



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



Contents

| | |
|--|-----------|
| Section 1: | |
| Introduction | 3 |
| Section 2: | |
| Routes to Justice | 8 |
| Section 3: | |
| Change Required to Achieve Justice for All | 11 |
| Section 4: | |
| Inclusion of Key Issues in a New Human Rights Bill for Scotland | 13 |
| Section 5: | |
| Models of Incorporation | 20 |
| Section 6: | |
| Putting the Puzzle Together | 22 |
| Section 7: | |
| Conversations with the Scottish Government | 26 |
| Section 8: | |
| The Future of the Board | 29 |
| Section 9: | |
| Feedback from the Board to Date | 30 |
| Section 10: | |
| Conclusion and Recommendations | 32 |

Section 1:

Introduction

Making sure real positive change is achieved for people with learning disabilities through the new Human Rights Bill for Scotland is like solving a puzzle. In relation to achieving justice for people with learning disabilities in Scotland, we operate in a cluttered policy and legislative landscape. Therefore, the puzzle feels very complicated, but in truth, solving it may be more straightforward than it first appears.

This report details critical discussions from the Human Rights and Learning Disability Lived Experience Board blocks three and four. These blocks were separated into two separate themes. The theme of block three was **'Accessing Justice'**. Block four's theme was **'Solving the Human Rights Puzzle'**.

Based on comments from the Board, this report seeks to solve the puzzle of realising human rights in Scotland. 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.

You can read the Board's first report here:

<https://www.sclid.org.uk/wp-content/uploads/2022/06/Human-Rights-Lived-Experience-Board-Report-1.pdf>

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

<https://www.sclid.org.uk/wp-content/uploads/2022/07/final-LEB-easyread-report-pdf.pdf>



Purpose of the Human Rights and Learning Disability Lived Experience Board

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.

Within blocks three and four, the Board chose to focus on specific aspects of the Bill and its functionality, such as the powers it must have to support access to justice and ensure the accessibility of essential services for people with learning disabilities.

The Board expressed that they wanted to understand better how legal frameworks work and how they interact with each other. As a result, the Board spent time in each meeting discussing the structure and powers of laws and policies.

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. Each session is attended by at least one representative from the Scottish Government, who provides regular updates 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**.



What is Meaningful Participation?

In line with both the PANEL Principles of Participation, Accountability, Non-Discrimination, Empowerment and Legality as well as SCLD's organisational values, we understand a **meaningful participation process** to embody the following criteria:

- **Change-making:** The input of the Lived Experience Board will result in changes for people with learning disabilities in Scotland. It will ensure their human rights are realised through the new Human Rights Bill for Scotland and other relevant legislation following this.
- **Inclusive:** The Lived Experience Board meetings are welcoming. Our meetings are focused on informing change in a fun and light-hearted way.
- **Respectful:** Members of the Lived Experience Board and their contributions are valued. Travel expenses are paid, and members receive cash vouchers to thank them for their contributions.
- **Accessible:** This means that people with learning disabilities are supported to take part using a range of communication tools. For example, easy-read agendas and presentations and finding new and innovative ways to explain complex ideas.
- **Accountable:** Both the Scottish Government and members of the Lived Experience Board are responsible for the process. Following an initial expectations exchange between Government and the Board, both parties clearly understand what is required from them. For Government, this means attending regular meetings and feeding back on what they have done based on the advice of the Board. For Board members, this means attending regular meetings and offering ideas and suggestions.

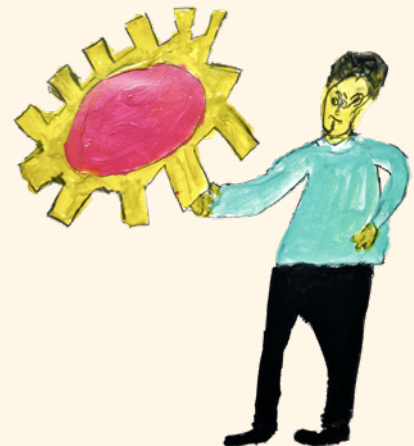
Change-making

Inclusive

Respectful

Accessible

Accountable



Who are the Board Members?

Members who attended meetings in the second two blocks were:*

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

*Names partially anonymised at the request of Lived Experience Board members.



Board members with Scottish Government and SCLD team at the first meeting of block 4 meetings.

Update Following Blocks One and Two

As the Board was set up to inform the development of the new Human Rights Bill for Scotland, the Lived Experience Board planned to respond to the various stages of the Bill development. For blocks three and four, the Board had scheduled time to respond to the Bill consultation. Unfortunately, at the time of writing this report, the Bill consultation has been delayed until early 2023.

The Scottish Government explained to the Board that a review of the current Bill concluded that more work needs to be done to create strong policies for the consultation. The progress of the Bill is also being 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 UK Supreme Court has requested that parts of the UNCRC Bill are altered. This impacts the progress of the Bill because the Scottish Government must ensure that incorporated international treaties, such as UNCRC, have legal authority within Scottish law and cannot be challenged.

Due to the delay in the consultation process, the Board decided to focus on access to justice, implementation of critical issues and broader laws and policies being worked on at a Government level that directly impact people with learning disabilities. The Board also spoke with the Scottish Government about how the Lived Experience Board could best continue their involvement in the Bill development process **(See Section 7: Conversations with the Scottish Government).**



Section 2:

Routes to Justice

In the previous report, accessing justice was identified as a critical issue for the Board and an essential aspect of the new Human Rights Bill for Scotland. The Board focused on this theme in more depth throughout the third and fourth blocks of meetings.

