Inclusion Gloucestershire Survey

May 2022

Social Care & Advocacy

Chapter 4

INCLUSION GLOUCESTERSHIRE

BIGGER DREAMS ▶ BETTER LIVES ▶ BRIGHTER FUTURES

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Introduction

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

In June and July 2021, we invited people who face disabling barriers to give us their opinions and experiences, along with any ideas they have for improving things.

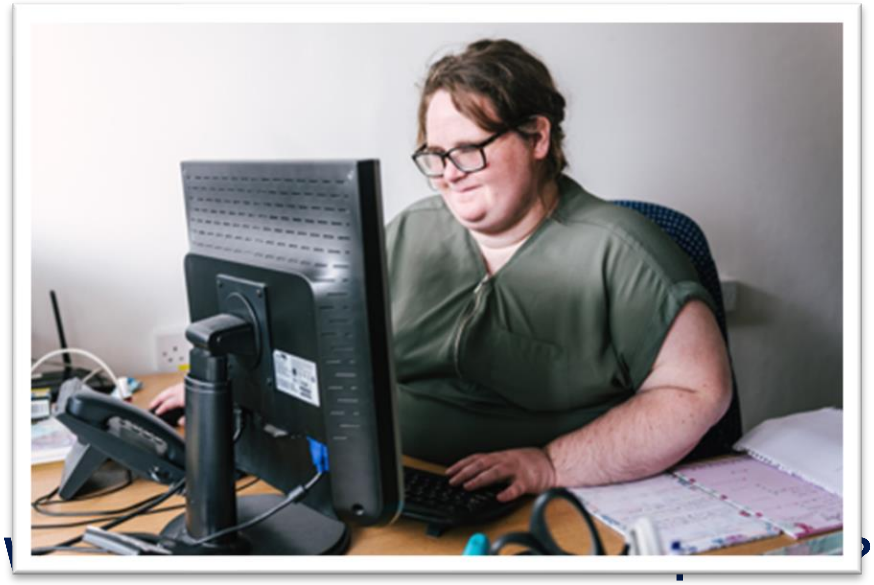
We asked people who face disabling barriers, family and friends, and paid staff members who support people facing disabling barriers.

As a user led organisation we want to make sure that our work is led by those who face disabling barriers, and their families and friends.

We have used the information we have been given to guide our organisational strategy (big plan) for the next 3 years.

For more information on how we found out about what people thoughts, please see our headline report at:

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



135 People Gave Us Their Views!

There is more information about who gave us their views in the headline report but here is a summary:

- Most people identified themselves as female.
- Most people did not identify as transgender.
- Most people identified themselves as heterosexual.
- The largest group of people who gave us their ideas were aged 55-64. The second largest group were aged 45-54, closely followed by people who were in the 35-44 age group.
- Nearly all people used English as their first language.
- Most people identified themselves as White British.
- The largest group of people who gave us their ideas have lived experience of a mental health condition. The closest group to this were people with learning disabilities and then people with a physical impairment.
  Several people had more than one "type" of lived experience.
- Most people live in Gloucester or Cheltenham, but there are still many participants who live in other areas in or near to Gloucestershire.
- Most people who gave their ideas are not members of Inclusion Gloucestershire at the moment.
- Most people have not used Inclusion Gloucestershire's services in the last 6 months.

For more information on how we found out about who responded to our survey, please see our headline report at:

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

What areas of life are worrying people?

We asked people who gave us their ideas and opinions to tell us how worried they are about 22 areas of life.
We asked people to tell us if they were:

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

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

One area that was causing people some worry was in relation to Social Care and Advocacy, and this report is going to tell you more about what people have told us.

This report covers things like social care assessments for individuals and family carers; changes to social care support; financial contributions; support to family carers; and access to, and quality of, advocacy support.

