

Locked Down and Abandoned

Disabled People's Experiences of Covid-19

February 2021



NOTHING
+
ABOUT US
-
WITHOUT US

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About Inclusion London

Inclusion London is a London-wide organisation run by and for Deaf and Disabled people. We promote equality for London's Deaf and Disabled people and provide capacity-building support for over 70 Deaf and Disabled People's Organisations (DDPOs) in London. Through these organisations, our reach extends to over 70,000 Disabled Londoners.

Further Information

Please contact Shamima Akhtar, Inclusion London's Policy and Campaigns Officer, at Shamima.Akhtar@inclusionlondon.org.uk.

Locked Down and Abandoned



Introduction

“Locked Down and Abandoned”, our second report documenting Deaf and Disabled people’s experiences during the Covid-19 pandemic, reveals a continuing bleak picture of marginalisation where governmental failure has led to anxiety and hardship. The government continues to fail at putting in place recommendations that would improve the situation of Disabled people, despite the stark figures released by the Office of National Statistics (ONS) showing that Disabled people have made up about 60% of Covid-19 related deaths¹. Urgent action is needed to address the harms caused to Disabled people during the pandemic and the systemic structural inequalities that are putting Disabled people at increased risk.

The report describes how Disabled people continue to experience hardship across all areas of life: increasing mental distress, social isolation and loneliness, food poverty, financial difficulties, workplace discrimination, problems accessing healthcare, and unequal access to medicine, vaccines, and social care. These critical problems accessing essential services and support are compounded by a failure to engage and listen to Disabled people and Deaf and Disabled people's organisations (DDPOs). As a result, we are seeing many Covid-19 emergency responses themselves negatively impacting on Disabled people, for example, changes to streetscapes introduced by local authorities

¹ (C. Putz and D. Ainslie, 2020), ‘Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020’. Available at: [Coronavirus \(COVID-19\) related deaths by disability status, England and Wales - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/coronavirus/articles/relateddeathsbydisabilitystatus)

across the country that have made the community environment less accessible. Transport for All explains, “Disabled voices are not present in decision making”².

Despite the messages about protecting and supporting those in greatest need, the government's approach has been to introduce legislation, guidance and policies which have actively undermined our ability to protect ourselves and our rights to critical support. Whilst Covid-19 of course requires a public health response, the wider policy approach appears to have largely failed to take into account the social and wellbeing needs of Disabled people, which require the provision of strengthened support, fit for purpose statutory and community services and a commitment to tackling the structural inequalities and barriers we face in our day-to-day lives.

The Covid-19 pandemic and the responses to it, including lockdown measures, have disproportionately affected Disabled women and people from ethnic minority groups³. A large body of research is emerging, identifying health disparities and wider social and economic inequalities such as poor housing and barriers to healthcare that are putting these groups at increased risk⁴. One study found that people from Black communities are four times as likely to die from Covid-19 than people from White ethnicities⁵. It also found that people living in the most impoverished areas are 50% more likely to die of Covid-19 than those in more affluent areas. Disabled people are also women, are from BAME communities and are from socio-economically disadvantaged backgrounds. This intersectional experience alongside its compounding disadvantages must be recognised and addressed.

There needs to be more scrutiny and enforcement of protections for those at higher risk from Covid-19 due to their occupation and economic precarity. For example, Disabled people are 17% more likely to work in retail sectors than

² (TfA, 2021), ‘Pave The Way’. Available at: [Pave-The-Way-full-report.pdf \(transportforall.org.uk\)](https://transportforall.org.uk/Pave-The-Way-full-report.pdf)

³ (Dixon, 2021), ‘Health Foundation response to ONS data on COVID-19 related deaths by occupation in England and Wales and Healthy life expectancy in different local authorities in the UK’. Available at: [ONS data provides further evidence of the unequal impact that COVID-19 is continuing to wreak | The Health Foundation](https://www.healthfoundation.org.uk/ONS-data-provides-further-evidence-of-the-unequal-impact-that-COVID-19-is-continuing-to-wreak)

⁴ The disproportionate impact of Covid-19 on Disabled people was demonstrated in reports and research from other organisations. See: [Crisis, Challenge and Change - Reflections from DDPOs regarding the impact of COVID-19 – Shaping Our Lives](#); [GM Disability Survey: Covid 19 by Greater Manchester Disabled People's Panel](#); [Scotland's Wellbeing: The Impact of COVID-19 | National Performance Framework](#); [An unequal crisis - Citizens Advice](#); [What are people telling us: July to September 2020 | Healthwatch](#); [Page template with branding \(shelter.org.uk\)](#)

⁵ (The Health Foundation, 2020), ‘The same pandemic, unequal impacts. How people are experiencing the pandemic differently’. Available at: [The same pandemic, unequal impacts | The Health Foundation](https://www.healthfoundation.org.uk/the-same-pandemic-unequal-impacts)

non-disabled workers⁶, a sector that is especially vulnerable to the emerging economic crisis. Recent studies found that Disabled people are more likely to be unemployed because of the changes to the job market, rely on welfare benefits to get by, and have been the first to be considered for redundancies⁷⁸. This unequal impact has shed light on existing structural inequalities, which must be urgently addressed and central to all “building back better” recovery work to prevent further negative long term consequences for these communities⁹¹⁰.

As we write this report, the UK has passed 100,000¹¹ Covid-19 deaths. These deaths were not inevitable¹². Urgent action must be taken to rectify and address the underlying factors that have resulted in the higher rates of deaths amongst Disabled people.

The erosion of Disabled people’s rights and quality of life must end and there must be a corresponding commitment to fully include Disabled people in the “leveling up” and “building back better” agenda. It is time for the government to understand the needs of Disabled people and work with Disabled people and our organisations to ensure lessons are learnt and future policies promote our rights and create a society which is free from disabling barriers, where diversity and human rights are valued and where Deaf and Disabled people have dignity, inclusion and equality.

⁶ (Department of Health & Social Care, 2020), ‘The Employment of Disabled People

Data to 2019’. Available at: [The employment of disabled people 2019 \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)

⁷ (Citizens Advice, 2020), ‘An unequal crisis: Why workers need better enforcement of their rights’. Available at: [An unequal crisis - final \(1\).pdf \(citizensadvice.org.uk\)](https://citizensadvice.org.uk)

⁸ (TUC, 2020), ‘Disability pay and employment gaps’. Available at: [Disability pay and employment gaps | TUC](https://tuc.org.uk)

⁹ (SAGE, 2021), ‘Covid-19: Racialised stigma and inequalities’. Available at: [Stigma-and-Inequalities 16-12-20_D6.pdf \(independentsage.org\)](https://independentsage.org)

¹⁰ (E. Linsey, N. Jacobs, L. Parker et al, 2020), ‘The Impact of COVID 19 on Disabled Women from Sisters of Frida’. Available at: [The-impact-of-COVID-19-on-Disabled-women-from-Sisters-of-Frida.pdf \(sisofrida.org\)](https://sisofrida.org)

¹¹ [Prime Minister's statement on coronavirus \(COVID-19\): 26 January 2021 - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

¹² (Independent SAGE, 2021), ‘IT’S A TRAGEDY’: CHRISTINA PAGEL REACTS TO MILESTONE OF 100,000 OFFICIAL DEATHS ON BBC NEWS’. Available at: [‘It’s a tragedy’: Christina pagel reacts to milestone of 100,000 official deaths on BBC news | Independent SAGE](https://independentsage.org)

Research Methods

The data presented in “Locked Down and Abandoned” is drawn from our survey exploring the impact of Covid-19 on Disabled people. In total, 559 people responded between July and October 2020. To provide breadth, we also included data collected from focus groups and workshops conducted via Zoom, or where requested, by email. Coding was used to identify the key themes emerging from the data.

