



INDEPENDENT LIVING
MOVEMENT IRELAND
FREEDOM • RIGHTS • EMPOWERMENT

www.ilmie.ie

**(Image shows ILMI logo with Text: Independent Living Movement Ireland.
Freedom, rights, empowerment and website address www.ilmie.ie)**

Independent Living Movement Ireland submission on the Assisted Decision-Making (Capacity) (Amendment) Bill 2021

21st January 2022

Introduction to Independent Living Movement Ireland

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. ILMI works with disabled people on a cross-impairment basis. Central to the way we work is to ensure that policy and legislative discourse and decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected.

Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

ILMI Observations on the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Draft General Scheme and Heads of Bill

Given the importance of the Bill and the scale of the legislation to be reviewed (174 pages) and that the consultation period encompasses the year end, the timeframe places undue burden on Disabled Persons Organisations (DPOs) to organise participative spaces to fully review the legislation.

The Initial State Report to the UNCRPD notes that the Assisted Decision-Making Capacity (ADMC) Bill will provide “for the presumption of capacity and the protection and promotion of a person’s will and preferences”. This is absent from the heads of Bill. In order that the ADMC Bill meets Ireland’s commitments under the UNCRPD (specifically Article 12 “Equal recognition before the law” and Article 14 “Liberty and security of the person”), there needs to be specific reference in the ADMC about the aim of legislation to ensure the autonomy of disabled people to live the lives of their choosing.

The heads of the ADMC bill solely reference the UNCRPD and are in relation to the role of IHREC as a monitoring body in relation to reasonable accommodation. The heads of bill need to reference the UNCRPD articles in relation to Equal Recognition before the Law and Liberty and security of the person.

The UNCRPD at its very core is informed by a social model of disability. The current ADMC Bill lacks any references to social model language and the need for this legislation to give expression to the rights of disabled people to be supported to reach decisions about their lives to live as equals.

Specific reference needs to be made to the role of ADMC to ensure the autonomy of all disabled people is upheld including those who require supports to make and communicate their decisions to live the lives of their choosing equal to others. This includes those in all institutions and inappropriate settings who may need specific supports at specific points in their lives.

In relation to additional supports that some disabled people may need in order to access the Decision Support Service (DSS) under the ADMC, the bill needs to recognise that many disabled people have multiple impairments.

The ADMC Bill needs to recognise the intersection of impairment label, gender, gender identity, sexual identity, socioeconomic status, family status, ethnicity and age.

The ADMC needs to recognise the need for other supports in order that disabled people can access ADMC, such as Irish Sign Language (ISL), independent living supports such as Personal Assistance Services (PAS), peer advocates and spaces free from people who potentially may have conflicting interests, including family members and service providers.

The ADMC needs to specifically recognise legally binding advanced healthcare directives for disabled people to define what supports they would like to access or not access where they experience emotional distress. This must include specific reference to the ADMC supporting disabled people to reach decisions to refuse “treatments” recommended by medical professionals. There is an absence in the ADMC on the need to recognise the right of disabled people to refuse the administration of “treatments” against people’s expressed wishes which contravene Articles 14 and 15 of the CPRD in terms of the use of restraints, denial of liberty and use of ECT. Currently once a psychiatrist determines someone lacks capacity to consent such ‘treatments’ against someone’s will, these ‘treatments’ are deemed lawful under the Mental Health Act 2001.

There is an absence of reference to what decisions the ADMC will support disabled people to reach decisions on. Explicit reference need to be made to advanced care directives, choice of where and with whom to live and the full expression of human experiences, including the right to relationships under Article 23 of the UNCRPD.

In many instances, family are supportive of the right of disabled people to full, independent autonomous lives and welcome the role of DSS under the ADMC Bill. However, there are many instances where the will and choice of disabled people will be contrary to the views of family, and this needs to be named. Under the ADMC where there is any proposed fee to register with the DSS it needs to recognise that disabled people face additional cost as highlighted in the cost of disability research. Therefore, any cost to register should be minimal so disabled people do not face another additional barrier to exercising their rights.