

COVID-19 Committee: Call for Evidence

Scottish Commission for People with Learning Disabilities (SCLD) Submission



The Scottish Commission for people with Learning Disabilities (SCLD) is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life* (2013)¹ and *The keys to life* Implementation Framework (2019-2021)².

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning/intellectual disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning/intellectual disabilities and other disabled people are not inevitable. These barriers stop people with learning/intellectual disabilities and other disabled people being included in society and participating on an equal basis.

SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what works.

People with learning/intellectual disabilities experience of the COVID-19 emergency

Evidence shows that people with learning/intellectual disabilities are at higher risk of underlying health conditions, including respiratory disorders such as asthma, COPD, and an increased prevalence of swallowing and eating problems which can lead to chest infections and pneumonia¹. This suggests that people with learning/intellectual disabilities may face poorer outcomes if infected with COVID-19. These poorer outcomes could be because of increased risk of respiratory illness and due to limited access to appropriate healthcare which meets their needs² and diagnostic overshadowing³.

In responding to this call for evidence SCLD has reflected on evidence gathered as part of a survey of people with learning/intellectual disabilities (127) responses and a survey from their parents, carers and supporters (223) respondents and has commented on the key areas identified for comment by the committee below.

Scotland's Approach to the COVID-19 emergency and easing restrictions

SCLD welcomes and commends the Scottish Government on its approach to managing the COVID-19 emergency. We recognise these are unprecedented times in which we are all experiencing challenges. SCLD welcomes Scotland's cautious approach to the lifting of restrictions and has supported many parts of the '*COVID-19 Framework for Decision Making*'⁴ and believes there are opportunities for a differentiated approach on easing restrictions in Scotland from the rest of the UK based on the infection rates, risk factors and consideration of human rights implications.

¹ [NHS Scotland \(July 2017\)](#)

² [People with learning disabilities die on average 20 years earlier than the general population. \(Keys to Life, 2019\).](#)

³ [NHS Scotland \(July 2017\)](#)

⁴ [SCLD \(May 2020\)](#)

SCLD supported the Decision-Making Framework's commitment to the right of life of all people. We also highlighted several areas which we believed could be strengthened. For example, the framework does not discuss specific issues which may be faced by people who have learning/intellectual disabilities and others with protected characteristics. We also asked that further detail and clarity in terms of who will be prioritised for testing. This is critical given those with learning/intellectual disabilities and their family carers who may be especially at risk due to existing health conditions. We were therefore pleased to see that testing has been extended to unpaid carers and support workers⁵.

We also supported the follow-up document to the initial Decision-Making Framework⁶. In considering these documents, SCLD made several suggestions including:

- The use of several key questions regarding equality and human rights implications should be considered (Please refer to PANEL Approach⁷). These questions should prompt decision-makers to evaluate the impact that lifting restrictions will have on groups of people with protected characteristics.
- We asked that moving forward these documents address the specific complexities presented by digital tracking and tracing: challenges for people with learning/intellectual disabilities in understanding the system, digital exclusion and issues surrounding capacity.

Following the publication of *'Scotland's route map through and out of the crisis'*⁸, SCLD is pleased to see a strong commitment to human rights and individuals with protected characteristics, including learning/intellectual disability. However, while the progressive and cautious approach to lifting restrictions is welcomed there several areas which will require clarity for people with learning/intellectual disabilities. This includes:

- Guidance on how and when home support is reinstated at least at pre-lockdown arrangements
- Timelines and procedures for identifying and meeting the needs of people with learning/intellectual disabilities created by the lockdown process and impacts
- Implementation of physical distancing and hygiene measures in public services
- How services will maintain and promote physical health, mental health, and social connectedness for those individuals continuing to shield
- How digital inclusion can be addressed for individuals not known to services (please refer to suggested priorities for action on page 5 of this document).

Maintaining public confidence and support in the public sector response to COVID-19 whilst easing current restrictions

With restrictions to be gradually eased from the 28th of May, SCLD is concerned about how people with learning/intellectual disabilities will be affected during the transition period. Despite the easing of restrictions, public messaging must remain clear about who is required to shield from the virus and the steps which should be taken to protect them. This includes why care and support staff may be communicating wearing PPE. This messaging will need to be conveyed in a way that everyone, including those with learning/intellectual disabilities, can understand.

⁵ [Scottish Government \(May 2020\)](#)

⁶ [Scottish Government \(May 2020\)](#)

⁷ [SHRC](#)

⁸ [Scottish Government \(May 2020\)](#)

One key issue which has emerged from our survey of people with learning/intellectual disabilities, their families, and supporters was the public anxiety which was initially created because of unclear messaging. We must remember that people with learning/intellectual disabilities who may struggle to understand the information in the media often have to rely on information from friends, family, and acquaintances. This information can, at times, be inaccurate and may lead to confusion. As one person told us “*[I'm getting] mixed information, only received info from friends*”. Confusion surrounding public information is leading to increased levels of anxiety and has led to some people with learning/intellectual disabilities and in some instances has resulted in people with underlying health conditions not following advice regarding shielding.

SCLD has been working with the Scottish Government to produce [Easy Read resources](#) on key pieces of public information. As of the 11th May, we know these resources have been accessed by 18,104 people via NHS Inform. Despite this, we remain concerned about how this information is being distributed to people with learning/intellectual disabilities living alone. Clear guidance must be issued for in-home support services on providing information and the use and distribution of easy-read materials. This will need to be supported by the reintroduction of support packages when safe to do so and with the appropriate use of PPE.

