COVID-19 INQUIRY
MODULE 6

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

INTRODUCTION

1. CARE: Across the life cycle we all *live in care*. We are all being cared for, caring for someone, or relying on others to provide care. If our living in care is not immediate, it is always poised *to be* by the stages of our bodies, the unexpected accidents, and the diversity of the human condition. The human geography of care is in our homes, our families, and in our variations of personal and community assistance. Care is in our access to other care settings of treatment, wellbeing, respite and residence. The quality of the care we need and that we give may be variable, but its importance when it becomes due is universal.[1]

2. SYSTEM: In PART 1, the DPO reflect on the dissonance between how human beings generally care about caring and the UK system of social care that existed at the outset of the pandemic. The Inquiry has already found that the system was running "*close to, if not beyond, capacity in normal times*".[2] The underlying flaws lay in: [A] Structure, [B] Government and [C] Planning.

3. COVID-19: The system's flaws were starkly revealed during the pandemic in two extreme ways. Care settings became life threatening. Care services to sustain everyday basic quality of life were withdrawn, or seriously diminished. PART 2 focuses on [A] Data, [B] Labour, [C] Easement, [D] Lockdown and [E] Unpaid Carers.

PART 1: SYSTEM

[A]. STRUCTURE

4. COMPLEXITY: The UK Department of Health and Social Care ('DHSC') recognises the profound importance to the human condition to care and be cared for.[3] However, the funding, size and diversity of the UK's Adult Social Care ('ASC') sector has been allowed over decades to become complex, that lends itself to a fatalism that it is now impossible to fund, plan for, or lead. The King's Fund Report in 2021 pointed to the system's "*hugely tangled*" mixed economy of public and private funding, its workforce that is larger than that of the NHS, and its labyrinthine nature, all of which made its leadership extremely challenging.[4] In each of the four nations delivery of

[1] For DPO approach to these matters, see DPO M2 Opening 26.09.23 [§§1.1-1.1.11, 4.1-4.5]
[2] UKCI M1 Report, The resilience and preparedness of the United Kingdom, July 2024 [2]
[3] Marron & Dyson 'A' [INQ000587735/3 §§8-10]
[4] King's Fund Stories Report (2021) [INQ000498620/8]

social care services involves different but equally long and complex governing chains combining local authorities, trusts, inspectorates, a range of specialist organisations with Central Government often at arm's length.[5] The challenges are exemplified by the 25 years of green papers and consultation exercises, white papers, multiple reviews, two government commissioned inquiries, all without resolution of key structural deficiencies and allegations of political neglect.[6] Unlike the NHS, the ASC system is not national,[7] not free at the point of delivery, largely privatised,[8] and increasingly diminished in its public financing.[9] Health and social care are two separate systems with different funding, governance and legislative and service regimes.[10]

5. FRAGMENTATION: Another salient description of the social care system is that it is "*fragmented*".[11] That is the language used by Professor Harries, the former Deputy Chief Medical Officer.[12] It is the common description of leadership and the representatives of staff and service users.[13] The Minister for Social Care, Helen Whately, for instance, warned in an email to No. 10 Downing Street in April 2020: "*The whole social care sector is incredibly fragmented, and it will only take one small care home to fall over when no staff turn up for us to have a serious crisis on our hands*".[14] The Technical Report produced jointly by the Chief Medical Officers described the pre-pandemic care sector as "*complex, large, varied, fragmented and in places… fragile"* with "*a high turnover of care workers and many in multiple settings or for agencies"* and "*it was… evident from early in the pandemic this was one of the most at-risk sectors but also one where mitigation of risk was not easy in a fragmented sector operating under multiple pressures*".[15]

6. VULNERABLE: The recognition in the Technical Report that the system was "*fragile*" is tantamount to acceptance that it lacked resilience and was vulnerable to the pressures that the pandemic

[5] For the UK see Marron & Dyson 'A' [INQ000587735/9 §§34-53]; for Scotland see Freeman [INQ000606530/2 §6-11]; for Wales see Morgan [INQ000598534/5 §§21-23] Heaney [INQ000551798/5 §§18-26, 31-32]; for Northern Ireland see Holland [INQ000475016/6 §§11-39]
[6] King's Fund Stories Report [INQ000498620/45] Nuffield Trust, Building a resilient social care system in England (2023) (hereafter 'Nuffield') [INQ000553858/14] Abrahams [INQ000509808/7 §§17-18, 32] Rayner [INQ000475131/8 §§2.1, 2.9]
[7] For the arguments it should be, see Adamson [INQ000474426/2 §§3.2, 3.4] Nolan [INQ000520202/38 §§131-137, 148] Feeley Review (2021) [INQ000280640/2, 6, 29, 38-54, 108] NCS Bill (2022) [INQ000280641] Davies [INQ000520201/46 §139(2)-(3), (11)]
[8] Marron & Dyson 'A' [INQ000587735 §§15-16, 20-24] Nolan [INQ000520202/7 §§21-22]
[9] Daly *COVID-19 and care homes in England: What happened and why?* [INQ000148331/9 §3.1.2] Abrahams [INQ000509808 §§19-28] Mallick [INQ000520998/5 §§15-16] Nolan [INQ000520202/5 §§17-18]
[10] Daly [INQ000148331/7 §3.1.1]
[11] Kings Fund Stories Report [INQ000498620/10] Smyth [INQ000543049/49 §248]
[12] Harries [INQ000587394/58 §9.2]
[13] Williams [INQ000571608/20 §6.5] Adamson [INQ000474426/2 §3.2] Holzhausen [INQ000587612/14 §32] Abrahams [INQ000509808/32 §§85, 116] Heaney [INQ000532383/62 §§155, 162] Featherstone [INQ000569768/10 §32] Foyer [INQ000569884/12 47-48] Knight [INQ000569774/24 §10.5] Allen [INQ000572015/42 §148] FMWG [INQ000474919/5 §§14, 180] Smyth [INQ000543049/49 §248] Smith [INQ000576035/7 §31] McAnea [INQ000587381/40 §96.4] Pereira [INQ000587395/4 §§12, 15, 44] Llewelyn [INQ000613908/54 §§136, 214] Robinson [INQ000587563/2 §2.5]
[14] Whately-No.10 Email 22.04.20 [INQ000198061/2 §4)]
[15] CMO Technical Report 01.12.22 [INQ000203933/296-297] Williams [INQ000571608/24 §6.16] Heaney [INQ000532383/62 §§155, 162]

would pose. If the system was vulnerable, it would render its users vulnerable; and, as it turned out, rapidly and acutely so. This discourse of 'fragmentation' and 'complexity' is helpful as a description of the challenges. But the discourse is a challenge itself because it obfuscates the extent to which the system has been built this way. It was vulnerable because the care sector has always been treated differently from the health service in terms of political status and funding priorities.[16] Compared to the NHS, a national icon, it has never had parity of cultural recognition as a public possession, or remotely comparable funding.[17]

7. MARGINALISATION: There are features of ASC that cause it to be marginalised; and that marginalisation mirrors Disabled peoples' own social precarity. It is a system that deals with areas of the life cycle that are less amenable to social empathy, less quantifiable by reference to hard-edged outcomes, and less attractive to philanthropy. As a function ASC can be politically overlooked because it is capable of being privatised at a low-cost scale, including by relying on unpaid, low income and informal labour. It leverages heavily off the social capital of women, families, Disabled people caring for Disabled people, and migrants; and in doing so it exploits the comparative lack of constituency of those groups in the formation of public policy. As Disabled people depend heavily on ASC, the erosion of the system prior to the pandemic was intrinsic to the structural discrimination that Disabled people faced during its course.[18]

[B]. GOVERNMENT

8. INCOMPREHENSION: The other common criticism of the care system is that Central Government did not understand it.[19] The situation was aggravated because experts on ASC were not embedded in decision-making structures, a situation that only partly remedied with the establishment of the Social Care Taskforce in the summer of 2020.[20] However, the problem was never properly remedied with regard to DPO, Third Sector and other civil society groups, who in initial departmental planning were not even listed as "*stakeholders*".[21] Exclusion from any formalised system of engagement with Government meant that their capacity to provide rapid insight on policy formation and operational risks was never properly utilised.[22] Disabled people

