COVID-19 INQUIRY
MODULE 6

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

INTRODUCTION

1. OUTLINE: Disabled people are not a homogenous group, but their history and social reality give many of them cause to be particularly wary about four things: (I) The way Disabled people are rendered invisible. (II) What happens to Disabled people in institutions. (III) How Disabled people can be abandoned in the community. (IV) Whether their lives are valued less than others. The Inquiry's examination of the care sector during the Covid-19 pandemic brought all these concerns to the fore. The DPO offer concluding observations below under the headings of: INVISIBILITY (PART 1), INSTITUTIONS (PART 2), COMMUNITY, (PART 3) and VALUE (PART 4).

PART 1: INVISIBILITY

[A] RECOGNITION

2. CHOICE: The long-term flaws of the Adult Social Care System ('ASC') were starkly revealed during the pandemic in two extreme ways. Care settings became life threatening (see PART 2). Care services to sustain everyday basic quality of life were withdrawn (PART 3). The most dispiriting feature of those outcomes is that in the absence of profound alteration of the structure of the system they were essentially inevitable. While an Inquiry of this nature can offer technical recommendations to improve the margins of those outcomes, there can be no significant change without understanding the extent to which the present system was chosen to be that way. The fundamental problem that Disabled people face is the failure of society to recognise that choice. Instead 'disability' is continually categorised as the unfortunate consequence of individual or medical differentials that are socially accepted as largely beyond the realms of 'reasonable' state intervention. The possibilities for doing things differently are consequently covered up.

3. VULNERABILITY: From the perspective of emergency and contingency planning, the invisibility of Disabled people begins with the failure to recognise the following matters, which the DPO have submitted as relevant to all parts of this Inquiry: (1) The vulnerable situation of Disabled people, beyond the challenges of their conditions, is a social construct. (2) All people experience vulnerability across the life cycle, but the opposite of vulnerability is not invulnerability, it is resilience. (3) Resilience is not an individual trait, it

derives from assets, including capital, but also social networks, knowledge, access and influence. (4) Disabled people are socially and politically vulnerable, because of the unequal distribution of resilience-sustaining assets. (5) Disaster planning, preparedness and response all suffer from a failure to consider inequalities and social need that affect resilience.[1] From (1) to (5) above it follows that the Inquiry should make recommendations that plan for and enable more profound distribution of assets to sustain resilience during an emergency. The obligation to do so is contained in Article 11 of the UN Convention on the Rights of Persons with Disabilities ('UNCRPD') which requires "*all necessary measures*" to be adopted to protect Disabled people for the advent of emergency. This is not simply an obligation of equal treatment.[2] It imposes a positive obligation to ensure special protection.

[B] KNOWLEDGE

4. HUMAN-ACCOUNTING: Against that overall approach, it is imperative for the state to know about its people, their needs and inequalities, and to use that knowledge to co-produce adequate and effective policies. That cannot be done without data and as the Inquiry is aware, especially in terms of the visibility of Disabled people, the state's existing capacity to collect and share information relevant to socially vulnerable people is poor.[3] The deficiency was identified in the care sector prior to the outset of the pandemic by, amongst others, Operation Cygnus,[4] and the Office of Statistical Regulation ('OSR');[5] and more generally by the UN Committee on the Rights of Persons with Disabilities.[6] If one of the essential attributes of disaster management is situational awareness, both central and local government did not have it.[7]

5. DEFICITS: SAGE concluded in May 2022 that no UK nation was able routinely to identify who is resident in care homes, who is receiving social care at home, or who works in or visits a care home or person's home.[8] The deficits faced by emergency planners and decision makers included (1) PROFILE. The real-time numbers, needs, and other

[1] For DPO approach to these matters, see DPO M2 Opening 26.09.23 [p. 1 §§1.1-1.1.11, 4.1-4.5]
[2] Cf. Article 10 UNCRPD "*States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others*"
[3] DPO M2 Closing 15.01.24 [INQ000399541/23 §§35-37] DPO M2A Closing 23.02.24 [p. 11 §§23-25] DPO M2B Closing 05.04.25 [p. 6 §§13-14, 34-36] DPO M2C Opening 19.04.24 [p. 13 §3.16]: see also Bambra & Marmot [M1/T4/68/22-69/10] [M1/T4/70/18-71/8] Sudlow Review (2024) [M4/INQ000513700/15, 27, 56] Diamond [INQ000553814/61 §§226-232] OSR (2021) [INQ000092812] Update (2022) [INQ000092810]
[4] Pandemic Influenza Briefing Paper: ASC and Community Health Care 01.06.18 [INQ000105391/6-7]
[5] OSR January 2020 [INQ000502199/3-4, 10-12]
[6] UNCRPD UK Country Report (2017) [M2/INQ000182691/10 §§64-65] *Cf.* Art. 31 of the UNCRPD [INQ000279959/24]
[7] CMO Technical Report 01.12.22 [INQ000203933/96, 122-124]
[8] SAGE Consensus Statement 22.05.22 [INQ000215624/7 §3] Shallcross [INQ000613177/27 §§53, 58] [T2/203/25-204/1] CMO Technical Report 01.12.22 [INQ000203933/305 §4]

characteristics of UK adult care recipients in terms of age, sex, gender, race, ethnicity, and disability, including individual impairments, were not known.[9] (2) SERVICES. Unlike in the NHS there were no records of admissions to care homes or of those in receipt of publicly funded care at home,[10] with no collection of data at all in relation to people who receive self-funded services.[11] (3) LOCATION. Other than data on the number of available beds in care homes, there was no further information on the types of setting for different care recipients (e.g. residential, domiciliary, assisted living, other), or the geographical spread of those settings.[12] (4) LABOUR. Care providers are required to register with the Care Quality Commission ('CQC') but there were no centralised records on (a) the type of employed labour (i.e. salaried, agency supplied, directly employed personal assistants, or unpaid carers); (b) the location and movement of labour (between hospital, care home, home care, and wholly unrelated settings); and (c) the education and qualifications of the labour force.[13]

6. CAUSES: These deficits exist because of historic underinvestment and neglect of social care data infrastructure especially when compared to health care.[14] The dissonance between comparatively data rich and digitally accessible health records, and far more limited and fragmented still digitalising care records has several causes:

   (1) STATUS: Higher cultural, managerial and political status is afforded to the NHS and health care provision over and above social care.[15] Government planning and data collection therefore initially focused on health, without any involvement of social care expertise or related data input.[16] ASC had diminished status, expertise and civil service ranking within the DHSC.[17] Version 1.0 of the DHSC Covid battleplan in March 2020 had a workstream on clinical vulnerability, but nothing on social care or non-clinical

[9] Davies [INQ000520201/49 §137(10)]: see also Mallick [INQ000520998/34 §101] Davies [INQ000520201/21 §60] Nolan [INQ000520202/29 §§98-100] Sansome [INQ000520343/29 §§96, 99]
[10] Harries [INQ000587394/11 §§5.5, 5.8, 5.13, 7.1-7.2, 9.5] Diamond [INQ000553814/59 §§213-215] McKay et al [INQ000578133/8, 58-59] Khaw [INQ000587702/92 §§350] Abrahams [INQ000509808/24 §§65, 108, 122] Bottery [INQ000502030/3 §8] King's Fund 'Stories' Report February 2021 [INQ000498620/9, 30-32] Nuffield Trust 'Building' Report May 2023 [INQ000553858/36] Rayner [INQ000475131/10 §§2.6-2.7, 10.14]. For DPO, see Mallick [INQ000520998/33 §100] Davies [INQ000520201/21 §60] Sansome [INQ000520343/30 §98]
[11] Diamond [INQ000553814/39 §140] Howarth INQ000572013/61 §174]
[12] Khaw [INQ000587702/92 §§352-353]
[13] Whately [T12/136/25-140/4] [INQ000587788/115 §59(e)] Shallcross [INQ000613177/28 §53] Townson [INQ000587670/38 §129] Khaw [INQ000587702/39 §129]
[14] OSR, ASC England (January 2020) [INQ000502199/5] Diamond [INQ000553814/60 §§216-217] McKay [INQ000578133/58] OSR, Scotland (March 2020) [INQ000503458/3] SAGE Consensus Statement 22.05.22 [INQ000215624/7 §3] Rayner [INQ000475131/10 §§2.6-2.7, 10.15]
[15] Whately [INQ000587788/106 §§12-13] McAnea [INQ000587381/1 §2] Daly [INQ000148331/11 §3.2.2]
[16] Williams [T15/96/10-97/3]
[17] DPO M6 Opening 19.06.25 [p. 5 §11] Whately [INQ000587788/106 §14] Whately [T12/36/24-39/13] Hancock-Whately WhatsApp 17.05.20 11:35 [INQ000274068/13] Williams [INQ000571608/29 §8.9] Rayner [INQ000475131/57 §10.1]

vulnerability, which were only belatedly included in May 2020.[18] Social care researchers ended up creating data studies by way of filling in gaps that the system had previously overlooked.[19]

(2) STRUCTURE: In the absence of a National Care Service, there has since 1945 been a "*desperate landscape*" of governance of ASC with division of responsibility across the DHSC for standards setting, the MHCLG for local authority oversight and the Treasury and DWP for various forms of funding. But no single department of Government is operationally responsible for ASC data.[20] More broadly there is no "*chain of command*" or coordinating body for social care.[21] It is essentially a private business with local authorities acting as a major purchaser of services and supplying some supplementary services of their own, and thereby some gateways of knowledge of what is going on, and some influence as to direction.

