

The Right to Equal Rights

How can the Human Rights Bill for Scotland ensure equal human rights for people with learning disabilities?

The Human Rights and Learning Disability Lived Experience Board

Report July 2023–March 2024



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This is the Lived Experience Board's third report

You can read the Board's first report here:

[Human-Rights-Lived-Experience-Board-Report-1.pdf \(scl.d.org.uk\)](#)

You can read the easy read of the first report here:

[The Right to be Heard! The Learning Disability Lived Experience Board on the new Human Rights Bill for Scotland \(scl.d.org.uk\)](#)



You can read the Board's second report here:

[06813-Solving-the-Human-Rights-Puzzle-report_WEB.pdf \(scl.d.org.uk\)](#)

You can read the easy read of the second report here:

[06813-Solving-the-Human-Rights-Puzzle-report-easy-read-combined.pdf \(scl.d.org.uk\)](#)

Section 1:

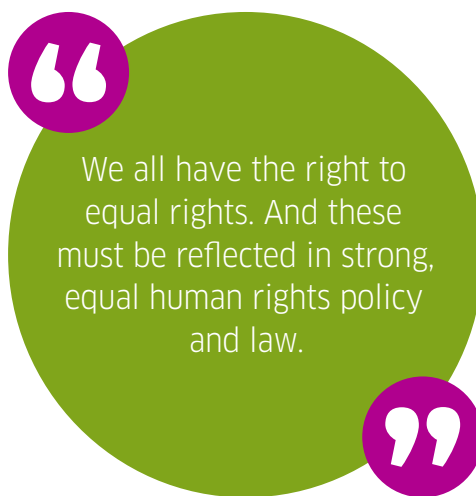
Introduction

Human rights are for every person. Regardless of their situation. We all have the right to equal rights. And these must be reflected in strong, equal human rights policy and law.

In the UK each person is entitled to enjoy equal human rights. The UK government has committed to equality through the ratification of various international human rights treaties, such as ECHR, ICESCR, UNCRPD, as well as introducing UK legislation such as, the Human Rights Act, and the Equality Act. These are strong statements of commitment in law. However, when we stop to listen to the real-life lived experiences of people with learning disabilities, it becomes clear that this human rights legal landscape can be devastatingly superficial. People with learning disabilities continue to tell us that human rights on paper do not translate into human rights in real life, and that many people continue to suffer a lack of basic human rights enjoyment in the UK.

This report details critical discussions and recommendations from the Human Rights and Learning Disability Lived Experience Board from July 2023 to March 2024. During this time, the Lived Experience Board continued its work alongside the Scottish Government developing the Human Rights Bill for Scotland, over three blocks of work. The first block ran from July until October, following the Human Rights Bill for Scotland Consultation. The Lived Experience Board spent this time investigating, sharing and responding to the Consultation. In the second block, the Board held two feedback meetings with the Human Rights Bill Team via Zoom. The Board chose to use these meetings to discuss the consultation process and to highlight the key issues and concerns raised in the Lived Experience Board consultation response. In the final block, the Board worked on this report, **'The Right to Equal Rights'**, and met with the Scottish Government's Director of Equalities, Inclusion and Human Rights.

Overall, the Board has worked to advise the Scottish Government of the essential steps it must take to ensure the Human Rights Bill for Scotland works for people with learning disabilities.



Recent developments in national law threaten to significantly regress human rights in the UK. We cannot achieve equality by going backwards. Especially as those with their rights most at risk, such as people with learning disabilities, are already living with significant barriers to their human rights. We have a collective responsibility to work to ensure that every person benefits from these inalienable rights. Society must work together to ensure full equality and, while civil society can do this by working to create awareness and provide support, government and duty bearers must adopt the burden of implementing and enforcing a legally strong system of human rights laws. Without this, a government cannot claim to have a just and fair society.

The Scottish Government has a valuable opportunity to change the lives of people with learning disabilities for the better by creating a Bill that will, in its own words, 'make Scotland a world leader in human rights.' ([New Human Rights Bill - gov.scot](https://www.gov.scot) (www.gov.scot)).

The Scottish Government has described the work around the Human Rights Bill as 'challenging, ambitious and will need continued bold leadership to implement... by far the biggest step taken in Scotland's human rights journey.' [New Human Rights Bill - gov.scot](https://www.gov.scot) (www.gov.scot). People with learning disabilities and lived experience recognise this challenge and are also the best people to work with the government to ensure this Bill works for everyone.

Based on the feedback given by people with learning disabilities, this report includes recommendations to the Scottish Government for consideration as part of the new Human Rights Bill for Scotland.

Section 2:

Purpose

The Scottish Commission for People with Learning Disabilities created the Human Rights and Learning Disability Lived Experience Board to help the Scottish Government involve the opinions, ideas, and experiences of people with learning disabilities in the new Human Rights Bill for Scotland.

The Board focuses on what the members have identified as the most important and impactful aspects of human rights for people with learning disabilities. This includes the incorporation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) into the new Bill, the implementation process, and the removal of key barriers to human rights realisation.

The Board also said it wanted to continue to understand how legal frameworks work, how they interact with each other, and the work of government bodies and decision makers such as the Human Rights Bill Team. As a result, the Board spent time in each meeting discussing the structure and powers of laws and policies. Additionally, the Board identified the importance and value of co-production and knowledge exchange, and so was keen to adopt these principles in its interactions with the Scottish Government.



The Lived Experience Board comprises up to 15 members who attend regular meetings. Members are primarily people with learning disabilities, with the addition of one family member who supports a member with profound and multiple learning disabilities. Members attend meetings voluntarily. The Board receives regular updates from the Human Rights Bill Team on how the Lived Experience Board informs the Scottish Government's work on the new Human Rights Bill for Scotland. It is of critical importance that the work of the Lived Experience Board is a meaningful participation process.

