



Behind Closed Doors

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

Part 1: Survey results

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Introduction

In June this year, 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 of the consequent national and regional lockdowns across England, on d/Deaf and Disabled people, Deaf and Disabled People's Organisations (DDPOs) and Patient Participation Groups.

This report details findings from a survey about the longer term impacts of COVID-19, and 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, and 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 substantial impacts on their abilities to independently live their day-to-day lives. 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.

Our members told us about a number of their own recent experiences. Among the many stories we heard were the following:

- I used to be acrophobic because of mental health issues and I am not sure if this is going to recur because of lockdown.



- I am too anxious to do my usual involvement and voluntary sector activities as I am completely overwhelmed with organising everyday help to get shopping.
- I reached out to my father and he did not remember who I was because of his dementia.
- My eye operation has been cancelled and my sight has got much worse. I cannot get out on my own anymore and need mobility training.
- I do not want to use public transport until there is a vaccine.

The subsequent survey investigated some of the issues that had been reported to Shaping Our Lives as potential long-term impacts of COVID-19 on d/Deaf and Disabled people's abilities to live independently. 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.
- **Impacts on health and wellbeing** due to the cancellation of operations and treatments.

The findings in this report have been collected through an electronic survey of 36 questions and a section of monitoring data collection that indicates the reach across age groups, location, employment, impairment, shielding status and long-term health condition. This survey was only for d/Deaf and Disabled people. In this report, Disabled people are those people with sensory, cognitive or neurodevelopmental conditions, people with learning disabilities or physical impairments, people with mental health issues and people with



long-term health conditions (consistent with descriptions provided in the Equality Act 2010).

A Microsoft Word version of the survey was available on request. The survey was also available for completion over the telephone. A further 21 in-depth interviews were conducted with Disabled people as part of this research. The findings from those interviews are described in Part Two, a narrative of Disabled people's experiences.

There were 131 survey respondents. Monitoring data for those respondents can be found in Appendix One of this report. All responses were anonymous and consent was gained before submitting the completed survey. No questions were compulsory and more than one answer could be selected for multiple-answer questions.

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 three 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.



Key Findings

This report has five main sections. The key findings below relate to these sections and have the same headings as in the report.

Confidence

- Of the 131 Disabled people who took part in this survey, 98 people (75% of respondents) have lost their confidence as a result of COVID-19 and national and regional lockdown measures.
- Of those 98 people, 72 (or four fifths of those who reported a loss of confidence) said they would need help to regain their confidence.
- Most respondents told us that they needed support communicating and getting out and about. Those respondents suggested that buddies, peer supporters and other types of support worker would be able to provide that kind of support.

Independent Living Skills

- We asked participants to say if they agreed or disagreed with the statement that, "COVID-19 and lockdown measures have had an overall long term negative impact on my ability to live independently." Of the 104 respondents who answered this question, 60 people (58% of respondents) selected 'strongly agree' or 'agree'. Only 21 people disagreed with the statement.
- Of the 120 people who responded to the question, 'Have you lost daily living skills because of COVID-19 and lockdown?' 76 people (63% of respondents) felt that they had lost some of their independent living skills.



- Of the independent living skills that respondents reported they had lost, the most commonly reported were 'being able to go out and about,' and 'being able to take part in social and leisure activities'.
- 57 people (just over 50% of respondents) said they needed help to regain their independent living skills.
- 39 people (about two thirds of respondents) asked for the following types of support and help:
 - Support workers and personal assistants, to help with practical tasks and getting out and about
 - Befriending services and an increase in accessible social activities, particularly activities involving friends and family
 - More (and more accessible) public health information
 - Mobility and orientation training
 - Mentoring to support re-enablement
 - Professional health and social care professionals, who have the knowledge and expertise to help people stop and reverse any deterioration in independence.
- Other independent living skills that were not on the original list but were mentioned by people in responses included: motivation; self-management of mental distress; and cognitive skills.
- When asked what skills they had gained during the pandemic, the most common answer from respondents was technology skills, including skills for using social media and video meeting software.



Loneliness and Isolation

- 92 people (79% of respondents) reported that they had become lonelier or more isolated during the pandemic.
- Our respondents mentioned that the following things could help alleviate their loneliness and isolation: the opening of businesses and services; being able to see people; and a vaccine.
- Ideas for dealing with loneliness and isolation that our respondents provided included: accessible peer groups, personal buddies or supporters; clearer and more accessible public health information; better access to broadband and equipment; access to a health professional; and appropriate (or safer) social opportunities.

Health and Wellbeing

- 86 people (72% of respondents) said that at least one of their health or social care appointments had been delayed during the pandemic.
- Of these respondents, 64 people (about three quarters of this group of respondents) said that these delays had contributed to their worsening wellbeing.
- Of that group of 64, an overwhelming 50 people (more than three quarters of that group) said that some sort of medical or social care appointment, treatment or care solution would actively improve their wellbeing.



Beyond COVID-19

- When asked if something good had come out of their experience of COVID-19, and of the national and regional lockdowns, 75 people — more than half of the participants in this survey — gave a positive answer.
- Common themes in responses to this question included:
 - **Improved Wellbeing:** some people described changes in their lives that have had a positive impact on their wellbeing, such as deeper connections with their family, friends and local communities.
 - **More Time:** 15 people, a fifth of the positive respondents, talked about the benefits of having more time and a less hectic life.
 - **Home working:** there have been reported advantages for those people who were employed and able to retain their jobs and work from home.
 - **Leisure and exercise:** others described positive experiences accessing new leisure and exercise opportunities.
 - **Reflection and Understanding:** some people found that the experience has helped them to reflect on their own lives; respondents also found that this experience has helped other people in their lives to understand and empathise with the challenges and isolations that many Disabled people experienced before the pandemic.
 - **New technologies:** the remainder of respondents talked about how having time to self-teach meant they were able to develop skills related to the use of remote technologies and social media.



