

COVID-19 PUBLIC INQUIRY

Module 2

SUBMISSION ON BEHALF OF DISABLED PEOPLE’S ORGANISATIONS:¹ DISABILITY RIGHTS UK, INCLUSION SCOTLAND, DISABILITY WALES & DISABILITY ACTION (NORTHERN IRELAND) Opening Statement – 3 October 2023

Disabled people died more of Covid-19 than anyone else. They died more than anyone else in each successive wave of the pandemic.² Six out of ten of the Covid dead are Disabled people. A learning Disabled person between 18 and 34 was thirty times more likely to die of Covid. They suffered physical and mental harm during the lock downs and associated measures, and in ways that others did not. People who took years to set up and maintain systems of independent living lost those systems overnight. They suddenly did not have food, medicine, hygiene, or basic human contact. They lived with the real fear of non-resuscitation, lesser prioritisation for treatment, or dying in their homes because no one knew they were ill. The care system, long neglected and hugely undervalued, collapsed. The questions our clients bring to this Inquiry are how and why did Disabled people fare so badly during the pandemic and what does it tell us about the society we have chosen to live in and could choose to change? The submissions below deal with [I] Context [II] Rights [III] Government and [IV] Citizenship.

I: CONTEXT

1.1. DISASTER: Of all the many features of a disaster, one that is pertinent here, is that it is an event which exposes realities of society that were there all the time but screened from general view. Covid may well be the greatest collective crisis of our time but it is also its greatest collective revelation. For an Inquiry poised to consider decision making during the pandemic it is important to study those decisions within the context of the belief systems and social structures in which they were made. The Inquiry has made ground-breaking rulings on its terms of reference and commission of expert evidence to enable this to happen.

¹ 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. 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.

² Office of National Statistics (‘ONS’) (09.05.22) {INQ000089783/2 §§2-3}

- 1.2. CHOICE: Disabled People’s Organisations (‘DPO’) suggest an essential starting point: that the bulk of their fatal and damaging outcomes during the pandemic were chosen. They were the product of the way our society is organised and the dominant values and beliefs that guide it. To recognise the extent to which these outcomes are chosen is important; if uncomfortable. It should be uncomfortable. Most of us remain determined to see Disabled people in terms of their biological impairments, casting their fate as primarily a matter of difficult resource distribution and charity. This overlooks how disablement is determined by environment, culture, politics and economics.
- 1.3. DENIAL: Why do we insist on seeing things otherwise? To speak of Disabled people is to speak of some 20% of the population of the four parts of this country.³ That figure should make their fate one of the most significant of public issues, but it is not. Due to fear of prejudice, many whose conditions are largely invisible would rather exercise their right to keep them hidden if they can. Others would if they could, but because of visible conditions, have no choice. We have problematic substitutes for treating Disabled people as equals. They must be Paralympian objects of valour, who have overcome adversity; or they must be charitable objects of pity. In neither designated role are they human beings respected for their inherent human dignity and part of human diversity and humanity. Until disability comes into a person’s life it is something they would prefer not to think about; with intermittent fear and pity we otherwise live in studied thoughtlessness about its significance.
- 1.4. DEFINITION: The terminology of ‘Disabled people’ is appropriate because people are disabled by the fact that social spaces, services and provisions are modelled around certain kinds of bodies and minds to the disadvantage of others. That does not deny the reality of impairments: what hurts us or limits us is real and individual, but what disables people because of their conditions is the constructed barriers and attitudes that are not experienced and largely unseen by those without such conditions. Disability rights campaigners refer to this as a ‘social model’. Society has chosen their situation; although part of what is most disabling are dominant narratives in society that deny it is chosen. Instead, they locate the essential problem of Disabled people in their medical conditions, and other differences.
- 1.5. INEQUALITIES: The predicaments of Disabled people overlap with being of lower educational attainment, lesser employment and income, living in inappropriate and overcrowded housing without outside space or clean air, suffering food scarcity, isolation

³ Watson and Shakespeare, Module 2 Report, *Structural Inequalities and Disability* {INQ000280067/3 §3}

and hate crime.⁴ Disabled people are often treated worse because of their age, race, sex and gender. Their conditions can make them sometimes dependent on essential care, which is mostly provided by those who are paid little or must work unpaid. Many carers are Disabled themselves,⁵ or otherwise discriminated against. The unpaid carers are overwhelmingly women. All these intersectional inequalities add to marginalisation. Although inequality has now been claimed as a core issue by this Inquiry, during the height of the pandemic these matters were initially not spoken of, or otherwise characterised in Orwellian euphemism - as ‘disparities’, or ‘non-clinical vulnerability’ or ‘risk’ - anything other than the constructed inequalities and inequities that they are.

1.6. AUSTERITY: One of the reasons for euphemism was to defend the indefensible. Austerity policies that chose to asset strip from benefits and services, rather than by way of taxation on the very highest of incomes, had particularly severe consequences for Disabled people.⁶ Disabled people’s cost of living is inescapably higher because their impairments create expenses that others do not have.⁷ The ‘Bedroom Tax’ victimised Disabled people for the extra space they require either for equipment - such as wheelchairs or hoists - or else for sleeping, or personal assistance. It also aggravated pre-existing housing insecurity for those who had to move because they could not pay rent for homes that had taken years to acquire.⁸ Social care funding was scaled back, not just in care homes, but for those in domiciliary care,⁹ and it was vastly underfunded compared to the NHS.¹⁰ The care allowance for those who provide more than 35 hours unpaid care a week, and hence so much that they often cannot have other jobs, is £69.70.¹¹ The average pay for support workers in England who assist people to live independently in the community is £17,695 or £9.05 per hour.¹² It is perverse for the architects of austerity to deny that it left Disabled people in a perilous

⁴ EHRC, *Being Disabled in Britain – A Journey Less Equal* (March 2017) Executive Summary pp 7-15 and Watson and Shakespeare {INQ000280067/4 §6 and pp 6-8 §§15-28}

⁵ ONS, Unpaid care and protected characteristics, England and Wales: Census 2021 (24.04.23) Fig.1: Watson and Shakespeare {INQ000280067/10-11 §§33-34}; see also Glasby, J. et al (2021). *A lost decade? A renewed case for adult social care reform in England*. Journal of Social Policy, 50, 2, 406-407 and pp 418-419

⁶ Watson and Shakespeare {INQ000280067/10-11 §§30-36}

⁷ Watson and Shakespeare {INQ000280067/6-7 §19}

⁸ Watson and Shakespeare {INQ000280067/7 §§20-21, *Burnip v Birmingham CC* [2012] EWCA Civ 629) §47

⁹ Pearson, C. et al. *Covid-19 and the Crisis in Social Care: Exploring the Experiences of Disabled People in the Pandemic*. (2022) *Social Policy and Society*, 1-16, pp 4, 12-13

¹⁰ Daly M. *COVID-19 and care homes in England: What happened and why?* (2020) 54 Soc Policy Adm, 985–998, pp 993-996

¹¹ Carers UK {INQ000099707/10}

¹² Inclusion London, *Westminster Government Civil Society Shadow Report*, (March 2022) {INQ000279965/27 §55}

position by the time that shielding and lockdown policies were introduced. Equally, the peril should have been obvious to decision makers once the pandemic began.¹³