[16] Daly [INQ000148331/7 §§3.1.1-3.1.2] Mallick [INQ000520998/7 §20]
[17] Daly [INQ000148331/11 §3.2.2] McAnea [INQ000587381/1 §2]
[18] Mallick [INQ000520998/5 §§14-20] Davies [INQ000520201/5 §13] Nolan [INQ000520202/5 §§17-19] Sansome [INQ000520343/5 §§14-23] Watson & Shakespeare [M2/INQ000280067/10 §§30-36, 41]
[19] Nuffield [INQ000553858/7] Williams [INQ000571608 §§2(b), 8.9-8.10] Weatherley [INQ000504053 §§3.8, 4.1, 4.6, 4.7, 4.11, 4.14] Abrahams [INQ000509808 §§63-67] Rayner [INQ000475131 §§2.15, 3.6-3.8] Killian INQ000587382/30 §78] Nolan [INQ000520202/20 §§69-70] Llewelyn [INQ000613908/32 §80]
[20] Nuffield [INQ000553858/6] Bottery [INQ000502030/33 §25] Rayner [INQ000475131/58 §10.3]
[21] Marron & Dyson 'B' [INQ000587736/7 §27] ("*care homes, home care providers and local authorities*"). *Cf*. for the function of DPO/Third Sector to fill gaps and bridge, see Watson & Shakespeare [M2/INQ000280067/12 §38] McKay [INQ000578133/99-101] 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
[22] For the UK, see Mallick [INQ000520998/23 §69-97]; for Scotland, see Nolan [INQ000520202/32 §§110-130, 149]; for NI, see Sansome [INQ000520343/22 §§70-90]: *Cf*. Wales, see Davies [INQ000520201/6 §§15, 79]

were given limited consideration as a distinct planning category in the first months of the pandemic, and even when engagement efforts were made, DPO were not involved in the co-production and co-design of policy as required under article 4(3) of the United Nations Convention on the Rights of Persons with Disabilities ('UNCRPD').[23]

9. MISTAKES: Fundamental mistakes were duly made: (1) The transfer of patients from hospitals to care homes whose differences in terms of design, operations, equipment and capability were not afforded the appropriate risk status.[24] (2) 'Supported living' as a distinct category was significantly neglected and/or omitted from guidance, which used 'care homes' (often associated as only housing the elderly) as a catch-all definition.[25] (3) There was "*pronounced lack of understanding*" about the social care workforce: who they were, how they lived, their income precarity, and competencies.[26] (4) Certain Disabled groups, for instance those with learning disabilities and dementia, were the subject of damaging lack of attention.[27] (5) Vast swathes of the ASC sector were outside of professional regulation or registration, for example most of the ASC workforce;[28] but there were also profound data gaps (see §§16-19 below).

10. DISCONNECTION: The incomprehension of Central Government about ASC arose from what has become a minimal role, leaving the operation and delivery of the system to local authorities and private providers. The funding is sourced from fee payment, local taxation and block grants set and distributed by other Government departments. DHSC has no responsibility for supervision, data collection or national regulation.[29] The outcome was a department disconnected from its subject matter and therefore ill-pressed to command a crisis response. DHSC therefore left the provider market to face its significant structural issues,[30] with its Secretary of State's foremost "*steer*" being that primary planning responsibility was for local authorities.[31] Even when it understood risks, the ASC ministerial representation was often unable to impose its concerns on the rest of Central Government. When Minister Whately saw care workers and people with learning disabilities overlooked in the draft prioritisation approach to vaccination roll-out, it was difficult to change attitudes.[32] It was similarly not possible to effect significant change to staff

[23] DPO M6 Witnesses, ibid above; and generally, DPO M2 Closing 15.01.24 [§§32-34] M2A DPO Closing 23.02.24 [§§14, 21-22] DPO M2B Closing 05.04.24 [§§31-33] DPO M2C Closing 06.06.24 [§§32, 37]
[24] Mallick [INQ000520998/23 §§68, 70-71] Williams [INQ000571608/29 §§8.8, 9.1] Rayner [INQ000475131/4 §1.15] Ahmed [INQ000515683/13 §§43, 51, 54, 58, 65-66] Abrahams [INQ000509808/29 §78]
[25] Nuffield [INQ000553858/49-50] Hodgkinson [INQ000474414 §§9, 11.1.1] Rayner [INQ000475131/4 §1.15]
[26] Abrahams [INQ000509808/24 §64]
[27] Watson & Shakespeare [M2/INQ000280067/12 §38] Lee [INQ000498137/5 §§3.1-3.11, 5.10, 5.12, 9.12]; Abrahams [INQ000509808/15 §41] Nuffield [INQ000553858/7] Nolan [INQ000520202/20 §70] McKay [INQ000578133/76-77] Davies [INQ000520201/9 §§24-25, 61] EHRC [INQ000253853/2 §§5, 19, 25, 27-28, 68] Sansome [INQ000520343/19 §§62-63]
[28] Whately [M2/INQ000273897/5 §21] Featherstone [INQ000569768/11 §§33-34, 202(b)]
[29] Whately [M2/INQ000273897/4 §19] Hancock [INQ000587746/4 §§13, 39] Marron & Dyson 'A' [INQ000587735/9 §§34-39]
[30] Bottery [INQ000502030/31 §§16-18] Green [INQ000585008/12 §§24-29]
[31] ASC meeting readout 11.02.20 [INQ000049363/2]
[32] Whately [M2/INQ000273897/70 §§315-316]

movement despite it being understood, from early on, as a significant transmission risk (see §§22ff. below).

11. CAPABILITY: Within a huge Whitehall department dedicated to health ***and*** social care, the leadership on the latter had long been treated as a subservient capability. Between 2016 and April 2020, there was no Director General with responsibility for social care in the DHSC, rather Jonathan Marron, as Director General for Community Care and Preventions, doubled up both online management and reporting up to Permanent Secretary.[33] There was, at least, a risk to 'bandwidth' and leadership void for ASC as a distinct topic within the DHSC.[34] ASC had lower visibility and representation in senior positions in government[35] and received lower resources. At the outset of the pandemic, the dedicated ASC staff numbered only 89/90 full time employees.[36] Whately, who took up post on 13 February 2020, felt "*thinly spread*" and expressed her need for someone senior who knew the sector to come in and help grip the problems and more senior figures "*to give the team resilience*".[37] By its own admission this meant that at the point of the pandemic the DHSC only "*had limited reach into the sector*" with "*no source of operational data, no direct route of communication to all care providers and no way of directly distributing funding or supplies*".[38]

12. DIVISION: Even if they sat within one Department of State, the price of health and social care being two separate and complex systems was division. Excessive division of the health and care services is inherently problematic because of their considerable overlap;[39] especially for Disabled people who are also the key recipients of social care for primary health care needs.[40] The systemic divide hampered integration of policy, resources and operations when it was most needed. For instance (1) the lack of parity of access to PPE, testing and other infection, prevention and control measures between hospital and social care settings;[41] (2) mass discharge of patients from hospital to care homes, without the capacity to track alternative settings;[42] (3) acceleration and escalation of "discharge to assess", with the consequence of unsuitable placements and with unmet support needs;[43] (4) irregular usage of DNACPR notices (see §§19 below); and (5) mistaken assumption that GP systems would be sufficiently accurate to facilitate

