

Witness Name: Jackie O'Sullivan

Statement No: 1

Exhibits: 7

Dated: 22nd May 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF JACKIE O'SULLIVAN

I, Jackie O'Sullivan, acting Chief Executive Officer at the Royal Mencap Society will say as follows: -

1. I make this witness statement in response to a request from the Inquiry to provide evidence for Module 3, detailing the impact on people with learning disabilities of the way the healthcare systems functioned in the United Kingdom during the Covid-19 pandemic.

Mencap

2. Royal Mencap Society is a registered charity that works across England, Wales and Northern Ireland. We provide social care support to 4,000 people with a learning disability. We also provide employment support, such as supported internships and are an Ofsted registered provider. We have helplines in England and Wales, to provide advice and support to people with a learning disability and their families. We campaign and seek positive change for people with a learning disability and their families, and our current strategy aims to make the UK the best place for people with a learning disability to lead happy and healthy lives, with a focus on-
 - Increasing participation in paid employment from the current low rate of around 25%, as well as securing a social security system that is fair and provides an adequate level of support.
 - Tackling barriers to people being able to access timely and high quality healthcare, and preventing avoidable deaths.

- Increasing funding for social care, addressing unmet need, and securing greater reward and recognition of the social care workforce
- Addressing the cost of living crisis, with a focus on financial support and wider accessibility of utilities and financial services
- Ending the detention of people with a learning disability and autistic people in mental health hospitals under the Mental Health Act when they do not have a mental health issue.

Engagement during COVID

Engagement with English policy makers during COVID

3. Mencap's interaction and interventions at senior official (policy) and Ministerial level within the Department of Health and related agencies (NHS England, Public Health England, JCVI) throughout the pandemic were typically urgent, and necessary to ameliorate real time adverse impact of decisions that were being made without cognisance of the needs and experiences of people with a learning disability, their families, and the settings, such as supported living, within which many people are supported.
4. A key route of engagement for us was through the Learning Disability and Autism team at NHS England, who had set up weekly collaborative webinars including their own team, the Department for Health and Social Care, and other experts/organisations brought in as necessary. Included on the calls were various other key information and advice providers, campaigning organisations and those supporting self-advocacy. This was an excellent platform to raise concerns in real time and get feedback from others. Issues could be raised as verbal questions during the meeting, or asked in the 'chat', and answers would be distributed later in a weekly FAQ. Outside of these meetings we were also able to raise concerns via email.
5. We made oral and written submissions across a range of issues-

- Problems with COVID-19 guidance relating to the provision of health services and failing to make reasonable adjustments as required under the Equality Act, 2010, for people with a learning disability. This was the case in relation to guidance on hospital visiting and also transport by ambulance. We 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 we 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'. We 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 our comments.
- 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. This 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. 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. 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.
- 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 **I&S** dated 24th March 2020, and another from **I&S** dated 24th March 2020. 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.

- Hospital discharge guidance that led to unsafe discharges; not allowing for the time, nor the planning and safeguards needed to safely discharge disabled people who had care needs in the community. In addition to the concerns we set out in our 'My Health, My Life' report we also fed our concerns into Healthwatch England's report into discharges (590 people's stories of leaving hospital during Covid-19, October 2020).
- Changes to the format of GP consultations, with the move to remote phone or video contact, had taken place with little apparent equality impact assessment. Our concern was that this move to remote consultations could lead to increased difficulties with communication for people with a learning disability, diagnostic failures and 'diagnostic overshadowing', where serious underlying illness is not detected because a clinician makes mistaken assumptions about the person with a learning disability's baseline and usual presentation. We heard from people with a learning disability and their families that in the main adjustments were not being made to this policy for those that could struggle with communication.