(3) TECHNOLOGY: ASC did not have the equivalent integrated platforms of NHS Digital and COPI (Control of Patient Information). Even if they did, only 20% of social care providers had digital records at the start of the pandemic; only 40% had become fully digital in terms of capability in 2021; services throughout remained still largely paper based; and if technology was installed there was a lack of training and confidence to use it.[22]

(4) ECONOMICS: Ministers who complained about lacking the levers to influence the direction of the ASC[23] overlooked the extent to which recent governments of both main political parties have proved reluctant to over regulate the predominantly privately funded business models that prevail in care provision,[24] including their reliance on a low paid, temporary and insecure labour market.[25] Within this economy, there are large corporations, but there are also smaller providers, who do not necessarily have extensive back offices with the capacity to comply with over exacting administrative duties, or the means to purchase into expensive digital systems.[26] In homecare, the economies are even more exacting, with workers paid by the minute, and sometimes

[18] Wormald [M2/INQ000144792/94 §§296-297] Battleplan 22.3.20 [M2/INQ000106286/2, 15] Battleplan 'Version 2.0' 04.05.20 [M2/INQ000106902/3]
[19] Shallcross [INQ000613177/29 §59] [T2/197/25-198/25]
[20] DPO M6 Opening 19.06.25 [pp 1-3 §§4-7] OSR, ASC England (January 2020) [INQ000502199/3-4, 10-12] NCF [INQ000532338/1] Hancock [INQ000587746/4§§13, 39] Dyson [INQ000587738/3 §8]
[21] Whately [INQ000587788/10 §32, /105 §§5-6] Hancock [T3/2/18-20] [T3/3/1-3] [T3/5/19-6/9]
[22] Rayner [T4/74/4-13] Townson [INQ000587670/37 §127] DHSC White Paper, People at the Heart of Care (2021) [INQ000571019/45 §4.36] and Sudlow Review (2024) [M4/INQ000513700/15, 27]
[23] Hancock [INQ000587746/4 §13] [T3/3/1-6] [T3/4/24-5/16] [T3/6/12-8/16] Whately [INQ000587788/105 §7] Javid [T/9/53/4-55/6] Freeman [INQ000606530/2 §6] [T14/34/22-35/18]
[24] Hancock [T3/7/23-11/13] McAnea [T6/164/7-165/2]
[25] DPO M6 Opening 19.06.25 [pp 1-3 §§4-7]
[26] Killian [INQ000587382/132 §477] Covid 19 Strategy Ministerial Group Deep Dive Meeting 06.05.20 [INQ000146701/5] (5,000 care homes had under 12 beds)

not for travel, and if a client is hospitalised payments are stopped.[27]

(5) REGULATIONS: Compared to health care the information sharing duties incumbent on ASC providers were far less exacting. Other than registration, the reporting obligations of providers to the care inspectorates in the four nations extend to notification requirements in relation to individual deaths and incidents relating to health safety and welfare occurring during the course of a regulated activity;[28] and response to discrete inspections.[29] Unlike in Wales from 2016, UK Ministers only gained the power to compel the provision of information directly from ASC providers after the pandemic.[30] Similar powers to compel local authorities to disclose information concerning only suspected failures of their duties under Part 1 of the Care Act were also only introduced then.[31] During the pandemic, despite tentative discussion, the decision was made to induce, as opposed to compel, voluntary information-sharing by providers through making access to the Infection Control Fund conditional on entering data on the Capacity Tracker (see §8 below).[32]

(6) EXEMPTIONS: Under the present law there remains a vast area of care provision that is exempted from regulation, including the requirement to register or provide data to statutory inspectors, which under the relevant regulations extends to suppliers of agency staff, and any form of care employed privately by an individual or a third party on their behalf.[33] The consequence was that about 95% of the care home workforce, drawn from agencies, was believed by Government to be unregistered.[34] More than 20% of privately purchased personal homecare assistants were also acquired through agencies and gig-hiring services, that promotes flexibility to the buyer and seller of labour, but with consequential risks to both parties in terms of access to testing, PPE, vaccination, support, training and overall situational awareness.[35]

(7) UNPAID CARERS: As unpaid carers were known only in so far as they were registered for state carer allowance payments, they were neither a subject of data nor a

[27] Townson [T9/27/14-28/21][INQ000587670/25 §§83-84] McAnea [INQ000587381/2 §3] TUC [INQ000525632/5] Marshall [INQ000474919/15 §§40-42]
[28] Care Quality Commission (Registration) Regulations 2009: Regulations 16 and 18
[29] Health and Social Care Act 2008, ss. 10, 64-65
[30] Dyson [INQ000587739/13 §41] Health and Social Care Act 2012, s. 277A inserted by the Health & Care Act 2022, s. 99 Cf. the power already existed in Wales (Regulation and Inspection of Care (Wales) Act 2016, s. 32)
[31] Care Act 2014, s. 72A(2)(c) inserted by Health & Care Act 2022, s. 164
[32] Dyson [INQ000587738/9 §§32-33] Hancock [INQ000000587746/57 §§262-263]
[33] Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, Para 1(3)(a)-(c) Sch. 1. See also Regulation and Inspection of Social Care (Wales) Act 2016, Para 8(2) Sch 1
[34] Covid 19 Strategy Ministerial Group Deep Dive Meeting 06.05.20 [INQ000146701/4]
[35] Townson [INQ000587670/37 §§124-126, 290] [INQ000571017] [T9/40/20-41/25] Abrahams [M6/T11/33/10-35/9]

sufficiently harvested source of it.[36]

7. DISTORTION: The result during the pandemic was that the available data on care recipients heavily relied on primary healthcare records and registered providers of care homes, with the effect of distorting the visibility of Disabled people. Foremost it meant that knowledge was significantly dependent on the medical model of disability, based on the happenstance and quality of contact with medical services.[37] Those records did not necessarily capture impairments accurately, if at all, and did not document social aspects of disability, for instance, carer details, or the nature of non-medical health and social care needs.[38] Equally, as only the registration of care providers, and not the details of care provision, is mandatory, there was no requirement routinely to provide suitably anonymised "person level" data about the detail of care provision to Disabled people,[39] or the transmission footprint and risks posed by and to care workers.

8. MAKESHIFT: The makeshift data solution of adapting the Capacity Tracker ('CT') bore its own distorting effect, for even once adapted from its original function to find residential care home beds for discharged hospital patients, the subject matter of CT remained predominantly confined to care home placements. Indeed, CT was criticised as apt to overly encourage discharge to care homes whether appropriate or not.[40] Compliance with entering additional data on CT was never mandatory and not monitored.[41] CT did not have care recipient or resident representative group input. CT was not a function utilised by self-employed, privately financed and personal assistant care providers.[42] CT could interfere with local data sharing initiatives.[43] Its reliability to track the appropriateness of a placement for an individual person was not trusted by the Association of Directors of Adult Social Services in England ('ADASS').[44] It was no substitute for granular analysis of the impact of individual interventions (e.g. response to vaccines, or deterioration in a condition due to lack of visits).[45] Despite requests, CT was also never used to provide benchmarking and updating to local authorities and providers to enable them to assess available services in a more strategic way.[46] Overall, CT never grew beyond its origins as a service to aid

[36] DPO M6 Opening 19.06.25 [pp 19-20 §§48-51] Whately [INQ000587788/107 §16]
[37] McCaskill [INQ000509530/14 §53]
[38] ONS 07.06.22 [M2/INQ000089787/17, 22 and 23]
[39] Sudlow Review (2024) [M4/INQ000513700/213]
[40] Dyson [INQ000587738/4 §§13(c), 31-38] Killian [INQ000587382/132 §§477, 496-498] Williams [INQ000571608/22 §§6.13, 12.11]
[41] See Footnote 32 above
[42] Williams [INQ000571608/62 §13.22] Killian [INQ000587382/136 §492]
[43] Killian [INQ000587382/136 §§493-494] Williams [INQ000571608/44 §11.3(c), 13.20-13.21] Rayner [INQ000475131/17 §§3.10, 8.8-8.13]
[44] Williams [INQ000571608/35 §10.2, 13.22] Killian [INQ000587382/136 §495]
[45] Shallcross [INQ000613177/29 §58]
[46] Killian [INQ000587382/136 §§493-500]

hospitals and thereafter as a makeshift mechanism to protect care homes. Even since it has become mandatory under the Health and Social Care Act 2022, CT remains limited to: (i) bed vacancies, (ii) workforce resourcing and absences, (iii) vaccination status of staff and residents and (iv) visiting options.[47]

9. CONSEQUENCES: Without an integrated digital system of combined personal medical and social care records Disabled people, their families and carers, and *where necessary* government, regulators and investigators, were unable readily to access what services, treatment or medication a person received, from whom, and if not, why not. If Disabled people used personal assistants or relied on unpaid carers, there was no voluntary means to formally record those details, with consequences for the provision of Infection Prevention Control ('IPC') and Personal Protective Equipment ('PPE'), as well as access to testing, vaccines and boosters.[48] In response to widespread experience of the sudden and considerable increase in discussing, recording and relying upon Do Not Attempt Cardiopulmonary Resuscitation ('DNACPR') notices, there was no central means to monitor the issue; and there still is not (see PART 4 §40 below).[49] More broadly, the absence of developed information sharing structures, meant that local and regional resilience initiatives did not get access to information that they needed to see to establish who or what was excluded from the orbit of formal ASC, and thereby to coordinate local multi-agency response to fill in the gaps.[50]

[C] CHANGE

10. WELLBEING: Given that care of the self and of each other is not simply about medicine, but a continuum across medical, psychological, social, and societal care for the promotion of individual and relational wellbeing, this incomplete and distorted data capability, especially in the isolated and chaotic circumstances of a pandemic, was problematic.[51] First, as recipients of care can be in dependent positions, where life and basic needs are at stake, it is unacceptable that actions in the field of ASC are far less documented than medical care. Second, if health and wellbeing are more expansive than medical care, then the resilience of social care (and what the Sudlow Review calls "*truly transformational [data] insight*"[52]) requires cross-partnership working, and there must be a means of

[47] Whately [INQ000587788/111 §37]
[48] Dyson [INQ000587738/4 §12] Whately [INQ000587788/105 §§7-9, 16] Keegan [INQ000587790/12 §§52-53] Hancock [T3/174/13-176/4]
[49] DHSC 04.09.20 [INQ000478907/2] DHSC-MS(C) 24.09.20 [INQ000058389/2 §4] McBride [T16/73/16-74/4]
[50] See the independent C19 National Foresight Group Reports: First Report 11.05.20 [M2/INQ000075330/9§§2.3, 3.2, 3.5] Second Report 20.07.20 [M2/INQ000075331/20-21, 25, 30-32]
[51] Williams [T15/97/15-98/5]
[52] Cathy Sudlow, Uniting the UK's Health Data: A Huge Opportunity for Society ('Sudlow Review') [M4/INQ000513700/157 §7.1.1]

communicating information across those partnerships including central, regional, and local governments, providers, recipients, families, communities and representative groups. Third, engagement with the subjects of care is essential, because the individual recipients will be best placed to judge their own wellbeing and to communicate need; or those close to them will be able to do so.

