Working Paper prepared for Discussion Forum on
Pregnancy and Childbirth

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Abstract:
This working paper is to inform the first discussion forum of the Re(al) Productive Justice Project on the topic of **Pregnancy and Childbirth**. It provides an overview of the Irish legal and policy landscape in which persons with disabilities experience pregnancy and childbirth as well as the conditions within which medical, social and legal practitioners deliver their services. It highlights previous research on the experiences of persons with disabilities during pregnancy and childbirth as well as case-law surrounding decision-making relating to disability, pregnancy or childbirth. This indicative work suggests that while significant legislative and policy progress has been made to shift maternity care and services from a traditionally patriarchal and disempowering system towards a more woman-centred approach, much work remains in terms of providing the specific supports required for persons with disabilities during pregnancy and childbirth.

This working paper aims to inform the Discussion Forum on Pregnancy and Childbirth on 20th September 2019. It provides an overview of the Irish legal and policy landscape in which persons with disabilities experience pregnancy and childbirth as well as the conditions within which medical, social and legal practitioners deliver their services. This working paper will be used to familiarise participants from different backgrounds of the context in which disabled people's experiences of pregnancy and childbirth have occurred. Firstly, it will discuss international law relating to disabled people's experience of pregnancy and childbirth. Secondly, it will explore the Irish context in terms of existing policy, caselaw and previous research. It will then conclude by summarising the discussions on pregnancy and childbirth during the Opening Conference of the Re(al) Productive Justice Project held in May 2019 by the Centre for Disability Law and Policy in the Institute for Lifecourse and Society at NUI Galway.

International law

(i) International Conventions and European Case law

International human rights instruments aim to promote and protect the right to safety in pregnancy and childbirth. The most pertinent to his discussion is the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD was ratified by Ireland in 2018, almost a decade after originally signing the document.

Within the CRPD:

- Article 6 relates specifically to women with disabilities being protected from discrimination.
- Article 12 protects the right to exercise legal capacity on an equal basis with others.
- Article 17 protects the physical and mental integrity of persons with disabilities on an equal basis with others.
- Article 23 relates to respect for home and the family.
- Article 25 supports the right to health for persons with disabilities.

While Ireland ratified the Convention, it made a declaration and reservation to Article 12. This states that "to the extent article 12 may be interpreted as requiring the elimination of all substitute decision making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards."[1]. Substituted decision making can arise if someone is deemed to lack capacity to

[1] Deputy Peter Fitzpatrick, Oireachtas Debates Wednesday 7th March 2018, UNCRPD: Motion, https://www.oireachtas.ie/ga/debates/debate/dail/2018-03-07/17/ On Article 12, Ireland recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Ireland declares its understanding that the convention permits supported and substituted decision making arrangements which provide for decisions to be made on behalf of a person, where such arrangements are necessary, in accordance with the law and subject to appropriate and effective safeguards. To the extent that Article 12 may be interpreted as requiring the elimination of all substitute decision making arrangements, Ireland reserves

make their own decisions and can be imposed on persons with disabilities who are pregnant, or during child-birth. In order to be compatible with the UNCRPD Irish laws must be changed to replace substituted decision making with assisted decision making. This will be discussed further below in the 'Legal Interventions' section.

The UNCRPD is monitored by the Committee on the Rights of Persons with Disabilities. This is an 18-person body of independent experts who examine reports from States on a four-year cycle and assess their compliance with the UNCRPD. The Committee makes recommendations for improving compliance of each State. Periodically the Committee produces in-depth reports informed by the most concerning, or prevalent issues, arising from their review of States reports which are themed by a UNCRPD article. Further interpretation of the UNCRPD text has been provided by the Committee in General Comments. General Comment No. 3 relating to Article 6 of the UNCRPD refers to coerced, forced or otherwise involuntary pregnancy as a form of inhuman and degrading treatment to which women with disabilities are subjected[2]. Frequent childbirth is also a risk for girls with disabilities who are married at a young age[3]. Harmful presumptions that women with disabilities will give birth to children with disabilities resulting in eugenic practices and discouraging women with disabilities to fulfil their reproductive wishes is also referenced[4].

Ireland has not signed the Optional Protocol to the UNCRPD which means that individuals will not be able to take complaints about disability rights violations to the Committee on the Rights of Persons with Disabilities. Ireland is obliged to produce a State Report every four years to be examined by the Committee. As part of this process a Shadow Report may be submitted by a collection of civil society organisations. The Irish Human Rights and Equality Commission – the monitoring body for human rights and equality issues in Ireland – also has an opportunity to present their perspective on the implementation of the UNCRPD to the Committee. These are all mechanisms where issues affecting a large portion of the disabled population can be brought to the attention of the Committee.

