



Re(al) Productive Justice

GENDER AND DISABILITY

Final report



OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY
LAW & POLICY



Introduction

Re(al) Productive Justice Project, was an Irish project undertaken from 2019-2023 and funded by the Wellcome Trust. The project was carried out by the Principal Investigator, Prof. Eilionóir Flynn, postdoctoral researchers Dr. Jenny Dagg and Dr. Aine Sperrin, research associate Emma Burns, and research assistant Maria Ní Fhlatharta, from the Centre for Disability Law and Policy at University of Galway. The research was centred on the desire to make visible the experiences of disabled people making reproductive choices in Ireland within regulatory frameworks that limit their available options.

The concept of 'reproductive justice' is one that emerged from activists who sought to inject a social justice focus into mainstream discourse on reproductive rights. It is described as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities' (Sister Song [\[online\]](#)). The reproductive justice framework explores the experiences of injustice that surround the reproductive journey. We have used this approach throughout our research, gathering experiences and insights from disabled people and professionals supporting them. Our research made analytical distinctions between different stages of the reproductive journey to encapsulate and investigate different barriers encountered at different phases of reproduction for disabled people. Our topics included fertility and contraception (incl. surrogacy and assisted human reproduction); abortion; pregnancy and birth; and parenting (incl. fostering and adoption).

For the purposes of the project, the approach our research takes to the conceptualisation of 'disability' follows the ethos of the UN Convention on the Rights of Persons with Disabilities. We understand 'disability' to include "those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"¹. We view this statement as an open-ended inclusive approach to the question of 'who counts' as disabled. Within our research, we took care to use different terminology to be as inclusive as possible in understanding the diversity of the disability community.

A disability human rights research method² was adopted that adhered to the three core principles for rights-based disability research.

- I. *Ensuring the research is initiated and led by voices from the disability community.*
- II. *Ensuring that the research responds to a rights concern.*
- III. *The research is returned to the community.*

Qualitative data in the form of key informant interviews with health, social care and legal professionals, and in-depth narrative interviews with disabled people were collected during

¹[United Nations \(2006\), Article 1 – Purpose, accessed 20 April 2022 at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html)

² Arstein-Kerslake, A., Maker, Y., Flynn, E., Ward, O., Bell, R., Degener, T. (2020), 'Introducing a Human Rights-based Disability Research Methodology', *Human Rights Law Review*, **20** (3), 412–432.

2019-2021. In total, we carried out twenty seven interviews with expert informants from legal, health and social work professions and thirty two narrative 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.

As part of the requirements of the project, the Re(al) Productive Justice research team analysed the laws and policies in operation in Ireland that regulate reproductive choices and produced a series of working papers on the regulatory system in Ireland across the topics of the project. In line with the principles of our research method the oral histories have been archived with the Digital Repository of Ireland for future use and are available [here](#).

Additionally, the research team developed topic toolkits for health, social care and legal professionals along with a communication guide for professionals, and a 'Know your rights guide' for disabled people. These resources can be accessed on the website of the Centre for Disability Law and Policy.

Overarching themes

The reproductive justice framework is not about concentrating on a distinct aspect of reproduction, instead it focuses on the experiences of injustice that surround the reproductive journey. Support, and the denial of support appears heavily within the qualitative data, along with accessibility and inaccessibility of services, service provision, information, and transportation. From these overarching themes where support was received or denied, or where services were accessible or not, we distilled further barriers and facilitators to reproductive decision-making that occurred across the topics. We also identified topic specific barriers and facilitators when making reproductive decisions that are discussed individually in the topic sections below.

Support as a facilitator of reproductive justice includes any instance where a person feels supported physically, emotionally, socially or economically by another person or organisation. This presented in narratives as instances where a person is provided with information that assists their decision-making process; is given a referral pathway to a professional or expert that can further inform their decision-making process or facilitate the development of their skills; is provided with advocacy to express their will and preferences or situations that improved their social capital. Support was particularly pronounced when disabled people encountered health and social care professionals that sought to understand, from the disabled persons perspective how they would like to be supported, and then acted in line with this. Such encounters enabled the disabled person to feel visible as a person capable of reproduction equal to their non-disabled peers. For example, we heard how a referral to an occupational therapist assisted a physically disabled pregnant person develop techniques to care for her newborn infant. This supportive relationship to find solutions enhanced the agency and subjectivity of the person as a disabled parent, instilling confidence at the everyday level.

Denial of support was described by participants when they did not feel supported either through information, by a professional, or organisation, or their family, peer or social network. Distinctive within the barriers as opposed to the facilitators was the presence of ableism. Ableism, as described by Bogart and Dunn³, 'refers to a network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is presented as perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human'. More broadly, ableism is also aligned with stereotyping, prejudice, discrimination, and social oppression toward people with disabilities. Participants narratives of ableism often entwined feelings of being stereotyped, or of prejudice that gave way to stigma at the social, personal and institutional level. However, discrimination was understood when participants discussed experiences where they felt a denial of their rights based on disability. For example, we heard how a mother with aspergers syndrome experienced a lack of understanding and denial of support for her disability that resulted in compounding issues which culminated in the removal of her child from her care.

