OUR CHANGING WORLD

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

barn wood

" Covid has taken my job, the one part of my life I could control, and it has thrown me into despair. **"**

Gloucestershire resident

Our Changing World: Executive Summary

The Covid-19 pandemic, and the lockdown which ensued, has presented one of the most significant challenges to people, organisations and services in generations. Between April and June 2020, Barnwood Trust conducted a study which captured the impact of this unique period of time on disabled people and people with mental health challenges in Gloucestershire.

Over 40 local voluntary and community sector (VCS) organisations in direct contact with diverse groups of individuals took part in the study, as well as representatives from the statutory sector, including health, social care and local government. Disabled people and people with mental health challenges also contributed to the project, including by sharing case studies.

This summary presents the key findings from this study, including eight key challenges identified as being experienced by disabled people and people with mental health challenges. As well as these eight areas, two overarching challenges were also clear: uncertainty and the impact on mental health. These two themes run through much of the entire report and the below diagram highlights the overarching nature of these themes.

The following sections describe the key findings relating to each of the eight challenges. It is important to note that whilst these challenges are explored in turn, one of the key findings of this study is that many of these challenges are interrelated and can compound one another; and that people often experience multiple challenges in different combinations.

"We asked all participants about what had helped them to stay strong during the pandemic, but people mostly talked with us about the challenges."

Roz Warden, Head of Research

Contents

Information Provision

Provision and accessibility of clear information was reported to be a widespread challenge for disabled people and people with mental health challenges during the pandemic. This contributed to people feeling isolated or considered a low priority and impacted upon their mental health.

- **Lack of information:** There were concerns that individuals were not aware of the support available to them or were unaware of vital government guidance.

- **The importance of accessible information:** This included both the format and content of information, particularly for people with sensory impairments and learning disabilities.

- **A need for clear information and communications:** Including key government information around who is on the shielding list and who is on the vulnerable list. Messages in the media have been thick, fast and changing all the time and it has been hard for people to keep up.

- **The need to moderate the effects of exposure to too much negative information about Covid-19:** Exposure to negative information, or bad news, about the pandemic was reported to be affecting people's mental health. Whilst people need information about Covid-19, it was acknowledged by some that it was important to balance this with activities that lift people's spirits.

> **We did not receive any documentation regarding the need to be shielded, regardless of being on the list, and in the outset this was very anxiety provoking.**
>
> **Gloucestershire resident**

Accessing Practical Goods

Throughout the pandemic, disabled people and people with mental health challenges have experienced difficulties accessing basic essential goods.

- **Barriers to accessing to food:** including due to the eligibility criteria for protected supermarket hours and delivery slots. The role of small-scale local community projects were highlighted in helping address this.

- **Barriers to accessing medication:** including due to social distancing measures being inaccessible to disabled people, for example for people with visual impairments.

- **Barriers to accessing PPE:** a particular challenge for people with physical impairments, which had resulted in a lack of respite care or people having to purchase PPE themselves.

- **Accessing white goods, IT equipment and other essential equipment has also been problematic:** for some families, a lack of sufficient IT equipment and other technological limitations reduced access to counselling, schoolwork and contributed to stress and tensions within the home.

> " 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. "
>
> **Gloucestershire resident**

Unpaid Care and Parenting

Particular challenges were highlighted for parents and unpaid carers of disabled children and adults, as well as parents experiencing mental health challenges themselves.

- **Managing multiple demands and additional pressures, in some cases with less support than prior to the pandemic.** In some cases it has also been possible to see a deterioration in disabled children's behaviour and mental health.

- **Experiencing feelings of isolation and impacts on their mental health.** Organisations reported an increased demand for parent support services, with organisations supporting whole families (rather than just the child).

> **Before Covid we had a carer 2 days per week every other week to allow Abigail a break, but we haven't had a carer lately.**
>
> **Gloucestershire resident**

Increased Financial Pressure

This has been a period of real financial concern for a lot of people, with existing financial challenges being exacerbated as a result of the pandemic.