The pandemic has meant that we cannot conduct face-to-face interviews in a physical setting or talk to Deaf and Disabled people in care homes, psychiatric wards, or other institutional settings. Moreover, Disabled people make up a large proportion of adult internet non-users¹³ and are therefore excluded from engaging with the digital world. Consequently, we think it is reasonable to suggest that the responses to our online survey, focus groups, forums, and interviews do not fully reflect the extent of exclusion and hardship being experienced by the most marginalised and digitally excluded groups of Disabled people. The Joint Committee on Human Rights, for example, reported that “young people's rights are at risk through unlawful blanket bans on visits, and increased use of restraint and solitary confinement¹⁴”. People who live in institutions and communal settings, such as supported living facilities have experienced more significant restrictions, including on visits, the ability to form bubbles, imposed self-isolation and limited opportunities to access the outside world, as well as higher death rates¹⁵¹⁶.

Finally, though our survey did not capture demographic data to enable an intersectional analysis it is critical to understand that nearly half of London’s Disabled population are from BAME communities and are women and we have

¹³ (P. Serafino, 2019) ‘Exploring the UK’s digital divide’. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

¹⁴ (Joint Committee on Human Rights, 2019) ‘The detention of young people with learning disabilities and/or autism’. Available at: <https://publications.parliament.uk/pa/jt201919/jtselect/jtrights/121/121.pdf>

¹⁵ (CQC, 2020), ‘CQC publishes data on deaths of people with a learning disability’. Available at: [CQC publishes data on deaths of people with a learning disability | Care Quality Commission](https://www.cqc.gov.uk/news-and-features/cqc-publishes-data-on-deaths-of-people-with-a-learning-disability)

¹⁶ (Public Health England, 2020), Press release: People with learning disabilities had higher death rate from COVID-19. Available at: [People with learning disabilities had higher death rate from COVID-19 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19)

included some key findings from other research on the impact of Covid-19 on minority groups¹⁷¹⁸.

¹⁷ (E. Linsey, N. Jacobs, L. Parker et al, 2020), 'The Impact of COVID 19 on Disabled Women from Sisters of Frida'. Available at: [The-impact-of-COVID-19-on-Disabled-women-from-Sisters-of-Frida.pdf \(sisofrida.org\)](https://www.sisofrida.org/wp-content/uploads/2020/07/The-impact-of-COVID-19-on-Disabled-women-from-Sisters-of-Frida.pdf)

¹⁸ (Independent SAGE, 2021), 'COVID-19: RACIALISED STIGMA AND INEQUALITIES, RECOMMENDATIONS FOR PROMOTING SOCIAL COHESION – BRIEFING NOTE FROM INDEPENDENT SAGE'. Available at: [Covid-19: Racialised stigma and inequalities, Recommendations for promoting social cohesion – Briefing note from Independent SAGE | Independent SAGE](https://www.independent-sage.org.uk/wp-content/uploads/2021/03/Covid-19-Racialised-stigma-and-inequalities-Recommendations-for-promoting-social-cohesion-Briefing-note-from-Independent-SAGE-1.pdf)

Executive Summary

The Covid-19 pandemic continues to have a significant and adverse impact on Disabled people and our lives. Over **40%** of Disabled people told us that they have experienced mental distress. This was due to many factors, including the collapse of existing support systems and services, the dependence on other people's goodwill for essential support, the struggle to access basic necessities, confusing inaccessible and fast-changing information and isolation which increased anxiety. Financial difficulties, stress about having to make ends meet, fears over resource rationing, poor housing conditions and often bereavement were contributing factors.

Over **37%** of Disabled people told us that they were experiencing employment and financial difficulties because of Covid-19. Access to Work (a government scheme that supports Disabled people in work), has been slow to adapt its procedures and requirements to the needs of recipients shielding, working remotely or in lockdown therefore putting jobs at risk. We found that employers failed to comply with the Equality Act 2010 and often did not make reasonable adjustments for Disabled people working from home. Shielders were left without a right to furlough and were pushed to take leave or accept woefully inadequate support provided by Statutory Sick Pay. The high costs of food, medicine and utilities also pushed Disabled people into greater poverty.

The right to independent living, choice and control has been further undermined for many Disabled people who have experienced reduced support due to high levels of support staff sickness, cuts to care packages, and increases in social care charges. This was exacerbated by a failure of many local authorities to adapt, innovate and work in partnership with Disabled people and local DDPOs to ensure there was clarity about Disabled people's needs and the services and support they can expect.

Over **81%** of Disabled people told us that they experienced problems accessing healthcare. Treatment was delayed, and healthcare resources were rationed, which has significantly impacted Disabled people's health and resulted in worsening health conditions. Inappropriate use of phone appointments for Deaf people and to replace services like physiotherapy have been a recurring problem. There have been problems with the vaccine's rollout, for example, Disabled people who employ Personal Assistants are struggling to understand when their staff can be vaccinated.

Service providers and public bodies have ignored their duties under the Equality Act 2010 and often failed to make adjustments for Disabled people. For example, supermarkets refused to allow visually impaired people to bring their guide dog into shops. Over **36%** of Disabled people told us that they were experiencing difficulties accessing the community due to changes in the external environment, like streetscapes and the majority of services and support having moved online. As a result, many Disabled people continue to struggle to get food and the streetscape and road layout changes have made it harder for many Disabled people to travel.

Incidents of disability hate crime have also increased as Disabled people have found it challenging to navigate the sudden changes to the streetscapes and maintain social distancing, and Disabled people exempted from wearing face masks have been confronted and abused.

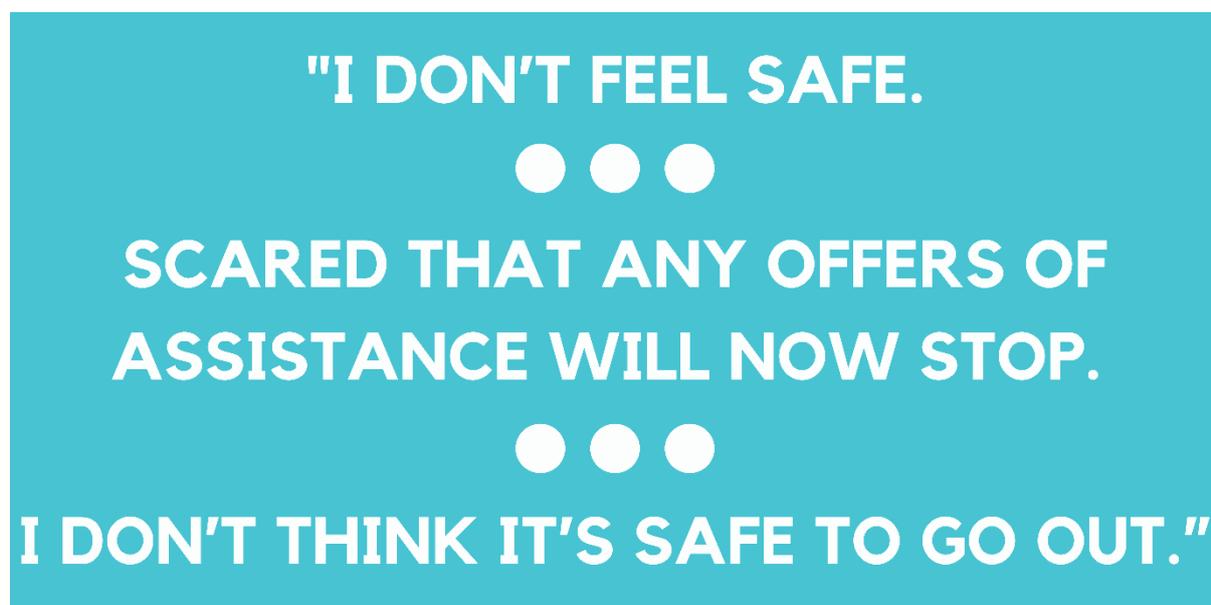
Recommendations

Looking ahead

1. Urgently restore Disabled people's rights currently open to easements under the Coronavirus Act.
2. Ensure the active participation and representation of DDPOs across all Covid-19 planning and Covid-19 recovery work at a local, regional and national level.
3. Central and local governments must develop and implement a digital exclusion plan to close the digital divide, including the provision of free access to broadband, technology and training for all Disabled people.
4. Urgent investment is needed in preventative, community and acute mental health services to address the increased level of mental distress. These services need to be co-produced with Disabled people, be culturally competent, be in line with the Social Model of Mental Distress and the UNCRPD and be appropriate to people's specific needs.
5. Hold an independent inquiry to investigate the disproportionately high numbers of Disabled people's deaths from Covid-19, including the impact on Disabled people from communities that experience multiple and intersectional discrimination.

