Full
Report

OUR
CHANGING
WORLD

A report into disability and mental health in Gloucestershire during the Covid-19 pandemic

barn
wood

Our Changing World

Experiences of Disabled People and People with Mental Health Challenges in Gloucestershire During the Covid-19 Pandemic

Contents

Introduction

The Covid-19 pandemic is impacting on the lives of Gloucestershire residents in many ways. Emerging national evidence indicates that disabled people and people who have mental health challenges are being disproportionately affected by the crisis[1] [2] [3].

Barnwood Trust has undertaken this mapping exercise to help further an understanding of the impact the pandemic is having on disabled people and people with mental health challenges in Gloucestershire. Previous research and work to define the Trust's organisational response to Covid-19 identified six groups as being particularly likely to be disproportionately impacted by the pandemic. The mapping exercise focused on gathering information about the experiences of people within these groups. That is:

- Adults with mental health challenges
- Children and young people with mental health challenges
- Learning disabled children, young people and adults
- Physically disabled children, young people and adults
- People with sensory impairments
- People at risk of domestic abuse

In light of evidence that Black, Asian and Minority Ethnic (BAME) communities are being disproportionately affected by Covid-19[4], this project has included seeking to understand issues that are particular to different parts of the BAME community as an important element. People at risk of domestic abuse have also been included in this study as ONS data published prior to the pandemic indicates that disabled adults are three times more likely than non-disabled adults to experience domestic abuse[5]. The study also pays attention to the challenges being experienced by homeless people, in recognition of the link between homelessness and mental health[6].

The purpose of the mapping exercise is to help:

- Prompt immediate action where disabled people and people with mental health challenges are being disproportionately impacted by the circumstances relating to the pandemic.
- Ensure that in the instance of future lockdown measures or another outbreak of the virus in the medium-term, Gloucestershire is well prepared to ensure that disabled people and people with mental health challenges can keep strong and retain their rights and choice about their lives.
- Inform a comprehensive understanding within Gloucestershire about the circumstances which meant that disabled people, people with mental health challenges and communities kept strong throughout the pandemic, in the hope that

this will lead to long-term change in how communities, services (including statutory services) and individuals interact.

The mapping exercise drew on several sources of data to build a picture of individuals' experiences: their concerns and the challenges they have faced; what has helped them to maintain their mental and physical health; and the support and services they have and have not been able to access. Voluntary and Community Sector (VCS) organisations working with people in the six groups provided accounts of the experiences of the people they support, either during group conference calls or in their responses to questions sent via email. They also facilitated case studies being contributed directly by disabled people and people with mental health challenges, as well as by various frontline staff. Disabled people and people with mental health challenges who are engaged with Barnwood Trust's work told us about their experiences during conference calls, via an online form and/or by providing case studies. Representatives of statutory organisations also provided information during conference calls. The information gathered was analysed and key themes were identified.

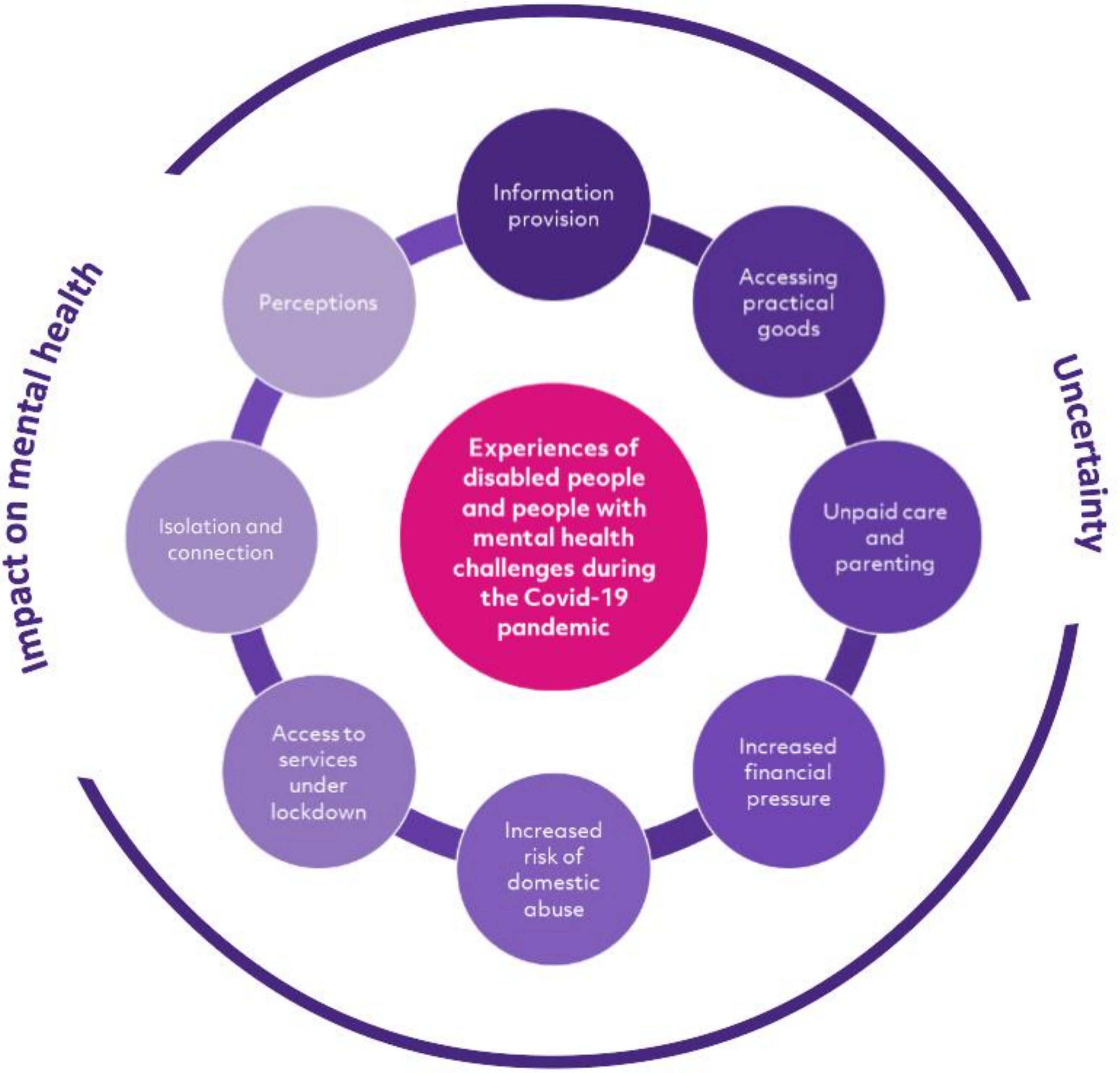
This report includes three sections:

- Section One provides key contextual information, including an overview of the ways in which life has changed for disabled people and people with mental health challenges as a result of the pandemic.
- Within Section Two, key challenges and concerns, and the ways in which individuals have navigated these, are explored.
- In Section Three, findings related to future concerns are presented: concerns about the easing of lockdown, anticipated demand for services and the consequences for people's mental health.

A key aim of this work was to provide a holistic picture of people's experiences. Each of the key themes in the data has been described to inform an understanding of the issues, however in many of the examples given an individual was impacted by more than one issue or challenge. A number of case studies have been included in the report to help provide a holistic picture and highlight the importance of considering individuals' experiences in totality. Where these case studies are included, names have been changed to help ensure anonymity

It is also important to note that the aim of this mapping exercise was not to be able to make generalisations about the impact the pandemic is having on people within the six groups, but rather to begin to build a picture of their experiences. The views of a larger, and representative, sample of individuals would be required in order to be able to make definitive statements about the disproportionate impact the pandemic is having on specific groups.

Whilst this report has sought to highlight the views of a variety of disabled people and people with mental health challenges in Gloucestershire, we are also aware that it primarily reflects the experiences of individuals living in the community, and not those living in residential settings or who may lack capacity (including those with dementia). There is the scope for further studies to document the challenges being experienced by these individuals during the pandemic.



Section One:
How the World Has Changed

Setting the scene

Research carried out prior to the current pandemic has highlighted a range of existing health inequalities for disabled people and people with mental health challenges in Gloucestershire.

Estimates about the number of disabled people and people with mental health challenges in Gloucestershire vary (in part depending on how such terms are defined) but recent figures suggest that there are **106,809 disabled people** living in the county (16.7% of the population) and **75,012 people with a mental health challenge**[7].

At a more local level, the **Forest of Dean** and **Gloucester** rank as the first and second most deprived of the county's six districts and they are also the two districts with the highest proportions of disabled residents (at 19.6% and 16.8% respectively)[8].

Specific health inequalities highlighted by Public Health England data have included **higher rates of admission of hospital admissions for self-harm by young people** aged 10-24 in Gloucestershire than the England average[9].

The 2011 census also found that Gloucestershire residents with a long-term limiting illness or disability were more likely to be **providing unpaid care** than those in the county without such illnesses or disabilities. Furthermore, amongst people aged 65+, **Asian people and Black people** were more likely than people from other ethnic groups to have **a long-term limiting illness** and be in **poor health**[10].

These statistics give a sense of some of the challenges being experienced by particular groups of disabled people and people with mental health challenges prior to the current crisis.

How life has changed for people in Gloucestershire

Looking holistically, the findings from this study about the **multiple challenges** that disabled people and people with mental health challenges are experiencing indicates that **everyday life has changed** for people in **three different domains**: at home, going out, and in getting support.

Further to this, many participants also described two **overarching challenges** of **uncertainty** and **impacts on mental health as** being experienced in addition to the range of specific challenges affecting different domains of everyday life. As a result, discussion of these two challenges is interwoven throughout different parts of section Two which looks at particular themes in more detail.

Everyday life

The multiple challenges being experienced by disabled people and people with mental health challenges can be understood as having changed everyday life in three different domains.

This included:

1. **At home**: A changed home environment due to challenges of accessing practical goods (such as food and medicine), financial challenges, providing extra unpaid care, feeling isolated, and rising tensions and the risk of abuse.

   Challenges experienced **at home** were described as **interconnected** with each other. For example:

   - Financial pressures causing increasing tensions at home and the risk of abuse
   - Lack of access to and barriers to using technology presenting an additional difficulty in maintaining social connections
   - Parents of disabled children needing to provide them with additional care due to challenges obtaining PPE

2. **Going out**: A changed experience when going out due to challenges around social distancing measures not being accessible. For example, due to guide dogs being unable to follow distancing rules at shops, and parents of children with learning disabilities being unable to take children with them to the supermarket.

3. **Getting support:** A changed level of support due to challenges of a lack of accessible information, services (such as routine therapies and mental health services) being cancelled or postponed, and extended family members being unable to provide unpaid care.

Challenges to **going out** and **getting support** could **compound** the challenges being experienced **at home**. Participants told us of:

- Routine therapies for disabled children being stopped and respite breaks cancelled, in addition to parents having to provide extra unpaid care
- Face-to-face mental health services being cancelled or moving online, on top of a lack of access to and barriers to using technology
- Unclear and confusing government guidelines and distressing stories in the media, on top of living alone or being isolated.

Overarching challenges

Two key **overarching challenges** described by many participants were feelings of **uncertainty** and **impacts on mental health**. Looking at these in more detail, it is possible to see how the range of different challenges bringing about changes to everyday life contributed to these broader challenges.

Uncertainty

General concerns about the length of the lockdown and the potential for a second lockdown were highlighted by respondents. Specific questions causing **uncertainty** for disabled people also featured in many discussions about individual challenges such as **accessing basic goods**, **services**, and **information**.

Some of these related specifically to risk from the virus, for example: do I or my disabled child need to shield? If so, how long for? If I contract the virus, am I eligible for treatment?

Many also voiced concerns about future support they may receive, asking: will my cancelled medical appointments be resumed? How will socially distanced environments be managed? Will the supply chain of my medicine be affected?

There were concerns that disabled people and people with mental health challenges may be left behind as lockdown lifts, causing increased isolation.

Impacts on mental health

A striking finding of this study was that disabled people with a wide variety of impairments – not just people with pre-existing mental health challenges – told us about impacts the current crisis is having on their mental health.

Loneliness, isolation, and anxieties stemming from uncertainty (as described above) were contributing factors impacting on people's mental health. For some, the experience of lockdown worsened existing mental health challenges, including those who have previously experienced trauma. Some factors, such as isolation, which were impacting on people's mental health were described as being due to social distancing guidelines not being accessible for disabled people (e.g. not being able to lipread due to use of masks). These challenges also coincided with concerns about access to mental health services, with barriers caused for some by a move to online support.

These two overarching challenges of **uncertainty** and **impacts on mental health** are threaded throughout the report to highlight how they were described as interwoven within many different aspects of everyday life.

Case studies

Looking at the case studies gives us a sense of how this range of challenges in different domains has been experienced in the lives of particular disabled people and people with mental health challenges in Gloucestershire. Below are two examples of the experiences of Gloucestershire residents.

Case Study: Douglas

Douglas lives in the Cotswolds. He is registered blind, since having a brain tumour a few years ago, and he experiences mental health challenges. Douglas lives alone.

"I felt ok at the start. I didn't expect how long it would last or how restricted I would be. My initial concerns were around shopping, food, and speaking to friends and family, but that's been ok. I started on 'Slimming World' the week before lockdown. The meetings have continued as Zoom calls which have been a boost to get the support online. The weekly Zoom calls and messages from the group leader have been a great source of support. June is an especially tough time for me as it is the anniversary of my Dad's death and being in lockdown has given me a lot of time to think. This support, texts and calls from the 'Slimming World' group leader has been very important.

I have been walking every day; either combining it with a trip to the shops or going past friends' houses to speak from doorways. I have found it really helpful to get human contact. I have daily phone calls from a friend, to check in that I'm ok. I live alone without a garden."

(Continued below)

Case Study: Douglas (continued)

"I have had a few issues keeping socially distanced. One incident was when I was trying to put my prescription in my bag, and someone tried to help me but I told them they couldn't touch me or come close and they were rude about it. I have had issues with people walking across me, going the wrong way down one-way systems in shops, shelf-stackers not staying 2-metres away etc. I had a positive experience at a chemist's where the staff were very helpful, they stopped me at the door and told me when it was safe to enter and then took me to the check-out to help me pay.

Re: getting food delivery slots, it's been difficult. I got a letter from the CEO of a supermarket saying they were making slots available for me but whenever I checked there wasn't anything available. Someone told me I had to check after midnight as apparently this is when they release more delivery slots, but this didn't work for me either. There has been no information available as to how vulnerable people access these delivery slots. I gave up in the end.