- When asked to say if they agreed or disagreed with the statement, 'COVID-19 and lockdown measures have reduced the choice and control I have as a disabled person,' 89 people (83% of 107 respondents) agreed or strongly agreed with the statement. Only 8 people disagreed with the statement.
- 32 people (about a third of respondents) told us that, if lockdown restrictions were lifted, they would live their life again as they had done prior to lockdown. 72 people (the remaining two thirds of respondents) said that they would not live their life as they had before lockdown.
- When asked what they would need to live their life as they had prior to lockdown, respondents said that they would first need to be safe from COVID-19, either because the virus had gone or because an effective vaccine had been rolled out. Some said they would have to regain their health, mobility and confidence before they would be able to live their lives as before.



Section One: Confidence

The responses detailed in this section are about the impact of the COVID-19 pandemic, and of national and regional lockdown measures, on Disabled people's confidence.

We asked our participants the following questions:

Have you lost confidence because of COVID-19 and lockdown?		
Answer Choices	Responses	
Yes	75%	98
No	25%	33
Total responses		131

Do you think you will need help to get your confidence back?		
Answer Choices	Responses	
Yes	55%	72
No	45%	58
Total responses		130

We also asked our participants, **What kind of help do you think you need?**

93 people (70% of all respondents) answered this question. 12 people (just over one-tenth of this group of respondents) said that they did not need any help.

The remaining 81 people said that they needed some help to regain their confidence following the COVID-19 pandemic and the national and regional lockdowns. Figures below are drawn from the answers given by the 81 respondents who said that they needed some kind of support.



35 people (about two fifths of respondents) said that they would need help to go out and about and to regain their confidence to communicate with people. In most of these responses, the respondent suggested that they could be accompanied by a 'buddy', peer supporter, support worker or personal assistant, who would help them build their confidence up to the level that they felt they were at before the pandemic.

"Carer support on trips out."

"Reassurance and support to actually go out, lost all confidence and independence now."

"Talking to people and seeing people again."

15 people (just under one fifth of respondents) said that they would need more support from health and social care professionals, local authorities, the national government and the commercial sector.

"Community/governmental/local authority/business pro-active actions to make the outside world disabled-friendly, especially in relation to the chronically-sick. I'd suggest some kind of national symbol, awareness campaign and financial backing to ensure all can go out as safely as possible."

11 people (just over one tenth of respondents) said that they would need some form of mental health support, talking therapy or other therapy to support them in managing their anxiety or distress.

"Mental health support and emotional wellbeing support."

"Counselling or some sort of talking therapy. Contact with someone to provide encouragement or support to get out the house."



Seven people said that they would need greater empathy and understanding from society at large.

"More awareness among the public, and a responsibility for staff working in anywhere open to the public, that disabled people may not be able to do certain things like queuing and social distancing. They will need to let us jump the queues or help us to keep our distance from others...."

Six people said that they would need a vaccine to empower them and help them feel safe to leave the house.

Five people said that they were not sure what they would need, as they did not know what was available.

Two people gave answers that were not echoed by other respondents. One said that they would need more money; the other expressed shock at the impact of COVID-19 and the lockdowns on their ability to live independently.

"My realisation that my attempts of living independently were undone easily. Scares me."



Section Two: Independent Living Skills

The responses detailed in this section are about the independent living skills that Disabled people feel they have lost as a result of the COVID-19 pandemic, and of national and regional lockdown measures.

We asked our participants the following questions:

Have you lost daily living skills because of COVID-19 and lockdown?		
Answer Choices	Responses	
Yes	63%	76
No	37%	44
Total responses		120

Respondents then chose from a list of independent living skills. People could choose more than one skill from the list. They could also leave a comment in the free text box provided.

Answer Choices	Responses	
Going out and about	73.40%	69
Taking part in social and leisure activities	73.40%	69
Shopping	48.94%	46
Communication	43.62%	41
Mobility	43.62%	41
Household chores, such as cleaning or cooking	25.53%	24
Looking after yourself	24.47%	23
Using technology	10.64%	10

25 people left comments in the free text box. In those comments, respondents highlighted the following independent living skills that they felt they had lost, including: loss of motivation; loss of the ability to self-manage one's anxiety and depression; and loss of cognitive skills.

"...not lost skills but have lost my ability to keep motivated."



"Lost all my confidence – I lack drive. I've become very depressed. I'm back to barely existing."

"Cognitive skills – my memory and attention have been awful. I can barely work for more than 30 minutes at a time and then I'm exhausted. My sleep patterns have been massively disrupted, so I've needed to sleep during the day to cope and then can't wake up on time the following morning – I've just needed so much more sleep than normal."

One respondent commented on losing the wellbeing benefits associated with being able to get out of the house, and the negative impact of being unable to access non-urgent health care.

"Accessing outdoor areas where I would usually go to photograph wildlife. Getting to hospital appointments that I used to travel to on public transport."

Other respondents left comments about losing support systems and feeling abandoned during the lockdowns.

"I had organised having a cleaner, gardener and my food delivered before lockdown. Afterwards I have a dirty house, a garden that is overgrown and food delivery is once a month now. "

"I have lost support that I relied on, not skills."

"Feeling part of a valued society, feel abandoned."



