The lived experience of disabled people during the COVID-19 pandemic

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Disability Unit

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[1] Policy Lab is an established innovation function for policy-making, operating as a service for commissioners in government departments. The team has 7 years' experience of testing, learning and demonstrating how policy innovation works, partnering with policymakers right across the UK Civil Service and internationally, through policy projects, training and knowledge-building activities. Policy Lab is multidisciplinary, drawing on expertise from social research, ethnography, design, data and futures, alongside policy expertise.
Policy Lab: https://openpolicy.blog.gov.uk/category/policy-lab/

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Executive summary

From July to September 2020, the Cabinet Office Disability Unit commissioned the Policy Lab to conduct ethnographically-led research into the experiences of disabled people during the COVID-19 pandemic.

The aim was to understand the impact of COVID-19 on the lives of disabled people, to identify problems that could be resolved through policy changes and to make the changes necessary that would lead to positive outcomes.

This research will not only feed into short-term responses to COVID-19, it will also be considered regarding policies within the Disability Unit's [National Strategy for Disabled People](#) and long-term planning efforts regarding possible future pandemics.

Chapter summaries and main findings

Chapter 1 explores participants' 'disabled' identities and self-perceptions. Labels such as 'clinically extremely vulnerable' have brought the topic of 'health status as identity' to the forefront for some participants such as Efstathia and Joyce.

Some participants reported that such labels have led to them feeling embarrassed and have created a sense of guilt around their 'disabled' identities. Various experiences of shielding were also described, the majority focusing on participants' perceptions of whether they should have been shielding or not, the challenges shielding has posed to maintaining daily routines, and how shielding has negatively impacted expectations for the future.

The chapter shows that COVID-19 has created additional barriers for disabled participants. In some cases, participants have felt an extra burden of social responsibility in protecting themselves and their own health, while the perception is that

some non-disabled people have not adhered to COVID-19 rules in public places, with scant regard for anyone else at all, let alone those with impairments and underlying health conditions.

In Chapter 2, 'uncertainty' emerges as a key recurring experience for many participants in numerous areas. In particular, uncertainty has been experienced in relation to COVID-19 guidelines, the availability of health services, and transport options.

Participants told us that they found making sense of the changing rules around COVID-19 harder because of their impairments. This extended period of uncertainty has exacerbated mental health issues and distress.

Chapter 3 demonstrates that participants have been regularly confronted with an array of barriers and socially imposed limitations over and above those experienced by non-disabled people. These limitations have sometimes been material, as in the case of physical walls, or spatial, such as the ability to observe social distancing rules or to obtain necessities.

Sometimes new limits have been externally imposed, such as the enforcement of shielding. Others have sometimes followed self-imposed limitations, like choosing to avoid negative reactions from others by wearing a face mask despite being exempt.

Chapter 4 examines how COVID-19 has impacted participants' independence, sometimes reducing opportunities for independence, sometimes increasing dependency.

This has manifested in areas such as support and care arrangements, shopping, transport, and in numerous other ways. Some of our participants, such as Joyce and Roxanne, have had to negotiate new living arrangements as they were no longer being covered by their care providers for specific support needs.

Some participants, like Jessica, have experienced lockdown as an additional pressure on their wellbeing, while others such as Efstathia have felt better equipped to cope with adversity as a result

of her prior experiences with socially imposed isolation.

Similarly, COVID-19 has lessened the number of available options and affected participants' ability to choose at all. They reported not having a 'good' option and a 'better' option but rather that they were required to choose between 2 non-preferred options. For many participants, a lack of formal support during the pandemic has meant that they have had to rely on family and friends.

Chapter 5 focuses on the concept of 'time' in an abstract sense. During the pandemic, participants have felt the passage of time more intensely than usual, to varying degrees. Joyce, for example, has felt time "slowing down", even "coming to a halt", as plans and routines have been disrupted.

The main disadvantage of 'time' faced by participants, however, has been the extended waiting times and delays to formal government services and support, including health services, as well as an impact on practices such as repairs, building improvement works, online shopping, and in other areas of necessity. These have always

been key lifeline services for our disabled participants and have been significantly disrupted during COVID-19 times.

Chapter 6 outlines some of the few positive outcomes of COVID-19 for our participants. The pandemic has provided personal opportunities for some, or opportunities for participants like Kathryn to manage their health conditions more positively.

COVID-19, at times, has enhanced participants' independence, often changing the ways and means in which participants have achieved their version of independence. For participants like Latanya, the pandemic has caused them to reflect on the significance of independence in their lives, and on potential future paths they might not have considered before, including changes to their living arrangements.

Research methods

The research for this project was conducted over 6 weeks during a 3-month period between July and September 2020. During this time insights about

disabled people's daily experiences were gathered, focusing on what changes they have experienced in light of COVID-19.

The research was ethnographically led, and involved researchers employing reflexive interviewing techniques, meaning that the researchers did not go into the interviews with a set of questions or script to work through. This allowed the interviewees to dictate the flow of the conversation, as well as suggest changes and challenge interpretations that were being made.

Researchers spoke to disabled participants weekly, allowing them to discuss and observe the impacts of COVID-19 on their own lives and on their families as they occurred over time. The researchers also explored participants' experiences of interacting in communities and with wider government services and independent businesses. This resulted in the research gathered being based on the lived experiences of the participants.

We worked with 9 participants from across the East of England, Yorkshire and the Humber,

London, the South East and South West of England, and Wales. They had a range of physical impairments and mental health difficulties. Their ages ranged from mid 20s to early 70s. Participants were given a thank you payment for their time, a small financial reimbursement for each interview.

8 of the 9 participants had taken part in a previous ethnographic research project from 2019 to 2020 into the everyday lives of disabled people. These participants were chosen and approached by the researchers because we were interested in examining the impact of COVID-19 on their lives and charting the changes over time.

To adapt to COVID-19, Policy Lab and Disability Unit undertook research using video calls and digital messaging services. Where such platforms were not suitable or accessible for participants, alternative research strategies were used (such as phone calls).

Due to its intensive nature, ethnographically-led research typically works with a small number of participants. It is unique in that it illustrates

people's complex experiences, thoughts and feelings which are not typically captured by surveys. Research of this kind is not designed to be, nor does it aspire to be representative of a given population.

The findings therefore should not be used to make generalised statements about the group being studied. Qualitative research of this kind ought to be considered alongside analyses of survey data and quantitative research, as both together can more effectively inform and inspire innovative and strategic policymaking than either can alone.

Anonymised details for each participant are presented below in Table 1.

Table of participants

Pseudonym	Approximate age	Area of residence
Diane	Late 30s	South East
Efstathia	Late 50s	London
Jessica	Early 30s	Yorkshire and the Humber
Joyce	Mid 50s	East
Kathryn	Early 70s	South East
Latanya	Mid 20s	London
Roxanne	Mid 40s	South West
Roy	Early 40s	Wales
Shawn	Mid 60s	South East

Our methodology for this research consisted of one-to-one interviews and activities over a 6-week period:

- Initial interview (90 mins, week 1)
- Weekly activities (completed in the participants' own time, weeks 1 to 5)
- Weekly check-ins (30 mins, weeks 2 to 5)
- Close-out interview (30 to 60 mins, week 6)

Interviews were participant-led and followed the principles of reflexive interviewing. Each week, for the activities, participants were given a prompt and asked to produce photos or videos to illustrate their experiences. The prompts were created by researchers, in response to discussion points raised in the initial interview and subsequent check-in interviews. For example, "You mentioned that you have been keeping up with the news more since lockdown began. Could you submit one video showing us how you keep up with the news and what type of media you look at?"

Using the material from the interviews and activities, we identified 6 cross-cutting themes from the research:

- Identity and self-perception
- Uncertainty
- Shifting challenges – navigating boundaries and limits
- Independence and choice
- Time
- Good things to emerge

Organising the data in this way allowed Policy Lab and Disability Unit to turn the ethnographies from individual stories into a body of evidence. The body of evidence is presented in this written report.

