IN THE UK COVID-19 INQUIRY

MODULE 3

OPENING SUBMISSIONS ON BEHALF OF THE DISABILITY CHARITIES CONSORTIUM

Introduction

1. The Disability Charities Consortium, DCC, is a coalition of major disability charities in the UK. It is made up of the following: Business Disability Forum; Leonard Cheshire; Mencap; Mind; National Autistic Society; Royal National Institute of Blind People ("RNIB"); Royal National Institute for Deaf People ("RNID"); Scope; and Sense.

2. The DCC has been in existence for over fifteen years and was set up to facilitate co-ordination of activity and communication between disability charities in the UK. The DCC reaches a large majority of the 16 million disabled people in the UK and their member organisations address the broad range of issues that disabled people face. The DCC looks at the collective impact of policy on disabled people and highlights particular issues for specific groups of disabled people. The DCC works with Government to ensure disabled people's views and experiences are reflected in UK policy making, and that their own policy positions are informed by disabled people. The DCC regularly meets with the Minister of State for Social Security and Disability, the Disability Unit in Cabinet Office and with other key ministers who impact upon disabled people's lives. The DCC's members have a long track record of engaging with and influencing key stakeholders across the country, and are recognised by government as a primary representative body for consultation on issues that face disabled people.

3. These submissions supplement the evidence already provided to the Inquiry, of Matt Stringer, Chief Executive Officer of the RNIB, and the impact statements of Dr Sarah Powell and Vivienne Wilkes.

Disproportionate Impact of Covid-19 on Disabled People

4. The Covid-19 pandemic had a severe and significantly disproportionate impact on disabled people, both in terms of the mortality rate and the impact of interventions such as lockdowns and shielding. At the end of 2020, data from the Office for National Statistics (ONS) revealed that of the 50,888 Covid-19 deaths that happened between January to November, 30,296 were disabled people. Disabled people, who account for only 22 per cent of the population, made up six in 10 deaths.[1]

5. The disproportionate number of deaths among disabled people was compounded for particular groups. Compared to people of the same age without such impairments, working-age people with both a hearing and visual impairment in England were nearly 12 times more likely to die due to Covid during the pandemic (24 January 2020 and 20 July

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[1] www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020

2022).[2] People aged 30-69 with a visual but no hearing impairment were more than eight times more likely to die, and those with just a hearing impairment were still four times more likely to die a Covid-related death.[3] Even after taking into account a wide range of other characteristics, the risk of a Covid-related death for people with a hearing, visual and dual-sensory impairment was still 1.30, 1.38 and 1.42 times higher than those without. The Health and Social Care Committee reported in its Sixth Report that the impact of the pandemic was disproportionately severe for individuals with learning disabilities, with the death rate for people with learning disabilities over six times higher than the general population when adjusted for age.[4]

6. The increased mortality rate is not the only marker of the severe impact of the pandemic on disabled people. For example:
    a) The restrictions in respect of hospital visiting and shielding had a disproportionate effect on disabled people.
    b) The changes to healthcare services, such as delaying or cancelling routine appointments, and moving consultations online or via telephone had negatives consequences for many disabled people.[5]
    c) The closure of support services had a very negative impact on disabled individuals who rely on support for everyday living.[6]
    d) In a number of instances crucial information failed to be consistently communicated to disabled people in accessible formats.
    e) The blanket imposition of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices on the records of those with learning disabilities is perhaps one of the most egregious effects of the miscommunication and misapplication of guidance during the pandemic.
7. The overwhelming impression from the evidence submitted to the Inquiry and the experience of DCC's members is that the needs of disabled groups were seriously overlooked.[7] The interests, needs or views of disabled people were not canvassed or considered either at all or until much too late in the day. The lives of disabled people appeared to be considered more expendable than those of others.

Relevant law

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[2] www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/estimatesofcoronaviruscovid19relateddeathsbyhearingandvisionimpairmentstatusengland/24january2020to20july2022

[3] www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/estimatesofcoronaviruscovid19relateddeathsbyhearingandvisionimpairmentstatusengland/24january2020to20july2022

[4] Sixth Report of the Health and Social Care Committee and Third Report of the Science and Technology Committee of Session 2021–22 – [INQ000090541] para 314.

[5] See Matt Stringer's witness statement – [INQ000239594]at para 26.

[6] See MENCAP's Report "My Health, My Life" – [INQ000216426].

[7] Also a finding made in respect of people with learning disabilities in the Sixth Report of the Health and Social Care Committee and Third Report of the Science and Technology Committee of Session 2021–22 – [INQ000090541] - para 324.

Equality Act

8. Section 29(6) of Part 3 of the Equality Act (EA 2010) prohibits discrimination and harassment by a person exercising a public function that is not the provision of a service to the public or a section of the public. There are exceptions to this provision, including constitutional matters, in Schedule 3 EA.

