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Disabled People and the Dying with Dignity Bill: Prioritising the right to die, over rights to live

“We are not Pawns, we need to be listened to and heard in this discussion”.

Independent Living Movement Ireland submission in relation to Dying with Dignity Bill

January 2021

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. 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.

Disabled people have become aware of the dangers associated with the state and international call for assisted suicide to be legalised. As a Disabled Person’s Organisation (DPO), ILMI facilitated discussions on-line for disabled people to openly discuss the proposed Dying with Dignity Bill. Our intention was to create a safe space to capture the diversity of views that disabled people had on the Bill and to

bring this as a submission to legislators at the Joint Oireachtas Committee on Justice and Equality who will receive submissions at Committee Stage of the proposed Bill.

The ILMI discussion forums identified the argument that distinction between disability and terminal illness is a myth and subsequent definitions of 'terminal illness' can never be precise. The proposed legislation has the potential to place disabled people back into a medical model narrative, as it is fundamentally about protecting the medical profession's involvement with assisted suicide and not about lived experience choices. All those involved in ILMI on-line discussions are disabled people, on a cross-impairment basis (including people with physical and sensory impairments, learning difficulties, and people experiencing emotional distress or other mental health conditions). Terminal illness and disability are not mutually exclusive. Many people who are terminally ill are disabled people but not all disabled people are terminally ill.

“Nothing About Us Without Us”

The core message was that **disabled people do not want to be used as pawns for either side of the debate**. No politician can or should claim to speak for disabled people. Too often in discussions like this, disabled people's lives are used as a "political football". It is vital our voices are heard in any discussion about this Bill.

'Choice' is central to the philosophy of Independent Living. It should be about disabled people having control over all aspects in their lives and appropriate supports and resources in order to achieve our life goals. Choice should not just happen at moments of crisis or imminent death. It is the lack of choice, control and agency throughout our lifecourse that is the underlying reason why society is so inaccessible to disabled people and excludes and isolates us systematically.

Resourcing disabled people to live their lives full of Dignity

Many disabled people are hugely concerned that discussions about "Dying with Dignity" will inevitably lead to discussions about assisted suicide. In other jurisdictions where assisted suicide has been legislated for, disabled people frequently speak about feeling hopeless, "having nothing to live for" or feeling they would be "better off dead". Opposition to assisted suicide legislation protection is not

just confined to the medical profession and religious groups. Most importantly, it includes the very people that would be most affected by any change in legislation - disabled people and their lived experience costs and values.

Disabled people believe that the primary discussion should be about **the fundamental right to live a life of dignity**, not the rushing of a bill that has not effectively engaged with the voices and concerns of disabled citizens. That means supporting and resourcing life for everyone and ensuring people with impairments get the supports they require so they can live the full lives of their choosing and not have their life options limited by society. We are at an important point as a society, where disabled people are lobbying politicians to bring about a right to a Personal Assistance Service (PAS) and it would sadden (and incense) disabled people if the right to die was granted over the right to live.

Disabled people who have the supports they require to live full, independent lives with choice and control are then “freed” from lives lacking agency or hope, they can and do live lives full of value. Many disabled people in other “right to die” discussions use narratives of not wanting to be a “burden” and often talk about the impact the lack of supports to live the lives of their choosing has on them. Disabled people believe that the priority right now is not a one of legal standing to assist suicide, but a requirement to ensure the supports for dignity in living and for a right to live independent lives is legislated for a priority given Ireland’s obligations under the UNCRPD.

The discussion around this Bill should be about the quality of life supports. It should not be about people feeling that they must end their lives because of a lack of supports and services

Many disabled people are against the Bill as it could become a “slippery slope” moving from dying with dignity to assisted suicide, where the conversation changes from people who are terminally ill to people choosing to end their lives, which in other jurisdictions has often focused on people with impairments, who without the supports to live a free full life feel that their lives are not worth living. There are fears which are

real and justified by very recent history. We live in a society that is obsessed by “productivity”.

The Bill gives medical authority which could be used to judge “quality of life”. The Bill is very much enshrined in a medical discussion of impairment as opposed to a more rights-based social model of disability. It is only eighty years ago that across Europe people who were viewed as “unfit” or a “burden” in society were murdered in their thousands. Many disabled people were concerned about the language and name of the Bill. There are huge concerns about assisted dying, for example who would decide and how, including the capacity of people making choices about their lives. If the discussion moves from people who are terminally ill towards discussions about “quality of life”, then who decides what quality of life is? In other jurisdictions, conversations about assisted suicide have led to societal discussions about “quality of life” which have impacted on disabled people.