Disabled people's rights during pregnancy and childbirth are also protected through other international human rights instruments as they apply to everyone equally. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW):

- Article 11 (2) prohibits discrimination based on maternity and a mother's effective right to work.
- Article 12 mandates that States provide adequate maternity and post-natal services, including nutrition during lactation periods.

With respect to the International Covenant on Economic Social and Cultural Rights,

- Article 10 protects the family and motherhood.
- Article 12 provides for the right to health.

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the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards.

[2] General Comment No. 3, para 32.

[3] General Comment No. 3, para 36

[4] General Comment No. 3, para 39.

Additionally, the European Convention on Human Rights (ECHR):

- Article 8 promotes the right to respect for private and family life.

The European Court of Human Rights is responsible for the enforcement of the European Convention on Human Rights. Individuals from any state which is a party to the ECHR can take a case claiming a violation of their rights to the European Court of Human Rights. The majority of ECHR caselaw relating to pregnancy and childbirth focuses on the failure to diagnose a disability through pre-natal screening, however this is not the focus of our research.

Similarly in Ireland, litigation relating to pregnancy and birth is more common in situations where birth has been improperly managed resulting in injury to the child. A financial award is the most common reparation for negligence to children which is then intended to provide for care for the duration of the child's life. Disability services for children are not the focus of this working paper and are well accounted for across academic and mainstream literature for the bureaucratic and difficult nature of engagement with families[5]. There have also been efforts to litigate unnecessary medical treatment to the mother, such as symphysiotomy, where these interventions resulted in disability and reduction in quality of life for her and her family. This has been brought to the attention of numerous international human rights monitoring bodies including the Committee on the Elimination of Discrimination Against Women[6], the Committee Against Torture[7] and the Human Rights Committee[8].

(ii) Irish Context

Domestically, the Irish Constitution provides rights that are relevant during pregnancy and childbirth. These include the right to liberty[9] and privacy, which has been extended through litigation to include marital privacy[10]. Article 40.1 refers to equality before the law but qualifies this with the fact that the state will have 'due regard to differences of capacity, physical and moral, and of social function.' In general, Article 40.1 is regarded as a relatively weak constitutional equality guarantee, and has not been particularly successful in litigation to establish a violation of constitutional rights, including with respect to maternity care.

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[5] Carroll, Murphy, Sixsmith, J (2013) 'The Progression of Early Intervention Disability Services in Ireland'. Infants And Young Children, 26 :17-27. And Cormac Fitzgerald, 'Brendan O'Connor: Children with Disabilities are not taken care of in Ireland' https://www.thejournal.ie/brendan-oconnor-2-2770018-May2016/

[6] Irish Maternity Support Network, Report of the Irish Maternity Support Network to the UN Special Rapporteur on Women on
Mistreatment and violence against women during reproductive health care with a focus on childbirth
17 May 2019
https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/Issues/Women/SR/ReproductiveHealthCare/Irish%20Maternity%20Support%20Network.docx&action=default&DefaultItemOpen=1

[7] Committee against Torture: Concluding observations on the second periodic report of Ireland - Adopted by the Committee at its sixty-first session (24 July-11 August 2017). Para 29

[8] Human Rights Committee: Concluding observations on the fourth periodic report of Ireland - Adopted by the Committee at its 111th session (7–25 July 2014), para 11.

[9] Article 40.4.1

[10] This will be discussed with the McGee case below.

While the 8th Amendment of the Irish Constitution is largely considered relevant to the provision of abortion, it is also very pertinent to this discussion. Care provided by maternity services until 2nd January 2019 was influenced, and often mandated, by this Constitutional recognition of the equal right to life of the unborn to the mother. The 8th Amendment has now been repealed and the Supreme Court has clarified that the unborn enjoys no rights under the Constitution other than the right to life in the 8th Amendment.[11] This should mean the use of coercive interventions during pregnancy or birth against the wish of the pregnant person cannot be constitutionally justified on the basis of the rights of the unborn, although litigation on this point has not yet come before the courts.

Maternity services in Ireland were formally established through Part III of the Health Act 1947. Since then there have been numerous developments, including the controversial and unsuccessful attempt to introduce free maternity and child health services in 1951 by Dr. Noel Browne[12]. Currently, the National Women & Infant Health Programme provides the framework for maternity services[13]. This was established in 2017 and includes gynaecology and neonatal services also. In employment legislation, the Maternity Protection Acts 1994 to 2004 regulate the payment of social welfare while on maternity leave and protection from unfair dismissal due to pregnancy and parenting.