Section 3:

Co-production and knowledge exchange

The Lived Experience Board members identified that they were keen to promote a knowledge exchange between people with lived experience and the Scottish Government. They believe that government decisions must be made with the meaningful involvement of people with learning disabilities, so the group investigated the concept of co-production and how this can be used in the creation of the new Human Rights Bill for Scotland.

Co-production is essentially making decisions together with the people who are impacted by the outcome of these decisions.

Mind UK describes co-production as an ‘approach to influence and participation [which] allows staff and people with lived experience to have an equal relationship when designing activities, projects, or services.’ Effective co-production between governments and people with lived experience also promotes the realisation of key UNCRPD rights, such as political participation, access to information, equality, access to justice, and awareness raising.

To the Lived Experience Board, knowledge exchange means recognising the value of the experiences and knowledge that each member has, and the worth of this in realising human rights. Knowledge exchange is of particular importance to the members of the Board, because, as one member pointed out,

‘We can do anything if we take the time to learn from each other. We need to work together.’

To facilitate this knowledge exchange and promote co-production throughout the creation of the Human Rights Bill for Scotland, the Board asked that the Scottish Government give the Board more information on how the government teams function and how the Bill is created. For example, the Human Rights Bill Team and senior government member Alison Byrne shared information on their roles in the Bill process, the impact they believe their work has, and their own goals and hopes for the Bill. The Board found this to be a very positive experience with one member stating that they felt

‘more included in the process and that we are thought better of’.

Section 4:

Who are the Board members?

- Fiona D
- Brian B
- Kerry M
- Lindsay K
- John G
- Sandy S
- Aaron H
- John C
- Leanne C
- Anne P

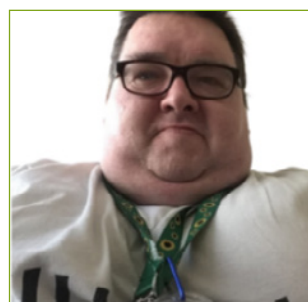
(Names partially anonymised at the request of the Lived Experience Board members. Not all Board members chose to be featured here.)



Fiona



Aaron



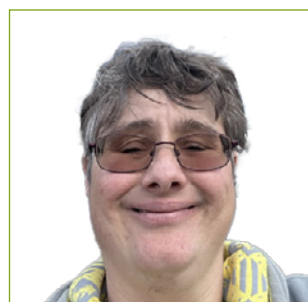
John C



Sandy



John G



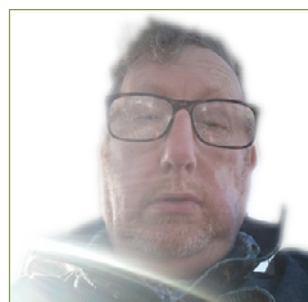
Kerry



Leanne



Lindsay



Brian

Section 5:

Update

In 2022, the Bill process was delayed due to the Scottish Government identifying that more work was needed on the Bill to create strong policies for the consultation. The progress of the Bill was also impacted by other legislation, for example, the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) Scotland Bill and the British Bill of Rights.

The Bill process continued in June 2023 with the release of the Consultation. Following on from the Consultation, the Scottish Government published a Consultation Analysis.

The Consultation Analysis is significant in reinforcing several of the Lived Experience Board's key messages and recommendations from previous reports, with respondents broadly showing support for solutions such as:

- Data gathering to support monitoring, reporting duties, accountability, and to allow for targeted action to remedy issues identified by data collection
- A commitment to human rights based education and effective information dissemination about human rights that will reach every group of people
- Adopting a multi-institutional approach to accessing justice, including reform of the legal aid system to prioritise the rights-holders and to address inequalities. For example collaboration between legal, advocacy, and public body services was deemed crucial to streamline processes and minimise bureaucracy
- Support for human rights based training for public bodies, recognising that successful implementation of the Human Rights Bill depends in part on capacity building across public services
- Resources and support from the Scottish Government to develop and increase access to specialist accessible advocacy services
- Stating specific groups to be protected by the equality provision, explicitly inclusion of people with physical or mental health issues, disabilities, autism or neurodiversity
- Full incorporation of the UNCRPD with a duty to comply placed on all public bodies to cover all rights, with direct incorporation of all international treaties recommended by the National Taskforce on Human Rights Leadership

Section 6:

Understanding the consultation

The Lived Experience Board spent several meetings working on understanding the Human Rights Bill Consultation and key concepts within the Scottish Government's proposals for the Bill content.

What Model?



Scottish Government is proposing direct incorporation

Direct incorporation means a country makes a new law (Human Rights Bill) that brings a treaty (eg UNCRPD) into their national law.

It uses the same words as the treaty. It means that governments must follow the treaty.

Board members were keen to understand the more technical language of the Bill, with several members making clear how important it is that people with learning disabilities have the opportunity to learn about governmental decision-making processes, not only for personal interest but because

'it is much easier to respond if we understand what they're saying'.

One aspect of the Bill that the Board quickly identified as important is the way the human rights in the Bill are realised in real life. Hence the Board chose to focus on understanding and responding to the Scottish Government's incorporation proposal.

The Board held two meetings on incorporation, with members being guided through the methods of incorporation. They then had several discussions on what impacts could be achieved and which method would most likely be the most effective for achieving real-life human rights realisation for people with learning disabilities.

Why is Incorporation Important?



The way treaties are incorporated into the Bill impacts how effective and strong the rights are in real life

How much power they have in life

Strong incorporation makes sure that people and organisations who make laws and policies always consider human rights

Strong laws that people have to follow are more likely to mean people get their human rights

Reactions from the group

SCLD staff explained how incorporation of rights works and members were encouraged to envision how this would impact human rights realisation in real life circumstances.

Several members volunteered their own life experiences and the group discussed how the different levels of rights incorporation could impact these events. For example, one member talked about a health crisis they experienced several years ago, which, without access to a named social worker or robust person-centred support, resulted in a severe deterioration of their health and the person ending up on life-support. This person recalled to the group

‘No one was listening to me when I said I was unwell. Then there was no one to help me. I remember thinking what’s the point of me being here if no one cares?’