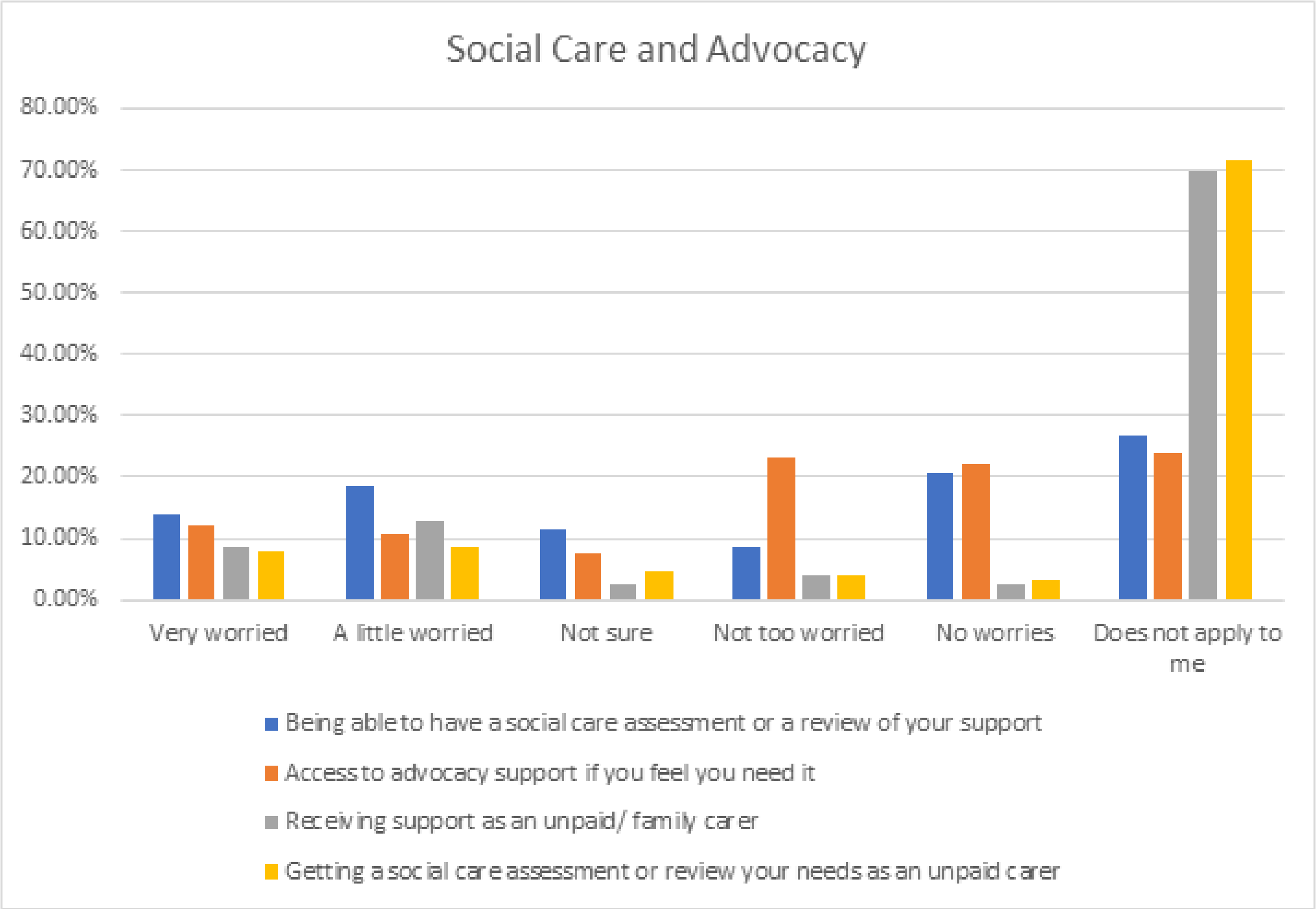
If you want to know more about the other areas we asked about, we will be writing more reports in the next few weeks and months.You can see our headline report and specific chapters on the following areas on our website:

- Health
- Choice and Control
- Social and Leisure

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

Summary and key messages regarding Social Care and Advocacy

This is a summary of the key information we found out about social care and advocacy:



- **More than one fifth of people in our survey did not believe that access to a social care assessment or advocacy was relevant to them.**
- **More than half of people in our survey did not receive support from social care.**
- **Changes in social care support had happened, but some were increases and some were decreases. For a number, there was no change.**
- **Large numbers of people in our survey (over 70%) did not feel that the questions relating to family carers applied to them, so the sample is small in this area.**

