**COVID-19 INQUIRY**

**MODULE 4**

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# OPENING SUBMISSIONS OF DISABLED PEOPLE'S ORGANISATIONS (DPO): DISABILITY RIGHTS UK, DISABILITY ACTION NORTHERN IRELAND, INCLUSION SCOTLAND AND DISABILITY WALES

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## INTRODUCTION

0.1. Outline: The Inquiry is about to consider an official narrative that the way in which government, science, and industry carried out pharmaceutical interventions during the pandemic is something that the UK did well. Whatever value is placed on that narrative, for Disabled people it is complicated by a tendency to judge success by non-disabled standards. It declares how pharmaceutical interventions offered society a means to reclaim its *normality*, without sufficiently acknowledging what was problematic for Disabled people. DPO therefore view the Covid-19 pharmaceutical interventions as a case study in how medical and scientific solutions to the pandemic were still encumbered by disabling social barriers and attitudes, which are outlined below by reference to [I] FORESIGHT [II] GOVERNMENT [III] PRIORITISATION [IV] INEQUALITIES [V] ACCESSIBILITY and [VI] LIMITATIONS. What happened to Disabled people, who make up more than 22% of the UK population serves as a lesson of how the state needs to become more responsive in its governance; and how society can become better integrated in its future states of crisis.

## [I]: FORESIGHT

1.1. DISABLED PEOPLE AND EMERGENCY: As the Inquiry has established in Module 1, due to long term failure to plan, the system of government, including the resilience of its health and care sector, was deeply vulnerable to a pandemic.[1] For Disabled people the position was one of distinct precarity and government knew that was so. Despite obvious humanitarian common sense to plan for Disabled people during emergencies, the principles contained in disaster management doctrine and human rights obligations, under the United Nations Conventions on the Rights of Persons with Disabilities ('UNCRPD'), were not embedded in central and local government bureaucracies; and the UK had been warned of its non-compliance with international obligations by a UN Investigation in 2017.[2] Despite Disabled people's greater exposure both to a viral pandemic and countermeasures, that were known and documented,

[1] UK Covid-19 Inquiry Module 1: The Resilience and preparedness of the UK (2024) ('M1 Report') pp 2-3
[2] DPO M2 Written Closing 15.01.24 [§§5-11]

there was no plan.[3] The needs of Disabled people arising from impairments, intersectional factors, and geography, were not properly accounted for by available data infrastructures.[4] Consultation with Disabled people was discretionary and ad hoc, rather than systematic, rights based and institutional.[5] During the spring of 2020, the Disability Unit ('DU') began to commission studies of the harm done to Disabled people during the pandemic by both the virus and its countermeasures.[6] In June 2020 the Office for National Statistics ('ONS') revealed that Disabled people made up 59.5% of the first wave fatalities.[7]

1.2. AWARENESS: This was the context in which government rushed to find pharmaceutical solutions, but with awareness of its considerable shortcomings in planning and capability to protect Disabled people while doing so. By October 2020, Michael Gove alerted the Covid O meeting that "*time [was] running out for the second wave*" and fundamentally more ambitious programmes were needed.[8] The DU responded in November 2020 with proposals for (1) a Data Commission "*to understand the factors driving increased mortality risk*", (2) a National Panel for Disabled People "*to create a channel to hear voices of lived experience and feed these into HM Covid policy makers*" and (3) a National Centre for Digital Access "*to improve digital accessibility for disabled people*".[9] All of these proposals were essential for a targeted and effective rollout of vaccines to Disabled people, but none of the proposals were developed during the pandemic.

1.3. TIMELINE: It is the extraordinary speed, of less than a year in development, and 15 months to Phase 1 mass roll-out to 32 million people, that inspires praise of the vaccination programme from witnesses and the King's Fund which described it as "*one of the few almost unqualified successes of the United Kingdom's response to the Covid-19 pandemic*".[10] However, as even this high praise recognises, the success was not unqualified and for Disabled people there are key issues of how well government planned for whom, how, and in what order vaccination should happen, and for those who were vaccine intolerant, or for whom the vaccine would not be effective, what alternative arrangements should be made.

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[3] DPO M2 Written Closing 15.01.24 [§§11-12]
[4] DPO M2 Written Closing 15.01.24 [§§35-37] DPO M2A Closing 23.02.24 [§§23-26] DPO M2B Written Closing 05.04.24 [§§34-35] DPO M2C Opening 19.04.20 [§3.16]
[5] DPO M2 Written Closing 15.01.24 [§§32-35] DPO M2B Written Closing 05.04.24 [§§28-30] c.f White [Draft p.88/§7.3.3]
[6] Bell [M2/INQ000198850/26 §§61-62]
[7] ONS Death rate 19.06.20 [INQ000089756/4]
[8] DPO M2 Written Closing 15.01.24 [§§15-17] Gove [M2/INQ000083956/8-9] [M2/T27/133§9-136§12]
[9] Covid O DU Submission 12.11.20 [M2/INQ000083918/1 §3, 5 and Annexes A-C]
[10] DHSC Press Release 13.04.21 [INQ000257444/2] NAO 25.02.22 [INQ000065228/45 §3.4] Lawson [INQ000492335/93 §§316-317, 329] Vallance [INQ000474482/1 §§2-3] Hancock [INQ000474375/3 §7] Zahawi [INQ000474307/57 §154] Goodall [INQ000499055 /68 §212] Swinson [INQ000474334/63 §242] Bell [INQ000499442/9 §§27-28] Atherton [INQ000474446/47 §190] Banfield [INQ000474589/2 §6] King's Fund, The Covid-19 Vaccination Programme: Trials, tribulations and successes [INQ000283354/5]

