

People First Scotland – Law and Human Rights Group

People First Alternative Summary on the Scottish Mental Health Law Review

People First

People First Scotland is the national disabled person's organisation of people with learning disabilities in Scotland.

Within People First, our work on law reform in Scotland and the absence of human rights for people with learning disabilities has been mostly carried out by the Law and Human Rights Group.

All of our policy positions have been agreed by the wider membership of People First – over 1,000 members meeting in more than 100 groups across the country.

We have been campaigning for most of them over the last 20 years.

Why do we need to produce this summary?

Although we produced a written response in Phase 1 of the consultation to the Scottish mental Health Law Review and we have met a number of times with John Scott, the chair of the Review, we were initially disappointed to see that not a single mention of People First was made in the Summary of responses to the Phase 1 Consultation report.

We object to that on the grounds of the Minister's promise that the Review would have people with lived experience at the front and centre of the Review; on the grounds that the Review itself makes a big deal about listening to those with lived experience (and carers). We also object on the grounds of Article 29 of the UNCRPD and General Comment 7 from the UN Committee which makes it clear that involvement of organisations of disabled people at all levels is an obligation of States Parties.

What the official summary appears to do is include contributions from people who have lived experience of mental ill-health and treatment, under the Mental Health Act, for mental illness. It also includes contributions from carers of people who have or have had mental illness.

We fully expect that and support that.

What was less expected was the exclusion of contributions from people with lived experience of the legislation who do not have mental ill-health and whose treatment under the Act was not for mental illness but for other reasons and other conditions.

On first reading of the Summary report, we saw that there was no mention of the issues raised by our organisation. On further reading, and fairly extensive reading of other consultation submissions, we realised that it was not just the People First contributions that were missed out from the summary.

Effectively, it was the issues affecting people with learning disabilities that were missed out, no matter who had raised them. For example, the plea for legislation for people with learning disabilities to be different from legislation for mental health treatments was raised by:

- People First
- Scottish Commission for Learning Disability
- SOLD Network
- Social Work Scotland
- Inclusion Scotland
- National Autistic Society Scotland and Scottish Autism

As well as others, including some of the individual responses.

Where some of the issues were briefly touched on, they were included by other organisations such as VOX or Learning Disability Service Heads and do not reflect the strength of feeling or the detail in our own submissions or those who specifically addressed learning disability experience of the legislation. These mentions were often explained away by the same contributors.

We do fully accept that not every point made by every contributor can be included in a summary of the consultation.

We also accept that the Rome Review of Learning Disability and Autism under the Mental Health Act has concluded and has given considerable attention to the issues.

However, it seems to us that the purpose of the SMHLR consultation summary is to lay the ground for the debate to come in Phase 2 and Phase 3 and if a significant voice and a number of issues have been excluded from that, then it does suggest a pre-determined outcome to the review.

We find it hard to believe that issues which have been entirely left out of the consultation summary can reappear in later phases.

We make a similar point about the workstreams and advisory groups to the review.

The Review Executive has made a big point about including people with lived experience. While we acknowledge that there is some representation of people with experience of serious mental illness and of people who are carers for those with mental health issues, there is no inclusion of the voice of people with a learning disability who are also described as mentally disordered and who are subject to the 3 pieces of legislation under review.

People with learning disabilities are more affected by the Adults with Incapacity Act than any other single group and have more serious breaches of our human rights under that Act than any other single group.

People with learning disabilities are more frequently affected by the Adult Support and Protection Act than any other single group.

People with learning disabilities, under the Mental Health Act, are more likely to be detained and treated under compulsion **when there is no treatable mental health condition** than any other single group.

People First has also done more work on Supported Decision-making than any other organisation and has published a Framework.

To be excluded from all of the workstreams and advisory groups and to be entirely missed out in the summary is simply unacceptable.

For the Summary of consultation to say that the recommendations of the Independent Review of learning disability and autism in the Mental Health Act (IRMHA) will be “taken account of” is not an acceptable response. When the Minister set up the Scottish Mental Health Law Review, the impression we were given was that those recommendations would be considered alongside the review of the 3 pieces of legislation and it does not feel as if that is what is happening.

