Date 2nd August 2023

Witness Name: Matt Stringer

UK COVID 19 INQUIRY

WITNESS STATEMENT OF

MATT STRINGER

I, Matt Stringer, of The Grimaldi Building, 154a Pentonville Road, London N1 9JE, will say as follows:-

1. I am Chief Executive Officer at the Royal National Institute of Blind People ("**RNIB**"). I am duly authorised by the Disability Charities Consortium **(DCC)** to make this statement.

2. I make this statement to provide information to the Inquiry on the experience of disabled people during the pandemic in accessing healthcare systems across the four nations of the UK.

3. The contents of this statement represent the collective experience of DCC members during the pandemic. To the extent that the contents of this statement are not directly within my own knowledge or that of RNIB, the source of the information is indicated and they are true to the best of my knowledge and belief.

About the DCC

4. The DCC is made up of the following charities: Business Disability Forum; Leonard Cheshire; Mencap; Mind; National Autistic Society; RNIB; Royal National Institute for Deaf People ("RNID"); Scope; and Sense ("the DCC's members"). I have included brief details below about each of the members:-

a. Business Disability Forum is the leading business membership organisation in disability inclusion. They work in partnership with business, Government and disabled people to remove barriers to inclusion. Their 500+ members employ over 20 per cent of the UK workforce and an estimated 8 million people worldwide.

b. Leonard Cheshire is one of the UK's leading charities supporting disabled people. They support individuals to live, learn and earn as independently as they choose, whatever their ability and to play their part in creating a fair and inclusive society. Led by people with experience of disability, Leonard Cheshire are at the heart of local life — providing opportunity, choice and support in the communities they work in.

c. Mencap's vision is for the UK to be the best place for people with a learning disability to live happy and healthy lives. They provide services that model their vision and ambition, campaign for change, support people with a learning disability to ask for what they want and need (including supporting them to campaign for change), support people with information and advice for all areas of their lives, carry out research into important issues to create a positive impact and see real change and support people to find solutions in their own communities.

d. Mind is the mental health charity for England and Wales. They believe no one should have to face a mental health problem alone. They provide advice and support to empower anyone experiencing a mental health problem. They campaign to improve services, raise awareness and promote understanding.

e. The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people. They transform lives by providing support, guidance and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. They change attitudes by improving public understanding of autism and the difficulties many autistic people face, working closely with businesses, local authorities and government to deliver better services and improve laws.

f. RNIB is the UK's leading sight loss charity and the largest community of blind and partially sighted people. We provide a wealth of services including practical and emotional support through our RNIB Connect community and our Sight Loss Advice Service, guide business and public services on accessibility, campaign for change, and have a library of over 60,000 accessible reading materials, including daily newspapers.

g. RNID is the national charity supporting the 12 million people across the UK who are deaf, have hearing loss or tinnitus. Together they work to end the discrimination faced by their communities, help people hear better now and fund world class research.

h. Scope is a disability charity in England and Wales. They're a strong community of disabled and non-disabled people with a shared vision of equality. They provide practical advice and emotional support whenever people need them most. They do this through their Scope helpline, their online community, a range of employment and child sleep services, community engagement programmes, partnerships and more.

i. Sense is a national disability charity supporting everyone who is deafblind or has complex disabilities. The organisation delivers commissioned and charitable services across England, Wales and Northern Ireland. Services the charity provide include adult social care, specialist support for children and families, education and college provision, employment support, holidays and short breaks and inclusive arts sports and wellbeing activities. As well as delivering direct services, Sense campaigns and influences to improve the lives of the 1.6 million people in the UK with complex disabilities.

5. The DCC has been in existence for over 15 years and was set up to facilitate co-ordination of activity and communication between the main disability charities in the UK. The DCC reaches a significant proportion of the 16 million disabled people in the UK and their member organisations address the broad range of issues that disabled people face. The DCC looks at the collective impact of policy on disabled people and highlights particular issues for specific groups of disabled people.

6. The DCC works with Government to ensure disabled people's views and experiences are reflected in UK policy making, and that their own policy positions are informed by disabled people. The DCC's members have a long track record of engaging with and

influencing key stakeholders across the country and are recognised by Government as a key representative body for consultation on issues that face disabled people.

