



Easy Read Summary

Solving the Human Rights Puzzle

How can we support people with learning disabilities in Scotland to achieve justice?

The Human Rights and Learning Disability Lived Experience Board

Blocks three and four Report

July–October 2022





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 organisation present their ideas and ask for other people's opinions on what is good and bad about it



Database

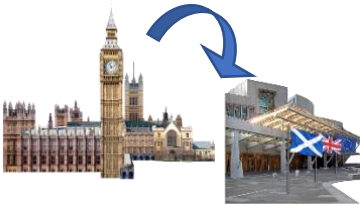
Part of a computer system that stores information



Detained

Kept somewhere without your permission and without being able to leave

For example in a secure hospital



Devolution

When a bigger government gives some power and authority to a smaller government

Usually the bigger government gives the smaller government power and authority over some decisions but not all



Empower

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



Inclusion

Making sure a person or group are included

For example in decision making



Incorporation

When two or more things are brought together or when one thing is included in the other



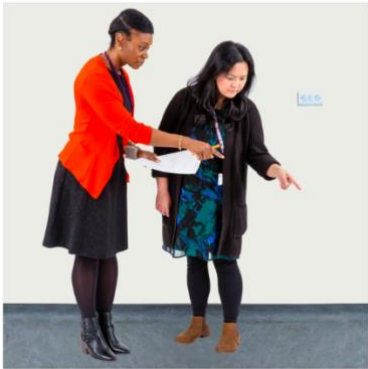
Mandatory

Something that must be done
For example following the law is mandatory



Minister

A politician who is the head of a specific government department



Monitor

Checking to make sure something is being done properly



Profound and Multiple Learning Disabilities

Describes a group of people who have a combination of learning disabilities with complex healthcare and support needs



Policy

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



United Nations Convention on the Rights of the Child

International agreement between countries on the human rights of children

It is sometimes called the UNCRC



United Nations Convention on the Rights of Persons with Disabilities

International agreement between countries on the human rights of people with disabilities

It is sometimes called the UNCRPD



Vague

Not communicated clearly and difficult to understand



This report includes discussions from block three and four of the SCLD Lived Experience Board

Each block has a different theme

Block three is Access to Justice

Block four is Solving the Human Rights Puzzle



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 Human Rights and Learning Disability Lived Experience Board

Section 1 Introduction



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

They 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 mainly online and are voluntary
A person from the Scottish Government also comes to the meetings to give the Board 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

Being accountable means making sure the Board and the Scottish Government do what they agreed to do



Lived Experience Board Members

Fiona D
Kate S
David B
Brian B
Kerry M
Lindsay K
John G
Sandy S
Aaron H
John C
Katherine G
Suzanne F
Leeanne C



What's Happened Since the Last Report

For block three and four the Board had planned to talk about the bill consultation

But the consultation has been delayed so the Board decided to talk about access to justice, key issues for the bill, and how to make other laws work with the new Human Rights Bill

The consultation has been delayed because the Scottish Government need to do more work on it first

The Board also spoke to the Scottish Government about how the Board could stay involved in the bill process



Section 2 Routes to Justice

In the last report getting justice was an important issue for the Board



In block three the Board talked about why equal access to justice is so important for people with learning disabilities

The Board said that if you can't get justice you can't get your human rights because access to justice impacts almost every part of your life



They also said it is really important to be able to talk about access to justice and to understand what happens when you don't get equal treatment in justice

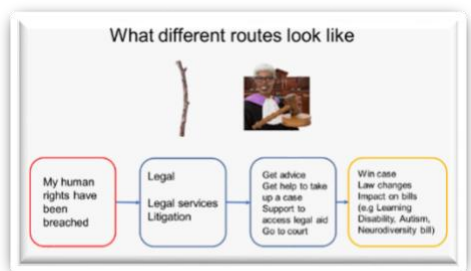
SCLD staff explained the two main routes to justice as the carrot and the stick

The carrot means non-legal routes to justice like mediation or advocacy



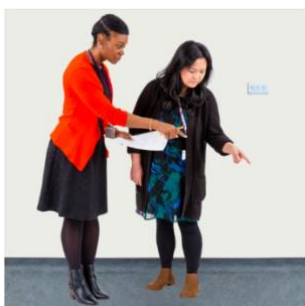
These try to get justice by rewarding good behaviour or finding a positive way to settle disputes without using legal force or punishment