We asked participants:

Do you need support to regain these skills?		
Answer Choices	Responses	
Yes	50.5%	57
No	49.5%	56
Total responses		113

We also asked participants, **What kind of help do you think you need to get those skills back?**

63 people left a comment for this question. There were some similar responses to those we received for the previous question, which asked what support respondents needed to regain their confidence.

39 people (just under two thirds of this group of respondents) said that they would need the following types of support and help:

- Support workers and personal assistants, to help with practical tasks and getting out and about
- Befriending services and accessible social activities, particularly activities involving friends and family
- More (and more accessible) public health information
- Mobility and orientation training
- Mentoring to support re-enablement
- Professional health and social care professionals, who have the knowledge and expertise to help people stop and reverse any deterioration in independence.

"A 'buddy' on the phone perhaps weekly, alongside there being activities to attend. That would help encourage me, give me more confidence. I have been receiving this kind of support for cooking and healthy eating over the phone from a volunteer for a few months now and find it very helpful."

"Someone to go with me when I'm going out or to events."



"Some kind of professional (like an occupational therapist?) who understands the causes of these problems and how to regain skills—whether by small steps, or something else, I don't know. But seeing a specialist might help me work out how to go forward."

Eight people said they were not sure what kind of support they would need, as they did not know what is available.

"What is there? I couldn't recruit enough PAs to cover the basics before Covid-19. All of the DPOs (Disabled People's Organisations) in our borough have been closed, and our adult services team is a joke."

Seven people stated that they would need mental or physical therapy, such as psychological therapy or physiotherapy, the latter in particular due to people experiencing a loss of mobility as a result of restricted exercise and leisure opportunities during the pandemic.

"Medical help to improve mobility. To improve confidence and mental clarity."

Six people said they would need greater empathy and understanding from society.

"...people to remove their face masks or wear face shields so I can lipread."

"Awareness and patience from the people I meet."

Two people told us that they would need help with their motivation. As this answer was not explained in either case, it has been listed separately from the point above relating to support needs.

One person said that they would need a vaccine to empower them to regain their lost independent living skills.



We also asked participants to respond to the statement, 'COVID-19 and lockdown measures have had an overall long-term negative impact on my ability to live independently.' This was one of three statements in the survey about which we asked participants to agree or disagree with its premise. For each of the statements in question (the other two are included in Section Five: Beyond COVID-19), the survey gave people the option to respond with the following: Strongly Agree, Agree, Neither Agree or Disagree, Disagree or Strongly Disagree.

104 people responded to this particular statement. Of those respondents, 60 people (58% of respondents) selected agree or strongly agree. 21 people disagreed with this statement; 23 people neither agreed nor disagreed.

We asked our participants the following question:

Have you gained skills because of COVID-19 and lockdown?		
Answer Choices	Responses	
Yes	56%	66
No	44%	51
Total responses		117

There were 67 written responses to this question (one more than responded 'Yes' above). The skills people described were:

- 35 people (just over half of respondents in this group) stated they had gained new skills using new technologies. The majority of respondents had learned how to use video meeting software, such as Zoom or Microsoft Teams. Others had learned video production skills, social media skills and live streaming skills.
- 23 people (about one third of respondents) described developing new hobbies or activities, including leisure



activities, studying and exercise. For some, this meant learning a language or reading new material; for others, this meant mindfulness training or daily walks with previously unknown neighbours.

"I am learning to read, write & speak Portuguese."

- Six people (nearly one tenth of respondents) described that they had developed resilience so that they could cope with the difficulties of lockdown, often without support from their usual paid or unpaid carers. Two people felt that the extra time resting had been beneficial to them, both physically and mentally.

"Learnt how to cope with being both disabled and the primary carer to a disabled partner and two elderly parents, ensuring everyone gets their medications from pharmacies that refuse to deliver, going out to buy food because deliveries from supermarkets had the items in their stores but not included in their deliveries, or the food sent was out of date or just before use by."

- Three people had developed household skills such as cooking.



Section Three: Loneliness and Isolation

The responses detailed in this section are about feelings of loneliness and isolation that Disabled people feel they have developed as a result of the COVID-19 pandemic, and of national and regional lockdown measures.

We asked our participants the following question:

Have you become lonelier and/or more isolated because of the COVID-19 virus and lock-down?		
Answer Choices	Responses	
Yes	79%	92
No	21%	25
Total responses		117

We asked our participants why they felt they had become more lonely or isolated. Our respondents provided a number of reasons, listed below:

- Not getting out and about
- No social activities or usual club events
- Not seeing friends and families
- Nowhere to visit such as a gallery
- Not being able to go to work.

Of particular note is that some respondents expressed fear and anxiety about going out generally, particularly if they were in a shielding group.

"Have been unable to meet friends face to face due to their self-isolating, face to face activities, unable to be spontaneous in doing anything either because there was nothing to do, or everything has to be booked in advance. Also unable to travel further afield to visit friends."

"Have found online socialising very hard work so now do very little."



"I have not been going out at all until recently, as a result I was only in contact with members of my household and PAs. I was trying to keep in contact with friends via video call but it is not the same as seeing someone face to face."

"I haven't been able to see friends and family. I haven't been able to have a day out (even just walking) because of public transport ban. I had just moved in with a new flatmate, and being forced together 24/7 actually made me feel more lonely than when I lived by myself, because I had more control over what I did in my own home then, whereas now I don't. I've also lost motivation and confidence to do things like go out to exercise, which I used to do. I feel like it'll be climbing Everest."

These reasons are understandable given the many restrictions imposed on socialising and meeting with others under national and regional lockdowns, not to mention shielding measures. However, it should be noted that many Disabled people experience isolation and loneliness most of the time. For many, the national lockdowns and the measures for people needing to shield have simply intensified these problems.