1.4. LEARNING DISABLED PEOPLE: The approach to Learning Disabled people is especially important. Against a pre-pandemic medical awareness that respiratory disorders were known to be the predominant cause of death for people with intellectual/learning disabilities,[11] from March 2020 DHSC acknowledged the risk of greater susceptibility to respiratory diseases and GPs were notified that individuals with a learning disability fell within the category of those who were at "*particularly high risk of severe morbidity and mortality from coronavirus*".[12] Studies made available by the end of September 2020 indicated a 10-fold greater likelihood of death from Covid, causing recommendation for Down's syndrome to be added to the CEV list in October 2020, but for the decision to be officially communicated to GPs only on 2 November.[13] However, from November 2020, Public Health England ('PHE') published findings that showed a death rate around 6 times higher for people with learning disabilities (without exclusively distinguishing Down's syndrome) and 30 times higher for younger people with learning disabilities aged 18-34.[14] The delay in considering, prioritising and ensuring accessible vaccine delivery for Learning Disabled people is one of the great failures of foresight.

## [II] GOVERNMENT

2.1. SOCIAL MODEL: Against the successes in how government's pharmaceutical interventions assisted the population are the more problematic questions about a sizeable majority of the population who were still marginalised. DPO use the 'social model' of disability based on the premise that people are disabled, not by physical and mental impairments, but by the social attitudes and barriers they face in consequence of those impairments.[15] The social model is important as a method for evaluating government decision making especially because (1) policies tend to be designed to accommodate non-Disabled people, causing recognition of Disabled people to be an afterthought;[16] and (2) Disabled people are under-represented in government, not prioritised in the structure of government machinery and consequently made politically vulnerable in their capacity to influence the production and design of policy.[17]

2.2. ETHICS: The social model is no less relevant to vaccines and therapeutics. With matters which might be regarded as singularly 'clinical' and 'medical', there is potentially an even greater risk that the problems of Disabled people will be reduced to their medical conditions.[18] This is not

[11] Watson and Shakespeare [M2/INQ000280067/4 §8] [/12 §39]
[12] Submission to SSHSC 08.03.20 [M2/INQ000106161/6 §27] Letter to GPs 19.03.20 [INQ000048143/1]
[13] DPO M2 Written Closing 15.01.24 [§§30-31]
[14] PHE Press Release 12.11.20 [INQ000279971/2] PHE Report: Summary 12.11.20 [INQ000417384/4]
[15] DPO M2 Opening Submission 26.09.23 [§§1.2-1.11]
[16] DPO M2 Written Closing 15.01.24 [§§8-9, 28-29]
[17] DPO M2 Written Closing 15.01.24 [§§20-24]: see further §2.8 below
[18] DPO M2 Written Closing 15.01.24 [§§25-27] Banfield [INQ000474589/99 §§235-6]

a criticism of medical science, or the necessary role of experts in decision making, but without social considerations it is incomplete; and should certainly not be treated as exhaustive or determinative. Questions of categorisation and prioritisation are also ethical ones; and transparent ethical analyses and ethical frameworks are particularly important as a guide to policy and decision making, especially in the face of scientific uncertainty—which pervades pandemics especially in the earlier stages.

2.3. PRACTICE: In practice, prioritisation decisions (particularly in Phase 1) were not dynamically informed by the social model and moral and ethical reasoning did not play a transparent, integrated and structured role. The witnesses[19] and the policy documents[20] describe "*clinical*" (or "*medical*", "*scientific*") decisions based on "*clinical*", "*scientific*" advice from experts, limited to similarly discrete bodies of evidence. Even though the JCVI determined at the outset that its advice would "*not include detailed ethical considerations which were for DHSC to consider, informed by MEAG* [Moral and Ethical Advisory Group]",[21] in practice UK Ministers deferred very strongly to JCVI's medical/clinical led process and the content of its advice,[22] with only limited divergence by Devolved Ministers,[23] and resistance to MEAG's suggestion, in April 2020, of publishing an ethical framework.[24]

2.4. EXPERTISE: For DPO the problem of affording such reliance on this 'clinically led process' was that the overall fusion of science and government that constructed the pharmaceutical response – as with other parts of the pandemic response – contained no Disability specialists, service providers, subject-matter experts or end users. The JCVI itself had no sub-group related to the risks which Covid-19 specifically posed to Disabled people,[25] nor did its membership comprise expertise in Disability.[26] It was apparent to some in the devolved administrations that the JCVI, was pursuing a "*narrowly medically modelled*" approach.[27] In so far as its membership did include expertise in ethics, this was at subcommittee, not voting level, and a single expert.[28] Vaccine prioritisation should have been the subject of ethical