A local financial support organisation has been in touch. I was referred to a local community charity and I think that financial support organisation got my details because I filled out a request with the help hub. I was asked if I needed anything urgently and had bread and milk delivered the same day. Friends have also done my shopping for me. It was hard at the start as I didn't know how to access help, but that has got easier.

Lots of voluntary organisations have been a big help and I have felt supported by my local community. The local Community Response is a Facebook group that my friend set up. I was approached to see if I needed help, but I also offered to help others through this. I was helped to fill out the form over the phone. I offered to help with teaching children who are off school, and with languages as I am fluent in French and Spanish, and I have tried to think of other skills I can offer, as well as offering to do printing for people.

I received a letter to say I was on the 'shielded list', my doctors surgery followed this up with a phone call to check I had the letter and understood. They had to check the reason for me having to be shielded and this was confirmed as being due to me having blood clots on my lungs in the past. The communication with my doctor has been good and I'm very happy with my GP surgery.

(Continued below)

Case Study: Douglas (continued)

"I have had hospital appointments cancelled or moved to be phone appointments. I was due to have nerve conductor tests and an MRI which have been cancelled, I am waiting for new appointments. Communication has been good although I do have to keep requesting that letters are sent in large print for me.

Being in touch with friends on the phone and over Facetime, Skype etc. have helped. My friends who live locally walk round and wave and ask after me. My immediate neighbours who I talk to have invited me over to their split-level garden which I have felt safe to do.

I hope things will change soon, as I am desperate to be able to socialise and interact with other people. I don't want it to go back to how it was before though, and I won't stay in all the time; I want to make the most of life. I have realised what I've missed by staying in and I want to make the most of life and freedom. I also want to try and participate more in local groups etc. I used to do lots of things but since Dad died two years ago, I've become more reclusive (it's only been 2 years). On the anniversary last year, we did a memory walk around villages where my dad used to live. I don't know what will be possible this year but hopefully a socially-distanced picnic.

I feel that the community around me has been very helpful and supportive. I felt on my own at the start but the more people I spoke to, and the more I found out, I realised how much support is out there. I only feel isolated by the fact that I live alone."

This case study was provided by a Gloucestershire resident.

Case Study: Harriet

Harriet lives in Cheltenham. She has cerebral palsy, is in her fifties and lives alone.

"At the moment I'm trying to get access at the back of my flat. Before the pandemic, the NHS had given me an electric wheelchair to get out and about, but I need a ramp. A voluntary organisation has been helping me get access but we're waiting for the committee here to give approval. They will give me a grant for the door, but they won't give me a grant for the walkway, as it's a communal grant.

(Continued below)

Case Study: Harriet (continued)

“I’ve been in this flat for about 16 years, I have cerebral palsy. My mobility isn’t as good as it used to be, that’s why I need an electric wheelchair, I felt like it was time to have one, to give me more independence. I got the wheelchair about 2-3 weeks before the lockdown. The voluntary organisation has been supporting me, and they’ve been fighting my case. That’s one of the things they’ve been helping me with, they’ve been wonderful.

When the lockdown happened, I started to get symptoms, I was very poorly for about 6 weeks. I had to call a doctor; I was getting a lot of pains in my chest and had 2-3 weeks of hardly any sleep. The voluntary organisation were so good and kept in touch with me, and one of their volunteers checked up on me and would call me to see how I was getting on.

I had a holiday booked, and that was another problem I had. There’s a company who take disabled people on holiday. Last year I went with them to Wales, and I decided it was time to book a holiday abroad. I was due to go in April but unfortunately it was cancelled. I’ve had a lot of problems getting a refund. I wanted to get out there and meet new people, because I’m quite isolated, but when that happened, I spoke to the company they said they can’t give a refund for a couple of months. I was getting quite upset. The voluntary organisation spoke to them on my behalf. After 2-3 weeks of chasing I got my money back. Getting hold of these companies is not accessible for disabled people, there’s a communication barrier.

One of the good points about what has happened recently is virtual meetings. For someone like me it’s a new way of working, we can see one another – if you’re speaking to someone on the phone it can be quite difficult, so one of the things that maybe should come out of this is that companies should have a link to arrange a meeting. The credit card company did have links for people who are hard of hearing, but it helps for people to be able to see me, it would be good if banks could offer that service.

Another organisation that I’m involved with is a local college. I was a student there in the ‘80s. I’m a part of their advisory board, and we have virtual meetings now and I try to make suggestions on how to improve things.

The biggest frustration of it all has been the food deliveries. The local hub, they’ve been doing shopping. Before lockdown I always did my online shopping from one supermarket, but since lockdown I’ve been unable to get an online delivery slot. I wrote to them, but because I’m not classed as ‘at risk’ I can’t be a priority. I think that’s wrong.”

(Continued below)

Case Study: Harriet (continued)

"I've spoken to my GP surgery about it. One supermarket does a delivery; you can ring them up but it's only on certain items and that's no good for me because of my physical disability. I like to choose ready-made meals, or fresh fruit that is already prepared, but that's not on their list.

At the moment, I get a volunteer from the Council, they ring me up and I give them a list of things to get me. The Council phone me once a week, although sometimes they forget, recently they haven't been reliable. They delivered me some frozen ready-made meals, but they sent me 3 of the same, so there's not much variety but going back 4-5 weeks there was more variety. I noticed on Deliveroo that another shop is now doing Deliveroo food slots. I'm very worried, because you have to be careful with the packaging in case you catch the virus.

I live on my own, and when I had the symptoms, they wouldn't test me, because at the time they were only testing people who went into hospital, so it's been frustrating because I don't know if I've had the virus or not. I'm quite isolated and I haven't been out since the lockdown, apart from in my garden.

I have good days and bad days. I've been working for a user-led organisation. I read a lot of books through Audible, I do exercise and watch TV. I do get very lonely, but I'm trying desperately to make sure I have a structure to my day. At least I'm a lot better now. Unfortunately, I haven't had my cleaner come in, so I've been trying to do a bit at a time, I slowly do my housework. Normally I have a duvet cover, but because I can't put the cover on my duvet, I bought some fleece blankets online, and I can just about manage to put a clean sheet on the bed.

Before the lockdown, a local voluntary organisation has tried in the past to see if I can get a carer, but they say I don't meet the criteria, because I can do my personal care by myself and can warm things in the microwave. Because I've been coping for many years, I have found ways to overcome things. Before my Mum died 4 years ago, she would help me a lot and support me, but I don't have her anymore. I need a cleaner, but I have had to accept that, unless I need personal care, the care provider won't help.

(Continued below)

Case Study: Harriet (continued)

"I think it's going to be very tricky for me after lockdown. Social distancing is going to be the problem. Before I would go to the cinema, meet a friend, go to the pub. What's really important to me is I need to get this access for my wheelchair, but the lockdown has delayed that result. I feel very isolated and I haven't been out since the end of March, which everyone says, 'Why don't you get in the car and go somewhere?', which I will do but I'm being very careful, and if I break down anywhere I have to make sure I have a mask. When the shops open, I don't know if Shopmobility in Cheltenham will open, what the shops' guidelines will be, and how accessible it will be to get around in a wheelchair and maintain social distancing. Some shops have special times for certain people to go in, that could be one way to help accessibility.

Maybe if local organisations could have online meetings. I know there are a lot of quizzes at the moment but that's not my thing, I need something a bit more fun. Maybe exercise, like meditation, or just having a conversation. Another thing is maybe having online dating for disabled people, or maybe like an online disco or something. My achievement whilst in lockdown was a virtual job interview. I am delighted that I am successful in gaining a new job at a user-led organisation. My new role is to support people on one to one and group sessions. I desperately need to get wheelchair access to my flat so I can carry out my new role independently.

The lockdown has taken my independence away. Volunteers are very good, but it's not the same as doing it myself."

This case study was provided by a Gloucestershire resident.

Section Two:
Navigating a Changed World

Eight key themes were identified in the accounts provided by VCS organisations and individuals that participated in the study:

- Information provision
- Accessing practical goods
- Unpaid care and parenting
- Increased financial pressure
- Increased risk of domestic abuse
- Accessing services
- Isolation and connection
- Perceptions

These themes are explored in detail in this section. It is interesting to note that, although the core questions we asked both the VCS organisations and individuals included, 'What is keeping people 'strong' or helping them to cope?', relatively little was shared about this in relation to the volume of challenges and concerns that were raised.

Alongside relaying what they knew about individuals' challenges and concerns, many of the organisations told us about their work to support people. Information about organisations' work has been included where we believe it may be useful in providing context or informing plans for any subsequent lockdowns.

Information Provision

The findings of the mapping exercise indicate that disabled people and people with mental health challenges have experienced significant difficulties associated with information provision.

Lack of information

Concerns regarding a lack of information about Covid-19 and sources of support were raised. One VCS organisation, for example, reported that there had been a lot of concern around the lack of information and advice for families caring for children with serious illness. Another organisation reported that people were very unsure of where to get things. During a recent 'ring around' of approximately 250 clients, this organisation had been asked a wide range of questions related to finding things.

Examples of **people missing important guidance from the government** were also cited. One organisation, that supports Deaf and hard of hearing people, highlighted that access to information was an issue for British Sign Language (BSL) users and profoundly Deaf people. This organisation reported that some of the people they support were five to six weeks behind in terms of accessing information. They provided the example of a client who, at the end of April, had asked "Can we go out?" and "How long for?". This was more than a month after relevant guidance from the government had been made widely available.

One of the organisations identified ensuring that the Deaf community have information about what to do when they go to hospital as a particular difficulty. They stated that going to hospital was currently a massive barrier for the Deaf community, highlighting that the use of face masks in hospitals prevented people from being able to lip read. This organisation also reported being aware that lots of Deaf and hard of hearing people were **lacking information and isolated**, and that these two things **combined were having a negative impact on** the **mental health** and wellbeing of this community.

Organisations also highlighted the **need to raise awareness of available support** and possibilities that may help to alleviate people's mental distress. An organisation supporting people in suicidal crisis presented the following example related to people who have experienced trauma:

> Lockdown may exacerbate post traumatic symptoms for people who have experienced trauma because it replicates aspects of the original trauma, such as feeling powerless and trapped. This may lead to the individual experiencing suicidal thoughts. It would be entirely appropriate for someone in this situation to get permission from a GP to leave their home more frequently, yet many people were not aware of this possibility during the phase of strict lockdown.

Another organisation reported increasing frustration that people in need were not receiving the message that some counselling services, such as the service they offer, were still operating. They commented that, despite contacting them about this, their MP was only giving out national information: local information was not being distributed.

Accessibility of information

The issue of a lack of information is closely linked with the accessibility of information: a theme that was particularly evident in the accounts of the experiences of people who have sensory impairments. Issues related to the accessibility of information were reported to be impacting on people's knowledge and understanding of both current government guidance and where to find support.

The following challenges experienced by Deaf and hard of hearing people were highlighted:

- Many organisations communicate and provide information via text or phone. Deaf people and the hard of hearing community cannot necessarily make telephone calls to access services.
- Face masks present a barrier in terms of lip reading.
- One organisation told us that they were aware that it was not possible to communicate with anyone in Gloucestershire County Council (GCC) via any visual means, as GCC employees were not able to use platforms such as Zoom, or Microsoft Teams on their work computers.
- The government has not provided BSL interpreters for state announcements. One of the organisations commented that not providing interpreters for the daily briefing demonstrated that Deaf and hard of hearing people were very low on the priority list for access to information.

One of the organisations reported that access to information was particularly difficult for profoundly Deaf people.

A specific challenge encountered by people who have sight impairments was also stressed: Letters about Covid-19 from Gloucestershire County Council (GCC) and the NHS were not necessarily being sent in large print. It was perceived that GCC and the NHS were not linking up with sight registers to make sure people were receiving communications in braille, large print or audio versions. There were also concerns that statutory services did not understand that communication is vital for people who have sensory impairments.

Although particularly evident in the accounts of the experiences of people who have sensory impairments, **challenges related to the accessibility of information were widespread**. For example, one organisation was aware that people had not been able to read letters due to poor literacy, which had been very distressing for these individuals. They linked this difficulty with the fact that many advice organisations had very quickly closed their doors after lockdown began. Another organisation told us that they were aware of people who have had **difficulty understanding the guidelines**. They gave the example of volunteers who had been shopping for a man who has learning difficulties discovering that he was going out to shop for his sister. Another example given was an autistic man who was

One of the organisations told us that some of the young people they work with have been reliant on others to interpret and share information. Members of their team were beginning to improve their skills in Makaton, a unique language programme that uses signs, symbols and speech, to support these young people to be independently communicating with them.

struggling to understand why he cannot go to his mother's home for fortnightly visits as he did before lockdown.

Referring to social distancing guidelines, it was highlighted that there were people in the county who would not be able to understand how far 2 metres or 6 feet was. One organisation reported recently seeing easy read information that spoke about ***"three big steps"***. They believed that if this had been used in guidance about social distancing, people's confidence in understanding the requirements would have been very different.

One of the organisations reported that they had been working with partners to use iPads for interpreters in hospital. This was requiring a considerable amount of time: they had spent hours with one client explaining how the system works. Providing this explanation remotely was challenging, and there were additional complexities when clients had not used an iPad before.

The case study below provides an example of one of the challenges associated with accessing information.

Case Study: Mary

Mary lives in Cheltenham. She has a learning disability, dyslexia, problems with balance, severe arthritis associated with psoriasis and may be experiencing mild depression. Mary is in her forties and lives alone.

"Mary was unable to read the information sent to her to tell her to shield for three months. She takes medication which means her immune system is compromised. She eventually received a phone call from the GP's surgery to make sure she understood.

Mary is very conscientious and tries hard to follow rules. She gets very anxious about domestic issues, for example: how to replace a light bulb; whether she should leave the flat to go to another part of the building to check her electricity meter; whether she has enough money to manage. Ordering food is not easy for Mary as she is used to going to the local shop. She was promised a hamper, but she did not receive one. There was also a problem with Universal Credit – she usually has a part time cleaning job in the summer, but this was cancelled this year.

Mary spends much time watching television and listening to Coronavirus stories. The Warden of the flats speaks to her on the phone occasionally and she talks to her parents who I think are elderly and in need of support themselves. She has a volunteer friend through our organisation who contacts her at least three times a week and who provided food parcels at one point. She has also been contacted by a disability employment support service."

