



# The **State** of Our Rights

The human rights issues facing people with  
learning disabilities in Scotland (2021-2023)  
and a route map for change



# Contents

---

<b>Forewords</b>	<b>3</b>
Aaron Hume	3
Fiona Dawson	5
<b>John's story</b>	<b>7</b>
<b>Introduction</b>	<b>10</b>
<b>1. The Universal Periodic Review: process and methods</b>	<b>12</b>
Process	12
Methods	14
<b>2. Outcome of the 4th Universal Periodic Review of the United Kingdom for people with learning disabilities</b>	<b>15</b>
<b>3. The state of our rights: where are we now?</b>	<b>17</b>
<b>4. The Scottish constitutional and legislative framework</b>	<b>18</b>
<b>5. Acceptance of international norms</b>	<b>21</b>
Complaints mechanisms	21
Gender-based violence	23
<b>6. Equality and non-discrimination</b>	<b>25</b>
Hate crime	25
Data collection	26
<b>7. Emerging human rights violations experienced by people with learning disabilities in Scotland</b>	<b>28</b>
Failure to protect the right to life during the COVID-19 pandemic	28
Restrictions on independent living during, and following, the COVID-19 pandemic	30
Failure to respect liberty	32
Failure to ensure equal recognition in the law	35
Failure to protect from torture, cruel, inhuman, or degrading treatment or punishment	37
Failure to provide an adequate standard of living and social protection	38
<b>8. The route map for change</b>	<b>43</b>
<b>9. Recommendations for change</b>	<b>46</b>
<b>Conclusion</b>	<b>50</b>

# Forewords

---

## Aaron Hume

**Aaron Hume is a Human Rights Defender. He promotes the human rights of people with learning disabilities in Scotland. Aaron has served on the Scottish Government's Human Rights and Learning Disability Lived Experience Board and has collaborated with SCLD on the Human Rights Town app. Aaron is also a board member of Values into Action Scotland (VIAS). He participated in the campaign 'This is me: valuing the lives of people with learning disabilities.'**



I am pleased to co-present **The State of Our Rights** to you all. This report is about our human rights, but it is also about how they impact on us in our day-to-day lives too.

Human rights can be simple things like accessibility and making sure you can travel from one place to another without any barriers getting in your way. Human rights can also mean getting your voice heard in a meeting about you.

In recent years people across the UK don't always get their rights upheld. This is even more so the case for people within the learning disability community who are often ignored while being deemed as less capable than others in society.

Over the years, some things have improved, such as the closure of long-stay hospitals and a move towards community inclusion. The UK Government introduced the Equality Act in 2010, which defined disability as a protected characteristic. Despite this, we know people with learning disabilities remain in hospital, experiencing out-of-area placements, delayed discharge and violations of their rights through the use of restraint and seclusion.

In 2022, there was a Disclosure documentary about people with learning disabilities and autism being locked in hospitals in Scotland. It told us that some of these people had been trapped in hospitals for more than 20 years after being sectioned under the Mental Health (Care and Treatment) (Scotland) Act 2003 by professionals during a crisis. Some professionals say these people would be a 'danger to society'. This is a heart-breaking label to give someone with a learning disability or autism. We need to bring people back home to their communities to be around their loved ones so they can live a whole and happy life!

I don't believe in terms like 'challenging behaviours'. Instead, what some people call 'challenging behaviour' is the only way that a person who may not communicate verbally might be able to express an opinion. It's not always dangerous, and it's not on purpose. This is a critical human rights issue that we must fix.

In this report, SCLD will highlight several human rights issues that people with learning disabilities are still facing today. One of the most significant issues is that a learning disability is still considered a 'mental disorder'. This doesn't seem right. Some people may need support for a mental health condition, but it's not because they have a learning disability. People with learning disabilities in Scotland want learning disability removed from the Mental Health (Care and Treatment) (Scotland) Act 2003.



This report is informed by the experiences of people with learning disabilities from across Scotland who came together in 2021 to discuss the top human rights issues impacting them the most. These issues were then shared with the United Nations. We hope that the Scottish Government, local authorities and decision-makers across Scotland take all of the recommendations in this report on board and put them into practice.

We must remember that everybody has human rights, no matter who we are and where we come from. Human rights must be accessible to everyone at the end of the day.

*AHume*

**Aaron Hume**

Human Rights Defender

# Fiona Dawson

**Fiona Dawson is a Human Rights Defender. She promotes the human rights of people with learning disabilities in Scotland. Fiona has served on the Scottish Government's Human Rights and Learning Disability Lived Experience Board and has collaborated with SCLD on the Human Rights Town app. Fiona is also an Include for Good Rapporteur and the Co-Chairperson of the National Involvement Network for Scotland. She participated in the campaign 'This is me: valuing the lives of people with learning disabilities'. Fiona has also worked with her local health and social care partnership to develop the new Learning Disability Strategy for South Ayrshire as part of the League of Champions.**



Human rights matter to every one of us. Human rights are there to protect us, and it's there for a purpose. We have a voice, and it needs to be heard! Human rights have a place in our hearts. Human rights do matter, and we need to stand up for them.

For many people with learning disabilities, human rights are not being met, and we are being left out or locked away in hospitals. People with learning disabilities need support to break down these barriers and get our human rights. We need to get this right for everyone. We need to keep moving forward with a commitment to making our human rights a reality.

People with learning disabilities need choice, flexibility and control. We have a right to do what we want in life. We have a right to live our lives. For this to happen, we need to see changes. We need to have choices, make our own decisions, and have the right help and support when we need it. We need freedom as well as responsibilities. We need to use our human rights to care for others and ourselves.

Scotland is changing; we are creating a new human rights law for Scotland. I have had the opportunity to be part of a Scottish Government Lived Experience Board which gives us a chance to make sure people with learning disabilities get their rights and have the life they choose.



I have also participated in the Human Rights Town App Development Group. People with learning disabilities co-produced and co-designed Human Rights Town for people with learning disabilities across Scotland. You can download the app on the Apple App Store or the Google Play Store. The app deals with our everyday life and the situations we experience. Not everyone knows about human rights, so this app makes sure that human rights are accessible and understandable.

I welcome **The State of Our Rights**. This report is important because it will help to get the message out about people with learning disabilities' experiences in Scotland. It is crucial that human rights are considered and that we ensure disabled people and people with learning disabilities get their human rights. It should be a priority!

People with learning disabilities should never be left out or locked away. We are not monsters and should be treated equally in getting our human rights.

Decision-makers from across Scotland should talk to us directly. Let us have a voice; we must be heard, so that we can stand up for our human rights.

*Fiona Mary Dawson*

**Fiona Mary Dawson**

Human Rights Defender

# John's story



**Trigger warning:** the following story describes the institutionalisation of a person with a learning disability and the restriction of their fundamental human rights and freedoms. Some people may find this account distressing.

“My name is John.<sup>1</sup> I grew up in the Royal Scottish National Hospital (RSNH) when I was a wee tot. I don't remember my life before that. I went in there when I was about two or three years old. They put me in the hospital because they said I had epilepsy and I was having fits, but I don't remember if I ever had fits.

The juvenile hospital I grew up in was big. More than 100 people were living in it. It was noisy. The wards in the hospital were all named after Scottish islands, like Uist, Mull and Iona. It was all different weans in the hospital, some who didn't need that much help and some who needed a lot of help. We all kept to ourselves, the staff talked to the staff, and the patients spoke to one another. Nobody ever asked how you were feeling.

We slept in big wards with all the beds lined up back-to-back; we had wee lockers you could put your stuff in. But none of us really had anything like toys or anything like that. If we did have anything, it wouldnae last long; someone would break it.

None of us had our own clothes. We had wee hospital uniforms, but they didnae belong to us. The staff would just decide in the morning what would roughly fit each of us, and that would be it.

I remember the shirts had RSNH stamped on them in red with dots, and our shoes had them on the soles as well. If we went out on day trips, we would try to cover the RSNH logo up. We didnae want people to see that.

Occasionally we would go out on wee trips to the football, or I would go swimming at Polmont Borstal. I remember I used to see the man mopping the floor there. But most of the time, we couldn't do what we wanted. We mainly sat in the parlour in the daytime, twiddling our thumbs. We just did what we were told to. You get institutionalised.

---

<sup>1</sup> Person's name changed to protect anonymity.

We did have school, and we did basic reading and writing, but that never really worked. Occasionally one of the teachers brought in soft toys, and we could draw them. I quite liked that.

When I was a bit older, 14 or 15, I moved to another hospital called 'The Colony'. It had big cast iron baths, and the staff would come in and watch you take a bath and get dressed. It wisnae very dignified. I had a friend in that hospital; he used to play the chanter in the bathroom.

Sometimes in the hospitals, I would help the staff make the beds. A few people had wee jobs like cutting the hedges or cleaning. You could earn like £1 or £2, but no much, just pocket money to buy sweeties or a packet of cigs from the hospital tuck shop. Better than nothing.

I never knew my family growing up; I never really had many visitors in the hospitals I lived in. When I was growing up, I never knew when my birthday was, and for many years didn't even know it had passed. Sometimes, if a staff member at the hospital noticed it was my birthday, they might give me a card, but that didnae always happen.

I never really got many Christmas presents as a kid; one year, the hospital gave me a glass wae Tom and Jerry on it, and another year I got a black and white polaroid camera. Later on, another patient gave me a colour polaroid camera, but that was it.

Now I love photography; I take photos all the time. I keep them all in my house now in albums or Jacob's cracker tins. I probably still have the photos I took in the hospital on the black-and-white camera, but I'd need to dig them out.

In the past, I could be a bit of an angry young man at times, but the staff in the hospital would really wind up the patients. I was restless, so the staff gave me a lot of tablets. If I had been a 'bad boy', I would be sent to see the doctor, who would give me more tablets.

I was on a lot of tablets. I was on phenobarbital for a long time, but I don't take any tablets any more. The tablets would come around in the dining room at mealtimes on a big silver trolley with the food. The food was alright, usually cold or lukewarm. I'm no a fussy eater.

After about 20 years, I got out of the hospital. I moved into a group home with three other people. I needed that then, but I didnae really like the people I lived with, personality clashes, you know? I guess that's what happens when you don't pick the people you live with.



I did make some friends from other places. During the day, I would go to a day centre where we would do chair weaving, but it was busy and noisy. Occasionally I would see the minister from the hospital, I went around and did his garden, and sometimes we would play badminton. We would run about like hooligans; it was like sword fighting. I was doing a lot of gardening for a while, one woman whose garden I did worked me hard but always gave me a wee brandy, sherry or whisky when I finished. I still do a bit of gardening, but I'm not taking on any more right now.

Eventually, I got into my own house; it's got two bedrooms and is filled with my artwork, photos and DVDs. I have photos of my friends on the fireplace.

I got involved with the art project<sup>2</sup> cause I've always liked art since I was a youngster. I've been with that project for a long time now. I work in all art forms like ceramics, tapestry, lino cutting, watercolour, papier-mâché, everything really. My least favourite is probably acrylic. I have had a load of exhibitions, between 40 and 50 of them. Some of my favourites were the ones I did, where I painted on a gallery wall to illustrate a road trip. I've had exhibitions all around the world. I like what I do and think I'm alright at it. The National Galleries of Scotland recently bought a collection of my work.