[33] Marron [M2/INQ000283155/9 §36] Marron & Dyson 'A' [INQ000587735/20 §72] Abrahams [M2/INQ000281296/12 §28]
[34] As to Marron's responsibilities see Williams [INQ000497031/68 §§4.19, 4.305]
[35] Featherstone [INQ000569768/10 §§29-30, 68] Nuffield Trust Report May 2023 [INQ000553858/6]
[36] Whately [M2/INQ000273897/5 §22]
[37] Whatley-No.10 Email 22.04.20 [INQ000198061/2 §1] Whately [M2/INQ000273897/1 §2]
[38] Marron & Dyson 'E' [INQ000587739/9 §29]
[39] Harries [INQ000587394/59 §9.4] Williams [INQ000571608/33 §9.6] Pereira [INQ000587395/10 §30]
[40] For description of NHS funded ASC see: Marron & Dyson 'A' [INQ000587735/6 §22]
[41] Lee [INQ000498137/23 §9.5] Abrahams [INQ000509808/23 §§61, 78-83] Daly [INQ000148331/6 §2.3]
[42] Cridge [INQ000584245/169 §§536, 538-539, 542, 545]
[43] CQC State of Care Report October 2021 [INQ000235497/34] ADASS Survey 2020 [INQ000103772/8]

vaccine prioritisation for those with learning disability.[44]

[C]. PLANNING

13. FORESIGHT: The flaws in the structure and governance of the ASC system inevitably impacted on its ability to respond to Covid. But the greatest fault of government is that although the sector was known to be highly exposed in the event of a pandemic, it was largely outside of any civil contingency planning, and in this failure to plan there was particular oversight of the needs of Disabled people and other socially vulnerable groups.[45] The 2011 Influenza Strategy had predicted "*particular challenges in maintaining social care services*" with the need to "*reduce or cease non-urgent activity*" and anticipated "*increased pressure in primary and community services, social care, voluntary agencies and the private sector companies that support these services*".[46] In 2015, Exercise Silver Swann in Scotland, acknowledged the "*likely impact on [the Care] sector and increased demand*".[47] In 2016, Exercise Cygnus specifically identified the lack of "*capability and capacity*" in social care "*to surge resources*" and the need for "*arrangements for 'scaling up' the local response*". The report also pointed to the underlying structure of the system, which lacked clarity between the Department of Health and Local Governments as to who would lead, and recognised that it was not possible to assess social care capacity because much of it lay with private providers.[48]

14. FAILURE: The belated response to the Exercise Cygnus report was the 2018 Pandemic Influenza briefing paper. It identified "*a knowledge gap in community services preparedness, including…adult social care*", data gaps on care home occupancy, and domiciliary care, and the need for emergency plans with each service user.[49] Before Covid, neither the UK Government, nor the Devolved nations carried out the intended follow up work.[50]

15. CONSEQUENCE: On 13 March 2020 the words written on the White Board in the crisis room in No 10 Downing Street were, "*Who looks after people who can't survive alone ???*"[51] The consequence of failure of foresight was having to start from "*scratch*".[52] Whately, as Minister, had called earlier in March 2020 for local authority plans for emergency social care. She received just two examples – both of which were manifestly not good enough – which caused at least her and Hancock to realise that the system would not be able to cope.[53] In Scotland, Nicola Sturgeon's

[44] M4 DPO Opening 13.12.24 [INQ000474794/8 §3.3] and M4 DPO Closing 17.02.25 [5 §14]
[45] Module 1 Report [p.116 §§5.55-5.58]
[46] UK Influenza Pandemic Preparedness Strategy 2011, DOH [INQ000102974/50 §§6.1-6.5, 6.17-6.19]
[47] Nolan [INQ000520202/8 §25]
[48] PHE, Exercise Cygnus Report, 18-20 October 2016 [INQ000056232/8-9, 24] Module 1 Report [p. 112 §5.40]
[49] Pandemic influenza Briefing Paper: ASC and Community Health Care, 01.06.18 [INQ000105391/2, 6 and 9]
[50] Module 1 Report [p. 125 §5.96-5.97, 5.101]
[51] Cummings [INQ000048313/3] *Cf.* Harries Email 14.02.20 [INQ000151466]
[52] Cummings [T15/250/6-21] [INQ000273872/84 §§400-408]
[53] Whately [M2/INQ000273897/11 §§44-46] Hancock [INQ000587746/12 §§52-53] M2 DPO Closing 30.01.24 [INQ000399541/3 §§7-8]

equivalent denouement was not so much to discover that there was no plan, but that there were not even the underlying capabilities to discharge a plan.[54] In any kind of whole system emergency, social care was bound to be at the jagged edge of impact, and yet it was never at the centre of preparedness and resilience thinking. From the perspective of disability rights this was a violation of the State's positive duty under Article 11 of the UNCRPD to "*take all necessary measures*" to ensure protection of Disabled people in disasters.[55] From the perspective of the basic human need to care and be cared for, the consequences of the failure were damning.

PART 2: COVID

[A] DATA

16. EXPOSURE: All the Inquiry Modules thus far have revealed profound weaknesses in data systems and analysis.[56] More specifically they have shown "*disability*" to be the "*major gap*".[57] What distinguishes this module is that the health care system can be regarded as "*data rich*" compared to ASC;[58] a situation that arises because the same level of funding has historically been denied to the task.[59] Deficiency of ASC data was identified in 2018 as part of the unfinished work on Exercise Cygnus.[60] The deficiency was extant at the outset of the pandemic when the Office of Statistical Regulation ('OSR') reported that the vast volume of the delivery of social care occurred in a private market outside of statutory control, which meant that Local Authority recording duties could only measure part of the picture. Limited data from a relatively small pool of state-funded social care activities therefore acted as a "*unrepresentative proxy*" for the whole social care sector. Other gaps included the scale of expenditure on privately funded care, the value of unpaid care and transitions between health care and social care. The "*disparate landscape*" of state responsibility for social care, including across the various departments of Government, impeded leadership and development of statistics as a capability.[61]

17. CONSEQUENCES: The lack of data made Disabled people particularly vulnerable during Covid-19. The profile, geography and numbers of care recipients could not be accounted for with any degree of reliability, or capability of sharing that data in real time, or acting upon it as a resource for policy making, risk management and service delivery.[62] In particular: (1) The DHSC had no

[54] Sturgeon [M1/T12/42/5-18]
[55] DPO M2 Closing [INQ000399541/36 §56] DPO M2A Closing 23.02.24 [§§35-37] DPO M2B Closing 05.04.25 [§§16, 31-33] DPO M2C Closing 06.06.24 [§39(7)]
[56] DPO M2 Closing 15.01.24 [INQ000399541/23 §§35-37] DPO M2A Closing 23.02.24 [§§23-25] DPO M2B Closing 05.04.25 [§§13-14, 34-36] DPO M2C Opening 19.04.24 [§3.16]
[57] Diamond [M2B/T3/95/19-96/3]
[58] OSR, ASC England (January 2020) [INQ000502199/5]
[59] Diamond [INQ000553814/60 §§216-217] McKay [INQ000578133/58] OSR (March 2020) [INQ000503458/3]
[60] Pandemic Influenza Briefing Paper: ASC and Community Health Care 01.06.18 [INQ000105391/6-7]
[61] OSR January 2020 [INQ000502199/3-4, 10-12]
[62] 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] Harries [INQ000587394/11 §§5.5, 5.8, 5.13, 7.1-7.2, 9.5] Diamond [INQ000553814/59 §§213-215] McKay et al

national source of operational data on the total numbers of people in receipt of care, including self-funded users and NHS-funded users.[63] (2) There was limited data on the movement of people from hospitals and care settings;[64] and the movement of staff between those settings (see §§20ff below). (3) Deaths of those in domiciliary care were only recorded for those who died in the context of a regulated activity.[65] (4) Data was not often disaggregated to reflect different types of impairment, or other equality protected characteristics despite the obligation under Article 31 of the UNCRPD to do so.[66] (5) Data identification of adults with learning disabilities was deficient with adverse implications for specialist support needs as regard shielding status, access to information and prioritisation for vaccines.[67] (6) The "Capacity Tracker" focused on care homes and did not adequately cover community provision or Personal Assistants ('PAs') or unpaid carers; neither did stakeholders trust its accuracy.[68] (7) Differences in policies, definitions, and legislation across the four nations meant that the comparability of social care data was not possible.[69]

18. CONTINUATION: There were belated efforts to create regular data collection for ASC sector other than care homes during the pandemic itself,[70] but this could not have hoped to have overcome the structural limitations described in the OSR report of 2020. The regulator has since reiterated that social care was poorly served before the pandemic, adding that although some improvements have been made to data collections from the sector, "*these are inconsistent and require system-wide leadership and collaboration to maintain momentum for change*".[71]