9. Pursuant to s.6 EA 2010 a person has a disability if they have a physical or mental impairment which has a long term and substantial adverse effect on their ability to carry out normal day-to-day activities. By section 6(3)(b) of the Act a reference to persons who share a protected characteristic is a reference to persons who have the same disability.

10. According to section 15 EA treatment of a disabled person amounts to discrimination where a service provider treats the disabled person unfavourably; this treatment is because of something arising in consequence of the disabled person's disability; and the service provider cannot show that this treatment is a proportionate means of achieving a legitimate aim.

11. For the avoidance of doubt this differs from direct discrimination in that the unfavourable treatment is because of something arising in consequence of the disability rather than the disability itself. Another difference is that it does not require a comparison to be made with the treatment of another person.

12. The duty to make reasonable adjustments is contained in ss.20 and 21 and Schedule 13 EA 2010. The duty includes the following requirement: where a provision criteria or practice ("PCP") puts those who share the protected characteristic of disability at a substantial disadvantage compared with those who are not disabled, the duty is to take reasonable steps to avoid that disadvantage. A failure to comply with that requirement constitutes a failure to comply with a duty to make reasonable adjustments, which, in turn, constitutes discrimination: s.21(1) & (2). The duty is anticipatory, so that the public authority has to anticipate the reasonable steps necessary to ensure that disabled people generally, or of a particular class, will not be substantially disadvantaged: *MM v Secretary of State for Work and Pensions* (above) at [§43].

13. The objective of the duty to make reasonable adjustments is to require those who make decisions affecting disabled people to take positive steps to remove or ameliorate, so far as is objectively reasonable, the difficulties which place them at a disadvantage as compared with those who are not disabled: Elias LJ in *MM v Secretary of State for Work and Pensions* [2013] EWCA Civ 1565 at [35]. The duty is at an end only when the disabled person is no longer at a disadvantage: *Archibald v Fife Council* [2004] ICR 954, HL [§15].

14. The disabled person must be at substantial disadvantage "*in comparison with persons who are not disabled*". This does not mean that the comparison must be with 'non-disabled' people in general, but rather it refers to the particular disability: *MM v Secretary of State for Work and Pensions* [2013] EWCA Civ 1565 at [§34; §43]. The PCP may involve stress or anxiety for the non-disabled too, but if it "*bites harder on the disabled*" then the

duty arises: *Griffiths v Work and Pensions Secretary* [2015] EWCA Civ 1265 at §§47 and 58. Substantial disadvantage means more than trivial (s.212(1) EA).

15. Indirect discrimination may occur when a service provider applies an apparently neutral provision, criterion or practice which puts persons sharing a protected characteristic at a particular disadvantage (s19(1) and 19(2) EA). A person claiming PCP is indirectly discriminatory must be at a disadvantage as a member of a group of people, whether real or hypothetical: see *Eweida v British Airways Plc* [2010] I.R.L.R. 322. The court is asked in indirect discrimination cases to conduct a formal comparative exercise between the cohort of people who share the disabled person's protected characteristics – their particular disability – and the cohort who do not.

16. It will be difficult for a public authority to show that treatment was proportionate if it has not complied with the public sector equality duty at section 149 EA 2010, a point recognised by the Supreme Court in *R (E) v JFS* [2009] 1 W.L.R. 2353 at [§212].

17. Section149 EA provides that -

> *(1) A public authority must, in the exercise of its functions, have due regard to the need to—*
>
> > *(a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;*
> >
> > *(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;*
> >
> > *(c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it. [...]*
>
> *(3) Having due regard to the need to advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it involves having due regard, in particular, to the need to—*
>
> > *(a) remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic;*
> >
> > *(b) take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it;*
> >
> > *(c) encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.*
>
> *(4) The steps involved in meeting the needs of disabled persons that are different from the needs of persons who are not disabled include, in particular, steps to take account of disabled persons' disabilities. [...]*

18. The following principles are to be derived on the public sector equality duty (PSED):

    a. The duty must be exercised with a *"conscious approach and state of mind"; "the duty must be exercised in substance, with rigour and with an open mind." Brown v Secretary of State for Work & Pensions* [2008] EWHC 3158 (Admin) [2009] P.T.S.R. 1506 at [90] - [92] per Scott Baker LJ.

b. A Minister must *assess the risk and extent of any adverse impact* and the ways in which such risk may be eliminated: *R (Bracking) v Secretary of State for Work and Pensions* and [2014] Eq LR 60 [25(4)] citing Moses LJ in *Kaur & Shah v LB Ealing* [2008] EWHC 2062 (Admin) at [23 – 24].