I see my family sometimes now. My mum used to be a painter, and my dad used to be an engineer; I think I maybe get some of my artistic traits and problem-solving skills from them. I found out when I was around 40 years old I had a sister, the Salvation Army Tracing Service contacted me and said, "Do you want to meet your sister? I just said, "Aye", right away. I was glad to see her. I don't see her as much as I would like now, though.

When I think back on my life and what I would want to see different for people now, I would say we need the government to try and improve people's lives, no put people in institutions. I never thought I'd be where I am now; when I lived in the hospital, I used to think, I'll be 10 foot in a wooden box before I get out of here. I'm going to die in here."

---

<sup>2</sup> Project's name removed to protect anonymity.

# Introduction

---

“Listen to our choices!”

Universal Periodic Review focus group participant (November 2021)

Scotland is changing, and for people with learning disabilities these changes could be significant in empowering them to live the lives they want. While Scotland no longer has a universal approach to confining people with learning disabilities in institutions, many people with learning disabilities still face significant barriers to realising their human rights. These problems remain unchallenged in part because of the invisibility of this population and the dehumanisation they face.

Despite this, people with learning disabilities are clear they will have their views and voices heard. The Human Rights Town app,<sup>3</sup> launched in August 2021, supported people with learning disabilities to engage with human rights developments in Scotland and, most critically, gave them the language of human rights to frame and better understand the inequality they face. The app built on the continued organisation of people with learning disabilities and their unwavering self-advocacy through organisations like People First (Scotland), the National Involvement Network, Central Advocacy Partners, and the Assembly.

**The State of our Rights** further develops this work and is based on an expanded and updated version of the SCLD and Values into Action Scotland (VIAS) joint submission to the Universal Periodic Review in 2022. It is SCLD’s ‘state of the nation’ report, highlighting the most severe human rights violations facing people with learning disabilities in Scotland. It seeks to establish a baseline of the most significant human rights failings faced by people with learning disabilities, and to propose a route map for change.

It is a challenging reality for Scotland that the baseline detailed in this report is so low. Despite a move away from widespread institutionalisation, the practice still exists, and there is no shortage of examples. One of these relates to Kyle Gibbon,<sup>4</sup> who is currently detained in The State Hospital, Carstairs, based on disability.

SCLD believes that cases like Kyle’s exist in Scotland because people with learning disabilities are denied their fundamental human rights, including their right to justice. Central to this is the existing Mental Health (Care and Treatment) (Scotland) Act 2003, which defines learning disability as a ‘mental disorder’. This means that people with learning disabilities can be detained in hospital on the grounds of disability

---

<sup>3</sup> [SCLD \(2021\)](#)

<sup>4</sup> [Press and Journal \(August 2022\)](#)

alone – they do not need to have a mental health condition. SCLD believes this is unacceptable in a Scotland that is committed to being a world-leading proponent of human rights.

Furthermore, when people with learning disabilities do live in their communities, they are systemically excluded from many areas of public life, including but not limited to education, employment, relationships and family life.

In the most horrifying instances, we see people with learning disabilities being denied their right to life due to a public failure to intervene, such as in the case of Margaret Fleming.<sup>5</sup> Margaret was a woman with a learning disability who went missing for over 18 years. Margaret's carers were subsequently found guilty of murder and her body has never been found. In the light of this example, and the many cases of people with learning disabilities across the UK being detained, restrained, abused and excluded, SCLD would argue that the experience of people with learning disabilities must be a priority for key decision-makers and they should engage with this report in detail.

SCLD believes it is our collective responsibility to make progressive changes to fully realise human rights for people with learning disabilities. In doing this, we must also recognise the considerable value people with learning disabilities bring to Scottish society, despite the significant human rights violations they experience.

Towards the end of this report, SCLD presents a route map for change. This outlines a five-year work plan for Scotland, along with a series of recommendations which have people with learning disabilities at their heart. SCLD believes this route map can support people with learning disabilities in the progressive realisation of their human rights.

**The State of Our Rights** has been co-produced with people with learning disabilities and builds on all the evidence collected by SCLD from its engagement with people with learning disabilities. People with learning disabilities have told SCLD they will no longer accept being at the 'bottom of the pile'<sup>6</sup> and are determined to no longer be invisible and ignored.

SCLD would like to thank everyone who offered their contributions to this report.

---

<sup>5</sup> [BBC \(2020\)](#)

<sup>6</sup> Women with a learning disability told SCLD they were, "fed up with people with learning disabilities being at the bottom of the pile" at an engagement event.

## Section 1

# The Universal Periodic Review: process and methods

## Process

The Universal Periodic Review (UPR) is a process enabling the human rights progression in UN Member States to be examined in detail by the United Nations Human Rights Council. This includes assessing the status of human rights in the United Kingdom (UK). Member States participate in the UPR every four years. The review process leads to a series of recommendations for each Member State to help them improve their national human rights situation. The Member States are expected to implement these recommendations before the next review.

At the beginning of a new UPR cycle, documents are submitted to the United Nations, including a stakeholder summary report based on individual submissions by relevant stakeholders, such as non-governmental organisations (NGOs), national human rights institutions (NHRIs), and civil society organisations (CSOs). 'Pre-sessions' are then held at which selected stakeholders present their reports and encourage other Member State delegations to raise the issues at the Member State review.

SCLD was pleased to take part in the UK's 4th UPR cycle by submitting a report (available to download [here](#), along with accompanying [factsheets](#)) and participating in the pre-session in the summer of 2022. At the pre-session, SCLD spoke about three key issues:

1. The inclusion of learning disability within Scottish mental health legislation.

**SCLD FACT SHEET**

**INCLUSION OF LEARNING DISABILITY WITHIN SCOTTISH MENTAL HEALTH LEGISLATION**

**The 'Coming Home' Report Findings**

**Delayed Discharge**

- 67 people with learning disabilities and complex needs were subject to a delayed discharge.
- Of these, 22% had been in hospital for more than 10 years and another 9% for 5 to 10 years.

**Out-of-Area Placements**

- Of the 705 people living in Out of Area Placements, 45% had been out-of-area for more than 10 years.
- 109 people had not chosen their placements and were identified as a priority to return.
- 79 people were placed outside of Scotland.

Source: Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs, Dr Anne Macdonald, Scottish Government (2018)

**More Information**

oonaigh.b@sclcd.co.uk | www.sclcd.org.uk | 0141 248 3733

Scottish Commission for People with Learning Disabilities

People with learning disabilities left in Scottish hospitals for decades. Every people had stayed at 10 years or more. BBC Documentary

The Independent Review of Learning Disability and Autism in the Mental Health Act

**SMHLR**  
SCOTTISH MENTAL HEALTH LAW REVIEW

2. Torture and cruel, inhuman or degrading treatment or punishment of people with learning disabilities.
3. Equality and non-discrimination, including gender-based violence and hate crime.

The UPR process aims to ensure that Member States meet their human rights obligations and is an important step in ensuring that people across the UK can realise their human rights.

To SCLD's knowledge, no specific mention of people with learning disabilities in Scotland was made in recommendations submitted to the UK during the three previous UPR cycles. However, recommendations regarding disabled people and other minority groups have been made in the past which are relevant to people with learning disabilities. These include recommendations relating to gender-based violence, hate crime and disaggregated data collection.

SCLD believes that without a specific reference to the experience of people with learning disabilities in the UPR, a significant opportunity to raise the issues facing them internationally is being missed, along with the opportunity to drive change at both a UK and devolved-nation level. SCLD therefore took part in the UPR with the intention of increasing awareness around the human rights issues facing people with learning disabilities. The outcomes of this involvement are outlined on pages 15–16 of this report.

For more information on the UPR process, visit the UPR website [here](#).

## SCLD FACT SHEET

### TORTURE, CRUEL, INHUMAN, DEGRADING TREATMENT OR PUNISHMENT OF PEOPLE WITH LEARNING DISABILITIES

The 2018 'Coming Home' Report revealed how restrictive practices were used against people with learning disabilities and autism in out-of-area placements and when experiencing delayed discharge. The report also found that antipsychotic medications are used to manage 'challenging behaviour'.

#### The 'Coming Home' Report Findings

**Of 705 people in out-of-area placements:**

- 21% were subject to physical restraint
- 11% were subject to seclusion
- 44% were in receipt of medication to manage behaviour
- 36% were subject to environmental restrictions
- 9% were subject to technological restrictions.

**Of 67 people experiencing delayed discharge:**

- 37% were subject to physical restraint
- 10% were subject to seclusion
- 63% were in receipt of medication to manage behaviour
- 43% were subject to environmental restrictions.

Source: Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs, Dr Anne Macdonald, Scottish Government (2018)

**More Information**  
[donagh.b@sclcd.co.uk](mailto:donagh.b@sclcd.co.uk) | [www.sclcd.org.uk](http://www.sclcd.org.uk) | 0141 248 3733  
 Scottish Commission for People with Learning Disabilities

## SCLD FACT SHEET

### EQUALITY AND NON-DISCRIMINATION

#### Gender Based Violence

**Globally, 90% of women with learning disabilities have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18.**

Robust data collection is critical to advancing equality and non-discrimination in Scotland. However, we are still to see disaggregated data routinely produced on the experience of people with learning disabilities in basic health data and across social, economic, and political life. Intersectional data on gender-based violence and learning disability are even poorer. In Scotland, there is no dataset on women with learning disabilities who experience gender-based violence.

The best evidence from Scotland includes a small-scale study conducted in Glasgow that showed that 73% of the 62 participating disabled women had experienced domestic abuse, and 43% had been sexually assaulted (Wise Women, 2015).

“**[He] stabbed me in the neck. Then the police asked me if I was doing foreplay; I didn't even know what that meant.**”

UPR Focus Group Participant (2021)

**Margaret Fleming: The teenager who was forgotten for 17 years**

**More Information**  
[donagh.b@sclcd.co.uk](mailto:donagh.b@sclcd.co.uk) | [www.sclcd.org.uk](http://www.sclcd.org.uk) | 0141 248 3733  
 Scottish Commission for People with Learning Disabilities

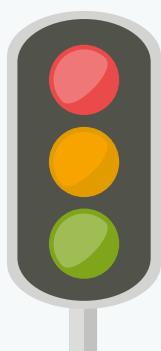
# Methods

To make sure SCLD's involvement in the UPR process was meaningful to people with learning disabilities, we held a consultation process to decide what to include in our submission. Between November and December 2021, we held three engagement events:

1. A public event for people with learning disabilities and those who support them.
2. A small focus group of SCLD Expert Group members.
3. A session as part of an Assembly meeting supported by Values into Action Scotland.

All three sessions aimed to gather qualitative data to inform our joint submission to the Universal Periodic Review. We engaged 42 people with learning disabilities and those who support them from across Scotland at these events.

