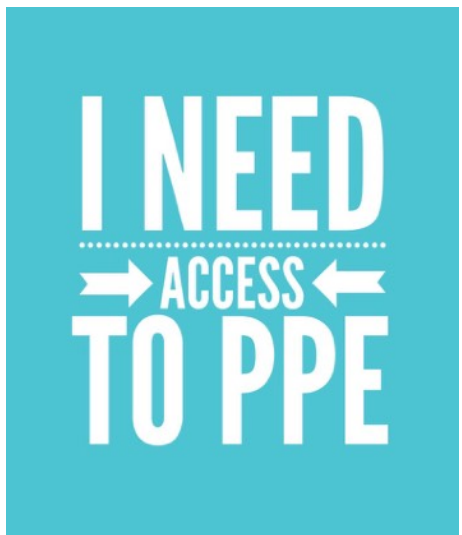


Abandoned, forgotten and ignored

The impact of the coronavirus pandemic on Disabled people

Interim Report - June 2020



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About Inclusion London

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

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Images: www.itechdisability.com and Time to Change





.....
**"WE SHOULDN'T HAVE TO
PROVE OUR VALUE TO SOCIETY"**
.....

Abandoned, forgotten and ignored

Introduction

Our interim report exploring the lived experiences of Disabled people from the outbreak of the covid-19 pandemic paints a stark picture. From the outset, we have been discriminated against, forgotten, and in some cases abandoned as policymakers have ignored our needs. Or, at best considered them as an afterthought.

The pandemic has also shone a light on the long-standing structural inequalities and discrimination that Deaf and Disabled people experience. The dreadful disparities are reflected in the grim data released as we write this report by the Office for National Statistics, who found those who reported their daily activities were "limited a lot" by an impairment at the 2011 census were about twice as likely to die from covid-19.¹

We have collected over three hundred responses and our survey reveals along with emerging data ²³⁴ that the pandemic is impacting on Deaf and Disabled

¹ Rates of deaths involving COVID-19 by disability status, England and Wales, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/ratesofdeathsinvolvingcovid19bydisabilitystatusenglandandwales>

CQC publishes data on deaths of people with a learning disability (June 2020) <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

³ Statement on COVID-19 and the human rights of Disabled people <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25942&LangID=E>

⁴ The Impact of COVID 19 on Disabled Women from Sisters of Frida <http://www.sisofrida.org/the-impact-of-covid-19-on-disabled-women-from-sisters-of-frida/>

people across every area of life. Disabled people are experiencing increasing levels of psychological distress, social isolation, a lack of social care support, workplace discrimination, food poverty, and unequal access to health care.

Our report demonstrates that the measures designed to support at-risk groups introduced by the government, local authorities and other service providers, including supermarkets and pharmacies, are not working for everyone. Indeed, the crisis has exposed and amplified the structural inequalities that for decades have excluded, discriminated against and marginalised Deaf and Disabled people. The failures, moreover, have reinforced the widespread perception that the voices of Disabled people are being ignored and have led many of us to conclude that we have been forgotten and abandoned.

The failure of the state is epitomised by the Coronavirus Act, which has downgraded and curtailed Disabled people's rights and branded us as 'vulnerable'. Despite the government's rhetoric about protecting and supporting Disabled people, the reality is that during the pandemic we have been treated less fairly and discriminated against across all areas of our lives.

As we write this report, the government has begun to ease restrictions and as the lockdown is lifted it is crucial that the rights of Disabled people are not further eroded and undermined. Indeed, it is an ideal opportunity for the government to make it a priority to understand the needs of Disabled people and take seriously our findings and recommendations.

It is also vital that government works with Disabled people and Deaf and Disabled People's Organisations (DDPO) to tackle the structural inequalities and to take meaningful and focussed action to create a society which is free of disabling barriers, where diversity and human rights are valued and where Deaf and Disabled people have dignity, independence and equality of opportunity.

Survey Limitations

Disabled people make up a large proportion of adult internet non-users. Many Disabled people who are shielding, self-isolating, in care homes, on psychiatric wards or in other institutional settings are either excluded from or not engaging effectively with the digital world. We hypothesise, therefore, that the responses to our on-line survey are the tip of the iceberg.

According to the Office of National Statistics⁵, across all age groups, disabled adults make up a large proportion of adult internet non-users. In 2017, 56% of adult internet non-users were Disabled people, much higher than the percentage of disabled adults in the UK population as a whole, which in 2016 to 2017 was estimated to be 22%. Disabled people also encounter additional barriers including lack of training, specialist knowledge and tools to navigate the digital world effectively.

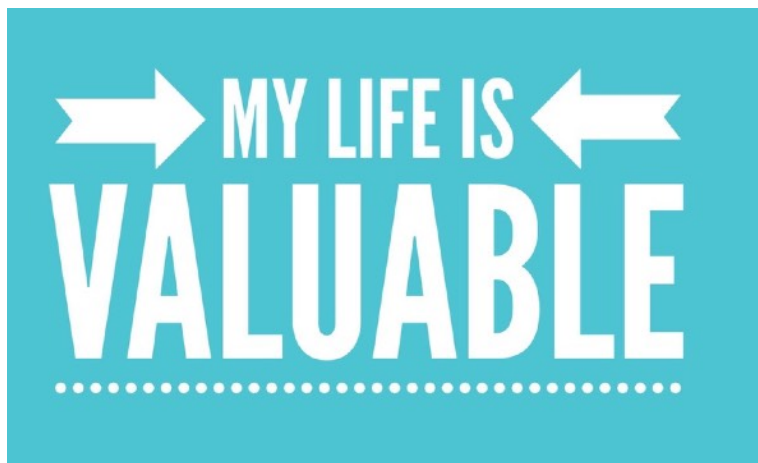
Young people in institutional settings, for example, are unlikely to be aware of our on-line survey. The Joint Committee on Human Rights has recently reported that “young people rights are at risk through unlawful blanket bans on visits, the suspension of routine inspections, and increased use of restraint and solitary confinement.”⁶