7. The DCC regularly meets with the Minister for Disabled People and the Disability Unit in Cabinet Office. It has established a regular programme of meetings with the ministerial disability champions in each government department, which continued during the pandemic. The Chief Executives of the DCC meet quarterly, and the DCC's Policy Group, made up of the Policy Heads of the represented charities, meet regularly to develop joint positions on different areas of policy. Annually, members agree the key policy initiatives behind which the DCC will align and produce a manifesto.

8. During the pandemic DCC members both individually and collectively engaged directly with the Department for Health and Social Care and with NHS England to ensure that disabled people could access healthcare including accessible information about healthcare. The DCC was also a vital source of advice and information about healthcare for disabled people during the pandemic, via our helplines and frontline services. For example, Sense and NAS are both part of the Health and Wellbeing Alliance. Through the Alliance, and from as early as 25th March 2020, they participated in meetings to discuss plans for the pandemic, hosted by NHS England and bringing in leads from across NHS England and the Department for Health and Social Care. The Alliance met regularly (often weekly) with additional ad hoc calls and meetings. We detail below other meeting attended by DCC members including information about the outcomes of those meetings.

Disability in the UK

9. There are 16 million disabled people in the UK; one in four of the population. 11 per cent of children, 23 per cent of working-age adults and 45 per cent of state pension age adults have a disability. I provide more information below on the incidence of disability amongst the groups of disabled people represented by DCC members:-

    a. One in ten disabled people have complex disabilities, a total of 1.6 million people. Someone has complex disabilities if they have two or more of the following conditions: sight loss, hearing loss, autism or learning disability, and they report that their life is impacted by their disabilities.

b. There are 1.5 million people with a learning disability in the UK. Please note that learning disability should not be confused with a learning difficulty like dyslexia or ADHD.
c. 12 million people in the UK are Deaf or have hearing loss.
d. Almost two million people in the UK are living with sight loss that has a serious impact on their daily lives and activities. This includes 350,000 people who are registered as severely sight impaired (blind) or sight impaired (partially sighted).
e. At least 700,000 people in the UK are autistic.

The legislative/regulatory context

10. In 2010 the Government enacted the Equality Act. There are nine protected characteristics under the Act including age, race, sex and disability. The Act makes it unlawful for a service provider or those exercising public functions to treat a disabled person less favourably on the basis of their disability. In addition, and most importantly from the perspective of disabled people, service providers and those exercising a public function are required to make reasonable adjustments. This includes the provision of information in alternative formats. The duty to make reasonable adjustments is anticipatory. This means an organisation cannot wait until a disabled person wants to use its services, but must think in advance (and on an ongoing basis) about what disabled people with a range of impairments might reasonably need (in order to access a service), such as people who have a visual impairment, a hearing impairment, a mobility impairment or a learning disability.

11. In addition to the substantive provisions of the Equality Act. Those exercising public functions are also subject to the Public Sector Equality Duty. This requires them to have “due regard” to the need to eliminate discrimination, advance equality of opportunity and foster good relations (between persons who share a relevant protected characteristic and persons who do not). In order to comply with the duty, organisations are expected to impact assess policies and practices before implementing them, and on an ongoing basis, in order to understand the impact and to identify potential mitigating steps to reduce or remove adverse impacts.

12. Although the Equality Act was introduced in 2010, the duties outlined above in respect of disability are much more longstanding and were previously contained in

other legislation. The Disability Discrimination Act (DDA) was introduced in 1995. The reasonable adjustments provisions came into force in 1999. The DDA is still in force in Northern Ireland. The Disability Equality Duty (the forerunner of the PSED in respect of disability) was introduced in 2006. Despite the longstanding nature of these obligations, and an expectation that they would, by this time, have been firmly embedded in decision making, the experience of disabled people during the pandemic, including in relation to access to healthcare, was that little, if any regard, was given to the impact that measures were likely to have on disabled people or the need to make any necessary adjustments. The response frequently given when a discriminatory impact was raised was that decisions were being made at speed and there was simply not time to give consideration to equality issues. However, this simply shows that equality obligations/considerations had long been neglected and were not embedded in decision making. This meant decision makers were therefore going from a standing start. In addition, decision makers often didn't understand that building equality considerations into the decision making process was vital in order to keep people safe and would potentially save time in the future. And even when DCC members had specifically alerted decision makers to equality considerations, the same mistakes were made time and again.