Maternity services within hospitals also fall within the remit of the Freedom of Information Act 2014. The Association for Improvement of Maternity Services Ireland provides guidance on how to make a Freedom of Information request under this legislation[14]. Chapter 2 of the Freedom of Information Act 2014 outlines the onus on the public body to assist a member of the public to access information with Section 11 (2)(b) mandating reasonable assistance for persons with disabilities in particular.

Data protection is also an important issue for users and patients within maternity services. The Data Protection Act 2018 and the General Data Protection Regulations in force since May 2018 are the current frameworks governing these issues. Section 42 permits the processing of personal data for scientific or historic research purposes which might be of relevance to users of maternity services. Section 53 (b) refers to processing personal data in the interest of public health in relation to ensuring high standards of safety in medical products and devices. Section 97 of the Data Protection Act outlines the circumstances in which restrictions can be imposed on data rights. These include the protection of public and national security, the safety of other persons, the security of institutions such as prisons, mental health and detention centres. These restrictions on data rights have the potential to disproportionately impact on persons with disabilities, who may be denied access to personal data where a data

[11] IRM v Minister for Justice and Equality [2018] IESC 14.
[12] http://www.theirishstory.com/2013/06/19/the-controversy-of-womens-health-the-mother-and-child-scheme-the-role-of-church-and-state/#.XWZflJNKhcA
[13] https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/
[14] http://aimsireland.ie/requesting-your-birth-notes-and-making-a-complaint/

controller deems this is necessary to protect the life, safety or well-being of any person, including the data subject herself.[15]

Maternity Service Users warranted individualised attention in the Data Protection Commissioners report on Hospital Services[16] in May 2018. The risk identified for maternity service users is the optional nature of keeping custody of their personal medical file. There is an increased risk of data breaches if the expectant mother retains custody of the file. It is recommended that hospital staff fully inform expectant mothers of these risks and have protocols in place to ensure the return of the medical files after the delivery of the baby.

(iii) Legal Interventions

Under the Regulation of Lunacy Act (Ireland) 1871, a person can be made a Ward of Court. There are two types of wardship, one that covers persons over 18 and another that relates to persons under 18. Generally, an adult over 18 is taken into wardship if they are deemed to be of 'unsound mind', incapable of governing his person or property. Minors, those under 18, who are placed into wardship require the Court's protection for particular reasons, not necessarily related to disability. Consideration of whether an adult should be taken into wardship is based on evidence from two medical experts. The person is then appointed a committee of the ward that makes decisions about the personal care and estate of the ward. The wardship jurisdiction has been imposed on pregnant persons with the explicit purpose of making treatment decisions during pregnancy and birth, as discussed further in the case law section below.

The Assisted Decision Making (Capacity) Act, 2015 (ADM), aims to replace the wardship system. The ADM includes in its guiding principles a presumption of capacity, that persons are entitled to make 'unwise' decisions, that intervention must be necessary and least restrictive of one's freedom, rights and dignity, that the person must participate in the intervention, and that the person's will and preferences must be given effect to as far as is practicable.[17] It provides a legal decision-making framework including assisted decision making, co-decision making, and decisions by the court or decision-making representative. The substantive provisions of the Act have not yet been commenced. Codes of Practice are being prepared by the Decision Support Service which are due to be circulated for public consultation in Autumn 2019, and the goal for commencement of the main provisions of the Act is the end of 2020.

Part 8 of the ADM provides a legislative framework in which people can make Advanced Healthcare Directives (AHD). An AHD enables a person to set out their decisions on future medical treatments. However, where a person who lacks capacity is pregnant, and her AHD sets out a specific refusal of treatment that is to apply even if she were pregnant, and it is

[15] Section 94(3)(f), Data Protection Act, 2018.
[16] Data Protection Commissioner, 'Data Protection Investigation in the Hospital Sector', May 2018, https://www.dataprotection.ie/sites/default/files/uploads/2018-12/DPC%20-%20Hospitals%20Sector%20Overall%20Report%20_0.pdf p.51 and 52
[17] Section 8, Assisted Decision-Making (Capacity) Act 2015.

considered by the health professional concerned that the refusal of treatment would have a deleterious effect on the unborn, an application can be made to the High Court to determine whether or not the refusal of treatment should apply. Additionally, an AHD shall be complied with unless the person is involuntarily detained under Part 4 of the Mental Health Act 2001. These provisions on AHDs present specific barriers for pregnant persons with disabilities who make advance decisions about their treatment during pregnancy and birth which may not be upheld or deemed legally valid. While the provision regarding refusal to respect an AHD which would have a deleterious effect on the unborn seems to have been inserted as a result of the 8th Amendment, it has not yet been removed from the legislation. Some minor amendments to the 2015 Act have been proposed in the Disability (Miscellaneous Provisions) Bill 2016, but none of these to date address AHDs. A Private Members Bill has also been introduced to ensure that lawfully made AHDs would continue to be legally binding following detention under the Mental Health Act; however this has not been enacted.[18]

