

**COVID-19 INQUIRY  
M6 SECOND PRELIMINARY HEARING**

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**SUBMISSIONS ON BEHALF OF DISABLED PEOPLE’S ORGANISATIONS (DPO):  
DISABILITY RIGHTS UK, DISABILITY WALES, INCLUSION SCOTLAND  
DISABILITY ACTION NORTHERN IRELAND**

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Further to the Chair’s Ruling of 12 April 2024 following the first Preliminary Hearing on 19 March 2024 (“**Ruling**”), Counsel to the Inquiry Note for the second Preliminary Hearing dated 13 January 2025 (“**CTI Note**”), the provisional list of issues (“**LOI**”) and the proposed hearing agenda, the following brief submissions address: **[I]** Care Settings, **[II]** Key Decisions, **[III]** Deaths, **[IV]** Evidence & Experts

**[I] CARE SETTINGS**

1.1. SUPPORTED ACCOMMODATION: DPO welcome the Chair’s Ruling that the Inquiry will examine the impact of the pandemic on additional groups of people in receipt of social care, such as those with learning disabilities: Ruling §7. It is estimated that a quarter of adults with learning disabilities in England who receive long-term social care live in supported accommodation. Adults with learning disabilities also draw on a wide variety of social care services, including social workers, day services and short break / respite services. A key failing during the pandemic was a lack of comprehension and consideration by key decision makers of the full range of adult social care support, beyond care home residential settings and domiciliary care. By considering additional groups that access a range of adult social care services, the Inquiry will avoid replicating the same error and ensure essential lessons are learned across the whole Care Sector.

1.2. OTHER GROUPS OF DISABLED PEOPLE: In keeping with the openness to consider different aspects of Disabled people’s experience during the pandemic, DPO upon consideration of what would be most relevant invite the Inquiry to examine the impact of the pandemic on:

1.2.1. ADULTS WITH CEREBRAL PALSY: As a cohort adults with cerebral palsy (CP) access a range of adult social care services, including Personal Assistant (PA) support for physical and other impairments. Access to PAs is a fundamental feature of Disabled people’s enjoyment of human dignity and human rights, including independent living pursuant to Article 19 of the UNCRPD. The inquiry heard evidence in Module 2A from Dr Jim Elder-Woodward OBE, the Co-Convenor of

Inclusion Scotland, who 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, such that the weight of change brought about by NPIs caused him to suffer nervous and physical breakdown.<sup>1</sup> In Module 4 the Inquiry has also heard that there was insufficient consideration of PAs in the vaccine rollout, despite PAs forming part of the frontline social care workforce for Disabled people.<sup>2</sup> DPO therefore regard consideration of the role of PAs within the adult social care sector within Module 6 as a crucial matter.<sup>3</sup>

1.2.2. AUTISTIC PEOPLE: Again, during Module 4 the Inquiry has received evidence that there are an estimated 700,000 people in England diagnosed with autism.<sup>4</sup> Autistic people vary greatly in their support needs. Some people live independently but others need support with certain tasks or need 24-hour specialist support.<sup>5</sup> As a cohort, autistic people have much higher rates of co-occurring psychiatric conditions than the general population. Research by the National Autistic Society in 2020 found that the Covid-19 pandemic had made this situation considerably worse, with nine out of ten autistic people worried about their mental health during lockdown.<sup>6</sup> Autistic people are particularly vulnerable to admission to mental health settings and Assessment and Treatment Units. The withdrawal of mental health and social care services during the pandemic left many autistic people without the support they needed to adapt, against a background that the number of autistic people identified in mental health hospitals in England has increased.<sup>7</sup> DPO reiterate that Module 6 should receive evidence about the impact of the pandemic on autistic people and their families.<sup>8</sup>

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<sup>1</sup> DPO Oral Closing Submissions [M2A/T12/91/21-92/8] Jim Elder-Woodward [M2A/T2/55/23-58/9] Elder-Woodward Narrative Summary 18.06.2020 [M2A/INQ000274175/6]

<sup>2</sup> Mallick [M4/INQ000474256/10 §§33-34]