In block three, the Board spoke about why equal access to justice is essential for people with learning disabilities. Board members agreed that obtaining justice when things go wrong is crucial to realising your human rights. The fact that accessing justice continues to be more difficult for people with learning disabilities means that people with learning disabilities continue to be denied full realisation of their rights. The Board also agreed that access to justice impacts almost every part of your life, both everyday life and significant life-changing events in the long and short term. The Board said that it is also essential to be able to talk about access to justice and to be educated on the implications of not receiving equal treatment in justice.

The Board began by talking about the main routes to obtaining justice. Board members had previously identified access to justice as a subject that needs to be more accessible and easily understood. For example, one person said they had never received any education on how the justice system works or how to access help when denied their rights.

SCLD staff began the meeting by presenting the two main routes to justice using carrot and stick metaphors.

“

The Board also agreed that access to justice impacts almost every part of your life, both everyday life and significant life-changing events in the long and short term.

”

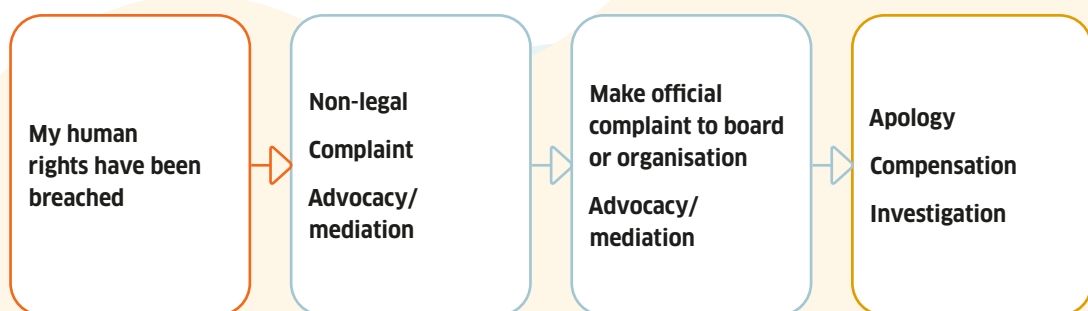


Current routes to justice

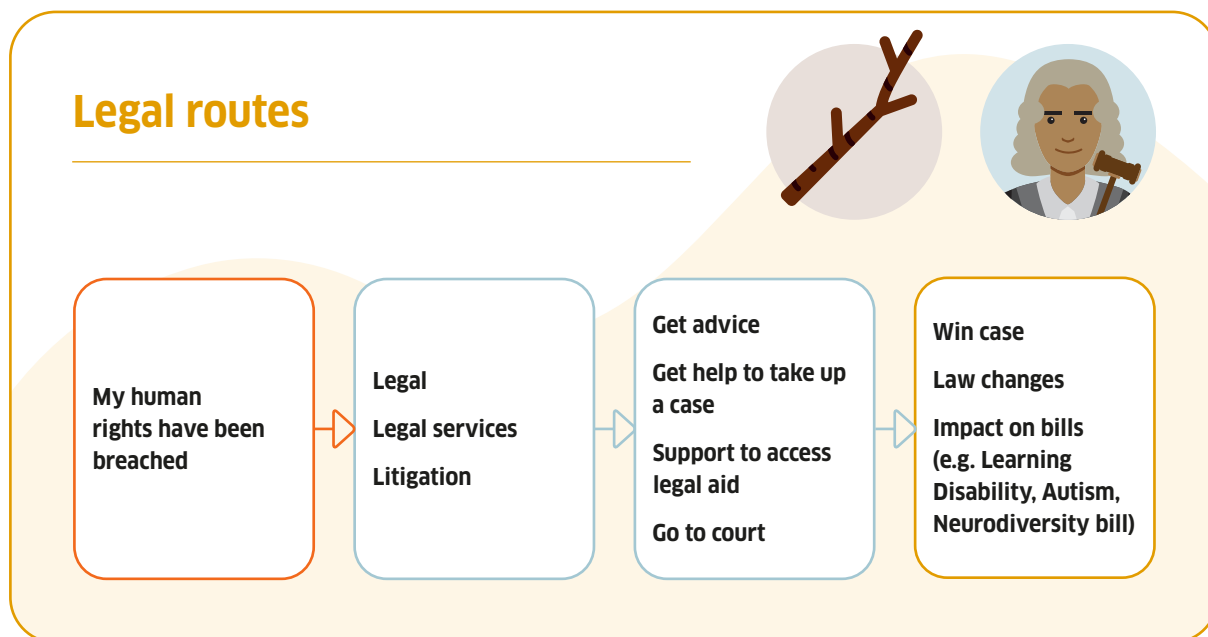


The carrot represented non-legal or soft methods, such as mediation or advocacy, focused on obtaining justice by rewarding good behaviour or finding a positive way to settle disputes without legal force or punishment.

Non-legal routes



The stick represented legal methods, such as going to court, that use punishment to achieve justice, encourage better behaviour, and deter future wrongdoing through the threat of legal action.



The Board members were then asked if they felt one route was more significant. The members agreed that both were necessary as the severity of the injustice might merit the carrot, the stick, or both.

The Board then discussed the barriers to accessing justice. For example, in some cases, incompatibilities exist between implementation and International Human Rights Law, as set out in the UNCRPD, which results in a lack of legal power to hold others to account when a person or organisation does the wrong thing. To remedy this, procedures must exist, such as monitoring mechanisms and focused investigative bodies with strong legal powers. The Board were clear that this was the only way to achieve justice.

