



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Opening Statement to the Joint Committee on Health on the UN Convention on the Rights of Persons with Disabilities and its relevance for health and well-being

17th May 2017

Kathryn O'Shea:

As the Chairperson of Inclusion Ireland, I would like to thank the Chair of the Committee Dr. Michael Harty TD for the invitation to address the committee.

Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability. Our work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

Health and wellbeing matter and the United Nations recognises the relevance of happiness and well-being as universal goals and aspirations in the lives of human beings around the world, and the importance of their recognition in public policy objectives.

Research¹ shows that adults with a disability experience multiple quality of life challenges (including poor health, mental distress and housing problems) and it is clear that Ireland must improve.

The United Nations Convention on the Rights of Persons with Disabilities offers us a way to address the challenges and our presentation today focuses on 3 of the UNCRPD Articles, all of which are relevant to this particular committee.

Article 25 (Health),

Article 12 (Equal Recognition before the law),

Article 19 (Living Independently and Community Inclusion)

Sarah Lennon:

UN Convention on the Rights of Persons with Disabilities

The UNCRPD does not create any new rights but was designed as a response to the unique barriers that our society throws up for persons with disabilities. We will look at only 3 of its 50 Articles today.

Article 25 – Health requires that States Parties provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as other persons.

People with disabilities have lower uptake of health promotion and screening services such as cervical and breast cancer screening. Disabled women may find health screening information inaccessible or may not have the support to attend. Information on these services should be provided in a range of accessible formats.

Health inequality becomes even more important as persons with disabilities age. The Irish Longitudinal Study on Ageing reported that people with disabilities were more likely to experience social exclusion and loneliness and 3 times more likely than the general population to experience depression as they age.

¹ Department of Social Protection and the Economic and Social Research Institute (ESRI) 'Social Risk and Social Class Patterns in Poverty and Quality of Life in Ireland' reveals that people with disabilities are more at risk of poverty and experience greater rates of deprivation than the general population

Additionally, older adults with disabilities were more likely to experience vision and mobility challenges, chronic constipation, higher prevalence rate for falls, higher incidence of mental health and emotional health issues, higher incidence of polypharmacy (using 5 or more medications).

People living in institutional settings and community group homes were more likely to report feeling socially excluded.

Health and social care services should plan for the appropriate supports needed in the future and these supports should be person-centred to protect against social exclusion and loneliness particularly for those in or leaving institutional settings

Article 12 Equal Status described as the 'beating heart of the Convention' and concerned with equal recognition before the law which is central to accessing health services and important for well-being.

Equal status means supported decision-making and having a choice on how to spend money, where to live and living in the community.

We retain the Lunacy Act 1871 on statute until the commencement of the Assisted Decision-Making (Capacity) Act 2015 (ADMCA15) and with it a status-based approach to decision-making which strips people of their right to choose.

ADMCA15 introduces modern infrastructure for supporting people to make decisions or to have decisions made for them in some circumstances.

Budget 2018 must include appropriate resources for the Decision Support Service (DSS) within the Mental Health Commission. It has taken almost 2 years for the recruitment of a Director of the DSS, and once appointed s/he must be given the resources to carry out their functions such as developing codes of practice and self-advocates and experts through experience must be consulted.

Funding must be also put in place that allows for education of individuals, their families and members of the public.

Article 19 Community Living requires States parties to recognize the equal right of all persons with disabilities to live in the community. A recent comment by the CRPD Committee² said institutions create “isolation.. lack of control .. lack of choice .. rigidity and a paternalistic approach”

Today 2580³ persons remain in residential institutions in Ireland in spite of their planned closure by 2018⁴. The Programme for Partnership targets a move of 1/3 of residents by 2021, a figure most likely to be reached by the deaths of residents. Ireland must accelerate their process of de-institutionalisation while ensuring that persons with disabilities receive individualised supports in the community.

UNCRPD reaffirms the right of people with disabilities to health and social supports in the community, rather than segregated services. Ireland must commit to and resource a Personalised Budget system. In the UK, Direct Payments have improved independence, well-being and quality of life⁵ and the CRPD Committee has said that States parties should “ensure personalization of support, including personal budgets”

Conclusion

I would like to thank the Committee for the opportunity to raise these issues relating to health and well-being. They are only the tip of the iceberg in relation to the UNCRPD and its potential impact.

The Convention has the potential to radically change how we think about persons with disabilities and how as a society we interact with each other. It is to our shame that Ireland is the last EU-country to ratify and we know from other countries that ratification has accelerated reforms. In Ireland, the progress has been slow and we urge the State to ratify as soon as possible.

² Committee on the Rights of Persons with Disabilities Draft General Comment No. 5 (2017) Article 19: Living independently and being included in the community

³ PQ 5585

⁴ Time to Move on From Congregated Settings Report

⁵ Pearson, (2006) *Direct Payments and Personalisation of Care*, Edinburgh, Dunedin Academic Press