



# **The Right to be Heard!**

## **The Learning Disability Lived Experience Board on the new Human Rights Bill for Scotland**



Scottish Government  
Riaghaltas na h-Alba  
gov.scot

## **Report on Blocks 1 and 2**

### **April - May 2022**

# Definitions



## Consultation

A meeting with a group or organisation that want your opinion on something



## Bill

A bill is a draft law



## UNCRPD

United Nations Convention on the Rights of Persons with Disabilities



## Voluntary

Something you do of your own free will and without being paid money for



## Exclusion

When you are left out or not included in activities or decision making



### **Accessible**

Easy to get or understand



### **Inclusive**

Something that does not exclude any person or any groups



### **Executive Board**

A group of people who look after a lot of the important decisions in a project or organisation



### **Advisory Board**

A group of people who give the organisation suggestions or help solve problems on a project



### **Scottish Government Equality and Human Rights Directorate**

The team of people who advise the Scottish Government on how to make sure all of its decisions are equal, inclusive and support human rights



## The Right to be Heard!

The Learning Disability Lived Experience Board on the new Human Rights Bill for Scotland

Report on Blocks 1 and 2  
April - May 2022



This report includes discussions from Block 1 and 2 of the SCLD Lived Experience Board.

Each block has a different theme

Block 1 is 'Getting to Know You'  
Block 2 is 'Your Rights, Right Now Impacts and Solutions'





## Section 1

### Introduction

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

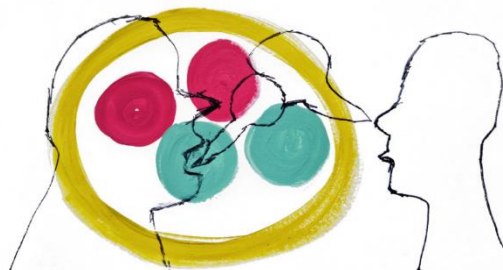


### Purpose of the Learning Disability Lived Experience Board

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 for Scotland

The Board is made of about 15 people Meetings are online and are voluntary



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

At the first meeting the Board and the Scottish Government made an agreement about what they would do for each other



For example the Board will listen to the Scottish Government and the Scottish Government will listen to the Board

The Scottish Government will keep the Board in the loop about the progress of the Bill and the Board will work to break down barriers

2



At the second meeting the Board was asked why they wanted to be part of this work



We took what was said and turned it into 3 important outcomes that we want to achieve

1. People with learning disabilities have space to talk share experiences and be involved in decision making
2. People with experience of having their human rights denied have the opportunity to challenge this and to make positive changes

3. Barriers to opportunities are removed and people with learning disabilities can live the life they want



### **Why is a Lived Experience Board for People with Learning Disabilities Needed?**

Scotland is changing and we want to make sure these changes are a good thing for people with learning disabilities

People with learning disabilities still face lots of barriers in their lives

Problems like unemployment, exclusion, trauma, bad education and healthcare, and unequal justice

One reason why these problems still happen is because people with learning disabilities often don't have a voice to speak out and challenge these problems

We hope the Lived Experience Board can make sure that people with learning disabilities can speak out and be heard and make changes





## **Lived Experience Board Members**

Fiona D

Kate S

David B

Brian B

Daniel G

Kerry M

Lindsay K

John G

Sandy S

Aaron H

John C

Katherine G

Suzanne F

Leeanne C

Michael M





## Section 2

### What changes for people with learning disabilities should a new Human Rights Bill in Scotland make?

In the first block members were asked what important changes they would like from the new Human Rights Bill for Scotland

Here are some of the main points

People with learning disabilities are meaningfully included in decision-making  
People with learning disabilities must have their voices heard



Excellent training for employers and staff to help them to protect the human rights of people with learning disabilities



Accessible education for people with learning disabilities including human rights education



Services must give equal quality of support to all disabled people  
Services must make sure changes to support cause less disruption to the lives of people with learning disabilities



People with learning disabilities should not be forced to use support that isolates them from their support networks  
For example support far away from home



### Section 3

#### **Making a consultation on the new Human Rights Bill work for people with learning disabilities**



At the first meeting the Board were clear that a consultation must be accessible and inclusive

The group said a good consultation process should



Use videos and audio

Have an online version and a paper version



Let family members speak on behalf of people who cannot communicate



Have an Easy Read Version of the consultation that does not miss out valuable information

Have questions that are easy to answer

Have definitions of difficult words to help people understand



## **Section 4**

### **Your Rights Right Now**

**Lived Experience Board Members talk about their experiences of realising their human rights in Scotland**

We asked Board members to think about their own experiences of their human rights under the UNCRPD

We grouped these discussions into different topics by thinking about specific UNCRPD rights

The topics were



### **Awareness of human rights**

The Board agreed that it is very important that people with learning disabilities are able to access accessible information about their human rights

One example is the Human Rights Town App that was created by people with learning disabilities to help others learn about and understand their human rights



The Board all agreed that this app should be used as part of training in work and education to help everyone learn about human rights and how they affect people with learning disabilities



## **Access to Justice**

Board members emphasised that they often feel that they do not have equal access to justice

Several members shared examples of experiences when they felt they had been unfairly treated and were unable to access justice



## **Living independently and being included in the community**

People with learning disabilities are often unable to live independently and be a part of their community

Members said that one of the main barriers is being detained in hospital against their will



People with learning disabilities are often forced to stay in hospitals or use services far away from their support networks

This causes a lot of harm to emotional and physical wellbeing

Lack of resources and good quality support sometimes causes these problems







## **Mobility**

Barriers to mobility and accessible travel are often a big problem

This can lead to other problems

For example not being able to access employment healthcare and a social life

It can also have a big impact on finances for example paying for private travel as accessible trains are not reliable