c. It is accordingly beholden on decision makers to find out the relevant facts before consideration of the equality duty and the authority cannot be said to have properly complied with the duty if not: see *R (Lunt) v Liverpool City Council* [2009] EWHC 2356 (Admin) [2010] RTR 5 [43] – [44] and *R (Law Centres Federation Limited t/a Law Centres Network) v The Lord Chancellor* [2018] EWHC 1588 (Admin) (below).

d. Thus, in *R (Bracking) v Secretary of State for Work and Pensions* and [2014] Eq LR 60 the Court of Appeal referred with approval to the statement of the principle in *R Brown) v Secretary of State for Work and Pensions (Equality and Human Rights Commission intervening*) [2009] PTSR 1506, where Aikens LJ explained at para 85 that in having due regard to the need to take steps to take account of disabled persons' disabilities (under a predecessor provision to section 149(4)): *"the public authority concerned will, in our view, have to have due regard to the need to take steps to gather relevant information in order that it can properly take steps to take into account disabled persons' disabilities in the context of the particular function under consideration."*

e. Compliance should not be treated as a "rearguard action following a concluded decision", but as an "essential preliminary to such decision, inattention to which is both unlawful and bad government": *R (BAPIO Action Ltd) v Secretary of State for the Home Department* [2007] EWCA Civ 1139 per Sedley LJ at [3].

National Health Service Act 2006

19. Under s.1C of the National Health Service Act 2006 (as amended) in exercising functions in relation to the health service, the Secretary of State must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service.

Key Issues

Extent to which healthcare inequalities were considered as part of the core decision -making process (Issue 2d)

20. The former Secretary of State for Health and Social Care, Matt Hancock, states at paragraph 170 of his fifth statement [INQ000421858_0041] that he considered the impact of his decisions upon *inter alia* disabled people, and that "many of the decisions we made were put in place precisely with their protection in mind." He says he received "expert advice from world-leading clinicians, including the Chief Medical Officer (CMO), on how to reduce the unequal impact of the pandemic" and "impact assessments and equality impact assessments from Departmental officials." He advises in the general terms that the "effect of this advice was to reinforce my decision to try to limit the spread of the virus,

increase NHS capacity and find a vaccine as quickly as possible, in order to protect all members of the public and particularly those worst affected by the virus."

21. Mr Hancock's successor, Sajid Javid, asserts that health inequalities was a "central concern" of his and that "equality impacts and the potential effect on vulnerable groups" was ""baked in" to the decision-making process." (para 52) [INQ000485736_0021/0022]. Yet Mr Javid goes on to state at para 70 INQ0000485736_0029/0031]:

   > "I can't from this distance identify particular decisions I made because of a particular equality impact assessment or other impact assessment: the system does not work like that. They are part and parcel of policy making, and so will always be considered carefully by both ministers and policy officials before making decisions. Unfortunately, in respect of Covid it was the case that unpalatable and difficult decisions had to be made which did have differential impacts on some groups over others — for example decisions about closing schools, about placing services online, about working from home all had an impact. Even where I may not have had a specific equality impact assessment, the disparate impact on different groups was usually a point of discussion and debate before the decision was made and was part of the policy development and thinking."

22. In the submission of the DCC, these comments betray a common and yet fundamental error whereby disability is all too often elided with ill-health or clinical vulnerability, with the consequence that policy makers fail to comprehend the lived experience of disabled people and operate on the premise that if they are protecting the sick and the vulnerable, then ipso-facto they are protecting disabled people. Relatedly, the duties in relation to disabled people are not limited to merely acknowledging adverse impacts of government policy or naturally occurring phenomena but extend a positive obligation to anticipate and take all reasonable steps to remove disadvantages experienced by virtue of disability – a duty to level the playing field. At least some of the other evidence before the inquiry suggests that these errors in approach were potentially responsible for the degree of adverse impact experienced by disabled people.

23. For example, the duties in relation to disabled people should surely have included considering how to make critical public health information available to all members of society. From the beginning of the pandemic, DCC members raised concerns regarding the accessibility of Covid 19 related public health information provided to disabled people, initially in broadcast announcements, shielding letters, and social media posts, for instance.

24. In April 2020 Mark Atkinson, Chief Executive of RNID wrote to the Prime Minister on behalf of a number of disability charities including RNID, Sense, SignHealth, National Autistic Society, Thomas Pocklington Trust, Visionary, Royal Association for Deaf People, Macular Society and SeeAbility expressing shared concerns regarding the accessibility of Covid related information being put out by the Government, and in particular the lack of a British Sign Language (BSL) interpreter at major announcements, including the initial lockdown announcement.[8]

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[8] See Matt Stringer's witness statement – [INQ000239594], para 39 and [MS/12-INQ000216422].