We asked our respondents, **What would help you feel less isolated and/or lonely?**

Most respondents echoed their answers from the previous question, saying they would feel less isolated and lonely if business and services began reopening; if they were able to see people more regularly; or if a vaccine was rolled out. A number of specific ideas were suggested and listed below.



1. Accessible peer groups:

"...an accessible physical peer support group or day centre. Tasks within my abilities (writing, computer use, playing music) that could make me feel I'm of some use again."

2. A buddy or supporter:

"A buddy- like a running buddy or someone that I could be partnered with to do things like exercise, or going to do an activity/outing. Someone who maybe struggles with things themselves."

3. Clearer and more accessible information:

"Clearer information from the government on ALL platforms and channels around exemptions so that able / none disabled people can have greater empathy."

4. Better access to broadband and equipment:

"Better access to broadband, devices and data for my friends. I have it provided via adult services and Access to Work but that's no help if my friends are digitally excluded. I can't access voice calls, only video calls."

5. Seeing a health professional:

"If I could have some of my GP appointments in person with both of us wearing face coverings, I think that would help."

6. More appropriate (or safer) social opportunities:

"Better support for social activities and more financial resources for support and for disabled people's organisations to organise social events. Maybe befrienders."



Section Four: Health and Wellbeing

The responses detailed in this section are about the impacts of the COVID-19 pandemic, and of national and regional lockdown measures, on the health and wellbeing of Disabled people, particularly due to the cancellation of appointments, treatments and operations.

Participants were asked the following questions:

Have any health or social care treatments and appointments been postponed because of COVID-19 and lock-down?		
Answer Choices	Responses	
Yes	74%	86
No	26%	30
Total responses		116

Has the delay worsened your health and wellbeing?		
Answer Choices	Responses	
Yes	59%	64
No	41%	43
Total responses		107

When we asked participants, **Is there something that would improve your wellbeing or support you to get better?** 67 people responded 'Yes'.

65 people left comments describing things that might improve their wellbeing. An overwhelming 50 people (more than three quarters of respondents who left comments) said that getting some sort of medical or social care appointment, treatment or care solution would improve their wellbeing. These solutions included:



1. The resumption of regular health services, for example, seeing a dentist, getting an aid (such as a hearing aid), or resuming usual therapy sessions (mental and physical):

"Having access to a hot tub or hot water so I can completely submerge in to get my muscles working again."

2. Access to face-to-face appointments:

"Face to face appointments (if pubs can reopen why are essential services, such as social services, still predominantly home working? Easier access to GP."

"Seeing my doctor in person sometimes. I find it hard to communicate as well over the phone. I wanted to discuss a referral to a consultant before the lockdown but I haven't done this because I want to discuss it in person not over the phone."

3. Diagnosis of new or changing conditions:

"Finding out what is wrong with me, getting treatment."

4. Having certainty about when appointments will happen:

"Knowing when the appointments will be rescheduled so that I can at least be mentally preparing for them. I have surgery lined up but they can't give me a new appointment yet, so I'm just living with the pain that comes with the condition and don't know when it will end. I also don't know who will come to hospital with me (and escort me back) because I don't know when the surgery will be and all my family and friends need notice to plan and take time off work. It's getting me more anxious."



5. Being able to arrange or rearrange appointments and treatment:

"Having my appointments - was supposed to have a cancer investigation op in March nothing happening. Already been delayed a year."

"I cannot chase the social worker, and especially now need him to check on me."

6. Having treatments that are needed, but have been cancelled due to the pandemic, rescheduled and set in stone:

"Appointments set back up to deal with various health issues or information on how to access the services you need."

"I have waited literally years to be seen by the pain clinic. I was asking for ten years and I finally get my appointment and lockdown happened."

The remaining 15 people (still nearly a quarter of all respondents who left a comment in this section) said that they needed opportunities to go out, regular social interactions, and support to do activities (including financial support).

"Getting myself out there, particularly to the leisure centre and to socially distance, organised gatherings."

"Support with getting exercise in an appropriate and helpful way - that works with me, autistic, wheelchair user, limited energy. Helps to rebuild skills. I've been left supporting elderly mother whose health is deteriorating and it's overwhelming."

"Support with weight and exercise, nutrition. Gluten-free food, a lot cheaper or vouchers to help buy. Financial to support education. Local support for people being isolated."



Section Five: Beyond COVID-19

In this section, we asked participants about good things that had come out of their experiences during the COVID-19 pandemic and associated national and regional lockdowns.

Of the 131 respondents to this survey, 75 people – more than half of those respondents – gave positive responses to this question. Those answers reflected a number of common themes, which are highlighted below.

1. Improved Wellbeing: Some people described positive changes in various aspects of their day-to-day lives. Some people described building deeper connections with family, friends and their local communities, while others described experiencing better health outcomes. We have grouped these comments under the banner of 'general wellbeing'.

"Well I have lived with my girlfriend throughout lockdown and we were certainly not thinking along those lines prior to lockdown and initially I loved the peace and quiet out and about and the clean air and zero traffic noise. Was good for the planet !!!! I have been very good at structuring my days and have taken on new tasks and hobbies as well as experiencing personal challenges with ill health to family members. I have managed to cope well though..."

"Appreciating people and places more. Also being able to spend more time with my mum... I think it has also helped me to start my first full time job from home to work out my limits in an environment I am safe in where family are around."

"I have more control over my diet and I have shed 14kg."



2. More Time: 15 people, a fifth of respondents, talked about the benefits of having more time and a less hectic life.

"Time to tackle outstanding work in house, gardening, doing paper work etc. More time to plan for future, get up to date."

