

### **Consultation Response**

Human Rights Bill for Scotland Consultation Response from the SCLD Human Rights Lived Experience Board

The Scottish Commission for Learning Disability 2023



#### Introduction

The Scottish Commission for People with Learning Disabilities (SCLD) Human Rights Lived Experience Board welcomes the opportunity to respond to this important consultation. The Board believes it is important that the voices and opinions of people with learning disabilities are meaningfully included in all decision making processes.

This response has been put together by the SCLD Lived Experience Board, using evidence from an analysis of the Human Rights Bill for Scotland Consultation, and from engagement work with other learning disability groups. The Lived Experience Board have been clear that meaningful engagement with people who have lived experience of learning disability is vital to the creation of a human rights bill that fully supports and protects the human rights of people with learning disabilities.

In order to write a consultation response that reflects the opinions and voices of people with learning disabilities, the Lived Experience Board engaged with three learning disability groups in Scotland; The Assembly, Get2gether, and Dates n Mates. The Lived Experience Board spoke to each group about the consultation, gathered opinions and thoughts on what impact the consultation could have on the lives of people with learning disabilities, and what changes should be made to ensure their human rights are realised.

#### Work of the SCLD Human Rights Lived Experience Board

The Human Rights Lived Experience Board was created in early 2022 and is funded by the Scottish Government. The Board works to ensure the voices of people with learning disabilities in Scotland are included throughout the Human Rights Bill for Scotland process.

The Scottish Government has outlined its intention to create a Human Rights Bill that works for people with learning disabilities<sup>1</sup>. They have acknowledged that this cannot be achieved without the active participation from people with learning disabilities<sup>2</sup>. The Board therefore welcomes this ongoing opportunity to be a meaningful part of the Bill creation process.

<sup>&</sup>lt;sup>1</sup> <u>human-rights-bill-scotland-consultation-june.pdf</u> (www.gov.scot)

<sup>&</sup>lt;sup>2</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

The Lived Experience Board has thus far written two reports to the Scottish Government<sup>3</sup>. These reports are the result of Board meetings in which members identified and explored the human rights most relevant to the lives of people with learning disabilities, and the full realisation of their rights within society and the law. Board members spoke openly and candidly about their own experiences, both positive and negative, and identified what human rights are most at risk.

Within the two reports the Board made 11 recommendations to the Scottish Government of what should be included in the new Human Rights Bill for Scotland<sup>4</sup>.

## Importance of the Human Rights Bill for Scotland to the lives of people with learning disabilities

As outlined above, the Board identified several areas in which they feel they are most significantly denied their rights:

- Education
- Access to justice
- Work and employment
- Access to society
- Access to healthcare services

Despite the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) being ratified by the United Kingdom in 2009<sup>5</sup>people with learning disabilities have continued to face social, cultural, and institutional barriers to their human rights.

The UNCRPD makes clear that people with a disability should enjoy equal access to human rights. However, the work of the Lived Experience Board has shown that people with learning disabilities continue to be denied this.

The Board have spoken about their own experiences of being denied access to human rights. For example:

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<sup>&</sup>lt;sup>3</sup> Learning Disability Lived Experience Board - SCLD

<sup>&</sup>lt;sup>4</sup> 06813-Solving-the-Human-Rights-Puzzle-report WEB.pdf (scld.org.uk)

<sup>&</sup>lt;sup>5</sup> <u>The UN Convention on the Rights of Persons with Disabilities: UK implementation - House of Commons Library (parliament.uk)</u>

- being denied equal access to education<sup>6</sup>, resulting in a lack of job prospects and a negative impact on income and social involvement<sup>7</sup>.
- being denied equal access to justice, resulting in people with learning disabilities being unfairly and inhumanely treated<sup>8</sup>
- being denied equal access to information, resulting in an inability to access key services such a healthcare, public transport, financial services, and social opportunities<sup>9</sup>

The result of the above lack of realisation of human rights is profound, hugely restrictive, and often life-long. Without proper realisation of rights under the UNCRPD, many people with learning disabilities do not believe that they can enjoy full lives free from inequality and inhumane treatment.

The Board identified the importance of participation and culture change, as well as robust equality laws, as being key to realising the human rights of people with learning disabilities<sup>10</sup>.