- **Almost a third of people said they were very worried or a little worried about getting a social care assessment or review.**
- **Fewer people said they were either very worried or a little worried about getting access to advocacy support.**
- **A number of people were either very worried or a little worried about the support they receive in their caring role.**
- **21 people said they were very worried or a little worried about getting a social care assessment as a carer. This was a high number of those who identified as being an unpaid carer.**
- **People have concerns about accessing social care assessments, either as an individual or as a family/unpaid carer.**
- **People have low expectations of whether they will be able to get a carers assessment and how it will support them.**
- **There is a lack of understanding about the social care assessment process and how to access it.**
- **There are concerns about communication and attitudes, this has resulted in some lack of trust in the social care assessment process.**
- **There are a few concerns about the quality of staff support in social care.**
- **There are mixed views about charges for social care support.**
- **Access to advocacy support has been problematic for some, and there is a lack of understanding as to what support is available and how it may help.**
- **For those who have had advocacy support, their experience has been positive.**

Social Care and Advocacy: more information about what people said is worrying them

We asked people 12 questions about how worried they were about things to do with social care and advocacy.

The questions we asked were:

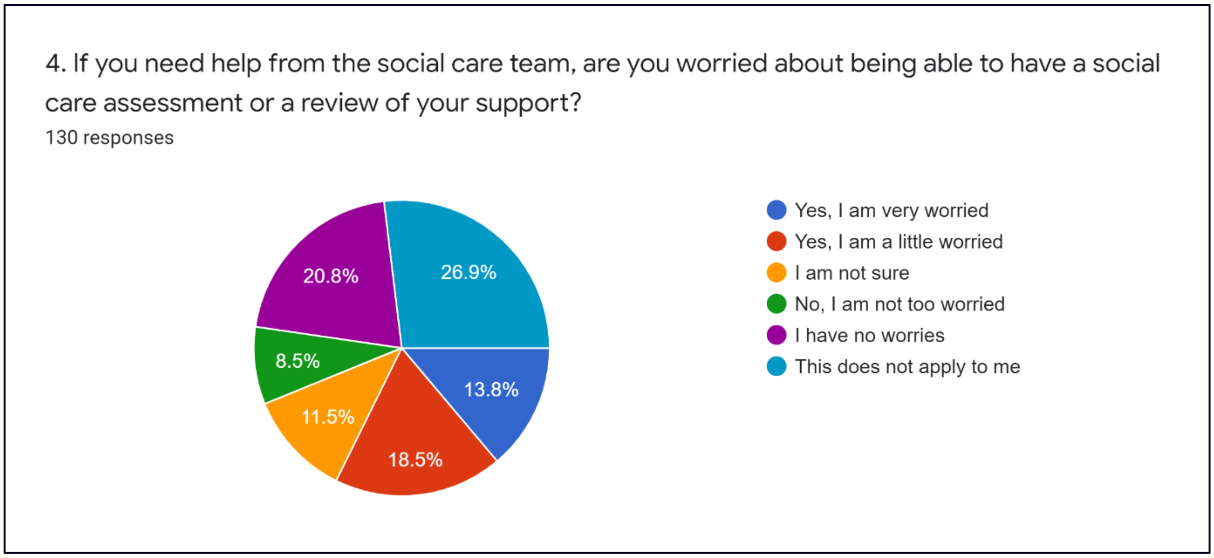
1. If you need help from the social care team, are you worried about being able to have a social care assessment or a review of your support?
2. Are you worried about getting access to advocacy support if you feel you need it? Advocacy is speaking up for yourself or asking other people to speak up for you.
3. If you are an unpaid or family carer, are you worried about the support you receive in this role? This might include breaks from your caring role.
4. If you are an unpaid carer, are you worried about being able to get a social care assessment or a review of your needs as a carer?
5. If you are concerned about getting a social care assessment or review, what are your concerns?
6. If you have support from social care, has the amount of planned support that you have changed in the last year?
7. Please tell us about any changes that have happened in your social care support and how you feel about them.
8. If you have support from social care, please tell us what you think about how much you pay towards this and how this is worked out.
9. If you have wanted advocacy support and not been able to get it, please tell us more.
10. If you have had advocacy support, can you tell us what support you had and how it worked for you.
11. If you are a family/unpaid carer, please tell us more about the support you receive in your caring role. This can be good or bad things.
12. If you are a family/unpaid carer, please tell us your experiences of the carers assessment or review if you have had one or asked for one.

We also asked people what the one thing causing them most concern was, and how they think things could be improved. If this related to Social Care and Advocacy we have included them in this report, along with any other information we were told about regarding concerns in this area.

What did people tell us?

