

Submission of evidence on the disproportionate impact of COVID-19, and the UK government response, on people with disabilities

30th April 2020

Centre of Resilience for Social Justice www.brighton.ac.uk/crsj/index.aspx

University of Brighton and Boingboing CiC www.boingboing.org.uk

Blackpool HeadStart www.blackpool.gov.uk/Residents/Health-and-social-care/HeadStart-Blackpool/HeadStart-Blackpool.aspx

on behalf of the Resilience Revolution www.rrblackpool.org.uk

[Professor Angie Hart](#), [Vicki Dunham](#), [Mirika Flegg](#), [Caroline Beswick](#) and Pauline Wigglesworth

In this submission we draw on our collective organisational and personal experiences, relating them to policy and practice changes currently happening. We are a community of academics, students, practitioners, parents/carers and young people working together to beat and change the odds as and with disadvantaged communities. Many of us have our own complex life challenges including physical and learning disabilities. Some of us are already experiencing adverse effects of the changes to government legislation.

We outline and discuss how people with disabilities in the UK are likely to be disproportionately affected by COVID-19 and the UK government's response to it. We also make recommendations for immediate and more long-term interventions.

In terms of our general democratic rights to have our voices heard and to socially participate at this time, some of us are also excluded due to our lack of access to digital devices for reasons of financial hardship and/or learning disability (1).

1. Impact of Coronavirus Bill

On 26th March 2020, the Government passed the Coronavirus Bill, to last for 2 years, enabling action in five key areas. One key area is:

“Easing the burden on frontline staff – by reducing the number of administrative tasks they have to perform, enabling local authorities to prioritise care for people with the most pressing needs, allowing key workers to perform more tasks remotely and with less paperwork, and taking the power to suspend individual port operations.” (2)

This includes making changes to the Care Act 2014 in England, and the Social Services and Well-being (Wales) Act 2014, to enable local authorities to prioritise the services they offer, even if this means not meeting everyone's assessed needs in full or delaying some assessments. This includes removing the duty to meet the eligible needs of disabled people (Section 18) and their carers (Section 20). Longer term this could result in serious hardship and suffering for disabled people and their carers, as cash-strapped local authorities will no longer be under any obligation to meet their needs. Even in the very short period that the Bill has been in place we have seen amongst some of our

learning-disabled community members that support hours have been reduced by local authorities, leading to anxiety, depression and safeguarding risks. This cut in hours for some of the most vulnerable members of our society at this time is extremely worrying, and our belief is that unless this legislation is reversed, things can only get worse. Ultimately this will not be a money saver either – giving vulnerable people the care and support they need saves money for the health, social care and criminal justice budgets later.

Other changes introduced through the Coronavirus Bill allows health bodies to delay carrying out an assessment for eligibility for NHS continuing care. Duties to support young people transitioning to adult social care have also been suspended. Again, if not reversed, this measure will result in costs to the criminal justice budgets etc. further down the line.

There are further implications for education provision for children and young people with Education and Health Care Plans (EHCP). The Secretary of State for Education now has the power to disapply the duty on schools and other institutions to admit a child to a school where they are named on an EHCP and is able to vary provisions of the Act, such as the core duty to procure provision set out in an EHCP; so instead of being an absolute duty, it becomes a ‘reasonable endeavours’ duty. This could mean that children with complex needs miss out on vital educational support and fall even further behind. We already know from research by the Sutton Trust and others that educational inequalities are set to increase massively as a result of the coronavirus crisis (3).

Under the Coronavirus Bill, local authorities will only have to provide care ‘if they consider it necessary’ for the purposes of avoiding a breach of the European Convention of Human Rights (ECHR). The high threshold of the ECHR means that there could be a significant reduction in the care received without breaching ECHR (4,5). The implications of the Coronavirus Bill are that disabled people will be left without care and support, which will inevitably have a significant impact on disabled people’s health and well-being. And as some of our members say, it is already having an impact.

2. Access to treatment

Prior to the passing of the Coronavirus Bill, the public had been assured that the government’s “most important task will be to protect our elderly and most vulnerable people during the peak weeks when there is the maximum risk of exposure to the disease and when the NHS will be under the most pressure” (<https://www.gov.uk/government/speeches/pm-statement-on-coronavirus-12-march-2020>). Yet evidence suggests that this commitment has not been upheld within health services. For example, the NICE guidelines initially set out a plan for rationing care based on use of the Clinical Frailty Scale (CFS) for all.

