

# The Equality and Human Rights Implications of the COVID-19 emergency for people with learning/ intellectual disabilities

Scottish Commission for People with Learning Disabilities  
(SCLD)



## Briefing

### Introduction

The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to provide this briefing to the Equality and Human Rights Committee on the impact of the current COVID-19 emergency on people with learning/intellectual disabilities. SCLD believes Scotland's recovery and renewal must be both fair and inclusive. To achieve that consideration must be given to the disproportionate impact the COVID-19 and the emergency measures have had on people with learning/intellectual disabilities, their families and those who support them.

SCLD invited people with learning/ intellectual disabilities, their family carers to take part in a survey which ran from 14<sup>th</sup> of April until the 5<sup>th</sup> of May 2020. 126 people with learning/intellectual disabilities responded as well as 223 family careers and support staff. Using evidence from this survey, alongside emerging publicly available evidence and commentary this submission outlines key issues impacting on people with learning/intellectual disabilities as well as highlighted links to relevant human rights treaties and equalities legislation.

***Question 1: Which equality groups are being disproportionately negatively affected by the coronavirus, and by some of the measures taken to deal with it?***

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 pneumonia<sup>1</sup>. This suggests that people with learning disabilities may face poorer outcomes if infected with COVID-19. These poorer outcomes will not just be a result of increased risk of respiratory illness but because of already documented limited access to appropriate healthcare which meets their needs<sup>2</sup> and diagnostic overshadowing<sup>3</sup>.

As we know the impact of the COVID-19 has been felt most acutely by those living in care homes<sup>4</sup>, residential settings and prisons, where social distancing may not be able to be achieved. This is greatly concerning when we consider that in 2019 in Scotland, 3,466 adults with learning/intellectual disabilities lived in supported accommodation and 1,837 lived in registered adult care homes<sup>5</sup>.

SCLD have heard concerns regarding the disproportionate impact emergency measures may have on people with learning/intellectual disabilities under amendments to the Mental Health (Care and Treatment) (Scotland) Act 2003 and Adults with Incapacity (Scotland) Act 2000<sup>6</sup>. This sits alongside considerable concerns regarding emergency powers allowing for amendments to existing requirements to provide community care under S.13ZA of the Social Work (Scotland) Act<sup>7</sup>. This, alongside concerns raised in relation to people feeling pressurised to sign Do Not Resuscitate Orders (DNRO)<sup>8</sup> and the possible use of the Clinical Frailty Scale in medical decision making has left many

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<sup>1</sup> NHS Scotland (July 2017)

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

<sup>3</sup> NHS Scotland (July 2017)

<sup>4</sup> 3,948 cumulative cases of suspected COVID-19 in care homes. ([Scottish Government, 6<sup>th</sup> of May 2020](#))

<sup>5</sup> [SCLD \(2019\)](#) of 23,584 adults known to local authorities.

<sup>6</sup> [Centre for Mental Health and Capacity Law \(24<sup>th</sup> of March 2020\)](#)

<sup>7</sup> [Coronavirus \(Scotland\) Act 2020](#)

<sup>8</sup> [SILC \(17<sup>th</sup> of April 2020\)](#)

disabled people and people with learning/intellectual disabilities feeling left behind and/or overlooked in Scotland's response to COVID-19.

It is therefore critical that in advancing equalities and nondiscrimination (as committed to in Part 2 Section 9 Coronavirus (Scotland) Act 2020)<sup>9</sup> we seek solutions to these concerns. For SCLD there are several ways in which this can be addressed. The first is an ongoing commitment to robust data collection regarding people with learning/intellectual disabilities in Scotland. This is a considerable issue which predates the current emergency. COVID-19, however, has again highlighted this issue as there is limited access to date on disaggregated data regarding protected characteristics. This includes, fatality rates, numbers of confirmed cases and numbers of individuals shielding. These gaps in disaggregated data regarding learning/intellectual disability should be considered more widely as part of Scotland's recovery and renewal planning in line with Article 31 of the UNCRPD.

Alongside this ask, SCLD would like to highlight the following issues based on findings from our survey for the committee's consideration below.

