Witness Name: Mark Hodgkinson
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Exhibits:
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UK COVID-19 INQUIRY - MODULE 6

WITNESS STATEMENT OF DISABILITY CHARITIES CONSORTIUM (DCC)

I, Mark Hodgkinson, Co-Chair of the Disability Charities Consortium and Chief Executive of Scope, Here East Press Centre, 14 East Bay Lane, London E15 2GW, will say as follows : -

1. Overview of the Disability Charities Consortium

1.1 The Disability Charities Consortium (DCC) brings together Chief Executives and policy leads from nine of the UK's leading not-for-profit disability organisations. We make sure disabled people's experiences are reflected in UK policy making, by working collaboratively to influence the Westminster Government (MH/01-INQ000496098).

1.2 The DCC's members are: Business Disability Forum (BDF), Leonard Cheshire, National Autistic Society, Mencap, Mind, Royal National Society for Deaf people (RNID), Royal National Society of Blind people (RNIB), Scope, and Sense.

1.3 The DCC feeds insights and topical concerns into the Disability Unit, within the Cabinet Office, to help inform disability related policy development.

1.4 DCC member CEOs regularly meet with senior officials in the Disability Unit, the Minister for Disabled People (MfDP) and other key ministers.

1.5 DCC member policy leads regularly engage with the Unit's stakeholder engagement team.

1.6 In relation to module 6 it is important to note that some DCC members do not provide social care services (RNIB, Mind, Business Disability Forum, Scope). However, some members, such as RNIB and Scope did seek to influence government and agencies around social care support and provision. Others, such as Mind and BDF did not, and worked on other issues outside of module 6. Our responses to the Inquiry's questions therefore feature responses from different DCC members, depending on whether they were delivering social care services and/or whether they were seeking to influence pandemic related policy around social care support and provision.

2. DCC members and their role in delivering social care services and campaigning around care and support.

2.1 Below, we have set out more information about DCC members who provide social care services, or who seek to influence national and local policy and provision around such services, and therefore whose work has direct relevant to module 6.

2.2 Royal National Institute of Blind People (RNIB)

The charity works across the four UK nations. It does not have any care services, but campaigns on social care and rehabilitation support for blind and partially sighted people.

2.3 National Autistic Society (NAS)

The charity works across the four UK nations. It provides adult social care services to around 640 autistic adults across the UK, many of whom also have a learning disability. Services include: residential care, supported living, day services and outreach. The average number of staff in the National Autistic Society in FY22-23 was 2,469. In financial year 21-22 it was 2,527; in financial year 20-21: 2,706 and financial year 19-20: 2,910.

2.4 Royal National Institue for Deaf People (RNID)

The charity works in all four countries of the UK. The charity rebranded back to RNID from Action on Hearing Loss in November 2020, so some items below will refer to different names. The charity does not have any care services.

2.5 Sense (The National Deafblind and Rubella association)

Sense works across England, Wales and Northern Ireland.

2.5.1 The charity has 41 residential services (40 in in England, 1 in Northern Ireland) and 29 supported living services (26 in England, 2 in Northern Ireland, 1 in Wales). The charity has day services across 19 locations/Sense centres. It provides adult social care day services via 9 locations of Sense College. It also has Community based support in the form of communicator guides and intervenor services.

2.5.2 In 2023/24, the charity supported **341** people in its accommodation services. **626** people accessed either a day opportunity, individual support or both through 10 Sense Centres. The charity's specialist college sites worked with **356** young people and adults.

2.5.3 In 2020/21 the charity

- supported 335 people in accommodation services in 71 registered care services and 23 supported living services in England, Wales and Northern Ireland.
- supported 674 people through day services, attending 9 resource centres, or using Communicator Guides, Interveners and other community services.
- 226 people receiving services through nine college sites.

2.5.4 In 2021/22:

- In partnership with local and education authorities, the charity supported **335** people in accommodation services, and **542** people accessing day and community services through **10** Sense Centres.
- The charity's **9** specialist college sites worked with **322** young people and adults.

2.5.5 Sense supports people with complex disabilities (people with complex disabilities tend to have two or more of the following: Deafness or hearing impairment; Blindness or vision impairment; Learning disability; Autism), including those who are deafblind.

2.5.6 There are 1.6 million people in the UK with complex disabilities. They may have other needs as well. Most of the people the charity supports need significant or constant care in their daily lives.

2.5.7 Some of the people Sense supports have had complex disabilities from birth. Others have developed complex needs due to illness, injury or ageing.

2.5.8 The charity employs a range of staff from support workers to registered care managers and more senior social care staff. The organisation has a practice development team who provide bespoke support for individuals and staff teams working with them, as well as a team of Identity, Sexuality and Relationships advisors who support services and the people who the organisation supports. In the charity's community based teams there are intervenors and communicator guides.

2.6 Royal Mencap Society

There are 1.5 million people with a learning disability across the UK. Mencap works across England, Wales and Northern Ireland. The organisation has over 7,000 staff directly providing support to nearly 4,000 people with a learning disability. This is mainly in supported living settings, but the charity also has a small number of residential care services that it has taken over from other providers. Mencap has a total average staff number of 7,534 across all functions. The organisation also supports 104 children in its early years centre in Belfast. As well as providing social care support, the organisation provides advice and casework services on social care to people with a learning disability and their families via its helplines. Mencap also provides employment support to enable people with a learning disability to move towards, into and sustain work.

2.7 Scope

Scope is registered to work across all four UK nations, but at the time of the pandemic worked in England and Wales. The charity provides advice, information and emotional support to disabled people, as well as campaigning to create a fairer society.

2.8 Leonard Cheshire

2.8.1 As of 31 March 2023 (most recent full year reporting) 1,673 people were supported every day through Leonard Cheshire's care services. The organisation has 62 residential services (care and nursing homes) and 36 supported living services. During the first year of the pandemic the organisation supported over 3,000 disabled people living in its UK residential services.

2.8.2 Leonard Cheshire provides care support to people with wide-ranging physical and learning disabilities, sensory impairments and/or long-term health conditions.

2.8.3 As of 31 March 2023, the organisation employed 4,479 people, with 92% being employed in frontline social care or support roles.

2.8.4 (2021-22)

As of 31 March 2022 the charity supported 2,266 people through its care services- 69 residential services (care and nursing homes) and 56 supported living services and employed around 5,000 people. The average monthly headcount during 2021-22 was 5,004 staff (2021: 5,246 staff).

2.8.5 (2020-21)

As of 31 March 2021 the charity supported 2,587 people through its care services - 71 residential services (care and nursing homes) and 53 supported living services. The charity employed around 5,200 people. The average monthly headcount during 2020-21 was 5,246 staff (2020: 5,587 staff)).

3. How DCC operated as a coalition during the pandemic

3.1 As DCC is a collaborative coalition, with limited secretariat support, work undertaken by the coalition is driven by its members working together, with some limited support provided by a jointly funded part-time secretariat. During the pandemic, there was peer support between the organisations, with its policy group meeting regularly to exchange information and developments around national policy relating to the pandemic. The Chief Executives group also met to discuss similar issues. Some DCC members are also part of other social care sector specific coalitions, such as the Voluntary Organisations Disability Group and the National Care Forum.

4. Overview of government departments, agencies and advisory bodies that DCC members worked with.

4.1 Scope

Lobbied, liaised and worked with DWP and Cabinet Office (Disability Unit) in particular, as well as No.10 policy staff, DEFRA (at the time) on food and supermarkets and DHSC on shielding and advice.

4.2 Sense

4.2.1 The charity worked with DHSC, NHS England, PHE and CQC. The organisation attended regular stakeholder calls with the DCMO teams, vaccination teams and others. The charity also worked with the Disability Unit and DfE.

4.2.2 On a ministerial level-

- (DWP) Minister for Disabled people (Justin Tomlinson MP)
- DHSC Social Care Minister (Helen Whately MP, as well as Matt Hancock MP. There were regular stakeholder sessions with Helen Whately that other DCC members attended.
- Vaccines Minister (Nadhim Zahawi MP).
- Labour Shadow teams, including Vicky Foxcroft (Shadow Minister for Disabled People) and Liz Kendall (Shadow social care minister).

4.2.3 On a local level staff were engaging with local authorities/commissioners on individual issues. There was significant variation in terms of engagement, interpretation of guidance and understanding of the services the organisation provided.

4.2.4 There were also the local groups that were set up to support with infection control, eg PPE distribution groups.

4.3 RNID

4.3.1 RNID worked with other organisations, in and out of DCC, to make representations to the Cabinet Office (MH/02-INQ000496106) regarding the accessibility of Government communications during Covid, particularly the provision of BSL interpreters at the daily

No.10 press conferences. Although not directly related to social care provision, a number of relevant announcements and pieces of public information around social care were miscommunicated in this way.

4.3.2 RNID lobbied PHE and NHS England about the accessibility of its messaging and social media content, which included a meeting with the Chief Nursing Officer, Ruth May, in July 2020.

4.3.3 RNID lobbied DHSC around the provision of clear face masks (MH/03-INQ000505529), both for the NHS but also for publicly funded social care. Although much of the decision making on this issue sat with individual Trusts and CCGs, RNID did not lobby them, instead focusing on national level engagement with DHSC.

4.4 RNIB

4.4.1 RNIB has engaged with the UK Government, Welsh Government and NI Executive at points throughout the period covered by the inquiry, as well as local authorities and health bodies, through our national, regional and devolved nation teams.

4.4.2 In our own right and via the DCC we attended stakeholder briefings with civil servants, the Deputy Chief Medical Officer and the Minister for Social Care and RNIB was part of other sector coalition and consortia including the Care and Support Alliance (CSA).

