



Opening statement to the Joint Committee on Disability Matters, Wed 22 November 2023

‘Awareness Raising: Article 23 Respect for home and family life’.

The Centre for Disability Law and Policy at the University of Galway welcomes this opportunity to present to the Disability Matters Committee on Article 23 of the UN Convention on the Rights of Persons with Disabilities. In this opening statement, I will outline Ireland’s key obligations under the Convention in respecting the right to home and family life of disabled people, and some of the barriers and facilitators in realising these rights in Ireland as evidenced in a research project funded by Wellcome which we completed last year.

UNCRPD Article 23 and Article 8

Article 23 explicitly references the right to equality for persons with disabilities in decisions about fertility, reproductive and family planning. It requires States to ensure “the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.”¹ Further, it recognises that persons with disabilities, including children, have the right to “retain their fertility on an equal basis with others.”² This must be read in tandem with the right to the highest attainable standard of health, including sexual and reproductive health, for disabled people and the provision of healthcare on the basis of free and informed consent in Article 25. When read together with the awareness-raising obligations the State has in Article 8 of the Convention, and the obligations to actively involve disabled people in the development of laws and policies which affect their lives in Article 4, it becomes clear that the Convention represents a significant commitment to making these rights a reality for many disabled people.

The Re(al) Productive Justice Research Project

Re(al) Productive Justice Project, was a research project undertaken from 2019-2023 and funded by the Wellcome Trust. The project was carried out by myself as Principal Investigator, alongside my colleague Emma Burns with me today, two postdoctoral researchers Dr. Jenny Dagg and Dr. Aine

¹ Article 23(b), UNCRPD.

² Article 23(c), UNCRPD.



Sperrin, and research assistant Maria Ní Fhlatharta. The research explored the experiences of disabled people making reproductive decisions in Ireland, in all aspects of their lives – including in fertility, contraception, abortion, pregnancy, parenting and birth.

Between 2019 and 2021, we carried out twenty seven interviews with expert informants from legal, health and social work professions and thirty two oral history interviews with disabled people including people with chronic or long-term illness, physical, sensory, and intellectual disability, people with experience of mental health services (including those who identify as survivors of psychiatry), the Deaf community, autistic and neurodivergent people, and those who do not identify with any label or diagnosis but have experienced discrimination because they are perceived by others as disabled. In this opening statement I will briefly outline the key findings from our research project as they relate to each of the focus areas identified by the Committee.

Sex Education for Students with Disabilities

Ireland has limited sexual health education for disabled adults who did not have access to mainstream education in their youth. These adults are subject to the ethos and knowledge of their disability service provider or families. Where education is provided through disability services, the focus tends to be purely biological.³ Without relationship education to accompany the biological knowledge, disabled people have gaps in what to expect of sexual relationships, how to protect themselves against abuse, and the realities of child-rearing, which are all factors in fertility and contraceptive decisions.

Suppression of the sexuality of disabled people has long been commonplace. Segregation by sex within religious-run disability services – including schools, training centres and residential settings – continues today, reducing the opportunities for people to meet others and form intimate relationships, while disabled LGBT people face ‘double discrimination’, often choosing not to disclose their sexuality as long as they remain under the control of family or disability service staff.⁴ These settings place barriers to disabled people’s pursuit of relationships, family life and reproductive

³ Kelly, Crowley and Hamilton (2009)

⁴ GSD report 2005 (quoted in Independent <https://www.independent.ie/irish-news/double-discrimination-for-the-gay-and-disabled/25992574.html>)

choices. This is compounded by the State's failure to provide comprehensive, inclusive sex education to the general population from youth.⁵

Bren, a participant in our research, told us about his lack of sex education as a person with an intellectual disability.

