Re(al) Productive Justice Project: gender and disabilities

Background paper on **disability, fertility and contraception**

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1. Introduction

This paper outlines the international and domestic law and policy context of fertility and contraception issues for persons with disabilities in Ireland. Throughout the world, the fertility of persons with disabilities has often been subject to coercive control, with eugenic practices featuring in some public health policies[1]. In this paper, we explore to what extent these policies and practices appear in Irish law, and compare Irish law and policy on fertility and contraception for disabled people to international human rights obligations.

2. International human rights law

2a. UNCRPD

The starting point for this discussion is the United Nations Convention on the Rights of Persons with Disabilities. Each of the provisions contained within the UNCRPD are interrelated but the most relevant to the issue of fertility and contraception are outlined below.

Article 23 explicitly references the right to equality for persons with disabilities in decisions about fertility, reproductive and family planning. It requires States to ensure "the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided."[2] Further, it recognises that persons with disabilities, including children, have the right to "retain their fertility on an equal basis with others."[3]

Article 25 requires states to ensure that public health programmes, including those related to fertility and contraception, are affordable or free to persons with disabilities, on an equal basis with others. Healthcare, including fertility and contraception services, must be provided based on informed consent of the person concerned and should be delivered in a manner which is respectful of the human rights, dignity and autonomy of the person.

1Her Body, Her Choices, Sexual and reproductive health and rights of young women and girls with disabilities, UN Special Rapporteur on the Rights of Persons with Disabilities, 2017, A/72/133, available from: http://www.embracingdiversity.net/files/report/1508487659_report-srhrfor-web.pdf

2 Article 23(b), UNCRPD.

3 Article 23(c), UNCRPD.

Being denied control over one's fertility can amount to a violation of the physical and mental integrity of the person, in contravention of Article 17 UNCRPD. Article 21 requires States to ensure that any information provided to the general public (including information provided by private bodies) must be available in accessible formats for persons with disabilities. This is particularly pertinent to our discussion of fertility and contraception as currently in Ireland the assisted human reproduction industry is comprised of predominantly private actors with limited statutory regulation[4].

Article 22 requires that the privacy of personal and health information related to persons with disabilities be respect in the same way as non-disabled people. For many persons with disabilities, decisions around fertility and contraception can unnecessarily involve disability support staff or family members[5].

2b. Protections for fertility and contraception within other international human rights instruments

International human rights instruments prior to the UNCRPD also contribute to the protection of the right to fertility and contraception for disabled people. The International Covenant on Civil and Political Rights prevents unlawful interference with the family under Article 17 as well as equality before the law under Article 26. Article 26 is pertinent as it prevents States introducing discriminatory legislation which could be used to enforce or deny fertility or contraceptive services to disabled people.

The International Covenant on Economic, Social and Cultural Rights under Article 12 recognises the right to the highest attainable standard of physical and mental health.[6] Although it does not mention disability, fertility or contraception specifically, the Committee on Economic Social and Cultural Rights has clarified in General Comment 14 that Article 12 includes access to family planning services.[7] Further, the Committee clarified that "States should refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health, from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, as well as from preventing people's participation in health-related matters."[8] All of these rights must be equally accessible to persons with disabilities to avoid discrimination as promoted under Article 2 of this Covenant.

The Convention on the Elimination of All Forms of Discrimination Against Women protects the right to access family planning health services under Article 12 on the right to health. States parties are obliged to include advice on family planning in the education process[9] and

4 Contributions from Dr. Ciara Staunton at the Opening Conference of the Re(al) Productive Justice project, May 2019 as well as Key Informants working in the fertility service sectors.

5 Statements from Key Informant 10

6 Article 12(2)(a), ICESCR.

7 UN Committee on Economic, Social and Cultural Rights, General Comment 14: The Right to the Highest Attainable Standard of Health (Art. 12) (E/C.12/2000/4), para. 35.

8 Ibid, para. 34.

9 Article 10(h), CEDAW.

to develop family codes that guarantee women's rights "to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights".[10] CEDAW applies equally to women with disabilities.

The Convention on the Rights of the Child recognises the importance of the right to family planning services of the child's parents to promote the child's wellbeing as well as access to education around family planning during childhood in order to be prepared for planning their own families in the future. Article 24 (2) (f) 'States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: To develop preventive health care, guidance for parents and family planning education and services.' Further guidance from the Committee on the rights of the child clarifies that family planning and contraceptive services should be available to benefit adult couples, sexually active adolescents and that age-appropriate information should be available to children.[11] As with all provisions of the CRC, these should apply equally to disabled children and adolescents.

