Witness Name: Frank McKillop
Statement No.: 1
Exhibits: FM
Dated: 1 May 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF FRANK McKILLOP

In relation to the issues raised by the Rule 9 request dated 27/11/2023 in connection with Module 3, I, Frank McKillop, will say as follows: -

Introduction

1) My name is Frank McKillop. I have worked for Enable since August 2017, and was appointed Director of Governance and Policy in December 2023. During the relevant period of the pandemic from March 2020 to June 2022, I worked in Policy, Public Affairs and Charity Development roles for Enable, closely supporting our CEO, our frontline workforce and the colleagues supporting them to keep up to date with changing Government guidance and to help ensure Enable was following best practice across our projects and services to prioritise the health and wellbeing of the people we worked for and with throughout this uniquely challenging time.

2) This statement from Enable is in response to the UK Covid-19 Inquiry's Request for Evidence under Rule 9 of the Inquiry Rules 2006, dated 27th November 2023, in relation to Module 3 of the Inquiry. The views expressed regarding the impact of the Covid-19 pandemic on healthcare systems in England, Wales, Scotland and Northern Ireland are drawn from Enable staff who supported or directly delivered the charity's services during the Covid pandemic, and from Enable's members who have a learning disability and who shared their views on the issues referenced in this statement during the pandemic period.

3) Enable is a charity that supports people, employers and communities across its three pillars – Enable Cares, Enable Works and Enable Communities. We believe in an equal society

where everyone has the right to live, work and participate as active and respected citizens in the communities of their choice.

4) The charity that would become Enable was founded in Glasgow in 1954 by five sets of parents of children who had a learning disability who believed that their children had the same rights as everyone else to live the life they choose. 70 years later, this remains what Enable believes and fights for today.

5) Across the organisation, we deliver self-directed health and social care (Enable Cares), employability and training services (Enable Works), and community projects and campaigns (Enable Communities) for people across Scotland.

6) Employing 2,500 staff and with 12,000 members and supporters, Enable actively supports over 13,000 people to live independently as active citizens in their local communities.

Engagement and submissions

7) From approximately April 2020 and March 2021, Enable met weekly with the Scottish Government Mental Health and Learning Disability team, alongside the Scottish Commission for People with Learning Disabilities (SCLD), Promoting a More Inclusive Society (PAMIS), National Autistic Society Scotland, Scottish Autism and Alzheimer Scotland, to reflect on the changing landscape and to feed in live issues impacting on the population of people who have learning disabilities, autism, and dementia whom we respectively supported. Over the course of the pandemic, we raised issues including:

a) Data collection on infection and mortality rates of people who have a learning disability;

b) Access to the vaccination programme, including support for people to access vaccinations via Learning Disability Nursing Teams;

c) Highlighting PPE supply chain issues in the early days of the pandemic;

   - This included concerns about variations in access to PPE hubs between different geographical areas, with some encouraging emergency access only, while others allowed regular uplifts. The most acute challenges were faced in the early weeks of the pandemic around March to May 2020, but we continued to encounter issues with inconsistencies in approach and capacity to meet local demand through to June 2021.

  - We also encountered situations where standard hub-issued PPE did not necessarily meet the requirements of some providers for more specialised PPE, such as FFP2/3 respirator masks and gowns. This often required additional measures to source specialised PPE or to transport PPE from areas where there was a good supply to areas where there were shortages, and remained a capacity issue through to June 2021.

d) Highlighting the lack of records available to identify the population who have a learning disability for targeted vaccination or shielding support;
  - Data relating to the number of people who have a learning disability was not routinely collected by the Scottish Government. The annual Learning Disability Statistics Scotland collated by SCLD was last published in 2019, and identified 23,584 adults "known to local authorities across Scotland". However, it is acknowledged, including by SCLD, that this is not a full measure of the population with learning disabilities as a significant number do not receive formal support through local authorities. In 2020, the University of Strathclyde's Fraser of Allander Institute estimated that there are in fact 175,000 people with learning disabilities in Scotland [FM/5 – INQ000176348]. It was not clear whether GP surgeries had clear records of which of their own patients had a learning disability, which required some people to proactively approach their GP to request referral for the vaccine when this was rolled out.

