
**SUBMISSIONS ON BEHALF OF DISABLED PEOPLE’S ORGANISATIONS:
DISABILITY RIGHTS UK, DISABILITY ACTION NORTHERN IRELAND,
INCLUSION SCOTLAND AND DISABILITY WALES
Preliminary Hearing – 13 September 2023**

Further to the Note for the Hearing prepared by Counsel to the Inquiry dated 22 August 2023 (hereafter ‘CTI Note’) the following addresses [I] Disabled People’s Organisations [II] Scope and [III] Listening.

I: DISABLED PEOPLES’ ORGANISATIONS¹

- 1.1. CORE PARTICIPANTS: Each of the above are organisations run by and for Disabled people (‘DPO’). They are to be distinguished from charities that represent Disabled people, however well, rather than enabling them to represent themselves.² The DPO 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 difficulties, d/Deafness (including those that use BSL as their first language), visual impairments, learning difficulties and neurodiversity.
- 1.2. SOCIAL MODEL: The DPO’s approach is informed by the ‘Social Model’, that essential injustices of being disabled are the product of socially constructed barriers and attitudes. They do not ignore medical issues and other individual predicaments, but they are particularly concerned with the preventability of disablement that society all too readily accepts as inevitable. During the pandemic Disabled people faced a triple jeopardy:³ death from the disease; compromised access to other health and care services; and disproportionate impact from non-pharmaceutical measures. Of considerable significance to the DPO in this Inquiry is the way in which ‘vulnerability’ and ‘resilience’ operated as

¹ For an overview of the DPO approach to the issues arising in the Inquiry see [DPO M2 PH Submissions 24.2.23 §§1-2 pp 1-5](#)

² [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, CRPD/C/GC/7 §§11, 13, 27](#)

³ [Shakespeare, T., Ndagire, F. and Seketi, Q. \(2021a\) ‘Triple jeopardy and the Covid-19 pandemic’, The Lancet, 397, 10282, 1331–3](#)

core policy discourses without sufficiently acknowledging their socially and economically determined dimensions.

- 1.3. ‘AFTERTHOUGHT’ SYNDROME: The primary issue with the fusion of science and government that constructed the Covid response – including vaccine and therapeutics - is that none of it contained Disability specialists, service providers, subject-matter experts or end users. The treatment of Disabled people as an “afterthought” was a syndrome identified by a House of Lords Select Committee reviewing the impact of the Equality Act 2010 prior to the pandemic.⁴ It is likely to characterise the evidence of all Modules, including Module 4.
- 1.4. HUMAN RIGHTS AS METHOD AS WELL AS OBLIGATIONS: The United Nations Convention on the Rights of the Persons with Disabilities (‘UNCRPD’)⁵ is commended to the Inquiry not simply as including obligations that are binding on the UK under international law and of relevance to the scope of ECHR rights. They provide a set of tools for understanding the lack of protection that Disabled people endured during the pandemic and how to positively avoid such exposure in the future. To that end we particularly draw attention to the relevance of Art. 4(3) (active involvement of Disabled people in policy formation and delivery), Art. 10 (right to life on an equal basis), Art. 11 (emergency planning and response), Art. 25 (health care) and Art. 31 (data collection).
- 1.5. CO-PRODUCTION AND CO-DESIGN: Domestic administrative law does not contain a fundamental right to effective consultation and participation in policy formation and there is no nationwide statutory right to this⁶, but the UNCRPD obligates States parties under Art. 4(3) to “*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*”.⁷ An approach to government that embeds its potentially Disabled people in the co-production and co-design of policy that affects them is a core recommendation of the World Health Organisation⁸ and

⁴ [House of Lords - The Equality Act 2010: the impact on disabled people - Select Committee on the Equality Act 2010 and Disability \(parliament.uk\)](#) Report of Session 2015-16 (March 2016) HL Ch. 1 §16

⁵ [United Nations on the Convention of the Rights of Persons with Disabilities 2006](#)

⁶ See however [Part 3 of The Community Empowerment \(Scotland\) Act 2015](#) which affords some statutory rights in Scotland