## **Right to Education**

The Board said there must be more and better opportunities for education

Education must be accessible and flexible to fit around the person and support people with learning disabilities to gain qualifications



## **Freedom of expression and opinion, and access to information**

Access to information is very important



There is not enough accessible information on human rights and how it affects people with learning disabilities



People must be taught about their human rights and how to stand up for their rights



## Health

Access to health information and emotional support are very important

Communicating with healthcare providers must be easier

## Work and Employment

There are not enough opportunities for people with learning disabilities to find jobs

Sometimes people aren't taught new skills or get excluded from the workplace

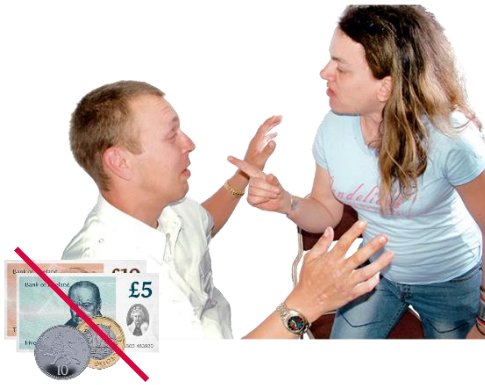
Employers and staff need better training on how to support people with learning disabilities

Transitions in work or education are often difficult because there is not enough physical or emotional support

Lack of support can mean someone struggles to find and keep a job

This impacts independence and ability to achieve life goals





## Standard of Living

There are many things that can affect how much financial support people with learning disabilities are able to get

For example couples with learning disabilities who live together can have their financial benefits reduced

This can mean people can lose their independence and be at risk of financial abuse

Many aspects of life cost more when you have a disability

For example having to pay for private transport and the cost of support





## **Section 5**

### **Impacts and solutions**

**How can we make human rights real for people with learning disabilities in Scotland?**

The Board spent two meetings talking about ways that the new Human Rights Bill can change to make rights real for people with learning disabilities

They looked at two scenarios and talked about the ways that the people had their human rights impacted

The Board then talked about solutions to make sure the person's human rights are protected



### **Scenario 1**

Someone is experiencing delayed discharge from hospital because there are problems putting a home care plan in place

The social worker is on long term sick and there is no one to take over

He is given the choice to stay in hospital or go home with an emergency care plan in place





## Impacts

The person had lost their right to independence and to make their own decisions about the way they live their life

These situations are common and there can be long term negative impacts on mental and physical health

There is often no support to help with mental health and wellbeing when stuck in hospital or under guardianship



## Solutions

More treatment choices for people with learning disabilities especially mental health services



## Scenario 2

This person's employer said they would get a pay rise after three months because they would be given more responsibilities at work

But the employer decided not to give the extra responsibilities because the person has a learning disability



So they did not get the pay rise  
There is no accessible contract and so they didn't know about rights and how to fight this decision



## Impacts

This person has been discriminated against and is being denied their human rights

Many people with learning disabilities don't understand how to access support  
Information on how to access support is often not accessible



Sometimes people with learning disabilities often think they have no option other than to leave their job because they don't believe they will get justice



## Solutions

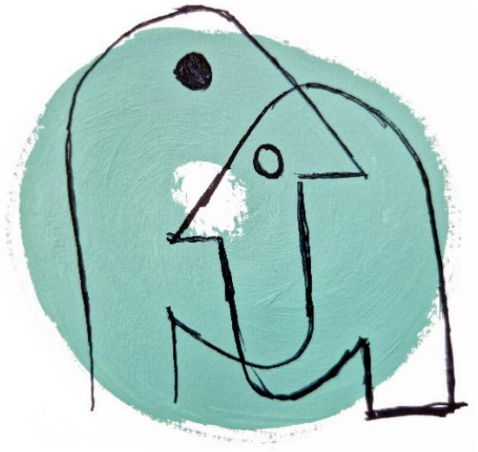
Accessible information is very important because people need to know how to get support and justice to claim their human rights

Advocacy is really important too



All information should be available in Easy Read and there should be better training for employers and staff on how to support people with learning disabilities





## Section 6 Conversations with the Scottish Government

At each block of meetings a member of the Scottish Government comes to meetings

This to tell the group what action the Government has taken with the Bill  
They also give the group updates on the work of the other lived experience boards

## The resulting actions for Scottish Government are

There must be accessible versions of the consultation and these versions must be made available at the same time as other versions

Organise a joint meeting with other lived experience boards

Promote the Human Rights Town App with the Bill consultation

Promote accessible versions of the Bill consultation in schools





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## Section 7 Conclusion and Recommendations

The Lived Experience Board and SCLD believe that changes to government laws can make life changing differences to the lives of people with learning disabilities

This report has taken all the of the above information and made 6 main recommendations for the Scottish Government

Make sure the Bill includes equal support for groups not listed in the Equality Act  
The Bill must be clear in its support for people with learning disabilities and who are most at risk

2

To make sure rights are being protected the Bill must make sure that data is given about the experiences of people with learning disabilities in Scotland

3

This information should come from the Scottish Government local authorities and public services

4

Commit to making sure there is rights-based education, including for people with learning disabilities across Scotland from school age into adulthood

The Bill must support a multi-institutional approach to accessing justice and be able to support strong justice when things go wrong

5

Make sure public groups undertake disability awareness training including learning disability awareness training

6

Make sure local areas provide access to learning disability advocacy and legal support to support access to justice

**The next report will be about block 3 and 4**



If you have any questions about the work of the Lived Experience Board please contact Sarah D'Agrosa  
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