e) Connecting in with programmes to support individuals to become digitally connected;
  - The focus of these programmes was on social connection and access to communities of support which could no longer meet in person, rather than a specific focus on access to healthcare.

f) The creation and provision of accessible information about the changing restrictions;
  - This was particularly important early in the pandemic when measures like social distancing and advice on limiting or cancelling meetings and events was so new and unusual to the population at large, and required particular work to ensure the restrictions and the reasons for them were communicated to people who have a learning disability in a clear, appropriate and considered manner. As new restrictions were introduced up to and beyond the first lockdown in March 2020, this exercise needed to be repeated to ensure people who have a learning disability understood the measures that were now in place, such as

restrictions on entering other people's homes or having other people come into your own home. Throughout the early weeks of the lockdown, changes to restrictions were made at times on a daily basis, and further efforts were required to ensure these changes were communicated and understood. As restrictions were loosened somewhat from July 2020, we also sought to communicate this, but then had to reiterate the new restrictions introduced as we headed into the winter of 2020/21. Much of the resource intensity of this task fell upon charities like Enable, although there was some Government support with easy read information.

g) Pressures on family carers and the availability of support.

8) Responding to concerns from people we support who were anxious about allowing staff into their homes, including autistic children we support, we also had direct contact with the First Minister's office to clarify that paid frontline social care staff were still permitted to enter households. This generated significant media coverage and reassured many more people that this practice was permissible.

9) Enable continued to provide the secretariat to the Scottish Parliament's Cross-Party Group on Learning Disability throughout the pandemic, and was instrumental in securing an ongoing dialogue with Scottish Government officials and Ministers at that time. This included a letter which was issued in February 2021 to the Cabinet Secretary for Health and Sport by the Convener and Vice Convener of the Cross-Party Group, sharing the Group's concerns around issues including DNACPR decisions (including anecdotal experiences of DNACPR conversations and forms being taken forward for individuals who have a learning disability, despite assurances and guidance that this would not be the case), vaccination, public health data, social care support and the rights of people in inappropriate long term out of area placements [FM/1 – INQ000176349). The Group's significant concerns about the disproportionate impact of the pandemic on people with a learning disability was based on the evidence published by the Scottish Learning Disabilities Observatory in February 2021 [FM/3 – INQ000417458], which showed that people who have a learning disability were twice as likely as the general population to contract Covid-19, twice as likely to be hospitalised, and three times more likely to die from Covid-19 infection.

10) A response was received from the Minister for Children and Young People on 23 June 2021 which stated that no changes had been made to NHS Scotland's policy on DNACPR as a result of the pandemic, outlined measures being taken to ensure all people who have a learning disability had access to vaccination, and made commitments to improve collection of data and evidence on the population of people who have a learning disability to strengthen policy-making (FM/6 - INQ000471394).

11) A corresponding Motion on support for people with learning disabilities during the Covid-19 pandemic achieved cross-party support, and was debated in the Scottish Parliament on 16th March 2021. Enable prepared a full briefing ahead of the debate highlighting the key issues from our perspective, which included clarity on the guidance and number of DNACPR orders issued for people who have a learning disability during the pandemic, steps to ensure that the visibility of people who have a learning disability in public health data is improved, assurances on the provision of social care support (including Self-Directed Support) to which people are entitled, and the process for using the £20m Community Change Fund to support people out of inappropriate institutional care settings. This briefing was circulated to MSPs from all parties [FM/2 – INQ000417457].

12) In responding to the debate, the Minister for Mental Health stated that the Scottish Government was *"determined to build support to tackle health inequalities as a fundamental human right"*, reiterating that guidance on DNACPR orders had not changed and that the Scottish Learning Disabilities Observatory had agreed to continue to collect and analyse data during the pandemic (FM/7 - INQ000176344).

Access to healthcare

13) It is recognised that people who have a learning disability are in the poorest health of virtually any group in Scotland, and die on average twenty years younger than their peers who do not have a learning disability. Evidence published by the Scottish Learning Disabilities Observatory in 2021 showed that adults who have a learning disability are twice as likely to die from preventable illnesses. In June 2022, recognition of the elevated propensity to poor health of people who have a learning disability led to the Scottish Government introducing The Annual Health Check for People with Learning Disabilities (Scotland) Directions 2022, which provide a duty on Health Boards to provide

Annual Health Checks to all people in Scotland aged 16 and over who have a learning disability.

