
**SUBMISSIONS ON BEHALF OF DISABLED PEOPLE’S ORGANISATIONS:
DISABILITY WALES (ANABLEDD CYMRU) & DISABILITY RIGHTS UK
Preliminary Hearing – 16 November 2023**

Further to the Note for the Hearing prepared by Counsel to the Inquiry dated 30 October 2023 (hereafter ‘CTI Note’) the following addresses [I] Disabled People’s Organisations [II] Scope [III] Witnesses and [IV] Reasonable Adjustments.

I: DISABLED PEOPLE’S 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
- 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. Of considerable significance to the DPO in this Inquiry is the way in which ‘vulnerability’ and ‘resilience’ operated as 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 – especially as regards political and administrative decision making – is that the evidence from Module 2 makes clear that none of it contained Disability specialists, service providers, subject-matter experts or end users.³ The issue is particularly pronounced with Disabled people, not only because of their under representation and lack of empowerment, but also with the risk of unconscious ableism in decision making. 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

¹ For an overview of the DPO approach to the issues arising in the Inquiry see [DPO M2 Opening Submission 26.09.23 §§1.1-1.11 pp 1-7](#) and [DPO M2B Submissions 22.03.23 pp.1-2 §§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, 15, 27 and 78 {INQ000279951/3}](#)

³ [DPO M2 Opening Submission 26.09.23 p 17-18 §§3.5 \[no expertise\] and 3.7 \[no engagement\]](#); and see recognition of the issue in general, but not specifically as regards Disabled people, by SAGE sub-group witnesses, e.g. Hayward {INQ000267868/9 §§4.9, 4.12, 4.14 and pp §§9.6-9-9.10} {M2T10/184/1-187/5}

2010 prior to the pandemic.⁴ The consequences became all too apparent during the pandemic, where in the period March to July 2020, 68%, or almost 7 in every 10 COVID related deaths in Wales were disabled people.⁵ The fate of Disabled people should have been a top priority for Government, but it was not. It is likely to characterise the evidence of all Modules, including Module 2B. A significant question that the DPO have for Module 2B is whether Wales, which formally adopted the Social Model in 2002⁶ developed more sophisticated structures for civil society engagement, including with Disabled people, and whether these structures were effective during the pandemic.

- 1.4. HUMAN RIGHTS AS METHOD AS WELL AS OBLIGATIONS: As set out throughout the DPO submissions to date, the United Nations Convention on the Rights of the Persons with Disabilities ('UNCRPD')⁷ 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, but also as providing 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.⁸ The pertinent question for Module 2B will be to ascertain whether the practice, ethos and policies of human rights compliance in Wales, which in a Framework For Action on Independent Living in 2013, updated in 2019, set out how it planned to fulfil its obligations under the UNCRPD,⁹ is different, better, or the same.¹⁰
- 1.5. CO-PRODUCTION AND CO-DESIGN: Domestic administrative law does not contain a fundamental right to effective engagement and participation in policy formation for those who will be impacted by its consequences and there is no nationwide statutory right to this.¹¹ However, the UNCRPD requires States parties under Art. 4(3) to "*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*".¹² 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 Organisation¹³, a key part of the Sendai Framework

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 [ONS](#) Coronavirus (COVID-19) related deaths by disability status, England and Wales: 02.03.20-14.07.20

⁶ [Action on Disability: The Right to Independent Living Framework and Action Plan \(October 2019\), pp.7-9](#)

⁷ [DPO M2 Opening Submission 26.09.23 p 7-13 §§2.1 and 2.12](#)

⁸ For further detail, see [DPO M2A PH Submissions 19.10.23 p.2 §1.4](#)

⁹ [Action on Disability: The Right to Independent Living Framework and Action Plan \(October 2019\)](#)

¹⁰ For introductory analysis of the issue in Wales, see [DPO M2B PH Submission 22.03.23 pp 3-7 §§2.1-2.8](#)

