Background paper on abortion and disability

1. *Introduction*

This paper has been prepared for the final Discussion Forum of the Re(al) Productive Justice Project. The Discussion Forum focuses on abortion and disability. This paper outlines the international and domestic legislative, case law, research and policy context of access to abortion services for persons with disabilities in Ireland.

Please note that the discussion of UN Jurisprudence and Irish caselaw sections of this paper include references to traumatic issues such as rape and coercive medical practices.

2. *International Human Rights Law*

The international framework for abortion spans numerous United Nations instruments and treaty bodies as well as the jurisprudence of the individual complaint mechanisms. The most relevant international human rights instruments are discussed below.

2a. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD does not specifically reference abortion. The Ad Hoc Committee which drafted the Convention made a deliberate decision not to include a reference to abortion under Article 10 of the CRPD on the right to life.[1] As the understanding of the project is that abortion is a fundamental health service, the provisions within the Convention pertaining to equality, privacy and healthcare can be incorporated into the human rights framework promoting access to safe and legal abortion.

Article 23(b) UNCRPD requires that States respect disabled people's right to control over the number and spacing of their children and the means to realise their choices on this matter. Article 25 of the UNCRPD protects the rights of disabled people to the highest attainable standards of health. Where health services, including reproductive health services such as abortion, are provided to the general population, these must be available on an equal basis to disabled people. The principle of non-discrimination on the basis of disability applies to pregnant disabled people seeking abortion, as does the obligation to reasonably accommodate their needs in accessing abortion services, under Article 5.

Numerous submissions made to the Committee on the Rights of Persons with Disabilities during their consideration of General Comment 6 on Article 5 referenced abortion as a potential area of discrimination[2]. However, the Committee references abortion only once in

[1] Grandia, Lex, "Imagine: To Be A Part of This" in Sabatello, Maya, and Schulze, Marianne, eds. Human Rights and Disability Advocacy. Philadelphia: University of Pennsylvania Press, 2013.

[2] European Centre for Law and Justice, Written submission on the Draft General Comment No. 6 on the right of persons with disabilities to equality and non-discrimination (article 5) and ADF International's Submission to the CRPD Committee on General Comment No. 6 on Article 5 of CRPD, November 2017 both argue that abortion based on fatal fetal anomaly and disability is discriminatory under the Convention.

General Comment 6 to note that forced abortion performed on pregnant disabled people amounts to discrimination[3].

In the Committee's Concluding Observations to the United Kingdom and Northern Ireland[4], the CRPD Committee highlighted the right of disabled women to reproductive services while being critical of an abortion regime which facilitated abortion based on foetal impairment at any stage of pregnancy. The Abortion Act 1967 permits the termination of pregnancy where there is a risk to life or health of the mother in England, Scotland and Wales. It also facilitates termination under Section 1 in situations where '*there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped*.' The Committee was concerned '*about perceptions in society that stigmatize persons with disabilities as living a life of less value than that of others and about the termination of pregnancy at any stage on the basis of foetal impairment*.'

These Concluding Observations prompted concern from sexual health and reproductive rights advocates who consider any restrictions on the availability of abortion as violating the pregnant person's rights to autonomy[5]. The comments also do not conform with guidance from other United Nations bodies on the issue of abortion and the fact that human rights are applicable from birth onward, as will be seen below. The Committee have since clarified their position on safe and legal access to abortion in a framework which respects the individual's autonomy and calls for full decriminalisation.[6]

2b. UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)

Article 12 of CEDAW promotes equality of healthcare for women, including equal access to reproductive health services such as abortion. This is reinforced by Article 16 (e) which requires states to take measures to ensure women can decide freely on the number and spacing of their children and to realise these choices. The Committee on the Elimination of Discrimination Against Women have also considered both forced abortion and denial of abortion in the context of gender-based violence through their General Recommendations[7].

[3] Committee on the Rights of Persons with Disabilities General comment No. 6 (2018) on equality and non-discrimination, April 2018, at para 7

[4] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, 3rd October 2017, paras 12 and 13, https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHIkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2BldQaLP31QDpRcmG35KYFtgGyAN%2BaB7cyky7

[5] Marge Berer, International Coordinator, International Campaign for Women's Right to Safe Abortion, Open Letter to the Committee on the Rights of Persons with Disabilities https://www.safeabortionwomensright.org/isad/open-letter-to-the-special-rapporteur-and-committee-on-the-rights-of-persons-with-disabilities/

[6] Joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of All Forms of Discrimination against Women Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities" , (Adopted the 29 August 2018)

[7] Committee on the Elimination of Discrimination Against Women, General recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19, 14 July 2017, at para 18. Available from: https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1_Global/CEDAW_C_GC_35_8267_E.pdf

As will be discussed further below the Committee has also developed a joint statement with the CRPD Committee on the issue of abortion.