19. MONITORING: Aside from structural data acquisition and management, the ASC during the pandemic had critical weaknesses in terms of scrutiny and oversight. Regulators in all four nations suspended so-called "routine" on-site inspections of residential and domiciliary care settings.[72] For Disabled people living in accommodation settings or receiving domiciliary services such oversight is anything but "routine",[73] and was even less so given reduced services through

[INQ000578133/8. 58-59] Rayner [INQ000475131/10 §§2.6-2.7, 10.14] §10.14]. For DPO, see Mallick [INQ000520998/33 §100] Davies [INQ000520201/21 §60] Sansome [INQ000520343/30 §98]
[63] Marron & Dyson 'D' [INQ000587738/3 §8] Marron & Dyson 'E' [INQ000587739/13 §§41-42] Hancock [INQ000587746/4 §§14, 39, 51]: see also Heaney [INQ000532383/63 §157] OSR Report March 2020 [INQ000503458/3] Baranski [INQ000569773/57 §175] NISRA [INQ000474699/15 §31] Byrne [INQ000514105/14 §§48-50] PHS [INQ000587252/77 §7.4.3-7.4.7]
[64] OSR January 2020 [INQ000502199/13]
[65] Diamond [INQ000553814/37 §135(c)] BIJ article 10.05.21 [INQ000509854/2]
[66] Mallick [INQ000520998/34 §101] Davies [INQ000520201/21 §60] Nolan [INQ000520202/29 §§98-100] Sansome [INQ000520343/29 §§96, 99]. On vaccination, see DPO Closing M4 17.02.25 [§§25, 28-29]
[67] Hatton and Hastings [INQ000587296/59 §219(a)] Sansome [INQ000520343/30 §97]
[68] Williams [INQ000571608/22 §§6.13, 10.2, 11.3(c), 12.11, 13.19-13.22]
[69] Diamond [INQ000553814/21 §§98-102]
[70] Cridge [INQ000584245/168 §§535-536] CQC, DHSC, NHSE/I Joint Statement 30.03.20 [INQ000525032] Marron & Dyson 'D' [INQ000587738/4 §13]
[71] Diamond [INQ000553814/61 §§226-232] OSR (2021) [INQ000092812] Update (2022) [INQ000092810]
[72] Cridge (CQC) [INQ000584245/74 §220, 223] Baranski [INQ000569773/25 §86] Mitchell [INQ000475130/52 §178] Donaghy [INQ000475143/35 §119]
[73] Donaghy [INQ000475143/35 §119] Baranski [INQ000569773/25 §86] Mitchell [INQ000475130/52 §178]

easements (see §§30ff below) and as lockdowns and visiting restrictions meant that more services were effectively operating as closed environments.[74] Rather than arming itself with data to assess these circumstances, the State retreated to a situation where officials could not provide assurances about fatalities, extent of infections, or numbers in different care settings.[75] In this adapted regulatory approach there was no structured process for making enquiries of Disabled people, their families and advocates, or DPO to supplement the now much more limited intelligence available.[76] The lack of data also impeded effective analysis of DNACPRs.[77] The consequence is that the State remains unclear as to how many unlawfully premature deaths or instances of withheld treatment occurred through the use of "blanket" or otherwise unlawful DNACPRs, and how many notices were placed and remain improperly on individuals' records.[78]

[B] LABOUR

20. MARKET: Going into the pandemic the labour market in ASC was characterised by mutual reinforcing factors of (1) low pay, insecure contracts and challenging working conditions; (2) workforce demand often chronically outweighing supply; (3) policy and planning uncertainty caused by data deficiencies and lack of regulation and transparency, especially in its private sector; and (4) exploitation of migrant labour (subject to immigration control) and other socially vulnerable employment pools. These factors combined to cause multiple movements of staff significantly drawn from bank and agency providers to deploy between (a) different locations and types of care settings, (b) healthcare and the social care sectors, and (c) other sectors entirely (such as hospitality) where IPC protocols were not the same.[79]

21. MOVEMENT: The movement of staff posed serious risks of virus transmission.[80] The situation of domiciliary care workers delivering care in multiple houses during a shift was particularly complex.[81] Two compelling questions arise: (1) Why was the risk not acted upon earlier? (2) Why did the government not resort to more radical market interventions – as it did to address other aspects of the emergency – to limit staff movement and pay people not to work?

[74] CQC Closed Cultures Guidance [INQ000524881/3]
[75] MS(C) Assurance Meeting 11.06.20 [INQ000524915/2] Donaghy [INQ000475143/71 §275]
[76] Sansome [INQ000520343/13 §42] *Cf.* Baranski [INQ000569773/35 §§115-116]
[77] Nolan [INQ000520202/27 §90] DHSC email 04.09.20 [INQ000478907/2] DHSC to MS(C) 24.09.20 [INQ00058389/2 §4]
[78] Mallick [INQ000520998/41 §123] Nolan [INQ000520202/27 §90] O'Sullivan [INQ000479878/13 §19] Stringer [M3/INQ000235594/10 §25]
[79] McAnea et al [INQ000587381/2 §§3, 19, 45]; Pereira [INQ000587395/2 §§3-4, 13-14] Frontline Migrant Health Workers Group [INQ000474919/14 §§40-42, 48-49, 54, 135] Harvey [INQ000569775/21§10.14] Abrahams [INQ000509808/30 §79] Allen [INQ000572015/10 §29] Harries [INQ000587394/62 §§9.12-9.13] Townson [INQ000587670/25 §§81-83, 96, 109, 521] Smyth [INQ000543049/40 §213]
[80] CMO Technical Report 01.12.22 [INQ000203933/297-298] Hayward [M2/INQ000267868/6 §§3.9-3.10]
[81] Townson [INQ000587670/123 §521]

22. FORESIGHT: The foresight of the problem is often presented as arising with publication of the Vivaldi study in July 2020,[82] which demonstrated correlations between care homes that did not pay staff during periods of absence due to sickness, their greater dependency on agency staff, and a greater risk of outbreaks.[83] But foresight of the risk from staff movement arose much earlier based on the known economics of the care sector and the early research into virus transmission.

23. AWARENESS: Basic understanding of the ASC ought to have immediately caused alarm that workers "*move consistently from house to house, community to community, and care home to care home*". That is what Disability Rights UK warned the Minister for Care and the Minister for Disabled People in a letter of 16 March 2020.[84] The practice of staff moving regularly between settings had been raised at a Ministerial meeting ten days previously.[85] These observations chimed with DHSC's awareness of several surveys conducted for pandemic preparedness, that care homes expected to be reliant on "*bank*" workers as their own staff took sick leave that could leave care homes "*particularly vulnerable*".[86]

24. RESEARCH: Two PHE research projects in April 2020 demonstrated to the UK Government that staff in care homes posed a "*significant source of transmission*" due to the volume of their movement "*in particular between care homes*" and their considerable profile as *"bank/agency staff, low paid"* and working "*multiple jobs etc"*.[87] Based on what the DHSC corporate statement describes as the then "*largest international dataset and strongest evidence to date*" decision makers now knew (what was being credibly reported according to the CMO since January) "*that it was likely that the virus was being transmitted asymptomatically"* and also *"that staff played a key role as a vector of asymptomatic transmission"*.[88] In tandem Government was also aware that the success of Singapore and South Korea in preventing ingress of Covid-19 into care homes had involved "*very strict processes*" to isolate and test all care home residents and staff who not only had symptoms but who may have had contact with people with the virus.[89]

25. RESPONSE: In the following days DHSC and No 10 determined that it was necessary to make "*significant changes to working practices*" with regard to reducing the movement of agency staff.[90] The Scottish Government issued guidance to that end.[91] The deep dive meeting with the Prime