Chapter 1: Identity and self-perception

Key findings

- During the pandemic, participants have felt increased levels of shame and guilt about their 'disabled' identities and the needs that accompany them.
- Participants' experiences and perceptions of being classified as 'vulnerable' during COVID-19 have differed markedly.
- Participants have felt particularly vulnerable when receiving social and healthcare services during the pandemic.
- Lockdown restrictions and other actions mandated by the government, aimed at stemming the spread of COVID-19, have given some participants the impression that their needs do not matter.

Introduction

The COVID-19 pandemic has caused rapid changes within society and to social norms. These changes have given prominence to our participants' perceptions of self and the important influence of society on their 'disabled' identities.

Findings

Feelings of shame and guilt

In the ethnographic research project, some of our participants said they felt embarrassment and guilt about being 'disabled', a term some of them disliked using but had to use out of necessity. During the current project, the participants were clear that the pandemic has exacerbated these feelings. Diane told us that since some of her impairments were invisible, she felt anxious interacting with others. The introduction of masks heightened this issue as she could no longer lip-read, leaving her feeling embarrassed. Though, Diane was clear that she did not experience shame in the same way when it came to her more visible impairments.

The 'vulnerable' label and the shielding category

Participants' experiences and perceptions of being classified as 'vulnerable' varied. Latanya was very aware of her health risks in relation to COVID-19. She recognised her vulnerabilities in a medical context: "Cold and flu has been an issue for me just in general, because someone's cold turns into a chest infection for me, or my bronchitis is up again. I'm always at a risk for catching nonsense. So, now when you throw in a deadly virus, it's a sick joke really."

Conversely, Efstathia felt embarrassed about being identified and labelled as clinically extremely vulnerable (CEV). While this categorisation had enabled her to receive a food parcel at the start of the first national lockdown, she told us that she had stopped delivery of the parcels immediately.

Diane questioned the validity of the label that she had been given: "I would be classed as clinically vulnerable. Whether I feel like that, I don't know."

Kathryn said that she had been contacted at the beginning of the first lockdown and told that,

because of her age, she would be treated as a 'vulnerable' person. She talked about the services that this label had allowed her to access: "I've been able to get a shop from them every week when I've needed it."

Joyce had been looking forward to the end of her shielding period but had received a phone call from the hospital saying they needed her to attend an appointment, and that following this appointment she would need to shield for another month. Joyce had been disappointed: "So, that's really hard. That's going to be a difficult one."

Participants generally felt that labels referring to their vulnerability had led to them being perceived differently, and often incorrectly, by others. Efstathia observed: "The world doesn't see the real me."

Even when a label was useful, and aided in obtaining services, this too could cause issues. For example, being labelled as 'vulnerable' may have assisted Jessica with receiving support but a lack of knowledge from professionals about the label of 'shielder' resulted in risks to her health.

Jessica felt that her status as someone who had been shielding had not been understood in the social care system: "They have no idea of health. They didn't even seem to get what shielding meant. Some of the carers that came in the early days, they had no masks, no gloves, no PPE. 'No, I'm shielded [sic]. You can't do that'. They were like 'What does that mean?' I need to be surrounded by medical people who understand that."

Social care

Participants said they felt particularly vulnerable when receiving social care services during the pandemic. Jessica's personal assistants (PAs) had not wanted to come into work. Jessica explained: "[This] instantly threw us into the no care situation […] One of the PAs left to go to a high-paying job because the care companies were suddenly giving them higher wages, because of coronavirus – they needed them – so, they were paying them more […] One was quite an anxious lady anyway and didn't want to leave the house and give it [coronavirus] to her kids, so she stopped. And the

other one [PA] became quite depressed and didn't want to leave the house. So, we were thrown into the no care situation right at the start, when everything was up in the air."

Following this experience, Jessica and her husband Simon had been sent over 14 different PAs within a 6-week period. Jessica discussed the impact this had: "We've just lost all the PAs, so we're still emotionally raw […] So, to then have loads of strangers trooping in who don't know us, it's not exactly trusting. We're not exactly feeling enough to open up to them yet. I don't even think most of them realise we've been employers before. I think they're just thinking we've only just started in the care world and we need teaching on how the care world operates, which is not at all true."

Jessica's experience relates to broader findings from the ethnographic research project, on the difficulties disabled people face when they employ PAs directly and the challenges they experience as employers rather than service users.

Jessica further discussed the problems associated with starting a new working relationship: "How can it work until we get to know them, when you've built a relationship? It's going to be thorny or rocky in the beginning because you don't know each other, you don't trust each other […] You aren't going to completely be yourself for the first 6 weeks."

She continued: "Everybody treads very carefully around each other. Like, everything they do, they ask every 5 seconds at the beginning, because they don't want to do something wrong. Like, they walk in and go: 'Should I take my shoes off? Where should I put my shoes? Where should I put my coat? Does this live in a set place?' […] So, it's more tiring, it's more exhausting […] They haven't finished that stage yet […] because they keep sending different people."

This also links to our previous findings in the ethnographic project, where participants talked about care giving and receiving being viewed by others as a functional relationship, where in reality it is a very personal and intimate relationship for many disabled people and their PAs.

For this reason, established and consistent relationships are the preferred option for most disabled people. COVID-19 seems to have exacerbated an existing limitation to these types of relationships. This and other systemic problems identified in the research concerning the care system will need to be addressed during, and beyond, the pandemic.

Healthcare services

Participants felt that COVID-19 caused additional barriers when it came to accessing healthcare. For Joyce, it was quite important to be examined by medical professionals in person.

Efstathia had similar concerns regarding the change from in-person to telephone appointments with doctors. She explained: "[…] how frustrated I feel at the lack of face-to-face consultations with hospital consultants. Well, I emailed the rheumatology department yesterday, to say: 'No, I do not wish to have another telephone consultation'. I pointed out that the telephone conversation I had with the consultant back in

June led to absolutely nothing, no proper diagnosis or easing of the pain in my shoulder. It proved, therefore, as effective as a mesh teapot! I also said that unless their doctors are psychic, they cannot diagnose a precise condition over the phone."

Shawn was also critical of telephone medical appointments: "Well, I've got letters. I've got quite a few out there on my noticeboard telling me that instead of going to see the doctor at the hospital, I'll be having a telephone consultation, which is what I had the other day. My heart specialist rang me up for a consultation over the phone. It's not the same. You can't really show them. My haematologist, she rang me a couple of weeks ago. Again, it was over the phone: 'How are you?' 'Well', I said, 'I'm still coming up in bruises', and this and that. She said to me: 'Oh well, carry on with the iron tablets and we'll give you an appointment again in 3 months'. But in 3 months' time it'll probably be the same again […] I see a skin doctor as well, you know, a dermatologist. I'm due an appointment, but how can he do it over the phone? It's something you've got to look at, isn't it, your skin? So, I don't know."

Efstathia pointed out the lack of availability of medical appointments during COVID-19: "People haven't been able to see specialists, get treatment they need. That's where the NHS has failed us really … Other patients have suffered." Shawn talked about the lack of communication between different departments in the health service during the pandemic: "When I went to see the podiatrist, my GP told me originally – when I said to him about my foot and how I was in pain and everything – he said: 'Well, I don't think they're working at the moment'. And he just left it like that, nothing. When I spoke to the podiatrist, she said: 'We've been working all the time. We've had to, because of emergencies such as yours' […] So, how I think they could improve it is all talk to one another, and make sure they know the facts before saying to you: 'Oh no, they're not doing anything at the moment'."

After this experience Shawn had phoned the GP and spoken to the receptionist, who had told him: 'The doctor does not ring back anymore'. Shawn had been asked to fill out an extensive online form about his medical history. This experience

supported the earlier findings from the ethnographic research project, where disabled people were constantly asked to repeat the details of their medical conditions.