On 25th March 2020, these guidelines were amended to include the statement, “The CFS should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism. An individualised assessment is recommended in all cases where the CFS is not appropriate” (6). These guidelines appeared to have been drawn up without the input of disabled people (7).

However, the British Medical Association (BMA) guidelines, updated 9th April 2020 (8), states, “The presence of co-morbidity may exclude individuals from eligibility” of both initial and ongoing treatment (p. 4) and that, “younger patients will not automatically be prioritised over older ones” (p. 4). It acknowledges prioritisation policies disproportionately affects some, but goes on to argue that denying those with underlying comorbidities and older people treatment:

“...would be lawful in the circumstances of a serious pandemic because it would amount to ‘a proportionate means of achieving a legitimate aim’, under s19 (1) of the Equalities Act – namely fulfilling the requirement to use limited NHS resources to their best effect.” (p. 6)

This guidance was released on the same day that NHS assurances were made that non-disabled people would not receive priority treatment (<https://www.homecare.co.uk/news/article.cfm/id/1624223/People-with-disabilities-will-not-be-denied-life-saving-treatment-says-NHS-England>). This suggests disabled people are receiving false assurances.

Concerns surrounding access to treatment have been raised in the press. For example, there have been reports of ‘do not resuscitate orders’ being controversially applied (see for example <https://www.theguardian.com/commentisfree/2020/apr/08/do-not-resuscitate-orders-caused-panic-uk-truth>). Concerns have also been raised in regards to access to treatment for conditions not related to COVID 19 (<https://www.theguardian.com/commentisfree/2020/apr/29/coronavirus-disabled-people-inequality-pandemic>) and surrounding new powers associated with sectioning individuals experiencing mental ill health during the pandemic (<https://www.hrw.org/news/2020/03/26/uk-covid-19-law-puts-rights-people-disabilities-risk>). These require further investigation.

The European Disability Forum (EDF) have stated that,

“In countries where healthcare professionals will not be able to provide the same level of care to everyone due to lack of equipment and underfunding of the healthcare sector, medical guidelines need to be non-discriminatory and follow international law and existing ethics guidelines for care in the event of disaster and emergencies. These are clear: persons with disabilities cannot be discriminated against.” (9)

Left unchallenged, discrimination against disabled people could set a dangerous precedent for discrimination against other groups that have been suggested to be susceptible to COVID-19 (e.g. black and minority ethnic groups <https://www.ft.com/content/5fd6ab18-be4a-48de-b887-8478a391dd72>). It also sets a precedent for the discrimination of other protected groups potentially more susceptible to future health challenges.

3. Shielding Implications

‘Guidance on Shielding and Protecting Extremely Vulnerable Persons from Covid-19’ states that those cohabitating with someone who is a shielding person do not also have to shield (10). However, employers of health care professionals are expressly recommended to make alternative living and working arrangements when employees are cohabitating with someone who is especially vulnerable (11). It is unclear how aligned shielding guidance is with the government’s ‘Coronavirus Job Retention Scheme’ which suggests that staff who, “need to stay home with someone who is shielding” can be furloughed (12). Further confusion may result from the document ‘Support for those affected by COVID 19’, whereby it states that those who are shielding can apply for Statutory Sick Pay (SSP). This includes, “individuals who are caring for people self-isolating in the same household and therefore have been advised to do a household quarantine” (12). This seemingly contradictory information creates confusion for employers surrounding their responsibilities. It shifts responsibilities to individuals who are shielding and to members of their households. The need to review multiple documents may be challenging for some. Some may further be challenged in engaging with government policy due to individual accessibility needs or lack of internet access.

Many disabled people rely on their friends, family and members of their household to provide care and incremental support, which is increasingly inaccessible due to social distancing requirements. Although additional support is provided by the government, individuals are expressly suggested to seek assistance from friends and family prior to requesting government support (<https://www.gov.uk/guidance/coronavirus-covid-19-accessing-food-and-essential-supplies>). This may prevent some individuals from requesting government assistance when needed and place additional responsibilities on the friends and family of those especially vulnerable to COVID-19.

