but there are things I agree with and things I don't
- Never had any problems
- I don’t get help with that but its ok with me. I want it to be private.

Please explain your answer



How do you feel about sharing concerns, complaints or compliments with any of the organisations who support you?

84 responses

46 responses

- No answer
- I always feel I should raise a complaint if the service is lousy, or something I bought is not as advertised.
- I am chronically fatigued, socially anxious and not confrontational so if it wasn't for my mother I would probably let everything lie, but thanks to her everything gets sorted out.
- It is always more difficult to complain
- I have no support
- I am considering making a complaint to a [service] who refused to accept me and then gave me a diagnosis (that meant I couldn't use their service) via letter on the basis of what was written in the referral. I am not sure about doing this in case I do actually end up receiving a service from them after all. I know how important it is to be seen as a 'good patient', that you can be labelled if you're not

well behaved and this impacts how staff in the service treat you. I'm also not sure I want to go through the emotional upheaval of it but I feel it was unprofessional and irresponsible of them.

- It's hard to complain about a service when you still have to interact with employees of that service.
- I'm scared they will shout at me or not listen and take it seriously
- Most of the services I feel confident in raising complaints and concerns. After a recent poor experience of making a complaint I do not feel confident complaining to them. The language used to speak to me was unprofessional at times, some of the things said were not acceptable and I have never felt so patronised in my life.
- I understand there is so much pressure on services, I wouldn’t want to raise a complaint or concern unless it was really serious
- I feel they were unapproachable, questioning everything like you’re a liar
- I don’t know how to do this
- I have been abused, bullied and intimidated for the last 12 years and I have got some support from organisations that lead these horrific actions to stop, but with me it has created a life trauma that will never end until the last day of my life….
- Things are going well at the moment. It's tricky to complain.
- [Service] took three months to respond to a complaint. My pension provider have so far taken 3.5 months and still have not responded.
- I could complain at the [service].
- I understand the delays with seeing my Consultant due to the current status of [service]. It isn't good but I understand it is how it is for everyone in this country at the moment.
- I find it easy to compliment but difficult to complain
- I'm ok about it. I would tell the [service] if I had a complaint.
- I would find this hard to do.
- I don't receive any support currently, in the past I think I would have felt nervous about raising a complaint. I let my therapists and nurses know how grateful I was for their support and how much they have changed my life. I would worry that if I shared a

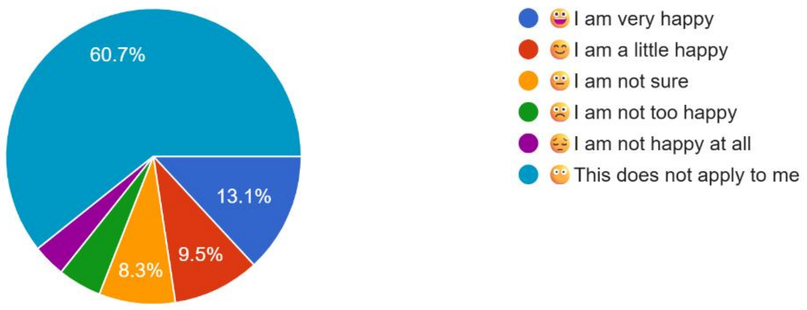
complaint this might be used against me in terms of the support that I was offered.

- No answer
- I am happy to do so but don't they would listen
- Yes I wouldn't mind doing that at all.
- I just want to get better and that’s my focus rather than acting upon things when they have gone awry
- I feel that I am very confident in challenging and praising when necessary. Sometimes I feel that carers may not realise my disability does not result in some learning difficulties.
- No support offered
- I submit complaints when needed to organisations but try to add constructive ideas with them in the hope that things will change.
- Responses are often superficial and do not address the points raised
- I frequently give feedback, be it good or bad.
- I’m quite confident person in terms of saying what I think when things are not right/services are not provided. Usually I’m okay to just tell the person straight away how I feel or to go to their Manager.
- The only people I find this hard with are my care provider, it took me a long time to get the confidence to complain about some big problems with my care provider (work stepped in to help me to do this) and I’m currently working with an advocate and the funders to get things resolved.
- They usually take far too long to reply and usually the answers are not what the complainant wants to hear
- I've got to know the person well to tell them how I feel about things. I would go to [service]
- I find it difficult to tell the difference
- I know the complaints procedure but I’ve not had a reason to complain
- I would talk to staff at work or if it was bullying I would talk to PCSO.

- I want to raise a complaint about [service], but the process is daunting and I worry about implications for using the services again
- I love it when friends, colleagues and family help to explain things. It's difficult for me to adapt to changes compared to other people.
- I just say if I'm not happy with something.
- I rely on my mother I wouldn't be able to make a complaint or raise concerns
- I haven't had any complaints to make
- I’m not a confrontational person, so find it hard to complain, but I do try to compliment people when they deserve it.
- I got told off by the care company manager for complaining about carers being late.
- I wouldn't know how to do that.
- From past experiences it doesn’t matter if you complain about a service because the complaint goes absolutely nowhere personally I get the feeling it’s sent into a vortex never to be read. When I have spoken about discrepancies I haven’t been heard or listened to
- Some places are very easy to do but [service] are really closed to listening to complaints or suggestions

How do you feel about the services you receive meeting your cultural or religious needs?

