COVID -19 UK INQUIRY

SUBMISSIONS OF THE DISABILITY CHARITIES CONSORTIUM

MODULE 3

PRELIMINARY HEARING 1: 28 FEBRUARY 2023

The DCC

1. The Disability Charities Consortium ("DCC") is a coalition of disability charities in the UK. It is made up of: 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 ("the DCC's members").

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 14 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 charities are all members of the business leaders' group of Disability Confident, which represents over 20,000 employers in the UK.

3. 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'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. The chief executives of the member charities meet quarterly and the DCC's Policy Group, made up of the Policy Heads of the represented charities, collaborate to develop joint positions on different areas of policy.

4. During the pandemic, the DCC met regularly with the Disability Minister, the Disability Unit in Cabinet Office and with the Prime Minister's Office. Its established programme of meetings with the ministerial disability champions in each government department also continued during the pandemic.

The DCC and Module 3 of the UK Covid 19 Inquiry

5. The DCC is pleased and grateful to have been granted Core Participant status in Module 3 of the Inquiry. Disabled people's healthcare needs and their access in the pandemic to appropriate and necessary healthcare (related to Covid-19 and generally) was of high-level importance to the DCC during the inquiry period (January 2020 – February 2022).

6. The potential unequal impact of the pandemic has been rightly situated by the Chair at the forefront of the Inquiry's work. Similarly, the DCC's involvement is motivated primarily by the need to obtain a proper understanding of and accountability for the massively

disproportionate impact that the pandemic had on disabled people. In particular:

a. 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 22 per cent of the population, made up six in 10 deaths.[1] Given that the DCC's members reach a large number of the 14 million disabled people in the UK, the DCC has a significant interest in this Module for this reason alone.

b. 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 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.

[1] www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020
[2] www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/estimatesofcoronaviruscovid19relateddeathsbyhearingandvisionimpairmentstatusengland/24january2020to20july2022
[3] www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/estimatesofcoronaviruscovid19relateddeathsbyhearingandvisionimpairmentstatusengland/24january2020to20july2022

c. As recorded by the Chair in her decision to grant it CP status, the DCC believes disabled people were adversely affected by the pandemic in other respects relevant to Module 3. For example, miscommunication and confusion about eligibility for healthcare, the application of DNACPR notices and NHS England's decision to discharge patients infected or potentially infected into care homes and the community, all affected disabled people. Similarly, the interests of disabled people were engaged directly and indirectly by the decisions made around shielding and the clinically vulnerable.

d. Also relevant to Module 3, disabled people faced much higher costs of living and correspondingly higher levels of destitution during the pandemic, often directly because of government policy (clinical and otherwise).[4]

7. In their work with government ministers referred to above, DCC members sought to ensure that disabled people could access healthcare, and information about healthcare, during the pandemic. Specific work was done with the Cabinet Office and the DHSC to ensure that critical public health advice was accessible to disabled people. The DCC members were also a vital source of advice and information about healthcare for disabled people during the pandemic, via their helplines and frontline services. Therefore, having worked with the government, as well as with large numbers of the general public, the DCC played a direct and significant role in the matters to which Module 3 relates.

[4] https://www.jrf.org.uk/report/financial-impact-covid-19-disabled-people-and-carers

8. The DCC's members also carry extensive institutional knowledge about disabled people in the UK and the state of enjoyment of disabled people's rights generally. This is an important backdrop against which the virus and the response to the pandemic unfolded.

9. Finally, as noted by the Chair in her Core Participant determination, as "a coalition of leading disability charities in the UK the [DCC] can assist the Inquiry in understanding the experiences of healthcare and healthcare systems from the perspectives of a broad range of disabled patients, as well as assisting the Inquiry with understanding the perspectives of and impact on those deemed or those who may have been deemed clinically vulnerable." The DCC will to the greatest extent possible, critically where necessary, assist the Inquiry in fulfilling its crucial role in understanding the pandemic and avoiding the mistakes of the past being remade in the future.

Other modules

10. The DCC and its members have already notified the Inquiry of numerous specific concerns and issues which in its view fall within the provisional scope of Module 3. These are referred to further below. However, for the avoidance of any doubt, the DCC's interest in and capacity to assist with the Inquiry's work is not limited to the subject matter of Module 3. It should be acknowledged that at this stage the DCC's understanding of precisely what will be covered in Module 3 as opposed to future (and, to some extent, current) modules is necessarily limited by the absence of clarity from the Inquiry. The DCC understands that Core Participants in other modules have raised the importance of receiving further particularisation about the scope of the modules as and when the

Inquiry can provide it. The DCC respectfully makes the same request.

General points

11. The DCC wishes to make three general points at the outset before addressing the discrete issues identified in Council to the Inquiry ("CTI")'s Note dated 14 February 2023.

12. First, without detracting from its significant role and representative capacity described above, the DCC and its members do not purport to speak exclusively on behalf of all disabled people. It is mistaken to treat disabled people as a homogenous group with the same interests and points of view. The DCC promotes as equally valid the autonomous voices of individual disabled people. It therefore believes that their experiences should be prominent in the Inquiry. Similarly, the DCC recognises the distinct perspective and important role of Disabled People's Organisations ("DPOs").

13. Second, a particular concern in Module 3 (but of general application to the Inquiry), is the risk of eliding disability with ill-health or medical vulnerability. This would obscure the necessary focus on the social model of disability (which holds that people are disabled by barriers in society and not by impairments or medical needs) and narrow unduly the scope of Module to the exclusion of the rights of disabled people. Even in a pandemic, the interests of disabled people are broader than the universal right to healthcare.