Active and meaningful participation in government and local authority decision making processes is essential to ensuring that laws and policies work for people with learning disabilities. Decision-makers must understand the real-life impact that laws and policies have on whether or not someone can claim their human rights. An effective way to ensure this is to involve people with lived experience of life with learning disabilities in all stages of decision making. This would ensure that people with learning disabilities are rightfully involved as experts, and are leading the work to improve policy, legislation, and practice. People with learning disabilities are also the best choice to advocate for others and to defend their own and other people's human rights.

For these reasons, responding to the Human Rights Bill Consultation is an essential part of meaningful participation in the developing Bill process. To ensure the human rights of people with learning disabilities are properly realised and protected, the Lived Experience Board urges

<sup>&</sup>lt;sup>6</sup> Human-Rights-Lived-Experience-Board-Report-1.pdf (scld.org.uk)

<sup>&</sup>lt;sup>7</sup> Human-Rights-Lived-Experience-Board-Report-1.pdf (scld.org.uk)

<sup>8</sup> Human-Rights-Lived-Experience-Board-Report-1.pdf (scld.org.uk)

<sup>&</sup>lt;sup>9</sup> <u>06813-Solving-the-Human-Rights-Puzzle-report WEB.pdf (scld.org.uk)</u>

<sup>&</sup>lt;sup>10</sup> <u>06813-Solving-the-Human-Rights-Puzzle-report WEB.pdf (scld.org.uk)</u>

the Scottish Government to fully consider the contents of this response in its work on the Human Rights Bill going forward.

# "Involve people with learning disabilities and listen to their voices." (Lived Experience Board Member: 2022)

This consultation response has been written with a focus on responding to two of the Human Rights Bill Consultation questions:

- Question 4
   What are your views on the proposed model of incorporation?<sup>11</sup>
- Question 5
   Are there any rights in the equality treaties which you think should be treated differently? If so, please identify these, explain why and how this could be achieved?<sup>12</sup>

These two questions were chosen specifically to highlight the impact of the Bill on the lives of people with learning disabilities and their relevance to the issues highlighted by the Lived Experience Board in its work thus far.

Question 4, 'What are your views on the proposed model of incorporation?', is particularly relevant as the incorporation of the treaty will have significant impact on its legal strength and implementation status within duty-bearer policy and procedure. For example, unclear or vague implementation is likely to be difficult for duty-bearers and rights-holders to understand and could result in key rights within the law being open to interpretation. Lack of clarity could also mean that rights-holders do not understand what rights are protected under the law or how to claim them.

<sup>&</sup>lt;sup>11</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

<sup>12</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

Question 5, 'Are there any rights in the equality treaties which you think should be treated differently?', links with the Board's concern for specific learning disability rights being diluted.

It is also important to note that these questions have been taken from the full text version of the Human Rights Bill Consultation. While the Lived Experience Board appreciates the release of the easy read consultation alongside the full text version, the Board identified what they felt was a distinct lack of coherence between the content and questions in the full text version compared with the easy read version. Although it is acknowledged that translating policy documents and/or technical language into easy read often results in diluting some information, the Board felt that the content and questions in the easy read consultation did not sufficiently reflect the content of the full text consultation. The worry of the group is that this results in people with learning disabilities missing out on valuable information when responding to important consultations.

The Lived Experience Board identified three specific concerns within the consultation. These concerns were explored by the board with a view to answering the above questions.

#### 1. The concept of dignity

The group identified that the consultation puts significant emphasis on the concept of dignity; recognising that that 'human dignity is the value which underpins all human rights'<sup>13</sup>, and that the concept of human dignity can be a 'helpful tool in understanding and interpreting key human and comparative constitutional rights'<sup>14</sup>.

The consultation states that the Scottish Government 'want to ensure that human dignity can be taken into account in the interpretation of the rights in the Bill'<sup>15</sup>. The group felt that this appears to suggest that the concept of human dignity could be used to measure the value and worth of person's human rights when decisions are being made that are likely to impact a person's quality of life. For example, within a legal challenge or when creating care plans.