<sup>3</sup> Baroness Campbell of Surbiton, as someone who does not have cerebral palsy but has 24-hour support from a Personal Assistant, wrote to Minister Whately and others on 15 March 2020 at the outset of the crisis to warn that her situation could be overlooked, “*Because we are not seen as part of the professional care infrastructure (nursing homes, agencies, NHS staff) we have been effectively ignored.*” Mallick [M2/INQ000280035/8 §21] [M2/INQ000279964] Mallick [INQ000520998/11 §§30-39]

<sup>4</sup> Russell [M4/INQ000474228/153 §553]

<sup>5</sup> National Autistic Society, *Social care for adults in England*, [Available online](#)

<sup>6</sup> National Autistic Society, *Left stranded: The impact of coronavirus on autistic people and their families in the UK* (2020), p.5, [Available online](#)

<sup>7</sup> Id.

<sup>8</sup> DPO Submissions M6 Preliminary Hearing, 11 March 2024, p.9 §4.2(5)

## [II] KEY DECISIONS

### DOWNGRADING OF SERVICES WITHOUT ACCOUNTABILITY

- 2.1. EASEMENTS: The provisions in the Coronavirus Act, which became law on 25 March 2020, resulted in the established statutory needs of Disabled people to obtain social care and mental health services being reduced through ‘easements’ to Local Authority duties.<sup>9</sup> Between April and June 2020, eight local authorities with adult social care responsibilities in England (but none in Wales) triggered ‘easements’ that permitted them to cease formal Care Act assessments and reviews, and permitted whole system prioritisation of need. This protected local authorities from legal action for failure to comply with their statutory duties. Although government maintained that local authorities still had “*to meet everyone's Human Rights as an absolute minimum*”,<sup>10</sup> in practice that meant the only way easements could legally be challenged was if the person was able to go to court and establish that the cessation of their care would amount to inhuman and degrading treatment.<sup>11</sup>
- 2.2. ACCOUNTABILITY: It remains an extraordinary feature of the pandemic that in three of the four nations of the UK the very first thing that the state did to protect the so-called ‘vulnerable’ was to ease its duties in relation to them. The dispiriting dimension of the matter will now be obvious to the Inquiry. However, it is the consequence of the legislation, including the transparency and monitoring of decisions made under it, that requires consideration. In effect, services were downgraded with little accountability. The system was introduced with minimal debate and process. For those Local Authorities that registered easements, there was no follow up system to disclose how, or whether they were used, and no external monitoring of their effect.<sup>12</sup> Moreover, as DR UK emphasises, many other authorities suspended or reduced services without triggering easements.<sup>13</sup> Across local authorities that invoked easements and those that did not, individuals experienced significant changes from their usual care and support, which in many cases resulted in unmet needs - including of tasks for basic hygiene - acute distress and suffering, and very

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<sup>9</sup> Coronavirus Act 2020 Schedules 8 and 12: see M2 DPO Closing Statement p.8 §13; M2B DPO Opening Statement p.9 §3.10

<sup>10</sup> Tomlinson [M2/INQ000233735/24 §79] Letter from Tomlinson 26 March 2020 [M2/INQ000187624] Mallick [M2/INQ000280035/30 §96]

<sup>11</sup> *R (McDonald) v Royal Borough of Kensington and Chelsea* [2011] UKSC 33 [2011] 4 All ER 881 §18

<sup>12</sup> Kamran Mallick [INQ000520998/30 §91]

<sup>13</sup> Kamran Mallick [INQ000520998/22 §65]: e.g. Think Local Act Personal, ‘*A Telling Experience - understanding the impact of Covid-19 on people who access care and support - a rapid evidence review with recommendations*’ (October 2020) [INQ000509867/8]

poor mental health.<sup>14</sup> 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.*”<sup>15</sup>

2.3. ISSUES: DPO therefore invite the Inquiry to address (1) the decision to introduce ‘easements’ to Local Authority duties in respect of social care and mental health services, (2) the consequential approach of Local Authorities to formally utilise ‘easements’ and/or significantly reduce social care provision, without using the benefit of the easements, and (3) whether reduction of services was sufficiently proportionate, transparent, or consulted upon, including with DPO, and externally monitored.