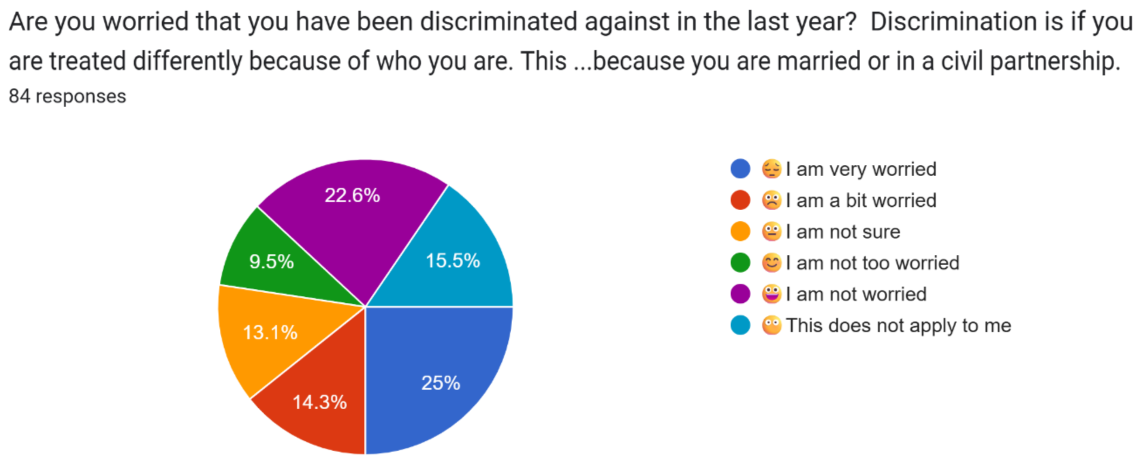
84 responses



Please explain your answer

20 responses

- I'm unaware of support.
- Na
- I haven't been to church in a while, but I would be supported if I wanted to go
- I have stopped going to mosque because I have been abused inside. I have been watched and observed by the committee of the mosque because they have orders from the authorities to do so….
- I attend a wonderful friendly church
- Not applicable
- The services in my area, have literally no knowledge of Judaism. I have had mental health nurses chat to me and say, "I have never met a Jewish person before," I have had organisations make ignorant comments about my religion.
- No answer
- I’m of no real religion
- If somebody takes me to church I will go but I wouldn't like to go alone, I definitely need an extra person. Someone would help if I badly wanted to go but it is not something that can happen spontaneously. Everything needs planning here unfortunately.
- I feel I need to explain more towards others about my beliefs especially to the public
- I feel accepted with my religion and culture
- I am not sure many people know about SGI Buddhism, which is very different to meditation
- I go to church every Sunday.
- I've had my bible on the table before and got mocked for it.
- Pretty good, I'm a regular church goer, the church I go to are generally quite inclusive, which is a blessing.
- No specific religious or cultural needs
- People are very supportive of my choice, and I don't make people participate in things they don't want to.
- I’m agnostic and have no cultural concerns.
- Atheist - don't like it when a service contract is given to a religious group



Are you worried that you have been discriminated against in the last year? Discrimination is if you are treated differently because of who you are. This ...because you are married or in a civil partnership.

84 responses

Please explain your answer

39 responses

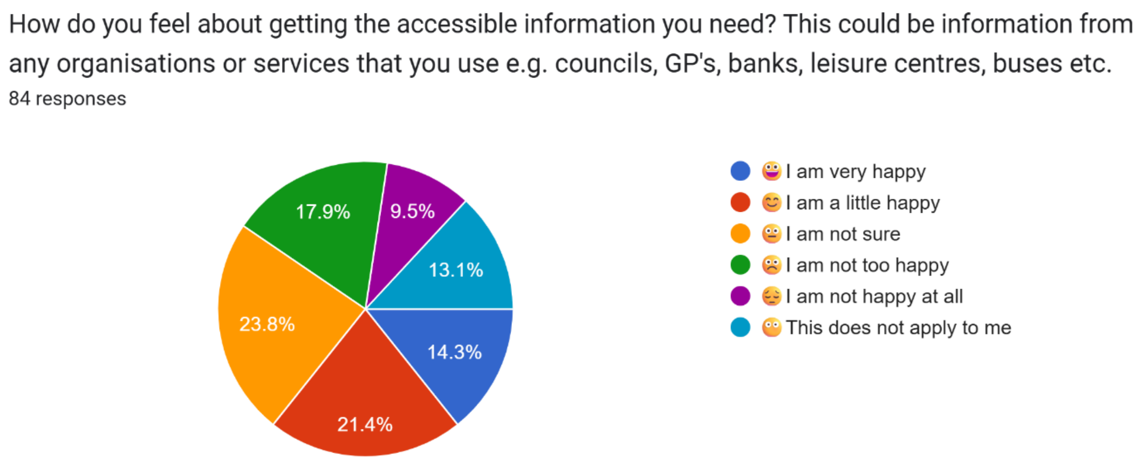
- I feel I was discriminated against at work
- I know that I am kind of oblivious to that sort of thing, so I might have been discriminated against but not noticed.
- Often looked down on for being different
- My workplace often fires neurodivergent people.
- Na
- At a certain age or disability, you feel invisible at times
- I don't go out on my own
- I need to go deeper on this case. Maybe if I have a chance to speak to someone.
- This hasn't happened to me.
- Employment with a chronic illness
- If anyone starts shouting I shout back
- Even when outward discrimination is not evident there is a lot of assumption about ability and conscious/unconscious bias in place. This is evident in the workplace, socially and in the healthcare system
- There was a time I thought my friends were being mean to me.

- I sometimes feel that as I look ok people do not understand my needs due to the Aspergers and I am made to feel that I am being a nuisance.
- Not getting into places, like Bath Road in Cheltenham- I can't get into half the shops because they are not wheelchair accessible.
- Due to concerns about my absence at work - for my medical condition
- I have experienced discrimination and a campaign of abuse/harassment in the last year and it has had a significant impact on my mental health
- I was badly treated in my last job. However, my current job have been amazing
- Often discrimination I face is more around accessing buildings or transport. It is not necessarily directly at me personally more about a general attitude to disability
- Businesses know little about autism accommodations
- Disability discrimination is rife, people just don’t understand that we are people!
- There is a LOT of public misunderstanding re disabilities in general but hidden disabilities in particular.
- Not worried in the home.
- The police has used my mental health to diminish my experience as a victim of a crime.
- There have occasions where I’ve been trying to catch the bus and the driver has told me that they do not have space. Whenever they tell me this I question whether the place is occupied by a wheelchair user or whether there are push chair/someone using a walking aid in the space. Many times I’ve been told it’s just too many prams or push chairs. I always argue with the bus driver if the space is not occupied by wheelchair user, usually I manage to persuade them to move people, whilst it’s a big inconvenience to them I feel it’s important for me to argue my rights to make them think about what they are doing, I am able advocate for myself but other people would just accept what the driver says which is not acceptable. I would estimate it’s happened 15-20 times in the last year.