Lack of clarity in communications

Lack of clarity in communications was another theme that was evident in the reports of the experiences of disabled people and people with mental health challenges.

A representative of statutory services reported that there had been **confusion about the shielding list**. They explained that there were a lot of people who thought that their cared for person should have been on the shielding list, but they had not received a shielding letter. Then GPs started identifying and calling people who were 'vulnerable', so people were told that they were vulnerable during these telephone calls, but there was confusion about whether that was the same as being on the shielding list. An organisation that supports carers reported that they had been telephoning vulnerable people, and this had helped to alleviate the confusion for carers.

An organisation that works with adults who have mental health challenges and people experiencing domestic abuse commented that the **messages in the media have been thick, fast and changing all the time**, and it has been hard to keep up. The people they work with have therefore found it valuable to have someone they can ask when they do not understand, or they need help. This organisation has continued to provide a variety of advocacy services during lockdown. They believe this has been equally as important as doing shopping etc. for the people they support. They reported that a lot of advice organisations had ceased to operate early into lockdown and they are aware of people who have not known what to do, which has caused these individuals distress. They highlighted the **need to help people to navigate through the confusion**. They also reported that some people had been bombarded by different organisations: for some people, there had been a surplus of contact. The same organisation reported that 'the government boxes' had caused confusion: people who received them did not know why they had been sent one or who had sent it.

The need to moderate the effects of exposure to negative information about Covid-19

Exposure to negative information, or **bad news**, about the pandemic was reported to be **affecting people's mental health**. During discussion with organisations supporting people with sensory impairments, there was acknowledgement that people needed information about Covid-19, but also agreement that it was **important to balance** this **with activities that lift people's spirits** to help prevent negative impacts on mental health. Reflecting on their experience of both being a very hard of hearing person and setting up a community support initiative in response to the pandemic, one individual shared that it was wrong to assume that what people want is just information: people need information about Covid-

19, but for those people only accessing information via subtitles on television, or via telephone, that is all they are receiving and *"constant doom and gloom"* is affecting their mental health.

One of the disabled people we spoke to told us that they were limiting their exposure to news about Covid-19 because of the negative impact this information was having on their mental health. This individual explained that they kept updated via a specific website, choosing what they wished to read, because they could not cope with watching the news.

One of the organisations set up a community support initiative in the Cotswolds to help tackle isolation. The aim of this initiative was two-fold: to provide information about Covid-19 and lift people's spirits. They have taken the approach of providing information via post, rather than phone, as they think many of the people they wish to reach will not want to struggle with the phone at the moment. The organisation has also been putting something through people's doors, such as puzzles, jokes or poems to lift their spirits and keep them entertained for an hour or so during the day. They believe this approach has been successful: they have found that this is helping people and is lifting their spirits.

Accessing Practical Goods

Challenges reported in terms of accessing practical goods predominantly related to obtaining three types of basic items: food, medication, and PPE. Each of these areas is explored in turn below, alongside potential solutions which had been identified and in some cases were already in place.

Access to Food

Obtaining food was a widespread challenge for people with a range of different types of impairment.

Barriers to acquiring food included being unable to **access protected supermarket hours and delivery slots**. One organisation which supports people experiencing acute mental distress, highlighted that individuals with long-term mental health challenges (such as bipolar disorder or being profoundly depressed) would usually be classed as being disabled or vulnerable. However, during the lockdown, these individuals have not met the **eligibility criteria** for accessing protected shopping hours and delivery slots.

Struggles to access shopping slots online were also highlighted for individuals with a range of other impairments, including people with acquired brain injuries and wheelchair users. One wheelchair user, who also experiences mental health challenges, spoke of how they had only been able to access a delivery slot after members of a fellow support group on social media had shared the contact details for a supermarket which are not usually publicly available.

Examples were also shared by VCS organisations of schemes and initiatives which have supported disabled people and people with mental health challenges to access food during the lockdown. Hyperlocal schemes by shops to deliver food boxes were highlighted as well as hot meal deliveries supplied via the Community Meals scheme (subsidised by Gloucestershire County Council) and via two VCSE organisations. The availability of hot meals was highlighted as crucial by one organisation who gave the example of an individual who had contracted food poisoning after consuming food delivered to them which they had been unable to heat themselves.

One statutory organisation highlighted the challenges involved in implementing the Governmental food programme within the county to deliver food parcels. Of the 25,000 people on the shielding list in Gloucestershire by week 12, around 3,000 people had received a food parcel. The statutory organisation reported providing ongoing support to individuals to resolve issues accessing food parcels due to earlier confusion and additional changes being made to the process. Concerns were raised about a national call centre contacting those receiving food parcels to ask if they may be able to start accessing their own food, as well as concerns about local authorities taking on a ***"broken system"*** from the government. This was contrasted with the responsiveness of local community initiatives.

The ability of **small-scale local community projects** to be responsive in addressing issues such as food provision was also highlighted by VCS organisations in the example of one Gloucester ward where a network of over 100 street reps are in place, collaborating with local VCS organisations and community centres to deliver 50 meals daily. This community was described by an organisation involved in this response work as being ***"self-sufficient."***

Challenges in accessing food also resulted from **a lack of clarity** about what could be obtained and how. One organisation supporting people with learning disabilities, including by delivering shopping, spoke about delivering a bag of treats to one individual who had thought they could only order basic necessities. Similarly, an organisation supporting 250 individuals with sensory impairments reported widespread uncertainty about how people could obtain items and that they were referring individuals for support with shopping and specialist equipment as a result.

The role of food banks and school lunch vouchers were also identified in enabling disabled people, people with mental health challenges, and their families to access food. This included in circumstances where a family may **not be able to afford to purchase enough food**, for example, due to low income resulting from furlough, sick pay or benefits. These avenues of support were identified as a ***"lifeline"*** by one organisation. In addition to issuing food bank vouchers, another organisation spoke about their role in collecting surplus supermarket food to deliver small food parcels to families, as well as collating donations.

One foodbank contacted as part of this research reported working with more than 100 statutory and voluntary agencies, both for the purposes of referral and to enable ongoing support for recipients of emergency food parcels, many of whom they identified as being people with mental health challenges or disabilities and/or are young people.

Shopping was also a challenge for families with a disabled child where **social distancing restrictions** meant that multiple family members were not permitted to shop together yet it was also not possible to leave a child alone at home. Such situations where disabled people faced barriers to accessing essential items due to social distancing restrictions (rather than due to being clinically vulnerable to the virus) also occurred when trying to acquire medication

Access to Medication

Current social distancing measures were highlighted by several organisations as presenting additional barriers for people with sensory impairments to visiting shops and pharmacies. For people with visual impairments, this included being unable to do sighted guiding or to take someone's hand if you get lost. The example was given of one young person who went to the chemist to pick up a prescription but as their guide dog was unable to follow the social distancing rule of waiting to enter the shop they returned home without their medication.

Access to PPE

Challenges to accessing PPE were reported by both organisations and individuals with **physical impairments**. In some cases, insufficient PPE had resulted in paid carers being unable to visit people's homes and so no **respite care** was available for families. One organisation supporting physically disabled people in residential accommodation highlighted a lack of sufficient PPE for people who need personal and intimate care in particular.

One Gloucestershire-based national organisation supporting disabled children and their families had received almost 800 individual requests for help with sourcing PPE, food deliveries and medicines, with new requests coming in every day.

Case Study: Jenny

Jenny lives in Cheltenham. She has cerebral palsy, epilepsy and needs oxygen on a regular basis. Jenny is a teenager and lives at home with her family.

"Jenny's parent made a request for support via our Covid-19 response service, requesting support with Personal Protection Equipment (PPE). Jenny has cerebral palsy, epilepsy and needs oxygen on a regular basis but at the time of making the request the family had not received confirmation that Jenny should shield.

The family had a great care package in place from their complex care team who supply PPE to their own care staff, but Jenny also has care from a nurse once a week. This nurse is employed by the parents and paid for via a personal independent payment, and they had no PPE for her.

The NHS does not supply PPE for the nurse, as she is a private carer. Without the PPE we provided, Jenny may not have been able to receive care from her nurse. We provided the family with plastic aprons, surgical masks, gloves and hand gels.

Jenny's parent said, "The PPE is like a security blanket; I feel much more confident when my daughter's carers can wear it, as she is potentially very vulnerable to the virus."

This case study was provided by a member of staff at a VCS organisation.

The challenge of distributing PPE easily within the county was highlighted during a call with a statutory organisation as resulting in part from staff from across Gloucestershire Care and NHS Foundation Trust needing to be redeployed in order to distribute 750,000 pieces of equipment a month.

Access to other basic items

Another challenge highlighted by organisations supporting disabled people and people with mental health challenges was being unable to take deliveries of **essential white goods** (such as refrigerators) due it not being possible for multiple individuals to install such items during the lockdown.

A domestic abuse charity supporting women at a Gloucestershire refuge described providing other **emergency items** in addition to food such as cleaning equipment, microwaves, toys for children, general items to support children and adults' wellbeing, as well as helping with barriers linked to IT and transport. An employee from another organisation described connecting an autistic individual experiencing distress, who had been made redundant, with opportunities to participate and support in a music group remotely which could help with **keeping occupied** for several hours a week. This was in addition to helping them access a food parcel. Several VCS organisations also highlighted delivering activity packs to people at home, including to children and families, as well as those tailored to recipients with a particular impairment or health condition (such as an acquired brain injury).

A lack of sufficient **IT equipment** and associated technological limitations were described as a challenge for some families and individuals in being able to access counselling or complete schoolwork online, the latter of which also contributed to stress and tensions within families. Ensuring **digital inclusion** was highlighted as being about more than having a device, but was also about reliable internet connections and having confidence about the security and safety of technology, particularly for older people who may have heard about the dangers of being online but less about the positives. One organisation highlighted that the internet is becoming as essential as other utilities such as electricity and that ***"people need to be given access in an affordable way."***

Unpaid Care and Parenting

This section focuses in detail on the challenges being experienced by two groups in Gloucestershire:

- Parents and unpaid carers of disabled children and children with mental health challenges
- Parents and unpaid carers with pre-existing mental health challenges

Challenges for older carers and grandparents are also noted. Each section also highlights support which a range of organisations have provided for these parents, carers, and families.

Parents and unpaid carers of disabled children and children with mental health challenges

Multiple VCS organisations supporting parents and unpaid carers of disabled children and children with mental health challenges highlighted the difficulties which these individuals have been experiencing since the beginning of the current crisis. During this time, parents and unpaid carers have been managing multiple demands and additional pressures, in some cases with less support available and easily accessible than prior to the pandemic.

For parents and unpaid carers of children with **learning disabilities** (some of whom also have physical impairments), current challenges have included:

Parents needing to provide additional support for their children but with less external support available

- Increased **levels of support required** by young people
- **Not having** the **support of wider family** members (especially grandparents)
- **Not having specialist support** from schools
- Increasingly **challenging behaviour** for those children who already had challenging behaviour, as well as the emergence of new behaviours in children who did not typically show such behaviour (in some cases caused by changing routines)
- **Lack of** formal or informal **respite opportunities**
- **Not feeling confident** to approach a neighbour to **ask for help** due to being aware that lots of others are struggling too

Concerns about treatment and care that their child might receive, including if the child contracted Covid-19

- Being **fearful** of the treatment their child will receive in hospital and concerns about **equality of access to treatment**
- Concerns about **who will look after their child** if they become unwell
- Concerns about a 16-year-old child being asked about **DNR** (Do Not Resuscitate) decisions and parents supporting children to go back to GPs and say no
- Feeling **frustrated** due to not knowing when support services can reopen
- Concerns about **exiting from lockdown**

Being able to go shopping or get food delivered

- Shopping- often people with learning disabilities cannot be left at home by themselves but they are also **not being allowed into the shops with their parents** despite wearing the sunflower lanyards
- Difficulties **registering for supermarket slots** unless you have a letter from your GP to say your child is 'vulnerable'

For parents and unpaid carers of **physically disabled children**, specific challenges have included:

- **Lack of PPE** resulting in carers who could attend being unable to attend, resulting in no respite care for some families
- Parents managing **multiple demands**. For example, loss of access to **routine therapies**, such as physiotherapy and occupational therapy, with parents having to take on this support in addition to home **schooling** (and without respite)
- Some children's **behaviour** becoming more challenging
- Deterioration in both parents and children's **mental health**

For parents and carers of children with **sensory impairments**, challenges were reported for Deaf children who are currently not able to attend school and whose parents are unable to use British Sign Language (BSL).

The complex decisions facing parents at this time are also evident in the findings of a survey carried out by a Gloucestershire school for pupils with special needs.

Over 60% of parents responding to the survey noted concerns about the child returning to school, many of whom reported multiple worries. These included concerns about children being unable to follow social distancing guidelines, due to children not understanding the guidelines as well as due to them needing care which requires making distancing difficult.

At the same time, over half (54%) of parents who responded were concerned that their child was missing out on important learning opportunities. This included learning new skills and opportunities for physical activity and social interaction.

For parents and unpaid carers of children with **mental health challenges**, current challenges have included:

- Some children **initially having more positive mental health** at home before it then deteriorating
- **Parents feeling stressed** due to not being able to **support distressed children** under the confined circumstances of lockdown
- **Home-schooling** resulting in some children experiencing **heightened anxiety**, due to home being a ***"safe place"*** now being blurred with school which has negative emotional connotations
- Heightening anxiety being compounded by differing ideas within families about **schoolwork, expectations, pressures and approaches**
- Parents having to be a **teacher**, **therapist** and **parent**, whilst also working from home- with impacts on the wider family too
- Parents trying to manage things at home and keep a child safe

It was also highlighted that many parents of disabled children are **single parent families** and that challenges for these parents could include trying to **ensure children followed the lockdown guidelines** by staying indoors. Being unable to do so had resulted in conflict with neighbours and the police for some families.

Anxieties and concerns for older unpaid carers, including grandparents, were also reported. This included grandparents feeling overwhelmed with home schooling responsibilities (including due to a lack of equipment). Anxieties were also caused for older carers who were not receiving respite, causing them to feel very stressed and tired. This lack of support was also evident in the example of one older carer of their spouse who had dementia needing to move into emergency accommodation due to their spouse attacking them.

Many organisations who participated in the project also spoke about **support** which they were offering to parents and unpaid carers of disabled children and children with mental health challenges.