### **ENGAGEMENT**

2.4. CONSULTATION: In considering the adequacy of communication, consultation and engagement in respect of key decision-making and guidance (LOI §3(c)) it is important to consider not just social care providers, but also social care users and their representative organisations, including DPO. Social services across the UK had committed to principles of co-production in partnership with service users in their guidance documents<sup>16</sup> but failed to live up to these commitments during the height of the pandemic. By way of example, DR UK wrote to the Directors of Adult Social Care Services on 3 April 2020 in respect of Care Act ‘easements’, asking any director of social care to consult with DPO in the local area before making any decisions, to ensure that through improved co-production social care directors could “*gain insight and understanding of lived experience, which will enable person-centred solutions to be found.*”<sup>17</sup> The response received on 8 April 2020 was disappointingly brief<sup>18</sup> and a further offer to engage went unanswered.<sup>19</sup>

2.5. HUMAN RIGHTS: DPO continue to encourage the Inquiry to utilise the tools of Human Rights analysis to assist its examination of government policies and decision making, by reference to Art 4(3) UNCRPD (close consultation and active involvement with Disabled people and their representative organisations in decisions).

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<sup>14</sup> University of Manchester and NIHR, *The Impact of Care Act Easements* (2022) [INQ000492905/7, 11]

<sup>15</sup> Ibid [INQ000492905/34]

<sup>16</sup> Adult Social Care Services during the Covid-19 Pandemic [M2B/INQ000350818/3-4]

<sup>17</sup> Letter from DR UK sent to Local Authority Directors of Social Care on 3 April 2020 Mallick [M2/INQ000280035/9 §27] and Ex. KM/13 [M2/INQ000238541]

<sup>18</sup> Letter from Julie Ogleby 08 April 2020 [M2/INQ000238490]

<sup>19</sup> Letter from Kamran Mallick 15 April 2020 [M2/INQ000238491]; Mallick [INQ000520998/30 §90]

### [III] DEATHS

3.1. DOMICILIARY CARE: DPO welcome the intended focus of the Inquiry on the management of the pandemic in adult residential and nursing homes, failures of which contributed to the shocking mortality rates in those settings (LOI §4). DPO invite the Inquiry, in considering available statistics on the number of people within the Adult Care Sector who died, to also scrutinise carefully the reasons why large numbers of recipients of domiciliary care died during the pandemic. By May 2021, approximately 28,000 recipients of care in their homes had died across England and Scotland during the pandemic,<sup>20</sup> a greater increase in proportional terms than those who died in care homes.<sup>21</sup> As noted by the Bureau of Investigative Journalism, these figures are likely to be incomplete as they only include deaths reported to the CQC, which by law is only required if a person dies as a result of their care or if a care worker was in the home at the time.<sup>22</sup> The personal experiences behind each of these shocking figures must be learned from so that they are not repeated in future health emergencies.

### [IV] EVIDENCE & EXPERTS

4.1. PROPOSED RULE 9 REQUESTS: In addition to the suggestions made by DPO at the first Preliminary Hearing,<sup>23</sup> DPO suggest that Rule 9 requests are issued to the following organisations requesting information as to the impact of the pandemic on their constituent groups:

4.1.1. **Inclusion London**: Inclusion London was established in 2008 and supports over 70 Deaf and Disabled People's Organisations in London. The organisation has authored several reports highlighting the inequalities suffered by Disabled people that were exacerbated during the pandemic and given its reach can provide evidence relevant to the impact of the pandemic on the Adult Social Care Sector in London including related to the deaths of Disabled people who receive domiciliary care and the situation faced by those who have Personal Assistants.