¹¹ See, recently, *SSDWP v Eveleigh* [2023] EWCA Civ 810

¹² General Comment (No. 7), Fn. 2 above, §§3-5, 11, 13, 15, 18-20, 27, 42

¹³ [WHO World Disability Report](#) (2011 Rec. 4 p. 265)

on Disaster Risk Reduction,¹⁴ and a practice belatedly adopted as policy in the UK Government’s National Disability Strategy (July 2021).¹⁵ The evidence before Module 2 is that this did not happen in practice with the UK Government,¹⁶ and the recognition that engagement is a mandated human right is essentially non-existent.¹⁷ In contrast, in Wales statutory mechanisms require an integrated, inclusive and collaborative approach to service delivery (section 5 of the Well-being of Future Generations (Wales) Act 2015) and the right to be heard as an individual to shape the decisions that affect them, and to have control over their day to day lives (section 6 of Social Services and Well- Being in Wales Act 2014).¹⁸

1.6. LESSONS FROM AND FOR WALES: As set out in the DPO M2B PH Submissions on 22.03.23,¹⁹ there is a body of law and policy concerning human rights, equality and wellbeing in Wales that distinguishes it from the other four nations. The Inquiry will need to consider the extent to which those commitments in principle were achieved or failed in practice during the emergency response and the extent to which the practices, as developed in the latter part of the pandemic response, compared and contrasted with the approach on the other four nations. For its part DISABILITY WALES recognises the efforts of its Government but equally draws attention to the gap between the rhetoric of national policies and what happens on the ground.²⁰ The report Locked Out provides evidence of how well intended compliance with the UNCRPD, the various well-being devolved legislative initiatives, together with a commitment to the social model of disability, too often fell away under the strains of an unplanned for emergency.²¹ The question for Module 2B will be whether differences in principle in Wales made a difference in practice.

II: SCOPE

2.1. GENERAL: The DPO welcome the Revised List of Issues (‘LOI’) for Module 2B and in particular §1(a)(xiii) (“What structures and core-decision making processes did the Welsh

¹⁴ [The Sendai Framework for Disaster Risk Reduction 2015-2030](#) §§7, 19(d), 32, 35 and 36(a)(iii)

¹⁵ {INQ000089722/19}

¹⁶ See fn. 3 above and Kamran Mallick, CEO of Disability Rights UK {INQ000280035/8-9 §§24-25 and pp 13-17 §§42-50 and pp 26 §§86-89}

¹⁷ As to the description of how engagement might work better, see Mallick {M2/T5/64/15-65/16}

¹⁸ [DPO M2B Submissions 22.03.23 p.4 §2.2](#)

¹⁹ [DPO M2B PH Submission 22.03.23 p7 §2.8](#)

²⁰ DISABILITY WALES, Rule 9 Response, 15.12.22 {3 §5} (“Many expressed the view that it was not necessarily the attitude and commitment of Welsh Government to disabled people that is the problem but the implementation gap between policy and practice. The lack of engagement with disabled people in local service planning and policy development has led to even greater exclusion, ranging from lack of access to shops and suitable housing to timely and appropriate health and social care.”)

²¹ [Locked out: liberating disabled people’s lives and rights in Wales beyond COVID-19, pp 24, 31](#)

Government have and use to consult those it identified as vulnerable and at-risk groups? How effective were they?”) read with §1(a)(xii) (“Was there appropriate access to and use of advice from bodies external to these governmental structures?”). Thereafter their focus will be especially on §§3(b)(i)-(v), 4(c) (vii) and 7 (a)-(c). The DPO advance the matters set out at §§1.4-6 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 occurred during the Covid-19 pandemic, and are essential to correcting it in any recommendation for change.

2.2. ENGAGEMENT: The emerging evidence from Module 1 and 2 is that both the ethos and structures to enable engagement with at-risk and marginalised parts of society and their representative groups is crucial. In a ‘whole-society’ emergency, Central Government simply cannot plan or act alone. It must create resilient collaborations. This is not a new concept in so far as the civil contingency framework envisages pre-planning involving the ‘voluntary sector’.²² The general consensus is that the pre-pandemic situation was ineffective.²³ Without pre-planning, it is difficult to plan during an emergency from a standing start. The evidence in Module 2 also suggests that it was particularly difficult to do that in our current political and administrative structures and culture. The effect of not planning and thereafter not effectively engaging was generally devastating for Disabled people. The question for Module 2B is whether the situation was structurally and culturally better in Wales.