4.5 NAS

National Autistic Society worked with officials at DHSC, NHSE, Cabinet Office, DEFRA and the Scottish Government

4.6 Leonard Cheshire

4.6.1 At the beginning of the pandemic, the organisation wrote to 50 English MPs with a Leonard Cheshire service in their constituency to raise concerns that care homes for disabled people were unable to access Covid-19 tests MH/04- INQ000505522). Multiple MPs responded with advice and/or commitments to escalate concerns. Laura Trott, MP for Sevenoaks and Swanley, raised this with the Secretary of State for Health and Social

Care [see Hansard - Covid-19 Response Volume 676: debated on Tuesday 2 June 2020.

4.6.2 Laura Trott MP said *"I welcome the progress that has been made on testing, but I have a specific case of a care home in my constituency that caters for people with disabilities. Because the residents are typically under 65 and do not have dementia, they do not have access to testing in the same way those in other care homes do. Could the Secretary of State look into this case?"*

4.6.3 The Secretary of State confirmed he would look into the case. Within a week, testing was made available to care homes in all adult settings, including those with residents with disabilities. This was a vital step in helping us further support the people who live in our services as well as our frontline staff.

4.6.4 "I was deeply concerned to hear about the challenges the Leonard Cheshire service at Chipstead Lake was facing in accessing testing kits. I hope this will provide much needed support to staff and residents, as well as the 6,000 similar care homes across the country, and I pay tribute to the staff who do such an incredible job every day." Laura Trott MP for Sevenoaks and Swanley

4.6.5 The organisation met Minister for Care, Helen Whately MP, on 5 March 2020.

4.6.6 There was ongoing liaison with local authorities where the organisation had services, including attempts to negotiate fee uplifts to reflect additional costs of social care delivery.

4.6.7 The organisation also engaged with Public Health England via Service Managers to report a Covid-19 outbreak. It should be noted that the reporting requirements for PHE, and each CCG and Local Authority where it works also differed, with different requirements for the devolved administrations.

4.7 Mencap

4.7.1 The charity had significant engagement with PHE, as well as DHSC ministers around vaccine rollout, and the prioritisation given to supported living settings within the overall context of 'care homes', which did not adequately encompass the range of regulated care provision. Similar enagagement also took place around policy relating to visiting care settings, and other issues, such as people we support being able to visit and stay with family members.

4.7.2 There was ongoing engagement with the Neuodiversity & Disability department within DHSC, as well as NHS England, particularly the learning disability & autism programme, regarding accessibility of policy and guidance, and how this impacted on people with a learning disability and family members and staff supporting them.

4.7.3 The charity had significant engagement with NICE around the impact of their rapid guidance on access to acute care, and on this issue CQC, NHSE and DHSC.

4.7.4 As with other DCC colleagues, Mencap took part in meetings with the Minister for Disabled People, addressing cross government issues.

5. Submissions and representations provided by DCC members

5.1 Scope

- Co-ordination and submission of a number of 'open letters' supported by the DCC/others in the disability sector on the need for the Westminster government to prioritise disabled people.
- The publication of research into the experiences of disabled people during lockdown (MH/05-INQ000216430) with intention of influencing national policy on advice and support for disabled households

5.2 Sense

- Sense MP Briefing – Disabled people & Social Care during COVID19 (August 2020). (MH/06-INQ000496104).

- Social Care Funding & Workforce (Health and Social Care Select Committee submission (June 2020) (MH/07-INQ000496105).

- Letter to Health Minister, Matt Hancock MP, on testing in supported living settings (July 2020).

- October 2020: MP briefing, disabled people and covid-19 (MH/08-INQ000496101).

- November 2020, submission to Health and Social Care and Science and Technology Select Committees Joint Inquiry (MH/09-INQ000496102)

5.3 RNID

- Women and Equalities Select Committee: Written Evidence (MH/10-INQ000496100, and MH/11-INQ000496096).

5.4 NAS

5.4.1 The charity shared the findings of its Left Stranded report (full report supplied) to the Department of Health and Social Care, which included:

- Compared to the general public, autistic people in June and July were seven times more likely to be chronically lonely; and six times more likely to have low life satisfaction
- Those requiring support all of the time were significantly more affected by lockdown.
- One in five family members had to reduce work due to caring responsibilities.

5.4.2 Visiting Guidance:

- During December 2020, the charity expressed concern to DHSC about the impact of guidance relating to visits out of care homes. This applied to people the charity supported being able to visit their families over Christmas. Guidance required a period of isolation upon returning that would not be possible to achieve without causing serious distress to the people supported.

5.4.3 Mask wearing:

- Raised concerns about inconsistent practice in NHS establishments to NHSE regarding the requirement of masks to be worn.

5.4.4 Adult Social Care Strategy Draft

- Invited by DHSC (David Nuttall, Deputy Director for Neurodiversity & Disability) to comment on draft Adult Social Care Strategy draft on 11/04/2020. Comments included concerns about the rigour of the Ethical Framework around Care Act easements. NAS called for more guidance on how to prioritise needs.

5.4.5 Regular Autism and Learning Disability Webinars (NHSE)

- These were set up as regular calls with charities across autism and learning disability to raise issues.

Structure and capacity of the adult social care sector

6. Concerns about the pre-pandemic funding and capacity of adult social care, and the impact this had on the sector's ability to respond to the pandemic.

6.1 Skills for Care recorded that before COVID-19, there were 122,000 vacancies in adult social care in any one day. This rose further to a historic high vacancy rate of 10.7% in 2021/2 before dropping gradually driven by a change to government immigration policy in February 2022 leading to a sharp increase in recruitment of overseas care workers. The Kings Fund reports that the number of UK domestic workers fell by 30,000 over this period, and pay remains a significant factor in domestic recruitment.

6.2 Sense repeatedly briefed and campaigned on the pressures on social care before the pandemic, focussing on chronic underfunding, workforce pressures and a lack of understanding about what social care is and who it supports. The charity, pre-pandemic, was already seeing care packages reduced, prioritisation going to those with the highest need and a significant reduction in anything low level/community based.

6.3 Before COVID-19, social care faced a funding gap of £810 million in 2020/21 rising to £3.9 billion in 2024/25.[1] LGA now estimate that despite the additional £.3.2bn support from Government that Local Authorities will still face a social care funding shortfall of £3.5 billion due to the coronavirus pandemic.[2] This situation reveals that the systematic underfunding of the social care sector left a system vulnerable to the pressures of a pandemic.

6.4 In its 2019 inquiry with the All Party Parliamentary Group on Autism, NAS found that:

- 71% autistic people said they weren't getting the support they needed
- Only 10% autistic adults felt that social workers understood autism
- There were significant gaps between the support people needed and the support they received.

6.5 Leonard Cheshire, in a written submission to the 2020 Public services Committee Lessons from coronavirus inquiry, emphasised that pre-Covid, the adult social care sector had faced significant financial pressures due to staffing. As a care provider, Leonard Cheshire's biggest funding challenge is meeting the year-on-year cost increases related to wage inflation. Increasingly, the organisation did not receive sufficient funds to support these cost increases: out of a total of 322 purchasers of the charity's care services across UK local authorities and Clinical Commissioning Groups, 52 had not budgeted for any inflationary increase in costs over the last 5 years. The Competition and Marketing Authority's industry-wide analysis of nursing and residential care illustrates that staff costs account for over half of residential and nursing home costs. Leonard Cheshire therefore called for funding to be available to ensure that care staff receive proper recognition and fair wages as often providers are not appropriately funded to do so. In 2024, we are still yet to see the situation solved.

6.6 The LGA estimated additional staffing costs due to the pandemic to be £1.018 billion up to the end of September 2020. This covers the increased staffing costs across care homes, supported living and home care and incorporates the costs of recruiting workers to cover for staff who were off sick or self-isolating. Leonard Cheshire launched its own recruitment drive to backfill roles during the pandemic, with 28 new staff members recruited. The charity also redeployed staff to work in care homes to fill temporary vacancies caused by staff self-isolating and set up a PPE distribution network, operated by re-deployed staff. In total, 1,204 out of 5,000 staff members were required to self-isolate.

7. Access to care

7.1 During the pandemic, DCC members raised concerns that, as a result of the suspension of the Care Act, 2014, the Coronavirus Act set out the removal of disabled people's established rights to social care. The changes to the duty to meet the eligible needs of disabled people (Section 18) and their carers (Section 20) were of particular concern. This meant that local authorities were more likely to place disabled people in settings inappropriate to their needs in order to save money. Instead of specialist disability care support (typically costing c£1200/ week), we were concerned that disabled people were increasingly likely to be placed in care homes for the elderly (costing c£600/week). We were concerned that this would exacerbate practices seen before the pandemic.

7.2 Four years on, local authority budgets are increasingly strained. There's a context of increased demand for, and costs of social care, yet it is not being met with proportionate increases in funding to local authorities. Due to local authority funding pressures, there is often a race to the bottom when it comes to care commissioning. Nearly a third of Directors of Adult Social Services have been asked to make additional in year savings to their budgets because of the challenging financial environment facing adult social care and councils [ADASS Autumn Survey Report 2023]. In November 2023, 7 in 10 councils polled by the County Council Network said they were likely to cut adult social care services due to funding pressures.

7.3 In Leonard Cheshire's submission (MH/12-INQ000496097) to the Public Accounts Committee's inquiry into 'COVID-19: Government procurement and supply of personal protective equipment' in December 2020, it reported that Covid-19 had exacerbated the funding strain being experienced by care providers due to the additional costs that providers were facing in delivering services. The Local Government Association had indicated that councils experienced a funding gap of £6bn beyond the £3.2bn provided by government in the first three months of the pandemic. Leonard Cheshire spent £2.8 million, often at inflated prices, on purchasing enough PPE to protect its 5,000 strong workforce and the 3,000 disabled people who lived in 120 residential homes and independent living facilities. Prior to the UK Government's introduction of free PPE to care homes on 1st October 2020, Leonard Cheshire was spending £95 per customer per week. By its estimations, Leonard Cheshire funded approximately 95% of the PPE it sourced.