14. Third, the DCC has previously set out specific recommendations to ensure the Inquiry is accessible for disabled people (see the DCC's response to the Terms of Reference

Consultation dated 6 April 2022). These are not repeated in these short submissions, save for the offer to work with the Inquiry and the other Core Participants to improve accessibility to the highest obtainable standard.

Issues set out in the CTI Note 14 February 2023

a. Designation of Core Participants

15. The DCC may wish to make submissions on this issue once the Core Participant list for Module 3 has been publicised.

b. Provisional Outline of Scope for Module 3

16. The DCC is grateful for the provisional outline set out in the "Module 3 Provisional Scope" document and the further elaboration at §33 of CTI Note. The combination of these documents is referred to below as the "Provisional Outline".

17. Whilst encouraging clarity where possible, the DCC agrees that the Inquiry's task demands flexibility and that module scoping should be iterative, albeit that there may be room for disagreement about the degree to which this is necessary. As is acknowledged by CTI, the Inquiry's approach to Rule 9 requests for evidence will bear on the evolution of the Module's scope.

18. As stated above, the DCC has notified the Inquiry of a (non-exhaustive) list of its concerns in Module 3. Further, annexed to these submissions is a document setting out which of its concerns the DCC believes are to be addressed in Module 3 or otherwise appear more relevant to other modules. At present, there is only one issue that the DCC cannot easily place in the particulars of the

"Provisional Outline", namely "*poor coordination of healthcare services across the borders of the devolved administrations".* If necessary, the DCC will pursuant to §35 of CTI Note propose this as an additional area for consideration in Module 3.

19. It is hoped that this document will promote common understanding and efficient dialogue between the Inquiry and the DCC (and possibly other Core Participants). Moreover, the DCC endorses and supports the suggestion made by other Core Participants that the Inquiry (like other public inquiries) should develop in dialogue with Core Participants a 'List of Issues' for Module 3.

20. Finally, on provisional scope, the DCC makes two further points: (1) DCC may make additional proposals pursuant to §35 of CTI Note once it better understands the scope of Module 3 and (2) whilst the Inquiry must adhere to its Terms of Reference as per §34 CTI Note, the DCC firmly believes that the state of healthcare systems at the commencement of the pandemic was highly material to the performance of those systems during the pandemic and should remain firmly in scope.

c. Evidence gathering

Rule 9 requests

21. The Inquiry Chair has ruled against disclosure of Rule 9 requests. Core Participants in previous modules highlighted the inherent risks with this approach, which have particular significance for those concerned with potential omissions in decision making and planning (for example pertaining to children or disabled people). The

DCC shares those concerns, particularly as recipients of Rule 9 requests are to themselves "flag" important material and are not being asked to prepare Position Statements. This could work against the production of relevant material in two ways: organisations wary of being publicly criticised may be insufficiently forthcoming, whilst inexperienced organisations (such as some CSOs) may not appreciate what is expected of them.

22. The justification for the ruling also appears somewhat circular, premised as it is on Core Participants being able to engage with evidence gathering, but only with the *responses* to Rule 9 requests. This system is likely to generate additional work for Core Participants forced to deduce what information has been requested by reference only to what has been provided.

23. Ultimately, the DCC recognises that the Chair has made a ruling and does not propose to invite her to repeat it. It is also reassured by the "monthly updates" confirmed at §40 CTI Note and the general commitment to keep Core Participant engagement with evidence gathering under review (§42). This is plainly a matter to be kept under close review.

24. The DCC may in due course suggest to the Inquiry appropriate recipients of Rule 9 requests.

<u>d. Disclosure to Core Participants</u>

25. The opportunity for the Core Participants to assist the Inquiry with disclosure issues is limited, as not only are Rule 9 requests confidential, but the Inquiry is also not publishing a Disclosure Protocol or a list of obtained material that is not being disclosed to

Core Participants. This means that the work of identifying any gaps in disclosure will be undertaken without the benefit of Core Participants' direct knowledge of matters or acknowledged interest in the outcome, which is regrettable.

Expert evidence

26. Similarly, whilst the identity of experts will be shared with Core Participants, the letters of instruction will not and therefore the capacity of Core Participants to influence the obtaining of expert evidence will be somewhat limited. However, the DCC is content at this stage with the process described in §56 of CTI Note as that would seem to allow for engagement with experts *before their reports are finalised* and over and above Rule 10 questions to experts (by which time it may be too late to raise an issue).

27. The DCC looks forward to receiving confirmation of the "specialist areas in relation to which both lay and expert witnesses are likely to be giving evidence in Module 3" as per §58 of CTI Note. The DCC may in due course suggest that the Inquiry hear evidence specifically on matters related to disability.

28. As for the identity of proposed experts, the DCC acknowledges that this is a matter for the Inquiry and will only propose an expert where it is considered necessary to do so.

e. The listening exercise/Every Story Matters

29. The DCC understands that the Inquiry will (a) feed the evidence obtained through the listening exercise into the juridical process and (b) take evidence from individuals about their experiences in the normal way where relevant to possible systemic

failures. This appears to be consonant with the Terms of Reference which require the Inquiry to "listen to and consider carefully the experiences of bereaved families and others who have suffered hardship or loss as a result of the pandemic." Of course, the DCC welcomes and endorses this commitment but whether is it achieved will depend on the detail of the processes and decisions made in relation to lived experience.

30. As regards the process, the DCC again reiterates its offer to assist the Inquiry obtain the highest standard of accessibility possible for disabled people.

f. Future hearing dates

31. The DCC notes that a further Module 3 preliminary hearing will be listed in 2023. This is welcomed by the DCC as there should by then be greater understanding of various matters relevant to Module 3 process, procedure and content as foreshadowed above.

Conclusion

32. The aim of these submissions is to assist the Inquiry. The DCC looks forward to continuing to assist the Inquiry as an active and conscientious Core Participant in Module 3.

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