⁷ General Comment (No. 7), Fn. 2 above, §§3-5, 11, 13, 15, 18-20, 27, 42

⁸ [WHO World Disability Report](#) (2011 Rec. 4 p. 265)

a key part of the Sendai Framework on Disaster Risk Reduction,⁹ and a practice belatedly adopted as policy in the Government's National Disability Strategy (July 2021).¹⁰

II: SCOPE

- 2.1. GENERAL: The DPO acknowledge the relevance and importance of the matters contained in the Provisional Outline of Scope for this Module as providing an overarching framework for initial discovery and consideration of evidence (CTI Note §§31-33). For their part the DPO advance the matters contained above as principles and methodology that the Inquiry should adopt as part of its preparation. They assist in ensuring that Disabled people's issues become intrinsic and mainstream to all aspects of the module. Mainstreaming a Disability perspective is a proper approach in its own right, but it also ensures that the process of enquiry does not repeat the oversights that arguably befell its subject matter and are essential to correcting it in any recommendation for change.
- 2.2. PARTICULAR ISSUES: From their work to date the DPO have focused on four areas that were outlined in detail in their application for Core Participant status together with supporting footnotes. These can be summarised as (i) Development, (ii) Prioritisation, (iii) Accessibility and (iv) Monitoring and Efficacy.
- 2.3. DEVELOPMENT: The DPO wish to understand the extent to which there was testing and/or analysis of the interaction between vaccines and therapeutics with pre-existing health conditions, including the direct involvement of Disabled people in clinical trials. A perceived lack of testing/safety led to vaccine hesitancy in some quarters and it will be important to identify what was done to ensure safety, to what extent Disabled people were included in the safety design, and how that safety was communicated (including how quickly) once results were known. Associated with this is the extent to which the outcome of any such testing was considered when deciding whether certain vaccines or therapeutics were more suitable for those with certain pre-existing health conditions.
- 2.4. PRIORITISATION: Given the 'Triple Jeopardy' that Disabled people faced during Covid (§1.2 above) the DPO wish to establish the extent to which the pandemic's discriminating effect

⁹ [The Sendai Framework for Disaster Risk Reduction 2015-2030](#) §§7, 19(d), 32, 35 and 36(a)(iii)

¹⁰ {INQ000089722/19} committed to "putting disabled people at the heart of government policy-making and service delivery – laying the foundations for longer term, transformative change", and required that it "Consider disability from the start", "Increase participation" through "Enhancing our engagement with disabled people"

on them translated into inadequate prioritisation of Disabled people and their carers – both paid and unpaid - on the vaccine prioritisation list. They particularly query:

- 2.4.1. INITIAL LISTING: that placed Clinically Extremely Vulnerable (CEV) people in Category 4 and those in other ‘at risk’ groups in an even lower priority in Category 6. On such issues the Chief Executive of DISABILITY RIGHTS UK, Kamran Mallick, has spoken of his own struggle to access the vaccine and its implications. He was not given sufficient priority despite the fact his reduced lung capacity and polio should have placed him on the ‘extremely vulnerable’ list.¹¹
 - 2.4.2. OVERSIGHT OF LEARNING DISABLED PEOPLE: Given the established risk of fatality they were known to face, particular examination is required of the delayed vaccination prioritisation and differential treatment of those with learning/intellectual difficulties across the four nations.
 - 2.4.3. FAMILY AND VOLUNTARY CARERS: Across the four nations there was inconsistency as regards domiciliary carers. Some were treated as akin to working in care homes (Category 1) or frontline health and social care workers (Category 2), whereas other carers were treated “unpaid adult carers” (Category 6). This differential treatment failed to acknowledge the significant role that carers and Personal Assistants play in supporting Disabled people and led to many Disabled people being exposed to risk through delayed protection.
- 2.5. ACCESSIBILITY: The provision of vaccines for Disabled people was often compromised by a lack of physical and informational access:
- 2.5.1. PHYSICAL ACCESS: To physically reach the centres DPO across the country often had to supply transport. The makeshift nature of centres meant they frequently lacked inclusive design and amenity; hearing loops and BSL interpreters were largely not available and home and/or third sector space vaccinations were not apparently a standardised or widely provided option.
 - 2.5.2. INFORMATIONAL ACCESS: With regard to communications, while information was available online, its utility was compromised by digital inequality and exclusion, that is likely to be a central theme of the Inquiry as whole. There was also a failure in letter writing to provide standard communications in Easy Read, picture format,