6. Allocate urgent funding to local authorities to ensure Disabled people get social care support that provides dignity, choice and control, and ensure Disabled people and DDPOs are fully involved in developing proposals for the reform of social care. Guarantee that future reforms will recognise, support and resource Disabled people's right to live independently in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities.
7. Urgently take action to ensure there is a parity of pay, recognition and importance between social care and NHS workers.
8. Take urgent action to ensure social security provides an adequate level of income protection for people, including maintaining the £20 Universal Credit increase, extending this increase to other disability and legacy benefits and increasing rates of Statutory Sick Pay to match living wage equivalents.
9. Support Disabled people in getting and keeping good jobs, with good pay and working conditions. This must include extending and improving Access to Work support, providing high quality employment support, strengthening protections for Disabled workers against discrimination and equipping employers with the knowledge that allows them to support and develop Disabled workers in an inclusive work environment.
10. The priority categories for vaccination rollout must reflect those disproportionately at risk. Information about vaccinations must be produced in accessible formats and actively shared with Disabled people and the infrastructure must be in place to ensure vaccinations can be delivered to people in their homes.
11. Improve Disabled people's access to healthcare services by resuming face-to-face appointments as soon as it is safe to do so and ensure healthcare treatment considers the impact on a person's quality of life, not just their impairment or health condition.
12. Ensure all health service providers take active steps to make their services and communications accessible, including the provision of BSL interpreters and information in Easy Read.

Mental Distress



Summary

In our first report, we described the significant impact of the pandemic on mental distress being experienced by Disabled people. A key theme emerging from “Locked Down and Abandoned” is the increase in distress, anxiety, grief and depression. Confined to the home without access to essential support, Disabled people often have had to rely on voluntary or mutual aid support to access necessities. Loss of control, social isolation and feelings of dependency coupled with the additional strain of making ends meet have had a devastating impact.

Disabled people before the lockdown complained of being imprisoned in their homes. Covid-19 has made the situation worse with some people reporting not leaving their house for almost a year. For those trapped at home and subject to domestic abuse, the situation has worsened¹⁹.

Fast changing, inaccessible and often confusing guidance has increased anxiety and distress. Disabled people are struggling to understand their rights and what they should do and how to keep themselves safe. For example, clinical

¹⁹ (Stay Safe East, 2020), ‘Response to Women and Equalities Committee consultation: impact of Covid 19 on people with protected characteristics’. Available at: [Stay-Safe-East-Response-to-Consultation-Equality-Impact-of-Covid-19-final.pdf](https://staysafe-east.org.uk/wp-content/uploads/2020/07/Stay-Safe-East-Response-to-Consultation-Equality-Impact-of-Covid-19-final.pdf) (staysafe-east.org.uk)

guidance for Shielders contradicted government guidance²⁰. Despite other devolved national governments managing to provide BSL interpreters at their Covid-19 briefings²¹, Downing Street continued not to have interpreters at their Covid-19 briefings²². Some information was put online in Easy Read, but this was not sufficiently accessible for many Disabled people²³, especially those who are digitally excluded.

The relationship between unemployment, poverty and poor health has been well documented. Living in poverty is extremely stressful, as was evidenced in “Health Equity in England: The Marmot Review 10 years on”: “insufficient income is associated with poor long-term physical and mental health and low life expectancy.”²⁴ Four million Disabled people live in poverty²⁵ and there is clear evidence that the impact of Covid-19 interacts with and magnifies pre-existing social inequalities and structural disadvantage.

Key Points

Confusing communications about rules, advice, guidance and information

- *"Very nervous about not shielding and not enough information about what we can and can't do after August 1st" – 9th July 2020*
- *"My mood has dipped as others begin to expect more from me for some reason. Their understanding of my shielding status seems to be vanishing as restrictions on them are eased. I don't understand this, and I'm feeling the pressure and stress. I am also stressed about the safety of official shielding coming to an end and what pressure from others will feel like then too." – 9th July 2020*

²⁰ (N. Bostock, 2020), ‘GP anger as shielding advice changed ‘without warning’’. Available at: [GP anger as shielding advice changed ‘without warning’ | GPonline](#)

²¹ (E. Cruse, 2020), ‘Deaf campaigners launch legal action against Government over lack of sign language at coronavirus briefings’. Available at: [Deaf campaigners launch legal action against Government over lack of sign language at coronavirus briefings | London Evening Standard | Evening Standard](#)

²² (Centre for Deaf and Hard of Hearing People, 2020), ‘Where Is the Interpreter campaign’. Available at: [Where Is the Interpreter campaign - Centre for Deaf \(cfd.org.uk\)](#)

²³ (Mencap, 2020), ‘The Government consistently ignores the needs of people with a learning disability’: Mencap responds to the inaccessible “three tier system” COVID-19 announcement’. Available at: ["The Government consistently ignores the needs of people with a learning disability": Mencap responds to the inaccessible "three tier system" COVID-19 announcement | Mencap](#)

²⁴ (M. Marmot, J. Allen, T. Boyce et al, 2020), ‘Health Equity in England: The Marmot Review 10 Years On’. Available at: [Health Equity in England: The Marmot Review 10 Years On | The Health Foundation](#)

²⁵ The EHRC’s research found that 18% of Disabled people aged 16-65 live in food poverty. See: https://www.jrf.org.uk/reports?gclid=Cj0KCQiAsvTxBRDkARIsAH4W_j9Fier-VfWXkIs4BMhGu-ftAUIMXb4kU84f_ZyZwRd9yLr-N7Oc5qUaAvbwEALw_wcB

- Concerns that the general public were not adhering to social distancing guidance and worried and anxious about experiencing abuse and harassment when going out for food, medicine, hospital appointments and other activities.
 - *"I'm terrified that because lockdown has eased, I'll be forced to go out for food and meds. Scared of visiting hospitals for appointments. Scared of being abused because of health problems. Scared about going on public transport. I don't feel safe. Scared that any offers of assistance will now stop. I don't think it's safe to go out."* – 14th July 2020
 - *"I am semi shielding being ultra cautious the odd time [I go] out such as hospital visits &...going to [the] bank. Would be impossible to completely shield still. Need help & support from brother. Have put off house maintenance, but will have to get problems sorted now"* – 13th September 2020
- Lockdown rules intensified domestic abuse
 - *"I have felt isolated with my abuser and getting support has been a nightmare, no one knows what they are doing re housing and abuse. I don't feel lonely because I am an introvert, just don't like being left alone to escape from abuse"* – 8th August 2020

Lack of information and reassurances about Covid-19 safety deterred people from getting support, including access to health services

- *"Impact on other Disabled people: NHSE Hospital Visiting Guidance and impact of 'banning' PAs and carers against guidance. Lack of accessible, EasyRead and BSL information on Covid-19 guidance. Inconsistent policies on face-to-face therapy (mental and physical health)."* – 15th September 2020

Delays and cancellations to medical treatment and other support

- *"I have no support. All promises made before leaving mental health ward have come to nothing other than assessments completed, but no actual practical support... I'm terrified and not coping, but no one can help."* – 11th July 2020
- *"It seems, just like in care homes the impact of Covid-19 on disabled people in receipt of care, like myself, has been ignored. Instead care charges have been increased pushing us into more poverty, stress and anxiety at this difficult time. Cuts to care hours implemented on assumption we are not going out! And the difficulties we [have] been facing accessing food, medicines, care support workers minimally addressed only by volunteers if we can communicate to right people our needs and the volunteer [is] available."* – 15th January 2021

Disabled people feeling expendable, and institutionalised

- *"I don't think disabled people have had the reassurance that if we need to go to hospital with Covid that our lives will be saved."* – 2nd August 2020
- *"I thought since I am usually semi housebound it would be quite 'normal'. But the removal of what small outside freedoms and choices I do have has been far harder than*

expected. It has also been incredibly difficult hearing other people moan that they have to stay in because in their eyes, only vulnerable people will die and what's the big deal? I have been ok for food and money but honestly no services would have known if I wasn't and no one told me how to access help. I live in a low income area and the 'help a neighbour' thing was clearly designed for middle class people to feel useful. None of them came down my estate where people are key workers...like me poor and shielding."
9 September 2020

