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AsIAM Submission to the Joint Oireachtas Committee on Equality, Disability, Integration and Youth on the Pre-Legislative Scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021

17th February 2022

AsIAM is delighted to be invited to make a submission to the Oireachtas Joint Committee on Equality, Disability, Integration and Youth on the subject matter of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021. This Bill covers a significant ambit of the lives of many people in our society who have a disability. The proposed legislation touches upon a number of fundamental and indivisible rights we as people hold, such as, *the right to respect for inherent dignity, personal autonomy including the freedom to make one's own choices, and independence, the right to equal recognition before the law, the right to physical and mental integrity, the right to private and family life, live independently and the right to engage with the legal system on an equal footing, free from any encumbrances as a result of one's disability or diagnosis.*

Given the fundamentally transformative impact the proposed legislation has for many members of the autism community and disabled people and their community, we appreciate this opportunity to engage with the Joint Committee on Children, Equality, Disability, Integration and Youth on this timely and critical piece of legislation.

Who are AslAm?

AslAm is Ireland's National Autism Charity and Advocacy Organisation founded in 2014. AslAm aims to advance and promote the rights of the Autism community in Ireland. From providing the public and autistic people and families with a portal of information about autism, to providing a platform for the autism community to share their stories and views, to providing a strong voice for the concerns of the community.

Our Issues with the Proposed Bill

From the outset, AslAm warmly welcomes this legislation and the potentially transformative impact that it will have on members of the disability community, including autistic people and disabled people, in Ireland. We particularly welcome the changes that will be brought in regarding the phasing out of the current Ward of Court system, which is an outdated and anachronistic system that has no place in a modern 21st century Ireland. The proposed Bill also includes measures to further realise the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Ireland, including legislating for the Irish Human Rights and Equality Commission's (IHREC) position as the national monitoring body for the UNCRPD, and increasing the public sector duty regarding the employment of persons with disabilities in public bodies from 3% to 6%. All of these are welcome measures and will go some way to bring about meaningful change to the lives of disabled people in Ireland.

The Assisted Decision-Making (Capacity) (Amendment) Bill 2021 is a significant step forward in progressing disability rights in Ireland and towards the full ratification of the UNCRPD. Within the current frameworks of this Bill, there are however some outstanding concerns which need to be addressed by this Joint Committee, and by legislators in any proposed amendments to the Bill:

- We would echo the calls of many other Disabled Persons Organisations that the Bill should be fully scrutinised by disabled people and by Disabled Persons Organisations and for the Bill to be presented in accessible formats, including Irish Sign Language and

Easy-to-Read, to allow for such scrutiny to take place. We also echo calls for the Bill to be enacted into law as planned in June without any further undue delay so that disabled people can fully access their rights, and to exercise their agency and autonomy in a timely manner.

- It has been identified that there are weaknesses present around the limited nature of appeals given to Relevant Persons (RP's) under the 2015 Act compared with the Mental Health Act, 2001. The 2015 Act and this General Scheme only allows for a limited appeal on the many decisions that can be made on capacity and other related issues, and "on a point of law only". This compares unfavourably for example to the full right of appeal provided by the Mental Health Act 2001 at s.19. This ultimately creates a two-tier process which would contravene Article 14 of the UNCRPD, and could have grave consequences for disabled individuals, particularly those with psychosocial disabilities, who have the right to have their decisions respected and to not be arbitrarily restricted because of their disability.
- It is unclear from the 2021 Bill as to the manner in which legal representation will be afforded to Relevant Persons. Certainty around this issue, and around how the State should financially support people with disabilities to meet the costs of getting legal representation should be addressed by the Committee.
- Greater detail/clarity is needed regarding how Wards themselves will be updated during any transition periods, and to the accessibility of such information therein. Specific detail on this should be referenced and contained within this General Scheme, and Wards of Court should receive information in accessible formats about all stages of the process, including about their rights.
- It is important that clear and fully accessible communication and information is made to Relevant Persons if any changes to their circumstances arise.
- It is important a system of equity is used in determining an inclusive community process/model, and that this should be implemented

with regards to moves away from wardship to the Decision Support Service in terms of 'priority caseload'. For example, a clear process in determining why 'ward A' is to benefit from the new Supported Decision-Making process in the first month of its operation, compared with 'ward B' who may have to wait 2 years etc.,