## **Key issues impacting people with learning/intellectual disabilities during the COVID-19 Emergency**

### ***Question 2: What equality and human rights impacts there have been?***

#### **1. Removal of support and a loss of independence**

A key concern for people with learning/intellectual disabilities who completed our survey was the removal of their support hours at the start of the pandemic. This has had a detrimental impact both on people with learning/disabilities and their family carers. In our survey, 64% of individuals said their support had changed due to the COVID-19 emergency. One person with a learning/intellectual disability told us, *"My support has stopped, and I feel nervous"*.

This has left many people with learning/ intellectual disabilities feeling isolated and abandoned. This feeling of abandonment is not only felt by people with learning disabilities, but also their family

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<sup>9</sup> *"In exercising a function conferred by virtue of Part 1 (including a function of making subordinate legislation), the Scottish Ministers must have regard to opportunities to advance equality and non-discrimination."* [Section 2 Part 9 Coronavirus \(Scotland\) Act 2020](#)

carers. 58% of parents, family carers and support workers said that people with learning disabilities were not getting the support they needed during the COVID-19 emergency. SCLD has heard of numerous examples of support being removed without continuation of contact from support agencies or social work services. For example, one person told us, *"[We have had] no contact from Social Services or his care providers. Would have been nice to have received a phone call to see how we are coping and how my son is. Feel like they are not interested."*

This removal of home-based support has led to a loss of independence for many. In Glasgow, there has been a reduction of 1,884 people who previously received support<sup>10</sup>. This means that many people with learning/intellectual disabilities have had to rely on or live with their parents instead of living independently. For example, we were told *"[I am] not working. Living with my parents I don't get any support now. I miss my support worker and missing my flat, I am missing being on my own."* For many people with learning/intellectual disabilities, independence is an ongoing issue and the experience of confinement at present may, at times, feel like a loss of choice and control. This loss of support could be interpreted as at odds with the Public Sector Equality Duty (Equality Act, 2010)

**International human rights which have been restricted include:**

**UNCPRD: Article 19**

## **2. Social isolation and the impact on people with learning/ intellectual disabilities mental health**

Some people with learning/intellectual disabilities are facing challenges in being isolated from their friends and family. 57% of people with learning/intellectual disabilities who responded to the survey said they felt lonelier since lockdown measures were put in place. This issue appears to be particularly felt by those in residential settings (including supported accommodation) who can no longer receive visits from their family.

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<sup>10</sup> [BBC \(April 2020\)](#)

In addition to this, everyone is being encouraged to utilize technology to maintain connectedness with our loved ones. It is worth remembering that for many people with learning/intellectual disabilities, this is not an available option. This may be because of the experience of poverty, safeguarding and/or adult support and protection or having access to these resources or having them controlled by professionals. Take for example the experience of a parent carer and their son who is currently in a residential setting:

*“What failed was the attention to ensuring FaceTime was preserved...For three days FaceTime wasn't working. The day before, my son was crying on screen, letting out his emotions, which he can safely do with me because I speak his language fluently...he gets heard and I support him. It's more than just 'chatting' to mum...With me, he puts forward stories about his life, his friends, significant places; and we talk with hope about what lies ahead. There is a lack of recognition of the spiritual needs of somebody with a complex and profound learning disability, in general, and in particular in this situation. Remembering that my son, too, for all his profound cognitive impairment, is frightened, wants to know when he will come home again when he will see familiar people again...”*

Furthermore, the removal of social support networks and loss of independence is likely to be harming people with learning/intellectual disabilities' mental health. As one person told us, “[/] can't do anything I used to do. Life is boring and I am sleeping a lot more.” In addition to this families are noticing changes in their loved one's behavior “my daughter can't understand why she has no visitors so a lot of behaviour issues.”

For these reasons, SCLD welcomes the announcement of the Connecting Scotland [5 million pound fund](#) to enable those who are digitally excluded to have access to computers and support to get online. However, we also have concerns regarding how accessible this fund is to people with learning/intellectual disabilities who do not have social work to support an application and for those whose access to devices may be controlled by professional gatekeepers.