Shawn explained: "They want to know all your medications and everything. Well, I take so much medication, I couldn't remember it all […] And then they want to know all your medical conditions. Well, they've got all of that there […] Anyway, so I filled it all in, and it said that the doctor would ring me back within 24 hours […] They sent me an email, and they said: 'Oh, the doctor's referred you to the podiatrist' […] I heard nothing from them for about 2 weeks. So, I phoned them, and eventually I got through to the right department, and they said: 'Well, we've got no appointments at the moment until sometime in September'. I said: 'That's ridiculous. I've had this for months. I've been in so much pain with it, with this ingrown toenail. It's all gone yellow now, it's all infected, you know. So, she said to me: 'Oh well, there's nothing we can do until that date'. I said: 'Okay, I'll have to wait then'. About 10 minutes later she rang me back. She'd obviously spoken to somebody. And she said to me: 'Oh, I'm a bit concerned about

your toe. Can you come in today?' That's funny, isn't it? They had nothing for 2 weeks and suddenly they can see me today."

Work and finance

COVID-19 has brought up a whole new set of experiences of being disabled. In some cases, it has presented additional challenges to contend with. In others, it has reformulated and reframed existing barriers.

While Diane believed the lockdown had made her more productive, as a disabled person, lack of space in her home had become an issue because of her need for specific equipment to help her work without discomfort. She said: "[My adapted office chair] will take up half a living room or half a bedroom, and I already have the wheelchair in my bedroom so it just doesn't work."

As part of her job, Diane had performed home visits to help disabled people access social services. She found joy in this. However, the visits had stopped. At the time of our interview, she had started doing phone appointments again, but

Diane found these slow and less fulfilling, and she also did not feel phone appointments were as effective for the clients.

Latanya's options to seek additional sources of income had been negatively impacted by COVID-19. She explained: "To get additional money, I used to do a lot of market research and things like that. Now, because everyone's at home and everyone is doing market research, they don't have as many […] I'm always trying to find, like, unconventional means of making money besides professional routes, because with the professional route, there's the interruption when it comes to my health stuff. With the unconventional route, there's options and I can have things on the side. I can figure that out […] I found the market research stuff and it was working out really well, a good 6 months. But then obviously, when the [COVID-19] situation came about, it just changed drastically."

Shopping

Participants said they faced difficulties when going out to the shops in the COVID-19 environment. Joyce felt that she had lost some of her confidence

because she had been required to shield for a long period. Joyce shared that she had to ask her husband what she was meant to do while they were shopping, as she had not experienced this during the pandemic.

Pre-pandemic, Efstathia had used Dial-a-Ride to take her out, but she said that has not been an option during COVID-19, and she did not have her own car to go out. Efstathia also shared her concerns about the lack of availability of shopping delivery slots: "When everything first started, I started panicking a bit because for 4 weeks I couldn't get any deliveries."

Wearing face masks

The requirement to wear a face mask has presented distinct challenges for our participants, in terms of managing their medical conditions safely and effectively, and negotiating the stigma associated with not wearing a mask.

The widespread adoption of continuous mask wearing, for example, has made effective communication challenging for the participants

who lip-read and who are more reliant on facial expressions. Masks muffle speech, making it more difficult to communicate using spoken language, even for those who do not have hearing impairments.

Participants who were exempt from wearing a mask felt strongly that they were being negatively judged by others when they did not wear them. The exempt status has created new hurdles for society to understand and recognise the needs of our participants as 'disabled' people.

Shawn shared his embarrassment when he did not wear a face mask: "Yesterday, I went out to the shop, and because I was quite breathless, I thought: 'I'm not going to wear a mask'. I don't have to wear one anyway, but I've been wearing one […] because I don't want any arguments with people for not wearing one. But yesterday I was quite breathless, and I just thought: 'No, I'm not going to wear it. I can't wear it'. So, I didn't wear it. Anyway, I did cough a couple of times, and I did see a couple of people, sort of, look round … look up at me as if to say: 'You're coughing and you haven't even got a mask on', you know. They

never actually said anything to me, because I would have soon told them if they had. But I did notice […] they actually looked round as I coughed. I always cover my mouth anyway and I haven't got COVID. It's just the breathing problems I've got […] It makes you feel a bit annoyed and embarrassed really. That's why when I do go out, I always try to wear the mask, so I don't get that problem."

Shawn had heard other people being spoken to harshly when they were out without a mask: "People saying: 'You haven't got a mask on. Don't come near me', and that sort of thing […] People get quite angry […] Some people get quite nasty about it. It's a bit like supermarket rage … 'Why aren't you wearing anything? Everybody else has got to wear one. You could catch this and we could catch it off you'. It's a bit like road rage."

Kathryn said she chose to wear a face mask even though she was exempt from doing so. She said: "Because I have the agoraphobia and the vertigo, I've sent away for a badge from Hidden Disabilities that says: 'I am exempt from wearing a mask'… If I reach the stage when I'm really panicking in the

shop, I can slip it down, so people can see I'm making the effort."

Society's acknowledgement and perception of disabled people during lockdown

Lockdown activities have given the impression to some participants that they are invisible. Joyce talked about the invisibility of disabled people's loneliness: "I think the disabled voice is a bit fuzzy. You know, there is no particular focus on how it has been affecting people who have been shielding and are perhaps alone on their own – and that's an awful long time to be alone – and perhaps they managed to contact and be in contact with people who are alone. And, you know, it brings into sharp focus […] exactly what it means to be alone."

Latanya explained how she felt the public perceives her: "I find it a little bit comical, because obviously when people watch you, they either just like 'baby' you – they want to have this whole sniffling thing like: 'Oh, I'm so sorry about this', you know, like patronising talk and stuff like this – but

realistically they have no idea what you're going through, and nor do they want to know what you're going through, in any way, shape or form."

Efstathia noted that she hoped COVID-19 would build empathy for disabled people's isolation from non-disabled people, now that they were experiencing a similar situation.

Joyce shared that people kept to social distancing rules around her when she used her wheelchair in shops, even when they took less care with each other: "Now that people are wearing masks, not so many people social distance. I guess people don't take as much time to take distance from others. Because of the physical size of my wheelchair, most people tend to give me more room, because I take more space […] I think they're more aware to keep their distance from me." She compared the behaviour to pre-pandemic times: "It used to be that people used to dash in front of the wheelchair without giving [it] a single thought."

Conclusion

Participants shared with us their views on the 'vulnerable' label and the issues present in the 'shielding' category. They felt that these labels affected how they were perceived by others.

Participants discussed a range of additional barriers arising for them during the COVID-19 pandemic such as with social care, healthcare, work, shopping, and loneliness. Many of these extra hurdles contributed to them feeling embarrassed and guilty about their 'disabled' identities. They also reported feeling an extra burden of social responsibility in public places, especially around mask wearing, when compared with non-disabled people.

Policy makers are invited to reflect on the following questions:

- How can we acknowledge and protect people who are at higher risk of disease without reinforcing a deficit model of disability?
- How can we ensure that vital services such as social care provide continuity during a crisis?

- How can we ensure consistency of care?
- How can we learn from disabled people's experiences of accessing social and health care, work and shopping services during the pandemic in order to effectively shape policy?
- How can we learn from disabled people's experiences of being classed as 'vulnerable' during the pandemic in order to ensure that future policy reinforces inclusive and positive (rather than deficit and negative) images of disabled people?
- How can we improve communication within different services to meet disabled people's COVID-19-specific needs and address long-term inequalities?
- How can we improve awareness, understanding and recognition of disabled people's pandemic-related needs and concerns such as the reasons why they may not wear face masks, and learn from this after the pandemic?

Chapter 2: Uncertainty

Key findings

- Participants found the changing rules around COVID-19 difficult to understand and follow across different areas of their lives.
- Uncertainty throughout the COVID-19 pandemic has had a negative impact on participants' mental health.
- Some participants have found new and existing coping strategies particularly helpful in managing their health conditions during the pandemic.

Introduction

The COVID-19 pandemic has created more and greater uncertainty for disabled people. This uncertainty relates to COVID-19 guidelines, the availability of health services, interrupted transport options and other changes to the provision of services and goods required to meet participants' needs. While these uncertainties negatively

impacted some of our participants' mental health, others relied on their existing coping strategies.

Findings

General confusion and uncertainty

Our participants generally felt confused about COVID-19 rules, and the support and information available to them during the pandemic. They also felt anxious about not having a clear idea of how long lockdown was going to last, how long they needed to follow social distancing guidelines, and how they would cope with the disruption to their lives. Diane said: "They're saying keep social distancing with those who aren't in your household, but you think: 'How long is this going to last?'"

