

NDA opening statement to the Joint Oireachtas Committee on Assisted Dying

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Introduction

The National Disability Authority (NDA) thanks the Chair and the members of the Joint Committee on Assisted Dying for the opportunity to present on the topic of protecting vulnerable groups and individuals, including those with disabilities and older people.

The NDA provides independent and evidence informed advice to Government on policy and practice relevant to the lives of disabled people. We also incorporate a Centre for Excellence in Universal Design, promoting the design of digital and built environments, services, and systems so as to be readily accessed used and understood by people regardless of age, size, ability or disability.

The work of this Committee is on a complex and sensitive topic. The NDA proposes to input on those areas directly within our competency. We also advise the importance of this Committee engaging directly with groups with the potential to be affected by this matter. While the NDA provides independent advice to Government on disability, it is not a representative body. There are a number of Disabled Persons Organisations (DPOs) who may have valuable and potentially differing perspectives to bring to the attention of the Committee, as –

in common with the general population – there may not be consensus among disabled people and organisations on this matter.¹

Work to date

The NDA understands that the Committee has heard from a wide variety of witnesses, including those from other jurisdictions where Assisted Dying has been introduced. During these discussions, you have heard about some of the reasons for an individual wishing to avail of Assisted Dying. In Oregon for example, 2022 data indicated that the three most frequently reported end-of-life concerns were decreasing ability to participate in activities that made life enjoyable, loss of autonomy, and loss of dignity.

The Committee has also heard about the importance of safeguards in this area, and in particular guarding against coercion or pressure that might lead someone to consider Assisted Dying as a preferred option. We would advise the importance of considering how the barriers and challenges in place in our society that prevent people with disabilities from living independent and included lives in the community could contribute to a perceived sense of coercion by impacting a person's dignity, autonomy or enjoyment of life.

Health and social care supports

Some of the supports relevant to enabling disabled people to live autonomously within their communities include access to adequate personal assistant services

¹ The NDA has previously prepared guidance for public bodies on engagement with disabled persons, as required under the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), and this may be of assistance to the Committee as it continues its work. [Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making - National Disability Authority \(nda.ie\)](https://nda.ie/participation-matters-guidelines-on-implementing-the-obligation-to-meaningfully-engage-with-disabled-people-in-public-decision-making)

or homecare supports. Research has shown that the provision of these supports is inconsistent across healthcare regions, and that in many cases people do not receive enough support to enjoy good quality of life.² Our research on wellbeing and social inclusion published earlier this year shows the extent to which disabled people are at higher risk of depression and lower well-being than their non-disabled counterparts, often because they do not have access to the same social and leisure activities due to barriers within society³. The NDA advises the importance of adequately resourcing our health and social care system so that an absence of the necessary supports does not become a reason for disabled people to feel that they cannot enjoy a good quality of life.

We also note the importance of people being able to live within their own homes and communities as they age. Accessible, or universally designed housing stock, is a critical enabler in this regard, and in its absence, people can be routed towards institutional models of care. The NDA has produced research that shows that residential services and supports within the community lead to better quality of life outcomes for people with disabilities than institutional settings⁴, and so advise that any consideration of Assisted Dying is not progressed at the expense of work to ensure disabled people can be supported to age in place in their communities. We also advise that further consideration be given to how disability supports and older age / end of life supports work together.

Constraints on resources can also mean a lack of forward planning to address the support needs of disabled people living with family members. If there is not sufficient access to homecare supports or respite, family members can exhaust

² [Disabilities | Free Full-Text | Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People \(mdpi.com\)](#)

³ [National Wellbeing and Social Inclusion Survey - National Disability Authority \(nda.ie\)](#)

⁴ [Moving in, Moving on - National Disability Authority \(nda.ie\)](#)

their capacity to make up the shortfall. This can give rise to a narrative in which the disabled person considers themselves to be a burden, and so their options for living with dignity and autonomy seem more constrained. We advise the importance of ensuring all necessary supports are in place, so that in a situation where Assisted Dying might be introduced on medical grounds, the risk of ‘scope creep’ into other areas is minimised.

Choice and Control

The NDA also advises the importance of considering how any legislation in this area has due regard to the recognition of capacity of disabled people, as provided for in the Assisted Decision Making (Capacity) legislation. This legislation is founded on a principle of presumption of capacity, whereby an individual is given any supports necessary to assist them in understanding and making a decision, and that assessment of capacity is done on a functional basis. Any moves to introduce Assisted Dying in an Irish context should ensure equal recognition of the rights of disabled persons, and provision of any supports necessary for people to realise these rights, while clarity would be required on how decisions in this space are distinct from those made under an Advanced Healthcare Directive. It is also important that any healthcare or medical supports such as provision of information to guide decision making, are offered in a fully accessible manner, and medical staff may require training in this area.

Cost of Disability

We are also aware that the cost of medical or social care supports has been cited as a reason for considering Assisted Dying in other jurisdictions. An Indecon

report on the Cost of Disability⁵, published at the end of 2021 through the Department of Social Protection, has highlighted the additional costs that can attend having a disability. The additional costs vary depending on the person and on the disability but can be considerable. The NDA notes that disabled people are also at greater risk of living in poverty than the general population. When these two factors interact, the risks of challenges arising in relation to the costs of managing a condition and any associated medical issues, are increased. The NDA advises the importance of ensuring that any framework in which Assisted Dying might be introduced in an Irish context is developed to ensure that poverty or lack of access to funds does not become a reason for people to choose Assisted Dying.

Conclusion

The NDA notes concerns that where Assisted Dying has been introduced, it can be possible for initial safeguards to be reduced over time, increasing the risk of abuse of the concept for groups in more vulnerable situations. We advise that if Assisted Dying is placed on a legislative footing in Ireland, it is available on an equal basis for disabled people, but that additional care should be taken to ensure that work continues and accelerates to ensure a society in which the necessary supports for autonomous and dignified living are in place, and that their absence does not become a source of pressure or coercion for disabled people to see Assisted Death as a more viable option.

⁵ [gov.ie - The Cost of Disability in Ireland – Research Report \(www.gov.ie\)](https://www.gov.ie/publications-and-resources/reports/2021-12-01-the-cost-of-disability-in-ireland-research-report/)