25. As a result, the Minister for Disabled People published an open letter on 19 May 2020, setting out the steps government was taking to ensure the accessibility of public health information during the pandemic. This included establishing an accessible communications working group, appointing an accessibility lead (Director, of National Resilience Communications, COVID-19 Communications Hub) and issuing guidance to Government departments.[9]

26. Although this led to some improvements (such as around the accessibility of social media posts and the availability of a BSL interpreter on the BBC News channel) problems remained, particularly around the accessibility of shielding information, and test and trace.

<u>Collation of data and responding to the disproportionate impact</u>

27. From 15 March NHSE asked hospital trusts to submit notifications of deaths detailing the presence of protected characteristics (Powis (3) para 853 [INQ000412890_0225). The same month NHS England set up a 'MHLDA Cell' (mental health, learning disabilities, autism) for the purpose of supporting the pandemic response and on 25 March 2020 the Cell published guidance including the following principles to inform a system-wide response (Powis (4) para 1677 (c)(ii) [INQ000485652_0483]:

> *"People with mental health needs, a learning disability or autism should receive the same degree of protection and support with managing COVID-19 as other members of the population. This might mean providing additional support, including making reasonable adjustments.*

28. From April 2020 HMG conducted research into the disproportionate impact of the virus culminating in a 'PHE Review of Disparities in Risks and Outcomes June 4 2020' ([INQ000399820] Hopkins para 436 [INQ000410867_0166; Agrawal para 8.26 [INQ000436880_0072]). It seems that much of the activity in government in relation to inequalities was prompted by this Review, which was subsequently <u>updated</u> and <u>reissued</u> in August 2020 ([INQ000101218]; Hopkins para 436 INQ000410867_0166).

29. However, whilst on <u>14 May 2024</u> the ONS first published data on the social impact of disability ([INQ000089755] Agrawal's statement, para 8.55 [INQ000436880_0080]) and on <u>19 June 2020</u> the ONS reported that disabled people were experiencing higher mortality rates ([INQ00 308703] Agrawal para 8.55 [INQ000436880_0080]), the Review <u>did not list disability</u> as a relevant inequality and hence no follow up work was commissioned.

30. Indeed, there is very little focus in the witness statements in this module of the key decision-makers of any considerations they gave to disability or disabled people as part of their decision-making during the pandemic. There is an absence of detail as to what active steps, if any, key decision-makers took to uphold the positive obligation to comply with its equality obligations under the Equality Act, the Public Sector Equality Duty when they formulated and undertook measures. For example, when sending out information to disabled individuals, creating policies and guidance such as the Visitor's Guidance or the

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[9] See Matt Stringer's witness statement – [INQ000239594], para 40 and [MS13/INQ000216423]

rapid NICE Guidelines on Clinical Care. At para 98 of his second statement [INQ000472172_0029], Matthew Style lists four examples of work that was done by DHSC in relation to inequalities, but these are all at a very high level, addressing matters such as the introduction of the Coronavirus Act 2020.

31. Similarly, NHSE's statements, while acknowledging PSED requirements, demonstrate that those responsibilities were not always met. Andrew Goodall, Chief Executive of NHS Wales (para 227 [INQ000485721_0095]) and Jeane Freeman at paras 256 (INQ000493484_0057) and 257 (INQ000493484_0058) explicitly state that it was not always possible to comply with these duties in the fast-moving crisis of the pandemic. Moreover, even where full impact assessments were undertaken, they were not comprehensive. For example, the impact of the Social Distancing Policy was considered only in terms of vulnerability to loss of income and financial resilience rather than health and wellbeing (Agrawal para 7.74 [INQ000436880_0056]/8.17 [INQ000436880_0068]). Ruth May (para 217) states that in March 2020 a new simplified Equality and Health Inequality Impact Assessment was developed by her team and adopted across the NHSE on the 8 July 2020 It is not clear whether this document improved performance of the PSED or the reasonable adjustments duty.

32. On the 24 Sept 2020 COVID-O considered the PHE Review and set up the Equality Hub with four teams focused on Disproportionately Impacted Groups including one on disability. Notably however, the Equality Hub's responsibilities did not include a role in reviewing and monitoring EIAs of individual departments including Health and NHS.

33. As regards disability specifically, the Director of the Hub made a presentation to multiple government departments on 30 October 2020 in which the disproportionate impact on disabled people in terms of deaths, accessing healthcare, wellbeing and other matters was set out. The impact regarding mortality rates was tentatively explained by the ONS by reference to several factors, including that disabled people are on average older, more likely to become infected because of contact in care homes, experience higher levels of comorbidities, socio-economic deprivation and barriers in accessing care [INQ0000 89747].

