

Written evidence submitted by Disability Rights UK (MRS0200)

Introduction to Disability Rights UK

Disability Rights UK is the leading charity of its kind in the UK. We are run by and for people with lived experience of disability or health conditions. We are disabled people leading change, working towards our vision of a society where everyone can participate equally. We are a membership organisation that campaigns for change, based on our members' views and with information about their experiences around the country.

1. How people have been affected by the illness or the response to it:

Disabled people and those with serious health conditions have been hard hit by the coronavirus crisis. The vast majority of people who have died, as a result of the virus, have been those with existing serious health conditions. These deaths have been in hospitals, care homes and in the community.

It was known at the outset that disabled people and those with serious health conditions would bear the brunt of the crisis, however, there was not enough government focus or concerted action, to protect our wellbeing or our lives. More action was needed in the following areas:

Targeted Information

There has been insufficient targeted information to disabled people and those with serious health conditions. It was not enough to send a letter to 1.5 million people identified by NHS England, as having specific medical conditions, which meant that they should shield themselves. Three weeks after lockdown, government appointed Chris Townsend to lead action in respect of this group.

Millions of disabled people and people with severe health problems were not part of the NHS vulnerable group, and were not offered any additional information or advice. This left many disabled people and those with serious health problems feeling anxious and unsupported.

Access to Health Care

The crisis has revealed that the lives of disabled people and those with serious health conditions aren't always treated as of equal value. On 20 March NICE produced critical care guidance, which referred to a Clinical Frailty Scale. This Scale reduces your chances of receiving critical care, if you require support with daily living, which many disabled people do. Following protests, NICE said the Scale shouldn't be used with young people or people with stable long term disabilities including learning disabilities, autism and cerebral palsy. However, there is still concern about the existence of the Scale and how it is being used.

A further cause of anxiety was a series of incidents, where GPs sent letters to groups of patients, suggesting that they sign Do Not Attempt Resuscitation (DNAR) notices. One can only imagine the hurt and distress caused by these letters. Steps were taken to stop these actions, and CQC re-emphasised that blanket approaches to DNAR were wrong. Nevertheless, anxiety about the extent to which our lives are valued, remain.

On 7 April, in response to an open letter signed by thousands of disabled people and disability organisations, NHS England wrote, confirming that under the NHS Constitution we are all entitled to NHS care and stating that blanket approaches to DNAR notices were not acceptable. On 15 April in the daily government broadcast, Matt Hancock repeated the message that blanket approaches to DNAR notices were not appropriate.

Despite the above positive actions, concerns continue. On 21 April disabled people with the support of a legal team, launched a judicial review calling for the NHS to produce non-discriminatory guidance on access to critical care. On 23 April the EHRC wrote to the BMA asking them to review ethical guidance, to ensure that non-pertinent health conditions and impairments did not affect decisions. The BMA have advised that they will review the guidance.

Access to Social Care

Even before the Coronavirus Act was passed, we heard from disabled people, who were experiencing cuts to their care and support. Only people with high support needs receive social care, so reducing care, has extremely serious consequences for individuals. The lack of PPE and testing for care workers has also been a major issue, with the Social Care Action Plan only being produced 3 and a half weeks after lockdown.

For those in Care Homes and other residential settings, guidance was produced on 20 March. It covered the need to isolate residents with coronavirus and the importance of using PPE. It is now well documented that Care Homes struggled to implement the Guidance and received insufficient support from NHS and social care services, and inadequate testing and PPE, which contributed to the unnecessary deaths of many residents.

For the thousands of disabled people, who receive direct payments to organise their own care and support, which is sometimes round the clock, the government only issued guidance on 21 April. This delay left disabled people feeling extremely anxious about the steps they need to take, should they or their personal assistants become ill.