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[19] Whitty [INQ000474401/86 §7.46] Lim [INQ000471988/10 §§35, 74] Van-Tam Email 18.11.20 [INQ000153237/1] O'Neill [INQ000474425/7 §24] McBride [INQ000474249/42 §§123, 127-135]
[20] JCVI Minute 07.05.20 [INQ000354439/16 §91] Cabinet Minutes 21.07.20 [INQ000088881/6 §(b)] Covid-O Meeting 22.09.20 [INQ000090166/5] DHSC Briefing 22.01.21 [INQ000401329/3 §8]
[21] JCVI Minute 07.05.20 [INQ000354439/16 §91]
[22] Hancock [INQ000474375/39 §§124,134] Whitty [INQ000474401/29 §6.31] Van-Tam [INQ000474404/19 §2.24] Swinson [INQ000474334/54 §203] Phin [INQ000474427/8 §31] Swann [INQ000474451/7 §§22- 24].
[23] Drakeford [INQ000474420/18 §§65-66] Sturgeon [INQ000506900/8 §33]
[24] Montgomery [INQ000474339/6 §22] Email PS Bethell to PS Hancock and others 19.05.20 [INQ000486316]
[25] Mallick [INQ000474256/5 §15]
[26] Lim [INQ000471988/12 §§41-42] JCVI membership [INQ000489463/1] JCVI Code of Practice [INQ000145984/9 §23]
[27] Payne [INQ000507523/16 §55]
[28] Lim [INQ000471988/13 §§42(iii), 74] (a non-voting ethics expert was co-opted at sub-committee level)

scrutiny, but it was discussed by MEAG in May 2020 and then not until March 2021, save for passing reference in an otherwise "*brief discussion*" about vaccine rollout in November 2020.[29]

2.5. SOCIAL CARE: The fusion of science and government similarly lacked expertise on social care. In mid-November 2020 Helen Whately, Minister for Social Care, became concerned about the position of under-65 year old adults in care, and care staff, which prompted her Private Office to ask a question on her behalf ("*Who on the JCVI knows about social care[?]*"); the DHSC's answer was "*no one specifically*".[30] The Whately question was pertinent given vaccine prioritisation and rollout involved myriad issues of definition, identification and logistics of social care workers, including unpaid carers; much of which external agencies feared government did not properly understand.[31] The answer to the question defaulted to the province of the Chief Medical Officers ('CMOs'), who on 1 December 2020 convened as a group to define who was included in vaccination priority group 2 (frontline health and social care workers), thereby determining what their email chain thereafter described as "*who counts as 'frontline'*" [32] and "*the bounds around the JCVI priority*".[33] While the CMOs identified a comprehensive list[34] of those with the "*important function in caring for the vulnerable*", that list did not translate into prioritisation of the full workforce until well into the vaccination rollout.[35]

2.6. DISABILITY UNIT: Against these gaps relating to expertise and lack of clarity about different forms of care, the sufficiency of the DU and the Minister for Disabled people stood to be tested. The DHSC Equality impact assessment of the prioritisation policy of 23 November reassured Ministers that the DU was "*closely engaging with a wide range of charities and other relevant stakeholders who represent disabled people to hear their concerns*",[36] but at that very time (see §1.2 above) the DU was submitting to Covid-O that what was needed was a National Panel for Disabled People to better *"test and refine C19 policy which impacts on disabled* groups" than had been possible in the engagement process to date.[37]

2.7. CO-PRODUCTION AND CO-DESIGN: In no sense could government contend that Disabled people and their representative organisations were "*closely consulted and actively involved*" in the development stage of the pharmaceuticals policy as required by Article 4(3) of the UNCRPD. Regional Stakeholder Network meetings with the DU had only begun properly in July 2020,

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[29] Montgomery [INQ000474339/12 §§40-41, 45] MEAG meeting 13.05.20 [INQ000401387] MEAG meeting 03.03.21 [INQ000496176] MEAG meeting 18.11.20 [INQ000193133/2-3]
[30] Whately [M2/INQ000273897/70 §§315-316] Email Correspondence 16.11.20 [M2 /INQ000328014//1-2]
[31] ACASS (Williams) [INQ000485166/2 §5] LGA (Killian) [INQ000474430/19 §§67-69]
[32] Email 01.12.20, Prioritisation (Phase 1) decision for Pfizer/BioNTech Vaccine [INQ000071966/2]
[33] Email 02.12.20, Frontline health care workers defined and internal priority [INQ000463990/4]
[34] Briefing for CMO Meeting 02.12.20 [INQ000416129/5]: see §§3.4-3.5 below
[35] *Cf.* Kasstan-Dabush and Chantler [INQ000474623/23 §60]
[36] DHSC Equality Analysis 23.11.20 [INQ000059040/9 §38]
[37] Covid-O DU Submission 12.11.20 [M2/INQ000083918/1 §3.2 and Annex B pp 6-10]

and the group met only three times before December 2020, and the DPO Forum that started in July 2020, met only 4 times, and not beyond 12 November 2020.[38] There was no *close* engagement on prioritisation as the Equality Assessment suggested, none of the meetings discussed vaccination in detail, and while the DU also met with the Disability Charities Consortium ('DCC'), the minutes of the meeting on 18 November 2020 also do not refer to vaccination.[39]

2.8. POLITICAL VULNERABILITY: The apparent outcome on the available evidence is that neither the DU nor the Minister for Disabled People made representations in relation to vaccines prior to the roll-out beginning. One letter was written to the JCVI on 10 December 2020, drawing attention belatedly to the risk to those with learning disabilities, but not challenging the current prioritisation categories and otherwise welcoming the approach to stratification.[40] Minister Tomlinson did not attend the Covid-O meeting on 10 December that discussed risk stratification for vaccine prioritisation; objections were not made about the prioritisation categories when he did attend Covid O Meetings;[41] and neither the DU nor DWP made representations about care workers.[42] A second Tomlinson letter, written this time to Nadhim Zahawi, Minister for Covid Vaccine Deployment, on 15 December offered support to enhance data awareness. This progressed to a meeting on 4 January to explore how the DHSC could "*utilise existing stakeholder networks*" with Zahawi then attending a meeting of the DCC, but without apparently finding cause to question the JCVI advice.[43] Only in February 2021 did Tomlinson report to the Regional Stakeholders Network that the DCC (among many other NGOs) had intervened to influence vaccination priority for those with learning disabilities.[44] Given the consequences for Disabled people both in terms of risk of fatality, but also the harmful consequences of continuing shielding, this was not extensive input. The DPO view the inability of the DU to correct flaws in the prioritisation policy prior to its activation as an indicator of their political vulnerability under current constitutional arrangements (see §2.1 above).[45]