Engagement with Welsh policy makers:

6. Our colleagues at Mencap Cymru similarly engaged with Welsh Government officials through opportunities we had as members of the Wales Learning Disability Consortium. Welsh Government officials met weekly with members of the Consortium to present updates and listen to the issues affecting people with a learning disability. We also had representation on various Public Health Wales Vaccines Task and Finish Groups relating to Covid Responses.
7. The Learning Disability Consortium are the 6 third sector organisations which sit on the Learning Disability Ministerial Advisory Group in Wales. The Consortium members are Learning Disability Wales, All Wales People First, All Wales Forum of Parent/Carers, Downs Syndrome Association, Cymorth Cymru and Mencap Cymru and usually meet monthly in addition to the formal meetings of the Ministerial Advisory Group. The Consortium represent the voices of people with a learning disability and family carers and providers of support services and is a direct route into Ministers and officials in Government.

8. During the Pandemic, we would raise issues of concern to our membership such as prioritisation for Covid vaccination, access to accessible information and use of DNACPR and make recommendations to Government on how to address these concerns. Further information on who we raised these concerns with, on what date, and what response was received, is set out below.

Priority for Covid vaccination

On 16th November 2020 we wrote to NHSE's National Director for Learning Disability & Autism, as well as DHSC's Deputy Director for Dementia & Disabilities, asking whether DHSC, NHSE or PHE were making representations to the JCVI on reconsidering their priority criteria for vaccination in light of the PHE and LeDeR reports' insight into the increased rate of death from Covid amongst people with a learning disability. DHSC confirmed on 16th November that the PHE and LeDeR reports had been shared with JCVI, as well as with SAGE.

I attended a stakeholder call on 17th November 2020 with Public Health England's Head of Immunisation and the Minister for Care. The call was to outline the government's plan for vaccine rollout across care settings. On this call I emphasised the importance of prioritising people with a learning disability for vaccination, and the evidence that had been coming out from the Learning Disability Mortality Review and Public Health England's own research on the much increased rate of deaths from Covid-19 amongst people with a learning disability.

Access to accessible information

One early example of Mencap making representation around accessible information and Covid-19 related guidance was on 3rd April 2020, when we established contact with the Deputy Director for Dementia & Disabilities at DHSC, requesting an update on whether the department would be producing easy read versions of public facing materials on the Care Act easements and also on easements to the Mental Health Act. We received updates that day, passing on an easy read document that had been produced by Dorset Advocacy covering the Care Act easements guidance for local authorities that had been issued by government on 31st March 2020.

Use of DNACPR

This 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 NICE's Director for the Centre for Guidelines. 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. 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 on 23rd March 2020 and responses were received from both that day, and Mencap passed to them details of key contacts at NICE we were working with, for their follow-up. A letter was issued on 3rd April 2020 to primary care, Acute Trust CEOs, and Community Trust CEOs, by NHSE's National Mental Health Director, setting out NHSE's position in relation to NICE's Covid-19 rapid guideline, and use of the Clinical Frailty Scale. A further letter was issued on 7th April 2020 by the Chief Nursing Officer (England) and NHSE's National Medical Director, referencing the joint statement on advance care planning and DNACPR made by the BMA, Care Provider Alliance, RCGP and CQC on 1st April 2020. The letter challenged blanket policies in relation to DNACPR.

The issue of DNACPR was discussed at NHS England's Learning Disability and Autism Partners calls. The first of these calls took place on 24th March 2020. In a written document issued by NHSE, dated 17th April 2020, on responses to questions from stakeholders on the call, information was given about the above mentioned letters (3rd April and 7th April 2020) being sent out by NHSE to GPs via the primary care bulletin.

In relation to engagement with the Care Quality Commission (CQC) on use of DNACPR, following the DHSC's announcement on 1st October 2020 of CQC's independent review, we attended the first meeting on 29th October 2020, around the establishment of their review into the use of DNACPR. On 6th November we submitted to CQC, through their Head of Public Engagement, case studies relating to use of DNACPR.