The Coronavirus Act, rather than introducing measures to provide increased support and protection to disabled adults and children, did the opposite. It stated that in times of crisis our care, support, services and protections, could be reduced. This is extremely difficult to understand, as we are the group bearing the brunt of the crisis. DR UK wrote to directors of social care, asking that disabled people and their organisations be consulted prior to any rights being removed. Coronavirus Act Guidance set out specific conditions, which needed to be met before suspending Care Act rights, as well as outlining a consultation process. On 23 April it was reported that Six local authorities had suspended aspects of the Care Act, days after the government promised an additional 1.6 billion pounds to local government. The reasons for the suspension and the nature of consultation, are not clear. The councils are Birmingham, Staffordshire, Warwickshire, Solihull, Sunderland and Middlesbrough.

Access to food

The government food delivery scheme was initially solely targeted at the 1.5 million vulnerable group. It is likely that many within this group had access to food through family,

friends or local volunteers. However, there are many disabled people and those with serious health conditions, who were not identified as part of the vulnerable group, and who desperately need access to food supplies. The government has widened access to this service, but many people in need continue to be excluded.

There are millions of disabled people, who have found shopping for food very challenging during the crisis. These include, disabled people who aren't able to stand for long periods of time in queues, disabled people who can't socially distance within stores, and disabled people who struggle to obtain online delivery slots. Supermarkets have tried to address these concerns, but their approaches have been varied and fragmented, leaving many without suitable options. The major supermarkets are refusing to talk directly to disability organisations and are saying they will only talk to government; this is completely unacceptable. Under the Equality Act supermarkets have a duty to make reasonable adjustments for disabled people. DR UK has written to supermarkets and not received replies from Sainsburys, Tesco's, Asda or Morrisons.

There is confusion between the role of supermarkets in supporting those in the government's vulnerable group, and their wider role of making reasonable adjustments under the Equality act for all disabled customers.

2. If there have been specific impacts on people due to them having a protected characteristic:

Consultation with Disabled People

There has often been no or insufficient consultation with disabled people with regard to the various guidance and measures being introduced. The need for speed is well understood and mechanisms to suit the fast pace of decision making should have been found.

Accessible Information

Government broadcasts have not been communicated in sign language. The Prime Minister's letter wasn't in braille, large print, audio or easy read. The basic accessible information requirements of the Equality Act need to be met. The NHS Accessible Information Standard also needs to be complied with.

Benefits

The Government has introduced interim measures that we warmly welcome, such as:

- the suspension of face-to-face assessments for all ESA and disability benefits; and
- not requiring DLA and PIP claimants to complete and return renewal claim packs issued to them.

However, even before the Covid-19 crisis, benefit cuts and austerity hit disabled people the hardest:

<https://www.disabilityrightsuk.org/news/2019/july/disabled-adults-four-times-worse-financially-non-disabled-adults-finds-new-dbc-report>

The £20 per week temporary increase to Universal Credit and tax credits is welcome but should be made permanent. It should also properly be extended to those on ‘legacy benefits’ such as ESA. The Work-Related Activity Group and UC equivalent Limited Capability for Work addition should be restored. In addition:

- the five week wait for Universal Credit pushed those in financial hardship into immediate debt. Instead, the option of fortnightly payments should be offered;
- the two-child benefit limit, should be scrapped as it detaches benefit levels from actual family need;
- the benefit cap should be removed as it punishes people for not getting a job, even where they are not expected to work;
- the next phase of the rollout of Universal Credit due in December should be suspended.

There should also be a strengthening of discretionary funds such as the restoration of the central Discretionary Social Fund, but providing grants rather than loans and Discretionary Housing Payments.

Digital Exclusion

Many people including disabled people find themselves without access to digital communications during lock down, as they previously used computers and wi-fi in public spaces. This has exacerbated loneliness and isolation.

Employment

Disabled employees have found themselves without the necessary adjustments, to enable them to work from home. We believe that this has resulted in disabled people being disproportionately furloughed or losing employment. The government’s Access to Work Scheme has been slow to support disabled people needing to work from home, and to adjust its claim procedures.

Education

Families with disabled children have found themselves without the necessary support and adjustments, to enable home education. Disabled students in Further Education have found themselves with minimal support. The majority of higher education providers have replaced face to face teaching with online platforms. For some disabled learners, online courses are not appropriate. Where households cannot afford computers or broadband, access to online learning is denied.