34. Disability charities were rightly concerned at the emerging data, and Jackie O'Sullivan of Mencap asked for more information on what lay behind the increased mortality rates, firstly in a stakeholder meeting held with the Chief Medical Officer and Deputy Chief Medical Officer, and then twice asking again in an email to Jenny Harries through a DHSC official, sent on 24 September 2020 and 9 November, but never receiving a substantive response. [10]

35. After further research was undertaken, the Hub developed several policy proposals that were discussed at a Covid-O meeting on 8 December 2020 [INQ000083956]. These were designed to improve: data regarding the drivers of the impact; government interventions by setting up a 'National Panel' of disabled people, communications with disabled people and digital accessibility. After discussion, some of these proposals were adopted by HMG

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[10] These emails are appended to these submissions

(Agrawal para 8.59, [INQ000436880_0082] and [INQ000091234]). The National Panel was not set up. It is not clear why not.

36. Meanwhile, in December 2021 the then Equalities Minister was compelled to write to government ministers giving general advice on how to approach their ongoing duties in relation to inequality (Agrawal para 8.18, [INQ000436880_0069])

37. Finally, the Cabinet's Office's 2021 "Outcome Delivery Plan' (valid from 15 July 2021) confirmed that the Equality Hub was to contribute to the objective of improving levels of equality across the UK, including the "delivery milestone" of analysing and tackling the disproportionate impacts of Covid -19 for disabled people. Plainly this work will be relevant to future modules regarding the impact of the pandemic. However, the analysis of why the disproportionate impacts materialised is integral to Module 3.

38. The DCC urges the Inquiry team to put themselves in the position of disabled people when carrying out their investigative function in Module 3, and to scrutinise the decision-makers so as to understand what steps, if any, were taken to understand, consider and support by way of reasonable adjustments for disabled people during the pandemic.

Primary Care (Issue 4(b)(i)

39. Persistent concerns were raised on behalf of disabled people about the move to remote consultations and access to primary care generally. RNID research [MS/8-INQ000216431] in September 2020 found nearly 60 per cent of 384 respondents admitted they had 'put off' seeking medical advice from their GPs after the introduction of remote appointments during Covid. As stated by Matt Stringer at para 31 "people with learning disabilities may not be able to communicate verbally, and/or may have difficulty expressing pain or discomfort. They also struggle to navigate healthcare systems, including services such as 111 and remote consultations which rely on an individual's ability to accurately communicate symptoms." [INQ000235594_0012] Jackie O'Sullivan from MENCAP highlights at para 5 of her statement [IN0000479878_0002/0003] that these changes appear to have been introduced without any reference to the equality assessment:

> "Our concern was that this move to remote consultations could lead to increased difficulties with communication for people with a learning disability, diagnostic failures and diagnostic overshadowing', where serious underlying illness is not detected because a clinician makes mistaken assumptions about the person with a learning disability's baseline and usual presentation. We heard from people with a learning disability and their families that in the main adjustments were not being made to this policy for those that could struggle with communication."

Inequalities in access to hospital care or critical care due to patients' age, disability or comorbidities (Issue 5(a))

40. As stated above, the work done by the ONS in late 2020 regarded barriers to healthcare as being a potential cause of the disproportionate impact of Covid -19 on disabled people. It is not clear whether this knowledge led to any adjustments being made to improve access for disabled Covid-19 Patients.

41. Notably, Snook and Edwards' expert report refers to the triage tool used by 999 and 111 services during the pandemic to identify high risk patients, and notes that unfortunately the accurate use of this tool "was fairly low in terms of identifying patients at high risk of serious consequences from Covid-19 and excluding those at low risk" [para 70, INQ000474285_0023]. This is supported by the Health and Services Safety Investigation Body's report published in 2022 on the "NHS 111's response to callers with Covid-19 related symptoms during the pandemic" which highlights that the triage "did not allow for an assessment of caller's comorbidities to establish whether a clinical assessment would be beneficial" [para 73, [INQ000474285_0024]]. This resulted in the avoidable deaths of many individuals with comorbidities, many of whom may have been disabled.

42. The DCC invites the Inquiry to explore these important issues. Was access to healthcare for disabled Covid-19 patients adjusted to account for the needs of disabled people?

DNACPRs (Issue 7b)

43. Early in the pandemic, DNACPRs were unlawfully and inappropriately applied in a blanket fashion to the records of those with learning disabilities and autism.[11] The catalyst for the application of such a measure is not clear to DCC, however the practice appears to have been widespread. The Joint Committee on Human Rights reported in its Seventh Report of Session 2019-21 (published on 21 September 2020):[12]

> "We have received deeply troubling evidence from numerous sources that during the Covid-19 pandemic DNACPR notices have been applied in a blanket fashion to some categories of person by some care providers, without any involvement of the individuals or their families. It is discriminatory and contrary to both the ECHR and the Equality Act 2010 to apply DNACPR notices in a blanket manner to groups on the basis of a particular type of impairment, such as a learning disability; or on the grounds of age alone. There have been longstanding concerns about the discriminatory application of DNACPR notices to older and disabled people and the way that they have been administered in some instances. The Covid-19 pandemic has brought these concerns sharply into focus."