2c. United Nations Guidance and Jurisprudence

Each international convention has a monitoring mechanism, known as a Committee, which monitor states compliance through reporting every 4 years. The Committee is also a mechanism to which individuals can take complaints against their states on issues covered by the Convention. States must have agreed to this individual complaint mechanism by ratifying the Optional Protocol to the relevant Convention. In this section, we explore statements made by various UN Committees about fertility and contraception as they apply to persons with disabilities.

Sterilisation and Contraception

As far back as 1994, General Comment Number 5 from the Committee on Economic, Social and Cultural Rights indicated that Article 10 of ICESCR is violated by sterilisation without consent[12]. More recently, the UN Special Rapporteur on Torture publicised in 2013 that forced sterilisation, denial of reproductive health information and denial of emergency contraception within health care settings constitutes torture[13]. The UN Committee on the Elimination of Discrimination Against Women have also criticised the connected policies of sterilization of Roma women and women with disabilities without their consent.[14]

10 Article 16(e), CEDAW.

11 General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), Available from https://www.refworld.org/docid/51ef9e134.html

12 UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 5: Persons with Disabilities, 9 December 1994, E/1995/22, available at: https://www.refworld.org/docid/4538838f0.html [accessed 16 November 2020]

13 Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, delivered to the Human Rights Council Twenty-second session, Agenda item 3 Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. Available from https://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

14 J.D. v Czech Republic, CEDAW Committee, Adopted by the Committee at its seventy-third session (1–19 July 2019). Para 3.5, http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsujVF1NesLff7bP5A183yaz0IbxrFKRFr7MqKQ%2fp%2fPCvqF%2bxUCsMyV3t7biS%2brHrcfLV76LG0QEsxBHKGTsF4OD3Z%2fbUJad1mP0zlom4Kg%2fbPmlpxF0AHsRmSqmLpUo4nGAButH0Aq7ibxrA5WXCuqw%3d

General Recommendation 24 from the CEDAW Committee identified non-consensual sterilisation as a violation in 1999[15]. An interagency statement from 2015 by numerous UN agencies[16] identified the prevalence of sterilisation of disabled people and discounts any rationale around protectionism or fertility management to justify such long lasting interventions, often performed without full and informed consent[17].

The Committee on the Rights of Persons with Disabilities have been vocal about their concerns surrounding forced sterilisation and forced contraception as violations of Article 17, the integrity of the person. This is referenced as particularly important in relation to women and girls with psycho-social and intellectual disabilities in residential settings. The Committee's Concluding Observations to India[18], Myanmar[19], Kuwait[20], Australia[21], Turkey[22] and El Salvador[23], among many others, demonstrates the prevalence of this issue throughout the world.

A 2014 report from WHO and other agencies highlights that increased risk of persons with disabilities being subjected to forced sterilisation, abortion and contraception alongside substituted decision-making[24]. The report identifies physical barriers to reproductive health services as well as lack of awareness of service providers and support staff in providing services to persons with disabilities and the isolation of persons with disabilities not living in the community. The report recognises that inaccurate assumptions and stereotypes of persons with disabilities being either asexual or hypersexual, infertile and incapable of parenting are also barriers to accessing reproductive health services internationally. This is further impacted by situations of humanitarian risk or emergency.

Discrimination in access to fertility services

In many countries, disabled people face discrimination when seeking access to fertility services, including assisted human reproduction. This issue was addressed in *SC and GP v Italy*[25], a case taken to the UN Committee on Economic, Social and Cultural Rights, the complainants were availing of IVF. The couple were aware of a genetic condition which would result in the disability of a child born to them. Initially pre-implantation genetic screening was denied to them, although after litigation in the domestic courts this was rectified. The

15 CEDAW General Recommendation No. 24: Article 12 of the Convention (Women and Health), Available from https://www.refworld.org/docid/453882a73.html

16 Office of the High Commissioner on Human Rights, UN Women, UNAIDS, UN Development Programme, UN Family Planning Agency, UNICEF and WHO

17 Eliminating forced, coercive and otherwise involuntary sterilization An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO

(2014, available from

https://apps.who.int/iris/bitstream/handle/10665/112848/9789241507325_eng.pdf;jsessionid=A1A1A81080185B26A50C43E65083C33C?sequence=1

18Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of India, October 2019, Para 36

19 Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Myanmar,,Para 33

20 Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Kuwait

October 2019, ,Para 34

21Committee on the Rights of Persons with Disabilities Concluding observations on the combined second and third periodic reports of Australia, October 2019, Para 33.

22 Committee on the Rights of Persons with Disabilities Concluding observations on the initial report of Turkey, October 2019, para 34

23 Committee on the Rights of Persons with Disabilities Concluding observations on the combined second and third periodic reports of El Salvador, October 2019, para 34

24 https://www.unfpa.org/sites/default/files/pub-pdf/UNFPA-WEI_Guidelines_Disability_GBV_SRHR_FINAL_19-11-18_0.pdf, at p.93.