## [III] PRIORITISATION

3.1. LEARNING DISABLED PEOPLE: People with learning disabilities were not one of the initially most prioritised cohorts, despite available data on mortality risk (see §1.4 above). Seized with

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[38] Mallick [M2/INQ000280035/14 §§44, 48-49]
[39] Ministerial Brief for DCC Meeting 18.11.20 [M2/INQ000187652]
[40] Tomlinson [INQ000474588/6 §12] Tomlinson to JCVI 10.12.20 [INQ000083878]
[41] Minute Covid O Meeting 10.12.20 [INQ000486427] Tomlinson [INQ000474588/8 §§24-25]
[42] Briefing Covid O Meeting [INQ000060717], [INQ000090045/1 §2], [INQ000091191/3]
[43] Tomlinson [INQ000474588/6 §14] Tomlinson to Zahawi 15.12.20 [INQ000499493] DU Note 04.01.21 [INQ000083879] DU Handling 19.10.21[INQ000083905/6 Annex B §4a] Zahawi [INQ000474307/54 §146]
[44] RSN Meeting 24.02.21 [M2/INQ000187653/1]
[45] DPO M2 Written Closing 15.01.24 [p.12 §§20-24] Tomlinson [M2/T20/167/18-169/3] Mallick [M2/T5/67/1-69/19]: *Cf.* Tomlinson [INQ000474588/11 §§35-36]

awareness of the issue, Helen Whately internally queried on 10 November 2020 "*[based on] the reports coming out re mortality for those with LD and autism, have JCVI identified this group as priority for vaccinations?*". On the following day she wanted to know further why "*working age adults in residential care / with learning disabilities"* were 6th in line when "*Surely*" they should be given "*top priority*" being at "*high risk but also have more years of life that those who are older*".[46] Her Director of Adult Social Care informed the DHSC's Head of Vaccine Deployment that "*on prioritisation, [the Minister] will definitely want to make the case for vulnerable under 65s to be in the first wave*", but the response to Whately's Private Office on 16 November did not address the specific issue of adults with learning disabilities.[47] The Minister's concern was met by some form of discussion described by the Deputy CMO email of 18 November, in which Professor Van-Tam reported that the JCVI had "*considered all of these groups*" and further that he had been "*very robust indeed"* with Whately that Ministerial interference with JCVI priority setting would not be allowed.[48]

3.2. AFTERTHOUGHT: Starting with the fact that people with learning disabilities were not specifically mentioned at all in the JCVI interim guidance of 25 September 2020, and then revisions were made on an incremental basis in December 2020 and February 2021, there is a serious question about the failure to properly consider the issue in preparedness planning.[49] DR UK and other DPO wrote to the JCVI on 27 November expressing their concern, noting that health inequalities and discrimination experienced by people with learning disabilities led to worse outcomes and premature mortality.[50] The JCVI revised its advice on prioritisation of people with learning disabilities on 2 December 2020 to include people with "*severe and profound learning disability*". As the reply to the letter from DR UK and others confirmed on 18 December, this was done on the assumption, which proved mistaken, that primary care records would accurately reflect that 'severe/profound' distinction.[51] That was the revised position that Justin Tomlinson's letter to the JCVI failed to critique on 10 December, written at a time when the DU were acutely aware of the need to improve data for Disabled people, including a breakdown of different types of impairment.[52] Prioritisation was again revised some three months later when all individuals on the Learning Disability Register, and not just those with "*severe and profound learning disability*", were belatedly included in category 6.[53]

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[46] Whately Email Exchange 10.11.20 [M2/INQ000328008/3], [M2/INQ000273897/70 §315-317]
[47] DHSC-Whately PO Email Correspondence 16.11.20 [M2/INQ000328014/1-3]
[48] Van-Tam Email 18.11.20 [INQ000153237/1]
[49] Kasstan-Dabush and Chantler [INQ000474623/22 §§55-59] Mallick [INQ000474256/7 §22-28] Banfield [INQ000474589/100 §236]
[50] DR UK et al to JVCI 27.11.20 [INQ000474682]
[51] JCVI to DR UK et al 18.12.20 [INQ000059943]
[52] Covid O DU Submission 12.11.20 [M2/INQ000083918/1 §5 and Annex A pp 2-4]
[53] JCVI to SSHSC 23.02.21 [INQ000354486/2]

3.3. SYSTEM: The reasons given by JVCI for the change were "*due to concerns raised by NHSE about the coding of learning disability on GP systems*",[54] which the explanatory letter added were "*particularly with regard to the coding of severity of any disability*", given that sample testing showed high mortality and morbidity regardless of how the severity was coded. This delay in combining clinical assumptions with a real world understanding of GP data banks would not have happened with a more integrated system that combined clinical science with social science, public health disability expertise, and lived expertise of Disabled people and DPO. In Wales, the Devolved CMEAG was concerned that the modelling on those with "*mild to moderate*" learning disability was complicated by their being less likely to be reflected in GP records and that threshold definitions like severity and profoundness left room for interpretation.[55] ADASS (the Association of Directors of Social Care) emphasised the "*wealth of evidence that people with a learning disability/and or autism are hard to identify and have difficulties accessing health services*" with potential not to be "*known to GPs who are being asked to identify those eligible for vaccination in cohort 6 from their records*".[56] A targeted enquiry of Disabled people in the preparedness planning of policy would likely have established these things, but the fragmentation of the system meant that even Minister Whately's intervention took three months to impact sufficiently; and after that, regional and national variation continued.[57] On a basic level of humanity, the equivocation over Learning Disabled people was deeply disquieting given the death rates and the understandable anxiety in which in the midst of disaster certain categories of persons could count for less.[58]

