

Submission to the Oireachtas Committee on Disability Matters

The Centre for Disability Law and Policy at the National University of Ireland Galway welcomes this opportunity to make a submission to the Oireachtas Disability Matters Committee on the subject of the lived experience of disabled people in Ireland. In this brief submission, we will address two key issues – the need for accessibility and flexibility from the Committee in communicating with disabled people, and the specific topics on which it may be particularly valuable for the Committee to seek targeted inputs from disabled people with respect to their lived experience. In both respects we will focus on the lessons we have learned as researchers working with disabled people, and on the human rights principles which inform our work, drawn from the United Nations Convention on the Rights of Persons with Disabilities.

Communicating with Disabled People

The Centre for Disability Law and Policy welcomes the call for submissions to this Committee and its specific focus on the lived experience of disabled people. In order to ensure this call reaches the most marginalised disabled people and gives everyone an equal opportunity to be heard, we provide the following suggestions for accessibility and flexibility.

The call for submissions was made within a fairly tight deadline. While we appreciate that the members of the Oireachtas are incredibly busy, and that the initial deadline of 9 February was extended to 13 November, even the extended deadline will mean that many disabled people are unable to participate in the process at this stage. Many disabled people's organisations rely on volunteers, rather than paid staff, which may be available in other NGOs to write submissions.¹ Some disabled people's organisations and individuals require significant support in order to make their submission, and will need to gather their members to contribute to and consult on the text of the final submission, all of which takes time, and for many disabled people, requires additional support (for example, the National Platform of Self Advocates rely on the support of a Facilitator to assist them in making submissions).² Further, the fact that submissions are limited to a formal written format, presents access barriers for many disabled people. The Committee has not made the call for submissions available in an Easy to Read format which would make it more accessible to people with intellectual disabilities, nor has it provided the information Irish Sign Language to make it accessible to the Deaf community, many of whom do not have literacy in written English.

¹ Chris McNerney and Cian Finn, 'Caring- at what Cost? Rebuilding and Refinancing the community and voluntary sector' (IMPACT Health and Welfare Division, 2015) 6-14

<https://www.ul.ie/ppa/content/files/Funding_Community_voluntary_sector_organisations_to_deliver_services.pdf> accessed 13 November 2020.

² National Platform of Self- Advocates, 'The History of the National Platform of Self- Advocates' <<http://thenationalplatform.ie/history/>> accessed 13 November 2020.

Access for disabled people to communicate with the Oireachtas Committee could be improved by providing the option for people to make a brief recorded audio or video submission as a form of reasonable accommodation, especially given the tight deadline for receiving submissions. Furthermore, while the call for submissions has been widely advertised, we would advise the Committee, based on our experience of conducting research with disabled people, to reach out particularly to specific groups run and controlled by disabled people, and if desired, to extend the deadline further for these groups and be open to receiving submissions in alternative formats from them. These groups include the National Platform of Self Advocates, Recovery Experts by Experience, the Irish Dementia Working Group, Voice of Visually Impaired Ireland and the Irish Deaf Society.

There are structural issues to be addressed in order to guarantee the full participation of people with disabilities, which should be considered by the Oireachtas Committee. The CRPD Committee has made clear that the participation of people with disabilities of all making of decision making, reflected in the Oireachtas Committee's commitment to hearing about the lived experience of people with disabilities. The CRPD Committee is explicitly clear that this is best served by facilitating representative organisations of people with disabilities or disabled persons organisations [DPOs]. These are independent organisations by people with disabilities with the aim of defending the rights of persons with disabilities. These organisations are distinct from, or organisations which represent service providers. Significant barriers exist for DPOs operating in Ireland, and the position which is rightly held by them is often filled by advocates or service provider organisations. It is important that the committee recognises these barriers and seeks ways to support the growth of these organisations, including by recognising non traditional structures of organising, and ensuring that funding is made available.

The same accommodations should be made when disabled people are being called to give oral submissions before the Committee (and indeed, in all Oireachtas proceedings). More notice may be needed to allow groups to prepare their oral submission, there may need to be extra time factored in for people to speak depending on their methods of communication, and supporters or interpreters may be needed to attend the Oireachtas Committee. The Committee should also allow time during oral submissions for technical glitches if people are permitted to make oral submissions remotely where they cannot attend in person, especially with COVID concerns. Members of the Committee should also be aware of using plain language in their questions, and if needed, provide questions in advance to groups to allow them to prepare. Any broadcasts of the Committee's sessions should also include sign language interpretation, and video recordings uploaded subsequently should also include captions to make them fully accessible to all disabled people.

