## MODULE 2:

SUBMISSIONS ON BEHALF OF DISABLED PEOPLE'S ORGANISATIONS: DISABILITY RIGHTS UK, DISABILITY ACTION NORTHERN IRELAND, INCLUSION SCOTLAND AND DISABILITY WALES

### I. Introduction

- These submissions are made by the Disabled People's Organisations ('the DPOs') that have been granted Core Participant Status in Module 2 of the Covid-19 Public Inquiry: Disability Rights UK, Disability Action Northern Ireland, Inclusion Scotland and Disability Wales.
- 2. All four organisations are run by and for Disabled people: they are majority led, directed, governed and staffed by Disabled people.<sup>1</sup> They use the term 'Disabled people' to mean people facing disabling societal barriers due to their impairments or conditions (regardless of their age). This includes physical impairments, mental health conditions, hearing impairments, deaf people with BSL as their first language, visual impairments, learning difficulties and neurodiverse people.
- 3. The Terms of Reference for the UK Covid-19 Inquiry require the Inquiry to consider disparities evident in the impact of the pandemic on different categories of people. In her Opening Statement for the Inquiry in July 2022, the Chair referred to her commitment that inequalities will be at the forefront of the Inquiry's investigations

<sup>&</sup>lt;sup>1</sup> The organisations meet the definition of a representative organisation of Disabled people pursuant to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) see further UNCRPD General Comment No.7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention (9 November 2018).

when investigating all these issues.<sup>2</sup> She reiterated this commitment most recently in her decision to grant the DPOs status as core participants in Module 2.<sup>3</sup> With this commitment in mind, the DPOs welcome the Chair's recognition that they are well placed to assist the Inquiry as to whether the interests of Disabled people and those with pre-existing health inequalities were considered as part of the process of core political and administrative decision making.

- 4. During the pandemic, the risk of death from Covid-19 was far greater for Disabled people compared to non-disabled people:
  - a. In England, a study of Covid-19 mortality rates from January to 20 November 2020, found that Disabled people in England made up 59.5% of deaths involving Covid-19.<sup>4</sup> The risk of death involving coronavirus was 3.1 times greater for more disabled men compared with non-disabled men and 3.5 times greater for more-disabled women compared with non-disabled women.<sup>5</sup>
  - In Wales, a study of Covid-19 related deaths by disability status between 2
    March to 14 July 2020 found that the mortality rate for Disabled people was almost 7 in 10 (68%) of all deaths involving Covid.<sup>6</sup>
  - c. In Scotland, a study of mortality rates between March 2020 and January 2021, found that deaths of Disabled people accounted for almost 6 in 10 (58%) deaths involving COVID-19 in the study population (4,333 of 7,490 deaths). After adjusting for age, disabled women whose daily activities were limited a lot were 3.2 times as likely to die with COVID-19 compared to non-disabled

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

<sup>&</sup>lt;sup>2</sup> UK Covid-19 Inquiry Opening Statement, July 2022 at p.8

<sup>&</sup>lt;sup>3</sup> Partial Grant of CP Status for Disabled People's Representative Organisations

<sup>&</sup>lt;sup>4</sup> ONS, Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020 available at:

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

<sup>&</sup>lt;sup>5</sup> ONS, Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020 available at:

<sup>&</sup>lt;sup>6</sup> Coronavirus (Covid019) and the impact on Disabled people last updated 11 March 2021 available at: <u>https://gov.wales/coronavirus-covid-19-and-impact-disabled-people-html</u>

women. Disabled men whose daily activities were limited a lot were 3.0 times as likely to die with COVID-19 compared to non-disabled men.<sup>7</sup>

- d. In Northern Ireland, a study of Covid-19 mortality rates between March 2020 to September 2020 showed that the age-standardised mortality rate for Disabled people whose activities were limited 'a lot' was 111.4 per 100,000 persons and 71.2 per 100,000 for those whose activities were limited 'a little'. This was significantly higher than the rate for those without a disability: 48.5 per 100,000.<sup>8</sup>
- 5. It is important to contextualise the disproportionate impact of the pandemic on Disabled people in terms of the greater risk of harm from Covid-19 as well as the effect of decisions taken in response to the pandemic on them. Many Disabled people suffered disproportionate hardship as a result of the failure to consider their needs when imposing non-pharmaceutical interventions (NPIs) including the national lockdowns. These measures resulted in Disabled people experiencing unequal access to emergency health treatment, social isolation and psychological distress, difficulties accessing food, medicine, personal protective equipment, social care, housing benefits and other basic necessities.<sup>9</sup> The persistent failure to consider Disabled people in public health communications also had a significant impact. For example, unbalanced government messaging on face covering policies in early 2020 resulted in Disabled people facing discrimination and hostility over the implementation of the face coverings policy.<sup>10</sup>

https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/Covid%20by%20S75%20provisional%20report %20-%20updated%207%20feb.pdf

https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Finclusionscotland.org%2Fwp-content%2Fuploads%2F2021%2F05%2FInclusion-Scotland-Shielding-Report-July-