"I have managed to get some of the jobs done that I didn't have time to do before. Also I think it makes you appreciate life more."

3. Home Working: Those people who were employed during the pandemic, and were able to retain their jobs and work at home, reported a number of advantages.

"Working from home - my health has been better managed - no sick days."

"Being allowed to work from home all the time - it's shown that it's possible. I've really appreciated having more control over ..."

4. Leisure and Exercise: Others described positive experiences accessing new leisure and exercise opportunities.

"I do more walking."

"There have been many positives for me... I have seen a lot more of one particular friend online since lockdown, whereas before I didn't have anywhere near as much contact with her before. We are now much closer. I have had a lot more opportunities available to me - free community wellbeing/exercise sessions, online adult education classes, community group get-togethers. Given that I often struggle with leaving my home and using transport (due to anxiety and hyper-vigilance from PTSD) I would not have been able to participate in these opportunities had they been happening at a location I needed to get to, face-to-face."



5. Reflection and Understanding: some respondents have found that the experience has helped them to reflect on their own lives. Respondents also found that this experience has helped other people in their lives to understand and empathise with the challenges and isolations that many Disabled people experienced before the pandemic.

"Yes, receiving the shielding letter to shield. Made you aware just how fragile and vulnerable you are and accepting the reasons why."

"People are more understanding of what I go through on a daily basis. I am often in lockdown where I can't go out as I am ill. It has allowed me to be included in friends' activities without feeling the odd one out or they have to work around me."

6. New technologies: the remainder of respondents talked about how having time to self-teach meant they were able to develop skills related to the use of remote technologies and social media.

"Easier access to GP and remote access to meetings."

"...the potential offered by web-cams making zoom meetings normal which is easier for me than phone calls."



Is there one thing that would have made lock-down easier for you?

Responses to this question were mainly about practical and access issues. Responses included:

- Regular shopping deliveries
- More contact, company and/or help at home
- More care and/or support at home, especially compared to the start of lockdown, during which some respondents reported having no care at all
- BSL interpretation on the news and accessible public health information
- Access to health practitioners, mental and physical therapies
- Clearer rules, particularly around self-distancing, and more widespread adherence to them, so that Disabled people feel safe to go out.

These responses pointed to broader issues heading into the future. When asked to say if they agreed or disagreed with the statement, 'COVID-19 and lockdown measures have reduced the choice and control I have as a disabled person,' 89 people (83% of 107 respondents) agreed or strongly agreed with this statement. Only 8 people disagreed with the statement.

We also asked participants, **If lockdown restrictions are lifted for everyone would that mean you would live your life again as you did before lockdown?** 32 people, about a third of respondents, responded 'Yes'. 72 people, the remaining two thirds of respondents, responded 'No.'



When asked what they would need to live their life as before, most respondents said that they would need a guarantee that they would be safe from COVID-19 in the future, either as a result of the virus disappearing or as a result of there being an effective vaccine. Some said they would need to regain their health, mobility and confidence before they could live their life as before.

"My health would need to improve to get me back to life as before. I'd need help to get out the house more, to start looking after myself again (diet and exercise), to spend spare time doing leisure activities instead of sleeping I think I'd need someone with me to help me start doing that."

Finally, we asked our participants to say whether they agreed or disagreed with the statement, 'COVID-19 and lockdown measures have made me more determined to get involved in designing public services to make a change for the better for me and other disabled people.'

105 people responded to this question. Of those respondents, 59 people (56% of respondents) agreed or strongly agreed with this statement. 33 people neither agreed nor disagreed with this statement; only 13 people disagreed.



Conclusions

This report reflects 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. Indeed, the gains referred to in Section Five are likely to have been commonly shared across the general population.

The same could be said of some of the negative impacts identified in Sections One to Four, such as people experiencing greater feelings of loneliness and isolation or experiencing deteriorations in their mental health. However, the following quote reveals how these impacts have had significantly more devastating consequences for Disabled people:

"I feel badly damaged. Lost all my trust and faith in human nature. All that wasted money spent by the government on defective PPE is scandalous. Those with disabilities are an afterthought. The little equality we had has totally been eroded. The help is tokenism if at all. We are left to rot and die stuck in a no-man-land limbo. The government don't care it's an illusion that they want to help. They don't even understand basic infection control. You have to fight for everything you need to live day after day after day."

The results of this survey have revealed extensive deterioration of d/Deaf and Disabled people's **confidence** as a result of the pandemic and consequent lockdowns. Disabled people will need help and support to rebuild their confidence, get out and about



again and resume social and leisure activities, including, in some cases, practise in communicating with others.

Many Disabled people have felt too vulnerable to leave their homes. Others have been forced by lockdown measures to stop making trips for social and leisure activities, voluntary services, and independent living activities such as involvement activities, work, shopping and daily outdoor exercise. This has led to a widespread loss of **independent living skills**, such as the loss of practical skills, like using a white cane as a mobility aid; the inability to remember transport routes and timetables; a reduction in confidence about get around in one's local community; and deterioration of the social confidence needed to take part in a range of activities. There has also been a physical effect on some Disabled people; some respondents to our survey said they had experienced a loss of mobility and limb strength.

Social distancing and shielding requirements have meant that many Disabled people have been socially isolated for most of the year. In many cases, they have been unable to see the people and volunteers who support them every day. Informal networks and social contact provide Disabled people with social interaction; this contributes to greater confidence, which in turn is a protection against **loneliness and isolation**. For many of the Disabled people who have experienced increased levels of acute loneliness and isolation as a result of this pandemic and the consequent lockdowns, a vaccine is the only plausible solution for restoring their previous levels of social interaction.