- That has also been one occasion where the bus driver told me that their bus does not have a ramp (it was an old fashioned bus with a separate ramp) due to being in a lot of pain and a rush to get home for a meeting I did not argue with them however I should have done. Instead, I got another bus going in a similar direction I intended to report the incident to [service] but became unwell the day afterwards and then had forgotten about it until very recently. This used to happen a lot but has only happened once in the last two years now.
- I also feel discriminated against purely because of some bus drivers attitudes, sometimes just their body language and other times it's what they say or the way they speak to me or speak over me to communicate with my PA.
- Whilst I understand getting out of the cab and shuffling passengers around, getting the ramp out (especially when it's raining), waiting for me to board and manoeuvre my chair into the tiny space provided is an inconvenience to the driver and also delays the bus it does not give them the right to be rude or treat me differently to any other passenger .
- I feel I have been very badly treated by the Trust I work for and I have received emails that are very unpleasant from management
- My mum has a new boyfriend which he understands me much more than her previous boyfriends
- This is what I get most of the time in social places
- I do not feel in any way discriminated against, my gender, sexuality and my faith are always respected, but I don't make it an issue I try and show respect to people working hard to help, me and as a old [job] I appreciate the effect each person has made to become the professional they are
- Treatment by [hospital] A&E nighttime staff - insistent on discharging with no care package and unable to walk. Threatened with police, disbelieved and made to feel a fraud, ignored, bullied, physically abused, medication placed out of reach. Terrified of having to use the service again, which is likely.
- Not getting jobs, not getting identified for promotion,
- Nothing jumps out as obvious. I'm of the attitude that 'this is me', I can take this in my stride. It has only happened once when people

don't talk directly to me, and they assume. I feel guilty that other people in the home can't get out and I can.

- There is also the issue of drop curbs being on one side of the road but there is nothing the opposite side of the road, so you have to go for miles before reaching it.
- I feel the doctors discriminate against me because I am autistic. They do not take my chronic pain seriously
- I haven't been in the last year.
- No, we wouldn't get it here because we would tell them its wrong and challenge them. Staff would help me if I was out and about but I'd deal with it myself first. I like when people talk to me and not the staff
- I have had discrimination due to my age and size. But I try to avoid these situations.
- On the bus - I fell off the bus and everyone kept laughing. I was attacked by someone and I'm worried about bumping into them. I know what to do if I see them.
- People don't talk to me.
- I haven’t been discriminated the past year but I have faced discrimination for much of my life as in previous answers people have a problem with the way I am and take it personally therefore causing me even more problems then my mental health. It’s like society doesn’t want people with mental health living amongst them
- When I broke my leg, the doctor said "any other 25 yr old we would operate" - my parents were able to challenge that view and the consultant then explained all of the options properly. Worried about what happens when I don't have people to advocate strongly for me



How do you feel about getting the accessible information you need? This could be information from any organisations or services that you use e.g. councils, GP's, banks, leisure centres, buses etc.

84 responses

Please explain your answer

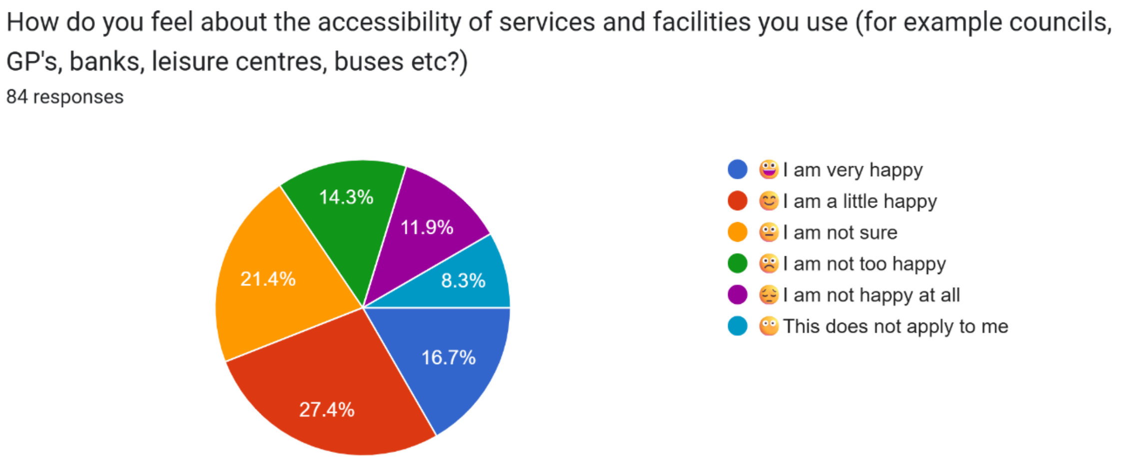
41 responses

- I don’t have any issues doing this
- I find all official documentation incomprehensible, and it feels like it switches my brain off. Fortunately, my mother will read and understand things and relay them to me. Unfortunately, even she finds some communications to be unclear, confusing and obscure. Like a pain clinic appointment that didn't make it clear if it was online or in person.
- It's often hard to find and might involve telephone calls which are hard for me.
- Would be easier if they shared information rather than having to ask for it sometimes more than once
- I can access this information well.
- I am helped to understand information, some of the staff will explain it to me
- I have help from my family

- I get a letter from the doctor for annual health checks, but they make the appointment on the phone. I get a text, but they aren't easy to understand.
- Council information is complex and hard to source.
- Someone else reads this for me
- Sometimes it's difficult to find information before visiting places as to their accessibility
- All the information is difficult to understand.
- I really do struggle with all of these issues.
- For the most part, I don't need accessible information however, a transcript and written record of the doctor's phone calls would be useful. It can also be difficult to get the printed record of blood test results.
- 99.9% yes, there is the odd occasion where it is not accessible. You are not always able to get hold of anyone. Some information is taken for granted that could be better,
- There needs to be more of this, I need an audio version of things as I can't read them. It must be audio described
- If there was bigger support for M.E. in Gloucestershire that would be amazing
- I'm good at doing my own research so find things out myself
- I don’t feel like I have any indication of the support I can get locally
- I do not need any changes in the information that is available.
- Some accessibility info is good but some is abysmal and provided by people who just don't understand things like wheelchairs don't climb steps or go very well on loos gravel for instance.
- Some access info is downright wrong or at best misleading. There needs to be a national standard for this type of info.
- Sometimes I need help to understand things- this is easily available. I can't do it on my own, as I need reminding and helping. If it's something I've not done before extra support is necessary.
- It’s hard for me to take it in, they don't give me easy information. Big words are hard.
- My mum deals with GP, banks, buses and other things
- I mostly access information through social media, website, Google