## Priorities following Traffic Light System Review



**Failure to respect the right to life**

**Restrictions on independent living**

**Failure to respect liberty**

**Failure to ensure equal recognition in the law**

**Failure to protect from torture, cruel, inhuman, or degrading treatment or punishment**

**Failure to provide an adequate standard of living and social protection**

In addition to these events, SCLD hosted a key stakeholder and trusted adviser meeting in December 2021. This included our Human Rights Town App Development Group members, PAMIS and VIAS. At this meeting, we discussed the critical issues raised during the focus groups and asked stakeholders to prioritise these issues using a traffic light system.<sup>7</sup> The most urgent human rights violations to be addressed were identified as 'red'. For example, failing to respect the right to life during the COVID-19 pandemic.

Quotes from participants across the three engagement events are highlighted throughout this report. This is in addition to quotes from significant pieces of research that relate to how people with learning disabilities experienced the COVID-19 pandemic, as well as their experiences of restraint and seclusion.

<sup>7</sup> As a result of the methods used to select the issues that were submitted to the UPR, some other issues that are significant for people with learning disabilities, including the right to family life and transport, are omitted from this report. This does not mean these issues are not significant, but rather that they were not the focus of the original submission.

## Section 2

# Outcome of the 4th Universal Periodic Review of the United Kingdom for people with learning disabilities

Alongside other NGOs from the UK,<sup>8</sup> SCLD used its submission to the UPR to explain how institutional failings are breaching the rights of people with learning disabilities, as well as to highlight that their invisibility within officially published statistics contributes to their disempowerment. SCLD argued that gathering disaggregated data would demonstrate the need for legislative, policy, practice and cultural change. This message and the evidence were persuasive and acted on, with the UK Government supporting SCLD's recommendation "to take measures to improve data collection on gender-based violence, including disability disaggregated data when reporting such violence".<sup>9</sup>

SCLD also argued that there is a need to "strengthen awareness-raising campaigns aimed at eliminating negative stereotypes and prejudice towards persons with disabilities".<sup>10</sup> This recommendation acknowledged that everyone has human rights that must be respected and protected and was also supported by the UK Government.

Furthermore, in March 2023, SCLD and People First (Scotland)'s Equally Safe Group published a report on gender-based violence.<sup>11</sup> The results were shocking and the recommendations forthright. The power of the report comes from women with learning disabilities who courageously agreed to speak about their experiences of severe, frequent and repeated abuse. The extent of rape, sexual assault, domestic violence and commercial sexual exploitation is profoundly troubling and exposes the human rights abuses regularly facing women with learning disabilities in Scotland today. The intersectionality of discrimination can lead to failures in detecting and addressing the violence and abuse experienced by women and girls.

---

<sup>8</sup> [United Kingdom | UPR info \(upr-info.org\)](#)

<sup>9</sup> [Recommendation 212: UK Government \(2022\)](#)

<sup>10</sup> [Recommendation 257: UK Government \(2022\)](#)

<sup>11</sup> [SCLD \(2023\)](#)

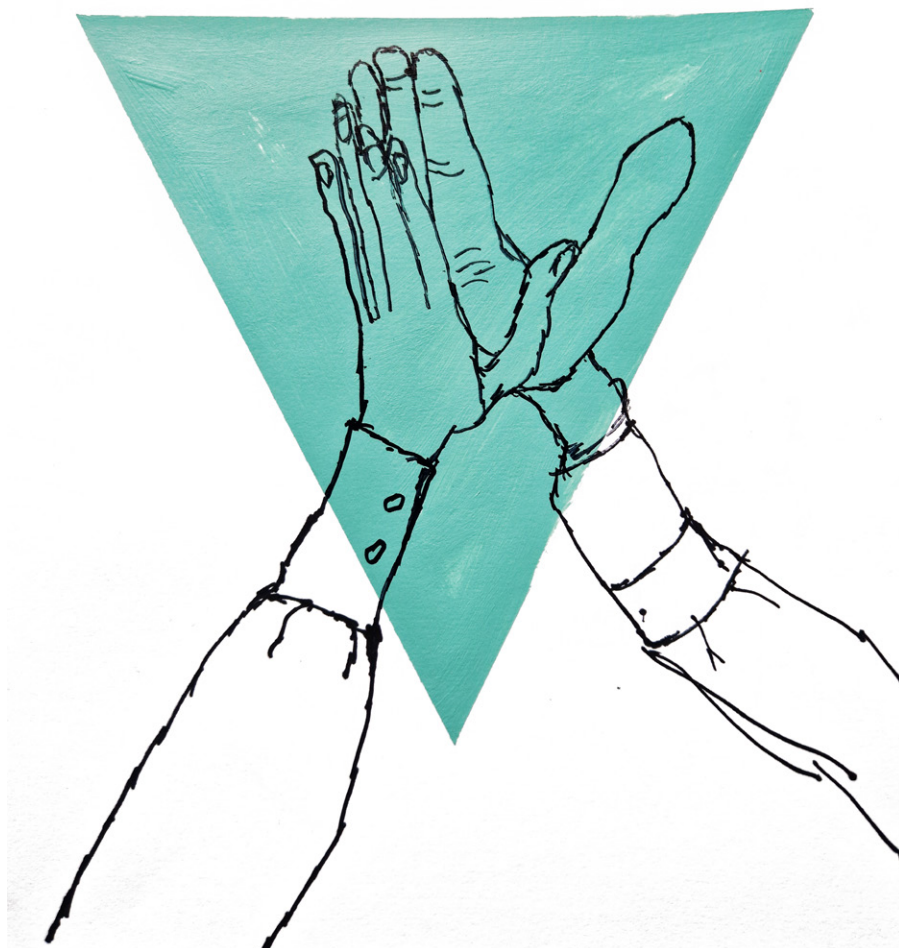


This report provides further compelling evidence that there is a need for awareness-raising campaigns for the public and those delivering public services in order to make a difference in the future.

SCLD believes that eliminating negative stereotypes should also address some of the concerns we highlighted in the development of the Hate Crime and Public Order (Scotland) Bill in 2020. At the time, SCLD was keen to ensure that levels of hate crime against people with learning disabilities, experienced within their own communities, were collected to prompt specific and targeted interventions. Data matters and refusing to gather evidence of a problem allows it to be ignored. Whilst gathering data on disability is increasingly mainstreamed, failing to 'disaggregate' this data to acknowledge the identity of people with learning disabilities is a significant issue. SCLD were successful in encouraging the Scottish Government to address this issue in the Hate Crime and Public Order (Scotland) Act 2021. However, we are yet to see this approach being taken in wider legislative and policy-making data collection processes.

Therefore, the support of the Human Rights Council on this issue in relation to gender-based violence is an invaluable and important step forward.

SCLD looks forward to seeing the impact of these recommendations in the next UK reporting cycle in 2026/27.





## Section 3

# The state of our rights: where are we now?

---

The remainder of this report outlines the situation following our contribution to the UPR in 2022 and details the existing and ongoing human rights issues faced by people with learning disabilities in Scotland. This is based on the work we did to inform the UPR process, along with new evidence and a range of recent policy and legislative developments. SCLD believes the recommendations that are included throughout this report, along with the proposed route map for change, are critically important to achieving a Scotland where people with learning disabilities can live full, safe, equal and loving lives.



## Section 4

# The Scottish constitutional and legislative framework

---

“Human rights are about choice, flexibility, and control. They are about getting your voice heard.”

UPR focus group participant (November 2021)

Until recently, the UK faced the risk of considerable weakening of the Human Rights Act to a Bill of Rights. The proposals made by the UK Government appeared to be focused on the idea that many human rights cases are spurious, and that human rights are dependent on ‘good behaviour’. The proposed reforms to the Human Rights Act aimed to reduce the number of human rights cases on matters including economic rights; to undermine the strength of the courts; and to increase deportations – all while purporting to protect freedom of speech and British democracy. Despite an apparent rollback on overhauling the existing Human Rights Act, the threat to universal human rights is ongoing and is illustrated in the attacks on refugees’ and asylum seekers’ rights in the Illegal Migration Act 2023.<sup>12</sup>

For people with learning disabilities in Scotland, any roll-back on human rights for any group is deeply concerning, as it sets a worrying precedent in light of the inequitable negative impact human rights reform often has on people with learning disabilities. This is compounded by their lack of opportunity to engage in legislative and policy reform processes.

At the time of the initial proposals around a Bill of Rights for the UK, SCLD raised the issue of the lack of inclusion of people with learning disabilities in the reform process.<sup>13</sup> The exclusion of people with learning disabilities was illustrated in the UK Government’s failure to produce and publish a suitable easy read consultation document. As a result, a joint letter was sent to the Joint Human Rights Committee signed by over 205 organisations and individuals, including SCLD. Following this, and a day before the UK Government’s consultation on the Human Rights Act was due to close, a six-week extension was given for responses by those who required an accessible version. Had civil society and individual advocates not intervened, this would not have occurred.

---

<sup>12</sup> [UK Parliament \(2023\)](#)

<sup>13</sup> [SCLD \(2022\)](#)

Over the last three years, the UK Government's approach to the human rights incorporation agenda has appeared to differ significantly from Scotland's. This is illustrated in a paper by Dr Katie Boyle and Professor Nicole Busby on human rights and devolution:

“It is apparent that, for some time, those in the devolved nations have fostered a receptive approach to human rights development with any obstruction in this respect being more likely to be confined to England.”<sup>14</sup>

These different approaches, along with the complexity of devolution agreements and legislative competency for devolved nations, led to a Supreme Court challenge to the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill.<sup>15</sup> The result has been a delay in the work of the Scottish Government to pass the bill,<sup>16</sup> despite UPR recommendations.<sup>17</sup>

Unlike the rest of the UK, Scotland has made significant progress in aligning law to international treaties.<sup>18</sup> This is best illustrated by Scotland's commitment to incorporating several conventions as part of a new Human Rights Bill for Scotland.<sup>19</sup> The ongoing work on the new Human Rights Bill for Scotland has involved public and civil society engagement.

Initially, SCLD was pleased to see proposals and recommendations for a new Human Rights Bill in Scotland, including the intention to incorporate the Convention on the Rights of Persons with Disabilities (UNCPRD) into Scottish law and a commitment to work with a lived experience board of people with learning disabilities in the Bill's development.

However, following the publication of 'Equality, opportunity, community new leadership – a fresh start',<sup>20</sup> which failed to reaffirm previous commitments to incorporate the UNCPRD, SCLD became increasingly concerned about the potential for these prior commitments to be overlooked. In June 2023, the Scottish Government launched its consultation on a new Human Rights Bill for Scotland.<sup>21</sup> SCLD was pleased that the document recognised that further attention needs to be given to particular rights contained within the UNCPRD, including Article 19 on the right

---

<sup>14</sup> Boyle and Busby (2021)

<sup>15</sup> Supreme Court (October 2021)

<sup>16</sup> On the 27th of June 2023 the Scottish Government Cabinet Secretary for Social Justice outlined the Government's outlined plans to make amendments to the United Nations Convention on the Rights of the Child Incorporation (Scotland) Bill after parliamentary recess.