1. **Almost a third of people (32%) said they were very worried or a little worried about getting a social care assessment or review. This was 42 people.**

   36 people said that social care assessments did not apply to them.

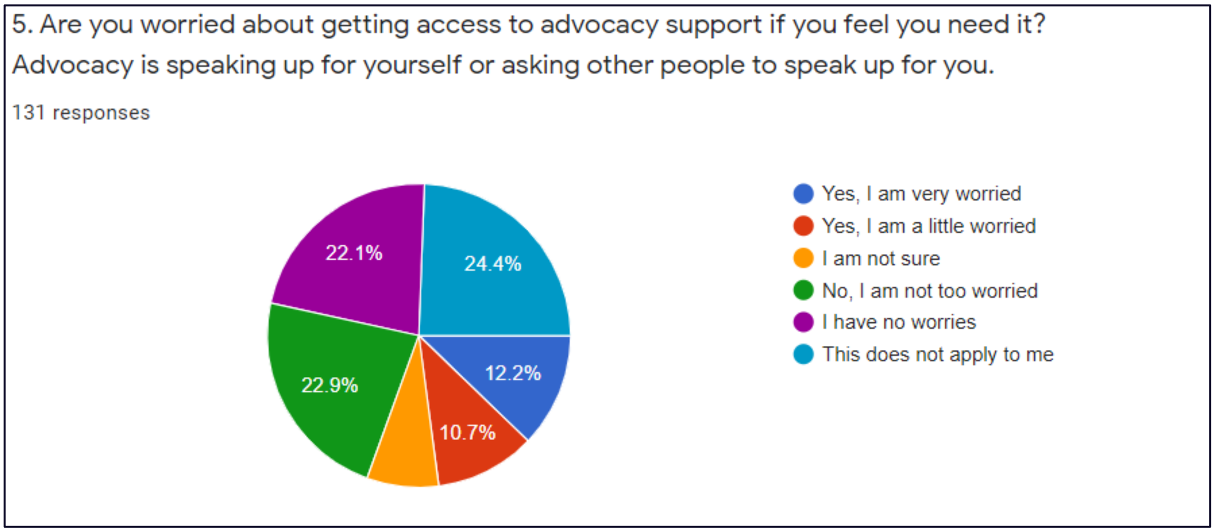


4. If you need help from the social care team, are you worried about being able to have a social care assessment or a review of your support?

130 responses

2. **Under a quarter (22.9%) of people said they were either very worried or a little worried about getting access to advocacy support, this was 30 people. Just under half (45%) said they were either not too worried or not worried at all, this was 59 people.**

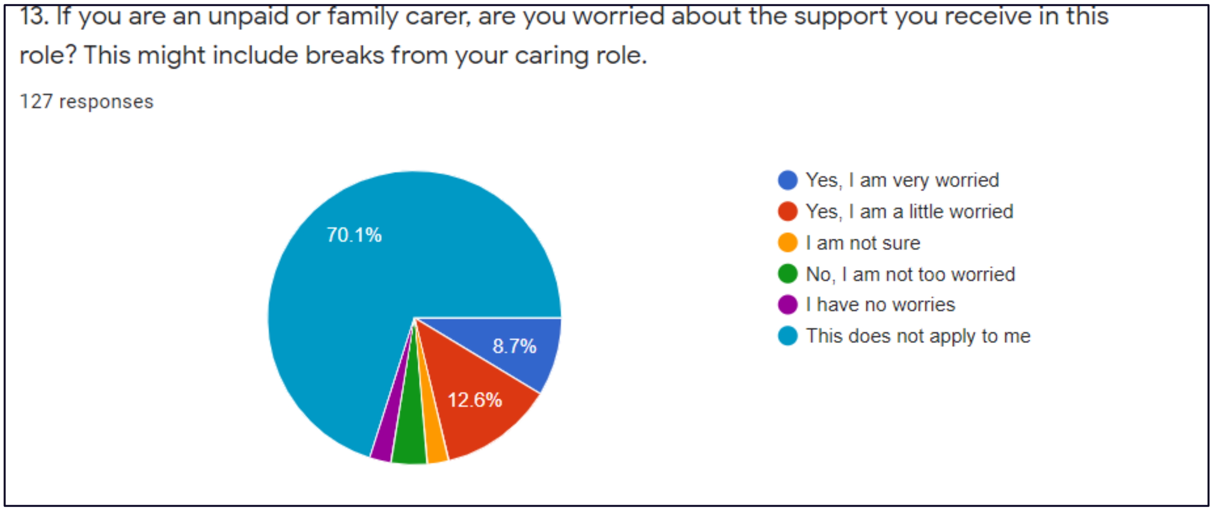
32 people said that access to advocacy support did not apply to them.



