



People First (Scotland) works for the human rights of people who have the labels of Learning Disability or Intellectual Impairment. People First (Scotland) is controlled by its members, who all identify themselves in that way. People First (Scotland) campaigns to establish and protect the same freedom, choice, dignity and control held by other citizens across all areas of life.

People First (Scotland) Law and Human Rights Group Statement re: Scottish Mental Health Law Review Recommendations

People First has been actively campaigning for a review of the place of learning disability within Mental Health law and the label of “mental disorder” for nearly 20 years. We have done this because it has been clear to us from the start that including learning disability in a framework designed from the perspective of mental health and illness is not appropriate.

We have met with successive ministers of the Scottish Parliament to lobby for the Review until at last a review was agreed by Jamie Hepburn MSP, then Minister with responsibility for Mental Health (as Minister for Sport, Health Improvement and Mental Health), in 2015. The Review has taken place in two parts. Firstly, the Independent Review of Learning Disability and Autism under the Mental Health Act (The Rome Review) which was principally set up to review the inclusion of learning disability in the definition of Mental Disorder under the Act. Secondly, the wider review of mental health legislation including the Mental Health Act, the Adults with Incapacity Act and the Adult Support and Protection Act. Our concerns about some of the processes and recommendations of the Scottish Mental Health Law Review are detailed below.

We want to acknowledge the huge amount of work that has gone into the Review and to recognise the efforts made by executive members and others to establish safeguards against abuse and introduce a human rights model to the legislation. However, we fail to see how any of these safeguards or the introduction of a human rights model will bring about positive change as long as people with a learning disability are grouped in legislation with people who experience mental illness.

- Participation and involvement of people with lived experience

We were disappointed with the level of participation and involvement of people with learning disabilities in the Review. We accept that because the Rome Review was only about the experience and position of people with learning disabilities that there had to be a similar approach for people with mental illness (and others covered by the legislation). However, we do not accept that, in terms of involvement and participation, confining that involvement to lived experience of mental illness and carers of people with mental illness was justified. After lobbying extensively for involvement in the working groups our input was limited to one member who sat on the ‘lived experience reference group’. This is not what meaningful involvement looks like.

The unified voice of people with learning disabilities (intellectual impairment) and the organisations that represent their views, including People First (Scotland), as the



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independent disabled persons' organisation was that learning disability should be removed from the definition of "mental disorder".

Our expectation of being "front and centre" to any review is that if there is a unanimous voice of people with lived experience, then that voice should hold sway. In this case it did not, which makes it impossible for us to feel heard and listened to.

- The definition of Mental Disorder

For years we have made compelling arguments about the human rights abuses that people with learning disabilities experience as a result of being imprisoned in a system that is built on the medical model of 'care and treatment'. The Rome Review recommended that learning disability be removed from the definition of "mental disorder".

We have shared horrific stories of people detained all their life under a legal framework that does not meet their needs. Recently, our Chair spoke powerfully in a BBC documentary about the abuse that people inevitably suffer in closed institutions. We heard from families who are desperate to have their adult children removed from mental health wards where they face seclusion, restrictions, and are medicated for their "challenging behaviour", which is emotion being communicated as a result of being detained in the worst of environments.

The Review fails to identify any benefit to people with a learning disability being included in a system that is designed to support people who have a mental illness. We cannot 'recover' or receive 'treatment' for what is our lifelong condition.

We also struggle to see how the Coming Home Implementation Strategy can be effective when the law continues to allow us to be detained on the basis of our 'mental disorder' or, under the Scott Review recommendations, 'intellectual and mental disabilities'. Both of these categorisations group intellectual impairment together with mental ill-health as if they were the same thing.

- The issue of supported decision-making

As an organisation we have been speaking about supported decision-making for a number of years. We wrote a 'Framework for Supported decision-making' in 2017. In this document we talk about a system of supported decision-making that **does not require the removal of legal capacity** for people with a learning disability. It also does not require us to be subject to legal intervention before we can benefit from it. Instead, supported decision-making should be for everyone, all of the time.

For us, the current system of substitute decision-making is not any different from what is being proposed by the Review team, although the language has changed. The principles under the current Adults with Incapacity Act (Scotland)(2000) already require support for the individual, expressions of wishes and feelings and the 'least restrictive' option. And yet, when it comes to adults with learning disabilities, these principles result in Guardianship Orders, and for some of us, lengthy, inappropriate, and restrictive detentions in assessment and treatment units or in the criminal forensic system, often *without* convictions.

So, while we are generally supportive of the concept of supported decision-making, we do not support the version of supported decision-making described in the recommendations of the Review. This version still allows for substitute decision-making and will continue to pose a great risk to our community. We don't see how the experience of people with learning disabilities will be improved by this.

The UNCRPD has also made it clear that substitute and supported decision-making are not compatible with each other and we continue to advocate for a complete change to the system, replacing substitute decision-making with supported decision-making for people with a learning disability.

- Guardianship

The Review recommends removing guardianship but this is misleading.

The Review recommends a system that is essentially a re-wording of the system that Scotland currently has in place for people with a learning disability. Instead of Guardianship, the Review recommends a 'Decision-Making Representative' who will continue to have the power to make decisions about our lives. Instead of capacity assessments there will be an Autonomous Decision Making Test. Instead of the Courts deciding on capacity cases that responsibility will fall to the Mental Health Tribunal. We do not see how this can have a positive impact on the experiences that people with learning disabilities have under the mental health and capacity laws that exist in Scotland.

Furthermore, the fact that we were excluded from the working groups on capacity and supported decision-making when we are most negatively impacted by these systems is entirely unacceptable.

Not including us in the discussions about the Adults with Incapacity Act during the review process is also a serious oversight. Adults with learning disabilities continue to be the group who are most affected by substitute decision-making in our society. The Mental Welfare Commission and others have acknowledged publicly that Guardianship numbers are higher than the act ever anticipated as a result of misuse,



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legal aid policy, and society that does not view people with learning disabilities as equal human beings. The misuse of Guardianship for people with learning disabilities has been made possible as professionals judge us to 'lack capacity' on the basis of our learning disability.

Nothing in the proposals is very different from the system that is in place now. We predict that numbers of people with learning disabilities who have decisions made about them against their will because professionals deem us to be 'incapable' will continue to be higher than any other group in society due to prejudice, discrimination and an inappropriate legal framework.

- Learning Disability, Autism and Neurodiversity Bill

When the Scottish Government announced the work on a Learning Disability, Autism and Neurodiversity Bill we were quietly hopeful that this may create a legal framework tailored to our needs.

What we have been campaigning for is a complete overhaul to the legal framework recognising people with intellectual impairments and difference are citizens and human beings and not 'others' that need to be removed and locked away in institutions such as Assessment and Treatment Units. Appropriate support, meaningful involvement and inclusion in our communities, activities that meet our needs as human beings, and a society that views us as equal citizens is what we have been hoping from the new legislation. We see this as an opportunity for Scotland to fully incorporate the UNCRPD.

We worry, however, that the Bill will not go far enough in protecting and promoting our human rights especially if the legislation will once again cover groups of citizens with vastly different life experiences.



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