In order to assist the Committee in its work, and to ensure that it receives the broadest possible range of submissions, we also recommend that the Committee offer some clarity on who is considered a person with a disability or disabled person for the purpose of making a submission to the Committee. We suggest that the approach to disability should be kept broad and inclusive in keeping with the UN Convention on the Rights of Persons with Disabilities, and include anyone who self identifies as a person with a disability/disabled person, or who is perceived to be disabled by others, or who prefers to use one of the

following identities: autistic or neurodiverse person, user or survivor of psychiatry, person with experience of mental health services / psychosocial disability, d/Deaf person, chronically ill person, person with an intellectual disability, person with acquired brain injury or person with dementia.

Disability applies across all ages and does not (as some supports would suggest begin at 18 and finish at 66) have a clear start or cut off point. The Committee must recognise that the issues affecting children and young people with disabilities may differ greatly from adults or older people with disabilities in some respects. Children and young people with disabilities should also be facilitated to express their views independently of family members or family representative organisations if they wish. An open ended, non-exhaustive list of who may be considered a disabled person can help to clarify the scope of the Committee's work and who is eligible to make a submission.

Specific Topics on which further submissions may be sought

The Centre for Disability Law and Policy welcomes the Committee's approach in keeping the first call for submissions broad and open in order to allow for all kinds of issues to be included. However, there are some issues of serious concern with respect to Ireland's human rights obligations under the UN Convention on the Rights of Persons with Disabilities upon which we think, based on our research experience to date, it would be wise to secure more targeted submissions. In this submission we will focus on four main areas which have emerged in our research, although we appreciate that there are many other issues of interest to disabled people in respect of their human rights.

Legal Capacity

Disabled people in Ireland continue to have their right to legal capacity – that is, their right to make legally binding decisions (e.g. consent to medical treatment, consent to sex, enter a marriage, make a will, etc.) denied. Disabled people have powerfully articulated their experience of injustice in existing laws in a number of research projects, including the VOICES project at the Centre for Disability Law and Policy.³ While the Ward of Court system is widely recognised as constituting human rights violations and in need of reform, we submit that the rights of disabled people cannot be fully respected simply by commencing the provisions of the Assisted Decision-Making (Capacity) Act 2015.⁴

Along with many disabled people, the Centre for Disability Law and Policy campaigned for amendments to the Act during Dáil and Seanad debates, amendments which would have brought the legislation into closer alignment with the UN Convention on the Rights of Persons

³ See Voices of Individuals Collectively Exploring Self Determination (30 November 2018), available at <<https://ercvoices.com/participants/>> accessed 13 November 2020. Disabled people in Ireland provided stories about their right to legal capacity in this project, including Paul Alford, Claire Hendricks, Helen Rochford Brennan, Dermot Lowndes, Maria Mahony and Ronnie Harris. See also the edited collection published by the project: Flynn, Eilionóir, Anna Arstein-Kerslake, Cliona De Bhailís, and María Laura Serra, eds. *Global perspectives on legal capacity reform: Our voices, our stories* (Routledge, 2018).

⁴ Mary Carolan, 'Ward of Court System does not protect Vulnerable adults HSE' *The Irish Times* (Dublin, 16 January 2018).

with Disabilities.⁵ These included a change to the eligibility criteria for each of the new options under the Act (decision-making assistant, co decision-maker, decision-making representative), the retention of substituted decision-making mechanisms, as well as a reversal of the decision to make advance healthcare directives not legally binding where an individual became involuntarily detained under the Mental Health Act. While these amendments were not ultimately accepted, we would urge the Committee to consider the need for further changes to our existing law to protect this right,⁶ and to seek further submissions from people with lived experience of the current law on this specific issue.

Involuntary Treatment

The Mental Health Act 2001 continues to provide for people labelled with mental disorder to be detained and treated against their will. In 2017, the United Nations Special Rapporteur on the Right to Health, Dainius Puras (a former child psychiatrist) reported that “immediate action is required to radically reduce medical coercion and facilitate the move towards an end to all forced psychiatric treatment and confinement.”⁷ The UN Special Rapporteur on Torture, has also stated in 2020 that “practices such as ... psychiatric intervention on the grounds of “medical necessity” or the “best interests” of the patient generally involve highly discriminatory and coercive attempts at controlling or “correcting” the victim’s personality, behaviour or choices and almost always inflict severe pain or suffering. In the view of the Special Rapporteur, therefore, if all other defining elements are present, such practices may well amount to torture.”⁸

While the Programme for Government includes a commitment to revise the Mental Health Act in light of the Report of the Expert Review Group in 2015,⁹ there are currently no legislative proposals under discussion in Ireland that would achieve the goal set out in the UN Convention on the Rights of Persons with Disabilities to end medical treatment of disabled people, including psychiatric treatment, provided without the informed consent of the individual concerned.¹⁰ The Centre for Disability Law and Policy encourages the Oireachtas Committee, to seek further submissions from people with lived experience of the current law, especially users and survivors of psychiatry, on this specific issue.