5. Are you worried about getting access to advocacy support if you feel you need it? Advocacy is speaking up for yourself or asking other people to speak up for you.

131 responses

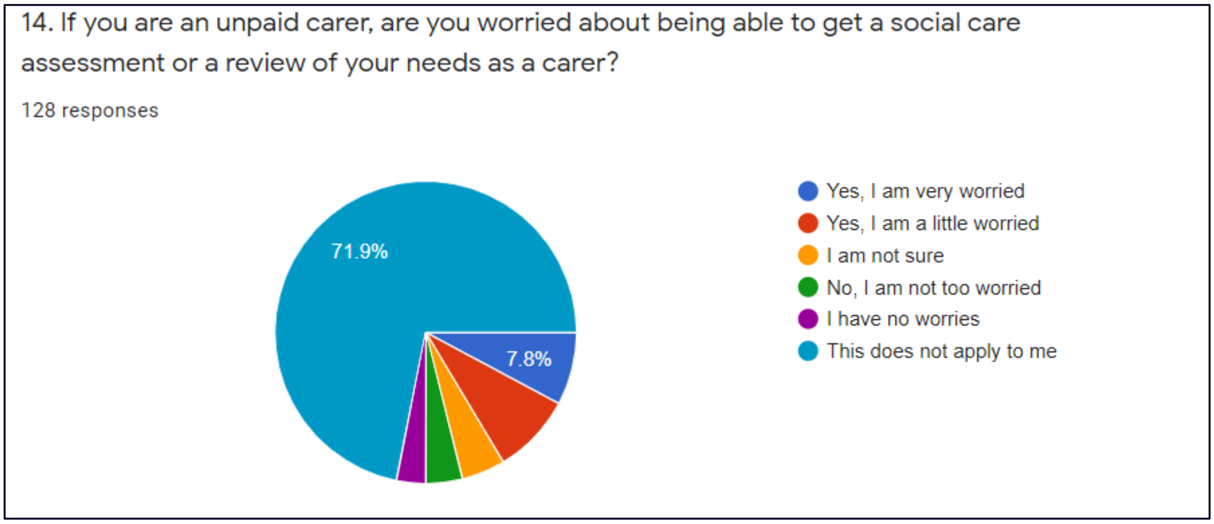
3. **21.3% of people said they were either very worried or a little worried about the support they receive in their caring role. This was 27 people.**
   Almost three quarters of people (70.1%) said that support in their caring role did not apply to them.



13. If you are an unpaid or family carer, are you worried about the support you receive in this role? This might include breaks from your caring role.

127 responses

4. **16.4 % of people said they were very worried or a little worried about getting a social care assessment as a carer. This was 21 people, a high number of those who identified as being an unpaid carer as 71.9% (92 people) said that this question did not apply to them.**



14. If you are an unpaid carer, are you worried about being able to get a social care assessment or a review of your needs as a carer?

128 responses

5. **More than half of the people (52.7%) said they didn't have support from social care. This was 49 people.**

   12 people who answered this question (13%) were not sure if they had support from social care or preferred not to answer.

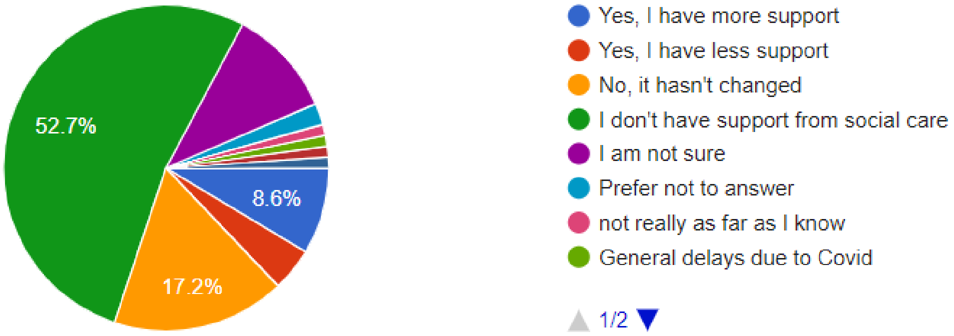
   Of the 32 people who did answer this question (34.3%) and have support from social care:

   - **8 people have more support**
   - **16 people have had no change in their support**
   - **5 people have less support**
   - **1 person was unsure**
   - **1 person noted that there had been delays due to Covid and**

- **1 person noted that they could get support through their sheltered housing**

28. If you have support from social care, has the amount of planned support that you have changed in the last year?

93 responses



28. If you have support from social care, has the amount of planned support that you have changed in the last year?

93 responses

Experiences of Social Care and Advocacy

People told us about their experiences in the areas of social care and advocacy, and we have been able to use this information to explore which areas are common to several people. We discuss these further below.

Concerns with accessing social care assessments

For some people, getting access to social care assessments has been difficult, or has led to an outcome they have not been happy with.

“I may come to need one in the future, but I don’t know what it entails.”
“After the last one which (was) thoroughly underwhelming, I don’t want another one as they refused to support me.”
“I can look after myself at the moment. However, in the future I would have used most of my benefits for my personal care.”
“An assessment of my son’s support needs has been refused despite referrals from multiple professionals. He is a disabled child.”
“Waiting times.”
“Staff say they are overwhelmed due to the pandemic and are dealing with emergencies, so it is not possible to have an assessment or review.”
“I would be worried if I could get one. If I get assessed, I usually get told I can cope. I don’t like assessments over the phone, I prefer in person. Why do they want to do it over the phone? Why can’t they meet my needs? I must insist to my carer.”
“Do not get any social care, could do with some help.”
“Although being a carer, my needs have never been assessed”

Concerns with how social care assessments are completed

For a small number of people, they have concerns about how they were interacted with, and concerns were voiced about communication and attitude. This appears to have impacted on the trust people had in social care professionals and processes.

"I find social workers generally bossy, and they talk to me like a child which I do not like. It's all about funding so I wonder if the people who are doing the assessments have really got the persons best interests at heart."

"Having choice taken away."

"That the council just wants to cut funding."

"Not being believed."

"(I am concerned) that needs will continue to be met and that people have a good understanding of the person being reviewed."

"They don't communicate what is going on. When you talk over the phone you don't know who you are talking to."

"(I am concerned that) either that there's no help available or that they will take a negative view of my living situation and tell me to improve it without understanding that I can't, and I need physical help. (Both have happened to an extent)"

"Being let down by them."

"Because they are going to tell my parents about things I say, and I want it to be confidential. Therefore, I am reluctant to have it."

"I was assessed by conversation 3 and they decided I could live by myself instead of with Shared Lives Carers but I am not able to live by myself and they changed their minds after a year reassessment"

“It’s stopped, so there is less support, it makes things more difficult”

“I haven’t seen my social care worker for at least a year. I don’t know if I need it or need a review”

“(I am concerned) that my ongoing care needs will be met in the future”

Concerns about the quality and quantity of social care support people are receiving

There were some concerns voiced about the availability and quality of staff, and some concerns about support that is no longer available.

“The staff are paid the same money and expected to do more.”

“The company I get support from have had to bring in another care agency to fill in the gaps. The other day the agency was short staffed, and they wanted to send someone I didn't know.”

“Less staff at the moment”

“Only had 1 lady who helped me (named). But she left. So, I don't have any others that I trust”

“Covid infection fear, less support”

“Carers are always saying they are ill or must isolate. They are happy to be furloughed and have taken up other interests like sport or gardening so have no time to work.”

“It’s stopped, so there is less support. It makes things more difficult.”

“I feel uneasy (about the changes in my social care support)”

“Lost swimming lessons through the council-support”

“Due to illness and behavioural changes, no extra support is given, just medication”

“(I am concerned about) not getting the urgent support I need”

“I would like more 1 to 1 hours so that I can be supported to get out and about more”

“Who can I trust for PA help…recommendations would be great”

“(I am) not wanting to contact adult social care in case they reduce my support hours”

“(I am concerned about) managing day to day life and running a house. I can’t manage it and it overwhelms me but there is no help available”

“(I am concerned) if my carer became ill again. Even though I don’t need 24/7, I do need reassurance to do things and to check if things are ok…..”

