ALLIANCE FOR CHOICE

Alliance for Choice
Evidence Submission
Northern Ireland Assembly
Health Committee
Severe Foetal Impairment Private Members' Bill

6th May 2021

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Abstract - Call for Evidence Information:

The NI Assembly Committee for Health would like to hear your views on the **Severe Fetal Impairment Abortion (Amendment) Bill**.
The **closing date** for written submissions is **7 May 2021**.

Overview

The Bill was introduced by Paul Givan MLA on 16 February 2021. The purpose of the Bill is to amend the Abortion (Northern Ireland) (No. 2) Regulations 2020 to remove the grounds for an abortion in cases of severe fetal impairment.

Further information on the Bill can be found below:
A copy of the **Bill** and **Explanatory and Financial Memorandum** .
The **hansard report** of the Second Stage Assembly debate on the principles of the Bill that took place on 15 March.
The **hansard report** of the briefing session on the principles of the Bill at the Health Committee meeting on 11 March.
A **research paper** prepared by the Assembly's Research and Information Service on the Bill.

How to submit your views

Your submission should be structured to address the specific clause of the Bill. If appropriate, it should include any amendments you wish to propose to the text of the Bill.
Written submissions should be sent electronically in Word format (not PDF) to: Committee.health_sfiabill@niassembly.gov.uk. If you cannot submit electronically you may send in a hard copy written submission to: The Health Committee Clerk, Room 419, Parliament Buildings, Ballymiscaw, Stormont, Belfast, BT4 3XX.
Organisations or individuals responding to this call for views should note that their written submission (either in whole or part) may be published on the Committee webpage and may be quoted in the Committee's report or referred to in Committee meetings (which are public and are broadcast).
The Committee recognises that in some circumstances people may prefer for their evidence to be treated as confidential, or published anonymously. If you wish to do this please make this clear when submitting your evidence.
Before sending us your views please read the Northern Ireland Assembly Privacy Notice. This tells you how we process your personal data.
If you have any queries or require any further information about the call for evidence or the Committee Stage of the Severe Fetal Impairment Abortion (Amendment) Bill please contact the Health Committee Clerk by email: Committee.health_sfiabill@niassembly.gov.uk or by phone: 028 9052 1787.

Many thanks,
Committee for Health
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Introduction -

1) **Alliance for Choice (AfC) are the largest grassroots group campaigning for abortion rights in NI. We are people who have had abortions, people who support full abortion access and people who facilitate abortions, even in a previously illegal context.**

2) We represent the 70K people who travelled to England since 1970, we represent 1000s more who accessed abortions online and finally we represent all those who need access in the midst of a global pandemic in NI.

3) In July 2019 we were part of the coalition that saw decriminalisation for NI via both the CEDAW inquiry report published in 2018, along with *Stella Creasy, BPAS and London Irish Abortion Rights Campaig*n. AfC won the Liberty Long Walk to Freedom award with London Irish Abortion Rights Campaign and the FPA in 2017 and the Political Studies Association Campaign of the Year Award of 2018 for our work aiding the Repeal referendum in Ireland and the continuing work in NI. We supported Ashleigh Topley in the NIHRC Supreme Court case as interveners. AfC have contributed significantly to the change in public discourse in NI to date. We are now established as a trusted and reputable organisation who lobby on abortion based on robust evidence, personal testimony and community experience.

4) AfC continue to receive calls from women and girls in distress due to the lack of information on abortion services in NI, we note that despite the CEDAW assertion that travel to England was never a tenable solution to the Human Rights breaches, it continues. We are pleased to have been called to offer evidence as we are concerned that a rolling back on rights has begun before they have fully realised.

5) Our evidence will recap on the multiple and various forms of evidence that have already been sufficiently gathered in light of this particular issue, including previous calls to give evidence to Stormont and Westminster and to the United Nations Special Rapporteurs.

General Comments

6) While AfC agree that addressing anti-disability discrimination is a profoundly important issue, we are adamant that rolling back newly won rights is not the place to start.

7) Debating the intricacies of severe foetal anomaly cases can have a devastating re-triggering impact on the people who have already had to travel to England for compassionate healthcare they should have received on this island.

8) Families deciding whether or not to continue with their pregnancy, is a heartbreaking decision, especially if it isn't the first pregnancy for which they have received this diagnosis. Families need time to properly consider their options and seek support from loved ones and even counselling services, and gather all the available information. Foetal abnormalities, including Downs Syndrome, are generally not identified until around 19 to 23 weeks. If faced with a 24-week cut off, many would be forced to make a snap decision – which in some circumstances could make them more likely, not less, to terminate the pregnancy.

9) As a pro-choice organisation, we vehemently advocated for an information-led approach, not a restriction on rights or instructive to families. We think it is vital to give the person who is pregnant an opportunity to learn more about conditions such as Down's Syndrome, in order to fully understand the full spectrum of potential outcomes.

10) We support calls for up to date, evidence-based, non-stigmatising information about Downs Syndrome to be made available to all families considering an abortion due to a foetal abnormality. We also support the right of families and individuals to make whatever decision is best for them without judgment. Clinical support must always focus on listening to the pregnant person, in a non-directive way.

11) AfC want the Department of Health to fund and provide meaningful, well-funded counselling and information-sharing to address potential anti-disability discrimination rather than further restricting reproductive choices.

12) A word about terminology;
This has become very loaded. We need to avoid the phrase 'abortion for disability' as this is deliberately provocative. It immediately affords the fetus personhood, as only a born person can be described as disabled, this is not matched in law or in the understanding . Prenatal diagnosis of a genetic or structural condition represents a potential disability or health issue(s). We are most often talking about families and individuals ending desired/wanted pregnancies so they can often struggle with the word 'abortion' as it is associated with unwanted pregnancy and all the polarising polemics. Termination of pregnancy is consistently used instead in this context. **The term that is widely used now is 'termination for medical reasons' or TFMR**.

Main Issues:

13) **One of AfC's main contentions is that making a law prohibiting an abortion does not prevent it from happening. It simply means the families must travel to England, leave their support network and hopes of any joined up care. If the law will not reduce SFI abortions by excluding them from the legislation, the bill cannot confidently assert that it's main aim will be met or justified.**
14) "I am very concerned that opponents of reproductive rights and autonomy often actively and deliberately refer to disability rights in an effort to restrict or prohibit women's access to safe abortion,"
said Theresia Degener, Chairperson of the CRPD. "This constitutes a misinterpretation of the Convention on the Rights of Persons with Disabilities." Disability rights and gender equality are two components of the same human rights standard that should not be construed as conflicting, she added.[1]

Transportation of Foetal Remains

15) Women who wish to organise cremation or burial of the foetal remains, or want a post-mortem examination to be carried out, experience particular hardship. Transportation of foetal remains to Northern Ireland can be carried out by couriers like DHL, which can be expensive, or the woman must carry the remains herself. There is inevitably, therefore, not only an additional financial and practical burden to be borne, but a further emotional burden. Marie Stopes clinics often decline to treat patients requiring surgical abortions who are not able to arrange a friend to collect them from the clinic

16) One of only two paediatric pathologists resigned in September 2016, stating that the final straw was having to advise a couple to use a picnic cooler bag to return their baby's remains to NI following a late-term abortion in England. Dr Gannon stated that:

17) "Had the couple been in Northern Ireland, there would have been midwives present and hospital processes in place so they could sit with their baby...Somebody else would be responsible for bringing their baby down to the mortuary to ensure the post mortem is carried out..But they had to organise that themselves and transport their own baby's body back in a picnic cooler, in the boot of the car, on the overnight ferry."

18) It is not known if Westminster or Stormont propose to fund the costs of returning foetal remains to Northern Ireland in the event of a family or an individual travelling for a SFA abortion.

19) The situation can be further complicated for those who are forced to travel to England for a termination but wish to bring their baby's remains back to Northern Ireland for

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[1] https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23503&LangID=E

burial or cremation, or even to have genetic testing carried out which may benefit them in a future pregnancy.

20) A report by the Royal College of Obstetricians and Gynaecologists (RCOG), Royal College of General Practitioners (RCGP), Royal College of Midwives (RCM), British Paediatric Association, the British Medical Association and the Clinical Genetics Society clearly stated that, "it would be inhumane to these mothers, their babies and families to insist on the continuation of a pregnancy when the foetus was known to be seriously abnormal".[2]

21) The decision to proceed or not should lie with the woman with support from her clinician. If the decision is to terminate the pregnancy then this should proceed as soon as possible with the necessary support and aftercare in place. This is not the case for women in Northern Ireland.

22) BPAS have made a briefing on Termination for Foetal Abnormality, in it they say, Opponents of abortion often latch on to cases of termination for fetal anomaly, using emotive claims about how children born with particular disabilities can lead a good life. This obscures the emotional anguish and practical difficulties experienced by women who receive a diagnosis of fetal anomaly in an otherwise wanted pregnancy, and who cannot see their way to raising a child with a serious disability.

23) Women's reasons for terminating a pregnancy on grounds of fetal anomaly may include the emotional and financial cost of raising a disabled child; the effect on a woman's ability to care for her existing children; and the feeling that it is cruel to have a child that will need constant medical intervention and may live in pain. The heartbreaking reasons why a small number of women may need terminations for fetal anomaly are the reasons why it is important that such terminations can continue to be provided, in as sensitive a way as possible.

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[2] Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, Royal College of General Practitioners, British Medical Association, British Paediatric Association, Clinical Genetics Society. *Report on the advantages and disadvantages of imposing an 18 week gestational age limit on legal abortion.* 27 November 1987: para 3.1.

Women of Colour and Migrant Women

24) Accessing abortion in Northern Ireland requires complicated navigation of the health system. Most GPs and hospital staff are too afraid to even recommend travel to England and the Dept. Of Health have as yet, refused to publish any information about abortion services anywhere on their site, the PHA site or any of the Health Trust's websites.. These complications make it difficult for women who speak English and have access to the internet or networks of women who have had the same experience. Women who are new to the country will not have the same access to this information, or even know where to get help.

25) Travel to England becomes intensely more complicated when your migration status is at risk or you have a complex visa arrangement. Similarly students who are from overseas often find travel difficult due to the restrictions of their travel visa.

26) Expectant parents often have optimistic expectations of the obstetric ultrasound examination and are unprepared for a diagnosis of foetal anomaly. Research that gives voice to the experiences of immigrants faced with a prenatal diagnosis is scarce, and there is a need for more exploratory research that provides insights into the experiences of these persons.

27) A study revealed three themes for migrant families upon being given an SFA diagnosis:
(1) an unexpected hurricane of emotions,
(2) trying to understand the situation though information in an unfamiliar language, and
(3) being cared for in a country with accessible obstetric care and where induced abortion is legal.[3]

28) Immigrant women described an unexpected personal tragedy when faced with a prenatal diagnosis of foetal anomaly, and emphasised the importance of respectful and empathic psychological support. Their experiences of insufficient and incomprehensible information call attention to the importance of tailored approaches and the use of adequate medical interpreting services. There is a need for more descriptive studies that investigate decision-making and preparedness for induced abortion among immigrants faced with a prenatal diagnosis

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[3] Carlsson, T., Balbas, B. and Mattsson, E., 2019. Written narratives from immigrants following a prenatal diagnosis: qualitative exploratory study. *BMC pregnancy and childbirth*, *19*(1), pp.1-7.

Inability for concrete FFA diagnosis

29) Peter Thompson, who is a fetal medicine consultant at Birmingham strongly advised against being prescriptive and using the term lethal or fatal abnormality during evidence hearings at the Irish Citizen's Assembly on abortion,

30) "According to the Office for National Statistics in the UK, as many as 190,000 abortions were performed in England and Wales in 2016. Of these, however, only 3,200 were performed under clause E. As in the Republic of Ireland, the main foetal anomaly ultrasound scan is performed at approximately 20 weeks gestation in England and Wales. Despite this only 500 of the 3,200 abortions, that I have mentioned, were performed after 22 weeks of pregnancy. Also, there were 140 selective terminations of pregnancy, involving multiple pregnancies and over three quarters of these were under clause E. These can be life-saving procedures for the co-twin and I have described one such case in the case studies that I have submitted. Over half of these terminations of pregnancy are performed for chromosomal or central nervous system differences in the foetus.