Engagement with UK wide consultations and inquiries during the pandemic

9. The following are consultations and inquiries with which we engaged around the above issues:

- **Public Accounts Select Committee**, 'Covid-19: Supporting the vulnerable during lockdown', written submission, by Mencap, is exhibited to this statement as JS/1-INQ000176401 (February 2021)

The submission set out a range of concerns that we had in relation to access to healthcare services, such as problems with NHS111, the move to remote GP

consultations, barriers to people with a learning disability having visitors when in hospital, and problems accessing wider healthcare support for pre-existing conditions, such as epilepsy or diabetes.

- **Joint Committee on Human Rights**, 'The Government's response to Covid-19: human rights implications'. The written submission from Mencap and Challenging Behaviour Foundation is exhibited to this statement as JS/2-INQ000176402 (July 2020)

The submission highlighted our concerns about NICE guidance on critical care, and use of the clinical frailty scale. We also highlighted concerns about whether people with a learning disability detained under the Mental Health Act in in-patient mental health settings were able to access support and treatment for physical health needs.

- **House of Lords, Covid-19 Committee** inquiry into 'Life Beyond Covid', written evidence by Mencap, is exhibited to this statement as JS/3-INQ000176403 (August 2020)

The submission highlighted our concerns about access to critical care during the pandemic, including the NICE acute care guidance. It also highlighted concerns around access to general healthcare services, issues with support and visitation for people with a learning disability in hospital, and the need for key legislation, such as the Equality Act to be followed relating to provision of reasonable adjustments in healthcare settings.

- **Women and Equalities Select Committee Inquiry: *Coronavirus and the impact on people with protected characteristics***: written submission by Mencap, exhibited as JS/4-INQ000425439 (June 2020)

The submission set out our concerns about equal access to healthcare, NICE's critical care guidance, issues with DNACPR practice, as well as concerns about adherence to the Equality Act and the making of reasonable adjustments in areas like hospital visitation for people with a learning disability.

- **Public Accounts Committee Inquiry: Readying the NHS and social care for the COVID-19 peak**, written submission by Mencap, exhibited as JS/5-INQ000425440 (June 2020)

In this submission we set out concerns about the ability of people with a learning disability to access essential healthcare services during the pandemic, as well as concerns set out above relating to NICE's critical care guidance, inappropriate use of DNACPRs. We also set out concerns around barriers to hospital visitation through restrictive guidance and reflections on how national guidance should in future be developed.

- **Joint Committee on Human Rights: The government's response to covid-19- human rights implications of long lockdown**, Mencap submission exhibited as JS/6 - INQ000425441 (January 2021)

In the submission we covered concerns around national guidance on hospital visitation limiting support for people with a learning disability, and placing them at risk and serious disadvantage. We also highlighted concerns around visitation and health support for people with a learning disability detained in in-patient mental health settings. We also highlighted issues with restricting when people with a learning disability could be accompanied in a medical emergency by ambulance.

Evidence relating to the My Health, My Life report:

10. We published the 'My Health, My Life: barriers to healthcare for people with a learning disability during the pandemic' report [JS7 - INQ000176404] on 7th December 2020 because of the urgent need to document experiences and promote action to address concerns about the many areas of health provision that were rapidly changing or had changed during the pandemic. The report was part of the 'Treat me Well' campaign, which we launched in partnership with the Royal College of Nursing in 2018. This built on over a decade of previous work we had undertaken, highlighting the avoidable deaths of people with a learning disability through reports like 'Death by Indifference' (2007), '74 and Counting' (2012) and then 'Treat me Well' (2018).