25 Committee on Economic, Social and Cultural Rights Views adopted by the Committee under the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, concerning communication No. 22/2017*

complainants argued that Italy's law governing assisted reproduction had violated their right to benefit from scientific progress. Further, the IVF providers insisted on the implantation of a less-optimal embryo and threatened SC with legal action if she refused the implantation. This eventually led to a miscarriage, causing significant distress. While the argument about violating their right to scientific advancement was deemed to be inadmissible, the law preventing the refusal of implantation of an embryo was deemed to violate the complainant's right to the highest attainable standard of health in this case.

Aligning human rights standards for women and disabled people

The United Nations monitoring Committees often collaborate on thematic issues which affect populations. A joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination Against Women from 2018 promotes a human rights-based approach to sexual and reproductive health services which is accessible to persons with disabilities[26]. States must ensure that women have access to accurate information about fertility and contraception to enable them to make their own decisions. Women with disabilities must be protected from forced sterilisation or contraception. The autonomy of the woman must be at the centre of services providing for fertility and contraception. This statement applies to all states who have ratified either, or both, CEDAW and CRPD, including Ireland.

While access to fertility and contraceptive services for disabled people has not yet been explicitly addressed by any UN Committee in their comments to Ireland, some related issues have been discussed. For example, under Ireland's most recent examination in 2014 by the Human Rights Committee monitoring the ICCPR, reference was made to persons with disabilities in psychiatric facilities being subjected to non-consensual medication and coercive practices[27]. While there was no explicit mention of the provision of non-consensual contraceptives in that context, this is an issue which deserves further scrutiny. The CEDAW Committee noted in their Concluding Observations to Ireland's combined sixth and seventh state report that there must be increased efforts to increase awareness raising, availability and accessibility of contraceptives to the general public.[28] This should include information and access to contraceptives for persons with disabilities.

3. European protection mechanisms for fertility and contraception

3a. European Court of Human Rights case law

At the European Court of Human Rights the issue of sterilisation of women with disabilities has been litigated. A key case on this issue has been *Gauer & Others v France*[29] which

26 Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities, Joint statement by the Committee on the Rights of Persons with Disabilities (CRPD) and the Committee on the Elimination of All Forms of Discrimination against Women (CEDAW), 29 August 2018.
Available from:

27 Human Rights Committee, CCPR/C/IRL/CO/4, 19th August 2014 at paras 12 and 13

28 Committee on the Elimination of Discrimination
against Women, Concluding observations on the combined sixth and seventh periodic reports of Ireland, 9 March 2017, CEDAW/C/IRL/CO/6-7

29 Application no. 61521/08, Fifth Section Committee, 23/10/2012 Case only available in French, summary in English from European Court on Human Rights Factsheet, 'Persons with disability and the European Court on Human Rights', https://www.echr.coe.int/Documents/FS_Disabled_ENG.pdf, at p.9.

concerned the ligation or removal of fallopian tubes as contraception without informed consent of five women with intellectual disabilities. All the women were under guardianship of the Association for Adults and Young People with Disabilities and all worked within a sheltered employment scheme. At the time, French law permitted the performance of these procedures without the consent of the women themselves. The European Network of Human Rights Institutions (ENHRI) submitted an amicus curiae urging the ECHR to take into account the principles of the UNCRPD in its decision. Further, ENHRI recommended the ECHR consider international guidance including CEDAW's General Recommendation 24 and CESCRs General Comment 5, discussed above. Ultimately, the Court found that the case was inadmissible as it had been lodged outside of the appropriate time frame. The use of international human rights law to challenge these non-consensual practices against disabled people nonetheless drew attention from the global human rights community.

The issue of coerced contraception on a young woman with intellectual disabilities featured in the facts of the recent case of Evers v Germany[30]. The applicant claimed a breach of his Article 6 (fair trial) and Article 8 (privacy) rights under the European Convention on Human Rights. He challenged state orders that he not be allowed contact with a young woman with an intellectual disability, who he is alleged to have sexually assaulted. Evers claimed the young woman consented to the relationship. Later he wrote to her legal guardian, requesting the removal of the young woman's contraceptive coil, which he described as "harmful and forced."[31] The court did not make any decision about whether the contraception the young woman was receiving was consensual, and did not find that any of the applicant's rights under the ECHR had been violated but did note that in this situation it seemed to be "the wrong case involving the wrong applicant."[32]

3b. The European Social Charter

The European Social Charter Article 13 regarding the right to medical assistance, outlines that state parties must 'provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want. No applicant from Ireland has taken any collective complaints under this provision of the European Social Charter. However, the European Social Committee has issued a statement that resourcing of medical assistance programmes in Ireland are inadequate[33]. This could have implications for disabled people attempting to access fertility and contraception services.