One statutory organisation spoke about their recent initiative to develop a Carer Aware badge to help enable unpaid carers and parents to be able to visit supermarkets during protected hours and to easily access goods from shops and pharmacies. As part of this initiative they were planning to also provide training and encourage more people to recognise themselves as carers and not just family members. Carers Assessments have also been made available online.

One VCS organisation which had recently carried out a survey of its members, all of whom care for children with a range of impairments, found that a key aspect of the support they offered was felt to be "***knowing you're here.***"

Other **examples of support** given to parents and unpaid carers of disabled children and children with mental health challenges included:

- Weekly information emails
- Weekly parent carer forums
- Coffee and chat sessions over Zoom
- Digital fitness sessions
- Connecting families to strengthen friendships
- A closed Facebook support group where parents can ask questions (including to a support worker)
- Providing SEN support to parents, on topics such as behaviour management, communication techniques, meal planning, sleep routines, safeguarding, and activities for children
- Supporting parents with psychoeducation
- Looking at how to re-open services for small groups of children and young people with learning disabilities to meet in order to support parents

Parents and unpaid carers with pre-existing mental health challenges

Multiple organisations supporting parents and unpaid carers with pre-existing mental health challenges highlighted the difficulties which these individuals have been experiencing during the pandemic.

These challenges have included:

- **Increasing stress** for both parents and families, including encouraging young people to **engage with schoolwork** and young people being bored and ***"unable to be contained"***
- Parents feeling **isolated**
- Parents feeling that they are **not doing a good job**
- Struggling to plan and prepare **meals**
- **Limited access to school or childcare**, which also presents a barrier to the practical or emotional support that parents may be able to receive due to them needing to look after children
- **Anxiety** or **paranoia** around their child attending **school**
- Struggling with rigid **criteria** around which **children can attend school.** For example, some schools have not allowed children to attend if they were in the process of

receiving an EHCP, My Plan, or My Plan Plus, but instead they had to be in receipt of higher-level support.

In describing the support being given to parents with mental health challenges, organisations who participated in the project highlighted that this had included:

- **Increased demand** for parent support services, supporting parents with mental health challenges on a **daily** rather than a monthly basis
- Some services which were originally supporting a child with mental health challenges were now supporting their parents and **whole family units**
- **Providing outreach family support**, including with tasks such as planning and preparing simple meals
- Supporting children to have **something to do**, particularly due to becoming aware that parents "***have started to visibly slip***" and that some children "***are at risk of neglect***"

Case Study: Zoe

Zoe lives in Cheltenham. She has physical impairments and a learning disability and requires 24hr care. Zoe is a teenager and lives at home with her parents and siblings.

"As a family their lockdown experience has been stressful at times, they have experienced a lack of physical support as they have had no carers since before the lockdown, and the only respite care they and Zoe receive, provided by a local hospice based in Worcestershire, was cancelled because of the global pandemic. This has left the family in a situation where they are providing for all of their daughter's 24/7 care needs and looking after their family; all with no opportunity for a break to recharge their 'batteries'

However, on the positive side their respite provider has been in regular contact with them via text and telephone calls, making sure they are feeling ok and providing them with an outlet to talk if needed; this was provided for siblings too. The respite provider has been delivering regular food parcels to the family to help prevent them from needing to go to the supermarket.

The family have been without a PA to help care for Zoe since October last year. Due to the lockdown situation, even if this had been in place they would not allow a carer to come into their home as Zoe is 'shielding' and they are protecting their daughter. During this time, it is also worth noting that they have been unable to recruit any such carer and will not be able to do so until lockdown is lifted."

(continued below)

Case Study: Zoe (continued)

"Zoe's Occupational Therapist (OT) has been very supportive about their need to not have any people in their home, unless absolutely necessary. When recently facing an issue with a repair that was needed in a vital piece of equipment (Zoe's chair), the OT organised a video call with the repair company who then guided them through installing a new part onto the chair, enabling Zoe to sit comfortably. They also had issues with another piece of vital equipment (sling) which was too large and therefore unsafe to use; by using video call they could show the OT exactly what the issue was and get it remedied quickly. Both instances were extremely helpful to the family.

Zoe has outgrown her wheelchair (she has had it for 8 years) both in size and as her needs have changed because of changes in her conditions. Wheelchair services were in the process of trying to arrange appointments to try new chairs, unfortunately, lockdown has prevented that happening leaving Zoe with a chair that is too small, uncomfortable and unsuitable. It could be months before they get to see anyone about this which also means months not being able to leave the house even into the garden as Zoe is completely dependent on her wheelchair.

If lockdown continues and if they were able to leave the house for walks with their daughter, they would be comforted knowing there was a safe, local area they could visit without putting their daughter at risk, i.e. no other visitors. Maybe a garden or parkland or open space that could be booked in advance where you are the only family there. At present there is no such safe space for them to go where they can get some fresh air and relax together.

As members of our organisation's support network, they have been receiving support from us in the form of peer to peer support from other families who are also shielding; helping to reduce the feeling of isolation they are experiencing. They also feel reassured in the knowledge that they can post any questions they have about the current situation, their daughter's health, and any challenges they are facing, even if just to vent any frustrations they may have and receive support from other families who understand the stresses they face."

This case study was provided by a member of staff at a VCS organisation.

Increased Financial Pressure

This section looks at the impact of Covid-19 on the financial situation of disabled people and people with mental health challenges, as well as some of the secondary impacts on mental health of these increased financial pressures.

The immediate, practical challenges of not having enough money

A number of VCS organisations told us about the **urgent, practical financial problems** for some of the people they were working with. Some people have lost work, or found themselves facing a reduced salary on furlough; people who were now at home all day often had increased utility bills; food prices in the supermarkets had increased; some people with children found that there were extra costs involved in home-schooling, with the need to buy food which had previously been covered by free school lunches, or the need for a laptop or tablet for schoolwork. Some organisations working with women and families living in complex and challenging circumstances told us that **financial pressure was the biggest concern** that people were reporting to them.

At Barnwood Trust, too, we have seen some evidence of the financial difficulties that people are experiencing. Barnwood offers grants to individuals in the county who are disabled or who have a mental health challenge. In anticipation of an increase in the number of people needing practical support during lockdown, in early April the existing individual grants programmes were temporarily replaced with a new, more flexible grant called 'Keeping Strong'. **Barnwood received four-and-a-half times more applications for grants in the three months since lockdown started than in the three months before**, despite having to pause the grant to new applications twice (1,948 compared to 418).

While Barnwood is not able to offer grants for food or household costs, members of Barnwood Trust's staff who answer the phones for grant applicants reported calls from people who were worried about being able to buy food, or that the foodbank would not have enough food for them. This included one parent who could not afford to replace a broken stairgate, and so was sleeping outside their child's room every night to stop them from accidentally falling down the stairs.

People already living with financial insecurity hit particularly hard

Organisations working with people who were already in a situation where money was tight were particularly likely to have seen the financial impact of the lockdown. Those working with people who are homeless, for example, told us that there was a long-standing challenge that some people were housed in homes which were completely empty – without carpets, white goods, or furniture – which made it **difficult for people to sustain their tenancies**.

As well as those who were already living in financial insecurity, though, there was also a sense that the situation had become worse for people who previously hadn't experienced these problems. One organisation working with young people through an arts programme told us that they were **now needing to signpost young people and families to resources like foodbanks** which they had never before needed to know about.

Particular financial challenges for disabled people and people with mental health challenges

There were also some specific practical financial challenges for disabled people and people with mental health challenges. One person with a physical impairment who receives care at home told us that in the early days of the crisis, the NHS was not providing PPE equipment for their carers. The person looked into trying to buy it themselves, but found that it was being sold for ***"stupid prices"***. In the end, the NHS agreed to a much more flexible use of the person's personal care budget, allowing them to **use their personal care budget to purchase PPE for their carers themselves**, which they did until the policy changed and the local authority began providing PPE to carers.

An organisation working with families of disabled children and young people told us that due to financial concerns, **families were less able to buy toys and sensory equipment** for their children to keep them stimulated during lockdown – at the same time as not being able to access toys and resources for children from relevant organisations.

Another problem was identified by organisations working with young people with mental health challenges. Multiple organisations we spoke to reported that young people had been suddenly discharged from Child and Adolescent Mental Health Services (CAMHS) during the pandemic, meaning that **families of young people who had been receiving therapy through the NHS now needed to either self-fund counselling**, or to rely on charities providing lower-cost counselling locally.

The secondary impacts of not having enough money: mental health, tension, and abuse

These immediate practical challenges were also, for some people, having another effect: an **increase in stress, a deterioration in mental health**, and in some cases, **tensions within the home.**

Several VCS organisations spoke about their concerns that the financial pressures that people are facing would create so much stress that they would contribute to a rise in the number of people experiencing mental health challenges.

Organisations working with people who are at **risk of domestic abuse** told us that these **financial pressures are also sometimes contributing to increased tension between partners**, in some cases to the extent that it is triggering more domestic violence. Even so, for some women they work with, the financial challenges themselves are so urgent that they can sometimes outweigh the other challenges in their lives. There was a concern that **some women were not seeking support for domestic abuse simply because the financial pressures were so urgent that that was their primary focus.** We look in more detail at the issue of domestic abuse during lockdown in the following section.

Below is a case study from a person who has lost income during the pandemic.

Case Study: Fred

Fred lives in the Forest of Dean. He has a brain injury and severe tinnitus. Fred lives as a lodger with his landlady.

"I suffered from a brain injury and I have very bad tinnitus which makes my life very difficult, especially in these troubled times of COVID 19 virus. I was on holiday in Malta when the virus hit the UK. All tourists were sent home early when Malta became infected. I returned home only to find that my landlady would not allow me into the house for 14 days. I was forced to stay in a local hotel which closed the day of staying there. Luckily, I knew the manager and he let me stay longer, as I would have been on the streets with my suitcase.

I have since returned back to my home and life here is unbearable. I need to move out asap. My landlady works from home with a high-pressure job. The kitchen has turned into an office and I am forced to stay in my tiny bedroom to avoid the receiving end of her stress.

I am on benefits and declare my part-time business as a photographer and greeting card manufacturer. The extra income has ended due to no sales or work and now my bank is pressurising me to pay off my overdraft, which of course I cannot do because of the Covid-19 virus restrictions.

I have a book publishing deal which has to be completed by December. It involves visiting locations in Great Britain and due to the loss of sales, no access to Scotland or Wales, no campsites open for accommodation etc. I am also unable to repair my best camera and fear that I will be unable to complete the deadline."

(continued below)

Case Study: Fred (continued)

"I am strong and have been through far worse. It's hard to deter the depression but I try to always remind myself to stay strong and keep believing that one day all this bad luck will end. Karma will return for all those good things I have done and will change my life at present for a better one.

I have had no support whatsoever and nothing is available. I can't answer about life after lockdown until it happens, but I know my life will be much better when I have a new home with new surroundings, being able to travel with a new camera and no debts."

Increased Risk of Domestic Abuse

Organisations working locally with people at risk of domestic abuse are reporting signs of an **increase in people seeking support, support which is now much more difficult to provide.**

Most of the organisations who we spoke to thought that the full extent of the domestic abuse happening during lockdown would **likely not become clear until after the initial emergency has passed** and people are able to reach out.

Figures since released by Gloucestershire Constabulary have shown a **26% increase in domestic abuse** incidents and a **20% increase in sexual assault** incidents in May 2020 compared to May 2019.[11]

Domestic abuse and mental health

As **financial pressures and prolonged isolation have taken their toll on people's mental health**, some experts we spoke to were concerned that there may be an increased risk of domestic abuse as a result. One local organisation working in mental health described the shifting state of people's emotional wellbeing:

> ***"People were battening down the hatches to begin with, but they're now moving into a depressive state. It's likely that we will be moving towards a phase of grief and anger, which could drive domestic abuse."***

According to one local organisation, the police are already reporting a higher number of domestic abuse calls involving people with significant mental health challenges. Another organisation working primarily with women in the BAME community also told us that they were finding growing difficulties with mental health challenges and with domestic abuse.

As well as a potential link between mental health challenges and the incidence of domestic abuse, there is also a risk that victims and survivors of domestic abuse may be **more susceptible to mental health challenges** during lockdown. The experience of an enforced lockdown will, for some people, have triggered traumatic memories of coercion. One organisation working with women at risk of domestic abuse described this risk:

> ***" An incredibly challenging issue for some women was the impact of lockdown itself. When people have recently left a controlling environment where they had been told what to do and isolated, being told what to do and isolated further had a re-traumatising effect. "***

Tension and crisis points

The **conditions of lockdown itself are also causing more tensions** to bubble up, as people are at home together all day for weeks at a time. Multiple organisations told us that women were reporting more tension at home; in one example, **a once-abusive relationship which had successfully stabilised was now** *"exploding"* **again**; in another, a woman who had not previously felt that she needed to engage with their service was now in a situation which was reaching crisis point and asking for help.

In other situations, some women who had separated from their abusive partners have been finding the conditions of lockdown and furlough so challenging that they have **allowed the perpetrators of abuse back into their homes** or back in contact with their children, as they are finding it impossible to cope on their own.

There were particular challenges reported too in situations where a **teenage child was perpetrating abuse**, with additional tensions arising from the family having to spend extended periods of time together at home.

Isolation at home

One of the particular challenges of lockdown for people at risk of domestic abuse has been the prolonged isolation. With neighbours, friends, family and professionals such as health visitors no longer coming into the home, there are **fewer opportunities for support and safeguarding interventions**. At the same time, people are not able to leave the house to go to other places such as schools or contact centres, again reducing the opportunities for safeguarding. This was a source of concern for several of the organisations we spoke to. One organisation said:

> *" Women were previously coping because they had outlets that were keeping them safe, like taking the children to school. Lockdown cut these off. Services are not there, and they can't get out. At the same time, their children are also more exposed."*

Getting support

A huge part of the challenge facing people at risk of domestic abuse is the **near impossibility of being able to access face-to-face support** in the community. Some programmes of support have had to stop altogether, and almost all face-to-face support has ended.

We also spoke to one organisation who run a residential refuge for women and families at risk of abuse. They have kept the essential refuge open, but it has been particularly **challenging in that setting to keep everyone safe**:

> *"Life has undoubtedly been difficult in the women's refuge, and our team have worked hard to meet physical and mental wellbeing... Our team are trying to balance meeting the needs of families fleeing abuse whilst balancing safety and social distancing."*

Occasionally, organisations have had to offer **socially distanced face-to-face community support in emergencies**. In one example, a woman living in a situation of domestic abuse reached out to a specialist organisation and told them that the only way she would be able to access their support would be to meet a professional out of the house.