<sup>17</sup> UPR Recommendations (2017) A41:134.59/60/65

<sup>18</sup> UPR Recommendations (2017): A: 41:134.63

<sup>19</sup> National Taskforce for Human Rights Leadership Report (2021)

<sup>20</sup> Scottish Government (2023)

<sup>21</sup> Scottish Government (2023)

to independent living. While this recognition is positive, SCLD remain concerned that a failure to place a duty on public bodies and private actors to comply with substantive human rights within the UNCRPD fails to translate into the promised ‘maximalist’ approach to UNCRPD incorporation within the confines of devolution. If this commitment is not met there is a risk that people with learning disabilities will be left behind on Scotland’s human rights journey by allowing them to remain under the purview of mental health legislation<sup>22</sup> (further expanded upon on pages 32–36 of this report). This issue would become increasingly challenging if the new Human Rights Bill were to be included within the constitution of an independent Scotland,<sup>23</sup> without first addressing the need for a duty of compliance for relevant Scottish public bodies and private companies (operating a public function) in regard of the CRPD and its incorporation.

As well as ensuring compliance with the CRPD, steps must be taken to make sure the most recent SNAP 2 report<sup>24</sup> and recommendations are implemented promptly. SCLD remains cognisant that prior human rights work in Scotland, such as the Scottish National Action Plan 1 (SNAP 1) only had a minor impact on people’s lived experience, and this should not happen again.

## Recommendations

- 1 Scottish Government to continue to incorporate international human rights treaties through the new Human Rights Bill for Scotland alongside enforceable and accessible remedies.
- 2 Scottish Government to ensure the incorporation of substantive UNCRPD rights as part of the new Human Rights Bill for Scotland. This should be done within devolved competence.
- 3 Scottish Government to conduct an audit of relevant Scottish legislation to ensure compliance with substantive UNCRPD rights.
- 4 Scottish Government and public bodies to support and implement SNAP 2, with milestones and an audit process built in to evaluate impact.
- 5 Extend the powers of the Scottish Human Rights Commission (SHRC) to ensure the right to an effective remedy for human rights breaches is equally available in Scotland.

<sup>22</sup> [The Scottish Mental Health Law Review’s Final Report](#) published (2022) in has recommended that learning disability remains under the purview of mental health and psychiatry and that the remit of mental health legislation is extended as the primary legislative framework for rights realisation of people with learning disabilities.

<sup>23</sup> [Scottish Government \(2023\)](#)

<sup>24</sup> [Scottish National Action Plan for Human Rights \(SNAP 2\) \(2023\)](#)

# Acceptance of international norms

---

## Complaints mechanisms

There are two national human rights institutions in Scotland, the Equality and Human Rights Commission (EHRC) and the Scottish Human Rights Commission (SHRC). They have powers to promote human rights, provide information, guidance, education on rights and monitoring of law, policies and practices, and powers to intervene in civil proceedings. However, as far as the SHRC is concerned, this does not extend to offering an advice service, representing individuals, or taking on their cases.<sup>25,26</sup>

Additionally, Scotland has the Children and Young People's Commissioner Scotland (CYPCCS).<sup>27</sup> One of the most significant advances of the rights of children and young people with learning disabilities in Scotland has come from its investigation into restraint and seclusion in Scottish schools.<sup>28</sup>

However, people with learning disabilities and those who support them do not feel enough action has been taken to improve their lives, and as a result some<sup>29</sup> people with learning disabilities, autism and those who support them called for a Learning Disability, Autism and Neurodiversity Bill, along with a commissioner/commission<sup>30</sup> with significant powers of investigation and enforcement. A commitment was made to pursue this in Scotland's Programme for Government 2021.<sup>31</sup>

---

<sup>25</sup> [The Scottish Commission for Human Rights Act \(2006\)](#)

<sup>26</sup> [Equality and Human Rights Committee \(2018\)](#)

<sup>27</sup> [The Children and young Peoples Commissioner for Scotland](#)

<sup>28</sup> [The Children and Young People's Commissioner Scotland \(2020\)](#)

<sup>29</sup> This was a campaign led by Enable Scotland, Scottish Autism and the National Autistic Society Scotland. It should be noted it is not an approach welcomed by all people with learning disabilities in Scotland.

<sup>30</sup> [Enable \(2021\)](#)

<sup>31</sup> [Scottish Government \(2021\)](#)

---

SCLD views this as a potentially significant development which could further reinforce the UPR recommendation to:

“...allow individual complaints mechanisms under United Nations human rights treaties such as the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.”<sup>32</sup>

SCLD is aware that following an initial scoping exercise on the proposed bill in 2022,<sup>33</sup> the Scottish Government is undertaking a programme of engagement throughout 2023 with an advisory panel including people with learning disabilities and autism.<sup>34</sup> In addition, SCLD is also conscious of concerns about the proliferation of calls for commissions/ers.<sup>35</sup> SCLD would therefore welcome continued dialogue on this issue to ensure the rights of people with learning disabilities are best upheld, and that any forthcoming Learning Disability, Autism and Neurodiversity Bill is robust.

## Recommendations

- 6 Scottish Government to develop and consult on a robust Learning Disability, Autism and Neurodiversity Bill in conjunction with the Human Rights Bill for Scotland. This process should explore interconnections and opportunities for positive rights realisation for people with learning disabilities between the two bills.
- 7 The Learning Disability, Autism and Neurodiversity Bill to place additional duties on all public bodies to support people with learning disabilities to realise specific UNCRPD rights. The Bill should create a monitoring and accountability mechanism to support this.
- 8 Scottish Government to ensure the development of a bill and a commission/commissioner which is led by and informed by the views of people with learning disabilities.

<sup>32</sup> UPR Recommendations (2017) A:12 134.12

<sup>33</sup> [Scottish Government \(2022\)](#)

<sup>34</sup> [Scottish Government \(2023\)](#)

<sup>35</sup> [SHRC \(2023\)](#)

# Gender-based violence

“They stabbed me in the neck. Then the police asked me if I was doing foreplay; I didn’t even know what that meant.”

UPR focus group participant (November 2021)

Following the recommendations made during the UK’s 3rd UPR cycle in 2017, the issue of gender-based violence has garnered significant attention. For example, £38 million<sup>36</sup> has been invested in projects to tackle gender-based violence<sup>37</sup> and support the delivery of Scotland’s ‘Equally Safe’ strategy.<sup>38</sup>

However, there is still no robust dataset on women with learning disabilities’ experience of gender-based violence. Global data tells us that 90% of women with learning disabilities have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18.<sup>39</sup> A small-scale study in Glasgow<sup>40</sup> supports this, showing that 73% of the 62 participating disabled women had experienced domestic abuse, and 43% had been sexually assaulted.<sup>41</sup>

Gender-based violence was a significant concern that emerged from our UPR engagement sessions, with several women detailing their experiences and one woman saying,

“I could have been like Sarah Everard;<sup>42</sup>  
I could have been dead.”<sup>43</sup>

While research<sup>44</sup> is clear that the intersectional experience of women with learning disabilities places them at an increased risk, we have not seen wide-scale developments in focused support for this group. Instead, we have observed challenges in accessing support.<sup>45</sup> The life-threatening consequences of not accessing the right support is evidenced in the significant case review of the death of Miss A in North Lanarkshire in 2016.<sup>46</sup>

---

<sup>36</sup> [Scottish Government \(2021\)](#)

<sup>37</sup> [Scottish Government \(August 2021\)](#)

<sup>38</sup> [Scottish Government \(2018\)](#)

<sup>39</sup> [United Nations General Assembly \(2017\)](#)

<sup>40</sup> Glasgow is the most populous city in Scotland.

<sup>41</sup> [Wise Women \(2015\)](#)

<sup>42</sup> Sarah Everard was a woman from London who was murdered by a member of the metropolitan police after falsely arresting her in 2021.

<sup>43</sup> UPR Focus Group Participant: (November 2021)

<sup>44</sup> [McCarthy et al \(2015\)](#)

<sup>45</sup> [Engender \(2018\)](#)

<sup>46</sup> [North Lanarkshire Adult Protection Committee \(2016\)](#)

In March 2023, to address the absence of data on this subject, SCLD published 'Unequal, Unheard, Unjust: But Not Hidden Anymore. Women with Learning Disabilities' Experience of Gender-Based Violence in Scotland'<sup>47</sup> in partnership with People First (Scotland). The research highlighted that there is no consistent approach across Scotland to enable women with learning disabilities to access support and justice when they experience gender-based violence. Worse still, women with learning disabilities encounter significant barriers to reporting crimes, including limited access to safe spaces and appropriate adults, and not being believed or taken seriously.

SCLD also found it was particularly challenging for women and girls with learning disabilities to identify and respond to incidents of gender-based violence and abuse. This was attributed to a lack of education programmes focusing on sexual health, relationships and parenthood in addition support needs educational provision and other settings.

SCLD examined whether existing policy and legislation supports and safeguards women with learning disabilities appropriately and concluded that it does not. As a result of these research findings, SCLD made a series of 14 recommendations to the Scottish Government, justice services and NHRIs. A Scottish Government steering group co-chaired by People First (Scotland) and SCLD will oversee the implementation of the recommendations.

In addition to this, following SCLD's submission to the UPR, women with learning disabilities were invited to participate in the Independent Strategic Funding Review of Violence Against Women and Girls Services. As a result of their input, the Review made key recommendations relating to the provision of minority women's 'by and for services', training for specialist services on learning disability, and accessibility standards for services.<sup>48</sup> If implemented, SCLD believe this could lead to considerably improved outcomes for women and girls with learning disabilities.

## Recommendations

- 9 Scottish Government, justice services and NHRIs to implement recommendations from 'Unequal, Unheard, Unjust: But Not Hidden Anymore. Women with Learning Disabilities' Experience of Gender-Based Violence in Scotland'.
- 10 Scottish Government to review the appropriateness and effectiveness of adult support and protection referrals based on women with learning disabilities experiencing gender-based violence and support the roll-out of an accessibility audit for all gender-based violence support services by 2024-25.



# Equality and non-discrimination

---

## Hate crime

In the last three years, Scotland has advanced equality and non-discrimination through the Hate Crime and Public Order (Scotland) Act 2021.<sup>49</sup> As noted earlier, Sections 14 and 15 of the Act are significant to people with learning disabilities, as they commit the Scottish Government to publishing disaggregated figures on disability hate crimes. Data on reported crimes collected in 2018–2019 showed that in over half of disability-aggravated hate crimes (59%), the perpetrator showed prejudice towards those with a learning disability.<sup>50</sup> This figure has increased since then, with data from reported hate crimes in 2020–21 rising to 73%.<sup>51</sup> This data is concerning, and even more so given that research<sup>52</sup> found that people with learning disabilities said they were often not believed when they reported crimes. Equally worrying is that, while the legislation passed, there were widespread concerns that it would have a detrimental impact on individuals' freedom of speech, and there have been consistent threats to repeal the Act.<sup>53</sup>

Since the legislation came into force, we have seen the publication of the 'Tackling Prejudice and Building Connected Communities Action Plan'<sup>54</sup> and the 'Hate Crime Strategy for Scotland'.<sup>55</sup> While both documents make many welcome commitments, given the data that is now available, it is disappointing not to see any focused actions on tackling prejudice against people with learning disabilities. SCLD therefore awaits the publication of the proposed delivery plan<sup>56</sup> and hopes this process will involve people with learning disabilities to ensure the existing gap is addressed.