The Board identified where there should have been better support mechanisms in place, and suggested that if this person had been treated as the expert in his own health, and had been recognised as a person in need of a strong support package, the outcome would likely have been much more positive. The group believe that full incorporation of UNCRPD rights, such as the right to equal health, rehabilitation, protecting the person’s integrity, and right to life, could stop experiences like this being commonplace for people with learning disabilities.



I remember thinking what’s the point of me being here if no one cares?

Thinking about two different models of rights incorporation; duty to comply (full incorporation) and duty to consider (piecemeal incorporation), the group discussed how both might impact the strength of UNCRPD in law and therefore the human rights realisation of people with learning disabilities. Members were clear that people with learning disabilities need equal support and protection of their human rights under Scottish law, furthermore that they deserve to be recognised as equal members of society and that this is reflected in the status of their human rights under the law.

‘Human rights are something we have because we’re human. Well, we are human, as much as any other person on the planet. So the laws should show that.’

Members were asked what positive changes full incorporation of UNCRPD would bring to the lives of people with learning disabilities.

‘We have been ignored for so long in laws, this would show the government care about us. A lot of people with disabilities don’t trust the government because they don’t think they care. This would give us more trust in the government.’

‘Things were bad with human rights before COVID, for disabled people but especially for people with learning disabilities. COVID is over but lots of our lives haven’t returned to normal. We lost so much support and never got it back. For some people it’s as bad as when we had COVID. If we had full UNCRPD in law this would help force people and businesses to help to make our lives better.’

‘We could finally matter as much as everyone else. For example we could get the same access to law and justice as everyone else. It’s so important to know that if someone does wrong to you then you have a law that will help you. That’s how you feel like you matter.’

‘Having UNCRPD fully in law would give people with learning disabilities the opportunity to show people what we’re worth. People say oh we have too many people on benefits or don’t have anyone to do jobs, but here we are. See our potential and what we can bring to Scotland. I want to go to college, and get a job, and learn, and make money. If things were equal under UNCRPD I could do that.’

‘People with learning disabilities are lots of times just invisible. People like Margaret Fleming just disappeared and no one noticed. What if that was me? That makes me feel scared sometimes. We need to be supported and counted and checked on in case we need help. UNCRPD [in law] would probably make people care more.’

The Board also discussed what the impact might be if the Scottish Government chose the ‘wrong’ method of incorporation.

The Lived Experience Board members were clear that they feel that piecemeal incorporation, or duty to consider, is the wrong method of incorporation for UNCRPD.

‘If we don’t have equal human rights then what’s going to be different to before the Human Rights Bill?’

‘We said [in a previous meeting] that this Bill is going to be a foundation for other human rights laws. If you build a house you need a strong foundation so what happens if this Bill isn’t strong? The other laws won’t be strong enough either.’

‘To me it’s like you’re setting a standard. The Human Rights Bill is a big important thing and it could be great for Scotland but if they [the Scottish Government] don’t make sure people with learning disabilities are equal then it’s like you’re saying to other countries that that’s the standard. Also people without learning disabilities won’t think we matter as much either.’

‘I said it before and I’ll say it again, we already have the Human Rights Act and the Equality Act and the Declaration of Rights [Universal Declaration of Human Rights] so why do we even need this too? Because if we’re not equal in it then what’s the point, because it won’t make anything better really.’

‘Learning disability is under the Mental Health Act [Mental Health (Care and Treatment) (Scotland) Act 2003] and the government said they don’t want to change that. But how will that work with the Human Rights Bill? UNCRPD means we’re equal but the Mental Health Act says people can be locked up if they have a learning disability. That’s not equal.’

What should we talk about in the consultation response?



From reading the consultation we have identified 3 big issues

- Dignity
- UNCRPD is not strong enough
- Consultation hasn’t included any of the Lived Experience Board recommendations

After spending time understanding some of the key concepts most relevant, in the Board’s opinion, to the human rights of people with learning disabilities, the Board chose two consultation questions to respond to. The Board felt that it was important to respond in depth to specific issues and decided to focus on two questions rather than several or all.



We chose to answer 2 questions from the Consultation

This was so we could focus more on what is most important to the lives of people with learning disabilities

These questions were;

- **Number 4** - What are your views on the proposed model of incorporation?



Question 4

What are your views on the proposed model of incorporation?

This question is asking what people think about the way the Scottish Government want to include the rights in the UNCRPD.

This is important because the UNCRPD says people with learning disabilities must be treated equally and have the same human rights as everyone else. So it is important that these rights are strong in the law.

- **Number 5** - Are there any rights in the equality treaties which you think should be treated differently? If so, please identify these, explain why and how this could be achieved.

The group chose to answer questions from the non easy read consultation because they felt these gave them a better opportunity to address important issues. They also felt that the questions in the easy read consultation didn't fully match the non easy read consultation.

The Lived Experience Board arranged meetings with three learning disability organisations and prepared presentations that had three main aims:

- to support people to understand the key points of the Human Rights Bill Consultation
- to facilitate discussion around how the Bill will work for people with learning disabilities
- to use these discussions to inform the Lived Experience Board's consultation response

The three organisations were The Assembly, Dates-n-Mates, and Get2gether. Some of the points raised by members of these groups are outlined below.

Question: What might be the impact of UNCRPD not being equally incorporated in the Human Rights Bill for Scotland?

'My life will not be equal.'

'People with learning disabilities will still be vulnerable to abuse.'

'Who will make sure people with learning disabilities are being treated properly or have their human rights?'

'If the law isn't strong enough the Human Rights Bill cannot support people with learning disabilities properly.'

'A new law should make things better not worse.'

'How will all local authorities be held to account in sticking to these laws?'

'Learning disability should not be under Mental Health Act [Mental Health (Care and Treatment) (Scotland) Act 2003]. Without full UNCRPD incorporation this won't change.'

'Everyone in Scotland must have equal access to their rights, have equal protection under the law.'