“ Incompatibilities exist between implementation and International Human Rights Law, as set out in the UNCRPD, which results in a lack of legal power to hold others to account when a person or organisation does the wrong thing. ”

Section 3:

Change Required to Achieve Justice for All

As part of block three's theme of accessing justice, the Board spoke about creating a learning disability commission and/or commissioner. First, the Board members spent some time discussing the definition and role of commission and commissioner as they felt this was something they didn't know much about. SCLD staff presented the commission and commissioner using the metaphors of Batman and Commissioner Gordon, with Batman being people with learning disabilities in Scotland. They also discussed Commissioner Gordon, as a person or a group of people (which could be a group of people with learning disabilities) who had direct access to power and the authority to enact changes. Commissioner Gordon works with and on behalf of the commission.

Commission/Commissioner



Batman (or Batgirl) is the commission of people with lived experience. They tell Commissioner Gordon what needs to be done to achieve justice.

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

The Board members identified this model of commission or commissioner as a potential route to achieving positive change and supporting the realisation of human rights of people with learning disabilities. The members were clear that for this to work, a commission or commissioner would need to follow a new model and must be led by people with learning disabilities. One person said, **“we are the commissioners”**, referring to people with learning disabilities.



...one person said, **“we are the commissioners”**, referring to people with learning disabilities.

The Board agreed it's essential to have a commission/commissioner created and explicitly mandated to support the realisation of human rights for people with learning disabilities. To do this, they must have significant lived experience and an understanding of the needs of people with learning disabilities. They also stressed that the commission/commissioner should be elected with input from public expert groups, including people with learning disabilities.

The commission/commissioner must be created with legal powers to enact and enforce changes within public and private organisations. For example, they must be able to monitor the implementation of policies such as learning disability awareness training and hold businesses to account if they do not provide it.

The commission/commissioner must have the power to enforce universal standards of human rights law, as defined by the UNCRPD and Universal Declaration of Human Rights, in all aspects of society.



The commission/
commissioner must
have the power to enforce
universal standards of human
rights law, as defined by
the UNCRPD and Universal
Declaration of Human Rights,
in all aspects of
society.



Section 4:

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

Block four meetings were held in person in Edinburgh, with the option to join online for those unable to come along. SCLD staff arranged an overnight stay for the Lived Experience Board at Yotel in Edinburgh. Meeting in person was a valuable opportunity to bring the Board together to benefit from more interactive and hands-on discussions. Throughout the previous months, all meetings were conducted on Zoom. Since many of the Board had built friendships with their fellow Board members, this was also an excellent opportunity to meet in person and enjoy spending time together.

At the first two meetings of block four the Board members talked about how the Scottish Government could include critical issues in the new Human Rights Bill. As part of the theme of **'Solving the Human Rights Puzzle,'** the members held an active discussion with the representatives from the Scottish Government and then created a physical Human Rights Bill jigsaw puzzle by each writing their thoughts on a puzzle piece and connecting the components. (illustrated below).



In previous meetings, the Board had identified five critical issues for the Bill to address, which they focused on in more detail. These were:

1 Empowerment



2 Equality



3 Education



4 Independence



5 Inclusion



Empowerment

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



In terms of empowerment, the Board spoke about the importance of being given control of their own lives, decision-making powers, and the ability to run their own lives. Several members expressed that they never felt fully in control of their own lives or decision-making processes. For example, members were not supported to understand their GP diagnosis or treatment routes and options. One member shared their frustration at being unable to be involved in their relative's guardianship because they have a learning disability. This means they cannot help their family member be empowered to make their own decisions. As they said:

“ He's my brother; he wants me to help him make decisions; why can't I? Just because I have a learning disability? ”

The Board agreed that the new Human Rights Bill for Scotland should use specific language that emphasises empowerment, cooperation, independence in choice and decision-making, and equality to empower people. The Bill must also recognise the differences in people's needs and not **“lump people together based on their disability”**.



Equality

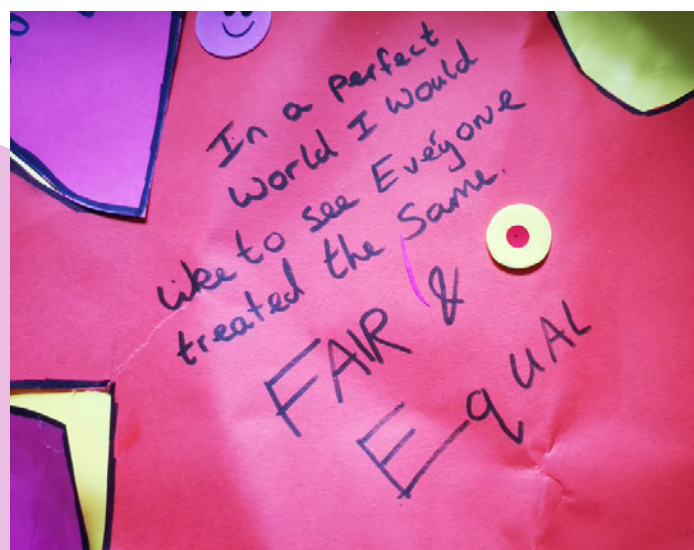
“ ..Everyone treated the same. FAIR and EQUAL. ”



On the issue of equality, the Board identified issues around access to justice as being an essential signifier of equality. Members agreed that everyone must have fair and equal routes to justice and in obtaining justice. Employment was one of the prominent examples of equality, with several members saying that, especially within the insecure climate of the current cost of living crisis, people must access work, work in fair conditions and feel secure in their jobs. As one Board member said:

“ Everything is hard enough with how much everything costs, and it's getting worse. Folk with learning disabilities always seem to get it worse anyway and a lot of us are scared we will get treated even worse at work because employers are under more pressure. If I lose my job, where will I go to get help? I don't understand how everything works. ”

The Board specified that to ensure equal access to justice, the new Human Rights Bill must have strong legal powers, with the ability to monitor and enforce fair and equitable treatment under the law, for example, when employers discriminate against employees with learning disabilities. Services that support accessing justice must also be made fully accessible.