13. In addition to the requirements of the Equality Act, the Department for Health and Social Care and the NHS in England are also subject to the NHS Accessible Information Standard DCB1605 ("the Standard"). The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. It has been in force since August 2016. As with requirements of the Equality Act, little if any regard was given to the need to ensure that health communications and services were accessible. It was not apparent that NHS England and the Department understood the requirements of the Standard and its potential application to their services and correspondence and the Governments faced Judicial Review proceedings in respect of the accessibility of shielding correspondence and covid briefings. RNIB also received a number of complaints regarding the accessibility of vaccine related correspondence.

Increased rate of mortality amongst disabled people

14. In February 2021, data published by the Office for National Statistics (ONS) revealed that of the 50,888 Covid-19 deaths that happened between January to November 2020, 30,296 were disabled people. Disabled people, who account for 22 per cent of the population, made up six in 10 deaths.

15. In November 2022, ONS published further data which showed that compared to people of the same age without such impairments, working-age people with both a hearing and visual impairment in England were nearly 12 times more likely to die due to Covid during the pandemic (24 January 2020 and 20 July 2022). People aged 30-69 with a visual but no hearing impairment were more than eight times more likely to die, and those with just a hearing impairment were still four times more likely to die a Covid-related death.

16. Even after taking into account a wide range of characteristics including age, residence type, geography, socio-demographics, health and vaccination status, the risk of a Covid-related death for people with a hearing, visual and dual-sensory impairment was still 1.30, 1.38 and 1.42 times higher than those without.

17. According to the Learning Disability Mortality Review (LeDeR) [MS/1-INQ000216420] data published in 2020, people with a learning disability were, in the first wave of the pandemic, dying at a rate six times that of the general population, rising to around 30 times for adults aged 18-34.

18. The number of excess deaths of people with a learning disability was also consistently higher than the general population with the proportion of people with a learning disability dying from COVID at 80 per cent in the week ending 22 Jan 2021, compared to the general public at around 45 per cent.

19. By contrast, NAS found that there was a lack of available reliable mortality data for autistic people. This is due to poor recording of autism in health and social care datasets. There is no means of recording autism on death certificates, and it is not regularly recorded in hospital data. These gaps in the data have been acknowledged in the Government's National Autism Strategy 2021-2026 [MS/2 – INQ000216425].

Eligibility for healthcare for people with learning disabilities

20. In December 2020 Mencap published a research report into the experiences of people with a learning disability in terms of accessing healthcare services during the pandemic [MS/3- INQ000216426]. Undertaken during the pandemic, the report demonstrates the impact of the pandemic, and the measures taken to combat COVID-19, on the ability of people with a learning disability to access healthcare. It draws upon official guidance, external reports, Mencap's Learning Disability Nurse Survey, and case studies, to show the negative impact felt by people with a learning disability across the healthcare system. The report's key findings include:-

    a. NICE acute care guidance initially appeared to suggest the use of the Clinical Frailty Scale to justify not treating disabled adults of working age [MS/15-INQ000228380]. The Clinical Frailty Scale is a tool used by healthcare practitioners to identify patients who are at increased risk of poor outcomes and who may not benefit from critical care interventions (see also para 22 below).
    b. There was a lack of reasonable adjustments in hospital and redeployment of key Learning Disability Nurse support.
    c. There was inappropriate discharge from hospital without proper care planning.
    d. There were barriers to accessing primary care through the wholesale move to remote consultations.

21. DNACPRs (Do Not Attempt Cardiopulmonary Resuscitation notices) were issued in a 'blanket' fashion across care settings for (working age) disabled people. Even where DNACPRs were used individually, the patient and/or their family were not consulted in advance, as the law requires. Learning Disability England has stated that one in five of its member organisations had seen DNAPCRs placed in people's medical records without consultation in March and April 2020. Mencap experienced both blanket and inappropriate individual DNACPRs in its own services and received many calls about the issue to its helplines.