2c. International Covenant on Economic, Social and Cultural Rights (ICESCR)

The right to the highest attainable standard of health is protected under Article 12 of ICESCR. When addressing the issue of maternal mortality, the Committee took the opportunity within its General Comment on Article 12 to promote the right to safe abortion, identifying persons with disabilities requiring particular attention to access abortion[8].

2d. International Covenant on Civil and Political Rights (ICCPR)

Article 6 of the ICCPR protects the right to life of every human. The content of this provision has been much discussed in discourse around abortion. The treaty body of the ICCPR, the Human Rights Committee, have clarified that the right to life does not prevent legal abortion. They stated in their General Comment 36 on the right to life[9] that abortion must be made available in a non-discriminatory manner, without arbitrary intrusion into private lives, in situations where there is a risk to life or health of the pregnant person. Abortion must be available as part of the provision of wider sexual and reproductive health services[10]. As part of the examination of Ireland's adherence to ICCPR obligations during 2017, the Committee have been critical of the unavailability of abortion in Ireland[11] .

2e. United Nations Convention Against Torture (UNCAT)

Denial of access to abortion for pregnant people has been recognised by the UN Committee Against Torture as a form of cruel, inhuman or degrading treatment. To date, the Committee has not made specific comments about the denial of abortion access to pregnant disabled people or indeed the issue of forced abortion experienced by pregnant disabled people.[12] Through the Concluding Observations on Ireland's most recent examination by the Committee Against Torture in 2017, the Committee noted that failure to provide legal access to abortion within Ireland had caused severe physical and mental anguish to the women impacted[13].

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[8] OHCHR, Right to sexual and reproductive health indivisible from other human rights - UN experts https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=17168&LangID=E

[9] Human Rights Committee General comment No. 36, 3 September 2019, Available from https://www.refworld.org/docid/5e5e75e04.html . http://opiniojuris.org/2019/03/06/the-un-human-rights-committees-general-comment-36-on-the-right-to-life-and-the-right-to-abortion/

[10] Para 8.

[11] Amnesty International Ireland, UN Human Rights Committee again finds Ireland's abortion ban violates women's human rights, https://www.amnesty.ie/un-human-rights-committee-finds-irelands-abortion-ban-violates-womens-human-rights/

[12] The only decision of the Committee relating to abortion and disability is *A v Bosnia Herzegovina* (CAT/C/67/D/854/2017), where during the armed conflict a woman was raped, became pregnant and accessed abortion. She acquired a psychosocial disability as a result of the trauma she had experienced. The case concerned her right to fair and adequate compensation and did not address the issue of abortion access in the context of her disability.

[13] Committee against Torture, Concluding observations on the second periodic report of Ireland, 31 August 2017, at para 31

3. United Nations Guidance

While there are no specific references to disability and abortion, the 1994 International Conference on Population and Development Programme of Action in Cairo asserted that abortion must be available safely and legally[14]. More recently, the United Nations Population Fund highlighted that abortion is a core component of Sexual and Reproductive Health for persons with disabilities[15]. The report is explicit in noting the importance of voluntariness of undertaking family planning and contraceptive methods. This is identified as being especially important to persons with disabilities who, as well as being excluded from mainstream reproductive health services, are often subjected to forced abortion, contraception and sterilization without consent.

The Joint Statement between the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Discrimination Against Women in 2018[16] highlights that reproductive rights and disability rights are interconnected. The Committees were prompted to draft a statement in response to the prevalence of violations of sexual and reproductive rights for disabled people. The Committees assert that abortion should be decriminalised and that laws, policies and practices which reinforce negative stereotypes around disability should be addressed, including the provision of necessary supports to parents of disabled children. The Statement recognises that "gender equality and disability rights are mutually reinforcing concepts" rather than oppositional forces. The Statement calls for the repeal of "abortion laws that perpetuate deep-rooted stereotypes and stigma". However, it does not explicitly state that abortion laws that permit abortion on grounds of foetal impairment perpetuate disability stigma and must be repealed. The Statement is strong on the right of individual pregnant people, including disabled pregnant people, to access abortion and the need to eliminate barriers, including the use of restrictive legal grounds, which limit access to abortion.

The 2020 United Nation's Information Series on Sexual and Reproductive Health and Rights[17] reinforces the Joint Statement. It notes that states must ensure legal and accessible abortion services are provided while simultaneously implementing measures to protect against disability discrimination.

4. United Nations Jurisprudence

[14]Cairo Programme of Action, available from: https://www.unfpa.org/sites/default/files/event-pdf/PoA_en.pdf at p.45-47.

[15] Women and Young People with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights (2018), Available from: https://www.unfpa.org/sites/default/files/pub-pdf/UNFPA-WEI_Guidelines_Disability_GBV_SRHR_FINAL_19-11-18_0.pdf

[16] 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), 'Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities'. August 2018.