- *"Disabled and vulnerable people have been shut out in all this and whilst it's "to protect us" it shouldn't be this way. More should be done to allow us to live some sort of normal lives too. We've almost been blamed for everyone else having to shut themselves down to protect us and its caused more hate towards us and people even gotten to the point where they don't care and would rather us die than them stay locked up. It's appalling" – 11th September 2020*
- *"Disabled people are disproportionately represented in the number of Covid deaths, this has not been widely circulated in the mainstream media." – 13th September 2020*

Anxiety and mental distress exacerbated by a range of factors such as poverty, loss of income, the uncertainty of being able to pay rent and bills and the lack of financial support for Shielders

- *"I'm a single parent. I can't use the food vouchers online for free school meals. I have no help with my care or looking after my teenager. There is no help financial or otherwise for shielding parents." – 10th July 2020*
- *"My bathroom is unsafe and was due to [be] sorted and this ha[s] been delayed indefinitely. I am experiencing extra pain because things like hydrotherapy are not available - I can't independently exercise or leave the house so my overall health is suffering" – 9th July 2020*
- *"The mental impact this has had on me & many other people is becoming worse due to the uncertainty of being able to earn a living & pay my rent, bills etc." – 11th July 2020*
- *"I have been trying to get rehoused to get away from my abuser. The abuse has increased since the pandemic. The housing department has been very unhelpful. For example, I have been waiting since [the] end of May for help and now have been made 'homeless' in part from eviction and in part from trying to escape from an abusive household. [My] council have also wanted to get in contact with my abuser to confirm eviction - I explained this puts me more at risk." – 8th August 2020*
- *"I've been alone, in my single room studio flat for almost half a year. Faced extreme difficulties accessing food delivery because all the usual services before lockdown were taken by non-disabled people, with no way to access [a] priority queue or such. My landlord and letting agent have tried repeatedly to show off the flat to prospective tenants knowing I can't afford to stay here much longer, despite knowing I'm shielding in a studio flat." – 10th September 2020*
- *"Before [the] Pandemic, I had a job, I'm unemployed now, I've got very little savings anyway, and come October 10th I'm homeless. Definitely worse. Oh and the shops are all*

now charging us more for home delivery so my food costs have gone up dramatically too." – 10th September 2020

Employment and Financial Difficulties

"IMPOSSIBLE TO GET A JOB.



FAST FINANCIALLY."

Summary

Before the Covid-19 pandemic, Disabled people had an employment rate lower than that of non-disabled people. According to the ONS 2019 employment survey, roughly half of Disabled people were in employment (53.2%) compared with just four out of five non-disabled people (81.8%)²⁶. Following the outbreak of the pandemic the situation has deteriorated and research illustrates that Disabled workers have fared worse compared to non-disabled workers.

Job losses have been unequal and the most damaging impacts have been on Disabled workers, women, BAME groups and low paid workers. Research from the Citizens Advice Bureau, for example, found that one in four Disabled people faced redundancy, rising to 37% for those whose impairment had a substantial impact on their activities²⁷.

²⁶ (C. Putz, 2019), 'Disability and employment, UK: 2019'. Available at: [Disability and employment, UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peopleinwork/disabilityandemployment/bulletins/disabilityandemployment/2019)

²⁷ (Citizens Advice, 2020), 'An unequal crisis: Why workers need better enforcement of their rights'. Available at: [An unequal crisis - final \(1\).pdf \(citizensadvice.org.uk\)](https://www.citizensadvice.org.uk/assets/pdf/an-unequal-crisis-final-1.pdf)

Our survey and interviews revealed numerous issues faced by Disabled workers including problems with Access to Work and discrimination in the workplace where employers have failed to make reasonable adjustments for Disabled workers to work from home. For some, working from home was difficult because the home environment was not suitable or accessible.

Shielders who were unable to work from home were left to negotiate and convince their employers to put them on the Job Retention Scheme with many employers refusing to do so and insisting Disabled staff use their holiday pay or claim Statutory Sick Pay instead.

The impact of job losses and a more competitive job market has left Disabled people facing significant financial difficulties²⁸. Our survey showed that over 37% of respondents had experienced a worsening financial situation since the pandemic outbreak. Many Disabled people have struggled because of the increased costs of online deliveries, food, medicine and utilities. There was no £20 uplift to those on legacy benefits as seen with Universal Credit, and there were additional challenges to accessing support and advice to apply for benefits correctly.

Key Points

Problems with Access to Work, in particular, the slow processing of claims and strict administrative procedures. Indeed, several Disabled people had to threaten legal action.

- *"I have had to request changes to how I make claims as my upper limb impairments have deteriorated since February due to suspension of ongoing medical care. I can no longer do the physical 'wrangling' of lots of paper and was unable to get wet-ink signatures on my claim forms. I started emailing AtW on 13th March to ask them how they were going to adapt for the pandemic. I exchanged over 15 emails with AtW at several levels over several weeks and AtW still wouldn't agree to a fully e-claim as a reasonable adjustment for disability although they belatedly agreed on employers being able to confirm claims by email." – 28th October 2020*
- *"I am a co-director of a disabled organisation that's been able to pivot to providing emergency response and secured emergency funding. But doing this has taken lots of work and put pressure on me pain and energy wise. The extra costs are also a big burden on the org and me. Access to work have been slow and resistant to helping with extra costs" – 9th July 2020*

²⁸ (L. Judge and C. Pacitti, 2020), 'Coping with housing costs, six months on...New findings from the Resolution Foundation's Covid-19 study - wave two'. Available at: [Coping with housing costs, six months on... • Resolution Foundation](#)

- *"The delays with applications are always an issue. Time delays normally mean people have commenced work before support is agreed leaving people without the support they need to start a job which impacts everyone's confidence especially an employer who has been assured support will be in place!." – 10th November 2020*
- *"[I had a] separate assessment for home as pandemic has meant so many of us are now [working from home], particularly those of us who have been shielding since March 20. [There have been a] longer period to claim funds from ATW loan as everything has been slower during the pandemic- my employer is a hospital" – 30th November 2020*
- *"My current award is due to end in December 2020 and I have applied for a new award. DWP sent me an email asking for more information and I sent this back. Then they wrote me a letter in the post saying they had closed my claim because I had not responded! So I had to email them again to complain and then they re-opened the case and said they are progressing it. – 12th November 2020*

Employers not complying with Equality Act duties

- *"I worked until [I] found [out] I had M.E.[.] I was bullied out of work cos of my disability...NHS was my employer who disregarded [my] reasonable adjustments and have lied repeatedly since." – 10th July 2020*
- *"I think [the] government needed to have provided greater protection for shielders - job protection, wages protection, ensuring food supplies rather than relying on volunteers. Protection for shielders returning to work - advice on what employers must provide, how to protect us etc[.] Greater assistance to help us catch up on missed NHS treatment rather than pushing us to the back of the queue. My treatment is essential not me being able to carry on at work, let alone [to] be independent. If I continue to decline I'm going to end up having [to] stop working" – 27th July 2020*
- *"I have a zero hours job paid by PAYE. I isolated from mid-March and couldn't do my main job role by video for disability related reasons and the employer didn't keep up with an initial plan for me to do alternative tasks. I had reduced salary for March and April because the unions fought for it - I'd expected not to be paid. Initially I was refused furlough but pushed back and furlough was agreed for May to July where I got an averaged pay amount (the employer didn't take up furlough for me from mid-March which they could have done lawfully). The employer was going to avoid renewing my contract for August leaving me unemployed but I argued this was disability discrimination and suggested I would take legal action as non-disabled colleagues were kept on." – 9th September 2020*
- Failures to make reasonable adjustments in recruitment made it harder to find employment
 - *"I was only given the questions before an interview once out of six interviews as a reasonable adjustment" – 9th September 2020*

- *"Impossible to get a job. I'm sinking fast financially." – 21st September 2020*

People who could have been put on furlough were told to claim Statutory Sick Pay

The government's guidance on furloughing Shielders has been unclear throughout, leaving it to the employer's discretion. Consequently, some employers have denied furlough to Shielders and told them to claim Statutory Sick Pay (SSP) instead. This issue continued to impact Disabled people during the second and third lockdowns, where Shielders and campaigners have been calling for the government to make furloughing Shielders mandatory, especially since it is the government that have advised people to shield²⁹.