3c. The Istanbul Convention

Also known as the Istanbul Convention, Ireland has ratified the **Council of Europe Convention on preventing and combating violence against women and domestic violence** since July

30 (Application no. 17895/14)
https://hudoc.echr.coe.int/fre#{%22languageisocode%22:[%22ENG%22],%22appno%22:[%2217895/14%22],%22documentcollectionid2%22:[%22CHAMBER%22],%22itemid%22:[%22001-202527%22]}

31 Ibid, para. 21.

32 Ibid, para. 35.

33 Council of Europe, 'Ireland and the European Social Charter',
https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806449ac

2019[34]. Forced sterilisation is defined in Article 39 b) of the Istanbul Convention as 'performing surgery which has the purpose or effect of terminating a woman's capacity to naturally reproduce without her prior and informed consent or understanding of the procedure.' Through ratification Ireland is required to put prevention, protection and prosecution mechanisms in place for those who are at risk, or victims of, gender based and domestic violence[35].

4. Irish Context

Irish law on the issue of fertility and contraception has changed considerably in tandem with social norms. Historically, the influence of the Catholic Church was intertwined with the state's laws and policies.[36] However, since the late 1970s, the availability of some forms of contraception increased, with the disposal of the need for a prescription for emergency contraception only occurring in 2011[37]. While accessibility of contraception for the general public has now improved, the issue of access for disabled people, especially people living in congregated settings where the religious ethos of the service provider may present a barrier, is not addressed in current law. On the issue of assisted human reproduction, as will be discussed further below, there is still a lack of legal regulation, which presents challenges for ensuring equal access for disabled people.

4a. Irish law

Section 17 of the Criminal Law Amendment Act 1935 prohibited the sale, offer, advertisement or importation of any contraceptive. This ban remained the status quo in Ireland until it was challenged by the *McGee v The Attorney General*[38] case in 1974 (discussed below). Based on the judgement in McGee, the Health Family Planning Act 1979 repealed the total ban on contraceptives but still mandated a focus on natural family planning methods to be advocated by medical professionals. The Health Family Planning Acts from 1980 to 1993 became more progressive, liberalising availability of contraceptives to non-married persons, recognising their use to prevent Sexually Transmitted Diseases and removing the need for prescription for some forms of contraception.

Several commentators highlighted the uncertainty around the terminology of 'unborn' during the campaign to insert the 8th Amendment to the Constitution[39]. There were concerns around the extent to which Article 40.3.3 would apply practically and that it would render some forms of contraception, such as the morning after pill, illegal. These concerns were later clarified through legislation including the Health Acts discussed above. Immediately prior to the repeal of the 8th Amendment, the Supreme Court decided in M v Minister for Equality that the only rights of the 'unborn child' were those contained in Article 40.3.3 and now that this article has been repealed and replaced with alternative text, the Oireachtas is free to legislate on

34 https://www.ihrec.ie/istanbul-convention-combatting-violence-against-women-enters-force-in-ireland/

35 Council of Europe, The Convention in brief, https://www.coe.int/en/web/istanbul-convention/the-convention-in-brief#{%2211642062%22:[4]}

36 Joe Little, 50 years on the Catholic Church's ban on artificial contraception, 30 July 2018, rte.ie

37 RTE, 'IPU welcomes morning after pill decision', https://www.rte.ie/news/2011/0216/297748-pill/ 16 February 2011.

38 [1973] IR 284

39 Today Tonight Show, 1983 via IrishCatholic86 on YouTube: 'William Binchy v Mary Robinson (1983 Pro-Life Referendum) https://www.youtube.com/watch?v=GLWnoQjTNiw, published January 20, 2012.

issues of fertility and contraception unconstrained by any constitutional rights of the unborn child.[40]

The most recent legislative developments relating to fertility are the Children and Family Relationships Act 2015, the Assisted Human Reproduction Bill 2017 and the Civil Registration Act 2019. The Children and Family Relationships Act 2015 regulates the parentage of children born through Donor Assisted Human Reproduction (DAHR). It recognises that the donor of a gamete (egg or sperm) who does so with the consent that the gamete is to be used in DAHR is not the legally recognised parent of the resulting child. During the debate stages of this legislation, no reference to disabled people seeking to avail of DAHR was made, the only references to disability was the provision of advocacy for children with disabilities born of DAHR seeking information about their genetic history[41]. This legislation has been less clear about the recognition of parents using reciprocal IVF treatments, where the egg of one partner is used by the second partner to carry a pregnancy. This can be of relevance to LGBTQI couples where one partner has a disability which prevents safe pregnancy and childbirth by allowing their genetic donation to be used by their partner to become pregnant. Recent litigation has suggested that the legislation does extend to couples using reciprocal IVF to conceive but a judgement has yet to be published on the matter[42].