Overarching barriers that were identified across the topics from analysis of the regulatory framework and qualitative data included:

- Inaccessibility of services including geographic location, spatial distribution of services, transportation and information.
- Denial of support by health and social care professionals including the failure to provide referrals, to consider alternative options, or to adapt services to meet specific needs.
- Ableism including prejudice, bias and discrimination
- Invisibility of disabled people along the reproductive journey

Overarching facilitators that were identified across the topics from analysis of the regulatory framework and qualitative data included:

- Adaptability of services and accommodations made by service providers to recognise specific needs of disabled people
- Affordability of services
- Accessibility of services including information, transport and service provision
- Acceptability of relationship between provider and user including level of knowledge of disability by health and social care professionals

This report presents a brief overview of the context in which the topics of our project are regulated by laws and policies in Ireland. It then outlines the barriers and facilitators identified from our analysis of the regulatory frameworks that constrain and enable specific choices for disabled people, as well as our analysis of the qualitative data from each specific topic of the project. We then present key findings that are important to consider and implement to respect the human rights of persons with disabilities along their reproductive journey.

³ Bogart, K. R., Dunn, D. S. (2019), 'Ableism Special Issue Introduction', *Journal of Social Issues*, **75** (3), 650-664.

1. Fertility and Contraception

Overview of regulatory context

Irish law on the issue of fertility and contraception has changed considerably in tandem with shifting social norms. Between 1935 and 1979, heavily influenced by a conservative society and the Catholic Church, the import, sale and advertising of contraceptives was prohibited⁴ under Irish law. In 1974, the most revolutionary case law surrounding fertility and contraception in Ireland has been *McGee v The Attorney General*⁵ in 1974, in which a young married woman had been warned of the dangers to her health and life of becoming pregnant again. She argued that the ban on contraception was a risk to her life. The Supreme Court found that married couples have a right to privacy which included the right to family planning and accessing contraception. This ruling led to the repeal of the both the importation and advertising of contraceptives by Health (Family Planning) Act 1979. Since then, the availability of contraception has increased, with the disposal of the need for a prescription for emergency contraception only occurring in 2011.⁶ In September 2022, as part of the Women's Health Action Plan 2022 – 2023, a free contraception scheme was launched for women aged 17–25.

There is case law indicating that adults with disabilities who are wards of court have decisions made by the High Court in relation to their fertility and contraception. A recent application to the High Court in 2020 related to the administration of a contraceptive injection to a woman with physical and intellectual disabilities.⁷ Another case involved the administration of contraceptive injections to a ward of court, despite opposition from the woman.⁸ More recently case law has concerned the use of assisted reproductive methods to enhance or future-proof fertility. This remains a largely unregulated area of medical care in Ireland and the potential impact for reproductive justice of persons with disabilities is significant. While these do not relate to persons with disabilities explicitly, the case law has contributed to the current and future legal landscape on assisted reproduction in Ireland which it is anticipated persons with disabilities will avail on an equal basis with others. The *Roche*⁹ case involved a dispute over the use of frozen embryos. The former husband of a woman seeking to have the embryos implanted objected to their use. Clarity was sought on the extension of the protection of the 'unborn' under Article 40.3.3. Embryos at pre-implantation stage were not considered to amount to the 'unborn'. Since the repeal of Article 40.3.3 in the Irish Constitution, this judgement may not be so influential in future caselaw surrounding assisted human reproduction. Other cases involving donation¹⁰,

⁴ Criminal Law Amendment Act 1935, s. 17

⁵ *McGee v. AG* [1974] IR 284

⁶ RTE, 'IPU welcomes morning after pill decision', <https://www.rte.ie/news/2011/0216/297748-pill> 16 Feb 2011.

⁷ Mary Carolan, 'Judge orders contraceptive injections for vulnerable mother of two', Irish Times, Wed, Jan 15, 2020.

⁸ Mary Carolan, 'Mentally ill woman may be given contraceptive injection', Irish Times, Mon 26 June 2017.

⁹ *Roche v Roche & Others* [2009] IESC 82

¹⁰ [2007] 8 I.C.L.M.D. 61

surrogacy and assisted human reproduction¹¹ have highlighted the precarity of legal protections surrounding guardianship and parental responsibility for the resulting children.