Some Disabled people have had **appointments** for treatments and surgeries cancelled; these, too, have negatively impacted their general wellbeing. Those people may need remedial



services for short-term, and sometimes permanent, deterioration in their conditions. Routine medical appointments have also been cancelled as a result of lockdown measures, contributing to anxiety about personal health and concern about minor ailments. These issues could have been resolved if Disabled people had been able to readily access General Practitioners (doctors) during the lockdowns.

More than half of the respondents to this survey feel that COVID-19, and the consequent national and regional lockdowns, have had a long-term negative impact on their ability to live independently. Four fifths of Disabled people responding to this survey agreed that COVID-19 and consequent lockdown measures have reduced the choice and control they have as a Disabled person.

In some instances, the reported impacts of the pandemic and lockdown measures on d/Deaf and Disabled people will need time, understanding and investment to get people back to a life similar to that they had before. User-led organisations and peer organisations are best placed to provide this remedial support and intervention.

However, many 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, though, there now needs to be a longer-term funding commitment to enable this work to happen.



Recommendations

- National and local policy-makers need to consider the issues raised in this report and create appropriate long-term strategies to positively contribute to Disabled peoples' efforts to rebuild their independent living skills.
- The national government and local authorities should fund local user-led and d/Deaf and Disabled People's organisations to support the longer-term recovery of their communities.
- A national vaccination programme needs to prioritise Disabled people as those most at risk and create practical solutions for the safe vaccination of a community that is largely unable to leave home for a range of reasons.
- Peer support, buddying and general support needs to be prioritised so that Disabled people who have lost the confidence to do their usual activities are able to regain that confidence.
- Routine medical and social care appointments need to be reinstated to alleviate anxiety and growing negative impacts on wellbeing. Disabled people should be considered a priority for more significant hospital or health care.



Appendices

Appendix One: Monitoring Data Summary

Total of number of people questioned: 132.

1.1 Gender:	
Answer Choices	Responses
Male	30
Female	72
Neither	3
Other	1
No. answered	106
No. not answered	26

1.2 Age:	
Answer Choices	Responses
Under 18	0
18-30	12
31-50	27
51-64	44
65-80	21
Over 80	2
No. answered	106
No. not answered	26



1.3 I live in a:	
Answer Choices	Responses
rural location	7
semi-rural location (e.g. village)	20
a town	44
a city	36
No. answered	107
No. not answered	25

1.4 Did you have a voluntary job before lockdown?	
Answer Choices	Responses
Yes	44
No	64
No. answered	108
No. not answered	24

1.5 Do you still have that voluntary job?	
Answer Choices	Responses
Yes	35
No	47
No. answered	82
No. not answered	50

1.6 Did you have a paid job before lockdown?	
Answer Choices	Responses
Yes	38
No	69
No. answered	107
No. not answered	25



1.7 Do you still have that paid job?

Answer Choices	Responses
Yes	32
No	51
No. answered	83
No. not answered	49

1.8 Did you get paid or voluntary work relating to COVID-19?

Answer Choices	Responses
Yes	17
No	85
No. answered	102
No. not answered	30

1.9 What are the reasons you no longer have that job (paid or voluntary)?

Answers	Responses
Retired	1
Chose to leave	1
Project closed or job suspended/no longer possible due to COVID-19	13
No. of Answers	15



1.10 I have the following impairments and/or long term health conditions:

Answers	Responses
Mental health condition	36
Physical impairment (including wheelchair users)	39
Hearing impairment	18
Long term pain	23
Arthritis	23
Sight impairment	10
Skin condition	1
Cerebral palsy	3
Diabetes	9
ME/Chronic Fatigue Syndrome	8
Gut condition	7
Postural tachycardia syndrome (PoTS)	2
Epilepsy	2
Neurological condition	4
Cancer/side effects of chemotherapy	2
Autism or Asperger syndrome	10
Learning difficulties	5
Reduced immune system	3
Respiratory conditions, including asthma	13
Thyroid condition	3
Heart or circulatory condition	8
Multiple Sclerosis	3
Cognitive deficit	1
Osteoporosis	4
Auto-immune conditions	3
HIV	1



1.11 Have you been shielding?	
Answer Choices	Responses
Yes	61
No	46
No. answered	107
No. not answered	25



Appendix Two: Survey Questions



Introduction

You are taking part in a research project called: The longer term impacts of COVID-19 on independent living for Disabled people. This study is being done by Shaping Our Lives. This survey is only for d/Deaf and Disabled people. Disabled people are people with sensory, cognitive, neurodevelopmental conditions, learning disabilities or physical impairments, mental health issues and people with long term health conditions.

We encourage anyone who takes part to read the Research Information sheet on page 10 of this document. If you have any questions please contact Becki Meakin, General Manager at Shaping Our Lives:
Mobile phone - 07956 424511
Email - becki@shapingourlives.org.uk

There is no involvement payment offered for completing this survey. Taking part is voluntary, and you can drop out at any time. You can skip any question.

There are 9 small sections in this survey with a few questions in each. Many of the questions have a choice of answers and just a few ask you to add some of your own answers. It should take no longer than 20 minutes.

Your answers will be kept anonymous. What you and other people tell us will then be used to tell people in national and local government the support d/Deaf and Disabled people need to get back to living independently, feeling safe and confident.



We do not ask for your name or address, but we would be grateful if you would answer some optional monitoring questions at the end. This will help us to make recommendations.



Please note: In the following sections, there are several types of questions:

Some require you to just choose Yes or No.

Other questions are open, i.e. you can type your answer in the space below the question.