People with a learning difficulty also experience widespread digital exclusion and are likely to be underrepresented in our survey. The Care Quality Commission reported in June that people with a learning difficulty or autism who died in a care setting between April and May has more than doubled.⁷

⁵ Exploring the UK's digital divide, Office of National Statistics (March 2019)<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

⁶ Coronavirus has left young people in detention facilities highly vulnerable to Human Rights abuses <https://committees.parliament.uk/committee/93/human-rights-joint-committee/news/146834/coronavirus-has-left-young-people-in-detention-facilities-highly-vulnerable-to-human-rights-abuses/>

⁷ Coronavirus: Care watchdog warns of risk to learning disabled people as deaths double, <https://www.independent.co.uk/news/health/coronavirus-deaths-care-homes-cqc-ons-learning-disability-autism-a9544001.html>



Key Themes

- **Over 60% of Disabled people questioned said they had struggled to access food, medicine and necessities.** The issues are wide-ranging and interconnecting, including inaccessible websites, spending hours searching for on-line delivery slots and confusing guidance and information. Some Disabled people, for example, who are visually impaired, no longer feel safe going out to shops as there is a lack of social distancing infrastructure in place. Supermarkets and shops have, in many cases, failed to make reasonable adjustments such as supporting people who cannot stand in queues or reach items on shelves.
- **Over 35% of respondents talked about increasing levels of psychological distress.** The coronavirus lockdown has increased levels of anxiety, confusion, and fear for many Disabled people. There is a range of factors including, social isolation, loss of control and agency, and a lack of access to mental health support services in the community. Disabled people have also talked about being abandoned by the government and expressed fears of being denied life-saving health care. Other factors include the daily emotional toll of juggling care, families and securing food deliveries.

- **Nearly half of the respondents talked about inaccessible information, confusing guidance and lack of advice.** Public health information and government guidance have to be accessible, unambiguous and concise. If it is confusing Disabled people cannot take the necessary decisions to isolate safely, purchase food or access health and public services. The government has failed to provide information in alternative and accessible formats. For example, despite repeated requests and the threat of legal action the government has refused to provide British Sign Language Interpreters at its televised daily coronavirus briefings.⁸ This not only disadvantages Disabled people but puts lives in danger.
- **Disabled people feel abandoned and neglected.** While we have come across local authorities who are working closely with Disabled people, this does not appear to be widespread. This is illustrated by the stories of Disabled people who despite being in high-risk groups have been unable to obtain personal protective equipment, have had care packages cut, assessments delayed or have lost existing social care support
- **The right to life and rationing of resources.** Disabled people have told us that they feel valued less. Several respondents explained that they had been asked to sign Do Not Resuscitate (DNR) notices. Others have expressed fears of being denied access to emergency treatment and being left to die if they contract covid-19.
- **Social care is being cut, reduced or failing to provide protective equipment.** The coronavirus pandemic has exposed and amplified many existing structural and systemic flaws within the social care system. The consequences are stark. Over one in four respondents have had problems getting hold of personal protective equipment. And, nearly 40% have had issues with Personal Assistants, Direct Payments, housing benefits, and care packages.

⁸ Coronavirus: BSL-users launch mass legal action over government 'discrimination', <https://www.disabilitynewsservice.com/coronavirus-bsl-users-launch-mass-legal-action-over-government-discrimination/>

- **The coronavirus pandemic has thrown into stark relief the extent of the discrimination and exclusion Disabled people face.** The failure of the government to publish guidance on how doctors will decide which patients will receive life-saving treatment during the covid-19 pandemic has raised fears that Disabled people will be discriminated against and left to die. For example, the National Institute for Health and Care Excellence was threatened with legal action for telling doctors they should assess patients with learning difficulties, autism and other impairments as scoring high for frailty. The effect would be to deny some Disabled people critical care and life saving treatment.

Employers are failing to introduce reasonable adjustments to enable Deaf and Disabled people to work from home. Food retailers have fallen short and made it impossible for many Disabled people to go out and shop for food. The government's inability to provide accessible information and communications has also increased marginalisation and exclusion. Moreover, the term 'vulnerable' reinforces Disabled people as objects of pity and diverts attention from removing disabling barriers, making reasonable adjustments, upholding human rights and promoting independence, choice and control.



**"HAVEN'T BEEN ABLE
TO GET A DELIVERY SLOT DESPITE BEING
A TESCO ONLINE GROCERIES
.....
CUSTOMER FOR OVER 20 YEARS."**

Disabled people are struggling to access food and medicine

Summary

Over 60% of Disabled people questioned said they had struggled to access food, medicine and necessities. The issues are wide-ranging, including inaccessible websites, spending hours searching for online delivery slots and confusing guidance and information. Other obstacles include failures to assist Disabled people in shops or making adjustments, for instance, providing seating for people who find it difficult to stand in a queue.