The stick means legal routes to justice For example going to court



The Board agreed that both are important routes to justice because sometimes you need one or both

The Board decided that a new Human Rights Bill for Scotland must have more legal power to make sure everyone gets justice



The Board decided that a new Human Rights Bill must be able to monitor and investigate injustices So it can make sure everyone is doing what they should be doing to support equal access to justice

Section 3 Change Required to Achieve Justice for All

The Board thought about ways to make positive changes for justice

They spoke about the possibility of a learning disability commission/commissioner

SCLD staff explained the commission and commissioner as Batman and Commissioner Gordon

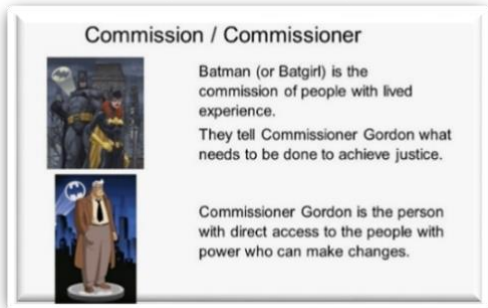
Batman is the commission of people with lived experience

Commissioner Gordon is the person with direct access to the people with power who can make changes

The Board agreed that a commission/commissioner could be a good thing to support the human rights of people with learning disabilities

But it must be made with the help of lived experience expert groups and must have strong legal powers to help get justice and hold people to account

The Board suggested that the commission should include people with learning disabilities



Section 4 Inclusion of Key Issues in a New Human Rights Bill for Scotland

Both meetings in Block 4 were in person and held in Edinburgh



Two representatives from the Scottish Government came to the meetings

The Board talked about how the Scottish Government could include key issues in the new Human Rights Bill



The theme of these meetings was 'Solving the Human Rights Puzzle' so the Board worked with the Scottish Government representatives to create a Human Rights Bill jigsaw puzzle

Each Board member had their own puzzle piece and wrote on it what they think is a key issue for the new Human Rights Bill for Scotland



The Board connected the pieces together and had a discussion about what the bill has to do to achieve what is written on the puzzle pieces



Here are some of the Board's thoughts on what the Bill must be able to do

"All of us has a story to tell... every voice speaks volumes"



The Board said people with learning disabilities must have control of our own lives and have decision making powers over what they can do

For example not being able to make informed decisions on medical treatment or be involved in a relatives guardianship order

The new Human Rights Bill must empower people by using specific language that talks about empowerment, independence, and equality



The Bill must also see the differences in people's needs and not group people together based on their disability

"Everyone treated the same. Fair and equal."

The Board talked about equality and said that justice must be fair and equal for everyone



Justice in employment was important to the group. They said that people must be able to work in fair conditions and feel secure in their jobs. Especially in the cost of living crisis

The new Bill must ensure equal access to justice by having strong legal powers to hold people to account. For example if employers

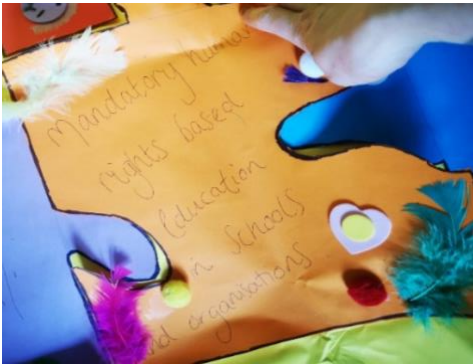
discriminate against employees with learning disabilities



“Mandatory Human Rights Education”

The Board agreed that good education is key to making sure people understand and respect the rights of people with learning disabilities

For example training that helps people recognise when they are not getting their human rights and what to do when that happens



The new Human Rights Bill must make learning disability and human rights training mandatory in schools businesses and other organisations

The bill must also have the power to make sure this happens and hold people to account when it doesn't



“We need to keep focused on what’s happening in our daily lives”

The Board said that the everyday decisions are just as important as the bigger decisions

Because being able to make these decisions yourself has a big impact on your mental and physical health and wellbeing



For example, a Board member said they were given a flat which needed a lot of repair and



re-decoration but they weren't allowed any say on when or how it was decorated

This made them feel like it wasn't their own home or their safe space

The new Human Rights Bill must protect independence and personal choice by challenging the barriers that stop people with learning disabilities having control of their own lives