- I am fine with information personally but there is still a lack of easy read for adults with learning disabilities but I know there are moves in the right direction
- I ask people to spell things slowly. I give letters to my step dad.
- They don't always make it easier for me, and I need it to be explained
- Whilst most services explain how to access, you have to do this for each one, which is very fatiguing and overwhelming.
- I do understand non- Easy Read information. If there are words I don't understand I google it.
- If I get the option I will go for the easy read one, as I struggle with reading and writing. I have more of a chance if it is bigger writing. The majority of place send A4 size 12 font letters which doesn't work for everyone.
- Some services are better than others, the council are pretty awful. The banks send all my statements in brail. They put brail on medicine packets, I hope they never stop doing that. Bowel cancer screening test was brilliant, they sent me this aid, and instructions in brail and on a CD, I could follow the instructions and do it myself.
- Don't have any interaction with any services apart from GP. My mother deals with all my other services. This is a real worry if anything happened to her as I would have no clue who to speak to and even if I did, I would not be able to vocalise my worries
- On an recent hospital letter I was pleased to see easy read being one the options as an alternative method of communication however the appointment letter is always long and confusing and the paragraph saying if you need the letter in brail big print or easy read is in small type
- Not always to get information.
- People can read it to me and clarify.
- People always assume that you have the information you need; and seem put out if you ask for any information or advice.
- Automated systems at GPs and hospitals are being used a lot more in place of receptionists and service is poor. They can't always address the query at hand which means you enter a cycle

of being diverted from a phone line back to online system....which then results in putting everything into an email and not receiving an answer until 7 days later.
- I don't get any easy read
- I don't really know where to start or who to ask.
- Sometimes it's easy to access information sometimes it's hard it depends on who you see that day!



How do you feel about the accessibility of services and facilities you use (for example councils, GP's, banks, leisure centres, buses etc?)

84 responses

Please explain your answer

45 responses

- We do not have any local buses that I know of? I am fine with contacting all organisations should I need any information
- Given that we live in a rural area and I use a wheelchair, we need accessible parking, and it is getting harder and harder to come by, especially at the hospitals where it is needed most. And I wish gravel paths with no alternative were illegal as they just make my wheelchair tyres spin.
- GPs appts can take weeks. The pharmacy takes 10 days to process prescriptions
- GP accessibility is awful. Weeks for an appointment which has to be made via a complicated online form that's only available during

very limited hours. Telephone appointments offered with no time given just a day and if the call is missed, a second call is made immediately after the first (no good if you're sat in the loo!)

- Transport is bad and everything seems to be a fair distance away and can't always travel to get to these things and then I get told off for not being able to attend appointments even though I try to cancel as early as possible there is no bank local now have to travel 12 miles
- I can drive and my service providers are accessible. If I need to go to work meetings, this is not very accessible from the front entrance and I have been made late due to not being to access the lifts.
- I understand the stress on services but a lot of people are being left untreated and in pain
- I go with assistance (my PA), it is not accessible in a large power wheelchair. I wouldn't go on the bus alone
- Hospitals aren't easy to get around. The signs aren't clear.
- £2 bus scheme is very helpful
- Where I live I'm on a good bus route however due to my disability I use taxis
- There are some places that I am not able to visit on my own due to lack of wheelchair accessibility. Parking can also be an issue, particularly in car parks where a barrier is in operation as I am unable to reach out of the car window to operate them.
- Often I cannot drive and the lack of public transport is limiting
- Accessibility is ok for me in these places
- I struggle with all of these.
- In person appointments would be better as well as extra time given to explain things thoroughly.
- You work out where you can get in and you just stick with that
- A lot still are not fully accessible and the burden is on you as a disabled person to work out what you can and can't access
- If there was more support for M.E. in Gloucestershire that would be be amazing!
- I find out myself on google info I need

- Despite rising the issue in many forums over many years it is difficult to be able to identify any significant changes. Transports and the Times of transport is a particular issue, and the state of pavements and drop curbs is something else that creates issues for me. I often feel I am being blamed for being disabled rather than it is the environment or lack of consideration causing inconvenience, and why would I need to get access to places that other people might like to go. Given the fact that I have a disability, even on things like trains where help and assistance can be requested I do not have the let's go now option that other people can take for granted. Often access issues are unnecessary, by this I mean there are alternative ways of doing things that do not create such difficulties; for example Putting displays in the aisles of shops or on pavements thus creating obstacles that become difficult for people with physical and sensory impairments. Simple things like being able to access the buttons to operate a lift without assistance Is something that is often ignored, as is providing tables and space to accommodate wheelchair use or design features avoiding the use of steps.
- GPs appts can take 3 to 4 weeks when I might need one the same day or at least that week
- Mostly ok
- Sometimes not that accessible as I'd have problems getting into some areas and people don't understand me.
- It is variable
- Most leisure activities I access are places to eat, whilst they are physically accessible (in terms of ramps & doors) there are some issues such as being able to get a wheelchair close enough to the table and moving around in tightly packed areas, usually people are willing to move tables and chairs to accommodate Wheelchair users but finding tables that don’t have legs that are in the way, that don’t have lips underneath or that are the right height is not something they can do. I used to mention it to managers but it never gets me anywhere and distracts from the time I’m trying to enjoy so I no longer do this and unless there was a safety concern. Most places to eat have the same kind of table throughout the

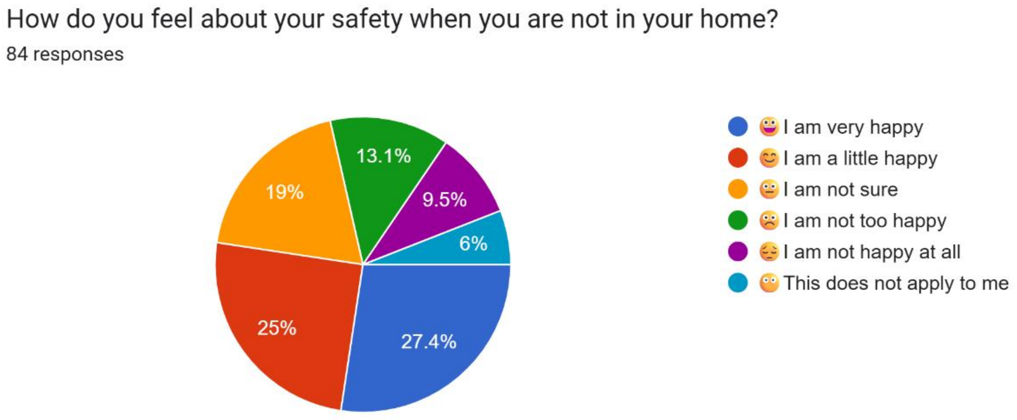
restaurant or the whole chain (if there are lots of them) so getting different tables for one or two customers is not a priority for them

