



6 December 2022

Name Redacted

UK Covid-19 Public Inquiry

Dear **Name Redacted**

**UK COVID-19 Inquiry: Module 2 – Rule 9 Request to ENABLE Scotland
Reference: 2/R9R/ES/TJS**

Thank you for your invitation to ENABLE to provide information to the UK Covid-19 Public Inquiry. Please find below our responses to the questions set out in the questionnaire:

- 1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.**

The charity that would become ENABLE Scotland was founded 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. 68 years later, this remains what ENABLE Scotland believes and fights for today.

ENABLE Scotland is a charity registered in Scotland (No. SC009024) and a company limited by guarantee (No. SC278976). Across the charity's three pillars – ENABLE Scotland, ENABLE Works and ENABLE Cares – we deliver community projects and campaigns, employability and training, and human rights-driven self-directed health and social care for people throughout Scotland. To date, all of ENABLE's service delivery has been in Scotland only.

ENABLE's vision is a society where every person who has a learning disability will have the choice and control to live the life they choose. Our mission is to support our members to campaign for change, and to deliver services that support people who have a learning disability to live independently as active citizens in their local communities.

- 2. A brief description of the group(s) which the organisation or body supports or represents.**

ENABLE Scotland supports people who have a learning disability, their families and carers. ENABLE is chosen by over 1,000 people who have a learning disability and/or complex needs in 27 of Scotland's 32 local authority areas to deliver social care and support in the community. Our ENABLE Works pillar delivers employability support for 5,500 disabled people, and our charitable projects and services support a further 2,500 people. ENABLE Scotland has a network of 12,000 members and supporters right across Scotland.

An equal society for every person who has a learning disability

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3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

As soon as the potential threat posed by Covid-19 was identified in early 2020, we developed and published a comprehensive suite of easy read resources to help people who have a learning disability and family carers to stay informed, connected and empowered. As the crisis intensified to the point of lockdown, we maintained, updated and disseminated these resources through mailing lists, social media channels and trusted partners. The dedicated coronavirus hub on the ENABLE website received over 2,500 unique visits during the first four months of the pandemic, and 1,015 families on our mailing list were sent information, resources and details of support available. This information was regularly refreshed as the situation and the restrictions were updated.

ENABLE continued to deliver its frontline social care and support services to over 1,000 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.

The PA Model – where the individual chooses and employs the PAs who support them, meaning those PAs are not supporting multiple individuals – proved to be highly beneficial in controlling the risk of infection and enabling consistent hours of support to continue.

[Research published by the Scottish Learning Disabilities Observatory in February 2021](#) 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. However, Covid-19 infection rates and the associated impact among the people supported by ENABLE's PA Model was demonstrably and significantly lower than that of the wider population who have a learning disability – and even of the general population.

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; 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.

Due to the Covid-19 pandemic, the charity was forced to suspend all ACE (Active Communities of Empowered people who have a learning disability) and ACE Youth Group meetings. We knew this would be devastating for many of our members, and made it a priority to contact ACE members by phone to check they were coping and to ask what we could do. Recognising the risk of loneliness, isolation, anxiety and mental health challenges, and with the support of a successful application to the Scottish Government's Wellbeing Fund, ENABLE launched ACE Connect to move our ACE and ACE Youth services online. 300 people who have a learning disability engaged across 273 Zoom sessions, including 80 mindfulness sessions, 48 exercise sessions, 48 film sessions, 32 Covid-19 updates, 32 evening workshops, 16 cooking/baking sessions and 17 party/karaoke sessions. An ACE Connect Helpline was also set up and available from 9am to 7pm throughout the week, taking 228 calls from people who have a learning disability and family members. A further 50 enquiries were handled via social media, and 30 people who have a learning disability were provided with hardware and internet connectivity to access digital support.

We also launched a new Family Connect service to give family carers a regular weekly opportunity to connect online and to hear from and ask questions to expert speakers on topics including health, benefits, personal finances and legal rights.

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4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.

[ENABLE Scotland calls for greater support for people who have a learning disability to access COVID-19 vaccinations – 11 February 2021](#)

[Scottish Parliament Debate on People with Learning Disabilities \(Support during Pandemic\) – 16 March 2021](#)

[Royal Society of Edinburgh, ReSource magazine – Care and Compassion, article by ENABLE CEO, Theresa Shearer – 1 April 2021](#)

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.

ENABLE had 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. This included some of the amendments made by the Scottish Parliament to the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000, and amendments to existing requirements to provide community care under S.13ZA of the Social Work (Scotland) Act 1968.

We were also concerned by reports of people who have a learning disability and their carers feeling pressurised to agree to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms, 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.

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 advised in a [letter 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."*

However, after that time, we still heard anecdotal experiences of DNACPR conversations and forms being taken forward for individuals who have a learning disability. 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.

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ENABLE was also concerned by the apparent invisibility of people who have a learning disability in the public health data collected and reported throughout the pandemic. Until the publication of the initial findings of the Scottish Learning Disabilities Observatory in February 2021 (almost a year after the country entered lockdown), there was no reliable data to back up the anecdotal experiences charities like ENABLE were hearing from our members. This adversely impacted upon our ability to make the case to Government for the additional support people who have a learning disability required in terms of access to vaccines and treatments.

- 6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.**

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 support. Over the course of the pandemic, we raised issues including:

- Highlighting PPE supply chain issues in the early days of the pandemic;
- Highlighting the lack of records available to identify the population who have a learning disability for targeted shielding or vaccination support;
- The creation and provision of accessible information about the changing restrictions;
- Connecting in with programmes to support individuals to become digitally connected;
- Pressures on family carers and the availability of support;
- Access to the Covid-19 vaccination programme, including support for people to access vaccinations via Learning Disability Nursing Teams.

Responding to concerns from people we work for 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. [More information about this is available here.](#)

ENABLE Scotland continued to provide the secretariat support to the 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, including the letter enclosed as an appendix with this submission, which was issued in February 2021 to the Cabinet Secretary for Health and Sport.

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7. **A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.**

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 safety 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. 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."*

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.

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.

As noted in response to Q5 above, the 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.

I hope this information is of assistance to the Public Inquiry. If you have any questions or if there is anything further we can do to help, please do not hesitate to contact us.

Yours Sincerely,

Personal Data

Theresa Shearer
ENABLE CEO

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