Behind Closed Doors

The longer-term impacts of COVID-19 on independent living for d/Deaf and Disabled people

Part 2: Narrative report

January 2021

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Introduction

In June 2020, Shaping Our Lives was awarded a grant by the National Lottery Community Fund to carry out and complete research into the impacts of COVID-19 and the consequent national and regional lockdowns on d/Deaf and Disabled people, d/Deaf and Disabled People's Organisations (DDPOs) and Patient Participation Groups.

Part One of this report detailed our findings from a survey about the longer term impacts of COVID-19 and the resulting lockdown measures on independent living for d/Deaf and Disabled people.

For Disabled people, independent living is about having choice and control over their everyday activities. It is also about being able to apply strategies themselves to overcome the social barriers that stand in the way of their doing those everyday activities independently.

This study developed out of conversations with our members, who told us that both the pandemic and the resulting lockdown measures had a substantial impact on their abilities to independently live their lives day-to-day. Our members told us that they were not sure how and when their confidence and independence would return. Some members told us they were not even sure if they would regain the levels of confidence and independence that they enjoyed before the pandemic.

The subsequent survey investigated some of those issues that had been reported to Shaping Our Lives as potential long-term impacts of COVID-19. These included:
- **Loss of confidence** to live independently and leave home.
- **Loss of independent living skills**, including mobility skills.

- **Loneliness and isolation** due to the postponement or inaccessibility of usual support networks.

There were 131 survey respondents. The methodology for the survey is further described in the Introduction to Part One of *Behind Closed Doors*.

A further 21 in-depth interviews were conducted with Disabled people as part of this research. Some narratives described in those interviews are outlined in this report*.*

This report presents a narrative of Disabled people's experiences, focussing on four common themes that arose out of the interviews and the survey. These themes are loss of confidence; loss of independent living skills; loneliness and isolation; and what structural improvements could have been made to improve peoples' experiences of the pandemic.

To protect the privacy of the people that we have interviewed for this report, all names have been changed and identifying details have been anonymised.

This report is published as part of a series of reports exploring the impact of the COVID-19 pandemic on d/Deaf and Disabled people. The other reports, published by Shaping Our Lives in December 2020, are:

Locked In or Locked Out? d/Deaf and Disabled People's Experiences of using Remote Technologies during COVID-19.

Crisis, Challenge and Change: Reflections from Deaf and Disabled people's user-led organisations about the impact of COVID-19 on their work in 2020.

Engaged or Ignored? Reflections from patient participation groups about practice during COVID-19.

Behind Closed Doors: The longer-term impacts of COVID-19 on independent living for d/Deaf and Disabled People – Part One: Survey Results.

Section One: Confidence

Tim's story

Tim felt incredibly vulnerable during the first lockdown. With the daily infection rate climbing, a lack of government leadership and a lack of public compliance with lockdown rules, Tim became very anxious about the possibility of coming in contact with the virus. He described his life at that point as "one big risk assessment" –

> Should I get the bus, should I take the car? All the things that were unproblematic become [problematic].

As a result, Tim found it difficult to leave the house, even to exercise. He also found it difficult to keep in regular contact with friends and family, partly because he had to plan phone calls and online hangouts – "it becomes more structured and less spontaneous" – and partly because he lacked the confidence or energy to chase people up.

This drop in social activities and in-person contact had a significant impact on Tim's confidence. He found it difficult to keep up his usual standard of appearance and spent a lot of time inside his head, 'overthinking.' For Tim, then, the first lockdown was a source of self-perpetuating anxiety.

Amit's story

Like many survey respondents, Amit had been shielding since the beginning of the first lockdown. Initially, Amit found the lockdown boring: an inevitable drop in in-person socialising meant that he was unable to enjoy people's company and conversation as he had before the lockdown. He regularly listened to radio broadcasts and took advantage of the spike in webcasts and webinars, but he was not fully engaging with them as they simply weren't interactive enough.

As the lockdown progressed, Amit became more frustrated and anxious as he felt that his independence was being taken away.

He was reluctant to go outside, as he was worried about the things that could happen. As a blind man, he was particularly worried about what might happen if he was unable to maintain the correct social distance; on the flipside, he was also worried about what might happen if someone with good intentions tried to help him and unwittingly infected him with COVID-19 in the process.