[17] Office of the High Commissioner for Human Rights, Information series on Sexual and Reproductive Rights and Health, Abortion, Updated 2020, Available from: https://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_Abortion_WEB.pdf at p.3.

Where states have ratified the Optional Protocol to human rights conventions, individuals are enabled to make complaints directly to the monitoring committee for the Convention. The issue of abortion and disability has arisen in these individual complaints. These cases are discussed here.

In the case of *TPF v Peru*[18] a girl who had been sexually abused became pregnant aged 13. Due to the pregnancy, she attempted suicide. This attempt resulted in extensive physical injury and surgical intervention was recommended to prevent permanent disability. This was postponed and later cancelled due to the risk of harm to the foetus. There are some instances, including sexual assault, where a therapeutic medical abortion in Peru is permissible but this was denied. The reason for the refusal was that there was no risk to the life, only the health of the girl. There was no consideration of the girl's mental health. The Committee found that an appropriate framework must be put in place to clarify eligibility of therapeutic abortions. Natural miscarriage occurred later but significant physical disability had been acquired due to delay and insufficient healthcare. This was found to violate multiple articles of CEDAW including Articles 12 and 16 discussed above.

LMR v Argentina[19] concerned a woman with intellectual disability who had become pregnant as a result of rape. An abortion was requested as this was permissible for women with intellectual disabilities in Argentina. However, there was an unclear framework for how to gain approval and to administer an abortion. LMR was refused an abortion at the first hospital she attended and had to travel 100kms to a second hospital. Despite litigation to clarify the abortion was permitted, no hospital was willing to provide it. This was due to a combination of public pressure and Catholic ethos of the providers. LMR was also at an advanced stage of pregnancy due to the delays. Eventually, with support from her family and an advocacy organisation she obtained an illegal abortion. The Human Rights Committee found there had been a violation of ICCPR Articles 2(3), 3, 7, 17.

5. Other Human Rights Guidance

Drafted and agreed by international civil society actors, the Nairobi Principles[20] affirm that there is no incompatibility between the protection of disability rights and the right to safe abortion. The principles promote the inclusion and participation of disabled people in discussions around access to abortion and reject harmful practices of eugenics. In realising the right to safe abortion, the Principles identify the right to accessible and accurate information when making decisions about one's own body. The need to challenge ableist attitudes and approaches to pregnancy is highlighted and that socio-economic and other supports must be in place to enable all parents to raise their children.

6. European Human Rights Caselaw

[18] Committee on the Elimination of Discrimination against Women. Communication No. 22/2009

[19] In the case of Human Rights Committee 101st session 14 March–1 April 2011 Communication No. 1608/2007

[20] The Nairobi Principles on Abortion, Pre Natal Testing and Disability https://nairobiprinciples.creaworld.org/principles/

At the European Court of Human Rights, the restrictive Polish abortion regime was examined. In *Tysiac v Poland*[21] a woman who already had children and was pregnant sought a termination of pregnancy on therapeutic grounds. She had been informed of a risk of blindness from her retina detaching which was considered to be caused by the pregnancy by her initial medical consultant. There were differing views by doctors on the link between her deteriorating eyesight and the pregnancy and she was ultimately refused. After the birth of her child her eyesight deteriorated significantly. She was encouraged to learn braille and was categorised as disabled officially. However, she was not entitled to disability welfare payment as she had not worked enough years due to caring for children. This resulted in financial hardship for the family. The Court deemed that there were insufficient mechanisms to determine whether she was eligible for termination of pregnancy which amounted to Art 8 violation.

The Irish case of *A,B,C v Ireland* at the European Court of Human Rights is discussed below.

7. Irish developments in the provision of abortion services

This section discusses the developments leading to the current framework for the provision of abortion in restricted circumstances in Ireland. These laws and policies have been equally applicable to disabled people but have had disproportionate impacts on disabled people compared with the non-disabled population. It is worth noting that while many of the high-profile cases which have led to abortion reform in Ireland involved pregnant people who would come within the CRPD's holistic conceptualisation of disability (especially those who experienced emotional distress or psychosocial disability), there is a lack of disability rights analysis on access to abortion in Ireland. In many cases, pregnant people have acquired disabilities as a result of being denied abortion access. It is further notable that the most frequent references to disability in abortion discourse in Ireland relate to foetal impairment, rather than to the pregnant person. This in part is one of the gaps which this project is working to address.

The Offences Against the Person Act 1861 formed the foundation for the restrictive abortion regime in Ireland until 2nd January 2019. Section 58 prohibited a woman from intentionally ending her pregnancy while Section 59 made it unlawful for another actor to terminate a pregnancy. The Offences Against the Person Act 1861 remained the status quo in Ireland until fears of a liberalised abortion regime prompted the Constitutional prohibition on abortion in 1983.

