

Doctors for Choice Northern Ireland

Response to the Severe Fetal Impairment Abortion (Amendment) Bill 2021

DFCNI

Doctors for Choice NI (DFCNI) is a group of NI clinicians who support the decriminalisation of abortion. We advocate for the provision of high-quality sexual and reproductive health services and access to safe compassionate abortion care. We provide evidence-based information to health professionals and the public, and provide support to clinicians on the issue of abortion.

DFCNI position

DFCNI fully supports the right to bodily autonomy, including in circumstances of severe fetal impairment. DFCNI surveyed members in 2019 in order to inform a response to the public consultation on the legal framework for abortion in NI; there was overwhelming consensus that there should be legal provision for abortion in circumstances of severe fetal impairment and fatal fetal anomaly at all gestations.

This is a position that is aligned to best practice as stated by the Royal College of Obstetricians and Gynaecologists (RCOG) and also international standards in human rights as highlighted by the United Nations Committee on the Elimination of Discrimination against Women (CEDAW) Inquiry and by the 2018 Supreme Court ruling.

DFCNI believes that the right to bodily autonomy should be underpinned by both the NI abortion legislation and by the commissioning of local services to ensure provision of safe compassionate abortion care in all circumstances that are laid out within the current legal framework. Therefore DFCNI do not support the Severe Fetal Impairment Abortion (Amendment) Bill.

DFCNI instead support the right to a high standard of healthcare, NHS provision of fetal screening and testing, unbiased non-directive counselling and adequate support for women whether they choose to have an abortion or whether they choose to continue with the pregnancy; this includes the provision of better services and social support for disabled children and their families.

Abortion provision according to best practice and human rights standards

The World Health Organisation (WHO) recognises abortion as essential healthcare which should be provided safely within the full extent of the law; it has long been recognised that lack of provision for safe abortion only leads to unsafe abortion and increases maternal morbidity and mortality. Aligned to WHO, RCOG 'Best practice in comprehensive abortion care' states that "safe

abortion should be and can be available and accessible for all women, to the full extent that the law allows”.

The legal provision for abortion in Northern Ireland (NI) is governed by a regulatory framework, the Abortion (Northern Ireland) Regulations 2020. With regards to severe fetal impairment (SFI) the current regulations state that there should be “access to abortion services in cases of SFI and fatal fetal abnormalities (FFA) with no gestational time limit. This is where there is a substantial risk that the condition of the fetus is such that the death of the fetus is likely before, during or shortly after birth; or if the child were born, it would suffer from such physical or mental impairment as to be seriously disabled”.

The basis for legislative change to abortion provision in NI followed the UN CEDAW Inquiry, which stated that “women being forced to carry almost every pregnancy to full term, involves mental or physical suffering constituting violence against women and potentially amounting to torture or cruel, inhuman and degrading treatment, in violation of articles 2 and 5, read with article 1, of the Convention”.

The enactment of the Northern Ireland (Executive Formation etc.) Act 2019 created a legal obligation for the Secretary of State for Northern Ireland to implement the CEDAW recommendations. CEDAW recommended that there be expanded grounds for abortion to include cases of severe fetal anomaly:

“SFI, including fatal fetal 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;”

The UK Government has sought to fulfil international human rights obligations in implementing this CEDAW recommendations to include a clause for SFI within the regulations. In addition to complying with the international human rights framework, it was intended that provision mirror “services in England, Scotland and Wales, where abortion for SFI and FFA is available without time limit”. It was considered that a different gestational limit for SFI in Northern Ireland, would leave women and girls with “no choice but to travel to other parts of the UK for a termination”. It was also intended that this would enable access to abortion until a late stage in pregnancy where invasive test results or screening may be delayed or there has been late presentation of an impairment. Diagnostic tests and specialist counselling require referral into tertiary fetal medicine services and may require onward referral to other specialists such as fetal cardiologists and clinical geneticists; this takes time.