- *"I am on Statutory Sick Pay as my employer declined [to] furlough me. Can't work from home as I'm a care assistant in a nursing home. I'm having to return to work on [the] 1st [of] August as government is stopping SSP on 31st July so I have no choice. Yet healthy people can remain on furlough until October. [Doesn't] seem right to me. Should've been mandatory to furlough shielders" – 25th July 2020*
- *"Employer supported me to shield but has made me forfeit [a] years allocation of sick pay and over half of my holiday allocation so, if I take any sick time between now and April it will only be SSP rather than full pay. I'm concerned about going back to work when shielding pauses as no extra provision will be made and the threat of going back into shielding worries me - will I still have a job if that happens?" – 27th July 2020*
- *"The Government paused so effectively ended shielding meaning employers said to use unpaid leave or sick leave or holiday to stay safe from a second wave. People on a single low income can't afford unpaid leave to stay safe and holiday shouldn't have to be used to stay stuck at home. Sick Pay isn't infinite or enough to live on." – 19th September 2020*

Higher costs of food, medicine and utilities resulted in Disabled people being further pushed into poverty

Disabled people are financially struggling to meet the higher costs of food, medicine and utilities. Some have been going without some of their meals to pay for higher utilities costs in order to heat their home and keep the lights on for longer. The cost of deliveries for food and other essential supplies have also contributed to higher costs. Others have found that they have needed to pay for PPE and medical supplies out of their finances where they normally would have this provided for free from hospitals.

²⁹ (TUC, 2020), 'TUC and charity coalition calls for furlough scheme to be extended for shielded and high-risk workers'. Available at: [TUC and charity coalition calls for furlough scheme to be extended for shielded and high-risk workers | TUC](#)

- *"Flat with very little natural light, being forced to stay home all the time meant extra [electricity] credit was being bought from food budget resulting in missed meals etc." – 22nd July 2020*
- Increased expenses of medical supplies and treatment
 - *"I am [on] ESA, and whilst those on universal credit received an increase in benefits, those of us on legacy benefits have not. COVID has made the cost of living increase dramatically, and I have found myself having to pay for medical supplies like syringes and dressings, because I have been unable to go to the hospital and pick them up so I am struggling financially." – 12th September 2020*
- High online food and delivery costs
 - *"Society changed overnight and barriers increased hugely from food to PPE. Things I rely on like gloves and wipes have increased in price x4 food. There is no pathway through my GP or social services for this. I feel quite abandoned." – 9th July 2020*
 - *"Food shopping each week costs far more than buying it from the shops myself and is often so short dated it has to be used in half a week and then I have to spend more on takeaway with extra for home delivery for the second half [of] a week. Not affordable on sick pay or unpaid leave nor is it sustainable. The government should restore full pay for shielding especially with a second wave due and not [even] flu jabs available from the GP yet, although chemists are advertising them." – 19th September 2020*

Social Care and Other Support

"CUTS TO CARE HOURS

IMPLEMENTED ON



ASSUMPTION WE ARE NOT

GOING OUT!"

Summary

Our first report highlighted how the existing structural and systemic problems within the social care system, compounded by a decade of austerity, have undermined Disabled people's choice, control and ability to live independently in the community. Early in the pandemic, easements were introduced as part of the Coronavirus Act which allowed local authorities to relax duties around the provision of care and support³⁰. Seven local authorities officially implemented the easements and whilst none are using them at this point in time, there has been a significant impact on Disabled people as local authorities have unofficially cut or reduced care³¹.

Research by Mencap³² following the first lockdown revealed that care packages had been halved for many people with learning difficulties. Emerging data

³⁰ (Legislation.gov.uk, 2020), 'Coronavirus Act 2020'. Available at: [Coronavirus Act 2020 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2020/57/contents/enacted)

³¹ (JCHR, 2020), 'The Government's response to COVID-19: human rights implications'. Available at: [The Government's response to COVID-19: human rights implications \(parliament.uk\)](https://www.parliament.uk/resources/jchr/reports/the-government-s-response-to-covid-19-human-rights-implications/)

³² (M. Samuel, 2020), 'Care packages halved for most people with learning disabilities during Covid, report carers'. Available at: [Care packages halved for most people with learning disabilities during Covid, report carers | Community Care](https://www.mencap.org.uk/news/care-packages-halved-for-most-people-with-learning-disabilities-during-covid-report-carers)

demonstrates that people who received care and support in care homes or other institutions were at higher risk of death from Covid-19³³³⁴³⁵.

Our research has found that Disabled people saw huge reductions in their support, where day services were closed with no alternatives put in place, some saw in-person support replaced by phone calls or their support hours were cut therefore stopping them from going out. Others struggled to source PPE, recruit and retain their care staff, and Disabled people struggled to ensure their staff could get tested and vaccinated. Many Disabled people reported that communication with local authorities was inadequate, with some individuals reporting difficulties in getting advice or any response.

Some local authorities also chose to increase the charges people had to pay for their care and support, further pushing Disabled people into poverty and causing some to stop their care altogether.

Key Points

Several local authorities asked Disabled people to pay more for care

- *"Charges increased so much, when [they] only had few hours of care, [so they] felt no choice but to stop the care support. Several have now stopped their Telecare support due to increased charges by council. Even though they at home they are so at risk of falls but just cannot afford the Telecare service which could help them. This has impacted many elderly and disabled people." – 20th January 2021*
- *"They increased my charges due to me starting to receive my state pension in January, fully aware of DRE which I felt was incorrectly assessed and I made a formal written complaint to the Council which they have partially upheld, I continue to fight and they have increased some of the DRE but after reading ombudsman findings in other cases I feel that this should go further but it's wearing me out. Health and social care are not joined up...in fact they work against each other to my detriment" - 20th July 2020*

- There were delays in getting support to meet changing needs

There were failures to address significant changes in support needs. For example, social workers were failing to assess the impact of shielding on support needs and whilst reviews

³³ (CQC, 2020), 'CQC publishes data on deaths of people with a learning disability'. Available at: [CQC publishes data on deaths of people with a learning disability | Care Quality Commission](#)

³⁴ (CQC, 2020), 'Our concerns about mental health, learning disability and autism services'. Available at: [Our concerns about mental health, learning disability and autism services | Care Quality Commission \(cqc.org.uk\)](#)

³⁵ (CQC, 2021), 'COVID-19 INSIGHT: Issue 7'. Available at: [COVID IV Insight number 7 slides \(cqc.org.uk\)](#)

were being carried out remotely, this did not shorten existing significant delays to support plans being put in place. In turn, this was preventing Disabled people from having their care needs met.