4.1.2. **Cerebral Palsy Scotland**: Cerebral Palsy Scotland was founded over twenty-five years ago and advocates for the CP community to have life-long access to knowledgeable, compassionate services and support. They could provide evidence on the impact of the pandemic on people with CP across a range of care settings

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<sup>20</sup> The Bureau of Investigative Journalism, 10 May 2021 [INQ000509854/1]

<sup>21</sup> The Health Foundation Briefing, 1 July 2020 [INQ000509820/8]

<sup>22</sup> The Bureau of Investigative Journalism, 10 May 2021 [INQ000509854/2]

<sup>23</sup> DPO Submissions M6 Preliminary Hearing, 11 March 2024, p.9 §4.2

including those who have PAs. The organisation has undertaken three surveys of the CP community to better understand the impact Covid-19 restrictions had on people with CP and their families.<sup>24</sup>

4.1.3. **The Centre for Independent Living Northern Ireland:** This organisation prepared guidance for people receiving Direct Payments during the pandemic and can provide evidence on the impact of the pandemic on those people and their PAs.

4.1.4. **The Adult Cerebral Palsy ('UP') Movement:** This organisation raises awareness of issues impacting adults with CP and can provide evidence on the impact of the pandemic upon them.

4.2. RULE 9 REQUESTS ALREADY ISSUED: In respect of the Rule 9 requests already issued, DPO suggest:

4.2.1. In respect of the **DHSC**, the Inquiry is invited to probe the limited membership of the Ministerial Oversight Group (MOG), the lack of consultation and coproduction with Disabled people, and the MOG's unexplained cessation of work after May 2022<sup>25</sup> (relevant to LOI §5b).

4.2.2. In respect of the **CQC**, the Inquiry is invited to explore the data available in respect of deaths for those receiving care in their homes, the limits of that data and the reasons for this, and the reasons why so many people receiving care in their homes died during the pandemic.

4.3. EXPERTS: With regard to proposed areas of expert evidence:

4.3.1. DPO endorse the proposal in Counsel to the Inquiry's Note for the First Preliminary Hearing §33(a) that the Inquiry would be assisted by expert evidence as to the structure of social care arrangements in each of the four nations. **Professor Mark Llewellyn**, Director of the Welsh Institute for Health and Social Care, and Professor of Health and Care Policy at the University of South Wales, could be a suitable expert for Wales; **Derek Feeley**, who completed the Review of Adult Social Services in Scotland which reported in 2021, could be a suitable expert for Scotland; and **Professor Deirdre Heenan** and **Professor Derek Birrell**, Professors of Social Policy, Ulster University could be suitable experts for Northern Ireland. DPO could assist with providing a full list of possible experts for each nation or commenting on any such list provided by CTI at a later date.

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<sup>24</sup> Cerebral Palsy Scotland, *The Impact of Covid on People with CP*, [Available online](#)

<sup>25</sup> See: [MOG Terms of Reference](#); [MOG Meeting Summary Notes](#), 17 May 2022, p. 2. Despite determining the MOG should meet again to address outstanding CQC recommendations, no further meeting was convened.

4.3.2. Expert evidence as to the impact of the pandemic on those with learning disabilities and dementia has been obtained in draft. DPO – without endorsing an impairment led approach to obtaining evidence – invite the Inquiry to obtain expert evidence on the impact of the pandemic on people with physical impairments, people with sensory impairments, and people with multiple or complex needs (e.g. catheter care; peg feeding; breathing apparatus; assisted communication).

4.4. IMPACT EVIDENCE: In respect of CTI Note §15 as to how impact evidence can be obtained in a sensitive but proportionate way, DPO suggest that this should be achieved through the Every Story Matters ('ESM') process in addition to the manner proposed. In this regard, it is necessary to enable submissions through video recordings without the need to first complete an on-line form to ensure equal access to ESM for the d/Deaf community who use BSL and for the wider Disabled community who will otherwise be unable to tell their stories in writing, in person or via the phone-line. Moreover, specific outreach work, sending 'listeners' to meet with people who have complex disabilities in environments in which they are comfortable, is necessary to (for example), ensure that people with learning disabilities, cognitive issues or who cannot otherwise use digital methods or a phone line can participate. DPO consider ESM should be prioritised to ensure a full range of impact evidence is obtained. DPO actively invite contact for them to be of any assistance in supporting use of the ESM in this module to gather impact evidence.