The Civil Registration Act 2019 amends the Civil Registration Act 2004 to allow for the birth registration of donor conceived children[43] in line with the Children and Family Relationships Act 2015. This will also be of particular importance for same sex couples who have conceived using a donor gamete through a facility in Ireland. Information about both the donor and the resulting child must be maintained on a National Donor-Conceived Person Register. Both parents can be recognised as parents to the child. Where a disabled person in a same sex couple is the partner or non-genetic parent of a child conceived through assisted human reproduction in the circumstances outlined in the legislation, they can now be fully recognised as a parent legally.

In 2017, the General Scheme of the Assisted Human Reproduction Bill was published, setting out an attempt to regulate fertility services in Ireland. At the time of writing the Bill itself has still not been published. The services the General Scheme aimed to regulate are predominantly privately provided, and the proposed legislation could constitute discrimination against persons with disabilities. In its section exploring the potential implications of the Equal Status Acts 2000-2004 for Assisted Human Reproduction, the Report of the Commission on Assisted Human Reproduction states that sub-section 4 of the Acts "provides that where a person has a disability that could cause harm to that person or to others, treating the person differently to the extent necessary to prevent such harm shall not constitute discrimination."[44] According to the General Scheme, providers of fertility services

40 M & ors v Minister for Equality & ors [2018] IESC 14.

41 Dáil Éireann debate - Tuesday, 24 Feb 2015, Children and Family Relationships Bill 2015: Second Stage https://www.oireachtas.ie/en/debates/debate/dail/2015-02-24/29/

42 Gay Community News, Peter Dunne, Irish LGBTQ+ couple who conceived through IVF receive declaration of parentage , 7th October 2020. https://gcn.ie/irish-lgbtq-ivf-declaration-parentage/

43 Section 2(1)(b), Civil Registration Bill 2019

44 Commission on Assisted Human Reproduction, Report of the Commission on Assisted Human Reproduction (Dublin, 2005), p. 165.

are required to consider the impact of the treatment on the health and well-being of the woman and any future children[45]. This could lead to judgements and stereotypes being applied which view potential parents who have disabilities as ineligible for the treatment and prevent them from conceiving children.

In discussions relating to the role of the proposed AHR Regulatory Authority, the National Women's Council note the need for public information to be accessible to people with disabilities and for any research component of the Agency to disaggregate data relating to the experiences of service users, including for disability[46]. Prof. Deirdre Madden identified the potential for discrimination against prospective parents on the grounds of disability being disguised as concern for the future child and advocated for a strong non-discrimination provision in the delivery of AHR services[47]. Prof. Madden also noted the need for diverse approaches to capturing consent which will be suited to persons with disabilities who use different communication methods than written and oral statements.

The proposed Provision of Objective Sex Education Bill 2018 would be extremely useful for future generations of the disabled and non-disabled population alike. The Bill proposes that factual, objective and age-appropriate education is provided on consent to sexual activity, different types of sexuality, gender, methods of contraception[48]. There is no reference to disability within the Bill but it does indicate that the provisions would apply in all educational settings, 'regardless of the characteristic spirit of the school'. This was a Private Members Bill introduced by Paul Murphy and Bríd Smith from Solidarity – People Before Profit, and it lapsed with the dissolution of the 34th Dáil and has yet to be reintroduced.

4b. Irish Caselaw

The most revolutionary caselaw surrounding fertility and contraception in Ireland has been *McGee v The Attorney General*[49] in 1974. This case also resonates with the disability element of this research as the plaintiff is a deaf woman, although her disability was not noted in the judgement nor in much of the media reporting around the case[50]. 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.

There is caselaw indicating that adults with disabilities who are wards of court have decisions made by the High Court in relation to their fertility and contraception. Reports regarding wardship and fertility or contraception decisions are anonymised. Some of the cases below

45 Under Head 6 and Head 7 of the General Scheme of the Assisted Human Reproduction Bill 2017.

46 at p. 176 and 178

47 https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/submissions/2019/2019-07-10_submissions-report-on-pre-legislative-scrutiny-of-the-general-scheme-of-the-assisted-human-reproduction-bill_en.pdf at p. 188

48 Section 4, Provision of Objective Sex Education Bill 2018

49 [1973] IR 284

50 Caroline O'Doherty, 'How much has really changed for women's sexual and reproductive rights in forty years?; Irish Examiner, Monday, October 3, 2016, https://www.irishexaminer.com/opinion/commentanalysis/arid-20423846.html

may relate to the same individual at different stages but it is not possible to definitively identify them as such.