31) In 2016, 3,265 Irish women had a termination of pregnancy in England and Wales. Of these 140 had a termination under clause E of the Act. Again, the foetal indications are predominantly chromosomal or central nervous system differences.

32) "As explained in previous sessions that I have read, detailed anomaly scans of foetuses are performed at approximately 20 weeks gestation, though the availability appears to be much less in Ireland than it is in the UK. In England and Wales if a difference is found in a foetus, a pathway is followed that may include a second local scan to confirm the diagnosis by an obstetrician with a special interest in foetal medicine. The second scan should be performed within five working days. In some cases local obstetricians will be able to fully counsel women on the outlook for their baby. In other cases, referral to a recognised foetal medicine unit will take place."

33) "We attempt to see women within three working days at my foetal medicine unit and that is the standard that has been set nationally. When we see these women we scan them, then sit them in a more homely room and counsel them and their families in the presence of a midwife. All options are discussed with the women including, where appropriate, intrauterine foetal therapy and the termination of pregnancy. On leaving the woman is given a detailed report that is read through with her prior to her leaving and contact numbers for the foetal medicine centre are given. A sub-group of women may need additional investigations, both invasive and non-invasive, and some will require counselling by a specialist in another field. It is important to acknowledge that women will need differing amounts of time to come to terms with this information and make their decisions."

34) If the woman opts to terminate her pregnancy this will be arranged at her local unit where she can get additional family support. Depending on the gestational age, both surgical and medical termination techniques are discussed with these women. As there is

an increasing chance of foetuses being born alive after 22 weeks of gestation, the Royal College of Obstetricians and Gynaecologists recommends that the foetal heart is stopped by performing foeticide prior to the termination of pregnancy for cases after 22 weeks of gestation unless the abnormality is not compatible with life.

35) If the woman opts for a medical termination of pregnancy then a tablet, an anti-progestogen, is administered and admission arranged for induction of labour with prostaglandins about 36 hours later. Around 95% of women will deliver on the day they receive their prostaglandins. A small proportion will require a second course. An infection, haemorrhage and retained placental tissue are the main short-term complications of the procedure. For the Irish women that we see in our unit, we complete the termination process in Birmingham but once discharged the women return to Ireland. While in Birmingham, they often express the difficulties that they have with regard to the limited number of people whom they can discuss this scenario with and gain support from.

36) *"The problem is there is no agreed definition as to what lethal means. Does it mean that all foetuses with the condition will die before birth? Does it mean that all foetuses will die either before birth or in the neonatal period despite supportive therapy? Does it mean that a baby will usually die in one of these two periods? Finally, has it just been noted that there is an association between the condition and death?"*[4]

37) "The first thing is to decide what is the definition of "fatal". As a result of the history of the law on abortion in Ireland, it will be very difficult for Ireland's obstetricians to decide. If it is decided in law that a fatal condition is one in which the baby always dies in utero, then we must consider that those conditions are exceptionally rare. As the committee can see in the other table I submitted, even babies with trisomy 18 have been noted to survive following birth, although very rarely. I worry that if the term "fatal" is used, some would argue that everything is fatal. **The contrary argument is that nothing is fatal because it does not result in a death in every single case**. A baby could live for a short period after birth. That is my main consideration about the term "fatal"."

38) Dr Thompson's fears have been realised in Ireland (see Other contexts: Ireland this paper) as we know 100ss of women have still travelled every year from Ireland even with a potential FFA diagnosis, which is one of the MOST severe breaches of human rights to be found in jurisprudence.

What is Pre-Natal Screening:

39) Its most basic function is to monitor the health and development of a foetus during pregnancy, and to provide information to doctors and parents-to-be. Anyone who has been through maternity services will know about the booking scan and the "big" scan.

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[4] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_the_eighth_amendment_of_the_constitution/2017-11-29/3/#spk_52

The first scan is done at around 13 weeks and is used to confirm pregnancy, to check for twins or more, and to check for conditions like spina bifida. The "big scan" happens at 20 weeks, again to confirm dates and to check growth. It is at this scan that many parents learn for the first time that their baby has a disability or a serious foetal abnormality.

40) Sometimes pregnant people in higher risk categories are offered additional testing to screen for genetic or chromosomal conditions like Down Syndrome. In Northern Ireland, screening is only offered in some hospitals but is recommended to all women over 35 in NHS guidelines. Private clinics have begun to offer scans and other diagnostic tests, such as Non-Invasive Prenatal Testing (NIPT), which can tell with 99% accuracy from a single blood test whether or not a foetus has a vast array of diseases, conditions and disabilities.

41) Prenatal testing will always be necessary, particularly for pregnant people with complicated medical histories. Tests and scans are essential for planning treatment during pregnancy and postnatal interventions in cases when a baby will be born with a serious illness or condition. At the Joint Oireachtas Committee on the Eighth Amendment recently, Gerry Edwards of the advocacy group Termination for Medical Reasons described how his 11 year old twin girls are alive today solely because of an anomaly scan. Clearly, prenatal testing is an important part of a modern, patient-centred healthcare system.[5]

42) The harmful perceived "burden" of parenting children with disabilities is not the effect of the disability, but rather the effect of disability-related stigma and discrimination, lack of inclusion and participation of persons with disabilities in society, and the lack of affordable and locally available supports and services for people with disabilities and their families.[6]

Mental Health of Pregnant Person

43) "Previous interview studies and surveys describe acute grief reactions and psychological distress among women following prenatal diagnosis of a fetal anomaly"[7]

44) The decision to terminate the pregnancy entails the prospect of chosen loss and lost choices, separating it from other types of perinatal losses.[8]

45) Women consider the decision very difficult, and the most difficult factor in decision-making is the attachment to the pregnancy.[9] A second-trimester abortion is both emotionally and physically painful,[10] and many women who terminate the pregnancy because of a fetal anomaly suffer of significant long-term psychological morbidity.[11]

46) Lack of supports for single parents, disabled parents, disability in general
Proposer of Bill has always argued against abortion in all forms

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[5] https://www.bpas.org/get-involved/campaigns/briefings/fetal-anomaly/

[6] Abortion and Disability: Towards an Intersectional Human Rights-Based Approach, Women Enabled International. January 2020 Women Enabled International

[7] (Garcia et al., 2002), (Sandelowski and Barroso, 2005), (Wool, 2011)

[8] (Sandelowski and Barroso, 2005)

[9] (Ramdaney et al., 2015)

[10] (Andersson et al., 2014)

[11] (Korenromp et al., 2009)

Overview of AFC Work:

Women and Equalities report

47) The week of the announcement of government funded abortins in England for women in NI, AfC took two calls from women who could not travel;
48) The first was from a support worker who was risking her job even speaking to me about her client needing to "TRAVEL TO ENGLAND". Her client was fleeing a violent relationship and had young children already, they had made an appointment in England but all of the woman's personal documents, including her ID, had been burned by her ex-partner in a controlling violent outburst.

49) The second woman had an infant with cystic fibrosis, she was pregnant again but there is a 25% chance the pregnancy would result in another child with the same condition; cross contamination is dangerous for such an illness so her maternity care offered her testing, yet they did not advise her that she would not be eligible for treatment in NI, we were effectively breaking the news to her that she would have to travel, so the **great news** of being funded in England, didn't seem so great to her with a young ill child, when she had been left in the dark about the availability of treatment by scared medical professionals.

50) We also know that women and pregnant people face other barriers to travel: time off work in precarious employment, disability, immigration status, mental health, abusive relationships and childcare. Girls under 18 who are pregnant will face further barriers to travel.

APPG Sexual and Reproductive Health

51) In the absence of government consultation public opinion polls provide insight into support for legal reform. Two large scale polls have been conducted in recent years, both of which have demonstrated broad support for reforming the law.

52) In a poll conducted by Amnesty International (2014) respondents asked if abortion should be legal in cases of[1]: Rape: 69% yes, Incest: 68% yes and Fatal foetal abnormality: 60% yes

53) A similar poll conducted by the BBC/ RTE in 2015 provided further indication of support for reform, with respondents supporting access to abortion in the following cases[2]:

Woman's life at risk 84%
Rape 84%
Incest 75%
Fatal foetal abnormality 67%
Woman's health at risk 62%

54) The Northern Ireland Life and Times Survey a robust academic survey on attitudes in 2017[3] also found approximately the same results as above as well as:
77% felt it was unfair that women in Northern Ireland cannot have an abortion on the NHS
70% stated that abortion should be a matter for medical regulation and not criminal law

55) In October this year Alliance for Choice with the Trade Union Campaign to Repeal the 8th Ulster University and a number of Trade Unions, published the results of in depth research into Abortion as a Workplace issue across NI and Ireland. The findings echoed the above surveys and can be summarised thus:

56) In relation to overall views on abortion and legal reform, the findings mirror those of previous surveys and public opinion polls, with the majority favouring some form of legal reform and in favour of a woman having a right to choose. Of the 3,180 trade union members who completed the survey:

- 87% believe a woman should not be criminalised for having an abortion.
- 48% were in favour of use of the abortion pill at home.
- 51% believe abortion should be available when a woman asks for one.
- Only 9% believe abortion should not be available for any of these options.

57) As the results indicate, the overwhelming majority of respondents (87%) did not believe a woman should be criminalised for having an abortion. Alliance for Choice witnesses these attitudes first-hand as we deliver workshops on abortion throughout the country to various demographic groups.

58) Although these reflections on public opinion are important for showing how far behind the public Assembly in Northern Ireland are, we would like to underline that human rights do NOT depend upon public opinion, neither do the obligations of the State Party, in this case, Westminster to uphold those rights.

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[1] https://www.amnesty.org.uk/abortion-poll-research-majority-people-northern-ireland-want-decriminalise

[2] http://downloads.bbc.co.uk/tv/nolanshow/RTE_BBC_NI_Cross_Border_Survey.pdf

[3] http://www.ark.ac.uk/publications/updates/update115.pdf

British Irish Parliamentary Assembly

59) The inquiry heard from Government representatives, academic, medical and legal experts, and campaigners representing all points of view on the issue. It took account of political developments across the BIPA jurisdictions, including the referendum in the Republic of Ireland; the Northern Ireland Court of Appeal's June 2017 ruling on Northern Ireland abortion law, as well as the UK Supreme Court's ruling of 7 June; and the UK Government's announcement (since echoed by the Welsh and Scottish Governments) that it would fund abortion services in England for women from Northern Ireland.

60) Purpose

"The next day, I woke up and felt better physically, but was incredibly angry and that anger has never left me. I wasn't angry about the abortion, I wasn't angry about being unexpectedly ill – that's just one of those things and whilst unlikely, it happens. I was angry about what I was forced to go through to access an abortion. An unnecessarily complex, expensive process of secrecy, judgement and humiliation, all of which was compounded by the awful journey and being forced to travel. One where, following a surgical procedure I couldn't even go back to my own house without waiting for hours before boarding a plane, all the while trying not to mention the discomfort and pain I was in. But that's the thing – we don't mention it. It's an abortion. I thought about all the women who travel on their own and are forced to stay in hotels and hostels overnight. I counted myself lucky that at least I was accompanied and that I got home eventually". One woman who had to travel

61) The purpose of this evidence is to highlight the structural and social discrimination experienced by women in Northern Ireland with a crisis pregnancy. It is important that the BIPA is aware of the strong anti-abortion socialisation process that manifests in Northern Ireland life through schools, churches, media and the political sphere. This stigma women face can negatively impact on mental health and hinders their ability to reach out for support.