- I do not often access council buildings but when I have done this been fine in terms of accessibility.
- Hospital, dental surgeries and doctors surgeries are physically accessible but sometimes the treatment rooms can be quite small or have tables & chairs in the way so is not easy for wheelchair uses to manoeuvre in. Particularly in buildings where I’ve had mental health appointment tables and chairs need to be moved to accommodate my wheelchair, they are not built for medium/large wheelchairs (which are very commonly used to used)
- An online portal where some appointments still happen is not accessible to people who use subtitles, during Covid a portal was created where they host these appointments, this did not have subtitles, despite having had several years to rectify this I was recently offered an online appointment but upon checking I was told that the portal still did not have subtitles would not be able to access the appointment, due to this I will have to wait several months for an in-person appointment
- I use a bank in [city], whilst the actual building is physically accessible, wheelchair users have to go through a back alley/sidestreet and up a long ramp. The alley is in very poor condition and not great for the wheelchair users as the pavement is broken, slopes are very awkward ankle and is full of potholes, the ramp is quite long and narrow and the angle of the doors is not easy to get through as there are 2 which do not line up with each other. People using this back entrance also have to be able to physically press a door entry button which not everyone is able to do, I am not able to do this independently but always have a PA with me so do manage. Whilst I know I could change banks and choose one which is more accessible, I have not done this due to the anxiety surrounding having to change the details and go through so many processes to get it done. The staff in the branch are really lovely they have gotten to know me over the past 20 years, they know how to support me so I can do my banking without relying on my PA which I really appreciate

- Buses are a real challenge for me, despite being my primary source of transport they are also something that causes me a lot of stress and anxiety. I live fairly close to [city] and have three bus routes that I can travel between my home address and the city Centre or in the opposite direction to different destinations) I have a median/large electric wheelchair and struggle to fit in the space provided. There are few buses that have a decent size turning space and space for the wheelchair but are very much in the minority (they mostly happen to be routes I do not use regularly). Mostly I only just fit into the designated space and if I have a shopping bag on the back then I may not fit. Getting on is a challenge as I have to swing my front end into the designated push chest space and then reverse around the bar into the wheelchair space. If there are pushchairs or people using mobility aids in the pushchair space then I have to either get them to move into the central alleyway or get them to move off the bus whilst I park and then get them to back on. This is a nightmare at busy times. I regularly catch my footplates, wheels and elbows whilst trying to park my wheelchair, when getting on the bus I regularly scrape the driver's cab, I also catch the bar when getting on and off the bus, on multiple occasions this is cause damage to myself, my chair or the bus. I also find that I cannot press the designated stop button for a wheelchair user because of its position, sometimes the button is to the right of the person by the window, this is not too bad (but is still fiddly) but when it is to the left on the bar which is kind of set back it is impossible to negotiate my arm right behind myself to feel for a button which I then have to press. This leads to me having to ask someone to press a regular stop button but the driver does not then know then that it is a wheelchair that needs to get off and they do not designate extra time, the amount of times I've had to shout asking them to stop because I'm still manoeuvring when they started to move off is scary. As well as struggling the physical accessibility of the bus I also struggle with the attitude of the drivers, sometimes it is the way they speak to me or the person with me but other times it is body language and face expressions that demonstrate how they feel, often they do not appreciate being told that they need to ask other passengers to move in order to make space for a wheelchair user to safely park in the designated space, they also do not appreciate me directly telling other passengers what they need to do because they have not done it. I was so fine that the attitude of drivers is worse and it’s busy times, I understand that having to do negotiate a wheelchair user onto the bus when you have three pushchairs and someone using a walker already on a bus at busy times or when they are running late is not ideal. It is something that they are paid to do.

- Banks are all closed near me and doctors surgery isn’t easy to get to
- Bank - Wheelchair users find it difficult to reach to put in the PIN number at the staff desks. Two wheelchair users cannot use the bus at the same time. GP - Booking flu and covid jabs the times are too early or late in the day as this is difficult to get transport.
- I can drive and that's how I get around. I also use a scooter and a walker.
- I can access anything I like
- Something it difficult to access services because of my condition and how people treat me
- On days when I have back pain it’s not possible but I could gain access via the internet or my partner helps me
- It is too small for me to get in at times
- Whilst most have facilities and processes in place, have to negotiate each one separately, often inconsistent, very fatiguing and overwhelming. Screens, even when at wheelchair height are hard to read as designed to be read standing, common with cashpoints. If you're using walking aids very hard to hide inputting PIN
- 'Dead easy' particularly when I am travelling on my own.
- I've been in a wheelchair for so long that I don't recognise what I can't get in. I know what I can get in so I will just go for those.
- Lots of places that do "accessible" hours or events only do this in working hours.
- It varies.

- I tend to make my own reasonable adjustments - for instance I always have headphones or my step dad accompanies me
- I cannot easily use the bus. Too many busy roads to cross to reach the bus stop.
- I can because I come to [city]
- We always have someone with us, some places are hard for me to get in as there's not enough turning space and it can be narrow. Things could be more accessible
- So far not had a problem
- It is much harder to get appointments at GPs and hospitals and the continuity of care is lacking, which is key when you have a long-term condition.
- No answer
- It feels like the process for requesting accessibility is, in itself, not accessible.



How do you feel about your safety when you are not in your home?