- 1.7. ADJUSTMENTS: In parallel to the predicaments of Disabled people, the rest of society generally lives without appreciation of the accommodations they enjoy, but were not recognised as such, until Covid brought some of them into jeopardy and multiple adjustments were introduced into the economy and everyday life. This was presented as exceptional. In fact, a major way in which disability is socially constructed is that we unconsciously live with adjustments and accommodations that have been made for the rest of us to make our work and lifestyles possible. We do not call them adjustments, but they are.¹⁴ Extended hours in banks and shopping centres, food deliveries, lifts, and online shopping are all accommodations that make contemporary leisure and working life viable. You might think that you can feed yourself, but you rely on shops, farmers, transporters, health inspectors, etc. to provide you with food. We are all dependent on adjustments made to the world around us. A dependency on good roads to commute to work, though more common than a dependency on Braille signage, is still a dependency. The fact that the former is not registered as a dependency at all, but as normal, while the latter is seen as an adjustment, is a political and social choice.
- 1.8. PERSONHOOD: What holds up the choices that rendered Disabled people particularly vulnerable during Covid is a dominant ideal of personhood in liberal societies that has developed around the politics of free market economics since the 1980s. That person is seen as autonomous, independent and self-sufficient. That person lives in a state system that now plays only a restricted role in peoples' lives, providing limited services and provisions to those who have not accumulated sufficient wealth to purchase their health and wellbeing privately. That is not to say that the modern government cannot be compassionate to those in need; but its motivation comes from a place of virtue and charity for those who are regarded as dependent and vulnerable, as opposed to recognition of rights that can be enforced, or some greater ethic of caring and interdependence relevant to everyone. The vulnerable is someone 'other'. As a result, caring of all types is undervalued, including that which is provided within families and homes. The intricate relationships of dependency and

¹³ Watson and Shakespeare {INQ000280067/12 §41 }

¹⁴ For a summary of this position, see Herring J., *Law and the Relational Self* (2020) Ch. 2 p. 30 and for a first-hand account, see Lindeman K. *The Ethics of Receiving*, (2003) *Theoretical Medicine* 24: 501-509

care that, in reality, underpin this dominant ideal of personhood are at best ignored and at worse, stigmatised.¹⁵

1.9. VULNERABILITY: There is a different way to see all of this. It arises from the truth that we are *all* vulnerable. We are all in a state of dependency at the beginning of our lives and are likely to be so at the end of it. In between we all will, in some way and at some point, be diminished by physical ailment, emotional suffering, or some kind of bodily limitation. In that respect, vulnerability is universal. Martha Albertson Fineman's writing on vulnerability is particularly helpful when thinking about the Covid response; and likewise our treatment of Disabled and other marginalised people.¹⁶ She distinguishes between "*embodied vulnerability*" which from time to time across the life cycle affects us all and is thus universal, and "*embedded vulnerability*" which is socially structured and functions to produce unequal outcomes for those designated as vulnerable, notably Disabled people, but also others who do not conform with the dominant liberal idea of an autonomous, independent, invulnerable person.

1.10. RESILIENCE: In so far as the opposite of vulnerability is not invulnerability, but resilience, there are challenges faced by Disabled and other marginalised people in becoming resilient. We are not born resilient, rather resilience is acquired over time by virtue of resources and relationships, which the state is critical in either fostering or denying depending on its policies.¹⁷ The ideal of personhood is therefore particularly damaging when it comes to resilience, because it assumes that narrow laws against discrimination that secure 'a level playing field' and equality of opportunity will be enough to produce a fair society. Those things are fine in their own right, but they do not deal with differences of power and situation that require a more positive conception of rights and responsibilities. Nothing could more clearly demonstrate this than the inescapable tension between, on the one hand, governments removing Disabled people's assets and withdrawing services in the ten-year period before Covid and, on the other, the central reliance on 'resilience' as an essential feature of UK Government emergency doctrine and policy. Practically speaking, the

¹⁵ Kittay E. *The Ethics of Care, Dependence and Disability*, 2011 Ratio Juris, Vol. 24, 1, 49-58

¹⁶ Fineman M. (2008) *The vulnerable subject: Anchoring equality in the human condition*. Yale Journal of Law & Feminism 20(1): 8–40, pp 5-6, 17-18. For the application of Vulnerability Theory to Covid, see Scherer et al., 'Do they ever think about people like us?': *The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic*. (2023) Critical Social Policy, 43(3), 423–447 and Gordon-Bouvier E. *Vulnerable Bodies and invisible work: The Covid-19 pandemic and social-reproduction*, (2021) Int. Journal of Discrimination and Law, Vol. 21(3) 212-229

¹⁷ Fineman (2008 p 13-15) and Fineman M., *Vulnerability and Inevitable Inequality* (2017) Oslo Law Review, Vol. 4, 133-149, Emory Legal Studies Research Paper, pp 146-147

Government needed to confront this jeopardy from the outset of the pandemic, but to have done so would have required an awareness and an admission that the jeopardy was of its own making.

1.11. SYNDEMIC: The source of ill-preparedness and denial, however, runs deeper. There is longstanding resistance to seeing disability and ill-health as the subject of political and economic choice and acting to change those choices. The views of Professor Sir Michael Marmot on health inequalities went almost unchallenged in Module 1, but their reception into the mainstream has not been straightforward.¹⁸ Marmot led the team in the World Health Organisation (‘WHO’) *Commission on Social Determinants of Health* in 2008, concluding that “*social injustice is killing on a grand scale*”.¹⁹ Following the WHO report he was commissioned by the Labour Government to chair a strategic review into United Kingdom public health and produced the 2010 report *Fair Society, Healthy Lives*, on the eve of the Coalition Government coming into power, finding that “*people in poorer areas not only die sooner, but they will also spend more of their shorter lives with a disability*”.²⁰ He was independently commissioned to produce *The Marmot Review 10 Years On*, which was published in the weeks before this pandemic, and found England to be “*faltering*”. It concluded that life expectancy had ceased to improve for the first time since the beginning of 20th century, in more deprived communities it had fallen, and overall there were more negative health outcomes for minority ethnic population groups and people with disabilities.²¹ That is why Professors Marmot and Bambra have called Covid a “*syndemic*”. It “*acted synergistically with existing socio-economic and health inequalities to exacerbate and amplify the impacts of the pandemic but also the impacts of those existing inequalities*”.²² Recognition of health inequalities as a primary risk of a pandemic was not written into any plan before it; and emerged only incrementally in its wake. Hence the triple jeopardy of Disabled people in Covid: as regards the illness itself, the lack of access to other health care, and the adverse consequences of NPIs were appreciated too little too late (see Part III below). But the challenge the DPO and other civil society core participants bring to

¹⁸ Bambra and Marmot, M1 Expert Report, *Health Inequalities* {INQ000195843/1-2 §§2-7}

¹⁹ WHO *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health: Commission on Social Determinants of Health Final Report* (August 2008) Executive Summary

²⁰ Marmot et al *Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post 2010* (The Marmot Review) (February 2010) p. 16

²¹ Marmot et al, *Health Equity in England: The Marmot Review 10 Years On*, Institute of Health Equity (February 2020) p. 5

²² Bambra and Marmot {INQ000195843/75 §181} and {T/4/55/6-10}

this Inquiry is that all of this was not just foreseeable and avoidable, it was chosen. Any program for a different outcome must confront that reality to inform its recommendations.