"Even in my school, we didn't get sex education. Because I ended up being in the special class, they didn't taught sex education. So, well obviously you watched like obviously porn to figure out what it is and how a man and a woman end up having a child and whatever. And plus, my brothers and sisters tell me about sex education. Yeah. So, I had to watch it on TV to find out what's it all about. Because I didn't know anything about it and they didn't know anything about mental health or anything about composition or condoms or women's health or men's health or if a man is stuck with... All stuff I did not know. And now still stuff that I don't understand"

Disabled parents are more at risk of losing custody of their children

The legislative and policy frameworks around parenting for persons with disabilities in Ireland are complex. The focus of all law and policy in this field is the best interest of the child, which means that the rights of disabled parents are often a secondary consideration. Statistically, we do not know how many disabled people become pregnant and go on to parent, nor do we know how many disabled people become parents through fostering or adoption. While we can see the emergence of the notion that the best interests of the child are generally best served by being supported within their family of origin, this is often undermined for disabled parents when the supports they need to parent effectively are not available, and when the existence of a (perceived) disability is used as a justification for state intervention in family life. Jurisprudence from international bodies, the ECHR and Irish courts demonstrate that discrimination based on disability against parents in childcare proceedings occurs frequently. While there is recognition that disability cannot be the sole basis for interference with a family by external actors, the failure to provide reasonable accommodation and appropriate supports often results in the interference.

⁵ McGuire, P. (n.d.). *Ireland's historic lack of sex education*. [online] The Irish Times. Available at: <https://www.irishtimes.com/news/education/ireland-s-historic-lack-of-sex-education-1.1679110> [Accessed 25 Feb. 2022].

The Childcare Law Reporting Project and Voluntary Care in Ireland project⁶ reports that disabled parents are disproportionately represented in formal and informal childcare proceedings. Care orders requiring children to be separated from their parent/s can operate through voluntary care agreements which do not require legal process, or a formal involuntary basis sanctioned by a judge. A voluntary care agreement may be less adversarial, stressful, or costly for parents, however the UCC study on Voluntary Care in Ireland⁷ raised significant concerns from the perspective of parental rights. They highlighted the prevalence of parents with disabilities particularly those with experience of mental health services or a cognitive impairment, and the lack of independent legal advice before signing, unlike parents in childcare court proceedings that require legal representation.⁸ Additionally, disabled parents may feel under duress by social workers to consent to a voluntary care agreement or have an application made against them to be brought to court instead.⁹ The reality of voluntary agreements that are not subject to consistent review is that as time passes, fewer opportunities present either for parent or for child to express their views on decisions affecting them, all the while remaining separated from one another.

The HSE Child Protection and Welfare Practice Handbook 2 (2018) maintains parental mental health and parental disability issues as key risk factors and states that appropriate supports available should be identified in the first instance to minimise interventions. While the recommendation to make appropriate referrals for parental support is important, there is a high risk that the services offered as 'support' may be experienced by parents as intrusive or unhelpful, and that this can be used as further evidence of parental incapacity.

The problem with identifying specific disabilities as high-risk results in parents with such labels or diagnoses being held to a higher standard of what is expected of their parenting prior to any interventions being imposed. Rather than raising red flags that from the outset scrutinise disabled parents further or even removing the child, parents could benefit from a system of coordinated family supports within our family resource centres that are disability inclusive, trauma informed and non-invasive at both the universal and low intervention level as indicated within the Parenting Support Strategy (2013).

⁶ The Child Law Project <https://www.childlawproject.ie/about/>

⁷ Brennan, R., O'Mahony, C. and Burns, K. (2021), 'The rights of the child in voluntary care in Ireland: a call for reform in law, policy and practice', *Children and Youth Services Review*, pp. 1-38

⁸ The Child Law Project. <https://www.childlawproject.ie/about/>

⁹ O'Mahony, C., Burns, K. and Brennan, R. (2020a) What are voluntary care agreements? *RTÉ Brainstorm*.