The social model of disability must inform any discussions about how disabled people are included in Irish society.

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 about what barriers 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. As a campaigning, national representative organisation that promotes the philosophy of independent living we are working to build an 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 influenced by those whose lives are directly affected.

ILMI’s work is to develop policies and campaigns based on disabled people’s lived experiences in order to remove barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives. Barriers are not just physical.

Attitudes found in society, based on prejudice or stereotypes (also called disablism), also disable people from having equal opportunities to be part of society. Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

The social model of disability informs key International Conventions such as the UN Convention of the Rights of Persons with Disabilities (UNCRPD) and is in contrast to the “medical / charity model” of disability.

The medical / charity model individualises disability and promotes the idea that people are disabled by their impairments or differences. The medical model always focuses on people’s impairments from a medical perspective. In some ways it still looks at what is ‘wrong’ with the person and not what the person requires. It creates low expectations and leads to people losing independence, choice and control in their own lives. The medical / charity model never recognises the rights of disabled people and assumes that disabled people need to be “looked after” or “cared for”. The medical / charity model has professionals make decisions for disabled people. People informed by the medical / charity model, being focused on disabled people’s impairments, use the term “people with disabilities”.

The Dying with Dignity Bill reinforces medical views of disability

The medical view of disability and naming of specific impairments within the bill is of huge concern to disabled people. Many disabled feel that an attempt to provide a definitive medical definition of “terminal illness” is problematic as it can never be precise. Identifying impairments in the Dying with Dignity Bill could lead to people with certain impairments viewing their lives as worth living or not. What Ireland requires is a conversation about the effective and sustainable life affirmation supports for and with disabled people: proper, practical, emotional and medical support is required to live dignified lives.

For many, there was a feeling of unease with the timing of this bill, given the silent narrative going around during this pandemic, where many disabled people were

nervous about whether they will receive equal care and treatment for COVID-19 if the health services become overwhelmed.

Resourcing end of life supports for everyone

Any discussion about dying with dignity must clearly identify what is the most efficient and equitable instrument and platform for such discourse. ILMI questions whether a bill focussed on legal protection of the 'actors' of assisted suicide is the most effective instrument to facilitate the discourse around Dying with Dignity. Dying with Dignity is a health policy platform and so, the legislation suggested is not the appropriate mechanism to effectively deal with the discourse nuances of what should be a rolling health policy dialogue led process. Dying with Dignity is a health policy instrument facilitating the state and community resourcing for a high-quality palliative care system, which is respectful and supportive of people at the end of their lives and recognises the role of families and support groups.

The role that hospices play is vital in Irish society, yet they have to fundraise continuously, which in itself undermines the affirmation of Irish citizens dying with dignity, instead they die within a charity model narrative. End of life support and choice of care requires to be recognised as a vital part of our health care system and resourced accordingly. Many countries have advanced health care directives, which need be addressed in any full Health policy discussion about death and dignity.

Disabled people and the right to choose

Some disabled people strongly felt that dying with dignity was an expression of choice and equality and being in control of the fundamental aspects of their lives. Many people have seen people in the end of terminal diseases wracked with pain, and felt that this was something that they do not wish to see again. It also could be seen as the "final" human right for people who wish to leave the world at their choosing, free from pain.

In terms of how the Bill is worded, many people had specific questions. There are three pieces of legislation referenced in the Bill but no specific reference to the Assisted Decision-Making Capacity Act, which must be rectified. The Bill also references the Minister for Justice and Equality, which are now two separate

departments and Ministerial roles. There is a reference to the island of Ireland and there was a question in terms legal jurisdiction, or whether the Good Friday Agreement assumes equivalence of rights for this Bill.

The idea that disabled people, including those who do not have long to live, are “better off dead” is not new. Many activists involved in ILMI's recent on-line discussions believe that some individual disabled people's suicidal cries for help come from a lack of proper practical, emotional and medical support essential for living dignified lives, rather than from the ‘suffering’ they experience as a result of a medical condition. Such loss of hope – which forces some to see death as their only option – is easily misinterpreted in a society that continues to see and treat disabled people as second-class citizens. ILMI's collective on-line discussion spaces have shown how activists have a supporting role that can facilitate individual isolated disabled people to be mentored by their peers to explore choices beyond just a blunt assisted suicide process. Individuals risk being easily exploited by the ‘right-to-die’ movement or, worse, by family, friends and health care professionals. Their attitude is not compassionate – it is **prejudiced and disablist**. We question legislative processes that are just focussed on singling out citizens for legalised assisted suicide based on a narrative led by a medical condition or prognosis.