Q1. Given that the Learning Disabilities, Autism and Neurodivergence Bill has been delayed by the Scottish Government, what outcomes do you think could be achieved without legislation?

There will be no change for us without legislation that fully realises our human rights.

For years we have been saying that people who have a learning disability should be empowered, equal and safe.

For years we have said that no law or policy in Scotland should be prejudicial or discriminatory towards people with a learning disability.

Our Board meeting last month stated five priorities. These will form the base of our development work for the coming 3 years. Each year the priorities set are in response to risk, including those that increase and continue year on year.

> **Priority 1. We will develop and share Key Message Documents** Because Law in Scotland does not secure us as humans with rights.
>
> **Priority 2. We will spread the work load out more**
>
> Because others still do not believe we are experts, that is exhausting.

Priority 3. We will refresh our company Governance

Because plans are made without meaningfully including us in other places and we must do it best ourselves.

Priority 4. We will proudly show others what collective advocacy means to us

Because there is a lack of positive change in our lives.

Priority 5. We will work with partners but celebrate our Powerful, Expert Voice

Because grouping us with others means everyone has to compete.

Supported decision-making

Supported decision-making is key to realising our rights and our equal status under the law.

Sir Robert Martin, the only person with a learning disability to ever sit as a United Nations committee member, never failed to make the powerful case for supported decision-making in Scotland. He died earlier this year, having asked again in March.

We want a full system of Supported Decision-Making to be established and resourced that would offer us support to have choice and control in our own life.

We want quality, flexible support to live a full life in our own home. These rights are laid out in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) yet, Scottish law still says that substitute decision-making can happen.

Article 12 of UNCRPD talks about equal recognition as persons before the law and to have the right to make our own decisions about our own lives.

Article 12 Human Rights Indicators talk about “abolishing all forms of substitute decision-making” and “recognising supported decision-making arrangements and ensuring that they respect the person’s autonomy”.

However, the proposals to amend the Adults with Incapacity Act will not lead to the creation or implementation of supported decision-making nor will they abolish Guardianship. In fact, the proposals will still allow for people with a learning disability to have their legal capacity removed. This will continue to deny us our human rights.

Through the committee we ask the Government one thing:

How does the Scottish Government reconcile Article 12 of the UNCRPD on equal recognition before the law with Scots law that still says that substitute decision-making can happen?

Coming home report

As we said to the committee, the Scottish Government promised to “significantly reduce” long hospital stays and out-of-area residential placements for people with learning disabilities or complex needs by March 2024.

We set a countdown clock running on our website when that was said (referred to during the evidence taking session).

The deadline has been and gone without the commitment being met.

No legislation is required to honour that commitment.

Public Health Scotland published a report in May this year called Insights into Learning Disabilities and Complex Needs: Statistics for Scotland.

That Report gives the most accurate list of hospital detentions published so far for people with a learning disability. This is a grim read because it is real.

Table 3 on page 12 and table 4 on page 13 in the Report are of particular interest.

The Report tells us that, in Scotland, as at 28 March 2024 1,463 people with a learning disability / complex needs were on the Dynamic Support Register (DSR), against 1,243 in September 2023.

The DSR provides information about people with learning disabilities at a local and national levels.

The DSR was launched in May 2023, as one of the key recommendations from the Coming Home report.

The person, not the "system" should determine where we want to live. But, this will continue as long as there is no supported decision-making.

One person living in these conditions is one too many.

Of those 1,463 people, we learn that:

- 192 were in hospital.
- 75 were "inappropriately out-of-area". This means the person and/ or family did not choose where they will go, but it happened anyway because of a lack of suitable resources and/ or accommodation within the person's preferred community setting.
- 222 were at "risk of support breakdown" (154 in September 2023). Because there is no supported decision-making, we are not offered choice and control when being discharged from hospital.

We also learn that out of the 192 people in hospital, 83 were classified as a "delayed discharge".

And out of those 83 people, 11 have been delayed for more than 6 years (against 5 people in September 2023). This is neither excusable nor justifiable.

For 2 people with a learning disability out of the 83, the details of the date of their admission to hospital is unknown.

Through the committee we ask the Government one thing:

When will the Government honour its promise to significantly reduce long hospital stays and out-of-area residential placements for people with learning disabilities or complex needs? As we have said to the Committee, actions speak louder than words.

Q2. What key outcomes would you like to see, and what might be the barriers to achieving those outcomes?

Learning disability law

We have said all along that a law that is only about learning disability is what people with a learning disability need.

That would be meaningful for us.

We invite the Committee to watch our short film (referred to during the evidence taking session) in which we set out why a new law on learning disability is necessary to offer us dignity as humans and citizen with rights.

The current inclusion of learning disability under the definition of mental disorder means that we can be detained in hospital on the basis of our learning disability.

We would like to remind the committee that, unlike mental illness, there is no cure, no treatment for learning disability.

No amount of medication or forced sedation has ever cured a learning disability.

As long as learning disability is considered in law as a mental disorder no person with a learning disability can feel safe.

Indeed, we often live in the fear that we might end up under guardianship because of our learning disability.

Guardianship means we lose our freedom to choose who we want to see, what we want to eat, the movie we’d like to watch, even the clothes we’d like to wear, simply because we have a learning disability.

The consultation paper on the LDAN Bill proposal said that “We agree that collaboration between forensic and general mental health services is required to put the needs of people with learning disabilities and neurodivergent people at the forefront”.

The term “forensic” still brings us fear.

Forensic services are very efficient to not only deprive us from the most basic human rights such as freedom but also mean we can be forced to be medically treated for something that is not treatable: a learning disability.

So, the very proposal that is supposed to help and support people who have a learning disability still maintains the confusion between learning disability and mental disorder.

The same consultation paper says that “A diagnosis of autism or a learning disability in itself is not a cause for detention in the State Hospital”.

But, because the law groups learning disability together with mental disorder, some people with a learning disability end up in forensic services to undergo treatment under the supervision of a mental health team.

The Committee asked about the barriers to achieve outcomes. In our case it is very simple. People with a learning disability are not seen as a priority, we are not seen as citizen or even, sometimes, human beings. If that was the case our human rights would not be routinely brushed off or ignored. So, keeping us under mental health law certainly does discriminate against us.

Through the committee we ask the Government one thing:

Will the Government introduce legislation specifically designed to protect and support people with a learning disability?

Q3. What steps should the Scottish Government and other public services be taking now to improve the lives for people with learning disabilities and neurodivergent people?

Policy makers and deciders need to listen to, and hear, what we have been saying for 35 years. 35 years of evidence taking sessions, sharing our lived experience, discussions, pleas, workshops, conferences and events with all the various political parties have come to very little.

We would refer you again to the Report of Public Health Scotland mentioned on page 4.

Our life expectancy is 20 years lower than for others[1].

The information to manage our health conditions, to book and attend appointments, to order medicines that can maintain better health is provided in ways that fail to include us.

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[1] https://fraserofallander.org/new-research-on-learning-disabilities-in-scotland/

Yet, we have been asking for years that information that is relevant to us be provided in a format that works for us.

Article 4 of the UN Convention says that Government should "closely consult with and actively involve persons with disabilities through their representative organisations in decision-making processes".

Yes, *sometimes*, we are consulted on the very matters that directly impact our lives. But we are not listened to and we remain unheard. There is a lack of genuine and meaningful inclusion. This too, is exhausting.

We are the experts about our own lives, we know what works for us and what does not but our voices are still not heard.

Thank you.