Views about how much people pay towards their social care

There were mixed responses about the amount people pay towards their social care. There were a variety of different circumstances with some people not contributing towards the cost of their care and others paying an amount, although not all were happy with it.
Some people were unsure if they were paying towards their social care.

“It’s fair”

“It is okay”

“Happy with what I pay”

“I contribute in excess of £100 a week, which I understand to be the maximum contribution. it does reflect the fact that I am a resident in a care home which means that bills and living costs are covered”

“It is expensive”

“It’s a lot of money”

“Carers are not available due to the cost”

“The social care I receive is currently free”

“I don’t know (what I pay)”

“I don’t know because my dad pays”

“I stopped having carers as I couldn’t afford to pay for them out of my benefits”

“I stopped my carers as I couldn’t afford them”

Some positive experiences of social care

“A video call system has been installed in my flat, this lets me see who rings doorbell”
“I have a new support worker who has been more accessible and available to assist me”
“I feel very calm”
“I really enjoy living at (named place) and I don’t want to move. Staff are really kind and helpful to me”

Access to advocacy support

Several people have experienced difficulties when trying to access advocacy support. A few people were unsure about how they could access advocacy, or what it might help with.

“I have recently been told that Advocacy are not able to help me”
“Six years ago, I was not able to get advocacy support, and this caused stress and anxiety.”
“Due to illness and behaviour changes, needed advocacy to support but did not get back to me”
“It is hard to get advocacy support”
“I have a child in care. As it went to court, I need one (an advocate) for this but never happened. As I got scared.”
“I asked for help and not able to get it”
“I found in the past, trouble getting advocacy. One advocate was not helpful”
“I asked for help and not able to get it”
“I don't want to ask because I am afraid to ask for it.”
“I am not sure what this means in practice, but I would probably have benefited from it.”
“There needs to be more advocacy and it should be easier to access.”
“I don't know where to go to get it.”
“There is a huge need for advocacy support when trying to talk to local psychiatric services.”

Experience of advocacy support

Several people shared their positive experiences of having support from advocacy services and the impact that this had.
Others also talked of the importance of support from paid support, family, and friends.

“(Provider) collaborated with me to speak up for reasonable adjustments to my access outside my flat. They supported me with meetings with OT, Grant Officer, Director of Resident Committee, and Surveyor. (Provider) supported with support letters and emails to my MP.”

“(Named person) was amazing in every way… I can find it hard to trust and connect with people supporting me but with her it was easy, and she helped a lot before unfortunately having to leave before we finished our work together.”

“I had to go to court regarding me walking, this (an advocate) helped as I have PTSD”

“Had advocate for GCC assessment. I think she was very helpful.”

“(Provider) are great”

“I had support with replying to social services with a complaint I had. I went to the guy's office, and he typed the letter out and sent it and then let me know when they replied. It worked well”

“Had advocacy support in the past and found it to be extremely effective”

“(Had) Advocacy support in Workplace bullying.”

“I can talk to staff”

“My sister and staff help me”

“A friend has come along with me to hospitals, doctors to help as I feel I am not taken seriously.”

“I would like to thank all of the staff and volunteers at (named provider) for their amazing work, innovative approach and resilience throughout the past few years. I know it can’t be easy but you go over and beyond your roles and responsibilities and I would like to say that it is noticed and greatly appreciated”

Access to carers assessments

Although not many people identified as being a family/unpaid carer, it was apparent from the feedback received from a few people that their access to and confidence in the impact of carers assessments is low.

"I have never requested one as I don't think it would make any difference."

"Not sure it does much except a chat."

"No carers assessment undertaken."

"Not had one as a secondary carer"

"Not sure about this - I've asked for an assessment of my son's needs; this has been refused."

Experiences of being supported as a family/unpaid carer

As above, the number of people who identify as family/unpaid carers was low. Their experiences were largely poor, and concerns were voiced about lack of training and awareness of autism, intimidating staff and bureaucratic systems.

"I did get the vaccine and flu jabs by registering as a carer with GP."

"I found that social workers could be intimidating so it helped to have someone with you. You need to be assertive & have a witness to take notes"

"Staff mostly understand my child, but much more training is needed in autism."

