

Consultation Response

Consultation on Stage 3 of the Independent Review of Learning Disability and Autism in the Mental Health Act

1. Introduction

- 1.1. Inclusion Scotland is a national network of disabled people's organisations (DPOs) and individual disabled people. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.
- 1.2. Inclusion Scotland subscribes to the social model of disability. We understand disability to be the disadvantage or restriction of activity caused by a contemporary social organisation, which takes little or no account of people who have impairments.
- 1.3. Disabled people have defined Independent living as "all disabled people having the same freedom, choice, dignity and control as other citizens at home, work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life". This is consistent with Article 19 of the United Nations Convention of the Rights of Disabled People (UNCRPD).
- 1.4. Inclusion Scotland welcomes the Independent Review of Learning Disability and Autism in the Mental Health Act. This was set up following evidence given by Inclusion Scotland and People First (Scotland) to the Scottish Parliament's Health and Sport Committee during its consideration of the Mental Health (Scotland) Act 2015.
- 1.5. Inclusion Scotland endorses the response to Stage 3 of the Review submitted by People First (Scotland). Along with People First, Inclusion Scotland broadly supports the main findings of the Review, but has concerns regarding some of the detailed proposals.
- 1.6. As a general point, the Social Model refers to disabled people - as people are disabled by the barriers they face - and not people with disabilities, which attaches the disability to the person. Inclusion Scotland requests that the final version of the report uses "disabled people".

2. How we understand autism, learning disability and mental health

- 2.1. Inclusion Scotland agrees that autism and learning disability should be considered as disability in line with the Social Model, and not "mental disorders", which is a medical model approach. These are life-long impairments, and not treatable illnesses. However, the term "disability model" does not make sense and risks retaining the medical model approach.
- 2.2. People with autism or learning disability can have mental health issues, just as any other person, and should have the same rights to treatment for mental health as

anyone else. However, we are concerned that as currently phrased the Review is conjoining issues that should be dealt with by appropriate support to the disabled person to address barriers they are facing (social model) with treatment for the disabled person for their reactions to these barriers (medical model).

2.3. Inclusion Scotland agrees with the Review on the importance of embedding and promoting human rights across all areas of society, and that this requires a culture change from professionals and decision makers.

2.4. Inclusion Scotland welcomes the Review's recognition of the legal capacity of all autistic people and people with learning disabilities, which is in line with Article 12 of the UNCRPD. However, we are concerned that the approach of the parallel review of the Adult with Incapacities Act is not taking the same human rights based approach, and this may significantly undermine the recommendations of this review.

3. Support for Decision Making

3.1. Development of supported decision-making is essential if Scotland is to meet the requirements of Article 12 of the UNCRPD, and we welcome the Review's recognition of the importance of putting in place a framework for supported decision-making. In a General Comment on Article 12 published in April 2014, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) stated:

“State Parties have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity”¹.

This includes supported decision-making, and can include as peer support, advocacy (including peer- or self-advocacy support), or assistance with communication.

3.2. The General Comment also made clear that only “after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences” must replace the “best interests” determinations.”

3.3. In other words, even where there is a “statement of will and preferences”, professional must still make every practicable effort to ensure that the person is supported to make a decision in specific circumstances, even if this is contrary to the statement of will and preferences. We all have the right to change our mind.

3.4. Supported decision making should be based on the principles that:

- All people have a right to make own decisions
- The decision maker is in charge
- It is about assisting the decision maker to make the decision they think is best for them – including right to make mistakes
- Are measured, fair and free from undue influence
- This can include support to implement the decision

3.5. Inclusion Scotland is concerned that, despite the best intentions, Section 3 as currently worded still places too much authority in the hands of the professionals to override the will and preferences of the individual where they consider this to be justified. This is in effect a “best interest” test, which is incompatible with Article 12.

3.6. It is essential that autistic people and people with learning disabilities have access to independent advocacy and decision supporters. It should be recognised that

¹ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

“advocacy” and “decision support” are not the same thing, and the disabled person should have access to whichever service is most appropriate to meet their needs in the specific circumstances.