Key Points

- Deaf and Disabled people have found buying food a challenge. A significant factor is because many who are in high-risk situations are not on the Extremely Vulnerable register. The register was set up by the government to provide supermarkets with lists of those who fall into the 'extremely vulnerable category'. This group includes Disabled people who have been using online shopping for years and have been 'frozen out'. And, those who for various reasons are not venturing out at this point.

- Disabled people have faced barriers inside supermarkets due to a failure to make reasonable adjustments for people before the outbreak of the pandemic shopped in-store. For example, failing to provide support to people who cannot stand in queues or help to those who need assistance reaching items on shelves.
- Food boxes for Disabled people on the 'clinically extremely vulnerable' list do not always cater to people's access and dietary needs. For example, some people are not able to open cans, or prepare meals from fresh ingredients. Others live with dependents and a single person food box is not sufficient.
- Disabled people who need support to prepare their meals are not getting this help due to shortages in social care staff. They are also having problems accessing ready-made meals.
- Disabled people are forced to spend more money on food, by having to shop in more expensive supermarkets or high street shops or order meals online.

This is what people told us

A combination of strict criteria accessing the extremely vulnerable list, a lack of support and difficulty getting hold of PPE equipment:

“The rules for getting on the extremely vulnerable list are so strict, my doctors want me on it but can not get me on it. I use a home nebuliser and home suction machine as my asthma is extremely bad, but nebuliser is not mentioned for asthma only COPD. PPE is impossible to get hold of and when you can it's very expensive. Food delivery spots are hard to get and then they don't have what you need. There is not enough advice or help for disabled people or family carers and none provided in a clear format for those who struggle to read.”

No slots for non-shielding Disabled people who are not on the Extremely vulnerable register

“There appears to be insufficient delivery slots from major supermarkets necessitating my husband going out to shop. My son who is learning disabled (with an additional kidney condition) and I (physically disabled) stay home.”

“I have been unable to get food deliveries for six weeks now. I am a single parent who cares for my daughter who is 11 and she has conditions that would lead to serious complications if she caught the virus. We have chosen to shield but we have had to rely on friends to deliver infrequently and when they can due to their own commitments/situations. We are currently not listed on any vulnerable list and looking into registering as vulnerable with the government there was nowhere to explain our situation and that my daughter is a child or that I am a single parent.”

“It took 4 weeks to get any food delivery to my home. The information about who needs to shield and who doesn't is confusing added to which I don't even trust it. It's hard being locked up by yourself for 5 weeks, not that I'm not used to being on my own of course, I am. I'm disabled it's almost a given but the lack of open space is getting to me.”

No online delivery slots for Disabled people who rely on them as the only way to get food

“Haven't been able to get a delivery slot despite being a Tesco online groceries customer for over 20 years. I am not on the extremely vulnerable list but I am not able to manage shopping in store due to impairments.”

“I am not considered vulnerable as I don't have any of the qualifying conditions on the government website, but due to blindness, I'm unable to get priority access to online deliveries for food shopping. Being blind and living alone with no support nearby, I cannot physically attend a supermarket as I require a member of staff to guide me around the shop. I have no idea where my next meal is coming from. It would really help to be given access to this support.”

“Food deliveries - government list only cover people extremely vulnerable to the virus, this leaves vulnerable disabled people off the list who aren't capable to go to the shops, and may have had care or PAs stopped as a result of the virus, basically left to starve. The list needs expanding, people on severe disability premiums, meaning they live alone with a severe disability, should be a bare minimum, or blue badge holders if they don't live with someone who can't go for them. Just because you aren't extremely vulnerable to the virus doesn't mean you don't need food delivered as you were already housebound through disability.”

“I always relied on food delivery to my door, and the kind delivery guy always unpacked for me, sat and had a tea, then went on his way. Now I haven't had food delivered in 3 weeks because all the slots are booked endlessly. I'm having to rely on another disabled person who can do some shopping but honestly, we're both really struggling getting adequate supplies- and even then it's twice the cost of the usual stuff.”

“I am self isolating, not leaving my flat for well over 2 weeks now. It's almost impossible to get a food delivery slot, I registered as an extremely vulnerable person on the government site but heard nothing. My GP claims not to have heard of it. I don't want to use volunteers who are going from house to house because it's risky.”

“I have no idea how I’m meant to get my medication at this time and I’m very worried because friends of mine on the same medication have found that their pharmacies have run out of it.”

“I’ve been provided very little information about what to do and where to get help. I feel very isolated and my mental health is really suffering. I don’t know how to cope.”



No health without mental health

Summary

According to the Institute of Fiscal Studies, Mental health in the UK worsened substantially as a result of the Covid-19 pandemic.⁹ Although the coronavirus pandemic is affecting the mental health and well-being of people in different ways Disabled people, are at increased risk. This is because poverty, poor physical health, inequality, discrimination, and exclusion from employment and education are all major risk factors.¹⁰ The coronavirus pandemic - with the extra burdens of lockdown, shielding, and lack of social care and support - has increased these pre-existing inequalities.

While some Disabled people will come through without any lasting negative effects on their mental health, for many the coronavirus lockdown has increased levels of anxiety, fear and psychological distress. **Over 35% of respondents have talked about worsening mental health and psychological distress.** Disabled people are distressed and scared due to the immediate impact of coronavirus. The anxieties are wide-ranging including fears of dying,

⁹ <https://www.ifs.org.uk/publications/14874>

¹⁰ Commission for Equality in Mental Health, 2020

being denied life saving health care treatment, or not having enough money to put food on the table or heat the home.

