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7 April 2022

Dear Madam/Sir

## **Public Consultation on Covid-19 Inquiry Terms of Reference Submissions on behalf of Representative Organisations of Disabled People**

1. We act for Disability Rights UK ('DR UK'), Disability Positive, Inclusion London, Disability North, Disability Peterborough and WinVisible. Each of our clients meets the definition of a representative organisation of disabled people, pursuant to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>1</sup>; they are majority led, directed, governed and staffed by Disabled people.
2. We write to provide our clients' submissions in response to the Inquiry's Draft Terms of Reference ('ToR') and questions for stakeholders as published on 10 March 2022. This letter follows DR UK's attendance at the stakeholder meeting held on 15 March 2022.
3. Our clients support calls made by bereaved families and survivors, including those with Long-Covid, for there to be a comprehensive investigation into all aspects of the pandemic and its response. The focus of our submissions is to ensure the ToR has the capacity to ensure such an investigation into the discrete experience of Disabled people. We use the term 'Disabled people' as our clients have traditionally done, to mean people facing disabling societal barriers due to their impairments or conditions (regardless of their age). This includes physical impairments, mental ill-health, hearing impairments (including Deaf people with BSL as first language), visual impairments, learning difficulties, neurodiverse people, and those with chronic illness or fatigue.

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<sup>1</sup> See UNCRPD 'General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention' (9 November 2018)

## **Accessibility of this consultation**

4. You will recall that DR UK raised concerns with you at the meeting on 15 March 2022 as to the fairness of the consultation process given inadequate accessibility for Disabled people. Our clients acknowledge your reply of 15 March 2022 and welcome your assurance that the Inquiry website meets AA accessibility. However, it remains incumbent upon the Inquiry to provide easy read versions of the documents on the site. Those documents are currently only in pdf which is not accessible to all those who are using screen readers and so they ought to be provided in Word format. Moreover, video material should have sign language interpretation given that subtitling is not an adequate alternative but should, instead, be used as an additional aid to accessibility. As we set out below, Disabled people have suffered from a lack of adequate communication throughout the pandemic, a matter our clients anticipate will be examined in due course. It is therefore important that the Inquiry itself does not repeat those failures both to ensure Disabled people can be properly consulted and also to ensure there is faith that the impact upon Disabled people, including of inadequate communication during the pandemic, will be properly investigated.

## **Terms of Reference**

### **Question 1: Do the Inquiry's draft Terms of Reference cover all the areas that you think should be addressed by the Inquiry?**

#### **Context**

5. The context for our submissions is that throughout the pandemic the Disabled people our clients have supported have experienced mistreatment, reckless indifference and gross negligence. They have been dehumanised and afforded inadequate health care, social care and financial support in full knowledge of the harm that would be caused. This is not simply a case of thoughtlessness, but of deliberate policy decisions where disadvantageous outcomes for Disabled people should have been foreseen, but were implemented nonetheless. The Inquiry must be capable of examining and exposing this through its Terms of Reference.
6. Disabled people have died in disproportionate numbers during the pandemic. The Inquiry will be aware of ONS data that confirms that up to November 2020, Disabled people made up 59.5% of all deaths involving COVID-19. Moreover, that between 24 January and 20 November 2020 in England, the risk of death involving COVID-19 was 3.1 times greater for more-disabled men and 1.9 times greater for less-disabled men, compared with non-disabled men. Amongst women, the risk of death was 3.5 times greater for more-disabled women and 2.0 times greater for less-disabled women, compared with non-disabled women. The risk of death involving COVID-19 was 3.7 times greater for both men and women with a learning disability, compared with people

who did not have a learning disability; after using statistical models to adjust for a range of factors, a raised risk of 1.7 times remained unexplained for both sexes.<sup>2</sup>

7. The extent to which deaths during the pandemic, including this disproportionality, could have been anticipated and avoided must be properly examined.