11. The report sought to highlight that pre-pandemic, health inequalities were already severe for people with a learning disability, with the 2019 Learning Disability Mortality Review report (NHS England) showing women with a learning disability died 27 years earlier than the general population and men 22 years. The pandemic had made these inequalities even more stark, with Public Health England data from November 2020 estimating that people with a learning disability were dying from Covid-19 at 3-4 times the rate of the general population (Covid 19 deaths of people identified as having learning disabilities: report, 12th November 2020). Through the report we also wanted to set out evidence we had gathered from our survey of Learning Disability Nurses, and what they were reporting relating to the treatment of people with a learning disability that they had observed first hand, as well as the experiences of some of the people who had raised concerns to us about the care they had received in the pandemic.
12. The main themes and concerns in the report were identified from a number of different sources, which we outline below. These included calls and contact from families and people with a learning disability to our information and advice service (helpline) and detailed casework we undertook to support them, our survey of learning disability nurses, guidance from our Treat me Well Steering Group of people with a learning disability and our detailed policy engagement with NHS England, the Department of Health and Social Care and other bodies. Key issues highlighted in the report were-
- Guidance, such as that on visiting people in hospital, or on conveyance to hospital by ambulance (Covid-19: guidance for ambulance services, first published 21st February 2020) did not initially consider the needs of people with a learning disability or reasonable adjustments they had a right to under the Equality Act, 2010, and was therefore potentially unlawful and discriminatory. These pieces of guidance saw people with a learning disability isolated in hospital, or transported alone in ambulances, in fear and without support to express their needs. As guidance evolved and representations from organisations such as ourselves were acted on, there were inconsistent improvements in policy but we remained concerned about how effectively these updates to guidance were communicated to health professionals and operationalised. Throughout the pandemic we consistently raised concerns regarding the visiting guidance (Visiting healthcare inpatient settings during the Covid-19 pandemic, first published 16th March 2020), which after some initial

improvements, reverted back to not meeting the needs of disabled people in October 2020 (as detailed in the report). Calls came into our helpline throughout the pandemic from families who were concerned about their loved ones safety and chances of recovery due to experiencing difficulties being with them in hospital. Several families who had these concerns told us their loved ones who needed support had died before they had been able to address the issues around visiting. Alongside concerns regarding visiting, we also heard about difficulties communicating with wards: where loved ones or supporters were not able to visit, we feel communicating should have increased, however the experience was sometimes the opposite, and we heard of one case where a family were asked not to get in touch at all.

- In terms of specific difficulties in communicating with wards, the primary barrier families and care staff highlighted was being unable to physically accompany a person with a learning disability in hospital, or visit them, due to the restrictive guidance. In addition, we heard that some families were unable to get through by telephone to secure updates on their loved one's progress. We also heard positive stories, from our survey of Learning Disability Nurses, where ward staff were able to support people to communicate with loved ones using tablets, showing how Learning Disability Nurses were able to play a vital role in making reasonable adjustments and facilitating use of technology.
- Our survey work of Learning Disability Nurses suggested that people with a learning disability in hospital were not always getting good quality care, with significant concern expressed by survey respondents about whether reasonable adjustments were being made. Many Learning Disability nurses reported being redeployed, meaning that in many Trusts there may have been a lack of specialist support for patients with a learning disability. Respondents to the survey cited concerns about family members and support staff not being able to accompany someone with a learning disability onto a hospital ward, as well as paperwork not being allowed, meaning key information, such as that in hospital passports, was not available and no-one was there to support and advocate for the person. Respondents also set out concerns about inappropriate use of DNACPRs, as well as the sheer pressure of workload meaning that staff did not have the time to properly support patients with a learning disability in the way they might have done pre-pandemic. They also highlighted the impact of PPE and how this could impede communication and understanding if not adapted to be patient centred.