Trust in the guidelines

Some participants had received minimal information about COVID-19 and the protocols they needed to follow. Latanya had received the original shielding letter but had not received any information to mark the end of the shielding period.

Therefore, there was a level of uncertainty and mistrust around the information she received or guidance she was instructed to follow.

Similarly, Kathryn was uncertain: "I should be shielding until the 18th of August. After that, who knows what's going to happen." By the end of our interview time with Diane, she was questioning the severity of COVID-19 and whether all the disruption was ultimately worth it. Her enthusiasm for following the rules had distinctly waned.

Shawn was also unsure: "Who knows when it's going to return to normal. This could be the new normal, couldn't it? It doesn't make sense to me. It doesn't make sense. I don't know anybody who's died of COVID. Touch-wood, I've got nobody in the family who's had it. I've got plenty of people who've had influenza, normal flu, and survived. Different people say different things. They reckon the survival rate of this is about 99%. It only kills people with underlying – not everybody either – illnesses, really. There's more people who die every year of influenza, so I don't know what this is all about […] It's all over the place. You don't know when it's going to go back to what we know as

normal. It's ridiculous. It makes you a bit down, that you can't do what you want to do when you want to do it."

Jessica was critical of the government for not considering the needs of people with autism in both the guidelines on shielding, and the need to implement any changes gradually. She felt the government constantly updated the COVID-19 regulations.

Confusion about healthcare services

Participants were unclear as to which services they could access during the pandemic. During lockdown, Jessica had fallen in her bathroom, yet she and her husband Simon had not been sure who to call, whether 111, their GP, or 999. Jessica explained: "I'm shielded [sic]. Should we be ringing anyone? So, that was pretty scary."

One set of paramedics had visited Jessica, but because they did not know her, and were not familiar with how she displayed pain, they had simply left Jessica at home. Jessica described how difficult it had been: "So, then we were left

struggling, because I couldn't stand […] So, we went, almost overnight, to not being able to get out of bed, not being able to stand, not being able to move, and no care." At this point they had called their local council and applied for extra support from the government, but nothing had happened. They had then called 111 and paramedics had arrived for a second time to take Jessica to hospital.

Roy had been unsure what to expect from a visit to his GP surgery, as for months he had only communicated with his doctor by telephone. Roy was also uncertain about the COVID-19 rules in place at the practice: "Doctor's surgeries, dentists – they're daunting, aren't they? […] I expect it'll be very clean like it normally is, well cleaner than normal […] They'd have, sort of, social distancing in place. They'd make sure that seating arrangements were, again, you know, sticking to guidelines and that […] I'm, sort of, a bit apprehensive about what it will be like, you know. I found out that if you cough, or if you sneeze as well at the moment, people, sort of, glance at you, like, you know. Will there be that sort of atmosphere there? It'll be interesting to see."

Uncertainty about transport arrangements

Jessica felt very apprehensive about using public transport herself and was also worried for Simon: "And for my husband to juggle a bag of clothes and medication and a wheelchair on a bus under social distancing, I'm not even sure the bus driver will allow it […] I don't know what to expect. When we used to go, we used to put the wheelchair into the wheelchair space and then my husband used to stand next to me. Well, will he be allowed to? Will he be made to go somewhere else? It's just too unknown. It's too big – big and frightening and unknown at the minute, so we're just not going near them yet."

Jessica had to temporarily relocate houses due to her home needing repairs. She discussed the difficulties with arranging transport for moving to this temporary accommodation with her husband during the pandemic: "Originally they wanted to put us out of this area, but they were telling us to get in the car and drive to it. But we don't have a car. They just assumed [that] because we've got a wheelchair, we've got a car." She continued talking about how the pandemic uncertainty had increased the number of unknowns related to the

move: "It'd be helpful to know a rough date […] It'd be helpful for us to know what's going to be in the building that we're going to. Is there going to be a bed, or are we going to be expected to find one? Is there going to be an oven, kettles, cups? Or do we need to pack ours to take […]? It will literally be, Simon will sit me in the wheelchair, a box on my knee and we'll walk down, so some transport would be … None of this has been discussed […] We're in the middle of coronavirus. How many people are we going to encounter who could actually give us the virus? It's just very unknown and very big."

Concerns about the future

Our participants expressed uncertainty about their future and that of wider society. Joyce was particularly worried about her son who would be studying away from home in the event of a second wave. She said: "It would be a concern if the area he will be living in would be a bad area for COVID. We would be worried about him and what's going on there."

For Kathryn, already living with a mental health condition, not knowing when the restrictions would end was troubling. She reflected: "I do think sometimes, you know: 'I'm [in my early 70s], this could go on for the rest of my life. I don't know how long I've got […] It could be that I'll have all these restrictions in place … forever', you know, 'forever to me'. So, I'm finding that very difficult to, kind of, come to terms with, what the future might hold."

Roy commented that a few months into the first wave of COVID-19, he had still felt as unsure about everything as he had when it all started: "Even though we've got this, kind of – well, we're moving forward […] it is still a possibility, especially with the winter coming now soon. Who's to say it won't come back two-fold then […] actually mutate itself again or something […]? I've had some stuff going on personally as well […] where I don't know what the future holds. So, I don't know, I'm really uncertain at the moment."

Impact of COVID-19 on mental health

The consequences of large-scale and long-term uncertainty can have a considerable impact on

disabled people's wellbeing. Roy reflected on the impact of the uncertainty on his mental health: "These things are difficult enough as they are […] My stress levels are up there anyway. But with what's been brought on with the lockdown and that, it is tough […] It's difficult to get on with your day because you don't know what tomorrow brings."

Joyce was worried about the effect of a second wave on her emotional wellbeing during winter. Roxanne described how her daily routine, on which she depended, had been disrupted by COVID-19 and all her activities had been moved online. Not being able to see her friends had very much affected her wellbeing and quality of life.

For some participants, it was not just uncertainty about the future but the lived reality of the present day that was having a considerable impact on their mental health. Shawn described how lockdown had impacted him: "I have been getting depressed being indoors all the time. I suffer from anxiety anyway – anxiety, depression. I've been more so because of lockdown, you know."

Joyce expressed her feelings about losing control and being restricted: "If I wanted to get something done, I would do it. And it does fill me with frustration when you can't move forward and you have to, you know – this job has to wait, this job has to wait, this job has to wait."

Jessica felt daunted about the prospect of leaving the flat after a long period of staying at home: "That's the big one at the minute, is actually leaving the flat […] seeing the housing officer again, seeing people in 'real', not virtual […] We've got so used to being in here. We feel quite comfortable in here. We know what food's in here, we know what's where in here. But everything out there has changed. Bus times have changed, people are saying shops are now one-way […] And we've got no support to help us relearn what's out there. And everybody else will have already done it. So we're going to be entering the world and expecting to know the unknown."

Coping mechanisms

Certain participants reported experiencing a personal opportunity during the pandemic, or

potential opportunities arising to manage their health conditions differently.

Roy said that lockdown had helped him to focus on doing basic things, like drinking plenty of water, eating regular meals, and sleeping properly, as a strategy to manage his depression. He explained: "When COVID happened, I'd, kind of, not forgotten it, but it meant that we, kind of, went back to surviving on our own, because we didn't have that, sort of, socialness – people around us – family and stuff was distanced. So, you, kind of, relied on yourself. And it just reminded me again of what I had to do […] like: 'Well, I've done this before. I've had experience with it. So, let's see if it helps'. And it did, actually, you know […] I had forgotten about it for a while, but when COVID came in and stuff […] it was something that I went back to. I just found it useful to do them steps again."

Roy thought the pandemic might have given him a more positive perspective: "I have a tendency to withdraw, that's my thing, and I haven't been. I've been, sort of, making a point – I don't know what it is – I don't know whether lockdown has sort of

given me, kind of, a healthier way of looking at life. I don't know."