Clarification required on the definition of “hardship and loss”

8. The Draft ToR appear broad, however our clients are concerned that there is no specific mention of Disabled people anywhere in the document with an associated risk that Disabled people’s experiences will be airbrushed out of history. The ToR’s ability to facilitate a comprehensive investigation into the impact upon Disabled people therefore depends upon its interpretation, about which we seek urgent clarification.
9. In this regard, our clients note the Inquiry intends to *“listen to the experiences of bereaved families and others who have suffered hardship or loss as a result of the pandemic”*. In addition to dying in disproportionate numbers, Disabled people have suffered disproportionate hardship and loss in the pandemic response across all aspects of their lives. This was acutely felt by those who were not placed on the ‘clinically vulnerable’ list at all or notified far too late. Specifically, hardship has been experienced by Disabled people in relation to necessities being inaccessible including: food, medical and social care, financial support, PPE & testing kits, education, ongoing employment, social contact and exercise.<sup>3</sup>
10. There has also been hardship in accessing vaccines due to poor and inaccessible communication and a lack of consistent prioritisation for ‘clinically vulnerable’ people. At the moment, we are not clear whether an examination of this government failure is covered by the ToR’s reference to *“the development and delivery of therapeutics and vaccines”*. It ought to be included.
11. All of the above hardship has impacted upon Disabled people’s physical health, mental health and emotional wellbeing. For many Disabled people, periods when social distancing measures have been relaxed have provided little respite from hardship given their ongoing need to shield, for their carers to shield, and associated fear of contracting the virus. Moreover, detrimental changes to social care provision through Care Act easements introduced by the Coronavirus Act, have served to attack the wellbeing of disabled people at a time of enhanced need.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020>

<sup>3</sup> See for example [“Locked Down and Abandoned, Disabled people’s experiences of Covid-19” \(February 2021\)](#)

12. Our clients therefore seek urgent clarification that the “*hardship or loss*” suffered by Disabled people which is to be examined will include hardship associated with all of the above matters in both residential care as well as private domestic settings and at Disabled people’s places of work.

#### Decision making and communications

13. Our clients welcome the draft ToR’s proposed commitment to investigate how decisions were made and implemented. This should encompass any failure to adhere to the Equality Act and the common law duty to consult.
14. Throughout the pandemic, our clients have lobbied responsible authorities, raising alarm bells as to the loss and harm suffered by Disabled people as a result of both the pandemic and its associated policy response. They have provided concrete examples of the hardship and loss suffered by Disabled people across the country. They have warned of Disabled people suffering discriminatory outcomes, risks to life and risks of inhuman and degrading treatment. We invite the Inquiry to examine failures on the part of the authorities to give due weight to those communications in their decision making as well as the impact of those failures.
15. Our clients welcome the proposed examination of how decisions were communicated. Disabled people have suffered inaccessible, inaccurate and delayed communication in breach of Human Rights Act and Equality Act obligations, even where those communications were essential for Disabled people to understand what decisions they needed to take to keep themselves safe.

#### Equality Act and intersectionality

16. Our clients note specific reference to the examination of disparities in the impact of the pandemic with regard to Equality Act 2010 protected characteristics. In this regard they expect the Inquiry will also examine how protected characteristics such as race, ethnicity and disability have combined to produce even worse outcomes for Disabled people.

#### Amendment to ToR to include reference to the Human Rights Act

17. Our clients seek amendment to the draft ToR to state that the Inquiry will “*consider compliance with the requirements imposed by the Human Rights Act 1998*”. The UK government is under a positive obligation to take appropriate measures to protect the life and health of those within their jurisdiction.<sup>4</sup>
18. As matters stand, not least given the explicit reference to the Equality Act, the omission of the Human Rights Act appears deliberate and our clients

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<sup>4</sup> See e.g. Vavřička and Others v. the Czech Republic [2021] [GC], § 282.

struggle to see why it has not been included in the ToR given that it specifies what rights Disabled people have had throughout the pandemic, and there is an existing framework under the Act for assessing whether the state has met those obligations. At the gravest end of the scale our clients are deeply concerned at the use of 'Do not attempt cardiopulmonary resuscitation' (DNACPR) decisions in relation to Disabled people. A Human Rights Act compliant investigation as to whether the state met its obligations to those who have died in the context of a DNACPR can only be undertaken with reference to the State's obligations under Article 2 ECHR (right to life) and Article 3 ECHR (prohibition of inhuman or degrading treatment), read in conjunction with the state's obligation not to discriminate against individuals in their enjoyment of convention rights pursuant to Article 14 ECHR. All of this is in addition to the inquiry's focus on discrimination against those with protected characteristics under the Equality Act.