4. Widening social inequalities

Prior to the pandemic, disabled people and those with whom they cohabitate were known to the government as being statistically more likely to be on low incomes (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/875261/households-below-average-income-1994-1995-2018-2019.pdf; p. 11). This inequality is likely to be exacerbated by COVID-19 and any associated economic repercussions.

On 3rd January 2020, a parliamentary research briefing paper highlighted the disability employment gap (<https://commonslibrary.parliament.uk/research-briefings/cbp-7540/>). Those in employment earn on average 12.2% less than non-disabled people (<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilitypaygapsintheuk/2018#disabled-employees-earned-on-average-122-less-than-non-disabled-people>; Section 6). Some disabled people, however, may be disadvantaged in continuing to work through this time, as they require specialist equipment to work from home. MPs were given £10,000 for equipment and expenses to enable remote working (<https://www.thetimes.co.uk/article/coronavirus-mps-given-extra-10-000-each-for-home-working-expenses-w0h5sx99l>), however, employers are not expressly required to provide accessibility equipment to enable shielding and disabled employees to work remotely. The current 'Coronavirus Job Retention Scheme' (12) rather states shielded persons may be furloughed in the short term. Thus, many disabled people may potentially be denied access to contributing to the employment sector and may not have sufficient savings to cover reductions in wages or costs associated with remote working.

The coronavirus lockdown has amplified the importance of digital technology, from the ability to search for the latest health information, staying socially connected to friends and family, ordering on-line shopping, or undertaking paid work from home. However access is not equally distributed and a 'digital divide' is clear, with 11.3 million people in the UK not having the basic digital skills and equipment they need to thrive in today's world; many of these will be disabled people (13). Digital access also raises ethical issues (<https://www.boingboing.org.uk/my-moves-to-becoming-a-digital-odds-changer/>).

As the result of employment trends, disabled people at work may be at increased risk of contracting COVID-19. For example, they are more likely than non-disabled people to be in 'Caring, Leisure and Other Service Occupations' and 'Sales and Customer Service Occupations' (<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilitypaygapsintheuk/2018#disabled-employees-earned-on-average-122-less-than-non-disabled-people>). Thus, key workers supporting the general population throughout this crisis may likely include a high percentage of disabled people.

Moreover, women with disabilities, young disabled persons and people in need of high-level support are more likely to be discriminated against and excluded fully from the labour market (9). It is

inevitable, therefore that disabled people will be affected disproportionately in this volatile labour market. Whilst the UK government's position is that such workers should apply for Universal Credit, this is not an adequate response, since Universal Credit remains problematic due to its lengthy wait period and monthly assessments. People locked in poverty face increased challenges staying afloat in the face of rising costs and income loss that will come as a result of the Coronavirus outbreak. They are also more likely to be in poor health, disabled, and to be caring for others.

Disabled people may also be less likely to access support packages associated with COVID-19. For example, disabled people are less likely to own their own home than non-disabled people (<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandhousinguk/2019#housing-situation-by-disability>). Thus, non-disabled people will disproportionately benefit from government-backed mortgage holidays and disabled people may be more likely to accrue debt associated with rental repayments (see for example https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878995/Covid-19_fact_sheet.pdf). There is a general sense that shielding guideline timeframes will be extended and therefore vulnerable people and their households need reassurances that support will be extended.

Not only are disabled people disadvantaged members of their communities due to social inequalities, they are also likely to live in the most disadvantaged communities with the poorest local authorities. The change in the funding formula for COVID-19-specific funding for local government has seen a significant impact, moving funding from the most deprived areas to the most prosperous. The initial phase of funding acknowledged the impact of deprivation levels and the associated additional investment needed for social care, however the move to a population-based formula has seen an inexplicable rise in funding for more affluent local authorities, and in particular district councils, who have gained more than a 2,000% increase in their allocation, whilst other areas are receiving reduced funding (14). This reduction in funding will create a disproportionate impact on disabled people in more deprived areas that struggle to provide the level of social care support needed through this global crisis.

Recommendations

Our submission of evidence indicates that the UK government response, including its emergency legislation, does not fully consider the inequalities broadly experienced by people with disabilities. We offer the following suggestions to support the UK government with its commitment to safeguarding people with disabilities as a key group with protected characteristics.