Shawn said he had found driving helpful in coping with pandemic-related stress: "Just going down the road, you know, a couple of miles down the road, turning round, and driving back. It kept me sane. I thought: 'Because I've got to keep the engine running' […] So, that's what I did, I had a little drive."

Others had found existing coping strategies particularly helpful during the pandemic. Amid all the COVID-19-related uncertainty, Efstathia's faith had provided certainty and comfort. She explained: "My faith is very strong. It's a living faith. There is communication there." She had also started creative art projects to combat the feeling of losing control over the future and her life.

Latanya's perspective on the pandemic helped her to cope with the situation better. She was reflective and made an interesting comparison: "I feel a bit estranged compared to normal times before, but again it's a weird time for everyone. They're dealing with the whole uncertainty and lack of

control, they're taking it really hard. But for me, this is just regular life."

Conclusion

Participants shared with us their confusion and uncertainty regarding COVID-19 guidelines and the changing world outside their doors.

Our research participants were concerned about the uncertainties surrounding healthcare, transport, and the provision of other services during the pandemic. Participants felt that the pandemic was adversely affecting their mental health, and that it may continue to do so for a long time. Some participants had found different coping mechanisms and opportunities to help with COVID-19-induced stress.

Policymakers are invited to reflect on the following questions:

- How can we produce clear, accessible, and up-to-date government guidelines for different

areas of disabled people's lives, which the disabled community can trust and rely on?

- How can the guidelines and communication around the pandemic be made impairment-specific to accommodate a wide range of needs?
- How can we support disabled people with mental health issues resulting from the impact of COVID-19 and periods of lockdown?

Chapter 3: Shifting challenges – navigating boundaries and limits

Key findings

- The pandemic has exposed and exacerbated the existing inequalities experienced by our disabled participants.
- Some participants felt that COVID-19 restrictions have conflicted with their disability access needs.
- Participants felt that people in wider society have often been able to 'cherry pick' the COVID-19 rules they are going to abide by, because they have more freedom to do so, whereas disabled people cannot, mainly due to new and existing social barriers.

Introduction

Participants discussed various COVID-19 regulations and how they have been required

personally to negotiate these newly imposed social boundaries and limitations. In order to comply with the guidelines, participants have often assessed how their disability and impairment needs would be met, and whether any adjustments would have to be made to their routines in light of new restrictions. They also shared with us their views on how the general public has followed the guidelines.

Findings

Boundaries and limits

The pandemic has imposed a range of material, physical, social and perceived restrictions, many of which have acutely affected our participants. Participants discussed a range of boundaries and limitations presented by COVID-19.

During the lockdown, Joyce has felt trapped in her house. She said: "I found it difficult to not move around freely. Suddenly this space [her home and garden] that I have here wasn't big enough. I wanted to see more people, you know, people moving around, living their lives. So, it was quite tricky. Perhaps I did have a period of low mood."

Joyce has been unable to go out as her impairments have led to her being classed as 'vulnerable' and having to shield. Due to the support she was receiving from her family, they too were required to shield in order to protect Joyce from the virus. Joyce said that this felt suffocating: "It almost felt, like, hot sometimes, here. There were just too many people. Too many personalities … Too many disparate parts, and, you know, it just stopped working. I think that lockdown certainly causes that overheating. You know, young people can't get out of the house and away from us and just be their own people, you know. We were always here, and they were always here."

Participants shared with us their perspectives on boundaries imposed by COVID-19. Some of these were self-imposed rules participants chose to follow, while others were externally imposed. For example, Kathryn was exempt from wearing a face mask and wore an exemption lanyard, but she still mostly chose to wear a mask.

Roy talked about his dad and his son, who live together separately from Roy. They had visited him when lockdown had eased. Roy explained the externally imposed rules and the difficulties of not being able to have close contact: "We've been having contact, but it's been distanced, you know. I know they say there is the phone but it's not so easy just to phone sometimes […] When they, sort of, started coming down, it was few and far between, but we, sort of, managed. Again, we weren't sure what the rules were, so we maintained what contact we could have […] It wasn't exactly a great situation for all of us, but for where I was at and what was needed […] it was nice to see them. They would, sort of, turn up and wouldn't have a lot of time to, sort of, tell me this or that. Keeping in guidelines, you know, the 2 metre rule, it's difficult. You instantly want to hug them […] and then you can't [laughs]. You know, they're unsure of who I'd been in contact with or where I'd been and stuff, and the same with them […] It felt unusual, you know. When they left, it just didn't feel right, you know, not being able to hug them, to have that, kind of, closeness with them […] That personal side of it wasn't there."

COVID-19 guidelines and accessibility

Some participants did not feel that COVID-19 boundaries intersected with their access needs.

Shawn talked about the inaccessibility of his visit to the dentist during the pandemic: "They were only seeing one person. There was nobody else in the waiting room: 'Only one person in the building at a time', she said […] So, I had to wait for a few minutes when I got there. She said to me: 'There's somebody still in the chair, so if you wait outside'." When Shawn was asked how accessible the outside of the building had been for him to wait, he commented: "It was a bit of a nuisance. There weren't no chair or nothing to sit on. I had to lean myself up against the window sill, because the window sill wasn't even low enough for me to sit on, it was high up. So, I just leant on it. But anyway, I could have done with a chair really […] My legs were aching, so I could have done with sitting down." Whilst Shawn appeared to be pleased to be able to book a dental appointment at all during the pandemic, and was therefore very tolerant of issues and problems, this does not take away from the lack of consideration given to access needs within the practice.

The team of volunteers supporting Jessica and Simon during the first lockdown had helped them plan meals using the food they had at home rather than buying new food items, because online shopping had not been accessible. Jessica explained: "Because we couldn't work out doing an online food shop, we just couldn't get the technology. Our devices that we had at the time were just not conductive [sic] for trying to do a food shop on it. And then once you got on, there were no spaces, no delivery slots. So, we quickly gave up with that." Given that during the pandemic, online shopping has become more prevalent for disabled people, the lack of accessibility and support for the technology has meant that a system that should have made shopping easier has only added to the barriers.

Safety and risk

Participants discussed their perceptions of the level of risk they faced in different situations. For Latanya, anywhere outside the home was a place of risk. She reflected: "I look at everyone and think they carry around death. That's all I see. I see

them just rubbing their clothes everywhere. I can't deal with that, I just can't. Any clothes I wear outside, it goes straight in the wash. Even if I just go to the reception. I'm not putting it on again, it's not happening."

Latanya's home, an assisted living unit, was the only place she felt was a safe space for her. She had restricted the entry of carers during the pandemic. She continued: "We have carers and stuff here, but I'm not letting them in the house. I don't have time for that. They barely do anything anyway, and then I'm just going to have to clean up after them. It just takes too much energy. They're literally trekking COVID into my home. They're not informing themselves properly." Efstathia also talked about being careful "[…] by virtue of being locked in my house".

Roy discussed how risky it felt travelling when other people did not follow the rules: "You don't want to think too much about it, 'cause otherwise you start going down a COVID, sort of, rabbit hole [laughs]. Really, sort of, daunted … surprised … yeah."

Navigating boundaries

Sometimes participants had crossed some of the COVID-19-imposed boundaries. For the most part, prior to transgressing the rules, participants would conduct an assessment concerning the danger of not having their needs met versus the risks of exposure to COVID-19.

Shawn explained why he had not been able to stay shielded from his daughter: "[My daughter] had to [visit], because she has to do my food and keep the place clean and all that sort of thing for me. It was essential, really, that she still came to see me, you know. She couldn't be shielded from me."

Diane said she wanted to follow the rules but had made the decision to have a hug with her mum. She said she had needed it for her mental wellbeing. Diane admitted this had been a conscious choice: "I'm the kind of person who […] I want to follow the rules. I have broken a couple, I put my hand up, but it was for my mental health. That was because we've got to carry on living as well". Diane explained: "It's trying to stick to the

rules, but knowing that, in my mind, there's a little bit of a leeway."

Reflections on society's compliance with the rules

Participants shared their thoughts on how others had been interpreting and adhering to the guidelines. They felt that some people in wider society had been able to 'cherry pick' the rules they would follow, as they had more freedom, and disabled people could not do so because of their various impairment-related needs and risks.