Following the repeal of the 8th Amendment to the Constitution, new legislation relevant to decision-making in pregnancy and birth has been introduced in the form of the Health (Termination of Pregnancy) Act 2018, which replaced is the Protection of Life During Pregnancy Act 2013 (PLDPA, 2013). These will be discussed in further detail in the abortion working paper for this project, however, with respect to the provision of maternity services in Ireland the 2018 Act allows for the termination of a pregnancy where there is a risk to the health, including mental health, as well as to the life of the mother. This had not been provided for in the PLDPA, 2013, and is a welcome inclusion.

Irish context

(i) *Policy*

In 2016 Ireland launched its first national policy framework and standards for maternity services - National Maternity Strategy: Creating A Better Future Together 2016-2026[19], National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[20], and HIQA's Safer Better Health Standards for Maternity Services[21]. Adding to this, in 2017 it created a specific implementation plan[22] as well as the National Women and Infants Health Programme[23] to oversee the delivery of maternity, gynaecological, and neonatal services across the country. Fundamentally, the new maternity strategy aims to provide woman-centred care with a focus on the health and well-being of mothers and families, access to safe,

[18] Assisted Decision-Making (Capacity) Amendment Bill 2019, section 2.
[19] Creating a better future together, https://health.gov.ie/wp-content/uploads/2016/01/Maternity-Strategy-web.pdf
[20] 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.
[21] https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf accessed on 13 August 2019.
[22] https://www.hse.ie/eng/services/publications/corporate/national-maternity-strategy-implementation-plan.pdf accessed on 13 August 2019.
[23] https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/ accessed on 13 August 2019.

high quality care from appropriately resourced maternity services provided by skilled staff, and to facilitate the woman's choice of birth, where safe to do so. The HSE has commissioned research on the legal framework surrounding the provision of home birth services in Ireland[24]. This was prepared in coordination with staff at the UCD School of Nursing, Midwifery and Health Systems in May 2016, so does not reflect the current legislative context, but it is useful.

Monthly maternity safety statements, detailing the number of births, methods of delivery and major obstetric events[25], are now provided online to provide public assurance that maternity services are delivered in an environment that promotes open disclosure. The provision of these statements is a result of investigations into previous incidences of unsafe practices at maternity hospitals across the country.

Overall, the National Maternity Strategy does not refer to persons with disabilities specifically, rather concentrating on facilitating care for complex pregnancies, and social issues such as isolation, domestic violence or addiction. However, the National Standards for Safer Better Maternity Services, HIQA includes:

- Standard 1.3 that maternity services should be available without discrimination due to disability.
- Standard 2.7.4 that the physical environment in which women with physical disabilities give birth will be appropriate.
- Standard 5.6.2 that antenatal care should be accessible to all, including those with disabilities.[26]
- Standard 5.2.6.1 recognises that persons with disabilities are part of a group of society for whom targeted antenatal education is important.[27]
- Standard 6.3.20 indicates that all healthcare staff will receive disability competence training to provide appropriate person-centred care.

These standards are reflected in The National Guidelines on Accessible Health and Social Care Services[28]. It contains six guidelines outlining how health and social care services should be developed as inclusive of disabled persons from the outset, including staff competence around disability issues, accessible services, communication, accessible information and infrastructure. Draft HIQA Guidance on a human rights-based approach to care and support in health and social care settings refer to the practical element of supporting someone in

[24] O'Shea, 'The Legal Aspects of the HSE National Home Birth Service: A review of legislation and case law' https://www.hse.ie/eng/services/list/3/maternity/new-home-birth-policies-and-procedures/legislative-dataset.pdf
[25] https://www.hse.ie/eng/services/list/3/maternity/mpss/mpss.html

[26] https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdft p. 91
[27] https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf p.92.
[28] https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/part1.html#advice36

residential setting with disabilities to access fertility & contraception[29] but is lacking on examples on provision of pregnancy services.

The liaison role of Registered Nurse of Intellectual Disability in maternity services and during pregnancy is briefly noted in the policy 'Shaping the Future of Intellectual Disability Nursing in Ireland'[30]. There is potential for a generalist role to support accessing primary care and a specialist maternity services role. It is also suggested that further qualified Clinical Nurse Specialists can provide support for persons with intellectual disabilities using maternity services.