11. REFORM: The Inquiry will be neither the designer nor the deliverer of the integrated data information system that health and social care needs. But it can detail the reasons and human cost to Disabled people's visibility that arises from not having it and it can suggest the combination of ethics, interests, experts and users that would be necessary to make the system effective, national, and trusted by people that it is foremost there to serve. From the Sudlow Review, commended by Professor Whitty,[53] and other concurring views, what is needed is (1) national digital infrastructure that is inter-operable between health and social care services[54] with content that includes (a) de-identified person-level data concerning profile, service, location and staffing input, (b) registration of care workers, and not just providers,[55] and (c) bespoke linkages to other data sources which are still largely "*untapped potential*" (e.g. concerning disability, Care Act packages, Third sector etc);[56] (2) a national data service to lead and co-ordinate;[57] (3) an engagement strategy that enrols agencies, experts, and communities in both data contribution and analysis (see further §12 below);[58] (4) a UK wide approach to data access for de-identified information to enable joint policy making and research;[59] (5) universal standards across the Four Nations for accreditation for data handling.[60] To that should be added: (6) a voluntary mechanism for individuals who self-fund their care to register those services, and for data in relation to those matters to be actively sought and analysed;[61] (7) continuing development of education and qualification for care workers to use digital tools;[62] and (8) building the data research culture within the care sector that has historically and constitutionally compared

[53] For commendation of the Sudlow Review, see Whitty [M4/T5/50/24-51/6] [M4/T5/51/11-23]
[54] Sudlow Review [M4/INQ000513700/18 Rec. 1, §§6.3.1, §7.1.1] Diamond INQ000553814/60 §218] Shallcross [T2/205/2-13]: see also [Howarth INQ000572013/60 §§169, 172] Khaw [INQ000587702/92 §§350-351]
[55] NCF Submission 2022 [INQ000532343/2, 11] Rayner [INQ000475131/63 §10.13 vi.] Curry [INQ000475008/36] Cridge [M6/T5/59/4-14] McAnea [M6/T6/191/18-192/9] Javid [M6/T9/87/5-17] Whately [M6/T12/192/1-193/15] Ahmed [M6/T13/177/21-178/20]
[56] Sudlow Review [M4/INQ000513700/143 §§6.2, 7.2(3)]
[57] Sudlow Review [M4/INQ000513700/19 Rec. 2, §7.1.2]
[58] Sudlow Review [M4/INQ000513700/20 Rec. 3, §7.1.3] CMO Technical Report 01.12.22 [INQ000203933/97-98 §§1-4]
[59] Sudlow Review (2024) [M4/INQ000513700/20 Rec. 4, §7.1.4] Diamond [INQ000553814/21 §§98-102]
[60] Sudlow Review (2024) [M4/INQ000513700/21 Rec. 5, §7.1.5]
[61] Cf. Sudlow Review (2024) [M4/INQ000513700/88] (still not data that local authorities actively gather)
[62] Rayner [INQ000475131/54 §§8.35-8.37, 8.41, 8.42-8.44, 10.15(iii)]; see generally, IPC Impact of Technology in Provider Services (July 2020) [INQ000532381/35 §§6.3-6.4 and p. 40 Rec. 7 7-10]

badly to the health sector.[63] As recommended by the Disability Unit of the Cabinet Office; (9) within the dedicated infrastructure there should be a commission-led process to enable gathering of information in relation to individual impairments and to monitor policies in terms of evaluating their effectiveness;[64] and (10) the process should be linked to a proper forum for engagement with Disabled people and DPO.[65]

12. ENGAGEMENT: Engagement with communities remains key to make the experience of those in care more visible while at the same time complying with ethical aims to respect privacy and autonomy.[66] The future development of data infrastructure and research in this area therefore depends on partnership with care recipients, their families, and representative groups, as much as the equivalent in the health sector requires partnership with patients and their representative groups. The description of patient/user engagement in the Sudlow Review, still reads like a one-way process, at the discretion of the state.[67] The qualities of participatory policy building (as part of a more deliberative form of democracy[68]) include:[69] (1) CO-PRODUCTION at the design stage, and ongoing meaningful engagement;[70] (2) INTEGRATION of representative organisations, and their local networks, into a two-way pipeline of ideas, information, and action; (3) DIALOGUE – most imperatively about difficult matters – which in the context of data will include ethics but also safeguards against the use of data beyond a purpose to promote health and wellbeing, when Disabled people could reasonably fear it will be used to cut services; (4) FACILITATION of representative groups such as DPO to be management consultants and co-leaders, not just expected to be volunteers.[71]

13. VISIBILITY: What effective and structured engagement can ensure is far better visibility – and human accounting – which data gathering is there to serve. Genuine two-way engagement, systems of information gathering and distribution enjoy trust and endorsement from the care recipient communities. There can be pre-testing and review of

[63] Shallcross [INQ000613177/30 §§60, 62-64] [T2/199/1-201/24] [T2/202/6-203/24]
[64] Covid O DU Submission 12.11.20 [M2/INQ000083918/1 §3.1, §5 and Annex A pp 2-4]
[65] Covid O DU Submission 12.11.20 [M2/INQ000083918/1 §3.2, and Annex B pp 6-10]
[66] Shallcross [T2/205/14-206/7]
[67] Sudlow Review [M4/INQ000513700/161 §7.1.3]
[68] Sansome [T18/171/10-172/7]: see also Mallick [M2/T5/64/15-65/15] Elder-Woodward [M2A/T2/70/21-71/11] John [M2B/INQ000286066/9 §4.6]. For criticism of state engagement with DPO, see for the UK, Mallick [INQ000520998/23 §69-97]; for Scotland, Nolan [INQ000520202/32 §§110-130, 149]; for NI, Sansome [INQ000520343/22 §§70-90]: *Cf.* for Wales, Davies [INQ000520201/6 §§15, 79-108]
[69] Reicher [M2/INQ000273800/16 §47] Burgess et al [M2/INQ000273405]
[70] DPO M2B Closing 05.04.24 [p. 17 §35] Freeguard [M2/INQ000260629/48 §§95, 97,113-114] John [M2B/INQ000286066/37 §§6.75-6.79] [M2B/T4/129/14-132/3] Scottish Human Rights Commission [M2A/INQ000130421/8 §§5-7]
[71] Watson & Shakespeare [M2/INQ000280067/12 §38] Fernandes-Jesus et al [M2/INQ000273352] Cullingworth 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* Voluntary Sector Review 2022: 1–18, pp 1-2, 15

the extent to which policy decisions based on data capabilities are practical in terms of implementation and do not bear unintended, unforeseen or disproportionate consequences.[72] The Inquiry has seen how the visibility of Disabled people becomes obscured in data collections; this commends that in any methodology of change, DPO must be included and funded to work at all stages, including at the design specification stage.[73]

PART 2: INSTITUTIONS

14. CLOSED CULTURES: For many Disabled people institutions – particularly various forms of residential homes and confinement – are complicated spaces. Their history is intertwined with further invisibility and asymmetries of power. The continuing absence of accessible data from modern care settings does not sit well with the power that providers hold over persons in highly dependent situations. The CQC itself captured the importance of the issue in its concept – developed pre-pandemic – of "*closed cultures*".[74] Its June 2020 guidance recognised the "*increased likelihood*" of the risk factors of closed cultures during the Covid-19 because more services were "*effectively operating as closed environments with reduction in external oversight and with potential staffing and leadership challenges*"[75] Lack of pandemic oversight of care facilities was similarly recognised as a key red flag by multiple experts and reviews.[76]

15. INSPECTIONS: Against this knowledge that even the most committed working cultures can become fearful of criticism and closed off to change the sustained shutting down of on-site face to face regulatory inspections should never have been allowed to occur. Instead, the method and content of inspections could have been recalibrated to the pandemic situation. The inspectors obviously needed access to PPE and testing on parity with health and social care staff.[77] The failure to secure parity of access by inspectors along with key workers in the sectors they inspected was indicative of a mindset that underestimated the importance of oversight.[78] ADASS put it bluntly in April 2020, describing itself as "*alarmed*" that inspections could be stopped at the very moment when "*local systems need basic safety monitoring to collate and sift through rises of infections and deaths in regulated provision, sudden staffing reductions, increases in hate crime for care staff and disabled*

[72] Shallcross [INQ000613177/29 §§59, 61]
[73] Mallick [INQ000520998/32 §§96, §129(a)]
[74] Cridge [INQ000584245/113 §§349-355]
[75] Guidance for CQC staff [INQ000524881/3, 6 and 9-10] Cridge [INQ000584245/115 §359]
[76] Lynch [INQ000474926/49 §§147-151] Allen [INQ000572015/27 §§91-96]
[77] Cridge [INQ000587795/7 §§19-22] Cridge [T5/10/9-11/8] [T5/13/15-18] [T5/16/23-17/2] Mitchell [T6/41/5-25] [T6/42/1-17] Donaghy [T5/107/25-108/14]. For the lack of key worker access to Covid testing, see Cridge [INQ000587795/8 §§23-35] [T5/12/8-16] Baranski [INQ000569773/31 §105] [T5/153/2-5] Mitchell [T6/42/1-6] Donaghy [T5/99/1-3]
[78] Cridge [T5/40/14-41/8]

people, increases in domestic abuse of older and disabled people".[79] That reality came to the fore in the meeting with Minister Whately on 1 July 2020 where the CQC accepted that there were insufficient systems in place to reassure that when inspections were resumed they would not reveal a spike in cases of neglect, abuse and/or poor standards. The concern at Ministerial level was of a "*black hole*" on safety.[80]

16. BENEFITS: What was lost was the opportunity to view the records, see the residents, not just staff, understand the environment, and reassure relatives.[81] These were matters that remote calling could never duplicate and their loss was aggravated by arising at a time when other additional critical safeguards were removed. Family and other visitors, and the essential expertise they have, were mostly blanket excluded.[82] Confidential meetings were not possible.[83] The expanded use of DNACPR notices was not properly investigated (see §40ff below). Death certificates could be completed by non-attending physicians.[84] Inquests were unlikely (see §§49-50 below). Funding for IPC had no auditing. Then, in struggling to obtain their own PPE and testing packs for themselves, the regulators – the ones who were supposed to establish the quality of IPC in services – exposed their lack of capacity and faith to manage the issue themselves.