2.3. MACHINERY OF GOVERNMENT: Similarly, there is evidence in Module 2 that the internal ministerial structures of the UK Government did not produce effective oversight and leadership of a range of well foreshadowed health equality issues, and especially so with regard to Disabled people. That situation arose partly through there being no lead Secretary of State, and the UK disability ministerial portfolio residing in the Department of Work and Pensions. The relevant Cabinet Secretariat is a vehicle of policy not operations.²⁴ The DPO

²² Cf. First responders under the CCA are only required to ‘have regard’ to the Voluntary and Community Sector: see Civil Contingencies Act 2004 (Contingency Planning) Regulations 2005 (‘CCR 2005’) Reg 23

²³ [DPO M2 Opening Submission 26.09.23 p. 14 §3.2](#)

²⁴ [DPO M2 Opening Submission 26.09.23 p. 16 §§3.4](#)

wish for equivalent structures and roles to be examined in Module 2B in order to assist the Chair in any consideration of whether better structures can be put in place in the future.

III: WITNESSES

- 3.1. GENERAL: Further to the Inquiry's updates and helpful outline of which witnesses have been approached to provide Rule 9 Statements, the DPO consider that the equivalent Ministerial office holders with portfolios dealing with the elderly and other equality issues should be sought, as they have been obtained in relation to the UK Government. In addition, the DPO would request the Inquiry to obtain a statement from Professor Debbie Foster, the co-ordinator of the Locked-Out Report.²⁵ The DPO note that a witness statement has been requested from Professor Emmanuel Ogbonna who wrote the report about the impact of Covid-19 for Black, Asian and Minority Ethnic communities. A witness statement from Professor Foster would assist in providing the Inquiry a fully rounded picture of the effect of the pandemic across society within Wales.
- 3.2. DPO WITNESS: In addition to the evidence of Professor Foster, the DPO suggest that DISABILITY WALES be asked by way of a Rule 9 application to provide a DPO statement that would add a Wales perspective to the evidence already supplied to the Inquiry by Kamran Mallick of Disability Rights UK, and especially with regard to specific matters that will assist the Inquiry to evolve its understanding on methods and structures for more effective engagement, adequate planning and more useful and disaggregated data collection. The DPO will identify a proposed witness and will write to the Inquiry separately shortly.

IV: REASONABLE ADJUSTMENTS

- 4.1. EVERY STORY MATTERS: 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. Previous submissions addressed how the process can be more inclusive and what reasonable adjustments would be required.²⁶ The DPO acknowledge that developments are being made, especially with regard to enabling BSL users to provide their accounts.

²⁵[Locked out: liberating disabled people's lives and rights in Wales beyond COVID-191](#)

²⁶[DPO M4 PH Submission 05.09.23 pp 5-6 §§3.2-4](#)

4.2. BRITISH SIGN LANGUAGE: The DPO have previously requested that the YouTube videos of the hearings should include BSL.²⁷ The Inquiry has now determined that provision of such a service will not be made for the M2 hearings, but has indicated that when d/Deaf people attend the Inquiry, then suitable arrangements will be made for BSL interpreters provided and funded by those attending. As set out in previous submissions the failure to provide BSL services during the Covid press conferences is now regretted by a range of witnesses, including the previous Prime Minister.²⁸ For reasons explained in *R (Rowley) v Minister for the Cabinet Office* [2021] EWHC 2108 (Admin) §§5 and 15, there is a sizeable section of the D/deaf²⁹ population who do not necessarily read subtitles or transcripts and/or identify with them as a mode of communication. The present position is that a vast part of the d/Deaf community are therefore not able to enjoy their basic means of following the hearings. This remains a disquieting gap in the coverage of all public inquiries, including this one, where so much emphasis is otherwise put on ensuring public access. If the Inquiry will not provide BSL for the YouTube videos of the whole of the M2B Hearings we would request that the Inquiry fund a BSL interpreter to attend with Core Participants who require them at the hearing, and to provide BSL during live transmission for at least the opening and closing submissions, which would allow the D/deaf population to access the key submission of CTI and Core Participants on an equal footing.

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07 NOVEMBER 2023

²⁷ [DPO M2B PH Submission 22.03.23 p. 13 §5.4](#) and [M2 PH 01.03.23 {T/116/17-22}](#)

²⁸ Johnson {INQ000255836/199/§686}

²⁹ See Scottish BSL National Plan 2017-2023. The capital D 'Deaf' is used as a cultural label and refers to people who are profoundly deaf, whose first or only language is sign language and are part of a cultural and linguistic minority known as the Deaf community".