**International human rights which have been restricted include:**

UNCRPD: Article 19, Article 28, Article 30.

ICESCR: Article 12

### **3. Confusion and Anxiety Surrounding Public Information**

Confusion and anxiety surrounding public information may be adding to the deterioration of mental health for people with learning/intellectual disabilities during this time. People with learning/intellectual disabilities may struggle to understand information on the news sometimes and must rely on information from friends, family, and acquaintances. This information can at times be inaccurate and lead to confusion for some. 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 not following advice regarding shielding.

SCLD has been working with the Scottish Government to produce [Easy Read resources](#) on key pieces of public information. Despite this, we remain concerned about how this information is distributed to people with learning/ intellectual disabilities living alone who do not have access to digital resources.

**International human rights which have been restricted include:**

UNCRPD: Article 9, Article 21.

### **4. Concerns Regarding Medical Decision Making**

A considerable source of anxiety for both people with learning/intellectual disabilities and their families has been the confusion surrounding clinical decision making and access to life-saving medical interventions should they require medical treatment. This began with the suggested use of

the Clinical Frailty Scale in the NICE COVID-19 Rapid Response Clinical Guidance. Despite the later amendments to the document, the suggested use of the Clinical Frailty Scale to assess disabled people and people with learning/intellectual disabilities has created an understandable level of critique<sup>11</sup>. It has also created a heightened sense of anxiety for people with learning/ intellectual disabilities and those who support them. As we have heard:

*“Underneath all that is fear: fear of losing him to the virus if he got it - fear of death; fear of challenges to nursing him as he would be so frightened in the main hospital, he wouldn't tolerate an IV drip or a mask; fear of virus causing damage to his lungs, the heart if he got it badly...Fear of being helpless to influence the nursing plan if it came to the point of making decisions because I have already been through that experience once in my life and was overruled by doctors.”*

SCLD also have concerns about people with learning disabilities not being tested for COVID-19 due to diagnostic overshadowing or behaviour deemed as challenging. We, therefore, believe it is important that consideration is given to how we ensure that people who may face challenges in communication are tested and supported to, where possible, make informed choices and have treatment. This should be in line with existing guidance<sup>12</sup>. For more information please see SCLD's commentary on the right to life and health for people with learning/ intellectual disabilities during the COVID-19 emergency<sup>13</sup>.

Further, a greater profile and wider distribution of *'The Clinical Guide for Front Line Staff to Support the Management of Patients with a Learning Disability, Autism or both during the Coronavirus Pandemic'*<sup>14</sup> may be helpful.

**International human rights which have been restricted include:**

ECHR: Article 2, Article 14,

UNCRPD: Article 10, Article 25.

ICCPR: Article 6

<sup>11</sup>[Scottish Independent Living Coalition \(SILC\) of Disabled People's Organisations \(April 2020\)](#)

<sup>12</sup>[Mental Welfare Commission \(2011\)](#)

<sup>13</sup>[SCLD \(2020\)](#)

<sup>14</sup>[Scottish Government \(2020\)](#)

## 5. Access to School Hubs

As a result of school closures many children and young people with learning/intellectual disabilities and additional support needs are now being educated at home without specialist support provision. This is contrary to The Equality Act (2010) as these children are currently being denied services such as additional support for learning.

We have heard concerns from both people with learning/intellectual disabilities regarding access to education and school hubs during this time. In the initial stages of lockdown in Scotland, reports from the Scottish Government showed the low numbers of children with multi-service agency plans accessing these resources:

*“Between 470/530 children who are regarded as vulnerable attended these provisions on each day in the week before Easter. This week, 400/450 have been attending. This represents around 0.5% of the children with multi-agency child’s plans”.*<sup>15</sup>

The low uptake of available places presents concerns. SCLD is also aware of circumstances in which children with complex needs whose parents have learning/intellectual disabilities have been denied places or who are not aware that places could exist for their children. In one circumstance losing both school and home-based support has resulted in a parent’s child being moved into foster care for the duration of lockdown.