This posed potential health risks to Amit, and also had a major impact on his confidence. He found himself caught in negative patterns of thought, questioning everything and worrying that he might be a burden to his friends and family. Without regular conversation with others outside of his household—"I have been through days where I have not spoken to anyone" –Amit also lost much of his energy and his motivation to connect with the world around him. This made it difficult for him to choose to leave the house – and it already took a lot of confidence and motivation for him to choose to go out prior to the first lockdown.

Amit has been able to start rebuilding his confidence with the help of support networks in his life. However, he says that the support of a person from outside his family with an understanding of sensory loss would be a great help to him as he works to regain his confidence.

Section Two: Independent Living Skills

Lauren's story

Lauren had been living on her own prior to lockdown; "to some extent, I felt that I was self-supporting." However, Lauren was forced to shield on her own, away from her partner.

As the pandemic progressed, Lauren found that she was losing her confidence and becoming more isolated. Her independent living skills deteriorated, and the "difference between [her life] and other peoples'" seemed greater than usual.

Because she was shielding, Lauren was unable to live her life as usual. She could not go shopping, meet friends or take part in her usual classes, which had been cancelled as a result of the pandemic.

This meant that Lauren was more reliant on help from others, but was unable to get that help because she was shielding. Her personal assistant withdrew early in the pandemic, as she had children; her cleaner was unable to come over and perform her usual services; she was even unable to get people over to carry out repairs on her house –

> …things in the house need doing that haven't been done, curtains torn, and back door falling off, one of the neighbours put tarpaulin on the front of the bungalow but feel even more isolated. The hob on the oven has split, all these things have happened and my ability to cope with them has been reduced as I have not been able to get people to help with them and they have amassed.

Lauren rarely left the house during the first lockdown because of this lack of support. She avoided people and public transport, and she limited her movement around the house in order to reduce her chance of having a fall while in her wheelchair. She struggled to manage tasks that she usually performed with the help of her personal assistant or cleaner. The added stress and exertion contributed to an increase in pain and a deterioration of her mobility.

Lauren also has a historic brain injury that makes it difficult for her to remember things or make decisions. Without support people around to help her, she struggled to make everyday decisions about, for example, what to buy from the supermarket or how to repair a broken door. While she received some support from neighbours and local support networks, the stress of the pandemic made these decisions more difficult, and made life harder for Lauren.

Eve's story

Prior to the first lockdown, Eve was a part-time student. Early on in the pandemic Eve came down with an illness which she suspects may have been COVID-19 (she was unable to confirm this as testing was unavailable at the time). When her illness subsided, Eve found that she had difficulties with fatigue, focussing and thinking, and she lost confidence in her ability to study. She had to take time out from her studies because of this:

> I… feel as if my mind is foggy (can't think clearly, can't concentrate) and not entirely sure how I'll feel when I go back to [study].

In order to manage this loss of focus, Eve had to plan her time more carefully, writing lists and taking other steps to organise her day-to-day life. She needed help to address these difficulties but found it very difficult to find anyone to help, whether it was through her university or from elsewhere.

Like many of the respondents to our survey, Eve said that she experienced a loss of mobility and a loss of support as a result of the pandemic. Her personal assistants were unavailable at times because they themselves had contracted COVID-19, and without their support she found it difficult as a wheelchair user to carry out day-to-day tasks such as shopping.

Section Three: Loneliness and Isolation

Maureen's story

Maureen had been shielding throughout the pandemic, only leaving her house for fresh air during the first twelve weeks. Over this time she felt isolated and unsupported, missing the things that that 'make you feel part of the community' – theatre performances and cinema screenings, markets, in-person meetings with friends.

A lot of Maureen's friends felt similarly isolated. She was also concerned that other older people with experience of trauma/mental distress had felt isolated in the same negative way during the pandemic.

Maureen learned how to use Zoom in order to keep in touch with her friends and to continue with work meetings. She found that this worked better for her than phone calls as she could see people, even if it was just on screen. However, this did not eliminate her sense of isolation and distress.

Those feelings were aggravated by a lack of properly-funded support from central government and local authorities. In the absence of that support, Maureen often relied on spontaneous help from people in her neighbourhood, such as the man who offered to do her shopping for her. She valued their generosity, but found it hard that the local authority was not more proactive.