Genetic testing using chromosomal microarray analysis and exome sequencing is an advancing field that can yield very valuable diagnostic and prognostic information. Due to the nature of emerging genomic testing strategies, such as next generation sequencing, which currently have protracted turnaround times, delays in ascertaining a precise genetic diagnosis may continue to be a common scenario in NI until the genomic service is mainstreamed throughout the NHS. Restricting access to 24 weeks in NI, means that women who wish to

access local services may not have an opportunity to wait for the results of these specialist investigations prior to making their decision; results which may have otherwise provided reassurance and enabled her to continue with the pregnancy. Those who choose to wait for the results of investigations, may instead face the daunting prospect of having to travel to access services in England, not uncommonly alone and without the support of family or friends.

DFCNI would like to highlight that there are situations in pregnancy, such as the presence of pregnancy-related complications or significant caring responsibilities, where travel to other parts of the UK is neither safe nor feasible; this has been demonstrated at a population level during the course of the COVID-19 pandemic. Additionally, onward referral to another centre limits the availability of post-mortem examination and genetic testing in an attempt to mitigate recurrence risks. It also offers significant challenges in relation to burial and cremation as well as the associated emotional trauma for the woman to have to make such a journey in addition to such a challenging decision. Failure to facilitate continuity of care by the same NI obstetrician, from prenatal diagnosis to termination to pregnancy to postnatal follow-up for women can lead to an increase in adverse outcome for the woman; particularly for those with complex medical needs.

Health Inequality

In addition to patient safety concerns, there is the issue of health inequality; DFCNI notes the specific statutory duty of the DoH and HSC Trusts to reduce health inequality under sections 3(g) and 21 respectively, of the Health and Social Care (Reform) Act (Northern Ireland) 2009. Inequality relates firstly to that between NI women and their UK counterparts and secondly there is the inequality that exists for women who are socially disadvantaged. This is further exacerbated by the lack of a first trimester fetal screening programme within the NHS in NI; the women most likely to be impacted by having a child with a severe fetal impairment, are those who are least able to afford a non-invasive prenatal screening test within the private sector. Due to the lack of an NHS screening programme in NI, a diagnosis of SFI tends to be following the 19-20 week anomaly scan, with a further lag in establishing a prenatal diagnosis due to the investigative pathway required for confirmation.

Guidance from the Royal College of Obstetricians and Gynaecologists and the British Medical Association

RCOG highlight the difficulties this poses for women and their partners. In their 2010 guidance entitled 'Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales' RCOG outline the decision-making process for women when faced with the diagnosis of a SFI:

"The decision-making process for women and their partners after the diagnosis of fetal abnormality is a difficult one. They must try to absorb the medical information they have been given, while in a state of emotional shock and distress, and work out a way forward that they

can best live with. In such sensitive circumstances, women and their partners must receive appropriate counselling and support from the healthcare practitioners involved. All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a nondirective, non- judgemental and supportive approach. The use of appropriate literature and the availability of help from non- directive external agencies, such as Antenatal Results and Choices, is extremely helpful.

After the diagnosis, the woman will need help to understand and explore the issues and options that are open to her and be given the time she needs to decide how to proceed. She must not feel pressurised to make a quick decision but, once a decision has been made the procedure should be organised with minimal delay. Although usually there will be no time pressure put on her decision making, there may be occasions when the pregnancy is approaching 24 weeks of gestation when, because of existing legislation, a rapid decision will have to be reached. In this instance, the reasons must be sensitively outlined and the added distress this may cause acknowledged. Table 4 illustrates the complexity of making a diagnosis and the steps taken before a decision is reached.”

Whilst removal of the SFI clause, would still allow for abortions to be performed up to 24 weeks in cases of fetal anomaly where maternal mental health grounds were met, this in itself is not without its challenges. The British Medical Association (BMA), like the RCOG, recognise the complexity of the decision-making process and caution against putting pressure on women to arrive at a decision prior to 24 weeks. In their paper, ‘The law and ethics of abortion’, the BMA state:

“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.*

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. 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 or seek a termination. 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.”

Late abortion

DFCNI believe that in accordance with UN CEDAW recommendations and established best practice as per RCOG, that the regulations should allow for decisions to be made on a case-by-case basis at all gestations in NI.

