



The Right to Equal Rights

How can the Human Rights Bill for Scotland Ensure Equal Human Rights for People with Learning Disabilities?



Report July 2023 –
March 2024



Scottish Government
Riaghaltas na h-Alba
gov.scot



Definitions

Commission



A group of people who have been given the task of making sure specific rules are followed.

A commission is also in charge of investigating complaints if the rules are not followed.



Commissioner

The head of a commission who is in charge of leading an investigation or making sure rules are followed.



Consultation

When a person or organization present their ideas and ask for other people's opinions on what is good and bad about it.



Co-production

A way of working where service providers and service users work together to reach an outcome.

This can be an extremely effective way for people with lived experience to be able to influence change.



Detained

Kept somewhere without your permission and without being able to leave.

For example in a secure hospital.



Empower

Support a person or group to have power and control over their lives and to achieve their goals.



Incorporation

The way that laws or ideas are included within a bigger piece of law.



Mandatory

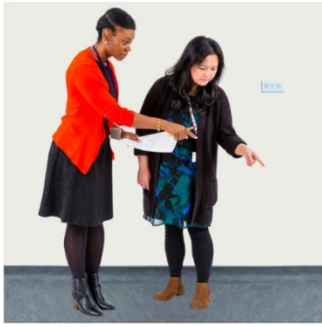
Something that must be done.

For example following the law is mandatory.



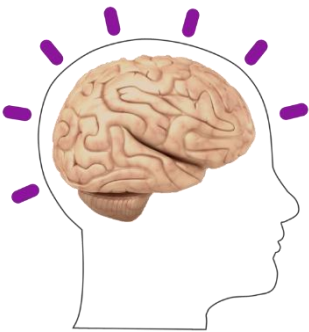
Human Rights Bill Team

Group of Scottish Government employees who work on the Human Rights Bill.



Monitor

Checking to make sure something is being done properly.



Neurodiversity

Neurodiversity is way of describing all the differences in the ways our brains work within humankind.



Policy

The rules or guidelines an organization makes to help it achieve a specific goal.



ICESCR

International Covenant on Economic, Social and Cultural Rights.

International agreement between countries that says that people have the right to self-determination, work, social security, education, culture and more.



UNCRPD

United Nations Convention on the Rights of Persons with Disabilities.

International agreement between countries that says that people with disabilities have exactly the same human rights as everyone.



Advocacy

Getting support from another person to help you express your views and wishes, and help you stand up for your rights.

Someone who helps you in this way is called your advocate.



This report includes discussions from the Lived Experience Board from July 2023 to March 2024.

The Scottish Government is writing a new Human Rights Bill for Scotland.

They have asked SCLD to help them make the new Bill work for people with learning disabilities.



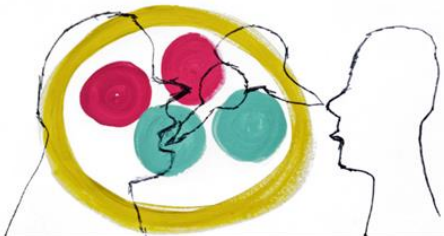
To do this SCLD is working with a group of people with learning disabilities to write recommendations for the Scottish Government.



This group is called the Lived Experience Board.

Section 1

Purpose of the Learning Disability Lived Experience Board



This Lived Experience Board talks about the lived experiences of people with learning disabilities.

The group use their own experiences of human rights to work out how to include the UNCRPD in the new human rights Bill from Scotland.

The Board is made of about 11 people.

Meetings are online and are voluntary.

A person from the Scottish Government also comes to the meetings to give the group updates on the Bill.





One of the main goals of the Lived Experience Board is to make meaningful changes to the lives of people with learning disabilities.



The Board want to do this by:

- Influencing the new Human Rights Bill for Scotland and other important laws.
- Making sure the meetings are inclusive.
- Always being respectful.
- Always being accessible.
- Being accountable. This means making sure the Board and the Scottish Government do what they agreed to do.

Lived Experience Board Members



Fiona



Aaron



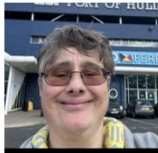
John C



Sandy



John G



Kerry



Leanne



Lindsay



Brian

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

What's Happened Since the Last Report



In 2022 the Bill process was delayed because the Scottish Government decided that more work was needed on the Bill to create strong policies for the consultation.

In June 2023 the Consultation was released.