3.4. ALL CARERS: For *all* carers, including paid and unpaid carers, there was confusion as to which prioritisation cohort applied to them. Depending on their working relationship, they could fall under cohort 1 as carers working in care homes for older adults, cohort 2 as carers who were frontline health and social care workers, or (from 30 December 2020) cohort 6 as unpaid carers if they fell within the limited definition at footnote 3 of the JCVI advice, of "*those who are in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill*". That definition was itself the subject of unexplained change in the UKHSA/DHSC Immunisation Green Book in February 2021 to "*those who are eligible for a carer's allowance, or those who are the sole or primary carer of an elderly or disabled person who is at increased risk of COVID-19 mortality and therefore clinically vulnerable*".[59] In this confusion can be seen the practical consequences of

[54] Lim [INQ000471988/54]
[55] Payne [INQ000507523/16 §54] Jenkins-Gething Email 17.02.20 [INQ000410094/3]
[56] ADASS 22.02.21 [INQ000397416]
[57] Mallick [INQ000474256/9 §§28-30]
[58] SSC Stakeholders 25.02.21 [INQ000060237/8] Kasstan-Dabush and Chantler [INQ000474623 §§55-59]
[59] Mallick [INQ000474610 §4] JCVI 30.12.20 [INQ000354469/20] GB Ch. 14a 12.2.21 [INQ000474586/11]

the failure to answer the Whately question (see §2.5 above). An account in Every Story Matters ('ESM') from one of those carers points to their incredulity that her Disabled mother could be the subject of a home vaccination, but she as the carer could not be vaccinated at the same time.[60]

3.5. CONSEQUENCES: For UNPAID CARERS, there was a delay in the JCVI explicitly prioritising them as they were not mentioned at all in the interim September 2020 advice, and then only included via a cross reference to the Green Book on 2 December, before finally being included as an obscure footnote to the 30 December advice. The situation was not helped by the change of the eligibility criteria from "*main*" carer in December 2020 to "*sole or primary*" carer in February 2021; and with different approaches to both the definition and identification of unpaid carers taken across the devolved nations.[61] However, the most pressing problem was the ignorance that government labours under with regard to the volume and geography of the unpaid labour economy, with DHSC depending on the Department for Work and Pensions for some digestion of those in receipt of benefits and NHS England not knowing the figures or having the contacts within GP records.[62] PERSONAL ASSISTANTS faced a discrete confusion as to which cohort they fell into, as they were not expressly referred to in the JCVI advice. Even when personal assistants were eligible because they fell within an existing cohort description, some local authorities and GPs failed to identify and call them for vaccination, with risk of delay.[63]

## [IV] INEQUALITIES

4.1. NEW STRUCTURES: The absence of the DU in the planning and prioritisation of the pharmaceutical policy during 2020 was a problem in its own right (see §§2.6-2.8 above). As for *new* equality structures which were *created during, but not before,* the vaccine rollout programme, these were belated, formed without consultation of DPO, and had no dedicated focus on Disability. The Vaccines delivery plan of 13 January 2021 and the Vaccine uptake plan of 13 February 2021 referred to a new Equalities Board and new Vaccination Equalities Committee respectively, which appear to be the same committee.[64] There was no dedicated focus on Disability,[65] despite the live and pressing issues for Disabled people with the vaccine programme which were at this time prompting revision of JCVI advice and concern among Ministers, social services, the devolved administrations and civil society. Membership of the Committee did not include representation from the DU,[66] only Race Disparity Unit officials

[60] ESM [INQ000474465/37] *Cf.* Mallick [INQ000474610/5 §15]
[61] Mallick [INQ000474610/2 §§5-11]
[62] Lawson [INQ000492335/56 §§178, 212, 339(b), 341(e)] Mallick [INQ000474610/5 §§12-15]
[63] Kasstan-Dabush and Chantler [INQ000474623/23 §60, /108 §374(c)] Mallick [INQ000474256/10 §34]
[64] Vaccines delivery plan 13.01.21 [INQ000411678/43] Vaccine uptake plan 13.02.21 [INQ000087230/6]
[65] Vaccine Equality Committee Draft TOR 04.02.21 [INQ000502101/3]
[66] ANNEX 1 membership 04.02.21 [INQ000502101/5-6]

attended the meetings,[67] and the Minister for Disabled People makes no mention of the committee in his Module 4 statement.[68] By contrast, Disabled people and DPO were included in the Vaccine Equity Committee established in Wales.[69] While ethical advisory groups were not a substitute for incorporation of Disability experts and issues into the work of the dedicated Equalities Committee, the Ethics advisory group in Wales was also considerably more active on equalities issues and included DPO representation.[70]