---

<sup>49</sup> [Hate Crime and Public Order \(Scotland\) Act \(2021\)](#)

<sup>50</sup> [Scottish Government \(February 2021\)](#)

<sup>51</sup> [Scottish Government \(2023\)](#)

<sup>52</sup> [Wiseman and Watson \(2021\)](#)

<sup>53</sup> [Herald \(2021\)](#)

<sup>54</sup> [Scottish Government \(2021\)](#)

<sup>55</sup> [Scottish Government \(2023\)](#)

<sup>56</sup> [Scottish Government \(2023\)](#) proposed a delivery plan as part of the Hate Crime Strategy for Scotland.

## Recommendations

- 11** Scottish Government to ensure the representation of and engagement with people with learning disabilities in developing the delivery plan for Hate Crime Strategy for Scotland.
- 12** Scottish Parliament to work with the National Union of Journalists to produce national guidance for media on reporting on learning disability.
- 13** Scottish Government to develop awareness-raising campaigns on the experiences of people with learning disabilities in line with UPR recommendations.

## Data collection

“Although we are aware of work which starts to consider how improvements can be made to existing data collections and an acknowledgement of where some of the data gaps exist, there remains a lot to be done in building a more complete and ultimately fit for purpose evidence base for supporting people with learning disabilities in Scotland.”

Fraser of Allander (2023)<sup>57</sup>

As outlined earlier in this report, robust data collection is critical to advancing equality and non-discrimination in Scotland. While there have been some advancements in data collection (e.g., hate crime and early learning and child care<sup>58</sup>), we are yet to see widespread improvements.

The lack of disaggregated data collected on the experiences of and outcomes for people with learning disabilities in Scotland has long been an issue. Commenting on this topic in 2021, Fraser of Allander said,

“Without better data to underpin policy-making, Scottish Government ambitions to improve the lives of adults with learning disabilities are unlikely to be realised.”<sup>59</sup>

<sup>57</sup> Fraser of Allander (2023)

<sup>58</sup> Following the publication of Building Blocks: Exploring the barriers and facilitators to early learning and childcare provision for children with learning disabilities in Scotland, the early learning and child care census began to disaggregate disability data to include learning disability as part of their Data Transformation project (Scottish Government, 2022).

<sup>59</sup> Fraser of Allander (2021)

This statement was evidenced when trying to determine how many people with learning disabilities had died from COVID-19.<sup>60</sup> A lack of available data in Scotland resulted in an unacceptable delay in understanding how the crisis affected people with learning disabilities. The death rate between January and August 2020 was not published until February 2021. What was published was based on Census data captured more than ten years earlier. No additional data has been published since then and we are still to see disaggregated data compiled on the experiences of people with learning disabilities in basic health data and across social, economic, and political life. In terms of intersectional impacts, the data is even poorer<sup>61</sup> and is particularly stark in relation to experiences of gender-based violence.<sup>62</sup>

## Recommendations

- 14 In line with Article 31 of the UNCRPD and UPR recommendations, the Scottish Government and other public bodies must examine approaches to improve data collection to build evidence on whether people with learning disabilities can realise their human rights.
- 15 Scottish Government and public bodies to implement recommendations from Fraser of Allander Institute report, 'Data on the lives of people with learning disabilities in Scotland: short term actions for change.'

---

<sup>60</sup> In England, the death rates of people with learning disabilities from COVID-19 were reported from two sources: a targeted piece of work by the Office for National Statistics using information on [care home deaths reported to the Care Quality Commission](#), and a weekly update of [COVID-19 deaths reported to the Learning Disability Mortality Review \(LeDeR\)](#).

<sup>61</sup> [Scottish Government \(2017\)](#)

<sup>62</sup> [SCLD \(2023\)](#)

## Section 7

# Emerging human rights violations experienced by people with learning disabilities in Scotland

---

## Failure to protect the right to life during the COVID-19 pandemic

“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 the virus causing damage to his lungs, the heart if he got it badly...”

Parent/carer’s response to SCLD COVID-19 survey (2020)<sup>63</sup>

Before the COVID-19 pandemic the health outcomes for people with learning disabilities were poor. Best evidence suggested that people with learning disabilities died 20 years earlier than the general population.<sup>64</sup> The figures in regard of childhood premature mortality were equally concerning, with a study by the Scottish Learning Disability Observatory (SLDO) finding that premature mortality from preventable illnesses was 12 times higher for children and young people with learning disabilities, compared to other children and young people.<sup>65</sup> For girls and young women, risk of death was 17 times higher than their non-disabled peers. The same research also found that treatable conditions contributed to many deaths, and some accidental deaths were potentially preventable.

It is notable that given these findings the Scottish Government made £2 million available to health boards to support the delivery of annual health checks for people with a learning disability. SCLD was pleased to note that some local areas have

---

<sup>63</sup> SCLD (2020)

<sup>64</sup> The Keys to Life (March 2019)

<sup>65</sup> SLDO (2020)

started offering these checks. For the boards that have not yet implemented this, a deadline of 31 March 2024 is in place.

Despite this positive step, people with learning disabilities are still facing poor health outcomes which were exacerbated during the COVID-19 pandemic. At the height of the pandemic, people with learning disabilities experienced significantly higher death rates from COVID-19 than the general population.<sup>66</sup> Data from Scotland<sup>67</sup> shows that people with learning disabilities were at least three times more likely to die from COVID-19 than the general population.

Another significant source of anxiety for people with learning disabilities at the height of the COVID-19 pandemic was clinical decision-making in relation to frailty and access to life-saving medical interventions. During the initial stages of the pandemic, people with learning disabilities were pressured to sign Do Not Resuscitate notices. In other cases, these notices were found to have been added to case notes without discussion.<sup>68</sup> The Scottish Parliament's Equality and Human Rights Committee<sup>69</sup> and the House of Commons Health and Social Care Committee<sup>70</sup> acknowledged that although there was never national NHS guidance for applying Do Not Resuscitate notices to people with learning disabilities, notices were issued inappropriately for some individuals, thus infringing their right to life.

Therefore, SCLD believes it was unacceptable that the Terms of Reference<sup>71</sup> for the Scottish COVID-19 Inquiry failed to include a focus on disproportionately impacted equalities groups.<sup>72</sup> It is also troubling that the Terms of Reference did not extend to examining how the lives of people with learning disabilities were devalued through political and media messaging that stated that the pandemic would only impact the 'vulnerable'.<sup>73</sup> Given this, SCLD believes it is critical that the ongoing Scottish COVID-19 Inquiry makes significant efforts to hear the views of people with learning disabilities and seeks to ensure similar failures experienced by this population do not continue and are never experienced again.

---

<sup>66</sup> [Public Health England \(2020\)](#)

<sup>67</sup> [SLDO \(2020\)](#)

<sup>68</sup> [The Christian Institute \(2021\)](#) – Of the 2,048 social care providers who submitted information to the Care Quality Commission (England), 508 stated that DNRs had been applied without the agreement of the person, their relative or carer between 17 March and 21 December 2020. This amounts to more than five per cent of all DNRs put in place by respondents.

<sup>69</sup> [Scottish Parliament EHRC Committee \(2021\)](#)

<sup>70</sup> [House of Commons Health and Social Care Committee \(2021\)](#)

<sup>71</sup> [Scottish Government \(2021\)](#)

<sup>72</sup> [The National \(2022\)](#)

<sup>73</sup> [SCLD \(2020\)](#)

## Recommendations

- 16 The Scottish COVID-19 Inquiry should include evidence sessions from people with learning disabilities.
- 17 Both the UK and Scottish COVID-19 Inquiries should include investigations into political and media messages surrounding the COVID-19 pandemic.

## Restrictions on independent living during, and following, the COVID-19 pandemic

“I’m worried that if I don’t get back to my groups soon, what is going to become of me? I’m going to be a nobody and lost and very upset.”

Individual response to SCLD’s COVID-19 survey (2020)<sup>74</sup>

According to a UK-wide longitudinal study,<sup>75</sup> over a quarter (27%) of people with learning disabilities and 58% of people with more severe<sup>76</sup> learning disabilities used day services before the pandemic started. The same study found that in December 2020, almost all day, respite and community services had stopped. By August 2021, a third of people with learning disabilities (32%) and nearly half of those with more severe learning disabilities (48%) had not returned to their day service, either in person or online. By 2021, a quarter of people with learning disabilities and over half of carers of people with more severe learning disabilities said they received less support than before the pandemic started. The latest wave of the study, from October 2022, showed that services and supports were still not back to where they were pre-pandemic; nor were these services able to compensate for the long-term impact that COVID-19 has had for people with learning disabilities.<sup>77</sup> However, Scottish Government survey results,<sup>78</sup> published in June 2023, indicated that progress was being made, with an increase in the number of services that had reopened. In cases where services had not returned to pre-pandemic levels, a shortage of staff was given as the explanation.

<sup>74</sup> SCLD (2020)

<sup>75</sup> UKRI (2021)

<sup>76</sup> See [Challenging Behavior Foundation](#) for Definition of Severe Learning Disability. This definition uses medical diagnosis. The language of severe learning disability terminology is from the UKRI report.

<sup>77</sup> UKRI (2023)

<sup>78</sup> [Scottish Government \(2023\)](#)

SCLD's own research showed that the reduction in availability of services significantly impacted many individuals, with 58% of respondents to one survey saying they were lonelier than before COVID-19.<sup>79</sup> Within another study carried out by UK Research and Innovation (UKRI), people expressed real fears that life would never return to normal.<sup>80</sup>

When services stopped, many people with learning disabilities were encouraged to access support online, with digital platforms playing a major role in people's lives throughout the pandemic. However, official statistics show that disabled people are more than four times as likely to have never used the internet.<sup>81</sup> A survey undertaken by SCLD in 2019 showed that only 33% of people with a learning disability had used social media in previous weeks.<sup>82</sup> According to the Office for National Statistics (ONS), this compares to 59% of disabled people and 71% of non-disabled people.<sup>83</sup>

Given the elevated levels of digital exclusion faced by people with learning disabilities, SCLD is pleased to be working with the Scottish Government's Technology Enabled Care (TEC) team to identify barriers and facilitators to digital technology for people with learning disabilities, and to look at where technology can transform people's lives within health, social care and beyond.<sup>84</sup>

## Recommendations

- 18** Scottish Government to ensure the new National Care Service places human rights compliance at its centre, as recommended by the Independent Review of Adult Social Care in Scotland.
- 19** The digital front door team to continue their ongoing engagement and development work with people with learning disabilities from across Scotland.