<sup>&</sup>lt;sup>7</sup> Deaths involving coronavirus (COVID-19) in Scotland, Week 11: Report (nrscotland.gov.uk)

<sup>&</sup>lt;sup>8</sup> NISRA, 'Covid-19 Deaths in Wave One: Analysis of Equality Group, Health and Socio-demographic characteristics, 21 December 2021 available at:

<sup>&</sup>lt;sup>9</sup> See for example Inclusion Scotland's Report, Disabled people's lived experience of shielding: Key survey Results available at:

<sup>&</sup>lt;u>2020.docx&wdOrigin=BROWSELINK;</u> See also ONS, Coronavirus and the social impacts on Disabled people in Great Britain: September 2020 available at:

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirus andthesocialimpactsondisabledpeopleingreatbritain/september2020

<sup>&</sup>lt;sup>10</sup> DRUK, Disabled people still facing discrimination over face coverings, 14 July 2020 <u>https://www.disabilityrightsuk.org/news/2020/july/disabled-people-still-facing-discrimination-over-face-coverings</u>

- 6. Disabled people's experiences cannot be considered in isolation from other protected characteristics that they may have. An intersectional analysis of their experiences in the pandemic is important to understand the differential impact of the pandemic on Disabled people.
- 7. Throughout the pandemic, all four DPOs actively advocated for Disabled people's interests to be considered by relevant decisions makers during the pandemic. They have a significant interest in the Inquiry's investigations because of the profound impact of the pandemic on Disabled people.
- Drawing on their experience advocating on behalf of Disabled people during the pandemic, the DPOs are committed to assisting the Inquiry in their investigations in Module 2.

## II. Reasonable Adjustments

- 9. Conscious of the disproportionate impact of Covid-19 on them, many Disabled people maintain a keen interest in the Inquiry and given all they have been through it is important they have confidence in these proceedings. The DPOs are aware that Disabled people would like to follow the Inquiry proceedings and/ or view a record of evidence and documents or procedures provided to the Inquiry. The absence of reasonable adjustments can be a significant barrier to access.
- 10. Section 19(1) of the Inquiries Act provides that the Chair must take such steps as she considers reasonable to secure that members of the public are able (a) to attend the inquiry or to see and hear a simultaneous transmission of proceedings at the inquiry and (b) to obtain or to view a record of evidence and documents given, produced or provided to the Inquiry or inquiry panel.
- 11. In order to fulfil the statutory duties under section 19(1), the DPOs respectfully ask whether the Inquiry has carried out a review of barriers to access to the Inquiry

proceedings for Disabled people. The Inquiry is strongly encouraged to work from a social model of disability – identify the barriers and remove/ mitigate them.<sup>11</sup>

12. Simple measures can be instituted which have a profound effect on Disabled people's access and by extension participation in public proceedings. An obvious simple measure may be the completion of an access statement based on an audit for how the Inquiry will be run. Other measures which can facilitate access could include:

## a. Accessible Inquiry proceedings:

- Access for wheelchair users and those with mobility impairments (e.g. level access, turning spaces, accessible toilets)
- ii. Access for those with visual impairments (e.g lighting, contrast, tactile surfaces)
- iii. Access for those with hearing impairments (e.g. hearing loops)
- iv. Accessible correspondence
- v. Have staff available who can assist people requiring support;
- vi. Support for experts/people giving evidence (e.g. guides, advocates and BSL interpreters)
- vii. Support for people with a Learning disability human support as well as easy read

## b. Accessible communication of proceedings:

- i. Live streaming with captioning/ British Sign Language
- ii. Easy Read communications
- iii. Screen reader friendly online documents
- iv. British Sign language videos
- 13. The DPOs would invite the Inquiry to review whether any reasonable adjustments are required to the transmission of proceedings and publication of evidence produced or provided to the Inquiry. They remain available and willing to work with the Inquiry to identify additional reasonable adjustments which could be instituted for Disabled

<sup>&</sup>lt;sup>11</sup> DRUK, Social Model of Disability: Language, <u>https://www.disabilityrightsuk.org/social-model-disability-language</u>

people recognising that people are 'disabled' by multiple and varied barriers operating in society that exclude and discriminate against them.