84 responses

Please explain your answer

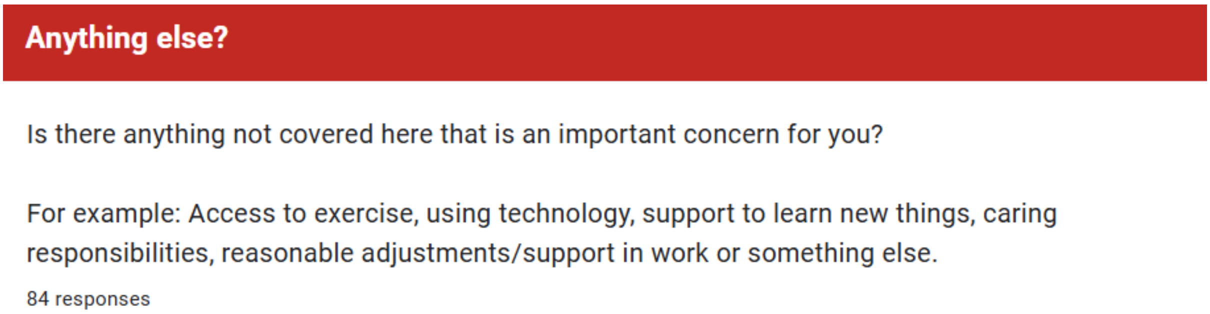
44 responses

- I feel OK in our village but we don’t have street lights so I wouldn’t go out walking on my own in the dark for example. I also don’t think I would like to walk around the town areas at night on my own. I always feel safe with my husband

- I have never really felt in danger but that might be because I am oblivious.
- I often worry about my safety
- Domestic abuse means I'm always looking over my shoulder
- Pavements uneven and have pot holes same as roads lack of decent buses and lots of accidents often mean delays and the buses run every 2 hrs so that can make it hard as have to leave extra early and waste time before appointment or after
- I try not to think about it but one of my conditions means I can pass out. I also have sudden loss of strength, onset of exhaustion and pain in my joints from dislocation. I can’t have a day out or go to a big supermarket without support. I wear a lanyard with my health conditions and Emergency contacts in case something happens to me. I don’t have a PA so I'm reliant on my friends and family. It makes me feel like a burden so I don’t ask for help like that often. I mourn my loss of independence in that manner and stay home a lot more often.
- I sometimes worry I would not be able to defend myself or escape if I was attacked because of my chronic fatigue and pain
- I go out with staff
- I have phone numbers if I do not feel safe
- I have been stared at many times and ridiculed by some members of the public. Sometimes people that should protect me are those who lead this actions….
- Now that it's dark, I have to walk up a hill in the dark so I have a torch.
- Yes because of the police.
- I feel safe where I live we have little anti-social behaviour in my area
- I have the philosophy of 'just getting on with it' as I won't let my health problems interfere with anything if I have the energy, time or money to do it and having a low pain day. There have been times when I have fallen and injured myself and that is a worry so I do try to get someone to accompany me on dog walks etc

- If I was on my own I would feel very vulnerable but don't venture out by myself because of this
- This worries me as I struggle when out.
- For the most part I feel really safe. I often do worried when I am out of the house by myself as I feel slightly vulnerable and my senses are heightened.
- The pavements around Cheltenham are so bad, you have to watch where you're wheeling. There are cars parked across the drop curbs.
- Gloucestershire can be unpredictable
- I have been targeted in the past (hate crime and a mugging - separate) and I don't believe these would have happened if I wasn't visibly disabled
- I feel vulnerable out there because of my eyesight
- I feel safe most of the time and have my car to get me around
- I am scared something’s going to happen to me
- I feel safe
- Outside is scary. Work and home nothing else
- I feel vulnerable in crowded places & in car parks as drivers just don't seem to even see you.
- Ok mainly but have had a few unpleasant moments due to uninformed public
- If I go out on my own people know about it. I feel reasonably safe and confident.
- I feel safe as I always have a PA with me (at home and in the community)
- I usually go out with my husband so I feel safe
- I feel safe when I am walking outside
- I feel safe because of the people living around me are my family members
- Obviously you have to be mindful of where you go, but in general I feel safe in Cheltenham and Gloucestershire, I think the media portrays Gloucester with knife crime so a little more careful in Gloucester,
- Unable to have DC fall/alarm system as I don't have a landline or 01453 number, only mobile phone.

- When I go out in the dark, I always think about it being unsafe for females but for me I feel perfectly fine especially when I'm wearing a puffer or motorbike jacket.
- Up until last year I was fine, then I had to go to hospital after a fall when I came out of [shop]. After my injury I was back to being ok after being out and about but I have to make sure that I'm careful after this incident as I don't want it to happen again. I'm more wary when I go out now.
- I find this difficult, I wouldn't go out on my own, I don't feel safe doing that. The pavements round here are atrocious; I don't feel safe walking around on my own.
- Never taken anywhere I don't feel safe. Either with family or friends whenever out
- I feel quite safe
- People around me are not always friendly.
- I would not go out on my own, I need a person with me.
- Most of the time I'm happy, but if I'm somewhere that I don't know, I worry about trips, fall and toilet facilities.
- This is because of the person who attacked me.
- No answer
- Due to mental health conditions I always worry when I'm out of the house always thinking about what could go wrong I'm scared of this world, and I have to teach my children not to be in this society these days it scares me
- Always with 2 support staff



Anything else?

Is there anything not covered here that is an important concern for you?

For example: Access to exercise, using technology, support to learn new things, caring responsibilities, reasonable adjustments/support in work or something else.

84 responses

- N/A
- No
- None

- No
- no
- no
- Actually Potholes are a nightmare where I live (they don’t seal them when they come to fill them in so they just keep blowing). This can affect me as I have a bad back so any jolting or hitting potholes can be quite uncomfortable.
- I can't think of anything.
- Reasonable adjustments don't feel like a reality in education/work place
- Not leaving my house, having no friends
- Support for gaining more independence and the life skills/lessons needed to survive alone as an adult
- I don't know
- Access to exercise and weight loss cooking courses learning new things
- As a disabled person caring for a disabled child makes my life very hard. We cannot access the community or activities easily and life is stressful for me.
- Caring responsibilities and working
- I wish there was more awareness and understanding especially from professionals about the impact of conditions and neurodivergence. I think stereotypes are still too relied on, but these things always present differently
- Long waiting lists even if you were eligible
- Have help to get a flat on house list is complicated
- I have been in the college and I have faced many struggles…
- Support to learn new things at work. I have to make sure things are easy to understand.
- Opening hours of access (radar) toilets.
- No.
- Invisible disabilities can be difficult to navigate. I wish people didn't judge when they can't see the disability or health concern. When these things are invisible it is difficult not to have Imposter Syndrome at work for example. At work and in meetings particularly, I battle pain and fatigue from my Rheumatoid Arthritis,