- *"My social worker hinted that I could just be flexible and change my support [w]ithin [the] budget but this hasn't been written down anywhere. They fail to assess any change in need created by shielding." – 9th July 2020*
- *"Our mental health needs have not even been considered, though this has been for non-disabled people. Yet those of us shielding, in fear of our lives, isolated with reduced or no care are left to fend for ourselves. As though it does not matter, our lives are irrelevant is very clearly the message, except for care charges." – 15th January 2021*
- *"I am in receipt of a Personal Health Budget. I have had a long delay in getting my support plan completed. I have been waiting since November 2018 before the pandemic, so in effect my PAs have not had their promised pay increase and I have not had my needs updated." – 20th January 2021*

Cuts to care packages undermined choice, control and independent living

- *"I advocate for several service users, one had all hours removed for going out and was refused [their] request to have them back when lockdown eased. Even though she was desperate to get outdoors she could not without help so has been stuck indoors since March 2020, not shielding, but trapped due to so few care hours." – 20th January 2021*
 - *"The council aren't directly responsible for my care as it is funded by CHC and provided through an agency. My care has been reduced, but this was on the recommendation of my immunologist [to] reduce possible exposure to coronavirus." – 9th July 2020*
 - *"They put a blanket closure on my son[']s day centre and I found out today that when he does start to go back it will be reduced days and that the transport with his escort has been cancelled." -15th July 2020*
 - *"Disabled asylum seekers have been left to fend for themselves, with support from voluntary groups. Lack of support and infrastructure for people without access to the internet - particularly people in 'supported living', ATUs and MH system, asylum seekers and refugees." – 15th September 2020*
 - *"Had to cancel staff due to being too high [risk] to have them here. This means I'm caring 24/7 for 2 disabled young adult sons myself. CCG refuse to pay me." - 23rd September 2020*
- There were failures with transition processes for young people with high support needs and Disabled parents were struggling to isolate without support

- *"No support regarding daughter[']s transition. No speech and language support. No physio support. Hardly any continuing care support...daughter needs ventilator support, but no communication has been made since the Covid 19 pandemic...." - 26th July 2020*
- Disabled people have had to rely on family members to meet their care needs
 - *"Initially I stayed 5 months at home [-] myself and two young children didn't leave at all. My new partner had stayed to isolate with us as I need so much care he became my carer as I couldn't receive my care. It ruined our relationship and now he's left me. I'm too afraid to send my children to school but really struggling having them home being a single parent. My social worker left just before the lockdown and I still haven't had a new one. My Community Mental Health [team] discharged me right as the pandemic hit as my mental health had stabled and now I'm all over the place but can't get back to them as they've refused me" – 11th September 2020*
- In-person care was replaced with inappropriate alternatives like phone calls
 - *"I used to [have] 42 hours of care per week pre lockdown. I now only have one 15 minute telephone call per day." - 26th September 2020*
- There were problems retaining existing care staff
 - *"My main Personal Assistant went awol indefinitely just before lockdown, when I decided to start shielding, just after 10th March, and said she would come back "when things calm down". As we know, it's now late November and the pandemic isn't over." – 24th November 2020*
- During the second lockdown, there were problems accessing tests for carers, which meant that they needed to self-isolate repeatedly for two weeks leaving Disabled people without care
 - *"Unfortunately Covid situation continues to affect staffing. Because any time the staff may have come into contact with Covid they need to stay off [for] a fortnight because they couldn't get tests. This happened twice between lockdowns. Any time the staff or a housemate have any slight illness I need them to stay home for a week this has happened once. Any time that they have suspected Covid or a house mate [has] they need testing before they come back." – 24th November 2020*

Accessing Healthcare, Medicine and Vaccines

"HALF OF MY [PERSONAL ASSISTANTS]



ARE ANTIVAXXERS



WHICH IS A WORRY FOR ME."

Summary

Early in the pandemic, the NHS changed the way it delivered healthcare by moving to remote appointments and often indefinitely delaying or cancelling treatments. This meant that Disabled people faced huge disruptions to accessing healthcare throughout the pandemic³⁶. Healthcare was the most significant area that survey respondents felt that they had negatively been affected, with 81% of respondents telling us that their hospital treatment had been delayed due to Covid-19 during the first lockdown and beyond.

The delays to treatment impacted Disabled people in several ways, and in some cases, the consequences have been irreversible. The devaluation of Disabled life was apparent in this area too as resources such as ventilators were rationed, Disabled people were asked to sign Do Not Resuscitate (DNR) notices and refused permission to have Personal Assistants accompany them to hospitals.

Phone and video call appointments were also inferior replacements for in-person tests and monitoring and were inaccessible for Deaf people and other

³⁶ (C. Putz and D. Ainslie, 2020), 'Coronavirus and the social impacts on disabled people in Great Britain: September 2020'. Available at: [Coronavirus and the social impacts on disabled people in Great Britain - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandcare/articles/coronavirus-and-the-social-impacts-on-disabled-people-in-great-britain-office-for-national-statistics/2020-09-01)

Disabled people who struggle to explain their needs on the phone. Many needed to pay privately for treatment to mitigate the damage to their health³⁷ and others with terminal health conditions like cancer were left to deteriorate or die³⁸.

Disabled people also needed to challenge the vaccine priority list during the second lockdown to ensure those classed as CEV (clinically extremely vulnerable) were in the top two groups to be vaccinated³⁹. Now, as we look ahead to the rollout of vaccines in the third lockdown, there have been issues with the lack of clarity on how to secure vaccines for those that directly employ Personal Assistants or receive social care through non-traditional care providers.

Disabled people who are not in the CEV group but have multiple and complex conditions and employ Personal Assistants are also worried about their continued exposure to the virus⁴⁰. There are also concerns about the antivaxxer discourse reducing take up of the vaccine⁴¹ and increasing infection rates, which would have devastating consequences for Disabled people who already make up two-thirds of Covid-19 deaths and have been hardest hit by restrictions on their lives⁴². Therefore, it is crucial to invest in accessible official information about the vaccine and set up accessible and culturally appropriate education campaigns.

Moreover, those living in institutionalised settings like supported living facilities or those detained in psychiatric hospitals have no choice but to share communal areas like bathrooms and dining rooms. These groups have

³⁷ (Healthwatch England, 2020), 'What are people telling us: July to September 2020'. Available at: [20201208 A review of our evidence Q2 2020-21.pdf \(healthwatch.co.uk\)](https://www.healthwatch.co.uk/20201208_A_review_of_our_evidence_Q2_2020-21.pdf)

³⁸ (C. Maringe, J. Spicer, M. Morris et al, 2020), 'The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study'. Available at: [The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study - The Lancet Oncology](https://www.thelancet.com/journal/S0140-6736(20)32533-3)

³⁹ (J. Pring, 2021), 'Peer calls for disabled people to 'take control' over PA vaccinations'. Available at: [Peer calls for disabled people to 'take control' over PA vaccinations – Disability News Service](https://www.disabilitynews.org/2021/01/27/peer-calls-for-disabled-people-to-take-control-over-pa-vaccinations/)

⁴⁰ (Independent SAGE, 2021), '4TH JANUARY 2021: NEW STATEMENTS ON THE UK VACCINE STRATEGY'. Available at: [Indie-SAGE-Will-new-variants-compromise-vaccines.pdf \(independentsage.org\)](https://www.independentsage.org/indie-sage-will-new-variants-compromise-vaccines.pdf)

⁴¹ (L. Holland, 2021), 'COVID-19: Concerns grow over number of carers turning down vaccine'. Available at: [COVID-19: Concerns grow over number of carers turning down vaccine | UK News | Sky News](https://www.sky.com/news/uk-news/covid-19-concerns-grow-over-number-of-carers-turning-down-vaccine)

⁴² (Independent SAGE, 2021), 'The Independent SAGE Report 30: Maintaining adherence to protective behaviours during vaccination roll-out'. Available at: [Adverse-behavioural-effects-of-vaccines-7.1.pdf \(independentsage.org\)](https://www.independentsage.org/adverse-behavioural-effects-of-vaccines-7.1.pdf)

experienced high levels of Covid-19 deaths compared to the community⁴³⁴⁴. To mitigate this, Disabled people in these settings must also be prioritised in the vaccine rollout, not just frontline staff⁴⁵.

As with social care, before the pandemic the NHS had significant staffing shortages with reports that stress levels were at 5-year highs, and only a third of staff felt there were sufficient staffing levels⁴⁶. This workforce shortage is a critical barrier to increasing NHS capacity. There is also a growing body of evidence that staff are developing post-traumatic stress disorder because of the pandemic, making it harder for them to do their job safely⁴⁷. This combination of high levels of stress alongside existing prejudices about the value of Disabled people's lives - worsened by the use of clinical frailty scoring to assess who got critical care early in the pandemic (but abandoned shortly after) and the use of DNR notices - is a lethal one for Disabled people. These moral decisions about who to save and who to give resources to in these highly medicalised settings are lacking a social model perspective and gave a clear message to Disabled people about their worth⁴⁸⁴⁹.