Some organisations who do not specialise in domestic abuse told us that they have in some cases been working to support their existing clients around issues relating to domestic abuse, in part because the face-to-face specialist support which is usually available has been more difficult to access.

One specialist organisation spoke about the **difficulty of maintaining progress** for some victims and survivors of domestic abuse who had been making positive steps, but who were no longer able to access the same level of support:

> *"People who have made choices or been supported to keep partners away can't action this on their own. They get completely desperate and think it'll at least give them a break. Some had made real progress but have now gone back."*

Every organisation we spoke to who worked with people at risk of domestic abuse had made considerable **efforts to offer support in alternative ways**: through online forums, one-to-one and group support via video calls, and proactive telephone calls to reach isolated clients. One organisation working primarily with families told us that they were beginning to plan for starting small group face-to-face contact in an outdoor setting, but that there were extra challenges involved with meeting outdoors as they needed to be able to maintain confidentiality, particularly if the activities might involve children. Another organisation spoke about offering support to survivors of domestic abuse to access things to support their wellbeing, such as hobbies, toys, and DVDs.

While the work that has been done remotely has provided a **crucial source of support and continued contact**, for many people living **in a situation where domestic abuse is a risk, it is not always possible to use these services safely**.

Digital service provision

The availability of **services via the internet, video call services and telephone calls have provided a lifeline** for many, meaning that specialist services for people at risk of domestic abuse have not had to simply stop operating completely over this period. The organisations we spoke to had found that these services had often provided important sources of support, particularly in **maintaining connection** with clients with whom they had already established – often hard-won – trusting relationships. **Training staff** in providing support via video or telephone calls was key; the confidence this gave the staff has a knock-on effect, enabling clients to feel more able to engage.

For those who are still living with perpetrators of abuse, this type of support has been very difficult or impossible to access. **Without a safe or confidential space at home to be able to talk freely**, it is extremely difficult for people to find opportunities to safely access support via video chat or by phone. One organisation providing regular one-to-one support said that many of their **clients had ended their sessions rather than continue over the phone**, often because they do not have a space to talk. One client had found a way of maintaining contact by calling from the car while she is in the car park at the supermarket; but that option is not practical for many people.

Another organisation noted that it was also **very difficult for people living with a violent partner to safely access support via online forums** or websites, even without the need to speak out loud.

Many of these situations were made more complicated by the **presence of children**. For parents, it is all the more difficult to have sensitive or confidential conversations over the phone or by video call if there are children at home. Again, some people have **stopped**

engaging in services such as family therapy as it has been impossible to find safe, confidential spaces at home. One organisation which runs a group for teenage mothers at risk of coercive control has found it more difficult to work with them during the day, while their children are awake. In response, they have adjusted their staff working hours to allow them to have one-to-one support over the phone in the evening, while the children are in bed.

One organisation spoke about a particular challenge for resident parents who have separated from **an abusive partner who has the right to contact with their children**. Prior to lockdown, parents in this situation could take their children to a contact centre who would facilitate contact with the other parent. Now, however, the contact centres are closed, and resident parents are expected to facilitate contact via video calling services instead. The organisation highlighted the potential **risks of doing this in situations where it might be dangerous for the perpetrator to find out where the resident parent lives**. The organisation is working with resident parents to make sure that there are no identifying features in the background to the video calls which might give the perpetrator any information about their home. This situation is causing considerable anxiety for resident parents.

Accessing Services

The Covid-19 pandemic was reported by multiple sources to have impacted on individuals' abilities to access services provided by both the voluntary and community sector (VCS) and statutory health and social care agencies. **The risk of spreading the virus and the implementation of the 'lockdown' caused many services to close entirely, open in a significantly reduced way or find alternative and creative ways of providing some services**. These changes were shown to have had a substantial impact on disabled people, people with mental health challenges and those at risk of experiencing domestic abuse.

Accessing Ongoing or Adapted Service Provision

Accessing a range of services during lockdown from counselling and activity groups, to advocacy and emotional support was a **challenge for all six groups** on which this report focuses. However, although every group was affected to some extent, it was evident that there were **particular challenges** for certain groups including **children with mental health challenges** and **people receiving routine therapies**. Some individuals remained well supported whilst at the same time others were left without the services they relied upon. Similarly, some could access the online alternatives to face-to-face provision that have been offered, but for others, this was impossible.

In spite of the well-publicised situation within social care and, in particular, care homes, one organisation suggested that the impact of service closures and changes may have been ***more impactful* on the day-to-day lives of those living independently**. This was also indicated within interviews with statutory organisations. Those in care homes (whether residential care for older people or for those with learning disabilities) have potentially been more shielded from the closure to services:

- They have still received the care they normally would, largely from the people who would usually administer it; and
- Activities have largely continued – albeit with distancing in place.

On the other hand, those who live independently (particularly **learning disabled adults**) were reported to have experienced huge changes to their routines and experienced a great deal of uncertainty as:

- Day services are closed;
- They have been unable to go outside (and may not fully understand *why* this is the case); and
- Everything looks very different to what they have been used to (e.g. supermarkets).

Another example of these contrasting experiences was shown in the differences between people's experiences of service provision according to **whether they were *already* connected** to services or not before the pandemic. For those not connected, it was reported to be much harder to access services that were often overwhelmed. In one example, a wheelchair user living with a mental health challenge told us how they had been seeking counselling since February and was still waiting to hear back from the organisation in June.

Similarly, a different statutory agency reflected how the pandemic had brought to light some misconceptions around people with long-term illnesses:

> ***"…In the early days [of the lockdown] we did quite a bit of ringing round the people on the [shielding] list, and it was a good exercise of challenging the stereotypes people might have with long-term illness. We were surprised at how little overlap there was between the shielding list and people to whom we're providing adult social care. We assumed that we would already know the people who should be on the list, and that we would already be supporting them, but that didn't prove to be the case."***

During the pandemic it became apparent that there were large proportions of people with long-term conditions who were not already routinely connected in with adult social care services and who may be missing out on much needed support at this time.

This was not to say, however, that those already using services had problem-free experiences. We were told by an organisation how they had found their service-users were being **contacted by so many services** and mutual aid groups that, for some, it had become overwhelming and left them feeling more **confused** than supported:

> *"Where so many people have wanted to help, the person has found themselves in the middle and left very confused."*

Several respondents pointed to the **importance of a co-ordinated response** and the **value of joint-working**. Where it had worked well, it was possible to see how it could benefit individuals. One VCs organisation described how:

> *"Our Outreach Family Support Worker agreed with a parent that she would telephone her on Monday, Wednesday and Friday morning to see how she was doing. This agreement was successfully made with the parent of young children under five, because two other organisations were providing other types of support on Tuesdays and Thursdays."*

This feeling that a co-ordinated approach was shared by both VCS and statutory organisations. A representative from the latter summed this up by saying:

> *"More than ever, we need to work together."*

When asked about what had been helping individuals during the crisis, it was apparent from the calls with VCS organisations that these **pre-existing connections were crucial for signposting to other services**, including:

- Women's refuges and organisations supporting those at risk of experiencing domestic abuse;
- Foodbanks and the provision of essential goods;
- Barnwood Trust's grants; and
- Gloucestershire's Community Help Hub that was set up in response to the crisis.

The Community Help Hub was established very quickly at the outset of the pandemic and was a place where individuals could request help with a number of activities, including: dog-walking; putting out their bins; and requesting deliveries of food, shopping and medication. At the same time, individuals and businesses could sign up to provide help and support. In conversation with a representative from Gloucestershire County Council, it was viewed to have been a system that worked well, largely due to the substantial **community response** within the county:

> *"The self-referral mechanisms – both to say 'I need help' and 'I can offer help' – worked really smoothly and really well…a critical success factor has been that it's been very organic, very community-led."*

As well as this community response, the same participant highlighted the **simplicity** of the system to be another key success:

> *"There were never any questions about whether you really need the support, we've been taking people at face value and trying to find a solution to what they have come to us with."*

The system was described as based on **trust and a willingness** to give support to those who required it**.** There was a view in the data that the **communities have been able to reach people who may have otherwise fallen through the net** through neighbourly connections and initiatives such as the Covid-19 leaflet drops that offered a contact to people requiring support.

Several organisations told us how they had been able to connect to individuals in one way (supporting food deliveries for example) but then continue to refer them internally to other services they may benefit from.

Digital Provision during the Covid-19 Pandemic

In response to the enforced changes brought by Covid-19, many VCS organisations shifted to a remote model of service delivery that could be accessed from home. Within the data there were examples of Zoom, Facebook, WhatsApp and Instagram being for a range of activities including:

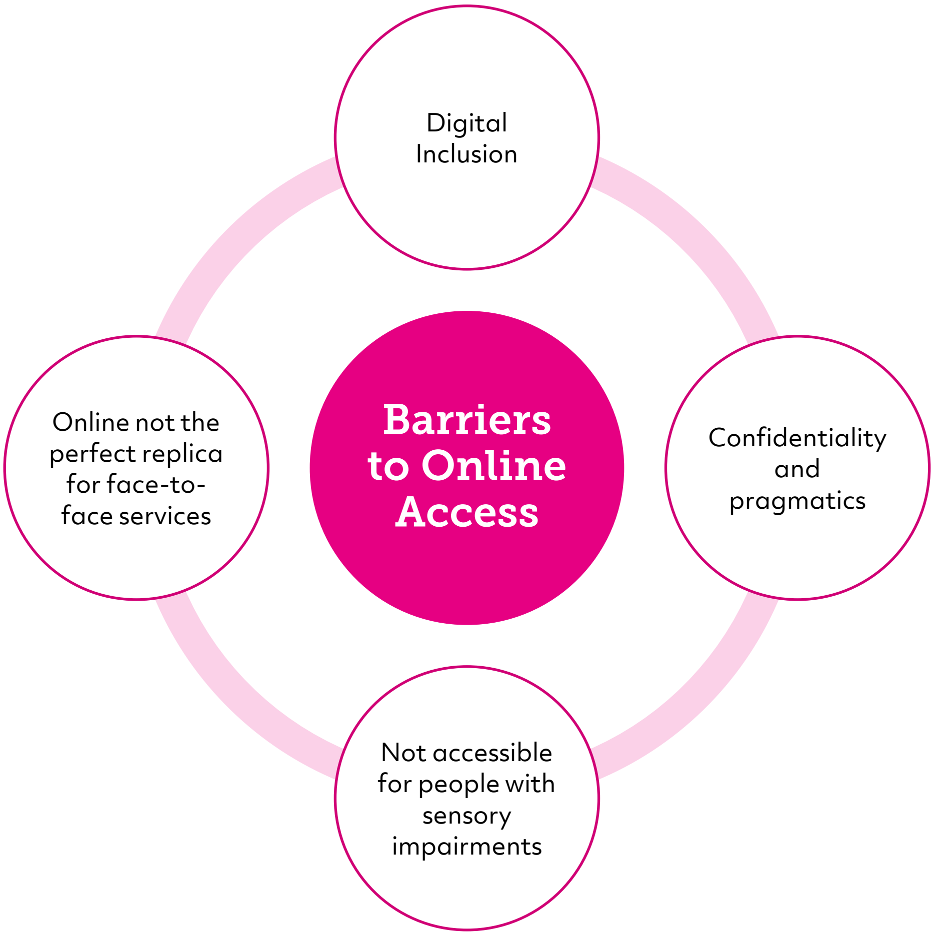
- Art and music sessions
- Exercise classes
- Mindfulness
- Support groups
- Coffee mornings
- Information sharing

Such activities helped to mitigate some of the challenges expressed throughout this report. For example, exercise activities sought to **encourage people to keep moving** at a time where it was very easy to lead to sedentary lifestyle, or, where services such as physiotherapy were paused (*see below*). Similarly, mindfulness, art and music activities provided an **outlet and a space to focus on positive mental health**, and coffee mornings and information sharing spaces brought **opportunities for potentially isolated families to**

connect with one another or to ensure everyone was aware of the latest government guidance and information.

Alongside these activities, mental health organisations spoke of how they had been able to offer **digital counselling and welfare services** to their existing service-users. Whilst digital counselling allowed for the **continuation** of sessions safely from home, remote welfare services supporting children's mental health enabled organisations to check-in with young people or provided informal spaces for them for remain connected to youth workers, counselling or other modes of support in a way that suited them. For some this involved online sessions but equally, others were more comfortable texting or using WhatsApp which were more anonymous. In providing these different options, the organisations were able to reach a wide range of individuals.

Despite so many services moving online in this way, for many accessing online content was challenging in itself and so such adaptions were not necessarily accessible to all.



Digital Inclusion

The theme of **digital inclusion** emerged in conversations with several organisations. Some people do not possess the technology required to access these services remotely: they may not have a smartphone, tablet or computer they could use and, if they did, may not have access to a reliable broadband connection. Moreover, one organisation highlighted the **psychological barriers** which may prevent people with pre-existing mental health challenges from accessing online support, including a range of reasons why people may not be comfortable appearing on camera.

Accessibility of Online Provision for People with Sensory Impairments

Not being able to join in with remote services or just to talk generally with friends and family was highlighted as an additional source of **isolation**. As one organisation explained:

> ***"Now that it is even more important to connect to technology, we're finding it extremely difficult to work with Deaf [British Sign Language (BSL)] users…We're now faced with a number of Deaf BSL users who are struggling at home, work, etc. and not understanding how to use technology to communicate. For most people, using technology by listening can be straight forward, but watching a person signing for hours on end is not easy as it could result in 'Zoom fatigue'"***

Even where hearing impaired people have access to technology and online content, this may not be possible for long periods of time.

One statutory service provider acknowledged how the Attend Anywhere service that allowed access to remote GP and hospital appointments had been a really positive initiative for improving access to healthcare during the pandemic. However, it was reflected that this was not wholly accessible to those with visual impairments, further highlighting that technology is not of universal benefit and could effectively exclude whole groups from accessing services.

Confidentiality and Pragmatics

Where technology is not the main barrier, challenges around **confidentiality and pragmatics** may be. In discussions with mental health and domestic abuse organisations, such challenges were highlighted as a significant factor preventing individuals from accessing services.

To mitigate such challenges, organisations also told us how they had been **routinely calling** their existing service users to stay in touch, as well as providing the option of phone services.