Key Points

- The coronavirus lockdown has increased levels of anxiety, confusion, and fear for many Disabled people. There is a range of factors including, social isolation, loss of control and agency, and a lack of access to mental health support services in the community.
- Disabled people have talked about being abandoned by the government (national and local) and expressed fears of being denied life saving health care. Other factors include the emotional toll of juggling care, dependents and accessing food and support.
- A broad body of research links social isolation and loneliness to poor mental health. Our report reveals that the coronavirus pandemic has deepened and entrenched social isolation and loneliness among many Disabled people.
- For Disabled people more likely to be shielding, self-isolating, or acutely restricted by lockdown measures digital lifelines are often out of reach
- Disabled people are telling us that there is a lack of access to mental health support services in the community. People are feeling abandoned, often not knowing where to go for help. People have told us that it can take days and sometimes weeks to get a response from the GP or local authority.
- Because of fear of contracting the virus and the need to shield, many people have reduced the support they get and instead heavily rely on family. This is causing emotional and psychological stress, and pushing some to breaking-point.
- Discussions of rationing resources, letters and calls from GPs encouraging people to sign DNR notes has caused alarm and fear. Disabled people are

fearful that if they contract the virus and require life-saving treatment this will be denied and they will be left to die.

This is what people told us:

The adverse impact of social isolation and lockdown

“I have been inside for three and a half weeks without going out, and I’m losing my mind. I have a pre-existing mental health condition, and this is seriously causing a big relapse. I feel trapped and controlled and claustrophobic and constantly on edge and irritable. But I’m too scared to leave the house because if I get sick, I know that, as someone with preexisting conditions, doctors will leave me to die in favour of someone who has a better chance of surviving. I know how undervalued disabled lives are, but this has really hit home, and I feel so sad and so angry that I even have to think this way, but I do.”

The lack of information has had an impact on mental health and wellbeing

“My parents are having to care for me as my carer is super shielded. So I have no care. My parents can’t provide the care I need. I don’t have the information I need for this scenario. I’ve been provided very little information about what to do and where to get help. I feel very isolated and my mental health is really suffering. I don’t know how to cope. I’m really scared for my health. If I get the virus I don’t know how we would cope as who would care for me.”

“I have been told by hospital nurse to self-shield but am not on any official list. It took quite a while to find out if I can go out for exercise. I can and I would like to wear a mask but don't have enough of them. I have a long standing mental health condition. I am currently on a long waiting list for CBT but NHS is offering me no support in the meantime. My pharmacy do not deliver and often do not answer the phone so I have had to find someone to collect medication for me.”

Cuts to support for Disabled children impact on the mental health of families.

“It was as though the moment schools closed there was a notion that I would be able to deliver to my child mental health support, counselling, therapies, education, social care. No responses when contacting local authority.”

“My child with special needs has been unable to attend school for the duration of the lock down, causing huge amount of anxiety and distress within the household. He has also had all external support and care removed.”

Difficulties accessing mental health support in the community

“I understand why the restrictions are in place but there is not much help for people who have long term health issues both physically and emotionally I would just like to see more being done about it.”

Social isolation is much harder for people who cannot use technology to stay connected

“I am homeless and need supported accommodation believe nothing else is suitable due to my needs (abuse/trauma after fleeing DV [domestic violence] and fearing being abused. I'm also autistic so not getting support to actually learn how to rent a house and rebuild my life. Mental health is suffering too. Can't work. This has been ongoing for nine months now since I first tried escaping. But COVID has messed it up as I was close to hopefully getting what i need.”



**"LACK OF INFORMATION,
LACK OF SUPPORT. NO ONE CONTACTED ME FROM SOCIAL
SERVICES TO SEE IF I WAS COPING."**

.....

Inaccessible information, confusing guidance and lack of advice

Summary

Nearly half of respondents to our survey have talked about inaccessible information, confusing guidance and lack of advice. Public health information and government guidance must be accessible, unambiguous and concise. Otherwise, it is challenging for Disabled people to make the necessary decisions to isolate safely, purchase food and access health and community services. Inaccessible and confusing information also puts Disabled people's lives in danger.

Furthermore, a large amount of information and advice is online. For many Disabled people – more likely to be shielding, in care homes, self-isolating, or acutely restricted by lockdown measures, these digital sources are often out of reach. According to the Office of National Statistics, across all age groups, disabled adults make up a large proportion of adult internet non-users.

Key points

- A lot of the coronavirus support, information and advice are online. However, for many Disabled people who are shielding, self-isolating or restricted by lockdown measures, digital sources are often out of reach.

- There is very little information in accessible formats (e.g. Easy Read, BSL) which is adding to the anxiety and stress.
- Very few of the respondents were contacted directly with advice and information relevant to them. Moreover, in cases where people were reached, the communication was often inaccessible and confusing.

This is what people told us:

The lack of information and direct contact contributes to feelings of abandonment.

“Lack of information, lack of support. No one contacted me from social services to see if I was coping. I got in contact as no PPEs, no key worker ID for my PAs. No info as to what to do if I or my PAs have to self isolate. I feel completely ignored as a direct payment client. I've been left to get on with it!”

Official information from the government is ambiguous and inaccessible which causes distress

“The thing which caused me more distress was the fact that you think it is going to be for twelve weeks and then it is going to be to the 30 June and that is 14 weeks And, how long is it going to be now?”