14. Turning to the issues on the Agenda, these are considered in order and only those items that the DPOs are addressing are listed here.

# i. Scope of Module 2

- 15. The DPOs note the scope of Module 2 will consider and make recommendations about the UK's core political and administrative decision-making in relation to the Covid-19 pandemic between early January 2020 to February 2022. Module 2 will consider both reserved and devolved matters in respect of Scotland, Wales and Northern Ireland in Module 2, Modules 2(A), 2(B) and 2(C).
- 16. The extent to which administrative and political decision making took into account the interests of Disabled people and the impact upon them is at the crux of the DPOs engagement in Module 2. The relevant decision makers in Module 2 were subject to the public sector equality duty (PSED) and in the exercise of their functions, they were expected to have due regard to the need to eliminate discrimination and advance equality for Disabled people and others sharing a protected characteristic. A failure to do so would only serve to perpetuate inequalities including inequality of treatment of Disabled people. It is only right then that the Inquiry will consider inequalities when investigating all the issues within the Terms of Reference.<sup>12</sup>
- 17. On review of the Scope of Module 2, the DPOs observe that inequalities is addressed only once at (3). If inequalities are truly to be at the forefront of the Inquiry's investigation, they should be threaded through the 6 elements of the scope of the Module. The DPOs would expect inequalities (including differential treatment of Disabled people) would be incorporated into each aspect of the scope. In the absence

<sup>&</sup>lt;sup>12</sup> UK Covid 19 Inquiry Launch Statement p.8

of explicit reference to inequalities in (1), (2), (4), (5) and (6), they propose the Inquiry amends the scope to incorporate the following additions:

- "And the extent to which individuals with protected characteristics including Disabled people were represented in central and devolved government structures and bodies";
- (2) "And the extent to which the government's development of initial strategies took into account inequalities";
- (3) [inequalities have been addressed]
- (4) "And the extent to which inequalities were factored into the approach to data collection and modelling and the dissemination of data on inequalities between government departments and between the government, the NHS and the care sector;"
- (5) "And the extent to which inequalities were factored into public health communications";
- (6) The public health and coronavirus legislation and regulations that were proposed and enacted: their proportionality and enforcement "<u>in view of</u> <u>inequalities".</u>
- 18. The DPOs raise two further matters in relation to scope. First, the DPOs, in particular Inclusion Scotland, have considered Counsel to Inquiry (CTIs) comments at §22 of his Note for the Preliminary Hearing for Module 2 in relation to avoiding duplication with the Public Inquiry on Covid-19 in Scotland. They also note that the Terms of Reference require the Inquiry to "set out publicly <u>how</u> it intends to minimise duplication" with any other public inquiry established by the devolved governments (emphasis added).
- 19. The Inquiry is invited to clarify how duplication of investigation, evidence gathering and reporting with the Public Inquiry into Covid-19 in Scotland will be minimised. If this is by way of a memorandum of understanding between the UK Covid-19 Public Inquiry and the Scottish Public Inquiry, it would be helpful for all relevant Core Participants to have sight of that agreement.

- 20. Secondly, the DPOs welcome CTI's commitment to develop the issues included within the scope of Module 2 public hearings (§38 of CTI's Note). The DPOs would invite the Inquiry to prepare a draft list of issues which can be shared with Core Participants. A list of issues will help Core Participants to understand how the Inquiry will focus their investigation in Module 2 where the scope at present admittedly introduces a "wide range of topics" (§37 of CTI's note).
- 21. In addition, and in accordance with the Chair's expectation that they are well placed to assist the Inquiry, the DPOs will be able to comment upon whether the breadth of issues is sufficient and if it is not, to usefully suggest further issues to be considered drawing on their experience. For example, the DPOs experience of engaging with UK Government decision making during the pandemic was that the Government was siloed and that each department failed to coordinate especially in relation to the needs of Disabled people. This meant that there was frequently a failure to take responsibility for considering Disabled people's needs when making decisions affecting them. The DPOs have also experienced different approaches in the Devolved Nations and consider that both the fact of differential treatment as well as its causes ought to be explored. Another concern is that there was a regression from the progress made towards moving to a 'social model' approach to disability rights before the pandemic. During the pandemic, the response reverted to a 'medical model' of considering vulnerability which focuses on treating, managing and curing people with impairments and views them as vulnerable and passive recipients of care. This had a significant impact on Disabled people's wellbeing and in some cases resulted in significant harm. An example of this was the approach to the 'vulnerability list' which was based on degrees of how medically unwell a person was. There was inadequate consideration or identification of individuals who were at risk due to their dependency on social support to access food, essentials and maintain dignity.
- 22. Early sight of a draft list of issues would assist the DPOs to know whether those issues and other related issues are being considered by the Inquiry during their investigations. The DPOs note that many Public Inquiries have adopted a list of issues,