Key Points

Delays to treatments caused significant and sometimes irreversible damage to Disabled people's health

- Indefinite treatment delays and cancellations with no communication of rescheduling
 - *"One procedure...hasn't yet materialised at all when I was told to expect an appointment for June [2020]. The longer I wait, the more damage is happening to*

⁴³ (CQC, 2020), 'CQC publishes data on deaths of people with a learning disability'. Available at: [CQC publishes data on deaths of people with a learning disability | Care Quality Commission](#)

⁴⁴ (CQC, 2021), 'COVID-19 INSIGHT: Issue 7'. Available at: [COVID IV Insight number 7 slides \(cqc.org.uk\)](#)

⁴⁵ (NHS, 2021), 'News: NHS organisations instructed to rapidly vaccinate staff'. Available at: [NHS England » NHS organisations instructed to rapidly vaccinate staff](#)

⁴⁶ (J. Buchan, B. Gershlick, A. Charlesworth et al, 2019), 'Falling short: the NHS workforce challenge'. Available at: [S05 Falling short The NHS workforce challenge.pdf \(health.org.uk\)](#)

⁴⁷ (V. M. E. Bridgland, E. K. Moeck, D. M. Green et al, 2021), 'Why the COVID-19 pandemic is a traumatic stressor'. Available at: [Why the COVID-19 pandemic is a traumatic stressor \(plos.org\)](#)

⁴⁸ (H. Fidler, 2020), 'Making the 'least worst' decisions: moral injury in the COVID pandemic'. Available at: [Making the 'least worst' decisions: moral injury in the COVID pandemic \(bma.org.uk\)](#)

⁴⁹ (H. Burns, 2020), 'Covid: With burnt-out NHS staff at risk of post-traumatic stress disorder, we must stick to the rules – Professor Harry Burns'. Available at: [Covid: With burnt-out NHS staff at risk of post-traumatic stress disorder, we must stick to the rules – Professor Harry Burns | The Scotsman](#)

the spine in my neck and the spinal cord...and the more symptomatic I am becoming. This could lead to permanent spinal cord damage and paralysis from the chest down." – 9th July 2020

- *"Pain management treatment halted leaving me in severe pain - alternative management hasn't be[en] effective. Physio to determine if I need age-critical surgery is suspended indefinitely, I could end up too old to have the surgery by the time physio restarts and orthopaedics re-open." – 9th July 2020*
- *"I've been shielding since March 2020 and I should have had at least 4 medical appointments/month for various conditions, as well as treatment, but most of them have been completely cancelled or indefinitely delayed. I need an in-person check up for my eyes to see if my visual impairment is getting worse, but I haven't had one since Jan[uary] 2020 and we're in Jan[uary] 2021 now. I'm only 26 and I was diagnosed with my visual impairment when I was 22." – 14th January 2021*
- Cancer investigations, monitoring and treatments were severely delayed
 - *"My colonoscopy for mystery GI illness was postponed for months, now my bowel cancer has spread to my stomach...giving it 3 extra months to grow probably hasn't helped. The delay also meant I continued to lose weight, so...I am now 5st 6lb and significantly weaker than I really need to be in order to endure chemo, surgery and recover from cancer. I received my cancer diagnosis over the phone." - 12th July 2020*
 - *"Neurology treat me every three months with injections, these have been delayed each time causing deterioration in [my] condition. Overdue for breast scan which I need each year as [I] had breast cancer 3 years ago." – 16th January 2021*
- Treatment for existing respiratory patients has been denied
 - *"My pain has increased due to routine treatment being cancelled eg hospital appointments, physio, hand therapy and also being unable to exercise regularly because of shielding. Awaiting "urgent" referral to respiratory consultant - referred by cardiologist in February. No appointment yet. Breathlessness is limiting my day to day life and ability to exercise and mobilise leading to overall decline in my condition." - 27th July 2020*
- Severe delays to gender clinic referrals forced trans people to seek private treatment
 - *"Waiting for gender clinic as [I'm] trans which in practise will no longer be viable. having to go private which I can[']t afford, this is on top of the likelihood of being gatekept due to my disability." – 23rd September 2020*

Disabled people felt their lives were less valuable than non-disabled people's lives because healthcare resources were rationed

- There were problems accessing ventilators and spare parts during the first lockdown

- *"I have had problems accessing ventilator spares during the first lockdown ie filters and masks. I had to get legal advice and complain to the hospital to achieve access to the filters for myself and other home ventilator patients." – 15th January 2021*
- *"Home ventilator shortages of spares. Problem with PA's travelling and the government says they don't need to Quarantine putting PA Employers at risk" – 11th July 2020*
- NHS patient transport stopped left some unable to attend appointments
 - *"Injections for dystonia delayed [I'm] in so much pain now I don't want to wake up each day. Also need an pelvic scan but can't get their due to no patient transport" – 11th July 2020*
- Those shielding were required to travel to appointments using public transport
 - *"All appointments cancelled but now [I'm] being told I must come to hospital despite saying I'm shielding. 90 minute journey by bus each way!!!" – 12th July 2020*
- Concerns about accessing emergency healthcare
 - *"I worry about my carer not being allowed to come with me to the hospital if I have to be blue-lighted to hospital because of an Adrenal Crisis or Anaphylaxis reaction. She advocates for me when I'm in these states." – 15th September 2020*
- Forced signing of DNR notices
 - *"Forcing disabled people (but not me) to sign DNR orders and deny treatment based on a doctors' ableist assumptions about disabled quality of life. Significant ableism in [the] media - often only referring to older shielders. The phraseologies around vulnerable and with ongoing health issues being framed in subtext as almost deserving death/serious illness and meaning non-disabled don't have to worry - "illness happens to others" and feed ableism." – 9th July 2020*
 - *"There needs to be better guidance and education for the intersectional issues that have occurred due to Covid and a robust addressing for the difference between what official guidance says and what's actually delivered. We've seen it with DNR notices where they're not officially being recommended, but you're seeing medical administrators and other people with little medical training asking if you'd like to sign one of these and reduce the burden on the NHS. There's a difference between practice and policy." – 24th November 2020*

Poor continuation of healthcare made consultations inaccessible and forced Disabled people to become destitute as they faced no choice but to pay for private healthcare

- Inappropriate use of telephone consultations to replace physical treatments
 - *"My GP appointments are now being held via "Engage Consult" method. How is that going to work? A virtual consult with GP - can't listened to my chest / breathing. Can't*

physically examine me. Can't take blood or other specimens for testing. I've already had to buy a blood pressure machine to monitor myself. Last phone consult I had with practice nurse re COPD in June she asked me if I had a Pulse Ox monitor too. Like what? Paying out to buy equipment to monitor myself!?" – 14th July 2020

- *"Hospital Consultant appointments moved to telephone only so limited benefit. No new physiotherapy referrals. Weekly group therapy now monthly 1:1 telephone service" – 30th July 2020*
- Inappropriate use of telephone consultations for Deaf people
 - *"Everything is accessible only by telephone which is inaccessible to people who are deaf and hearing impaired. Hospital appointments are over the phone. Inaccessible." - 25th July 2020*
- Paying for private treatment due to cancelled or indefinitely delayed treatment
 - *"I was due surgery and also therapies and had nothing. I've had to pay privately for physio mounting to £4000" - 20th July 2020*
- Reduced NHS support where Community Health Care plans are in place
 - *"Respiratory medical support and consultant appointments have become non existent. Regular speech and language has simply stopped and no answers as to when they will start again. Regular physio has stopped with no suggestion when they will start in the future. Continuing care and community nursing team support has heavily reduced it's nurse team, so I am fearful my daughter will never get back her guaranteed nursing respite hours again." – 26th July 2020*
- Problems getting prescriptions delivered by pharmacies
 - *"Prescriptions were difficult to get hold of due to them not giving them to people other than me. They said I had to come into the shop but as a wheelchair user not everything was accessible." – 24th November 2020*
 - *"I have experienced some problems accessing medication from the pharmacy since before christmas [as] they are out of stock and [having] problems with supply. I don't know if this is pandemic or Brexit related." – 15th January 2021*

Disabled people have lacked clarity on how to access vaccines and experienced an unequal rollout

- Problems accessing vaccines
 - *"In my own life, I have already suffered the consequences of the government's "age-based" rollout of the 'flu vaccine. By the time that my "turn" came around, the pharmacies could no longer provide the specific "cell-based" flu vaccine that I need. I dread the possibility of missing out on the COVID jab, too." – 15th January 2021*

- *"Half of my PAs are antivaxxers, which is a worry for me. I'm on CHCs and it looks like my CCG will be sorting out vaccinating my PAs, but I'm not sure on it" – 15th January 2021*

- *"According to vaccine priority I will not be given one till March/April as that's when over 65's [are] planned to have jabs. No thought given to multiple health issues I have. Only 'severely critically vulnerable' disabled people are prioritised. I have three PA's. I'm so worried every time they come to my home re contagion, yet no news on vaccination for them like front line health and social care workers. Yet, one of my daughters who is [a] pharmacy assistant is getting vaccinated and [has] regular tests." – 16th January 2021*

Access to the Community

"DISABLED ACCESS HAS BEEN TOTALLY



SCRAPPED OR REDUCED AT BEST."