7.4 The issues that Leonard Cheshire faced regarding financial insecurity in the face of the pandemic was amplified by the longstanding underfunding of the social care system. There had been a 5 per cent drop in the number of people receiving publicly funded social care per year – totalling around 600,000 people since 2010 – in spite of the increasing levels of need of an ageing population [IPPR, The Lord Darzi Review of Health and Care (2018)]. The Health Foundation estimates that spending per person on adult social care services fell by around 12% in real terms between 2010/11 and 2018/19 [cited in Health and Social Care Committee, Social care: funding and workforce]. Pressures on funding remain today. In order to stabilise the system and protect vital care services, a long-term funding package must be secured while making care support accessible and affordable.

8. The impact of the pandemic on providers of adult social care, people being supported by adult social care services, their families and staff working within the adult care sector.

8.1 When considering the impact of Covid-19 on disabled people, there were varying impacts on how they are supported-

a. People with high care and support needs who live in residential care settings, or supported living. They have received care and support but will have experienced staff in PPE, a reduction of opportunities to access the community and do normal routines and likely a significant reduction of contact with friends, family and visitors.
b. those who live at home, either independently or with family, who would normally access community-based support such as day services or respite which have been cancelled, closed, or significantly reduced in what they provide.

c. The increased rate of death from Covid amongst disabled people, and particular groups, such as people with a learning disability, was a huge concern for all DCC members. By 2021, research showed that the majority of people dying from Covid-19 were disabled people (60%). This was set out on 11th February 2021 in ONS 'Updated estimates of coronavirus (COVID-19) related deaths by disability status England: 24 January to 20 November 2020'.

d. 8.2 In addition, research by Public Health England (2020) (MH/13-INQ000216420) and the Learning Disability Mortality Review (LeDeR) (2020), showed the significant additional risk of death from covid relating to people with a learning disability, and particular groups, such as people with Down Syndrome.

8.3 The Covid-19 pandemic was an extremely difficult time for residents and staff working in care services. In particular, people with cognitive impairments struggled to understand why their routines and activities stopped. Staff worked tirelessly to keep services safe, often working extra hours to cover the shifts of colleagues ill or self-isolating.

8.4 PPE guidance was particularly problematic for DCC members such as Sense, who wanted to keep people clinically safe but masks prevented communication for many of those the organisation supports, including staff. Masks are also often seen as threatening and there was an increase of challenging behaviours towards staff. Despite multiple representations and requests for support from NHSE/PHE/DHSC, Sense couldn't get support or advice on how to proceed.

8.5 People living in care homes lost more freedoms than the general population. Leonard Cheshire reported that residents felt discriminated against by government-imposed restrictions. For example, while the general population was allowed daily walks, the majority of people in care homes were not. The general population had access to phones and ipads whenever they chose, care home residents were often dependent on staff time and availability for contact with families. Many residents, particularly those with cognitive impairments did not understand why their families stopped visiting.

8.6 Leonard Cheshire worked to highlight three specific issues-

- whether individuals with cognitive and learning disabilities were expected to 'self-isolate' if they did not understand it, did not want to and were unable to choose to stay in their bedrooms

- whether these individuals could and should live without any face-to-face family contact when they did not understand the pandemic and as a result felt abandoned and distressed; and
- whether the restrictions on accessing the community were proportionate. The UK government's guidance for care homes did not engage sufficiently and early enough with the Mental Capacity Act 2005 or with the Equality Act 2010 to address these issues.

8.7 A pandemic has a social impact as much as a health impact and requires social considerations to be built into the response at every stage. Unfortunately, the initial government guidance and legislation did not fully respect the rights and needs of disabled people. Although the driver to restrict the movement of people in and out of care homes was to protect people at risk from the virus, the result of this guidance caused many people to feel discriminated against and had unintended consequences.

8.8 For disabled people living at home, the easement of the Care Act 2014 facilitated by the emergency Coronavirus Act 2020 also resulted in the erosion of people's rights. 55% of disabled people responding to a Leonard Cheshire survey stated that their care package had changed because of Covid, with many individuals having their care stopped altogether. This includes domiciliary services being put on hold, fewer weekly visits from care workers taking place and wrap-around services like physiotherapy completely ceasing. [Leonard Cheshire (2020), this data was taken from the Covid-19 survey of over 1000 disabled people and carers between March and June 2020 (MH/14-INQ000505523).]

8.9 Leonard Cheshire's online survey asking disabled people and their carers about their experience of the Coronavirus ran from 9th April 2020 until 22nd June 2020 and had 1164 respondents.

See: Excel spreadsheet containing raw data for the relevant questions: '*Leonard Cheshire online survey 09.04.2020 - 22.06.2020 – 1164 respondents'*

Relevant findings:

Do you currently receive social care support?
[Number of responses = 1164]

24% - Yes [No.= 277]

76% - No [No.= 887]

If Yes:

Have you experienced any change to social care support during the Covid-19 outbreak?

[Number of responses = 277]

55% - Yes, experienced change [No.= 153]

45% - No [No.= 124]

Please let us know if daily life has been affected in any of the following ways:

[Responses = 277]

Not receiving the care needed to be independent
= 18% [No.=50]

Lack of contact with people
= 37% [No.=102]

Not being able to see friends and family
= 39% [No.=108]

Not feeling part of the community
= 27% [No.=75]

Feeling isolated
=33% [No.=89]

Not being able to go food shopping and/or have the food I need
= 26%
[No.=71]

Not being able to attend regular medical appointments
= 24% [No.=67]

Other
= 9% [No.=26]

8.9.1 Many disabled people told us about feeling anxiety and additional stress due to the fear that changes to their social care support – including physiotherapy and domiciliary support such as help with shopping - enacted during the pandemic will be made permanent. Social care support is a lifeline for huge numbers of disabled people. Decisions to reduce or suspend support must be proportionate. There must be full disclosure on the terms of any suspension and individuals need to be able to access redress for decisions made by councils so that disabled people can have much-needed reassurance.

9. Access to PPE and testing for social care and 'non care home' settings

The focus was very much on the NHS first, then care homes for older people. DHSC was slow to recognise the complexity of how people are supported, and supported living was significantly neglected and omitted from guidance, which seemed to use 'care homes' as a catch-all definition, but which didn't reflect differences in how people are supported. There was also a lack of guidance for day services and gaps for testing/PPE in these settings.

9.1 Procurement and commissioning

Particularly in relation to day services, commissioners had mixed views depending on contracts. Some providers were told not to open, or were asked to deliver different services. Some commissioners asked providers to reduce capacity, but with payment on attendance contracts, so it wasn't economically viable to open – The procurement policy note (supplied) helped in some ways but not others.

9.2 Wider service changes and the impact on care services

9.2.1 Some DCC provider members, such as Mencap and Sense saw an increase in commissioners/NHS colleagues wanting us to undertake delegated activities without renumeration or understanding that care providers don’t necessarily have medically trained staff.

9.2.2 Other services, such as healthcare, moved significantly to online or phone consultations. For some disabled people within care settings this had benefits, due to reducing levels of stress in visiting health settings. But it also presented challenges in terms of ensuring that accurate information could be relayed remotely about presentation and symptoms, with significant concern that risks of diagnostic overshadowing increased, with risk of symptoms being missed.

9.2.3 However, in relation to accessing in-patient acute care, there were significant barriers for staff teams, seeking to ensure people they supported were well supported. This stemmed from guidance restricting care staff from accompanying people they support by ambulance, and also in terms of supporting and visiting in hospital to advocate and assist with vital communication. Provision of in person communication support was a real challenge during this time – Sense had to challenge hospital guidance for staff to be able to visit/attend and support.

9.2.4 Mencap raised concerns about Public Health England’s guidance on accompanying a person in an ambulance with NHS England and DHSC on 21st October 2020. At the same time the charity also raised concerns about NHS England’s guidance, published on 13th October 2020 ‘Visiting healthcare inpatient settings during the Covid-10 pandemic and the ‘Visiting guidance adult healthcare settings trigger tool’. They received a response from NHSE’s National Clinical Director for Learning Disability & Autism on 21st October 2020 that they were acting on these concerns and would relay comments.

9.3 Blind and partially sighted people

9.3.1 RNIB’s main concern for blind and partially sighted people was regards to vision rehabilitation services, which have a low profile but provide essential support to enable people with sight loss to learn skills to live independently and safely in and out of the home, and to retain their employment, and other activities.

9.3.2 Vision rehabilitation, along with other preventative services, was not affected by easements or modifications made to the Care Act during the pandemic, and continued to be a duty of local authorities. However, we know that some local authorities suspended waiting lists, and that some vision rehabilitation specialists were redeployed away from rehabilitation duties in response to front-line pressures.

9.3.3 Those not redeployed were then conducting work by phone or online where possible but in the organisation's view this was not suitable or sustainable, for anything other than the short-term. RNIB argued that rehabilitation specialists needed to be considered as an equal priority to Occupational Therapists in the issuing of Personal Protective Equipment (PPE), in order to be able to work in a risk assessed way with individual clients.

9.3.4 There was already a substantial existing backlog of people across the UK waiting for vision rehabilitation assessment and services, upwards of 12 months in some areas, prior to the pandemic.

9.3.5 In one example, a person whose mobility training was stopped at the start of the pandemic had still not resumed by June 2021, contrary to their entitlement under the Care Act. In another example, a council cited the pandemic as a reason not to provide the mobility training sought by a blind person, despite guidance issued by ADASS which set out that some in-person training and assessment was perfectly possible, with some appropriate precautions.

9.4 Autistic people

9.4.1 National Autistic Society shared the findings of their Left Stranded report with the Department of Health and Social Care. The report set out concerning evidence of the impact of the pandemic on autistic people:

- Compared to the general public, autistic people in June and July 2020 were seven times more likely to be chronically lonely; and six times more likely to have low life satisfaction
- Those requiring support all of the time were significantly more affected by lockdown.

