



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Health

**On Part 13 of the Assisted Decision-Making
(Capacity) Act 2015**

March 2018

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Ireland plain English guidelines.**



Easy to Read Summary



This submission is about Part 13 of the Assisted Decision Making Capacity Act 2015.

It is about Deprivation of Liberty Safeguards.



Deprivation of liberty is about taking away someone's freedom.

The safeguards will try to stop this from happening.



Inclusion Ireland is asking the Department of health to make some changes to the safeguards of deprivation of liberty so that they work well for people with intellectual disabilities.



It is important that the safeguards are in line and give the same messages as the UNCRPD.

The new part of the act needs to be checked so that it gives the same message as the rest of the Assisted Decision Making Act of assuming that people can make their own decisions most of the time.

The language needs to be positive.

People do not want to be seen as people that need to be protected.





In the new part of the Act it talks about a 'Relevant facility' as residential centres or institutions where people can be deprived of their liberty or have their freedom taken away.



Relevant facility should include all facilities where people are deprived of their liberty including respite or hospitals.



A right to independent advocacy is really important for people who might have their freedom taken away. That way they can get help and support if and when they need it.

People need to have this right included in the safeguards.



Living in an institution is a real way in which your freedom can be taken away.

It should say in the safeguards that many other ways of supporting someone must be tried before they have their freedom taken away.



Medication is another way where someone's freedom can be taken away.

Sometimes people can be given too much medication to keep them calm or quiet.

This is called chemical restraint.



This is not right.

In the safeguards when chemical restraint is explained, it needs to include safeguards about giving too much medication and the effect of it.



There are people who are Wards of Court and this means that the court makes their decisions for them.

They are not included in the safeguards and they should be.



These changes to the safeguards will mean they work better for everyone.

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

The introduction of Deprivation of Liberty Safeguards is an important development and Inclusion Ireland welcomes the opportunity to make a submission to the Department of Health.

The introduction of these safeguards offers, much like the rest of the Assisted Decision-Making (Capacity) Act, an opportunity to address some of the cultures, practices and attitudes that have developed towards people who may be seen as vulnerable, including those with an intellectual disability.

The introduction of safeguards in other jurisdictions has seen some positive benefits including the removal of unnecessary restrictions on liberty and reviews of care practices¹ and in many cases, these improvements may not have been achieved without legislative reform. The potential for a similar impact in Ireland is strong, with many out-dated, institutionalised practices in focus as a result of Ireland's impending ratification of the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

¹ Mental Health Alliance Briefing Paper 1 – Deprivation of Liberty Safeguards: an initial review of implementation. (2010)

Rather than follow the format laid out in the consultation document questionnaire, Inclusion Ireland has decided make the following observations.

General note on terminology & definitions

Inclusion Ireland is concerned that the overall tone of the new Part 13 is not consistent with the Assisted Decision-Making (Capacity) Act 2015.

There is no mention of the presumption of capacity and Head 3 should restate this essential principle of the Act. Similarly, there needs to be an increased onus on supporting a person to maximise his or her capacity to make an admission decision.

Inclusion Ireland further suggests that the Department of Health develops a definition of 'deprivation of liberty' rather than using the definition of 'admission decision' to establish if a deprivation of liberty is taking place or not. 'Admission decision' represents an over-medicalised definition of what should represent the provision of a spectrum of care.

In our consultations for this document of people with lived experience of disability and residential care, we received feedback that

We shouldn't be admitted anywhere, we should have freedom to leave, admitted means we are trapped or in hospital.

In other countries, even when there was a definition put in place, there has been confusion² even among professionals and case law has failed to clarify matters.

Relevant Facility

Relevant facility is defined as being a designated centre under the Health Act 2007, or an approved centre under the Mental Health Act, or an institution at which residential services are provided by the Health Service Executive, a service provider or a Section 39 service provider.

² Chris Lennard, (2014) "Deprivation of Liberty Safeguards: complexity, confusion and case law – a commentary", Social Care and Neurodisability, Vol. 5 Issue: 4, pp.245-255

It is unclear whether the safeguards will apply to respite houses, hospital stays or other forms of 'residential' supports that do not amount to 'permanent' living arrangements. Deprivation of liberty, even for a short period of time is contrary to Article 14 of the UNCRPD.

Similarly, Head 5 allows for a temporary admission decision in 'urgent circumstances'. As the majority of new admissions to institutions are considered to be 'emergency' placements, this means that most 'admissions' could be on an urgent basis and the safeguards in the Act would not apply where deprivation of liberty is on a 'temporary' basis.

'Temporary' is not defined in the Heads and a strict time limit should be put in place in relation to temporary admissions.

Requirement to consider alternative living arrangements

Inclusion Ireland is concerned that the central thrust of the proposed amendments does not recognise that there are alternatives to living arrangements which deprive persons of their liberty.

Article 19 of the UNCRPD requires States parties to recognize the equal right of all persons with disabilities to live in the community.

A recent comment by the CRPD Committee³ said that institutions promulgated "isolation and segregation from community life, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment"

The continued use of such facilities by Ireland is in violation of Article 19 and these safeguards should include a responsibility to ensure alternatives to institutional forms of living where possible.