“You must fight for everything, then you are told that there are no resources for support. Sometimes what you are told is not true, maybe this is because the workers don't know the truth or maybe they have been told to say untrue things by their managers to protect resources. More resources should go in to preventing crisis and offering personalised care, by looking "outside the box" at innovative solutions often the cost is much less however the services seem to be ruled by bureaucracy and "the computer says no"

“I would argue that blindness is probably the biggest disability. But no support for carers”

“Unpaid carers count. I don’t know why they are not included in reports/facts/figures/surveys. They should be. They are important too.”

Other Research

Some of our findings in relation to social care and advocacy are similar to other research and information gathering.

For more information, please see the following reports:

Social Care

1) **Warwick University: "What we know about Supports and Services from people with a learning disability"**

https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave3results/easier_to_read_briefing_-_support_and_services.pdf

2) **Warwick University: "What we know about Physical Health and Well-Being from people with a learning disability"**

https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave3results/easier_to_read_briefing_-_physical_and_mental_health.pdf

3) **Barnwood Trust, "Our Changing World: A Report into disability and mental health in Gloucestershire during the COVID 19 pandemic"**

https://www.barnwoodtrust.org/wp-content/uploads/2020/09/Our-Changing-World-Exec-Summary-v6.pdf

4) **Social Care Institute for Excellence: "Negative Impacts of Covid on Social Care"**

https://www.scie.org.uk/care-providers/coronavirus-covid-19/beyond/adult-social-care/negative-impacts

5) **Community Care: “Budget cuts planned for social care”**

https://www.communitycare.co.uk/2021/03/11/budget-cuts-planned-social-care-councils-count-cost-pandemic-public-spending-watchdog-finds/

Advocacy

1) **Advocacy Project: “Valuing Voices and Protecting Rights Through the Pandemic and Beyond”**

https://www.advocacyproject.org.uk/wp-content/uploads/sites/19/2020/10/Valuing-voices-protecting-rights-through-the-pandemic-and-beyond-Oct-2020.pdf

Recommendations

- More accessible information, in a variety of formats, needs to be available about how to access a social care assessment.
- Additionally, clear information needs to be available about what is involved in the assessment and review process and what standards and timescales individuals should expect.
- Clear information needs to be available and shared about individual's rights and entitlement to support, to reduce fear around support being inappropriately reduced.
- Individuals should be given the opportunity to have assessments in person rather than over the phone, as a reasonable adjustment, where possible.
- Clear and accessible information is needed regarding when and how people may need to pay towards their social care and how this is worked out. (N.B. The current policy on the website of Gloucestershire County Council is dated October 2016 and states it is under review).
- Training needs to be undertaken by all frontline social care staff around communication and attitudes when working with individuals facing disabling barriers. Training such as Oliver McGowan Mandatory Training would be appropriate.
- Information about support to recruit Personal Assistants (PA's) (in particular about the Glos Assistants website) should be shared more widely, and with all individuals assessed to have care and support needs
- Clear and accessible information about advocacy needs to be available in a variety of formats.
- Consideration should be given to providing more funding and resource to advocacy services, in order to meet unmet need around advocacy support. These findings suggest that this should be a funding priority.
- More accessible and available information is needed in relation to carers assessments and the support available to family/unpaid carers

What Will Inclusion Gloucestershire Do Next

We will share this report with providers of health and social care services in Gloucestershire and with other local organisations and groups.

The report will be available on our website, publicised on social media and shared with individuals who were part of the survey and gave us their contact details.

We will ensure that in all forums in which we are involved we share the experiences and recommendations with decision makers. This includes connecting with the following workstreams and groups:

- **Learning Disability Partnership Board**
- **Physical Disability and Sensory Impairment Partnership Board**
- **Autism Partnership Board**
- **Carers Partnership Board**
- **Mental Health and Well Being Partnership Board**

We will continue to actively engage with people who face disabling barriers to seek their views and experiences in relation to healthcare via our Speak Up Groups; MHELO (Mental Health Experience Led Opportunities) Focus Groups; Inclusion Hubs; our user led Quality Checking visits and our regional network of self-advocacy groups.

If you would like any information on any of the above activities, please visit our website or contact us on the email below:

https://www.inclusiongloucestershire.co.uk/our-services/
info@inclusion-glos.org

We will implement the organisational specific recommendations highlighted above and work in partnership with others to achieve the system wide recommendations.

And finally, thank you!

We would like to thank everybody who gave their time to complete our survey and share their experiences with us.

We would also like to thank our small team of volunteers who have given their time and insight to enable us to present peoples experiences in this report.

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