National Federation of Voluntary Service Providers
Supporting people with intellectual disability (CLG)

National Federation of Voluntary Service Providers - Opening Statement

To:

Joint Committee on Children, Equality, Disability, Integration and Youth

Regarding:

Pre-legislative scrutiny of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021

15 February 2022

Thank you for this opportunity to meet with the Committee to discuss the Assisted Decision-Making (Capacity) (Amendment) Bill.

The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is a national umbrella body of not-for-profit organisations providing direct supports and services to people with intellectual disability in Ireland[i]. Across 57 organisations, our members support approximately 26,000 children and adults with intellectual disabilities and their families. As two thirds of disability services are provided on behalf of the State by the voluntary sector[ii] we welcome the Joint Committee's invitation to our organisation, to discuss this legislation, which will be of enormous importance in the lives of people with intellectual disability.

We welcome the focus of the Joint Committee on hearing today from individuals with lived experience, family members and from service providers supporting people with disabilities today. The UNCRPD recognises that:

> *"persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them".*

As the Assisted Decision Making (Capacity) Amendment Act will have particular relevance throughout the lifespan for people with intellectual disabilities, the UNCRPD in Article 3 places a responsibility on the State to meaningfully consult with people with intellectual disabilities, in an accessible format.

The implementation of the Assisted Decision Making (Capacity) Act will be a significant, positive milestone in the State's progress towards ensuring that individuals with disabilities enjoy equal legal capacity in all aspects of life, as envisaged in Article 12 of the UNCPRD.

The focus in the Act on supporting the will and preference of the individual offers a transformational opportunity in terms of how people with intellectual disability are legally supported in their rights to make choices fundamental to their own lives. It also has the potential to be a catalyst for society to develop a growing understanding of the capacity of individuals to make such choices and be respected in their decisions.

As time is short within this opening statement, there are a number of interlinked themes that we wish to highlight here.

- For many people, the onset of dementia or perhaps a life-changing accident, can mean that a person will begin to have decision support needs at a particular stage in their lives. However, many individuals with intellectual disability have lifelong support needs around decision-making, and therefore there will be very considerable implications from this legislation for the people we support, our staff and the families with whom we have long standing relationships.

- It is very important, therefore, that the legislation itself, its implementation, and the Codes of Practice it provides for, are equally suitable and accessible for those with lifelong decision support needs; as well as those who acquire support needs at a particular stage in their lives.

- A key concern that the National Federation wishes to highlight is the risk that more restrictive approaches will be brought in unintentionally on foot of the legislation; and in this context it is essential that the spirit of the Act is safeguarded in the legislation.

  For instance, our members have expressed concerns that there are people with intellectual disabilities (numbering in several hundreds, and often those who have lived in institutional settings for a long period) who have very few supports in terms of family and friends, and who may struggle to identify decision supporters. As set out in the Act paid staff cannot take on these roles.

  This may have the unintended consequence of pushing people further up the scale of decision supporters, which would be *more restrictive* than the spirit of the Act. (For instance, the proposed legislation indicates that where a person's capacity would identify that the most suitable support needed is a Co-Decision Maker, but there is a lack of availability of unpaid decision supporters in the person's life, they would instead be assigned a *Decision-Making Representative* from the panel, which is court appointed and most likely unknown to the person). We would welcome a focus on this issue to ensure that people for whom this is relevant are not disadvantaged by the measures set out in the legislation.

- Every effort must be made to ensure that individuals with an intellectual disability are not disempowered due to insufficient education and cultural change at a national level. Education, guidance and ongoing support for relevant people under the Act; their families; service providers; and wider society (such as the banking sector, medical professionals, etc); is critically important in the implementation of the Act and in adherence to the principles and spirit of the Act going forward. The cultural change required as this legislation is fully commenced and the Codes of Practice are rolled out will only work if this education, awareness and support is coordinated nationally. It is also essential that independent advocacy is adequately resourced to support people where required as implementation progresses.