About the UNCRPD not being strong enough

It's not right that another treaty has more power in the law than UNCRPD
This is not equal rights so the law is not strong enough

How will all local authorities be held to account in sticking to these laws?

Everyone in Scotland must have equal access to their rights and have equal protection under the law

Human rights treaties can change lives for good or bad depending on how strong they are

UNCRPD is supposed to make sure everyone is treated equally not as a second class citizen but this isn't being implemented

Question: What needs to change to make the Human Rights Bill equally support the human rights of people with learning disabilities?

'UNCRPD should have equal strength in the law.'

'It should have duty to comply like the other one [ICESCR- International Covenant on Economic, Social and Cultural Rights].'

'The Human Rights Bill should say that learning disability isn't a mental disorder.'

Feedback from groups



Lead investigators spoke to 3 LD groups

They talked to them about the consultation

Made it clear that UNCRPD is not strong enough in the law

Asked them what they think about this and what needs to change

Section 7:

The Lived Experience Board response

To compile the consultation response the Board worked in two groups, named Detectives and Investigators, to decide on the content and structure of the response. The Detectives chose to structure the response around three main concerns and their response to the two chosen consultation questions. The three main concerns are dignity, the strength of UNCRPD in law, and the inclusion of the previous Lived Experience Board recommendations.



1. Dignity

The group identified that the consultation puts significant emphasis on the concept of dignity; recognising that ‘human dignity is the value which underpins all human rights’, and that the concept of human dignity can be a ‘helpful tool in understanding and interpreting key human and comparative constitutional rights’.

The consultation states that the Scottish Government ‘want to ensure that human dignity can be taken into account in the interpretation of the rights in the Bill’. The group felt that this appears to suggest that the concept of human dignity could be used to measure the value and worth of a person’s human rights when decisions are being made that are likely to impact a person’s quality of life. For example, within a legal challenge or when creating care plans. The group found this very concerning, as several group members pointed out that there is no universally agreed concept of what dignity is.

‘Dignity might mean something totally different to them than it does to someone with a learning disability’.

Another member said,

‘How can someone make human rights decisions about me if I don’t agree with what they think dignity is?’

The group stressed how important dignity is in realising human rights, having so often experienced a loss of or lack of access to dignity, and knowing first-hand the negative impact this can have on a person's life. However, members agreed that it is not possible to fairly measure someone's human rights using dignity as everyone has a different idea of what dignity is.

The group said that in order to create a fair, equal, and inclusive definition of dignity that can be used to support human rights realisation, marginalised and at-risk groups, such as people with learning disabilities, must be involved in creating that definition. In particular, if the concept of dignity is to be used as measurement of human rights within a legal context, the inclusion of people with learning disabilities in creating the legal definition of dignity would satisfy several Human Rights Taskforce Recommendations. This includes Recommendation 21, which states that: 'Through engagement with key stakeholders, including those who face additional access to justice barriers, further consider accessible, affordable, timely, and effective remedies and routes to remedy that will be provided for under the framework'.

Additionally if the concept of dignity is, as the consultation suggests, to be used as a marker of a minimum core obligation, participation in defining dignity would also satisfy Human Rights Taskforce Recommendation 13, which states that 'there be a participatory process to define the core minimum obligations of incorporated economic, social and cultural rights, and an explicit duty of progressive realisation to support the effective implementation of the framework, which takes into account the content of each right'.

What's the solution?



Should people agree on a definition of dignity?

Who should be involved in agreeing on this definition?



The Board think that although dignity is very important this is worrying because people have different ideas about what dignity is

This means that someone could make a decision about your life that you don't agree with



The Board said that people with learning disabilities should be involved in making the definition of dignity

2. The strength in law of the UNCRPD

The group investigated the strength of the UNCRPD in the proposed Human Rights Bill for Scotland. The UNCRPD is an essential human rights treaty for people with learning disabilities, which outlines that people with disabilities are entitled to live independent, safe lives, protected against all forms of abuse, violence and exploitation. People with disabilities are entitled to 'effectively and fully participate in political and public life on an equal basis with others'.

Having made clear to the Scottish Government through previous reports that a strong incorporation of UNCRPD is essential to ensuring support and protection to people with learning disabilities, the Lived Experience Board was keen to investigate how strong within the law the UNCRPD would be if the Human Rights Bill was passed as it is. The Lived Experience Board is concerned that the UNCRPD has not been given equal legal strength with other human rights treaties, specifically ICESCR. Where ICESCR appears to be given duty to comply status, UNCRPD rights are protected only by an initial procedural duty.

One group member pointed out that this inequality in the law makes people with learning disabilities

'feel like we are still second-class citizens and nothing is changing'.

One member said,

‘If the rights of people with disabilities are not strong enough compared to other people, is this not discrimination?’

The group chose to highlight this concern when engaging with other learning disability groups.

The feedback from the three groups on this subject was overwhelmingly in agreement that the UNCRPD does not appear to be strong enough to support the human rights of people with learning disabilities.

‘This means people with learning disabilities will be vulnerable to abuse. A new law should make things better not worse.’

‘[If the UNCRPD doesn’t have enough strength in the law] how will local authorities be held to account in sticking to these laws?’



The Board members think that people with learning disabilities still don’t always get their human rights

They don’t think this will change unless the Human Rights Bill for Scotland equally supports the rights in the UNCRPD



Conclusion

The Lived Experience Board thinks it is a good idea to have a new Human Rights Bill for Scotland



But the Board thinks this can only work for people with learning disabilities if all human rights have equal strength in the law

3. Inclusion of Lived Experience Board recommendations

In 2022 the Lived Experience Board investigated the state of human rights for people with learning disabilities. The group explored various human rights and the impact, both positive and negative, that these have on the lives of people with learning disabilities. The group produced two reports for the Scottish Government, [The Right to be Heard](#) and [Solving the Human Rights Puzzle](#). These reports included recommendations which outlined what the group believes must be reflected in the Human Rights Bill for Scotland in order for the Bill to work for people with learning disabilities.