II: RIGHTS

- 2.1. HUMAN RIGHTS AS METHOD AS WELL AS OBLIGATIONS: While the inequities of Disabled people during the pandemic should be treated as an issue of public health, they should also be understood as human rights violations. Within this Inquiry there is a legitimate counterfactual to consider as to what might have happened if human rights compliance was more in the foreground of decision making. The DPO therefore urge the Inquiry to think about human rights and other global rights documents not simply as including obligations that are binding on the UK under international law and should have been highly relevant to decision making. They also provide a set of tools for understanding the lack of protection that Disabled people endured during the pandemic, and how to avoid such exposure in the future.
- 2.2. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES ('UNCRPD')²³: The UK signed and ratified the UNCRPD as long ago as 2009 and has undertaken to consider its terms in developing any policies that affect Disabled people.²⁴ In doing so it is in line with every country in the Council of Europe, save Lichtenstein, such that the European Court of Human Rights refers to the Convention when interpreting the articles of the ECHR.²⁵ The UNCRPD is one of the most recent international human rights instruments and has come after the creation of the third generation of discrete human rights documents agreed in the period between the 1960s and the 1990s to protect against discrimination on grounds of race and gender, and to provide more comprehensive protection of the human rights of children.²⁶ It includes a range of human rights principles that have been learned through the jurisprudence of those earlier Conventions, but are now contained as substantive Treaty rights and fill in what was otherwise regarded as a fundamental missing link in global human rights protection.²⁷ It contains social and economic rights to enable the elimination of

²³ United Nations on the Convention of the Rights of Persons with Disabilities 2006

²⁴ Government Response to the House of Lords Select Committee Report on The Equality Act 2010: The impact on disabled people (publishing.service.gov.uk) (July 2016) (p. 9)

²⁵ *Alajos Kiss v Hungary* (2013) 56 EHRR 38 §42, *Demir and Baykara v Turkey* (2009) 48 EHRR 54 §85

²⁶ International Convention on the Elimination of All Forms of Racial Discrimination (1965) (ICERD), Convention on the Elimination of Discrimination Against Women (1979) ('CEDAW') and the Convention on the Rights of the Child 1989 ('UNCRC'): for the relevance to such more specialised legal instruments to considering the scope of ECHR rights, see *Opuz v Turkey* (2010) 50 EHRR 28 §185

²⁷ Kayess R. and French P., *Out of the Darkness into the Light? Introducing the Convention on the Rights of Persons with Disabilities* (2008) 8 Human Rights Law Review 1-34 for general overview of UNCRPD

discrimination (Article 4), including access to the physical environment (Article 9), independent living (Article 19), personal mobility (Article 20), education (Article 24), health (Article 25) and adequate standards of living and social provision (Article 28). It also incorporates aspects of the ‘social model’ (Preamble Recital (e) and Article 1) and an approach to rights bearers that views people not only as autonomous, independent subjects (Article 3(a)), but multifaceted beings embodying different degrees of autonomy and vulnerability (Article 3(d)).²⁸

2.3. KEY PROVISIONS: Of particular significance to this Inquiry are the following provisions:

2.3.1. ARTICLE 11: requires “*all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of...humanitarian emergencies and the occurrence of natural disasters*”.

2.3.2. ARTICLE 4(3): requires that, with regard to both the development and implementation of legislation and policies concerning them, State Parties “*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*”.

2.3.3. ARTICLE 31: requires States Parties “*to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention...*” and that data collected “*shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.*”

2.4. UN COMMITTEE REPORT: The Inquiry is aware that the UN Committee on the Rights of Persons with Disabilities produced a UK Country Report in 2017 that criticised the present government for lack of consultation with Disabled people on policy and legislation that impacted on their lives (§§10-11), ill-preparedness to protect them in the event of emergency (§§28-29), damage done by austerity measures (§§58-59) and a lack of reliable data, including impairment specific and disaggregated intersectional data (§§64-65).²⁹ No

²⁸ Heikkilä M., Katsui H. & Mustaniemi-Laakso M., *Disability and vulnerability: a human rights reading of the responsive state*, (2020) *The International Journal of Human Rights*, 24:8, 1180-1200 for consideration of Fineman’s approach to vulnerability and its relationship with the UNCRPD

²⁹ Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland: CPRPD/C/GBR/CO/1 (03.10.17)

mention of that report has been made in any of the disclosed statements made by government witnesses to date. Three aspects of what was criticised are relevant to this module.

2.5. First. CONSULTATION AND CO-DESIGN: The obligation that Disabled people must be included in law and policy making - to collaborate in their co-production and co-design - is central to the UNCRPD and derives from the original Disability rights demand of “*Nothing About Us Without Us!*”. The DPO will ask for the Inquiry to test with witnesses whether discretionary practices of consultation conducted by this and previous governments really met the Convention criteria for inclusive decision making, including working with representative organisations run *by* Disabled people not just *for* them.³⁰ The Inquiry will hear evidence from the DPO, especially from England, as to how managed, minimalist and after-the-fact government contact was during the pandemic.³¹ Domestic administrative law does not contain a fundamental right to effective consultation and participation in policy formation and there is no nationwide statutory obligation to do this.³² An approach to government that embeds its Disabled people in the co-production and co-design of policy that affects them is a core recommendation of the WHO³³ a key part of the Sendai Framework on Disaster Risk Reduction,³⁴ and has been specifically urged as an aspect of compliance with Article 11 of the UNCRPD.³⁵ It is a practice belatedly adopted as policy in the Government’s National Disability Strategy (July 2021).³⁶ The Government has never explained how they will do it, and it is unclear whether they know how, or truly appreciate why it is important.

2.6. Second. DISASTER AND EMERGENCY PLANNING: Professors Watson and Shakespeare in their Module 2 report on structural inequalities and disability have emphasised that it is “*well*

³⁰ 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: see generally §§3-5, 11, 13, 15, 18-20, 27, 42}

³¹ Kamran Mallick, DR UK {INQ000280035/8-9 §§24-25 and pp 13-17 §§42-50 and pp 26 §§86-89}

³² See, recently, *SSDWP v Eveleigh* [2023] EWCA Civ 810 *Cf.* Part 3 of the Community Empowerment (Scotland) Act 2015 which affords some statutory rights in Scotland

³³ WHO World Disability Report (2011 Rec. 4 p. 265)

³⁴ The Sendai Framework for Disaster Risk Reduction 2015-2030 (March 2015) §§7, 19(d), 32, 35 and 36(a)(iii)

³⁵ General comment No. 7 (2018) provides §78: “*In situations of risk and humanitarian emergencies, it is important for States parties and humanitarian actors to ensure the active participation of and coordination and meaningful consultation with organizations of persons with disabilities, including those at all levels representing women, men and children with disabilities of all ages. This requires the active involvement of organizations of persons with disabilities in the development, implementation and monitoring of emergency-related legislation and policies, and the establishment of priorities for aid distribution, in accordance with article 4 (3).*”

³⁶ {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*”

documented” that disasters and emergencies often disproportionately impact the disability community.³⁷ The UN Committee criticised the UK in 2017 (at §§28-29 of its findings) for “*the absence of comprehensive policies related to disaster risk reduction that include persons with disabilities in the planning, implementation and monitoring processes of disaster risk reduction*” and recommended that planning and strategies: “(a) *Provide for accessibility and inclusion of persons with disabilities, in close consultation with organizations of persons with disabilities, (b) Mainstream disability in all humanitarian aid channels and involve organizations of persons with disabilities in setting priorities on aid distribution in the context of risk and humanitarian emergencies, (c) Develop information and warning systems in humanitarian emergencies that [are] accessible for all persons with disabilities; and (d) Ensure that organizations of persons with disabilities participate in resilience teams at the local level and [have] an active role in advising on and formulating policies and guidelines regarding disaster preparedness and planning*”. Those recommendations are a short form summary of what did not happen during the pandemic.³⁸

2.7. Third. DATA: Numerous witnesses are poised to identify to the Inquiry how considerable problems in the collection, dissemination and analysis of data were exposed in real time during the pandemic.³⁹ That evidence will join what was said in Module 1.⁴⁰ Gavin Freeguard’s report gives an overview summary of the technical, legal and cultural barriers to data sharing, including their implications for inequalities.⁴¹ What is yet to be confronted is that the UN Committee similarly criticised the UK in 2017 for the “*lack of a unified data-collection system and indicators across the State party concerning the situation of persons with disabilities*” and limited collection of disaggregated data (§64), and recommended that the UK “*significantly increase the availability of high-quality, timely and reliable data disaggregated by, among others, income, sex, age, gender, race, ethnic origin, migratory, asylum-seeking and refugee status, disability, geographic location and other characteristics*

³⁷ Watson and Shakespeare {INQ000280067/12 §37} and *Civil Society Shadow Report* Exhibit KM/70 {INQ000279965 p.83 §178}

³⁸ Bamba and Marmot {INQ000195843/61 §146} see also {T4/54/8-25} have already confirmed to the to the Inquiry that “*Health inequalities were only considered in a minimal way in the UK’s and devolved administration’s pandemic planning, and then largely in relation only to age and clinical risk factors. Wider issues of vulnerability (such as socio-economic status or ethnicity) were seldom considered...*”.