- Early communication on the implications of this legislation and meaning of the Act for people with intellectual disabilities, will be essential. This will require a targeted, fully accessible, campaign of training and information.

- There are adults with intellectual disabilities who are at this time Wards of Court, and there are also some young adults who live in the care of the state who currently become Wards of Court when they are transitioning into adult services, in particular where there are safeguarding concerns that apply. We would welcome clarification on the alternative process for these young people who come through the transition period after the commencement of the Act, as well as for those who already in the Wards of Court process.

- The process for those people who are Wards of Court will necessitate particularly detailed communication planning– since the legislation will have a very significant impact on these people’s lives and without early communication is likely to lead to anxiety and concerns about next steps.

- A key area of importance is around the requirement for significant support to families in relation to how this legislation will be understood and implemented. For many people with an intellectual disability, their primary supporters are family members from their family of origin. Many of these family members are continuing in primary carer roles into later life. Our own research has indicated that more than 1250 people are supported in the family home by a primary carer who is over the age of 70, at least 400 of whom are over the age of 80.

In this context it is essential that the structures for decision supporters are accessible to these family members. For many, a digital-only platform will not be accessible. For some, the onerous reporting requirements will be difficult. There is a need to examine how these families can be appropriately supported, and for detailed planning around how the Act will affect people who are primarily supported by families, some of whom are ageing or may have their own health and/or decision-making challenges emerging.

- In terms of how this Act will work on the ground in disability services, it is already becoming clear that there will be substantial work required in terms of training, policy and practice. We recommend that an impact assessment is carried out on the implications of the Act for resourcing in disability services, since there will be significant requirements that need to be put in place to ensure that people with intellectual disability have full access to their rights under the legislation.

- It is vital that the importance of existing informal decision supports is emphasised in all communication strategies. This should include key staff, who know the person well and are currently often involved in supporting the person's choice, will and preference., Their knowledge; interaction with the person; and expertise should be included as a key source of information and support - where that is the person's wish.

- The timing of the consultation process on this legislation and on the draft Codes of Practice during the current wave of infection of Covid 19, has not allowed for as sufficient a level of detailed analysis across our organisations as would be required for full consideration, since we have had an unprecedented challenge in terms of staff shortages over the last two months. This has made it very difficult to bring together the relevant staff, for sufficient time periods, to allow the depth of analysis which legislation of this gravity and with such particular relevance to people with intellectual disability, requires.

- Whilst we are very cognisant of the urgency of the legislation being brought through the House, we recommend that the Codes of Practice be fully reviewed – after Year 1 or Year 2 of implementation, to allow for consideration of their operation in practice and to identify any key issues that need to be addressed.

- Without access to options, choice cannot be meaningful. For instance, the choice of where and with whom we live is a fundamental life decision, and an area in which access to will and preference is essential, as set out in Article 19 of the UNCPRD. It is important to note that there are more than 2,000 people with intellectual disability who remain living in institutional/congregated settings today, and more than 1,000 people under the age of 65 inappropriately living in nursing homes for elderly people. There are many more people with intellectual disabilities who have not chosen where or with whom they live, and many express significant distress on a daily basis due to the incompatibility of those living together. The funding and resourcing of the required residential supports and other areas of support to meaningfully address the rights-based approach to providing choice to people with disabilities will need to be considered in the planning for the implementation of this Act, since this will be a key driver of access to will and preference for people with ID.

We thank you for the opportunity to meet with the Joint Committee on this important topic and to put forward our experience of supporting people with disabilities, in the context of the forthcoming legislation. We are happy to take questions and discuss further our understanding of key implications for people with intellectual disabilities, their families and the organisations and staff who support them.

[ii] See www.fedvol.ie for further information about the National Federation of Voluntary Service Providers.

[ii] *Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services*: https://assets.gov.ie/9386/6d02f4a9fb554e30adbebb3eec5091d9.pdf