62) While recently decriminalised, thousands were exiled to England for abortion because abortion was defined as a criminal act for over 150 years. Despite decriminalation, people who have abortions are still called 'murderers' by politicians and protesters which inevitably leaves abortion seekers with additional emotional scars and further impacts on an already complicated decision. Eventhough services have not been commissioned In Northern Ireland, abortions happen. Whether this is throguh the limited interim provision, traveling for abortion, or self managed abortion without medical care.

63) The BIPA found particular issues which are pertinent to this Bill:

"**<u>The treatment of foetal remains</u>**

We heard evidence that travelling home after a termination with foetal remains is traumatic for women.[1] The way that the remains are dealt with by medical professionals can also have an impact on women's mental and emotional wellbeing. There is little information available to women and girls who travel

> outside their jurisdictions about bringing home the remains of the foetus, for burial or genetic testing.[2]"

64) [1] Evidence from Dr Fiona Bloomer, Lecturer in Social Policy, Ulster University.
65) [2] Evidence from Dr Fiona Bloomer, Lecturer in Social Policy, Ulster University.

66) We stress, however, that any restriction on women's ability to access abortion services, and any legal process which has a detrimental effect on their recovery or general health and wellbeing, is likely to amount to an abrogation of their human rights. In the context of the United Kingdom, it will be the responsibility of the UK Government to ensure that these women's rights are protected.

Real Life Testimonies

"For us the decision to end a much wanted pregnancy was made easier because we were given a definitive diagnosis. Being exported was the most traumatic part.

Facing a choice when given a less certain but still serious diagnosis is horrific for families. Heaping trauma, exile and stigma on top of that is reprehensible. And to use people with a disability or genetic difference as a token to prop up your argument is offensive.

Restricting access will not prevent those of us with the privilege of freedom and means to travel from making our own choices.It will hurt those who cannot travel at an incredibly vulnerable and traumatic time. Those people without the money, support, physical ability, access to childcare, or freedom to travel. Including the community the amendment claims to wish to protect." A woman who travelled after an SFA diagnosis

***My wife had a termination after severe foetal defects were discovered in a series of scans at 21 weeks**. Our choices were limited. The thought of placing my already distressed wife on a plane to England was not only unthinkable but a denial of her basic human right to make a decision about her own body or face a humiliating, medically dangerous and deeply upsetting journey to another country and a strange hospital with little or no support as I would have had to remain at home with our other child. That the laws surrounding this issue are determined by faith and politics, rather than science and simply providing a choice to women, is still thoroughly shocking and archaic. Northern Ireland is embarrassingly behind the rest of the UK which the loudest of our politicians claim to demand parity with in all cases except providing a choice to women over their own bodies. A hypocritical disgrace."* Testimony for Women and Equalities Committee Inquiry

In 2013, at my 21 week scan, it revealed that my much longed-for baby boy had a bilateral ventriculomegaly and a severely underdeveloped heart.
After further tests it was discovered that he had a chromosomal disorder. My husband and I made the heartbreaking decision to end my pregnancy and on the 21st May under the care and guidance of midwives at Hillingdon Hospital in London I gave birth to my stillborn son. He was 23 weeks old. I was 42. It was made clear to me that my age WAS a contributing factor and made further pregnancies "high risk". However, it was also made clear that if I was to get pregnant again I would be closely monitored from the start of my pregnancy and all available tests would be carried out before my pregnancy progressed too far, to save me from further heartbreak. So, having moved from London to Northern Ireland in 2014 and got pregnant, imagine my abject HORROR when I discovered that the tests, freely available to women in the rest of the UK, are not even offered to women in Northern Ireland. I was "high risk" and yet I could not get ANY help or support here. I had to get on a plane and fly to London to have a blood test done privately (£300), a test that is free to women outside of Northern Ireland. Luckily, this test revealed no foetal abnormalities and I went on to have a healthy baby boy in July 2015. However, I can NOT imagine how any woman feels having to travel away from home to end a pregnancy. For some, an abortion is a compassionate end to a very difficult, life altering situation. For others, like myself, ending a pregnancy is a heartbreaking decision but an informed decision that is made to avoid further pain and

suffering. For me, having the full support of the medical & midwifery team at Hillingdon Hospital was not only comforting but it made the whole heartbreaking experience a little less traumatic. EVERY woman should have that level of care & support when ending a pregnancy. Stop making the women of Northern Ireland suffer." Testimony for Women and Equalities Committee Inquiry

"Up until I needed an abortion I had never given the abortion laws in Northern Ireland any thought and as a result knew nothing about them. My plan had been to get married, get fairly stable financially and then have a baby. This all changed in February 2014 when I found out during my 20 week scan that my baby had a condition that appeared to be incompatible with life. I was referred to the foetal medicine unit at the Royal hospital in Belfast for a second opinion. There were delays on this appointment due to specialists on annual leave so it wasn't until 10 days after we initially had the 20 week scan.

That consultant said that he agreed with what had been seen at the previous scan however he advised us to have a follow up appointment the following week to have another opinion. Again, this follow up appointment was delayed and I wasn't seen for another 10 days. The consultant at that appointment was much more clear and firm in her diagnosis, said that our baby did have a condition that was incompatible with life and that she would be happy to sign off on a termination. However, as this was not the hospital that I was under I had to have a further appointment back at my own hospital to discuss the next steps. This was arranged for the following day.

My husband and I discussed what we believed to be our options at length that evening and after many hours and tears we decided that the best option for us was to have a termination. We got to our local hospital the following day and we told the consultant that we saw that we wanted to have a termination. She replied, "Well that's not going to happen." I told her that the consultant from the Royal that we had seen in the foetal medicine unit said we could have one here and the consultant said, "Well I have friends in the Royal and that doesn't happen." I asked her what our options were and she responded, "Well the pregnancy would continue as normal." I was extremely upset and frustrated that we had been told one thing by one doctor who seemed to want to help us but couldn't yet a doctor that could help us didn't appear to want to. The consultant finally conceded, "Well you could go down the Marie Stopes route." That was as much information as she gave me. We left that appointment distraught and frustrated because we felt that we had arrived at the heartbreaking decision to have a termination of a much-wanted baby, an option that we didn't want to have to take but felt it was the best option for us, only to have that option snatched away from us coldly and without compassion.

Following that awful appointment, my husband and I talked and agreed that we would scrape together the money for the procedure and travel costs to England and have a termination there. This was extremely upsetting as I was terrified of travelling to a strange hospital in a strange town for a traumatic procedure and being separated from my support network of family and friends. I googled Marie Stopes England and rang the first number that came up. I said that I needed a termination. The person on the other end of the phone asked me how many weeks pregnant I was, I replied I was 23 weeks and 6 days. The person on the phone said, "I'm so sorry but we can't help you, the procedure has to be carried out before you are 24 weeks pregnant." Testimony for Women and Equalities Committee Inquiry

I started to cry and hung up the phone. I had just been told that I had no other option but to continue with a pregnancy that was doomed. ***Any hope that I had that this nightmare would soon be over was gone.*** *So I was forced to continue with the pregnancy until my daughter was stillborn at 35 weeks. I was signed off work by my GP following the 20 week scan in February and didn't return until October that year. The pregnancy itself was not only mentally very difficult but physically I had a number of complications.*

My daughter's condition meant that she was unable to process the amniotic fluid and as a result the fluid built up and up and caused me severe pain to my ribs and back. I was prescribed morphine to help manage the pain. The physical pain made it difficult to leave the house so I spent a lot of time at home alone. Mentally, the 15 weeks between the initial diagnosis at the 20 week scan and my waters breaking at 35 weeks can only be described as torture.

I woke up every day and wondered if that would be the day the hellish limbo would end, I willed my daughter's heart to stop so that I could begin the grieving process normally. I dreaded having to leave the house because people would notice my swollen, pregnant stomach and ask me questions like when was I due and did I know what I was having. I found that it was always easier to just play along and lie to them rather than tell them the truth. I broke down when I got home." Ashleigh Topley from her Testimony to the Women and Equalities Committee Inquiry

In 2006, I had a crisis pregnancy and chose not to go through with an abortion. I was brought up in a churchgoing family with pro-life views and did not feel as if I could turn to them. I was aware that my only option was to travel to GB. At the time I was very sick and could not face the journey to a strange place. I also had no idea of who to turn to for advice on termination. I was in a very poor relationship with a man I didn't love and hated having sexual relations with. I wanted to leave and was on a social housing waiting list and I was devastated by getting pregnant. We were using BC but there was an interaction with meds. Looking back, I feel that an early termination would have been my best option. There was such a lack of info in NI that I thought abortion involved an operation and a two-three day stay in England. I had no idea of how I would have explained this to my ex partner or employer - I had just started a new job and it was very awkward. While I love my son, he is disabled (a genetic disability) and I have been left alone to raise him. Twelve years ago I had a job, now I am reliant on benefits. I don't think unplanned parenthood has worked for me at all. I pushed myself through a crisis pregnancy due to a combination of guilt, fear, ignorance and a lack of other options. Having raised a child alone, I now have a more realistic view of parenting and how much it asks of the individual. I have struggled with depression for years and my son's father has zero interest in him. I doubt whether my son would have been successfully adopted due to his complex needs so I do not see adoption as a realistic alternative to abortion. Testimony from Women and Equalities Committee Inquiry

I am in my 40s, live in Belfast and am married with one child.
At the end of 2014 I was ecstatic to find out I was pregnant. We had been trying for a while for a brother or sister for my daughter and I had already been through a devastating and painful miscarriage.
At the 20-week scan (which took place a week late due to scheduling problems) I was told that there appeared to be fluid on the brain. It took a week to get a cancellation with a foetal medicine consultant and she carried out an amniocentesis which showed a severe chromosomal disorder.

As you can imagine, this was utterly devastating for us. She gave us some information on the condition and suggested Googling it to learn more about the prognosis, which is that 80-90% of babies with the condition do not survive the birth and the rest die within days or weeks.
We said we wanted to consider termination but the only thing they were able to offer us was a cardiac scan later in the pregnancy as many of the babies have heart conditions.
I have since learned that previously families in NI diagnosed with a fatal foetal abnormality (FFA) diagnosis were offered induction (as you can see from Gerry Edwards's experience - http://www.thejournal.ie/readme/terminations-medical-reasons-experience-3233583-Feb2017/)
However, in 2013 DUP health minister Edwin Poots published revised abortion guidelines which threatened 10 years' imprisonment for medical staff who carried out abortions that were not in line with the very strict laws in NI.
My consultant has since told me that following legal advice on those guidelines, medical staff were not allowed to provide any information that would help anyone to get an abortion, including recommending organisations that could help or advising on the most appropriate procedure.
We felt utterly cut adrift from any medical support and left to fend for ourselves at the worst moment of our lives. At this stage, we only had a week and a half before the 24-week cut-off point.

I didn't know who to go to. *Surgical abortion at that stage of pregnancy is carried out in very few clinics. The clinic told me I would need to book a hotel room for the night after the procedure as it would not be safe to travel.*
My husband and I left our daughter with her granny and stayed in a tiny hotel room in England the night before. I cried myself to sleep. We had to pay £1,100 ahead of the procedure, not including the costs of flights and accommodation.
There were complications during the procedure which left me with a punctured uterus and small intestine and I had to be rushed to hospital from the clinic. I had to undergo an emergency bowel section and a hysterectomy, before being moved to the high dependency unit and given 3 units of blood. It was more than a week before I was able to fly home. It was months before I was able to return to work and the experience has taken a toll on my long term physical and mental health. The impact was made immeasurably worse by having to travel so far from home and away from our own healthcare practitioners.
My consultant apologised to us afterwards and explained why we had been given so little information. She said we had received a second-class service because of the law here.

I am devastated that we were abandoned by our own healthcare system at one of the hardest moments of my life. My healthcare decisions should be between me, my husband and my doctor. I have spoken to a number of elected representatives who have been privately very supportive of my wish that women should not be forced to travel and are trying to work within their parties to move the issue forward. I see there have been a lot of calls for a referendum but this is the last thing we need. It only happened in the ROI because it was the only way to change the measure in the constitution and it was a hugely damaging and re-traumatising experience for many women who had to put their private stories out in public and experience horrific abuse.