- One in five family members had to reduce work due to caring responsibilities.

10. Key decisions made by the UK Government and Devolved Administrations

10.1 Discharge from hospital settings

Leonard Cheshire, at the start of lockdown, were concerned that some people were being discharged from hospitals into inappropriate care settings, especially with very little notice, where staff did not have the required skills and training. Although this was a concern at the start of lockdown, it was mainly disabled people with lower care needs who were placed in Leonard Cheshire care homes during the pandemic. For individuals joining a Leonard Cheshire home from hospital, handovers were of a similar quality as prior to lockdown.

10.2 Communication around lockdown

Lockdowns, and the highly variable national and regional rules around them, presented huge challenges for the care sector, in terms of reacting to changes at short notice, understanding the changes and updating policies and procedures, briefing staff, updating families and communicating changes to people being supported.

10.3 Vaccination as a condition of deployment

10.3.1 In 2021 regulations were introduced for all care home staff in England to be fully vaccinated against Covid-19, applicable to anyone working in a registered care home providing nursing or personal care on a full-time, part-time, or volunteer basis unless they had a medical exemption. However, family and friends of residents visiting a care service remained exempt from the vaccination requirement despite no limit on the number of ‘named visitors’ that a single resident could have or on the number of ‘named visitors’ who could visit in a single day. This approach was inconsistent and presented a gap in infection prevention and control measures which undermined the effectiveness of the new policy.

10.3.2 The backdown for NHS staff and not social care (initially) further embedded unhappiness in the workforce that social care wasn’t valued as much. Whilst the process was resource intensive, the long-term impact in terms of staffing was not significant for DCC provider members due to fairly high vaccine rates amongst staff, and active communications on the part of organisations with their staff.

10.3.3 Under the government's own impact assessment, the introduction of the mandatory vaccination policy was projected to cause a significant shock to the care workforce with around 40,000 staff unlikely to be able to work in care homes within 16 weeks and an associated cost of £100 million to recruit and train replacement staff.
10.3.4 Leonard Cheshire's own estimations led them to believe that 10% of their care workforce would lose their jobs when the regulations come into force, however in reality this did not come to pass, with a small number of redundancies. It did, however, drive up staff turnover and acted as a potential barrier to recruitment amongst those who were vaccine hesitant.

11. Understanding of the adult social care sector

11.1.1 As we have touched on previously in this statement, it was clear that the Westminster government did not have a clear understanding of the diversity of social care provision for disabled people of working age. In particular, there was poor or little knowledge of supported living, and its importance for large numbers of disabled people living in the community. The failure of 'care home' guidance to adequately address the specific and different nature of supported living settings was a major problem, that left providers having to repeatedly question which aspects of guidance did apply to them, and which did not.

11.1.2 Sense found that there was a real lack of understanding of the sort of support the organisation delivers (personal care, tactile communication etc) and that this was why PPE, isolation and other policies were so difficult to follow. Whilst it is understood that officials can't know everything, Sense and other members would have benefitted from having access to experts who could have listened to feedback/concerns and worked with organisations to agree best practice and document it.

11.1.3 Throughout the pandemic disabled people were often treated as an afterthought, a notable example being the significant delay in expansion of testing kits made available to disabled people living in residential care. Also, PPE supplies were not available to care homes, and disabled people experienced reductions to their social care packages in the community throughout the crisis.

11.1.4 Routine testing for care workers was introduced far later than was the case for NHS staff. Testing in care homes was also not automatically extended to disabled people in England as it was to older people and those with dementia. Disabled people could only get a Covid-19 test if they were symptomatic. Leonard Cheshire worked with Laura Trott MP to raise this issue with the government and on 8 June 2020 the Department for Health and Social Care expanded the care home testing portal so that all adult care home settings could access tests.

11.1.5 Scope's work at the time was based on the premise that disabled people felt 'forgotten' and 'ignored' by the Government during the Pandemic and in the majority of the national response. This include the lack of accessible communication with the public, delays to advice and financial support for those shielding – and who was required to shield, the disproportionate impact of the virus on people with disabilities. As a result of disabled people feeling ignored and forgotten this was felt by those who make use of adult social care.

12 Consultation and communication with the adult social care sector

12.1.1 In general, the Westminster government failed to listen to, and to hear, the voices of disabled people throughout the pandemic, with disabled people having very little say over the policies and guidance being developed. Although charities advocated for the rights of disabled people, more needs to be done to consult with and gain the views of people drawing on care when producing policy and guidance. It is also crucial to learn lessons for the future.

12.1.2 DCC members had good engagement with many individual officials, but they weren't the ultimate decision makers and may equally have struggled to access closed and rapid guidance development and decision-making processes.

12.1.3 In summary, communication was poor. It was short notice, last minute, ever changing and unclear. Whilst we had contacts we could raise questions with they weren't able to give us the answers or get answers from people.

12.1.4 Public and patient information wasn't available in accessible formats. Disabled people didn't have access to information they needed to keep themselves and others around them safe.

13 Guidance published

13.1.1 From Leonard Cheshire's experience, the 'politics' between the devolved administrations made the delivery of services complex due to conflicting guidance and advice. The public health bodies of each of the devolved countries and England differed throughout the pandemic on key issues like testing, hygiene measures, PPE and risk assessments. The lack of coordination and a joint approach during the pandemic caused significant confusion.

13.1.2 For example, the risk assessment guidance released by Public Health England stated that staff working in care were at the greatest risk if they are aged over 70. Public Health Wales on the other hand stated in its guidance that staff were at the greatest risk if they are aged over 50. There was no explanation as to why this guidance differed between countries. As a charity which operates across the UK this differing guidance made it difficult to operate and effectively protect its whole workforce. The Health and Safety Executive which operates nationally issued no legal guidance outlining a charity's obligations as an employer on this issue either.

13.1.3 In Leonard Cheshire's experience, there is significant room for improvement in the coordination of services between central government, devolved governments and local governments. Across the board we found public health bodies to be unprepared for the pandemic, leading to delays in guidance being issued, problems in sourcing PPE and testing, and an altogether inconsistent approach to issues like reporting infections across each local area and the country as a whole. The significant confusion caused took away staff time from running valuable frontline services. For example, in the early stages of the pandemic it took between four hours and three days to report an infection outbreak in care homes.

13.1.4 In its submission to the Commons Health and Care committee in May 2020, RNIB highlighted a number of key issues:

- Section 77 of the Care Act 2014, which requires councils to maintain a Sight Loss Register, did not appear to be covered by the Coronavirus Act.
- Requiring local authorities to identify and make contact with those who have lost sight should have been clarified in the 'Protections and safeguards' section of the guidance under the Act as an ongoing duty.
- Contact details on the Sight Loss Register are not actively maintained, and may be years out of date. This should be considered as part of emergency response preparedness in future, to ensure those who have alternative format preferences for communication are not disadvantaged in a crisis.
- Government should develop the use of the register, with the sight loss sector and blind and partially sighted people, so that in a future crisis, it can be used to proactively contact blind and partially sighted people with information that is most useful to them and in preferred accessible formats.

The management of the pandemic in adult social care

14. Concerns regarding access to healthcare services

14.1 As mentioned above, the wholesale change in general practice to remote consultations, had a huge impact. This change placed a significant responsibility on care staff to support people to outline symptoms and to follow-up with information requests from GPs. For people with a learning disability, particularly those who are non-verbal, this change undoubtedly created risks, whereby not being physically seen in person by a GP increased the possibility of presentation and symptoms not being adequately appreciated, and diagnostic overshadowing taking place, whereby key symptoms of pain and illness are mistakenly attributed to impairment related presentation.

14.2 Additional restrictions, such as guidance on ambulance transport stating that care staff and family members could not accompany a person created great concern about the lack of advocacy and support for people being transported. This was also the case with restrictive guidance on hospital visiting. Overall, guidance did not adequately consider the need for reasonable adjustments for disabled people who rely on support and advocacy from care staff and loved ones to ensure they can safely access healthcare services.

14.3 DCC members also had concerns about redeployment of healthcare staff, placing disabled people at a disadvantage. For example, RNIB received reports of some vision rehabilitation professionals being re-deployed to other frontline services, and longer waiting lists resulting for blind and partially sighted people awaiting professional support from their local authority. Mencap, from its survey of Learning Disability Nurses, saw clear evidence of that workforce being re-deployed and not necessarily available to support people with a learning disability when restrictions on hospital visiting in particular made this support essential.

15. Restrictions on visits

15.1 The main challenge was the changing and unclear guidance and the pressure this put on frontline staff to navigate difficult conversations with families. Whenever new guidance was published, provider organisations and representative bodies scrambled to issue advice and guidance to services and staff, but the timescales of guidance being issued and needing to implement it made it very challenging to do so. Christmas was a particularly challenging time, for example when the Westminster government ‘cancelled’ Christmas at short notice in December 2020.

15.2 Lots of the people who we support visited families for overnight visits and the guidance around this was problematic. People our organisations supported, having returned from an overnight visit with family, would have to self-isolate on return to the service but this was problematic in terms of people’s rights to move around their own home, especially when combined with the needs other people being supported who were clinically vulnerable and shielding.

15.3 We were able to setup some ways to communicate with families using tech etc. but it wasn’t always easy. Tech isn’t accessible for all, particularly those with complex disabilities. This also relied on services being able to access, buy and use technology.

16. Concerns regarding support provided during the pandemic

16.1 Inadequate funding for PPE

16.1.1 The Westminster government coordinated poorly with the NHS and local government to distribute emergency PPE to local authorities. In Leonard Cheshire's experience, this meant the organisation was unable to access PPE via the Clipper Service or via many Local Resilience Forums. The Local Resilience Forums which did supply PPE had very limited stocks. The result was that the organisation spent £2.8 million of charitable reserves on purchasing PPE, to keep residents and staff safe. This experience was shared by colleagues at Mencap, who likewise spent significant additional amounts of charitable resources in identifying and securing their own PPE supplies.