- NICE guidance on treatment of patients in critical care (Covid-19 rapid guideline: critical care, first published 21st March 2020) was unacceptable, as it suggested the Clinical Frailty Scale (designed for use with older adults without pre-existing support needs) be used to assess disabled adults of working age and older adults with pre-existing disability. A person is given a score according to the number of support needs they have and a person with a relatively high score was not recommended for critical care. This was direct discrimination for a reason related to disability and unjustifiable and unacceptable.
- Hospital discharge guidance (Covid-19 hospital discharge service requirements, first published 19th March 2020) that led to unsafe discharges; not allowing for the time, nor the planning, communication and safeguards needed to safely discharge disabled people who had care needs in the community. There were not sufficient provisions in the guidance for communicating with existing providers of social care, or how to allow for reasonable adjustments to respond to a patient's needs. We are aware of many stories where a person was discharged before they were well enough, and admitted as an emergency in the days that followed. We are aware of cases where people with a learning disability died following what we believe was an unsafe discharge. In addition to our own report we also fed our concerns into Healthwatch England's report into discharges (590 people's stories of leaving hospital during Covid-19, October 2020).
- It was clear that systems were not designed to accommodate the clinical presentation of people with a learning disability. Concerns in relation to 111 were flagged by the Learning Disability Mortality Review in their September 2020 report, which included recommendations made by reviewers into deaths of people with a learning disability (see page 15, 27). The issues identified included concerns about the algorithm then used by NHS111, which did not always identify subtle signs of deterioration in health that were being picked up by family members or carers and therefore did not trigger an alert. Many people with a learning disability may struggle to identify and verbally describe pain, discomfort and other symptoms. This puts them at a disadvantage when using remote consultation, or services such as the online or telephone 111 service, which rely on patients being able to describe their symptoms accurately.

- Some GPs were contacting individuals in care settings, or the care settings themselves 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.
- Changes to the format of GP consultations, with the move to remote phone or video contact, had taken place with little apparent equality impact assessment. Our concern was that this move to remote consultations could lead to increased difficulties with communication for people with a learning disability, diagnostic failures and ‘diagnostic overshadowing’, where serious underlying illness is not detected because a clinician makes mistaken assumptions about the person with a learning disability’s baseline and usual presentation.
- Equally, we were concerned about the ability of many people with a learning disability to fully participate in remote consultations, due to barriers with understanding, communication and technology. We heard from people with a learning disability and their families that in the main adjustments were not being made to this policy for those that could struggle with appointments in this format.

Evidence relating to the use of Do Not Attempt Cardiopulmonary Resuscitation (“DNACPR”)

13. From 24th March 2020 we began to be made aware by colleagues in our care services that some GP surgeries were sending out letters to care settings stating it would be better to keep people being supported at home if they became ill with Covid-19 and provide them with end of life care. This was based on the assumption, as set out in one such letter, that “There is no specific treatment for Covid-19; the care given is supportive only, including breathing support from a mechanical ventilator if required. However, we know that anyone who is frail enough to require full-time care is unlikely to benefit from mechanical ventilation and this is therefore unlikely to be offered in hospital” I&S). Other letters used similar language.

14. The key assumptions within the letters seemed to be that-

- Disabled people of working age who were otherwise healthy, but who required social care support were 'frail' and therefore not likely to benefit from hospital treatment from Covid, so should not be supported to seek hospital treatment. This aligned with the first version of NICE's guidance on acute care, which was released only days earlier on 20th March 2020. A do not treat policy was therefore being recommended.
- DNACPR decisions were sensible, due to, as one letter put it "The chances of success for a patient with advanced disease or frailty are virtually zero. CPR is therefore not appropriate for the vast majority of these people..." (I&S I&S)

15. We were never able to confirm whether the letters were a co-ordinated exercise, following the release of NICE's guidance, and if so where co-ordination was led from, or if they were independent initiatives with similar wording.

16. In addition to this, we 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 we supported was admitted into I&S 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.

17. In another example involving I&S senior managers worked to get a DNACPR removed from a person we 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. Our 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, staff were responsive and engaged with us on the appropriateness of the DNACPR.