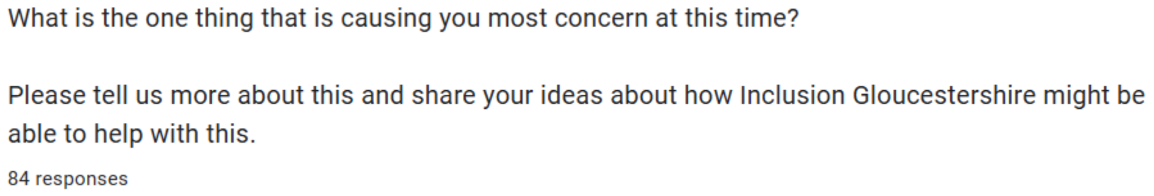
nausea and visual issues from the medication, memory, speech and balance issues from my Idiopathic Intracranial Hypertension/previous brain bleed, all whilst trying to perform my role with no-one having a clue. It's a lot of pressure and I manage it well but it's utterly exhausting. I have a huge range of skills and am an expert in my field but I have to overcome so much more that any of my peers just to be able to carry out the role, let alone compete for promotion and advance my career. There is a stigma still, however you cut it... a person with a disability or a health concern will often be overlooked if there is someone without that to interview, promote etc. So I try to hide my issues as much as possible to compete/participate on an equal footing.

- I don't know of any exercise that I have access to. I am hoping to return to part time work but am nervous about how I'll cope.
- All of the above!!
- Support through the transitions through different mental health services.
- Work - although I haven't had services around this, my flexible and supportive employers make a big difference to how much I can achieve in my career
- No this has been a comprehensive survey
- No I'm ok
- Most of the above, but in particular the access to exercise and an increase in the availability of voice assisted Equipment to help people with reduced dexterity. This is particularly important around transport and being able to get more information on times and availability by asking for it.
- Support in meeting people
- In general, I find that people are very helpful when needed, but do find that some organisations/shops/businesses just don't understand what reasonable adjustments are & what their obligations are
- Nothing
- I wish it was easier to get support to enable me to do a course, I started it feeling that I would be ok but my needs have slowly been changing, I know I need more support with handling books making

notes… Adult education are working with me to try and find a solution but it’s not very easy.

- I have a PA with me 24 hours a day however the care agency are currently only funded for medical needs only and not support me with things like this.
- I also struggle with time management and remembering to do things, however I do not have any diagnoses in this area therefore it is hard to get support
- Nothing I can think of
- Support for people who are disabled and the impact of getting older.
- I think that there should be questions about more access to exercises using technology and getting to a gym
- I am happy
- I think at times, services fail to recognise my impairments of dyspraxia because I get times and dates mixed up and really have to work hard to keep everything in a diary, text messages help but when you can’t think ok the dates this and easily connect the dates
- Not applicable
- Not sure
- Support in work - employer understanding and support for my condition but [Council] was poor, rather than being redeployed to a more suitable role I was made to leave via 'mutual consent'.
- Exercise - I like it but I worry about doing too much. This can damage you.
- Technology - I worry about future technology because they are always changing. I don't like AI.
- Caring responsibilities, reasonable adjustments, help in the home, support with finances
- How long is a piece of string
- Support in general to carry out my normal life and to get to and from my social activities
- The aqua aerobics class books up quickly and you have to book via the app late at night to get a guaranteed place. More classes would be better.

- Support to learn new things. I would like to be able to do things like being able to use a computer.
- Not really, I'm a solitary soul, but do worry about becoming too ill to seek help as I live on my own.
- Not that I can currently think of
- Access to exercise and nutrition support; access to learn new things
- There doesn't seem to be a lot of support for parents who are neurodivergent.
- My mum is having a lot of problems dealing with [service] and lack of transparency!



What is the one thing that is causing you most concern at this time?

Please tell us more about this and share your ideas about how Inclusion Gloucestershire might be able to help with this.

84 responses

- N/A
- Safety
- My mental health and being able to find another job so I can remove myself from a situation that is making my MH worse - although the thought of being interviewed is a bit scary. I have been in the same job for 25 years now but desperately want to leave my current department - due to discrimination
- Waiting lists. It takes too long to get appointments and when I do get one if it is at a bad time, like too early in the morning, then they make me wait another two months or longer. I wish I had a choice about appointment times, not just being given one without being asked if it is suitable first. I have chronic fatigue and live a long way away from the hospitals and I can't have appointments in the morning.
- If I need to access urgent care it can be traumatic in the hospital environment
- Having been stupid enough to reveal my diagnosis at work.
- Not being aware of / recommended what advice and help for my needs are available and how to access them.

- Getting good support for my mental health. I am accessing support but I am very wary about how I will be treated and whether it will retraumatise me being part of the service again. MH services should not make people worse!
- I feel stuck. Stuck in a house I can't keep clean or properly get around. Stuck in a body that doesn't work and a brain that rarely works. I feel at sea, abandoned. GP has left me to rot. Neurologist has fobbed me off with an FND diagnosis but no support or treatment. I have no money to do nice things to give joy to my life. I know I can't be the only person who feels like this.
- Lack of transport lack of free things to do lack of support lack of courses
- Getting diagnoses and support to manage. Also seeing a GP to look at you as whole is so difficult. I see different GPs for different things and no one is looking at me as a whole person.
- I was recently made redundant and have found the process of interviewing incredibly tricky with my LD. I'd love for employers to be more flexible around how they interview.
- Most my financial issues, I have to take days off work sick quite often and constantly worry about my money
- I've had treatment e.g exercise classes online in past but this was offered from a hospital miles away & it sometimes seems you get more help with bigger hospitals than local ones. They seem to be advanced or more to offer at times. Unfortunately, you have to wait an awful long time these days to get seen or have follow ups
- Getting a doctor appointment
- Finances. Being able to pay bills
- I hope that you work more with local authorities and explain to them what does it mean to have a mental health by stopping giving people free labels that destroy their lives….
- Having the money for buses. I heard they are going to stop bus passes for people with learning disabilities and autism and only have them for wheelchair users. I think IG can write a letter about this, like we did for the train ticket offices.
- Finding employment suiting of my health needs
- They all close far too early and do not serve my needs.