The group also presented these recommendations to members of the Scottish Government Human Rights Bill Team and the then Minister for Older People and Equalities. The group does not feel that these recommendations have been adequately represented within the consultation. For example, the Lived Experience Board was clear that the Bill must

‘ensure a commitment to rights-based education, including for people with learning disabilities, across Scotland from school age into adulthood’,

and that there should be a

‘duty on public bodies to undertake disability awareness training, including learning disability awareness training’.

The consultation mentions human rights training for health care workers and a right to education but not specifically human rights focused education or specialised awareness training. The Lived Experience Board also recommended that there should be an

‘inclusion of provisions for groups not listed in the Equality Act under a rights most at risk clause. It should be made explicitly clear this is to include people with learning disabilities.’

The consultation states that ‘To ensure everyone can access the rights under the Bill without discrimination, we want to include an equality provision.’ However, this is in relation to the delivery of ICESCR rights and the right to a healthy environment, and does not mention UNCRPD rights or people with learning disabilities. The Lived Experience Board is very concerned that this apparent lack of inclusion of recommendations reflects a general disinterest from the Scottish Government in ensuring that the human rights of people with learning disabilities are supported by the Human Right Bill for Scotland.

One group member said

'It feels like people with learning disabilities are being pushed out of the picture'.

While another stated that they feel as though

'We wasted our time saying to the Government what we think and what we need. Why ask for us to be involved if we're not listened to?'

3. Lived Experience Board Recommendations



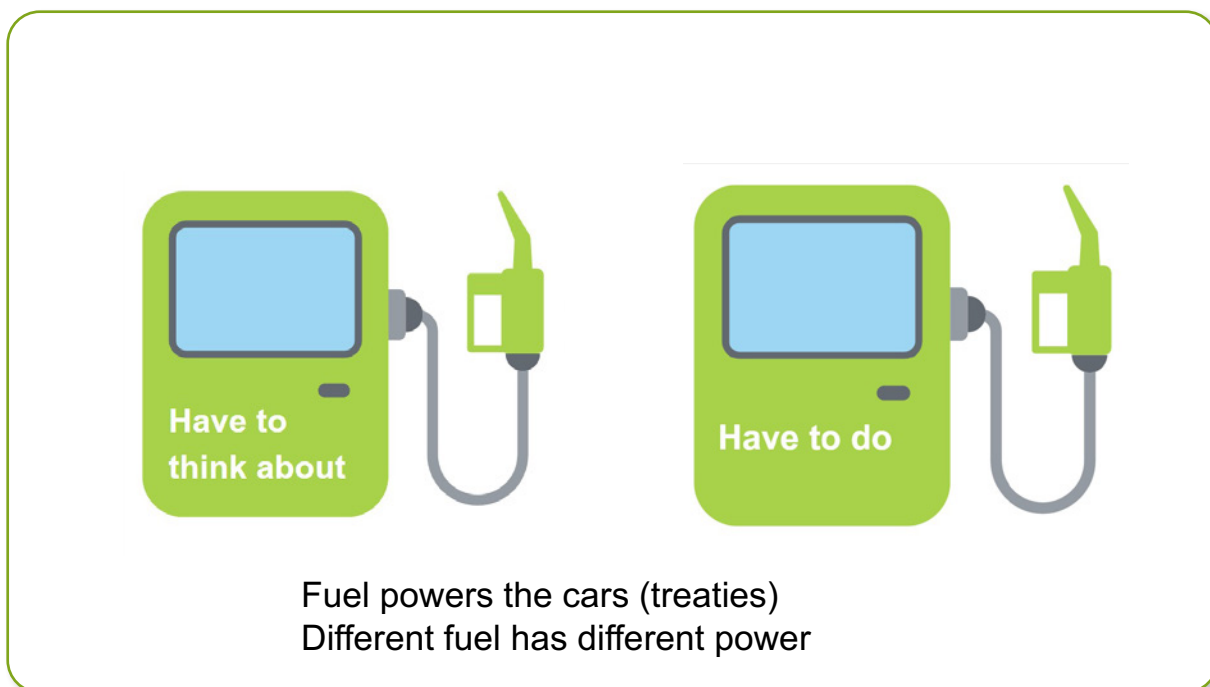
In 2022 the Lived Experience Board gave the Scottish Government recommendations on what to put in the Human Rights Bill for Scotland

The Board thinks these recommendations are very important to making sure the Bill supports the human rights of people with learning disabilities



The Board does not think that these recommendations have been properly included in the consultation

The Board feels that this means that the Scottish Government are not serious enough about supporting the human rights of people with learning disabilities



In response to consultation questions 4 and 5

Question 4. What are your views on the proposed model of incorporation?

- The Lived Experience Board does not support the proposed model of incorporation as the group has identified significant risks to the strength within the law of the UNCRPD
- The Lived Experience Board does not believe the Human Rights Bill can support human rights for all groups equally if all human rights treaties are not given equal power
- The Lived Experience Board maintains that the only way the Human Rights Bill for Scotland can fully support the human rights of people with learning disabilities is by giving equal strength to the UNCRPD otherwise these rights risk being lost
- Although the Lived Experience Board agrees with the concept of dignity as a universal right, and is pleased to see dignity recognised within the Bill, the Board does not believe that it is possible to achieve dignity for all if some human rights treaties are given more strength in the law than others

Question 5. Are there any rights in the equality treaties which you think should be treated differently? If so, please identify these, explain why and how this could be achieved

- Although the Lived Experience Board supports the rights within ICESCR and the right to a healthy environment, the Board believes that all rights within all treaties should be treated equally so as to ensure that all rights holders are supported and protected equally by the law
- In particular, the Lived Experience Board believes that all rights as outlined by the UNCRPD must be subject to a duty to comply to ensure that duty bearers are required by law to protect the rights of people with learning disabilities
- The Lived Experience Board believes that the rights of people with learning disabilities continue to go unrealised and that anything less than a duty to comply will only result in the continued invisibility and inequality of the lives of people with learning disabilities
- The Lived Experience Board is clear that without equal protection under the law people with learning disabilities cannot hope to have equal access to justice and will continue to be subject to injustice without remedy

