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(Image: shows ILMI logo with Text: Independent Living Movement Ireland. Freedom, rights, empowerment and website address <a href="https://www.ilmi.ie">www.ilmi.ie</a>)

# Independent Living Movement Ireland submission to the Inter-Departmental Committee: Referendums on Family, Care and Equality

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### **Introduction to Independent Living Movement Ireland**

Independent Living Movement Ireland (ILMI) is a campaigning, national cross-impairment Disabled Person's Organisation (DPO) that promotes social justice, human rights and equality for all disabled people. We endeavour to build a truly inclusive society. Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people have to be directly informed 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.

### Social model of disability

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) at its core is framed through an understanding of disability known as the social

model of disability. From ILMI's perspective, it is vital that there is a clear and full understanding of what the social model of disability is and how it should inform future discussions on policy development and improvement and policy implementation.

The social model looks at how society is structured and how it disables people. It is not based on a person's impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of ILMI.

# Language and representation of disabled people

ILMI recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this review has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term <u>disabled people</u> has been used throughout this review in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, people experiencing emotional distress and physical and sensory impairments.

#### **Executive summary**

ILMI submission to the inter-Departmental Committee in relation to the Citizens Assembly Constitutional Recommendations focuses on the need for any proposed constitutional changes to be reflective of the State's obligations to meet the needs of disabled people under the United Nations Rights of Persons with Disabilities (UNCRPD). Creating a constitutional conversation on equality and inclusion should be met with not only reforming outmoded language on family status and gender, but by progressively realising the rights of all people, including disabled people. It is about recognising the intersection between impairment and other identities and ensuring the rights of all are enshrined in constitutional change.

# Constitutional reform and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Ireland has ratified the UNCRPD with legally binding obligations to "undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability" (Article 4, UNCRPD).

According to Article 1: the purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." It acknowledges that all disabled persons are rights holders and that impairment cannot be used as a justification for denial or restrictions of human rights. It identifies and recognises disability as a social construct which is caused when impairment interacts with societal barriers. It is a significant, but ethically constructive and modern, paradigm shift from the medical/charity perspective to the social model of disability.

The UNCRPD makes specific references to state party commitments to ensure disabled people are effectively involved in all policy forums. Article 4.3 states:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations. (UNCRPD, Article 4)

## Furthermore, the CRPD notes that:

Organisations of persons with disabilities should be distinguished from organisations "for" persons with disabilities, which provide services and / or

advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests in which such organisations prioritise their purpose as private entities over the rights of persons with disabilities. States parties should give particular importance to the views of persons with disabilities, through their representative organisations, support the capacity and empowerment of such organisations and ensure that priority is given to ascertaining their views in decision-making processes.

(UNCRPD, General Comment 7.13)

Article 29. B outlines actively promoting an environment in which disabled people can "effectively and fully participate" in public affairs, without discrimination and on an equal basis with others. Article 29 B also states participation of disabled people in non-governmental organisations and associations concerned with public and political life. Most notably, article 29 B states disabled people should be involved in "forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels". For far too long disabled people have been excluded from participation in decision making structures at all levels.

"Nothing about us without us" succinctly describes the role of Disabled Persons' Organisations (DPOs). DPOS, unlike disability services providers, are led by and for disabled people. It is vitally important that this is understood to ensure that disabled people have their contributions heard, represented and recognised in policy development.

Article 12 of the UNCRPD focusses on equal recognition in judicial terms and specifies that disabled people are equal before the law and have the right to recognition everywhere as persons before the law. It states that disabled people should enjoy legal capacity on an equal basis. The state should take appropriate measures to provide access by disabled people to the support they may require in exercising their legal capacity and that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Moreover, Article 12 also outlines

that the state shall take all appropriate and effective measures to ensure the equal right of disabled people to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.

In Article 19, which centres on Independent Living, the convention outlines that disabled people have the right to live in, be part of, and use services and amenities in their communities. They should choose where and with whom they live with appropriate and adequate supports. While Article 23, Respect for the Home and Family, recognises that disabled people have the same rights as others to parenting, relationships and family planning.

ILMI responses to the Citizens Assembly Constitutional Recommendations

Article 40.1 of the Constitution should be amended to refer explicitly to gender equality and non-discrimination.

ILMI welcomes suggestions to amend Article 40.1, which as exists, can be read to have outdated concepts relating to "physical and moral capacity" which can and have been used to limit the rights of disabled people.

The proposed wording of the Citizens assembly is limited and misses an opportunity to explicitly embed equality and inclusion principles within our constitution. ILMI stresses the need for the Inter-Departmental Committee on Referendums to include equality and anti-discrimination in proposed constitutional amendments, such as was in the Interim Report (option 2):

"All persons shall be held equal before the law without discrimination on any ground such as gender, race, colour, national, ethnic or social origin, association with a national minority, sexual orientation, language, religion or belief, political or any other opinion, property, birth, disability, age, or other status".

To include equality and anti-discrimination within the Constitution, including disability, would meet obligations under the UNCRPD, namely Article 1, Article 5 and Article 12.

Article 41 of the Constitution should be amended so that it would protect private and family life, with the protection afforded to the family not limited to the marital family.

ILMI welcomes proposals to remove specific references to marriage and family and to recognise all family types. ILMI would like a reference to a right to family to be included, in light of Article 23 of the UNCRPD which is concerned with respect for home and the family, including the right of disabled persons to found a family.

Intending disabled parents often meet significant resistance from the Statutory and non-Statutory bodies in terms of preference of choice in relation to sexual expression, bodily autonomy, the right to marry (or not) and to have a family (or not). Historically in Ireland, disabled people are considered asexual, or our sexual desires were considered problems to be 'managed'.

A constitutional right that asserts a right to family would meet State obligations on the rights of disabled people under article 23 of the UNCRPD.

Article 41.2 of the Constitution should be deleted and replaced with language that is not gender specific and obliges the State to take reasonable measures to support care within the home and wider community.

The Inter-Departmental Committee needs to engage with DPOs before wording Article 41.2. Due to the medical/charity model of disability and how it has framed policy and practice in relation to the denial of disabled people's rights, "care" is a highly emotive term for disabled people. Due to this medical approach, disabled people have and are still considered passive recipients of "care". The term "care" for many disabled people is one which reflects an imbalance of power. It reflects lack of choice or control over their lives. Generations of disabled people have been "cared for" by medical professionals who have sought to "fix" or "cure" us. Generations of disabled people have been "cared for" by being trapped in our family homes, with no

expectations that we would have lives of our own. Many of us were "cared for" by being incarcerated in institutions and facilities, where we were denied our rights.

ILMI recognises that for most non-disabled people, the term "care" is one of love and a reciprocal relationship. The Inter-Departmental Committee needs to ensure that a constitutional referendum does not inadvertently include language that polarises disabled people and further alienates disabled people from the core document that should enshrine our rights. The Inter-Departmental Committee needs to ensure that a referendum is consistent with Article 19 of the UNCRPD and the measures that many disabled people need to participate in society as equals, inside and outside of our homes.

ILMI's preference and advice is that Article 41.2 of the Constitution should be deleted and replaced with language that is not gender specific and obliges the State to take reasonable measures to support people to live full lives within the home and wider community, without references to "care".