There is limited research available on access to fertility and contraception among the disabled population in Ireland. The stereotypes around disabled people's sexuality has been reported by Selina Bonnie who argues that because the focus of the disabled people's movement has been on independence, housing and employment that relationships and fertility have not been prioritised.¹² A core element of accessing fertility and contraceptive services is awareness and knowledge of these issues and how they relate to the individual. The Irish Sex Education Network in 2007 commissioned an overview of the available education to persons with intellectual disabilities¹³. The report acknowledges the balancing act which disability services must engage in to promote independence of their service users while also preventing harm within the then framework which criminalised sexual relations for adults with intellectual disabilities. The research found a lack of consistency in the provision of sexual health education and where it is provided it was considered to be of poor quality. It recommends that staff receive accredited training and support to families and carers to assist a service user to express their sexuality be provided.¹⁴ Kelly, Crowley and Hamilton note the impact of previous Irish laws¹⁵ in restricting the ability of adults with intellectual disabilities to be supported to engage in consensual relationships¹⁶. Their qualitative research indicates the lack of sex education received by adults with intellectual disabilities resulted in reliance on TV for information about sex and relationships. Disability services are identified by the research participants as core to their experiences of being supported to have or discouraged from having intimate relationships.

Persons with disabilities are considered within the Department of Health's Report of the Working Group on Access to Contraception in Ireland¹⁷. Reference is made to persons with disabilities under the 'marginalised and vulnerable groups' section. It recognises the need for contraceptive services that are accessible to persons with disabilities, along with ethnic minority groups, and to ensure education for these populations is delivered through community representatives. However, the report indicates that any scheme for contraception does not encroach on issues of consent.

¹¹ MR, DR, OR and CR v An tArd Chlaraitheoir, Ireland and the Attorney General, [2014] IESC 60

¹² Bonnie, Facilitated Sexual Expression in Ireland, 2002, <https://www.independentliving.org/docs6/bonnie200208.html>

¹³ Allen and Seery, The Sexual health centre, The Current Status of Sex Education Practice for People with an intellectual Disability in Ireland, <http://www.sexualhealthcentre.com/PUBLICATIONS/SHC%20Disability%20Report2.pdf>

¹⁴ *ibid.* 78

¹⁵ Criminal Law Sexual Offences Act 1993, Section 5, 'Protection of mentally impaired persons' makes it an offence to have intercourse or attempt to have intercourse with someone who is mentally impaired. This provision was intended to safeguard against sexual abuse.

¹⁶ Kelly, Crowley and Hamilton, 'Rights, Sexuality and Relationships in Ireland: 'It'd be nice to be kind of trusted'', (2009) British Journal of Learning Disabilities, Vol.37 (4), p.308-315

¹⁷ Department of Health, 'Report of the Working Group on Access to Contraception in Ireland', October 2019, available from: <https://assets.gov.ie/38063/89059243e750415ebf7e96247a4225ae.pdf>

It is well established in international human rights law that disabled people have a right to information which enables them to make decisions about their own fertility and contraception use. All interventions relating to fertility and contraception should be performed with the consent of the patient – although the imposition of these measures through wardship undermines this right of personal consent. Health and social care services which are available nationally related to fertility and contraception should be equally available to persons with disabilities. This includes the physical infrastructure where services are delivered, non-discriminatory attitudes from staff and the availability of information in accessible formats. Sex education and support for relationships among disabled people in Ireland has been influenced by protectionist laws and policies. More recent laws recognising the diversity of families is not fully inclusive of parents who have availed of fertility services abroad. The current lack of regulation of Assisted Human Reproduction and the proposals for the Assisted Human Reproduction Bill are concerning as these may allow for discrimination against intending disabled parents.

Barriers

- Ableism: disabled people reported being subject to attitudes that deny their status as sexual beings or which position them as being unsuitable or undesirable for procreation. Other aspects of disabled people's intersecting identities – such as class and race - can cause further devaluing of their fertility and status as sexual beings. Ableism can manifest in denial of access to services and the questioning of disabled people's parenting capabilities.
- Accessibility: from the inaccessibility of the physical infrastructure to the absence of inclusive design in contraceptive devices to the lack of accessible information in a variety of communication formats, accessibility remains a barrier across all aspects of fertility and contraception service provision.
- Cost: Disabled people are typically over-represented in lower income households in Ireland, restricting the reproductive choices available to them. This particularly affects access to long-duration contraceptives and to assisted human reproductive services which are predominantly provided through private fertility clinics.
- Lack of education: sex education has been poor for the population generally but it has been particularly lacking for disabled people, with people with an intellectual disability facing the most barriers, including lack of information in adult life.
- Coercive practices: whether pressure from professionals to accept contraception or the undue influence of family members on reproductive choices, exertion of control and coercion prevents many disabled people from accessing fertility and contraceptive services on an equal basis with non-disabled people.

Facilitators

- Support: having a supportive network – whether of family, friends or staff – has been shown to improve outcomes for disabled people as they encounter conflict in their pursuit of access to reproductive choice.