The quick shift to online teaching has resulted in the needs of disabled students often being overlooked. For example, students with visual impairments are finding that learning materials are not compatible with screen readers, which read and navigate course documents. Furthermore, online lectures do not always provide real time captioning, which would have been available when physically attending lectures. We have heard from a student with a sensory impairment who has been asked to take a temporary withdrawal from studies, as the university is struggling to meet his disability related needs.

Some disabled students have been unable to access Disabled Students Allowance funded non-medical helper support remotely, such as mentoring and study skills, and feel overwhelmed with deadlines that are looming and feel unable to cope with the pressures.

Leisure

The regulations relating to outdoor exercise have been relaxed for people with learning disabilities or autism, in particular where exercise is part of a care plan. However, more should have been done in terms of reasonable adjustments, to enable disabled people to take advantage of outdoor exercise.

Transport

There have been instances of passenger assistance staff refusing to support disabled people. The government has written to the Rail Delivery Group stating that such refusals are not acceptable.

3. Whether there may be unforeseen consequences to measures brought in to ease the burden on frontline staff, for example relaxing the measures under the Mental Health Act and Care Act):

Single Focus on NHS

Whilst we applaud the amazing work of the NHS, both for the care it provides and for the way it has increased critical care capacity, we feel that the government should have adopted a more joined-up approach across health and social care from the outset, treating them as equal partners.

Social care should have been given parity in terms of priority and investment, to support and protect disabled people and those with serious health conditions. Three and a half weeks after lockdown, a social care action plan was produced. Unfortunately, this was after many people in Care Homes had died.

Creation of a Vulnerable Group

An unintended consequence of creating a vulnerable group is that it has diverted attention away from many disabled people and those with serious health conditions, who need additional support and protection. A devolved approach to reaching vulnerable people might have been more effective. This could have been done through GPs, NHS community services and social care. Local responsibility and accountability for disabled people and those with serious health conditions, might have made people feel better supported.

Food Delivery Scheme

The creation of a group of vulnerable people who are entitled to food deliveries has led supermarkets to prioritise this group, and to put insufficient focus on measures required to meet the needs of all disabled customers.

Creation of NHS Volunteer Force

The establishment of a national NHS volunteers force sits awkwardly with local area and street groups. There might have been benefits in providing more support to local volunteer

groups. Advantages could have included, better checks on safety, improved deployment of volunteers and a stronger local legacy following the crisis.

4. The government has said that current measures will be reviewed in 3 weeks' time and measures in the Coronavirus Bill be voted on in 6 months' time:

What needs to change or improve, which could be acted on in three weeks' time:

- Provision of Accessible Information by central and local government, including sign language interpretation of government broadcasts;
- All NHS and social care services to implement the NHS Accessible Information Standard;
- Improved Consultation with disability organisations to include us in decision making and learn from our experiences;
- Improved non-discriminatory guidance on access to health care;
- Adherence to Coronavirus Act guidance relating to suspension of Care Act Rights;
- Proactive review of the situation of every person living in a Care Home, to ensure they have the best possible support and protection.;
- Increased funding of social care;
- Ability to self-refer to gain access to the government's food scheme;
- Improved and coordinated supermarket actions, to make reasonable adjustments for all disabled people;
- Changes to the Access to Work Scheme, to support disabled employees to work from home;
- Support to purchase digital equipment and broadband to enable learning and combat isolation;
- Devolved approach to supporting the vulnerable group, with national standards delivered through local authorities;
- Devolved approach to NHS volunteers, so they can complement local volunteer action;
- Reasonable adjustments made to guidance on outdoor activities, to enable the equal participation of disabled people.

What needs to change or improve, which could be acted on in 6 months' time:

- Repeal of parts of the Coronavirus Act, which reduce the rights of disabled people in respect of care, mental health and education;
- Plans to continue social distancing measures must recognise the adjustments that are needed to enable people with different impairments to be treated equally;
- As reliance grows on digital information and communication, additional support, training and funding are needed to ensure the inclusion of disabled people. Where digital access isn't possible, other options must be provided;
- As people return to work, disabled people must receive impairment specific support to retain and gain employment;

- Disabled pupils and students need to be given additional support to resume learning and to catch up on what has been missed.

April 2020