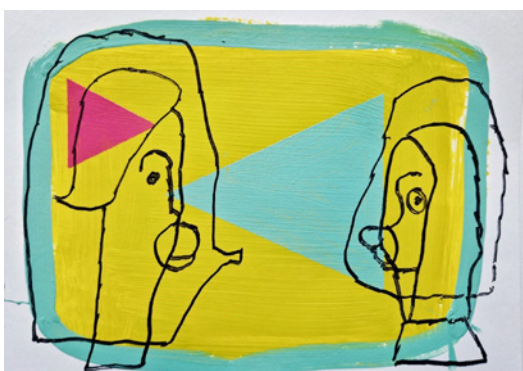
Section 8:

Conversations with the Scottish Government

The Lived Experience Board held three meetings with the Scottish Government. The first meeting was with a member of the Governance and Participation Team and focused on the Board members' experience of the consultation process. The second was with 6 members of the Human Rights Bill Team and focused on the Board presenting the key issues from their consultation response. The final meeting was with Alison Byrne, Director of Equality, Inclusion and Human Rights, as well as senior members of the Bill Team. This meeting focused on discussions around incorporation of UNCRPD and the Board's concerns about the impact of weak incorporation on the human rights of people with learning disabilities.

In the first meeting, the Lived Experience Board gave a presentation highlighting several positive and negative aspects of the consultation process, relating to their experience as people with learning disabilities. The Board was keen to communicate not just issues but also solutions, in the hope of influencing the way consultation processes are designed in the future.

John G



Thank you for talking to us about the consultation process

It's really helpful to understand how this process works

Often people with learning disabilities can feel excluded or that they are not allowed to know how things work in the Government

This means we can make suggestions to you about how the process could be improved or work better for people with learning disabilities

If the Human Rights Bill is to work better for people with learning disabilities, then its crucial the consultation does too

For example, one Board member made a point about how aware people were of the consultation.

'A lot of people didn't know there would be a consultation. Even if they knew that the government wanted to make a new Human Rights Bill for Scotland, they didn't know the consultation was coming out. It wasn't well promoted or advertised. The public won't know they can have an opinion. Many people with learning disabilities already feel left out or silenced.'

Sandy

What is a consultation?



Some people know what a consultation is but many don't.

There isn't enough awareness or understanding of government processes. We don't get taught about this enough.

People with learning disabilities aren't involved enough.

As a solution to this, the Board suggested that the Scottish Government

'promote and advertise where people with learning disabilities are likely to see it. For example, community groups and hubs, support providers, local MSPs. Don't just promote digitally, lots of people with learning disabilities can't access the internet or don't always get the support to use it. Ask people with learning disabilities where they would see it.'

Another member talked about accessibility,

'there needs to be a version of the consultation that works for people with complex needs. The consultation was really difficult to find online. The government website isn't very accessible. What's the point of an easy read consultation if we can't get to it? It's great to have accessible digital versions but please remember that some people don't have the money to buy the technology or don't have the support to use it.'

As a solution, it was suggested that

‘the government could hold in-person events to present the consultation and help people understand it. Send paper versions to support providers and community groups. A video or animation to help people understand the key points would be helpful.’

Fiona



Solutions

Education should be more about how governments work and how people can be involved.

Government should do more outreach work with learning disability groups.

Encourage support providers to give us information.

People often assume we won't understand or we won't care so they don't tell us what's going on.

Don't assume we are stupid. We are the experts on our own lives and we want to know how and why decisions about us are made.

In the second meeting the Lived Experience Board met with 6 members of the Human Rights Bill Team. The Board wanted this meeting to be an opportunity for each group to learn more about what the other does, what their hopes are for the Human Rights Bill, and what they think the future looks like for the human rights of people with learning disabilities.

Bill team members spoke about their individual roles in creating the Human Rights Bill, for example incorporation, implementation, legality, and participation. The Board found this hugely interesting and helpful in understanding more about the process of Bill. The Board then spoke about their individual interests and the various projects they have worked on as human rights defenders. They then presented the key points of their consultation response.

The main point the Board chose to make was in relation to the strength of UNCRPD in the Bill.

Lindsay



The UNCRPD says that people with a learning disability have equal rights to everyone else.

But many people say this doesn't always happen in real life and lots of people with learning disabilities still do not get all of their human rights.

This means they cannot live lives that are free from inequality and discrimination

One Board member said,

'Question 4 in the consultation asks, "what are your views on the proposed model of incorporation?" This question is asking what people think about the way the Scottish Government want to include the rights in the UNCRPD. This is important because the UNCRPD says people with learning disabilities must be treated equally and have the same human rights as everyone else. So, it is important that these rights are strong in the law.'

Leeanne



So it is really important that the new Human Rights Bill for Scotland can make things better for people with learning disabilities.

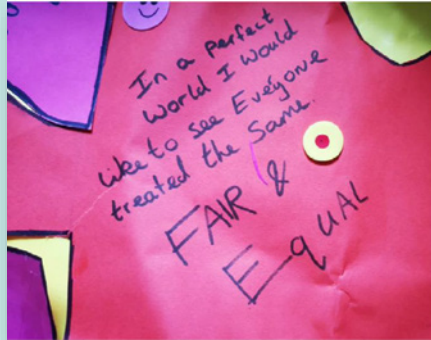
We need you to push for the changes needed to make this happen.

Aaron

It is essential that people with lived experience are involved in making decisions that will impact the lives of people with learning disabilities.

We can learn so much from each other.

After all, people with learning disabilities are the experts on what is best for their own lives.