Late diagnosis, after 24 weeks, of a severe fetal abnormality that would limit life length or quality is uncommon; affecting approximately six women per year in NI. These diagnoses may occur due to: (i) late presentation for pregnancy booking and prenatal diagnosis provision; (ii) an evolving anomaly which only presents late in pregnancy, as can be the case with some fetal brain anomalies; (iii) the woman requires time to absorb the information and obtain counseling from other disciplines e.g. paediatric neurology, clinical genetics etc. and; (iv) prolonged turnaround time for the investigative pathway to confirm diagnosis which in NI is currently more protracted than other regions in the UK due to the need to refine and develop pathways in fetal MRI and genomic testing. As there is no antenatal screening service for aneuploidy, most if not all diagnoses come to light beyond the second trimester of pregnancy, in those who can afford to avail only of an NHS service. In instances where the pregnancy is beyond 24 weeks' gestation and an SFI is diagnosed the pathway within an NHS organisation, as occurs elsewhere, would be for clinical experts from the multi-disciplinary team (MDT) comprising of fetal medicine consultants, the woman's obstetrician, senior midwives, neonatal consultant and other consultants (as dictated by the fetal abnormality) such as geneticists, paediatric surgeons, neurosurgeons and cardiologists. Such an MDT meeting will allow an evidence-based discussion regarding all available options and enable the woman to make an informed decision whether termination of pregnancy, is appropriate for her and her family in these circumstances. It is our firm belief that it is women who are best placed to make the decision whether or not to continue with a pregnancy. Whereas it is the role of the MDT to determine together from a medical, legal and ethical perspective if the relevant terms of the abortion legislation have been met.

In Northern Ireland, the Severe Fetal Impairment clause of Abortion (Northern Ireland) Regulations 2020, which mirrors Clause E of the Abortion Act 1967 in Great Britain, applies:

“Severe fetal impairment or fatal fetal abnormality

7.—(1) A registered medical professional may terminate a pregnancy where two registered medical professionals are of the opinion, formed in good faith, that there is a substantial risk that the condition of the fetus is such that—

(a) the death of the fetus is likely before, during or shortly after birth; or

(b) if the child were born, it would suffer from such physical or mental impairment as to be seriously disabled.”

Therefore, grounds for termination of pregnancy has to be believed by at least two medical practitioners in good faith and, if challenged, they would have to be able to persuade the court that their belief is honestly held.

On this basis, the diagnoses of SFI concerned are those of a severity and complexity as to cause significant life-limiting disability. This **does not include** an isolated cleft lip, palate, club foot or cases of Down's Syndrome where there is not an associated significant structural fetal anomaly. Rather they include significant structural abnormalities such as abnormalities of the nervous system and cardiovascular system and serious genetic conditions which fulfil the requirements of the Severe Fetal Impairment clause. Failure to commission a safe and effective NHS based pathway within NI for late termination of pregnancy could potentially see women seek late termination services with non-NHS organisations, where the aforementioned conditions which would not meet the criteria for late termination of pregnancy in the NHS may well lead to termination as there are less robust arrangements for risk-management, ethical and safety standards than those which exist with the appropriate oversight and monitoring within the NHS.

The impact of a Severe Fetal Impairment diagnosis on women

Women's circumstances vary. For these severe complex abnormalities, there are a variety of fetal factors to take into consideration such as degree of likely functioning of the child, the need for treatment including surgery, the degree of suffering the child may experience and the likely life expectancy. Equally, the women's personal circumstances will vary; the degree of family support, her financial situation, the needs of existing children and in some cases the presence of a disability affecting her existing children, her partner or the woman herself. There is a lot to consider when facing the possibility of looking after a child with complex needs and all the associated implications for women who may have to give up work to care for the child and who may be forced into poverty as a result. These tend to be much wanted pregnancies, but it is inevitable that given the significant lifelong implications of the diagnosis, that some women will wish to terminate the pregnancy.

DFCNI considers that forcing women to continue with the pregnancy in such circumstances is cruel and inhumane; as is forcing women to travel to access abortion care in Great Britain. Abortion care for SFI is best provided locally where woman can avail of the support of her family and friends during what is a very sad and difficult time.

Additionally, there is a shame and stigma that is only reinforced by forcing women to travel to access healthcare; this is particularly so, when some abortions are viewed as permissible, and others are not. This closely resembles the situation in the Republic of Ireland (RoI), from which DFCNI believe lessons can be learned.