Maureen felt more isolated and more distressed because of her housing situation. Her landlord had behaved in a very difficult way towards her throughout the lockdown: "I feel very bullied at the moment." She was not receiving any support from the local housing department, which had been reducing its services before the pandemic, and had not been protected by safeguarding processes. She also did not qualify for legal aid and did not have the resources to seek legal advice or take costly action.

Maureen also felt anxious and isolated after discovering that the recently-passed Coronavirus Act 2020 increased the powers authorised by the Mental Health Act, making it easier to section people in mental distress if authorised to by the Secretary of State. Maureen said that the existing powers under the Mental Health Act were already discriminatory, and that these new powers scared her and many of her colleagues: "Sectioning itself sets you apart and isolates you, as well as often causing huge trauma. In addition, detention has had fatal consequences during the pandemic; deaths of detained patients doubled at the start of it."

Patricia's story

In September 2019, Patricia began receiving treatment for cancer. She had finished her treatment and was starting to re-enter everyday life when the first lockdown began and she was forced to shield at home. This knocked her confidence quite early on. As she dealt with life in lockdown, with people unable to visit and all her usual leisure activities shut down, she became more isolated and anxious: "sometimes I don't want my own company. Ten months in the house does get you down a bit."

As a result of this isolation, Patricia lost the motivation to exercise and was unable to fully engage with new technologies until after the lockdown. Patricia also had issues with her support, particularly in the early days of the pandemic. A personal assistant who helped her with her shopping refused to enter her house, telling her that she had to self-isolate. The assistant instead 'dumped' her shopping outside and walked away. This had a real impact on Patricia's confidence and prompted her to have a conversation with the personal assistant about the effect of her actions.

However, Patricia received strong support from others in her life. In the period after the first lockdown, friends visited to help her with her shopping and to help her learn how to use

technologies like Zoom. She also began receiving support from a 'brilliant' social worker who focussed on assisting Patricia with her mental health. This social worker, Patricia says, made her feel less isolated in this difficult environment:

> This one was ringing me every day so she's been brilliant. She says she can hear in my voice that my mental health was going down so she's here to help.

Section Four: Structural Improvements

Richard's story

Richard had been shielding since the start of the pandemic, and this had a massive impact on his social life and his general wellbeing. Prior to the pandemic, Richard had a network of friends he could meet and hang out with, but the pandemic eroded the strength of this network. Richard had texted some friends and had Zoom meetings with others, but overall he no longer spent as much time taking to or spending time with his friends as he used to.

Prior to the pandemic, Richard also had a gym membership and was taking part in adult learning courses to build confidence. During the lockdown, Richard's gym was closed and he was unable to exercise there; similarly, his classes were cancelled and no alternatives were offered.

As a result of all of this, Richard became much more anxious and withdrawn. He no longer had the confidence to use public transport or go out in public, and he experienced a spike in his depression due to the lack of in-person social interaction. A lack of exercise inflamed his pre-existing mobility issues, and he was unable to get an appointment with a doctor to help with his condition. Richard also has a history of compulsive buying and hoarding, and he had to seek out online group support in order to replace the face-to-face group meetings that he relied on to manage his compulsion.

Richard firmly believes that some kind of buddy support system during the pandemic would have made his experience much easier. "It would help," he says, "if I had someone who would go on a bus with me to accompany me for a short distance to rebuild confidence."

> "Having a be-friender would help to re-engage with society, someone to talk to. Even a txt buddy or someone who rings once a week would be good."

As it is, the lack of social interaction with friends and family defined Richard's experience of the pandemic. A buddy support system would have helped Richard build and maintain his confidence, as well as improve his mood through regular social contact. A buddy system could even have helped him exercise more regularly or deal with other, everyday issues that he was unable to deal with.

Kate's story

Kate is an artist who lives with her partner. She and her partner were quarantining indoors for much of the first lockdown, as her partner contracted COVID-19 and she did not want to risk spreading the virus.

Because they were so isolated, Kate lost a lot of her motivation to seek out opportunities for work or socialising. This was particularly difficult for her as an artist, because she is essentially self-employed; as many opportunities for creative work dried up in the wake of the pandemic, it became much harder for her to find work in her field.

Kate also lost her confidence when it came to being out in public. She became nervous of people not wearing masks and not following social distancing rules, and found it difficult to get on public transport or enter shops and supermarkets.