17. PURPOSE: The principal objective of the regulators in all four nations is to protect care recipients. In England it is "to *protect and promote the health, safety and welfare of people who use health and care services*".[85] In Scotland it is that "*the safety and wellbeing of all persons who use, or are eligible to use, any social service are to be protected and enhanced*".[86] In Wales, it is "*to protect, promote and maintain the safety and well-being of people who use regulated services*".[87] In Northern Ireland, it includes "*promoting improvement in the quality of health and social care services*".[88] They can seek ways to best support providers to do that; but the regulators are there for the users.

18. COMPROMISE: In each of the four nations the regulators failed in that principal objective.

---

[79] Williams [INQ000571608/36 §10.2] ADASS 11.04.20 [INQ000103761/4] Lee [INQ000498137/19 §7.1] Jones et al [INQ000514104/94 §242] Abrahams [INQ000509808/29 §77] Ahmed [T13/163/17-165/14]
[80] MSC fortnightly meeting note 12.06.20 [INQ000524915/2] Whately PS Email 01.07.20 [INQ000609960] Whately-Hancock WhatsApp 01/07/20 12:52 [INQ000274068/18] Whately [INQ000587788/99 §§396-400] [T12/110/11-114/13] [T12/114/14-119/1]
[81] Cridge [INQ000587795/13 §42] [T5/6/11-25] [T5/7/1-16] Baranski [T5/148/8-9] Mitchell [T6/32/19-33/7] Dongahy [T5/102/18-19] [T5/110/18-24] [T5/137/15-141/9]
[82] See for example, Kilbee [INQ000614380/10 §38] McCusker [INQ000614377/9 §§25-26] [T2/81/24-82/9] Lyons [INQ000587637/18 §§57-58, 63-70]: see also CQC Guidance [INQ000524881/6, 9-10] BASW Article 13.01.2021 [INQ000509547/1 §§2-6] Lynch [T15/185/19-186/7]
[83] Lyons [T8/181/12-182/8]
[84] Coronavirus Act 2020 Para 4 of Schedule 13
[85] Health and Social Care Act 2008, s. 3(1)
[86] Public Services Reform (Scotland) Act 2010, s. 45(2)
[87] Regulation and Inspection of Social Care (Wales) Act 2016, s. 4(a)
[88] Health and Personal Social Services (Quality, Improvement and Regulation) (NI) Order 2003, art. 4(2)(b)

They allowed their independence to be compromised, the nature of their role to be confused, and the importance of their oversight function to be undermined:

(1) ENGLAND: From 11 March 2020 the CQC moved from suggesting it would adopt a "pragmatic" approach to inspections to a more emphatic position on 16 March when it suspended them other than for reported abuse allegations.[89] Part of that decision was pressure from DHSC and the Secretary of State that bore a strong bias against the appropriateness of inspections during a pandemic as "*distraction*".[90] Mr Hancoock's explanation of his WhatsApp messages of 16 March 2020 with the Chair of the CQC is that he wanted suspension not just to limit footprint on public health grounds, but out of a concern not to burden health and care services with unnecessary "*box-ticking*" bureaucracy likened to cramming for a GCSE exam, as if it could offer no more. The Chair of the CQC in turn promised a "*light touch*".[91] There was additional push (attributed to Simon Stevens, CEO NHS England) for inspectors to go back to working is hospital and care homes, even though that would blur their role in any future inspections.[92] The accusation in evidence to the Inquiry was that the CQC continuously "*disappointed*" for their "*defensive responses consistently to choosing to focus on what they couldn't do, rather than focusing on what they could do*".[93] The more blunt conclusion was that the CQC went "AWOL".[94] The organisation has never recovered its 2019 inspection rates (see §20 below).[95]

(2) WALES: The Care Inspectorate Wales ('CIW') suspended both inspections and the publications of reports, on the basis that the latter generated time consuming responses from providers.[96] CIW initially saw the stoppage as necessitated by public health grounds but does not seem to have sought parity of treatment as regards PPE and testing in an effort to address those matters. In the recovery phase after the first wave, it was also unwilling to *"unnecessarily add"* to the *"significant pressure on social care and childcare services"* with regulatory burden.[97] The close knowledge of all providers was described as a sound basis to limit inspections only to circumstances where there was a perceived risk of significant harm.[98] While these relationships with providers were explained as a basis for effective telephone monitoring, Helen Hough

[89] Cridge [INQ000584245/81 §§246, 249, 254]
[90] Hancock [T3/154/4-155/7] Cridge [T5/9/7-10/8]
[91] Hancock-Wyman WhatsApp 16.03.20 [INQ000419147] Hancock [INQ000587746 §258] [T3/157/15-23]
[92] Cridge [INQ000584245/79 §240] HSJ Article 11.03.20 [INQ000525119/2]
[93] Jones et al [INQ000514104/26 §69]
[94] Ahmed [T13/164/8]
[95] Cridge [INQ000584245/73 §215] [T5/32/11-33/3]
[96] Baranski [INQ000569773/25 §86-87]
[97] Baranski [INQ000569773/25 §§86,108]
[98] Baranski [INQ000569773/30 §100] [T5/159/16-160/4]

described the contacts as *"check-ups rather than check-ins"*.[99]

(3) SCOTLAND: Unlike the CQC, the Scottish Care Inspectorate ('CIS') did not make a formal declaration that it was suspending inspections, but in its actual approach, its threshold for making a visit was only where "*absolutely necessary*" where there was a "*serious risk to life*".[100] CIS briefings recognised this may have resulted in questions over their role and leadership and it was accepted in evidence that it led to a reduction in oversight.[101] The complication in Scotland was that the Directors of Public Health (DoPH) held a veto on visits,[102] such that when the CIS wanted to carry out an inspection in Skye where there was a perceived risk to life there was concerted opposition from the DoPH and the much needed inspection was only achieved after considerable negotiations and personal guarantees by CIS senior management.[103]

(4) NORTHERN IRELAND: The Regulation and Quality Improvement Authority ('RQIA') was particularly criticised in the *Home Truths* reports by the Commissioner for Older People in 2018 and 2019.[104] He was concerned about the combination of inspections stopping with the families simultaneously being shut out from visiting.[105] Of all the regulators, RQIA was seemingly most dysfunctional with the CMO via the Minister of Health drawing several officers into PHA and other work, and the full board resigning.[106] This meant that key decision-making between March and June 2020, including suspension of inspections, was made without oversight and scrutiny.[107] A subsequent review of the Board resignation found a clear lack of the "*basics of good governance*" and a failure of DoH NI to treat the RQIA like an independent entity. A recommendation to develop a partnership agreement between the two entities took over 4 years to complete.[108] At the time, the RQIA Board had concerns over the "*inherent risks associated with the… the reduction in Statutory Inspections"*.[109]

19. CRITICISM: As the reports of Penelope Dash and Sir Mike Richards show, the reputational crisis of care sector regulation continues, not least that the CQC's new chair calls for a re-centring of "*purpose, values and ways of working*".[110] The Dash review of October 2024 reported 200 interviews of CQC staff virtually all sharing "*considerable concerns*" about

[99] Hough [INQ000587639/13 §62]
[100] Mitchell [T6/37/20-38/8]
[101] CIS Briefing [INQ000520523/1] Mitchell [M6/T6/50/1-25]
[102] Mitchell [INQ000475130/96 §§338-347]
[103] Mitchell [INQ000475130/125 §§468-516]
[104] Lynch [INQ000474926/49 §147] Home Truths Summary [INQ000191269/17-19 §4.5]
[105] Lynch [T15/194/10-196/4] [T15/200/19-202/7]
[106] Donaghy [INQ000475143/14 §§45-48, 66]
[107] Donaghy [T5/91/21-93/5]
[108] Nicholl Review [INQ000260638/7-8, 17, 42, 57 and 68] Donaghy [T5/93/17-94/12]
[109] RQIA Letter 28.04.20 [INQ000377461/2]
[110] Cridge [INQ000584245/133 §409] [T5/33/12-18] (referring to the "*failed transformation*")

"*poor operational performance*", "*significant challenges*" posed by a new IT system, "*delays in producing reports*" and their "*poor quality*" and "*loss of credibility*" with the health and care sector due to the move to general inspectors and therefore loss of specific sector expertise.[111] In tandem, the Richards review concluded that the CQC has been "*unable to fulfil its primary purpose"*, far fewer inspections were being carried out, providers expressed "*serious concerns*" about the inspection process and staff were "*demoralised and angry*".[112]

20. FUTURE: This crisis is worthy of note given the UK Government has increased the role of regulators especially for local authority care. The CQC has been mentioned in the evidence as the vehicle for multiple recommendations, including monitoring pandemic planning,[113] easements,[114] DNACPR notices,[115] workforce development, including assurance of local authority social care commission to enable better terms of contract.[116] It has also had the scope of its functions extended by law reform to investigate local authorities for their compliance with duties under Part 1 of the Care Act.[117] Looking to regulators is a common approach to reform; including reforms recommended by public inquiries; because at best regulators offer a non-partisan means to circumvent the politics of public sector performance. However, the difficulties are that regulators depend on the quality of their leadership and resources. At worst regulators can be set up by Government to fail and they can also become compromised by an industry that it is required to predominantly fund its own regulation.