In Part 4, an amendment should be made that;

³ Committee on the Rights of Persons with Disabilities Draft General Comment No. 5 (2017) Article 19: Living independently and being included in the community

"Subject to Head 5, no relevant person shall be admitted to a relevant facility where he or she will be under continuous supervision and control and will not be free to leave unless all alternative living arrangements have been exhausted. An admission decision is required in order to admit a person to a facility where his or her liberty may be deprived"

Advocacy

Inclusion Ireland has argued the importance of independent advocacy for many years and consider its absence from the Assisted Decision-Making Act to represent a fundamental flaw in that Act.

The role of independent advocates in supporting persons with disabilities is of fundamental importance and Inclusion Ireland strongly believes that independent advocacy can play a key role in facilitating persons to understand and to exercise choice over their decision-making rights. This is particularly the case for persons living in residential care settings.

In our consultations for this document of people with lived experience of disability and residential care, we received feedback that;

When a decision was made by a psychiatrist that I had to go to a residential service, I had to go: I had no choice. I was very unhappy, stressed and sad and depressed, it was like I was gasping to get air into me, I was smothering because I had no choice in my life. They said maybe I could move in the future but I felt like they didn't mean it, they didn't listen to me

The current National Advocacy Service (NAS) that provides a representative advocacy service to persons with disabilities is limited in reach and not resourced to adequately support all persons with disabilities. Advocates possess no statutory powers and there are long waiting lists reported with 1 advocate for every 15,000 people in the adult population who have a disability.

In general, in Ireland, the provision of advocacy is fragmented and without cohesion. 'A Programme for a Partnership Government' makes a commitment to establish an independent patient advocacy service. Instead of an independent patient advocacy service, Inclusion Ireland believes that a National Advocacy Authority should be established that

has responsibility for coordination and oversight of all forms of advocacy services.

The Assisted Decision-Making Act could usefully be amended, through this legislation to provide for the right to an independent advocate, not only where there is a deprivation of liberty but where there is a decision-making representative appointed.

Wards of Court

The exclusion of Wards of Court from the Deprivation of Liberty Safeguards is unacceptable and not compliant with the UNCRPD.

A concern raised by the National Safeguarding Committee prior to the recent ratification of the UNCRPD relates to how the principles recognising the fundamental human rights of people with disabilities in the convention “are given no recognition in the current wardship system”.

The exclusion of wards from the protections of safeguarding on the deprivation of liberty are yet another sign that the State does not provide the same level of protections to wards as to other people with disabilities.

The Committee on the Rights of Persons with Disabilities has expanded on Article 12, equal recognition before the law, stating that a person with a disability should have their legal capacity respected on an equal basis with others, including their right to liberty. The Committee described problematic scenarios where people’s legal capacity is being denied while being detained in institutions, their consent was not provided or where it was provided by a decision making representative. The Committee believes that this practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. States parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.

Current wards in Ireland could potentially have their legal capacity denied through the wardship system pending the full commencement of the Assisted Decision Making (Capacity) Act 2015, unable to challenge their liberty being deprived in institutional settings. Safeguards on deprivation of liberty encompassing wards of courts would go a long way in ensuring

that such situations do not arise and do not undermine a wards right to liberty and security of person.

Chemical Restraint

It is important that a definition of chemical restraint is being included in these proposals. Inclusion Ireland recommends that an explicit prohibition of restraint of all kinds is included.

In our consultations for this document of people with lived experience of disability and residential care, we received feedback that;

You can get addicted to tablets and then coming off them can be really hard. I was lucky with my medication, I felt in control and that is really important. Changing my tablets was suggested to me but I had a choice and I was in control.

The definition of “chemical restraint” should include reference to not only the medication being required for a “*medically identified condition*” but that the dosage is also at the required level.

Inclusion Ireland recommends that the definition of chemical restraint could be altered to:

chemical restraint means the use of medication to control or modify a person’s behaviour when no medically identified condition is being treated, or where the treatment [or the dosage] is not necessary for the medically identified condition or the intended effect of the medication is to sedate a person for convenience or disciplinary purposes or to ensure that a person is compliant or is not capable of resistance.

3. Conclusion

The introduction of deprivation of liberty safeguards represents an important move towards Ireland complying with Article 14 of the United Nations Convention on the Rights of Persons with Disabilities.

Further consultation with people with lived experience of institutions and deprivations of liberty is essential in the further development of these safeguards. Inclusion Ireland recommends that the Department produces materials in an easy-to-read format for future engagement, something that was absent from this consultation.

The exclusion of wards of court from the safeguards represents a further compounding of the inequality experienced by wards and should not proceed.

Finally, it is essential that any system addressing deprivation of liberty emphasises the importance of non-institutionalised health and social care services so as to minimise the incidences of deprivation of liberty.

Recommendations:

1. An emphasis and responsibility to exhaust non-institutionalised forms of residential care services should be included.
2. The proposed new part is reviewed for consistency with the principles and tone of the Assisted Decision-Making Act.
3. 'Relevant facility' should include all facilities where people are deprived of their liberty including respite or hospitals.
4. A right to independent advocacy should be included.
5. An explicit prohibition of restraint of all kinds should be included.
6. The chemical restraint definition should reflect the issue that over-dosing can provide.
7. Wards of court should be included in the safeguards.
8. Further, targeted consultations with people with lived experience of institutions should be conducted and easy-to-read materials should be developed.