Article 40.3.3 of the Irish Constitution was inserted as an amendment following the 1983 referendum as follows: 'The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right.'

The *X case*[22] was arguably the most high-profile litigation in Ireland relating to abortion. A minor who was suicidal due to pregnancy attempted to travel to the UK. She was prevented

[21] European Court of Human Rights, Fourth Section, (Application no. 5410/03) March 2007.

[22] *Attorney General v X*, [1992] IESC 1

from travelling until the Supreme Court decision regarding the legality of abortion where there was a real and substantial risk to life, including by suicide. This prompted a referendum on the legality of travelling abroad to avail of abortion and for information about such services to be legally available in 1992.

The regulation of information about abortion services abroad was examined in *Society for the Protection of the Unborn Child v Open Door Counselling*[23] and *Society for the Protection of the Unborn Child v Grogan*[24]. Advertisements for UK based abortion services within sexual health and student union publications respectively were unsuccessfully challenged by SPUC.

While not a disability-specific case, the most influential case to clarify the balancing of right to life and to health of the pregnant person and right of unborn in Irish law was *A,B,C v Ireland*[25] in 2005. Three women who had been forced to travel to the UK to access abortion services argued that their right to abortion in their specific circumstances should have been fulfilled in Ireland. Only B was successful in her argument as the court found that the law was insufficiently clear regarding the continuation of medical treatment (chemotherapy) which would impact the foetus. The court found that the law prohibiting abortion had a chilling effect on medical practitioners who were unwilling to continue to provide vital health treatment.

D v Ireland[26] was a 2006 case of a pregnancy of twins with fatal foetal abnormalities. The mother had difficulty ascertaining whether she could take her medical file to the UK. As a result of the abortion ban in Ireland, she felt she could not inform staff in Ireland when she was having post-abortion complications. Instead she informed them that she was having a miscarriage upon returning to Ireland after the abortion. The mental and emotional strain damaged her health, her ability to work and relationship with her partner.

The similarly titled *D case*[27] in 2007 involved litigation on the right to travel for an abortion due to a fatal foetal anomaly diagnosis. An attempt was made by the HSE to prevent a minor in its care from travelling to the UK to secure an abortion. The High Court determined that the girl was free to travel to the UK for the procedure.

One of the most well-known tragedies arising from the prohibition on abortion in Ireland has been the death of Savita Halapanavar. Savita was a 31-year-old woman who died from sepsis as a result of being denied a termination of pregnancy at Galway University Hospital in 2012[28]. This tragedy attracted international attention and propelled the public discourse on the issue.

[23] (1993) 15 E.H.R.R. 244
[24] [1992] I.L.R.M. 461
[25] Grand Chamber, (Application no. 25579/05)
[26] (2006) 43 E.H.R.R. SE16
[27] Miss D' case to resume in High Court , Fri, May 4, 2007, https://www.irishtimes.com/news/miss-d-case-to-resume-in-high-court-1.806564
[28] Cullen and Holland, 'Husband's action over death of Savita Halappanavar settled' Wednesday 9th March 2016, https://www.irishtimes.com/news/crime-and-law/courts/high-court/husband-s-action-over-death-of-savita-halappanavar-settled-1.2566536

Partly prompted by the death of Savita Halpanavar and the resulting calls for reform in the wake of the *A,B,C* case, new legislation was drafted to clarify the availability of medical termination while also respecting the equal right to life of the unborn. The Protection of Life During Pregnancy Act 2013 permitted a termination of pregnancy in three cases: where there is a risk of loss of the pregnant person's life from physical illness; a risk to loss of life in an emergency; and risk to loss of life by suicide. This Act did not introduce abortion, it rather clarified existing practices. The Irish Human Rights Commission observations on the Protection of Life During Pregnancy Act[29] noted the need for information on abortion to be accessible to people for whom English is not a first language and for persons with disabilities[30]. In parliamentary debates and legislative submissions on this Act, there is little consideration of the needs of pregnant disabled people accessing abortion under this law.

Between 2014 and 2018, a total of 124 terminations were notified as being conducted under this law[31]. The Department of Health and Social Care in the UK record where women provided a Republic of Ireland address when accessing abortion services there. During 2014 to 2018 (inclusive) there were 16,349 patients from the Republic[32]. This does not include Irish people who may have provided a UK or no address.

The *PP* case[33] demonstrated the difficulties in implementing the Protection of Life During Pregnancy Act 2013. The case concerned a woman who was pregnant and clinically deceased but being artificially kept alive for the sake of the foetus. NP's family sought for treatment to be withdrawn. The HSE sought confirmation on their obligation to the unborn in this instance. The early stage of pregnancy and unviability of the foetus was discussed. The court deemed the 8th Amendment created an equal right to life. In this instance there was no realistic prospect of life for the foetus, and the life support could be removed without violating the 8th Amendment.

