

Which groups will be disproportionately affected by measures taken by the Government to address the COVID-19 pandemic?

SCLD believes that people with learning/ intellectual disabilities are being disproportionately impacted by COVID-19 emergency measures. SCLD is aware of several 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 2000¹. These sit alongside other concerns regarding emergency powers allowing for amendments to existing requirements to provide community care under S.13ZA of the Social Work (Scotland) Act², incidents where some people have reported pressure to sign Do Not Resuscitate Orders (DNRO)³ and other concerns about the possible use of the Clinical Frailty Scale in medical decision making. All these concerns have left disabled people and people with learning/intellectual disabilities feeling left behind or overlooked in the response to COVID-19.

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 pneumonia⁴. 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 also because of limited access to appropriate healthcare which meets their needs⁵ and diagnostic overshadowing⁶.

As we know the impact of the COVID-19 is felt acutely by those living in care homes⁷, residential settings and prisons where social distancing may not be able to be achieved. In 2019, 3,466 adults with learning/intellectual disabilities lived in supported accommodation and 1,837 lived in registered adult care homes⁸ across Scotland.

It is therefore concerning that the full scale of the impact of COVID 19 on people with learning/intellectual disabilities in the UK is not yet known. This gap in data collection has been a considerable issue which predates the current emergency. COVID-19 has, again highlighted the need for disaggregated data for those with protected characteristics, including learning/intellectual disability. We understand there is work ongoing across the UK re the provision of disaggregated data relating to learning/intellectual disabilities and this must be used when available to inform the planning of our recovery and renewal in line with Article 31 of the United Nations Convention on the Rights of Disabled Persons (UNCRPD).

What will the impact of specific measures taken by Government to address the COVID-19 pandemic be on human rights in the UK?

¹ [Centre for Mental Health and Capacity Law \(24th of March 2020\)](#)

² [Coronavirus \(Scotland\) Act 2020](#)

³ [SILC \(17th of April 2020\)](#)

⁴ [NHS Scotland \(July 2017\)](#)

⁵ People with learning disabilities die on average 20 years earlier than the general population. ([Keys to Life, 2019](#))

⁶ [NHS Scotland \(July 2017\)](#)

⁷ 3,948 cumulative cases of suspected COVID-19 in care homes ([Scottish Government, 6th of May 2020](#))

⁸ [SCLD \(2019\)](#) of 23,584 adults known to local authorities

SCLD surveyed people with learning/intellectual disabilities (127 respondents), their families and those who support them (223 respondents) during April 2020 about the considerable impact of COVID-19 and the emergency measures on their lives. The key issues which emerged from this survey are outlined below:

1. Removal of support and a loss of independence

Some people with learning disabilities have had their support removed. This has resulted in a loss of individual's independence. For example, in Glasgow, there was a reduction of 1,884 people receiving support.⁹ SCLD has also heard stories of people having their support removed but still having to pay for this support from their Self Directed Support packages at this time. This loss of support can be interpreted as at odds with the Public Sector Equality Duty (Equality Act, 2010). Furthermore, it could be argued that these measures contravene Article 19 of the UNCRPD.

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

People with learning/intellectual disabilities are facing significant challenges in being isolated from their friends and family. 57% of people with learning/ intellectual disabilities surveyed said they felt lonelier since lockdown measures were put in place. This issue is particularly significant for those in residential settings, including supported accommodation, who can no longer be visited by their family.

At this time, we are all being encouraged to utilise technology to maintain connectedness with our loved ones. It is worth remembering that for many people with learning disabilities, this is not an available option. This may be because of the experience of poverty, issues in relation to safeguarding and/or adult support and protection or not have access to the necessary equipment and finances to support this. It is likely that several human rights have been restricted under social isolation and distancing measures. This includes: Article 19, 28 and 30 of the UNCRPD and Article 12 of the ICESCR.

3. Confusion and Anxiety Surrounding Public Information

Confusion and anxiety surrounding public information during the pandemic appear to have had a negative impact on the mental health of people with learning/intellectual disabilities. People with learning/intellectual disabilities who may struggle to understand information in the media including social media may rely on information from friends, family, and acquaintances. This information sometimes can be inaccurate and lead to confusion for some. It appears that confusion surrounding public information is leading to increased levels of anxiety and has led to some people with learning/ intellectual disabilities not fully following advice regarding shielding. Human rights impacted include Article 9 and 21 of the UNCRPD.

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. 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 whose conditions are not '*stable*' has created an understandable level of critique¹⁰. Human Rights contravened due to the

⁹ [BBC \(April 2020\)](#)

¹⁰ [Scottish Independent Living Coalition \(SILC\) of Disabled People's Organisations \(April 2020\)](#)

proposed use of the clinical frailty scale could include: Article 2 and 14 of the ECHR, Article 10 and 25 of the UNCRPD, Article 6 of International Covenant on Civil and Political Rights (ICCPR) and Article 12 of ICESCR.

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. In addition, early reports from the Scottish Government showed low numbers (0.5%) of children with multi-service agency plans accessing these resources¹¹.

SCLD is also aware of circumstances in which children with complex needs whose parents have learning/intellectual disabilities have been denied places at the hubs or are not aware that places could be available their children. In one circumstance losing both school and home-based support has resulted in a parent's child being moved into full time foster care for the duration of lockdown. Human rights being restricted because of this could include: Article 23 and 24 of the UNCRPD, Article 28 of United Nations Convention on the Rights of the Child (UNCRC), and Article 12 of ICESCR.

6. Issues facing family carers and support staff

Alongside issues facing individuals with learning/ intellectual disabilities there are several potential human rights implications for both family carers and support staff. These include access to Personal Protective Equipment (PPE), procedural issues and uncertainty facing support staff, and additional pressure on family carers because of the loss of support packages. These circumstances potentially restrict full realisation of Article 7 of ICESCR and Article 11 of the Convention on the Elimination of Discrimination Against Women.

What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?

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 pandemic. To address these possible infringements on human rights, SCLD ask for consideration of the following:

1. Provide statistics on the experience of people with learning/ intellectual disabilities regarding COVID-19. For example, the number of people with learning disabilities who have had COVID-19, the number of fatalities and the number of people with learning/intellectual disabilities currently shielding.
2. Continue to ensure clear and accessible communication to people with learning/intellectual disabilities and their families. This should be clear about the rights of people with learning/intellectual disabilities and what they can expect should they require medical treatment.

¹¹ [Scottish Government \(April 2020\)](#)

3. With the adequate and expanding availability of PPE, ensure support organisations reinstate support to individuals' homes where this is requested, and it is safe and appropriate to do so. Clear instructions on the use of PPE and how to fit PPE should be re-issued to support agencies.
4. Ensure individuals self-directed support packages are not being used to pay for support which is not being provided. These should instead be used flexibly and transferred to meet additional support costs incurred by the COVID-19 emergency.
5. Ensure clear messaging for clinicians regarding the use of the Clinical Frailty Scale when it can be used and when it should not be used, 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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