“There is very little information around for disabled people. I read information from the charity that supports people with my condition that I could be classed as "vulnerable", yet I haven't had a letter.”

“Three weeks in and, apart from a letter saying the hospital has more guidance on my condition(s), I still haven't been told whether I should self isolate or not. I've had to rely on informal patient forums for information and help.”

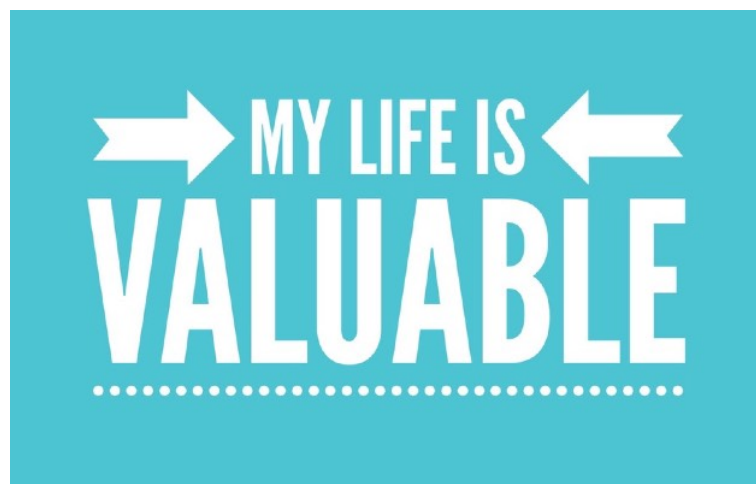
Disabled people are not being sent information in accessible formats nor being provided with necessary communication support.

“I've still not received any letter or contact regarding being in a susceptible group. However I'm visually impaired and an acquaintance who is also sight impaired received it and it has a tiny font that I wouldn't be able to read.”

“I have a learning disability with a mild stammer speaking on the phone is difficult for me . I can't go out to see face to face and it's hard.”

“There is not enough advice or help for disabled people or family carers and none provided in a clear format for those who struggle to read.”

“Not all disabled people will be able to leave the house at this time, especially if they are high risk. Additionally, this information is not being provided in text format. I had to call to find out this information, which is not accessible. There is a very large delay in responding to emails, and I am unsure if I will get a response. Meanwhile, my support workers need to be paid. One advisor told me that I could claim costs up to 6 months after the support was provided - but this isn't at all realistic. My support workers must be paid within 30 days, and I can't do my job without them”.



Some lives are considered less worth living

Summary

The coronavirus pandemic has shone a light on the human right to life, access to healthcare and emergency hospital treatment. Article 11 of the Convention on the Rights of Persons with Disabilities¹¹ oblige Governments to take all necessary measures to ensure the protection and safety of Disabled people in situations of risk, including situations of humanitarian emergencies and the occurrence of natural disasters.

Disabled people and family carers, however, have told us of instances of being pressured into agreeing to Do Not Resuscitate (DNR) notices with little or no consultation. Our survey has also revealed that Disabled people are being told they will not be admitted into a hospital if they fall ill or will be denied life-saving emergency treatment. We are also hearing from Disabled people who in light of these discriminatory attitudes are anxious going into hospital if they contract covid-19 and are fearful that in hospital they will be denied life-saving treatment and be left to die.

¹¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-11-situations-of-risk-and-humanitarian-emergencies.html>

Key points

- In light of these alarming practices around DNR notices Disabled people feel that some lives are considered less worth living.
- It is evident that little or no consideration has been given on how best to communicate and support Disabled people in discussions regarding medical treatment.
- The lack of and at times absence of Personal Protective Equipment (PPE) and effective testing for social care staff and Disabled people using services means that lives have been put needlessly risk.
- The shortage of PPE equipment and effective testing has resulted in several Disabled people foregoing essential social care. People have concluded that the risks of a Personal Assistant coming into the home with, for example, asymptomatic covid-19 is too high.
- As a result of NHS Englands measures to free up inpatient and critical care capacity¹² due to the covid-19 pandemic, staff have been redeployed leaving many Disabled people without routine planned support and medical treatment. This is likely to have an adverse impact on both the physical and mental health of Disabled people.

This is what people told us

The use of Do Not Resuscitate (DNR) notes

“Supposedly the government care but so far there's no support really. I can't access the government scheme for support because apparently I'm not disabled enough, However I'm disabled enough to get

¹² IMPORTANT AND URGENT – NEXT STEPS ON NHS RESPONSE TO COVID-19 (March 2020)
<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf>

suggested to sign DNR [Do Not Resuscitate], and inferred I'd be left to die if hospitalised."

"My GP then changed the subject and started telling me about a new initiative, 'MyCMC' which stands for Coordinate My Care. She said that in my CMC I could state my preferences for what I would like to happen if, for example, I had a fall and became unconscious. How would I want to be treated? She gave an example of an older person, who might feel that they had lived long enough and that they didn't want to live anymore, therefore, they would not want the Ambulance Service to take them to hospital! I couldn't believe what I was hearing at this point! I didn't understand why she had raised this example".

People are fearful they will not get life-saving treatment if they become gravely ill and have to go to hospital

"And, the thing that caused me more distress was when the government decided they were going to publish the frailty guidance. I looked to see how frail am I and am I going to be offered a ventilator if I need one. The reality according to that guidance was no, not necessarily. And, then thinking how can I prove my worth to people to make sure I get that treatment if needed."