[29] Irish Human Rights Commission, Observations on the Protection of Life During Pregnancy Bill 2013 July 2013',
https://www.ihrec.ie/app/uploads/download/pdf/ihrc_observations_protection_of_life_in_pregnancy_bill_2013.pdf

[30] Ibid at p.20.

[31] Government of Ireland, Annual Report of notifications in accordance with the Protection of Life During Pregnancy Act 2013, https://www.gov.ie/en/press-release/1cb04e-annual-report-of-notifications-in-accordance-with-the-protection-of-/

[32] This figure is calculated based on the annual reports from the Department of Health and Social Care. An Excel spreadsheet is available for each year. The Irish addresses are collated at Table 12D of each report. A breakdown of these figures are as follows: In 2014 - 3,735 (Department of Health and Social Care, Abortion statistics, England and Wales: 2014
https://www.gov.uk/government/statistical-data-sets/abortion-statistics-england-and-wales-2014)
In 2015- 3451 (Department of Health and Social Care, Abortion statistics, England and Wales: 2015
https://www.gov.uk/government/statistical-data-sets/abortion-statistics-england-and-wales-2015)
In 2016 - 3,265 (Department of Health and Social Care, Abortion statistics, England and Wales: 2016,
https://www.gov.uk/government/statistics/report-on-abortion-statistics-in-england-and-wales-for-2016
In 2017 – 3,019 (Department of Health and Social Care, Abortion statistics, England and Wales: 2017,
https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2017)
In 2018 - 2,879 (Department of Health and Social Care, Abortion statistics, England and Wales: 2018,
https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2018)

[33] [2014] IEHC 622

A further example of the barriers to abortion services under the 2013 Act can be found in the case of Miss Y. She was an asylum seeker who discovered her pregnancy upon arrival in Ireland while in the Direct Provision system. The pregnancy was reported to be the result of sexual violence in her country of origin[34]. Miss Y was suicidal because of the pregnancy. She could not avail of abortion services in the UK due to affordability and her inability to legally travel outside of Ireland. Miss Y had not been advised of the provisions within the Protection of Life During Pregnancy Act 2013 for termination based on risk to life by suicide. As a result of her hunger strike, Miss Y was told a termination would be provided if she resumed eating and drinking. There was much legal delay and in the interim the HSE obtained an order to force feed Miss Y. She agreed to a caesarean section without being fully informed of the legal processes taking place pertaining to her case[35].

8. Current Abortion Framework in Ireland

A referendum to repeal the 8th Amendment took place in May 2018 and was successfully passed with a majority 66.4% in favour of repeal. The Health (Regulation of Termination of Pregnancy) Act 2018 regulates a framework for abortion services in Ireland from January 1st, 2019. Providers of Termination of Pregnancy services must enter a contract to do so with the HSE. The contract for the provision of a Termination of Pregnancy pursuant to the Health Act 2018 states in Section 2.1 that '*This Contract is a contract for the provision of services. The Registered Medical Practitioner is an independent provider of services and is not an employee, partner, or agent of the HSE*.'[36] Based on information from key informants, this specific provision is having the effect of limiting the number of providers, particularly those contracted to provide GP services to people within the remit of the social inclusion branch of the HSE (such as those in disability residential services or homelessness services)[37].

The Health (Regulation of Termination of Pregnancy) Act 2018 permits a termination to be provided where there is a serious risk to the life or health of the woman. This includes a risk to the life or risk of serious harm to both physical and mental health under Sections 9 and 10. Where two doctors agree that there is a fatal foetal abnormality, a termination can be performed under Section 11. An abortion is permitted to be provided upon request within the first 12 weeks of pregnancy. Section 23 removes a criminal sanction for the self-termination of pregnancies. Conscientious objection to delivering abortion services is permitted by medical staff, however, they must ensure the person does receive abortion services in a timely manner.

A report on the number of abortions provided under the new law is required on an annual basis. To date, only one report is available covering 2019.[38] During this year 6,666 abortions were conducted. Under Sections 9 and 10 of the Act, 24 abortions were provided. Abortions were provided in 100 cases of fatal foetal abnormality. Most abortions – 6,542 - were

[34] Ms. Y case: Denied a legal abortion in Ireland, 21st March 2016, https://www.amnesty.ie/ms-ys-case/
[35] Ms. Y case: Denied a legal abortion in Ireland, 21st March 2016, https://www.amnesty.ie/ms-ys-case/
[36] https://www.hse.ie/eng/about/who/gmscontracts/termination-of-pregnancy-draft-contract/termination-of-pregnancy-service-contract-nov-2019.pdf
[37] Based on information provided by Key Informant 32, a General Practitioner in an urban region.
[38] Department of Health, Notifications in accordance with section 20 of the Health (Regulation of Termination of Pregnancy) Act 2018.

provided within the first 12 weeks without reason under Section 12. This data is disaggregated by month and county but there is no further classification of individuals receiving these services, and therefore no information on the numbers of disabled pregnant people accessing abortions.