Within a 3-week period

1. Ensure government policies, associated documents and briefings are available in a diverse range of accessible formats (e.g. easy to read, Braille, print copies, British Sign Language, etc.) so that the full range of disabled people can engage with policy.
2. Prevent patient prioritisation policies from discriminating against disabled people as a matter of urgency.
3. Provide clarification for employers of those working through the pandemic so that disabled people and members of their households can stay safe.

4. Provide clarification for employers of those working through the pandemic surrounding the provision of accessibility equipment for staff who are shielding and who may continue to work at home.
5. Put in place a mechanism to give people immediate support whilst they apply for Universal Credit to keep them afloat during the five weeks wait (without pulling them into debt which may lengthen financial hardship).
6. Reconsider support packages for shielding individuals and their families and give assurances that support timelines will be extended if needed.
7. Create a dedicated and fully accessible webpage that provides government information on Covid-19 and disability more broadly. Updated dedicated shielding webpages to specifically include employment information such as the one provided by The Scottish Government (<https://www.gov.scot/publications/covid-shielding/pages/employment-and-financial-support/>).
8. Reinstatement of the rights of children with an EHCP to be admitted to schools and other institutions and reinstatement of the core duty to procure provision set out in an EHCP.
9. Urgently put in measures to address the 'digital divide' experienced by many disabled people.

Within 6 months

1. Impact of the Coronavirus Bill on disabled people to be reviewed within 6 months, replacing the duty to ensure that disabled people receive the necessary care and support that they need.
2. Universal Credit to be reformed to ensure fast and effective financial security to those who need it when they need it.
3. In light of patient prioritisation policies, further questions should be raised surrounding disproportionate death rates of those with underlying health conditions (<https://news.sky.com/story/coronavirus-95-of-victims-in-england-hospitals-had-underlying-health-conditions-11979733>).
4. Review the current population-based formula for Local Authority funding.

References

1. Time for a Rapid Response to the Digital Access Challenge, 2020; <https://www.carnegieuktrust.org.uk/blog/time-for-a-rapid-response-to-the-digital-access-challenge/>
2. What the Coronavirus Bill Will Do Guidance, 26th March 2020 <https://www.gov.uk/government/publications/coronavirus-bill-what-it-will-do/what-the-coronavirus-bill-will-do>
3. Social Mobility and Covid-19, 2020; <https://www.suttontrust.com/our-research/social-mobility-and-covid-19/>

4. Inclusion London, 2020; <https://www.inclusionlondon.org.uk/campaigns-and-policy/act-now/coronavirus-bill-could-leave-thousands-of-disabled-people-without-support/>
5. The British Institute of Human Rights, 2020; <https://www.bihar.org.uk/coronavirusbill-20march>
6. COVID-19 rapid guideline: critical care in adults; NICE guideline Published: 20 March 2020
www.nice.org.uk/guidance/ng159
7. Disability News Service, March 2020; <https://www.disabilitynewsservice.com/coronavirus-anger-over-terrifying-and-discriminating-intensive-care-guidance/>
8. British Medical Association, April 2020; <https://www.bma.org.uk/media/2360/bma-covid-19-ethics-guidance-april-2020.pdf>
9. European Disability Forum <http://www.edf-feph.org/>
10. Guidance on Shielding and Protecting Extremely Vulnerable Persons from Covid-19, March 2020; <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>.
11. Ethical Guidance Published for Frontline Staff Dealing with Pandemic, March 2020; <https://www.rcplondon.ac.uk/news/ethical-guidance-published-frontline-staff-dealing-pandemic>
12. Coronavirus Job Retention Scheme, March 2020; <https://www.gov.uk/guidance/claim-for-wage-costs-through-the-coronavirus-job-retention-scheme#agreeing-to-furlough-employees>
13. Carnegie UK Trust, April 2020; <https://www.carnegieuktrust.org.uk/blog/time-for-a-rapid-response-to-the-digital-access-challenge/>
14. Local Government Chronicle, April 2020; <https://www.lgcplus.com/finance/jenrick-backs-districts-with-huge-boost-in-share-of-covid-19-funding-29-04-2020/>