Education

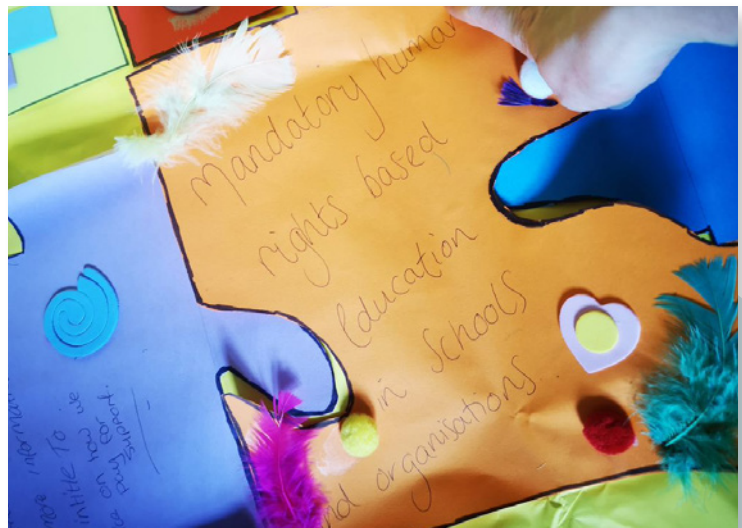
“ Mandatory human rights-based education...” ”



Concerning education, the Board was keen to highlight human rights and learning disability-focused education as crucial in creating and maintaining culture change. Several Board members suggested that education about how life is for people with learning disabilities and how to ensure the realisation of human rights must be integrated into school curriculums from an early age. The Board members stated education would foster respect and understanding for people with learning disabilities and help everyone understand and claim their human rights and stand up for others when their rights are compromised. Learning disability rights training that recognises and tackles abuse was essential to the Board. Several members pointed out that abuse can come in many forms and often isn't recognised as abuse and becomes part of everyday life. As one Board member said:

“ I'm lucky because I've learned a lot about human rights in this group, but most of the people I know don't ever get that kind of training or never got it at school. So, a lot of them don't know their human rights, and then they don't know if what's happening to them is abuse. They might just think that's how it is because they have a learning disability and just put up with it. ”

The Board was clear that the new Human Rights Bill should make learning disability and human rights training mandatory in schools, businesses and other organisations to make significant steps towards achieving culture change. The Bill must also be able to monitor the implementation of such education and hold to account those who don't provide it.



Independence

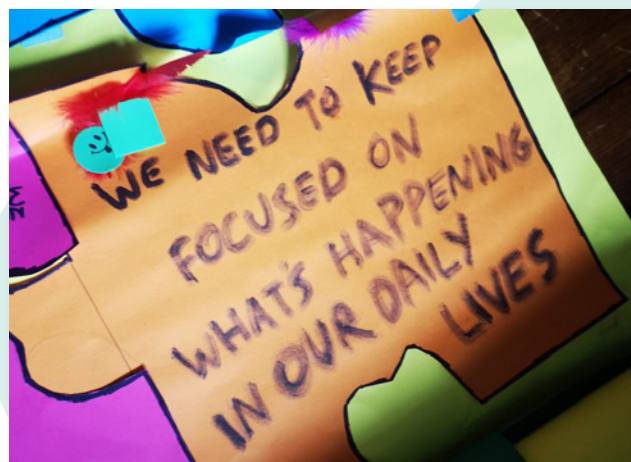
“ We need to keep focused on what’s happening in our daily lives. ”



Living independently was a key focus for the Board, who spoke about the importance of making their own decisions and controlling the important choices in life. They highlighted that how you run your everyday life has a considerable impact on overall health and wellbeing, as well as being able to set and achieve larger long-term goals. For example, one Board member spoke about their struggles to maintain a healthy, happy lifestyle as the unequal impact of budget cuts on people with learning disabilities results in them being denied opportunities. This Board member spoke about how rural transport cuts have left them unable to access employment opportunities, with the knock-on effect of not being able to support themselves, having to access benefits, being cut off from their community, and struggling with their mental health as a result. Another Board member explained that this also applied to the right to housing. This person shared that they were given a flat badly in need of repair and redecoration but were denied any decision-making rights, resulting in their struggle to feel like it’s their own home and a safe space for them. As they said:

“ I finally got my own place after so long fighting for it, but I wasn’t even allowed to choose how to decorate it. It had damp and everything, and I have health problems already. The association took months and months to do anything. How is it my home if I can’t choose how to decorate it and I can’t live in it because it makes me ill? ”

The Board agreed that to protect and support the independence of people with learning disabilities; a new Human Rights Bill must challenge the structural barriers of everyday life that stop people with learning disabilities from having control of their own lives. To do this, the Bill should develop upon the social model of disability and ensure services and organisations adapt to the needs of people with learning disabilities rather than allow people to lose their ability to make their own choices on how they run their lives.