The UN CEDAW report has already said that the UK is in breach of human rights by allowing the near-total abortion ban in NI. Human rights are not a devolved matter and it is the responsibility of

Westminster to legislate on this. I was in tears of relief when the first 8th referendum exit poll came through earlier this year and I wish with all my heart that a similar change could happen here. But it seems there just isn't the political will and compassion for the thousands of women who have been left to fend for themselves when they most need help. We were cut adrift from our health system when we needed it more than ever. But my experience barely even registers on the health records in NI as it happened in another jurisdiction. I have never felt so utterly faceless and abandoned by the government that is supposed to look after me. I shouldn't have been kept in the dark by my own medical staff and left to Google abortion clinics. I wanted my baby more than anything, but once we were told the diagnosis, we wanted to get past it and move on. Instead, I was expected to go through months of anguish carrying a dying baby and it seems as though a large number of people in my own Assembly are devoid of any kind of empathy for what I was going through." Testimony for Women and Equalities Committee Inquiry

Northern Ireland Case Studies

Women in Holly's situation who receive a diagnosis of a fatal foetal abnormality (FFA) — often much later in the pregnancy — are faced with the options of carrying the foetus until it dies and having a stillbirth, or arranging to travel to England for an abortion. In some cases of FFA, the foetus may survive the pregnancy but die shortly after birth.
Holly was left feeling angry about her experience. From 6:30am on Friday, Oct. 19, she will tweet a real-time account of her journey and time in Liverpool, under the username RatherBeHome, in order to highlight the difficulties faced by an estimated 28 women per week who travel from Northern Ireland to England for an abortion.

http://www.alliance4choice.com/rather-be-home

Ashleigh Sarah and Denise Case

http://www.irishnews.com/paywall/tsb/irishnews/irishnews/irishnews//news/northernirelandnews/2018/06/07/news/women-recount-harrowing-experiences-in-northern-ireland-abortion-case-1350618/content.html

Ashleigh Topley

https://www.irishtimes.com/news/social-affairs/pro-choice-campaigners-target-north-s-abortion-laws-1.3749396

"I couldn't believe they wanted to put us through the torture of knowing that a baby, our baby, wasn't going to survive, but I was still going to have to be pregnant and continue with the pregnancy for an unknown length of time," she tells Newsbeat, looking back.
That length of time turned out to be another 15 weeks - from February to May 2013.
'
http://www.bbc.co.uk/newsbeat/article/39437961/i-was-forced-to-carry-my-baby-knowing-she-would-die

Denise Phelan

"We were just set adrift, totally alone. We had no choices. I had to give up. I had to go out and get maternity clothes and people were congratulating me and asking when the baby was due. I was sent to a

bereavement midwife at the same time as the baby was still alive and active in my womb. I had to go to antenatal classes.
"We were also told that if the baby was still alive at birth she would be in pain and have to live her brief life on a morphine drip."

https://www.theguardian.com/world/2019/oct/06/the-doctors-in-northern-ireland-knew-my-baby-would-die-but-i-was-refused-an-abortion

Sarah Ewart case
The campaigner was at risk of infection if her unborn child died during pregnancy, but was still not eligible for an abortion under existing laws.
She was denied support and information because of the fear among health professionals that they could face prosecution, according to her lawyers.
Instead, Mrs Ewart travelled to a clinic in England in 2013 where the procedure was carried out.
The court was told she was left devastated by an experience described as "traumatic and undignified, like a conveyor belt, leaving her feeling vulnerable and humiliated".
She was also given no information about whether she could obtain an autopsy, it was claimed.

https://www.belfasttelegraph.co.uk/news/northern-ireland/northern-ireland-abortion-ruling-a-turning-point-for-women-says-sarah-ewart-38558956.html

https://www.lawsoc-ni.org/summary-of-judgment-in-re-sarah-jane-ewart-abortion-ffa-031019

A short film released today by the British Pregnancy Advisory Service, bpas, features a young woman from Northern Ireland who was 28 weeks pregnant. Emma, 18, discovered at her 20 week scan that her baby had anencephaly, a fatal condition where the skull does not form properly. While NI women have been able to access funded care in England since June 2017, there are women who are unable to travel due to caring responsibilities or the need to maintain their confidentiality. Emma, from Belfast, stated that she did not travel for abortion care because she wanted to with her family at this incredibly distressing time:
"I was given the option to travel to England for an abortion, but I didn't want to do that. I want to be with the support of my family, in a place that I'm familiar. I want in the moment that she is born, for her to be surrounded by her family and be surrounded by love."

https://nowforni.uk/

Press release with quotes
http://www.alliance4choice.com/repeal-58/59/2018/10/pce8x6eiwtl4marruapnmt0mz7be63

In her shoes NI travelling after a diagnosis.

- https://www.facebook.com/InHerShoesNI/photos/a.281703219139022/329304047712272/?type=3&theater

- https://www.facebook.com/InHerShoesNI/photos/a.281703219139022/317746605534683/?type=3&theater
- https://www.facebook.com/InHerShoesNI/photos/a.281703219139022/395270447782298/?type=3&theater

Still have to Travel after Repeal

There is a list of difficult case studies from the Abortion Support Network, including that of a woman with a severe foetal abnormality that wasn't severe enough for her to access care in Ireland.
"While this woman did not have financial need, the logistics of arranging travel over were overwhelming for her. We were able to help her make all the necessary arrangements," Clarke says.

https://www.independent.ie/life/health-wellbeing/health-features/british-abortion-service-is-still-receiving-requests-for-help-38829887.html

A woman who had two failed early medical abortions in Ireland, who was then told that the foetus had serious but not fatal abnormalities.

https://www.abortionrightscampaign.ie/2019/09/28/mara-clarke-the-law-and-resulting-provision-are-leaving-too-many-people-behind/

One woman ASN has helped since abortion was legalised is Eva, who tested positive for a serious foetal abnormality, but it was not deemed severe enough to warrant an abortion after 12 weeks. 'I had to wait until a certain point in pregnancy to have the test, and by the time I had the results I was beyond 12 weeks,' says Eva. 'That meant I had to travel [to the UK]. I work on contract and was not paid for the days I took off. I already have a special-needs child and other children and I'm barely managing.'*

Amy* also had to travel to the UK, after she unwittingly went to one of Ireland's rogue crisis pregnancy centres – claiming to offer unplanned pregnancy support, these are actually associated with anti-abortion campaigners. There, she was told she was more than 12 weeks pregnant, although she was actually only nine weeks at the time. Then there was the couple who were told by doctors that their foetus had a fatal abnormality (meaning they were eligible for an abortion post-12 weeks). But then a separate committee told them that 'the complex foetal anomaly' was not severe enough for them to be treated in Ireland.

In a seaside town near Dublin, I meet GP Siobhán Donohue. She travelled to Liverpool for a termination in 2011 – when abortion was still illegal in Ireland – after getting the diagnosis that her baby wouldn't survive. Now she's chair of Terminations For Medical Reasons (TFMR), a group that supports people who have been given a severe or fatal foetal anomaly diagnosis. She still sees many women who have been told their baby will be severely disabled but, as they're over 12 weeks, those wanting an abortion have to travel to the UK. 'You're talking about somebody whose baby might only survive for a few weeks or months, but it doesn't fit into the "fatal" definition,' she says. 'What wasn't discussed during the campaign last year was women who get a catastrophic diagnosis that's not considered fatal. They've not been considered.
Since January, she says about two women a month with this diagnosis have been asking TFMR for help. 'They've already got this awful diagnosis, they shouldn't then have to get on a plane,' she says. 'When they come to us, they're shaken and a shell of themselves. They ask where one finds the strength to get through it, because the biggest thing is waiting around for that flight to England. It was the hardest journey I ever had to make.'

https://graziadaily.co.uk/life/in-the-news/irish-women-travelling-to-access-abortion/

Woman carrying a baby diagnosed with a fatal foetal abnormality was refused a termination at the Coombe Hospital in Dublin. Although she was initially told the foetus would not survive, an 'internal' board (the Coombe Board put out a vague statement stating that they had no role in the certification of pregnancy) said that this was not a clear case of FFA and refused her the abortion. She contacted TDs who raised the case in the Dáil. The woman is going to travel to the UK for a termination.

Source: https://www.rte.ie/news/politics/2019/0117/1023832-dail-abortion/

https://www.irishtimes.com/news/health/coombe-hospital-says-board-has-no-role-in-certifying-terminations-1.3762054?fbclid=IwAR0LExSEq0Y-HJoA8TkVbT-A-pA2OQgCfKd7Pgj5SaJkioOXW21DvyTwB2M

'We were in a rare percentile of pregnancies and baby had a severe form of anencephaly, a fatal foetal abnormality which means the skull and brain do not properly develop.
The phrase "not compatible with life" is one of the few things I recall clearly from the rest of that day.

We learned that our baby either would die during delivery or moments after being born.
As long as he was in the womb he would continue to grow and thrive – completely and blissfully unaware of his condition.
And because of this fact, there would be no chance that we could safely deliver our little man in our chosen hospital, in our home country.
The only way I could physically give birth in Ireland was to go full term.
They could not induce me because I was healthy.
We were also informed that by going to 40 weeks the birth would certainly be far more traumatic, for both baby and myself.'

https://www.independent.ie/irish-news/abortion-referendum/the-journey-i-had-to-take-after-my-20-week-scan-was-torturous-36908423.html

CEDAW

67) The Abortion (Northern Ireland) (No. 2) Regulations 2020 introduced in March 2020 are designed to implement the recommendations contained in paragraphs 85 and 86 of the CEDAW Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of Discrimination Against Women (CEDAW Report), this includes provision for abortion in cases of severe foetal impairment. These regulations need to be implemented in full so that no pregnant person is forced to travel to England to access basic healthcare.

68) The Committee assesses the gravity of the violations in NI in light of the suffering experienced by women and girls who carry pregnancies to full term against their will due to the current restrictive legal regime on abortion. **It notes the great harm and suffering resulting from the physical and mental anguish of carrying an unwanted pregnancy to full term, especially in cases of rape, incest and severe foetal impairment, particularly FFA** (our emphasis)

69) The UN-CEDAW 2018 report called for 'A (iii) Severe foetal impairment, including FFA, without perpetuating stereotypes towards persons with disabilities and ensuring appropriate and ongoing support, social and financial, for women who decide to carry such pregnancies to term '

70) We agree with this position. There should be support for those who choose to terminate, and those who choose to carry pregnancies to term. This is a pro choice position. People should be empowered to make informed decisions, with the support of healthcare and other services whichever decision they make. We urge the Committee to consider other measures such as perinatal health and hospice services, as well as social and financial support for parents of disabled children so that options are truly available when one receives a SFI diagnosis.

71) UN-CEDAW in their remarks also referred to UN-CRPD saying 'While the Committee consistently recommends that abortion on the ground of severe foetal impairment be available to facilitate reproductive choice and autonomy, States parties are obligated to ensure that women's decisions to terminate pregnancies on this ground do not perpetuate stereotypes towards persons with disabilities.' While beyond the scope of this Bill, we agree that disabled people must be afforded social and financial support, and work must be done to address stereotypes about disabled people.

72) The CEDAW Report can be found here https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=22693&LangID=E

Other contexts:

Great Britain

73) The majority of conditions are detected before 24 weeks, many more now through first trimester screening (certainly true of Down's syndrome). However, the major anomaly scan is at around 20 weeks and a number of structural conditions will not be seen until then. Follow up scans and genetic testing can take women close to or beyond 24 weeks. It is also the case that serious brain anomalies can be seen for the first time during third trimester scans scheduled to check placental position, monitor foetal growth etc.