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[51]. The woman is a ward of court who is receiving support from foster carers and is the mother of two children. The Child and Family Agency have assessed that she can parent her first child with support from her foster parents but that the second child is in voluntary care with a view to adoption.

Contraception in the immediate aftermath of pregnancy for wards of court has been an issue. The HSE reconsidered seeking approval for contraceptive implants to a woman who was a ward of court immediately following the birth of her baby. Judge Kelly asserted that strong medical evidence on the need for this intervention would be required and that it was not an appropriate action in the circumstances[52]. The issue of the use of the contraceptive implant for a ward of court detained at psychiatric hospital was not considered to be urgent until closer to her release from psychiatric detention[53]. The woman, who had previously had a child while under wardship, had indicated her opposition to the contraceptive implant.

Another case involved the administration of contraceptive injections to a ward of court, despite opposition from the woman[54]. She recently had given birth and was being released from psychiatric care to reside with her baby's father. Despite her insistence that she would not pursue a sexual relationship, the HSE considered her to be at high risk of future pregnancies which would be detrimental to her mental health. This woman is thought to have been discharged from the ward of court system later in the year when her mental health was said to have stabilised[55].

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*[56] 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. Embryo's 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, especially in light of the M v Minister for Education

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

52 Tim Healy, 'Court rules no longterm contraceptive implants for mentally ill woman' Irish Independent, April 3 2017

53 Mary Carolan, Mentally ill woman indicates opposition to contraceptive implants', Irish Times, Mon, May 22, 2017

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

55 Mary Carolan, ' Woman who had court-ordered Caesarean 'makes extraordinary recovery'', Irish Times, Thurs, Oct 19, 2017.

56 Roche v Roche & Others [2009] IESC 82

decision of the Supreme Court, noted above, which clarified that the unborn child has no constitutional rights beyond those provided for in Article 40.3.3.[57]

Mc D v L and Another[58] involved a child born to a lesbian couple with the use of sperm donor. The donor had agreed the extent of his involvement would be the donation of the gamete to be used for the purposes of conceiving a child. All parties agreed that the sole care obligations and rights would lie with the same sex couple exclusively. After the birth of the child the donor attempted to prevent the couple moving to Australia with the child. On appeal to the Supreme Court the injunction was granted based on the welfare of the child having a relationship with its genetic father. This demonstrates the complexities arising after what was initially a straight-forward arrangement to conceive a child.

A further case involving surrogacy and assisted reproduction treatment is *MR, DR, OR and CR*[59]. This involved the non-recognition of the genetic mother, as opposed to the gestational mother, or twins born through surrogacy. The genetic mother and father were a married couple. The wife's sister acted as the surrogate. The Supreme Court quashed an order from the High Court which recognised the genetic mother for the purposes of civil registration. The Supreme Court declared that it was a matter for the Oireachtas to legislate for such situations. The then Equality Authority acting as amicus curiae drew the courts attention to the scientific developments which called into question the legal maxim of *mater semper certa est* (the mother is always known) and that the Constitution must be interpreted accordingly[60]. They argued that the existing legislative framework was capable of recognising genetic rather than gestational parentage. To find otherwise would lead to inequality of treatment between genetic parents and children of surrogacy arrangements[61]. Subsequently, as discussed above, the Children and Family Relationships Act 2015 and the Civil Registration Act 2019 have addressed the issues arising in the recognition of parents through assisted human reproduction. As disabled parents may seek assisted human reproduction through surrogacy or donors, they are equally impacted by the legal protections surrounding guardianship and parental responsibility for the resulting children.

4c. Irish research

There is limited research available on access 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[62].

57 M & ors v Minister for Equality & ors [2018] IESC 14.

58 [2007] 8 I.C.L.M.D. 61

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

60 https://www.ihrec.ie/download/pdf/mr_v_an_tard_chlaraitheoir_ors__13_jan_2014.pdf

At p. 5

61 https://www.ihrec.ie/download/pdf/mr_v_an_tard_chlaraitheoir_ors__13_jan_2014.pdf

at p. 7

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

The Commission on the Status of Persons with Disabilities from 1996 recognised that sterilisation and contraception, both voluntarily and without consent on disabled people in Ireland which warranted further scrutiny[63]. The Commission advised that sterilisation on the basis of disability alone be prohibited. Further, it recognised that advice and consultation services related to fertility and contraception must be available in an accessible manner to disabled people.