22. DNACPRs were regularly confused with Do Not Treat notices and ceilings of care, which should only ever be used for older people, were applied to otherwise fit and healthy disabled people of working age. When media reports emerged of inappropriate use of DNACPRs, both NAS and MENCAP contacted NICE to raise

concerns [MS/16 - INQ000228378] noting that otherwise healthy disabled adults were likely to score poorly on the Clinical Frailty Scale if they required assistance with activities of daily living. By way of response NICE clarified that it wasn't the intention of the guideline to be applied to otherwise healthy people and it was subsequently confirmed that it should not be used on autistic people or people with a learning disability. The guideline was eventually updated to make the position clear.

23. NAS also raised the issue of inappropriate use of DNACPRs in an online meeting with DSHC and NHSE on 2 April 2020. The following day, a letter was sent to all primary care establishments, acute and community trusts to make clear that learning disability should never be used as a reason for a DNACPR [MS/4- INQ000216427]. This letter was issued from NHSE to Primary Care Trusts, Acute Trusts and Community Trusts, clarifying how healthcare professionals should use both the Clinical Frailty Scale and DNACPRs in relation to learning disability and other specific groups. It reiterated the need for decisions not to be based on "the presence of learning disability and/or autism alone or" but rather on "an individual basis and in consultation with their family and /or paid carers, taking into account the person's usual physical health, the severity of any co-existing conditions and their frailty at the time of examination." However, the initial communications had already been issued and the damage had, to a certain extent, already been done. Unfortunately it had taken almost 10 days, from initially raising concerns, for the clarification needed to be provided.

24. In March 2021, the Care Quality Commission (CQC) published an interim report into the use of DNACPR decisions taken during the COVID-19 pandemic [MS/5-INQ000216428]. The report, commissioned by the Department for Health and Social Care, explores the experiences of over 750 people between November 2020 and January 2021. It tells the stories of people who were denied the opportunity to discuss their DNACPR decisions, as well as families and carers feeling unable to support their loved ones to challenge DNACPR decisions. The report found that staff required better training and support to ensure they are aware of the correct processes for the application of DNACPRs and the "need for a national approach to advanced care planning and DNACPR" to ensure accessibility of these processes. It highlighted the confusion among professionals caused by both the amount of, and rapidly changing, guidance issued during the pandemic. The CQC recommended the need for "comprehensive records of conversations with, and decisions agreed with, people, their families and representatives that support them to move around the system."

The report highlights the scale of use of inappropriate DNACPRs, the impact of this on people with a learning disability and their families, and actions required to improve outcomes. It also raised concerns that "people's human rights and rights under the Equality Act 2010 had not been considered or were at risk of being breached." The report concluded that all decisions about DNACPR must, in all circumstances, be made on an individual basis according to need.

25. The DCC believes that the "blanket" application of DNACPRs was (and remains) wholly unacceptable, even in the pressurised circumstances of the pandemic. We do not know how many of these inappropriately applied DNACPRs remain on individuals' medical records. This could result in more avoidable deaths in the future.

Access to general healthcare

26. The changes to health services during the pandemic resulted in delays to routine surgery, therapies, assessments, equipment maintenance, monitoring of medication, access to diagnostics, medical therapeutics, treatment and clinical trials. Healthcare appointments and therapies were cancelled or moved online or via telephone with no accessible alternative for many disabled people, which had negative consequences for many. For example:-

    a. 53 per cent of people with complex disabilities told Sense that their health had been negatively affected and 48 per cent had medical treatments delayed as a result of the pandemic [MS/6-INQ000216429]. This finding was part of polling for Sense's 2022 annual research on the experiences and aspirations of people with complex disabilities.
    b. Scope research found that 63 per cent of disabled adults were concerned (in May 2020) that they wouldn't be able to access hospital treatment if they became ill with Covid-19 [MS/7-INQ000216430].
    c. A poll of 1,207 working age disabled adults conducted for Leonard Cheshire by Savanta ComRes in February 2022 found that a third (32 per cent) of people felt that their physical health had been impacted during the Covid-19 pandemic. This rose to 50 per cent of those with chronic health conditions, 47 per cent for those with chronic pain or dexterity-related conditions, and 44 per cent for people with breathing or mobility related conditions. Half (49 per cent) of respondents also experienced a negative impact on their mental health.