Kate felt a great deal of anxiety about a perceived lack of collective responsibility at all levels of society, from people on the street to the highest levels of government. Kate said that she was less likely to go outside because others were not following the rules. She also said that the lack of collective responsibility was a real source of stress in her work with others in the mental health community:

> "[The] mental health community [is] quite split: you have some who are washing excessively; others don't believe COVID is a thing and are completely reckless and others believing they can cope better by assuring themselves they've had COVID so it's not an

> issue so that they won't get stressed by it – so that's quite concerning and challenging."

Kate traces this back to a lack of clarity and leadership from local authorities and central government. She holds that the government could have provided better guidance and support for d/Deaf and disabled people during the pandemic, particularly those who were shielding. They could have provided clearer information on how the virus travels and how it presents; they could have made masks mandatory, and made them more readily available through public funding; there could have been more consistency from members of the government in following the rules that they themselves had set.

Kate says that she was particularly frustrated by the process of getting her partner tested and treated for COVID-19 in early March. She reports that it took multiple calls for her to secure an ambulance to take her partner to the hospital, as he was told that he 'was not ill enough' to justify an ambulance. She says that he also was not tested before being discharged from hospital, meaning that it was not clear if he was still infectious, and that the NHS did not supply her with any information about how to protect herself if he was still infectious while she was caring for him.

Kate says that one thing that she and others would have massively benefited from is a central or local support structure for d/Deaf and Disabled people, to provide support and help with accessing necessities and other deliveries while shielding or in quarantine. With no clear structure for going out and running errands, or for getting help while stuck inside, Kate became anxious about going outside and found that this anxiety impacted her ability to do simple tasks like go to pharmacy or go to the supermarket.

Conclusion

Part One of *Behind Closed Doors* reflected both negative and positive outcomes for d/Deaf and Disabled people as a result of the COVID-19 pandemic, the resulting national and regional lockdowns, and the restrictive policies that have been implemented by central and local governments.

It is reasonable to say that the negative impacts have been considerably more significant to d/Deaf and Disabled people than the gains, such as having more time or learning how to use a new technology. Part One demonstrated that these negative impacts had resulted in an extensive deterioration of d/Deaf and Disabled people's **confidence** and **independent living skills**, and a significant increase in their **loneliness and isolation**, over the course of the pandemic. More than half of the respondents to that survey felt that COVID-19 and the consequent national and regional lockdowns had a long-term negative impact on their ability to live independently.

Drawing on the in-depth interviews that were conducted with a number of our survey respondents, Part Two illustrates the different ways that individual disabled people have experienced these negative impacts. The individual experiences contained in these interviews come from a broad and diverse range of interview subjects – people of different ages, ethnicities, sexual and gender identifications, geographic locations, work statuses, disabilities.

Rather than diffusing the potency of each person's experience, though, these interviews read together make clear the similarities between each person's experience. It also makes clear that these shared experiences – loneliness, isolation, loss of confidence and loss of independent living skills – are in part a result of structural shortfalls that urgently need addressing at all levels. From communities and health and social care

professionals to local authorities and central government, this part of *Behind Closed Doors* illustrates clearly the issues we identify in the conclusion to Part One of this report.

This part of *Behind Closed Doors* highlights some structural improvements that would have made d/Deaf and Disabled Peoples' experiences of the pandemic much easier. Our respondents have told us that support frameworks and buddy systems would have made a great deal of difference to their experiences of the pandemic, as well as clearer information about how to access the assistance to which they were entitled during the pandemic, regardless of whether they knew about it or not. It is important to point out, though, that these are only two solutions; we must re-emphasise that deeper structural improvements are required at all levels of service provision and policy-making.

We make a number of recommendations about structural improvements to be made in the Recommendations section of Part One of this report. Among those recommendations is longer-term local authority and central government support for user-led organisations and peer organisations. These organisations are best placed to provide remedial support and intervention to these people, and to others who share their experiences. They will need to be resourced properly in order to act on these experiences and create proper support structures for d/Deaf and Disabled people in their communities.

However, as emphasised at the end of Part One, many d/Deaf and Disabled People's Organisations have been overwhelmed with requests for help in the last six months. There has been some time-limited investment. Now, there needs to be a longer-term funding commitment to enable this work to happen.