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 disabilities[64]. 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[65]. This report is extremely important in identifying obstacles faced by persons with intellectual disabilities who are further isolated from accessible information and resources in their communities. The Irish Sex Education Network has evolved to become the Connect People Network and the direction of the group is steered by disability advocates, rather than professionals within disability services. Connect People Network have also compiled a database of national and international resources for relationship and sexuality training for adults with intellectual disabilities[66]. The resources include materials for professionals and adults with intellectual disabilities to discuss all aspects of fertility, contraception, pregnancy, relationships, sexual health and LGBTQI relationships.

Kelly, Crowley and Hamilton note the impact of previous Irish laws[67] in restricting the ability of adults with intellectual disabilities to be supported to engage in consensual relationships[68]. 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 important in supporting or discouraging relationships. Where sex education was provided it was informal and focused on menstruation and protection against sexual abuse for women, while the focus was on

63 Commission on the Status of Persons with Disabilities, 'A Strategy for Equality', Overview and Recommendations, Chapter 18, Sexuality and Relationships. Available from: http://nda.ie/Disability-overview/Key-Policy-Documents/Report-of-the-Commission-on-the-Status-of-People-with-Disabilities/A-Strategy-for-Equality/A-Strategy-for-Equality-Report-of-the-Commission-on-the-Status-of-People-with-Disabilities/Sexuality-and-relationships/

64 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

65 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 at p.78

66 Connect People Network, 'Database of Sexuality and Disability Resources', 2012, available from https://www.academia.edu/2241679/Database_of_Sexuality_and_Disability_Resources

67 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.

68 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

biology and procreation for men. The research recommends that disability services expand sex education beyond biological function and include the social and emotional elements of relationships with adults with intellectual disabilities. This will enable people to make informed decisions about their fertility.

The National Disability Authority report on crisis pregnancy indicates alarming practices of long term contraception being provided to women with intellectual disabilities without their full and informed consent[69]. O'Connor's review of Irish and international literature indicates that some elements of controlling or preventing fertility may be beneficial to women with intellectual disabilities who would be distressed by menstruation. Countries included within the scope of the research were Australia, Belgium, Canada, France, UK and the USA. The review is critical of the paternalistic attitude of protection from pregnancy and of the notion that the risk of sexual abuse of a woman with an intellectual disability increases if she is subject to contraception[70]. Literature from international qualitative and quantitative studies on the use of contraception among women with intellectual disabilities indicates that women are not fully informed about the impact of the contraception. The prevalence of long action contraception among the population of women with intellectual disabilities was reportedly higher than the non-disabled population. Convenience and maintenance for carers or support workers was a factor in the administration of contraception, rather than the will and preference of the women[71]. The report highlights that the need for fertility and contraceptive services required by women with intellectual disabilities is equal to that of the non-disabled population. Existing mainstream services must be accessible to women with intellectual disabilities and appropriate training is needed to assist women with intellectual disabilities to manage their fertility.

The 2005 Report of the Commission into Assisted Human Reproduction in Ireland has outlined attitudes of maternity hospital staff to the provision of fertility treatment to disabled patients[72]. 'Twenty-eight (60%) respondents would provide treatment for people with a history of psychiatric disorders; thirty-five (74%) for people with physical disabilities and twenty (43%) for people with intellectual disabilities.' Based on responses from members of the public there was even less support for the provision of assisted human reproduction to persons with disabilities. 'The situation regarding people with disabilities is the least clearcut. Over 40% agreed with the provision of AHR to people with disabilities, with a further 28% agreeing that AHR should be provided for people with disabilities in some cases'[73]. Recognition that disability is caused not be impairment but by social factors is outlined as an

69 O'Connor, 'Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy' National Disability Authority and the Crisis Pregnancy Agency, 2008, http://nda.ie/nda-files/People-with-Intellectual-Disability-Crisis-Pregnancy-Report.pdf

70 O'Connor, 'Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy' National Disability Authority and the Crisis Pregnancy Agency, 2008, http://nda.ie/nda-files/People-with-Intellectual-Disability-Crisis-Pregnancy-Report.pdf, at p. 39

71 O'Connor, 'Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy' National Disability Authority and the Crisis Pregnancy Agency, 2008, http://nda.ie/nda-files/People-with-Intellectual-Disability-Crisis-Pregnancy-Report.pdf, at p.41

72 Commission on Assisted Human Reproduction, Report of the Commission on Assisted Human Reproduction, (2005) Available from www.lenus.ie/bitstream/handle/10147/46684/1740.pdf?sequence=1&isAllowed=y at p.44

73 Commission on Assisted Human Reproduction, Report of the Commission on Assisted Human Reproduction, (2005), Available from www.lenus.ie/bitstream/handle/10147/46684/1740.pdf?sequence=1&isAllowed=y at p. 43

argument against pre-implantation genetic diagnostic screening[74]. In the Commission's consideration of the impact of the Equal Status Acts to the provision of assisted human reproduction services they note the limitation of reasonable accommodation as requiring a service to invest no more than a nominal cost to make accommodations. The Commission also considered the potential refusal of AHR services where provision of those treatments would cause harm to that person or others. Worryingly, the Commission concludes that this could be extended to include perceived future harm to a child born to a disabled parent[75].