PART 3: COMMUNITY

[A] COMMUNITY CARE

21. INDEPENDENT LIVING: The other reason why DPO are ambivalent about institutions is that they believe in independent living in the community. It is their human right, in the language of the UNCRPD, to be treated with respect for their "*physical and mental integrity on an equal basis with others*." (Art. 17) and to have "*access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community*" (Art. 19). The right to independent living, is not to be misconstrued as living independently in isolation (i.e. individuals living alone, doing things for themselves with

[111] Dash, Review into the Operational Effectiveness of the CQC 17.10.24 [INQ000551241/4-6]
[112] Richards, Review of CQC's Single Assessment Framework 15.10.24. p.2
[113] Whately [T12/16/12-21] Williams [T15/66/2-23] Jones [T15/138/6-139/7]
[114] Williams [T15/87/16-20]
[115] Hancock [T3/173/7-174/3]
[116] Whately [INQ000587788/116 §59(f)] [T12/100/21-101/10]
[117] Health and Social Care Act 2008 s. 46A inserted by Health and Care Act 2022. s. 163(3)

limited access to support and resources.[118] DPO respect *real* community care. 'Wellbeing' under section 1(2) of the Care Act 2014 includes "*participation*", "*relationships*", the "*social and economic*" and "*the individual's contribution to society*". DPO want *genuine* co-production between parties *treating each other as equals* even in their differences. These are the tools that enable Disabled people to be part of society. This is why the DPO say that, in gross contrast to these principles, the enacting of Care Act easements and failing to monitor how they were used was a straightforward abandonment.[119]

[B] EASEMENTS SHOULD NEVER HAVE BEEN ENACTED

22. SYSTEM: With the threshold for entitlement to social care so high and the means to challenge its refusal so limited, no Government should have legislated to allow local authorities to cease meeting eligible needs. The Ombudsman had reported in 2018 that the system was prone to illegal interpretations.[120] The knowledge of social care professionals about Care Act duties, and of human rights frameworks was known to be variable.[121] The "*painful juxtaposition*" of easement, for local authorities and providers was that Government injected yet a further element of discretion into a system that was already failing for want of finance, resources, and understanding and it did so without any form of whole system analysis as to whether the legislation was necessary, or what the alternatives might be.[122]

23. GOVERNANCE: Given the evidence before this Inquiry of how government decision-making occurred especially at the start of the pandemic, no deference should be given to the decision to enact easements at all. It was made in circumstances where no branch of government had the data to understand its implications. Previous planning on easements had been minimal, and papers offered by ADASS in 2018 had suggested much higher thresholds for activation, accompanying national standards, and had regarded it as "*vital*" to "*manage any easements and monitor care quality in a controlled and measured way*".[123] The provisions were then made law in 2020 without in-depth study of the consequences, including that they were now implemented in conjunction with lockdowns and multiple other ways that were turning Disabled people's lives upside down.[124] The decision that

[118] Davies [INQ000520201/47 §139(5)]
[119] DPO M6 Opening 19.06.25 [pp 12-17 §§30-41]
[120] Local Government Social Care Ombudsman, Under Pressure – the impact of the changing environment on local government complaints, December 2018, pp 6-7 §2
[121] Thomas et al, 'The Views of Practitioners on Care Act Easements during the Covid-19 Pandemic' (2023) Practice, Social Work in Action, 36:1, 55-67, p. 63 https://doi.org/10.1080/09503153.2023.2261664
[122] Williams [T15/85/2-24] [T15/86/11-87/3] Rayner [T4/132/18-133/1]
[123] Williams [INQ000571608/55 §13.1] ADASS Report (April 2018) [INQ000080776/1, 4] Marron & Dyson 'C' [INQ000587737/150 §§573-577]
[124] Mallick [INQ000520998/5 §13, 62, 69] Davies [INQ000520201/36 §109] Nolan [INQ000520202/25 §§83-84] Williams [INQ000571608/57 §13.5]

easements were necessary was also made by a DHSC which was overwhelmed by the "*significant imbalance*" of personnel and expertise as between its health and social care portfolios.[125]

24. AWARENESS: Nevertheless, civil servants still understood that general compliance with Part 1 Care Act duties was unstable "*with unmet need and failure in the system*"; and without detailed monitoring, hence the change of law in 2022 to give the CQC that monitoring role.[126] In 2020 there was no national oversight of the application of the Care Act by local authorities.[127] Accountability only to local populations was recognised by Whateley to be inapt for holding local authorities to account for delivery of their social care obligations.[128] Whately and Hancock also knew that local authority planning for a pandemic was non-existent.[129] To suggest in the Guidance for Easements that the CQC would play a "*pragmatic*" monitoring role when the issue was not even within its scope, and it had stopped inspections in any event, was near enough meaningless. The CQC were involved in no detailed discussion on the issue.[130] To accept that "*local authorities have the statutory duties here… They are real experts in adult social care*" and assume all would be well was also fanciful.[131]

25. ALTERNATIVES: This is an Inquiry into disaster management. What it has discovered is that there is no system in place nor any consideration that a system *could* be put in place that would enable the provision of labour and services to be scaled up regionally and nationally for emergency supply when needed. There needed to be a national and regional system to expand ASC through mutual assistance, secondment from other public services and business and with proper inclusion of DPO, third sector and community participation. Some consideration was given to the issue to boost the labour pool to enable statutory limitations on care worker movement to limit virus transmission, but the issue was just as important in order to enable care plan services to continue under the Care Act.[132] With control at the centre, temporary employment could have been offered as an alternative to furlough, and it could have combined workers with experience and those without. In this crisis, where local authorities had no contingency planning, what government should not have done, was to leave local authorities to their own devices.

---

[125] Whately [T12/36/24-39/13]
[126] Ministerial Submission 07.03.22 [INQ000576628/4 §11]
[127] Care Act Easements Core Brief 09.09.20 [INQ000109718/17]
[128] Whately [T12/206/15-22]
[129] Whately-Hancock WhatsApp 03.03.30 [INQ000327767] Whately [T12/13/12-15/23] [T12/19/6/21] [T12/20/7-21/22]
[130] Guidance 01.09.20 [INQ000509774/3]. *Cf*. Cridge [INQ000584245/78 §232]
[131] Dyson [T11/191/24-192/1].
[132] Whateley [T12/100/1-20] Hancock [T3/110/3-112/1]

[C] THE LAW OF EASEMENTS WAS UNLAWFULLY APPLIED

26. MISCONCEPTION: Once enacted, the lasting damage of this emergency legislation has been caused by the construction of a legal mythology that barely any authority across the UK needed to use it. The source of the misconception is the way in which the concept of 'flexibilities' has been inflated and distorted. Even now, some evidence before the Inquiry fails to acknowledge the extent of derogation from statutory duties during the pandemic and continues to explain the anomaly of mass withdrawal of Care Plan support within the scope of Care Act 'flexibility'.[133] The Director General's evidence, when questioned about whether de facto easements were used without declaring them to the DHSC, thought that not to be the case. What the local authorities had told them was that easements were not needed "*because we have flexibility within the Care Act*" and that the issue was whether discretion under the Care Act simpliciter was "*too wide*".[134] While the public can look to the Casey Review and other mechanisms to examine the ordinary functioning of the Care Act, it is imperative that the misconception that there was no withdrawal of provision during the Covid emergency is dispelled by this Inquiry and what happened during the pandemic is properly accounted for.

27. STATUTE: 'Flexibilities' is a word that does not appear in the statute. Section 18, of the Care Act unamended, provides that a local authority "***must** meet an adult's needs for care and support***"** which meet the statutory eligibility criteria (subject to residency and financial requirements). The source of the erroneous reliance on flexibilities to explain away easement is that, under section 8 of the statute, "*how*" the local authority meets eligible needs is flexible, and an adult's care and support plan must state "*how*" the local authority is going to meet their eligible needs.[135] 'Flexibilities' – as a concept – does appear in the Care and Support Guidance, but to encourage diverse thinking, again, about how assessed eligible needs are met, not whether the needs are met.[136]

28. GUIDANCE: The April 2020 Guidance if read correctly should have been understood to mean that easements were needed if eligible needs could not be met. However, it was still apt to be misinterpreted in its statement that "*current flexibilities within the Care Act*" could cover prioritisation in the short-term allocation of care and support, including where a "*Covid-19 related [staff] absence means services types need to be… cancelled short term*".[137] That could be read as suggesting it was permissible not to meet eligible needs

[133] Dyson [INQ000587737/159 §605] [T11/191/9-17]
[134] Dyson [T9/176/19-25] [T9/193/22-196/24]
[135] Care Act 2014 s.25(1)(c)
[136] Care and Support Statutory Guidance [Ch 10, esp. §§10.10-13, 10.26-27] Killian [T17/50/14-51/18] [T17/53/9-54/1]
[137] Guidance 01.04.20 [INQ000587896/8]: see also Guidance 01.09.20 [INQ000509774/10]

through flexibilities rather than easements, but that is not what the law allowed. The September 2020 Supporting Guidance sought to clarify the position "*if a service is not delivered… a local authority's duties to that person's needs remain under the pre-amendment Care Act if they are not operating easements*" and if "*eligible needs cannot be met by their usual service provider, the local authority must endeavour to arrange alternative support to ensure that the individual's needs are being met*".[138] The text then muddied the issue by claiming flexibilities *"do not allow a fundamental change to the care and support plans over a period of time, but offer a small degree of flexibility in exceptional circumstances*".[139] The correct reading was for one-off cancellations. If meetings in community groups had to be cancelled for reasons of lock downs, or the number of homecare visits for lifting or bathing were indefinitely cut, that was not a flexibility. Likewise, the inescapable need for a family member to cover the service in a short-term instance, was not by virtue of its ad hoc provision meant to involve a permanent amendment to the plan and should not have been characterised as such.