This ranged from calling individuals as often as the individual wants, to routine ring arounds of their service users. Again, however, a common theme within these approaches was the importance of having been connected to these services before the pandemic.

It was also possible to see some individuality in the way statutory organisations have contacted people and whom they have identified as requiring contacting. Within the district councils, one council's decision to contact everyone on the shielding and benefits registers among other databases, contrasted with that of another district council that contacted those who had difficulty putting their bins out.

Limitations of Remote Mental Health Support

Despite organisations working extensively to create and evolve their remote services – arguably reducing the impact of the pandemic for many – for some, **online services** were **not felt to be a perfect replica** for the face-to-face services valued by so many people. This was particularly pertinent in the calls with organisations that supported **children and adults with mental health challenges**.

Not only do face-to-face services help to overcome many of the barriers identified above, they were argued to allow deeper relationships to be built. This was noted by several organisations as being vital to those in complex situations. At the time we spoke to them, two organisations were considering resuming face-to-face services (with social distancing) whilst another opted not to remove this option.

One organisation supporting individuals experiencing mental health crises shared the following example:

> ***"For some of the clients we have supported (who are in suicidal crisis and at particular risk of suicide), it has been important that we have provided face-to-face contact for them. Most charities stopped all face-to-face contact with clients. It was a difficult decision for our charity to make but we felt face-to-face appointments were vital to accurately assess suicide risk in some cases – it's harder to do a comprehensive assessment by phone. I believe this face-to-face contact has also played an important part in ensuring their ongoing survival."***

In the immediate term it could be argued that **some individuals' mental health challenges are a greater threat to their lives than the potential risk from the virus**.

Nevertheless, it was obvious that organisations were not able to operate at the same capacity they were before Covid-19 and currently **face-to-face activity was the exception rather than the majority**. Conversely, some organisations questioned whether face-to-face counselling with social distancing restrictions in place was **equal** to that of counselling before the crisis. **Non-verbal communication** was identified as being vital to building rapport and trust between a client and their counsellor, but for these organisations, the need to social distance and wear PPE such as face masks were felt likely to impede this to some extent.

At the same time, it should not be forgotten that for many disabled people, access to face-to-face services has been a perennial challenge that they have had to navigate and **the range of online services available has opened the door to services they have never been able to access before** due to complications with transport, the availability of care, anxiety and agoraphobia, and physical access to buildings and facilities.

The development of **hybrid** systems in which face-to-face and remote services are able to complement one another was suggested as a way to help reach a wider range of people. This would, however, require radical investment and resourcing to be sustainable.

Despite these examples where disabled people have been able to access some services they had not before, at the same time, some key services were forced to close. People with **physical impairments**, for example, found that mobility services and engineers were unavailable to support them with key pieces of equipment:

> ***"People need equipment such as scooters, riser recliners and stairlifts servicing but can't have engineers in their home. There was one case of a person who was stuck downstairs, their bathroom was upstairs and their stairlift was broken."***

Individuals' Experiences of Statutory Services

Statutory representatives told us that:

- Health services have been stretched to their full capacities
- NHS contingency planning meant many healthcare staff were redeployed to other areas of the health services
- Intensive care, inpatient and crisis services were prioritised over the majority of community services
- Appointments were postponed for people's safety.

With regard to their experiences with statutory services, individuals identified two areas of difficulty that are explored below:

- The impact of **cancelled** services; and
- The way this has impacted upon individuals' **trust** in services and created **uncertainty**.

The Impact of Cancelled Services

As a result of the interruption of services, participants described impacts for physically disabled people and people with mental health challenges especially. These groups' experiences are explored in turn:

Physically Disabled People

For individuals living with physical impairments, services such as physiotherapy, occupational therapy and Botox clinics are services people told us are vital to managing their conditions and pain. For many, these have been stopped and, in some cases, individuals have been discharged altogether. As is described in the section on *Unpaid Care* (page 23) some of the responsibilities for these has fallen to family members and informal carers whilst others have missed out altogether or are trying to manage their symptoms by themselves.

People living with Mental Health Challenges

Therapies for adults with complex mental health problems were reported to have stopped abruptly since the pandemic struck. There were reflections within the data about how weekly face-to-face sessions had been replaced by regular phone calls to ensure people did not feel forgotten. However, these were said to be short and did not at all replicate the therapy they had been receiving – so were not meeting the same level of need:

> ***"Psychologists check-in with people under the [phone and online] service but that's not always prevented people from deteriorating. One man was doing extremely well – he had been a client [at our organisation] last year but was now making good progress under Complex Psychological Services. He deteriorated while it was on hold because of lockdown and his parents contacted us because they feared he may make a suicide attempt."***

One organisation voiced concern that short phone calls may not enable changes in a person's mental health to be accurately monitored, including their risk of suicide.

A similar loss was felt within inpatient services. A statutory representative told us about the Independent Mental Health Advocates (IMHAs) that visit wards and represent patients in decisions where they have been detained under the Mental Health Act, to help them understand their rights and participate in decisions about their care and treatment. These advocates become a source of trust and support for the patients as well as a routine part of their care. The pandemic has meant IMHAs are unable to be on the wards but are available via virtual drop-ins instead.

Even where services were kept open, such as Crisis and Improving Access to Psychological Therapies (IAPT) services, staff were working from home and were reported to have been more difficult to reach. An example was given of a woman who required these services but, despite ringing repeatedly, was only able to reach an answerphone:

> ***"The lady was contemplating calling 111 as there was no support through the normal channels."***

Participants described contrasting responses from services providers during this time: those who were seen to have **stopped all services and suddenly discharged their clients** and others, such as the examples above where organisations **continued face-to-face delivery** because they weighed up the risks and strived to provide the services that were essential to the people they support. In terms of the latter, this was framed as life or death.

Trust and Uncertainty

The decisions and responses explored in this section were felt to risk undermining trust in these services which could lead to significant challenges in the long-term. Several organisations suggested it could take as long as six months for young people to engage in a service. For services to suddenly stop without any prior communication was suggested make this engagement even more difficult. Some organisations felt this would have **longer-term consequences** because if young people do not trust services, they may be more reluctant to engage with them in the future – when their needs could be even greater and **there is risk of more complex needs developing**.

Child and Adolescent Mental Health Services (CAMHS)

Several organisations, some speaking in personal as well as professional capacities, reported that **CAMHS clients** had been **suddenly discharged** from their services via a letter without reason or explanation.

In one personal account, a participant shared that this decision had had a **massive impact on their child** who had been preparing to see CAMHS and would now have to **start again** by getting a referral from their GP.

The impact of this decision has been compounded by families reaching out to VCS counselling services instead and finding themselves on **long waiting lists** as these organisations attempt to cope with the demand. Moreover, **these services are not free,** and families are having to **self-fund at a time where many are facing significant financial hardship.**

Trust in services was also highlighted in relation to **care and treatment**. Early in the pandemic, when the potential impact of Coronavirus on the UK was unknown, guidance was issued that **implied treatment could be denied to certain groups** – mostly disabled people and people living with life-limiting conditions, and those with severe learning disabilities and autism.

Although this guidance was revoked, many disabled people and their families were still reported to be **sceptical** that they would receive the same treatment as someone who was deemed healthier and with a greater quality of life. One statutory provider told us how within the county GPs have been having ReSPECT form conversations with people. These conversations, which follow a national, standardised approach[12], allow people to discuss their choices about care and treatment (including end of life care). It was clarified that this process was about having a personalised discussion with people and not to have a 'blanket approach' to areas such as 'Do Not Resuscitate' directives.

Despite some challenging experiences with statutory services over the past few months, there were some positive feelings about the response within the data. For example, organisations within the VCS sector described how they had been able to link in with the Help Hub and with district councils to distribute the Covid leaflets offering help and support to tens of thousands of people across the county. Similarly, district councils were described as **supporting the establishment of mutual aid groups** which have been a key part of the response at a community grass-roots level. Moreover, an organisation told us how Gloucestershire County Council had been regularly engaging in question and answer sessions with parent carers.

Three disabled people engaged with Barnwood Trust who took part in conference calls spoke about their experiences with statutory agencies and all three were extremely positive about their interactions, particularly with GPs. These included:

- Receiving weekly check-ins with their consultant and regular calls with clinical psychologists
- Seeing a quicker response from the GPs and easier access to medication
- More flexible approaches to appointments utilising technology; and
- The continuation of existing treatment and care assessments.

In discussion with representatives from statutory services there was recognition the approach taken may even have been more extreme than required. Nevertheless, they described that at the time they did not have the benefit of hindsight we do now and were advised to prepare in a certain way by central government. These services are, however, now **beginning to look ahead to how services can be redesigned for the post-Covid world**.

Participants reported a **feeling that services cannot simply return to the old 'normal**' and there are opportunities to look at which elements of services past and present they want to retain, to return to and what should be resisted. At the same time there is an appetite for radical ideas that could overhaul these services to benefit more people.

Underpinning everything within these experiences is a huge amount of uncertainty:

- Uncertainty about whether people will receive the right level of care;
- Uncertainty about when services will reopen; and
- Uncertainty about the impact of these services being stopped for people's mental and physical health.

The Consequences on Mental and Physical Health

The challenges described in this section are more complex than just whether someone has access to various services, **there were also reported to be consequences for individuals' mental and physical health which could, continue well-beyond this initial emergency.**

There were particular concerns about eye health and access to hospitals generally for visually impaired people. **Social distancing was felt to be extremely challenging for this group and it was feared that many would not attend routine appointments, go to the hospital or try to get the medicines they require from a pharmacy**. There were therefore concerns of the possible implications for this group's physical health if such check-ups or treatments are missed whilst social distancing remains in place.

For people with pre-existing mental health challenges, lack of access to services could be the difference between being in control of their symptoms and being in crisis. Similarly, people missing out on support with their physical needs could see impacts to their quality of life if they are unable to access treatments and therapies that help manage pain or reduce the health impacts of their conditions. For learning disabled adults, the cancellation/postponement of annual health checks risks exacerbating existing health inequalities.

Isolation and Connection

Lockdown has meant for all of us an extended period of being at home. Disabled people and people with mental health challenges in Gloucestershire have experienced this period in a wide range of ways: some have found this period **especially lonely**; some have **maintained existing social connections**; some were **used to being isolated**, and so haven't felt much difference. Organisations and communities have responded to the increased risk of social isolation in creative ways, seeking to maintain connections or to forge new ones.

Isolation and Mental Health

It was striking that when people – both organisations and individuals – talked about isolation, they talked in the same breath about mental health.

There was a general expectation that there would be a ***"surge"*** or ***"deluge"*** in people with mental health challenges needing support in the months following lockdown. Part of this is likely to arise from people with new mental health conditions which have developed during lockdown, and part is likely to come from people with existing mental health conditions which have become so much more difficult to manage without their usual support, and which may have been exacerbated by new stress factors.

The rise of new mental health challenges

Many of the organisations we spoke to told us that isolation and its impact on people's mental health and wellbeing was one of their biggest concerns during the pandemic. One organisation referred to this period of isolation as an ***"iceberg"***, voicing a warning we heard from many others about the likely scale of mental health challenges following lockdown.

Several organisations told us that they were watching the **mental health of people they knew deteriorate over time**, including those who had not previously experienced difficulties with their mental health. One organisation working with people with sensory impairments spoke about there being a ***"new cohort"*** of people they work with who were not previously at risk of mental health challenges, but who now were needing support for their mental health. Another organisation, also working with people with sensory impairments, described being able to ***"physically hear the difference in people's voices"*** compared to the first week of the crisis, when people were still ***"bubbly and bright"***. For many people, **loneliness, boredom, and not being able to go out to participate in activities** which they had previously enjoyed were all beginning to take their toll. On the loss of social activities which people had previously used to stay well, one organisation noted:

> *"Previously resilient people are not able to cope as well as they could previously without their usual coping mechanisms, as they are locked in their homes"*

The impact for people with existing mental health challenges or trauma

In some cases, there was a sense that for some people who had already been experiencing mental health challenges and who were already socially isolated, lockdown hadn't actually made much of a difference to the situation that they were in – **things were already very difficult**. In other cases, lockdown and isolation was having a severe effect on people's mental health conditions and their ability to cope with them. For many people, a crucial part of managing mental health challenges is talking to people, and particularly talking to people face-to-face. **Not being able to talk to anyone in person**, friends or professionals, has in some cases been very challenging.

An organisation supporting people in suicidal crisis shared an example of how this has impacted one of their clients:

> *"One man explained how disconnected he felt from his family, his friends and his work. He was having thoughts of ending his life. The Covid-19 crisis was exacerbating the sense of disconnection he felt (social distancing and lockdown). We had previously supported him during a suicidal crisis several years ago and we had built a strong connection with him. indeed, I recall that connection being built during our first appointment with him. I think an important part of that connection with him had involved what he could see: my non-verbal communication including facial expressions and (for example) human warmth conveyed by my body language. This time it felt that he was disconnected from us and that concerned me. I felt his apparent total disconnection from everyone placed him at significant risk of a suicide attempt. I could hear the distance in his voice. It was very different in tone from the previous occasion we supported him. It was essential to offer face-to-face support to him."*

For people who have experienced abusive or controlling situations, **the isolation of lockdown can be re-traumatising**. One organisation who worked with homeless people pointed out that many of the people they work with have suffered with years of social isolation, and so it is particularly difficult for them to have to experience it again. An organisation supporting people in suicidal crisis described how lockdown might impact those who have experienced trauma:

> ***“Lockdown may replicate aspects of the original trauma: feeling trapped, powerless or with no escape route. It can exacerbate post traumatic symptoms and in some people, has led to thoughts of suicide. Sadly, suicide may represent a means of escape from the unbearable feeling of being trapped. Even leaving the home more frequently for exercise may not prevent the psychological distress of feeling forcibly confined/trapped at home and/or the feeling of having lost control.”***

There was a strong call from this organisation for people to have access to specialised support from professionals with experience of working in trauma, particularly in the case of a second lockdown.

Not going out: Loss of opportunities to connect with other people

Beyond the new experience of having to stay at home, there was also the loss of experiences which people had previously valued as ways to connect with others: going to work, volunteering, participating in activities, attending social groups or gatherings.

Here is a case study from a person who was made redundant during the pandemic.

Case Study: Megan

Megan lives in Hucclecote. She has an acquired brain injury and subsequent mental health challenges. Megan is in her fifties and is a single mother.