Ireland

74) The current law in Ireland allows for abortion on request up to 12 weeks, or for limited reasons at a later gestation; SFI is not a permitted reason for an abortion after 12 weeks. Figures published by Westminster show that while abortions for people normally resident in Ireland decresseaed by 87% overall following the change in legislation, the proportion of abortions poerfomed under 'Ground E' increased. This demonstrates that where abortion for SFI is not provided for locally, people will continue to travel to GB for legal care. [12]

75) Legislation which allows abortion only in cases of narrowly-defined “fatal” foetal anomaly exerts too much pressure on clinicians to produce indisputable evidence that a foetus will not survive after 28 days of birth. This strict legal definition does not comport with medical understandings and results in many women and pregnant people with a heartbreaking diagnosis being exiled to England for treatment.

76) There is clear evidence from the Health (Regulation of Termination of Pregnancy) Act 2018 in the Republic of Ireland that restricting abortion access to fatal diagnosis only means that families are forced to travel to England to access abortion after receiving the heartbreaking news. Restrictive definitions create high legal thresholds for abortion access which act as a barrier to healthcare, meaning travel to England remains the most common route to access abortion for SFA in the whole island of Ireland.

77) There is clear evidence from Ireland that any abortion provision policy including only fatal foetal anomlay means that many families are forced to endure the additional heartbreak of travel after a diagnosis of anomaly. As the Abortion Rights Campaign in Ireland has said in its report to CERD[13],

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[12] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/891405/abortion-statistics-commentary-2019.pdf

[13] https://www.abortionrightscampaign.ie/wp-content/uploads/2019/12/ARC-ASN-CERD-SUBMISSION-2019-1.pdf

78) *"Fear of criminal penalties hangs over doctors' decision making. Pregnant people given diagnoses of catastrophic but not necessarily "fatal" foetal anomalies have no choice but to travel abroad for abortion care, just as they did before Irish voters changed the Constitution."*

79) The Abortion rights Campaign commented in 2020

"The figures from the UK Department of Health (DOH) demonstrate clearly to those of us in the South that the compassionate care promised by politicians during the 2018 referendum has not materialised. On the contrary, we have heard heartbreaking stories from those who believed they were entitled to a legal abortion in Ireland being forced to travel. Our new law puts doctors in the position of making impossible distinctions between "fatal" and all other severe, complex, or life-threatening foetal anomalies, distinctions that are not rooted in medicine. With the threat of prosecution still hanging over them, many doctors are hesitant to make that distinction and so, as illustrated here by the UK DOH figures, many are still forced to travel to access the compassionate care we voted for in 2018."[14]

80) If SFI is removed as a permitted reason medical professionals in NI will be operating in a climate where they risk criminalisation as they decide whether a condition satisfies the fatal requirement, rather than being severe.

81) In 2017 over 3,000 women travelled from Ireland to England to terminate their pregnancies. Approximately 140 of them had a termination because their foetus was thought to have "a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped". The care pathway that is followed by Irish women is sub-optimal, removes them from their support network and is only available to a sub-set of women who are able to initiative their contacts with units in England.[15]

82) Finally, if legislation is brought in for foetal conditions, particular care must be taken when using the phrase "lethal or fatal". (see Inability for concrete FFA diagnosis)

83) *Richard Stevenson said he and his wife Emma were told it was unlikely that their baby would survive labour, and in the event that the baby did survive the birth "it would probably be only minutes or hours before they passed away and that time would be spent struggling to breathe".*

"In the even more unlikely event that our child lived any amount of time, and best we could hope for would be about a year, they would never be able to move their arms or legs, never be able to speak, never be able to feed by themselves and at no point would they ever recognise us as their parents," Stevenson said.

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[14] https://www.abortionrightscampaign.ie/2020/06/11/abortion-figures-show-hundreds-still-travel/

[15] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_the_eighth_amendment_of_the_constitution/2017-11-29/3/#spk_52

When they were told a termination could not be facilitated in Ireland, he said they were shocked. "How was this happening? This is Ireland. We're a liberal country. We just had a referendum for exactly this. I voted for it," he said.

84) They travelled to England and Emma was induced at King's Hospital in London. They said goodbye to their son Riley on 17 December.

85) There are countless examples in Ireland as to why adding in limitations in this way will not work[16] Claire Cullen-Delsol of TFMR told *The Journal* that of the around 30 women or couples who came to the support group last year following a diagnosis, 85% had to travel for a termination.

86) Cullen-Delsol said she has heard of a number of other examples like Emma and Richard Stevenson since the legislation was enacted, involving conditions which "are horrific but won't be covered".

87) "They probably could come under the legislation. The likelihood is these babies won't survive birth, but because of the 28 day expectation of life and the fact that two doctors have to certify it, it's restrictive and some doctors won't touch it.

88) There are three conditions in Ireland which will practically guarantee a termination for medical reasons; Anencephaly Patau syndrome and Edward's syndrome. Outside of that the doctors still feel criminalised. Now people are travelling after being told about conditions that three years ago you'd be told were fatal.

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[16] 'Two-tier system' means couples still forced to travel for termination after severe foetal diagnoses - https://www.thejournal.ie/fetal-diagnosis-5386250-Mar2021/

Medical Standpoint -

89) The British Medical Association report has said,
“Under the Abortion Act, a pregnancy may be terminated at any gestation if 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.”1[17] The Abortion Act is silent on the definition of “serious handicap”. It is therefore a matter of clinical judgment and accepted practice. “ Whilst our law is written differently it encapsulates the same experiences and diagnosis.

90) The RCOG (Royal College of Obstetricians and Gynaecologists) has detailed guidance for health professionals involved in late abortions for fetal abnormalities.[18] The BMA believes the factors that may be taken into account in assessing the seriousness include the following:
– the probability of effective treatment, either in utero or after birth;
– the child’s probable potential for self-awareness and potential ability to communicate with others;
– the suffering that would be experienced by the child when born or by the people caring for the child.

91) Doctors faced with a potential late abortion for serious fetal abnormality should be aware that women should be given information and time to understand the nature and severity of fetal abnormality, and should be offered specialised counselling where appropriate, in order to assist them in reaching an informed decision about how to proceed.

92) The purpose of prenatal screening is to expand the choices available to the pregnant woman and to allow her to make an informed decision about whether to continue with a pregnancy 8 British Medical Association The law and ethics of abortion – BMA views or seek a termination.

93) Women should not be rushed into making a decision, but if a decision is made to terminate the pregnancy, this should proceed without undue delay. Appropriate support should be provided before and after the termination.

94) Even before the passing of the NI Executive Formation Bill (2019), Doctors for Choice NI was set up as a subgroup of Doctors for Choice UK, with a particular focus on providing community to pro-choice medical staff and post-decriminalisation, developing training for medical staff willing to provide abortion care.

95) Research performed by Dr Fiona Bloomer with members of DFC NI showed that a majority of professionals in the field of obstetrics and gynaecology (54%) were in favour

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[17] Abortion Act 1967, s1(1)(d).

[18] Royal College of Obstetricians and Gynaecologists (2010) Termination of pregnancy for fetal abnormality. Available at www.rcog.org.uk/globalassets/ documents/guidelines/terminationpregnancyreport18may2010.pdf [Accessed 15 July 2020].

of access to abortion up to 24 weeks. Given that severe foetal anomalies are detected by healthcare staff post 12 weeks (up to 20-24 weeks), these are more likely to be the doctors who would be providing abortions to women with a diagnosis of severe foetal anomaly.

96) However, doctors are not separate from the legal and social context in which they practice. The Royal College of Obstetricians and Gynaecologists produced a report for the Working Party regarding Termination of Pregnancy for Foetal Abnormality. This report acknowledges the difficulty in providing an accurate prognosis regarding a pregnancy when the anomaly is more likely to result in morbidity rather than mortality, and that specialist advice is required, meaning these abortions may occur post-24 weeks.

97) The report also states that one third of all terminations post-24 weeks were for central nervous system anomalies, indicating that these pregnancies are the most difficult to provide an accurate diagnosis and prognosis for, and to restrict abortions further for this group is to make them even more vulnerable to a lack of options. [19]

98) Qualitative research has shown the difficulty doctors face in providing abortions for late gestations and for foetal anomaly. Medical professionals interviewed by Lotto *et al.* stated the legal definitions of severity of foetal anomaly are often unclear and difficult to determine, leaving medical staff to interpret the law with low levels of consensus even among medical staff, while also being subject to harsh scrutiny from the law and feeling vulnerable as a result. This fear of scrutiny led to some doctors restricting the options they provided to women. These clinicians understand that their role is as a facilitator to provide information and support their patients, however legal constraints and scrutiny impacts on their ability to support patients.[20]

99) Research by Crowe *et al.* shows the wide variation in healthcare provider opinions regarding termination of pregnancy for non-lethal foetal anomalies, and the lack of medical definitions for legal terms providing restrictions creates differences in opinion across the professional field, however more restrictive definitions are not necessarily welcome or needed in order to provide high quality support and care to parents with a foetal anomaly diagnosis. [21]

100) To summarise this research, it would seem that increasing the legal and political scrutiny on abortions for foetal anomaly would have a negative effect on both the ability of clinicians do fully do their job but also in the support that can be provided to families dealing with a diagnosis of severe foetal anomaly, especially if their access to multiple options is restricted by the proposed bill.

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[19] https://www.rcog.org.uk/globalassets/documents/guidelines/terminationpregnancyreport18may2010.pdf

[20] https://bmjopen.bmj.com/content/bmjopen/7/5/e014716.full.pdf

[21] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5855171/pdf/bmjopen-2017-020815.pdf

101) A note on fetal pain: Whether, and at what stage a fetus feels pain has been a matter of much debate.[22] The RCOG 2010 report Fetal Awareness – Review of Research and Recommendations for Practice concluded that the fetus cannot experience pain prior to 24 weeks' gestation, as prior to this point, the necessary connections from the periphery to the cortex are not present. They also found limited evidence to suggest that fetuses can perceive pain after 24 weeks, and noted increasing evidence to suggest that the fetus never experiences a state of true wakefulness in utero. [23]

102) The BMA recommends that doctors should give due consideration to the appropriate measures for minimising the risk of pain, including assessment of the most recent evidence. The BMA suggests that even if there is no incontrovertible evidence that the fetus feels pain, the use of fetal analgesia when carrying out any procedure (whether an abortion or a therapeutic intervention) on the fetus in utero may go some way in relieving the anxiety of the woman and health professionals.[24]

NIACT

Below is the extract from the NIACT report, which is the most tailored report for NI evidence, experience, expertise and recommendations on Termination of Pregnancy for Fetal Abnormality (TOPFA) which includes SFI - please see below.[25]

103) A study examining the experiences of people's care when undergoing termination of pregnancy for fetal abnormality found five themes underpinned that which was considered 'good care' (Fisher and Lafarge, 2015).

Being cared for in a timeframe and environment that feels right

104) The speed of diagnosis and a short wait for the procedure were positive factors. Gestational age impacted on care. Women who received a diagnosis of fetal abnormality in the first trimester reported increased pressure to make a decision at 13-14 weeks gestation. Pressure to make a decision was also commented upon around the 24-week legal limit. Most women had 'vivid memories' of the procedure and the environment they

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[22] See for example: Royal College of Obstetricians and Gynaecologists (1997) Fetal Awareness: Report of a Working Party; Fitzgerald M. (1995) Fetal Pain: An Update of Current Scientific Knowledge; Glover V. (1995) Fetal Stress and Pain Responses; The All-Party Parliamentary Pro-Life Group (1996) Fetal Sentience. Available at https://righttolife.org.uk/wp-content/uploads/2015/03/KS4FetalSentience.pdf [Accessed 15 July 2020].

[23] Royal College of Obstetricians and Gynaecologists (2010) Fetal Awareness – Review of Research and Recommendations for Practice. Available at www.rcog.org.uk/globalassets/documents/guidelines/rcogfetalawarenesswpr0610.pdf [Accessed 15 July 2020].

