

The Joint Committee on Children, Equality, Disability, Integration and Youth (CDEIY): 3pm Tuesday 15th February 2022 - Peter Kearns, Cross Border IT & Social Inclusion Project Coordinator for Independent Living Movement Ireland, opening statement:

Cathaoirleach and members of the Committee, the Independent Living Movement Ireland (ILMI) very much appreciates the opportunity to contribute this spring afternoon.

Unfortunately, I would like to begin by stating that given the importance of the Bill, and the scale of the legislation, the timeframe placed on responding by January placed undue burden on Disabled Persons Organisations (DPOs) to organise participative spaces to fully review the legislation.

Following ILMI's creation of on-line collective spaces to enable responses by disabled people, this presentation is communicating the essence of ILMI's submitted January 2022 observations on the Assisted Decision-Making (Capacity) (Amendment) Bill 2021: Draft General Scheme and Heads of Bill.

Introduction to ILMI

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 for and with disabled people. ILMI works with disabled people on a cross impairment basis from a social model and Disability Equality framework.

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), at its very core, is informed by a social model of disability. Yet, ILMI feels the current ADMC Bill lacks any effective references to social model language and values. We also feel the need for this legislation to support Disability Equality related expression to the rights of disabled people to be supported to reach decisions about their lifestyle choices. 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 communicate their decisions to live the lives of their choosing equal and equitable to other citizens.

ILMI appreciates that the Bill includes a number of necessary amendments to enable full commencement of the ADMC Act. Yet, ILMI feels there are some issues that must be addressed to uphold disabled people's human rights and ensure the spirit of conformity related to the capacity building potential that is the UN CRPD.

In terms of making real the human rights spirit of the UN CRPD, I would like to share one personal reflection on the important recognition of ADMC's promotion of 'will and preference' and my lived experience over the previous six decades as a disabled person, disabled activist and Disability Equality worker and lecturer.

My Disability Equality informed 'will and preference' practice has often come into direct conflict a medical model system of ideas including the phrases 'in my best interests' and disability and

health sector system use of ideas of 'duty-of-care'. The ADMC needs to recognise the need for other 'will and preference' supports in order that disabled people can effectively access ADMC. Such supports include Irish Sign Language (ISL), independent living Personal Assistance Services (PAS), peer advocates and collective disabled person led spaces free from non-disabled people who potentially may have conflicting interests, including family members and service providers.

As a 15 year old in the late 1970s Coolock, with the health system directed impairment-label of *Cerebral palsy* (CP) I really could have benefited from collective spaces of disabled young people. I had believed that I had eventually managed to escape the special-school system of the 1960s and delight in the working-class cauldron that was Dublin's Ballymun Comprehensive. I thought I had 'made-it'; I had become 'normal'. But my working class fantastic parents were summoned by the Sandymount special-school I thought I had left behind at 12-years old.

My parents had to enter a clinical space, with 'normal' me in-tow, to meet a Head psychiatrist, a very *nice* middle-class professional who was concerned about my 'best-interest'. In relation to this social model Intersectional aspect of my story, ILMI suggests that the ADMC Bill needs to recognise the intersection of impairment label, gender, gender identity, class, sexual identity, socioeconomic status, family status, ethnicity and age.

From her clinically communicated 'expertise' position, the well respected psychiatrist used the language of 'best interest' to inform

my parents that science had found a cosmetic cure for my 'CP' spasms with a new drug called Valium. In my 'best-interest', I was to be prescribed the new drug immediately. My parents were uncomfortable with such a move, but later told me they felt helpless up against the 'expertise' professional narrative of the doctor and state backed 'duty-of-care' health system.

As an unruly teenager, I fought against this imposition on my body independence and autonomy. The psychiatrist suggested that my mother hide the addictive daily Valium pills in my morning sugary porridge and evening mashed potatoes. For weeks I dodged those culinary traps until my parents said "Feck-it, Peter knows something we don't". And I did, even at 15-years old - I had seen other teenagers with the label 'CP' becoming quite quickly addicted to Valium and spiralling into depression and lethargic behaviour. Some of those teens ended-up back in their special-schools and day-workshops - a few took their own lives. It is interesting that as a national representative cross-impairment DPO, ILMI is seriously looking for the age related role of the Amended ADMC Act to proceed to young disabled people challenging the current Act's 18-year of age barrier to enabling young disabled people to access the benefits of its progressive law and legislation.

Without the extra disabling barrier of prescribed drug addiction I went on to make many young adult mistakes which were definitely not reflective of my 'best-interest'. I slept rough on Belgium beaches and Spanish railway stations on all my 1980s Inter-rail summers. I then dropped out of college as the first DCU/NIHE disabled student 'role-model' computer programmer to work in an

Amsterdam anarchists theatre. I eventually returned to mid 80s recession soaked Dublin as a mature student and enjoyed every moment of my four years at Trinity College doing an English Lit. Degree. A career choice that was not in my 'best-interest' and that would not get me a 'job-for-life'.