16.1.2 On 8th April 2020, LGA and ADASS issued guidance related to necessary temporary funding of social care providers to stabilise the system in the pandemic. For the period of 1st April until 30th June 2020 Leonard Cheshire had requested this 10 per cent uplift for a total contract value of £110,961,304, equating to an additional £2.77 million in fees for the three-month period. In this period the charity secured £1 million of the ask from 132 of the 233 funders contacted. The total ask across those 132 funders was £1.761 million. Responses from funders then slowed down and there was also confusion and concern around both the requirements for the local authorities and providers to accept and keep money from the £600m grant. The process for applying for an uplift was unclear, time-consuming and complicated. A standardised 10 per cent uplift awarded to providers would have been more efficient and allowed for much needed funds to be accessed quicker.

16.1.3 Through the Coronavirus Jobs Retention Scheme Leonard Cheshire was able to place 160 staff on furlough (2% of workforce) who were either shielding and could not attend their frontline place of work, or staff members whose workloads had decreased due to the impact of the virus.

17. The impact of easements to the Care Act 2014 on the adult social care sector

17.1 The provisions outlined in the Coronavirus Act 2020 that permitted easements to Care Act 2014 duties to provide social care assessments and support to disabled people and the unpaid carers who support them presented a significant risk to disabled people's health and wellbeing. It should have been essential that councils continued to assess the risks and vulnerabilities affecting disabled people and their unpaid carers, particularly when reprioritising services. Disabled people who draw on social care should have been provided with information on what they could expect in terms of service during this time as well as guidance on what they could do if they were concerned about their social care support entitlements under the Act's provisions.

17.2 While we welcomed the publication of the list of councils which had 'turned on' the Care Act easements to enhance transparency, we still had concerns around the lack of information being provided by local authorities on why easements had been turned on and the assessed impact this would have on their service users.

End of life care and planning

18. Concerns regarding the use of Do Not Attempt Cardiopulmonary Resuscitation Orders ('DNACPRs'),

18.1.1 DCC members, such as Scope, Sense, NAS and Mencap were speaking out in the media and making representations to decision makers on the issue of the NICE guidance around access to acute care, and letters that care providers were receiving from GP surgeries around advanced decision making and end of life care.

18.1.2 NICE guidance on treatment of patients in critical care, and its inappropriate and discriminatory application of the Clinical Frailty Scale to disabled adults of working age was first raised by Mencap with the Department of Health and Social Care by email on 23rd March 2020, and direct contact with NICE was established that day via DHSC's NICE Sponsor Team, with Dr Paul Chrisp, Director of NICE's Centre for Guidelines (MH/15-INQ000228378). Emails were exchanged over the following days as NICE drafted the amended guideline, and a Teams meeting took place on 27th March between Mencap and NICE (MH/16-INQ000505794, MH/17-INQ000505796, MH/18-INQ000505801, MH/19- INQ000505799). Mencap also raised the issue with the National

Director for Learning Disability and Autism at NHS England, and the Deputy Director for Dementia & Disabilities at DHSC (MH/20- INQ000505800).

18.1.3 Some GPs had been contacting care settings, suggesting that people with a learning disability supported in those settings would not be treated if they went to hospital with symptoms of Covid-19, and suggesting advanced decisions should be made not to seek treatment, as well as use of DNACPR orders. Mencap has submitted to the Inquiry examples of such letters, one from the Willow Green Surgery, dated 24th March 2020 (MH/21-INQ000505520), and another from Lakeside Healthcare, dated 24th March 2020 (MH/22- INQ000505521). These, and other examples, were shared with the Care Quality Commission, to inform their fieldwork and research for their 'Protect, respect, connect- decisions about living and dying well during Covid-19' thematic review into DNACPR decisions, which was ordered in October 2020 by the Secretary of State for Health and Social Care.

18.1.4 In addition to this, Mencap also encountered examples of DNACPR notices being applied to people with a learning disability in hospital without any contact with family or support staff. In one such case, the person supported was admitted into hospital on 31st March 2020 due to sepsis diagnosed by the GP. He was in hospital for 5 days, and was successfully treated. On arrival back to his home, which was a supported living service, staff discovered a DNACPR form at the bottom of his bag. There was no reason stated for its issue. The person had no pre-existing health conditions and was in good health prior to his admission for sepsis. The team who supported him were not contacted with regards to the DNACPR decision, and the person would not have had capacity to make the decision if an attempt to discuss it with him was made.

18.1.5 In another example involving **Irrelevant & Sensitive** NHS Foundation Trust, senior managers worked to get a DNACPR removed from a person Mencap supported who was in hospital, only for it to be reinstated on the basis of a conversation that doctors had had with a family member who had highly limited contact with the person and was unaware of their current situation. Mencap staff were very concerned about the practice in the hospital around DNACPR, for example in relation to the Mental Capacity

Act, and appropriate advocacy support being provided in the circumstances. However, in this case, medical staff were responsive and engaged on the appropriateness of the DNACPR.

18.1.6 One of the ongoing concerns that we have had is that people may well have DNACPR documents sitting in their medical files, which they, their family members or paid care staff are unaware of. The length of time DNACPRs are applied for can vary considerably, with some expiring when a hospital admission ends, or others being indefinite.

18.1.7 We feel it is important to consider the issues around DNACPRs within the wider issue of access to care and treatment. Our case work with families and the people we supported during the pandemic showed that often a decision that someone was 'not for active treatment' or not for 'escalation', went hand in hand with a DNACPR notice.

18.1.8 In several examples where a person had died relatively early on in the pandemic, decisions about ceilings of care had been documented as made on the basis of someone's support needs, which suggested that the Clinical Frailty Scale was still likely to be influencing people's decision making, even if not directly referenced. The Clinical Frailty Scale influenced decision making about care in that it drew adverse inferences for treatment based on someone having support needs. For people with a learning disability of working age this was highly inappropriate in that they might well need support to manage aspects of daily living, but due to that support be in good overall health and actively participating in their community.

18.1.9 It is clear to us that DNACPR decisions are associated with, and perhaps confused with, Do Not Treat notices, and ceilings of care, and that this is likely persisting.

18.2 The examples above show that during the pandemic there is evidence that some practice was clearly rushed, inappropriate and unlawful, showing outdated attitudes towards disabled people and unfounded judgements about quality of life, and 'vulnerability'. The pandemic also undoubtedly shone a light on wider issues around a lack of public understanding around DNACPR processes, advanced decision making, and practices like ceilings of care. There is an ongoing need for public education around advanced planning, and for transparency from the medical profession around practices like ceilings of care.

19. Infection prevention and control

19.1 Isolation of people we support following discharge from hospital and/or a positive Covid-19 test was difficult when providing personal care. For example, for Sense, many of the people they support also use tactile forms of communication so can't social distance. Explaining restrictions/rules to people with additional learning disabilities was also challenging, and balancing capacity with deprivation of liberty.

19.2 Training staff around infection prevention and control guidance was hard when the information we got was short notice and it didn't immediately or directly apply to the settings we deliver support in. We have previously set out in this statement, how Sense and RNID made representations around PPE and its usage in terms of communication with Deaf and other disabled people being supported, who lip read or rely on clear speech. The key issues was how to adapt guidance in a way that would be clinically safe and still enable providers to meet needs. The Clear Mask discussion was initially encouraging, but it didn't get anywhere. Finding masks that met clinical safety standards and enabled communication didn't really happen. When they were announced and found, there wasn't enough stock or understanding about the amounts needed to meet needs.

20. Personal protective equipment ('PPE')

20.1.1 Accessing PPE wasn't initially easy as a provider as there weren't clear routes to get hold of it and fund it. This was particularly the case for settings like supported living and day services which weren't covered in guidance so procurement routes weren't possible. The Infection Control Fund did help.

20.1.2 As outlined above, Sense asked repeatedly for clarity/support in how their staff could use the guidance to keep people clinically safe and manage safe practice in other ways. Residential services/supported living are people's homes, and balancing people being clinically safe and feeling safe was a lot for staff.

20.1.3 RNID also worked on the provision of Clear Face Masks – masks that could be used in health and social care settings which both met the required standards and utilised clear plastic panels which allowed the person engaging with the wearer to lipread. DHSC approved and released a limited batch of 250,000 clear masks in September 2020

20.1.4 RNID issued a statement in October 2020-

> "We are delighted, therefore, that a Type 2R transparent mask has now been approved for use and that the mask is currently being made available to NHS Trusts and social care providers across the UK.
>
> "We are pleased also that guidance has been issued to NHS Trusts clearly stating the barrier that PPE presents to those with hearing loss, as well as giving tips on how to communicate with people with hearing loss when wearing PPE. The guidance says that where possible, clear masks should be used by staff to communicate, or alternative communication methods such as speech to text apps and video relay can be used. We understand that the guidance also allows for exceptions to be made to the wearing of face coverings on an individual basis."
>
> "We also welcomed the limited reference in the Government's recent guidance on PPE in care homes to the scenarios in which PPE presents significant difficulties for some. Whilst this is welcome, comprehensive guidance on how to communicate with people with hearing loss when wearing PPE must be issued to all health and social care providers, as this is a challenge that goes beyond hospital and care home settings."

20.1.5 Early in the pandemic Leonard Cheshire raised concerns that PPE was being prioritised for the NHS, meaning that social care services were left without resources. Critical PPE was unavailable following extremely large orders being placed by NHS

Trusts. This put social care staff at high risk and, as a consequence, absence rose rapidly and staffing levels could become unsafe. In the worst case scenario, people the charity was supporting would then need to be transferred to hospital using vital NHS resources.