Others require multiple answers and are set out in a table. These will be described for each question.

Confidence

1. Have you lost confidence because of COVID-19 and lockdown? Yes/No
2. Do you think you will need help to get your confidence back? Yes/No
3. What kind of help do you think you need...

Skills

4. Have you lost daily living skills because of COVID-19 and lockdown? Yes/No

5. If yes, please place an x in the box for all that apply.

(Options shown in a table with column 1 providing the options and column 2 blank for you to put your answers)

Communication	
Mobility	
Looking after yourself	
Household chores such as cleaning or cooking	
Using technology	
Going out and about	
Shopping	
Taking part in social and leisure activities	
Other, please state	

6. Do you need support to regain these skills? Yes/No

7. What kind of help do you think you need to get those skills back?



8. Have you gained skills because of COVID-19 and lockdown? Yes/No

9. What skills have you gained?

Loneliness and Isolation

10. Have you become lonelier and/or more isolated because of the COVID-19 virus and lock-down? Yes/No

11. If yes, why has this happened?

12. What would help you feel less isolated and/or lonely?

Appointments

13. Have any health or social care treatments and appointments been postponed because of COVID-19 and lock-down? Yes/No

14. Has the delay worsened your health and wellbeing? Yes/No

15. Is there something that would improve your wellbeing or support you to get better? Yes/No

16. What would this be?

Remote Contact

17. Have you had a meeting, appointment or social experience using the telephone, video call or video meeting software for the first time during COVID-19 lockdown? (Examples of video calls are using Facetime or What's App. Examples of video meeting software are Zoom or Microsoft Teams.)
Yes/No

(If you have answered no to the above, please go to the next section (Involvement and Engagement Activities) starting with question 23).



18. Who were you having a telephone meeting, appointment or social experience with and how did you do this? (please place an x in the box all that apply).

(Options shown in a table containing 7 rows and 4 columns. Each row is for the type of person or organisation you communicated with, and the answer options are in the column headings).

People you communicated with	Telephone calls and appointments	Video calls (e.g. Facetime or What's App)	Video meetings (e.g. Zoom or Microsoft Teams)
Friends/family			
Health /social care person			
Paid or voluntary Work			
Education or training			

19. Was using each of these communication methods a good or bad experience?

(please place an x in the box all that apply).

(Options shown in a table containing 4 rows and 4 columns. Each row is for the type of communication used with the answer options in the column headings).

Communication method	Good	Bad	Neither Good nor Bad
Telephone calls and appointments			
Video calls (e.g. Facetime or What's App)			
Video meetings (e.g. Zoom or Microsoft Teams)			





20. Please explain why these were good or bad experiences

21. Would you use these communication methods again? (please place an x in the box all that apply).

(Options shown in a table containing 4 rows and 5 columns. Each row is for the type of communication used with the answer options in the column headings).

Communication method	Yes	No	I would prefer not to	I will have to because the service is now using remote technologies
Telephone calls and appointments				
Video calls (e.g. Facetime or What's App)				
Video meetings (e.g. Zoom or Microsoft Teams)				

22. What would make it easier for you to use in the future (if relevant)?

Involvement and Engagement Activities

23. Before lockdown where you doing any involvement or engagement activities? For example, a patient participation group, a coproduction board, a service user panel. Yes/No

24. If yes, has this carried on during lockdown? Yes/No

25. Will it carry on after lockdown? Yes/No/Not Sure

26. If No, can you tell us why it has been stopped?



27. If you were asked to take part in involvement, engagement or work activities, while the COVID-19 virus is still present, please place an x in the box for the one that applies.

(Options shown in a table with column 1 providing the options and column 2 blank for you to put your answers).

I can only take part remotely	
I can only take part if we get together	
I can take part remotely or get together	

28.If you get together with other people, what COVID-19 protection measures would you want. Please place an x in the box for all that apply. (Options shown in a table with column 1 providing the options and column 2 blank for you to put your answers).

Temperature checks	
Social distancing in a physical meeting	
Everyone to wear face masks at any event or meeting	
Hand sanitiser	
Cleaning of all surfaces after use by others	
Safe private transport e.g. taxi	
Anything else? (please specify)	

Changes

29. Is there one good thing in your daily life that has come from COVID-19 and lockdown?

30. Is there one thing that would have made lock-down easier for you?

31. If lockdown restrictions are lifted for everyone would that mean you would live your life again as you did before lockdown? Yes/No

32. If No, what would you need to live your life as before?



33. Is there another aspect of your life which has also caused you to be at a disadvantage during lockdown? Please place an x in the box for all that apply. (If you do not feel it disadvantaged you, please do not put an x in the box)

(Options shown in a table with column 1 providing the options and column 2 blank for you to put your answers)

Being pregnant or nursing a baby	
Being a member of the LGBTQI+ community	
Being transgender	
Being an older person	
Being from a Black, Asian or Minority Ethnic community	
Being from a Gypsy, Roma or Traveller community	
My religion or beliefs	
My sex (being a man or a woman)	

And finally, do you agree or disagree with the following statements?

Each of the following 3 questions have a table after them with the options in column 1 of Strongly Agree; Agree; Neither Agree nor Disagree; Disagree; Strongly Disagree. Column 2 is blank for you to place an x in the box for the option you choose.

34. COVID-19 and lockdown measures have had an overall long term negative impact on my ability to live independently.

Strongly Agree	
Agree	
Neither Agree nor Disagree	
Disagree	
Strongly Disagree	



35. COVID-19 and lockdown measures have reduced the choice and control I have as a disabled person.

Strongly Agree	
Agree	
Neither Agree nor Disagree	
Disagree	
Strongly Disagree	

36. COVID-19 and lockdown measures have made me more determined to get involved in designing public services to make a change for the better for me and other disabled people.