Summary

Many of us were and still are locked up in our homes, but those who did go out for work, education, leisure or other reasons have found that the built environment has become less accessible and at times more hostile.

Changes aimed at facilitating social distancing made it harder for some Disabled people to access services, with remote provision starting to dominate, excluding those who do not have technology or digital skills. When making changes service providers mostly neglected their duties under the Equality Act, which led to Disabled people to being denied assistance in shops or on transport. The layout of roads and street space was changed dramatically with widened pavements, street clutter, low traffic neighborhoods and the introduction of e-scooters. These changes reduced access mainly because they were introduced without engaging with Disabled people or thoroughly considering our needs and the impact on Disabled people⁵⁰. 36% of Disabled people responding to our survey said these changes created additional barriers for them.

⁵⁰ (BBC, 2021), 'Streetspace: Mayor of London and TfL 'acted unlawfully' in road scheme'. Available at: [Streetspace: Mayor of London and TfL 'acted unlawfully' in road scheme - BBC News](#)

In addition to changes to the physical environment, Disabled people experienced increased levels of hate crime and abuse when outside⁵¹⁵². From verbal abuse for "jumping" queues or not wearing masks when legitimately exempted to an increase in online abuse.

Key Points

Problems accessing food delivery slots, extra charges and the public not adhering to social distancing guidance left Disabled people feeling dependent and unable to access the community

- *"I have had no support for my care or getting access to food slots. It has been isolating and frightening. I have not left my flat since March" – 9th September 2020*
- *"Whilst shielding has paused, I am still shielding as the risk of me becoming seriously ill or dying has not changed. I am struggling to access food as the food boxes have stopped" – 15th September 2020*
- *"I feel that the community spirit from early in the lockdown has gone and that those at high risk have essentially been forgotten. Despite an increase in cases, the support for these people is no longer being provided." – 9th September 2020*

Social distancing concerns due to others not following the rules

- *"I live in a very crowded part of London with a constant stream of people outside my door. No one is social distancing and very very few wear masks. It isn't safe for me to even take the bins out unless it's after 10pm. I'd looooooove to go for a walk but because of other people's selfish behaviour it's not been possible since March." -13th September 2020*

Changes to street space introduced to promote social distancing and active travel made the environment less accessible and less safe for some Disabled people.

- Safety concerns for visually impaired and blind people
 - *"I am visually impaired and the changes in road layouts have affected my line of vision when trying to figure out whether a cyclist is coming my way. Motorised scooters are especially difficult to see and almost impossible to see at night. I have almost been hit many times when trying to go for a walk. This has increased my anxiety levels too" – 15th September 2020*

⁵¹ (J. Pring, 2020), 'Activist's terrifying ordeal sparks new e-scooter safety campaign'. Available at: [Activist's terrifying ordeal sparks new e-scooter safety campaign – Disability News Service](#)

⁵² (Inclusion, 2020), 'Inclusion London Briefing – Disability Hate Crime'. Available at: [Inclusion London Briefing - Disability Hate Crime | Inclusion London](#)

- *"As a deaf person it means more cycling and running and often I don't realise someone is close behind me. I've had people shouting at me to move out of the way" - 10th July 2020*
- Lack of ramps on expanded pavements for wheelchair users
 - *"I haven't been out much just to drive my car for the first time since March and noticed the expansion of pavements. I noticed that these would be inaccessible for myself as a wheelchair user as there were no ramps that allowed you to go onto the road in case you needed to avoid a crowd etc." – 11th July 2020*
- Use of pavements for hospitality social distancing reduced space for wheelchair users
 - *"as [a] wheelchair user some pavements now have lots people outside cafes, pubs, waiting in line outside shops, tables and chairs being placed outside without consideration of access." - 13th July 2020*
- Reduction in Blue Badge parking spaces
 - *"Disabled access has been totally scrapped or reduced at best. Eg parking blue badge spaces near to shops were the first thing to be wiped out and yet we couldn't stand to queue to get in a shop. Disability access in general to places and services has been HUGELY impacted. And it's very unfair." – 15th September 2020*

Changes to roads meant that accessing services or getting to work was much harder

- *"Road closures have increased my journey time to and from work to a total of 3+ hours instead of the usual 1 hour 50 minutes max. As a disabled person who cannot walk, cycle or use public transport I find these road closures discriminate against me. I will have no choice but to give up work as sitting in hours of traffic increases my pain." – 10th July 2020*
- *"I can't easily access my GP surgery. It has added a lot of extra time onto journeys. I feel like the design of roads didn't take into consideration the needs of those of us who drive due to mobility needs. The designs also seem quite ad hoc. And often aren't known on GPS providers which has left me feeling disorientated, frustrated and annoyed. It makes the prospect of leaving one's house very daunting and unpleasant." – 3rd September 2020*
- *"As buses & taxis are having to divert off the normal route I am having to pay more & it's taken much longer to get to my destination" – 11th July 2020*

Nothing About Us Without Us

Recommendations

Looking ahead

1. Urgently restore Disabled people's rights currently open to easements under the Coronavirus Act.
2. Ensure the active participation and representation of DDPOs across all Covid-19 planning and Covid-19 recovery work at a local, regional and national level.
3. Central and local governments must develop and implement a digital exclusion plan to close the digital divide, including the provision of free access to broadband, technology and training for all Disabled people.
4. Urgent investment is needed in preventative, community and acute mental health services to address the increased level of mental distress. These services need to be co-produced with Disabled people, be culturally competent, be in line with the Social Model of Mental Distress and the UNCRPD and be appropriate to people's specific needs.
5. Hold an independent inquiry to investigate the disproportionately high numbers of Disabled people's deaths from Covid-19, including the impact on Disabled people from communities that experience multiple and intersectional discrimination.
6. Allocate urgent funding to local authorities to ensure Disabled people get social care support that provides dignity, choice and control, and ensure Disabled people and DDPOs are fully involved in developing proposals for the reform of social care. Guarantee that future reforms will recognise, support and resource Disabled people's right to live independently in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities.
7. Urgently take action to ensure there is a parity of pay, recognition and importance between social care and NHS workers.

8. Take urgent action to ensure social security provides an adequate level of income protection for people, including maintaining the £20 Universal Credit increase, extending this increase to other disability and legacy benefits and increasing rates of Statutory Sick Pay to match living wage equivalents.
9. Support Disabled people in getting and keeping good jobs, with good pay and working conditions. This must include extending and improving Access to Work support, providing high quality employment support, strengthening protections for Disabled workers against discrimination and equipping employers with the knowledge that allows them to support and develop Disabled workers in an inclusive work environment.
10. The priority categories for vaccination rollout must reflect those disproportionately at risk. Information about vaccinations must be produced in accessible formats and actively shared with Disabled people and the infrastructure must be in place to ensure vaccinations can be delivered to people in their homes.
11. Improve Disabled people's access to healthcare services by resuming face-to-face appointments as soon as it is safe to do so and ensure healthcare treatment considers the impact on a person's quality of life, not just their impairment or health condition.
12. Ensure all health service providers take active steps to make their services and communications accessible, including the provision of BSL interpreters and information in Easy Read.