³⁹ Vallance {INQ000238826/20 §§47}, Harries {INQ000251906/187-90 §§788-799}, CMO Technical report {INQ000087225/148-50 and pp 158-60}

⁴⁰ Bamba and Marmot {T4/68/22-69/10} and {T4/70/18-71/8}, Vallance {T8/169/19-179/20}

⁴¹ Freeguard, Module 2 Report, {INQ000260629/ 5-12 §§1-13 and pp 46-49 §§89-100}

relevant in national contexts, including in all general population surveys and censuses” (§65).

2.8. SENDAI FRAMEWORK: Professor Alexander and Bruce Mann in their Module 1 report on Resilience and Preparedness did not deal with disability issues expressly, although reference was made to the Sendai Framework that does.⁴² In keeping with the obligations under the UNCRPD it details best practice under §19(d) that “*Disaster risk reduction requires an all-of-society engagement and partnership. It also requires empowerment and inclusive, accessible and non-discriminatory participation paying special attention to people disproportionately affected by disasters, especially the poorest. A gender, age, disability and cultural perspective should be integrated in all policies and practices, and women and youth leadership should be promoted. In this context, special attention should be paid to the improvement of organized voluntary work of citizens*”. To similar effect to Article 31 UNCRPD on data, the Sendai Framework at §19(g) maintains that “*Disaster risk reduction requires a multi-hazard approach and inclusive risk-informed decision-making based on the open exchange and dissemination of disaggregated data, including by sex, age and disability, as well as on easily accessible, up-to-date, comprehensible, science-based, non-sensitive risk information, complemented by traditional knowledge*”.

2.9. WORLD HEALTH ORGANISATION REPORT: The last document emanating from the global governance of disability issues is the groundbreaking WHO World Report on Disability (2011) that, like the Commission on Social Determinants of Health Report and the Marmot Reviews, should have been a bible to any government preparing for and then dealing with a pandemic, but no government witness presently disclosed has mentioned it. Of obvious significance is the emphasis placed on the UNCRPD as a social and economic reforming device (pp 9-10) which requires mainstreaming into all policies, systems and services (p. 264); the linkage made between disability and development including the link to poverty, such that disability may increase the risk of poverty and poverty may increase the risk of disability (pp 9-13); the essential function of improved data collection (pp 45-47, p. 267); access to health care and dismantling barriers to adequate service within it (pp 57-83) especially through more dedicated training and dedicated service provision; the adoption of a National Strategy (p. 265) which had not been done in the UK before Covid and has since been the subject of legal dispute;⁴³ the premium placed on involving people with disabilities

⁴² Mann and Alexander {INQ000203349/21-23 §§41-42}: see further Fn. 34 above

⁴³ It has been done in Wales and Scotland; but not yet in Northern Ireland

in the formulation of policies, services and laws (pp 265-266) with the attendant need to resource and build capacity for DPO; and providing adequate funding and affordability of services (p. 266).

2.10. COMPARATIVE NEGLECT: The DPO are going to suggest a standard set of questions to witnesses as to whether they have heard of these rights, reports and guidance documents referenced above and what consideration they believe was given to them in decision making. What is extraordinary is how little they feature in government discourse, but also how little they were seemingly embedded in government approaches at the outset and during the pandemic. To underscore the point, Marcus Bell, the Director of the Disability Unit and later the Equality Hub makes no mention of the UNCRPD at all, nor the critical reporting by the UN Committee, nor the WHO Disability Report. Likewise, Justin Tomlinson, the Minister for Disabled People, says no more than that the DU is responsible for “*co-ordinating the implementation*” of the Treaty “*across government*” without any detail.⁴⁴ He too makes no mention of the UN Committee report. Nothing is said about the WHO Disability Report. In global disability rights terms these are some of the most important documents in history. On present disclosure they left no footprint on the UK Government decision making during the Covid pandemic at all.

2.11. GOVERNMENT RESPONSE: The follow up questions to whether witnesses have heard of or seen implementation of these human rights protections is, if not, why not? In an exchange of letters in late 2020 between the Equality and Human Rights Commission and the Government, with the former pushing for direct incorporation of the UNCRPD into domestic law, Minister Tomlinson produced a formulaic reply. He wrote that the Government is “*fully committed*” to the UNCRPD, but “*The UK as a general principle does not incorporate international treaties into domestic law*”. That sentence is obviously not correct. The European Communities Act 1972 and the Human Rights Act 1998 are well known examples to the contrary. He added that “*the rights of disabled people under this Convention are largely reflected and given effect in existing domestic policies and legislation, including the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland*”. That sentence is only partially correct. No part of the Equality Act currently in force in England (or its Northern Irish equivalent)⁴⁵ deals with the socio-economic transformation of the lives of Disabled People

⁴⁴ Bell {INQ000198850}, Tomlinson {INQ000233735/3 §9}

⁴⁵ Cf. Wales and Scotland that have brought into force section 1 of the Equality Act 2010.

that the Convention mandates; nor does it require Government to comply with the obligation to co-design, plan for emergencies and collect relevant information.⁴⁶ The error embodies an essential problem in this area that non-discrimination and equality of opportunity are used as alternatives for greater substantive equality and social justice.

2.12. BROADER CONTEXT: UK government officials say that they are complying with the UNCRPD. In fact, they pick and mix from it.⁴⁷ The underlying reasons for Tomlinson's errors in his reply to the EHRC are political. They concern contested differences between municipal sovereignty and global human rights standards and different approaches to economics. Those errors were made at a time when the UK Government was contemplating revoking the Human Rights Act, in part because it created positive obligations on the state to protect rights, especially of those who have been rendered vulnerable by historical ill-treatment. At the same time the Devolved Administrations of the UK had taken steps to expand domestic human rights obligations.⁴⁸ Those errors in the Tomlinson letter were made in December 2020, in the knowledge that the UK Government had been heavily criticised by an external UN Committee in 2017 for shortcomings that were now starting to show in the terrible impact of Covid on Disabled people. A delegation of the same Committee had found "*grave or systematic violations of the rights of persons with disabilities*" arising out of UK austerity policies.⁴⁹ The chair of the Committee and respected human rights jurist, Professor Theresia Degener, told the UK Government delegation in Geneva on 24 August 2017 "*that social cut policies have led to a human catastrophe in your country, totally neglecting the vulnerable situation people with disabilities find themselves in*". This was the context for the pandemic.⁵⁰

III: GOVERNMENT

3.1. INVENTORY OF FAILURES: Against a background of denial about how much the fate of Disabled people is chosen, and an approach to governance that is ambivalent towards global human rights standards beyond minimum negative obligations, the containment of the risks

⁴⁶ Tomlinson to ECHR (14.12.20) {INQ000213340} replying to letter of 23.10.2020 {INQ000185329}