For example it should make organisations and services adapt their way of working to the needs of people with learning disabilities

“No voice left behind”

Choice

The Board spoke about inclusion and said that this is equally important in your community and in decision making processes



The Board talked about barriers to inclusion

For example support services that are not flexible

The Board also said inclusion in government decision making is an important part of getting your human rights



For example one member said being part of the Board makes them feel like they can make life better for themselves and for other people with learning disabilities

The new bill must support inclusion by being made with input from people with lived experience

For example by including expert groups and advocates for people with learning disabilities

Section 5 Models of Incorporation

As part of the block four meetings the Board talked about incorporation

SCLD explained three different types of incorporation to Board members

- direct incorporation
- indirect incorporation
- piecemeal incorporation

SCLD used the examples of a fish jumping from one bowl to another, fishes jumping into multiple bowls and a jigsaw


The Board talked about the positives and negatives of each one and were given the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill as an example of incorporation

Board members voted on what type of incorporation they thought was best

They decided that a mixture of direct and indirect incorporation would be best

Some Board members said that they found this topic difficult and would like to spend more time on it in the future

Incorporation



Incorporation means **including something as part of something larger**

For example: making sure your human rights are included as part of a Bill- incorporating your human rights into a Bill

There are three models (or ways) of incorporation


Direct Incorporation



Taking international law (for example the United Nations Convention on the Rights of Persons with Disabilities) and putting the **exact wording** into another law

Adding one law **exactly** as it is into another

Indirect Incorporation




International law has **some effect** in national law

This means a treaty can be used in a different legal way

For example a law could make courts and local councils use a human rights treaty when they are making decisions

Piecemeal Incorporation



Piecemeal means things that happen gradually or in small parts

This is when one or more bits of a treaty are put into the law of a country. It can include some rights but not other rights. It may not mention the original treaty

Section 6 Putting Together the Puzzle

In block four the Board got an update on other Scottish Government work related to human rights

Then the Board discussed ways that this work could make positive changes for people with learning disabilities

Here are some of the group's thoughts on what these pieces of work need to do

National Care Service

The National Care Service must promote accessible communication because good communication is key for achieving human rights

One Board member said that they struggle to understand their diagnosis and don't feel able to make their own treatment choices because there isn't enough accessible communication

The National Care Service must promote mandatory communication and all services and all information must always be available in accessible formats

This includes face to face communication

Good communication between services is also important

One member said that they struggle to get the support they need because services don't communicate with each other

The National Care Service should make accurate databases with information such as care plans and communication needs available to each service and to the person





Autism, Learning Disability, and Neurodiversity Commission/ Commissioner

The Board talked about a commission/commissioner and agreed that the commission/commissioner must be led by people with lived experience



Board members said that this would make sure that the voices of people with lived experience were part of decision making processes

Learning Disability, Autism, and Neurodiversity Bill

The Board said that the bill must be clear on the what groups it will support and how



One Board member said that bills to protect people with disabilities are too vague and some people are left out

For example the bill must make sure there are services for people with profound and multiple learning disabilities



These services should always be made involving the person and if the person needs help with decision making they must be able to choose who helps them



The Board also talked about guardianships

They said that these must be made specifically for the person or they can be too restrictive and deny someone their human rights



Mental Health Law Review

The Board talked about the Mental Health Law Review

They said that it is really important to use language carefully because the language used in laws can have a big impact on how people understand learning disabilities and they treat people with learning disabilities



For example phrases like 'behavioral issues' and 'challenging behavior' can create negative views of people with learning disabilities and mean they are treated badly

One person said that they feel that people with learning disabilities are labelled and they get stuck with these labels for life



The person said that they felt they have been labelled as having challenging behavior and this impacts how people react to them

The Board also said that learning disability should not be part of the Mental Health Care and Treatment (Scotland) Act (2003) definition of 'mental disorder' because a learning disability is not a mental illness



Board members said that this means that people with a learning disability can be wrongly and unfairly detained under the mental health act or put under guardianship

One Board member said that is very important for people with more complex support needs

For example someone with profound and multiple learning disabilities who has experienced long term hospitalisation and detention

Section 7 Conversations with the Scottish Government

The Board has had lots of positive feedback from the Scottish Government on its work so far

Minister for Equalities and Older People Christina McKelvie tweeted “The Lived Experience Board has been and will continue to be a very important part of the development of our Scottish Human Rights Bill.”