[24] https://www.bma.org.uk/media/3307/bma-view-on-the-law-and-ethics-of-abortion-sept-2020.pdf

[25] https://www.fsrh.org/news/northern-ireland-abortion-contraception-taskgroup-report-2021/

were in (gynaecology/labour ward). There was no consensus on the most suitable environment, although individual rooms were greatly valued and a gynaecology ward was favoured by some of those at earlier stages of pregnancy. Being in the 'wrong' ward was a cause of distress (Fisher and Lafarge, 2015).

Receiving the appropriate level of care

105) Being cared for by experienced members of staff was greatly valued. Short staffing and being cared for by junior or inexperienced members of staff (who admitted their inexperience) was a cause of distress. Access to analgesia, particularly the correct dose of morphine, was important to women undergoing medical terminations. Continuity of care, ideally by the same midwife, was also very important. Healthcare professionals who were new to the case, had not read the notes, and who made inappropriate comments were a cause of distress. The consequences of poor communication, a lack of continuity of care, and unsuitable aftercare, included some women being referred to antenatal care, being contacted by children's services, not being visited by community healthcare professionals after the procedure, and having to cancel antenatal appointments themselves and 'feeling abandoned' (Fisher and Lafarge, 2015:77).

The role of healthcare professionals and support organisations

106) Women valued information about the procedure which helped them prepare for the physical experience, the time it would take, psychological effects, and what would happen to the remains. Inconsistent information was a cause of distress, and the timing of information provision was not always appropriate (e.g., being asked about post-mortem consent while in labour). Empathetic care was very important and was not always given. A lack of understanding about women's circumstances and dismissals of the physical and emotional pain were causes of distress. Providing empathetic care is demanding on staff, and staff would benefit from receiving formal support themselves. Consistent signposting to support organisations is important, with women commenting that they would have liked to have been referred to support organisations earlier in the process. Support organisations alleviate a sense of isolation, and for some the information provided by support organisations was their only source of information (Fisher and Lafarge, 2015).

Acknowledging women's particular circumstances

107) Participants were keen for professionals to recognise the unique nature of TOPFA. This could include recognising that the pregnancy was wanted, that it was different to a miscarriage, and taking care with terminology – (e.g., being in tune with the woman as to whether to refer to a fetus or baby). Participants feared judgement and a high value was accorded to non-judgemental care from all professionals. In some cases where the decision for termination for fetal abnormality is made after the stage of viability, women may wish to have the option of fetal intracardiac

potassium chloride so that the baby does not show signs of life at delivery (Fisher and Lafarge, 2015).

Enabling women to make choices

108) Women who had limited choices reported more negative experiences. Most women 'greatly valued being given choices, including whether to have the termination or not, the method of termination, the types and levels of analgesia, whether to spend time with the baby or not, and what to do with the baby's remains. For many women, these choices appear to give them a level of control over a situation most felt they had no control over' (Fisher and Lafarge, 2015: 80). The lack of choice over the termination method was a particular issue with some women unaware that they could have had a choice.

109) Although 75% of all second trimester abortions for indications *not* related to fetal abnormality are done surgically in the UK, only 16% of those for indications related to fetal abnormality are done surgically, the majority being performed medically (Lyus et al., 2013). Reasons for this include the facts that on average these terminations are performed at a later gestation, the pregnancies were generally wanted, and importance is attributed to the delivery of an intact fetus for post-mortem examination in TOPFA. In addition, vaginal birth offers reduced risk for the woman wishing to retain her fertility.

Timely provision of care

110) Research shows most women have made the decision before they approach health professionals (Bloomer et al., 2018) and they experience delays as distressing. This can be of particular significance for women in rural areas where a clinic may only be weekly, may be far away, and accessing services presents financial and logistical challenges.

111) A study on provision for women from remote areas in Scotland found that the time between referral and assessment varied between 10 days and 3 weeks. Once women had made the decision, they wanted to complete the termination as soon as possible. Participants were aware that gestational age could alter the care received. The wait period was identified as a key problem and it was a cause of distress due to factors such as 'pregnancy-associated nausea, a wish to conceal the pregnancy, growing fear that the pregnancy would become evident to others in the woman's changing body shape, and concerns that they would begin to 'bond' with the pregnancy, despite certainty in their decision to terminate.' (Heller et al., 2016: 1687).

112) Timely provision of care should also be a factor when designing the model of service delivery. There is clear evidence that abortion services should be part of an integrated SRH service (Bloomer et al, 2018; Horgan et

al, 2019; RCOG, 2019). The current situation where SRH services also dispense medication is ideal, but this will obviously not be the case in a GP led service where women must be provided with a prescription for medication which is then dispensed by a pharmacist.

Myth Busting - Disability

113) As the disability rights academic Prof Tom Shakespeare said: *'I conclude that prenatal diagnosis is not straightforwardly eugenic or discriminatory. We should be on hand to offer counselling, good quality information and support, but we should not venture to dictate where the duties of prospective parents may lie. Nor should we interpret a decision or termination of pregnancy as expressing disrespect or discrimination towards disabled people. Choices in pregnancy are painful and may be experienced as burdensome but they are not incompatible with disability rights.'*[26]

114) Disabled Women Ireland have said:
We believe that social and financial support to disabled people and their parents is the strongest way to deal with concerns for disability rights. Recognising the full extent of disabled people's rights from infancy to old age – to education, to early childhood support, to personal assistance – will make meaningful changes to the quality of disabled people's everyday lives. Restrictions on abortion will only place further restrictions on the reproductive rights and freedoms of people with disabilities.[27]

115) Prenatal screening is an essential tool for monitoring pregnancy and foetal development, particularly for those patients with complex medical histories. In cases of severe or fatal prenatal diagnosis, it is essential that pregnant people are given clear and supportive information on all possible outcomes, including continuing or ending their pregnancy. Pregnant people and families continue to welcome children with Down Syndrome in countries where abortion is available for serious foetal anomolies. If the government really cares about people with disabilities, it would fund all needed support services.

116) *"I am a disabled woman and I will always support the right to choose. I am a disabled woman and I want to see all parties put actions behind their words and scrap all discriminatory policies they have introduced in the past decade that have killed many disabled people. I am a disabled woman and I am sick of us not being included in debates about disability. We are a broad community, with a diverse range of views, please do not only use disability when it suits your agenda. " Rachel Powell, Women's Resource and Development Agency, NI*

117) It is clear from the UN Committee on the Rights of People with Disabilities that abortion access is not in conflict with disability rights. It is disingenuous at best when politicians play rights off each other instead of supporting the wellbeing and autonomy of women and girls and disabled people alike.

The following section is a re-use of work done by the WPG and WRDA "Supporting Collective Women's Rights, Reproductive Rights and Disability

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[26] Shakespeare, T (2006) Disability Rights and Wrongs, Taylor & Francis p.102

[27] https://www.disabledwomenireland.org/news

Rights”

118) Abortion has been decriminalised in Northern Ireland yet the Abortion Framework has still not been commissioned. Despite this, more work has been done publicly in the NI Assembly to further restrict abortion access that has not yet been fully available. The issue of resrticing abortions for severe fetal impairment have been highlighted throughout his response, but it is worth noting that this would also negatively impact disabled women as well. Disabled women are also autonomous people who need access to reproductive healthcare and face greater barriers than non-disabled women in accessing it.

119) The WPG would like to encourage the Health Committee to look at alternative means of supporting disabled people in our society rather than rolling back the hard-fought, yet still inaccessible, rights of women and pregnant people in Northern Ireland.

120) WRDA has published an article in the past on ‘Disabled Women and Discrimination: The Facts We Need You to Know[28]’ and there are some shocking statistics from UK-wide data that we could suggest the Executive works to immediately address:

121) Disabled women earn 22.1% less than non-disabled men, and 11.8% less than disabled men

122) 26% of households with a disabled person are in poverty, compared to 22% of overall households in the UK (pre-COVID). This is likely an underestimation, as it does not take into account the estimated £570 per month of additional costs associated with a disability.

123) Women make up 55% of claimants for disability benefits and have been disproportionately impacted by the narrowing of scope in disability support entitlements. As a result, benefit sanctions, degrading PIP assessments, lost income and the removal of any independence has been a reality for many disabled women.

124) Disabled people, in general, have been disproportionately impacted by austerity cuts since 2010. Disabled women are set to lose 13% of their annual income by 2021 due to austerity and cumulative tax-benefit changes.

125) Disabled single mothers are losing out the most from these tax and benefit changes since 2010. By 2021, they will have lost 21% of their net income if they do not have a disabled child and 32% if they do have a disabled child too. 1/3 of this loss is due to a shift to Universal Credit.

126) Disabled people experience domestic violence at TWICE the rate of non-disabled people. ONE IN TWO disabled women experience it and face many additional barriers in seeking support.

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[28] WRDA (2020), Bold Women Blogging: “A Personal Perspective on the Abortion Motion NI Assembly 2nd June 2020’: https://wrda.net/2020/06/04/womens-sector-lobbyist-statement-abortion-motion-ni-assembly-2nd-june-2020/

127) Spending cuts to adult social care and housing support has also disproportionately impacted disabled people.

128) **Disabled women are losing their independence, are living in poverty and are being actively discriminated against, abused and underpaid**. We all need to be aware of this wide-spread systemic abuse. The WPG would welcome action taken by the wider NI Executive to address these issues facing disabled women in particular. Further, we would like to emphasise again that disabled women need access to abortions too, and restructing abortion on the grounds of severe fetal impairment will negatively impact disabled women needing access to abortion healthcare.

129) During the referendum in Ireland, Down Syndrome Ireland in reference to using images and the circumstances of people with Down Syndrome in the abortion debate stated ‘Downs Syndrome Ireland believes that it is up to each individual to make their own decision about which way to vote in the upcoming referendum. We are respectfully asking both sides of the campaign debate, all political parties and any other interested groups to stop exploiting children and adults with Down syndrome to promote their campaign views’.

Iceland and Down Syndrome: what the numbers really say

130) It’s vital that people with disabilities are treated with respect and given the support they need to live with dignity and participate in society. It’s very concerning to see anti-choice spokespeople using the lives of people with disabilities as political footballs, and to see anti-choice myths about conditions such as Down Syndrome making their way into everyday conversation.

131) We acknowledge the genuine fears that people with disabilities have about stigmatisation of disability and erosion of rights. We hope that this new series of blog posts will go some way to addressing those fears. With that in mind, we thought we’d take a moment to address and debunk a particular myth that has been popping up in conversations for some time now.

132) You may have heard commentators saying that there are supposedly no births of babies with Down Syndrome in Iceland, and that this is supposedly because of disability-selective abortion. While mostly confined to anti-choice pseudoscience circles, sometimes these unsupported claims make their way into mainstream sources – examples include a BBC documentary from 2015, and more recently, a speaker at the Joint Oireachtas Committee on the Eighth Amendment.

133) Figures about births of babies with Down Syndrome in Iceland (and other countries) are easily available online from the World Health Organisation.

134) “The first thing you’ll notice is that the numbers of births [of babies with Down Syndrome in Iceland] are not zero, except in 1989 and 2009. The second thing you’ll notice is that the numbers vary a lot from year to year. There’s a good reason for that. The WHO reports cases per 100,000 live births. Iceland is a small country, even smaller than Ireland. Its current population is just 334,252 people. *[For comparison, the population of Cork is 208,669!*

135) The total number of births each year in Iceland is almost always in the range 4000-5000. So a single baby with Down Syndrome contributes 20-25 to the rate, as reported by the WHO. The rate of 22 in 2012, for example, represents one child **(1)** *[Please see the footnote for more information about how these rates are calculated].*

136) The rates of zero in 1989 and 2009 aren't so surprising then. With only a few births in a typical year there will none in some years.*"*So the claims about Iceland not having any births of babies with Down Syndrome are clearly not true. What about the notion that Iceland's rate is unusually low?