Roxanne had been told by a worker in her assisted living institution that she could not go out during lockdown. With support, she could have worn a face mask and kept a distance from others whilst shopping, but this was not presented to her as an option. She felt that she had not been given the same freedom and choice as other people.

Kathryn commented on her perception of the behaviour of others: "A lot of people just think: 'We're not going to be told what to do. If we want to go to the beach, we'll go to the beach. We don't

have to wear a mask, so we won't'. I've seen a lot on Facebook in the last couple of days, people saying: 'Well, why should I wear a mask in the supermarket? They're not going to stop me. They're not going to make me do it'. I think there's a big chunk of people that feel like that, and you do see it all over social media."

Shawn had a similar concern to Kathryn: "[People have been] sharing things about: 'Look how many people have been on the beach'. Hundreds, and they're not social distancing, the majority of them. It's mainly young people who are not doing it, and they're going out to the pubs and they're absolutely crowded. I've seen pictures of it. They're mobbed on there. So, where's all this social distancing in the pubs? It's not there, is it? Especially when people have had a drink, they lose all of their inhibitions, they do what they want to do, don't they?"

Kathryn said she had felt the impact of other people's non-compliance affecting her more acutely: "Everywhere we go, we see people that aren't obeying the rules, and you think: 'Well, I've been obeying them since March and I'm fed up

with it now'. And, being older, you don't know how long you've got left. Do I want to spend the rest of my life in lockdown because people are going out and doing what they want?"

Participants were mindful that not everyone followed the social distancing guidelines in public. Roy shared his experience of social distancing on public transport: "It soon fills up. It's quite a busy route. When I first got on, you could see people being aware of where they sat […] There was, like, a few people sat at the back, a few people sat at the front, all distanced. So, I was […] sat there with no problems. There was plenty of room around me. But as the bus started to get to more and more stops, there's more people coming on. I'd say about a third of them wore masks […] By the time we got into town, the bus was more or less full and social distancing had gone out of the window, like. And there was no, kind of: 'Oh well, we'll have to stop here because you're only allowed so many' […] Even though it was obvious that people were sitting next to each other because there wasn't room […] I was taken aback […] I'd considered getting off […] But at the same time, I wanted to get to town."

Roy talked about the impact of the easing of the first national lockdown on people's shopping behaviour: "I've been to the shops and stuff […] and I'm really surprised how normal things have gone so quick. Even though something happened, it's, kind of, like people are trying to … pretend it didn't happen […] When you're surrounded by it, you just go with the flow. You, sort of, prepare yourself: 'I've got my mask, I've washed my hands', you do that. But then when you're in the traffic of people, it's, kind of, easy to just do what they do, like, follow the trend […] It's like people have rushed to, sort of, say: 'Oh well, it's over with now. We can get on with things' […] When we first started the easing of lockdown it was still there, and people went out of their way to, sort of, move out of the way for you, and you would for them […] Everyone would sanitise. Now I see people going into shops and they walk straight past [the sanitiser]."

Joyce summarised her thoughts about what might be a good way to interpret government guidance: "[I] think if we lived life by our own personal politics […] we know the things that we want to be

involved [in] on a personal level, we know what to expect from ourselves and people in our family."

Participants' experiences

Our participants experienced additional harassment due to their exemption from some of the rules because of their impairments. This resulted in isolating our participants further and they felt that this had widened the gap between the independence of disabled and non-disabled people. Participants' experiences indicated that some people were looking out for their own interests without considering of how these attitudes would affect those labelled as 'vulnerable'.

Conclusion

Participants discussed a range of experiences regarding COVID-19-imposed boundaries. Issues included the accessibility of the guidelines and various risk factors. Interviewees shared with us the ways they had navigated the rules in order to

meet their varying physical, mental health and social wellbeing needs. Participants also reflected on how they perceived public compliance with the guidelines and how this had affected them.

Below is a list of questions to reflect on, to create a more inclusive set of COVID-19 guidelines:

- How can we ensure pandemic-related rules do not conflict with disabled people's different access and support needs?
- How can we ensure that COVID-19 guidelines are being followed equally and fairly across the population without creating new hierarchies?
- How can we convey the impact personal actions have on other people's lives?

Chapter 4: Independence and choice

Key findings

- COVID-19 has presented new challenges for some of our participants in terms of living independently, reducing their ability to choose suitable support options.
- For some participants, independent living choices have been uninterrupted during the pandemic.

Introduction

COVID-19 has presented unforeseeable challenges to our participants' independence. For the most part, participants have had to make significant changes to their daily routine and activities.

Findings

Diminished choice and independence

The sudden changes caused by the pandemic have led to some of our participants being confronted with limited choices and compromised independence. The pandemic has presented threats to independent living.

Roxanne said she wanted to go out to her town on her own. The fact that she had to be accompanied by someone when going out made her sad. Previously, she had been able to go out unaccompanied, but once the pandemic struck, she needed support to apply hand sanitiser and put on her face mask. Additionally, her daily routine had been disrupted, and all her activities had been moved online. She had not been able to see her friends for months, other than virtually, and she felt that it was just not the same. Roxanne had not been able to see her mum either, whom she previously saw once a week.

In the previous ethnographic research project, our participants experienced considerable loneliness resulting from physical isolation and barriers to

social inclusion. COVID-19 has intensified participants' exclusion from the mainstream.

For Joyce, the closure of the palliative care centre that had provided respite for her husband who is her primary carer, had resulted in reduced independence. This service had been essential to their joint wellbeing and was cut at a difficult time: "I miss the fact that for those few hours my husband can do his own thing [...] It's good to have that separation because he is my carer, but he is also my husband and that's a strange situation."

In Jessica and Simon's case, the temporary accommodation the council provided for them during the pandemic, whilst their home was being repaired, had not only reduced Jessica's independence, but also added to her husband's roles and responsibilities. She explained: "We can't take my powered wheelchair, so I'm currently sat in my manual one. My powered one is in the property that's being repaired. It doesn't fit through the door of the temporary one. The temporary one hasn't got widened door frames. And each room has got a little lip on it so my husband has to flip

the chair back to get me over all the lips. So, I'm totally disabled by the property. I've lost independence and my husband's gained the full-time job of having to push me around. But that didn't seem to be of any importance to them [the council]."

Continuation of limited choices

For participants like Efstathia, daily choices such as socialising options and living arrangements had remained limited. She shared her experience: "I am very aware of being unable to implement any decision I make through lack of resources etc, and my life is a perpetual lockdown, so I've had good training […] I've been through a lot of adversity and learnt to cope with very difficult circumstances. There are times I feel: 'Should I just give up? Is it worth it?' but then I remind myself, life is actually quite short … There are conflicting ideas sometimes … Younger people might find it very difficult to cope, but I've had a lot of practice."

For Efstathia, life during COVID-19 had not been a big departure from her pre-pandemic life: "It hasn't

been that different from my normal life because I have been on lockdown for the last 6 years."

Latanya also felt that the lockdown had not altered her life choices: "Yes, I know there's a deadly virus, but honestly, this lack of control on how your day or week is going, it's normal for me. So, when they said you have to be locked up, it was no different for me apart from people were more of a risk for me." We asked Latanya whether she had felt more lonely since the lockdown. She responded: "I don't know, yes and no. It's generally the same for me. I'm usually alone. Because of everything that's happened with my health."

Interdependency

Some participants felt they were in interdependent relationships. The interdependency had felt even more important during COVID-19. Kathryn cared for her disabled adult granddaughter. Continuing this had given her a sense of purpose and she felt fulfilled. Similarly, Jessica and Simon supported one another, although they resisted the 'carers' label. Jessica explained: "Because we're husband

and wife living together we're deemed as we can manage everything together. No 'Can you […]?' or no 'What can you do? What do you need help with?' Just 'That's all we've got. You'll have to make do'. Neither of us say that we're carers for each other because we're husband and wife. We do not like the term carer […] We don't like the term disabled either, particularly because it feels like it's too closed and like a dead end, but we can't get rid of the disabled one. We need that one because that's what we are, but don't have to have the carer one." In the ethnographic research project, Jessica discussed the lack of recognition from social services that she and Simon faced of their interdependent relationship. The pandemic has further reinforced this.