The National Maternity Strategy aims to become more woman-centred, empowering women and mothers to engage in decision-making processes that respect their reproductive choices, albeit with the repeated caveat that this will only be permitted 'where safe to do so'. Consent, as understood within the National Consent Policy 2017[31] must follow the provision of sufficient information. It can not be given under duress and the patient must have capacity to understand the consequences of the procedure. The National Consent Policy 2017 proposes that medical professionals include information about the risks or likely outcomes of not treating, as well as risks to treating, whether the proposed actions are an experimental or research procedure, and indicative costs involved. The time and location of discussing consent to treatment is mentioned as very important, in that, it should be communicated in a quiet place with enough time to consider the information, medical jargon should be avoided, and language that is understood should be used with visual aids if necessary.

The general principles of the National Consent Policy include a preference for a functional assessment of decision-making capacity. The policy operates on the presumption of capacity and encourages supported decision-making to maximise capacity. A person can be deemed to lack capacity if all appropriate supports have been provided and the person cannot communicate a clear and consistent choice or demonstrate understanding of the issue. If incapacity is found, the medical professional must consider if it is temporary, try to get consent when the person is lucid, consider their past preferences, consider the best medical option, gain the views of those close to the person or already approved friends to be asked, or consider requesting the appointment of an independent advocate. However, no one else can authorise or refuse treatment on behalf of another adult, unless legally authorised. In the case of an emergency where consent cannot be given then none is deemed necessary. Even though the Policy was adopted after the enactment of the Assisted Decision-Making (Capacity) Act, no explicit mention of the Act is made in the policy and no clear legal pathway is outlined for health professionals if they deem a patient to be incapable of consenting to a

[29] https://www.hiqa.ie/sites/default/files/2019-06/Draft_Guidance_Human_Rights-Based_Approach_to_Care_Booklet.pdf
S3.2, p 15 and p. 18
[30] https://healthservice.hse.ie/filelibrary/onmsd/shaping-the-future-of-intellectual-disability-nursing-in-ireland-january-2018.pdf
[31] https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-august-2017.pdf

procedure during pregnancy or birth. If the pregnant person has not chosen to make one of the arrangements under the legislation such as the appointment of a decision-making assistant or co decision-maker, then it seems that the hospital would have to apply to court for a decision-making order or the appointment of a decision-making representative in order to secure the necessary legal authority to proceed with treatment, outside of emergency interventions which could be covered by the doctrine of necessity. Until the 2015 Act is fully commenced, the only option seems to be for the hospital to apply for a wardship order, as discussed further below.

Certain sections of the National Consent Policy have been updated in 2019[32] to reflect the Health (Termination of Pregnancy) Act, 2018. These additions include recognition that pregnant people must have received sufficient information in a manner that is comprehensible to them about the nature, purpose, benefits and risks of an intervention or lack thereof on their health and life. They will need to receive sufficient information about the benefits and risks of an intervention or lack thereof on the viability and health of a foetus as defined within the Act[33]. They will also require sufficient information on the benefits and risks of an intervention or failure to intervene on the viability and health of the child that will be delivered. Lastly, consent of the pregnant person is required for all health and social care interventions in pregnancy in accordance with section 1.4 of the policy that relates to the legal framework in place, this includes the right to refusal of treatment in pregnancy.

The Specialist Perinatal Mental Health: Model of Care[34] 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. Perinatal mental health issues are defined as those which impact on the person's pregnancy and/or continue up to one year postnatally. It is estimated that over twenty thousand women experience adjustment disorders and distress as a result of pregnancy, birth or becoming a parent each year, with over ten thousand experiencing mild to moderate depressive illness and anxiety states including persistent sadness, fatigue and a loss of interest and enjoyment in activities. Over two thousand experience PTSD or severe depressive illness, with 134 women experiencing chronic serious mental illness and postpartum psychosis[35].

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

[32] https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf

[33] The Health (Regulation of Termination of Pregnancy) Act 2018 defines as follows: "foetus in relation to pregnancy, means an embryo or a foetus during the period of time commencing after implantation in the uterus of a woman and ending on the complete emergence of the foetus from the body of the woman".

[34] 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

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

hospitals, referred to as spokes[36]. 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 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 deliveries[37]. It also recommends that community mental health services should have the option of ensuring there is no separation from children where desired. The intersectionality of health and social services is recognised as staff from psychology, occupational therapy and social work are listed as core staff within perinatal mental health services[38].