⁴⁷ The National Disability Strategy (July 2021) claims no more than "*We will be mindful in our review of our responsibilities under the UNCRPD*" {INQ000089722/94-95}

⁴⁸ E.g. DPO submissions in M2A Preliminary Hearing, Transcript 21.03.23 66/1-69/22

⁴⁹ Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention CRPD/15/4 (24.10.17) p. 20 §113

⁵⁰ Government cuts have caused 'human catastrophe' for disabled, UN committee says | The Independent | The Independent (25.08.17); UK cuts 'have created a human catastrophe for disabled people' ITVX (24.08.17).

faced by Disabled people during Covid was likely to be compromised. The DPO highlight nine failures:

- 3.2. First. NO SYSTEM: The evidence before the Inquiry together with what has been shown in the Grenfell Tower Inquiry⁵¹ absolutely underscores that the UK does not have a *system* of disaster management. The regime under the Civil Contingency Act 2004 ('CCA') is a network of arrangements and myriad guidance documents designed for local emergency, with national government only in an oversight role. Government has no significant duties itself under the CCA, or anywhere else. Emergency doctrine in this country is enmeshed in a notion of bottom up 'subsidiarity', which under Part I of the CCA does not recognise whole system challenges.⁵² It gambles on a lottery of local preparedness without any auditing of what is being done locally.⁵³ Its architect, Bruce Mann, has told the Inquiry that the Local Resilience Forums are not organisations, but meetings.⁵⁴ That is precisely what Robert Jenrick as Secretary of State warned the first meeting of General Public Sector Ministerial Implementation Group ('GPSMIG') on 17 March 2020.⁵⁵ Government has never used Part II of the CCA. It envisages a state of emergency when the country is under attack either from within or without. It does not cater for the critical collaboration between state and society that the Covid response demanded. The crucial links between central and local government are missing in the design.⁵⁶ Instead, default reliance is placed on the voluntary sector and community to fill gaps, but without mandating that they be involved in planning or response, or be funded to do so.⁵⁷ It contemplates the protection of vulnerable groups, but such terms are largely undefined in the guidance documents.⁵⁸ No one in either central, regional or local governments has express statutory duties of humanitarian assistance and

⁵¹ The weakness of the purported system was exposed in the days after the Grenfell Tower fire in June 2017 when the state effectively collapsed in the streets around the building and the bereaved, displaced and surviving local community itself became the humanitarian emergency response.

⁵² Mann and Alexander {INQ000203349/96-98 §§252-259}

⁵³ Thomas A. {INQ000236243/ 18 §61} refers to an IfG event in April 2018 in which Mike Adamson from the British Red Cross argued that the quality of LRFs varied hugely and Bruce Mann advocated far greater involvement of central governments in facilitating local preparedness and setting standards. Available at: <https://www.instituteforgovernment.org.uk/event/online-event/how-government-responds-to-crises>

⁵⁴ Mann and Alexander {INQ000203349/40 §§93-4} and {T3/142/13-143/6}

⁵⁵ GPSMIG Minute 17.03.20 {INQ00056023/6}

⁵⁶ Thomas {INQ000236243/ 36 §129}; see Mann and Alexander {INQ000203349/42 §101 and pp 109-110 §§305-7} describing the abolition of the Regional Resilience Forums as resulting in a loss of operational and efficiency benefits.

⁵⁷ Cf. Statutory responders under the CCA need only to 'have regard' to the Voluntary and Community Sector: see Civil Contingencies Act 2004 (Contingency Planning) Regulations 2005 ('CCR 2005') Reg 23

⁵⁸ Mark Lloyd {INQ000177803/43 §160}; see further Bamba and Marmot {INQ000195843/39 §88 and p.41/§99 and their conclusion at 61/§146.1.3}

recovery. Before 2020, none of the DPO were invited to engage on planning for a pandemic.⁵⁹ They have still not been invited.

3.3. Second. NO PLAN: With no plan beforehand Disabled people’s situation was then made worse by the delayed involvement of the Disability Unit (‘DU’) in the Ministerial Implementation Groups (‘MIGs’),⁶⁰ and especially the GPSMIG. Neither ministerial nor civil service attendance from an equalities standpoint was written into the GPSMIG terms of reference. No one from the DU attended a GPSMIG meeting until 21 May 2020, at which point Justin Tomlinson,⁶¹ and Sarah Baker as the lead civil servant, were present to deal with the agenda item of the impact of the pandemic on Disabled people.⁶² Before then, consequent to the Disability Minister not being a standing member of the GPSMIG from the outset, it was Minister Whately who by default was the person in the meetings who had the most relevant experience and responsibility for Disabled people and provided a link back into DHSC.⁶³ There is no evidence at present that she was briefed to articulate disability issues. Certainly nothing registered in the Minutes. DPO will wish the Inquiry to consider that not only was the end of May 2020 too late in its own right, but it contributed to further work on the issue being delayed into the Autumn of 2020 and ultimately into the start of 2021.⁶⁴ This gives rise to a significant concern to be examined with witnesses that a proper strategy for Disabled people was delayed in coming to fruition for both the first and second wave of the crisis. That was the case even though it was known by June 2020 that disabled people were dying in disproportionate numbers⁶⁵ and even though by October 2020, Michael Gove declared that “*time is running out*” for the risks to Disabled people, amongst others, to be mitigated in the second wave.⁶⁶ Instead, at the Covid O Meeting on 29 October 2020, a package to prevent transmission “*within groups that have been disproportionately*

⁵⁹ DR UK {INQ000185333/1 §4}; Disability Positive {INQ000104079/10 §38}; DA NI {INQ000148464/6 §17}; Disability Wales {INQ000183426/4 §10}; Disability Peterborough {INQ000106034/2 §4 and p.3 §7}; Inclusion London {INQ000184652/2 §5 and p.6 §15}

⁶⁰ Others, including those who constructed an approach to ministerial planning from scratch, will tell the Inquiry that the adoption of five MIGS, plus a PM Group, did damage in forcing Ministerial decision making into silos: e.g. Thomas {INQ000236243/40 §141.4}; Gove {INQ000259848/32 §§51-52}; Case {INQ000207294/9 §2.15} and {INQ000137215/2 §1}

⁶¹ For the Minister’s only known attendance at the GPSMIG meetings on 21.05.20, see {INQ000083626/5} at which point he spoke to the CO Disability Unit Paper titled Covid 19 – The Impact of C19 on Disabled People {INQ000083584}. The event is not mentioned in his statement.

⁶² Bell {INQ000198850/25 §60}

⁶³ {INQ000056023/9-10} Identifying that as her role at the first GPSMIG meeting on 17.03.20

⁶⁴ Bell {INQ000198850/27 §§63-65}

⁶⁵ ONS, Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020 (19.06.20)

⁶⁶ 19.10.20 Letter attached to the brief to present to the Covid O Meeting on disproportionately impacted groups on 26.10.20 and thereafter 29.10.23 {INQ000083956/8-9} and Bell {INQ000198850/27 §63}

impacted by COVID-19, focusing in particular on ethnic minority communities” was agreed. However, a more ambitious package to prevent disproportionate impacts from Covid for Disabled people appears only to have required development by the Prime Minister and Michael Gove (CDL) “*in slower time*”⁶⁷ and was never fully put into place.⁶⁸