[82] Hancock [INQ000587746/30 §129] Hancock "Pandemic Diaries" 15.07.20 [M4/INQ000474704/32] Whately [M2/INQ000273897/52 §224] Williams [INQ000571608/27 §7.8]
[83] Vivaldi (July 2020) [INQ000509883/6] Shallcross [INQ000613177/7 §15, 31-36]
[84] DRUK 16.03.20 [INQ000238504/2 §2]
[85] Harries [INQ000587394/22 §5.35]
[86] COVID-19 in care home settings [INQ000325269/8]
[87] Whately [M2/INQ000273897/51 §219] Burns Email 22.04.20 [INQ000198061/3] Marron & Dyson 'B' [INQ000587736/22 §104] PHE Draft Paper 20.04.20 [INQ000325267/2 §5] PHE Interim Paper Easter 6 Study [INQ000120155/1]
[88] Marron & Dyson 'C' [INQ000587737/9 §§25-27] Whitty [M2/INQ000233747/2] Whitty [M2/INQ000282744/3]
[89] COVID-19 in care home settings [INQ000325269/2 §11]
[90] Glassborow Email 22.04.20 [INQ000198061/2] No. 10 Email 25.04.20 [INQ000564742/1]
[91] Mitchell [INQ000475130/108 §382]

Minister on 28 April determined it as "*clear from the evidence that we must do everything we can to stop the movement of staff between care homes – including by providing financial support to workers where that's required*".[92] On 4 May, DHSC was still focussed on a range of labour controls coupled with financial incentives and recruitment drives.[93]

26. RETREAT: The DHSC changed its mind because it was told that the staff controls were too risky and beyond the capacity of the present structure to implement. An email from David Pearson on 5 May referred to 10% vacancy levels and 20% absence, such that staff controls threatened system collapse,[94] and by 6 May it was acknowledged that in a decentralised system with 95% of care home staff unregistered, the national recruitment campaign would do little to plug gaps created by restricting workforce movement.[95] By 8 May, the Secretary of State informed the Prime Minister that the labour pool should be expanded but officials had advised against making the reduction of staff rotation a legal requirement because it was "*fraught with operational risks*", which he summarised as structurally driven, for "*if providers cannot meet the requirement, they would be forced to operate with unsafe staffing levels which in itself may create further health risks or lead to providers exiting the market*". Instead, he would take "*a firm supportive approach*" for the sector to regulate itself.[96]

27. VIVALDI: The Vivaldi study reactivated the issue, when according to Matt Hancock he revived the initiative to reduce staff movement to zero. In response to an Inquiry question, he explains that a situation that was "*fraught with operational risk*" in May 2020 changed in July 2020 because of the gaining of "*detailed scientific knowledge*".[97] However, that "*scientific knowledge*" was there from April 2020 at the latest. The problem was not epistemological, it was economic, a point underscored by the fact that 29% of the workforce in the London care homes study were at work while exhibiting Covid symptoms. The problem was also political, because by July 2020 the number of fatalities in care homes across the four nations was profoundly shocking, and there was greater expectation of more radical state intervention to solve the problem.

28. FURTHER RETREAT: When Whately reached out to ASC sector leaders from Summer 2020 onwards to envisage circumstances where it could be legally compelled to forego its flexible and unregulated staff movement without collapsing, they could not advise on a viable option. What they did advise was to raise or supplement wages to incentivise staff not to work when

[92] Readout 28.04.20 [INQ000564723/2] Annotated Agenda [INQ000198069/3] Actions [INQ000327866]
[93] Roughton Email 04.05.20 [INQ000050345]
[94] Pearson Email 05.05.20 [INQ000050367]
[95] Mins C-19 Strategy Mtg 20(67) 06.05.20 [INQ00022078/4] Email No.10 06.05.20 [INQ000564773] FSS Deep Dive Readout 06.05.20 [INQ000088555]
[96] Hancock-PM, Care Homes and Nosocomial Transmission 08.05.20 [INQ000564753/2 §§6-8]
[97] Hancock [INQ000587746/35 §§155, 166]

symptomatic or subject to contact-and-trace notification.[98] In December 2020, Whately, with her Secretary of State's backing, recommended a furlough type scheme that incentivised, without compelling, workers to no longer to work in two places.[99] Despite the country being in the midst of a devastating second wave, and the recognition by Covid-O of 22 December 2020 that "*[on] stopping staff movement, there was a clear and shared understanding of the need to deliver the policy*",[100] the proposals did not go ahead, due to a fear of staff shortages and a refusal of the Treasury to fund it.[101] In Module 2 the Chancellor of the Exchequer reserved the HMT position as to why this was the case as he was not involved in the decision.[102] The DHSC corporate statement concedes that the alternative option of the £120 million Workforce Capacity Fund for care providers to apply for proved difficult to administer with at least £8.3 million going unspent.[103]

29. OUTCOME: The CMO Technical Report of December 2022 subsequently concluded that future control of transmission in care homes "*depended on alignment*" with the social care system that could overcome the endemic challenges of its unregistered, "*poorly paid and insecurely employed workforce*", with "*its high vacancy rates and poor sick pay provision*".[104] To that must be added the extent to which the same staff were providing domiciliary care, but with even less oversight and support,[105] and by the latter part of 2020 DHSC were concerned that the total number of deaths in domiciliary care were beginning to trend up.[106] Of the four nations, Wales and Northen Ireland introduced enhanced statutory sick pay, but they never paid people to work in one or limited placements.[107] Without state intervention, and specifically greater regulation of labour supply during a pandemic, the system remains structurally destined to be unsafe.

[C] EASEMENTS (IN FORM AND IN SUBSTANCE)

30. IMPACT: DPO contend that the impact of easements was fourfold: (1) The decision to downgrade statutory duties without adequate planning produced a crisis of confidence in service users. (2) The consequence of the statutory imprimatur to modify essential needs-based duties translated into an unaccountable situation where few local authorities utilised easements *in form*, but all authorities were able to operate easements in substance. (3) Reduction of services across the period lacked proper accountability mechanisms to assure proportionality, transparency,

[98] Marron & Dyson 'C' [INQ000587737/118 §465] Pearson submission 29.07.20 [INQ000292663/2 §§7-9, 19-21]: see also Williams (ADASS) [INQ000571608/22 §11.4] ADASS 10.08.20 [INQ000103760/20] Mins Social Care Sector C-19 Support Taskforce 19.08.20 [INQ000152728/3] Smyth [INQ000543049/40 §§212, 215-217]
[99] Whately [M2/INQ000273897/54 §§236-239] Hancock [INQ000587746 /35 §§156-158]
[100] Covid-O Action and Decisions 22.12.20 [M2/INQ000091096/1] Hancock [INQ000587746/36 §159]
[101] Whately [M2/INQ000273897/54§§236 -239] Hancock [INQ000587746 /36 §§160-161]
[102] Sunak [M2/T33/163/21-168/22] [M2/T33/194/5-196/9]
[103] Marron & Dyson 'C' [INQ000587737/106 §§414-415]
[104] Technical Report [INQ000203933/305 §3]
[105] Mallick (DRUK) [INQ000520998/12 §§33, 102] Roughton 14.05.20 [INQ000069265/2-3] Note to PM 14.05.20 [INQ000564754/3 §14] Sweeney Email 14.05.20 [INQ000198090/3]
[106] DHSC Paper for Covid O Meeting 23.10.20 [INQ000090126/2 §4] See also: Minutes COVID-O 23.10.20 [INQ000090302/9]
[107] Davies [INQ000520201/20 §§57-59] Swann [INQ000615082/29 §§73, 181-189]

engagement with DPO and Third Sector, and external monitoring. (4) Critical services that were removed have often not been resumed. For DPO, the evidence of easements in form and substance represent the essence of Disabled people's marginalisation before, during and after the pandemic.

31. MODIFICATIONS: The Coronavirus Act 2020, which became law on 25 March 2020, modified the powers and duties of local authorities in relation to the provision of care and support. The statute extended to England, Wales and Scotland, but not Northern Ireland.