29. CONFUSION: Confusion over interpretation was identified during the pandemic and flagged to the Government. The ASC Trade Association Group in July 2020 warned that "*staff at front line level thought [of easements that] there was a lot they didn't need to do. Most of them just thought they could just implement it, confused about the information around it*."[140] ADASS in October 2020 described the guidance as "*open to interpretation*".[141] The TLAP study in October 2020 identified the "*very grey line between [Care Act easement] implementation and other local authority responses to Covid-19*".[142] A submission to the Minister of State for Care in November 2020 reported ADASS's concern that the national guidance "*is unclear and open to interpretation and that this is limiting the use of easements by local authorities who are weary of challenges to decisions*".[143] The British Association of Social Workers having queried from the outset the lack of clarity as to "*when, and under what circumstances, this provision…would be activated*" continued to query how it was possible for people making decisions on the ground to assess whether a withdrawal of a eligible services was "*compliant*" with human rights obligations, or "*would know, [or] would understand how that might be the case*".[144]

[138] Care Act easements: supporting guidance, 01.09.2020 (Publicly Available: https://web.archive.org/web/20201003051504/https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-supporting-guidance)
[139] Ibid.
[140] ASC Trade Association 31.07.2020 [INQ000524998/1]
[141] ADASS (October 2020) [INQ000103777/12 §59]
[142] TLAP (October 2020) [INQ000509867/8].
[143] Ministerial Submission 17.11.20 [INQ000565723/10]
[144] Allen [INQ000572015/12 §37] BASW (March 2020) [INQ000509556] Allen [T4/18/16-19/9] BASW 24.04.20 [INQ000509557/5 §5]

30. OUTCOME: In the event, only eight out of 153 local authorities in England complied with the reported requirement in the guidance to notify the DHSC that they had triggered easements.[145] But it is highly likely that many local authorities operated de facto easements. This was reportedly accepted by a DHSC interviewee in saying "… *a lot of local authorities have… said 'we can't provide that anymore because of the Coronavirus Act or because of easements' but (they) never actually enacted the easements*".[146] The Manchester University Study concluded that this reflected "*the prevailing confusion as to what circumstances, and what changes in social care support, warranted the invocation of easements*".[147] The LGA evidence suggests a sensitivity on the part of local authorities that if they declared easements then they would be publicly outed.[148] The Government's own Social Care Taskforce, which amongst other significant witnesses to this inquiry, counted Sir Christopher Wormald, the permanent secretary of the DHSC as a member, reported in October 2020, that "*a number of organisations raised with us the concern that Care Act duties may be subject to prioritisation by local authorities"* and that it was "*important that the government and local authorities keep this under review, including the degree to which all Care Act responsibilities are being delivered*".[149] In October and November both TLAP and ADASS concluded that local authorities were operating easements informally.[150]

31. IMPACT: The impact was anything but a mere eight local authorities. Reductions in service were reported from early in the pandemic,[151] with, for instance, NACG at a meeting in March 2020 referring to *"changes to care packs"* being made without reassessment or communication with providers even before Care Act easements Guidance had been published.[152] A Homecare Association member received a similar letter in March from a local authority saying it needed to "*free up capacity for hospital discharge*".[153] Both Townson and Rayner told the inquiry that their respective members sensed that there was a far greater use of *de facto* relaxation of Care Act duties, without formally resorting to easements.[154] Townson, particularly, was in a position to testify to how the pandemic

[145] Guidance 01.09.20 [INQ000509774/6] Whately [T12/204/22-205/16] Townson [INQ000587670/105 §441]
[146] Mary Baginsky et al, The Coronavirus Act's Easements to the Car e Act 2014: A Pragmatic Response or a Red Herring *The British Journal of Social Work*, Volume 52, Issue 7, October 2022, Pages 3840–3857, p. 3851 https://doi.org/10.1093/bjsw/bcac009
[147] The Impact of Care Act Easements (November 2022) [INQ000492905/32-34].
[148] Killian [INQ000587382/109 §404]
[149] SCTF (October 2020) [INQ000574086/11]
[150] Ministerial Submission 17.11.20 INQ000565723/3 §§5-9]. ADASS (October 2020) [INQ000103777/14 §72]
[151] RIDC [INQ000509625/2] DCC [INQ000474414/16 §§8.8-8.9] SENSE [INQ000496104] Mencap [INQ000505525/1-2]
[152] NACG 26.03.2020 [INQ000545619/4]
[153] Townson [T9/38/21-39/4]
[154] Townson [INQ000587670/105 §§441-442, 444, 445] [T9/38/21-39/13] Rayner [INQ000475131/29 §4.28 [T4/132/11-133/1]: see also Hatton & Hastings [INQ000587296/29 §93] [T17/188/23-190/14] Abrahams

produced a cut in the purchasing of homecare services and that occurred in similar degrees "*across both easement and non-easement areas*".[155] The issue was of particular concern because the criteria of eligibility for state funded care service was at such a high level of need, that to cut agreed actions would bear a fundamentally onerous impact, including the risk of admission to hospital for those uncared for.[156] The point was underscored by the Convention of Scottish Local Government Authorities that not a lot of authorities could use easements compatibly with human rights protections, because "*they were already providing support to the people who were in the most need, there probably wasn't any higher you could go*".[157]

32. ESSENTIAL SERVICES: DPO surveys received multiple reports that care package services concerning homecare were cut, and that "*people reported negative experiences of assessment and changes to care and support in council areas where easements had not been enacted*".[158] Homecare Association members communicated "*instances where essential support was reduced or withdrawn without adequate consultation or consideration of the consequences*" with "*increased pressure on family carers, who found themselves having to fill substantial gaps in formal care provision*".[159] Even after easements were formally withdrawn local authorities admitted to reducing activity to life and limb protection. In response to the ADASS survey of January 2022 13% of councils reported they were delivering life and limb care only – e.g. limited to helping someone to eat, hydrate, go to the toilet and change continence laundry. 11% reported that they were pausing support for facilitated social contact – leaving people with dementia / learning disabilities / mental ill health isolated or alone for longer periods.[160] In the period January – March 2022, 2.2m hours of homecare could not be delivered.[161]

33. WORLD TURNED UPSIDE DOWN: The DPO evidence across the UK, combined with Every Story Matters, shows that in effect a fundamental change of care culture took place. This included: (1) Reduction in services relating to basic hygiene and mobility.[162] (2) Removal or significant decline of (a) facilitated human contact for those otherwise unable to leave their home due to immobility, dementia, or mental health conditions,[163] (b) services for

[T11/16/3-14]
[155] Townson [INQ000587670/105 §441]
[156] Townson [T9/39/17-40/7]
[157] Dickie (COSLA) [T13/141/7-11]
[158] TLAP (October 2020) [INQ000509867/27]
[159] Townson [INQ000587670/105 §444]
[160] ADASS Survey (January 2022) [INQ000514944/5].
[161] ADASS Waiting List (May 2022) [INQ000514941/3-5]
[162] Davies [INQ000520201/7 §§17, 20] Nafeh [INQ000587595/18 §§55-58] Nolan [INQ000520202/10 §30] McKay [INQ000578133/94]
[163] Williams [INQ000571608/41 §10.17] Contingency Planning Survey 11.01.22 [INQ000514944/5] Davies [INQ000520201/9 §23] Nafeh [INQ000587595/9 §§28-31] Smith [INQ000576035/39 §155]

those with learning disabilities and their families,[164] (c) language and culturally specific provision of (a) and (b) for BAME.[165] (3) Direct payments not reviewed to address inflation and the increase in the national minimum wage, leaving people unable to employ Personal Assistants or without guarantee of recoupment.[166] (4) Remote parts of the UK experienced particularly diminished coverage.[167] (5) Day centres and respite services (critical to wellbeing) remained long term closed.[168] (6) The backlog of those waiting for services, direct payments, assessments or reviews peaked at 542,002 and were still at 418,029 in 2024.[169]

34. ASSESSMENTS & REVIEWS: The Coronavirus Act also suspended local authority duties to assess adult needs for care and support, to prepare new care and support plans, and to review plans (s.15, Sch 12 paras 2, 11). Given that Disabled people's existing plan could become outdated and that the pandemic generated new impairments, this was not just a matter of procedure, but an easement of profound consequences, in which mental and physical deterioration was at stake. By April 2022 the estimated number of people wating for an assessment had ballooned to 294,449; with 73,792 waiting for over six months. By the same point, the estimated number of people waiting for care plan reviews was 210,106.[170]

35. DATA GAPS: The Minister and her civil service understood that they were unable to verify the reality on the ground, admitting in May 2020 to "*a gap in our knowledge concerning Local Authorities who are not operating under easements but whose actions mean they should be*".[171] Dyson regarded the position of not knowing how easements were being used as inescapable.[172] Other stakeholders across the UK criticised their governments for not being more proactive to collect data on the issue.[173] Whateley's evidence to the Inquiry accepted that local authorities did reduce care for people but did not operate easements. They did not follow proper processes. The lack of consequences for local authorities "*reflects a problem which is the lack of essentially oversight and accountability for whether – and this applies outside a pandemic as well as during - … local authorities are really delivering on their Care Act obligations*."[174]

---

[164] Davies [INQ000520201/9 §§24-25] Nolan [INQ000520202/13 §41] Hatton & Hastings [INQ000587296/43 §140]
[165] Mallick [INQ000520998/18 §52-55] VODG report [INQ000279963/27]
[166] Nafeh [INQ000587595/12 §§36-38, 73]
[167] Nolan [INQ000520202/13 §42] Inclusion Scotland Report (May 2020) [INQ000184673]
[168] Green [INQ000585008/15 §40] Nafeh [INQ000587595/9 §§28, 75] VODG report [INQ000279963/27]
[169] Williams [INQ000571608/40 §10.14]
[170] ADASS Spring Survey (April 2022) [INQ000514939/3]
[171] Ministerial Submission 19.05.20 [INQ000327904/3 §6]
[172] Dyson [T11/193/1-3] [T11/194/8-10]
[173] BASW 24.04.20 [INQ000509557/5 §4] Herklots [INQ000514106/46 §§219, 224-225]
[174] Whately [T12/206/4-10]

36. NON-MONITORING: The Minister for Social Care's admission is important, but it also reflects a failure of her department to grasp the issue in real time. In May 2020 Whately was reluctant to base a conclusion on what local authorities and ADASS were telling the Chief Social Worker in calls, because it would only give one side of the story; and what was needed was needed was an independent source of information and greater transparency, including feedback from a sample of care users.[175] However by July 2020, the Minister accepted the plan for monitoring of the overall system to remain *"light touch*".[176] Her email nevertheless emphasised her "*experience that the process has not felt very transparent about what has been happening locally*".[177] Whether reluctantly or otherwise, the Minister had given in, and even the reports of TLAP, ADASS and the Manchester study in the autumn did not turn the dial. Instead, Government moved to abolish easements on the erroneous reasoning that they had not, in fact, been used.