The Health (Termination of Pregnancy) Act 2018 is to be reviewed during 2021. This is an opportunity to highlight the shortcomings of the current legislation, including the difficulties around the 12-week limitations and the lack of service provision in parts of the country. Any revision of the legislation must recognise the additional barriers which unequal availability of services represents for disabled people. There is also a risk that the limited abortion services currently available could be further reduced. There remains a need to travel to access abortion services outside of Ireland, which is exacerbated for disabled people who may need accessible transport or support to travel. During 2019, 375 patients at UK abortion clinics indicated an Irish address[39] despite the change in abortion law here.

8a. Assisted Decision-Making (Capacity) Act and Wardship

The project is conscious of the lack of clarity regarding the interaction between the Assisted Decision-Making Act 2015 and the Health (Termination of Pregnancy) Act 2018 when considering the capacity of a person to give consent for an abortion. As the 2015 Act has not yet been commenced, there is no clarity for abortion providers on how to proceed if they are concerned that the pregnant person lacks capacity. The only applicable legislation governing capacity remains the Regulation of Lunacy (Ireland) Act 1871 which established the Ward of Court system. There are currently no reported cases of the wardship jurisdiction being imposed on a pregnant person in respect of decisions about abortion, but it is possible, although highly problematic from a human rights perspective, for wardship to be used in this manner.

Wards of court are not allowed to travel abroad for medical treatment (including abortion) without the court's permission, which would impose a further barrier especially if the pregnancy has progressed beyond the 12 weeks where abortion can be provided on request and risk to life or health needs to be demonstrated. Based on information from key informant interviews, we are aware that young disabled people in the care of the state had to seek permission from the District Court to travel to the UK to obtain an abortion prior to the Repeal of the 8th Amendment[40].

Once the 2015 Act is commenced, there will still be barriers for disabled people in accessing abortion if there are questions about their capacity to consent. One area of concern is the lack of clarity around conscientious objection of Decision-making Assistant, Co-Decision Maker and Decision-Making Representative. Conscientious objection should not extend beyond people actively partaking in providing abortion as a treatment option, however given the unique nature of the roles it is an issue that may arise. As an example, a Co-Decision Maker allows for a person to veto a decision which would cause harm to the person or others. If a co-decision maker were to believe that a foetus falls within the scope of 'others' according

[39] Department of Health and Social Care, Abortion statistics for England and Wales 2019, https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2019

[40] KI28, Transcript on file with research team.

to this harm principle, the Act is silent on whether the decision of a pregnant person could be vetoed. In the event a co-decision maker is concerned a person will regret the decision, it appears to be possible that they could veto it on the basis that it could constitute 'serious harm' to a person's emotional well-being. It is unclear how conflicting interpretations of will and preferences will or can be resolved if the person is not clearly communicating about whether they wish to have an abortion. Ultimately, significant guidance needs to be issued by the Decision Support Service in order to ensure that the law is not used as a tool to obstruct access, or to compel someone to have a termination against their wishes.

Advanced healthcare directives are permissible under Part 8 of the Assisted Decision-Making Act 2015. This allows individuals to make decisions about their healthcare to make their will and preferences known in the event of loss of capacity. While it is not possible to have legally binding specifications of exact treatments to be administered, the wishes expressed in the directive must be taken into consideration.

Section 86 (6) of the Act provides for a pregnant person who lacks capacity to make a decision and has an advanced healthcare directive in place. Where there is a refusal of treatment specified by the woman, but no indication about the circumstances of pregnancy, a healthcare practitioner can ignore the refusal of treatment if they consider that there will be a deleterious effect on the unborn.

If the directive specifies a refusal of treatment even in the case of pregnancy, and the health care provider deems that there will be a deleterious effect on the unborn, an application must be made to High Court to determine whether the refusal can apply. In making a decision the High Court must consider the potential impact on the unborn of refusing treatment as well as the potential impact on the directive maker of proceeding with the treatment.

8b. HSE Consent Policy

This policy was developed initially prior to repeal of the 8th amendment and was updated following the enactment of the Health (Regulation of Termination of Pregnancy) Act 2018. The revised policy now states that "service users who are pregnant 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 … They will also need 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."[41] The policy also reiterates that the consent of a service user is required for all health and social care interventions in pregnancy, updating its previous position on refusal of treatment in pregnancy.

Consent, as understood within the National Consent Policy 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 time and location where consent to treatment is obtained as very important, in that, treatment information should be communicated in a quiet place with enough time to consider the information, medical jargon

[41] HSE, National Consent Policy (2019, v1.3) p. 28.