Inclusion

“ No voice left behind. ”



In terms of inclusion, the Board felt very strongly that inclusion meant being included within their community and in decision-making processes at a national level. Board members spoke about how important it is to be involved in your community and how this can affect physical and mental wellbeing. Several members highlighted that inclusion can be restricted by factors such as poor communication by support providers or uncompromising support services, as well as a lack of accessibility, for example, not having the support to attend community events. One member shared that they depend on their support service to provide transport and personal assistance to visit friends and attend events. However, their support company often cancels or changes their support last minute, meaning they miss out and cannot maintain meaningful relationships in their community. As they said:

“ I used to go to a really good group where my friends go. Since COVID, it’s been the way I keep in touch with people. But my support uses lots of agency staff and they cancel on me late. Sometimes I have to call them and ask what’s going on, and it turns out they’re not even coming. So, I can’t see my friends. ”

Inclusion within high-level decision-making was also identified as crucial in the group discussion. Members highlighted the importance of people with lived experience being actively and meaningfully involved in Government decision-making processes, in policy development and implementation as well as consultation and advocacy. For example, one Board member said that since being part of the Lived Experience Board and being an active participant in Bill development, they feel they can make life better for themselves and other people with learning disabilities.

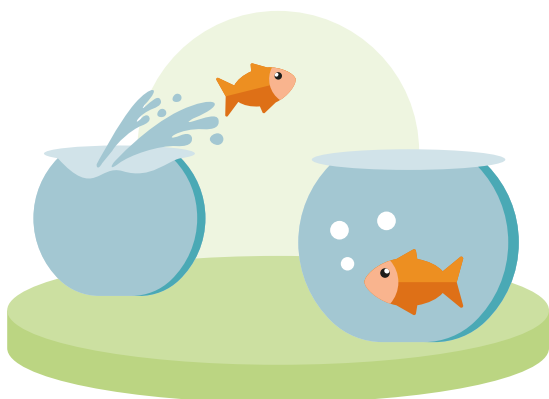
The Board agreed that to support full and meaningful inclusion, the new Human Rights Bill and any future decision-making processes that impacted the human rights of people with learning disabilities must include people with lived experience. It was suggested individuals could act in roles such as expert groups, advocates, and consultants in accessibility. Government bodies must also be able to evidence that decision-making processes have actively taken the views and opinions of people with learning disabilities.

Section 5:

Models of Incorporation

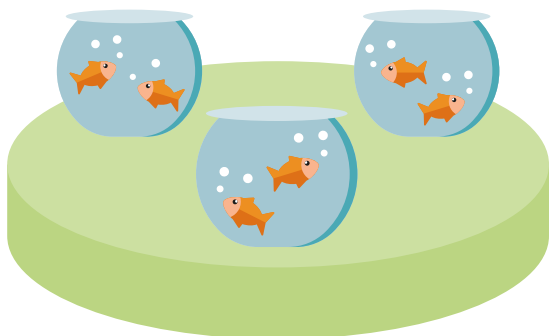
As part of the block four meetings, the Board discussed different models of incorporation. SCLD explained three different types of incorporation to Board members. These were direct incorporation, indirect incorporation and piecemeal incorporation. This was illustrated using the examples of a fish jumping from one bowl to another, fish jumping into multiple bowls and a jigsaw.

Direct Incorporation



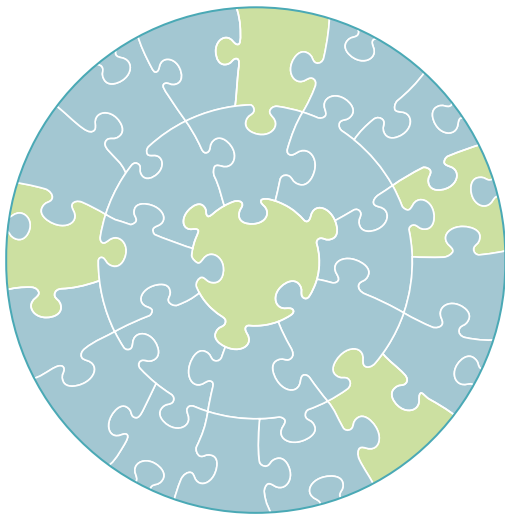
- Taking international law (for example, the United Nations Convention on the Rights of Persons with Disabilities) and putting the **exact wording** into another law.
- Adding one law **exactly as it is** into another.

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 all rights**.
- It may not mention the original treaty.

The Board then discussed the positives and negatives of each approach and was given the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) Scotland Bill as an example of what has been done to date.

The Board members were then asked to vote on the best model. The Board heard from Government about the challenges of direct incorporation due to the devolution agreement and therefore agreed that a mixed model of direct and indirect incorporation that aimed to incorporate the International Human Rights Treaties as far as possible within the confines of the devolution agreement would be most acceptable.

Some members of the Board expressed that they struggled with this topic due to its complexity. It was then requested that if the Board was to continue beyond the agreed four blocks, more time should be spent on this issue.



The Board heard from Government about the challenges of direct incorporation due to the devolution agreement and therefore agreed that a mixed model of direct and indirect incorporation that aimed to incorporate the International Human Rights Treaties as far as possible within the confines of the devolution agreement would be most acceptable.



Section 6:

Putting the Puzzle Together



As part of the fourth block, the Board were given an update on other Scottish Government work related to human rights realisation in Scotland. After the update, the Board discussed how each of these pieces of work could positively impact rights realisation for people with learning disabilities and what they would need to do to support the ambition of the new Human Rights Bill for Scotland.

National Care Service for Scotland

The Board shared their opinions on what a National Care Service must achieve to protect and support the human rights of people with learning disabilities.