Since first drafting this response, we have had the opportunity to speak with John Scott who has kindly acknowledged that the report could have been clearer in its intention to focus primarily on the Mental Health Act and on the experiences of those with mental health issues.

John has reassured us that the Scottish Mental Health Law Review fully intends to bring the topics covered by the Rome Review and the other pieces of legislation together when it comes time to make its own recommendations.

We do accept that reassurance and are grateful to John for taking the time to spell that out to us.

We are not persuaded by the absence of people with learning disabilities from all of the advisory groups and workstream groups since we still believe it is important to be part of the debate and discussion rather than simply have the opportunity to submit information to others who will have the discussion without us. Nevertheless, we will try to find other ways to contribute to the debate as it progresses.

In the meantime, to make up for the absence in the Summary Report of those issues which predominantly affect people with a lifelong intellectual impairment, we want to simply list them here.

Communication

We think this issue has been fairly dealt with in the Phase 1 summary report.

Alongside the communication issues experienced by people who have received treatment for mental health issues and the careful consideration of issues faced by carers, we want to stress that accessible information and clear communication is a major concern for people with learning disabilities, not least when we are subject to compulsion and detention. Our own submission made it clear that even the process of monitoring and scrutiny were largely ineffective since intellectually impaired people most often felt they would be punished for expressing dissatisfaction or for criticising their care and treatment. We explained that people mostly told us they had learned to “keep their heads down” to avoid being noticed. We gave examples of members of People First being refused entry into meetings held by multi-disciplinary teams to discuss their treatment or restrictions, even when accompanied by advocacy workers.

Independent Advocacy

Like other contributors to the consultation, we fully supported the presence of advocacy and, like others, we felt it was under-resourced and not always available. We pointed to the trend to allocate or refer to advocacy when there were statutory interventions but often the advocacy was available only very short term, arriving too near the intervention (such as Tribunal or Care programme approach meetings) to develop any kind of relationship with the advocacy partner or to get to know the person at all well. We gave examples of collective advocacy being terminated within hospital settings and replaced by selectively approved professional individual advocacy.

We were very clear that even if we were to be successful in persuading the review to have a separate legislative framework to those with mental health issues, we would want the right to access independent advocacy to be carried over into that new legislation.

We agree with Inclusion Scotland’s comment that access to advocacy is a particular issue for people with learning disabilities and autism.

Advance statements

We think that the section on advance Statements has been reasonably dealt with.

We need to add, though, that there is a logic flaw with advance statements when it comes to people with lifelong intellectual impairments.

For other people, the Advance Statement is drawn up in advance of becoming mentally unwell or “mentally disordered”.

For people with intellectual impairments, there is no point where the person does not have the learning disability (“mental disorder” under the Act) so it cannot be drawn up in advance of developing the condition.

The Summary notes that other contributors have said that there is a real possibility of the advance statement being ignored or having no influence over care.

We would argue that this is certainly the case for people with a lifelong intellectual impairment who have no “advance” status, ever.

Resources and availability of treatment

We think this section has been fairly dealt with in the summary for people with mental health issues.

For people with a lifelong intellectual impairment, the picture is different. People First has many members who do experience mental ill-health and research suggests that the proportion is higher than in the rest of the population.

The feedback we have had about good mental health service support and treatment generally comes from community-based treatment. Most often, the experience of being detained or treated with compulsion is in the absence of any mental ill-health diagnosis. Most people with intellectual impairments who are detained under the Act are detained for other reasons – breakdown of care packages, behavioural issues including resistance to compulsion and crises in the person’s life.

This is at the heart of the submissions by People First (and many other organisations who share our views) – that people with intellectual impairments are treated very differently from other people under mental health and capacity laws.

Arguably, this is a resources issue and if there was better social care support and more of it, the circumstances which lead to people’s detention and compulsion would be less dramatically dealt with elsewhere, without having to use Mental Health Act powers.

The same argument applies to the massive growth in Guardianship applications for people with learning disabilities. Provision of good support would remove most of the reasons for guardianships and removal of people’s legal capacity, decisions which are usually based on assumptions of incapacity associated with the designation of mental disorder under the Mental Health Act definition.