often in consultation with Core Participants, and it has become recognised good practice.<sup>13</sup>

23. The DPOs would suggest that a draft list of issues is shared before the next procedural hearing as the substantive hearings are due to begin in Summer 2023. It is anticipated that the Inquiry may have received sufficient responses to Rule 9 requests by this stage to prepare a draft list of issues. This will also provide for sufficient time for Core Participants to engage with the list of issues and provide further submissions if necessary before the substantive hearings.

## ii. Rule 9 requests

- 24. DPOs have noted that the Inquiry has sent a Rule 9 Request to all organisations listed at §40 of CTI's Note. In respect of the Rule 9 requests, the DPOs raise three further matters:
  - a. They would seek clarification that a Rule 9 request has been sent to:
    - i. the Department for Disabled People, Work and Health which sits under the Department for Work and Pensions (listed at §40(n))
    - ii. the Disability Unit which sits within the Cabinet Office (listed at §40(b))
  - b. If not already addressed in the existing Rule 9 requests, they would encourage the Inquiry to consider a further Rule 9 Request to the relevant organisations and departments asking whether they considered themselves responsible for assessing the impact of their decisions in relation to the pandemic on Disabled people and if not, who they thought held that responsibility.
  - c. All organisations have also been requested to provide a chronology and a corporate statement setting out a narrative of relevant events and the lessons

<sup>&</sup>lt;sup>13</sup> Beer KC, *Public Inquiries*, Oxford, OUP, 2011 at §5.21; Post Office Horizon IT Inquiry Completed List of Issues: <u>https://www.postofficehorizoninquiry.org.uk/publications/completed-list-issues;</u> Grenfell Tower Inquiry Updated List of Issues: <u>https://assets.grenfelltowerinquiry.org.uk/inline-</u>

<sup>&</sup>lt;u>files/List%20of%20Issues%2025%20September%202019%20%281%29.pdf;</u> UCPI has published four issues lists for Module 1 and 2 after consultation with core participants to date

https://www.ucpi.org.uk/evidence/#issues-lists; Infected Blood Inquiry – Revised List of Issues https://www.infectedbloodinquiry.org.uk/sites/default/files/2020-09/2020-10/Amended%20List%20of%20Issues%2027.9.2021.docx.pdf

learnt (§45 and 50 of CTI's note). The DPOs would suggest that the Inquiry asks for the Corporate Statements to also address each organisation's understanding of its responsibilities, remit, processes, policies and resources in place at the time. These factors will inform Core Participants understanding of the organisation's position in relation to the narrative of relevant events and it will put into context any lessons that are purported to have been learnt.

#### iii. Disclosure

- 25. The DPOs welcome the Chair's commitment in her Ruling on Module 1 that the Inquiry will be "as open as possible with Core Participants and with the public in relation to the disclosure of documents." This is in recognition of the purpose of disclosure being to enable Core Participants to participate effectively in public hearings (§10 of M1 Ruling). The Chair confirmed that the Inquiry's approach was to request documents "relevant to the issues and matters identified in a particular module." (§11 of M1 Ruling). With these commitments in mind, the DPOs raise a number of discrete issues in respect of disclosure.
- 26. First, in contrast to the Chair's Module 1 Ruling, CTI has indicated in his note for the preliminary hearing for M2 that some document providers will not be required to provide all documents relevant to a particular theme or area but instead to only provide documents relevant to "*key narrative events, the decision making procedures of those bodies and persons relevant to the core political and administrative decision-making and the core decisions themselves.*" (§44 of CTI's Note). The DPOs would request, in the first instance, disclosure of i) the key narrative events ii) the scope of the decision making procedures subject to the request iii) the persons considered relevant to the core political and administrative decision making and iv) the core decisions. The DPOs would also request confirmation as to whether it was the Inquiry or the Core Participant who identified the key narrative events, the scope of decision making procedures, persons and core decisions.