44. The CQC's Interim Report "Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic" dated November 2020, included numerous reports, from BIHR, Amnesty, Compassion in Dying, the Queen's Nursing Institute and Learning Disability England, of the inappropriate and blanket application of DNACPRs, including to the records of disabled people during the pandemic.[13]

45. Similarly, the December 2020 Women and Equalities Select Committee found that "DNACPR decisions had potentially been used in a discriminatory way. It also found that this showed a concerning disregard for disabled people."[14]

46. As stated by the CQC in its Interim Report, it is potentially unlawful to inappropriately apply DNACPRs:[15]

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[11] CQC Interim Report – [INQ000235491] p.7
[12] https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/265/26502.htm at para 74.
[13] INQ000235491 at p.8-10
[14] CQC Final Report on DNACPRs p.11.
[15] INQ000235491, p.5.

> "Inappropriate use of DNACPRs, including poor clinical-decision making, could be unlawful under the Equality Act 2020 if the decision-making is based on the protected characteristics of age and disability. It is unlawful for blanket decisions, with or without completing a DNACPR form, to be applied to groups of people of any description. Decisions must be made on an individual basis according to need."

47. If a decision to apply a DNACPR is made in such a way as to fail to protect an individual's right to life, there is a risk that Article 2 of the European Convention on Human Rights (ECHR) may be breached.[16] As the Equality and Human Rights Commission stated in October 2020:[17]

> "The right to life is 'non-derogable', which means it must be maintained even in times of emergency. Public authorities have positive obligations to protect life, including a duty to prevent avoidable deaths."

48. Not consulting with the person or their representatives risks breaching Article 8 of the ECHR and would be contrary to the presumption in favour of patient involvement as established in *R (on the application of David Tracey) v Cambridge University Hospitals NHS Trust and others* [2014] EWCA Civ 822.[18] Applying a DNACPR to an individual's record solely because of their disability would also risk breaching Article 14 of the ECHR.[19]

49. Clinicians, healthcare providers and systems have a positive obligation to ensure that people's rights are upheld including through their approach to DNACPRs. As stated by the CQC in its Interim Report:[20]

> "Younger disabled people with stable impairments or older people that might have stable long-term conditions should not need an advance care plan to prevent poor or discriminatory individual decision making and to protect their rights. The duty is on clinicians to ensure that they uphold people's rights through complying with equality and human rights law. Providers and systems must keep people at the centre of their care. This includes approaches to DNACPR to protect human rights and meet the individual needs of people."

50. On 20 March 2020, NICE published rapid Covid-19 guidelines on "Critical care in adults", which advised that all adults admitted to hospital, irrespective of Covid-19 status, should be assessed for frailty using the Clinical Frailty Scale (CFS) and such consideration should take account of co-morbidities and underlying health conditions.[21] CQC concluded in its interim report that "Use of the tool was interpreted by some as meaning that disabled people who were not 'frail' but needed assistance would be denied

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[16] INQ000235491, p.5.

[17] INQ000235491, p.5

[18] At paragraph 53.

[19] INQ000235491, p.5.

[20] INQ000235491, p.5-6

[21] Statement of Dr Paul Chrisp, para 98 [INQ000438429_0051]; Statement of Dame Ruth May, paras 369-70 [INQ000479043_0078]; CQC Interim Report, p.10. Guidance published 20 March 2020: INQ000315780 at p.6, para 1.1. The Inquiry should note that this guidance includes the amendments that were made as result of the intervention of MENCAP and the National Autistic Society.

access to critical care."[22] It was only after the persistent intervention of Mencap and the National Autistic Society, that the NICE guidance was amended.[23] The speed with which NICE were asked to produce the guidelines was blamed for the reason why NICE did not take some of its usual steps, most likely an Equalities Impact Assessment.[24]

51. On or around 25 March 2020, NICE revised the guidance to make it clear that the CFS should not be used for younger people, those with learning disabilities or stable long-term disabilities.[25] While the changes were widely communicated, Mencap concluded in its report "My Health, My Life" that "the original NICE guidance had ongoing damaging consequences" in that general practices had sent letters to care settings suggesting that people with learning disabilities would not be treated if they went to hospital and advanced decisions, included using DNACPR orders, should be made.[26] The DCC is unclear why and how the publication of the NICE guidelines on 20 March 2020 led to GP practices, and possibly other treatment providers, to recommend the use of DNACPRs.