The Current Mental Health Law

In the formal Summary of the Phase 1 consultation, there is half of a sentence which says:

the legislation does not cater appropriately for persons with long term conditions, those with learning disability, autistic individuals, persons with addictions and those at risk of suicide.

(page 21)

Regrettably, there is no explanation about why (“about 10”) respondents said this.

We think this is a crucial omission.

Fairly obviously, the Mental Health Act was designed for people experiencing mental ill-health who required intervention during mental health crises. It was not legislation designed for people with lifelong intellectual impairments and this was acknowledged by the Millan Committee and by the McManus Review, both arguing for an early review of whether learning disability should properly be included in the Act and the definition of mental disorder.

This has been addressed by the Rome review (IRMHA) which recommended that the definition should be changed and learning disability be removed from the definition and, instead, be defined as a disability under new legislation.

People First's own submission commented that it saw the Mental Health (Care and Treatment) (Scotland) Act 2003 as progressive legislation for people with mental health issues, despite the fact that it fails to deliver progressive service responses for many people for a number of reasons.

It is not, however, suitable legislation for people with intellectual impairments. Learning disability is not a medically treatable condition and, to properly benefit this population, there needs to be an accurate definition and description of intellectual impairment (learning disability) and an understanding about what responses would be useful for people with that impairment.

The vast majority of people with an intellectual impairment who are detained and/or "treated" using powers under the Act are mistreated and, we would argue, harmed by the use of those powers.

Including learning disability under the definition of mental disorder uses an outdated and inappropriate medical model of disability and wrongly leads professionals to believe that psychiatry is the correct discipline to determine treatment.

In the Summary, it is stated that a number of respondents mentioned the AWI Act and the need for reform of some kind.

The People First position (along with others) is that Capacity Law in Scotland needs to become compliant with the UNCRPD, particularly Article 12. The AWI Act as it currently stands and (from what we can gather) the proposed reforms from the AWI Review are based on continuing substitute decision-making arrangements in the form of Guardianship.

People with learning disabilities are the biggest single group affected by guardianships and by having their legal capacity removed from them in direct contradiction to the requirements of the UNCRPD.

Capacity and Support for Decision-making

While the formal Summary does mention a range of views, it leans heavily towards respondents who argue for reform of capacity assessment and retention of capacity

assessment instead of exploring how to replace capacity assessments with something else.

It also allocates many more pages to arguments about whether support for decision-making is realistic or whether it could work or not rather than looking at how it could be put together so that it could work.

It also fails to note the basic points that the UNCRPD Article 12 and General Comment 1 from the UN Committee make clear that there has to be a distinction between mental capacity and legal capacity; that support for exercise of legal capacity is required as an **alternative** to substitute decision-making rather than an addition to it; that all citizens have a right to hold and retain their legal capacity regardless of degree of mental capacity. It fails also to note that the AWI Act is based on substitute decision-making and the UN Committee has called for abolition of all substitute decision-making regimes.

The People First position (and the position of a number of organisational responses) is that a new regime of Support for decision-making and exercise of legal capacity needs to replace Guardianship and that capacity assessments should be replaced by assessments of need for support to make decisions and exercise legal capacity. While the Summary report does give brief mention of that, it is attributed to “one individual said” which is misleading since a number of responses say that.

The major problem that Scots law confuses and conflates mental and legal capacity is not addressed at all.

Training

We agree with other respondents that training is important for professionals involved with people subject to the legislation.

Our position is a little different from most, though.

Even if mental health professionals are well trained in mental health issues, it is still the wrong discipline for working with people who are intellectually impaired.

Of course, when people with intellectual impairments develop serious mental health issues, we would want those mental health professionals to understand mental health **and** intellectual impairment and be suitably trained so that they can communicate with and engage with us productively.

Appropriate treatment

This heading is at the heart of most of the submission from People First and from a number of other respondents whose consultation responses have been left out of the Summary.

Treatment for mental health issues is not appropriate treatment for someone who is intellectually impaired except only when that person also has a mental ill-health issue.

It has been acknowledged many times that people with intellectual impairments get detained and placed under compulsion and medicated when there is no mental illness present.

There is no “treatment” for intellectual impairment. It is a lifelong condition. There are ways of supporting people with intellectual impairments, but they are not the same approaches as are used for mental illnesses.