---

<sup>79</sup> SCLD (2020)

<sup>80</sup> UKRI (2023)

<sup>81</sup> Office for National Statistics (2019)

<sup>82</sup> SCLD (2022)

<sup>83</sup> Office for National Statistics (2019)

<sup>84</sup> Technology Enabled Care

## Failure to respect liberty

“It’s about having the right to live and be supported in your community. Not having to worry that if you have a crisis and end up in the hospital, you will be stuck there.”

UPR focus group participant (November 2021)

Over the course of SCLD’s UPR engagement sessions, people with learning disabilities expressed significant concerns about their treatment in law in relation to both mental health legislation and adults with incapacity legislation. During the last four years (2019–2023) two significant reviews have been published on this subject: the Independent Review of Learning Disability and Autism in the Mental Health Act (IRMHA),<sup>85</sup> which was followed by the Scottish Mental Health Law Review (SMHLR).<sup>86</sup> The reviews set out starkly different positions on the inclusion of learning disability (and autism) within mental health legislation and SCLD has been clear in its position that mental health legislation is not the appropriate vehicle for positive rights realisation for people with learning disabilities.

In SCLD’s response to the Scottish Mental Health Law Review,<sup>87</sup> we said that we believed the ongoing inclusion of learning disability within the definition of mental disorder constituted disability discrimination under the Equality Act (2010) and contravened Article 12 of the UNCRPD. This view is supported by the United Nations Committee on the Rights of Persons with Disabilities (CRPD) guidelines on deinstitutionalisation, including in emergencies, which said:

“Institutionalisation is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to Article 14. States parties should recognise institutionalisation as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilisers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17.”<sup>88</sup>

---

<sup>85</sup> IRMHA (2019)

<sup>86</sup> SMHLR (2022)

<sup>87</sup> SCLD (2023)

<sup>88</sup> CRPD Committee (2022)



The scope and scale of this issue was outlined in the 'Coming Home' report (2018), which indicated that at least 67 people with learning disabilities and complex needs had been subject to a delayed discharge. Of these, 22% had been in hospital for more than ten years, and another 9% for five to ten years.<sup>89</sup> An earlier report found that 32% of people on learning disability wards faced delayed discharges.<sup>90</sup> These figures are likely to be a significant underestimate given the gaps in the data provided at the time.

The 2019 Mental Health and Learning Disability Inpatient Census showed 54 delayed discharges in learning disabilities specialties in Scotland, with an average length of delay totalling just under four years.<sup>91,92</sup> Updated figures, published in 2022, showed that this figure had decreased, with 39 people with learning disabilities experiencing delayed discharge and a reduction in delays for those in both forensic and non-forensic settings to over two years.<sup>93</sup> Despite these small improvements, the same data-set highlighted that people with learning disabilities face the longest length of stay generally in inpatient health services. This was over four years and was experienced by those in non-forensic learning disability units.

In 2018, 'Coming Home' also identified 705 people living in out-of-area placements, 45% being out-of-area for more than ten years. Of those, 109 had not chosen their placement and were identified as a priority to return. There were also 79 people placed outside of Scotland.<sup>94</sup> The main reasons detailed by health and social care partnerships were lack of funding, suitable service provision, and/or suitable accommodation.<sup>95</sup> Updated figures from the Hospital Based Complex Clinical Care & Long Stay Census in 2022 showed there were a total of 603 people in long-stay hospital in Scotland, with a further 72 placed outside Scotland.<sup>96</sup>

Living in a hospital setting without clinical need or being placed out-of-area without choice is an excessive restriction on liberty and the right to home life. Institutional living also risks exacerbating individuals' mental distress and ill health, while closed cultures risk infringing the right to freedom from inhuman and degrading treatment. The aforementioned reports evidence a range of areas where rights are restricted, including access to the community.

One reason community access can be denied to people with profound and multiple learning disabilities is because of a lack of fully accessible changing places toilets.<sup>97</sup> The most recent figures show that there are 246 changing places toilets in Scotland

---

<sup>89</sup> [Scottish Government \(2018\)](#)

<sup>90</sup> [Mental Welfare Commission \(2016\)](#)

<sup>91</sup> [Scottish Government \(2019\)](#)

<sup>92</sup> This data excludes people with learning disabilities who were classed as requiring Hospital Based Complex Clinical Care

<sup>93</sup> [Scottish Government \(2022\)](#)

<sup>94</sup> [Scottish Government \(2018\)](#)

<sup>95</sup> [Scottish Government \(2018\)](#)

<sup>96</sup> [Supporting documents - Inpatient census 2022: hospital based complex clinical care and long stay - gov.scot \(www.gov.scot\)](#)

<sup>97</sup> [SCLD \(2022\)](#)

and 1,692 in the UK, with the Scottish Government committing £10 million in funding for additional provision in Scotland.

SCLD believes the ongoing institutionalisation of people with learning disabilities illustrates a failure to meet the standards set out in UNCRPD Article 19. It demonstrates the gap identified in CRPD General Comments No. 5, namely:

“...an inadequacy of social support and protection schemes for ensuring living independently within the community”<sup>98</sup>

In 2021, £20 million was allocated to integration authorities in Scotland to significantly reduce the number of out-of-area placements and hospital stays by 2024.<sup>99</sup> This was followed by a report from the Working Group on Complex Care and Delayed Discharge,<sup>100</sup> outlining the ‘Coming Home’ implementation framework. Following this, in 2023, the Scottish Government launched the Coming Home Dynamic Support Register and a memorandum of understanding between the Scottish Government and COSLA<sup>101</sup> to realise the vision of ‘Coming Home’.

Significantly, in June 2023 the Scottish Government published its response to the SMHLR.<sup>102</sup> SCLD welcomes the commitment to scoping and developing reforms to mental health law and hopes this approach will reflect what the Scottish Government heard from stakeholders about the need to better fulfil the rights of people with learning disabilities within developing legal frameworks. To achieve this, consideration must be given to the recommendation from IRMHA that learning disability be removed from the legal definition of ‘mental disorder’.

## Recommendations

- 20** Scottish Government to explore the need for legislative underpinning for the ‘Coming Home Implementation Report’ as part of the Learning Disability, Autism and Neurodiversity Bill to ensure accountability and enforceability.
- 21** Scottish Government and local areas to ensure the implementation and monitoring of recommendations within the ‘Coming Home Implementation Report’ by 2024, while investing in and promoting high-quality social supports, including changing places toilets, which may support people to move out of hospitals and out-of-area placements.

<sup>98</sup> [UNCRPD Committee \(2017\)](#)

<sup>99</sup> [Scottish Government \(2022\)](#)

<sup>100</sup> [Scottish Government \(2022\)](#)

<sup>101</sup> [Scottish Government \(2023\)](#)

<sup>102</sup> [Scottish Government \(2023\)](#)

# Failure to ensure equal recognition in the law

“I have another pal who’s on guardianship order from her cousin. Her cousin goes wherever she goes; she’s got no privacy, no say, and she doesn’t ken when she’s gonna get off it.”

UPR focus group participant (November 2021)

Under the Adults with Incapacity (Scotland) Act 2000 (AWI), the least restrictive option is required; however, this is often not reflected in people’s lived experience. People with learning disabilities who participated in SCLD’s UPR consultation events told us that guardianship orders result in serious restrictions to their choice, autonomy and privacy. This is concerning, given that 46% of all welfare guardian orders under the AWI Act relate to people with learning disabilities.<sup>103</sup> Furthermore, concern has previously been expressed about the lack of automatic, periodic judicial scrutiny of guardianship in relation to indefinite orders, which apply to 5% of people with learning disabilities.<sup>104</sup> Updated figures<sup>105</sup> from 2022 show that of the total guardianship orders in Scotland, 4% were indefinite orders.<sup>106</sup>

Pre-existing concerns regarding guardianship were heightened during the pandemic. Research<sup>107</sup> found that people had been moved during this time without the protection of legal authority and outlined significant concerns that these cases may also constitute Article 5 deprivation of liberty and a breach of the European Convention on Human Rights (ECHR). The same report also cited endemic examples of poor practice, including a lack of understanding of the law, limited knowledge of good practice, confusion over the nature of placements and misunderstandings over power of attorney.

It is because of these failings that People First (Scotland) have long called for an end to guardianship and have instead proposed a new way of thinking about legal capacity by applying a supported decision-making framework.<sup>108</sup> SCLD was therefore pleased to see exploration of a roll-out of supported decision-making models and a commitment to increase advocacy provision in the Scottish Government’s response to the SMHLR.<sup>109</sup>

---

<sup>103</sup> [Mental Welfare Commission \(2022\)](#)

<sup>104</sup> [Mental Welfare Commission \(2018\)](#)

<sup>105</sup> [Mental Welfare Commission \(2022\)](#)

<sup>106</sup> 4% of 17,101 guardianship orders

<sup>107</sup> [Mental Welfare Commission \(2021\)](#)

<sup>108</sup> [People First \(Scotland\)](#)

<sup>109</sup> [Scottish Government \(2023\)](#)

As well as the Adults with Incapacity (Scotland) Act 2000, people with learning disabilities have told SCLD that at times the Adult Support and Protection (Scotland) Act 2007 can also be used to limit their personal freedoms and choices. This came through most clearly during SCLD's research interviews with women who had experienced gender-based violence as part of 'Unequal, Unheard and Unjust: But Not Hidden Anymore'. Women told us they felt punished because of protection measures instead of those who perpetrated crimes against them. SCLD is aware that in 2019 the Scottish Government published its 'Adult Support and Protection Improvement Plan 2019–2022', and in July 2022, a revised code of practice was published regarding the use of the Adult Support and Protection Act.<sup>110</sup> In the future, SCLD would welcome demonstrable evidence of women with learning disabilities' experience of gender-based violence being included in this work, along with reform of the Adults with Incapacity Act<sup>111</sup> and the Adult Support and Protection Act.<sup>112</sup>

## Recommendations

- 22 Scottish Government to explore embedding a UNCRPD compliant national supported decision-making framework as part of the Learning Disability, Autism and Neurodiversity Bill.
- 23 Scottish Government to ensure appropriate safeguards that respect the rights, will and preferences of people with learning disabilities are available.
- 24 Scottish Government to align the work of the Gender-Based Violence and Learning Disability Steering Group and the Adult Support and Protection Improvement Project to explore the potential for future development given the ongoing human rights legislative change programme.
- 25 Future legislative reform focusing on either the Adults with Incapacity (Scotland) Act 2000, or the Adult Support and Protection (Scotland) Act 2007, to reflect the experience of people with learning disabilities placed under these measures. This should include women with learning disabilities who have experienced gender-based violence.

---

<sup>110</sup> [Scottish Government \(2022\)](#)

<sup>111</sup> [Adults with Incapacity \(Scotland\) Act \(2000\)](#)

<sup>112</sup> [Adult Support and Protection \(Scotland\) Act \(2007\)](#)

# Failure to protect from torture, cruel, inhuman, or degrading treatment or punishment

“Restraining and secluding Ben, locking him in rooms at school, has done untold damage to Ben and so nearly broken us as a family.”

