

Disability Charities Consortium consultation response on draft Terms of Reference for Covid-19 Inquiry

Submitted 07/04/2022

Which organisation are you submitting feedback on behalf of?

The Disability Charities Consortium (“DCC”). We are a coalition of leading disability charities in the UK, made up of the Business Disability Forum, Leonard Cheshire, Mencap, Mind, National Autistic Society, Royal National Institute of Blind People, Royal National Institute for Deaf People, Scope, and Sense. The DCC has been in existence for over fifteen years and facilitates co-ordination of activity and communication between disability charities in the UK. This submission made on behalf of all members of the DCC.

1. Do the Inquiry’s draft Terms of Reference cover all the areas that you think should be addressed by the Inquiry?

Background

The Disability Charities Consortium (“DCC”) broadly welcomes the Terms of Reference (“ToR”), and, in particular, the focus on disparities evident in the impact of the pandemic and the state’s response, including those relating to protected characteristics under the Equality Act 2010 and equality categories under the Northern Ireland Act 1998.

It is however important to consider DCC’s response to this consultation in the context of disabled peoples’ experiences during the pandemic. At the end of 2020, data from the Office for National Statistics revealed that of the 50,888 Covid-19 deaths that happened between January to November 2020, 30,296 were disabled people. Disabled people, who account for 22 per cent of the population, made up 6 in 10 deaths.

Both at the start and throughout the pandemic, disabled peoples’ rights were regarded as an “add on” or discarded in favour of general population strategies. Much of government response around care and support focused on older people and didn’t take into account the needs of working age disabled people and the variety of services they use.

The pandemic has exacerbated existing inequalities as well as creating new ones. It demonstrated that pre-existing legislation wasn’t being implemented and didn’t provide the safeguarding measures it should have, to protect and prioritise the needs of disabled people. Throughout the pandemic there has been a lack of meaningful engagement with the groups most impacted, including disabled people.

The Inquiry is an opportunity to learn lessons and take recommendations forward for daily life, as well as future pandemic responses, allowing us to tackle some of the long-term and persistent inequalities that exist. We want to see practical steps taken to ensure disabled people’s needs are understood and prioritised now and in the future. When preparing for future pandemics there must be more robust processes in place to ensure those who are most impacted are consulted with and able to influence and shape policies.

Overarching points

In that context, we make the following overarching points in response to the draft ToR.

Given the overwhelmingly disproportionate impact on disabled people summarised above, we submit that specific reference should be made to the impact on disabled people and their carers.

We believe that the Inquiry's consideration of disabled people should accord with the 'social model' rather than the 'medical model' of disability. The 'social model' holds that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them.

The ToR includes the governments' response, and the impact of the pandemic, up to and including the formal setting-up date of the inquiry. This is a relatively restricted period, given that disabled people continue to experience the impact of the pandemic and governments' response. It is vital that the inquiry therefore recognises and investigates both the short and long-term impacts of the pandemic and response and, to the extent possible, how they might be mitigated in the future.

Whilst we welcome the reference to the Equality Act and the related provisions in Northern Ireland, we believe that the Inquiry should also explicitly take a human rights-based approach. We note that the ToR for the public inquiry to examine the handling of the COVID-19 pandemic in Scotland state that "the inquiry will, as the chair deems appropriate and necessary, consider the impacts of the strategic elements of handling of the pandemic on the exercise of Convention rights (as defined in Section 1 of the Human Rights Act 1998)." We submit that similar wording should be included in ToR for the UK Covid inquiry. In addition, the Inquiry should where appropriate take account of material international human rights law, including most relevantly the UN Convention on the Rights of Persons with Disabilities ("UNCRPD"). We respectfully suggest that the Inquiry would be incomplete and risk failing disabled people if it did not consider in particular the rights of disabled people to live independently and access the community (Article 19 UNCRPD).

The draft ToR includes how decisions were made. In this respect, the absence of equality impact analysis by all forms of government when making decisions during the pandemic is striking. This must be a central aspect of the inquiry: how did governments seek to understand who would be impacted and how by their decisions so that they could minimise the impact and consequences for those people as much as possible? What data - particularly about disabled people's lives - was used to make decisions and understand the impact and consequences of those decisions?

We also submit that the inquiry should examine how decisions were communicated - to the public, to healthcare and social care providers and to employers and businesses. This has particular importance for many disabled people.

We make the following specific proposals in response to the draft ToR:

i. Central, devolved and local public health decision-making and its consequences.

Significant changes were made to transport as a response to the pandemic, both temporarily and permanently. Again, this had relevance for many disabled people and we suggest that "transport" merits a separate bullet point under this heading.

- Shielding and the protection of the clinically vulnerable;

We strongly submit that there should be a specific reference to the impact on disabled people. There has been confusion about the categorisation of most vulnerable groups throughout the pandemic; many disabled people were not categorised as ‘vulnerable’ but still needed to shield. Other disabled people may still have been societally vulnerable and so at greater risk as a result of, for example, underlying conditions, through living in areas of deprivation, or lack of access to support such as priority shopping or household finances or vaccine priority. We also know that many disabled people with long term conditions may have missed diagnoses and/or treatments.

ii. **The response of the health and care sector across the UK, including:**

- The management of the pandemic in hospitals

We note the reference to DNACPR decisions in relation to the management of the pandemic in hospitals. DNACPR decisions outside of hospitals must also be considered – in particular, decisions by GPs regarding people living in the community.