"At that time, I was so scared to contact the doctors. I was terrified, I didn't want to go into hospital. I was scared that I would not be ventilated and I would be left to die and no one would be allowed to go with me to hospital so no would know all my complicated health history. We shouldn't have to think like that at all, we shouldn't have to prove our value to society"

"I am very concerned about him getting ill and being treated by people that we, his parents, cannot communicate with due to

distancing rules etc and that his trauma will deepen. And that there won't be a discussion about resuscitation.”

“I have been inside for three and a half weeks without going out and I’m losing my mind. I have pre-existing mental health problems and this is seriously causing a big relapse. I feel trapped and controlled and claustrophobic and constantly on edge and irritable. But I’m too scared to leave the house because if I get sick I know that, as someone with pre-existing conditions, doctors will leave me to die in favour of someone who has a better chance of surviving. I knew how undervalued disabled lives are, but this has really hit home and I feel so sad and so angry that I even have to think this way, but I do.”

Impact on mental health, GP and NHS outpatient appointments

“Paul had a wheelchair assessment earlier this year, at the request of his physio, due to developmental curvature of the spine. He had the assessment which concluded that there were no wheelchairs available to fit our requirements; I found three online in as many seconds and requested a re-review. This was arranged and would be carried out by a “more experienced” person. Although they offered an at home assessment, which would have excluded Paul’s physio, we were unable to entertain such a gathering due mostly but not exclusively to Paul’s status as an NHS extremely vulnerable person. I have repeatedly suggested a “virtual” assessment....Zoom or whatever, based around established measurements, etc. No take up. The developmental spinal curvature hasn’t gone away.”

“I can’t get doctors appointments that I normally have so no physio, no injections (normal contraception for joint pain) or med reviews (for pain meds). Anxiety over whole situation but can’t access counselling as waiting list is now so long.”

“Can’t get doctors appointments that I normally have so no physio, no injections (normal contraception for joint pain) or med reviews (for pain meds). Anxiety over whole situation but can’t access counselling as waiting list is now so long.”

“I have been told by a hospital nurse to self-shield but am not on any official list. It took quite a while to find out if I can go out for exercise. I can and I would like to wear a mask but don't have enough of them. I have a long standing mental health condition. I am currently on a long waiting list for CBT but NHS is offering me no support in the meantime. My pharmacy do not deliver and often do not answer the phone so I have had to find someone to collect medication for me.”

“I have also not been able to get access to respirator masks that other vent users in other places have been told to use in case they get symptoms (and have to be fit tested at a hospital). No method to get testing for PAs/their family as of yet as other health workers get.”



Failed by the social care system

Summary

The coronavirus pandemic has exposed and amplified many existing structural and systemic flaws within the social care system. A decade of austerity and cuts to social care budgets coupled with rising demand, and the failure to protect, maintain and develop adequate support in the community promoting people's choice and control has undermined independent living for many Disabled people.

The consequences are stark. One in four respondents have had problems getting hold of personal protective equipment, while nearly 40% have had issues with personal assistants, care workers, direct payments, housing benefits, and care packages.

Key Points

- A significant number of care workers are unwilling to work due to the increased risk posed by covid-19. Disabled people, therefore, are losing essential care and support. Moreover, the lack of adequate PPE supplied

to personal assistants also puts Disabled people at increased risk of catching covid-19.

- In several cases, Disabled people have decided to stop care workers coming into the home after determining that the risk is too high. A higher burden, therefore, is placed on family members and other unpaid carers.
- Around 70,000 direct payment recipients employ their staff. However, there were lengthy delays in publishing guidance. Consequently, Disabled people who use direct payments were primarily left on their own, expected to deal with HR issues, source PPE and put in place emergency contingency plans.
- There is a significant difference in approaches by local authorities across England. Some councils are implementing Care Act easements and downgrading Disabled people's rights while others are taking proactive steps to engage with service users, developing innovative solutions to ensure social care providers can operate after the lockdown ends.
- Significant restrictions have been placed on Disabled people who live in institutions, with relatives and advocates not able to visit and remote contact not always facilitated or accessible. Moreover, the Care Quality Commission is operating a light touch inspection, even though Disabled people in institutional settings are at an increased risk of abuse.
- Those who received support through daycare provision, including young people who are in education, are not getting alternative means of support and are reaching crisis point.

This is what people told us

Disabled people are losing existing social care support and alternatives are not being put in place

“I am writing to you because today, when a PA developed symptoms of Covid-19 on shift, both Council adult services and Public Health England could not provide me with PPE instead asking me to go into a care home if my sick cover PA could not work without PPE. Having faced abuse at the hands of a care worker being placed in a care home would be particularly distressing for me.”

“Being exposed to someone with symptoms is stressful for a vulnerable individual, like myself, the idea of being forced into a care home is particularly distressing. Surely requesting care homes that receive LA funding provide a small supply of PPE to direct payment employers rather than institutionalise us, is far better for our wellbeing and the public purse.”

“Social care only agreed to 2 weeks of support for support workers with assistance for temporary accommodation and 2 weeks of work when my son has a 157 weekly social care package. Failed to provide PPE and uncertainty of their work conditions so they left. I have not been able to find support workers. The LA have provided me with a new agency to contact.”

“I have one young person with autism and complex needs and a young child at home. I have been left without appropriate support as per my sons EHCP. Education cannot provide a TA or teacher. My son suffers from anxiety disorder and is terrified about going back to school as it was closed during lockdown. My son requires one to one teaching. It's been stressful. I have written to my MP.”