14) While it is now recognised that it is critical that people who have a learning disability have greater access to primary healthcare services, the reduction in access enforced by the Covid pandemic was highly detrimental to this group. In particular, people who have a learning disability may have greater difficulty expressing and explaining their symptoms, which can make accurate diagnosis and appropriate treatment more challenging. Several individuals who engaged with Enable's online community groups in the early months of the pandemic (around March 2020 to June 2020) told us that the loss of access to in-person GP appointments meant they were less likely to seek medical advice for conditions or symptoms for which they previously would have done so, and where a video call was offered instead, many found it more difficult to explain their condition. In June 2020, two of our members reported finding other technological solutions designed to reduce pressure on GP and A&E services, such as multiple choice online triage questions, particularly difficult to engage with, which increased the risk that people who have a learning disability did not access the healthcare or receive the treatment they needed. Enable offered to support any of our members who might require support with completing online questionnaires and the like.

15) The risk of diagnostic overshadowing is well documented, and many of the people engaging with Enable told us they felt that the move away from in-person GP appointments increased the risk that symptoms associated with specific medical conditions would be dismissed as being related to their learning disability, and not investigated or treated as they would have been for other patients.

16) Enable continued to deliver its frontline social care and support services to over 1,100 individuals throughout the Covid-19 pandemic. In fact, Enable delivered 98% of all contracted hours through our PA (Personal Assistant) Model over the course of the pandemic, even at the height of lockdown. However, we are aware that for a variety of reasons, this was not the experience of all social care providers. Where it happened, the withdrawal of social care and support services had an undoubted impact on the wellbeing of people who have a learning disability, and without close contact with their

Personal Assistants, the risk of medical and healthcare needs going undiagnosed or untreated was significantly higher.

17) As noted above, research published by the Scottish Learning Disabilities Observatory in February 2021 [FM/3 – INQ000417458] found that people who have a learning disability were twice as likely as the general population to contract Covid-19, twice as likely to be hospitalised, and three times more likely to die. Having established the evidence of this elevated risk, Enable successfully campaigned for all people who have a learning disability to be offered the Covid-19 vaccine in Priority Group 6; with an announcement made directly by the First Minister within a matter of weeks in February 2021. This made Scotland the only part of the UK where anyone who has a learning disability – regardless of severity – was entitled to the vaccine at this earlier stage.

18) We welcomed the decision to make new antibody and antiviral treatments available to people who have a learning disability who met certain criteria (primarily those with Down's Syndrome) and tested positive for Covid from February 2022, as well as the opportunity for others to take part in clinical trials. We felt this was due recognition of the heightened risk of adverse outcome from Covid faced by the population who have a learning disability, and we ensured our frontline staff had all available information to support the people they worked for to make a decision about these new treatment options in the event that they tested positive for Covid.

DNACPR and Advance Care Planning

19) We were greatly concerned by reports of people who have a learning disability and their family carers feeling pressured to agree to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions, and the reported use of the Clinical Frailty Scale in medical decision-making around interventions to treat or resuscitate people who have a learning disability and complex needs who suffered severe Covid-19 symptoms. In the early stages of the pandemic (March 2020), the concerns of people who engaged with our online communities of support were largely based on media reports rather than on personal experience, with individuals worried – at a very stressful and frightening time for many people – that they could be denied treatment in the event of Covid-19 infection through a blanket application of DNACPR decisions or rationing of acute care. There was particular anxiety that the Clinical Frailty Scale could be used inappropriately to

deem learning disability as an underlying condition or comorbidity, with treatment decisions stemming from that.