With this eclectic lived experience in-mind, there is an absence of reference to what choices the ADMC will support disabled people to reach decisions on, even if those decisions go in the face of 'expert' conceptions of *best-interest*. Explicit reference needs to be made to advanced healthcare directives and choice over our full expression of human experiences, including the right to choose our own 'not-in-our-best-interest' relationships under Article-23 of the UNCRPD.

Before we 21st Century 'cancel' that 1970s nice middle-class 'expert' psychiatrist, whose *best-interest* treatment I plainly chose to ignore, let us remember that currently once a psychiatrist determines someone lacks capacity to consent to particular impairment label 'treatments' against someone's will, these 'treatments' are deemed lawful under the Mental Health Act 2001.

As a Disabled Persons Organisation, ILMI recognises there is an absence in the ADMC on the need to recognise the right of disabled people to refuse the administration of "treatments". Current ADMC text has the potential to contravene Articles 14 and 15 of the UN CPRD in terms of the use of restraints, denial of liberty, body autonomy and use of ECT. As the ADMC currently is written in terms of undermining the spirit of autonomous will and

preference regarding' treatments', my Valium dodging 15-year old self could be experiencing another social policy legislative oppressing barriers today.

As with my own fantastic Coolock parents, in many instances, families are supportive of the right of disabled people to full, independent and autonomous lives and would welcome the role of Decision Support Service (DSS) under the Bill. However, there are many instances where the 'will and choice' will be contrary to family and guardians throughout the Lifecourse of a disabled person. ILMI feel this needs to be named in keeping with the UNCRPD spirit of will and preference for and with disabled people.

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.

Under the ADMC, where there is any proposed fee to register with the DSS, the Bill needs to recognise that disabled people face additional cost as highlighted in the cost of disability research. A December 2021 report by the Dept. of Social Protection showed that disabled people incur €9,000 to €12,000 extra a year on top of everyday expenses. Bearing in mind disabled people in Ireland are four times less likely to be employed than their non-disabled peer any cost to register should be minimal so disabled people do not face another additional barrier to exercising their rights.

Although ILMI is only embraced the role of a national DPO since 2018 we appreciate that The Assisted Decision – Making (Capacity) Act 2015 was created to encourage Ireland to ratify the UNCRPD - which eventually came to pass in 2018. ILMI is all about using its collective mandated 100% disabled activists voice to support a need to make direct reference to the UNCRPD in the Guiding Principles of the Act.

As someone who worked with the DPOs and NGOs in New York at the United Nations building writing-up the effective participation Articles of the Convention in the early Noughties, I feel that ILMI and others here today are right to ask that a direct referencing of UNCRPD in the Bill is compatible with the human rights obligations in the 2018 ratified Convention.

ILMI feels It would also signal Ireland's commitment to a disability equality and human rights led interpretation to also further strengthen the ADMC Act. 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. ILMI suggest that 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.

ILMI and the Realisation of ADMC

ILMI's January 2022 submission identifies 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 healthcare directives, choice of where and with whom to live and the full expression of human experiences under the relevant Articles of the UNCRPD.

As ILMI is a campaigning, national representative cross-impairment DPO, we view the Act as central to the way we work in ensuring that policy decisions that impact on the lives of disabled people must be informed by disabled people through our representative DPOs. ILMI further recommends that DPOs are consulted by the Director of the Decision Support Service to develop codes of practice and guidance on interpretation and application of the Act through. Such a consultation framework with DPOs should be recognised towards meaningful participation of all those who are likely to be impacted. This could also entail possible practice roles for the Decision Support Service to develop the following additional guidance on the operation of the Act with DPOs to enable:

- Disability Equality Training for relevant persons, donors, directive-makers;
- Disability Equality Training for family members and guardians;
- Disability Equality Training with young people towards creating a support arrangement once they turn 18 years of age.

As a national Disabled Persons Org. (DPO) ILMI's collective spaces with its members and associated supporters constantly promotes such core provisions of the 2015 ADM Act of free and resourced effective decision support arrangements. ILMI feels that

a Disability Equality Technically led support should include who supports a person and how they support them, and how these eventual arrangements should be based on person's will and preferences.

Concluding Reflections on Role of ADMC

ILMI's philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Will and preference led independent living choices are relevant to all our lifestages throughout our Irish citizenship lifecourse.

Effective independent living is not just about living in a house or accessing the Dublin to Sligo 5.17pm train without phoning 24-hours ahead. It is about all the pieces of the Independent Living jigsaw fitting together directed by the lived experiences of disabled people. A jigsaw of many inter-connecting pieces of our lifecourse choices, our control, our dignity and autonomy. A complete colourful jigsaw must have a space for will and preference, alongside the adequate supports to have autonomy led life affirming 'messy-pieces' of our choosing.

I would like to take this opportunity to thank all members of the Joint Committee on Children, Equality, Disability, Integration and Youth this spring afternoon for listening and I look forward to your questions or comments.