- Accessibility: adaptations made as a result of the covid pandemic have in many cases improved access for disabled people, including telemedicine, reconfigured physical spaces and increased innovation and flexibility of staff.
- Individual professionals: positive encounters with individual professionals who are willing to take an open approach and engage in problem-solving with the disabled person.
- Service-wide training and ethos: where services 'get it right' with regard to information provision and support, disabled people report increased feelings of trust in their support and as a result confidence in their own decisions.

Key Findings

- Disability awareness training is needed for all practitioners.
- The Health (Assisted Human Reproduction) Bill 2022 is scheduled for enactment in 2023. It is essential that the associated regulatory framework will not discriminate on the basis of disability. The current General scheme, combined with the ableism inherent to current fertility service provision, could lead to judgements and stereotypes being applied which view potential parents who have disabilities as ineligible for treatment, preventing them from conceiving children.
- Sex education for young people is not consistent across schools and does not always include the particular issues that disabled young people may face. There are few programmes available to older people – particularly people with an intellectual disability who lived in residential facilities or attended segregated schools when younger.
- Training on the supported decision-making mechanisms of the Assisted Decision Making (Capacity) Act 2015 should help staff to understand and discontinue – and help families to discontinue – coercive practices

2. Abortion

Overview of Regulatory Context

From the 1980s, the law within the 8th amendment restricted reproductive care and freedoms for women in Ireland. Historical accounts of people travelling from Ireland to receive abortion care in England point towards not only the issue of prohibition but also wider systemic societal failings of note for reproductive justice – lack of employment, of unmet housing need, and taboo relationship statuses (RTE Archives). Reproductive care was refused or prohibited in instances where medical professionals believed they were contravening the 8th amendment. It was not until a grassroots campaign which had been building in the decades before succeeded in repealing the 8th amendment in 2018, that constitutional and legislative change for the provision of abortion care and services in Ireland became possible. Grassroots movements emerged to call for radical overhaul of Irish laws governing reproductive care, many of which were inclusive of or focused on the experiences of more marginalized groups including trans people, disabled people and migrants. However, the official platform from which the campaign to repeal the 8th was directed in the final weeks leading up the referendum sought to appeal to a more conservative audience, and in this process, many

different groups were excluded, including disabled people.¹⁸ A focus on easing the discomfort of those who are anti-choice has resulted in a system that does not serve everyone equally and has left disabled people in the margins.¹⁹ As a result, Ireland has failed to completely decriminalize abortion resulting in a conservative interpretation of the Act, has included measures such as waiting periods, and fails to ensure equitable access to services.²⁰

Ireland has undergone significant change in the regulation of abortion services since 2018 moving from a structure where abortion was almost completely prohibited to a system which provided for abortion. Abortion is now available on request in early pregnancy, in cases of fatal fetal anomaly, and in situations of risk to health or life.²¹ The Health (Regulation of Termination of Pregnancy) Act 2018 provides for abortion care on a number of limited grounds: on request with restrictions up until 12 weeks, where there is a risk to the life or health of the pregnant person, or in situations where the foetus is unlikely to survive birth. While the current legislation is a significant improvement in recognizing the rights of pregnant people in Ireland, many of the difficulties facing disabled pregnant people occur as a result of the narrow grounds on which abortion care can be accessed under the Act.

Barriers:

- The interaction of ableism and the ongoing stigma of abortion makes support difficult to access and contributes to feelings of shame.
- 3-day wait period increases the labour of access and cost on disabled people to receive abortion care.
- Lack of accessible information in a variety of communication formats.
- Presumption of capacity when a disabled person is making an abortion decision is not guaranteed and often subject to scrutiny.
- Weaponising the Assisted Decision Making (Capacity) Act 2015 as an obstruction to timely decision making in line the persons will and preferences.
- Inaccessible service provision given the geographic availability of termination services in Ireland.
- Inaccessible restrictions for those who may need to travel overseas to obtain an abortion beyond 12 weeks.

Facilitators:

- Support from community, and in particular peer support

¹⁸ Burns, Summer School (2019) <https://emmaqburns.com/2018/09/19/10thdss-intersectionality-and-the-irish-abortion-rights-campaign-of-2018/>

¹⁹ Abortion Rights Campaign and Grimes. Too Many Barriers: Experiences of Abortion in Ireland after Repeal. Sept. 2021. https://www.abortionrightscampaign.ie/wp-content/uploads/2021/09/Too-Many-Barriers-Report_ARC1.pdf

²⁰ de Londras , “Intersectionality, Repeal, and Reproductive Rights in Ireland” in Shreya Atrey and Peter Dunne (eds) (2020), Intersectionality and Human Rights Law (Hart Bloomsbury), 125-145; Conlon et al UNPAC Study (2021) <http://hdl.handle.net/10147/634195>

²¹ Health (Termination of Pregnancy) Act 2018

- Agencies which offer support often bridge that gap where a person's natural support structure is unavailable.
- Ability to access abortion from regular healthcare provider ensures understanding of the persons access requirements.
- Telemedicine option provides greater access for disabled people.