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 during 'lucid periods', 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 revised following 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 an abortion, as discussed above.

8c. Guidance for medical practitioners on delivery of abortion services

There is no specific reference to persons with disabilities in the Irish Council for General Practitioners guidance on the provision of abortion services. The guidelines are currently being updated[42]. The guidelines also exclusively use the pronoun 'she' which fails to recognise diversity of gender identity. Section 2.3.3 regarding consent has the potential to impact disabled people disproportionately. GPs are advised that they must ascertain that the patient has the capacity to consent[43]. No further detail is provided about how this is to be satisfied.

The guidance envisions three consultations with a patient, the last of which is at the patient's own discretion whether to attend. The first consultation is to explain the risks of the procedure, to date the pregnancy and to direct the patient to counselling. There is a three-day waiting period between the first and second consultations. During the second consultation the medication is dispensed, and advice provided around side effects and complications. The third, and optional, consultation is to ensure the successful completion of the procedure and to check the woman's mental and physical health. Where the GP providing the abortion is not the patient's regular GP, consent must be ascertained to share relevant medical history of the patient with the new GP.

A surgical termination might be required due to a failed medical termination or if the pregnancy is dated between 9 and 12 weeks. Guidance has been issued by the Institute of

[42] Email communication between ICGP Quality & Safety in Practice Project Office and Dr. Áine Sperrin 01 February 2021.

[43] Section 2.3.3 file:///Users/ainesperrin/Desktop/Interim_Clinical_Support_for_Termination_of_Pregnancy_in_General_Practice_08.01.2019.pdf

Obstetricians and Gynaecologists[44] on the provision of surgical abortion within the 12-week limit and beyond where there is a risk to the life or health of the pregnant person. Conscientious objection is permitted unless the situation arising requires emergency medical attention. There is no reference to disability or capacity in the 12-week OBGYN guidance.

The Institute of Obstetricians and Gynaecologists have also issued guidance on abortion in the cases of fatal foetal anomalies or life limiting conditions diagnosed during pregnancy[45]. The term disability does not feature in these guidelines. There is explicit recognition that only the individual can consent to medical treatment, unless another actor has legal authority to do so. Patients are to be provided with all information surrounding termination as well as perinatal palliative care. The principles of maternity health and wellbeing are to be continued for patients availing of termination due to fatal foetal anomaly or life limiting condition[46].

9. Existing literature on provision of abortion to Irish people

For the past 30 years or more, research on the experiences of people travelling outside of Ireland to use abortion services has been relatively scant. It is estimated that 170,000 Irish women have travelled for an abortion since 1980[47]. Sexual health information services such as BPAS in the UK and IFPA and Well Woman in Ireland, have over the years reported on the number of women with Irish addresses accessing services abroad to indicate the level of demand for such a service in Ireland. For instance, BPAS reported that between January 1997 – June 2000 some 8,281 Irish clients presented for abortion care in the UK with almost 80% presenting for care at 12 weeks' gestation or less[48]. Prior to the repeal of the 8th amendment legislation in 2018, of all the abortions carried out in England and Wales in 2018, 4,687 were non-residents of which 61% were from the Republic of Ireland[49]. Despite capturing statistics on those who were successful in travelling to obtain abortions concern and awareness was raised for those women for whom such a measure was inaccessible due to financial constraints, immigration status, abusive relationships or those who have accessed abortion pills online. We can also include people with disabilities in this category, those who may find, for example, accessing information or support to travel for an abortion inaccessible to them.

As Duffy et al. (2018)[50] highlight, there is a complex relationship between legality and accessibility. That is, liberalisation of abortion law and policy does not automatically ensure increased accessibility. Rather, access to abortion provision is socially and culturally

[44] Institute of Obstetricians and Gynaecologists, Royal College of Physicians Ireland, Interim Clinical Guidance – Termination of Pregnancy under 12 weeks, Version 1.0 2018.
[45] Institute of Obstetricians and Gynaecologists, Royal College of Physicians Ireland, Interim Clinical Guidance – Pathways for management of fatal fetal anomalies and life limiting conditions diagnosed during pregnancy, Termination of Pregnancy Version 1.0, 2019.
[46] *Ibid* at p12
[47] https://www.independent.ie/breaking-news/irish-news/170000-irish-women-have-travelled-for-an-abortion-simon-harris-says-36501013.html
[48] https://www.ifpa.ie/ifpa-and-bpas-release-detailed-irish-abortion-statistics/
[49] https://www.irishnews.com/news/northernirelandnews/2019/06/14/news/increase-in-women-travelling-from-northern-ireland-for-abortion-1641564/
[50] Duffy DN, Pierson C, Myerscough C, Urquhart D, Earner-Byrne L. Abortion, emotions, and health provision: Explaining health care professionals' willingness to provide abortion care using affect theory. *Womens Stud Int Forum*. 2018;71:12-18. doi:10.1016/j.wsif.2018.09.002

contingent. They argue that it is not just the availability of legal abortion but about abortion provision and how practitioners *feel* about providing that service and how patients *feel* about accessing such a service. In their qualitative exploration of abortion among health care professionals in Ireland they found the affective dynamic of importance, that is, how health care professionals deliberated their decision to provide or withdraw care based on a future imagining of both the practice and the subject. They argue that the consideration of the affective dimension is important, as despite the liberalisation of abortion law, other emotional factors remain in need of further analysis and discussion to enable change in practice and provision.