The Board were all in agreement that good communication is vital, both in terms of accessibility and effective working between services. For example, all services and all information must be available in accessible formats as standard. This also relates to face-to-face communication between professionals and the individual person. This could be achieved by high-quality, mandatory human rights-based communication training and monitoring mechanisms to ensure training is implemented and followed.

When considering the existing health service, one Board member expressed that they struggle to participate in their treatment choices because their GP service does not communicate with them appropriately. They said they feel that treatment is being done to them rather than with their consent. As they said:

“ I went to the GPs about things to do with fertility, and they told me what my diagnosis is, but it was out of the blue, and no one had told me how they got to that. I should have been involved and been able to decide what to do. When I asked them to explain, the doctor wasn't good at helping me understand. ”

Effective communication between services was also highlighted as key by the Board. One member said they often go around in circles trying to get the support they need because services and departments don't communicate with each other or refuse to share important information between them or even with the person themselves. This member said that having to explain their circumstances and needs over and over again to different people made them feel like less of a person and that it made obtaining support a drawn-out and inherently harmful process. The Board felt this could be avoided by having accurate, up-to-date databases with information such as care plans, accessibility, and communication needs documented and available to each service and fully accessible to the person. As one Board member said:

“ Whenever I go to the doctors, and it's a different doctor, or something has changed in my support, I have to explain it to them all over again. They should have all my information already; I don't know why different services don't talk to each other. I wasn't even allowed to look at my own support plan because they said it was confidential. ”

Learning Disability, Autism and Neurodiversity Bill and Commission/Commissioner

The Board welcomed the Scottish Government's commitment to creating a Learning Disability, Autism, and Neurodiversity Bill but stressed that it must be clear on who it aims to support. One Board member said the Bill would be too vague if it were intended to protect all people. For example, members of the Board were clear the Bill must enable specialist support for people with profound and multiple learning disabilities and require the creation of person-centred and human rights-focused support services. They said it must ensure that services and care packages should be made with the involvement of the person receiving the support, and this should extend to choosing who can support them in decision-making. The Board said the Bill must ensure guardianship processes are built around the person, not simply given a one size fits all package that can be unreasonably restrictive and compromise the person's human rights. For example, one member shared how they had been put under guardianship and, as a result, were subject to so many restrictions they were unable to top up their mobile phone.

The Board was keen to discuss establishing a commission/commissioner and agreed that the commission/commissioner must be led by people with learning disabilities, autism and neurodevelopmental differences. The Board felt this would ensure that the voices and needs of people with lived experience were integrated into decision-making and accountability processes. They also felt that people with direct knowledge of this group of people's challenges are more likely to actively listen to them.

The Scottish Mental Health Law Review

The main issues the Board were keen to focus on were the use and impact of specific language within the law and the inclusion of learning disability within the act. Board members agreed that legal frameworks must be incredibly mindful of the language and terminology they use concerning people with learning disabilities and disabled people more generally. The use of terms such as **'behavioural issues'** and **'challenging behaviour'** has long been opposed by people with learning disabilities and their advocates due to the negative connotations and misunderstandings these create, which result in people with learning disabilities being stigmatised and unfairly treated in society. This can also lead to people having their human rights compromised or denied, for example, if restrictive treatment plans are put in place without the person's agreement based on **'challenging behaviour'**.



One member said they feel that people with learning disabilities are given labels and get stuck with them for life. The person said they thought they had been mistreated because they had been labelled as having **'challenging behaviour'** and could not get away from it. They said this impacts how people see them as a person and the support they get. The person explained that their **'challenging behaviour'** in the past was frustration due to people not communicating effectively with them. The person said it all could have been avoided if there had been better training on communicating with people with learning disabilities. As they said:

“ I just got angry because I didn't understand what was going on or what they were saying I had done. If they had left me alone to calm down or spoken to me in a way I understood, it would have been fine. ”

The Board also felt strongly that learning disability should not be defined in the Mental Health Care and Treatment (Scotland) Act (2003). Board members said that as long as this is the case, someone with a learning disability can be detained under the Mental Health Act and have their intellectual impairment cited as a reason for detention and that this was unacceptable.

The Board was also clear that people with learning disabilities must be able to access mental health support on an equal basis to all others. Several Board members worried that, due to the current link between mental health and learning disability, seeking support for mental health issues might put them at risk of detention.

One Board member expressed that this issue is significant for people with profound and multiple learning disabilities who have suffered long-term institutionalisation. This person spoke about people with profound and multiple learning disabilities who have had their human rights denied for years under unfair and unnecessary guardianship and detention orders based partly on the conflation between learning disability and **'mental disorder'**.

Overall, the Board was clear that for the new Human Rights Bill for Scotland to work the National Care Service, the Learning Disability, Autism and Neurodiversity Bill and Commission/Commissioner and the proposed reform of mental health legislation in Scotland would need to ensure compliance with not only the European Convention on Human Rights but also the UNCRPD and seek to progressively realise the highest standard of rights realisation for people with learning disabilities in Scotland.

Section 7:

Conversations with the Scottish Government

Following blocks one and two, the Lived Experience Board has received positive feedback from the Scottish Government on its work so far, with the Minister for Equalities and Older People Christina McKelvie tweeting that **“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 Scottish Government also stated that **“Their insight will be invaluable as we develop our Human Rights Bill”**. The Minister also wrote to the board to thank them for their work.

The Board were pleased to be able to meet online with Minister McKelvie in July and to spend time sharing with her their visions for a new Human Rights Bill for Scotland that makes human rights real for people with learning disabilities.