d. RNID research [MS/8-INQ000216431] in September 2020 found nearly 60 per cent of 384 respondents admitted they had 'put off' seeking medical advice from their GPs after the introduction of remote appointments during Covid.

e. The ONS report [MS/17-**INQ000228379** on coronavirus and the social impacts on disabled people in Great Britain: September 2020, also showed that 47 per cent of people with a hearing impairment reported that coronavirus had impacted their access to healthcare and treatment for non-coronavirus related issues, compared to 20 per cent of non-disabled people.

27. Many NHS audiology services moved to using the telephone and video conferencing platforms to deliver part of their services remotely, while complying with Covid-19 restrictions. However, RNID research showed that many people who are deaf or have hearing loss were unable to access essential audiology services that could have been offered remotely, for example, getting replacement batteries by post [MS/9-INQ000216433]. Hearing aids are a lifeline to many and RNID found that those who were unable to access audiology during the pandemic were twice as likely to experience acute loneliness, whereby someone feels lonely 'often' or 'always', compared to those who were able to access audiology services.

28. Specsavers' 'The State of the UK's Eye Health 2021' [MS/10-INQ000216421] report (undertaken by Deloitte Access Economics) estimated that 2,986 people lost vision due to delays in the identification and treatment of eye disease. The report used data from Specsavers UK database on referrals (stratified by level of urgency) from optometrists to hospital eye services to estimate the number of patients who did not receive an eye test and the decrease in referrals. It was assumed that cases which otherwise would have been an urgent referral from optometry may have been at risk of permanent sight loss from their condition. Similarly, for patients who either cancelled an appointment with their ophthalmologist or had their appointment cancelled, it was assumed that there is a level of risk of progressing to sight loss due to delayed treatment. Compared to 2019, the report also found a 23 per cent drop in the number of eye tests delivered in the UK during 2020. Referrals to ophthalmology fell by 28 per cent. Ophthalmology outpatient attendance and day case procedures declined by 36 per cent and 45 per cent respectively between March and December 2020. An estimated 235,000 necessary eye surgeries were missed or delayed in 2020. Treatment for wet age-related macular degeneration, diabetic retinopathy and NHS glaucoma decreased significantly.

29. The COVID-19 Urgent Eyecare Services (CUES) framework was developed by NHS England to ensure high-risk, urgent and emergency eye care services continued during the pandemic. This was a good response when implemented effectively but implementation was not consistent across all parts of the UK.

30. Many glaucoma patients were diverted to their primary eye care provider without complete medical details such as their target IOP (intraocular pressure). Low vision services were closed and many were very slow to reopen due to other medical priorities and floor space being used for other medical teams who needed additional space and were considered a greater priority.

31. There were particular challenges for people with learning disabilities to access healthcare. People with learning disabilities may not be able to communicate verbally, and/or may have difficulty expressing pain or discomfort. They also struggle to navigate healthcare systems, including services such as 111 and remote consultations which rely on an individual's ability to accurately communicate symptoms.

32. Despite clear guidance allowing exemptions from wearing face coverings, NAS heard of examples of people being turned away from health settings for not wearing a mask, despite not being able to.

Hospital visiting

33. At the start of the pandemic, NHS England issued guidance on hospital visitors, without consultation with the DCC and/or disabled people. These changes prevented equal access to healthcare for disabled people and I have outlined some of the impact these rules had on particular groups below. I understand that the guidance was only amended after legal action was threatened by a disabled person [MS/11-INQ000221469].

34. For many people with a learning disability or autism, having someone with them in hospital who knows them well can be a vital reasonable adjustment. Yet the guidance repeatedly changed, making the system more difficult to understand and navigate. NHS England Visitor Guidance published in April 2020 allowed an exception for people with 'mental health conditions' including learning disability and/or autism' to have visitors. However, subsequent guidance removed this, making no specific

reference to reasonable adjustments for people with a learning disability, leaving decisions on visits with the Trust Incident Management team.