Another said

'The Board does not agree with the way the Scottish Government want to include the UNCRPD in the Human Rights Bill for Scotland. Because we do not think it will be strong enough in the law. The Board does not think the Human Rights Bill for Scotland can support everyone equally if the UNCRPD is not strong enough in the law. We do not think that people with learning disabilities will get dignity if their human rights are not properly supported in the law.'

John G

2. How strong the UNCRPD is in the law

The Consultation talks about how strong some human rights will be in the law.

The Board looked at what the Consultation said about how strong the human rights in the UNCRPD would be in the new Bill.

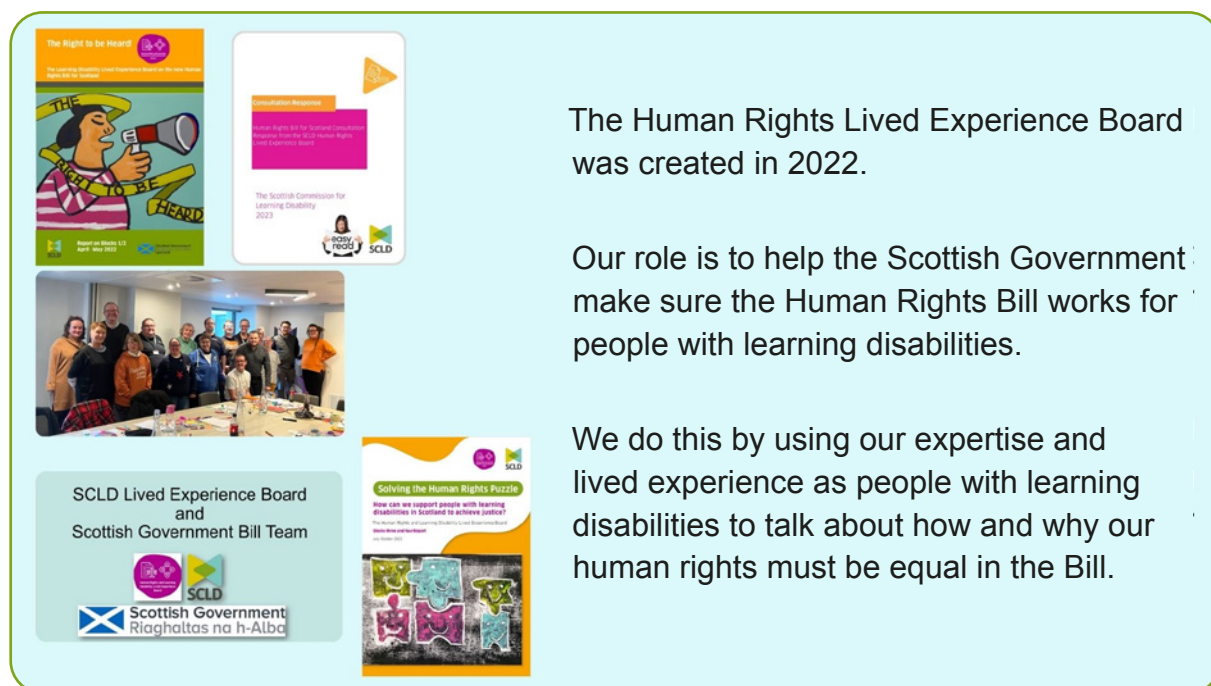
We do not think the UNCRPD is as strong as other human rights treaties.

This is because the rights in the UNCRPD are not strong enough and people will not be forced to follow them.

What is the solution?

Give all treaties the same strength in the law.

The final government meeting, with Alison Byrne Director of Equality, Inclusion and Human Rights, focused on discussing the incorporation of UNCRPD and the Board's concerns about the impact of weak incorporation on the human rights of people with learning disabilities.



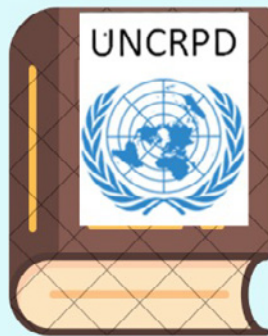
The Human Rights Lived Experience Board was created in 2022.

Our role is to help the Scottish Government make sure the Human Rights Bill works for people with learning disabilities.

We do this by using our expertise and lived experience as people with learning disabilities to talk about how and why our human rights must be equal in the Bill.

The meeting began with Ms Byrne introducing herself and thanking the Board for all the work it has done, and its valuable contributions to the creation of the Human Rights Bill for Scotland. Ms Byrne recognised the importance of including people with lived experience in decision-making processes and was clear that this involvement should continue throughout the Bill's development.

The Lived Experience Board members confirmed that they are keen to continue working with the Scottish Government and look forward to opportunities to do so in the near future. Bill team members explained that the next stage of the Bill's development, when the Bill goes to Parliament, means that the Scottish Government loses a lot of its control over the content. Therefore, they need to find other ways to ensure that people with lived experience are included meaningfully in the development process. One suggestion was that this could be as part of the implementation process. The Bill Team stressed that although this part of the work is nearing its end, the door is open for people with learning disabilities.



What are we really worried about?

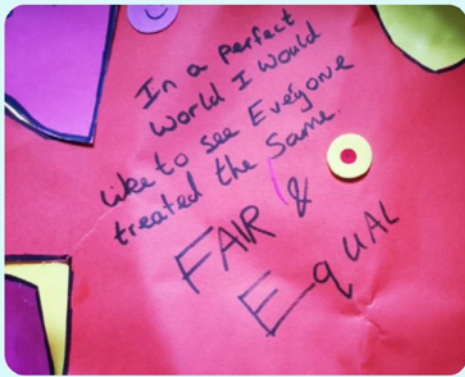
The strength of the UNCRPD in the law.

We need strong laws to have equal human rights.

The Board members told Ms Byrne that they are incredibly concerned about the level of UNCRPD incorporation proposed in the current version of the Human Rights Bill.

The Board asked the Bill Team and Ms Byrne what the problems are around fully incorporating UNCRPD.