- **The immediate, practical challenges of not having enough money.** This included people struggling to pay bills or to obtain essential items. Disabled people and people with mental health challenges have also faced some specific additional costs, such as purchasing PPE or funding private counselling due to being unable to access NHS mental health services.

- **The secondary impacts of not having enough money:** mental health, tension, and abuse. Rising stress levels and tensions at home were felt to be a real cause for concern. This was both in terms of increasing the risk of developing or exacerbating mental health challenges, and a higher risk of domestic abuse.

"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.

Gloucestershire resident

Increased Risk of Domestic Abuse

The combination of increased tensions and stressors, prolonged isolation, being cut off from sources of safe intervention, and the reduction in the ability of services to provide support, has led to a higher risk of domestic abuse.

- **An increased risk of domestic abuse:** Gloucestershire Constabulary recorded a 26% increase in domestic abuse incidents in May 2020 compared with May 2019. Organisations reported concerns that the full extent of domestic abuse which has taken place would not be seen until after the initial emergency has passed.

- **Tension, isolation, and mental health:** Increased pressures and tensions at home, compounded with prolonged isolation and fewer outlets for escaping tension, has resulted in some people being at greater risk of domestic abuse. Lockdown may also be re-traumatising for some victims and survivors of historic domestic abuse.

- **Getting support for domestic abuse during lockdown:** Organisations reported switching to providing remote services, however these were described as not being accessible to all, particularly where clients were living with a perpetrator of abuse.

Accessing Services

Being unable to access services during the lockdown was described as having impacts for disabled people and people with mental health challenges both in the immediate and longer-term.

- **Challenges to accessing ongoing or adapted service provision – especially for those not already connected in with services.** Organisations reported offering online activities, however these were not accessible to all. For those already connected in with services before the pandemic there was reported to be an abundance of available support and signposting. This was contrasted with those not connected in who were waiting for support as services became overwhelmed with demand.

- **Barriers to accessing digital support:** whilst the availability of online support made accessing help easier for some, others experienced barriers such as a lack of IT equipment or lack of confidential space at home. For people with sensory impairments there were particular issues with accessibility.

- **Limitations of online support:** It was suggested that online provision may not be appropriate for those experiencing significant mental distress or domestic abuse.

- **Impact of disrupted and cancelled services on people's physical and mental health:** Routine therapies that are vital for managing conditions were stopped for many, and people reported suddenly being discharged from mental health services without reason or explanation. This was suggested to impact on people's trust of services.

> **Much of my treatment, aside from regular medication, has stopped during lockdown. As a result, my condition has progressed more in the last 3 months than in the last 10 years.**
>
> **Gloucestershire resident**

Isolation and Connection

Disabled people and people with mental health challenges in Gloucestershire have experienced the lockdown in a wide range of ways, but isolation and the impact on mental health was a widespread concern.

- **Social isolation is one of the key causes for concern about the impact of the Covid-19 crisis on people's mental health.** There were concerns both that new mental health challenges would arise, and that people with existing mental health challenges would experience a deterioration in their health. This was in part due to loneliness, boredom, and tension at home, as well as the possibility of re-traumatisation.

- **Not going out:** A loss of avenues to connect with other people. 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, and attending social groups or gatherings.

- **The particular impact of isolation for disabled people.** Disabled people experienced lockdown very differently depending on their individual circumstances. For some who were shielding, lockdown was felt as something of a temporary leveller – but there was also concern about how that dynamic would change as lockdown began to lift for some. Again, isolation – and the uncertainty about how long the isolation would persist – was having an impact on many disabled people's mental health.

- **The particular impact of isolation for young people.** Organisations working with young people have been very concerned about a rise in mental health challenges, including as a result of isolation and tensions at home.

- **A creative, much-valued response to combat social isolation – but it can't reach everyone.** Participants spoke about a great deal of often creative work being done, both by organisations and communities, to try and combat social isolation, but while that has been a crucial lifeline for many, it hasn't been accessible or available to everyone.