### **International human rights which have been restricted include:**

UNCRPD: Article 23, Article 24

UNCRC: Article 28

ICESCR: Article 13

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<sup>15</sup>[Scottish Government \(April 2020\)](#)



## 6. Key issues facing family careers and support staff

We have also heard from both family careers and support staff about key issues facing them during the COVID-19 emergency. This includes:

### Lack of personal protective equipment (PPE)

A lack of access to personal protective equipment (PPE) was a theme which emerged throughout survey responses. Both family careers and support workers expressed serious concerns about not having access to it and the implications this had on providing care. As we heard, [A central issue is] *“Being confined to the client’s home, general anxiety around the family of a client being in a vulnerable group, minimal protective equipment”*

Since the completion of our survey, we recognise and welcome the steps taken by the Scottish Government to increase availability of PPE<sup>16</sup>. We however have concerns about the consistency of its use in service provision.

### Procedural issues facing services

Staff from services expressed concerns regarding a lack of procedures surrounding COVID-19 and what steps they should take if individuals were diagnosed with it. For example, one respondent said, *“We don’t have a clear procedure for what happens when a case is confirmed in service. Would the staff stop coming in? Would 2 staff members have to move in full time to stop their being so many people coming in and out of the house”...*

### Additional pressure on family carers due to the removal of home support

Parents and family carers told us about the impact of additional caring responsibilities. As they said *“I’m a lone parent & sole carer. It’s now 24 hours a day, 7 days a week with no respite at all.”* Another parent spoke of how their son’s anxiety made their own experience of anxiety worse. Another asked why family carers would not be compensated for lost hour of work like others. They

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<sup>16</sup>[Scottish Government \(April 2020\)](#)

stated, *“Unpaid carers seem to be a group who have been left to pick up the work when services to those with LD is stopped. Everyone seems to be compensated by the government...but, not us.”*

**International human rights which have been restricted include:**

ICESCR: Article 7

CEDAW: Article 11

## **Conclusion**

### **Question 3: *What the Scottish Government can change or improve to mitigate these impacts?***

For SCLD, it is critical that recognition is given to the fact that the inequalities experienced by people with learning/ intellectual disabilities were not caused by the current COVID-19 crisis. These inequalities existed before and have been further exacerbated by the current situation. We therefore ask that, as we move towards recovery and renewal in Scotland, we seek to ensure this is a process which is both fair and inclusive. To do this we must seek to address the longstanding inequalities faced by people with learning/intellectual disabilities and make sure that we do not return to a *‘normal’* which sees people with learning/intellectual disabilities experiencing disadvantage.

We would therefore ask the committee to consider the following actions:

- 1.** Provide statistics on the experience of people with learning/intellectual disabilities about COVID-19. For example, the number of people with learning disabilities who have had COVID-19, the number who have subsequent fatalities and the number of people with learning/intellectual disabilities currently shielding. This should sit alongside a broader commitment to address data gaps regarding people with learning/intellectual disabilities as part of Scotland’s programme for renewal.
- 2.** Ensure clear and accessible communication to people with learning/ intellectual disabilities and their families continues to be a priority. This should be explicit about the rights of people

with learning/intellectual disabilities and what should be expected should they require medical treatment.

3. Ensure access to the Connecting Scotland Fund<sup>17</sup> for people with learning/intellectual disabilities who do not have local authority input by looking at a broader method of referral. For example, through third sector partners and individual referrals for those in crisis. There should also be guidance for support staff on how to promote individuals to access technology during this time.
4. With adequate and expanding availability of PPE, support organisations should reinstate support to individuals' homes where safe and appropriate to do so. Clear instructions on the use of PPE and how to fit PPE should be issued to support agencies and used consistently.
5. Producing clear guidance about the removal of support and how people get support reinstated as restrictions are lifted.
6. Ensure clear messaging is issued for clinicians regarding the use of the Clinical Frailty Scale and crucially when it should not be used to assess people with learning/intellectual disabilities and long-term conditions in line with human rights.

SCLD will take further opportunities to submit evidence to the committee and provide commentaries as we continue to gather evidence. We are happy to present oral evidence if this would be helpful. Thank you for taking the time to read this submission.

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<sup>17</sup>[Scottish Government \(May 2020\)](#)

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