20) We were assured in April 2020 that disability – including a learning disability – alone is not ever a reason for completion of a DNACPR form. Scotland's Chief Medical Officer, Dr Gregor Smith, advised in a response to Epilepsy Scotland at that time that the Scottish Government was: "*currently updating our clinical guidance to ensure that there is clarity in relation to the use of the Clinical Frailty Scale (CFS) which will make it as clear as possible that this should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disability or autism. An individualised person centred assessment is recommended in all cases where the CFS is not appropriate.*" [FM/4 – INQ000417459]

21) A subsequent letter from Interim Principal Medical Officer, Dr John Mitchell, on 5 May 2020 formally outlined this advice to all clinicians (FM/8 - INQ000471396), which was reflected in the Scottish Government's updated COVID-19: Clinical Advice (FM/9 - INQ000471397). The feedback summary annexed to that document, published on 13 July 2020, outlined concerns raised by the groups with which Enable was involved and those of SCLD, disabled people's organisations and the Scottish Human Rights Commission, and the changes made to the guidance in response, including the amendment to say: *"It should be noted that the CFS must not be used in younger people with stable long-term disabilities (for example cerebral palsy) learning disabilities or autism. In these situations, an individual risk assessment is recommended."* (FM/10 - INQ000236638)

22) However, after that time, we still heard anecdotal experiences of DNACPR conversations being taken forward for individuals who have a learning disability, including from two families of young people who had a range of complex needs in the summer of 2020. We were concerned that there seemed to be a disconnect between the direction from the clinical leads within the Scottish Government, and the practice on the ground. At its root, we were particularly troubled that this approach seemed to come from a prejudiced position in terms of assumptions being made about the health, wellbeing and quality of life enjoyed by people who have a learning disability, and

manifestation of the diagnostic overshadowing that too often impacts on healthcare decisions concerning people who have a learning disability.

23) It was apparent to us that many individuals who have a learning disability did not receive sufficient support in relation to advance care planning, and that this impacted people who were on the shielding list as well as those who were not. Primarily, this impact was heightened anxiety not only for individuals who have a learning disability, but for their families, carers and support teams. Specifically, the emotional stress of the emergence of a new and frightening virus plus the significant disruption to everyday life of lockdown restrictions was further compounded by an expectation to consider and discuss the prospect of severe illness and end of life decisions, with limited support, guidance and resources in place to manage these conversations.

24) It was our experience that there was a lack of anticipatory care planning across the board, and it was a challenge for teams at a local level, and for the charity at an organisational level, to effect change because the information required was difficult to obtain. Existing gaps in support from NHS bodies with anticipatory care planning became all the more acute when there was an expectation to address this in the early weeks of the Covid-19 pandemic (March 2020), and resources such as consistent templates, recommended language and approaches, training and guidance would have been helpful for charities like Enable to support the people we worked for and their families. We expressed our desire for such resources through the national groups we were involved with in the early stages of the pandemic, and there initially seemed to be a hope that an NHS board might develop something that could be shared, but this did not seem to be strategically led or prioritised.

25) Communications and information around anticipatory care planning were not immediately provided in an accessible way, which is sadly too common with the low prioritisation often given to easy read and accessible communication for people who have a learning disability. For example, the frequently changing Scottish Government Covid-19 Guidance around lockdown rules and behavioural restrictions was not immediately available in easy read format as those changes were implemented in the early months of the pandemic. Enable stepped in to produce our own easy read resources which were circulated to our mailing list of people who have a learning

disability and their families to help ensure knowledge and understanding of the latest rules, and we also discussed changes to Covid-19 rules in our regular Zoom calls with members. This issue is in itself reflective of the challenges in statutory resources and services, with Community Learning Disability Nurses lacking – and reduced – in numbers to a degree which directly impacted proactive health planning. Enable was represented at the Scottish Learning Disability Nurse Leads Group throughout the pandemic, which served as a means of getting access to quality resources developed by Speech and Language Therapists which could be disseminated across our teams and services.

26) The urgency of the pandemic increased the risk of discussions about anticipatory care planning taking place with people who have a learning disability without input from family members. Although we were not aware of any examples where this happened, this was identified as a risk by the Care Inspectorate, particularly in care at home or supported living services, and good practice was promoted. Enable's Practice Development Team, Quality Manager and Regional Managers worked together to develop and communicate the required practice around anticipatory care planning to ensure appropriate input was sought.