Managing the interests of civic society and the economy

SCLD has been clear that the right to life of people with learning/intellectual disabilities cannot be put at risk due to a focus on economic growth. In our earlier commentary on the Decision-Making Framework⁹ we stated,

“SCLD recognises that it is essential to safeguard the economy during this time. However, we have concerns regarding the balance of emphasis between economic and human safety. The original framework document should make it clear throughout that the number one priority is to ensure that there is no avoidable death or harm to any citizens. We accept this must include the interests of ‘broader society’ but this must not be to the disadvantage of marginalised groups.”

To balance the right to life to people with learning/intellectual disabilities with wider economic concerns we would ask that the Scottish Government adopts an approach embedded in human rights law¹⁰. The use of the PANEL human rights approach based on participation, accountability, non-discrimination and equality, empowerment and legality will be helpful¹¹. Consideration should also be given to several human rights treaties including The European Convention on Human Rights (ECHR)¹² (Article 2 and 14); The United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)¹³ (Article 10 and 25); and the International Convention on Civil and Political Rights (ICCPR)¹⁴ (Article 6).

Areas of development in data collection

Gaps in disaggregated data regarding learning/intellectual disability in Scotland has been an issue which predates the COVID-19 emergency; however, our current circumstances have again highlighted this. At present, there has been no

⁹ [SCLD \(May 2020\)](#)

¹⁰ [Human Rights Act \(1998\)](#)

¹¹ [SHRC](#)

¹² [European Convention on Human Rights \(1953\)](#)

¹³ [United Nations Convention on the Rights of Persons with Disabilities \(2006\)](#)

¹⁴ [International Convention on Civil and Political Rights \(1976\)](#)

published data regarding people with learning/intellectual disabilities and COVID-19. We acknowledge and welcome the First Minister's Commitment to this during First Minister's Questions (21/5/2020)¹⁵.

SCLD welcomes the commitment from the Government to ensure the rates of fatality of people with learning/intellectual disabilities is available. Beyond this, we must ensure an ongoing commitment to robust data collection regarding people with learning/intellectual disabilities in Scotland who are required to shield and those with confirmed cases of COVID-19. This will allow for a greater understanding of the implications and timing of lifting restrictions. This is in line with the route map proposals which states that Scotland must incorporate international learning while understanding that *"...each country's experience of the virus is different and we need to consider Scotland population and characteristics as we apply lessons"* (2020,p.10)¹⁶.

A clear picture of the number of people with learning/intellectual disabilities being asked to shield will be critical in ensuring a fair recovery for Scotland. We must be mindful that while restrictions may begin to ease for *'broader society'*, for those most at risk, little or nothing will change. Therefore, action should be taken to ensure data on the number of people with learning/intellectual disabilities shielding in Scotland. This fits with Scotland's Commitment to human rights law and international treaties that we have ratified, including the UNCRPD (Article 31)

Developing an inclusive messaging strategy

As previously stated, easing the changes to restrictions must be articulated clearly to people with learning/intellectual disabilities, their families and those who support them. The use of Easy Read and its effective distribution and support to understand key messages will help to achieve this.

SCLD also believes that more must be done to ensure people with learning/intellectual disabilities and disabled people do not feel left behind in Scotland's renewal and recovery. It should be acknowledged that several initial actions left some disabled people feeling left behind in our initial response to COVID-19. These created considerable, but avoidable, anxiety amongst people with learning/intellectual disabilities and those who support them. These include:

- Proposed amendments to Mental Health (Care and Treatment) (Scotland) Act 2003 and Adults with Incapacity (Scotland) Act 2000¹⁷
- Amendments to existing requirements to provide community care under S.13ZA of the Social Work (Scotland) Act¹⁸
- The pressure to use Do Not Resuscitate Orders (DNRO)¹⁹
- The proposed use of the Clinical Frailty Scale in medical decision making²⁰.

To learn from this experience and to ensure we work more inclusively in the future, SCLD believes our recovery and renewal must highlight the need for public sensitivity and responsibility. To achieve this, members of the public in Scotland will require greater clarity regarding the new restrictions. As far as possible, there should be no room for interpretation of these restrictions which could risk potential spikes in the infection rate, in turn leaving many people

¹⁵ [Scottish Parliament \(21/5/20\)](#)

¹⁶ [Scottish Government \(May 2020\)](#)

¹⁷ [Centre for Mental Health and Capacity Law \(March 2020\)](#)

¹⁸ [Coronavirus \(Scotland\) Act 2020](#)

¹⁹ [SILC \(April 2020\)](#)

²⁰ [SILC \(April 2020\)](#)

with learning/intellectual disabilities at greater risk. We would, therefore, ask that further guidance is developed to ensure clarity.

Moving Forward

As we begin to ease restrictions in Scotland, SCLD would ask that the Committee consider the following priorities for action:

1. A continued focus on data collection regarding COVID-19 and learning/intellectual disability which should include robust data on the protected characteristics of fatalities, alongside the number of people being asked to shield and rates of infection among people with learning/intellectual disabilities
2. Clear national guidance for support workers to deliver consistency in approach. This could include a pamphlet for support workers and an online short video to explain and show best practice
3. A clear plan for those continuing to shield, regarding health care, mental health support and social connection. Particular attention should be paid to individuals with learning/intellectual disabilities who may be living alone and/or under adult support and protection
4. A clear and well-resourced action plan regarding how individuals who are digitally excluded and not known to support services are given access to technology moving forward
5. Training for trackers on how to engage with people who have learning/intellectual disabilities and their carers.

SCLD thanks the COVID-19 Committee for the opportunity to submit to this call for evidence. SCLD would welcome the opportunity to give oral evidence if this would be helpful.



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