Essentially, being subject to the Mental Health Act does not deliver appropriate treatment for intellectual impairment.

We believe that appropriate support and treatment is much more likely to be delivered for this population if intellectual impairment is properly defined as an impairment and disability under separate legislation.

Children and Young People

The issues for children and young people with intellectual impairments are quite different from the issues for children and young people experiencing mental ill-health.

Rather than “transitioning from children’s services to adult services”, we think intellectually impaired children and young people need support to transition from childhood to adulthood and citizenship in a way that has been denied them up to now.

In particular, the attempt to avoid persons with intellectual impairment reaching adulthood by taking out guardianship orders and removing legal capacity before they reach the age of majority should be abolished.

Language

The Summary notes that the term “mental disorder” is not universally popular, that it is described as the language of deficit and some people find it offensive.

For people with intellectual impairment, it is also entirely inaccurate and encourages our lifelong impairment to be seen as a subset of mental illness.

We believe there is no acceptable alternative but to remove intellectual impairment from the definition of mental disorder (whatever language is finally agreed upon), to completely distinguish intellectual impairment from mental illness and to construct a new and separate piece of law to address the needs and rights of people with intellectual impairment.

Of course, language needs to be easy to understand and accessible.

Convergence of legislation

In our own submission to the phase 1 consultation, we said that convergence of mental health and capacity legislation would do nothing to address the issues we have with the law as it currently stands.

We need intellectual impairment to be removed from the Mental Health Act.

We need Capacity law to be wholly rewritten to remove substitute decision-making and guarantee the right to legal capacity regardless of degree of mental capacity and be founded upon Rights, Will and Preference being paramount with Support for decision-making and exercise of legal capacity.

We noted that Adult Support and Protection legislation was not as oppressive as the MH Act or the AWI Act and would prefer that to stand apart from the other pieces of legislation.

We are not impressed with the Northern Ireland Mental Capacity Act as a model to be copied since it is still based on the idea that an adult can be considered to be “incapable” and substitute decision-making imposed. As a device to combine mental health and capacity matters, it is far too early to see it as offering anything as an example of good practice since it is not yet even in force.

We believe that Scotland could, and should, aspire to full compliance with the UN Convention on the Rights of Disabled People which the Northern Ireland legislation is not.

Equality issues

While we do, of course, support the mention in the Summary of discrimination on the basis of sexuality and passing reference to black and minority ethnic people but we are surprised that the views presented by disabled persons organisations about disability discrimination were simply passed over.

Again, the core of People First’s submission was that people who are intellectually impaired are treated quite differently and in a discriminatory way on the grounds of our disability alone. The definition of mental disorder in the Mental Health Act, for example, includes “learning disability, however caused or manifest” which is, in itself, discriminatory.

Other issues

We are really worried when we read what reviews are saying about the UN Convention. Most of them talk about **moving towards** compliance or supporting people to make their own decisions **as far as possible** or **except when they lack capacity**.

Our worry is that these comments suggest that people making them do not properly understand the convention.

We think it is time to incorporate the UN Convention on the Rights of Disabled People into domestic law in Scotland.

Conclusion

We do understand that the Independent Review of learning disability and autism under the Mental Health Act was exclusively about the experience of those groups and it will have its recommendations considered by the Law Review.

We do accept, also, that the Scottish Mental Health Law Review has a duty to predominantly look at the experiences of those people whose experience under the law is because of mental ill-health.

Nevertheless, we do not consider that missing out anything to do with the experiences of people with learning disability under the Act from the Summary of responses is warranted or justifiable. We expect that the same could be argued on behalf of people with acquired brain injury or dementia.

In that respect, we think the Summary of consultation responses is incomplete and flawed.

We think it is important to point this out. Although we accept the reassurances given to us by John Scott that the Review will not, in further stages, exclude issues affecting people with learning disabilities, if the Summary of consultation responses at the end of Phase 1 does that, we think it will be difficult for others not to see this as the foundation for stages 2 and 3 and it is quite possible that the debate will have been narrowed down to give less attention to the arguments for reform of law to meet the needs of different groups of people affected by the law but skipped over in the Summary.