The Bill Team and Ms Byrne explained that the biggest challenge is around reserved versus devolved powers. They stressed that ultimately they want the Bill to pass, and so want to reduce the risk of the Bill ending up in court and being challenged by the UK Government. For this reason, they are looking at the UNCRPD very closely to work out which rights can be incorporated into Scottish law without challenge. It was acknowledged that the consultation responses confirmed a real strength of feeling around the need for UNCRPD to be fully incorporated. The Bill Team stressed



Lived Experience Board member at the in person SCLD-SG meeting

After all, no one has human rights unless we all have human rights, equally.

that the realisation of human rights for people with learning disabilities is incredibly important and that the Scottish Government will continue to try to find a way through the complexity of devolved powers.

The future of the Lived Experience Board

At the time of writing this report (February 2024), the Lived Experience Board and SCLD are aware that the future of the Board has not been confirmed by the Scottish Government.

The Lived Experience Board would like to highlight the importance of continuing to meaningfully include people with learning disabilities in the Human Rights Bill process. The consultation response analysis heavily supports the need to involve stakeholders and rights bearers, particularly those with their rights most at risk, such as people with learning disabilities, as an essential aspect of co-production and capacity building. Involvement of people with lived experience is also essential to realising UNCRPD article 29 'Participation in Political and Public Life', as well as commitments made by the Scottish Government to recommendations by the National Taskforce for Human Rights relating to participatory processes, engagement, and accountability.

Section 9:

Conclusion and recommendations for Scottish Government

The Lived Experience Board believes that a new Human Rights Bill for Scotland has the potential to make significant and life-changing differences for people with learning disabilities. Changes that are long overdue. A new Human Rights Bill for Scotland provides an incredible opportunity to change both the culture and legislative framework for the country in ways which could provide much needed improvements in the lives of people with learning disabilities. The Lived Experience Board believes that the Scottish Government has an opportunity to create a Human Rights Bill that sets the standard for realising the human rights of people with learning disabilities. However, this can only be achieved if the Scottish Government implements the recommendations of people with learning disabilities and supports the human rights realisation of those who have so far been neglected and marginalised.

Following the recommendations outlined in the first and second reports, SCLD has listened to the views expressed by the Lived Experience Board and developed further recommendations that are considered essential for creating a new Human Rights Bill for Scotland that fully supports the realisation of human rights for people with learning disabilities. These are as follows:

1. Fully incorporate UNCRPD

Incorporation of the UNCRPD into Scots' law is crucial to advancing the human rights of people with learning disabilities. Whilst the Scottish Government has been clear that rights can only be incorporated insofar as devolution allows, it is essential to ensure that the substantive rights within the UNCRPD are incorporated to the maximum extent possible. This can be achieved by the Scottish Government investigating the incorporation status of each UNCRPD right, to fully understand the legal limitations of incorporation, and then seek to incorporate the UNCRPD into law to the maximum possible extent within devolved responsibilities. Such an approach would fulfil previous commitments made by the Scottish Government with regards to UNCRPD incorporation. Furthermore, a maximalist approach to incorporation is the best opportunity for Scotland to advance the human rights of people with learning disabilities.

2. Removal of learning disability from the Mental Health (Care and Treatment) (Scotland) Act 2003

The continued inclusion of people with learning disabilities in the legal definition of 'mental disorder' in the Mental Health (Care and Treatment) (Scotland) Act 2003 continues to threaten and undermine any progress towards human rights realisation and directly contravenes rights within the UNCRPD. While people continue to be at risk of detention for having a learning disability, Scotland cannot claim equality.

The new Human Rights Bill for Scotland must support the separation of learning disability from mental health legislation. The Bill can do this by ensuring that UNCRPD rights have a clear duty to comply, as this will help to set a minimum core standard in Scotland where legislation supports the human rights of people with learning disabilities on an equal and non-discriminatory basis.

3. Support the creation of a justice system that ensure equal access to justice and right to remedy

The new Human Rights Bill for Scotland must ensure that people with learning disabilities have equal access to justice. A strong incorporation of UNCRPD rights is essential, particularly Article 13 'Access to Justice'. Appropriate support to access services is essential and could be achieved with the creation of specialist advocacy services. To be effective, such services must be supported by appropriately trained and qualified staff. Additionally, people should be empowered to be able to identify and claim their own rights, which could also reduce demand on legal routes to justice. Education is key here and the creation of a National Hub of Human Rights Education, Advice and Information should be resourced and co-produced to provide human rights and justice information.

4. Data collection

The Human Rights Bill must include data collection duties on public and private service providers. Data drives change as it creates an understanding of how human rights are experienced by specific groups and informs policy developments to improve realisation. Without robust disaggregated data relating specifically to the human rights realisation of people with learning disabilities, it is arguably impossible to understand the real-life impact of human rights legislation. A lack of data is a failure to acknowledge people with learning disabilities as being entitled to equal protection under human rights legislation and equal within society.

5. Use of language and definitions

The new Human Rights Bill must use positive, supportive language that supports inclusivity by promoting mandatory human rights-based education and adapted communication and accessibility within public services as a critical aspect of human rights realisation. Definitions must be legally robust and written with lived experience input. The Scottish Government should be aware that writing definitions without the input of those defined can result in unconscious bias and impact negatively on human rights realisation.

The Lived Experience Board would like to thank the Scottish Government for the opportunity to help create a Human Rights Bill for Scotland that equally protects and supports the human rights of people with learning disabilities.

The Board hopes that the Scottish Government continues to meaningfully involve people with lived experience in the future stages of the Bill. Together we can realise equality.

If you have any questions about the work of the Lived Experience Board, please contact SCLD via email on admin@sclد.co.uk.

With thanks to Sarah D'Agrosa who was the Human Rights Engagement Adviser who worked with the Lived Experience Board throughout the project and supported them with the production of this report.

Also, thanks to the work of Jonathan McInstry for the cover image and to Project Ability artists for the images used throughout the content of this report. Other images credited to Photosymbols.





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