- We would share the concerns made by the Irish Penal Reform Trust regarding the need for consideration to be provided for people with disabilities in our prisons, who might need to ascertain decision-making supports while detained, and to make any legislative amendments needed to provide such supports.
- We would also share concerns made by Disabled Women Ireland about the privacy rights of Relevant Persons who are making decisions under the new process, and it is important to ensure that the Relevant Persons' right to privacy is fully protected in accordance with the UNCRPD.
- We would also share concerns made by the Independent Living Movement Ireland in their submission in that there is no specific reference to the UNCRPD in the General Scheme, particularly around Articles 12 and 14, which set out a person's right to make decisions and to be protected from unjustly losing their rights and liberties because of their disability. In its current guise, the Bill does not adequately meet Ireland's obligations under the UNCRPD, nor does it meet the commitment expressed in the Initial State Report to enact "for the presumption of capacity and promotion of a person's will and preferences". For the Bill to comply with the Convention, the Bill needs to contain more explicit references to Articles 12 and 14 and include provisions which protect the right to make decisions and to access supports which respects a disabled person's will and preferences. It should also contain provisions ensuring that any safeguards should not impinge on a disabled person's right to exercise legal capacity.
- The Bill also needs to have a specific reference to the fact that the Act's aim is to ensure that all disabled people, across the full diversity of strengths and support needs, including those deemed to have 'profound' disability or who are deemed to have 'high' or 'complex' support needs, have the right to exercise their agency and

autonomy and to make decisions which support them to live the lives they want.

- In the current Bill and General Scheme, there is a need to identify a sunset clause on the current structures of the wardship model for those cases of a difficult nature. The inherent jurisdiction of the High Court should not be used to continue the guardianship model via Wardship through the ‘backdoor.’
- There is no definition of what defines ‘disability’ under the Bill and General Scheme; given the fundamental importance of this proposed legislation, it is important such a definition is included in this Bill and reflects the Social Model of Disability, which promotes a rights-based approach to all aspects of disability and permeates through all aspects of the UNCRPD. It should also be consistent with definition used in the UNCRPD, as this presents a more inclusive interpretation of disability compared to the 2005 Disability Act. Rights-based language should be used throughout the Bill which gives expression to the right of autistic people and disabled people to be supported to make the decisions they want to fully participate in society.
- The Assisted Decision-Making (Capacity) (Amendment) Bill also should recognise and take into consideration that many autistic people and disabled people may not just be autistic or have just one disability or neurodevelopmental difference, but may also have one or more other impairments, or differences which can impact how they make decisions, or how others perceive their agency and autonomy to make decisions. It should also recognise the impact that intersectionality has on people with disabilities’ lives, and the role that gender or gender identity, sexual orientation, socioeconomic status, family status, ethnicity, age or disability can play in the types of decisions that disabled people make and how they exercise their legal capacity in real terms.
- A concern to many autistic people we engage with is that many autistic characteristics can potentially be perceived by others as having a negative impact on an autistic person’s ability to exercise their legal capacity on a day-to-day level, even though this should

not be the case. This augurs the need for Decision-Making Representatives to receive training on best practices from autistic-led and from other organisations led by or centred around disabled people, such as Disabled Persons Organisations. These characteristics may include, but are not limited to, the following:

- 'Masking' or camouflage more overtly autistic traits to try to fit into society,
 - Sensory processing differences,
 - Being more likely to experience 'Autistic burnout' from living in a society which often fails to accommodate their needs,
 - Being more sensitive to stress or trauma, or mental health conditions,
 - Stimming (Self-stimulatory movements or actions),
 - Communicate differently or need to use different communication modes at different times to express their will and preferences.
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- A particular concern from our community is around autistic people with co-occurring differences or disabilities, particularly if they are distressed, or are perceived to engage in 'challenging behaviour' if their will and preferences are not respected. This is also the case for non-speaking or partially speaking autistic people, whose use of different forms of communication or who may act atypically may not always be understood or appreciated by decision-making representatives without the requisite training. They may also be informed by outdated preconceptions or stereotypes about autism, or by practices that are harmful to autistic people. This stresses the need for all parties involved in the decision-making process to receive Neurodiversity-affirmative training around autism which affirms and respects autistic person's right to engage with the world as themselves and to refrain from approaches which rely on outdated 'behaviourist' attitudes or techniques which place an onus on an autistic person to fit into society.

 - More generally, specific reference should be made in the Assisted Decision-Making (Capacity) (Amendment) Bill to protect the full autonomy of all people with disabilities, including those who use different forms of communication, and those who need access to support to make and communicate their decisions to ensure that they can live their lives how they want.

- The Assisted Decision-Making (Capacity) (Amendment) Bill should also recognise the need for autistic people and disabled people to access supports, to support them to make decisions, outside of the Decision Support Service including Personal Assistants, autistic-led spaces, and peer support networks. It should also recognise situations where an autistic person or a disabled person's will and preferences come into conflict with the view of others, such as their family, carer, or their wider support network, or where they make decisions that others consider to be unwise, unsafe, or risky, or where others might see the person's preferred decision as making a mistake. In all these instances, a person's will and preferences should be respected and this should be reflected in the Bill.

The AslAm Policy Team