Conclusion

Participants shared their experiences of living independently during the pandemic. Some felt their daily choices and levels of control had been curtailed. For others, COVID-19 had not altered their already limited choices. Participants in

interdependent relationships, providing reciprocal support, felt the pandemic had magnified the importance of formally recognising such arrangements as the need for them was increased.

Addressing the following questions may help to overcome some of the difficulties participants experienced while wanting to stay independent:

- How can we listen empathetically to disabled people and understand their needs, to enable them to live independently?
- How can we validate disabled people's first-hand experiences and their right to independent living?
- How can we tailor the support provided in assisted living environments to respond to disabled people's particular concerns during a pandemic in order to facilitate and continue their independent living?
- How can we offer the right level of health services that addresses disabled people's health needs during a pandemic?
- How can we take into consideration disabled people's various needs when offering social housing options and support them during the

transition period, particularly during a pandemic?

- What lessons can we learn from disabled people who had been in 'lockdown' long before the pandemic to inform the post-pandemic landscape?

Chapter 5: Time

Key findings

- Participants used words such as "slowing down" when referring to their experience of 'time' during the pandemic.
- Participants have experienced pandemic-related delays and disruptions to their routine healthcare appointments.
- The pandemic has extended waiting times for our participants with high support and medical needs.

Introduction

During the pandemic, the concept of 'time' has become all the more important for our participants. They report having felt the passage of time more intensely. In the previous ethnographic research project, many participants reported spending long periods of time waiting for diagnosis and appointments. They waited for treatments to

become available, and then waited to recover after treatment.

COVID-19 has further increased the length of deferral periods and waiting times for disabled people with more urgent medical and support needs. Due to the urgency of some of their health conditions, our participants have not always felt that their medical needs have been attended to in a timely fashion, in some cases resulting in a deterioration of their health. Participants reported before the pandemic that their time was devalued, an issue felt even more acutely during COVID-19 times.

Findings

Slowing down

Some participants, like Efstathia, said they were conscious of time "slowing down". Having more time and energy had made Diane feel bored in the evenings because she had generally used her evening time to rest and recuperate, and this had stopped being necessary.

Joyce had experienced a slowing down, and even a "coming to a halt", of many of her plans, routines and the ways things were done. Essential building works in her home, intended to allow her to live mostly on the first floor, had not taken place. Joyce used the words "frustration" and "loss of patience" to describe her feelings about this.

Kathryn expressed concern that her return to pre-pandemic life would take a lot of time. In the summer, between lockdown periods, when others had appeared to be starting to go back to their everyday lives, Kathryn had not been able to do so. She said: "I think it will be a very long time before it goes back to normal. I've been concerned all the way through because of the agoraphobia. I was at a level where I […] knew what I could do, I knew how far I could go. And now I think: 'Can I even go to the supermarket?' You know, the supermarket is a place that I hate. I panic. And now I'm going to panic even more. I panic before I go, so I'm a bit worried about that aspect, that it will take a lot of time to […] feel that I'm able to do it."

Deferrals and delays

Participants had experienced delays to their routine healthcare appointments. Kathryn's routine steroid injections for her back pain had been disrupted.

Efstathia discussed the fact that her routine treatments had been impacted: "The podiatrist is no longer coming to the house. I can't bend down to do my toenails at all and I'm prone to ingrown toenails … The scissors slipped out of my hand and straight into an artery and there was blood all over the bathroom."

Shawn had been told that the only face-to-face appointments available were for emergency cases. He explained: "I don't know why they can't see us. I know this pandemic is supposed to be as bad as it is, but it doesn't seem to be as bad as it is to me […] I would have normally gone to the hospital to see the doctors, yeah, but […] you can't go there […] I had my liver appointment regularly. Haematology, dermatology. That's the main regular ones at the hospital. Twice a year, I have to have a tube put down my throat to have a look in my stomach and my liver and all that sort of

thing. I normally have that done twice a year. Well, I haven't even had a letter about that at the moment."

Latanya had experienced deferrals: "I already missed a few [pain clinic sessions] and then the COVID thing came about, so they told us not to come in, then I was finished [with the sessions]. And then with the hospital appointments, it was the same thing, everything has been postponed to, like, next year […] and we just had, like, phone calls and stuff."

Diane's consultation for her elbow pain had been significantly delayed. Diane said: "I was hoping to have my elbow sorted this year, but I expect it won't be till next year now." Jessica had been left 12 weeks without physiotherapy after her fall in May 2020.

Waiting

Participants reported that waiting for appointments had always been an issue for them, but that the pandemic had made waiting feel more acute and more present. Diane had experienced much higher

levels of pain and discomfort as a result of her extended wait for treatment, which was having a considerable impact on her ability to carry out everyday tasks such as eating with a knife and fork.

Jessica talked about the time when their social worker, who had supported her and her husband, had gone on annual leave when they had also just received the 28-day termination notice from their regular care provider. She reflected on the impact of the social worker being away: "I understand people have annual leave, but to leave you with a sand-timer effectively going down is pretty tough, because you want to be acting while the timer is going down […] Because we're both autistic, they don't want to change people. So, they see it that they're doing us a favour by not changing people. But, actually, the waiting and the unknown, they're not doing us any favours. Because then everything will have to be done in a rush in 7 days which is the worst possible scenario."

Jessica described how time had been critical in ensuring that she and Simon had a choice about how their needs were met. Lack of time had

effectively removed their ability to choose: "We're 14 days into termination with one care provider, and the council are saying that they don't have any other commissioned providers that can possibly have us, [asking us] will we go back to a direct payment: 'It's the only option'. So, they've now decided that direct payment is no longer a choice, it's the only way to go, which was quite an unexpected twist. At the moment the social worker is on annual leave, so it's just a case of waiting for her to return, which will push us to 21 days of termination, leaving us 7 days to work out care going forward. [I'm] not impressed, because I've always been told it's a choice […] In my eyes, that would be the council removing their duty of care."

Not having appropriate support with organising, planning and communication had been distressing for Jessica, especially significant for her during the pandemic as face-to-face communication with the council, pharmacy and NHS had been limited. She described the importance of in-person communication: "[Meeting] people face to face is so much easier because I've got clues from the body and the face language on top of the words. When the words aren't making sense, I've got

more clues as to whether the person's angry, happy. Can't tell by the tone of voice on the telephone, but when I can see somebody I can see by their body and their face."

Left in "limbo"

Shawn described being kept in "limbo" waiting for a podiatrist to remove his infected toenail: "[I can't make any plans] because of my toe. Once that's all sorted out, I can start doing things. At the moment I don't feel like doing nothing, just sitting with my leg up, you know. I've got no real plans for this week."

Roy would normally have meetings twice a year with the local addiction unit. He had not heard from the unit: "Before COVID, I hadn't heard from them for months and I was due a, sort of, review […] The last time I done it was Christmas, I think … and I was about due another one. But COVID was just about starting and she phoned me […] She said: 'I'll be in touch to make another appointment' […] Since then, I haven't heard nothing. There's been no letters, no calls […] So, I've asked the doctor to, sort of, put a note on the system for

them to reach out to me […] I don't actually know what's happening with them, if they're even open […] I don't want them going: 'Well, you haven't been in touch' or 'You haven't made an effort, so we're going to stop your script'."

Conclusion

Participants discussed their perceptions of time during the pandemic. They had experienced long waiting times and delays with health appointments and social care visits. Whilst this is an issue that was present pre-COVID-19, the pandemic has exacerbated the problem and has meant that vital treatments and support have been further delayed, giving our participants the impression that their time and needs are of less value than those of non-disabled people.

Below is a list of questions for consideration to make time-efficient services and appointments available:

- How can we design services which value disabled people's time, both during the pandemic and beyond?
- How can we consider disabled people's impairment-related needs whilst offering a range of appropriate solutions, to ensure no time is wasted in responding?
- How can we respond to disabled people's health needs in a time efficient way during a pandemic?
- How can we prioritise disabled people's social care needs during a pandemic?
- How can we ensure the continued health of both medical providers and those who need ongoing care during a pandemic?