“I have a brain injury following a sub arachnoid haemorrhage 5 years ago and since then I have suffered with mental health problems.

When the pandemic hit, I was working 32 hours a week for an aerospace engineering firm carrying out a sometimes very stressful job and for a company that didn’t really understand how my hidden disability affected me on a daily basis. Before lockdown we were advised to work from home, and this in itself filled me with dread: How would I manage my already stressful job without friends and colleagues to bounce ideas off! Each day became progressively harder, my mood slumped, and I became withdrawn, to the point that my children began to notice.”

(continued below)

Case Study: Megan (continued)

"I had no contact from work until one day I had a phone call advising me I was at risk of redundancy; I felt physically sick and hit an all-time low, I found myself sitting in my car at 2am wondering what I could do to make it all stop, for everything to stop being so hard, and for people to "get" what it felt like to be me. I have been having counselling for my anxiety and depression on a weekly basis for most of this year and a text to my counsellor was all I could bring myself to do.

I somehow got myself to the doctors and was faced with a sea of masks which was even more daunting and was prescribed the medication which I have managed to avoid for so long. But this pandemic has made it impossible for me to avoid any longer, I can't have the hugs off friends that I so desperately need and the thought that I don't know if I ever will be able to again is quite hard to comprehend.

So Covid has taken my job, the one part of my life I could control, and it has thrown me into despair. Without two support workers, I'm not sure I would get through each week. I probably come across to them that I'm doing ok and coping day on day, but the truth is this event has just made me scared of everything and losing my job has made me unable to trust colleagues and friends. Covid has made the world with a brain injury an even lonelier place."

Perhaps particularly for those disabled people and people with mental health challenges who **do not usually work**, the ability to participate in regular **activities**, **volunteer** in their community, and attend **social groups** form a really significant part of the ways in which people are able to form relationships, have regular social interaction, and stay well. Now that all of these activities have ended, there was real concern about the impact that this would have on people's ability to maintain positive mental health.

An organisation running social groups for people with sensory impairments, for example, told us that some of their clients found that having the group dates in the diary gave them something to look forward to, and they worried what would happen now that people were no longer able to attend. There were similar concerns from organisations working with people with learning disabilities and people with physical impairments.

One organisation specialising in mental health, but with a varied client base, gave this example of a client they worked with who had existing mental health challenges, a learning disability, and physical impairments:

> *"One woman lost all her mental health support group meetings, and her voluntary work, when lockdown started. These were very important to her mental wellbeing, particularly her volunteering. Unfortunately, she explained that she would not feel able to do the kind of volunteering that [was needed], because she had very particular needs and has a physical disability and a learning disability"*

One professional working in the Muslim community in Gloucester spoke about some of the specific challenges faced by members of the community who were not able to attend their mosque during lockdown; a particular challenge as this fell during the month of Ramadan.

Impact of isolation for physically disabled people

For some – but by no means all – people with certain physical health conditions, **lockdown has not actually brought much of a change in practical term**s. One person who has multiple health conditions and mental health challenges told us:

> *"I think I've coped better, especially in the beginning, than lots of people, because I suppose I'm sort of used to this in a way – I'm used to not going out, I'm used to not interacting with people, I'm used to just staying at home and just staying in bed for months. So, I've been kind of used to it."*

Many people who are at particular risk from Covid-19 reported that they had already been shielding for some time before the government imposed a lockdown. One organisation noted that – at least in the early days of lockdown – there may have been the feeling that **lockdown has been something of a** *"leveller"* for disabled people who cannot often go out; a sense that *"we are all in the same boat"*.

For many other people with physical impairments, however, lockdown has been a very difficult experience – particularly for those people who are at more risk of serious harm if they contract Covid-19, and are therefore shielding.

The **uncertainty around how long people would have to stay indoors** has sometimes compounded the impact of this. One person we spoke to who both has physical impairments and experiences mental health challenges said:

> *"I don't think I'd handle 18 months. I don't think I'd be able to not go out or that long. Physically as well as mentally, it won't help."*

Impact of isolation for people with other types of impairment

The running thread through the concerns about the impact of isolation has been the impact on mental health, regardless of other health conditions, but there were a few elements to the experience of lockdown which have been specific to people living with particular types of impairment.

An organisation working with people with acquired brain injuries told us about the specific challenges that the people they work with were experiencing. Some have experienced a **breakdown in the relationships** they have at home; or feel ***"misunderstood and alienated"*** within their communities – all of which compounds the sense of **isolation**, along with impacting their **confidence and self-esteem**. Some have felt so "***lonely and hopeless***" as a result that they have "***battled to keep themselves safe***".

An organisation working with Deaf and hard of hearing people noted that **many people in the Deaf community were already struggling with isolation**. The heightened isolation of lockdown, combined with a lack of accessible information provision, has meant there was a considerable impact on people's mental health. The organisation was concerned that "***more and more Deaf people are struggling to live in isolation safely***".

Young people

This is a period of life when connections with peers are especially important, and when there can often be **tensions within the family**. Being **cut off from peers** and being at home with family has sometimes been very difficult for young people, and organisations working with those young people have been very concerned about a rise in mental health challenges as a result. On the other hand, some young people with anxiety are actually finding home-schooling suits them better than going to school, so their concerns are less about having to stay at home, but about how they will cope when they have to go back.

As it has been for many people during lockdown, **social media** and connecting over **digital tools** have been really important ways for a lot of young people to stay connected. We also heard about how **video games** have been useful, both as a way of staying mentally stimulated during this time, and also as a way of staying connected with peers.

Concerns about young people in isolation were particularly heightened where they are living in **crowded or challenging home conditions**, including in supported accommodation, where they may be less able to access some of the remote support which is available. Similarly, where young people have **less access to the internet**, there was felt to be a higher risk of isolation – not all young people have phones or tablets which help them to stay in touch; and one organisation noted that sometimes young disabled people in particular have less access to online connections as their parents can be more concerned about internet safety.

An organisation working with families of disabled children noted that some of the young people they work with have a lot of energy, making it all the more difficult for them not to be able to go out. Part of the work organisations were doing during this time has been to encourage young people to follow the guidelines and stay at home.

There was a great deal of work being done by organisations to try to **maintain their relationships and connections with young people**, even if they were not able to continue the same level of support as before. Arts sessions and therapeutic activities had often been replaced with Zoom meetings, largely just as an opportunity to have a chat and reassure them that they hadn't been forgotten, rather than to replicate the original activity. Another organisation had been sending cards and little gifts in the post, again to reassure people that they were still there, and to help to maintain the relationship that they had built up.

Combatting isolation: Community connections

While lockdown has been a uniquely isolating time, it has also, in some ways, been a time of unique togetherness. We have heard many stories of **communities and neighbours coming together** to connect and support one another.

One person who had both physical health conditions and mental health challenges told us how their neighbours had come together, both to keep up their social connections, and also to look out for them specifically:

> ***"My neighbour has been absolutely terrific. A neighbour set up a WhatsApp group so we can all keep in touch. We used to meet up for coffee once a month last year, so she set up a WhatsApp group to keep in touch with that. And we've been meeting up on a Saturday evening; we all sit in our front gardens and have loud conversations across the street. And they said to me that if I don't open my curtains by 10 o'clock in the morning, then they'll be in touch... They've been fantastic."***

Other people – both disabled people and non-disabled people – spoke about their communities setting up WhatsApp and Facebook groups, dropping leaflets through the doors, trading skills, setting up fairy walks and teddy bear walks, hosting VE day street parties, coming together to clap for the NHS on Thursday nights... One person told us that an elderly neighbour had been asked seven times in one day if she needed anything! Members of the Muslim community in Gloucester told us that while their community had always been close, centred as it is around a shared cultural, religious and ethnic identity, this period had seen people come even closer together, and one person noted that there were now more integrated connections across other communities too. Organisations working with disabled people told us that these organic connecting activities had really helped people to **form new relationships and to feel more a part of their community**; sometimes to feel that they had been **remembered and thought about** by the people around them.

As well as the informal work of neighbours, there has also been a rise in more formal connecting work in volunteering. Many organisations we spoke to talked about having an influx of volunteers willing to step in and help out in their communities.

Combatting Isolation: Organisations providing remote support'

As local organisations have had to pull back from their usual work, they have been working to transition to offering support and activities in other forms, such as regular phone calls. The importance of maintaining existing connections and relationships was described as key here. More important than the activities themselves have been the emphasis on staying in touch with people, letting people know that they're remembered and cared about. One organisation deliberately kept the same telephone befrienders in contact with the same people, to keep the all-important ***"human connection"*** strong. While this type of support has provided an important lifeline for many, it has not been accessible to everyone.

Perceptions

Comments related to 'perceptions' can inform an understanding of what might prevent people from being offered or seeking support, or unnecessarily stop them from living as independently as they did before lockdown began. The accounts that were categorised in this theme were related to three areas:

- Feelings/thoughts about receiving 'charity'
- Individuals' perceptions that they do not need help
- Assumptions about who will and will not need support and fear of being judged by others

Feelings/thoughts about receiving 'charity'

An organisation that provides community-based activities reported that, within Muslim communities in particular, a number of women who were struggling were not accessing the support that was available, such as food banks. They believed one reason for this was that many people were not happy to accept 'charity'. This organisation had been involved in making very discreet deliveries of food as Ramadan gifts. It was their hope that the food would be accepted as a Ramadan gift, as opposed to being seen as 'charity'. They believed there were probably many families having similar issues accepting 'handouts' of food.

Individuals' perceptions that they do not need help

Reflecting on the findings of research that had been undertaken on food provision, one of the organisations highlighted that the situation was very complex, in part because people do not perceive themselves to be in need or want to ask for help. They linked this to a loss of agency and commented that what people really want is to be able to go to the shops and pick their own food.

Another organisation reported a similar observation that illustrated how perceptions about relative need could prevent people from accessing support. To set the context, they explained that if a young person is vulnerable it is hard for their parent to register their household as a vulnerable household unless they have a letter from a GP. This organisation commented that they were aware of many parents of vulnerable young people who do not feel they can ask a neighbour for help due to feeling that there are people who are in greater need than them.

Assumptions about who will and will not need support and fear of being judged by others

One of the organisations stated that support providers can assume that families from a Muslim background will not need help because they will have support from close-knit family, but this is not always the case. Another organisation reported that carers were telling them that one of their biggest concerns was that they could not access essentials, such as food and medication, in part because they could not use the priority shopping hours that some supermarkets had established for 'key workers'. There was a particular problem for carers of people with autism, for example, because food deliveries often include substitutes for ordered items. This can cause difficulties if the person they care for has very specific needs regarding having certain brands of food. In response, the organisation had handed out letters to carers saying that they are a key worker essentially, and that they should be able to access the priority shopping hours.

An individual who shared her experiences commented that many of her conditions are invisible and she worries that people will not recognise her as someone who is especially vulnerable, and consequently they will not take appropriate caution around her. She explained that she has sensory processing disorders, and is possibly on the autistic spectrum, which means that she struggles to understand instructions and gets confused. She is worried that she would not be able to follow the new rules in supermarkets etc. and that people would not understand this and may be rude to her.

It was also reported that some people with visible impairments fear being judged by others for going outside, even if they are not clinically at high risk. An organisation that provides opportunities for disabled children and young people reported being aware of some wheelchair users who wanted to go shopping but felt that they could not because people they meet would think they are highly vulnerable.

Section Three: Future Concerns

Sections One and Two of this report have outlined a broad range of challenges associated with the pandemic that have impacted upon the lives of disabled people, people with mental health challenges and those (at risk of) experiencing domestic abuse. In many cases, these challenges can be seen to be not unique to the current times, but rather, exacerbations of existing inequalities.

As the initial phase of the pandemic appears to be coming to a close, and the lockdown begins to ease, it was felt important that we learn from the challenges identified so far, and seek to understand any new challenges that may arrive in the short-, medium- and longer-term.

The mapping exercise identified a range of future concerns that required collective thought and attention – many of which overlap with those explored above. These include:

- Accessing services
- The easing of lockdown
- Mental Health
- Uncertainty
- The effect on children and young people

As in Section Two, each of these concerns is explored individually so as to understand the nuance of each, however, just as with the existing challenges, individuals' concerns about the future do not stand alone but rather inter-relate to one another and impact on disabled people and people with mental health challenges in various ways. For example, a person's feeling of uncertainty at the lockdown easing may trigger feelings of anxiety or prevent them seeking medical treatment for physical symptoms because they are too fearful that the virus is still circulating.

Mental Health

An **anticipated surge in demand** for mental health services was consistent across organisations who provide mental health services. Several reasons were cited for this:

- Bereavement
- Processing trauma
- Isolation
- The loss of confidence and anxiety about going outside.

Whilst these issues were felt to be a concern for everybody, this was especially the case for **those with pre-existing mental health challenges**. On top of the list of factors noted above, respondents gave indications that anxiety disorders were increasing, people had been destabilised by the closure or interruption of therapeutic services and individuals living with Obsessive Compulsive Disorder (OCD) were having difficulty managing their compulsions when 'wash your hands' is a central to public health messaging.

> *"Mental health issues have become more prominent during this period and many people have increased anxiety. Once this period is over and vulnerable people can again come out of their homes, we are anticipating problems. Some people will have lost confidence and will need new and additional support to get their lives back to normal. Some people who were not housebound may become so. They will need a great deal of staff support"*

Accessing Services

Even as the lockdown eases, social distancing is likely to remain whilst the virus is still in circulation, and therefore, organisations felt it would be a while before they could return to 'business-as-usual'. Organisations told us how they are going to need to **continue adapting** so that they are still able to reach everybody:

> *"There is going to be a messy period when one of either the counsellor or the client is ready to go back to face-to-face but the other is not"*

The benchmark for resuming 'business-as-usual' appeared to be less about the guidance and more about the feelings of the people they work with.

As highlighted elsewhere, organisations may require **substantial resources** to enable them to meet everyone's needs. At the same time, organisations are already stretched and overwhelmed, and this was felt to be a recurring theme as lockdown eased. One organisations that supports older people in the Cotswolds told us:

> *"We have picked up over 150 new [clients] in this period who are currently receiving telephone support for befriending, carer respite and shopping/pharmacy deliveries. These are clients who want to stay with [us] after this period...This is going to put pressure on already stretched services but is a genuine community need which we need to meet."*

Under pressure, organisations are still determined to support as many people as they can.