The National Women's Council of Ireland have highlighted the dearth of research into the reproductive freedoms of women with disabilities in Ireland[76]. Their 2008 report identifies prejudicial attitudes towards sexuality and family planning by persons with disabilities should be addressed by a rights-based approach to sexual education for young people with disabilities.

4d. Irish Policy

As part of the Maternity and Infant Care Scheme, the GP examination of mother and baby at 6 weeks includes a discussion on contraceptive choice[77]. This discussion should be available to everyone, without discrimination. GPs and Public Health Nurses should ensure that this discussion is conducted in an environment that the patient is comfortable and in a manner which is understood by their patients. This issue is identified within the HSE's National Guidelines on Accessible Health and Social Care[78] which outline that primary care staff must develop disability competence to respond to a disabled person's health issue which is not disability related, such as pregnancy[79].

The National Sexual Health Strategy applies to everyone in Ireland but specific reference is made to persons with intellectual disabilities[80]. Legal capacity to consent to medical treatment, including contraception is highlighted as problematic for this (problematically termed) 'vulnerable group'[81].

The Irish Family Planning Association runs an education support group for parents of children with disabilities to inform them on how to speak to young people with disabilities about sex education[82]. These are useful initiatives to equip the next generation of adults with disabilities about their own fertility and contraceptive choices. It is important that any initiatives are equally accessible to parents with disabilities also, who may or may not have children with disabilities.

74Commission on Assisted Human Reproduction, Report of the Commission on Assisted Human Reproduction, (2005), Available from www.lenus.ie/bitstream/handle/10147/46684/1740.pdf?sequence=1&isAllowed=y at p.62

75 Commission on Assisted Human Reproduction, Report of the Commission on Assisted Human Reproduction, (2005), Available from www.lenus.ie/bitstream/handle/10147/46684/1740.pdf?sequence=1&isAllowed=y at p165

76National Women's Council of Ireland, 'Disability and Women in Ireland, Building Solidarity' October 2008, At p. 38 -39.

77 https://www2.hse.ie/wellbeing/child-health/postnatal-check-up.html

78HSE and National Disability Authority, National Guidelines on Accessible Health and Social Care, (2016) https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/natguideaccessibleservices.pdf

79 Ibid at p.31

80 National Sexual Health Strategy: https://health.gov.ie/wp-content/uploads/2015/10/National-Sexual-Health-Strategy.pdf

81 National Sexual Health Strategy: https://health.gov.ie/wp-content/uploads/2015/10/National-Sexual-Health-Strategy.pdf at p. 31

82 'Handbook for primary health care providers on disability and sexuality', IFPA, not found online. Missing link.

Persons with disabilities are considered within the Department of Health's Report of the Working Group on Access to Contraception in Ireland[83]. 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, making reference to the statutory age of consent as 17 which will impact on the provision of contraception to those who are underage. This also has potential for restricting access to contraception for persons with disabilities who are deemed unable to consent to medical decisions.

5. Learning from Opening Conference:

Selina Bonnie, a disability activist and mother, spoke about her experiences of attitudinal barriers from fertility services that could have denied her assistance in starting her family. Further, she described the physical inaccessibility of the built environment within some fertility services for her as a wheelchair user. Her experience with private fertility services was of a higher quality.

Dr. Sinead Feeney, a Galway based GP, highlighted that awareness of contraception is low among general population. Dr. Feeney described how attempts are made by GPs to explain methods of contraception and the potential impacts of the contraceptive method for persons with disabilities. She is aware that a remote sign language interpretation service is available for Irish Sign Language users who hold medical cards when visiting their GP.

Dr. Ciara Staunton, a legal researcher in bioethics, detailed the discriminatory potential of the Assisted Human Reproduction Bill. She noted that there are proposed requirements for fertility clinics to consider the best interest of the mother and future child when deciding to make their services available. No independent appeals process to a decision to decline to provide fertility services is anticipated in the Bill. She outlined the financial barriers to availing of fertility treatments which may affect future parents with disabilities. A potential conflict of interest arises for clinics also as their work can involve screening out disabilities, as well as providing fertility treatment to a person living with those disabilities.

6. Conclusion

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

83 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

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.