3.4. Third. NO MACHINERY: As amorphous as the term ‘machinery of government’ might be, it ought to point to who or what part of the system is responsible. When it comes to equality matters the machinery is complicated, and deficient. Roles are dispersed across several departments and dual ministerial posts with no overall lead minister.⁶⁹ Disability issues sit within DWP, which is concerned with benefits not broader social change; and with the best will in the world will never be a welcoming environment for Disabled people who are dependent on its beneficence. No single lead Secretary of State is therefore embedded in Cabinet or Ministerial Committees. Like other junior ministerial roles, Ministers for Disabled People are forever revolving, as are their equality counterparts concerning race, ethnicity and gender.⁷⁰ Despite the intersectional effect of different inequalities, there is a risk that junior ministers with discrete portfolios will not integrate their work, especially when there is no dedicated Cabinet Committee to organise them into doing so.⁷¹ The various equality units, including the DU in government are now combined into the Equality Hub, which has been described as a creature of policy and not an operational department.⁷² Yet the actual Minister for Disabled People, Justin Tomlinson, will suggest that he deferred to the DU on the most essential features of his role,⁷³ and if he was not in higher level ministerial meetings he relied on briefing of the Secretary of State for Work and Pensions

⁶⁷ 05.11.20 Email from C-19 Secretariat {INQ000083917/2}

⁶⁸ 29.10.20 CDL Brief for the Covid O Meeting {INQ000090301/2-4} advised postponement until the end of November. It was still being worked upon from November 2020 into January 2021: see DU papers of 12.11.20 {INQ000083918} and 28.01.21 {INQ000083896} leading only to “*blogs on the DU website and some [unspecified] of the measures put in place*”: Bell {INQ000198850/27 §§64-65}

⁶⁹ Bell {INQ000198850/9-10 §17}, Truss {INQ000218370/3 §7 and p.4 §8(b)(iv)}. Liz Truss was the overarching Minister for Women and Equalities in conjunction with the position of Secretary of State for Trade and then Foreign Secretary but was not concerned with Disability issues, which fell under the rubric of the Minister for Disabled People, Justin Tomlinson and thereafter Chloe Smith, who reported to the Secretary of State for Work and Pensions, who was Thérèse Coffey.

⁷⁰ Mallick {INQ000280035/27 §90}

⁷¹ WESC, *Levelling Up and equality: a new framework for change* (22.09.21) {INQ000089734/14 §§25-34}

⁷² Truss {INQ000089733/15}: see also Bell {INQ000198850/3-4 §§7-8}

⁷³ E.g, Minister Tomlinson delegated to officials contact with the EHRC {INQ000233735/6 §17}, translating stakeholder engagement into influence on policy {p. 12 §41}, ensuring appropriate exemptions within Covid Regulations were included {p.16 §50}, collaboration with the ONS {§54}, drafting of PSED impact assessments relating to Covid 19 legislation {p. 25 §82} lessons learned exercises in the EH {p. 26 §88}, and was unaware of data being captured regarding the impact of Long Covid {p. 6 §18}.

to deal with his portfolio issues during those meetings.⁷⁴ There is no indication that she did. It has been established that the DU and its predecessors were involved in no emergency planning, including for a pandemic prior to 2020.⁷⁵ Once this pandemic began: aside from the abject failure to escalate disability issues (policy or otherwise) into GPSMIG decision making for months, other shortcomings of disability machinery included Minister Badenoch (whose portfolio did not include Disability) being commissioned in June 2020 (already too late) to conduct a review of Covid “*disparities*” in pandemic impacts that in due course focussed upon ethnicity only.⁷⁶

3.5. Fourth. NO EXPERTISE: One of the many political and decision-making problems with the slogan ‘follow the science’ was that SAGE was initially dominated by medical scientists, whereas the pandemic was a “*mixed crisis*” involving myriad social and economic issues.⁷⁷ Those who gave or acted upon SAGE’s scientific advice did not benefit from the expertise of service providers or end users, including Disabled people, able to proffer lived expertise. In all the gaps in planning, machinery and expertise, what is extraordinary is that for a very long time no one appears to have noticed the problem. When it was noticed, the corrective action involved primarily focussing on race, ethnicity and gender.⁷⁸ The perspective of Disabled people continued to go without recognition as missing. Only in hindsight did leading figures like Professor Sir Stephen Holgate recommend “*Co-producing guidelines and engaging relevant communities*” in “*equal partnership with service users, carers and communities at the earliest stages of design, development and evaluation*”.⁷⁹

3.6. Fifth. NO RECOGNITION: One of the outcomes of there being no consideration of the representation of those from ‘vulnerable and at-risk groups’ in the composition of UK Central Government, SAGE and related bodies, is that the characterisation of who is ‘vulnerable’ and/or ‘at risk’, and how that registered in administrative and political decision-making moved only incrementally from a clinical/shielding focus to a broader social focus. The movement is most obvious in the DHSC Covid 19 Battleplan which in March 2020 focussed in Workstream 6 on “*protecting the most vulnerable*” (in a clinical sense) through shielding and then evolved in May 2020 into Workstreams 7A “*Shielding the Clinically*

⁷⁴ Tomlinson {INQ000233735/6 §14 and pp 17-18 §§56-64}

⁷⁵ Bell {INQ000174833/4 §5}

⁷⁶ Badenoch {INQ000215534/2-3 §§5-8} {INQ00089747/5-7 and p. 32 Fn. 62}

⁷⁷ O’Donnell {INQ000215548/13 §60} elaborated upon in {INQ000189722/10-11} and {INQ000189723/16-17}; see also Thomas {INQ000236243/36 §128}, Hayward {INQ000267868/29 §7.29}, Vallance {INQ000238826/220 §685} and Woolhouse {INQ000250231/5 §§22-25}

⁷⁸ Rubin {INQ000056547/32 §6.4}

⁷⁹ Holgate {INQ000056483/12 §7.2(1)}

Extremely Vulnerable” and 7B “*Supporting other disproportionately affected groups and volunteering*” (which are shorthand referred to as “*other vulnerable groups*” and “*the non-shielding vulnerable*”).⁸⁰ Focus then began to turn to group categories such as people with disabilities requiring care in the home.⁸¹ Even then Disabled people remained subsumed within the marginalising notion of vulnerability, until August 2020 when the Covid Taskforce adopted the broader notion of the “*Disproportionately impacted groups*”.⁸² A powerful protest against the language of vulnerability in the context of the Covid response arose in an editorial dispute in the British Medical Journal in 2021 where it was argued that describing people with a learning disability as vulnerable to the virus “*locates the disproportionate risk of death from Covid 19 (and before Covid 19 too) as a property of individual people with learning disabilities. This not only removes agency from over a million UK citizens, but also can serve to remove any sense of urgency or even responsibility to see these inequalities for the injustices they are and to do something about them that matches the scale of the injustice.*”⁸³

3.7. Sixth. NO ENGAGEMENT: Despite obvious risks to Disabled people from the outset the Government did not engage with them or their organisations when formulating their response to the pandemic. There will be some debate about the number of meetings that Minister Tomlinson had with DPOs and other organisations, but what is obvious is that these encounters were qualitatively too little, too late, and too one sided to constitute compliance with the principles of co-production and co-design.⁸⁴ By the end of April 2020 the GPSMIG knew that the connection with the voluntary sector was not as dynamic as it should be.⁸⁵ In this vacuum Watson and Shakespeare describe how “*in the early stages of the pandemic the*

⁸⁰ Wormald {INQ000144792/94 §§296-297} Battleplan 22.3.20 {INQ000106286/2 and 15} Battleplan ‘Version 2.0’ 04.05.20 {INQ000106902/3} Battleplan ‘Version 2.0’ 04.05.20 {INQ000106902/3}

⁸¹ The notion of Non-Shielding Vulnerable coincided with Simon Case’s joining the Cabinet Office and taking up a dedicated Director role to focus upon them: Case {INQ000207294/57 §§2.1-2.9} and for its first detailed Cabinet Committee focus on 24.04.20, see the Paper titled ‘Non-Shielded, Vulnerable (NSV) Groups’ {INQ000088666} and the Minutes {INQ00088638} in which non-CEV Disabled people were first seen as one of the core aspects of the vulnerable cohort.