After the Consultation ended the Scottish Government published a Consultation Analysis.

The Consultation Analysis is a summary of what people said when they responded to the Consultation.

The Consultation Analysis confirms a lot of what the Lived Experience Board said in previous reports.

- We need better data on the state of human rights for people with learning disabilities
- We need the Scottish Government to commit to human rights based education for everyone
- A better and more accessible justice system with specialised advocacy for people with learning disabilities
- Mandatory human rights based training for public bodies
- Full incorporation of the UNCRPD in the Human Rights Bill for Scotland



Block One

The Lived Experience Board spent time working on understanding the Human Rights Bill Consultation.

Board members wanted to understand the more technical language of the Bill because of how important it is that people with learning disabilities have the opportunity to learn about government decision-making processes.

The Board decided to focus on the incorporation of UNCRPD within the Human Rights Bill.

Reactions from the group

SCLD staff explained how incorporation of rights works and members were encouraged to think about how this would impact the human rights of people with learning disabilities in real life.

One person talked about how they had a health crisis several years ago which resulted in them becoming incredibly ill. 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 said that there should have been better support systems in place and suggested that if there had been a named social worker to support them the outcome might have been better.

Full UNCRPD incorporation could result in better social work services for people with learning disabilities.

The Board also spoke about the differences full and part incorporation of UNCRPD might have.





They said that people with learning disabilities need equal support and protection of their human rights under Scottish law.

SCLD staff asked ‘What would the impact be if UNCRPD is fully incorporated?’

“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.”

“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.”

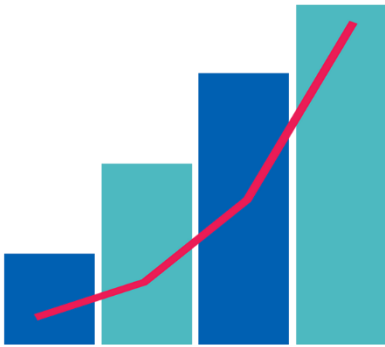
“We could finally matter as much as everyone else. For example we could get the same access to law and justice as everyone else. Its so important to know that if someone does wrong to you then you have a law that will help you. Thats how you feel like you matter.”



“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 Flemming 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.”



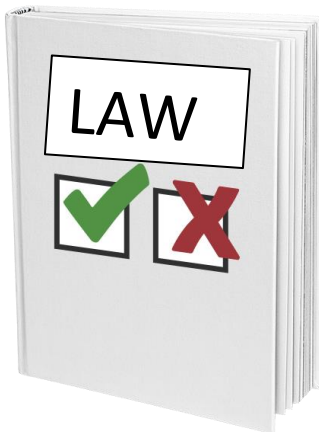
SCLD staff asked ‘What would be the impact if UNCRPD is not fully incorporated?’

“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.”

“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. Thats not equal.”



The Board chose 2 consultation questions to respond to.

These questions were

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

Question 5: Are there any rights in the equality treaties which you think should be treated differently?

Writing the Consultation Response

In their response the Lived Experience Board wanted to include as many opinions of people with learning disabilities as possible.

To do this they arranged meetings with three learning disability organisations and gave presentations on the key points of the Human Rights Bill Consultation.

The three organisations were The Assembly, Dates n Mates, Get2gether. These are some of the points raised by members of these groups.



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. Without full UNCRPD incorporation this won’t change.”

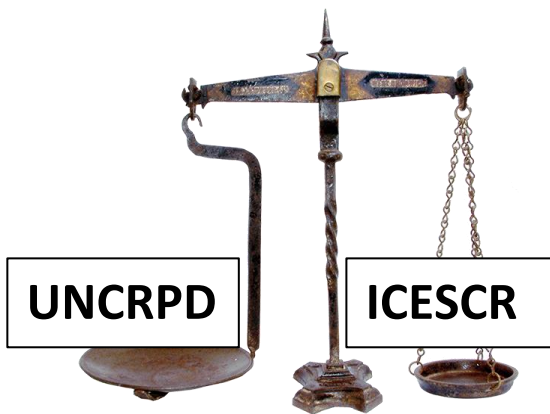
“Everyone in Scotland must have equal access to their rights, have equal protection under the law.”

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.”