Case study (2020)<sup>113</sup>

A joint report by Positive and Active Behaviour Support Scotland (PABSS) and the Challenging Behaviour Foundation (CBF) highlighted accounts of restrictive practices from family carers of 720 children and young people in the UK with a range of learning and developmental disabilities.<sup>114</sup> This reported that 86.5% of restraints on children and young people resulted in physical injuries.

In 2018, the Children and Young People's Commissioner Scotland (CYPCS) conducted a Scotland-wide investigation into the use of restraint and seclusion, which identified 2,674 incidents relating to 386 children.<sup>115</sup> The investigation also found that ten local authorities failed to record all incidents, and a further four did not record any. CYPCS found that the availability and content of local guidance on restraint and seclusion varied significantly, as did access to training standards in supporting children who have communication requirements and resulting behaviours that may be viewed as 'challenging'.<sup>116</sup>

Evidence also suggests that antipsychotic medications are used to manage 'challenging behaviour' of adults with learning disabilities. Research also found that adults with learning disabilities are prescribed antipsychotic drugs at much higher rates than reported rates of psychosis among people with a learning disability.<sup>117</sup> These drugs are found to be frequently prescribed to people with learning disabilities on a long-term basis despite significant side effects<sup>118</sup> and with no evidence of effectiveness beyond sedation.<sup>119</sup> There are concerns that these are frequently administered on a compulsory basis, often in the absence of appropriate structures for supported decision-making.

---

<sup>113</sup> PABBS & CBF (2020)

<sup>114</sup> PABBS & CBF (2020)

<sup>115</sup> The Children and Young Peoples Commissioner Scotland (2018)

<sup>116</sup> Enable Scotland (2019)

<sup>117</sup> Scottish Learning Disabilities Observatory (2020)

<sup>118</sup> Tyler & Cooper (2014)

<sup>119</sup> Scottish Learning Disabilities Observatory (2020)

As a result of these findings, Restraint Reduction Scotland was established in 2020 and aims to eliminate the misuse of restrictive practices, including physical, chemical, environmental, and mechanical restraints and seclusion.<sup>120</sup> Additionally, as a result of ongoing campaigning<sup>121,122</sup> steps have been taken to reduce the use of restrictive practices in Scottish schools, including a consultation on non-statutory guidance<sup>123</sup> and a Private Members' bill on the use of restraint and seclusion in Scotland's schools being launched in June 2023.<sup>124</sup>

## Recommendations

- 26 Scottish Government to embed national statutory human rights-based standards, guidance, and monitoring of restrictive practices across all settings. Exploration should be given to this being embedded as part of the Learning Disability, Autism and Neurodiversity Bill.
- 27 Scottish Government to establish a clinical review of prescribing practice in psychotropic medication, which makes recommendations on developing a national human rights-based approach.
- 28 Scottish Government to explore the role of a new Learning Disability, Autism and Neurodiversity Commissioner/Commission or other public body in monitoring restrictive practices in all relevant settings.

## Failure to provide an adequate standard of living and social protection

A considerable concern for people with learning disabilities is the failure of the state to support people with learning disabilities to realise their right to an adequate standard of living and social protection in line with Article 28 of the UNCRPD. This was discussed in relation to several interconnected rights listed below.

### Education

“I got very little support [at school] ... budgets seemed to be cut every month.”

UPR focus group participant (November 2021)

<sup>120</sup> [Restraint Reduction Scotland \(2021\)](#)

<sup>121</sup> [BBC \(2022\)](#)

<sup>122</sup> [Children in Scotland](#)

<sup>123</sup> [Scottish Government \(2022\)](#)

<sup>124</sup> [Proposed Restraint and Seclusion \(Prevention in Schools\) \(Scotland\) Bill \(June 2023\)](#)

People with learning disabilities' experience' of poverty relates to their economic exclusion, low levels of support and limited life choices. This often begins at an early age due to a lack of early years' provision for children and young people with learning disabilities, and extends into educational opportunities throughout their childhood, teenage years, and young adulthood. For example, SCLD's research<sup>125</sup> examining early learning provision for children with learning disabilities in Scotland illustrated a complex, fragmented system that can lead to children and young people with learning disabilities missing out on funded early learning and childcare places. These barriers continue into school education, with Enable Scotland finding that 52% of 116 children and young people with learning disabilities said they were not getting the right support at school.<sup>126</sup>

## Recommendations

- 29** Scottish Government to ensure the first phase of the rollout for free early learning and childcare provision for 1- and 2-year-olds to include children with learning disabilities; uptake should be monitored and enforced through the UNCRC Children's Rights Scheme.

## Transitions

“Everyone tells me what I have to do, and I don't like it.”

UPR focus group participant (November 2021)

These negative experiences often continue as children and young people with learning disabilities transition into adulthood. Research<sup>127</sup> has found that people with learning disabilities expressed widespread dissatisfaction with their transition planning. This is supported by a study from ARC Scotland and the Scottish Transitions Forum<sup>128</sup>, which shows that children with additional support needs experienced a significant gap between their ambitions and reality in the transition process. However, progress in improving transitions is underway with the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Members' Bill accepted into Parliament towards the end of 2021.<sup>129</sup> If passed, this bill will require the Scottish Government to have a strategy for improved opportunities for disabled children and young people, with ministerial oversight. In addition, local authorities will have to have to plan for each disabled child and young person as they move into adulthood.

<sup>125</sup> SCLD (2022)

<sup>126</sup> Enable Scotland (2022)

<sup>127</sup> Fraser of Allander institute (2021)

<sup>128</sup> Arc Scotland and the Scottish Transitions Forums (2017)

<sup>129</sup> Scottish Parliament (2021)



It should be noted the Bill was introduced by a different MSP in the previous parliamentary term. However, the Bill fell because Parliament was not able to complete its consideration in time. The Bill was reintroduced and is currently at Stage 1.

## Recommendations

- 30** Scottish Government and local authorities to support children and young people with learning disabilities' transitions through the resourcing of local area transitions workers to support children and young people with learning disabilities to access support and achieve their goals.

## Employment

“I have been for numerous interviews; the employers don't take my documents; that tells me straight away I'm not getting the opportunity.”

UPR focus group participant (November 2021)

Only 4.1% of adults with learning disabilities in Scotland are in paid employment<sup>130</sup>. This, in part, is the result of poor educational opportunities and transition planning alongside negative assumptions made about people with learning disabilities. These low levels of employment can prevent people with learning disabilities from establishing economic security.

The 2021 'Review of Supported Employment within Scotland'<sup>131</sup> found that there is a complex mixture of local and national provision of supported employment with high variability in access rates. The review clearly showed a considerable opportunity to improve access to supported employment for people with learning disabilities and autistic people.

The subsequent report made nine recommendations, including improving disaggregated data collection to drive consistency and oversight of supported employment provision. This would occur alongside a Scottish Supported Employment Guarantee that provided funding and set targets for local areas. Additionally, the review recommended that Fair Start Scotland contracts remove the requirement for 16 plus work hours. However, despite these recommendations, data collection continues to be poor and to date there appears to be no sustained improvement for people with learning disabilities in this area.

<sup>130</sup> However, the employment status of more than 50% of adults within this dataset is unknown. (LDSS, 2019)

<sup>131</sup> [Scottish Government \(2022\)](#)



## Recommendations

31

Scottish Government and relevant stakeholders to implement the recommendations from the 'Review of Supported Employment within Scotland (2021)'.

### Social care charges and adult disability payments

“Care charges are against people’s human rights.”

UPR focus group participant (November 2021)

“Just when you get used to one benefit, it changes to another ... they need to realise that we get confused.”

UPR focus group participant (November 2021)

As part of the UPR engagement sessions, people with learning disabilities highlighted that care charges and barriers in accessing disability payments stopped them from being able to live the life they chose.

These concerns are supported by research<sup>132</sup> highlighting that local authority thresholds for accessing social care have risen over the past decade. People with learning disabilities must increasingly be assessed as having a ‘critical’ need to be eligible for self-directed support. The same report highlighted that additional care charges for individuals varied from area to area and were subject to frequent increases. This is also reflected in England, where disabled people’s organisations have said that disabled people face a ‘tax on disability’ because of rising social care costs.<sup>133</sup>

---

<sup>132</sup> SDS (Self Directed Support) Scotland and The Alliance (2020)

<sup>133</sup> The Guardian (2023)

The ‘Independent Review of Adult Social Care in Scotland’, published in 2021 recommended that,

“People must be able to access support at the point they feel they need it, including for advice and signposting to local community-based resources and help, and for barriers to this, such as the current eligibility criteria and charging regime, to be fundamentally reformed and removed, to allow a greater emphasis on prevention and early intervention.”<sup>134</sup>

Since then, the Scottish Government and COSLA have committed to overhauling the current mechanism of social care eligibility criteria. This has included ending charges for non-residential services by 2026. However, many people who access social care support, including people with learning disabilities, are unhappy at the pace of progress. In February 2023 a campaign was launched calling for the end of non-residential social care charges by September 2023.<sup>135</sup>

SCLD awaits the outcomes of ongoing Scottish Government work and research in this area, including how this will develop alongside the National Care Service (Scotland) Bill.<sup>136</sup>

Meanwhile, in Scotland, the Adult Disability Payment has replaced the Personal Independence Payment (PIP). While this is a positive change, some have criticised the continued focus on isolated ‘activities’ within the eligibility criteria as creating additional barriers to people with learning disabilities to access these payments.<sup>137</sup>

## Recommendations

- 32** UK Government and devolved nations to end care charges.
- 33** Scottish Government to design a progressive, rights-based approach to adult disability payments that is person-centred and takes account of the social and structural barriers which infringe on people with learning disabilities’ right to independent living and equal participation in society.

<sup>134</sup> Independent Review of Adult Care in Scotland ([www.gov.scot](http://www.gov.scot))

<sup>135</sup> The Health and Social Care Alliance (2023)

<sup>136</sup> National Care Service (Scotland) Bill – Bills (proposed laws) – Scottish Parliament | Scottish Parliament Website

<sup>137</sup> SCLD (2019)

# The route map for change

---

People with learning disabilities in Scotland experience daily denials of their human rights, and despite our awareness of these issues we are yet to see actual transformative change in Scotland. The unacceptable dehumanisation and pathologising of people with learning disabilities is central to our collective failure to deliver change.

The inclusion of people with learning disabilities in the legal definition of ‘mental disorder’ in the Mental Health (Care and Treatment) (Scotland) Act 2003 has been central to their experience of dehumanisation. It allows people with learning disabilities to be detained purely on the basis of disability. This practice is a legacy of anachronistic ideas of ‘deviance’. It has been allowed to continue in Scotland despite being inherently at odds with the Equality Act 2010 and Article 12 of the UNCRPD.

Unjustly denying the liberty of people with learning disabilities has set the standard for the consistently poor treatment and horrifying experiences of people with learning disabilities in Scotland today. This includes violations of their right to life, barriers to accessing justice, and the use of restrictive practices, as well as being denied the opportunity to make decisions for themselves.