Deprivation of Liberty

Disabled people in Ireland are often deprived of their liberty in a wide variety of residential settings, where individuals have been placed without their express consent, and where they are subject to constant supervision and control and are not free to leave.¹¹ These include

⁵ Seanad Éireann 10 November 2015, vol 243 no 4, 181-183.

⁶ UN Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014): Equal Recognition Before the Law, (CRPD/C/GC/1).

⁷ United Nations General Assembly, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, (A/HRC/35/21) para 65.

⁸ United Nations General Assembly, Report of the Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment, (A/HRC/43/49) para 37.

⁹ Government of Ireland, Programme for Government, ‘Our Shared Future’ (Dublin, 2020) 54.

¹⁰ UN Convention on the Rights of Persons with Disabilities, art’s 12, 14 and 25.

¹¹ Eilíonóir Flynn, Mónica Pinilla-Rocancio and María Gómez-Carrillo, ‘Report on disability-specific forms of deprivation of liberty’ (April 2019) 10

psychiatric facilities, residential services for autistic people and people with intellectual disabilities, and nursing homes. While the Government has committed to introduce legislative Protection of Liberty Safeguards,¹² if these are to be based on the Draft Heads of Bill published in 2016,¹³ they will not satisfy Ireland's human rights obligations under the UN Convention on the Rights of Persons with Disabilities.¹⁴ The current proposals will continue to allow disabled people to be deprived of their liberty if they are assessed as lacking mental capacity to consent to their current placement, and if the placement is considered to be necessary to protect the person from harm. Apart from people living in direct provision, there is no other clearly recognised group in contemporary Irish society who are subject to this kind of deprivation of liberty beyond the criminal justice system. Significant investment in community supports would be required in order to ensure that disabled people do not continue to be deprived of their liberty by their placement into settings without their consent. The Centre for Disability Law and Policy encourages the Oireachtas Committee, to seek further submissions from people with lived experience of the current system on this specific issue.

Right to Choose Where and with Whom to Live

We imagine that the Committee will not have heard directly from disabled people living in residential institutions and suggest attention is paid to how people's voices can be heard on these matters. Ireland gathered data on the number of disabled people in institutions in 2008, published the report some three years later in 2011, which showed that nearly 4000 disabled people continued to live in congregated settings.¹⁵ The move from congregated settings has been extremely slow. Some 9 years from the initial report (and 12 years since the numbers were known), many disabled people have died rather than moved to community living. The most recent data available shows that only 2100 of the original 4000 people have now moved to live in the community.¹⁶

Covid-19 has highlighted the increased risk to people of living in institutional settings. People have been cut off from family in many cases, and due to a lack of IT support and equipment, have not been able to communicate with their loved ones, or if they are supported to communicate, may not have their privacy fully respected during this time. The Personal Budgets Demonstration Projects Pilot within the HSE which is intended to support the transition to community supports, is severely unfunded, with only one project co-ordinator. This project's aim was to develop a means in individualised funding and the potential to fundamentally change disability service provision, but there is growing concern that the project has been set up to fail. We recommend that the Committee seeks further submissions

<<https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/DoL-Report-Final.pdf>> accessed 11 May 2020.

¹² Dáil Debates 8 September 2020, vol 996 no 6, col 1405.

¹³ Department of Health, *The Deprivation of Liberty Safeguard Proposals: Report on the Public Consultation* (July 2019) <<https://assets.gov.ie/43856/286eb5d2ebca4b088d65cfef7b5c23a2.pdf>> accessed 9 June 2020.

¹⁴ UN Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014) Equal Recognition Before the Law (CRPD/C/GC/1); UN Committee on the Rights of Persons with Disabilities, 'Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with Disabilities' (2015).

¹⁵ Health Service Executive, *Time to Move On From Congregated Settings: A Strategy for Community Inclusion* (Dublin: 2011).

¹⁶ Dáil Deb 23 July 2019, Congregated Settings Debate, Question to Minister of State, Finian McGrath.

from people with living in congregated settings on this specific issue, and develops accessible and creative means to gather these experiences given the current public health restrictions in place.

In conclusion, the Centre for Disability Law and Policy appreciates this opportunity to make a submission to the Oireachtas Committee on Disability Matters and would be glad to assist the Committee in making contact with various disabled people's organisations, provide the Committee with further research on the lived experiences of disabled people on the specific issues mentioned and support the Committee to develop accessible means of communication with disabled people in its future work.