- n/a
- Benefits advice
- Finances
- Housing associations and lack of consideration for disabled tenants.
- Assumption, labelling and lack of meaningful proactive support
- 1) Finances - worrying how I afford to keep my house warm and therefore my body out of pain and keep the cupboards full with the cost of living rises.
- 2) The future - my daughter has ASD and executive function deficits and I'm not sure will ever live alone. What happens to her if something happens to me? Where would she live? Who would keep an eye on her and support her?
- 3) My health deteriorating further - who will pay the bills?, support my children? I have to work so hard to earn the money and keep us afloat. It's relentless, exhausting and it's probably killing me or at least worsening my symptoms. Not sure how I improve my situation.
- More public toilets in Gloucester
- I think lack of face to face contact with people, feeling isolated due to physical ability restricting what I can do. Unable to go places unless I have a lift.
- Would be great to have a social place to meet up with other people for a laugh and a chat
- I'm not too worried.
- Being left on my own with no real access to help or services.
- I don't have any major concerns at the moment. I do think services are becoming more accessible. Long waiting times are definitely an issue as well as in gaining access to in person visits to the GP.
- Carers rights
- Harassment and abuse that is ongoing
- Lack of support with my illness and mental health declining
- Mental Health
- Just help for people that do need it more than me in all areas relating to those with Mental Health and Disability Issues
- That my cancer will kill me

- Increased pressure on the caring system, Increased difficulty in recruiting and retaining suitable care staff and having access to suitable care homes particularly for younger people with disabilities. The need and support for such facilities being available is something that inclusion Gloucestershire could do to raise awareness of.
- I'm so isolated
- The lack of understanding of people with multiple chronic conditions by clinicians really concerns me. I get treated by symptom & not as a whole person who needs them to understand that they just can't look at individual symptoms but need to consider the whys & what happens questions before suggesting treatments.
- Difficulty in getting carers who really care - not for me, but a friend
- Being open about conditions for fear of them being used against me.
- The fear of neglect, the fear of people not understanding me and my situation.
- I wish I can be help me, helping me to not be so ashamed about telling people of my disability.
- As my eyesight changes, I am finding it more difficult to see in the dark when out at night. This is starting to concern me.
- Accessing the GP for any reason is a nightmare and often feels like you are fighting with them.
- As my doctor surgery are a super surgery it is really hard to get an appointment, last time I rang I was number 76 in the queue and was waiting for a call back from reception for more than five hours, if it is an emergency, they are usually quite good at getting you in within the next 2 to 3 days however it is not an emergency then you would be lucky to get an appointment with any time within four weeks. It’s usually longer than this though.
- I rang at the end of November to get an appointment for my mental health and was offered an appointment at the end of December, I went to attend this appointment and found that I could not login on the electronic tablet so I went to reception and waited for almost 30 minutes to be spoken to, it turns out that my PA had written the wrong time in the diary so I thought I was attending appointment at

5:30 pm however it was actually 5:15 pm. If I had been spoken to relatively quickly after I arrived I would only been a few minutes late (I arrived at the surgery at 5:20 pm) due to the amount of time that had passed between my appointment time and getting spoken to they refused to treat me and offered me appointment in mid January. The day before this appointment, I received a text saying they had to reschedule my appointment and offered me an appointment on the 3rd of March. I rang because I was not happy to accept this as my mental health had been declining between November and this point and managed to get an appointment on the 14th of February. Hopefully they keep this. Situations like this are not uncommon and I've had multiple appointments rearranged at short notice in the last six months.

- As I mentioned in the first section I've been fighting with them to get my medication synchronised for a very long time and this is having an impact me in multiple ways, mentally it's just driving me out and I feel like I'm fighting the system, physically it is draining and obviously it has an impact upon you if you run out of medication because the system is not working with you.
- Not being able to have a regular GP when you have a chronic/long term health condition also has an impact on you because you do not feel like there is anyone that completely understands you, often I do not go to the GP until I can't ignore a problem anyone because I know I'll have to explain myself again and the reasons that certain treatments are not viable for me- often I will try to go through other specialists involved in my care to see if they can help me before I go to my GP, I do not do this because I think they are the best person to go to, I do it because I can't deal with having to explain myself to a GP that doesn't know me.
- My housing, lack of mental health support or treatment
- Social Care
- Advocacy
- My job at [organisation]
- Taxi companies, and [charity] needs to be improved so that they can offer a better service to be able to book in advance. [Service] could work and fund in [organisation]. The council could explore funding financial support to drivers with accessible taxis to support

disabled customers so that they can get out and about. [Service] could work with charities to improve their services and costs.

- There should be more activity for people with disabilities and none disabilities that they like.
- Having someone to look after me and be with me.
- The news.
- Discrimination and how people treat me because of my condition.
- I have no big issues but the fear of changes to the rule in benefits scary, what would I do if my benefits were stopped. or changed.
- Accessible letters and information.
- Not sure
- Living in poverty in old age, having lost 1/3 of my employers pension having to leave work 12 years early. Not sure how can help
- Leaving my parents. I know that time will happen at some stage, it's good to prepare yourself. IG can help by looking at bereavement as a topic.
- Whether the financial split between me and my husband is equal.
- Finances. I think more needs to be done to campaign for disabled people not losing their access to benefits when they enter a relationship
- I would say the situation with [service] and also if I did need a carer, I wouldn't feel I could access that. I think it's mostly [service] really.
- My real concern is how I would manage if anything happened to my mother. I am unable to read or write (she is writing this for me). [Services] just say we'll deal with it when she's gone. I have other local family and no local friends only people I do clubs with but they are acquaintances not friends and most have no idea even where I live and I have no way of contacting them unless at a group. It is a real worry as my mother gets older and less able how I am going to have any sort of life.
- Maybe a little bit more work with the LGBTQ community but I know this is being done
- Crossing roads and busy traffic.
- Health Care

- Being able to do things at home, someone being able to take me out if I need to go out
- Not being able to summon assistance should I need it.
- Access to Healthcare, medication and preventative treatments.
- Provide social activity groups to join for things such as cinema, bowling
- The dentist. I don't like them doing the suction bit they don’t do anything different.
- Not filled in
- Ensuring that my child is receiving the services she is meant to have.
- Medication and the problems people face around accessing their own medication is something that’s not talked about nearly enough.
- I would really like my support workers to get training about advocacy and have the confidence to speak up for me - many are pretty good but need to be really good to tackle some services.