As a regressive approach to human rights at Westminster continues,<sup>138</sup> Scotland can and must do things differently for people with learning disabilities who face some of the most severe human rights infringements. While ensuring rights realisation for people with learning disabilities will not be without complications, SCLD believes we have a route map for change. If we follow it, we can ensure people with learning disabilities can live full, safe, equal and loving lives.

The first and most critical part of this route map is ensuring that people with learning disabilities lead the much-needed culture change required. Without people with learning disabilities leading, we will continue to search in vain for the answers that they have identified already.

SCLD has been proud to co-create and support the Include for Good Rapporteurs to lead the way. The rapporteurs have taken this opportunity, and in May 2023 they spoke to key decision-makers from across Scotland in the Scottish Parliament about what needed to change and how those in the room could work together to deliver critical actions.

---

<sup>138</sup> Illegal Immigration Act (2023)

# ROUTE MAP FOR Change



The rapporteurs are by no means alone in leading this change. Other groups of people with learning disabilities, like People First (Scotland), have long campaigned for transformational change, and it is time we listened and took action.

While there will be challenges ahead, SCLD believes that incorporating substantive UNCRPD rights within devolved competence by placing a duty on relevant Scottish public bodies and private actors to comply with these rights is the clearest and most significant action Scotland can take to address the long-standing abuse of rights faced by people with learning disabilities. To do this, people with learning disabilities must continue to develop their leadership and work together with others to see their vision become a reality.

The meaningful realisation of human rights for people with learning disabilities in Scotland should be a staged process that must include a widescale legislative overhaul. SCLD believes this must include, but should not be limited to:

1. Incorporating key articles of the UNCRPD into Scottish law within the new Human Rights Bill for Scotland. This should include elements of Article 12 (equal recognition before the law), Article 13 (access to justice), and Article 19 (living independently and being included in the community).

2. Auditing and amending non-UNCRPD compliant existing legislation. Amendments should seek to align existing legislation with the UNCRPD.
3. Removing learning disability (and autism) from the legal definition of 'mental disorder'.
4. Legislating for supporting people with learning disabilities to access justice, live free from violence, live independently and make their own decisions as part of the Learning Disability, Autism and Neurodiversity Bill. Consideration should also be given to whether the Learning Disability, Autism and Neurodiversity Bill would be an appropriate legislative mechanism for a number of parliamentary proposals and recent campaigns.
5. Legislating for robust data collection on the experiences of people with learning disabilities as part of the Learning Disability, Autism and Neurodiversity Bill.

SCLD believes people with learning disabilities and those who support them now have a once in a generation opportunity to work collectively to address systemic inequalities and create legislative measures to support them in achieving fairness in protecting their human rights.

Central to all this is incorporation of the UNCRPD within Scotland's new Human Rights Bill. Despite some positive commitments in the Scottish Government's response to the SMHLR, without a duty to comply with the substantive rights of the UNCRPD in the new Human Rights Bill for Scotland, the Scottish Mental Health Law Review recommendation that learning disability remains within the purview of mental health and psychiatry could go unchallenged. Ultimately, this will lead to people with learning disabilities continuing to experience unacceptable violations of their human rights: institutionalisation, abuse and harm. SCLD and our stakeholders are clear, this has to end now.

# Recommendations for change

---

**SCLD believes the following recommendations, if implemented, will begin to address the most serious rights violations facing people with learning disabilities in Scotland today:**

- 1** Scottish Government to continue to incorporate international human rights treaties through the new Human Rights Bill for Scotland alongside enforceable and accessible remedies.
- 2** Scottish Government to ensure the incorporation of substantive UNCRPD rights as part of the new Human Rights Bill for Scotland. This should be done within devolved competence.
- 3** Scottish Government to conduct an audit of relevant Scottish legislation to ensure compliance with substantive UNCRPD rights.
- 4** Scottish Government and public bodies to support and implement SNAP 2, with milestones and an audit process built in to evaluate impact.
- 5** Extend the powers of the Scottish Human Rights Commission (SHRC) to ensure the right to an effective remedy for human rights breaches is equally available in Scotland.
- 6** Scottish Government to develop and consult on a robust Learning Disability, Autism and Neurodiversity Bill in conjunction with the Human Rights Bill for Scotland. This process should explore interconnections and opportunities for positive rights realisation for people with learning disabilities between the two bills.
- 7** The Learning Disability, Autism and Neurodiversity Bill to place additional duties on all public bodies to support people with learning disabilities to realise specific UNCRPD rights. The Bill should create a monitoring and accountability mechanism to support this.
- 8** Scottish Government to ensure the development of a bill and a commission/ commissioner which is led by and informed by the views of people with learning disabilities.

- 9 Scottish Government, justice services and NHRIs to implement recommendations from 'Unequal, Unheard, Unjust: But Not Hidden Anymore. Women with Learning Disabilities' Experience of Gender-Based Violence in Scotland'.
- 10 Scottish Government to review the appropriateness and effectiveness of adult support and protection referrals based on women with learning disabilities experiencing gender-based violence and support the roll-out of an accessibility audit for all gender-based violence support services by 2024-25.
- 11 Scottish Government to ensure the representation of and engagement with people with learning disabilities in developing the delivery plan for Hate Crime Strategy for Scotland.
- 12 Scottish Parliament to work with the National Union of Journalists to produce national guidance for media on reporting on learning disability.
- 13 Scottish Government to develop awareness-raising campaigns on the experiences of people with learning disabilities in line with UPR recommendations.<sup>139</sup>
- 14 In line with Article 31 of the UNCRPD<sup>140</sup> and UPR recommendations,<sup>141</sup> the Scottish Government and other public bodies must examine approaches to improve data collection to build evidence on whether people with learning disabilities can realise their human rights.
- 15 Scottish Government and public bodies to implement recommendations from Fraser of Allander Institute report, 'Data on the lives of people with learning disabilities in Scotland: short term actions for change'.<sup>142</sup>
- 16 The Scottish COVID-19 Inquiry should include evidence sessions from people with learning disabilities.
- 17 Both the UK and Scottish COVID-19 Inquiries should include investigations into political and media messages surrounding the COVID-19 pandemic.
- 18 Scottish Government to ensure the new National Care Service places human rights compliance at its centre, as recommended by the Independent Review of Adult Social Care in Scotland.<sup>143</sup>

---

<sup>139</sup> Recommendation - 257 UK Government (2022)

<sup>140</sup> Article 31- UNCRPD (2006)

<sup>141</sup> Recommendation 212: UK Government (2022)

<sup>142</sup> Fraser of Allander (2023)

<sup>143</sup> Scottish Government (2021)

- 19 The digital front door team<sup>144</sup> to continue their ongoing engagement and development work with people with learning disabilities from across Scotland.
- 20 Scottish Government to explore the need for legislative underpinning for the 'Coming Home Implementation Report' as part of the Learning Disability, Autism and Neurodiversity Bill to ensure accountability and enforceability.
- 21 Scottish Government and local areas to ensure the implementation and monitoring of recommendations within the 'Coming Home Implementation Report' by 2024, while investing in and promoting high-quality social supports, including changing places toilets, which may support people to move out of hospitals and out-of-area placements.
- 22 Scottish Government to explore embedding a UNCRPD compliant national supported decision-making framework as part of the Learning Disability, Autism and Neurodiversity Bill.
- 23 Scottish Government to ensure appropriate safeguards that respect the rights, will and preferences of people with learning disabilities are available.
- 24 Scottish Government to align the work of the Gender-Based Violence and Learning Disability Steering Group and the Adult Support and Protection Improvement Project to explore the potential for future development given the ongoing human rights legislative change programme.
- 25 Future legislative reform focusing on either the Adults with Incapacity (Scotland) Act 2000, or the Adult Support and Protection (Scotland) Act 2007, to reflect the experience of people with learning disabilities placed under these measures. This should include women with learning disabilities who have experienced gender-based violence.
- 26 Scottish Government to embed national statutory human rights-based standards, guidance, and monitoring of restrictive practices across all settings. Exploration should be given to this being embedded as part of the Learning Disability, Autism and Neurodiversity Bill.
- 27 Scottish Government to establish a clinical review of prescribing practice in psychotropic medication, which makes recommendations on developing a national human rights-based approach.

---

<sup>144</sup> [Digital Health and Care Scotland](#)



- 28** Scottish Government to explore the role of a new Learning Disability, Autism and Neurodiversity Commissioner/Commission or other public body in monitoring restrictive practices in all relevant settings.
- 29** Scottish Government to ensure the first phase of the rollout for free early learning and childcare provision for 1- and 2-year-olds to include children with learning disabilities; uptake should be monitored and enforced through the UNCRC Children's Rights Scheme.
- 30** Scottish Government and local authorities to support children and young people with learning disabilities' transitions through the resourcing of local area transitions workers to support children and young people with learning disabilities to access support and achieve their goals.
- 31** Scottish Government and relevant stakeholders to implement the recommendations from the 'Review of Supported Employment within Scotland (2021)'.
- 32** UK Government and devolved nations to end care charges.
- 33** Scottish Government to design a progressive, rights-based approach to adult disability payments that is person-centred and takes account of the social and structural barriers which infringe on people with learning disabilities' right to independent living and equal participation in society.

# Conclusion

---

**The State of Our Rights** demonstrates the extent to which failures to respect, protect and fulfil the human rights of people with learning disabilities in line with the UNCRPD and other international treaties negatively impacts them on a day-to-day basis. SCLD is clear that one of the most significant failings to date has been the ongoing detention of people with learning disabilities under the Mental Health (Care and Treatment) Scotland Act 2003, and this must be addressed as a priority.

The report aims to establish a baseline of the negative experiences faced by people with learning disabilities and to capture some of the most serious violations of their rights. The scope of SCLD's original UPR submission in 2022 and the ongoing lack of robust data means that several critical issues for people with learning disabilities, most notably the removal of children from parents with learning disabilities<sup>145</sup> and their exclusion from accessing transport, have yet to be addressed in detail.

It is SCLD's hope that the baseline provided by this report can be reviewed and updated over the coming years as these gaps are addressed with a view to ensuring a full and robust picture of the progressive realisation of human rights for people with learning disabilities and to support international rights monitoring.

In the meantime, **The State of Our Rights**, the recommendations contained within it, and the proposed route map for change will help to begin the journey to ensuring the human rights of people with learning disabilities in Scotland are fulfilled.

Our collective goal must now be that future generations of people with learning disabilities do not face the injustice and prejudice that people like John,<sup>146</sup> Margaret Fleming, Kyle Gibbon and, sadly, many others have endured.

People with learning disabilities can and must live full, safe, equal and loving lives.

---

<sup>145</sup> SCLD (2016)

<sup>146</sup> Story available p.5-6 of this report





## **Scottish Commission for People with Learning Disabilities**

Suite 5.2, Stock Exchange Court  
77 Nelson Mandela Place  
Glasgow G2 1QY

✉ [admin@sclld.co.uk](mailto:admin@sclld.co.uk)

☎ 0141 248 3733

🐦 @SCLDNews

📘 @ScotCommission

📷 @sclldnews

📺 [vimeo.com/sclldnews](https://vimeo.com/sclldnews)