20.1.6 Leonard Cheshire wrote to all MPs representing constituencies in which we had services, raising PPE and wider Covid-19 concerns. Numerous MPs responded with commitments to raise the issue with government, sharing national guidance or locally focused advice. As one example, we reached out to Rt Hon Jeremy Hunt MP who was the constituent MP for three Leonard Cheshire care services in Surrey. In response, a telephone meeting was arranged between senior charity staff and Jeremy Hunt on 08.04.2020. On 17 April 2024 Mr Hunt raised the issue during an oral evidence session of the Health and Social Care Committee. In his role as Chair of the Committee, Mr Hunt questioned the Rt Hon Matt Hancock MP, Secretary of State for Health and Social Care.

> "Q352 Chair: Thank you. One social care provider, which actually has a home in my patch, Leonard Cheshire, looks after about 3,000 residents across the country. They say that it has been a battle but they have got basic PPE now for all their staff. However, what they can't get is any of the higher level PPE. They have nurses, for example, who are doing what are called aerosol-generating procedures, which means their staff could be infected if they get sprayed by a patient, and they could indeed pass that on to other residents. Many in the social care system feel that they have not had as equal access to PPE as the NHS has had. What would you say to them?
>
> Matt Hancock: I would say that it is vital that everybody gets the PPE that they need, according to the guidance that has been agreed by the clinicians and set out. That is what we are working incredibly hard to do. I would also say that the challenge is that many social care settings have normally bought PPE through their normal commercial suppliers and, because of the scale of the increase in PPE needs, those commercial suppliers have found it difficult to restock. Ultimately, we have a global shortage of PPE. There is more PPE being demanded and used across the world than there are supplies. That is why ramping up the domestic supply is also incredibly important. Just to finish off on

> social care, because it is an important point, we have thought carefully about the differing use of PPE in different settings. For me, it is just as important to get the right PPE to the right people, no matter what their setting.
>
> Q353 Chair: Would you allow social care providers to access the NHS supply chain for the higher-level PPE if they cannot secure it on the open market?
>
> Matt Hancock: Yes, absolutely. That is one of the big changes we have made. We are rolling out what is called the Clipper service to social care, because the NHS supply chain has brought in an online delivery and request system. If you think about it, the NHS supply chain has traditionally been an organisation that gets kit to about 230 hospitals. We now have a responsibility to deliver PPE to 58,000 settings, so the NHS supply chain has gone from what is essentially a wholesale distribution to a retail distribution in a very short amount of time, under intense pressure. I think they have done an amazing job. We have then brought in Clipper and the Army to bolster their logistical capabilities.
>
> It has been incredibly difficult, of course—I do not deny that. The team have been working incredibly hard on it, and I pay tribute to them. They deserve our thanks. On getting PPE out to everyone, I understand the pressures in the system and I understand why people feel so strongly about it, but the one thing I can be absolutely sure of, hand on heart, is that everyone in the system is doing all they possibly can to get the right PPE to the right places."

20.1.7 In Leonard Cheshire's experience, we were unable to access PPE via the Clipper Service or via many Local Resilience Forums. The Local Resilience Forums which did supply us with PPE had very limited stocks. Prior to the UK Government's introduction of free PPE to care homes on 1st October 2020, we spent £2.8 million of our charitable reserves on purchasing PPE, often at inflated prices, to keep our residents and staff safe.

20.2 Procurement of PPE and the NHS Portal

20.2.1 In March and April 2020 Leonard Cheshire's social care procurement team found that it was almost impossible to secure PPE due to the NHS ringfencing of supplies and available PPE was very scarce. Suppliers, including the charity's preferred supplier Blueleaf, confirmed this and were not able to supply either the PPE order the organisation had purchased from them pre-Covid or the face masks needed for safety in the pandemic. They therefore had to use all available resources to contact a range of nonstandard suppliers. This included contacting closed gyms, shops, nail salons, hairdressers to identify any access points. PPE supplies came at a huge premium. New supply channels established in the pandemic, for example products being air freighted in from China and other parts of Asia, meant that delivery lead times couldn't be guaranteed and led to additional exposure to risks and financial insecurity as suppliers would only supply on upfront payment and delivery to a single location address.

20.2.2 During the April - June 2020 lockdown period the Westminster government established an NHS supply chain helpline. This call handling service directed social care providers to initially four and subsequently five national suppliers. However, the helpline did not operate as a supply chain line and suppliers often stated either that they were not able to supply PPE to Leonard Cheshire. When the charity found that there was an available supply of PPE on the helpline, it was more expensive than they were able to source. As a result, the supply chain helpline did not enable them to effectively source PPE.

20.2.3 In order to be able to provide safe care for clients and residents – and a safe working environment for care staff – the charity had to identify new sources of PPE supply and make quick buying decisions, with immediate payments, to not lose the supply line to competing customers. This involved taking financial risks around due diligence of suppliers and products.

20.2.4 Leonard Cheshire experienced issues with poor guidance which impacted on the organisation's financial resources. The charity received conflicting advice and guidance from Public Health England and the local Care Quality Commission, among others. Initially, there was no guidance around the need for mask fit testing. However, in early July 2020, this new information was issued at short notice. Releasing this updated information in this way created a high and competitive arena regarding the need for appointing a mask fit testing provider, purchasing mask fit testing kits and consumables, services, mask fit testing kits and replacements hoods.

20.2.5 A great deal of misinformation or poor guidance resulted surrounding the requirements and safety criteria of PPE masks:

- KN95 masks: Leonard Cheshire was initially advised to buy KN95 masks in bulk. However, we the charity was subsequently alerted to the fact that the product was ineffective against the virus. This resulted in circa £100,000 wasted.

- The Fire Service advised of SAMSTROM masks and filters for clients with Aerosol Generating Procedure requirements. The charity spent circa £130k on these, to again be informed by mask fitting testers that they were ineffective. They were used, albeit as an expensive alternative.

20.2.6 By July 2020 Leonard Cheshire had developed a great deal more knowledge internally as well secure, trusted and high-quality supply lines. The pricing for PPE dropped considerably since the earliest stages of the pandemic. Ongoing issues in securing PPE remained however in the availability of specialist fitted 3M masks, the shortage of nitrile gloves and suppliers still requesting either 100% or 50% payments immediately/upfront.

20.2.7 When the NHS PPE Portal was set-up to address social care providers' PPE needs, all of Leonard Cheshire's services were registered with the system. The NHS PPE Portal proved, however, to be a difficult, clunky system and process and the charity's teams continued to have log-on issues in accessing it. The quota levels involved in the Portal were not in line with the weekly PPE requirements of Leonard Cheshire's services. In December 2020, the charity was only achieving on average 70% of what its services needed to manage the spread of the virus and comply with current UK Government guidance.

20.2.8 The PPE portal required a great deal of improvement. It was difficult to use and could not be accessed on a central basis. Each service was required to submit a request related to its own PPE needs. The amount of PPE that could be ordered was restricted and so still did not bear any relation to any assessment of needs in care services. It also did not provide any gowns or better-quality masks that were required if a resident was diagnosed with Covid-19 or if Aerosol Generating Procedures were required. Relying on this system alone would not enable sufficient access to resources should an outbreak occur in a residence.

20.3 PPE supply issues and the impact on visitors to care residences

20.3.1 In March/April 2020, there was not enough PPE to make provision for visitors. Despite improvements as the pandemic progressed, access to PPE supply in the social care sector was still extremely limited and PPE supply was reserved for visitors who were visiting Leonard Cheshire's clients at end of life. Initially, guidance around use of masks for visitor to social care services was minimal. The charity was concerned that guidance around visits to care services continued to be limited and inconsistent. In the future, advice must be evidence-based and must be integrated with the lockdown and tier systems so that it is effective and to alleviate confusion.

20.3.2 Leonard Cheshire spent £2.8 million, often at inflated prices, on purchasing enough PPE to protect its 5,000 strong workforce and the 3,000 disabled people who lived in 120 residential homes and independent living facilities. Prior to the UK Government's introduction of free PPE to care homes on 1 October 2020, Leonard Cheshire was spending £95 per customer per week. By its estimations, Leonard Cheshire funded approximately 95% of the PPE it sourced.

20.3.3 Central government coordinated poorly with the NHS and local government to distribute emergency PPE to local authorities. In Leonard Cheshire's experience, this meant that the charity was unable to access PPE via the Clipper Service or via many Local Resilience Forums. The Local Resilience Forums which did supply PPE had very limited stocks. The result was that the charity spent £2.8 million of our reserves on purchasing PPE, to keep residents and staff safe.

21. Testing for Covid-19 during the pandemic, including, but not limited to:

21.1 Providers incurred additional staffing costs during the pandemic, as staff with coronavirus symptoms were required to self-isolate. This resulted in the use of increased numbers of agency staff to cover the shifts of self-isolating staff members. Although changes in June 2020 opened-up Covid-19 testing to staff in care settings, the delay in the availability of this testing earlier in the pandemic placed significant financial pressure on care providers. Many staff in self-isolation for 14 days could have returned to work earlier if they received a negative test for Covid-19. As an example of cost, overall, between March and June 2020 Leonard Cheshire spent an additional £2 million per month.

21.2 Covid tests that were accessible to blind and partially sighted people to use independently were not available for many months (MH/23-INQ000505526).

22. DCC members' survey work

22.1 Mencap: July 2020: Family members and carers of people with a learning disability: experiences during the COVID-19 pandemic.

22.1.2 Mencap ran an online survey with 1069 family members and carers of people with a learning disability in the UK. The survey ran for 2 weeks from 29th June to 13th July 2020 (MH/24- INQ000505525).

22.1.3 Over two thirds (67%) said their loved one's needs have increased during the COVID-19 pandemic, while four in five (79%) had no choice but to increase the amount of care and support they offer.

22.1.4 The *survey* revealed that a lack of social care support has negatively impacted people with a learning disability in a number of ways, including their mental health (69%), *relationships* (73%), physical health (54%) and *independence* (67%), according to family carers.

22.1.5 Over half (52%) of family carers said that they have struggled to cope with supporting their loved one during the COVID-19 pandemic.