<sup>&</sup>lt;sup>13</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

<sup>&</sup>lt;sup>14</sup> <u>human-rights-bill-scotland-consultation-june.pdf</u> (www.gov.scot)

<sup>&</sup>lt;sup>15</sup> <u>human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)</u>

The group found this very concerning, as several group members pointed out that there is no universally agreed concept of what dignity is. 'Dignity might mean something totally different to them than it does to someone with a learning disability'<sup>16</sup> Another member said, 'How can someone make human rights decisions about me if I don't agree with what they think dignity is?'<sup>17</sup>

The group stressed how important dignity is in realising human rights, having so often experienced a loss of or lack of access to dignity, and knowing first-hand the negative impact this can have on a person's life. However, they agreed that it is not possible to fairly measure someone's human rights using dignity as everyone has a different idea of what dignity is. The group said that in order to create a fair, equal, and inclusive definition of dignity that can be used to support human rights realisation marginalised and at-risk groups, such as people with learning disabilities, must be involved in creating that definition.

In particular, if the concept of dignity is to be used as measurement of human rights within a legal context, the inclusion of people with learning disabilities in creating the legal definition of dignity would satisfy several Human Rights Taskforce Recommendations. Such as Recommendation 21, which states that: 'Through engagement with key stakeholders, including those who face additional access to justice barriers, further consider accessible, affordable, timely, and effective remedies and routes to remedy that will be provided for under the framework' 18. Additionally if the concept of dignity is, as the consultation suggests<sup>19</sup>, to be used as a marker of a minimum core obligation, participation in defining dignity would also satisfy Human Rights Taskforce Recommendation 13, which states that 'there be a participatory process to define the core minimum obligations of incorporated economic, social and cultural rights, and an explicit duty of progressive realisation to support the effective implementation of the framework, which takes into account the content of each right'20.

<sup>&</sup>lt;sup>16</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. https://us02web.zoom.us/j/85916329180

<sup>&</sup>lt;sup>17</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. https://us02web.zoom.us/j/85916329180

<sup>&</sup>lt;sup>18</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

<sup>&</sup>lt;sup>19</sup> <u>human-rights-bill-scotland-consultation-june.pdf</u> (www.gov.scot)

<sup>&</sup>lt;sup>20</sup> <u>human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)</u>

#### 2. The strength in law of the UNCRPD

The group investigated the strength of the UNCRPD in the proposed Human Rights Bill for Scotland. The UNCRPD is an essential human rights treaty for people with learning disabilities, which outlines that people with disabilities are entitled to live independent, safe lives, protected against all forms of abuse violence and exploitation<sup>21</sup>people with disabilities are entitled to 'effectively and fully participate in political and public life on an equal basis with others'<sup>22</sup>

Having previously made clear to the Scottish Government through previous reports that a strong incorporation of UNCRPD is essential to ensuring support and protection to people with learning disabilities<sup>23</sup> Lived Experience Board were keen to investigate how strong within the law the UNCRPD would be if the Human Rights Bill was passed as it is.

The Lived Experience Board are concerned that the UNCRPD has not been given equal legal strength with other human rights treaties, specifically ICESCR. Where ICESCR enjoys duty to comply status, UNCRPD rights are protected only by an initial procedural duty. One group member pointed out that this inequality in the law makes people with learning disabilities 'feel like we are still second-class citizens and nothing is changing'<sup>24</sup>. said, 'if the rights of people with disabilities are not strong enough compared to other peoples, is this not discrimination?'<sup>25</sup>.

The group chose to highlight this concern when engaging with other learning disability groups. The feedback from the three groups on this subject was overwhelmingly in agreement that the UNCRPD does not appear to be strong enough to support the human rights of people with learning disabilities. One meeting attendant said 'this means people with learning disabilities will be vulnerable to abuse', adding that 'a new law should make things better not worse'26

<sup>&</sup>lt;sup>21</sup> enable convention cover (un.org)

<sup>&</sup>lt;sup>22</sup> enable convention cover (un.org)

<sup>&</sup>lt;sup>23</sup> 06813-Solving-the-Human-Rights-Puzzle-report WEB.pdf (scld.org.uk)

<sup>&</sup>lt;sup>24</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. https://us02web.zoom.us/j/86585546497

<sup>&</sup>lt;sup>25</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. https://us02web.zoom.us/j/86585546497

<sup>&</sup>lt;sup>26</sup> The Assembly meeting attendee Anonymized. (2023, August). Zoom Meeting.https://us02web.zoom.us/j/82440809940

Another meeting attendant said that if the UNCRPD doesn't have enough strength in the law 'how will local authorities be held to account in sticking to these laws?<sup>27</sup>

#### 3. Inclusion of Lived Experience Board recommendations

In 2022 the Lived Experience Board investigated the state of human rights for people with learning disabilities. The group explored various human rights and the impact, both positive and negative, that these have on the lives of people with learning disabilities.