137) "[Using the WHO data] you can, for example, compare Iceland with other European countries. It's better to compare the rates for a full decade, because of the year to year variation I mentioned earlier. In the last ten years for which the WHO provides data, Iceland's rate was about 10% lower than the EU average. Scientifically, such a small difference can be considered random."

138) It's impossible to compare Iceland's rate to Ireland's as Ireland does not send data to the WHO on the number of babies born here with Down Syndrome. Other data sources tell us that in Ireland, about 1 in 600 babies will be born with Down Syndrome each year, and that there are approximately 7,000 people with Down Syndrome living in Ireland, out of a population that is estimated at between 38,000 and 66,000 people with intellectual disabilities.(2)

139) As adults, these people may form relationships, have children. They will find their rights restricted by the 8th amendment, as does every other pregnant person on this island. We will come back to that at a later stage. For now, let's stay in Iceland.

140) As it happens, Iceland has noticed some of the lies being told about it recently. In August, an American TV report broadcast false claims about Down Syndrome and abortion. Hulda Hjartardóttir, chief of obstetrics at Iceland's National University Hospital (who was misquoted in the piece) responded, thoroughly debunking the claims.

Here's what she had to say:

141) "The truth is that one third of mothers-to-be choose not to have more [pre-natal] tests done after the first indication of Down Syndrome. These women want to continue their pregnancies even with the increased chance of Down [Syndrome]. [Also], 80 to 85 percent of [pregnant] women choose to have the screening, so there are 15 to 20 percent who don't. Those women don't want the information. Of the women who have the screening and get results that point to increased risk [of Down Syndrome] about 75 to 80 percent get further tests done but 20 to 25 percent choose not to."

142) Dr Hjartardóttir also noted that in cases of prenatal Down Syndrome diagnosis, "women and parents are offered the opportunity to meet with doctors and nurses who work with people with Down Syndrome. They are also offered the opportunity to meet parents who have children with Down Syndrome. No effort is made to pressure the women to make a certain decision."

143) So there you have it: a far more nuanced and realistic state of affairs than that portrayed by anti-choice mythmakers. The experience of Iceland mirrors experiences elsewhere. At the Joint Oireachtas Committee meetings on the 8th Amendment on 22 November, Dr Eva Pajkrt, professor of obstetrics at the University of Amsterdam's Faculty of Medicine, gave evidence that the number of babies with Down Syndrome born in the Netherlands has remained stable over the past few years, despite increases in the uptake of prenatal testing and the availability of abortion.

144) Dr Hjartardóttir's statement and Dr Pajkrt's testimony show us that Icelandic and Dutch women think about their lives, their families, and their resources while making their decisions – the way pregnant people do everywhere. The only difference between them and pregnant people here is the fact that they have been able to make their private medical decisions without state interference.[29]

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[29] *(1) Because the WHO needs to compare rates all over the world, including in countries with high populations and low populations, they convert everything into the same fraction, out of 100,000. In 2012, 4533 children were born in Iceland. 1 of these children had Down Syndrome. Because of the way the WHO needs to compare different countries using the same units, they converted 1/4533 into 22/100,000. Therefore, a single baby with Down Syndrome contributes 20-25 to the rate, as reported by the WHO*
(2) Ireland keeps a register of the number of people in Ireland who live with an intellectual disability who receive 'health' services (the NIDD), but we do not categorise people according to their particular diagnosis. The 2016 census actually reports far higher figures than the NIDD of people who self declare as having an intellectual disability (over 66,000).

ECHR Compatibility and Recriminalisation

Severe Fetal Impairment Abortion (Amendment) Bill, ECHR compatibility and 're-criminalisation' - *AFC would like to endorse the below comments provided in the joint WPG response in partnership with CAJ*

145) Severe Fetal Impairment Abortion (Amendment) Bill is a Private Members Bill (PMB) introduced by Paul Givan MLA which aims to "*amend the Abortion (Northern Ireland) (No. 2) Regulations 2020 to remove the ground for an abortion in cases of severe fetal impairment*".

146) In 2017 the UN Committee for the Elimination of Discrimination Against Women (CEDAW) issued its findings in an inquiry under the Optional Protocol, ratified by the UK, into NI abortion legislation. The CEDAW inquiry – in relation to NI - found the UK responsible for: *"(a) Grave violations of rights under the Convention considering that the State party's criminal law compels women in cases of severe foetal impairment, including FFA, and victims of rape or incest to carry pregnancies to full term, thereby subjecting them to severe physical and mental anguish, constituting gender-based violence against women; and (b) Systematic violations of rights under the Convention considering that the State party deliberately criminalises abortion and pursues a highly restrictive policy on accessing abortion…"*[30]

147) The CEDAW ruling, at paragraphs 85 & 86, provided a blueprint for the State Party to remedy the incompatibility of NI law with the international human rights obligations under CEDAW. This included the repeal of sections 58 and 59 of the Offences against the Person Act 1861 "*so that no criminal charges can be brought against women and girls who undergo abortion or against qualified health care professionals and all others who provide and assist in the abortion*". It also proscribed legislation to be adopted to provide for expanded grounds to legalise abortion in three areas, including "*Severe foetal impairment, including FFA [Fatal Foetal Abnormality], without perpetuating stereotypes towards persons with disabilities and ensuring appropriate and ongoing support, social and financial, for women who decide to carry such pregnancies to term.*"[31]

148) Such matters relate to health and justice provisions, both of which are within devolved competence, and the incompatibility with CEDAW could have been remedied by the NI Assembly. In the absence of this however under the Good Friday Agreement (Paragraph 33(b) of Strand 1) the Westminster Parliament is to "legislate as necessary" to ensure the UK's human rights and other international obligations are met for NI.[32]

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[30] CEDAW/C/OP.8/GBR/1 Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, Paragraph 83.

[31] As above paragraphs 85 & 86. See also paragraph 62 for further elaboration on the on the CEDAW committee's alignment in the recommendation on severe foetal impairment with the UN Committee on the Rights of Persons with Disabilities

[32] For further information see: https://caj.org.uk/2018/05/31/is-it-westminsters-role-under-the-belfast-good-friday-agreement-to-legislate-on-northern-ireland-abortion-law/

149) Primary legislation was consequently passed in Westminster. Section 9 of the Northern Ireland (Executive Formation etc) Act 2019 repealed sections 58 and 59 of the Offences Against the Person Act 1861 (which criminalised abortions in NI). It also placed the Secretary of State under a legal obligation to ensure that the framework under paragraphs 85 and 86 of the CEDAW report are implemented, including a continuous and ongoing duty to make changes to NI law through secondary law Regulations to ensure such implementation.[33]

150) The Secretary of State consequently introduced The Abortion (Northern Ireland) (No. 2) Regulations 2020.[34] Regulation 7 provides for termination of pregnancy in cases of "Severe fetal impairment or fatal fetal abnormality." This is consistent with what is required by the CEDAW framework and primary legislation.

151) Strictly speaking the primary legislation, in repealing the provisions of the 1861 Act, dealt with decriminalisation. However, Regulation 11 introduces an element of re-criminalisation for medical professionals who perform a termination deemed to be outside the terms of the Regulations.[35] This re-criminalisation was not recommended by CEDAW. When medical professionals conduct procedures outside of the legal framework, such issues are usually dealt with administratively or through the application of professional standards, rather than through creating a criminal offence. Re-criminalisation may constitute a chill factor to providing services to which there are entitlements, in particular in a challenge to a precise diagnosis relating to severe impairment or FFA.

152) In relation the European Convention on Human Rights (ECHR) Article 8 covers the 'right to respect for private and family life' and restrictions on same must be 'in accordance with the law'. This is the principle of 'legal certainty' which has been consistently held by the European Court of Human Rights to apply to abortion services. Put simply this means when a person has a right to an abortion in law there must be a clear way of *accessing that service in practice*.[36]

153) Whilst the Primary legislation and Regulations have been in place for some time there have been well publicised difficulties in accessing services in practice due to the failure of the NI Department of Health to commission the services required. This conflicts with the 'legal certainty' provisions of the ECHR as well as compliance with the Primary legislation. In January 2021 the NI Human Rights Commission initiated legal action over the failures to commission and fund abortion services in NI.[37] In response the Secretary of State laid the Abortion (Northern Ireland) Regulations 2021 which provide an additional power of direction that, *inter alia*, can require the commissioning of services.[38]

154) The UK has further emphasised its commitment to full sexual and reproductive rights in the Agreed Conclusions of the recently concluded CSW 65 conference , and in

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[33] https://www.legislation.gov.uk/ukpga/2019/22/enacted

[34] https://www.legislation.gov.uk/uksi/2020/503/contents/made

[35] https://www.legislation.gov.uk/uksi/2020/503/regulation/11/made

[36] See e.g. Tysiąc v. Poland judgment (no. 5410/03) and ABC v Ireland.

[37] https://nihrc.org/news/detail/human-rights-commission-takes-legal-action-on-lack-of-abortion-services-in-ni

[38] https://www.legislation.gov.uk/uksi/2021/365/made

its commitment to the UN Generation Equality Forum initiative[39], which includes a new global Action Coalition on Bodily Autonomy and Sexual and Reproductive Rights. It should be emphasised that in its statement at the closing of CSW65, the UK stressed that action on the commitments made in the Agreed Conclusions also is required 'at home'[40]

ECHR compatibility of the PMB

155) In order to be within the legislative competence of the NI Assembly a bill, including a PMB, is to relate to a devolved competence (as health clearly is) but also be compatible with the ECHR.[41]

156) The current PMB would create a situation whereby Regulation 7 would be amended to remove reference to Severe Fetal Impairment, yet the Secretary of State would concurrently be under a binding legal duty under the Primary legislation to introduce Regulations to reinstate the provision and hence reverse the effect of the bill.

157) In addition, however the PMB, if and as long it was in place, would create a situation whereby there would still be an entitlement in NI to access abortion services in circumstances of Severe Fetal Impairment, derived from CEDAW and also from the duties under the primary legislation, yet in practice due to the absence of Regulations providing for same it would not be possible to access such a service in practice. Such a situation would conflict with the 'legal certainty' provisions of the ECHR and hence engages the question as to the PMB being outside the legislative competence of the Assembly.

158) It is essential to note that the Committee on the UN Convention on the Rights of People with Disabilities (CRPD), with the CEDAW Committee, has emphasised that using disability rights as an argument to oppose safe abortion is a misinterpretation of the Convention on the Rights of Persons with Disabilities[42]. The statement stresses that disability rights and gender equality are two components of the same human rights standard that should not be construed as conflicting, and clarifies that States must take effective measures to enable women, including women with disabilities, to make autonomous decisions about their sexual and reproductive health and ensure that women have access to evidence-based and unbiased information in this regard. It also underlines as a critical issue that all women, including women with disabilities, are protected against forced abortion, contraception or sterilisation against their will or without their informed consent.

159) Specifically, the comment states that 'States parties should fulfill their obligations under articles 5 and 8 of CEDAW and CRPD Conventions respectively by addressing the root causes of discrimination against women and persons with disabilities. This includes challenging discriminatory attitudes and fostering respect for the rights and dignity of

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[39] Generation Equality Forum blueprint for Compact on women, peace and security and humanitarian action

[40] See UK statement to the closing ceremony of CSW65 in a video recording by UN WebTV; the UK statement begins at 0'22"00 of the recording.

[41] See NI Act section 6(2)(c) with reference to Convention (ECHR) rights https://www.legislation.gov.uk/ukpga/1998/47/section/6

[42] CEDAW and CRPD Committees (August 2018). '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)

persons with disabilities, in particular women with disabilities, as well as providing support to parents of children with disabilities in this regard. Health policies and abortion laws that perpetuate deep-rooted stereotypes and stigma undermine women's reproductive autonomy and choice, and they should be repealed because they are discriminatory'.