22.1.6 Three quarters say the situation has been detrimental to their own mental health (75%), relationships (60%) and their physical health (61%).

22.2 November 2020

22.2.1 Mencap ran a survey with 410 family members and carers of people with a learning disability in the UK. The survey ran for 2 weeks from 05/11/2020 to 18/11/2020 and was hosted on Survey Monkey (MH/25- INQ000505524).

- Nearly nine in ten people with a *learning disability* still did not have all their *social care* support reinstated, eight months since the first lockdown.
- Almost three quarters of family carers surveyed were worried that there are more *cuts* to care packages to come, with some reporting that their *local authority* is already trying to cut their loved ones' care package further.
- Nearly two thirds (63%) of people with a learning disability had their social care package reduced or stopped during the second lockdown. 71% of family carers had no choice but to continue to increase the amount of care and support they offer – but with no breaks and *relationships* becoming more strained, families are at breaking point.
- Mencap warned that cuts to *day services* and *respite* for carers have had a devastating impact on people with a learning disability and their families.

22.3 Sense July 2020

22.3.1 Date - 21.07.2020 - 28.07.2020. Sample - 1000 Respondents who are caring for disabled adult family members/friends in their household

22.3.2 The survey formed the basis of media messaging and the Forgotten Families campaign in which Sense asked supporters to sign an open letter to Matt Hancock.

22.4 Sense Feb 2021

22.4.1 The research was conducted by Censuswide, on behalf of Sense. 1,011 disabled people were surveyed between the 20.01.2021 - 22.01.2021 (MH/26- INQ000505530).

22.4.2 It formed the basis of media work highlighting the impact of the pandemic on loneliness for disabled people ('Left out of life'). Also formed basis of our work launching a campaign to call for disabled people to be at the heart of the covid inquiry.

22.5 Sense Jan 2022

e. 22.5.1 1,001 disabled respondents across the UK were surveyed between 26.01.2022 - 31.01.2022 (MH/27 INQ000505532).

22.6 Sense May 2022. Follow up polling. 1,004 respondents with complex disability and 1,001 parents/family members caring for a disabled person

22.6.1 This was in response to the narrative that the 'pandemic was over' but this wasn't the case for many of those who we supported and their families.

22.6.2 The national disability charity, Sense, has labelled the decision to end the free testing in England on April 1st "unfair" on disabled people and their families, some of whom are immunocompromised, and more likely to suffer severe illness if they catch Covid compared to the general population.

22.6.3 The charity has highlighted the move comes amidst a cost of living crisis, which will disproportionately impact disabled people and their families.

22.6.4 Spring 2022 – Potential and Possibility Research. Polling of 1000 people with complex disabilities (MH/28-INQ000496103).

22.7 Scope

22.7.1 In May 2020 Scope published its disability report ''Disabled people and the coronavirus crisis'. The report brought together insight from a range of different sources, including Scope's helpline, online community, services, social media, research panel, and through research polling, to understand what the important issues were for disabled people.

22.7.2 The report highlighted disabled people's top concerns around feeling forgotten, struggling to access food and basic essentials, worries about accessing benefits, erosion of rights through temporary law changes such as Care Act easements, and barriers to work due to issues like shielding.

22.8 Leonard Cheshire

22.8.1 Savanta ComRes polled disabled adults for Leonard Cheshire in February 2022. Savanta ComRes interviewed 1,220 working age disabled adults (18-64) in the UK between 17th to 21st February 2022. Data were weighted to be nationally representative of working age disabled adults in the UK by age, gender and region.

Q. Have you been affected by any of the following during the Covid-19 pandemic?	**n=1207**	**%**
I've contracted Covid-19	253	21%
I've had difficulty accessing information on how to stay safe	87	7%
My household income has reduced	318	26%
I've had to rely on my Personal Independence Payment (PIP) to make up for a loss in income	132	11%
I've been unable to leave my house because I was shielding	251	21%
I've been unable to leave my house because I was frightened	284	24%
I've had to rely on my family and friends due to a lack of social care	178	15%
I've been unable to work	238	20%
I've experienced a negative impact on my mental health	588	49%
I've experienced a negative impact on my physical health	382	32%
I have felt isolated and lonely	532	44%
None of the above	91	8%
Net: Negative impact on health (physical/mental)	698	58%
Net: Unable to leave the house	424	35%
Net: ANY AFFECT	1116	92%

22.9 RNID

22.9.1 The survey was undertaken in September 2020 and involved 384 members of the charity's Research Panel (so a self-selecting group) made up of people who are deaf or have hearing loss. The focus on this was primarily looking at the impact for the community of remote GP appointments and therefore did not focus on social care. The only relevant mentions of social care in the write-up of this survey were to note the failure of implementation and enforcement of the Accessible Information Standard – which applies across NHS and publicly funded social care services.

23 NAS

23.1.1 Between June and July 2020, then charity ran an online survey for autistic people and their families across the UK around their experiences of coronavirus and lockdown. The charity received 4,232 responses (1,810 from autistic people and 2,422 from family members). Throughout the pandemic, NAS also asked people to email with their Experiences.

- Compared to the general public, autistic people in June and July 2020 were seven times more likely to be chronically lonely; and six times more likely to have low life satisfaction
- Those requiring support all of the time were significantly more affected by lockdown.
- One in five family members had to reduce work due to caring responsibilities.

24. Westminster government and Ministerial engagement

24.1 DCC members met with the Minister for disabled people individually and as the DCC. DCC members engaged with the Disability Unit and raised key issues. DCC members regarded the Unit as helpful for finding contacts in departments but couldn't really take matters further in their own right.

24.2 A number of DCC members had regular engagement with NHS England,via the Learning Disability and Autism programme online meetings, which regularly featured attendees from DHSC, PHE and other bodies. DCC members, such as Mencap, Sense and NAS also regularly engaged with NHSE staff within the Learning Disability and Autism programme.

24.3 DCC members, such as Sense and Mencap took part in regular sector calls with the Deputy Chief Medical Officer.

24.4 DCC members, such as Sense and Mencap, were in the stakeholder group that met regularly with Helen Whately MP, when she was Minister for Care.

25. Sense and National Autistic Society's engagement with NHS England and the Department of Health and Social Care

25.1 Sense and NAS are/were members of the Health and Wellbeing Alliance (HWA) as part of the Complex Needs consortium. The HWA is jointly managed by the Department of Health and Social Care (DHSC), the UK Health Security Agency and NHS England and is made up of 18 VCSE members that represent communities who share protected characteristics or that experience health inequalities

25.2 The HWA system partners convened working groups, and meetings and had weekly meetings for members to be able to raise issues and discuss concerns. The system partners brought key speakers and updates which was valuable and enabled members to hear from/follow up with people leading on key areas of concern, with a particular focus on public facing information and accessibility.

25.3 Sense observed that as time moved on the decision making in terms of policy and guidance became more senior, so it was harder to have impact in those meetings. However, the organisations had made good contacts in key areas and the HAW team were helpful at signposting where they could.

25.4 As we have raised above in this statement, many of the officials that we engaged with were very responsive and supportive but they weren't the decision makers and also couldn't get us the answers we always needed because of that. We also observed quite a bit of duplication of work between NHS/DHSC and other government departments. E.g. with accessible information and guidance etc.

26. National Disability Strategy

26.1 The government's plan to create a National Disability Strategy was announced in February 2020. Due to the early phases of the pandemic, the Disability Unit (DU) did not start substantive development work on the strategy until late summer 2020. The DCC's involvement with the strategy’s development began in September 2020 through workshops held with the DU on the emerging thematic areas of the Strategy. At the same time monthly meetings were held between the Minister for Disabled People, the DU, and DCC Chief Executives and policy leads until the Strategy's launch. DCC Co-Chairs also engaged regularly with DU officials, whose perspective from their position in the Cabinet Office was helpful in providing oversight and influencing other departments.

26.2 Throughout this engagement, the DCC sought to lay out a clear vision of what its members felt the Strategy should include to truly deliver meaningful change for disabled people, and act as a critical friend when providing feedback on the DU’s developing thinking on the Strategy’s content. A focus on the former led to the production of DCC’s ‘Manifesto for an inclusive National Disability Strategy’ (supplied) which was shared with government in January 2021.

26.3 The manifesto laid out six key themes the DCC felt needed to be embedded across the strategy: changing perceptions, enforcement, procurement, consultation and engagement, a focus on transitions into adulthood, and improved data on disabled people’s lives. These themes cut across nine areas of focus such as employment and products and services, where persistent barriers affecting disabled people’s lives were identified and needed to be tackled.

26.4 DCC Chief Executives were invited to read a draft of the strategy in May 2021. Feedback shared with the then government was that it lacked ambition and simply indicated what the government was already doing, or planned to do in the immediate future, across these areas rather than bringing them together underneath an overarching long-term vision and a coherent strategic direction for disability policy.

26.5 Concern was also raised on the potential to fulfil the Strategy without strong underpinning of funding, meaningful year on year targets, and well-resourced cross-government oversight for its delivery. Finally, before its launch in July 2021 a further meeting took place with the then Minister for Disabled People and DCC Chief Executives to discuss these shared concerns.

26.6 While engagement with the DCC was positive over the course of the Strategy's development, this engagement did not always translate into influence and input into the overarching vision of the Strategy and its content. It was also felt by some DCC members that there was an overreliance on the regular meetings held with the DCC and the DU to gather feedback rather than these fitting into a wider framework for engagement which included going out to representative groups, organisations, and disabled people. In particular, the DCC consistently raised the point that the DU should be engaging with Disabled People's Organisations (as well as the DCC and its members).

27. Adult Social Care Strategy Draft

27.1 National Autistic Society was invited by DHSC (David Nuttall, Deputy Director for Neurodiversity & Disability) to comment on draft Adult Social Care Strategy draft on 11/04/2020. Comments included concerns about the rigour of the Ethical Framework around Care Act easements. NAS called for more guidance on how to prioritise needs.