32. ENGLAND & WALES: Under these respective statutory regimes for social care the relevant duties modified were: assessments of an adult's need for care and support, a carer's need for support, and consequential reviews of both of those things. The modification was that the local authority did "*not have to comply with*" these duties.[108] The modifications also affected the core duty to meet an adult's eligible needs for care and support once they had been determined to exist.[109] In England, this was downgraded to a duty to meet needs only if necessary to avoid "*a breach of the adult's [ECHR] rights"*; and in Wales to a duty to meet needs only if necessary to protect the adult from (a risk of) "*abuse or neglect*".[110] The effect was to licence local authorities to prioritise what they reasonably considered to be the most pressing needs and temporarily delay or reduce other care provision.[111]

33. SCOTLAND: Similarly, the assessments duties for adults and carers were modified in Scotland, although with the added caveat that a local authority did not have to comply with these duties if "*(a) it would not be practical to comply with that provision, or (b) to do so would cause unnecessary delay in providing community care services to any person.*" [112] This allowed prioritisation in assessment of adults and carers with new or increased support needs,[113] and delayed assessments and provision of support. Although the core duty to provide previously assessed eligible support needs under section 12 of the Social Work (Scotland) Act 1968 was not modified, Disabled people still had their care reduced or completely withdrawn.[114]

34. PLANNING: The provisions were introduced with minimal debate and process, having been briefly referred to in a 2018 DHSC paper on influenza planning, and contemplated by an ADASS report of the same year which advocated derogations for streamlined servicing based on a threshold test of "*absolute necessity*" and that there should be specified "*floors below which [services] should never fall*". It was regarded as "*vital*" to "*manage any easements and monitor care quality*

[108] Coronavirus Act 2020 Paras 2, 11 Schedule 12 (for England) and Paras 20-24, 31 Schedule 12 (for Wales)
[109] Care Act 2014, s 18 and Social Services and Well-being (Wales) Act 2014 s 35
[110] Coronavirus Act 2020 Para 4 Schedule 12 (for England) and Para 26 Schedule 12 (for Wales)
[111] Marron & Dyson 'C' [INQ000587737/152 §578] Care Act Assessments: Guidance for Local Authorities Updated 01.09.20 ('Guidance'') [INQ000509774/2]
[112] Coronavirus Act 2020 ss 16-17 (for Scotland brought into force 05.04.20)
[113] SG Statutory Guidance [INQ000582761/15 §3.3]
[114] Nolan [INQ000520202/26 §85]

in a controlled and measured way".[115] ADASS' proposals emphasised that easements to normal standards and practices "*will need to be consulted on, planned for and rehearsed in advance to work safely and effectively*" and then subject to a "*national set of criteria and banding*".[116] The provisions were enacted in 2020 without in-depth study of the consequences, including that they were now implemented in conjunction with multiple other easements and lockdowns.[117]

35. PURPOSE: The Government described the overarching objective of easements to enable public authorities to respond to and manage the effects of the pandemic, including the consequences of reduced workforce and increased pressure on its services.[118] While those pressures were of course challenging, they arose because of the State's own failure to plan for them. Instead, the easements empowered local authorities to make *choices* to withhold services that the Legislatures in the Three Nations had previously established as *essential*. For example, in England, eligibility criteria focus on people's basic needs in terms of, for example, hygiene, toileting, nutrition and social contact. Such matters are intrinsic to basic wellbeing as defined in section 1 of the Care Act. The regime is also designed to comply with the State's duties under the UNCRPD.[119]

36. LEGALISATION: The equally important function of easements from the Government's perspective was to protect local authorities from legal action for failing to discharge their statutory duty to meet Disabled people's eligible needs and for failing to act "*in accordance with the law"* for the purposes of Article 8 ECHR.[120] On their face, the provisions contained no threshold for activation. Guidance issued under the Act[121] limited their use to when the local authority's workforce was significantly depleted or demand on social care had increased to an extent that it was "*no longer reasonably practicable for it to comply*" and to do so was "*likely to result in urgent or acute needs not being met, potentially risking life*".[122] However, the Guidance was not subject to Parliamentary debate, the extent to which it was binding was unclear, and contrary to ADASS' 2018 papers, detailed limits were not proscribed and there was no clear criteria or banding to create national standards.[123] Any decision making was conducted under only limited oversight by the CQC, whose routine inspections were suspended, and were only to take a "*pragmatic approach to*

[115] Williams [INQ000571608/55 §31.1] ADASS Report (April 2018) [INQ000080776/1, 4] Marron & Dyson 'C' [INQ000587737/150 §§573-577]
[116] ADASS Proposals (April 2018) [INQ000080777/7, 16]
[117] Mallick [INQ000520998/5 §13, 62, 69] Davies [INQ000520201/36 §109] Nolan [INQ000520202/25 §§83-84] Williams [INQ000571608/57 §13.5]
[118] Marron & Dyson 'C' [INQ000587737/149 §572] Whately [INQ000587788/11 §38]
[119] See: Care and Support Statutory Guidance §1.19; Social Services and Well-being (Wales) Act 2014 Part 2 Code of Practice §54; Social Care (Self-directed Support) Scotland Act 2013 Statutory Guidance pp.5-6; UNCRPD Arts 3, 17, 19
[120] *Macdonald v UK* App. No. 4241/12, 20 May 2014 §§43, 50-52
[121] Coronavirus Act 2020, s 17, paras 18, 35 Schedule 12
[122] Guidance Updated 01.09.20 [INQ000509774/5] Marron & Dyson 'C' [INQ000587737/152 §579]
[123] *Cf*. ADASS Report (April 2018) ADASS Proposals (April 2018) [INQ000080777/16]

inspection" (see §19 above).[124] While the Guidance contained record keeping requirements, there was only limited data upon which an external observer could objectively assess the reasonableness and consequences of any easement decisions.[125]

37. DEFERENCE: Public law principles of judicial restraint based on separation of powers and competence, even in normal times, defer to the reasonable judgment of local authorities over the scarcity of resources and provision of finite services. During the Covid pandemic, it was even less likely that courts would interfere with executive choices concerning emergency conditions.[126] Similarly the reference in the English provision and Guidance to the remaining duty "*to meet needs where failure to do so would breach an individual's human rights under the [ECHR]*"[127] was qualified by the caselaw on Article 8 that also accords deference to executive judgement. In practice, the only way failures to provide care and support could be legally challenged was if the person gained access to court during the pandemic and established that the cessation of their services amounted to inhuman and degrading treatment or risk to life.[128]

38. DOWNGRADE: It remains an extraordinary feature of the pandemic that in three of the four nations one of the very first things that the State did to protect the so-called 'vulnerable' was to ease its essential duties to assess, review and (in England and Wales) meet their needs.[129] "*We passed an act*" lamented Jane Hutt the Welsh Government's Deputy Minister, "*which singles out disabled peoples' most basic rights as something that can be switched off when expedient to do so*."[130] Easements are the paradigm example of the structural and culture dissonance between heath care and social care. They are not the same as pandemic health care decisions to postpone non-essential surgeries or other treatments, in effect a decision to suspend that which was not *needed*. Moreover, the capacity to formally suspend assessments and review services enabled local authorities to forego the very mechanism by which care and support could be accessed.

39. UNACCOUNTABILITY: Between April and June 2020, eight local authorities in England (but none in Wales) triggered the easements.[131] Between May and July 2020, six local authorities were reported to have used the provisions in Scotland.[132] It would be comforting to conclude that is evidence that there was no pressing need for easements and consequently no damage was done. Easements, in fact embodied a greater vice, whereby Local Authorities downgraded essential services with little transparency or accountability, whether the license of statute was