- 27. As this is a narrowing of the relevance test that the Chair committed to in her Module 1 Ruling, it is submitted that the DPOs and other Core Participants should be provided with an opportunity to make observations on that list of key narrative events, scope of decision making procedures, persons and core decisions. There is a real risk that disclosure following the current process could exclude relevant material. This risk is aggravated by the absence of an agreed list of key narrative events (and a list of issues) where the outline scope of Module 2 introduces such a wide range of topics.
- 28. Secondly, the DPOs would also request disclosure of the accounts provided by document providers of their document reviews including how documents were stored and search terms used (§16 of Module 1 Ruling). As part of this process, document providers should be requested to confirm if relevant information was deleted before or after they were asked to take steps to retain material potentially relevant to the Inquiry. This may include confirming if relevant decision makers shared information and conversations on Whatsapp, Signal and Cabinet Office instant chat applications and if those conversations/ information were not recorded.
- 29. The disclosure process described by CTI entails a significant degree of trust in the document provider undertaking a thorough disclosure review. In these circumstances, the document providers' process for identifying relevant documents must be subject to closer scrutiny and transparency.
- 30. Third, the DPOs would encourage the Inquiry to request equality impact assessments especially in relation to non-pharmaceutical interventions as well as other matters being investigated in Module 2. If an equality impact assessment was not carried out for a relevant decision, it would be helpful for the relevant organisation or department to confirm this and explain why.

#### iv. Expert witnesses

31. DPOs welcome CTIs commitment to disclose the identity of the witnesses and the questions that they will be asked to address (§65 of CTI's note). On this point, the

DPOs request that they are provided with the opportunity to provide observations on expert witnesses and their instructions at an early stage. The DPOs are acutely aware that the Inquiry is proceeding on a strict timetable and that a number of expert witnesses have already been approached. For them to be able to make meaningful contributions to the instructions and identity of the expert witnesses, there must be early disclosure.

### v. Listening Exercise and Evidence to be provided to the Inquiry

- 32. The DPOs have concerns about the listening exercise and raise three short points in this regard:
  - a. The DPOs seek assurances that this will not become a platform for a limited number of people who do not face barriers to accessing the listening exercise. The DPOs are acutely conscious that there is a danger of certain groups and their harmful experiences being air brushed out of history if reasonable adjustments are not made. The DPOs welcome the observation in STI's note regarding the Listening Exercise and Commemoration, that the Inquiry will be looking at ways to make the Listening Project "accessible to as many people as possible." (§1.7). However, they seek further information of what this means in practice including what reasonable adjustments are proposed to enable the project to obtain evidence from anyone who will want to share their experience (§1.7 of STI's Note). In this respect they would encourage the Inquiry to consider how they will seek out and support voices from people who may face barriers to participate. In any such exercise, an outreach strategy is important to ensure that particular groups and populations are included and not overlooked.
  - b. Secondly, the DPOs would encourage the Inquiry to consult with the DPOs and other affected persons in the development of the listening exercise. The DPOs emphasise that whether individual people's experiences can evidence systemic issues depends on the way the evidence is obtained, interpreted and analysed before key themes are drawn out. This can only be done effectively

if the people and organisations that have relevant lived experience are involved.

- c. Finally, the listening exercise cannot replace the need to hear direct personal testimony in the Inquiry proceedings. As the Chair noted in her Module 1 Ruling, evidence of the circumstances of death should be admitted if it is relevant to possible systemic failings [§40]. This extends equally to evidence of individual suffering caused during the pandemic due to systemic failings. Disabled people suffered during the pandemic first because they were at greater risk of dying from Covid-19 and secondly, because they were disproportionately impacted by decisions taken in response to the pandemic. There was a failure throughout the pandemic to consider Disabled people's needs and how reasonable adjustments might need to be made. Anonymised evidence cannot do justice to their experiences and context may be lost. The Inquiry is strongly encouraged to recognise the need for some individuals whose experiences provide examples of possible systemic failings to be called to give evidence. Direct personal testimony within the Inquiry proceedings from Disabled people and others is essential to ground the Inquiry in what happened, the human impact and the cost to people.
- 33. The DPOs remain willing to assist the Chair and her team in their Investigations in Module 2.

SHAMIK DUTTA BHATT MURPHY SOLICITORS SHANTHI SIVAKUMARAN DOUGHTY STREET CHAMBERS 27 October 2022

On behalf of: Disability Action Northern Ireland Disability Rights UK Disability Wales Inclusion Scotland