A member of the Scottish Government Equality and Human Rights Directorate attended meetings in blocks three and four to update the members on what action the Scottish Government have taken to implement feedback from the Lived Experience Boards and to give updates on the other Lived Experience Boards and human rights work is currently ongoing within the Scottish Government.



During block three, the Scottish Government updated the Board on the work of the other Lived Experience Boards, such as the Scottish Human Rights Consortium's Board and Together (Scotland's) Human Rights Detectives. The representative also spoke to the Board about the current work of the Advisory Board and the Executive Board. The Lived Experience Board were keen to hear more about the work of the Advisory and the Executive Board and suggested that a joint meeting is set up between the Boards to learn more about the work being done across all Boards.



The representative also thanked the Lived Experience Board for their first report, covering blocks one and two, stating that they welcomed the block one and two report and have noted the actions for the Scottish Government and the recommendations outlined within the report. They assured the Board that they would receive a complete response to the first report later in the year due to the need for the Government to do further work into the scope and capabilities of the new Human Rights Bill for Scotland.

The resulting actions for Government were:

- Initiate the creation of a joint Board meeting between lived experience Boards, the Advisory Board, and the Executive Board.
- Send the Human Rights Lived Experience Board a complete response to their first report.

During block four of the Lived Experience Board meetings, Scottish Government representatives attended the meetings in person and gave updates on the progress of the Human Rights Bill. They also spoke about other Scottish Government human rights work, such as the Mental Health Law Review, the Autism, Learning Disability, and Neurodiversity Bill and Commission/Commissioner and the Disability Commissioner Members Bill.

Regarding the new Human Rights Bill for Scotland, the Board were keen to discuss ways to continue to be involved throughout the Bill process, particularly concerning the creation, delivery, and outcome of the consultation and as part of the incorporation process. Additionally, the Board clarified their position on removing learning disabilities from the Mental Health Care and Treatment (Scotland) Act (2003) and their desire for Learning Disability, Autism and Neurodiversity Commission/Commissioner who has lived experience. The representatives also stressed that the Learning Disability, Autism and Neurodiversity Bill Team are planning their subsequent engagements with groups and individuals. They also plan to recruit for a lived experience panel in the future.

The Board were keen to know more about this and told the representatives that they would be happy to be involved and to advocate throughout their networks. **(See Section 6 for more in-depth information on the Board's response other ongoing human rights-based work).**

The resulting actions for Government were:

- To work with SCLD to clarify Board's future involvement in the Bills development.
- To keep the Board updated on the progress of the consultation planning and the new Human Rights Bill's progress.
- To give the Board more details on Bill's engagement plans as they develop.

Section 8:

The Future of the Board

The Board spoke with the Scottish Government representatives about the future of the Board and its involvement in the Bill process as this develops.

The Board stressed that they are keen to continue to be involved in the Bill development. One person on the Board said:

“ I want to see this Bill right through Parliament. ”

The Board made several suggestions on how they and others could continue meaningfully participating in developing the new Human Rights Bill for Scotland.

As part of the consultation process, the Board could act as peer facilitators in collecting views on the consultation. For example, Board members could support the Government by reaching out among their networks, for instance (People First (Scotland), The National Involvement Network, The Assembly etc.) and encouraging people to take part in the consultation, as well as gathering and feeding back opinions to the Scottish Government.



As part of this engagement work, the Human Rights Town app could initiate these conversations and provide context. The Board asked the Government who could help them to ensure that the Bill development process is as inclusive as possible. The Board were also keen to ensure the overall accessibility of the consultation and all other Bill engagement processes. Several Board members said they would be interested in helping the Government with this by advising as consultants and/or as an expert group on accessibility.

Section 9:

Feedback from the Board to Date



At the final meeting in Edinburgh, the Board members were asked to share their feedback on the four blocks of sessions and on being part of the Lived Experience Board more generally.

Feedback from the members was overwhelmingly positive.

The main positive points put across were that people with learning disabilities were:

Getting a seat at the table

Board members felt that the process had enabled them to be included in high-level decision-making. Members said that people with learning disabilities are largely left out of discussions on the decisions that impact their lives. One member said this had been the case for them since they were a child when the doctor would ignore them at appointments and not ask what they thought was best for them. They said that to be included now makes them feel like they finally have some control over their life and that they can advocate for others and to fight for what is best for people with learning disabilities.

Having some authority

Board members also said that they felt that being part of the Board has given their opinions authority. As a result, the Scottish Government takes their opinions on what needs to change seriously. They said they feel that whenever people with learning disabilities are given a chance to speak out, it is often tokenistic and that their opinions are never taken seriously. One member said that being part of the Board, speaking directly to the Scottish Government, and hearing their responses make them believe that they are genuinely being listened to.

Setting a standard

One Board member said that being part of the Board showed them that a group of people with learning disabilities can impact change. Having the Scottish Government representatives come to meetings and respond to the Board's work shows that it is possible to include people with learning disabilities in legislative decision-making and policy development. The Board were clear that there is no reason it can't be done in all decision-making. They also stated organisations assume it's too difficult to include people with learning disabilities, but this Board has shown that to be untrue.

Creating a community for change

The members also said that the Board has been valuable in bringing people together who have the same desire for change and want to advocate for others. One member said that during the pandemic, they have felt isolated and cut off from like-minded people but being able to come together as part of the Board, whether online or in person, has made them feel like they are part of a community again.