In 2016, Duffy et al[51] carried out a formative evaluation of online information to support abortion access in Ireland, N. Ireland and England. Their findings highlighted how 'useful' information is extremely limited and 'information retrieved by users is not always accurate within the jurisdiction where the search took place'. They concluded that the user needs to be central to the design of web pages.

10. Research on current abortion services in Ireland

There has been significant commentary on the implementation of abortion services since it began[52]. Even within the first month it has been noted that there are regional variations on availability, a need for protected exclusion zones to prevent protests hampering delivery of the service. While the traffic towards the MyOptions phoneline had balanced out within the first few weeks, as staff are unable to distinguish genuine seekers of service from malicious users the phoneline has been abused to identify service providers by anti-choice activists. At the 100-day mark, Cullen noted in the Irish Times that take up of the service is lower than anticipated and there were initial problems with referring a pregnant person to a medical professional willing to provide the service[53].

An evaluation of the operation of abortion services in Ireland funded by the HSE. This is being undertaken by the School of Social Work and Social Policy at Trinity College Dublin[54]. The study involved random sampling of people accessing abortion for a set period of time across 35 GPs regionally. Participants were also recruited through the foetal medicine unit of two maternity hospitals. Follow up interviews were conducted with 48 women. Findings from this research are not yet available.

The Irish Family Planning Association published anonymised data on the demographics and medical requirements of approximately 50% of the users of their abortion services during

[51] Duffy DN, Pierson C, Best P. (2019). A formative evaluation of online information to support abortion access in England, Northern Ireland and the Republic of Ireland, *BMJ Sexual & Reproductive Health* 45:32-37

[52]Bray,, 'Abortion in Ireland: Four weeks in, how's it working? https://www.irishtimes.com/life-and-style/health-family/abortion-in-ireland-four-weeks-in-how-s-it-working-1.3770442

[53] Cullen, ' I expected more protests': Doctors on 100 days of abortion in Irleand, April 13th 2019, https://www.irishtimes.com/life-and-style/health-family/i-expected-more-protests-doctors-on-100-days-of-abortion-in-ireland-1.3857216

[54] Unplanned Pregnancy Support and Abortion Care Study, Trinity College Dublin, Available from: https://www.tcd.ie/swsp/research/abortioncarestudy.php

2019[55]. The data is not disaggregated by disability but provides a useful overview of the operation of services to date in Ireland. The research found that almost half of the research participants are parents already and highlights the difficulties of the 12-week legal limit to organise abortion care under the current framework. Community based abortion care is working well as a model with a minority requiring hospital-based services. They also note concern about the inability to complete an unsuccessful medical abortion after 12 weeks and the impact of the abortion medication on a continued pregnancy.

The Abortion Rights Campaign is currently undertaking research regarding access to abortion under the 2018 Act. Data collection is ongoing, but will specifically include data on the experiences of disabled people accessing or attempting to access abortion services. The research is being carried out ahead of the Section 7 review of the legislation.[56]

11. Conclusion

The international human rights standards to which Ireland is subject promote free, safe and legal access to abortion without restriction. While there have been significant changes to the provision of abortion since 2019, Ireland continues to fail to meet these human rights obligations, including for pregnant disabled people. Under the current framework there remains significant barriers to disabled people accessing abortion services on an equal basis with others. Many parts of the country remain largely unserved by GPs and hospitals which are willing to provide Termination of Pregnancy services. There has been little consideration given to the circumstances of pregnant disabled people who might need an abortion by legislators and policymakers. Barriers experienced by the non-disabled population are magnified for those who cannot as easily access information and support to decide, to avail of transport or finance options to realise their decisions. The three-day waiting period and the need to travel long distances to source a provider also adds significant frustration and distress at an already difficult time in someone's life. Where disabled people have been supported to access abortion, their needs have been met in an ad-hoc fashion and without implementing system wide mechanisms for equal access.

[55] Henchion, C. and Spillane, A. (2020) 'Irish Family Planning Association early abortion service – results of an analysis of service activity data'. HSE National Sexual Health Newsletter, Winter 2020

[56] Abortion Rights Campaign, Evaluation Project Survey, (2020) Available from: https://www.abortionrightscampaign.ie/survey/