⁸² For earliest references see 21.08.20 {INQ000083902/1} and 28.08.20 {INQ00053734/3}

⁸³ Scherer et al. (2023), Fn. 16 above, p. 4: see further Mallick {INQ000280035/25 §85} (*The language...used stripped us of our agency and dignity. It repeatedly referred to an amorphous group of people as “vulnerable”*) and Welsh Government Disability Forum *Locked Out – Wales* (July 2021): “*Disabled people found themselves referred to as ‘vulnerable’ by Government and mainstream media, which for many felt demeaning and undermined the long fought for achievements of the disability rights movement. The ease by which the social model of disability was abandoned also suggests it was poorly understood or insufficiently embedded in governance and public service decision-making.*”

⁸⁴ See Fn. 31 above

⁸⁵ GPSMIG Minute (22.04.20) {INQ000083602/5} registering the “*Need to have a wider conversation about the role of the voluntary sector and what we could reasonable expect them to go and do – vs the role of the state*”: see also O’Donnell, *The Covid Tragedy*, IFS (24.09.20) {INQ000189722/20-21}

only organisations which seemed to be exploring the impact of Covid-19 on disabled people were third sector organisations of disabled people”.⁸⁶ Evidence of the likely lost opportunity of non-engagement is contained in a letter that DR UK sent on 16 March 2020 to the Minister for Disabled People and Minister for Care suggesting nine recommended changes to the initial Coronavirus Guidance, including more stringent protections for care home residents and funding for isolation units in care homes, better advice for carers on how to protect residents, and provision of PPE for carers even if asymptomatic, on the basis that the DPO were already aware of the risks of asymptomatic transmission of the virus and knew that carers moved from care setting to care setting. All recommendations were urged as important because the Government appeared to be modelling the virus response on influenza. Given the many people DR UK knew who were not on the radar of care provider networks, they offered to assist government in establishing grassroots communication networks.⁸⁷ Although this letter dealt minimally with financial matters, what DR UK got back in a response received on 9 April 2020 was a proforma letter from the DWP that failed to deal with the vast majority of these fundamentally prescient points and instead conveyed a limited number of matters exclusively concerning benefits.⁸⁸

3.8. Seventh. NO DATA: Government needed to be heavily engaged with Disabled people and their organisations because they began the pandemic bereft of sufficient data about them. Despite obligations under international law to collect disability data (including by different impairments and other personal and social characteristics), and despite more than a decade of advice on social determinants of illness and impairment, the UK had no existing methods to collect that data properly. In the second part of 2020 and 2021, the papers issued by its DU registered increasing awareness of the acuteness of the problem. Its first major paper to the GPSMIG on 21 May 2020, identified data gaps and proposed an action (as adopted) to “develop a plan” to address the issue.⁸⁹ That plan was still being developed on 30 October 2020, when it was acknowledged that there were still significant knowledge gaps concerning the possible impacts of both the pandemic and HMG Covid policy responses.⁹⁰ As of 12 November 2020, the DU proposed a Data Commission to

⁸⁶ Watson and Shakespeare {INQ000280067/12 §38}: see also Cullingworth, J et al “*They have been a saving grace in all this*”: the role of the third sector in disabled people’s experiences of COVID-19 and implications for sector–state relations, (2022) Voluntary Sector Review, 2022: 1–18, pp 1-2 and 15

⁸⁷ Mallick {INQ000280035/6 §19} and Ex. KM/3 {INQ000238504}

⁸⁸ Exhibit KM/4 {INQ000238515}

⁸⁹ Impact of Covid-19 on Disabled People, GPSMIG (21.05.20) {INQ000083584/3 and 7}

⁹⁰ Disproportionate Impacts of Covid-19 on Disabled People, Briefing (30.10.20) {INQ00083956/2 §7}

understand factors driving increased mortality risk and improving on data collected by the ONS.⁹¹ That proposal was not acted upon. On 30 March 2021, the DU still expressed concern about data deficiency, including health conditions being considered as binary variables (yes/no) rather than modelling the effect of different health conditions, and being highly dependent on disability status from the 2011 Census, which was outdated and contained no disaggregation of disability by impairment type. It therefore advocated the need for a data improvement program.⁹² In July 2021, the DU published the National Disability Strategy, that committed to “*strengthen the data and evidence base to support policies that will transform outcomes for disabled people*” but it did not say how it would do so.⁹³ Even in June 2022, the ONS acknowledged that there was much left to do for disability data, recognising that there were methodological problems in identifying the consequences of certain types of impairments, both because the way in which the impairment is identified and recorded in the first place is not standardised across different data sources (p.17 §§5-6 p.22 §2), and because not enough thought has been given to social factors that render an impairment more or less as disabling (i.e. the ‘social model’) (p.17 §9).⁹⁴

3.9. Eighth. NO PROTECTION: The Inquiry will look at what NPIs were introduced and how effective they were in protecting different sections of the population. What was lost in the failure to engage early with Disabled people and their organisations were some of the most significant protections. Of these, food insecurity is an important example. DR UK have repeatedly emphasised that they could have assisted earlier to prevent Disabled people confined to their homes who were not initially registered as CEV being left without food to the extent that they were. They wrote to the Secretary of State on 27 March 2020, but meetings and actions did not begin to bear fruition until the end of April. For those without assistance that timescale would have been terrible.⁹⁵ Other basic mistakes were made relating to sign language,⁹⁶ assumptions around digital and other information access,⁹⁷

⁹¹ DU’s contribution to the COVID (O) commission on disproportionate impacts of covid on disabled people (12.11.20) {INQ000083918/1 §3.1}

⁹² Disability and Covid-19 Deep Dive, DU, (30.03.21) {INQ000083885/15 and 32-6}

⁹³ National Disability Strategy (July 2021) {INQ000089722/87}

⁹⁴ ONS, Improving disability data to understand the effects of coronavirus (COVID-19) on people with different impairment types (07.06.22) {INQ000089787/17, 22 and 23}

⁹⁵ Mallick {INQ0002800358/8-9 §24-25 and p.28 §93} and KM/11 {INQ000238539}

⁹⁶ Mallick {INQ0002800358/28 §91}; WESC *Unequal impact? Coronavirus, disability and access to services* (15.12.20) {INQ/000089817/38-9 §§118-125}

⁹⁷ Watson and Shakespeare {INQ000280067/8 §25-26}; Mallick {INQ0002800358/28 §91}; This was recognised as an issue but only acted upon in late October 2020, see {INQ00083956/3-4}

making services available only to those on the CEV list,⁹⁸ and earlier identification of Long Covid,⁹⁹ all of which it is difficult to imagine would have been overlooked had better engagement with those with lived expertise occurred. However, the ultimate tragedy will forever lie in the lost protections for those in residential and domiciliary care. The emerging evidence is that Ministers feared early on that the system might not cope;¹⁰⁰ but it was equally apparent to civil society groups who dealt with them that they did not fully understand the system.¹⁰¹ The devastating risks were realised too late.¹⁰²