[124] Guidance 01.09.20 [INQ000509774/3]
[125] Guidance 01.09.20 [INQ000509774/6-7] As to lack of transparency see: Mallick [INQ000520998/30 §91] Davies [INQ000520201/7 §§19, 46] *The Impact of Care Act Easements* (2022) [INQ000492905/32-34, 37]
[126] *R (Dolan) v SSHSC* [2020] EWCA Civ 1605 [2021] WLR 2326 §§86-90
[127] Guidance 01.09.20 [INQ000509774/3]. *Cf.* Davies [INQ000520201/36 §109]
[128] *R (McDonald) v RBKC* [2011] UKSC 33 [2011] 4 All ER 881 §§16-18 *Macdonald v UK* Op cit, §§54-58
[129] Sloan [M2C/INQ000396853/14-15]
[130] Hutt-Morgan correspondence 11.11.20 [M2B/INQ000349992] Luxton [M2B/INQ000369755/7 §29]
[131] Mallick [INQ000520998/22 §65] Davies [INQ000520201/39 §117]
[132] McKay et al [INQ000578133/54-55]

used or not. For those Local Authorities that registered easements, there was no follow up system to disclose, publicly and transparently, how, or whether they were used, and no external monitoring of their effect.[133] The Manchester University led study of the issue discovered "*prevailing confusion as to what circumstances, and what changes in social care support, warranted the invocation of easements*."[134] The consequence is that many other authorities suspended or reduced services without triggering easements, because of the "*grey line*" between the provisions and the conduct of the already eroded care system.[135] ADASS also understood that the line between using or not using easements fell under a broader feeling that, "*of necessity*", local authorities were changing how they worked with people in need of care and support.[136]

40. DAMAGE: Across local authorities that invoked easements and those that did not, including in Northen Ireland where the provisions were never enacted, individuals experienced significant changes from their usual care and support, which in many cases resulted in unmet needs, acute distress and suffering, and very poor mental health.[137] In effect a fundamental change of care culture took place. This included: (1) Reduction in services relating to basic hygiene and mobility.[138] (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;[139] (b) services for those with learning disabilities and their families,[140] (c) language and culturally specific provision of (a) and (b) for BAME.[141] (3) Direct payments not reviewed to address inflation and the increase in the national minimum wage, leaving people unable to employ PAs or without guarantee of recoupment.[142] (4) Remote parts of the UK experienced particularly diminished coverage.[143] (5) Day centres and respite services (critical to wellbeing) remained long term closed.[144] (6) Backlog of those waiting for services, direct payments, assessments or reviews peaked at 542,002 and were still at 418,029 in 2024[145]

41. PERMANENCE: The consequence of downgrading services during the emergency is that many of

[133] Mallick [INQ000520998/30 §91] Davies [INQ000520201/7 §§19, 46]
[134] *The Impact of Care Act Easements* (2022) [INQ000492905/34]
[135] Mallick [INQ000520998/22 §65] Davies [INQ000520201/39 §117] Nolan [INQ000520202/10 §30] Abrahams [INQ000509808/12 §35] Rayner [INQ000475131/29 §4.28]
[136] Williams [INQ000571608/56 §13.4]
[137] *The Impact of Care Act Easements* (2022) [INQ000492905/11] Mallick [INQ000520998/12 §35] Nolan [INQ000520202/26 §85] Bottery [INQ000502030/27 §§94-97] Sansome [INQ000520343/15 §§50-55]
[138] Davies [INQ000520201/7 §§17, 20] Nafeh [INQ000587595/18 §§55-58] Nolan [INQ000520202/10 §30] McKay [INQ000578133/94]
[139] Williams [INQ000571608/41 §10.17] Contingency Planning Survey 11.01.22 [INQ000514944/5] Davies [INQ000520201/8 §23] Nafeh [INQ000587595/10 §§28-31] Smith [INQ000576035/39 §155]
[140] Davies [INQ000520201/8 §24-25] Nolan [INQ000520202/13 §41] Hatton & Hastings [INQ000587296/43 §140] Abrahams [INQ000509808/14 §39]
[141] Mallick [INQ000520998/19 §52-55] VODG report [INQ000279963/27]
[142] Nafeh [INQ000587595/12 §§36-38, 73]
[143] Nolan [INQ000520202/13 §42] Inclusion Scotland Report (May 2020) [INQ000184673/1-4]
[144] Green [INQ000585008/15 §40] Nafeh [INQ000587595/9 §28, §75] VODG report [INQ000279963/27]
[145] Williams [INQ000571608/40 §10.14]

them have not returned. Permanent damage includes: (1) Considerable reporting that care packages have not returned to pre-pandemic levels.[146] (2) Particular failure to reinstate socialising elements of care packages.[147] (3) Evidence of failure to restore services to adults with learning disabilities and their families.[148] (4) Certain seminal services closed for good.[149] (5) Failure to proactively audit lost services.[150]

[D] LOCKDOWN (DOMICILIARY CARE)

42. AFTERTHOUGHT: The person that the State primarily imagined when it told people to 'stay at home' was someone who could financially, physically, mentally and safely afford to stay there. Only in afterthought did it imagine the Disabled person who could only do those things with care and support; or the person with care responsibilities who could not leave the home, or absent themselves from work, without leaving a Disabled person in a state of physical or psychological jeopardy as a result of being at home alone.[151] This failure of imagination was embedded in the UK's long-term lack of preparedness for a pandemic, including that when it did contemplate social care, it focussed on care homes, and not domiciliary or supported care settings.[152]

43. CONSEQUENCE: Once social care brought itself more significantly into the Covid-19 plans and guidance after April 2020, insufficient attention was paid to domiciliary care,[153] which bore consequence in the failure to properly consider: (1) Staffing, in terms of the transmission risk it posed and the consequence of its absence. (2) Funding, in terms of the pre-pandemic austerity cuts and pandemic generated increased expenses. (3) Infection prevention control in the home where space (in the post-Bedroom tax era) was at a premium and where staff without PPE were often moving between domiciliary and residential settings. (4) Diversity of the situation of Disabled people and their carers.

44. ASSISTANCE: 'Personal Assistant' ('PA') although not a term of art, generally denotes non-agency permanent employees, paid for privately or out of state direct payments, with the benefits that entails for continuity and quality of support.[154] The pandemic created a labour crisis for all those dependent on domiciliary care, but in particular those who received it through PAs. Factors in the crisis included (a) absenteeism due to illness and shielding; (b) child or other family care commitments; (c) reduction of hours due to social distancing that made it uneconomic to work;

[146] Holzhausen [INQ000587612/14 §33] Cairns [IINQ000576045/16 §§133-134, 149] Hendery [INQ000576037/10 §55] Scottish Care (September 2020) [INQ000223115/3] Nolan [INQ000520202/12 §39]
[147] Nafeh [INQ000587595/11 §33] Macaskill [INQ00509530/27 §§102-104]
[148] Hatton & Hastings [INQ000587296/38 §122, 140, 149-150, 197, 204, 209, 215]
[149] Bottery [INQ000502030/27 §96]
[150] Swann [INQ000615082/172 §555]
[151] DPO M2 2 Opening 26.09.23 [p.22 §4.3]
[152] Module 1 Report pp 104-105 §§5.8-5.10 Exercise Cygnus Report [INQ000056232/8 §4]
[153] For the limited recognition see Harries [INQ000587394/12 §5.6, 5.35, 9.3] Roughton Email 14.05.20 [INQ000069265/2-3]
[154] Nafeh [INQ000587595/2-3 §5, 5.1-5.3]

(d) limited staff in remote rural areas; (e) delay in local authority assessments of direct payments and non-residential community charges that impacted on procurement of extra assistance.[155]

45. RISKS: Combined with risks over scarcity of labour were the countervailing risks of virus transmission from the multi-setting itinerant labour force.[156] PPE was also even less available in domiciliary settings than in care homes.[157] On 15 March 2020 Baroness Campbell of Surbiton, as someone who has 24-hour support from a PA, wrote to Minister Whately to point out that those who employ carers directly with a social or health care personal budget "*cannot simply ring up an agency for cover"* nor could such agency workers, even if available, appropriately replace personal care workers who are highly trained to assist a specific individual. In the belated undated and obviously proforma reply, Campbell was told by the Minister that "*the service user or somebody on their behalf should try to organise alternate arrangements"*. She was then referred to the local authority Care Act 2014 duty to carry out assessments (i.e. which Sch. 12 of the Coronavirus Act modified). The letter ended with the advice that if no such arrangements could be implemented "*this may mean family members stepping in and supporting them to receive the care and support they need*".[158]