Key findings:

- Access to clear, accurate information is paramount. This information should be in plain language and in accessible formats such as easy to read, video, and Irish Sign Language.
- The many areas of Ireland where abortion is not accessible in the local community results in disabled people having to travel and makes abortion inaccessible.
- The Health (Termination of Pregnancy Act) 2018 requires significant amendments including the health ground which needs to be expanded. Broadening access to abortion in legislation beyond specific grounds will benefit disabled people.
- The three day wait acts as a barrier which disproportionately impacts marginalized groups including disabled people.
- Greater choice of abortion method needs to be facilitated. Disabled women are disadvantaged by not having choice as to abortion method.
- The interaction between abortion and capacity law needs to be made clear, and capacity should not be used to either coerce someone into, or prevent someone from, accessing an abortion.
- Disabled people need to be respected in their choices, whether they decide to continue a pregnancy or not.

3. Pregnancy and Birth

Overview of regulatory context

In order to understand the lived and practiced realities of disabled people during pregnancy and birth in Ireland, it is essential to appreciate the regulatory context in which health and social care services during pregnancy are provided. The practical delivery of maternity services is an area more governed by policy than law, with developments such as the National Maternity Strategy: Creating A Better Future Together 2016-2026²², National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death²³, HIQA's Safer Better

²² [Creating a better future together, https://health.gov.ie/wp-content/uploads/2016/01/Maternity-Strategy-web.pdf](https://health.gov.ie/wp-content/uploads/2016/01/Maternity-Strategy-web.pdf)

²³ <https://www.hse.ie/eng/services/list/3/maternity/bereavement-care/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death.pdf> accessed on 14 August 2019.

Health Standards for Maternity Services²⁴, HIQA's programme of monitoring these Standards²⁵, the development of a model of care for specialist perinatal mental health services²⁶, and the first National Standards for Antenatal Education²⁷. Of these, only the HIQA standards contain specific guidance for disabled pregnant people – including an explicit requirement to provide services without discrimination on the basis of disability, ensure that antenatal care and education is provided in an accessible manner, and provide specific disability competence training for all healthcare staff. However, while HIQA can and does publish inspection reports on maternity settings, failure to comply with the standards does not necessarily have immediate or serious consequences for the ongoing operation of that particular provider.

Universal non-means tested healthcare is now available during pregnancy and following birth up to 6 weeks. This is typically provided by a combination of General Practitioners and maternity hospitals (including Obstetricians and midwives) depending on the stage of pregnancy and care needs of the individual. A number of free scheduled visits are provided for that alternate between primary care and the hospital setting or midwives clinic depending on whether the pregnancy is categorised as normal, medium or high risk. Normal risk pregnancies are categorised as receiving supported care which is midwife-led and delivered; whereas medium-risk pregnancies receive assisted care which is obstetric-led and midwife-delivered. High risk pregnancies receive specialised care which is obstetric-led and obstetric and midwife-delivered, with input from anaesthesia and critical care as required (Department of Health, 2020). Not all disabled people will automatically be categorised as high-risk pregnancies; however, a much higher rate of disabled people's pregnancies fall into this category compared with non-disabled people. This limits the choices for care which disabled pregnant people have available to them in several important ways, including their options to avail of midwifery-led care and home birth.

While all pregnant people in Ireland are entitled to use public maternity services free of charge, people can opt for semi-private or private maternity care. Disabled pregnant people with private health insurance may opt for more private care to try to retain greater control over the decision-making process during pregnancy and birth, particularly if they establish a positive trusting relationship with a particular Consultant Obstetrician. One of the advantages of private maternity care for disabled people is consistency in terms of the healthcare professionals the person encounters throughout their pregnancy and birth – in the public system the person may meet a different midwife or doctor on each visit and while information related to disability will be contained in the person's file, many respondents in our research

²⁴ <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf> accessed on 13 August 2019.

²⁵ HIQA. (2020) Overview report of HIQA's monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

²⁶ HSE. (2017) Specialist perinatal mental health services. Model of care for Ireland. Retrieved from <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>

²⁷ HSE. (2020) National standards for antenatal education in Ireland. Retrieved from <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>

reported having to explain their impairment and justify their decisions over and over again on each visit to a new professional which created barriers in the continuity of care and respect for autonomy.

There is evidence in broader literature on maternity services in Ireland that concerns about liability in the context of negligence claims impacts on their practice and can lead to more conservative decision-making in pregnancies. For disabled people, a risk-averse culture in Irish maternity services, compounded by medical hierarchies, and underpinned by legal regulation, can lead to disproportionate interventions in their pregnancies when compared with the experiences of non-disabled people.