### Placing victims at the heart of the process

19. Our clients note the Inquiry "*will not investigate individual cases of harm or death in detail*" however it is only through considering representative examples of harm that Disabled people's experiences can be brought to life and the true impact of the hardship suffered can be understood. Any assessment of proportionality in the state's planning & response must place the experience of those affected at the heart of the process. Policies and practices must be considered in the context of the harm which ought to have been anticipated and which ultimately was experienced by Disabled people.

### **Question 2: Which issues or topics do you think the Inquiry should look at first?**

20. We note that the ToR covers matters "*up to and including the Inquiry's formal setting up date*". The current situation facing Disabled people is dire and requires urgent, independent examination.
21. Our clients support Disabled people across the country who have been left to fend for themselves in the context of increased anxiety around contracting the virus with free testing and social contact restrictions all but abandoned. For at-risk people, this means even the most basic excursions on public transport, to shops and to places of work carry with them an enhanced risk. Many Disabled people are fearful to take this risk but face a stark choice: either leave their residence and take the risk of death or serious injury, or refuse to work and face financial hardship up to destitution.
22. Social care support has been reduced under the guise of the Care Act easements under the Coronavirus Act. Despite those easements having expired, the level of care support for Disabled people has not returned to pre-pandemic levels in practice. This has compounded the cost of living crisis for Disabled people causing significant harm.

23. One of the most pressing issues for examination is therefore current government policy and its disproportionate impact on Disabled people. In our submission this calls for immediate examination given its ongoing life-or-death impact.

**Question 3: Do you think the Inquiry should set a planned end-date for its public hearings, so as to help ensure timely findings and recommendations?**

24. Our clients agree the Inquiry ought to set a planned end date. However, this should not be at the expense of a thorough process that is fully accessible to Disabled people.
25. Whilst setting an end date, the Inquiry should commit to making interim recommendations at the earliest opportunity in relation to matters which can urgently save life and reduce significant harm to Disabled people. We would submit that the impact of the current reduction in COVID-19 measures on Disabled people provide the paradigm example of an area where recommendations are urgently required before identifying what other lessons can be learned.

**Question 4: How should the Inquiry be designed and run to ensure that bereaved people or those who have suffered harm or hardship as a result of the pandemic have their voices heard**

26. The Inquiry proceedings must be run in a manner which is accessible to Disabled people both in the conduct of hearings and its communications with the public.
27. The Inquiry would benefit from a modular format and in that context there ought to be a discrete focus on the impact on Disabled people of the measure/policy response being examined. The vastly disproportionate impact on Disabled people of both COVID-19 infection and the policy response in terms of harm suffered merits this approach.
28. We shall be writing further with an application for Core Participant status on our clients' behalf and note that a protocol for such applications is awaited. Without prejudice to such other matters as we may be instructed to advance, Disabled people's representative organisations should be granted Core Participant status so they can best assist the Inquiry by, amongst other things, gathering evidence from those they work to support, identifying systemic issues affecting Disabled people across the country, and ensuring there can be two-way communication with Disabled people on the Inquiry's work.
29. Disabled people's representative organisations should be placed on a level playing field with the government and have equal access to legal representation at public expense.
30. Finally, there must be space for individual cases to be ventilated in inquiry hearings - especially those which are representative of a systemic

problem - to ensure harm can be properly understood. Those who suffered it, and representative groups supporting them, should be invited to give evidence about their experiences.

31. We trust this letter has been of assistance and look forward to hearing from you as soon as practicable.

Yours faithfully

A handwritten signature in black ink, appearing to be the initials 'BM' in a cursive, stylized font.

**Bhatt Murphy**