4.2. UNDER-ASSESSMENT: Despite long recognised health inequalities and the emerging statistics on the high risk of mortality and morbidity of Disabled people, the Government failed thematically to review the needs of Disabled people in late summer 2020, in the way it did for race and ethnicity, despite terms of reference that required consideration of all disparities.[71] The JCVI annexed a paper from PHE on health inequalities to their advice of 2 December 2020 but its analysis in relation to groups for prioritisation did not expressly refer to Disability or Disabled people.[72] Equality impact assessments on vaccine prioritisation proceeded on the basis that vaccines were an 'unqualified good' for society as a whole, seemingly rendering detailed Disability impact analysis redundant. In particular, the DHSC's equality analysis for the policy on vaccine prioritisation of 23 November 2020 did not refer to the PHE review, published 11 days previously, of mortality rates for people with learning disabilities.[73] This omission remained in the further equality analysis of 28 December 2020, which only asserted in the most general terms that Disabled groups were likely to benefit disproportionately, in terms of health, from being prioritised for a Covid-19 vaccine.[74]

4.3. DATA: Despite the deficiencies in data collection and awareness that the DU identified in November 2020, the problems were not corrected, with the Local Government Association lamenting that at the point of vaccination, data and information to allow identification of care staff was not collected.[75] The Inquiry experts Kasstan-Dabush and Chantler refer to the lack of disability data associated with primary care records, which precluded risk assessment tools and data monitoring,[76] and further that there was no disaggregated data for social care workers including unpaid carers and personal assistants across UK nations.[77] The "Vaccine Equalities" tool did not focus on Disability, and overall data about Disabled people is not

[67] Bell [M2/INQ000198850/64§150]
[68] Tomlinson [INQ000474588]
[69] Vaccine Equity Committee TOR 18.03.21 [INQ000182550/4] Mallick [INQ000474256/23 §§74-76]
[70] Mallick [INQ000474256/23 §§74, 76]
[71] DPO M2 Written Closing 15.01.24 [p.14 §24] Banfield [INQ000474589/99 §235]
[72] JCVI Advice 02.12.20 [INQ000234638/16]
[73] Equality Analysis 23.11.20 [INQ000066761/8 §33-35]
[74] Equality Analysis 28.11.20 [INQ000401315/9 §36]
[75] Killian [INQ000474430/12 §42]
[76] Kasstan-Dabush and Chantler [INQ000474623/67 §210]
[77] Kasstan-Dabush and Chantler [INQ000474623/65 §206]

available from national immunisation systems,[78] and so despite its posited sophistication,[79] the Tool did not monitor the equality of delivery for Disabled people. The DU admitted in September 2021 that vaccination coverage data based on "*specific health conditions"* did *"not adequately cover the breadth of disability by Equality Act 2010 definition*".[80] Without fundamental data on vaccine uptake, it is not possible to consider and address the reasons behind any discrepancies, such as potential hesitancy or lack of accessibility.

## [V] ACCESSIBILITY

5.1. FORESEEABILITY: From the moment a vaccine programme was contemplated, it was obvious that planning would be needed to ensure that the accessibility requirements and needs of 14 million Disabled people in the UK making up 22% of the population were met, and to consider and make reasonable adjustments.[81] Planning for accessibility did not need to await the incremental inclusion by the JCVI of people with particular medical conditions or comorbidities in the prioritisation list, given Disabled people comprise part of every age and demographic cohort.[82] For any vaccination programme, regardless of where vaccination takes place, "*accessibility must be applied from start to finish – from deciding to get vaccinated, to booking systems, to the location and vaccination process itself*".[83] Accessibility therefore needs to be considered in all its facets: physical and environmental, communicational, digital and confidence building. Given accessibility needs were foreseeable, and relevant in different ways to 14 million people in the UK, it challenges the 'success story' of vaccines that there were regrettable and preventable barriers to vaccination[84] and Disabled people had accessibility and communication requirements that were not met.[85]

5.2. PHYSICAL ENVIRONMENT: Across the country there were basic physical barriers for Disabled people in terms of accessing vaccination sites, with difficulties in leaving home at all without assistance; thereafter, in reaching the sites, including via public transport, and entering step-free.[86] In terms of the vaccination centres, environment barriers included difficult or non-existent booking-in processes, long lines, and waiting, sensory overloaded spaces, noise and lighting, limited communications support, including no BSL interpreters (see also §5.3 below), a lack of seating and heating, sites in areas of high infection rates, no alternative formats or

[78] Russell [INQ000474228/156 §568]
[79] Russell [INQ000474228/25 §114]
[80] DU presentation [INQ000083893/4]
[81] Mallick [INQ000474256/2 §5]
[82] Pre-rollout matters identified in Scotland [INQ000427254/14-16]
[83] Mallick [INQ000474256/11 §35] Rotenberg et al [INQ000417410/1]
[84] Kasstan-Dabush and Chantler [INQ000474623/81 §§266, 273]
[85] Kasstan-Dabush and Chantler [INQ000474623/6 §3]
[86] ESM [INQ000474465/38, 41]; Scotland [INQ000501283/3]; Mallick [INQ000474256/13 §42]

tactile guidance, staff wearing opaque face covers, and lack of support for those with extreme needle-phobia.[87]