18. The Care Quality Commission, in response to the significant level of concern expressed by advocacy organisations and care providers, was asked by DHSC Ministers to undertake an investigation, which led to the research and policy report 'Protect, Respect, Connect: Decisions about living and dying well during Covid-19'. This report, as we expected, found system wide concern about practise in relation to DNACPR, and evidence of their blanket use. Mencap worked with other organisations to submit case studies to CQC (including those above), and suggested areas of the country where they might want to investigate.
19. 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.
20. The way in which some people with a learning disability and family members were approached by medical professionals around advance care planning and wishes in relation to resuscitation was not acceptable. In one specific instance, one of Mencap's support workers overheard a telephone conversation between someone she supported and their GP in which the GP said 'I'm just calling to tell you that I'm putting a DNACPR on your file'. When the lady, who was 42, and healthy, asked what that was, the GP said: "Nothing to worry about, they just won't give you the kiss of life". The person we support replied saying "Oh good, I wouldn't want anyone to kiss me, I might catch Covid".
21. This interaction is a telling example of the highly inappropriate conversations that were taking place around advanced care planning, where people with a learning disability were not being given information, in line with the principles of the Mental Capacity Act, to enable them to make informed decisions about very serious matters. Such information, for many people, would need to be accessible and in an easy read format. We would also expect such discussions to be supported by an advocate, paid carer or family member who knows the person well.

22. In other instances, doctors raised the issue of DNACPR with family members who said they would like time to think about it, and then doctors applied a DNACPR notice regardless.
23. 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 support from 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.
24. 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.
25. 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.
26. 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.
27. We feel it is also important to note that as an ongoing issue, we have seen decisions about care and treatment people with a learning disability influenced by a lack of knowledge and/or ability to make adjustments to care, where a decision can be made that a person is for 'palliative care only' based on a concern that they may not

'tolerate' a particular treatment (sometimes based entirely on conjecture), without seeking specialist help to consider what reasonable adjustments could be made/support could be offered. This was no less an issue during the pandemic and in one such example, an individual was struggling to wear an oxygen mask and was as such recommended for palliative care. Following a call to our helpline, and intervention, the team were able to support the person to manage oxygen by means of a 'tent' and the person went on to make a full recovery.

28. Our helpline service was open throughout the pandemic for people with a learning disability and their families to call if they needed advice around issues such as DNACPR or advanced care planning. Where people were concerned that there might be a DNACPR sitting within their medical notes, and which had not been discussed with them or their family or care staff, we advised contacting their GP to review their medical notes and ensure that documentation was up to date and in line with their wishes.
29. Where people contacted our helpline to express concerns about the way a loved one had died, regarding DNACPR or ceilings of care, or any other reasons, we offered to refer them for legal support.
30. In 2021 Mencap was contacted by two families, in separate areas of England, where healthy young people had been asked during their GP learning disability annual health checks their preferences on DNACPR.

The impact of infection control measures

31. In general, Mencap was, and remains concerned that infection control may have automatically outweighed the Equality Act without legal precedent or due consideration of the consequences, risks and/or benefits.
32. Earlier in this statement, I laid out the difficulties with the visiting policies (Visiting healthcare inpatient settings during the Covid-19 pandemic, first published 16th March 2020), and the ambulance policies (Covid-19: guidance for ambulance services, first published 21st February 2020). In particular, Mencap wish to draw attention to the impact this had on people being able to communicate with hospital teams about their health, and their support needs; this will also have impacted people's ability to be

involved in decision making and for families to be involved in best interest decision making as per the Mental Capacity Act 2005. We also heard stories of people not being allowed to have hospital passports due to an infection risk or not being allowed to take their wheelchairs with them in ambulances, further limiting their ability to communicate/demonstrate their needs. Hospital passports are designed to record key information about a person to enable clinicians to access that information in one document. A passport could cover how the person communicates (eg verbal non-verbal or using sign), what conditions they have, what medication they take, who could be contacted to support them, and what reasonable adjustments they need.

33. Information on policy changed quickly and it was extremely challenging to keep up with the changes and for the third sector to communicate these changes to people and their families/supporters in an accessible way.
34. Mencap heard of several people in one area who experienced difficulties accessing care and treatment as a result of the extra infection control demands placed on patients from a national policy level. We fear that issues accessing care may have been more widespread. For example, the Operating framework for urgent and planned services in hospital settings during Covid-19 (NHS England & Improvement, first published in May 2020), stated that patients had to isolate for 14 days before procedures, and test before elective admissions. Many people with a learning disability who lived in shared settings would not be able to isolate, and many others struggled with COVID testing and were not able to tolerate it. In February 2021, we met with the Test and Trace Team, who engaged with us, particularly concerning those people with a milder learning disability living independently, with no support, would find it difficult to comply and test as required – this was because the kits that were being proposed at that time were very difficult to use, even for those that could test, requiring people to build the packaging from a template, and time phone calls to couriers to collect samples.
35. Overall, infection control resulted in communication becoming harder for a group of patients known already to struggle with communication, with documented severe health inequalities known to arise from delays to care and treatment, and failure to make reasonable adjustments. There was increased reliance on telephone services such as 111, and the use of remote consultations, plus use of PPE limiting in person interactions for the many people who found it difficult to understand people wearing

