Opening statement to the Oireachtas Joint Committee on Assisted Dying

On the topic of

Protecting Autonomy and **Assessing Decision-Making Capacity**

Dr Caroline Dalton, School of Nursing and Midwifery, University College Cork

Firstly, I would like to thank the Cathaoirleach and the members and staff of the Committee for the invitation to appear before you, to present on the topic of Protecting Autonomy and Assessing Decision-Making Capacity. I do so, within the context of my experience as a registered intellectual disability nurse (RNID), and a lecturer in the School of Nursing and Midwifery in University College Cork. My PhD in 2020, focused on the area of End-Of-Life Care Supports and Decision-Making Practices in Intellectual Disability Services.

Within an Irish context, the ratification of the UN Convention on the Rights of Persons with Disability and the enactment of the Assisted Decision-Making (Capacity) Act, 2015, has led to a focus on autonomy and decision-making capacity, from a societal, governmental and legislative perspective.

While acknowledging these important legislative changes, difficulties will continue to be encountered in protecting autonomy, in a real-world context, specifically where issues in relation to capacity arise. It is this real-world context, that I wish to focus on today.

Many people, across all sectors of society, including people with an intellectual disability, will encounter difficulties when making decisions and the Assisted Decision-Making (Capacity) Act, 2015 affirms a functional approach to capacity. However, irrespective of whether a person is deemed to have decision making capacity or not, great care and attention must be placed on how capacity is assessed.

Safeguards must be in place to ensure an individual's right to autonomy is protected, to ensure people are not excluded from a range of decision-making opportunities relating to their end-of-life care, including where, when and how they would like to die. Conversely, safeguards must also be available to support those who may be vulnerable to pressure or are at risk of having their autonomy undermined, due to the impact of coercive control.

Therefore, I would argue that discussions relating to autonomy should not just be linked to assessing decision making capacity. This is too narrow a focus, given the importance of decision-making capacity within the context of all aspects of end-of-life care, which may extend to assisted dying. The scope of the discussion needs to broaden to view capacity, as a constructed state (McCarthy et al. 2011). Capacity is not simply a characteristic to be assessed but one that needs to be encouraged and promoted. Supports must be provided to enhance a person's capacity and address issues which might impede a person's capacity. These issues cannot be viewed solely within the context of the individual making the decision, but also within the context of the environment in which they live, their support circles and networks, and their access to services.

A continuum of constructive supports, reflective of the individual ability of each person, is required. Appropriate policies, protocols, guidance will need to be developed, to support a functional approach to decision making is implemented in a real-world context. In essence, the point I want to make to the committee, is that people will need time and access to appropriate resources to ensure their autonomy is protected. Without these, individuals may potentially be excluded from making decisions relating to all aspects of their end-of-life care, including how, where and when they die. I hope the committee will give due consideration to this point, in their deliberations and I thank the committee for its attention.