¹¹ <https://bylinetimes.com/2023/02/23/government-just-made-it-worse-covids-disproportionate-impact-on-disabled-people-of-colour-revealed/>

braille, and otherwise to make available communications in British Sign Language (BSL), or screen reading software. Many Disabled people also found booking systems, prioritisation and eligibility criteria confusing and therefore inaccessible. These deficits created unnecessary challenges for Disabled people booking vaccination appointments independently. More broadly, they undermined the capacity of many Disabled people to understand the vaccines and may have in some instances adversely impacted on vaccine uptake.

2.6. MONITORING AND EFFICACY: By the time the Inquiry reaches Module 4, it is likely to have established that public health data collection and monitoring was unfit for purpose.¹² The deficit is particularly unjust for Disabled people because the importance of the matter is underscored in UNCRPD (Art. 31), the Sendai Framework (§19(g)) and the World Disability Report (Rec. 8 p. 267). The DPO wish to examine the quality of data that decision makers had on the number of Disabled people who had received vaccines and their efficacy. Those matters are relevant to decisions on: (1) targeting 'low uptake groups', (2) identifying administrative errors in those contacted; and (3) the timing of loosening social distancing measures and withdrawal of support for Disabled and CEV people.

2.7. THERAPEUTICS: Disabled people struggled to access therapeutics even where they were on the shielding list or were otherwise informed that they were eligible. Challenges to access included difficulties in accessing GP appointments during the pandemic. More broadly, the DPO encourage discrete focus on what therapeutics were offered to Disabled people and why, with reference for example to Evusheld, Sotrovimab and Molnupiravir.

III: LISTENING

3.1. VALUE: The DPO recognise that Every Story Matters ('ESM') has the potential to be of great benefit to the Inquiry's outcome and of lasting benefit to society. It would be of considerable value for Disabled people to be able to tell their stories and for the DPO to be involved in supporting that.

3.2. KEY LINES OF INQUIRY: In terms of the efficacy of ESM as a listening device the DPO welcome the Key lines of Inquiry (KLOI) as a method (CTI Note §58). They would suggest additions along the following lines:

¹² Professors Marmot and Bambra were questioned generally about data gathering deficiencies in relation to at-risk excluded groups during their inquiry evidence in M1 [{T4/68/22-69/10}](#) [{T4/70/18-71/8}](#)

- (a) Clarity of messaging for Disabled people including those who are Learning Disabled
- (b) The extent to which DPO were enlisted in providing accurate information on vaccine and therapeutics availability and safety;
- (c) Any caution that Disabled people felt about the vaccines and therapeutics because of previous experience of health care and government service and messaging both prior to and during the pandemic.

3.3. INCLUSION: As the DPO have explained during the ESM consultation process, it is paramount that Disabled people are able to participate in the story telling on an equal basis. Further to acknowledgement by the Inquiry in its communication of 27 April 2023 the process must be accessible.¹³ However, it is understood that it is not yet possible for stories to be shared, for example, through sign language or video, which renders the process inaccessible to many. Neither has there been anything other than limited outreach to those in care settings.

3.4. ADJUSTMENTS: From the DPO perspective, enabling people to provide submissions through video recordings is necessary to ensure equal access to ESM for the d/Deaf community who use BSL, and for the wider Disabled community who will otherwise be unable to tell their stories in writing, in person or via the phone-line. The DPO welcome the Inquiry's commitment to taking a more targeted approach to listening (§1.4-1.5 Listening Exercise Update Note 27 January 2023). They invite the Inquiry to make contact with them and other national Disabled People's Organisations to facilitate listening exercises with those who would otherwise go unheard.

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¹³ <https://covid19.public-inquiry.uk/wp-content/uploads/2023/05/2023-04-27-ESM-Summary-Document.pdf>