(ii) *Previous Research*

The National Disability Authority undertook comprehensive research on the experience of disabled women during pregnancy and childbirth entitled 'Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood' [39]. The literature was coordinated through Trinity College Dublin and closely mirrors the theme of this discussion group, however the data is now a decade old. Three reports were subsequently published from that research. The report on policy provides an outline of Irish legislation and policy and that of eight other countries. The literature review encompasses national and international data sources. The final report sets out the strengths and weaknesses of the Irish maternity system in Ireland for women with disabilities. In general, their research found that maternity care in Western societies has become increasingly medicalised, neglecting the importance of the woman's voice and experience in regard to her care. They found that almost two thirds of their sample were unhappy with aspects of their care during their pregnancy or birth. Evidence from their literature review suggested that society undervalues women with disabilities, often exerting control over their sexual and reproductive lives, particularly women with intellectual or mental health disabilities.

In assessing the accessibility of maternity services for women with disabilities the NDA adopted Penchansky and Thomas's[40] approach which includes a review of availability, geographic accessibility, accommodations made by providers to women with disabilities, affordability and the acceptability of relationship between service provider and user. Failure to adhere to all five criteria resulted in inaccessibility, dissatisfaction with the service and inequality in delivery of services for persons with disabilities. Specifically, their findings in relation to women with physical and sensory disabilities were similar, in that they highlighted accessibility issues in relation to location and models of care, difficulties in transport and

[36] 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.
[37] At p. 44
[38] At p. 61
[39] Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood,
Prof. Cecily Begley, Prof. Agnes Higgins, Dr. Joan Lalor ,Dr. Fintan Sheerin, Dr. Jane Alexander
Dr. Honor Nicholl, Ms. Denise Lawler, Mr. Paul Keenan, Ms. Teresa Tuohy, Ms Roisin Kavanagh

[40] Penchansky, R. and Thomas, J.W., 1981. The concept of access: definition and relationship to consumer satisfaction. *Medical care*, pp.127-140.

moving around. Lack of accessible information created communication barriers, while lack of knowledge of particular disabilities and negative attitudes by staff were evident. On the positive side, buildings and services were being altered to enable greater ease of movement, while antenatal classes were providing sensitive information although it was noted that considerable work was needed to improve health professional's knowledge of, and attitudes towards, physical disability. Barriers for women with mental health difficulties were more pronounced or better documented.

They found:

- poor links between maternity and mental health services;
- a lack of motivation by pregnant women with mental health difficulties to attend clinics;
- a lack of knowledge by medical professionals of mental health issues during pregnancy and postnatally;
- stigma relating to the disclosure of struggles with mental health during pregnancy or postnatally;
- and affordability, particularly for low income families, to pay for childcare and transport resulted in people feeling they could not access health services.

In terms of facilitators, the research suggested:

- Improving lines of communication between maternity services and mental health services including increased training and knowledge for medical professionals;
- Providing designated perinatal multidisciplinary teams in the community and specialist mother and baby psychiatric units.
- Lastly, the findings in relation to women with intellectual disabilities highlighted society's negative attitudes to women with intellectual difficulties becoming pregnant, and caring for their children and as a result the lack of support they receive. Instead conservative and protective perspectives prevail from frontline staff and family members which can put women at risk of coercive sterilisation or forced contraception[41].

In 2016, bump2babe (Cuidiú) sent a comprehensive survey to the 19 maternity hospitals/units and midwifery-led units in Ireland. They queried general information about the hospital/units maternity services as well as specialised questions. For instance, it questioned the accessibility of each hospital/unit in terms of wheelchair accessibility, as a visually impaired person, or a person with a hearing impairment. Most units responded that their hospital was wheelchair friendly, although two units stated that there were departments within old buildings that were not accessible for wheelchairs. Most, but not all, maternity units have

[41] Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood,
Prof. Cecily Begley, Prof. Agnes Higgins, Dr. Joan Lalor ,Dr. Fintan Sheerin, Dr. Jane Alexander
Dr. Honor Nicholl, Ms. Denise Lawler, Mr. Paul Keenan, Ms. Teresa Tuohy, Ms Roisin Kavanagh. Pg. Xi-xv.

wheelchair accessible showers on every ward and wheelchair accessible baby-care areas. For those with a visual impairment, maternity units assess individual needs and care is tailored to suit the person.

Some units provided information as to how they could accommodate the needs of someone with a visual impairment. For instance, Cork University Maternity Hospital responded by saying 'Guide Dogs welcome, support person welcome. Met on arrival by a named midwife who will be their contact person for the antenatal period. The midwife will provide one-to-one antenatal classes. Social worker support is available. Single room in-patient accommodation', and Saint Luke's General Hospital Kilkenny responded 'Family member may stay in special cases. Located near toilet and shower'. In relation to people with a hearing impairment the maternity units assess each individual mother's needs and care is tailored to suit the person. Several units specifically mentioned sign language. Responses to the question ranged from providing a pad and paper, to use of sign language, to one-to-one care and single-room accommodation.

