

Question 1

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

The Disabled Children's Partnership (DCP) is a major coalition of more than 100 organisations, supported by a network of thousands of parent carers and allies, who campaign for improved health and social care for disabled children, young people and their families. A full list of members of the DCP is published on our website: <https://disabledchildrenspartnership.org.uk/about-us/>

The Disabled Children's Partnership exists to: provide a platform for the voices of disabled children and family members; challenge the inequalities and barriers in the provision of disabled children's health and social care services; improve the quality of services available; make sure families can access those services; and ensure professionals communicate with each other and work together. Throughout the pandemic, the DCP's research, campaigning and support for families spanned across education, health and social care.

The coalition is led by a Steering Group of 12 senior representatives from national charities from which the Chair and Treasurer have been appointed. The Steering Group is responsible for strategy and budget, and meets monthly to fulfil this function and provide oversight to the staff team who are hosted by one of the Steering Group members. The Steering Group consults with parent carers and the wider DCP membership to inform its' decisions through quarterly meetings, weekly newsletters and surveys. We invite two parent carers to attend all Steering Group meetings to ensure strategic decisions are made in co-production with families.

General observations

The DCP makes three overarching points in relation to the draft ToR:

1. Firstly, the DCP welcomes the wide scope of the ToR; and the commitment to listen to the experiences of those who have suffered hardship and loss as a result of the pandemic. We particularly welcome the Inquiry's aim to consider the differential impact of the pandemic and the state's response on those with protected characteristics under the Equality Act 2010.
2. We also believe the Inquiry should explicitly take a human rights based approach. We note the ToR for the public inquiry to examine the handling of the 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.
3. Currently the ToR are relatively limited in looking at the response to the pandemic in the short term and for a restricted time period. Whilst social and economic life may be returning to "normal" for many, the pandemic (and government response to it) continues to have devastating impact on disabled children and their families. For example, many social care packages were reduced during the pandemic and some have still not been reinstated at the correct level. Similarly, some disabled children who stopped attending school during the lockdowns have never returned. It is vital that the inquiry recognises and investigates the ongoing / longer term impacts of the pandemic that many disabled children, young people and families are still dealing with.

Turning to our specific proposals in response to the draft ToR:

- a) We note the ToR do not presently recognise the specific circumstances of disabled children and young people, and their families. We believe it is essential to consider the experiences of, and differential impact on, this particular group, as distinct to disabled adults, or children who are not disabled. The pandemic has exacerbated existing inequalities as well as creating new ones. Disabled children experienced the suspension of core statutory entitlements in response to the pandemic, redirection of resources and reduction in face to face support, therapies and care. This has left them isolated and abandoned. Vital support has been reduced or stopped altogether. A significant proportion of parent carers report that their

disabled child's disability or health condition worsened as a result. This has all damaged the emotional health and well-being of all family members, including disabled children's siblings.

The support disabled children and their family receive is provided by a range of services and agencies, across a number of sectors e.g. health, social care, education, across statutory and voluntary sector providers. The withdrawal of support had a cumulative effect on disabled children and families, wide reaching across various aspects of their lives.

We consider that the Inquiry should amend its ToR to expressly require investigation of the particular impact of the response to the pandemic on disabled children and their families, and that this should include the long term impact for child development, conditions, life outcomes and for the wider family. Such an approach would recognise the separate legal frameworks and different experiences of disabled children vis-à-vis disabled adults and children generally, and the wider impact on the whole family including parents, carers and siblings and their inter-related needs.

- b) In relation to the heading "central, devolved and local public health decision-making and its consequences", we believe the topics should be extended to also include:
- Mental health and wellbeing. At present, the ToR does not consider this issue. Many disabled children and their families were unable to access mental health support during the pandemic. High thresholds of need had to be met to access support and interventions provided were generic and not accessible for disabled children. In identifying lessons to be learned, we consider the Inquiry should consider the need for early intervention support for emotional and mental support, tailored to the needs of disabled children, preventing high level trauma at a later date.
 - In looking at the impact of 'restrictions on attendance of places of education', we would invite the inquiry to:
 - i. amend the ToR to make clear this should include the full range of provision that was affected; including early years, schools in both the mainstream and special school sector, colleges, alternative provision (for children unable to attend school pre pandemic) and training providers.
 - ii. Ensure that consideration of impact is not limited to educational/academic impacts, but also considers wider social and health impacts.
 - iii. We would also invite the Inquiry to amend the ToR to include not just the restrictions on attendance, but the restrictions placed on disabled children's access to special educational provision such as 1:1 support and essential therapies, when attending their places of education, as a result of the suspension of core legal duties to this group. The impact of the pandemic on children with special educational needs was particularly acute as many were unable to access any education during this period. Although the government response did not restrict attendance for children with Education, Health and Care Plans, in reality many parents were unable to send their children to school because the vital support they needed to attend was not available.
 - iv. Similarly, we consider the Inquiry should also consider the suitability and accessibility of 'remote learning' as an alternative to attendance at places of education, particularly for disabled children and children without access to suitable technology.
- c) In relation to the heading "response of the health and care sector across the UK", we consider that:
- consideration of "care homes and other care settings" should expressly include residential childcare, including residential special schools and colleges, and independent / supported living facilities. During the pandemic there appeared to be a misconception that only older people live in care homes and the impact on younger groups who accessed residential provision was often overlooked.

- Similarly, consideration of social care must not be limited to care homes, but must recognise that social care is often delivered in people's own homes or in the community – for example short breaks/respite provision, which stopped entirely for many families with disabled children.
- Finally, consideration of the health service must go beyond hospitals and also consider general practice and community services, including the provision of therapies.

Question 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, the families of disabled children 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 children and their families, these include:

- the protection of the clinically vulnerable, including those who in practice are still 'shielding';
- testing and contact tracing, and isolation;
- restrictions on attendance at places of education;
- the consequences of the pandemic on provision for non-Covid related conditions and need.

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 children and their families, and the preparedness for a new wave or vaccine resistant variant.

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?

We believe that ensuring that the Inquiry is both effective and accessible is more important than strict end-dates. As such, whilst we support a planned end-date, there needs to be flexibility to ensure timeliness it is not at the cost of effectiveness.

We fully support the need for timely findings and recommendations and consider this could be achieved through interim reports at the end of each Inquiry 'module' or topic. This will also assist to address concerns that the impact of the pandemic continues to be felt by disabled children and their families and that there is an urgency for lessons to be learnt in respect of these issues.

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?

The Inquiry must be designed and run with accessibility and inclusivity at its core. 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 include reference to the development and adherence to an accessible communications policy, to which all proceedings must be adhered to. We believe that this should incorporate the following:

- Social media outputs 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 should 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 should 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.

In addition, 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 and for accessible formats of documents to be requested.

In order to ensure that the voice of disabled children and their families is heard during the Inquiry, it will be important to ensure people feel 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 and creative ways, for example through other platforms including video, focus groups and storytelling.

The DCP has over 100 member organisations who all offer services, advocacy and work directly with disabled children and their families. We would use our networks to engage a wide group of organisations in evidence collection and promote any opportunities to be involved in consultation so that the voices of children and families are heard. Many of the DCP's member organisations have existing panels, ambassadors and close relationships with groups of families who regularly offer their lived experience to help shape ongoing work and services. The DCP 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 DCP's coalition will help ensure the evidence collection is far reaching and broad enough to capture a wide range of experiences.