There were also suggestions for improvements for future engagement with this Board or similar future Boards. This included:

Improving feedback

The Board members said they would have welcomed more feedback from the Scottish Government regarding their suggestions for change. They also noted that more regular updates on the progress of the Bill would be helpful as otherwise, they might feel that their input is being forgotten about.

Using accessible language

The Board members said that, at times, they found it difficult to understand the updates from the Scottish Government because the language used was too technical. However, being provided with easy-read versions made it much more manageable. Several members said they would be happy to advise Government staff on presenting work in easy read.

Continuing Board's involvement

The Board said they are keen to continue being involved in the Human Rights Bill for Scotland development process and that, ideally, Boards similar to this one should be involved in all decision-making processes within Government.

Section 10:

Conclusion and Recommendations

The Board are confident that a new Human Rights Bill for Scotland has the potential to make significant and life-changing differences for people with learning disabilities. However, this can only be achieved if the Scottish Government implement the recommendations of people with learning disabilities and support the human rights realisation of those who have so far been neglected and marginalised.

Both the Board and SCLD believe that the Scottish Government have a significant opportunity to create a Human Rights Bill that sets the standard for realising the human rights of people with learning disabilities.



Both the Board and SCLD believe that the Scottish Government have a significant opportunity to create a Human Rights Bill that sets the standard for realising the human rights of people with learning disabilities.



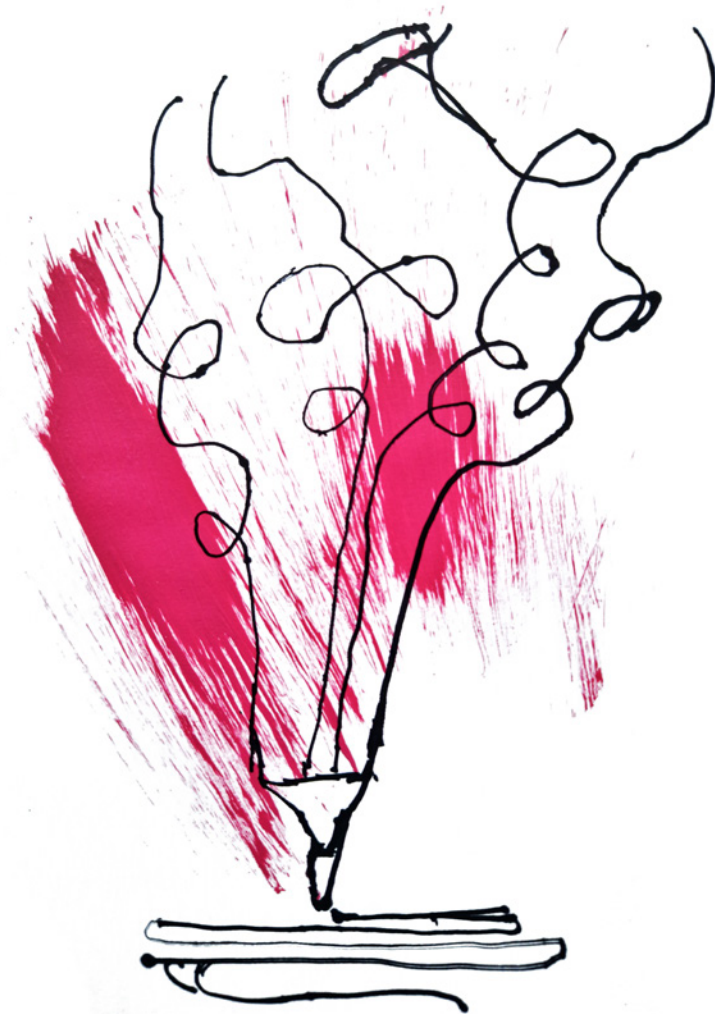
Following the first report's recommendations, SCLD has listened to the views the Board expressed and developed key recommendations for consideration in creating a new Human Rights Bill for Scotland. These are as follows:

- 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, 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 (i.e. minorities within minorities) 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 recommended by the National Taskforce on Human Rights Leadership (including the UNCRPD) as far as is legislatively competent within the context of devolution.
- 4** The new Human Rights Bill must ensure that incorporation of the UNCRPD into domestic law is followed by an audit of all legislation and policy to ensure compliance with the Convention. This audit should include the Mental Health (Care and Treatment) (Scotland) Act (2003) 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 critical aspect of human rights realisation.

If you have questions about the Lived Experience Board's work, please contact SCLD via admin@sclد.co.uk.

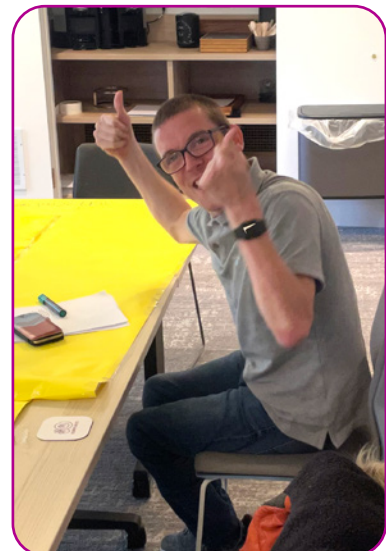


Thanks to Project Ability artists for their illustrations used throughout the content of this report.



An Easy Read version and audio version of this report can be accessed via SCLD's website.

<https://www.sclد.org.uk>





Scottish Commission for People with Learning Disabilities

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

✉ admin@sclد.co.uk

☎ 0141 248 3733

🐦 @SCLDNews

📘 @ScotCommission

📷 @sclدnews

📺 vimeo.com/sclدnews