Situation in RoI

The eighth amendment to the Irish Constitution, which since 1983 had given the unborn fetus the same right to life as the pregnant woman, was repealed on 25th May 2018 following a referendum. It passed by 66.4% to 33.6%.

The Health (Regulation of Termination of Pregnancy) Act 2018 came into effect in December 2019. This legislation permits abortion in any circumstances up until 12 weeks gestation. Following 12 weeks, abortion is permitted for reasons of fatal fetal abnormality, risk to life or risk of serious harm to the pregnant women. Abortion services in the Republic of Ireland commenced in January 2019.

In 2019, 64 (17.1%) of women from RoI accessing abortion in England and Wales did so under Clause E alone. Abortions for RoI women are largely undertaken by independent providers such as the British Pregnancy Advisory Service (BPAS) and MSI Reproductive Choices. Late abortions may be undertaken in NHS maternity hospitals where there are tertiary fetal medicine units such as St George's Hospital, King's College Hospital and Liverpool Women's Hospital or via a private non-NHS facility. Whilst undertaken at NHS facilities, women from RoI are not entitled to NHS-funded treatment therefore these abortions are privately funded.

RoI legislation permits abortion to be performed for reasons of fatal fetal abnormality. The Health (Regulation of Termination of Pregnancy) Act 2018 considers 'fatal fetal anomaly' to be "where two medical practitioners are of the opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth".

However, the difficulties in diagnostic certainty around whether a severe fetal impairment is likely to be fatal within 28 days and a resulting fear of prosecution amongst clinicians, means that RoI women are reported to be travelling to England and Wales to access abortion for fatal fetal abnormalities.

Further highlighting the challenges of restrictive legislation is a recent study, 'The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland' (2020). It examined the findings of coronial inquests into stillbirths and neonatal deaths with a congenital abnormality found that "less than half of the congenital anomalies could be classified as an FFA [Fatal Fetal Anomaly]; however, all were fatal".

Learning for Northern Ireland

As abortion has been decriminalised up until 24 weeks in Northern Ireland, DFCNI would expect to see significantly fewer women needing to travel for reasons of SFI than in the RoI. Presently the legislative clause for mental health grounds would permit abortion to be performed for SFI up until 24 weeks even if the severe fetal impairment clause were to be removed in its entirety.

The concern, however, is for those women with a diagnosis of SFI beyond 24 weeks. These tend to be complex, severe abnormalities that cause poor quality

of life and shorten life expectancy. As stated previously, it is estimated that this affects a small number of women per year from NI; approximately six. However, bearing in mind that abortion has only been decriminalised up until 24 weeks, it is possible that a fear of prosecution where there is a possible Fatal Fetal Abnormality may lead to more women travelling for these reasons, in cases where there may be prognostic uncertainty around the likelihood of fatality.

During 2013-2019 a very conservative interpretation of the previous legislation by the Attorney General caused a credible threat of prosecution of clinicians and led to many NI women travelling to England to access termination for reasons of fatal fetal abnormality. The trauma and suffering caused by this is well-documented as are the difficulties in providing appropriate aftercare, obtaining post-mortem examinations to inform future pregnancies and repatriation of the body for burial/cremation at home.

There is a legitimate concern amongst the fetal medicine specialists in NI, that legislative restrictions around abortion for fetal abnormality risk a return to this time. This is a particular risk, should there be any further attempts to curtail provision for abortion under mental health grounds as there was in 2013.

Conclusion

The Severe Fetal Impairment Abortion (Amendment) Bill is strongly opposed by DFCNI. It is neither compliant with human rights standards nor in keeping with best practice guidance. Should the Bill be enacted, it will lead to women who are already in very sad and distressing circumstances being forced to travel to Great Britain to access abortion services; services that our regional fetal medicine experts wish to provide here in Northern Ireland in accordance with the existing legal framework. The unnecessary additional suffering and harm caused by forcing women to travel in such circumstances is unjustifiable. It is not always safe or feasible for women to travel; forcing women to carry a pregnancy to term, when the child may not survive or, if does survive, will suffer significant lifelong disability requiring considerable medical care and treatment, is both cruel and inhumane.