Strongly Agree	
Agree	
Neither Agree nor Disagree	
Disagree	
Strongly Disagree	



Monitoring Information

Please provide some monitoring information to help us to make recommendations in our report.

(For the following 3 questions, options are shown in a table with column 1 providing the options and column 2 blank for you to put your answers)

37. I am:

Male	
Female	
Neither	
Other	

38. I am aged:

under 18	
18-30	
31-50	
51-65	
66-80	
over 80	

39. I live in a:

rural location	
semi-rural location (e.g. village)	
a town	
a city	

40. Did you have a voluntary job before lockdown? Yes/No

41. Do you still have that voluntary job? Yes/No

42. Did you have a paid job before lockdown? Yes/No

43. Do you still have that paid job? Yes/No

44. Did you get paid or voluntary work relating to COVID-19? Yes/No

45. If you no longer have your voluntary or paid job, please tell us why ...



46. I have the following impairments and/or long term health conditions...

47. I have been shielding Yes/No

48. All reports will be published on our website in December. However, if you would like us to send you a copy of the reports when they are completed please provide your email address:

Thank you for taking the time to complete our survey. If you have not already, please sign up to receive our regular ebulletins at www.shapingourlives.org.uk.

By returning this survey to us, you are consenting to participate in this research, as explained in the Research information sheet, which can be read below.



Shaping Our Lives COVID-19 Research Information Sheet

Name of project: The Longer Term Impacts of COVID-19 for Disabled people.

Where it will take place: All research is being completed remotely.

Overview: Shaping Our Lives has been awarded a grant by the National Lottery Community Fund to complete some research about the longer term impacts of COVID-19 and lockdown on Disabled people, d/Deaf and Disabled People's Organisations and Patient Participation Groups.

Our network members have told us that they are concerned about getting back to their usual independence and confidence after lockdown. Some of the concerns are:

- Loss of confidence and anxiety about leaving home.
- Loss of independent living and mobility skills.
- Cancellation of operations and treatments.
- Needing help to use new remote meeting technology.
- Patient and service groups are not informing practice.
- Capacity pressures for local user-led groups.

Aims of the research: We want to be able to tell policy makers in health and social care services what longer term support and other considerations they need to make for Disabled people including:

- What support Disabled people may need to regain their confidence and independence.
- Understand how remote meeting technology can help (or not) Disabled people to take part and get their voice heard.
- Hear from d/Deaf and Disabled People's Organisations about their success or failure to get funding and the services people have needed because of COVID-19.

Participant involvement: There are two short surveys, some longer interviews and some group discussions with d/Deaf and Disabled People's Organisations. There is no involvement payment for completing a short survey; the short surveys should take about 20 minutes. For people who take part in a longer interview there is an involvement payment of £30



offered; longer interviews will take about one hour. For representatives of d/Deaf and Disabled People's Organisations who take part in a round table discussion there is an involvement payment of £30 offered.

How we will use the information: The information we collect will be written about in three reports and shared with health and social care providers. We will not use anyone's names or the name of organisations and services in the final reports. All personal information provided is confidential.

If you have any questions, please contact
Becki Meakin, General Manager at Shaping Our Lives:
Mobile phone - 07956 424511
Email - becki@shapingourlives.org.uk



Appendix Three: Other Reports from d/Deaf and Disabled People's Organisations

The following reports help to paint a broader picture of the impact of COVID-19, and the consequent national and local lockdowns, on the lives of d/Deaf and Disabled people.

British Red Cross, "Life after lockdown: Tackling Loneliness among those left behind," report published June 2020. Find the report here: <https://www.redcross.org.uk/about-us/what-we-do/we-speak-up-for-change/life-after-lockdown-tackling-loneliness>

Greater Manchester Disabled People's Panel, "Greater Manchester Big Disability Survey: COVID-19," report published July 2020. Find the report here: <https://gmdisabledpeoplespanel.com/gm-big-disability-survey-covid19/>

Health Foundation (Jo Bibby, Grace Everest and Isabel Abbs), "Will COVID-19 be a watershed moment for health inequalities?" paper published May 2020. Find the report here: <https://www.health.org.uk/publications/long-reads/will-covid-19-be-a-watershed-moment-for-health-inequalities>

Inclusion London, "Abandoned, forgotten and ignored – The impact of the coronavirus pandemic on Disabled people," interim report published June 2020. Find the report here: <https://www.inclusionlondon.org.uk/disability-in-london/coronavirus-updates-and-information/campaigns-news-during-coronavirus-crisis/abandoned-forgotten-and-ignored-the-impact-of-covid-19-on-disabled-people/>



Public Health England, “Beyond the data: Understanding the impact of COVID-19 on BAME groups,” report published June 2020. Find the report here (note that you must email publications@phe.gov.uk to request a copy of the report in an accessible format):

<https://www.gov.uk/government/publications/covid-19-understanding-the-impact-on-bame-communities>

Sisters of Frida, “The Impact of COVID 19 on Disabled Women from Sisters of Frida: Voices of Disabled women in the pandemic,” paper published April 2020. Find the report here: <http://www.sisofrida.org/the-impact-of-covid-19-on-disabled-women-from-sisters-of-frida/>

Chronic Illness Inclusion Project, “Turning the remote access revolution into reasonable adjustments: Guidance on including disabled people in face-to-face meetings using videoconferencing technology”, guide published in 2020. The report is available via their website - <https://inclusionproject.org.uk/blog/covid-remote-access-revolution>



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