160) The UK is a party to the ECHR, and bound by the judgments of its adjudicative body, the European Court of Human Rights. From the early 2000s this Court has heard a number of cases related to restrictive legal frameworks for abortion. This provides a corpus of jurisprudence determining when human rights under the ECHR are engaged and may be violated. In cases where abortion is lawful but access is prohibited in practice – for example, by health professionals, structures or unclear information – the Court has found a violation of Article 8[i] and Article 3.[ii] These issues may be engaged in Northern Ireland due to a lack of appropriate and timely pathways and information on lawful abortion.[iii]

International Human Rights Law

161) The United Nations Human Rights Committee made a 'General Comment on article 6 of the International Covenant on Civil and Political Rights, on the right to life'. Within this includes the declaration that;

162) "*Although States parties may adopt measures designed to regulate voluntary terminations of pregnancy, such measures must not result in violation of the right to life of a pregnant woman or girl, or her other rights under the Covenant. Thus, restrictions on the ability of women or girls to seek abortion must not, inter alia, jeopardize their lives, subject them to physical or mental pain or suffering which violates article 7, discriminate against them or arbitrarily interfere with their privacy.*[43]

163) The UK is a signatory to all major international human rights treaties. In the past twenty years international human rights law has evolved to recognise the denial of safe abortion services as a human rights violation. The 1994 International Conference on Population Development and the 1995 Beijing Declaration and Platform for Action both outlined the importance of access to safe, legal abortion as a human rights concern.

164) The United Nations Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee Against Torture and the Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW) have stressed that states must guarantee accessible legal abortion services.[iv] In particular, they have noted that criminal frameworks and punishments for abortion are not human rights compliant.[v]

165) "In 2018 the UK Supreme Court and the United Nations CEDAW Committee outlined that the current framework regulating abortion in Northern Ireland is in violation of national and international human rights commitments. These developments reflect a wider international movement conceiving access to abortion as a human rights issue.[i] Human rights are not only a transformative language which transcends the limitations of polarised debate on abortion,[ii] but legal imperatives which the UK has commitments to protect, respect and fulfil."[44]

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[43] Full text on abortion rights from UN here https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23797&LangID=E

[44] Bloomer, McNeilly & Pierson, (2018) Reproductive Health Law and Policy Advisory Group, Briefing Paper, Northern Ireland and Abortion Law Reform, September 2018

[i] See further Rachel Rebouché, 'Abortion Rights as Human Rights' *Social and Legal Studies* (2016) 25(6): 765-782.

[ii] See Kathryn McNeilly, 'From the Right to Life to the Right to Livability: Radically Reapproaching "Life" in Human Rights Politics' *Australian Feminist Law Journal* (2015) 41(1): 141-159.

[i] *Tysiąc v. Poland* (Application no. 5410/03) (2007); *A., B. and C. v. Ireland* (Application no. 25579/05) (2010); *R. R. v Poland* (Application no. 27617/04) (2011); *P. and S. v Poland* (Application no. 57375/08) (2012).

[ii] *R. R. v Poland* (Application no. 27617/04) (2011); *P. and S. v Poland* (Application no. 57375/08) (2012).

Research and previous work conducted by NI assembly

166) There are many existing research reports and consultation responses on abortion law in NI, including the briefing paper for this Bill. Prior to the 2020 Regulations, the NI Assembly Department of Justice and Department of Health had commissioned a working group on Termination of Pregnancy for Fatal Foetal Abnormality. This lead to the proposal of the The Abortion (Fatal Foetal Abnormality) Bill which ultimately collapsed along with the Assembly. Many of the points made by the working group, which was limited in scope to FFA, can be applied to SFI.

167) In particular comments from healthcare professionals that 'there are woman who face risks to their physical health, mental health including acute trauma and distress and possible financial hardship, because they cannot access the health service they require in this jurisdiction'(pg6) is true for many people who need abortion care for SFI.

168) Healthcare professionals also highlighted that where women and pregnant people travel to access abortion care in GB they had serious concerns 'about the increased risk of harmful physical and mental health outcomes for women who travelled to other jurisdictions'(p26). This is the experience of many people who travel to GB for abortion care that is not available locally. Currently travel includes an additional health risk of Covid-19. Where someone has to travel to GB for an abortion for a SFI, they are less likely to be able to access support services such as bereavement care. Additionally it is less likely that they will be able to have tests or a post mortem carried out on the fetus, unless they travel home without the remains.

[iii] Kathryn McNeilly, 'Beyond Article 8: The European Convention on Human Rights and Abortion in Cases of Fatal Foetal Abnormality and Sexual Crime' *Stormont Knowledge Exchange Seminar Series* (2017) https://niassembly.tv/beyond-article-8/

[iv] For example, Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 22. UN Doc. E/C.12/GC/22. The Right to Sexual and Reproductive Health. 2016CESCR, General Comment No. 14. UN Doc. E/C.12/2000/4. The Right to the Highest Attainable Standard of Health. 2000 para. 12.Human Rights Committee (HRC), Communication No. 1153/2003. UN Doc. CCPR/C/85/D/1153/2003. K.L. v. Peru. 2005 para. 7.HRC, Communication No. 1608/2007. UN Doc. CCPR/ C/101/D/1608. L.M.R. v. Argentina. 2011 para. 10.Committee on the Elimination of Discrimination against Women (CEDAW Committee), Communication No. 22/2009. UN Doc. CEDAW/ C/50/D/22/2009. L.C. v. Peru. 2011.

[v] For example, CESCR, General Comment No. 14. UN Doc. E/C.12/2000/4. The Right to the Highest Attainable Standard of Health. 2016 para. 41.CEDAW Committee, Concluding Observations on Kuwait. UN Doc. CEDAW/C/KWT/CO/3-4. 2011 para. 43(b)Concluding Observations on Hungary. UN Doc. CEDAW/C/HUN/CO/7-8. 2013 paras. 30-31.

169) These risks are the same for someone travelling to GB for an abortion after a SFI diagnosis, not only those traveling for care after a FFA diagnosis.

170) In the RAISE paper accompanying this Bill many of the human rights implications of the law are clearly set out, as well as a number of comments from healthcare professionals. We would urge members of the committee to consider the research produced by the Assembly which summarises not only the relevant human rights instruments relating to this Bill, but also the potential impacts of the Bill in exacerbating inequalities.

171) The paper is right to draw attention to the fact that were SFI abortions not provided for, NI would be out of step with GB. Should someone choose to terminate a SFI pregnancy, they would have to travel to GB for treatment, which currently would be funded by the UK Government. However while the treatment would be funded, this would be in an unfamiliar location, away from support structures and their care team, with a limited referral pathway for aftercare. This is entirely at odds with the requirements. contained in 2018 UN-CEDAW, which are now law as outlined above. The paper states 'Such a scenario would be a return to 'exporting the problem'of abortions, which are unlawful in Northern Ireland, to other jurisdictions.', which is the crux of the issue.

172) Finally the RAISE report highlights access to reproductive health services 'is closely linked to socioeconomic status and educational attainment – enactment of the Bill as introduced could therefore cause inequalities in these areas'. This Bill would impact not only the human rights of those who need an abortion following an SFI diagnosis, but would also seep into other areas.

Conclusion and recommendations

I. Legislation which allows abortion only in cases of narrowly-defined "fatal" foetal anomaly exerts too much pressure on clinicians to produce indisputable evidence that a foetus will not survive after 28 days of birth. This strict legal definition does not comport with medical understandings and results in many women and pregnant people with a heartbreaking diagnosis being exiled to England for treatment.

II. We have yet to see the full and proper implementation of the abortion regulations in NI as laid in March 2020 due to lack of commissioning by Minister of Health Robin Swann; it is insulting to every family dealing with severe foetal anomaly, that Paul Givan wishes to exacerbate their grief by making them travel to England, even in the height of a pandemic.

III. Removing any part of the CEDAW recommendations from the current law clearly opens up the NI Assembly to further legal action as it directly contradicts the measures needed to prevent further breaches of rights.

IV. Increasing the legal and political scrutiny on abortions for foetal anomaly would have a negative effect on both the ability of clinicians do fully do their job but also in the support that can be provided to families dealing with a diagnosis of severe foetal anomaly, especially if their access to multiple options is restricted by the proposed bill.

V. The funding of NI abortions in England by the UK Government is welcomed, however we note that this was introduced as a stop gap until provision is enacted properly in NI. Travel is not a tenable solution to the breaches found in the UN Inquiry.

VI. This change in law would not prevent abortions for SFA it would simply transport the families to England, however it would make those abortions more difficult to access and force families to make rushed decisions. It would not prevent abortions for the reasons stated in the motion, the only thing that can ameliorate potential discrimination towards having a child with a Down Syndrome diagnosis, are a wide range of social supports for people with Down Syndrome, for their parents and other measures mentioned above.

VII. Re-introducing criminalisation does nothing to change the shame associated with being effectively disowned by Northern Ireland because of your pregnancy choices which feeds into stigma.

VIII. Despite the changes, health care professionals in NI still lack clear guidance as to what advice and care pathways can be offered, leaving abortion seekers in the dark.

IX. Public opinion polls show that despite a reluctant NI Assembly, most notably the majority DUP, the citizens in Northern Ireland support abortion law reform and decriminalisation. The most recent survey showed 87% of people are against criminal penalties for abortion seekers. Whilst rights should not be based on popular opinion, it is indicative of a broader problem of proper representation on issues of social justice in a tribal post-conflict society.

X. Harassment and stigmatizing language are an unnecessary and traumatic additional barrier to the already difficult to access reproductive healthcare for people with crisis pregnancies in Northern Ireland, yet it is allowed to continue unchecked and supported openly by the leading party in NI and with no consequences for those even upon arrest of harassment.

XI. The human rights standards recommended by the CEDAW Committee in their 2018 Report[45] are; that abortion on the ground of severe foetal impairment be available to facilitate reproductive choice and autonomy, States parties are obligated to ensure that women's decisions to terminate pregnancies on this ground do not perpetuate stereotypes towards persons with disabilities. Such measures should include the

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[45] CEDAW - Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women. 19 July 2017 , Legal Findings, 62

provision of appropriate social and financial support for women who choose to carry such pregnancies to term. Please note that the Committee expressly recognises the right to abortion on the ground of “severe” not “fatal” foetal impairment.

XII. Devolved government in Northern Ireland has a history of stripping away the human rights of disabled people as we have seen through their support of restrictive welfare reform and austerity. If political parties are really concerned by how disabled people are treated, there are many more meaningful ways they can support us such as reforming ensuring personal assistance, widespread access to health services, a decent standard of living and tackling discrimination against disabled people.

XIII. Many of the heartbreaking stories that won over the public who voted for a more progressive Ireland were those of people with such a diagnosis. To continue to force them to travel to England is to continue the shameful history of denying women and pregnant people the ability to decide about their own bodies, lives, families and futures. Party policies can be changed, but the trauma from forced travel for healthcare cannot.

XIV. The Abortion (Northern Ireland) (No. 2) Regulations 2020 introduced in March 2020 are designed to implement the recommendations contained in paragraphs 85 and 86 of the CEDAW Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of Discrimination Against Women (CEDAW Report), this includes provision for abortion in cases of severe foetal impairment. These regulations need to be implemented in full so that no pregnant person is forced to travel to England to access basic healthcare.

XV. We wish the Health Committee to note that the person and party who has proposed this bill has always voted against all abortion in all circumstances. We would also like to note that there are no bills to extend provision for Disabled People, especially Disabled Women or Pregnant People and their particular and specialist needs when it comes to abortion and maternal healthcare. It is therefore disingenuous for the motion to claim to make any difference to the lives of Disabled People. There are ways that can happen that are embedded into the public health and social care systems that do not need to impinge on a pregnant person's bodily autonomy.

XVI. Finally we would like to reflect that a governing body that attempts to skirt around and avoid the recommendations of an International Human Rights Inquiry, by undermining the importance of the UN treaties or how binding the findings of the inquiry are, is one that merely invites further legal scrutiny as to its inability to understand or implement fundamental and minimum human rights standards. It is not a good look either for its voting public or in a global setting, frankly it is embarrassing.