35. People with complex disabilities often have very individual communication needs and prior to the pandemic Sense would often provide in hospital support with communication. However, the new rules prevented the provision of this support leaving people isolated in hospital without the right support. It also meant others may have avoided seeking help so as not to be separated.

36. Blind and partially sighted patients experienced similar issues being told that they couldn't bring anyone with them to guide them within healthcare settings. This meant for a significant number of people that they couldn't attend their medical appointments (both general and eye clinic appointments).

The accessibility of Covid public health information

37. Covid is not the first pandemic where disabled people's ability to access health communications was raised as a potential issue. Around 2009, DCC members had met with NHS England on a regular basis to discuss contingency planning for another potential pandemic, that of "swine flu". This included discussions around the accessibility of information being provided to individuals in situations where anyone who came into contact with the virus would be immediately required to self-isolate and would not be able to rely on other people to read information for them. In the event, the outbreak turned out to be less serious than initially thought and the envisaged communications were not necessary. However, this episode should certainly have put the Government on notice of the need for accessible communications during a pandemic.

38. From the beginning of the pandemic, DCC members raised concerns regarding the accessibility of Covid 19 related public health information provided to disabled people; from the accessibility of the Prime Minister's letter, broadcast announcements, the shielding letters, social media posts, test and trace and arrangements for vaccination.

39. In April 2020 Mark Atkinson [MS/12-INQ000216422], Chief Executive of RNID, wrote to the Prime Minister on behalf of a number of disability charities including RNID,

Sense, SignHealth, National Autistic Society, Thomas Pocklington Trust, Visionary, Royal Association for Deaf People, Macular Society and SeeAbility, expressing our concerns regarding the accessibility of Covid related information being put out by the Government, and in particular the lack of a BSL interpreter at major announcements, including the initial lockdown announcement.

40. The Minister for Disabled People replied on 19 May 2020 [MS/13-INQ000216423] setting out the steps Government was taking to ensure the accessibility of public health information during the pandemic. This included establishing an accessible communications working group, appointing an accessibility lead (Director, of National Resilience Communications, COVID-19 Communications Hub) and issuing revised guidance to Government departments. Although this led to some improvements (such as around the accessibility of social media posts and the availability of a BSL interpreter on the BBC News channel) problems remained, particularly around the accessibility of shielding information (see below) and test and trace.

41. One of the particular concerns that RNIB raised repeatedly was about the accessibility of the shielding letters. In RNIB's view, communications relating to shielding were covered by the Accessible Information Standard (and the Equality Act) and as such NHS England was required to take steps to ensure that they were providing accessible versions of the letters from the beginning where data regarding preferred format was held by GPs and hospitals.

42. At the beginning of June 2020, in response to a request from the new accessibility lead, RNIB, Sense, RNID and others, provided a "shopping list" [MS/14-INQ000216424] of our requests in relation to the provision of accessible information during the pandemic. This included ensuring that all the following were accessible: public health information, broadcasting, social media, mailings, websites, contact methods and apps. DCC members had received concerns about all of these issues from disabled people.

43. We requested, in particular, for "a reliable system to be put in place to ensure blind and partially sighted people get letters in their preferred format across the country (E.g. Local Authority Registers or NHS Information Standard data)." In a meeting with NHS England in June 2020, RNIB asked if it would be using NHS data on preferred formats when sending out the second shielding letter and suggested that this was something they should be doing. NHS England representatives responded that this

was not a problem they could sort out at this time. We also asked for the same approach in a subsequent meeting with the accessibility lead, to no avail.

44. However, some progress was made in terms of providing accessible formats in that it was agreed that the next shielding letter that went out would include RNIB's details on it. A letter, which included our telephone number in a larger font at the top, and which instructed people to call in order to receive letters in their preferred format, went out on 22 June.

45. Clearly this was not our preferred approach because many blind or partially sighted people would find it difficult, if not impossible, to read the original letter independently, putting those living alone at a particular disadvantage/risk. In any event, only one of the subsequent shielding letters included RNIB information for transcription and none were sent out in an accessible format directly.

46. Without an accessible and timely version of the information provided in the shielding letter, blind and partially sighted people and other disabled people were left without an essential source of information providing advice on keeping safe and well, as well as other practical issues, such as how to register for additional care and support, how to access medication, priority shopping, and mental health support. The letter also acted as evidence for not attending work.