52. The DCC consider it important for the Inquiry to seek answers to the following questions:

    a. Was the publication of the NICE guidelines the catalyst for GP practices and others to recommend the use of DNACPR notices for individuals with learning disabilities and autism, or was there another cause? What was the reason for the cause?

    b. Why was no Equalities Impact Assessment carried out before the NICE guidelines on 'Critical care in adults' was published?

    c. Why were disabilities groups not consulted about the new guidance in advance of its publication? Could some form of emergency rapid consultation have taken place?

    d. The steps with which NICE have taken, or are going to take, to ensure that they will take account of equality considerations when publishing guidelines in the future in the event that they are asked to publish such guidelines at speed in the face of a future pandemic?

    e. What steps were taken, if any, to determine the scale of the use of inappropriate DNACPRs and whether any governmental body/department took action to monitor their use?

53. DCC also remain concerned that inappropriate DNACPRs still exist on disabled individuals' records as a hangover from the pandemic.[27] The DCC urge the Inquiry to find out what steps the Government has taken, or will take, to ensure that records of disabled people are removed and inappropriate DNACPR notices removed.

54. The Joint Committee on Human Rights called on the Government to implement a national DNACPR policy to prevent future systematic violations of the rights of individuals under

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[22] CQC Interim Report, p.10.
[23] INQ000228378
[24] INQ000228378 p.14
[25] CQC Interim Report, p.10.
[26] Jackie O'Sullivan witness statement [INQ000479878] p.3, second bullet point.
[27] The concern was also highlighted by the Equality and Human Rights Commission and Amnesty in the CQC's Interim Report - INQ000235491 at p.10.

Articles 2 and 8 of the ECHR.[28] The DCC would urge the Inquiry to consider recommending the same. It recommended that such a policy should include:[29]

> "Such a policy should make clear, amongst other things, that DNACPR notices must never be imposed in a blanket fashion by care providers; the individuals must always be involved in the decision-making process, or where the individual does not have capacity, consultation must take place with persons with an interest in the welfare of the patient."

55. It is unclear to the DCC whether the Universal Principles for Advance Care Planning[30] incorporated into the Care Quality Commission's (CQC) new assessment framework[31] adequately provides clear advice on DNACPRs and a framework that can be adopted in future pandemics. The DCC urge the Inquiry to consider the same.

Hospital visiting restrictions (9(c))

56. Guidance published in March 2020 did not consider the needs of people with a learning disability or the duty to make reasonable adjustments (para 344 of the joint witness statement of Jean White, Gareth Howells and Sumeshni Tranka [INQ000480133_0131] and para 32 of Mencap's statement [1N0000479878_0016/0017]. A subsequent revision of the guidance on 9 April [INQ000300097] made an exception for people with 'mental health conditions' including learning disability and/ or autism, allowing them to have occasional visitors to avoid 'distress'. Further guidance then stipulated exemptions for those attending to support the patient, following representations from disabled people with physical impairments. The various iterations of this guidance again failed to refer to the legal duty to make reasonable adjustments and afforded individual institutions significant discretion. Mencap remained concerned about the detrimental impact of this guidance throughout the pandemic [IN0000479878_0007 and IN0000479878_0016/0017].

57. Again, DCC invites the Inquiry to explore why needs and interests of disabled people were ignored and why the changes necessary to government policy were only made after proactive representations were made by DCC members and disabled people?

Shielding programme and the definition of those who were Clinically Extremely Vulnerable ("CEV") and Clinically Vulnerable ("CV") (Issue 12)

58. At the outset of the pandemic, the determination of which individuals should be categorised within the CEV and CV groups, which enabled the implementation of the shielding programme focussed exclusively on the clinical health conditions and on the age of individuals. This approach does not appear to have considered disabled people. Disabled people required extra support throughout the pandemic, such as accessing support for daily living, but they were ineligible for additional government support as they were not included in the CEV or CV groups.

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[28] https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/265/26502.htm at para 76.

[29] https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/265/26502.htm at para 76.

[30] INQ000339327

[31] INQ000339228

59. Those living with Down's Syndrome were added to the Shielded Persons List (SPL) on 30 September 2020. It was decided in England that those living with Down's Syndrome should be contacted by their GP, but it appears that the decision was only communicated on 3 November 2020. However, a number of individuals with Down's Syndrome were not told of the decision until early January 2021, after the November 2020 lockdown and the December 2020 Tier restrictions.[32] This delay caused confusion and difficulties for those with Down's Syndrome who were meant to be shielding but did not know. The witness statements do not reveal why this group of individuals were not contacted expediently and proactively, well in advance of the November 2020 national lockdown. The statements do not explain why, in the first instance, the decision was taken in England for over-burdened GPs to communicate the shielding information to those with Down's Syndrome instead of the Government contacting them. The DCC urge the Inquiry to consider these questions.