4. Safe and Secure Support Centres

4.1. Inclusion Scotland agrees that Scotland needs to stop using hospitals to detain autistic people and people with learning disability. One of the fundamental reasons why Inclusion Scotland called for the removal of autism and learning disabilities from the definition of “mental disorder” in the Mental Health Act is that are life-long conditions that are not “treatable”.

4.2. Autistic people and people with learning disability have the same right as anyone else to live where and with whom they want to live. Article 19 of the UNCRPD requires State Parties to recognise the equal right of all disabled to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

4.3. The UN CRPD’s General Comment on Article 12 also makes significant observations relevant to compulsory detention and compulsory treatment:

“The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention.” and

“Forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16).”

4.4. Inclusion Scotland fundamentally opposes the suggestion by the Review that Scotland is not ready to end all detention based on disability, or all compulsory treatment, in a safe way. This is wholly incompatible with Articles 12, 14, 15, 16, 17, 19 and 25 of the UNCRPD.

4.5. Whilst recognising that it will take time to develop new community based support services to replace all existing services, Inclusion Scotland demands that the Review should be unequivocal in stating that detention and compulsory treatment on basis of disability is unacceptable and must be ended as soon as practicable.

5. Human Rights Assessments

5.1. Inclusion Scotland fully supports the principle that human rights should inform decisions about support, care and treatment of all individuals, including disabled people, autistic people and people with learning disabilities. However we are concerned that the “human rights assessments” as currently envisaged by the Review are based on a negative approach to human rights – ie when it can be justified to restrict a person’s human rights – rather than a positive approach – ie what support does a person need to be able to fully exercise their human rights.

5.2. There are too many instances within the Review’s recommendations where a professional may exercise a judgement that it is justifiable to restrict the human rights of an autistic person or person with a learning disability. This is akin to a “best

interests” test, and, unless the same criteria are used for non-disabled people, discriminatory.

- 5.3. This is particularly important where deprivation of liberty is being considered. Article 14 of the UNCRPD states:
States Parties shall ensure that persons with disabilities, on an equal basis with others:
(a) Enjoy the right to liberty and security of person;
(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
- 5.4. Article 25 requires health professionals to provide care of the same quality to persons with disabilities as to others.
- 5.5. In summary, autistic people and people with learning disability should have the right to access mental health services on the same basis as any other person, and that they should not be subjected to additional restrictions.
- 5.6. Inclusion Scotland questions whether Mental Health Officers have either the capacity or the capabilities to carry out Human Rights Assessments. By definition, MHOs are specialists in mental health. This does not mean that they have the knowledge or expertise needed to make assessments for people with learning disabilities or autistic people.
- 5.7. In addition, there is a chronic shortage of MHOs. The latest Mental Welfare Commission Monitoring Report² shows that 50% of Emergency Detention Orders under the Mental Health Act were granted without the statutory Mental Health Officer consent. The MWC Report also highlights other areas where MHO reports were not being provided as required, for example Social Circumstances Reports and reminded local authorities “of their duties under legislation to designate MHO’s for each patient’s case and to appoint sufficient MHO’s for the purpose of discharging statutory functions.”
- 5.8. None of this gives confidence that MHOs would be able to provide human rights assessments in every case before any decision is taken to limit a person’s human rights.

6. Limits of Human Rights

- 6.1. Autistic people and people with learning disabilities should only be subjected to detention and treatment on the same basis as any other person, and never on the grounds of disability.
- 6.2. In relation to the criteria in 6.2 of the Review (page 83), we do not agree with the “disability model” terms “autistic disability” or “learning disability”, which we believe are medical model concepts (see 2.1 above). Similarly, the phrase “support care and treatment is available to reduce the person’s disability” attaches the disability to the person (medical model) rather than to the barriers they face (social model).
- 6.3. Inclusion Scotland welcome that the Review recognises that medical treatment cannot “cure” autistic or intellectual impairment. We also welcome the recognition that detention and restraint and seclusion are not support care or treatment. However,

² https://www.mwscot.org.uk/sites/default/files/2019-10/MHA-MonitoringReport-2019_0.pdf

there remains an underlying medicalised approach to providing the support and care that autistic people and people with learning disabilities need to live independently.