The group produced two reports for the Scottish Government, <u>The Right to be Heard</u> and <u>Solving the Human Rights Puzzle</u>. These reports included recommendations which outlined what the group believe must be reflected in the Human Rights Bill for Scotland in order for the Bill to work for people with learning disabilities. The group also <u>presented these recommendations</u> to members of the Scottish Government Human Rights Bill Team and the then Minister for Older People and Equalities.

The group do not feel that these recommendations have been adequately represented within the consultation.

For example, the Lived Experience Board were clear that the Bill must 'ensure a commitment to rights-based education, including for people with learning disabilities, across Scotland from school age into adulthood'28, and that there should be a 'duty on public bodies to undertake disability awareness training, including learning disability awareness training'29.

The consultation mentions human rights training for health care works and a right to education<sup>30</sup> but not specifically human rights focused education or specialised awareness training.

The Lived Experience Board also recommended that there should be an 'inclusion of provisions for groups not listed in the Equality Act under a rights most at risk clause. It should be made explicitly clear this is to include people with learning disabilities.'31.

Meeting.https://us02web.zoom.us/j/82440809940

<sup>&</sup>lt;sup>27</sup> The Assembly meeting attendee Anonymized. (2023, August). Zoom

<sup>&</sup>lt;sup>28</sup> Human-Rights-Lived-Experience-Board-Report-1.pdf (scld.org.uk)

<sup>&</sup>lt;sup>29</sup> https://www.scld.org.uk/wp-content/uploads/2022/06/Human-Rights-Lived-Experience-Board-Report-1.pdf

<sup>30 &</sup>lt;u>human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)</u>

<sup>31 &</sup>lt;u>Human-Rights-Lived-Experience-Board-Report-1.pdf</u> (scld.org.uk)

The consultation states that 'To ensure everyone can access the rights under the Bill without discrimination, we want to include an equality provision.' However this is in relation to the delivery of ICESCR rights and the right to a healthy environment<sup>32</sup>, and does not mention UNCRPD rights or people with learning disabilities.

The Lived Experience Board are very concerned that this apparent lack of inclusion of recommendations reflects a general disinterest from the Scottish Government in ensuring that the human rights of people with learning disabilities are supported by the Human Right Bill for Scotland. One group member said 'it feels like people with learning disabilities are being pushed out of the picture'<sup>33</sup>. While another stated that they feel as though 'we wasted our time saying to the Government what we think and what we need. Why ask for us to be involved if we're not listened to?'<sup>34</sup>.

#### In response to Questions 4 and 5

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

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

<sup>33</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. https://us02web.zoom.us/j/86585546497

<sup>32</sup> human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

<sup>&</sup>lt;sup>34</sup> Lived Experience Board Member Anonymized. ( 2023, September). Zoom Meeting. <a href="https://us02web.zoom.us/j/85916329180">https://us02web.zoom.us/j/85916329180</a>

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

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

#### Conclusion

In conclusion, the Lived Experience Board welcomes the creation of a new Human Rights Bill for Scotland. The current framework for rights realisation does not fully support the rights of people with learning disabilities<sup>35</sup>. This lack of support has unfortunately had horrendous ongoing consequences for the lives of individuals and groups<sup>36</sup>.

The Lived Experience Board recognise that this new Human Rights Bill for Scotland has significant potential to support a fully equal and fair society for people with learning disabilities. However, this cannot be achieved if all UNCRPD rights are not subject to duty to comply.

The Lived Experience Board therefore urges the Scottish Government to reconsider its current proposed treatment of UNCRPD rights.

The Lived Experience Board would like to make clear that it will continue to support the Human Rights Bill process and offer their support to Scottish Government in creating a Human Right Bill that works equally for everyone.

# SCLD Human Rights Lived Experience Board September 2023



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<sup>35</sup> The State of Our Rights (scld.org.uk)

<sup>&</sup>lt;sup>36</sup> The State of Our Rights (scld.org.uk)