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

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

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.