It is estimated that over twenty thousand women experience emotional distress as a result of pregnancy, birth or becoming a parent each year in Ireland and could benefit from perinatal mental health support services²⁸. The Specialist Perinatal Mental Health: Model of Care²⁹ was also launched in 2017 by the Mental Health Division of the HSE. This model of care supports the seven actions on mental health to be implemented by the HSE's National Women's & Infants Programme outlined in the National Maternity Strategy. The perinatal model of care outlines how six of the largest regional hospitals will serve as core hubs for perinatal mental health services and each hub will support a number of smaller hospitals, referred to as spokes³⁰. It identifies the need for a mother and baby unit, where a mother in need of mental health services can be treated while caring for and remaining with her baby, arguably an important aspect of the recovery. There is currently no such unit in Ireland; yet the model of care recommends a six bedded unit per 15,000 deliveries³¹. It also recommends that community mental health services should have the option of ensuring there is no separation from children where desired. Staff from psychology, occupational therapy and social work are listed alongside psychiatry as core staff within perinatal mental health services³².

While most births in Ireland take place in a hospital setting, the option of home birth is available in limited circumstances. A free public home birth service is available only in some parts of the country provided by self-employed community midwives on behalf of the public health services. The eligibility criteria for accessing this service would exclude many pregnant disabled people from home birth as their pregnancies would be considered too high-risk and not suitable for home birth³³. However, the criteria do not take into account important factors which might lead disabled people to opt for a home birth over hospital care. This include the inaccessibility of the hospital environment as compared to the person's home; where disabled people will typically have arranged and designed their homes to be highly accessible

²⁸ <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/spmh-infographic.jpg> accessed on 14 August 2019

²⁹ <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf> p 32-34.

³⁰ <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf> p 32-34.

³¹ <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf> p 44

³² <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf> p 51

³³ <https://www.hse.ie/eng/services/list/3/maternity/new-home-birth-policies-and-procedures/>

and responsive to their needs. The guidelines also do not acknowledge that disabled people may be more likely to have experienced medical trauma in the past or to be survivors of sexual violence, which can make giving birth in a medicalised environment extremely distressing for the individual.

For those deemed ineligible for public home birth services, there is the option to access private home birth services but again this depends on the individual having access to private financial resources which limits its availability for many disabled people. Where accessing private home birth services, midwives are not covered by the health services' Clinical Indemnity Scheme in the event of any later medical malpractice claim or inquest. Therefore individuals accessing private home birth services are advised to ensure their midwife has alternative insurance available. Even if disabled people have the means to access private home birth services, given the clinical risk involved in many disabled people's pregnancies, it would be difficult to secure this option as even private midwives may not be willing to support home birth for pregnancies categorised as high risk.

Many pregnant people in Ireland have reported non-consensual medical interventions during pregnancy and birth in situations which fall well outside the doctrine of necessity – including cervical sweeps, rupturing membranes to induce labour, vaginal exams, foetal heart monitoring during labour, etc.³⁴. In particular, the AIMS finding that 50% of respondents (over 3,000 women) felt unable to make an informed refusal of a proposed intervention during pregnancy or birth, is heightened in the context of disability, where pregnant people who participated in our research were very aware of the challenges to their parenting ability that quickly arose if they refused interventions proposed during pregnancy and birth. At times explicit links were made by health and social care professionals between someone's refusal of treatment or services during pregnancy – when professionals believed the intervention was what was best for the baby, and the pregnant person's ability to parent following the birth. In other cases, while no explicit link or threat regarding future parental rights were made by professionals, disabled people policed their own behaviour in anticipation of such a threat arising. This self-policing or internalised ableism does not arise in a vacuum, but is based on years of experience of engaging with health and social care services, and a deep understanding of how these systems can operate to undermine the individual's autonomy.

In this context, we consider how disabled pregnant people make choices about how they navigate maternity, ante-natal and post-natal care, based not only on what they know they need, but what they think is most likely to lead to a situation where their ability to parent is not subsequently called into question.

Barriers

- Ableism of professionals occurred frequently in the narratives of disabled pregnant people. This pivoted on assumptions that disabled people should not be pregnant, should not get additional support to become pregnant, or do not want to stay

³⁴ <http://aimsireland.ie/what-matters-to-you-survey-2015/womens-experiences-of-consent-in-the-irish-maternity-services/>

pregnant. For example, the exclusionary criteria that prevents disabled people from accessing different options e.g. home birth even if this might be a more accessible option for the person where they are comfortable in their own environment, compared with hospital environments that can be quite traumatic.