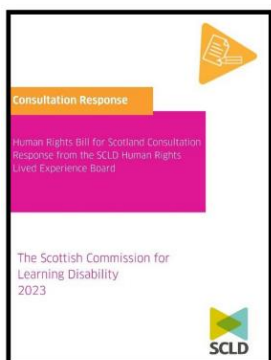
“It should have duty to comply like the other one [ICESCR- international Covenant on Economic, Social and Cultural Rights].”

“The Human Rights Bill should say that learning disability isn’t a mental disorder.”



The Lived Experience Board Response

The Lived Experience Board chose to highlight three main concerns in their response. These are dignity, the strength of UNCRPD in law, and the previous lived experience board recommendations.





1. Dignity

The group think that the Consultation says that the idea of human dignity could be used to measure the value and worth of a person's human rights when decisions are being made.

For example, in court or when making care plans.

The group think this is worrying because there is no set definition of what dignity is.

Members said

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

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

The group think that it is not possible to fairly measure someone's human rights using dignity because everyone has a different idea of what dignity is.

To make an equal and inclusive definition of dignity people with learning disabilities must be involved in making that definition.

2. The strength of the UNCRPD in the law

The Lived Experience Board is worried that the UNCRPD has not been given equal legal strength with other human rights treaties.

One group member said that this inequality in the law makes people with learning disabilities “feel like we are still second-class citizens and nothing is changing.”





Members also said

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



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 produced two reports for the Scottish Government, *The Right to be Heard* and *Solving the Human Rights Puzzle*. These reports included recommendations for the Human Rights Bill for Scotland.



The group does not think these recommendations have been included in the current draft of the Human Rights Bill for Scotland.

Members said “it feels like people with learning disabilities are being pushed out of the picture.”

“Why ask for us to be involved if we’re not listened to?”

Responses to Consultation questions

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

The Board does not agree with the way the Scottish Government wants to include the UNCRPD in the Human Rights Bill for Scotland.

Because they 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.

The Board agrees that dignity is very important but thinks that people with learning disabilities will not get dignity if their human rights are not properly supported in the law.

Question 5: Are there any rights in the equality treaties that you think should be treated differently?

The Board believes that all rights in all the treaties should have equal strength in the law.

This would mean that everyone would be equally treated and supported by the law if the UNCRPD had equal strength in the law duty duty-bearers would have to follow the law and protect the rights of people with learning disabilities.

The Board thinks 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.

Block two

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.

In this meeting the Lived Experience Board gave a presentation about the positive and negative parts of the consultation process for people with learning disabilities.

Board members talked about awareness. One said “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.”



To make this better for future consultations 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.”



Board members also talked about accessibility. One said “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.”



To make this better for future consultations the Board 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.”



The second government meeting was with 6 members of the Human Rights Bill Team and focused on the Board presenting the key issues from their consultation response.

The Board wanted this meeting to be an opportunity for each group to learn more about what the other does.

The Board also talked about the key points of their consultation response. The Board wanted to focus on their worries about the strength of UNCRPD in the Bill.



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.

Ms Bryne 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 said that they are keen to continue working with the Scottish Government and look forward to opportunities to do so in the near future.



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



The Bill Team and Ms Bryne explained that the biggest challenge is around what the Scottish Government has the power to do. The Scottish Government has to get permission from the UK Government to do certain things. They said that they want the Bill to pass but that the Bill might be challenged by the UK Government.

The Bill Team said that the human rights for people with learning disabilities is incredibly important and that the Scottish Government will continue to try to find a way to make these rights a reality.

The future of the Lived Experience Board



At the time of writing this report (February), 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.

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.



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 the country in ways which could make much needed improvements to the lives of people with learning disabilities.

The Lived Experience Board believe that the Scottish Government have an opportunity to create a Human Rights Bill that sets a worldwide standard for realising the human rights of people with learning disabilities.

This can only be achieved if the Scottish Government implement the recommendations of people with learning disabilities and support the human rights of people who have so far been neglected and marginalised.

The Lived Experience Board have made further recommendations for creating a new Human Rights Bill for Scotland that fully supports the human rights for people with learning disabilities:

1. Fully incorporate UNCRPD into the Human Rights Bill.
2. Remove learning disability from the Mental Health (Care and Treatment) (Scotland) Act 2003.



1

2

3

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

4

4. Support data collection and highlight the importance of human rights monitoring.

5

5. Use of positive language and definitions related to people with learning disabilities.



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 hope that the Scottish Government continue 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 email SCLD at admin@sclld.co.uk.

With thanks Sarah D'Agrosa 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.



Thanks also to 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.