- 6.4. The recently published report from the Mental Welfare Commission on Autism and Complex Needs³ noted that of the 54 people met by the Commission, 45 were prescribed psychotropic medication [on a regular basis, with 40 of those being prescribed regular antipsychotic medication. The MWC said
- “On the use of psychotropic medication and restraint to manage behaviours, while we cannot say that in individual cases it was unjustified, we are nevertheless very concerned by the scale of its use.”⁴
- 6.5. Thirteen of the 28 people who were living in hospital were ready to leave, but were on delayed discharge, waiting for suitable accommodation.
- 6.6. If a person does not receive the services they need to support independent living in the community (which includes when living in residential care settings) then that is a breach of their rights under Article 19 of the UNCRPD, and amounts to a severe restriction on their liberty.

7. Professional Roles

- 7.1. Inclusion Scotland does not agree with the proposal to create “care managers” for autistic people and people with learning disabilities. This runs contrary to the principles of self-directed support. The aim should be to ensure that the disabled person has the support they need to determine and manage their own support and care, using the principles of supported decision-making.
- 7.2. In any event, the term “care manager” is inappropriate, as not all autistic people or people with learning disabilities will require “care”, although they may need varying levels of support.
- 7.3. We agree that there needs to be better training for all professionals on learning disability and autism. We also believe that there should be an increased role for psychologists and other professionals who are able to assist autistic people and people with learning disabilities with learning and understanding and developing behaviours and roles in society. There should be a diminishing role for mental health professionals such as psychiatrists except where the person has a mental illness.

8. Monitoring

- 8.1. Inclusion Scotland is unclear why the Mental Welfare Commission and Mental Health Tribunals would be appropriate for monitoring whether autistic people and people with learning disabilities are receiving the support they require, except in circumstances where they have mental health problems. In these circumstances, they should be subject to the same criteria as anyone else under the Mental Health Act.
- 8.2. Inclusion Scotland supports the proposal from the Review for a new Act, which will give positive rights to support to autistic people and people with learning disabilities. We believe that in addition to the National Autism Service, the Act should include the establishment of an Independent Commission of Learning Disability charged with monitoring implementation of the Act, including investigating complaints, and reporting to the Scottish Parliament on any recommendations for improvements.

³ https://www.mwscot.org.uk/sites/default/files/2019-10/ASD_ThemeVisitReport-20191030.pdf

⁴ <https://www.mwscot.org.uk/news/more-support-needed-people-autism-and-complex-needs>

9. Offenders

- 9.1. Inclusion Scotland welcomes the recognition by the Review that more needs to be done to ensure that autistic people and people with learning disabilities are treated equally and fairly within the justice system.
- 9.2. This needs to include reasonable adjustments so that autistic people and people with learning disabilities have the same rights to a fair trial and reasonable adjustments to ensure that sentencing, whether to custodial or community settings, does not treat the disabled person more harshly than a non-disabled person. This must include appropriate support to help the disabled person understand why their behaviour was inappropriate and to assist them to address their offending behaviour.
- 9.3. However, we are not convinced that the correct way to do that is to set up separate detention centres for autistic people and people with learning disabilities. Whilst an improvement on inappropriate detention in a forensic hospital setting, which can lead to people being detained indefinitely for even relatively minor offences, it does not address the fact that every autistic person or person with learning disability is different and has different support needs.
- 9.4. Inclusion Scotland recognises that prisons and the prison service may not be in a position at present to provide the reasonable adjustments that will provide the appropriate environment and support for every prisoner, we would argue that the investment should be in developing the prison service rather than establishing a stand-alone facility.

10. Conclusion

- 10.1. Inclusion Scotland welcomes the recommendations of the Review that:
- Autism and learning disability should not be defined as mental disorders in the Mental Health Act.
 - Scotland needs for a new Act for the support and care of autistic
 - Autistic and offenders with learning disabilities should receive the same disposals as anyone else would receive under criminal law.
- 10.2. However, Inclusion Scotland consider that the proposals do not go far enough to ensure compatibility with the United Nations Convention on Human Rights:
- The Social Model of disability should be used throughout rather than the “disability model”, which creates ambiguity and is too close to the “medical model”
 - Detention and compulsory treatment based on disability must end immediately.
 - Human Rights Assessments should be about ensuring the right to independent living, not about justifying where human rights can be limited.

If you have any questions on this response, or for further information, contact:

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