The Board were pleased to meet with Minister McKelvie in July and talk to her about their visions for a new Human Rights Bill for Scotland

The Scottish Government also said “Their insight will be invaluable as we develop our Human Rights Bill.”

Members of the Scottish Government came to meetings in blocks three and four to update the Board on what the Scottish Government has been doing with the recommendations from the Board so far

The Board suggested that a joint meeting is set up with all the Boards to learn more about the work everyone is doing

The Scottish Government representatives also gave updates on the progress of the new Human Rights Bill for Scotland and spoke about other Scottish Government human rights work

The Lived Experience Board were keen to talk about ways that they can continue to be involved throughout the Human Rights Bill process

For example as part of the consultation process





The resulting actions for Government are

- **Set up a Board meeting between Lived Experience Boards and the government Boards**
- **Send the Lived Experience Board an full response to the first report**
- **Let the Board know about being involved in future work**
- **Keep the Board updated on the progress of the consultation and the bill**

Section 8 The Future of the Human Rights Bill For Scotland Lived Experience Board



During the meetings in block four the Board spoke to the Scottish Government representatives about the future of the Lived Experience Board

The Board said they want to continue to be involved in the development of the bill and made the following suggestions

As part of the consultation the Board could be advocates, peer facilitators and accessibility consultants during the consultation

Members also suggested they could help the government reach and involve as many people as possible by speaking to their own networks and encouraging people to take part in the consultation

As part of this work the Human Rights Town App could be used to help with these conversations and to explain human rights issues





Section 9 Feedback from the Board to Date

At the meeting in Edinburgh the Board were asked to share their feedback on the four blocks of meetings and of being part of the Lived Experience Board generally

The main positive points were

Board members said that being part of the Lived Experience Board means members are included in important decision making processes

Being included makes people feel like they have control over their life and can advocate for others and fight for what is best for people with learning disabilities

Board members said that being part of the Lived Experience Board has given their opinions authority and this means their opinions are being taken seriously by the Scottish Government

Board members said that being part of the Lived Experience Board showed them that it is possible for a Board of people with learning disabilities to have a real impact on change and Scottish Government decision making

Organisations think it is too difficult to include people with learning disabilities but that the Board has shown that is not true

The Board has created a community by bringing people together who want the same thing and who want to be advocates for others





There were also suggestions for improvements which were

More regular feedback from the Scottish Government about the Board's suggestions and recommendations

More regular updates on the progress of the bill would be helpful so they don't feel like their input is being forgotten about

Scottish Government using clearer and easier to understand language

Continued involvement of the Lived Experience Boards in the Human Rights Bill for Scotland's Development and that similar Boards should be involved in all decision making

Section 8 Conclusion and recommendations



The Lived Experience Board and SCLD believe that the new Human Rights Bill for Scotland can make a life changing difference to the lives of people with learning disabilities

This report has taken all the comments from the Board and makes 5 main recommendations for the Scottish Government

These are

1

The new Human Rights Bill for Scotland must underpin and allow for the development of a Learning Disability, Autism and Neurodiversity Bill and commission/commissioner who is a person or a group of people or organisation led by people with learning disabilities, autism and neurodevelopmental differences

They must have the legal power to monitor and enforce learning disability human rights compliance in line with the UNCRPD

2

The new Human Rights Bill for Scotland must ensure groups of people not explicitly covered in equalities legislation are visible and included through duties to ensure their rights are realised

The approach taken to 'Rights Most at Risk' within The United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill and Children's Rights Scheme is a helpful approach to develop upon

3

The New Human Rights Bill for Scotland should take a mixed model approach to incorporation that seeks to directly incorporate all international treaties as far as is possible in Scotland

4

The new Human Rights Bill must ensure that incorporation of the UNCRPD into Scottish law is followed by an audit of all legislation and policy to ensure compliance with the Convention

This should include the Mental Health (Care and Treatment) (Scotland) Act and the recently published Review of this Act

5

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 key aspect of human rights realisation

If you have any questions about the work of the Lived Experience Board please contact

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