“My care agency are not getting adequate PPE, and they are so short-staffed at present that I've been lucky to get a shower once a month (and I cannot have a strip wash at all due to them sending male care workers to me 8 times out of 10 instead of female), and am not getting 1 in 3 of my daily care calls. On top of this the carers who do come are now so overrun that they can't help with informal assistance in the way they did before, such as taking my big dog for a brief walk while I am shielding at home. It's all a big mess.”

“My son who is aged 15 has severe learning difficulties and autism. His special school is closed to all but a very small number of children who are key-workers' children or are classed as vulnerable - he is not one of these. So he has no school. He also has no support from his care package – LA were meant to be arranging this via an agency but the care agency has never actually got back to us anyway. He also can't go to the KIDS ADventure Playground either as part of his care package or his short breaks because it is only open on a very limited basis to "vulnerable children" and again he is classed as insufficiently vulnerable. So we have no school and no support via his care package.”

Disabled people cancelling their existing support because of the risks of catching covid-19 and a lack of personal protective equipment

“We have had to cancel the social care that we receive (funded by Direct Payments) because of concerns our carers would bring the infection into the house, and would be inadequately provided with PPE. We were unable to access the government scheme to provide food parcels, in spite of my condition causing me to be immunosuppressed and therefore needing to be shielded. In addition, our council recently cut the care package due to financial constraints, and therefore I lost access to help with housework.”

“PA is self-isolating, unsure what is right. I need the support but the risk of the PA bringing the virus in with them and contaminating my house seems high, especially if they are visiting multiple settings. Uneasy getting a replacement PA when I can't trust them to follow essential hygiene measures.”

“Husband, who needs help with showering and dressing has had a self-funded care package for over 2 years. He became concerned that carers coming into the house increased the risk of infection and required me to stand them down so I am having to perform the tasks they would normally have done. This is a strain as I have an ongoing medical condition. If I become incapacitated he will have to go into care.”

No communication from social services, and no help sourcing PPE

“As an 89 year old with a number of health problems and being housebound 1) Has been extremely difficult to get on any online home delivery shopping slots, 2) No checking from social services that my live-in Carer is still happening 3) no real communication from the Care Agency who provides the live in Carers -we have had to arrange everything ourselves, they have had no real guidance and they haven't been sent any PPE”

“My sister has severe cerebral palsy, is a former ILF user, and requires 24 hour care. We have had no contact at all from the LA [local authority] since the start of the Coronavirus crisis. No letter about services, and no support. I have contacted a local councillor and MP to say that we desperately need PPE, several times, but there has been no practical help forthcoming. In the end I made several calls and had quite a few difficult conversations, and eventually was able to access PPE for my sisters carers. I still have no information about what to do if carers become unwell, or what happens if my sister becomes

unwell. I fear that other disabled people in the borough who are cared for in their own homes through direct payments might also be in this position.”

Cuts to care packages

“I have had some reduction in hours and aspects of my package. First time this was negotiated. Received a phone call from social worker saying: a) stock up with provisions for 3 weeks at a time - no advice on how to do this. b) If you are ill, someone will come, only if Coronavirus isn't suspected On your own, pal.”

“We have had to cancel the social care that we receive (funded by Direct Payments) because of concerns our carers would bring the infection into the house, and would be inadequately provided with PPE. We were unable to access the government scheme to provide food parcels, in spite my condition causing me to be immunosuppressed and therefore needing to be shielded. In addition our council recently cut the care package due to financial constraints, and therefore I lost access to help with housework.”

Delays to assessments

“My assessment is due and no one can come to do it so it is delayed until a time when someone can do it over the phone. The hours I was given 7 years ago have not been increased even though my condition has gotten worse”

Nothing About Us Without Us



Conclusion - Looking ahead

From the outset of the covid-19 pandemic, Deaf and Disabled people have experienced discrimination, disadvantage and multiple harms across all areas of life. From unequal access to emergency health treatment to problems with food deliveries, workplace accessibility, cuts to care packages to the increasing cost of daily living.

Furthermore, the emergency has increased pre-existing inequalities. Disabled people over the last decade have experienced high levels of structural and historical exclusion and discrimination coupled with rising poverty and inequality as a result of austerity, welfare reforms and cuts to public services. The coronavirus crisis has reinforced the view amongst many of us that society looks on us as second class citizens, a burden on the state and expendable.

Lessons must be learnt from this crisis. As we emerge from the lockdown, we must uphold and protect Disabled people's rights and ensure that the discrimination and marginalisation we experience in our daily lives are ended. It is wrong that Disabled people have had to resort to legal action to put an end to discrimination. However, on too many occasions, this has been the only remaining option. For example, to enforce changes to NICE guidance on critical care, hospital visitors' policies and ensure that supermarkets provide food delivery slots for Disabled people.

Although some of us are at a higher risk of becoming gravely ill if we contract covid-19, we are not inherently vulnerable. As Jenny Morris explains: "As many people have pointed out, it is government policies that make Disabled people

vulnerable - vulnerable to being poor, to insecure and inappropriate housing, to mounting debt, to being imprisoned within our own homes because of lack of support."¹³

As lockdown is easing, Disabled people will be further marginalised and excluded. At particular risk are Disabled people who are shielding and those of us from Black and Ethnic minority groups. Disabled people are a diverse group, and therefore, policies in all areas must take into account our rights, promote inclusion and dismantle the barriers we face in our daily lives.