> **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.**

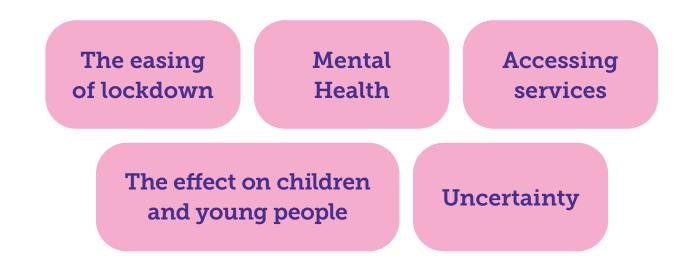**Gloucestershire resident**

Perceptions

There were also examples where individuals' perceptions prevented them from being offered or accessing support during the lockdown. In some cases, this may have stopped them from living as independently as they did before the pandemic.

- **A reluctance to accept 'charity'.** It was suggested that some have not accessed support due to not being happy to accept 'charity'.

- **Individuals' own perceptions that they do not need support.** This was linked to a loss of agency and it was commented that what people really wanted was to be able to go to the supermarket themselves and choose their own food.

- **Others' judgements about who requires support and/or is 'vulnerable'.** Such concerns were raised in relation to those with both visible and invisible impairments, and related to others' perception and recognition of who is clinically vulnerable

Future Concerns

Participants identified a range of future concerns that require collective thought and attention in the immediate and longer-term. These included:

The easing of lockdown

Mental Health

Accessing services

The effect on children and young people

Uncertainty

- **The easing of lockdown:** There was a fear that we would see two-tiers of restrictions as **lockdown eases differently for different groups** (those who are shielding, for example). Others spoke about people being fearful and anxious about the lockdown easing and there was a worry that the **community response would diminish** as people return to work and 'business-as-usual'.

- **Mental health:** Organisations predicted a **surge in demand** for mental health services as everyone processes the last few months. For those with pre-existing conditions, it was reported how **treatment has been destabilised** by the closure or interruption of therapeutic services, and how anxiety disorders and OCD were being made worse by the pandemic itself.

- **Accessing services:** Organisations were worried that they would become **overwhelmed** as more people seek support

for mental health, domestic abuse, financial trouble and other such factors. There were also suggestions that **trust** would need to be (re-)built and the way services were **prioritised** should be changed in the event of further lockdowns.

- **Children and Young People:** There was concern that children and young people have been **missing out on support provided by schools** and that those who were disadvantaged before the pandemic are becoming more so. Some organisations advocated for trauma-informed support and predicted **increased demand for children's mental health services.**

- **Uncertainty:** **Underpinning all of these concerns was uncertainty.** Participants were fearful of going outside (as they did not know if it was safe enough), bringing the virus home from work, and felt a need for **clear and accessible information and guidance.**

Our Changing World: Report Recommendations

A note about application of these recommendations: they are not intended to be applied as a one-size-fits-all approach. A key finding of the Our Changing World report was that disabled people and people with mental health challenges experienced a varying range of challenges during the first 12 weeks of the pandemic. Providing support to individuals should consider their particular circumstances and recognise what each individual identifies that would be beneficial to them.

Immediate actions to address existing inequalities

These recommendations are to help address the disproportionate impact of the pandemic over the last 12 weeks on disabled people and people with mental health challenges in Gloucestershire.

1 Provide clear, timely, and accessible information about Covid-19 and sources of support

- Produce information in a range of formats, considering the needs of people who have visual and/or hearing impairments and people who may have difficulty understanding new or complex information. Create communications that are suitable for a range of reading abilities.

- Consult with experts in the VCS and statutory services to ensure that information is accessible

- Share information via multiple channels to ensure that it reaches everyone

- Link up with sight registers to make sure people receive communications in braille, large print or audio versions

- Provide information in Easy Read formats

- Ensure that support is available for people who require help with understanding information

- Ensure there is a clear definition of the term 'vulnerable' and the criteria for being placed on the shielding list. Use these, and other Covid-19 specific, terms consistently.

- Provide a centralised point to access information, ensuring that consistent information is available to everyone.

