

Assisted Decision-Making Presentation

- My name is Dr. Rosaleen McDonagh. The reason for being here today is that assisted decision making mechanisms have a direct impact on my daily life. My impairment is beautiful and complex. My speech lends itself to the perception that my capacity should and is questioned. As a Traveller, there's a history that most minority ethnic persons experience. Racism, poverty and being considered not worthy of an invitation to participate. We understand, we contribute and share the responsibility with regard to this particular, delicate issue. Thank you for having me.
- Context and conflict similar to assisted dying and assisted living is the fulcrum that swivels regarding who lives and who dies. The task here today is to determine whether people should have a statutory right to assisted dying. Safeguarding is the intent to protect. Yet there is a sense that safeguarding is flimsy because it can never be human proofed. In the war of words and diverse ideologies, ethics, politics and values become abstract and academic. The lived reality of lives that are often considered less, different and troublesome become void of agency. The perception of illness and disability is understood as loss of dignity, loss of agency and bodily integrity is presented as the loss of personhood. This issue is of huge concern and relevance to disabled people. We need to be central in this shaping of legislation.
- We are only 6 months in to this proposed legislation. There is a need for it to be fully embedded into all aspects of Irish society. Supporting disabled people and those facing terminal illness to have arrangements in place regarding the supports we need is paramount. Independent advocacy in this context needs to be resourced and available. Advanced healthcare directives and representatives need to be more accessible and affordable. Disabled people and lawyers identified difficulties within this complicated administrative matrix.
- Not implementing the UNCRPD before offering end of life options is limiting the choices and rights of people with terminal illness and impairments. The implementation of the UNCRPD will provide all of us with a sense of value, worth and ambition. Offering end of life options seems unethical and a conversation that's happening in a vacuum.

- The optional protocol – The reality is that disabled people including people with terminal illnesses are not rights holders. The state needs to engage with us in a real and concrete fashion. Those expensive ad campaigns are overloaded with the toxic subtext of the burden and cost of illness and impairment. Contribution and diversity as well as inter-dependency would be words that send affirmative messages.
- The accusation of scare mongering or conflating issues of the past would seem disrespectful to my and many others history and identity. The Canadian situation, where permissions for euthanasia have been extended beyond those facing imminent death and now covering many who don't have adequate social and health care provision is frightening and worth referencing.
- Across Europe where disabled people are targeted as being less than, particularly if we are not able to economically produce, demonstrates the perception of the low value of our worth. Many people with impairments like myself, internalise those messages.
- The right to a good life and a good death is the marker of our humanity. This means access to healthcare options - we know that many medics make decisions not to offer treatment routes to people with impairments. The call for more counsellors, social workers and clinicians including cohorts of professionals with impairments needs to be resourced and included in the context of this discussion. The right to be disabled and have reassurance from the State's apparatus and access to those rights are fundamental.