47. Given the particular risks to older people and other sections of the population where there is a higher prevalence of sight loss (including those with learning disabilities), it is even more critical that information about changes in policy, procedures or advice, were accessible. I have referred to the mortality statistics above in relation to disabled people.

48. Colleagues at Sense have also confirmed that research showed that 38 per cent of people with complex disabilities had not received guidance from government that was relevant to their situation and needs.

49. The Prime Minister's initial broadcast announcement for lockdown was not made available to BSL users and the Government was slow to ensure future broadcasts were accessible. In fact BSL interpreters were never made available on the main channels – so BSL users would always have to find the BBC News Channel to receive accessible information. The Government was also slow to develop BSL or

print alternative versions of vital mailings sent to the public, including the initial lockdown letter and mailings to the shielding group. Critical information on the GOV.UK website, including information on testing, was also inaccessible to BSL users.

50. One positive response in terms of communications was that the NHS 111 service was relatively quickly made accessible for the volume of BSL users that would now be using the service.

51. When vaccines became available, accessible information continued to be a cause for concern for DCC members, and this was regularly raised in discussions with the NHS England vaccine teams. However, the vaccine letters, like the shielding letters, were and continue to be, mostly inaccessible. It was not until July 2022 that RNIB was told that further correspondence could now go out in Braille and we are not aware of correspondence having yet gone out in other alternative formats.

Public Health England (PHE)

52. There was a lack of preparedness from public health bodies to manage this crisis, and a disjointed approach between Public Health England and devolved public health bodies. In Leonard Cheshire's experience, the 'politics' between the devolved administrations and central Government made the delivery of services more 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.

53. Leonard Cheshire and Mencap experienced difficulties in accessing guidance issued by PHE on a variety of topics including testing, hygiene requirements and PPE guidance. Often guidance was issued weeks after policy announcements and was difficult to find on the then PHE website. Guidance was often moved to different parts of the website once it was updated. Guidance to supported living settings for working age disabled adults on a range of issues also lagged behind guidance to care homes. As a result disabled people living in those settings were placed at risk.

54. Furthermore, the reporting of infection outbreaks to PHE during the pandemic was erratic and inconsistent between local areas. It often took hours, and in one case three days, for Service Managers to get through to PHE to report a Covid-19 outbreak. The reporting requirements for PHE, and each Clinical Commissioning Group and Local Authority also differed, with different requirements again for the devolved administrations.

Communication barriers included those presented by PPE

55. The widespread use of PPE presented a particular barrier to people who are deaf or have hearing loss who rely on facial expressions and or lipreading to communicate. This not only affected those using services but also those employed to deliver services. RNID called for and supported the eventual approval of transparent masks being made available to NHS and social care services, whilst also recognising the challenges with mainstreaming transparent masks. They also called on the Government to provide clarity for health and social care providers on how to navigate and balance duties to protect public health with their legal obligations under the NHS Accessible Information Standard. Some guidance was produced for care homes and NHS Trusts but delivery was slow and the guidance was not comprehensive.

56. Masks can have negative connotations for those who have had bad experiences in healthcare settings. Sense saw an increase in challenging behaviour in its services, sometimes with masks being pulled off the faces of staff. Some autistic people struggled with the change and the sensory experience of mask wearing, and some carers needed to not wear a mask so they could reassure the autistic person whom they were caring for. While mask exemptions were put in place, the guidance was not well understood across the healthcare system and was often applied incorrectly. For example, NAS heard of instances of autistic people being forced to wear a mask to be allowed into healthcare settings, like hospitals or GP surgeries, or being barred from entry. As a result, NAS updated the resources and information on its website to make sure that people could download an “I am autistic card” and also designed an information sheet that autistic people could use to communicate their exemption to someone who challenged them, in case they could not communicate it verbally.

57. Deaf people also faced particular challenges, with masks preventing patients from lip reading. When the ClearMask became available in July 2020, the accompanying guidance advised against their use in surgical or high risk environments. However, the guidance also recommended clinicians avoided using them with clinically vulnerable people because these masks didn't provide enough protection if the wearer was infectious. In RNID's experience different trusts took different approaches to this, with some not recommending using the mask at all with those aged over 70, and with others working on a case by case basis depending on communication needs.