27.2 In September 2020 NAS, together with Ambitious about Autism, Autistica, Scottish Autism, and the Autism Alliance, published 'Left Stranded'. This joint report outlined how the disruption, uncertainty and pace of change triggered huge levels of anxiety and for some was made worse by the withdrawal of support from social care, education and mental health services.

27.3 The Government's *Coronavirus Act* temporarily weakened many of the duties on councils to provide support. But even before these powers were created, or in areas where they never came into force, we heard of people losing their mental health, education and social care support services – sometimes with little notice. On top of this, many autistic people reported having huge difficulties shopping for food. The new rules about going into shops alone (without support), new layouts and the rules on masks left many feeling overwhelmed and, in some cases, like they couldn't go out at all.

27.4 While these concerns led to anxiety for most autistic people, the impact was felt most strongly by those with higher support needs, autistic women and non-binary people. This research was led by the National Autistic Society, as part of a project funded by the Pears Foundation, with a number of other autism charities supporting.

27.5 Autistic children and adults must be prioritised and protected from future waves of coronavirus. This would cover social care, health, education, transport and shopping and set out how the governments will avoid using the powers in the *Coronavirus Act* that limit councils' duties to support disabled people.

28. DCC members' work on summarising and interpreting guidance

28.1 The NAS hosted a Coronavirus Information Hub, funded by DCMS through DHSC, to provide accessible guidance for autistic people and their families.

28.2 Sense summarised all guidance for services and dissemination to the frontline – highlighting the relevant and key points. This was a regular occurrence (particularly when the guidance changed so much). The charity would link to the main guidance but summarise in a clear way for staff and services to know what they needed to do as a result and how the organisation would be implementing it. There were weekly emails that went to operational teams providing any updates or highlights of things that they needed to know/do.

28.3 Retrofitting was usually done in raising issues with DHSC and getting (some) answers or clarification. We did have to retrofit when it came to supported living and day services.

29. The impact of the Covid-19 pandemic on disabled people

29.1.1 NAS, in the launch of their 'Left Stranded' report (September 2020) (MH/29-INQ000224594), featured a number of stories of families seriously impacted by the lack of social care support and services during lockdown. The report called on government to take a wide range of actions to ensure that the experiences of autistic people and their families during the pandemic were not repeated. One such example, was Sylvia and her son Luca:

29.1.2 Since March, Sylvia White has been shielding at home in Dumfries and Galloway in Scotland with her 20-year-old son Luca. He is autistic, has learning disabilities and requires a lot of support. Yet Sylvia has seen this support drop away during lockdown and has desperately been trying to fill the gaps. She felt like she couldn't go on, like there was no-one to run to.

29.1.3 Sylvia, who is 53, said: "I've been shielding with Luca since March, we were practically house bound with no support. I'm on my own and he needs 24-hour care. In normal times he would attend a day service five days a week and go for respite 36 overnights a year with a council run service. But both these services have been suspended due to the pandemic and I've been told there won't be respite for the foreseeable future.

29.1.4 "I understand why the day service isn't running as it's not possible to socially distance. But his respite care is given in a self-contained bungalow with one member of staff and there's no sharing of facilities. I feel we've been abandoned.

29.1.5 "The last four months have taken a toll on both of us – I'm on my own since my mum died just before lockdown – and my mental health has really suffered. I need a rest – Luca doesn't sleep well and we're up most mornings between 4 and 5 am. Earlier this month I really didn't know how I could continue. I couldn't see a way out.

29.1.6 "Fortunately, we have now had some good news. Luca now has two carers coming to the house and we've now got extra funding for them to support him overnight. It's not ideal having someone in my house and I have to leave when they are here otherwise it wouldn't work for Luca, but it has made things a lot better. I know there are many other autistic people and families struggling out there and hope sharing our story will mean we're not forgotten."

29.1.7 Mencap, in August 2020, published results of the charity's survey of 1,069 people across the UK about their experiences of caring for someone with a learning disability during the pandemic. Alongside this, the charity published a range of anonymised stories from family carers who had taken part in the survey-

29.1.8 He was at residential college supported by an active programme of learning and life skills. This has stopped since mid-March. He has regressed, he has become subdued and is ripping his clothes and being destructive.

- Mother, 57, to 22-year-old son with a learning disability

29.1.9 "We have worked so hard for a number of years to support my daughter to join in group activities. Due to COVID-19, she has been confused and [is] completely shutting down [and] refusing to communicate."

- Mother, 50, to 15 year-old-daughter with a learning disability

29.2 I am here alone giving 24-hour care to someone who cannot be left. Behavioural issues have been terrible. I had to choose to keep him safe rather than going for a wee, I had to wee on the floor. He was safe though."

- Mother, 54, to 25-year-old son with a learning disability

29.2.1 "I am caring for a very challenging and strong individual for more than 100 hours per week and have had very little sleep. I am worn out and exhausted, my son is fully grown with the strength of ten men. It has left me feeling depressed and forgotten."

- Mother, 53, to 26-year-old son with complex needs

29.2.2 The charity published these stories alongside figures from a series of Freedom of Information Requests to Local Authorities in England, showing the extent of financial pressures in social care for people with a learning disability even before coronavirus hit. The FOI figures showed that at least 2,459 working-age adults with a learning disability had the support hours in their care package reduced in 2018/19. But the charity estimates that, factoring in all Local Authorities, this could have been over 7,000 people - equating to around one in 20 people with a learning disability who receive social care.

29.2.3 The charity highlighted that an £8 billion investment in social care in England is needed to restore adequate levels of quality and access to what it was a decade ago according to the Lords Economic Affairs Committee report. And that local councils in England faced at least a £6.6bn increase in social care costs due to coronavirus according to the Local Government Association and the Association of Directors of Adults Social Services.

30. Recommendations

30.1 Funding

30.1.1 Funding is a key issue that remains insufficiently addressed. The social care sector continues to struggle to recruit and retain staff, due to issues including low pay. Lack of funding also means that local authorities and care providers have had to go year to year, with little ability to engage in longer term strategic planning to build resilience. A long term funding solution is needed to build and secure the sector and improve resilience in the face of any future pandemic situation.

30.2 Understanding of disabled people of working age

30.2.1 Social care is a diverse sector, and the ways in which disabled people of working age are supported and the services they access, is different to older people. At the start of the pandemic there was poor understanding across government in particular of supported living and a focus on ‘care homes’, which failed to understand how large numbers of disabled adults of working age are supported and live their lives. Guidance and policy repeatedly failed to mention or address supported living settings and the disabled people living in them, their support staff or their families.

30.2.2 Disabled people were disproportionately affected by the pandemic, felt forgotten, and died at rates substantially above that for the general population. In government planning for a future pandemic, disabled people of working age must be explicitly considered in terms of the impact policy has on them and the care services they rely on. Government needs to better understand the care services people use and be able to develop policy appropriate to different types of setting.

30.3 Awareness of the care workforce

30.3.1 Despite being included in the government’s group of key workers, many of our social care staff experienced a lack of awareness that they were subject to entitlements, such as protected shopping time in supermarkets. This is resonant of a lack of parity between NHS workers and care workers. Over time there was increasing awareness among supermarkets and the wider public that care workers were subject to the same protections in accessing food supplies. Four years on, there is still a lack of parity between NHS workers and care workers – evidenced most clearly by the pay disparity. This must be addressed with urgency in order to stabilise the social care workforce.

30.4 PPE

30.4.1 Leonard Cheshire set out in detail in this statement how they had to source and pay for PPE supplies to keep people they support and their staff safe. Other DCC members, such as Mencap, experienced the same circumstances. In future, the supply of PPE for social care must be secure and reliable.

30.5 Accessible information

30.5.1 All public bodies and government agencies must make information available in a range of accessible formats, including easy read, at the same time as the equivalent standard publication is made available to the public.

30.5.2 RNID continues to call for the Government to adapt its accessible communications checklist – this isn't just a pandemic/emergency tool, but it's value is heightened during these occasions.

30.6 Joined up policy making

30.6.1 A genuine cross government approach to policy making for disabled people, that involved disabled people's organisations at the earliest possible stage, and where policy makers listen to lived experience and expertise.

30.7 Recognising the importance of care and support

30.7.1 The lived experience set out in this statement, particularly by NAS and Mencap, shows the disproportionate and enormous impact that the closure of various care services had upon disabled people and their families, such as day services, respite services and support within the family home. In future, we would want to see a very different approach taken, to ensure people and their families are not left alone, and potentially in crisis, for months on end. This is not an acceptable situation for policy to result in.

30.8 Equality impact assessment (EIA)

30.8.1 A meaningful and accurate EIA process that understands the true impacts that policy will have on people with protected characteristics.

30.9 Optimising the use of existing resources

30.9.1 RNIB is clear that the Government should develop the use of the sight loss register, held by Local Authorities, with the sight loss sector and blind and partially sighted people, so that in a future crisis it can be used to proactively contact blind and partially sighted people with information that is most useful to them and in preferred accessible formats.

30.9.2 The COVID-19 response highlighted a problem that contact details on the Sight Loss Register are not actively maintained, and may be years out of date. This should be considered as part of emergency response preparedness in future, to ensure those who have alternative format preferences for communication are not disadvantaged in a crisis.

30.9.3 The same applies for the Learning Disability Registers, held by GPs, which were used to an extent in determining vaccine eligibility. However, only 1 in 4 people with a learning disability across England are currently on a register.

30.9.4 Care staff worked tirelessly to keep people they support in services safe, often working extra hours to cover the shifts of colleagues ill or self-isolating, and in some cases moving in with people they supported. In the case of Leonard Cheshire's services, this resulted in fewer deaths in 2020 than in the previous year.

30.9.5 Services and providers made it through and were creative, innovative and persisted.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: **Personal Data**

Dated: 30th September 2024