- Higher level of professional interventions in disabled people's pregnancies and birth compared to non-disabled people. Participants also described feeling under intense scrutiny during the process and a need to 'prove' their ability to manage pregnancy and birth.
- Disabled people feeling they can't object to proposed interventions during pregnancy or make informed refusals of certain treatments because this may impact on their parental rights later on (and risk of being made a ward of court and denied legal capacity to make treatment decisions).

Facilitators

- Finding even just one professional who was open and trusted disabled people to know their own body/minds, and advocated for the person's choices to be respected with other professionals
- Peer support from other disabled people who had similar and different experiences of pregnancy and birth provided a safe space for disabled people to complain, strategise and find creative solutions together.

Key findings

- Need to abolish the use of wardship and inherent jurisdiction to order non-consensual interventions during pregnancy and birth and closely monitor implementation of Assisted Decision-Making (Capacity) Act to ensure will and preferences are respected in any interventions during pregnancy and birth
- Remove any exclusionary criteria which unfairly deny disabled people access to more flexible and accessible care options during pregnancy and birth including home births
- Build in accessibility through working collaboratively with organisations led and governed by disabled people to ensure access is available in all maternity settings across a wide spectrum of disability – rather than waiting for disabled pregnant people to arrive to request changes be made to how services are delivered. This can include access audits of maternity units, labour and delivery wards and antenatal classes by people with a wide range of experiences of disability. Individual reasonable accommodations will still need to be made as each person is unique – but provide a base level of access can start before individual requests are made.

4. Parenting

Overview of regulatory context

When it comes to the intersection of disability and parenting the majority of focus is on parenting disabled children. Similarly, the focus of law and policy in this field is the best

interest of the child, which means that the rights of disabled parents are often of secondary consideration. The main legislation governing parental rights, responsibilities and state intervention in Ireland include the Civil Registration Act 2004, the Child and Family Relationships Act 2015, the Guardianship of Infants Act 1964, the Child Care Act 2001, and the Adoption (Amendment) Act 2017. Increasing government interest in parenting support as a policy issue has contributed to a range of stakeholder activity and engagement in the area, while the notion of parenting as a set of skills that can be learned is now widespread. The first overarching national policy framework for children and young people (“Better Outcomes Brighter Futures 2014-2020”³⁵) provided improved support for parents to enable them to feel more confident, informed, and able in their parenting capacity. However, there is very little reference to parents with disabilities in the framework. In line with the national framework above, Tusla has published a new Parenting Support Strategy 2022-2027³⁶ where they recognise diverse forms of family including parents with disabilities and set out four levels of parenting supports: (i) A universal support service to all families forms the foundation for Tusla activities; (ii) this then progresses to low level intervention such as improving parental capacity through training at the second level; (iii) the third and fourth levels are more intense parental supervision and finally alternative care provision is identified where there is deemed to be a risk to the child. Given the barriers we have identified below we recommend that adequate and appropriate support be offered to disabled parents at the earliest stage possible to prevent subsequent and more intrusive interventions. Across the range of supports and tailored supports proposed for parents is it important that these are accessible and incorporate a universal design approach. The Family Resource Centre Programme supported by Tusla delivers universal services to families in disadvantaged areas across the country based on a lifecycle approach. It ranges from the provision of information, advice, support and referrals to delivering education courses (including parenting programmes), training opportunities and the establishment and maintenance of community groups.

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.

³⁵ <https://www.gov.ie/en/publication/775847-better-outcomes-brighter-futures/>

³⁶ https://www.tusla.ie/uploads/content/Tusla_Parenting_Support_Strategy_2022-2027_Web.pdf

We can see through the Childcare Law Reporting Project and Voluntary Care in Ireland project that disabled parents are disproportionately represented in formal and informal childcare proceedings. Care orders requiring children 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 Ireland³⁷ raised significant concerns from the perspective of parental rights. They highlight the prevalence of parents with disabilities particularly those with mental health challenges or a cognitive impairment, and the lack of independent legal advice before signing, unlike parents in childcare court proceedings that require legal representation³⁸. Additionally, they highlight how disabled parents may feel under duress by social workers to consent to a voluntary care agreement, or Tusla will have to make an application to court instead³⁹. The sad reality of such voluntary agreements that are not subject to consistent review is that as time passes less opportunities present for either parent or child to express their views on decisions affecting them, all the while remaining separated from one another.

Barriers

- Denial of support and advocacy for those experiencing legal interventions in the care of their children.
- Lack of visibility of disabled parents, lack of role models, and internalised ableism that links to their identity as parents.
- Inaccessible parenting spaces, for example, lack of universal changing stations, playgrounds, or accessible parenting support groups.
- Unsupportive health professionals
- Discrimination - particularly issues that begin during pregnancy that are not addressed in a supportive manner and that accumulate once the child is born and that can result in interventions that separate parent and child.