For those with a learning disability, again generally, maternity units will assess each individual mother's needs and care is tailored to suit the person. Some units encourage extra support people, others offer one-to-one care, and others involve social care workers if appropriate. Examples of specific responses include Coombe Women & Infants University Hospital – 'individual needs assessment via a multi-disciplinary team including appropriate referral', or Portiuncula Hospital who stated 'facilitated on ward as much as possible'. Lastly, for those experiencing mental health issues the response of maternity units was poor. Some units involve their mental health midwives/team or liaison workers, others offer one-to-one care and others involve social workers if appropriate. Specifically, some units mentioned referrals to mental health services while other units, such as the National Maternity Hospital suggested 'liaison Mental Health Nurse (Advanced Midwife Practitioner), Psychiatrist and Psychosexual Therapist staff available in hospital'.

Recently, there have been numerous examples in mainstream media retelling experiences of societal pressure on women and their experiences during pregnancy and childbirth[42]. For several weeks this year, the Irish radio show Liveline focused on people's stories of obstetric violence and coercion[43]. While the hospitals, time periods, and pregnancies were varied, there was significant overlap in underlying frustration being expressed. Women consistently reported not having their voices heard, and a disregard for their mental health and wellbeing, with care focused solely on the delivery of the child. These experiences are also reflected in the Association for Improvement of Maternity Services Ireland research in 2007[44], which documented issues surrounding breastfeeding support, hospital hygiene, post-natal care, and a lack of decision-making power during labour and birth.

[42] See Tanya Ward's series in the Irish Times available from https://www.irishtimes.com/profile/tanya-sweeney-7.3264423

[43] Liveline, RTE Radio 1,'Birth Experiences', available from https://www.rte.ie/radio1/liveline/programmes/2019/0404/1040698-liveline-thursday-4-april-2019/, 4th April 2019

[44] http://aimsireland.ie/wp-content/uploads/2014/04/AIMS-Ireland-What-Matters-To-You-2007.pdf

Irish Case law

(i) *Decision Making in Pregnancy and Birth*

Pregnancy has been raised in the courts a number of times. The high-profile cases, for the most part, have been focused on obligations to foetal life that existed under the now repealed 8th Amendment. Court ordered caesareans are not a new, or uniquely Irish phenomenon. Generally, there are exceptions to medical consent requirements when the person has a disability which is reflected in legislation globally.[45] There is significant ambiguity as to how these decision-making cases play out in court, for the most part cases are not reported, or are only recorded in the media. What is clear is that there is a disparity in the court experiences of disabled people and non-disabled people. The landmark Irish case in decision making and birth is that of *HSE v B*[46]. The case concerned a pregnant woman who was seeking to deliver by vaginal birth after a caesarean.

The *B case*, which occurred under the now repealed 8th Amendment was an attempt by the HSE to force a woman to undergo a Caesarean Section. There was a question as to whether the courts could order that a caesarean section be performed on a pregnant person without their consent. The order was sought under the protection of the right to life of the unborn under the 8th Amendment. There was disagreement as to the risk of a vaginal birth after a caesarean. The HSE maintained that there was a risk to the life of both the mother and the baby. Lawyers for the HSE attempted to call the capacity of Ms B into question based on undue influence of her birth supporter. This was rejected by the courts as Ms B had no disability. The court considered caselaw around parental decision making for born children and concluded that the intervention of the State in relation to unborn children could not be any greater than that for born children. The court ruled that to perform surgery on a non-pregnant person without their consent would be grievous bodily harm and could not be permitted in this case. This is a significant divergence from the manner in which disabled people are treated.

For example, in 2017 a reported case concerned a woman with a psychosocial disability "Jane", who was unresponsive about a birth plan and approaching labour. Jane was not a ward of court and was in significant mental distress.[47] The woman, who had previously expressed a desire to continue her pregnancy was said to have lost interest. She was not communicating her wishes with regards to the pregnancy, and there were concerns about her ability to tolerate a "vaginal birth and necessary examinations". Doctors argued that the woman was incapable of making informed decisions. An independent medical visitor also expressed the view that she was of unsound mind and incapable of making her own decisions. Judge Peter Kelly ordered that a scheduled caesarean take place, and gave orders to allow doctors to "carry out obstetric and other examinations and all necessary medical treatment

[45] Paton v BPAS
[46] [2016] IEHC 605
[47] Carolan, "Mentally Ill Woman Can Be Given a Caesarean Court Rules" Irish Times (2017) https://www.irishtimes.com/news/crime-and-law/courts/high-court/mentally-ill-woman-can-be-given-caesarean-court-rules-1.3008603

and ancillary treatment, including tube feeding if necessary." She was later taken into wardship. During later hearings the court also ordered that she be administered the contraceptive injection, which had been refused at earlier hearings. She was discharged from wardship later that year, it is unclear what happened to the woman's child.

