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Dear Prime Minister,

23rd July 2020

We are Disability Rights UK Voices, a group of disabled people's led organisations, who have been meeting to share and represent the experiences of disabled people during the pandemic, under the umbrella of Disability Rights UK.

The coronavirus pandemic has had a disproportionate impact on the 14 million people in the UK who live with a disability or long-term health conditions.

At the beginning of the crisis in March, daily life changed, support networks disappeared, access to food shops became difficult and the terror of the possibility of catching Covid-19 was real for many people. For disabled people however, all of these issues were heightened, and the crisis affected every aspect of our daily lives.

It immediately became clear that social care, which should have been a priority in the government's response, had been forgotten, and worse, targeted for reductions in the provisions of the Coronavirus Act 2020. This left some disabled people without the care they are entitled to and many more fearful about the future of their care provision.

For those not affected by the easements, access to care provision was still not straightforward. We heard that people were initially unable to access Covid testing for their staff and themselves, and experienced reductions in care received due to staff being off sick, or simply being anxious about coming to work.

Disabled people who employ a personal assistant through a Direct Payment (Health or Social Care) for daily care and support, were left without a plan for straightforward access to Personal Protective Equipment (PPE) for their employee(s). We were told that this left many people uncomfortable and feeling they had no choice but to reduce the care and support they received to stay safe.

We heard that many disabled people were no longer able to access online shopping slots that they had used before the pandemic. For those that were not on the shielding list as extremely susceptible to coronavirus, shops became difficult for them to access with long queues, closed toilets, policies of one customer per household, personal assistants not being recognised as key workers and difficulties complying with social distancing requirements all making them fearful.

Many disabled people were not on, or were missed off, the NHS 'shielding' scheme, leaving them with no recourse to extra support. For those that were on the shielding scheme, needing to rely on either food parcels or the goodwill of volunteers in order to eat, created a highly stressful situation.

The reporting of deaths of people 'with pre-existing conditions' fuelled the fears of many disabled people that they were unseen, unimportant and forgotten. Indeed, as of June 2020, disabled people accounted for two thirds of all deaths in the UK from Covid-19.

We also heard from disabled people and their families who had received letters from their GP suggesting that they should agree to a Do Not Resuscitate (DNR) order against their name in the event they became unwell with Covid-19. This naturally caused a huge amount of concern about what would happen to people with 'pre-existing conditions' who needed intensive care. Reassurances were eventually given, but by then the damage to disabled people's confidence in the treatment they would receive was done.

The government's daily coronavirus briefing continually failed to provide a live British Sign Language (BSL) Interpreter, reinforcing the sense that the government had forgotten disabled people at a time when they were disproportionately affected.

A return to language in government of 'the vulnerable' or 'vulnerable people' made many disabled people feel that they were seen as victims of the crisis, unable to speak for themselves or be part of the debate.

Whilst many disabled people have access to a digital device to access information, many do not, or they need help to use one. We heard that in the absence of their usual support networks, many disabled people became more digitally excluded at a time when news and advice was evolving fast and much of it was only accessible online.

Living with all of the issues above, many disabled people have been left feeling lonely, and report worsening mental health.

More recently, as the lockdown began to ease, things did not improve. An opportunity to make sure disabled people felt listened to and remembered was lost.

Unclear and unnecessarily complex government announcements and guidance have caused significant anxiety to disabled people and many remain reluctant to leave their homes.

We have heard that the interchangeable use of terms to describe people at risk from coronavirus meant many people were left unsure of what advice applied to them.

Most recently, announcements on the 'mandatory' requirement to wear face coverings on public transport and then in shops, did not highlight strongly enough the exemptions allowed for people unable to do so, leaving these people at risk of interrogation and abuse, and becoming further isolated.

For people who are deaf or hearing impaired, the requirement for face coverings means that they will now find it impossible to lip read where BSL is not used.

Looking to the future, many disabled people now fear leaving their homes and they fear being less employable in a difficult economic period, due to their status as 'vulnerable' or 'shielded'.

The recovery plan so far, has comprehensively failed to recognise the needs and ongoing difficulties faced by disabled people.

We know that the pandemic is not over yet. Covid-19 will be with us for some time and so we are calling on the Government to work with us to:

- Ensure the needs of disabled people are considered first and not last in future policy developments
- Develop and shape new policy proposals with disabled people, in particular the forthcoming green papers on benefits and social care
- Ensure all new build homes have to meet accessibility standards
- Give disabled young people full access to the Chancellor's education, training, and work initiatives
- Guarantee that any change of guidance or regulations with respect to Covid-19 goes through a thorough disability impact assessment. We stand ready to assist and engage
- Prioritise the development of the National Disability Strategy that was promised in the 2019 manifesto, recognising that it is even more vital now than ever before, and make sure there is full engagement of disabled people in shaping its ambition.

Yours sincerely,

Kamran Mallick CEO

Spectrum CiL

Breakthrough UK Disability Peterborough Disability Sheffield

Wheels for Wellbeing

Cheshire Centre for Independent Living
Disability Rights UK
Living Options Devon
WECIL
Wiltshire Centre for Independent Living