3.10. Ninth. NO REDISTRIBUTION: Despite some recognition of those that were socially and economically vulnerable during the course of lockdown measures, there was no change to the standard benefits position that people, while they remained unproductive, were only to receive exceptional financial provision. That was the essential ambit of the furlough schemes, the £20 additional Universal Credit and limited income support for those needing to shield from work attendance or from carers at risk from transmission. From the perspective of Disabled people these measures were extraordinarily limited. For those who did not work, or could not work, furlough meant nothing, but they also found themselves exposed to loss of employment despite furlough.¹⁰³ Those on Carers Allowance did not receive the extra £20 of Universal Credit.¹⁰⁴ Neither did those on legacy benefits, which in Northern Ireland included almost everyone due to transitional arrangements. Tentative deliberation that the situation should be corrected came to nothing.¹⁰⁵ In its briefing to the Covid O group on 30 October 2020, the DU acknowledged the disproportionate financial impact of Covid on Disabled people but proposed no remedy, save to refer to the possible provision of a “*financial package*”, which did not come.¹⁰⁶ One of the many long tails of

⁹⁸ Mallick {INQ0002800358/8 §24a}; WESC Report (15.12.20) {INQ/000089817/12 §§14-15}; Case 06.05.20 {INQ000129309} “*we need to use this review to bring order to the shielded/non-shielded madness...this is a continuum, not black and white - and so we need to approach policy response in this way.*”

⁹⁹ Mallick {INQ0002800358/21 §69}

¹⁰⁰ Hancock {INQ000232194/55 §230} Hancock-Whately WhatsApp 03.03.20 18.29-19.57 {INQ000176785/3}

¹⁰¹ Care England {INQ000099684/8 §§8.4-8.6 and p. 11 §§10.2.1-10.2.4}; National Care Forum {INQ00009970/4-5 §§5(1), 5(4) and pp 7-8 §§}; Relatives and Residents Association {INQ000099691/1 Lesson 1}; Homecare {INQ000099681/10 Lesson 2}; Age UK {INQ000099714/4-5}; Williams {INQ000207511/4 §9}

¹⁰² E.g. Social Care Update and Next Steps (28.04.20) {INQ000088490/2}

¹⁰³ E.g. by December 2020, HMT acknowledged that Covid had widened the disability employment gap {INQ000184604/15}

¹⁰⁴ Note UC monthly was £317.82 for single person over 25 and £498.89 for a couple

¹⁰⁵ Email exchange between Emran Mian, and Helen Dickinson, (Cabinet Office), and DHSC (05.11.2) {INQ000083917/3 §3}

¹⁰⁶ Disproportionate impacts of Covid on disabled people (30.10.20) {INQ00008956/6-7}; for summaries on financial impact, see e.g. Carers UK {INQ000099707/9-10}, Carers NI {INQ000099677/7}, Mallick {INQ0002800358/31 §101}; DR UK Written Evidence (December 2020) {INQ000176334/2}

the pandemic is the fact that it is highly unlikely that Disabled people will build themselves back better financially without collective societal assistance.

IV: CITIZENSHIP

- 4.1. CHOICE: To open these submissions with the reflection that what happened to Disabled people in the pandemic was chosen is a deliberate well-meant provocation that we could equally choose to live differently. The jeopardy Disabled people faced during Covid arose from choices embedded in state institutions and social policy. That requires understanding in its own right, but it also assists in understanding the disproportionately adverse outcomes of the Covid response on other groups in society, representatives of whom are justly included in these hearings because they each and cumulatively represent how over a generation they have become socially excluded and internally isolated in their own country. Most of the time the more affluent are secluded from the unequal and hostile environment that those other people live in. It treats their dependencies as something to pity, fear, deny or disdain. The result in countries like the UK and USA is extreme disparities in wealth with effective gradations of citizenship. These, of course, are also the countries that on a range of metrics appear to have performed less effectively in responding to the pandemic.
- 4.2. CONNECTEDNESS: The Covid era is often framed as the greatest crisis of our time and equivalent to a major war. Like a war the pandemic disturbed ordinary ways of life, and with it some illusions of invulnerability/vulnerability, independence/dependence, and by extension, ability/disability, that have come to prevail in societies like ours. In the opening stages of the crisis our joint fear was that an unknown virus might kill, disable, or impoverish any one of us, and in that real time veil of ignorance, we all wanted reasonable adjustments, not just for ourselves, but for each other. We became unusually more bound together, even though we were apart, and more determined to care for others. A renewed citizenship and fellowship emerged. A democracy so divided in the previous decade momentarily felt more social, with a promise that it could be more just.
- 4.3. RESILIENCE: Then at some point, that panic passed and we learned that while still in crisis, although we were all in the same storm, we were not in the same boat. Nothing signified that more than the central place of the ‘home’ in the Government’s pandemic response. Of the many adjustments that everyone now accepted, it was ironic for Disabled people that their long-ignored calls for remote working and other remote means of engaging with state and society were finally implemented, but only once non-Disabled people saw their benefit.

And yet the image of the person that the Government imagined when it told everyone to stay at home was someone who could financially, physically, emotionally and logistically afford to stay there. It did not imagine the person who had no spare room to isolate in. The person who had no means of certain bodily or cognitive functioning without personal assistance. The person who could not stay at home, or isolate within it, because they needed to care for someone else, a parent with dementia, an autistic child, a partner with depression. Instead, it imagined a non-disabled relatively autonomous person who would regard their home as a place of safety, and be capable of moving their life into it. In due course many of these people felt bound to confess that they were enjoying lock down as it had taken them out of their routines and enabled them to be closer to their families. It is not that those people did not experience their own vulnerability. They got sick, their independence was compromised, their children's development was arrested, people dear to them died and they and those around them suffer from Long Covid, delays in other medical treatment and less robust mental wellbeing than they knew before. In all this they too needed caregiving of their own or took care of others. But they also had the assets to sustain them: the space, the networks, the sufficient capital and the like; and for all of that they experienced gratitude amidst anxiety. These are the distinctions between vulnerability, which is universally embodied, and resilience which is constructed from social relationships and wider institutions.

4.4. PRESENT: For this Inquiry these distinctions are real and important, because it has set itself the task to consider in this module whether there were potentially different approaches to NPIs. Of those differences it is known that other countries were able to create more collective methods of shielding based on mandatory isolation through local test and trace but also through protected pathways into homes and within communities. However, to succeed in such measures more generally, a country needs to have a degree of connectedness in its culture and values and a responsive state that is able to harness that connectedness both technically and temperamentally. The UK experience during the pandemic suggests it has the potential to do this. For instance, certain communities bound together and many institutions at every level of society did their utmost to ameliorate adverse situations. However, the UK suffers from a disconnection between political society and civil society and between the centre of government and its localities. It has also stalled both institutionally and culturally in imagining a society where care for the wellbeing of one another is the primary goal.

4.5. FUTURE: To be more prepared and resilient for the pandemic and mass disasters of the future, this society is going to need a renewed recognition of citizenship and a rediscovered belief, that perhaps last prevailed strongly in the immediate period after 1945, that the state can be a source of collective good. Understanding the choice of what happened to Disabled people during the pandemic and reframing that choice through compliance with the UNCRPD is something that the DPO have come to this Inquiry to claim as of right, but their endeavours have a wider value. It is sometimes said that the UNCRPD is a treaty written by Disabled people for Disabled people, which is in fact true, but it is also a body of law for everyone. The UNCRPD values human life in all its diversity, respect for the human dignity of all, and the removal of barriers and the changing of attitudes to that end. What the collective experience of this pandemic can provide is the wisdom that we are all vulnerable and a humility that some people are *temporarily* more vulnerable because of the way that society has automatically adjusted for others but not for them *for the time being*. For those not now immediately sensing themselves at risk it could be tempting to continue as we are, but the scale of what happened in the height of the pandemic, and what could happen in the future, has made everyone more aware of the life cycle, the limitations of the body, and value of relationships. It has dispelled the illusion that we are islands unto ourselves. It has made the ethics of mutual care far more pertinent to the way we might live. One task of this Inquiry should be to embed those ethics into its recommendations for the future.

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26 SEPTEMBER 2023