In a second case from 2017 relating to capacity, consent, and pregnancy, a hospital sought orders for the forced induction of labour, and emergency caesarean section if necessary, to be performed on a woman with intellectual disabilities[48]. Judge Peter Kelly granted the order as the conditions of the best interest of the baby and the woman were deemed to be satisfied. Health professionals considered the small size of the baby a concern, and while there was no objection from the woman, they were concerned as to her ability to consent to procedures which may be required during labour such as a Caesarean Section. The family of the woman considered the court action unnecessarily heavy handed but did not object. The woman would also be assessed to determine whether she should be made a ward of court and TUSLA were notified of the case at this stage and preparing to make arrangements for the care of the child.

(ii) *Pregnancy and Wardship*

Disability, pregnancy and capacity also arise outside the context of birth choices. In 2002 Judge Finnegan ordered that a pregnant woman be treated for HIV, due to the risk it posed for both her and her foetus. Disability and pregnancy has also arisen in the context of medical negligence cases, for example, the Ms McGillin case where it was alleged that the treating psychiatrist failed to disclose the risks of an epilepsy drug to Ms McGillin thereby resulting in her child's impairment. The case was settled out of court.

Conclusion

It is evident from the international overview that the reproductive rights of persons with disabilities are protected primarily within the CRPD, in terms of discrimination, a right to have legal capacity respected, to physical and mental integrity on an equal basis, along with respect to home, family life and a right to health. Additionally, issues surrounding maternity and an effective right to work for mothers, and protection of family, motherhood and health are reinforced in other European conventions. Nationally, Ireland has ratified the CRPD with reservations documented in relation to Article 12 as the current ADM legislation contains provisions for substituted decision-making in certain cases. Constitutionally, Ireland respects the right to liberty and privacy, which is extended to include marital privacy, and although it accounts for equality before the law it prefaces this with a functional understanding of capacity across sectors of society. Legal interventions such as wardship challenge the above-mentioned constitutional rights, whereas the ADM goes some way towards mitigating this intervention, despite retaining an element of substituted decision making.

[48] Carolan, Doctors may induce birth of intellectually impaired woman's baby', June 14, 2017, https://www.irishtimes.com/news/crime-and-law/courts/high-court/doctors-may-induce-birth-of-intellectually-impaired-woman-s-baby-1.3119598

Policy surrounding maternity services in Ireland appear to have improved significantly considering the publication of the National Maternity Strategy 2016-2026 and its attendant programmes, models of care, and better health standards that indicate a move towards a more woman-centred approach. While the 'National Standards for Safer Better Maternity Services', 'The National Guidelines on Accessible Health and Social Care Services', 'The Specialist Perinatal Mental Health: Model of Care' and the 'National Consent Policy', address aspects of disability specifically, evidence from empirical research suggests that there is still a long way to go to address the issues raised by people with disabilities with regard to their care during pregnancy and childbirth. For example, previous research highlights the issues around poor accessibility, lack of accessible information, lack of knowledge of particular disabilities, conservative and protective attitudes towards women with intellectual disabilities, and poor links between maternity and mental health services. The Cuidiú survey highlighted the inconsistency of knowledge and services across maternity hospitals/units with regard to supporting people with disabilities.

Through the courts, we more commonly hear of disability caused during birth. Despite this, the nature of cases relating to disability and pregnancy or childbirth that do present in the courts indicate the enduring patriarchal and disempowering elements that surface with regard to disability and maternity care specifically. Issues surrounding capacity and consent remain contested with a legal resort to challenge to ascertaining and applying best interests of the individual rather than will and preferences.

Until now, the experiences of pregnancy and childbirth by people with disabilities have been relatively hidden in Ireland. Both quantitatively and qualitatively, we lack up-to-date statistics and research that enables us to understand the way in which the experience of pregnancy and childbirth for people with disabilities can be supported and improved. The Re(al) Productive Justice Project aims to explore the varied and intersecting barriers facing people with disabilities seeking reproductive justice including the impact of stereotypes, legislation, regulation and service provider policy.