

16th January 2024

Opening Statement to the Joint Committee on Assisted Dying

Independent Living Movement Ireland

We would like to thank the Joint Committee on Assisted Dying, for the opportunity to bring the voice of disabled people through our authentic collective DPOs to discussions about legislating for Assisted Dying.

As a Disabled Person's Organisation (DPO), we have created spaces for disabled people to talk about the proposed Dying with Dignity Bill to create safe spaces to capture the diversity of views that disabled people had on proposed legislation.

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 assisted dying legislation.

'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.

In November 2019, ILMI worked with Thomas Pringle TD to introduce a Private Members Bill to discuss the right to a Personal Assistance Service (PAS). It is telling that due to Dáil Standing Order 179 Deputy Pringle was unable to bring a PMB for debate in the Oireachtas. A motion passed on the 19th November 2019 in lieu of a PMB being introduced called “to ensure that any new legislation or Government policy on independent living conveys the right to access a personal assistance service in this country so that disabled people have choice, control and freedom to participate in society as equals”.

ILMI feels that the choice of the Oireachtas to resource a Committee to prioritise speaking about assisting people to die as opposed to an Oireachtas Committee developing systems that would allow disabled people to live in dignity is a worrying Development.



Many disabled people are hugely concerned that discussions about “Assisted Dying” 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” and take the State’s only clear support ‘option’ to cross the Rubicon to ‘clinical assisted suicide’.

Disabled people feel that the primary discussion needed right now is discussion about the fundamental right to have an effective ‘choice’; to live a life of dignity. That means supporting and resourcing life for everyone and ensuring people with impairments get the lifecourse supports they need so they can live 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 disabled people if the right to die was granted over the right to live a lifecourse of dignity. Disabled people who have the supports they need to live full, independent lives with choice and control are then “freed” from lives lacking agency or hope or burden, 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” are often talking about the impact the lack of supports to live the lives



of their choosing. Disabled people feel the priority right now needs to be ensuring the supports needed for a right to live independent lives is legislated for first over a priority option of assisted suicide as part of a constructed health policy informed by perceived narratives of lifecourse limiting impairment labels or ‘conditions’.

Before there is any discussion around possible health policy and legislation options enabling assisted suicide, there first needs to be discourse with disabled people through our mandated DPOs regarding the UN Convention of the Rights of People with Disabilities (UNCRPD) obligations ratified by the Irish State in 2018 about the quality of our life supports. A future health policy option of facilitating the systematic roll out of assisted suicide should not be about people feeling that they must end their lives because lack of supports and services. Real UN CRPD choice throughout a disabled persons’ lifecourse is very much not about a systematic health policy option of assisted suicide which can clearly imply that someone who has an impairment, including an acquired impairment, not being able to experience a full life at every life stage. Many ILMI members feel that this will include the fear that a State facilitated systematic option throughout one’s life stages of “assisted suicide” could lead to disabled people making choices where through lack of supports, they begin to view themselves as a “burden” on Families, the State and Irish Society.



Many disabled people are opposed to Assisted Suicide/ Dying legislation as it could become a “slippery slope” moving from the subjective undefined phrase of ‘dying with dignity’ to assisted suicide. This is where the subjective narrative of undefinable dying with dignity morphs into societal discourse where the conversation changes from people who are terminally ill to people choosing to end their lives due to perceived labelling, which in other jurisdictions has often focused on people with impairment labels, 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 on very recent history. We live in a society that is obsessed by “productivity”, even our national development plans have used the phrase ‘productive-units’ over people as citizens.

In other jurisdictions, health policy systematically supplied assisted suicide often gives medical authority to judge “quality of life” or the subjective phrase of ‘Life limiting condition’. Societal discourses about assisted living discussions in other jurisdictions are often enshrined in a medical model ‘problem’ discussion of the term ‘disability’. Such mainly non-disabled discourses show clear evidence of being impairment label led perceived general societal ideas and feelings of fear of becoming ‘disabled’ as opposed to a more rights-based social model of disability championed by the UN Convention and Irish and international disabled activists. It is only eighty years ago that across Europe people who were viewed as



“unfit” or a “burden” in society were murdered in their hundreds of thousands.

Many disabled have huge concerns about assisted dying, especially about who would decide a person has a ‘Life limiting condition’ or be on the spectrum of ‘dying’ of a terminal illness. Disabled activists and academics involved with ILMI and other national and local DPOs are concerned how the ‘system’ will cope with subjective ‘dying’ decisions, including the capacity of people, especially those with newly acquired impairment labels and ‘terminal’ diagnoses, are facilitated by Health and Care policies, family and the strong pro ‘dying with dignity’ discourse throughout Irish Society when making ‘problem’ led 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? In other jurisdictions, conversations about assisted suicide have led to societal discussions about “quality of life” and have enabled comments to go public such as ‘If I was you I’d kill myself’, all of which have impacted on disabled people.

The Social Model of Disability and the practical aspirations of the UN CRPD need to 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 isn’t based on a person’s impairment and they and Society perceiving the

lifecourse as a ‘problem’ to fix, it is about what 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.

When disabling 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 of the personal tragedy of perceived impairment life stages did not explain their personal experience of disability or help to develop more inclusive ways of celebrating living throughout one’s lifecourse.

The social model of disability informs key International Conventions such as the UN Convention of the Rights of People 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 needs. 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.

ILMI have concerns that assisted dying legislation in other jurisdictions reinforces the medical view of disability, including naming of specific so-called 'Life limiting' impairments within legislation 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 legislation could lead to people with certain impairments viewing their lives as worth living or not. What Ireland needs is a conversation about the needs of disabled people: proper practical, emotional and medical support needed to live dignified lives.

In other jurisdictions during Covid-19, the lives of disabled people were not valued or treated equally in terms of protection and care.



Disabled people were told that their lives were not worth saving. Whilst disabled people in Ireland did not face such discrimination, we need to be mindful of any discourse in relation to assisted dying that can trigger commentary with eugenic overtones about who is “worthy” of supports to live.

Any discussion about dying with dignity needs to look at the resourcing for a high-quality palliative care system, which is respectful and supportive of people at the end of their lives, which recognises the role of families. The role that hospices play is vital in Irish society, yet they have to fundraise continuously. End of life care needs to be recognised as a vital part of our health care system and resourced accordingly. Many countries have advanced health care directives, which need to be addressed in any full discussion about death and dignity.

Some disabled people do feel strongly felt that assisted dying is a natural 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.