The government need to make it a priority to understand the needs of Disabled people, giving serious consideration to our findings and recommendations. It is also vital that Deaf and Disabled people's Organisations DDPOs and Disabled people are involved in developing and planning policies that affect us at local, regional and national levels.

An adequate standard of living

The government has failed to protect Disabled people's standard of living. The covid-19 pandemic has amplified and exposed the inadequacy of the benefits system, especially as Disabled people are more likely to be on low incomes, unemployed and in insecure work.

Deaf and Disabled People's Organisations have told us about people who cannot afford shopping due to the supermarket's home delivery charges. The cost of living has also increased from higher energy bills (especially for those who have to shield at home) to the extra expenses of PPE supplies, and more expensive food items

The government during the covid-19 pandemic have also refused to uplift Disabled people's legacy benefits to match Universal Credit increases. This

¹³ See: (2018). Is Britain Fairer? The state of equality and human rights in Britain. [online]. Available at: <https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-accessible.pdf>

discrimination must be reversed, and in the longer-term social security system must be reformed to eradicate deep-rooted poverty.

Hate crime

Incidents of disability-related hate and abuse have increased during the pandemic due to several factors including broken and fragmented support networks, social isolation and less scrutiny in institutional settings. People whose conditions may cause similar symptoms as Covid 19 are facing particularly hostile reactions. Disability hate crime is often interlinked with ethnicity, race and gender violence and abuse.

Accessing and inclusion

Although duties under the Equality Act remain, many Disabled people feel they have been forgotten by providers of services, education, public bodies and employers. The redesign of public spaces to promote social distancing is often being implemented at the expense of accessibility. Local authorities are widening pavements, for example, and removing dropped curbs, the installation of plastic bollards is making it much harder for Blue Badge holders to park and the increase in cycling lanes often ignore the needs of Disabled people who use public spaces.

Disabled people shielding feel unsafe going outside despite the relaxing of lockdown rules at the beginning of June. People are anxious and worried about maintaining physical distancing. Unless there is clear messaging from the government and Mayor of London, Disabled people who are unable to wear a face mask on public transport will be at increased risk of being harassed and subjected to abuse for not covering their faces.

The new rules mean many Deaf and Disabled people will not be able to shop independently and communicate effectively. Information in accessible formats is often unavailable and at times unclear from the latest government advice on physical distancing, to support with education. Moreover, many cannot afford

the technology to access the digital world, such as broadband and smartphones. And, for those who can many sites are often inaccessible.

Right to health

The coronavirus pandemic led hospitals to suspend treatment and deter patients from seeking NHS care to focus on fighting covid-19. Large numbers of people have had diagnostic tests, outpatient appointments, surgery and other treatment cancelled. Many Disabled people's needs have gone unmet during the lockdown. In some cases, their conditions will have worsened when they should have been receiving care.

Moreover, many respondents to our survey have experienced an increase in psychological distress. But it isn't easy to access support for mental health in the community. People experiencing distress are facing cancelled appointments, difficulty getting through to their GP or being turned away by community mental health and crisis services.¹⁴ The lack of support in the community is likely lead to an increase in detentions as evidence shows when people do not get support early enough, they often end up in crisis.

Detentions also violate Disabled people's rights guaranteed by the UN Convention on the Rights of Disabled People.

Access to information for Disabled people about the latest government's advice on Covid-19 is still a significant problem and the apparent failure of the Test, Track and Trace system to accommodate different communication and access needs, Disabled people may be at higher risk of contracting the virus or not getting tested when necessary.

¹⁴ Mental health charity Mind finds that nearly a quarter of people have not been able to access mental health services in the last two weeks, <https://www.mind.org.uk/news-campaigns/news/mental-health-charity-mind-finds-that-nearly-a-quarter-of-people-have-not-been-able-to-access-mental-health-services-in-the-last-two-weeks/>

Social care:

The covid-19 pandemic has shone a light on the inadequacy of the existing social care system. There needs, therefore, to be a broader discussion focussed on a radical reform of social care and the creation of a system that supports people's choice and control and is community-based.

Inclusion London, as part of the Reclaiming Our Futures Alliance has been involved in developing a vision of independent living.¹⁵ Our National Independent Living Strategy details the principles and type of national support service we need to make independent living a reality again in the 21st century.

Employment:

There will be significant job losses over the coming months. Employers, therefore, must be encouraged and supported to retain their Disabled staff, especially those people who are shielding or live with others who are at high risk or unable to travel to work safely. Disabled people must get the adjustments they need to perform their jobs and this requires changes to Access to Work to ensure this system is accessible, fast and flexible in meeting people's needs.

Access to information and advice:

We anticipate that there will be a much higher demand for advice and support from Deaf and Disabled people after the lockdown is lifted and there needs to be increased funding for these services to meet demand. Likewise, we expect that there will be a significant need for new support services to support the thousands of Deaf and Disabled people who are likely to be required to shield over the next twelve to eighteen months. This community of at-risk people need to be fully engaged and consulted with about the implications of

¹⁵ Independent Living for the Future, Our vision for a national independent living support system, https://www.inclusionlondon.org.uk/wp-content/uploads/2019/06/NILSS_final.pdf

shielding and the support they will need to survive this extended period of lockdown. DDPOs must be funded to work with these shielded communities and provide the peer support services this community will need.