5.3. COMMUNICATIONS: Successive iterations of the Standard Operating Procedure for local vaccination services did not mention the NHS Accessible Information Standard, which sets out a framework for the NHS and adult social care systems to meet the information and communications support needs of Disabled people.[88] Instead, they included a watered-down suggestion that supporting literature in easy read formats "*may be helpful*".[89] This happened even though concerns about accessible communications were raised repeatedly by Disability organisations from early in the pandemic, long before vaccines became available, and despite assurances that these problems would be addressed.[90] Justin Tomlinson belatedly (a week after rollout commenced) asked Minister Zahawi that accessible information be provided in accordance with the Standard,[91] but the reply did not confirm that all communications regarding vaccinations and venues would comply with the Standard.[92] By January 2021 COVID-O noted that "*a very common theme*" in engagement was "*calls for accessible communications about all aspects of the vaccination programme – from safety information for each vaccine to information about where to go for local vaccination to allow disabled people to make informed choices*".[93] In March 2021 the Government conceded a legal challenge brought by a blind woman about an inaccessible shielding letter and agreed to review its communication with Disabled people.[94] In September 2021 accessible communications were still a Disability "*stakeholder concern*"[95] and in November 2021 the Royal National Institute for the Blind threatened civil litigation on behalf of a blind woman who had not been provided vaccine invitation letters or vaccine information in accessible format.[96]

5.4. CONSEQUENCES: In his statement to the Inquiry, Minister Zahawi expresses confidence that "*there were no substantial issues; every attempt was made to effectively communicate …as clearly as possible*".[97] In reality there were singular formats for letters, briefings without BSL interpretation, and information not being provided in both digital and non-digital formats.[98] d/Deaf or hearing-impaired individuals received phone calls rather than their preferred form of

[87] Mallick [INQ000474256/13 §§43, 48-49]; DANI report 01.02.22 [INQ000142173/271]
[88] NHS Accessible Information Standard [INQ000417405] Mallick [INQ000474256/11 §36]
[89] SOP COVID-19 local vaccination services deployment in community settings [INQ000329393/8]
[90] Stringer [M3/INQ000235594/13 §§38-51]
[91] Tomlinson to Zahawi 15.12.20 [INQ000499493]
[92] Zahawi to Tomlinson 24.12.20 [INQ000499496]
[93] COVID-O "Vaccine Update" paper 25.1.21 [INQ000092297/8]
[94] BBC, "*Covid: Blind woman forces government action in shielding case*, 19.3.21 (Publicly available)
[95] Disability Unit presentation 27.9.21 [INQ000083893/13]
[96] DHSC submission to PS VPH 22.11.21 [INQ000067441/2]: for N. Ireland, see [INQ000142173/271]
[97] Zahawi [INQ000474307/54 §146]: *Cf.* Tomlinson [INQ000474588/9 §27]
[98] Mallick [INQ000474256/11 §36-37, 40]

communication.[99] Vaccination invitation letters inaccessible to those who were visually impaired or had learning disabilities were sent out in England, Wales, Scotland and Northern Ireland despite the need for accessible communications having been raised from the outset of the vaccine programme.[100] Booking processes comprised online systems (see further 5.5 below) which were not high contrast, with lack of easy-to-read versions and telephone options for those unable to book online.[101] Accounts to Every Story Matters describe difficulty obtaining information in accessible formats including by those with visual impairments, who use assistive technology and screen readers.[102]

5.5. DIGITAL EXCLUSION: Doctors Kasstan-Dabush and Chantler refer to the exclusive use of digital booking systems as a barrier to access.[103] Professors Watson and Shakespeare have already described the impact of digital exclusion on Disabled adults, which was well evidenced before the pandemic.[104] None of this was new to government, who recognised in May 2021 when the COVID O meeting considered the introduction of vaccine certificates that Disabled people were most likely to be digitally excluded;[105] and consequently actioned further examination of off-line solutions.[106] The reality of the barrier had been foreseen in the previous year when the forerunner to COVID O confronted the increasing development of digital connectivity and the consequential isolation and exclusion of those unable to participate.[107] The DU in its November 2020 submission to COVID O had sought to create a National Centre for Digital Access seeking £17.5 million to progress from 2021-2023, but the project did not proceed, and awarded investment on the issue as of January 2021 was no more than £2.5 million.[108]

5.6. CONFIDENCE BUILDING: While there is much to be said for focussing on the causes of vaccine hesitancy, and taking them seriously, lack of sufficient information about whether vaccines were safe for particular Disabled people could itself amount to a basis for hesitancy on the part of a lay-person.[109] Surveys published by Disability Equality Scotland just before the vaccine rollout in November 2020 found that some respondents' concerns related to the speed that the vaccines were approved and whether all possible side-effects had been identified and

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[99] Mallick [INQ000474256/12 §41] DEF minutes 27.1.21 [INQ000282063/3 §2.8]
[100] Mallick [INQ000474256 §39] DEF minutes: 21.10.20 [INQ000353422 §4.5] 27.1.21 [INQ000282063/3 §2.8] Scottish Govt Inclusive Steering Group [INQ000501280/1]; DANI report [INQ000142173/271]
[101] Mallick [INQ000474256/12 §41]
[102] ESM [INQ000474465/14-15, 38]
[103] Kasstan-Dabush and Chantler [INQ000474623/108 §375(e)]
[104] Mallick [INQ000474256/12 §41] Watson and Shakespeare [INQ000280067/8 §§25-26] [M2/T5/35/16-40/8] UK Consumer Digital Index 2019 [INQ000489462/10, 15]
[105] Badenoch [INQ000492283/7 §12(d)] [INQ000083916/1 §4, p. 3 §4] DHSC Submission 13.5.21 [M2/INQ000111155/25 §§11-19] CO Equality analysis draft 30.04.21 [INQ000060799/7 §§27, 50-53]
[106] Covid O Meeting 20.5.21 Minute [INQ000091937/8 (i)] Covid O Actions 20.05.21 [INQ000083897/1 §5]
[107] GPSMIG 8.4.20 [M2/INQ000177567/16 §26(4) and 27(iii)] Annex A [M2/INQ000083403/9]
[108] Covid-O DU Submission 12.11.20 [INQ000083918/1 §§3-5, Annex C pp 10-14 Tomlinson [M2/INQ000233735/18] [INQ000083896/2 §9 and Table at p. 9]
[109] Mallick [INQ000474256/4 §§12-13, 18 §§58-59] ESM [INQ000474465/13-14]