- the management of the pandemic in care homes and other care settings, including infection prevention and control, the transfer of residents to or from homes, treatment and care of residents, restrictions on visiting, and changes to inspections;

It is important to ensure that “other care settings” includes health and care provision within peoples’ homes. There should also be specific reference to unpaid carers, who experienced many of the same issues as the health and care sector, often without the formal support which was provided to that sector. Restrictions on visiting should also clearly refer to visits in care settings and visits out of care homes – where different regulations applied. The disruption to many disabled adult’s lives through lack of routine visits to their family has had a significant impact.

- the consequences of the pandemic on provision for non-COVID related conditions and needs;

We submit that there should be specific reference to disabled adults and their carers within this section, for the reasons provided above.

In our view, the distinction in the ToR between the first two headings at (i) and (ii) above is not clear – it is not apparent where decisions made by government in relation to the health and care sector would fall to be considered. Our primary submission is that the provision of social care generally during the pandemic is critical and should be referred to in the ToR.

We cannot realistically set out here all of the issues which require consideration, but by way of example, the Coronavirus Act 2020 downgraded a wide range of adult social care duties under the Care Act 2014, and also impacted on other medical treatments and processes.

iii. **the economic response to the pandemic and its impact, including government interventions by way of:**

- benefits and sick pay, and support for vulnerable people.

This should be expanded to refer to disabled people as well as “vulnerable” people. There has been confusion about the categorisation of most vulnerable groups throughout the pandemic; many disabled people were not categorised as “vulnerable” but experienced disproportionate economic impacts compared to the general population. Indeed, this dichotomy between the “vulnerable” and “non-vulnerable” (or disabled) was very problematic during the pandemic and more generally – it is viewed by many as patronising and suggests a lack of agency or autonomy. It was (and is) often used without context; for example, whilst “clinically vulnerable” was capable of being understood in theory, used in isolation the term “vulnerable” is meaningless. We ask that the Inquiry avoids repeating this approach and ensures that any references to “clinically vulnerable” people are clearly defined. Employing the word “vulnerable” to describe groups of people should be avoided unless there is a clear meaning and context behind the description.

2. Which issues or topics do you think the inquiry should look at first?

We believe that the Inquiry should begin with an extended period of personal testimony from those directly and disproportionately impacted, including from bereaved families, disabled people, their families, and other groups with protected characteristics. An approach which ensures the voices of those impacted are heard first would be consistent with the Inquiry’s aim to listen to the experiences of bereaved families and others who have suffered hardship or loss as a result of the pandemic.

Thereafter, we consider that where the covid-19 response continues to impact on people with protected characteristics these issues or ‘topics’ should be prioritised. For disabled adults and their families, these include:

- shielding and the protection of the clinically vulnerable;
- testing and contact tracing, and isolation;
- the consequences of the pandemic on provision for non-COVID related conditions and need;
- the ongoing management of the pandemic in care homes and other care settings;
- the ongoing economic impact.

As explained in response to question one, lessons should be learned not just to inform the UK’s preparations for future pandemics, but to inform decision-making for the current pandemic; both in respect of the ongoing impact on disabled adults and their families, and the preparedness for a new wave or vaccine resistant variant. This is why it is so important that the Inquiry considers how decisions were made – what data was used, what was missing and what is needed in future – and how and when (if at all) equality impact assessments were used.

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?

Yes.

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

For the Inquiry to be truly accountable to the public it seeks to serve it must be carried out in an accessible and inclusive way. Many of inequalities that disabled people and their families have faced throughout the pandemic stem from government bodies and agencies failing to meet basic standards of accessible communication. The ToR should state that an accessible communications policy will be developed and implemented. We believe that this should incorporate the following:

- Social media output must be fully accessible. This includes alt text on images, subtitles on any video content and BSL translation on key announcements portrayed via video on the channels
- Web content to adhere to WCAG 2.1AA - in accordance with Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018
- All publications from the inquiry to follow best practice digital document guidelines (tagging, alt text etc) to ensure maximum compatibility for those using screen readers. Accessible formats of publications must also be available, including Easy Read and BSL summaries published concurrently to ensure equal and timely access to information. There should also be clear routes of request for additional formats as people require them.
- Public evidence sessions must have live Speech to Text Reporting (STTR), sometimes referred to as live captions, and BSL interpretation as default. This also needs to be reflected in any streaming or recordings shared.
- Throughout the Inquiry, disabled people should be consulted with and offered a variety of ways to have their views and voices heard. It is important that people are supported to give evidence and are not deterred from doing so because of the formal nature of the inquiry.
- In addition to formal written submissions, we would also like to see opportunities to engage and share experiences in different ways and creatively through other platforms including video, focus groups and storytelling.
- People who are disabled and/or older are more likely to be digitally excluded. The inquiry must consider how to engage and include these groups using offline channels. Steps should be taken to ensure that the inquiry can be contacted via non digital means (currently the only option is via email) and for accessible formats of documents to be

requested. The Inquiry should also visit disabled adults in service settings to hear directly from them.

- We would be happy to assist the Inquiry to ensure that disabled people have their voices heard. For example:
- The DCC members all offer services, advocacy and work directly with disabled people. We would use our networks to engage a wide group of disability organisations and disabled people in evidence collection and promote any opportunities to be involved in consultation so that the voices of disabled people are heard.
- All DCC members run a combination of existing panels and have ambassadors and close relationships with disabled people who regularly offer their lived experience to help shape ongoing work and services. We would both support individuals to share their own stories directly and give evidence, as well as gathering and curating ourselves.
- The wide-reaching nature of the coalition will help ensure the evidence collection is far reaching and broad enough to capture a wide range of experiences, while also allowing us to reach specific organisations, if evidence is needed on particular topics, e.g. impact on social care or access to goods and services during the pandemic and employment, furlough, redundancy and redeployment.