Shielding and the impact on the clinically vulnerable

58. The focus on protecting those deemed Clinically Vulnerable and Clinically Extremely Vulnerable as a result of following a (medical) model focussed on clinical risk, inadvertently resulted in too little protection for disabled people who did not fall into these categories but who also needed support. Many disabled people were ineligible for additional government support because their condition or impairment did not render them "clinically extremely vulnerable". However, underlying health conditions, living in areas of deprivation and being in households with lower incomes could have put many disabled people at greater risk than non-disabled people.

59. As more became known about COVID 19 over time, some groups of disabled people were identified as Clinically Extremely Vulnerable. In late Autumn 2020, around the time of the second national lockdown in England, it was announced that people with Down's Syndrome had been added to the Clinically Extremely Vulnerable list following data which showed they had been disproportionately affected during the first wave of the pandemic.

60. Prior to the announcement, various third sector organisations, including Mencap, were invited to engage with the Department for Health and Social Care to ensure that accessible messaging could be targeted successfully at people with Down's syndrome and their families. The decision was taken to inform GPs and primary care teams of the addition to the list, to provide easy read letters and leaflets to GPs, and to give GPs responsibility for contacting their own patients with Down's syndrome to inform them of the change.

61. However, it soon became apparent that this method of communication was ineffective, with many GPs being unaware of the responsibility that had been placed on them or struggling to find the easy read resources. Therefore, the decision was eventually taken to use the national system to contact people, directing them in turn to contact their GP surgery. As a result of this delay, some people did not receive a letter informing them they were advised to shield until early January 2021 (a few months later), putting many at risk.

Issues DCC is unable to comment on

62. In the Rule 9 request, the Inquiry asked the DCC to comment on a number of areas that were beyond our knowledge and experience. We have listed them below together with an indication, where appropriate, of alternative sources of information

    a. The concerns members of the DCC have with respect to the impact on people with disabilities working in healthcare settings during the relevant period. DCC did not generally receive enquiries/complaints from disabled people working in the healthcare sector. These issues would be best addressed by trade unions operating in the sector.
    b. Details of the impact on the mental health of people with disabilities during the relevant period, including people who are disabled by reason of a mental health condition as well as people with other disabilities. Whilst DCC members had significant concerns in relation to the impact of loneliness on disabled people during this period, we think that specific enquiries related to mental health would be best addressed by colleagues at MIND who are also core participants to this module.
    c. Whether DCC members raised any concerns with individual NHS Trusts or other healthcare providers about the treatments used or treatment options available to people with disabilities within the healthcare systems. DCC is not aware of members having raised specific concerns with individual NHS Trusts or other healthcare providers.

Conclusions

63. The DCC is concerned that disabled people were treated as an afterthought during the pandemic. There was a failure to listen to, and to hear, the voices of disabled

people throughout, with disabled people having very little say over the policies and guidance being developed. These failings are reflected in the disturbing and stark reality of the differing mortality data relating to those with disabilities compared to the wider population.

64. Although Disabled People' Organisations and charities, including members of the DCC, advocated for the rights of disabled people, future emergency preparedness and response should involve far more consultation with disabled people. The third sector should not have to intervene retrospectively when the Equality Act, public sector equality duty and the Accessible Information Standard are each in place to ensure that accessibility issues are considered in advance (or at the time) of policies etc being devised and should be understood and followed by decision-makers and officials.

65. Government needs to ensure that the equality impact assessment process is strengthened, and enforced with rigour across the public sector, including mechanisms within the policy making process to sense-check with disabled people and/or their organisations for unintended consequences of new policies, and take account of their input.

66. In future Government emergency planning, consideration should be given not only to the direct impact of the disease or threat, but also to the impact of the measures brought in to control it especially on those who fall within protected categories.

67. We hope that the Inquiry will be able to make recommendations to ensure that disabled people are never faced with the same situation again.

I believe that the facts set out in this statement are true. I understand that proceedings for contempt of court 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 in its truth.

Signed

Personal Data

2nd August 2023