face coverings. The use of remote consultations in particular raised specific concerns about an increase in diagnostic overshadowing, where a) individuals have experienced delays to diagnosis and treatment due to physical symptoms being attributed to learning disability or mental health and b) where people's symptoms have been attributed to COVID-19 and left to deteriorate e.g. chest infections due to dysphagia. We were also concerned about the ability of people with a learning disability to be able to engage fully in remote consultation, which are so reliant on a fulsome and accurate expression of symptoms, given in person observation is taking place.

36. These difficulties were combined with people being less likely to be able to access support from family carers and/or paid supporters in healthcare settings, as well as less likely to be able to get support from learning disability nurses due to redeployment. Furthermore, people then experienced difficulties accessing the services at all due to the demands placed on them for testing before elective admission to hospital and other services.

Recommendations/lessons learned:

37. Mencap has a number of recommendations that we would like to be acted on to ensure that in a future pandemic the issues set out in this statement are better addressed-
38. **Healthcare Guidance:** Guidance needs to specifically address the needs of people with a learning disability and other groups with protected characteristics as part of a robust Equality Impact assessment process. This must be addressed as part of the initial guidance, not once guidance has already been released. Guidance must address how to ensure that people with a learning disability are able to safely access care, with an eye both to removing any existing barriers to care and to putting extra support/adjustments in place (reasonable adjustments and/or allowing for disabled people to receive more favourable treatment to ensure access), Guidance and policy must also be reviewed to ensure that does not inadvertently cause harm or create barriers to care by anything within, or omitted from, the guidance.
39. There is a high level of risk within rushed and closed drafting of national guidance relating to health service delivery by bodies such as 'Covid cells', without adequate

rapid engagement and consultation with relevant stakeholders to work through unintended consequences, unforeseen issues and implications relating to the Equality Act 2010. **In future, public bodies should have established and well supported networks with key stakeholders to ensure that rapid consultation and development of guidance can be achieved within agreed timescales.** The government's Disability Action Plan (5th February 2024) sets out important commitments in relation to involving disabled people in emergency and resilience planning and lessons from Covid-19 need to be included within the development of the Action Plan's work.

40. **Any corrections to guidance must be clearly communicated with extra flagging to areas which may cause harm, merely correcting the guidance and redistributing is not enough.**
41. Fora, such as NHS England's Learning Disability & Autism partnership meetings, commenced during the pandemic using online meeting technology for the first time. These meetings have evolved and continued, owing to the value of information sharing and engagement, and the inclusiveness of the online sessions that enable large numbers of stakeholders to join from across the country. These networks need to be maintained and enhanced to ensure they can play a full role in any future pandemic situation.
42. **DNACPR, advanced decisions and ceilings of care:** the recommendations made by CQC in their 'Protect, Respect, Connect: Decisions about living and dying well during Covid-19' report need to be fully acted on and sustained within any future pandemic, ensuring that the principles of the Mental Capacity Act and Equality Act are fully respected, and the rights of people to make such decisions with appropriate support and consultation. There should also be much greater transparency around ceilings of care.
43. **Accessibility of information:** Guidance must be made available in formats, such as easy read, that are accessible for people with a learning disability, so they can understand how services are operating and how they will be supported. Extensive promotion of accessible guidance needs to take place, working with stakeholders. Accessible information needs to be released at the same time as standard versions

of information, not days or weeks later, which places disabled people at a substantial disadvantage.