46. ABANDONMENT: What followed was abandonment in circumstances where PAs became unavailable with local authorities not in a position to provide contingency measures and Central Government focussed far more on care homes. Dr Jim Elder-Woodward OBE, the Co-Convenor of Inclusion Scotland, used the phrase "*avalanche of issues*" concerning the arrangements of personal assistance; despite all his own connections as an academic and public figure in Scotland, the weight of change brought about by NPIs caused him to suffer nervous and physical breakdown.[159] Banane Nafeh, who worked for the DR UK Helpline, describes how her sister who lived with elderly parents was left without assistants on several occasions such that she had to sleep in her wheelchair and had nobody to wash and care for her when she soiled herself.[160] Across the country, Disabled people or their families engaged in life sustaining practices that they were not trained to administer, or were otherwise impaired in their capacity to do so.[161] Reduced access to PAs also meant reduced access to health care and vaccines.[162]

47. OUTCOME: By May 2021 28,000 recipients of domiciliary care had died across England and Scotland during the pandemic, a greater increase in proportional terms than those who died in

[155] Davies [INQ000520201/10 §77] Lee [INQ000498137/25 §9.10] Nafeh [INQ000587595 §27, 40-41] Mallick [INQ000520998/9 §§25, 27, 29-31, 33] Nolan [INQ000520202 /11 §§35, 38]
[156] Nafeh [INQ000587595/2 §5.3], Mallick [INQ000520998/8 §§23, 34, 102] Davies [INQ000520201 §§77, 82]
[157] Mallick [INQ000520998/11 §32] Davies [INQ000520201/20 §56] Adamson [INQ000474426/7 §§3.18-3.19] Macaskill [INQ00509530/11 §44]
[158] Mallick M6 [INQ000520998/20 §§58-59] Campbell 15.03.20 [INQ000279964] Whately [INQ000273825]
[159] Nolan [INQ000520202/9 §§29, 34] Elder-Woodward [M2A/T2/55/23-58/9] 18.06.2020 [INQ000274175/6]
[160] Nafeh [NQ000587595/18 §§55-58]: see also Davies [INQ000520201/7 §§17, 23-24]
[161] Nolan [INQ000520202/10 §31] Sansome [INQ000520343/16 §53]
[162] Davies [INQ000520201/45 §134] Mallick [M4/INQ000474256/10 §§33-34]

care homes. The figure was probably far higher than that, not least because the CQC only recorded deaths occurring during the provision of care giving services.[163] For the deceased in their time of death and for survivors the extent of abandonment detailed by DPO and Every Story Matters would have caused serious diminishment to quality of life.

[E] UNPAID CARERS

48. PARADOX: The number of unpaid carers and the amount of care they gave increased substantially during the pandemic due to enhanced needs, withdrawal of state services and the fear of allowing outside carers into the home due to the risk of transmission. The paradox of unpaid carers is that they present both the essence of the value of caring and being cared for and at the same time are in dissonance with the modern State that treats that value as a private matter and not something to be integrated and respected as a collective societal good.

49. PROFILE: Part of the paradox is that the State, in its failure to develop carer registers, remains relatively ignorant of the profile and economy of their industry, but the census and the Third Sector can at least express the societal fulcrum that this labour represents.[164] During the pandemic the number of unpaid carers increased by 4.5 million to 13.6 million people.[165] In Wales they amounted to a fifth of the population,[166] in Northern Ireland one person in 8,[167] and 1.1 million people in Scotland.[168] A high proportion were Disabled people.[169] Women considerably outnumbered men.[170] Existing financial insecurity based on austerity cuts for Disabled people that shifted on to carers increased with the pandemic's extra costs and withdrawn services.[171] The value of unpaid care for the year 2021/22 in the UK was worth over £184 billion.[172] Carers Allowance for those who provided more than 35 hours unpaid care a week, was £67.25 (pw) with only Scotland and Wales providing limited supplementary payments.[173]

50. RESPONSIBILITY: This workforce had to discharge grave responsibility without support, resources, recognition or system.[174] Some consequences mirror much of the experience of Disabled people whilst others were specific to the caring role. They suffered from (1) lack of access to PPE and a

[163] Mallick [INQ000520998/8 §22]
[164] Diamond [INQ000553814/60 §218]
[165] Mallick [INQ000520998/9 §§26-28] Carers UK report [INQ000509857/1]
[166] ONS Unpaid care [INQ000503456/2-3] Locked Out Report [INQ000177836/47]
[167] NISRA (2022) [INQ000396812/7, 34]
[168] McKay [INQ000578133/118-119]
[169] ONS 24.04.21 [INQ000509886/2] Nolan [INQ000520202/4 §§13, 49] Davies [INQ000520201/2 §4]
[170] Carers UK [INQ000474580/8] Carers NI [INQ000508170/4]
[171] Davies [INQ000520201/12 §34] Carers NI [INQ000508170/6-7]
[172] Holzhausen [INQ000587612/9 §§17, 101] Carers UK [INQ000574126/6]
[173] Carers UK [INQ000099707/9-10] Holzhausen [INQ000587612/26 §§67-68] Health Foundation [INQ000574187/22] Nolan [INQ000520202/24 §82] Mallick [INQ000520998/37 §§111-112]
[174] Feeley Review (2021) [INQ000280640/14]. *Cf.* limited forethought, see Harries [INQ000587394/12 §§5.6-5.7] JVT Email 18.03.20 [INQ000049727/3] Agrawal [INQ000576001/30 §4.14]

range of risks around infection prevention and social distancing;[175] (2) delayed assessments for support and funding under the modified legislation;[176] (3) minimal other state funding; (4) planning oversight in terms of vaccine prioritisation;[177] and (5) withdrawal of community and other services (or deliberate social distancing from them) that meant (a) more time at home, (b) less respite, (c) extra tasks including lifting and treatment.[178] There was widespread damage to physical and mental health.[179]

51. FUNCTION: In the pandemic unpaid labour filled the gaps in state services and gave life sustaining care in circumstances where pandemic fatalities would have been far higher and the degrading experience of Disabled people and others who required care, would have been far worse. But the capacity of the State to leverage unpaid care is a core reason why the overall ASC system remains fragmented and vulnerable rather than integrated and resilient. Multiple witnesses and sources available to this Inquiry call for a transformation in which unpaid carers and the broader Third Sector must be financed, networked and enabled to be part of the system rather than to be exploited by it.[180] Yet the paradox remains. Unpaid caring – from birth through to grave – is socially reproductive labour. Without it, survival is not possible. It is wholly counterintuitive that the State should devalue and neglect these labours as much as it did both before and during the pandemic. A State that is unresponsive to caring in this way, is not a resilient system.

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

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[175] Mallick [INQ000520998/35 §106] Adamson [INQ000474426/16 §4.25] Davies [INQ000520201/20 §56] Sansome [INQ000520343/16 §54] Nolan [INQ000520202/20 §§69, 103 105, 118]
[176] McKay [INQ000578133/133-135]
[177] Kasstan-Dabush & Chantler [M4/INQ000474623/20 §§49-54] Williams [INQ000571608/69 §14.17]
[178] Nafeh [INQ000587595/9 §28] Mallick [INQ000520998/10 §27] Nolan [INQ000520202/10 §§31, 33] Sansome [INQ000520343/16 §53] Davies [INQ000520201/27 §§82, 118] Care Rights UK [INQ000514104/10 §29] Hayo [INQ000509894/22 §§9.1.1-9.1.2] Nuffield (May 23) [INQ000553858/61-64]
[179] Davies [INQ000520201/11 §§32-33] Nolan [INQ000520202/17 §60] Abrahams [INQ000509808/40 §106] Carers NI [INQ000508170/11-12] Hatton & Hastings [INQ000587296/54 §198] McKay [INQ000578133/127-130]
[180] Feeley Review (2021) [INQ000280640/6, 37] McHugh [INQ000475047/25 §106] Mallick [INQ000520998/43 §129(b)] Davies [INQ000520201/11 §§32-33] Nolan [INQ000520202/42 §152] Sansome [INQ000520343/36 §117(b)] Hatton & Hastings [INQ000587296/61 §219(h)] : for DPO status see also Mallick [INQ000520998/36 §109] Sansome [INQ000520343/19 §60-61] Elder-Woodward [M2A/INQ000371664/22 §112] Davies [M2B/INQ000410946/44 §115]