37. ILLEGALITY: The authorities that ceased to meet eligible need but failed to declare easements broke the law. It should be obvious, but the Inquiry has the evidence from ADASS and others, that it is extremely difficult for people who are frail, isolated, and excluded, to engage with complaining.[178] Pandemic pressures on Disabled people, limited legal aid funding and a dearth of specialist practitioners were significant barriers to judicial reviews being brought. The remaining evidence before the Inquiry that Local Government was able to perform largely without easements is weak. The ultimate damage of that law breaking is that derogation from statutory rights has been refashioned as flexibilities. That is the legal mythology, and a terrible way of building back, not better, but worse.

PART 4: VALUE

[A] THE CONSTANT CONCERN

38. CONTEXT: Disabled people's most fundamental and constant of concerns is that their lives (and deaths) are not valued in the same way as others. The issue arises before Disabled people are born. It continues throughout life, with denial of rights and being treated as abnormal, defective, sad, and not worthy of finite resources. During the pandemic negative valuation of Disabled people manifested in the various ways outlined above. Disabled people were not counted in databanks. They figured as an afterthought in policy making. Under the justification of emergency, their rights were legislated upon as amenable to easement when no other rights were. However, the issue DPO most encountered, in the

[175] Whately 26.05.20 [INQ000327916/1-2] DHSC Email 07.05.20 [M2/INQ000327874] Actions "*Care Act Easements — Present a robust monitoring system for Care Act Easements before MSC's User Issue Meeting*."
[176] Submission to MSC [INQ000327933/3 §4]
[177] Whately Email 07.07.20 [INQ000327935]
[178] Williams [T15/88/4-17] Killian [T17/56/19-57/21]

several hundred communities they work with, was the increased and inappropriate use of DNACPR notices.[179]

39. MISCONSTRUCTION: There remains a tendency, in some of the evidence before the Inquiry, to misconstrue, and thereby unduly minimise the issue. By pointing to the reality that there was no formal change of policy in either health or social care, and no central directive to downgrade entitlement to medical treatment, what was overlooked was the positive duty of government to prevent what was reported as an alarming increased use of DNAPCR notices and the risk that they would contribute to a wider tendency to withdraw treatment beyond the narrow relevance of cardiopulmonary resuscitation.[180] The approach of the CQC and other reports contributed to this misconstruction of the problem because they too focussed on whether there was a national blanket policy as opposed to policies, or ad hoc practices applied in a blanket way in local settings or to certain groups – about both of which this Inquiry has now unearthed ample evidence.[181]

[B] BLANKET POLICIES AND WIDESPREAD PRACTICES

40. APPROACHES: There were undoubtedly blanket letters and other generic approaches adopted at the level of GP surgeries and residential/nursing homes in different parts of each of the four nations. The most publicised examples were in Wales;[182] but there were also instances both discovered and reported in England, Scotland and Northern Ireland.[183] In individual communications across the UK there was also inappropriate treatment of the issue in encounters with Disabled people and/or their carers, for example an 87 year old man, who was self-isolating, with no immediate support, with conditions of depression and hearing loss, who was telephoned to discuss signing a DNACPR, and found the whole interaction extremely distressing.[184] Rather than as part of structured and supported anticipatory care conversations for end of life, it was common for Disabled people with unrelated comorbidities to be confronted with questions about whether they had a

[179] Mallick [INQ000520998/40 §§122-127] Davies [INQ000520201/22 §64] Nolan [INQ000520202/26 §§87-88] Elder Woodward [M2A/INQ000371664/5 §19] Sansome [INQ000520343/35 §§114-115]: see also ESM [INQ000587564/16, 95] Herklots [T9/131/4-15] Abrahams [T11/25/20-26/19]
[180] Sleeman and Barclay [INQ000587295/72 §227]
[181] Cridge [T5/76/16-25] CQC Report November 20 [INQ000235491/2 §3] CQC Report 18.03.21 [INQ000235492/41]
[182] Davies [INQ000520201/22 §64] Herklots [T9/129/15-130/13] CIW Annual Report 2020-21 [INQ000501726/5 §4] Care home worker, Wales, ESM [INQ000587564/16] Wales care home [INQ000587669/13 §§16.1-16.2] Care home resident Wales, ESM [INQ000587564/93] Care worker, Wales, ESM [INQ000587564/94]
[183] Rayner [T4/122/17-123/14] Rayner-Roughton emails 26.03.20 [INQ000466452] Cridge [T5/76/21-77/3] Allen [T4/31/12-16] Bereaved family member, England, ESM [INQ000587564/93] Macaskill [INQ00509530/26 §96] Lynch [INQ000474926/44 §§137-138]
[184] Herklots [INQ000514106/34 §168] [T9/131/16-25]: see also Allen [INQ000572015/27 §88] Abrahams (Age UK) [INQ000509808/17 §46] Sansome [INQ000520343/35 §114] Nolan [INQ000520202/26 §88] Jones [INQ000514104/90 §234]

DNACPR notice.[185] This body of evidence makes it impossible to conclude that this was just the product of confusion in the early period of the pandemic.[186] Moreover, as a discrete aspect of data incapacity (see §9 above), there was never a means to systematically analyse what was taking place in real time,[187] and when the CQC did act it took many months to complete the task and was unable to draw on granular data.[188]

41. NON-CONSULTATION: Notwithstanding the duty to consult on DNACPR notices under Article 8 of the ECHR,[189] at various points at the care home itself,[190] and then in the movement from care setting to hospitals, notices signed by clinicians were added to records without consultation with those with power of attorney.[191] These included the parent who had a DNACPR notice inserted into her file during an ambulance journey to hospital[192] and the Deaf man who woke up in hospital to find that a DNACPR notice had been placed on his bed, with the reasoning noted by the medical staff to be "*communication difficulties*" (i.e. that they could not communicate with him regarding his wishes due to him being Deaf).[193]

42. LEARNING DISABILITIES: Care providers were contacted to fill out notices for their residents. These involved approaches being made to care homes on a generic basis, for all their residents,[194] as well as instances of care providers asked to consider creating notices for residents specifically because of their intellectual disabilities.[195] There were notices in which intellectual disability (e.g. 'learning disabilities', or 'Down's Syndrome' or care home resident') was improperly cited as the rationale for their creation.[196]

[C] FATALITIES OF A LESSER NEED

43. ABANDONMENT: Through public messaging against hospital attendance, NHS 111 advice, and reduced granting of home visits, there developed both a sense of clinical

[185] Lyons [INQ000587637/23 §§78-83] (see Ex. SL.03 [INQ000612649] and SL/04 [INQ000612650]) [T8/175/25-177/8] Hodgkinson [INQ000474414/29 §18.1.4] O'Sullivan [M3/INQ000479878/16 §30] Inclusion London [INQ000474761/21-24]
[186] *Cf*. CQC Report 18.03.21 [INQ000235492/41]
[187] Allen [T4/31/7-32/11]
[188] Rayner [INQ000475131/31 §6.1]
[189] R (*Tracey*) *v Cambridge University Hospital NHS Trust* [2014] EWCA Civ 822 [2015] 1 QB 543 and *Winspear v City Hospitals Sunderland NHS Foundation Trus*t [2015] EWHC 3250 (QB) [2016] QB 691: see also Sleeman and Barclay [INQ000587295/12 §28]
[190] BBC Scotland News 21.08.24 [INQ000507870] Ferguson [INQ000532753/9 §§23-24]
[191] Adamson [INQ000474426/19 §4.34] Sullivan [M3/T2/118/1-144/13]
[192] Ferguson [M3/INQ000360941/10 §50]
[193] Nolan [INQ000520202/27 §90] Deaf Action 04.06.21 [INQ000366005]
[194] Care Homes Pushed to Issue DNR notices during Covid, Article 08.28.24 [INQ000507871]
[195] Hough [INQ000587639/6 §24] [T2/131/18-132/10] BIHR 2020 [INQ000509838/3, 9-10, 17]
[196] Hatton [INQ000587296/27 §85] (citing Heslop et al, 2021) Allen [INQ000572015/26 §85-86] LeDoR Annual Report for 2020 (2021) [INQ000532327/13, 42-43, 71-75]

abandonment, and in some instances, its reality.[197] Families reported being positively told that taking elderly parents to hospital could result in them not being treated.[198] Similar messages were conveyed to care providers.[199] Doctors working across a range of settings including ASC reported creating more DNACPR notices, and adopting higher threshold for escalating patients to critical care wards and a lower threshold for palliating patients.[200] If residents did not have a DNACPR notice, there were examples where ambulances were reluctant to take them to hospital,[201] or care home workers would not ask, or were highly uncertain about doing so.[202] Conversely, where residents *did* have a DNACPR notice, ambulances and, on occasions, hospitals, would not take them, and people were kept in the care homes to die.[203] Either way, it is clear that DNACPR notices were being used to guide decisions over care and treatment beyond a decision not to resuscitate after a cardiac arrest.

44. PREDISPOSITION: All the above could only have occurred because of a predisposition to accord less value to the lives and needs of Disabled people that arose at an organisational level in different services across each of the four nations. What that teaches is that in states of public health emergency, mindsets and practices of hyper-utilitarianism can take hold.[204] No policies, or central directives, are needed. Rather, at the point of service delivery, in the face of indeterminate crisis and depleted resources, discriminatory biases can operate against medical treatment for the Disabled, the elderly and the frail. If there are no policies in place to assure against such biases during emergencies, they will happen; and a failure to create those policies and systems now, would amount to a countenancing of their future repetition.

45. RECKONING: DPO urge as a first step towards change that this Inquiry should acknowledge that this evidence calls for blunter conclusions than have hitherto been made by investigations of the issue. There needs to be a reckoning with the fact that there is no system of oversight on DNACPRs notices, in terms of how notices are generated and the manner in which they are used, especially on Disabled people. Misunderstanding and fatalism of providers over health and social care interventions, even in the face of

[197] Edwards [M3/INQ000474283/37 §115] Snooks [INQ000474285/24 §73] [M3/T23/124/14-19] LeDoR Annual Report 2020 (2021) [INQ000532327/70-71]
[198] McCusker [INQ000614377/6 §16]
[199] Featherstone [INQ000569768/39 §151]
[200] Sleeman and Barclay [INQ000587295/72 §225]
[201] Hough [INQ000587639/6 §§27, 29-32] [T2/132/22-133/2]
[202] Lynch [T15/188/12-14] Adamson [INQ000474426/8 §3.22]
[203] Herklots [M2B/INQ000276281/11 §3.22] [T9/131/4-15] Baranski email 05.04.20 [INQ000500163/2] Baranski [INQ000569773/97 §294] BIHR [INQ000509838/22] Tyczynski [INQ000576043/9 §37] Ferguson [INQ000532753/17 §§53-54]: see also Marsh [M3/T14/80/9-13] Amnesty International, 'As if Expendable' 04.10.20 [INQ000509643/22]
[204] Lynch [INQ000474926/44 §135] Hodgkinson [INQ000474414/30 §18.2] Minty [T9/188/17-189/9]

committed advocacy, is a norm for many Disabled people outside of a pandemic.[205] But during the Covid-19 crisis, the message to *Protect Our NHS* got distorted in some of the frontline cultures working in a terrible situation and produced an unconsidered eugenic tendency.