- 44. Reasonable adjustments:** As well as being a legal requirement within the Equality Act 2010, reasonable adjustments are vitally important for people with a learning disability. Though what is considered 'reasonable' may change in times of limited capacity, adjustments still need to be considered and made where possible – this can be a matter of life and death. **The government and national health bodies must issue clear communication about reasonable adjustments and use specific examples to illustrate how hospitals can make reasonable adjustments, even in a time of crisis. This should include specific guidance about what should be considered (i.e. provisions of the Equality Act, and seeking specialist support from a learning disability team or nurse), before a ceiling of care is imposed. It should also make very clear the things that are not acceptable as a reason for deciding not to proceed with further treatment, (i.e. support needs or fear of a person not tolerating a treatment/causing distress without considering reasonable adjustments or extra support).**
- 45. Remote consultations:** a review needs to take place of the equality impact of policy on remote consultations. This review should focus in particular on people with a learning disability, as well as other groups with protected characteristics who may be excluded from accessing healthcare services, such as older people, or where outcomes may be worse.
- 46. Staff re-deployment:** decisions about re-deploying key staff, such as Learning Disability nurses, who support a group with protected characteristics, known worse outcomes in terms of accessing health services, and known high levels of premature and avoidable deaths, should be considered very carefully. Combined with the need, as set out above, to ensure that reasonable adjustments are delivered, re-deployment initiatives need to show they have fully considered equality impacts and assessed these.
- 47. Awareness of existing health based research:** The evidence from LeDeR and Public Health England showed that people with a learning disability were disproportionately impacted by Covid and died in much greater numbers than the general population. Whilst JCVI took on board evidence and did change vaccination

policy to make it available to large numbers of people with a learning disability, in future JCVI and other public bodies should have much better pro-active awareness of the existing extensive research base that exists on health inequalities and premature deaths amongst people with a learning disability and the leading causes of avoidable deaths, which includes respiratory illnesses, so there can be a strong focus on those groups who are most likely to experience vulnerability as a result of policy failing to address their needs.

48. **Reviewing the use and adequacy of datasets:** The adequacy of data needs to be reviewed and a strategic approach developed to improving it. For example, the GP Learning Disability Register was initially used as a gateway to access Covid vaccination, yet only 300,000 out of 1.2 million people with a learning disability in England are on the register. A concerted effort is needed to improve coverage of the register, or recognise data limitations and adopt other approaches.
49. Datasets that were developed during the pandemic response as gateways for access to health services, such as vaccination, through initiatives such as the Standard Operating Procedure for unpaid carers, must be retained and permissions continued so they can be re-activated as soon as needed.
50. **Training and familiarisation of officials:** Officials, if drafted in from other parts of government, need to undertake rapid familiarisation and induction with key stakeholders and teams in the sector(s) to which they are going to be making policy. Government departments and public bodies, at the start of the pandemic, failed to make full use of their own learning disability specific policy specialists. All public bodies should have robust mapping of their in-house expertise relating to the development of policy and guidance, so better use is made of specific existing teams, such as the Department of Health's Disability & Neurodiversity Team and NHS England's Learning Disability & Autism programme, who proved invaluable throughout the pandemic in engaging with stakeholders, relaying serious concerns across government and working to achieve solutions with stakeholders.
51. During the pandemic, we supported families and our own supporters to escalate emergency issues with access to care in a number of ways, including directly intervening with hospital trusts and GP surgeries on their behalf, but also by seeking support directly from NHS England, exercising our own judgement on the degree of

urgency, and the method of resolution most likely to be effective, sometimes needing to use multiple routes, draining our own resources. **There should be a clear and effective escalation pathway for access to care issues for people with a learning disability in times of emergency.**

52. There should be a clear legal framework for how the requirements of the Equality Act and Mental Capacity Act, and Safeguarding, apply and should be considered and balanced alongside requirements for infection control in the event of an emergency.

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: 22/5/24