27) It is our view that systemically, the pace with which discussions and decisions around anticipatory care planning were required was overwhelming. Feedback from our frontline social care workforce was that an expectation to consider decisions in the event of severe and/or life-threatening Covid-19 infection, alongside the upheaval of managing Covid-19 restrictions and enhanced infection control and prevention measures, was highly stressful and emotionally draining, not least with the constant fear that our personal assistants themselves risked being infected and unknowingly transmitting the virus. Some of Enable's members, including some who would be considered to be young and in good health, told us they were very worried about what would happen if they contracted Covid-19, which again compounded by social distancing and visiting restrictions, had significant adverse impacts on their mental health.

28) At a national level, health and care services were under-prepared for a pandemic, and the pressure to urgently fill gaps in planning fell upon providers, and impacted the people we work for and their families. There were difficulties identifying the correct process for

anticipatory care planning, and inconsistencies across different Health and Social Care Partnerships, which created additional challenges for national social care providers. Resources were frequently being shared by personnel in NHS Boards and Health and Social Care Partnerships in an attempt to support providers, and while done with the best of intentions, these were often resources pre-dating the pandemic which did not cover the specific challenges of Covid-19. Although perhaps best described as slightly different versions of the same guidance, the variations between the versions used, for example, in Lothian versus Grampian versus Greater Glasgow and Clyde, caused doubt about which was the correct approach, or whether local variations in approach were being encouraged.

29) A Covid-19 specific anticipatory care planning template was eventually produced by Healthcare Improvement Scotland and available from around June/July 2020, at which point it finally felt like there was more solid and consistent support, guidance and resources in place. However, many conversations – and potentially, decisions – about anticipatory care planning had already happened by this point.

30) However, we have not identified from our experience any evidence of disparities between geographical areas or particular institutions in their approach to DNACPRs, or that healthcare providers interpreted a DNACPR as the equivalent of a "do not treat" order. Nor were we made aware through our membership of any examples of ambulance services interpreting a DNACPR as a reason to refuse to convey a patient to hospital. Compatibility or otherwise of the information respectively held about patients with a learning disability by primary and secondary care providers was not raised with us, and we are not aware of this being a problematic issue.

31) Enable prioritised the completion of anticipatory care plans for every person we supported who could be considered at high risk of severe outcomes in the event of contracting Covid. This included a review of the appropriateness of any existing DNACPR decision. The charity's Practice Development Team identified and cascaded the best available accessible information to support people who have a learning disability to understand their rights in relation to challenging existing DNACPR decisions. Enable staff were advised to raise any concerns they might have had about a DNACPR decision, although we are not aware of any of the people we supported seeking to challenge a DNACPR decision.

<u>Infection prevention control measures</u>

32) There is no doubt that restrictions on household mixing had a significant impact on people who have a learning disability who relied on social care and support. Enable's social care services are focused on supporting people to live independently in their own home in the community where they want to live. Therefore, the prospect of lockdown restrictions in March 2020 forced many individuals and families to make a decision on whether they would be physically separated from each other for the unknown duration of those restrictions, or would the disabled person move in with parents, a sibling or other relatives to form a single household for the purposes of Covid rules.

33) Where the individual remained in their own home, the prolonged physical separation – especially where regular contact had been the norm – had an undoubted impact on the mental health of many of those people. Although Enable adhered strictly to all PPE and infection prevention and control guidance, there was nevertheless an entirely understandable anxiety for the family that their loved one was exposed to an inherent risk associated with their Personal Assistants entering their home to deliver the care and support they required.

34) Where the individual moved in with their family, they not only lost the independence that had been important to them, but we are aware that a number of people no longer had access to the professional care and support that had enabled them to live independently, because the family – again, entirely understandably – made the judgement that they did not want to take the risk of Personal Assistants entering the household.

35) PPE was a challenge in general for some of the people we support, given factors associated with their diagnosis. We prioritised the production and availability of accessible information to support their understanding of why PPE was required and so important during the pandemic as a means of mitigating against distress. As well as the real risk that the use of PPE including face coverings – alongside news coverage of the pandemic – could impact on the mental health of the people we supported, we also had to consider the practical impact such measures could have on expressive communication and understanding between the individual we supported and their Personal Assistants.