60. The statements of Dame Jenny Harries[33], Professor Sir Stephen Powis,[34] and Professor Sir Chris Whitty[35] describe the decision-making process for determining the parameters of the CEV and CV groups in March and April 2020. It is unclear to DCC whether disabled groups were consulted and whether the risk factors presented by adults and children with disabilities were considered in the decision-making process.

61. The statements by the CMOs and Chief Nursing Officers (CNOs) do not on the whole consider the disproportionate impact COVID has on disabled people. Considerations of increased risk are articulated through the language of medical vulnerabilities and 'co-morbidities'. It finds its clearest expression in statements on the evolution of those categorised as Clinically Vulnerable (CV) and Clinically Extremely Vulnerable (CEV). Jenny Harries's statement, in particular, demonstrates the extent to which the 'clinically vulnerable' classification and the shielding policy which covered them grew from a cohort numbering 2.2M to 3.8M people by the time shielding guidance was lifted in July 2022.

62. The shielding policy was based on perceived clinical risks. Jenny Harries is explicit (Para 36) in that "Given this particular policy was clinically risk based this was firstly a medical question, i.e. which conditions were likely to confer particular individual vulnerability to COVID-19". This medicalised model and reliance on clinicians in developing it, overlooks the social and structural barriers and risks to which disabled people are exposed as well as the cumulative negative impact on people who share more than one characteristic. This is known as Intersectionality, from the American term for crossing or crossroads (the more crossroads the greater the risk). The question has to be whether an over-medicalised policy overlooked social and structural risks faced by disabled people and by doing so put them at greater risk or failed to alert them to the risk.

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[32] 5th witness statement of Professor Sir Chris Whitty, [INQ000410237] p.82; Statement of Matt Stringer [INQ000235594] p.18-19

[33] 5th witness statement: INQ000410865; 6th witness statement: INQ000489907

[34] 3rd witness statement: INQ000412890

[35] 5th witness statement of Professor Sir Chris Whitty, INQ000410237

63. The DCC urge the Inquiry to consider whether disabled groups were considered and if not, why not. The DCC is particularly concerned that the COVID-19 pandemic caused an increased mortality rate for adults with learning disabilities, being 6 times higher than the rate of the population as a whole. The reason for the increase in mortality rate for individuals with learning disabilities has not been explained. The DCC urge the Inquiry to focus its investigation on whether the exclusion of disabled groups from the Shielding Programme, and the SPL could have contributed to the increased mortality rate. The DCC also urge the Inquiry to consider the effect of excluding disabled individuals from the Shielding Programme.

<u>Inaccessible Information regarding shielding and related matters</u>

64. Letters sent in the shielding programme advising individuals to shield is a paradigm example of the inaccessibility of information communicated to disabled people throughout the pandemic.

65. The Government are under a positive duty, under the Accessible Information Standard[36] and section 20 of the Equality Act 2010, to make reasonable adjustments for disabled persons. Such a duty includes communicating information to disabled persons in a format accessible to them to avoid the disadvantage they would face.

66. Throughout the early stages of the pandemic, the RNIB raised repeated concerns with Government that the shielding letters were not provided in an accessible format to those who were visually impaired and for a "reliable system to be put in place to ensure blind and partially sighted people get letters in their preferred format across the country".[37] In the event, one of the shielding letters (dated 22 June) was sent with RNIB's details on it in larger font, and which instructed people to call RNIB to receive letters in their preferred format.[38] But, after this, only one subsequent letter included RNIB's details to allow people to request an alternative format of the information, and no letters were sent out in an accessible format directly to those requiring one. The consequence of those actions meant that the visually impaired were left without crucial information about shielding, so much so that an individual who met the CEV criteria took legal action against DHSC.[39] Even in a fast-moving pandemic, the DCC is of the view that it should not be for disabled groups to hold the Government to account to take action to meet its positive obligations.

67. DCC urges the Inquiry to focus on why the needs of disabled people were ignored by the respective Government bodies when communicating information to the wider population. Did the Government take advice on, and prepare for how to comply with its positive duty to make reasonable adjustments? And if not, why did it not do so. It is not clear to the DCC what practices, if any, have been recommended and/or adopted by Government to ensure that disabled persons will not be discriminated against in the same way again. The DCC encourage the Inquiry to consider such questions.

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[36] https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/#standard

[37] Matt Stringer witness statement [INQ000239594], paras 41-43.

[38] Matt Stringer witness statement [INQ000239594], paras 41-45.

[39] Powis witness statement [INQ000412890], para 647.

Conclusion

68. The DCC encourages CTI to explore these matters with the key witnesses and welcomes the opportunity to explore these issues in questions and closing submissions.

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23 AUGUST 2023