Chapter 6: Good things to emerge

Key findings

- The lockdown has provided an opportunity for some participants to re-evaluate their independence and seek ways to enhance their independent living.
- The additional time afforded by the pandemic has been particularly important for some disabled participants.

Introduction

COVID-19 has presented certain positives for some of our participants, who have been able to find new ways to negotiate living arrangements and adjust to having generally more time to reflect.

Findings

New independence

For some of our participants, the lockdown provided an opportunity to assess their level of independence. The period of shielding had made Latanya reflect on how she would gain independence in the future: "This time has opened my eyes to the independence I want to grow for myself. Like financially, the security that I didn't see as an issue before, I see it now. Things like family stuff, I can't really lean on that, I don't really want to. I want to have my own things, have my own back, be able to sort myself out, however that may look."

Initially, Jessica had found living without her usual support difficult to manage, but the lockdown period had then provided a possibility for a new sense of independence. She explained: "But then, from a positive, it's done us a favour as well […] Actually we're managing with very little care. The council aren't seeing this. They're, kind of, like: 'Oh, you should have so much more', and we're, like: 'You stopped it, not us! You were the ones that messed it all up' […] But we're actually

questioning, now we've done it without, how much more we could actually manage without […] Actually it got us out of being stuck in 6 hours a day." However, Jessica had later taken a fall and had seen her need for support with communication increase. She was reflective: "[…] physically, prior to the fall, it was going well, I was doing quite well. I was being quite independent. Since the fall it's all gone upside down and gone backwards."

The eventual availability of slots for online shopping had unlocked yet another opportunity for Jessica and Simon to feel independent. Jessica said: "What you do is you telephone [the supermarket], you read them what items you'd like off their list, they bring it to our bedroom window […], we'd stick our arm out, tap the machine, and they hand over the food shopping. And that is working really well […] For us, it's independence. We don't want to be taken food shopping. Equally we don't need to be guided through online food shopping. So, it's meant […] we could cancel the food box, which felt really good. It felt like an achievement. We can get rid of that, we can order our own. Whilst it's somebody else taking and bringing our shopping to us, we're doing it. So, it's

[…] a step in the right direction. We feel we don't need to ask the council for food shopping help, because [the supermarket staff] are our food shopping help."

For many people, COVID-19 has brought about the recognition of home-working practices. Going out to work and driving to her clients' houses to provide advocacy had previously caused Diane physical pain, but she had been keen to work for her wellbeing and mental health.

Working from home during COVID-19 times had not only significantly lowered Diane's daily pain levels, but she had also experienced considerably higher levels of energy. Diane's experience pointed to the general inflexibility of mainstream work practices pre-pandemic for many disabled people, no matter how accessible the design of the built environment.

Kathryn believed people were becoming more aware of the 'hidden disability lanyard'. She was pleased about this positive outcome of the pandemic: "I think it's been publicised more

because of COVID. So, that's helped quite a lot, that people do understand."

Positive perception of time-related changes

While for some participants, their changing perception of time during the pandemic had induced more anxiety, for others it had been a coping strategy. Jessica felt that the cancellation of her medical appointments had resulted in less chance of her communication being misunderstood. For Jessica, this felt like a positive outcome. However, she acknowledged relief would only be temporary, as misunderstandings would likely occur again once appointments resumed.

Pre-pandemic, Latanya had not been able to keep to a consistent routine and conform to what people expected of her. During the pandemic, however, everyone's routine had been unpredictable. Latanya found this comforting: "Before, it would have been probably the same thing [her irregular sleeping], but some people were like: 'Why? What's going on?' […] And I'm explaining myself every 5 seconds, so it's less explaining now. So, that's the only positive thing […]."

Additionally, the cancellation of Latanya's pain clinic appointments had felt liberating. She did not want to attend her appointments, partly because of the risk of COVID-19. Latanya felt that the cancellation of the appointments had meant that she no longer had to make the difficult choice about whether to attend or not.

Some of our participants described 'living in the now' since COVID-19 restrictions. For others, having additional time meant that they were able to focus on things that mattered most to them in life. Diane felt that there was more time available to her, allowing her to accomplish more tasks. The additional time Diane gained during the lockdown had allowed her to focus on something that was within her control. She had worked on building a summer house to function as her office space.

Latanya explained how she had made use of the extra time: "I'm trying to, like, concentrate on the future, getting things ready. You know, when you have the time."

Conclusion

Participants talked about the good things emerging from the pandemic. Some participants felt that the pandemic had resulted in them reviewing their lives and trying to identify positive opportunities. Others found the additional time gained during the pandemic had liberated them from everyday concerns, enabling them to be more present and focus on what was important for them.

The following set of questions can help us build on disabled people's positive experiences during the pandemic:

- How do we use the findings from these reports to restructure the care system to be more responsive to individuals, whilst taking a holistic view of disability and supporting disabled people's choice and control?
- What can we do to retain the positive outcomes of the COVID-19 situation for disabled people and promote wider opportunities post pandemic?

- How can we collaborate with the private sector in developing accessible versions of online activities, such as shopping?
- How can we ensure that organisations comply with the Equality Act (2010) to provide flexible work practices that are inclusive for the disabled workforce, in the same way as they have considered the built environment?

Conclusion

This report has presented the perceptions and lived experiences of a group of disabled people during the COVID-19 pandemic. We learned that COVID-19 has magnified social inequalities and injustices experienced by many disabled people. The pandemic has also brought about many new challenges.

The aim of the report is to understand the impact of COVID-19 on the lives of disabled people in order to inform existing planning, and to learn lessons should we be faced with a similar public health emergency in the future.

Chapter 1 highlighted that labels such as 'clinically extremely vulnerable', and shielding categories, have led to some of the participants feeling increasingly embarrassed. These labels have contributed to a sense of guilt about participants' 'disabled' identities. This resulted in some participants refusing to receive food boxes. The requirement to wear a face mask has led to participants expressing distinct challenges in managing health conditions as well as struggling with feeling stigmatised in public places. Participants have felt particularly vulnerable when receiving various services, such as shopping and social and healthcare services, during the pandemic.

In Chapter 2 uncertainty and confusion around COVID-19 guidelines emerged as a key experience for many of our participants. They expressed feeling unclear about what their future, and that of society more broadly, would look like, impacting on their hopes and fears. For this reason, participants felt the need to create their own clarity and approach to the situation they were in, a useful tool. Nevertheless, from our findings

and ONS data (2020), it is clear that long-term COVID-19 uncertainty has negative consequences on disabled people's mental health.

Chapter 3 documented that the pandemic has exposed and exacerbated the existing inequalities experienced by our participants. The COVID-19 restrictions have not always been compatible with our participants' different access needs.

In Chapter 4 it became evident that COVID-19 has presented new challenges for some of our participants in terms of living independently and has reduced their ability to choose suitable support options. Participants have faced significant changes to their daily routine and activities such as shopping. As a result, they have been left with limited choices and compromised independence.

Chapter 5 shed light on pandemic-related delays and disruptions to participants' routine healthcare appointments. While waiting for appointments has always been an issue for participants, COVID-19 has amplified the deferral periods and waiting times. Participants with more urgent medical and

support needs have felt the risks associated with long waiting times more acutely.

Chapter 6 revealed that during the lockdown periods, some of our participants have sought new ways to accomplish daily tasks and have experienced a new sense of freedom. For some of our participants, the pandemic has provided an opportunity to assess their level of independence and to reflect on their current quality of life and their goals for the future.

The report has identified the need for an inclusive, accessible, and clear set of responses to the pandemic, grounded in disabled people's experiences. Each chapter ended with questions relevant to the content of the chapter. Some of the questions and recommendations may also be relevant to improving the 'everyday' or 'non-COVID-19' lives of disabled people. This report, together with the ethnographic research project report, has provided us with a better understanding of the lived experiences of disabled people. These pieces of work have contributed to a sparse evidence-based body of knowledge on

the lives of disabled people during the COVID-19 pandemic.

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