Statutory Services

Within statutory services, the need to prioritise services led to the closure of many mental and physical health services that some organisations felt was detrimental to the people they support, or were in themselves, a cause of the surge in demand they are experiencing.

Two organisations, one supporting individuals with long-term neurological conditions, and the other supporting people with complex mental health needs, shared their hopes that were there to be a re-imposing of the lockdown or a future event, that **services were prioritised differently**:

> *"We would hope that the complex needs of people managing a long-term neurological condition (including [Acquired Brain Injury]) would be considered explicitly. We noted that emergency infrastructure seemed to follow the categories of physical disability, learning disability or mental health – and we felt the significant needs and vulnerabilities of a large number of people were not taken into account in the emergency service planning or response. We hope that this will change and that the learning from the first lockdown will not be lost"*

As well as the immediate impacts in which people have not been able to access these services, there was a view within the organisations – particularly those supporting children and young people's mental health – that beyond lockdown, **trust may have diminished** in these services and a concerted effort to re-build that trust will be required.

> *"If there is a second lockdown, I hope that mental health services will be considered an essential service and that they will be able to continue, with appropriate PPE, social distance and other safety measures, during the second lockdown...I never again want to have to witness the level of suffering that we have witnessed this time round among people with severe and enduring mental health difficulties"*

Demand for Services – Domestic Abuse

In calls with organisations supporting people who have either experienced domestic abuse or were felt to be at risk of doing so, **there was a belief that the true picture would not be known until lockdown was eased and services began to open up again**.

The challenges for this group are noted in the section on domestic abuse above. Lockdown has meant that:

- Contact and monitoring services are closed or operating at reduced capacities;
- Children are home and finding a confidential space to access support is more difficult;
- Partners/perpetrators may still be in the home (or allowed back into the home), further reducing access to support; and
- The pandemic has also increased tensions and pressures within households, from the restrictions to people's liberties, to the financial pressures biting as the economic impact of Covid-19 begins to be felt. All of which could lead to more violence within homes

As lockdown eases and women can begin accessing support in the community again, **it is anticipated that specialist services in the county will see a surge in demand**. Some of these services already had long waiting lists *before* the pandemic and there was a suggested that they could become overwhelmed.

One organisation also believed that there could be an increase in the number of women arrested for reactive partner violence due to the effects of being under lockdown. Organisations told us how they were **already seeing more women needing urgent support.** However, as with other services, **social distancing may still impact upon the type of support** these women are able to receive and **may prolong the experiences** of many.

The Easing of Lockdown

Since 1st June, after 12 weeks, the lockdown in England has gradually been eased. The organisations we spoke to reflected how the different restrictions for those on the shielding list, compared to those in the general population, had created to all intents and purposes, a two-tier system and there was a concern that these **people could be forgotten** or **become more isolated** as more people return to 'business-as-usual'**.**

For organisations, although there are significant implications for their finances and resources, these concerns have shown them the importance of maintaining their online service provision even when they are able to resume face-to-face sessions.

Moreover, even when the restrictions are fully lifted, there was a concern that the crisis of the last few months will have **impacted upon people's confidence to go outside and resume their lives**. For visually impaired people, particular concerns were raised about how Covid has enforced **changes to the environment** (for example, the introduction of social distancing and changes to supermarket layouts):

> *"[We] foresee problems when people come out from their home as the environment has changed. People often rely on memory so [we expect] a downturn in confidence."*

Other organisations reflected how **people's fears have heightened** over the past few weeks as people have been beginning to leave their homes more and the streets, towns and shops are becoming busier.

This fear was also implicit in the way others spoke about what impact changing the lockdown could have on the virus:

> *"How will they manage environments which are heavily dense with people? How long is social distancing going on for? They're making it sound like 4th July is when everything will get back to normal but realistically it might be another 18 months or a year."*

Three participants – all of whom were disabled people – expected there to be a second lockdown in the future.

It was also suggested by a small number of organisations that people's fear could see rising tensions within communities as some feel too anxious to go outside but others return to their normal lives.

There was a concern that the easing of the lockdown would see a **reduction in the number of volunteers** and in this **community action** as more people begin to return work and things return to normal. As highlighted at the outset of this section, many people will still be shielding, or too frightened to leave their homes, but the support they have had with food and help getting their medication may not necessarily still be there.

Uncertainty

As well as the uncertainty organisations themselves are feeling with regards to reopening and supporting people in the long-term which are well-documented in this report, **the fear of the unknown** featured as a key concern with regards to the easing of the lockdown and the uncertainty that comes with it. This was particularly visible in the interviews with disabled people who Barnwood Trust engage with. One individual who reflected that they were uncertain about how things could return to normal before a vaccine was developed described how:

> ***"Pre-Covid, I had started getting involved in more things, but now things have changed so much, I don't know how safe things would be for me to get out and engage. The uncertainty is a huge problem"***

As the guidance changes, there is a greater onus on individuals' own judgement but a lack of certainty about what was the right thing to do. This need for clarity (in an accessible format) as we move forward was especially required by parents of disabled children who may be shielding or those with learning disabilities such as autism:

> ***"People, particularly those on their own in the community, will require clear information about changes in the rules, particularly those who are shielding, and are anxious about change. This information needs to be delivered verbally as well as in written form as many have difficulty reading. Those on the autistic spectrum would find a change back into isolation difficult to understand..."***

The effectiveness of reducing the spread of the virus relies on individuals following the public health advice. If this is not clear, individuals' fears of a return to lockdown and a prolonging of the situation may more likely become a reality.

The Effect on Children and Young People

Beyond the need to work with more disadvantaged pupils to make up for the schooling they have lost to mitigate exacerbating existing educational inequalities, there was also a belief amongst the organisations in this exercise that these children will require **significant support** upon their return to school:

> ***"Schools will need to be trauma informed in their practice as we move into the second wave of this pandemic. Very few, if any learning will have taken place during lockdown...The approach of schools and indeed the education system as a whole will need to tailor support to meet the individual needs of the children based on their specific crisis Experience..."***

Indeed, it should be recognised that children and young people may have some of the same concerns as adults and their mental health and wellbeing could equally be impacted. The need to support these needs through traditional services as they develop was equally felt to be a concern within this exercise:

> ***"Potentially we could see the most vulnerable and disadvantaged become even more disadvantaged. More children and young people will require support for their mental health and wellbeing and statutory services were struggling to meet this need before lockdown. Post-lockdown the need is going to be far greater."***

What do people want now?

As well as highlighting their concerns for the future, it was possible to see a number of things organisations and individuals wanted to see right now. These are summarised below:

- Reopening face-to-face services where possible
- More clarity about guidance and next steps
- More resources to cope with expected demand
- Specific support for children and young people
- New ways of working (flexible, collaborative and hybrid services)
- New ways of funding services
- A continuation of the community support
- Recognition of carers needs
- Broadband recognised as an essential utility
- Accessible methods of communication
- Prioritisation of more services (e.g. complex mental health)
- Learning from the initial emergency and adjusting plans

Future Concerns: A summary of the key concerns beyond the pandemic

Easing Lockdown

- The creation of a two-tiered system as restrictions are relaxed for different groups.
- Fear and anxiety about the restrictions themselves easing
- The possible reduction in the community respsonse

Accessing Services

- Services becoming overwhelmed as demand increases
- Particular demand for domestic abuse services as society begins to open up and such support becomes accessible
- The need to reprioritise services if there was to be a second lockdown
- The need to re-build trust in services

Mental Health

- Surge in demand for mental health services across the population as the last few months are processed
- Exacerbation of pre-existing mental health challenges

Uncertainty

- The fear of the unknown and how safe it is to go outside
- Reintegrating into work and school - particularly if living with someone at risk from the virus.
- The need for clear and accessible information and guidance.

Children and Young People

- Children missing out of education
- The need to provide trauma-informed support
- Demand for children's mental health services.

Appendix A: Methodology

Between April and June 2020, researchers at Barnwood Trust undertook a mapping exercise to explore the experiences of different groups of people across Gloucestershire during the Covid-19 pandemic. This involved engaging with organisations and individuals across the county to understand the impact of the Covid-19 pandemic on disabled people, people with mental health challenges and those (at risk of) experiencing domestic abuse. The pandemic has created an unprecedented and traumatic experience for many: lives have been changed, support networks have been forced apart and services have either closed or been required to adapt to remote ways of working. Such factors have contributed extensively to the methodology in terms of ensuring no one would be asked to participate who did not have access to some support at this time.

Focusing the Study

The questions underpinning this mapping exercise sought to understand the impact of Covid-19 for the six groups above. To do so, we looked at five key areas:

- What has concerned them or been challenging over the past few months?
- What has been keeping them strong or helping them to cope with these challenges?
- What support have they received from the Voluntary and Community Sector (VCS) and from local community groups?
- What support have they received from providers of statutory services such as health, social care and local government?
- What are their concerns as lockdown eases and what has been learned that could inform the response in the event of a second lockdown?

Methods

The methods used were broad in order to capture the perspectives of a range of stakeholders in a way that was accessible to them. These included:

Capturing the views of Organisations

The following methods were used in capturing the views of organisations:

- **Community of Expertise Conference Calls –** bringing together VCS organisations with extensive experience in supporting each of the six groups from across the county, as well as the BAME community and people who are homeless.

- **Email Call Out –** VCS organisations were also emailed a list of questions related to the themes above and invited to share their thoughts.

- **Internal Conference Calls –** The wider Barnwood Trust team were invited to share what they had witnessed in their professional work including via the grants lines.

- **Video Interviews –** Representatives from statutory organisations including health, social care and local government were invited to participate in a one-to-one interview with a member of the Barnwood Trust team. These calls sought to gather these organisations' perspectives as they worked to implement emergency plans and interventions

Capturing the views of Individuals

The methods above were complemented by gathering the direct experience of disabled people and people with mental health challenges. This was done by:

- **Calls with Disabled People and People with Mental Health Challenges –** Through its various programmes, Barnwood Trust engages with a number of disabled people and people with mental health challenges. Some of these individuals shared their personal experiences via conference calls.

- **Online Form –** Some chose to answer the questions via an online form.

In addition to these methods, case studies were collected via organisations to capture individuals' personal experiences.

The Participants

It was decided that the mapping exercise would primarily involve organisations given the nature of the current situation. It was felt that the most appropriate way to collect this data via organisations to ensure that everyone who participated was connected in with support should they require it. At a time when services are closed or not able to support people to the same extent as they could before the pandemic, it was felt irresponsible to contact people about something as emotive as this subject when such support could not be guaranteed.

To this end:

- **42** VCS organisations participated in this study via a call or email.
- **32** VCS organisations participated in the eight Community of Expertise conference calls (**nine** of whom attended more than one call – learning and physical disability, for example).
- **17** VCS organisations replied to the email call out, of whom:
  - **Seven** had already participated in the Community of Expertise conference calls
  - **Nine** other organisations shared their experiences
  - **One** organisation requested to share their experiences via a focus group with members of staff.
- **Five** representatives from statutory organisations participated in this exercise. Four via a one-to-one interview, and one as part of the Community of Expertise conference calls.
- Two internal conference calls were held with Barnwood Trust employees to which 19 attended.
- **Nine** disabled people and people with mental health challenges (engaged with Barnwood Trust) answered the questions via call (five people) and online form (four people)
- **23** case studies were received. Some were shared directly by disabled people connected to VCS organisations and others were captured by organisations on behalf of individuals or via a phone call with members of the Communications, Campaigns and Events Team at Barnwood Trust.

Notes were taken by researchers at all of the calls and then shared with participants to check accuracy. These notes form the basis of the findings throughout this report.

Participants were sent a draft copy of the report in July and some shared contextual, clarifying or supplementary information

As noted above, this exercise did not intend to gather a representative sample of disabled people and people with mental health challenges in Gloucestershire. Rather, this primarily qualitative study sought to highlight the key challenges they may have encountered. Such findings may provide the scope for future research.

---

[1] **Disability Considerations during the Covid-19 Outbreak** (World Health Organisation, 2020)

Available at: https://www.who.int/docs/default-source/documents/disability/Covid-19-disability-briefing.pdf?sfvrsn=fd77acb7_2&download=true

[2] **Abandoned, Forgotten and Ignored: The impact of the Coronavirus pandemic on Disabled People** (Inclusion London, 2020)
Available at: https://www.inclusionlondon.org.uk/wp-content/uploads/2020/06/Abandoned-Forgotten-and-Ignored-Final-1.pdf

[3] **Coronavirus and the Social Impacts on Disabled People in Great Britain: May 2020** (ONS, 2020)

Available at:
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/may2020

[4] **Beyond the Data: Understanding the Impact of Covid-19 on BAME Groups** (Public Health England, 2020b)

Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/Covid_stakeholder_engagement_synthesis_beyond_the_data.pdf

[5]) **Disability and Crime, UK: 2019** (ONS, 2019) Available at:
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandcrimeuk/2019#:~:text=In%20the%20latest%20findings%20(year,20.7%25)%20(Table%20D3).&text=personal%20theft%3A%202.9%25%20of%20disabled,aged%2016%20years%20and%20over

[6] **Mental Health Statistics: Homelessness** (Mental Health Foundation, 2016)

Available at: https://www.mentalhealth.org.uk/statistics/mental-health-statistics-homelessness

[7] **Population Profile** (Gloucestershire County Council, 2020)
https://www.gloucestershire.gov.uk/media/2097102/equality-profile-2020-final.pdf

[8] **Indices of Deprivation – Gloucestershire** (Gloucestershire County Council, 2016)

Available at: https://www.gloucestershire.gov.uk/media/1520678/gloucestershire_deprivation_2015_v1_3-11.pdf

[9] **Securing the Health of our Future: The health and wellbeing of children and their families in Gloucestershire** (Gloucestershire County Council, 2017)

Available at: https://inform.gloucestershire.gov.uk/media/1521043/annual_report_of_the_director_of_public_health_2016-17.pdf

[10] **Population Profile** (Gloucestershire County Council, 2020)
https://www.gloucestershire.gov.uk/media/2097102/equality-profile-2020-final.pdf

---

[11] **Press Release: PCC's office wins snap bidding war on behalf of local domestic abuse victims** (Office of the Police and Crime Commissioner for Gloucestershire, 29th June 2020) Available at: https://www.gloucestershire-pcc.gov.uk/pccs-office-wins-snap-bidding-war-on-behalf-of-local-domestic-abuse-victims/

[12] The statutory organisation shared the following links for further information: https://www.resus.org.uk/respect and https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/dnar-forms/