36) It is our view that there is an insufficient number of Community Learning Disability Nurses in post to support the population who would benefit from their expertise, and that this pre-dates the Covid pandemic. We did not observe a particular impact from redeployment of Learning Disability Nurses as the shortage was already felt prior to the pandemic, nor did we observe any specific impacts on alternative PPE being utilised, such as oxygen hoods rather than face masks, as a result of redeployment.

Changes to legislation

37) We did not identify any particular issues related to legislative changes associated with placements for children and young people detained under the Mental Health Act 1983, or those discharged from detention under the Mental Health (Care and Treatment) (Scotland) Act 2003.

38) Enable did however have concerns around a number of the emergency measures taken to amend legislation impacting on the human rights of people who have a learning disability which were taken in the early days of the pandemic.

39) Specifically, we were concerned about the implications of Section 2 of the Coronavirus (Scotland) Act 2020 which amended existing requirements to provide community care under S.13ZA of the Social Work (Scotland) Act 1968. While we understood the intention to allow local authorities to move swiftly to support vulnerable adults during the pandemic, the human rights of people who have a learning disability and are assessed as not having capacity were sacrificed to this principle in a way that we would not expect any other group's rights to be so readily waived. Removing the requirement for the local authority to take into account the present and past wishes and feelings of the individual and the views of other interested parties was a regressive and, in our view, unnecessary measure.

40) We also had concerns about the amendments the same legislation made to the Adults with Incapacity (Scotland) Act 2000 with the effect of "stopping the clock running" on Section 47 certificates which authorise treatment for incapacitated adults, and on the duration of guardianship orders. The time limits applied to both of these by the 2000 Act are designed to ensure the individual's human rights are paramount and that these

restrictions on their rights and liberty are time limited and subject to review of their appropriateness and necessity. We considered that this action created the risk of indefinite compulsory treatment or guardianship, and that once again, the pandemic had been presented as justification for the human rights of people who have a learning disability to be quite casually sacrificed in the interests of institutional or administrative convenience.

Recommendations/lessons learned

41) Improved collection and reporting of data and statistics relating to people who have a learning disability is crucial to better understand the impact of a new virus such as Covid-19 on this group of citizens, and to quickly make informed decisions that protect and promote their health and wellbeing. The University of Strathclyde's Fraser of Allander Institute published *Scotland's invisible people: Support and opportunities for adults with learning disabilities* in September 2020 [FM/5 – INQ000176348]. The report notes the lack of data collected and reported regarding people who have a learning disability, and explains: *"This is why we have titled this report 'Scotland's Invisible People'. Not only are they not visible in public debate, but the support they receive has receded in recent years and this has largely happened under the radar. COVID-19 has meant that much of the service infrastructure that was relied on has been taken away, and there are grave (and valid) concerns that their human rights are being curtailed."*

42) It is important that the availability of accessible communications, including in easy read format, is a high priority for the dissemination of any future public health advice in pandemic or crisis situations. This includes information about the virus itself, symptoms and any isolation rules, and information about any future lockdowns and the rules that must be followed. There should similarly be accessible information tailored for people who have a learning disability regarding any specific risks they face, and their options for priority treatment or vaccination. To uphold the equal right to accessible information, it is essential that communications are prepared in accessible formats at the same time as general communications are prepared, and available immediately.

43) The maintenance – or where a brief suspension is truly unavoidable, the reinstatement – of full hours of social care and support in people's homes must be prioritised in the event of any future pandemic. The assumption that people who have a learning disability could

suddenly do without their support, that they did not need it when they were not able to go out in the community, or that family members would fill the void were not compatible with those citizens' human right. The availability and provision of whatever PPE is necessary to facilitate the continuation of care and support at home in the event of future pandemics must be a priority on a par with its provision for clinical settings.

44) The disturbing level of apparent ignorance and assumptions that were made about people who have a learning disability with regard to DNACPR forms and the Clinical Frailty Scale demonstrates that it is essential to improve training and awareness among medical professionals of learning disability and the quality of life people who have a learning disability enjoy in their communities when the right care and support is available. The distress this episode caused to so many people who have a learning disability and their families must never be repeated.

Statement of Truth

45) 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: 1 May 2024