considered before the vaccines were to be distributed to the most vulnerable in society.[110] What Disabled people experienced was the offer of a vaccine, not the opportunity through engagement to understand how the vaccine would interact with their pre-existing conditions, co-morbidities, or any other medications. Based on anecdotal evidence that it was not a problem, the Equality Hub chose not to prioritise work on vaccine hesitancy among Disabled people,[111] although evidence did emerge that previously vaccine hesitant Disabled adults remained concerned about the vaccine suggesting "deep rooted concerns".[112]

## [VI] LIMITATIONS

6.1. EXCLUSION: An inclusive pharmaceutical policy which respects the right of Disabled people to enjoy full and effective participation and inclusion in society must be one that considers the significant immunocompromised population in the UK, who either could not take the vaccine or for whom the vaccine was not fully effective. The Government's own figures suggest that 1.2 million people in this category "*faced a fourth year of shielding or restricted living due to fear of catching the virus, having no protection and becoming severely ill, or even dying*".[113] According to VTF Chair Dame Kate Bingham the UK was "*the only Western country not to protect its immunocompromised people using long-acting antibodies*" and condemned people to suffer through long term shielding,[114] with its attendant psychological effects.[115] The Treasury's cost resistance to funding antivirals[116] may have been shared by DHSC,[117] and overall there was reliance on the perceived indirect protection achieved by vaccine rollout.[118] The latter begs the question: protection *for whom*?[119]

6.2. INCOMPLETION: What remain to be conducted are full cost-benefit and comprehensive ethical analyses. First, the CMOs and others declared themselves constrained by lack of data in evaluating the benefits of certain neutralising monoclonal antibodies (NMAbs), of which Evusheld is an example. Problems included that much of the evidence directly comparing NMAbs was based on lab tests, not randomised clinical trials and pharmacometrics studies, and that new strains of Covid brought into question previous findings.[120] Second, this is an area, where uncertainty about benefits and costs resistance can carry disproportionate weight

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[110] Disability Equality Scotland [INQ000417433/2]
[111] Tomlinson [INQ000474588/10 §29]
[112] ONS bulletin [INQ000515050/6]
[113] APPG for Vulnerable Groups to Pandemics, *Forsaken But Engaged* [INQ000417415/2]
[114] Bingham [INQ000474406/42 §§38.12-38.13]
[115] Dix [INQ000474423/18 §9.1]
[116] Vallance's "Evening Notes" [INQ000506873 pp. 101, 275, 350]
[117] Bingham [INQ000474406/43 §38.14]
[118] DHSC Submission to SSHC 3.3.21 [INQ000497982/3 §4] Whitty [INQ000474401/80 §7.25] Van-Tam [INQ000474404/69 §3.35]
[119] Email PS Bethell to PS Hancock 19.2.21 [INQ000497981]
[120] White [Draft pp 49-40 §§5.33-5.37] [pp 75-76 §§6.14-6.16]

in prematurely blocking development. Whereas the drive for vaccines would not have succeeded without judging development costs for uncertain gain to carry its own societal benefit, there is evidence that trials for oral antivirals that prevented hospitalisation fell away once mass hospitalisation was no longer a societal threat.[121] Third, establishment of transparent ethical analyses and frameworks addressing pharmaceutical development and distribution is important. Cost-benefit analyses limited to how many hospitalisations are averted[122] overlook wider social factors affecting Disabled people, and other marginalized groups. Fourth, the whole subject of alternative pharmaceuticals needs to be informed by wider expertise and input (see §2.4 above).[123] Until then the impact on individuals is attested by accounts to *Every Story Matters* of clinically vulnerable individuals purchasing expensive medications to buy "*a few months of freedom*".[124] There is lack of awareness and understanding of eligibility for access of antivirals and therapeutics.[125] A coherent approach to immunocompromised people must be part of planning for any future pandemic[126] and the "*key gaps*"[127] in systems for the development and distribution of therapeutics must be addressed, not least given the possibility that in a future pandemic, vaccines may not be the preferred or more rapid means of response.[128]


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| **DANNY FRIEDMAN KC** | **KATE BEATTIE** | **SHAMIK DUTTA** |
| **ROBBIE STERN** | | **CALEB SIMPSON** |
| **MATRIX CHAMBERS** | **DOUGHTY STREET CHAMBERS** | **BHATT MURPHY SOLICITORS** |


**13 DECEMBER 2024**

[121] White [Draft pp 51-53 §§5.38-5.42] [p. 88 7.74-7.75]
[122] *Cf.* Whitty to Elliott 11.12.20 [INQ000507423]
[123] White [Draft pp 88 §§7.7.3 & 7.7.6]
[124] ESM [INQ000474465/36]
[125] ESM [INQ000474465/48] Mallick [INQ000474610/9 §§24-25]
[126] Gray [INQ000474342/33 §93]
[127] Bethell [INQ000474434/34 §§99-101]
[128] Vallance [INQ000474482/48 §126] White [Draft p. 86 §§7.3-7.4]