



Committee on Assisted Dying
Opening Statement, John Dolan,
Disability Federation of Ireland, CEO

Issued 11 January 2024 for Committee Session being held on the 16 January

Cathaoirleach and committee members,

I wish to thank the committee for this opportunity to contribute to your work. In preparing for this hearing, I have paid particular attention to the Order of Reference at (2), (a), (b), (c) and (d), namely, how such provision might operate, safeguards, Constitutional, legal and ethical issues and unintended consequences.

The Disability Federation of Ireland, DFI is a federation of over 120 member organisations working with people with disabilities to implement the United Nations Convention on the Rights of Persons with Disability, UN CRPD. Our mission is to ensure the equal participation of disabled people in society.

As CEO of DFI, I am comfortable about bringing my insights and thoughts to your attention to assist you in developing your report and recommendations. I aim to reflect the thrust of the foundational values of DFI which are to support disabled people to have full and meaningful lives. Member organisations of the federation may have different or similar views, as this matter, like no other, surfaces thoughts, emotions and questions which can be as unsettling as they are varied and challenging, while the objective here is a benign one.

Assisted dying is the focus of these hearings yet dying only has meaning as that which always brings a persons' life to a conclusion. Therefore, this presentation will focus on living and the quality of that living.

My intention today is to bring, as best I can, a perspective to your consideration in the hope that it can assist. That perspective supports the resolve that guides DFI, namely, to ensure that disabled people and those living with disabling conditions can experience life to the full through equal participation in society.

This consideration comes as Ireland is taking unprecedented steps on implementation of the United Nations Convention on the Rights of Persons with Disabilities, UN CRPD, including but not limited to the following Articles:

- Article 19 – Living independently and being included in the community¹
- Article 10 – The Right to Life²
- Article 17 – Integrity of the person³, and
- Article 25 – which addresses Health⁴

This fact helps me to make the point that your remit must be framed around, and subject to, being of assistance to people where, as a State, we have supported them to have had a full life.

Many disabled people in Ireland are caught up in a daily cycle of worry about how to survive on an income that the State has recognised for decades as being wholly inadequate because it does not factor in the varied and necessary additional costs of living with dignity. At the same time, they are consumed by worry about their lack of, or marginal, home support hours,

¹ "States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community".

² "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others".

³ "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others".

⁴ "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation".

before they can ever dream of having the supports that would make them independent members of the community.

In Ireland, disabled people have reported poorer health status than the rest of the population⁵. They are often subject to intersecting layers of social and economic disadvantage and other barriers that drive health inequity. As a result, they frequently experience worse health than people without disabilities. This is beyond the direct effects of their health condition or impairment. Evidence shows that social, physical and attitudinal factors hinder their health outcomes in terms of access to services and quality healthcare⁶.

I think it is fair to say that Ireland has a strong record in ensuring that people will survive life threatening events, thus avoiding death at that point, but not sufficiently to ensure that they can have a full life.

Within the past year the Department of Children, Equality, Disability, Integration and Youth, DCEDIY, has published the Action Plan for Disability Services 2024 – 2026 outlining the necessary increases in community-based disability services to address unmet need and meet demographic change over the coming years. In addition, the Department of Social Protection published the Green Paper on Disability Reform, to provide for the currently unmet costs of trying to live with a disability. These acknowledge the substantial and ongoing under-provision of the most basic elements for disabled peoples' lives.

I am asking you to consider how people with disabilities might think and feel about what is being proposed here in the light of their daily experiences and to factor that into your report and recommendations. This is about relating the trajectory and

⁵ The CSO findings (2019) show that three-quarters of people with a disability report having a long-standing health condition (compared to a State average of a quarter), and 35% of people with a physical or sensory difficulties surveyed by the CSO reported they are *Severely limited* in carrying out everyday activities due to a health problem (compared to a State average of 5% of persons aged 15 years and over).

⁶ Mitchell et al (2022) [An overview of systemic reviews to determine the impact of socio-economic factors on health outcomes of people with disabilities](#).

experience of someone's living within the context of any proposals that you make.

It is also important that the State does not unduly have an "invisible" hand, or influence, in the decision of someone to end their life because it has not supported disabled people to have a life of independence equal to everyone else.

"It is nothing to die. It is frightful not to live." - Victor Hugo.

ENDS