2

Reduce barriers to accessing services digitally and remotely, whilst recognising that this type of support may not be appropriate for all

- Provide financial support for individuals and families to access devices such as tablets, laptops, computers, and broadband to enable them to access support remotely and to keep connected

- Provide digital support to enable individuals to utilise technology to attend appointments and access services

- Consider the appropriateness of when to offer support remotely via video and/or phone call, recognising that some individuals may not have access to a confidential, safe space at home

- Enable individuals to access face-to-face support where necessary, including those who may be experiencing significant mental distress and those experiencing, or at risk of experiencing, domestic abuse

3

Return to offering routine therapies and treatments for people with physical impairments, with additional investment to ensure that support is provided to individuals as soon as possible. Routine therapies and treatments include physiotherapy, occupational therapy, Botox treatments, and annual health checks

- Recommence provision of routine therapies and treatments for disabled children and adults as soon as possible in order to avoid severe long-term implications due to delayed treatment.

- Prioritise further investment in routine therapies and clinics to ensure individuals are provided with vital support as soon as possible

4 Provide extra investment for both statutory and VCS mental health services and support, in recognition of the impact of the pandemic and disruption to treatment for those with existing mental health challenges, as well as anticipated growing numbers of individuals requiring mental health support

5 Ensure Covid-19 response initiatives are able to provide sustained support to individuals and communities, and that these initiatives are co-ordinated across sectors

- Make funding available for VCS and statutory initiatives to continue supporting individuals to have access to essential items and keep connected as lockdown eases

- Continue partnership working across sectors to develop and sustain response initiatives, recognising the specialised expertise and hyper-local knowledge of VCS organisations, and the trusting relationships they already have established with specific population groups

- Ensure a co-ordinated response across sectors, to avoid individuals being offered too much or too little support and information, and to prevent either a lack of services or the duplication of support available to particular groups. This includes recognising the role of micro-level and community-led approaches

- Ensure resources are available for organisations who have recruited additional volunteers, including in relation to safeguarding

- Recognise the need to support the wellbeing of those who are working and volunteering to support others

- Learn from what has worked well during the first 12 months and build on this going forwards

Further actions to prevent additional inequalities

These recommendations are to help ensure that in the instance of future lockdown measures, or another outbreak of the virus, that disabled people and people with mental health challenges can retain their rights and choice about their lives.

6 **Ensure that systems and services set up to support vulnerable individuals include those who are socially vulnerable (and not only those who are clinically vulnerable to the virus). Individuals who may be socially vulnerable include people with mental health challenges, learning disabilities, sensory impairments, neurological problems, acquired brain injuries and other impairments, as well as parents of disabled children and unpaid carers.**

- Recognise that individuals living independently and who are not usually connected in with services may become socially vulnerable in the context of the pandemic

- Ensure that individuals who are socially vulnerable are included in the eligibility criteria of initiatives to enable vulnerable individuals to access basic goods (such as protected shopping slots)

- Ensure that statutory registers of who is vulnerable and who may require additional support or services include those who are potentially socially vulnerable

- Consider the impact of future lockdown or social distancing restrictions on those who are potentially socially vulnerable to ensure that individuals are not further disabled by these restrictions, for example, when trying to access basic goods

7 **Provide PPE and make respite care available for families and carers of disabled adults and children**

8 Continue to provide essential statutory services to disabled people and people with mental health challenges, and clearly communicate any changes to service provision

- Ensure that decisions about which services to prioritise operating consider the longer-term impact of disrupted therapies and treatments on the physical and mental health of disabled people and people with mental health challenges

- Provide face-to-face mental health support for those who are experiencing significant mental distress and for whom remote or digital support may not be suitable

- Should appointments or services be postponed/cancelled due to another outbreak, ensure that suitable alternative forms or sources of support are provided in the interim

- Halting of services should be communicated clearly and sensitively, with information about alternative pathways or sources of support provided. Include information about when routine services may be resumed where possible.

- Recognising that people may not feel confident to access services, or know that they are eligible to receive them, proactively offer support rather than putting the onus on individuals to ask for it

If you would like to work with us at Barnwood Trust towards implementing these recommendations, please get in touch with Georgia Boon, Director of Relationships at **Georgia.boon@barnwoodtrust.org** to discuss this further.