CONCLUSION – THE PANDEMIC'S GROUND ZERO

[A] DEATHS

46. OUTCOMES: At one point in the pandemic, for the first time in modern recording, more people died in care settings than in hospital. Of the large percentage of care home residents who died of Covid-19, a much smaller percentage were taken to hospital.[206] Throughout the pandemic there was a dramatic increase of people who died at home than would normally be the case: more than a third higher than the average over the previous five years, and by 2022 over 100,000 more people than would be expected, with excess deaths from a range of conditions, such as diabetes, and Parkinson's disease.[207] As there was no routine testing, it is difficult to be certain about how many people died of Covid-19.

47. DOMICILIARY CARE: Between March 2020 and May 2021, 28,000 people in domiciliary care in England and Scotland died, which is a higher increase in proportionate terms than those who died in care homes.[208] Excess deaths compared to previous years were more than double.[209] The deaths were likely underreported because there is no duty for a provider to notify the CQC unless the death occurs during the course of care-giving services, or potentially as a result of them. In any event neither the cause of death, nor a detailed profile of the deceased, are part of the notification requirements.[210] There is no surveillance of the issue in Wales[211] or Northern Ireland.[212] Whereas care home addresses appear on death certificates, the same is not the case to indicate that a deceased person was in receipt of care at home.[213]

[B] SUFFERING

48. For those that did not die, and for those who endured neglect before they did, there was

[205] Lyons [INQ000587637/5 §§11, 32-34, 89]
[206] Marron and Dyson [INQ000587736/20 §§93-96] ONS 15.05.20 [INQ000252648/2] NIA Report [INQ000553511/30 §§80-81]
[207] Sleeman and Barclay [INQ000587295/25 §§78, 145-148] Townson [INQ000587670/41 §§143-145, 458-459]: see initial response by DHSC, Whately [INQ000587788/23 §86]
[208] Mallick [INQ000520998/8 §22] BIJ [INQ000509854/1-2]
[209] ONS 15.05.20 [INQ000252648/2 and 16] The Health Foundation 01.07.2020 [INQ000509820/1, 7-9]
[210] Care Quality Commission (Registration) Regulations 2009: Regulation 16: see also Diamond [INQ000553814/37 §135(c)] Townson [INQ000587670/109 §§460-462]
[211] Khaw [INQ000587702/88 §334]
[212] Donaghy [INQ000475143/25 §§84-88]
[213] Diamond [INQ000553814/39 §§139-140] Byrne (NRS) [INQ000514105/9 §29] Wales (NISRA) [INQ000474699/14 §29]

suffering. This Inquiry has been entrusted with strikingly wounded testimonies of what the death and suffering during the pandemic entailed. (1) DIGNITY: There was subjection to inhumane conditions that were contrary to human dignity.[214] (2) DENIAL: Through prioritising the protection of hospitals and staff from virus transmission, there was denial of physical and mental health treatments and therapies leading to lasting damage.[215] (3) END OF LIFE: There were terrible end of life experiences, due to shortage of staff and equipment, as well in insufficient oxygen and other pain relief.[216] (4) TRAUMA: There was moral distress for those who witnessed these matters.[217] (5) ANGUISH: And anguish and aggravated grief for those who were unable to be present for people who were dependent upon their care.[218]

[C] ACCOUNTABILITY

49. MONITORING: The lack of accountability for the deaths and potential improper treatment of care recipients in both residential and domiciliary care is one of the pandemic's lasting forms of damage. The cessation of onsite inspections and the lack of proper recording and monitoring of the use of Care Act easements are part of a far larger problem of unaccounted for events. Combined with the Coronavirus Act allowing for Medical Certificates of Cause of Death to be signed by a non-attending doctor,[219] the number of all deaths reported to coroners in England and Wales was the lowest figure since 1995.[220] The number of deaths of adults and children with learning disabilities reported to a coroner dropped from 41% in 2018 and 40% in 2019, to 22% in 2020.[221] Guidance issued by the Chief Coroner declared that Covid-19 as a cause of death (or contributory cause) was not a reason on its own to refer a death to the coroner.[222]

50. INVESTIGATIONS: In practice there were few inquests into Covid-19 related deaths. The reasons include, the narrow statutory purpose of coronial inquests only to examine the "direct circumstances" of a death, marked long term lack of resources faced by the coronial

[214] Teague [INQ000479888/18 §§59-60, 84]
[215] Graham [INQ000547481/17 §§78-79] Nafeh [INQ000587595/14 §44] Lyons [INQ000587637/14 §§41-45] [INQ000612644/3-4] Sansome [T18/160/11-23] Townson [INQ000587670/105 §445] Hatton and Hastings [INQ000587296/46 §§160-165] Hatton [T17/184/13-186/2]
[216] Sleeman and Barclay [INQ000587295/53 §§170-178, 197-204] Barclay [T19/22/19-25/14] Rooney 05.04.20 [INQ000500163/2-3] Kings Fund [INQ000574106/3] Townson [INQ000587670/42 §146] Adamson [INQ000474426/20 §4.38] Hough [T2/125/23-129/17] [INQ000587639/9 §§44-48] Kilbee [T2/52/7-20] [T2/56/16-57/2] [T2/58/12-17] [INQ000614380/10 §§36-37] Marsh-Reese [M3/T39/13/17-18/2] Hudd [T4/164/17-165/7]
[217] Hudd [INQ000614378/5 §§10-18, 30] [T4/158/22-161/6] [T4/166/2-13] Townson [T9/33/7-23]
[218] Adamson [INQ000474426/19 §4.35] McCusker [T2/74/1-12] [T2/80/20-81/23] Lyons [INQ000587637/17 §56] Sansome [T18/160/11-23]
[219] Teague [INQ000479888/10 §§37-39]
[220] https://www.gov.uk/government/statistics/coroners-statistics-2020/coroners-statistics-2020-england-and-wales (Not on Relativity) Teague [INQ000479888/22 §§68-69]
[221] LeDoR Annual Report for 2020 (2021) [INQ000532327/44, 113]
[222] Teague [INQ000479888/10 §35]

system and the guidance on non-referral.[223] Contributory factors concerning death such as absence of IPC and/or PPE, and withdrawal of treatment and/or care that might have prevented the death have not and likely will not be the subject of official state recording.[224] The handful of inquests that produced important insight, about erroneous care and avoidable exposure to the virus, therefore represent the tip of the iceberg.[225] In *varying degrees*, and more than we will ever know, people therefore died without basic medical attention and palliative care, with minimal inspection or oversight of unnatural factors that may have contributed to preventable or premature medical causes of death.

[C] JUSTICE

51. GROUND ZERO: The longer this Inquiry has gone on, including the extent to which much of society has moved on in the meantime, the more it is obvious that the pandemic response produced staggeringly unequal outcomes, and that the crisis has not produced sustained social solidarity. The above ways of death and suffering did not happen to most people with sufficient assets to buy or network themselves or their loved ones out of it. We may all spend our lives living in care, but we are unequal in our resilience to live those lives. There are those that tried their utmost to mitigate that reality and there are fixes that can be made to the system that can mitigate the pandemics of the future. However, the reason why this module is the ground zero of the Inquiry is because of the terrible inevitability of it all. It was inevitable, not just because of the lack of planning, but because of the constitutional and economic choices we have made about how we structure our care system. The shameful result is that under the system as it presently exists Disabled people's lives are absolutely valued less.

52. TRANSPARENCY: From that point of ground zero, Disabled people, like Joanne Sansome, have shown a more positive vision of deliberative democracy, and how there could be co-production that more justly deals with the inherent vulnerability and diversity of the human mind and body. John Rawls' thought experiment of the veil of ignorance requires us all to imagine ourselves in equal exposure to the same death and suffering as experienced by those in the care sector during the pandemic. Rawls' principle of justice holds that, in those circumstances, and all other things being equal, we would be best placed to consider what policy changes are required of ASC. Notwithstanding that much remains unaccountable, this Inquiry is able to powerfully assist such a thought experiment, because it can provide an account of the unjust consequences posed by whole-society emergencies under present social and economic conditions.

[223] Griffiths [INQ00474459/24 §73] CBFFJ [INQ000502221/1-2]
[224] Teague [INQ000479888/12 §§41, 50-52]
[225] Teague [INQ000479888/30 §87-90]

53. CARE/CARING: DPO submit that general matters relevant to the veil of ignorance in this context can be seen as follows. As care of the self and care for each other is intrinsic to being human, and as care/caring is relational and inescapably social, then it is the need for care that causes the creation of families, communities, society and the state. Care is a hugely important thing. Yet if we all spend our lives being cared for, caring for someone, or relying on others to provide it, it is also the case that the assets to sustain resilient care are unevenly distributed, even if its importance to human life is universal. That creates a very significant division in modern society between those who cannot survive without a publicly funded adult social care system, and those who invest their assets in making sure they do not have to depend on such a system. The situation of Disabled people, particularly in a pandemic, makes both human connectedness and division in this area of existence much more obvious. From that greater understanding of how social relations are chosen, society could choose differently.

DANNY FRIEDMAN KC	**KATE BEATTIE**	**SHAMIK DUTTA**
	ALICE IRVING	**CALEB SIMPSON**
MATRIX CHAMBERS	**DOUGHTY STREET CHAMBERS**	**BHATT MURPHY SOLICITORS**

19 SEPTEMBER 2025