Facilitators

- Different types of support that disabled parents received including supportive family members, peer groups, key workers, health professionals and advocacy services.
- Disabled parents' ability to self-advocate often resulted in the access and support they required, however, there is a class dimension attached to this, and also the burden of repeatedly performing this task to advocate for their rights.

³⁷ 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

³⁸ O'Mahony, C., Brennan, R., and Burns, K. (2020b), 'Informed consent and parental rights in voluntary care agreements', *Child and Family Law Quarterly*, Issue 4, pp. 373-395.

³⁹ O'Mahony, C., Burns, K. and Brennan, R. (2020a) What are voluntary care agreements? *RTÉ Brainstorm*.

- Parental connection - practices that seem unconventional or non-conforming to ableist or normative understandings of parental connection.

Key Findings

- Fully accessible and appropriate parenting evaluations that are disability specific.
- Adaptive parenting strategies including adaptive equipment; adapting home environment; accessing information, support and resources; seeking and receiving support, particularly information for prospective parents.
- Disability Awareness training for all practitioners.
- Creating formal peer support networks and place these on a statutory footing in family resource centres or through the PPFS network.
- Inclusive universal parenting programmes

Overall conclusions

We recognise the resource constraints that can stymie the work that legal, health and social care professionals are required to perform. Across the range of professions that we spoke with, staff were eager to enhance their understanding of disability and attune their practices to a rights-based approach, particularly in line with our obligations under the UNCRPD and the enacted Assisted Decision Making (Capacity) Act 2015. However, many of the barriers that presented within our research manifested from people's interactions with one another, reflective of the prevalence of ableism within Irish society and the invisibility of disabled people and their reproductive lives. When disabled people are denied access to reproductive care or decision-making, whether that is in the form of knowledge, services or support we are not committing to our legal obligations nor recognising their rights on an equal basis to their non-disabled peers. Along the reproductive journey, and when making reproductive decisions, our work has highlighted the ways in which disabled people may require specific knowledge or forms of communication, they may need specific support for their particular disability that may be specific to that person, they may need time to process information and to form a decision, they may request or need a support person, they may have particular accessibility requirements, they may require support that is not regular practice or a referral to another practitioner or specialist – all of these are part and parcel of disabled reproductive lives, not something disabled people need to labour to access time and again.

Removing ableism opens the space for what Mia Mingus has described as 'access intimacy' - to describe how it feels when others respond to her needs as a 'queer, physically disabled, transnational adoptee of colour'. She notes: "Access intimacy is that elusive, hard to describe feeling when someone else "gets" your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years. It could also be the way your body relaxes and opens up with someone when all your access needs are being met. It is not dependent on someone having a political understanding of disability, ableism or access. Some of the people I have experienced the deepest access intimacy with (especially

able-bodied people) have had no education or exposure to a political understanding of disability”⁴⁰.

Reproductive decision-making is an intrinsically intimate act, requiring relationships of trust between patients and professionals, between partners and within family and kinship structures. By focusing on ‘access intimacy’ and the ‘labour of access’ in these spaces and where these decisions are made, disability justice opens up new horizons for understanding what constitutes good reproductive care, and what creates an environment where reproductive justice can flourish.

Overall findings

- Disability awareness training is needed for legal, health and social care practitioners operating across the topics including training on the supported decision-making mechanisms of the Assisted Decision Making (Capacity) Act 2015 to help staff to understand and discontinue – and help families to discontinue – coercive practices.
- Build in accessibility through working collaboratively with organisations led and governed by disabled people to ensure access is available in all reproductive care settings across a wide spectrum of disability.
- Remove any exclusionary criteria within reproductive healthcare services which unfairly deny disabled people access to more flexible and accessible care options along their reproductive journey.
- Sex education for young people should be consistent across schools and include particular issues that disabled young people may face. There are few programmes available to older people – particularly people with an intellectual disability who lived in residential facilities or attended segregated schools when younger.

Suggestions for future research

From this research we highlight the need for better questions on disability in any future maternity experience surveys from the HSE (including diverse disability identities and unique disability barriers). We suggest a disability specific analysis of maternity units including built in access standards to HIQA inspections. We suggest inclusive parenting programmes, and disabled peer support groups. Lastly, we suggest more post-repeal analysis of abortion access and any subsequent reforms.

⁴⁰ Mingus, M. (2011), ‘Access Intimacy – The Missing Link’, accessed on 20 April 2022 at <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/>



Centre for Disability Law and Policy
The Institute for Lifecourse and Society
Upper Newcastle Road
University of Galway
Ireland
T. +353 86 4181673



realproductivejustice@nuigalway.ie



[@CDLPJustice](https://twitter.com/CDLPJustice)



Or visit the Re(al) Productive Justice website:

<https://www.universityofgalway.ie/centre-disability-law-policy/research/projects/current/real>



OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY
LAW & POLICY

W
welcome