Eva, a participant in our research, reported how she was treated differently from the moment she disclosed her autism diagnosis when pregnant. She felt health professionals were constantly on the lookout for things to go wrong, resulting in misunderstandings and false allegations after the birth of her child regarding the correct disposal of nappies, the swaddling of her child, and the correct feeding regime. As a result, Tusla recommended that Eva and her child be located in a residential parenting assessment unit for monitoring, where Eva felt surveilled and unable to parent her child in her natural home environment. She described to the team how she felt it had been a mistake to disclose her own diagnosis during the pregnancy:

“Yeah, I shouldn’t have mentioned it because it went all downhill from there. It was put on the front page of every section of my medical file that I had... And it was very intimidating. I wasn’t happy. I wasn’t happy with all the staff seeing it like that and I felt a difference in how I was approached and how people were communicating with me. I felt I was being looked upon as different even though the staff may not have seen it that way themselves. I definitely sensed that difference. The nuances of conversation. And [how] I was approached – it was like I wasn’t seen as being a normal person. They were looking out for things to go wrong”

Lack of linkage between maternity, community services and disability service providers

Disability services are often the primary connection for the person to a community beyond their immediate family and may be the only place a disabled person has to turn to for reproductive advice or information. The potential position of disability services as the main point of contact for reproductive care can result in ethos-led restrictions or can result in practical access to options for information and care. While there is evidence of progress to recognise human rights within disability services, progress is slow (HIQA, 2019). Historically, the entanglement between disability service provision and religious orders has resulted in the obstruction, refusal and restriction of a range of reproductive issues for disabled people in Ireland, including the provision of sex education, access to contraception, intimate sexual relationships, the decision to have or not have a child, and so on (IFPA, 2007).



Almost all participants in the Re(al) Productive Justice project who were parents described experiencing prejudicial attitudes or ableism from professionals. This was experienced on a sliding scale with parents with physical disabilities and Deaf parents describing excess scrutiny and unequal expectations of their parenting to those with intellectual and psychosocial disabilities experiencing removal of children from their care shortly after birth without any disability specific support being provided during pregnancy nor in place for when the child was born. For all disabled parents, questioning and scrutiny began during pregnancy with fear inducing questions for first-time parents such as “But how will you manage?” which was rarely followed up with practical solutions or suggestions from professionals as to how disabled expectant parents could access support to navigate their life with a newborn and beyond.

Bernie, single parent with a physical disability, who has been in residential care since the age of 18, spoke to our research team about the difficulties she faced when she became pregnant due to a lack of joined up thinking between disability support and housing accommodation. Her residential centre was unable to accommodate mother and child living together, and while efforts were made by the disability service provider to accommodate Bernie while she was pregnant, she was required to go on the homeless housing list once her child was born. This resulted in her having to put her child into voluntary foster care shortly after she was born, enter a mother and baby residential placement and undergo a parental capacity assessment solely for accommodation purposes, and then move to a family hub while awaiting suitable accommodation from the council where she continues to live presently.

Consideration of the need to move beyond protective, medical, and gender binary model (that research highlights is integral to Art. 23) to address sexual and reproductive rights of persons with disabilities / Reproductive Justice

As our research, and the human rights framework established in the UN Convention makes clear, there is an evident need to move beyond overly protective and intrusive responses, grounded in a medical model of disability, to achieve reproductive justice for disabled people. The term ‘reproductive justice’ was first coined by Black women in the Southern US to describe the ‘choice to have a child, to not have children, and to parent the children we have in safe and sustainable communities’ – and this is deeply relevant and necessary for disabled people in Ireland today. A disability justice approach is



needed to achieve reproductive justice for disabled people – which means that we need to redistribute the labour of access throughout disabled people’s reproductive journeys. As our research has shown, it is often disabled people themselves who are burdened by the system with finding all their own solutions to the supports they require to make reproductive choices, and they experience disability-specific barriers in accessing sexual and reproductive healthcare and related support services. Instead of asking disabled people to take on all this additional work, we need to redesign our systems in an inclusive and accessible way, to accommodate the needs of disabled people from the moment they first seek support with their reproductive choices. The active involvement and participation of disabled people and their representative organisations remains essential to achieve the goal of the UN Convention, and to ensure that in accessing sexual and reproductive services, in every arena from family planning, to parenting (including the laws on assisted human reproduction, custody and access, and fostering) that disabled people have choices equal to their non-disabled peers, and the support needed to make those choices a reality.