

The Severe Fetal Impairment (Amendment) Bill May 2021

Response from The Fetal Medicine Consultants, Belfast

Our understanding of this Bill is that it will remove abortion for severe fetal impairment at any gestation, whilst continuing to allow for abortion for fatal fetal abnormality.

We, the Fetal Medicine consultants working in the Regional Centre for Fetal Medicine were dismayed to learn of the Givan Bill and the inaccurate information that was circulated to support it prior to it passing the Second stage at the Assembly on 15th March 2021. The information provided by those in support of the Bill does not in any way represent practice in Northern Ireland nor indeed practice in those world renowned Fetal Medicine units in the UK from which we occasionally seek a second opinion.

No opinion was sought from the Fetal Medicine Team, nor to our knowledge, from other Obstetricians currently practising in Northern Ireland prior to this Bill being brought to the debate at the Assembly.

We are disappointed and especially concerned for those women who may no longer be able to receive local and compassionate care, should this Bill succeed.

We are deeply concerned about the focus that was placed on Down syndrome which does not reflect the values and attitudes within the Fetal Medicine Department nor indeed that of the other four Health Trusts.

Women and their partners attending the Centre for Fetal Medicine are supported in the informed decisions that they make in cases of 'fatal' fetal abnormality and severe fetal impairment, including the very many cases where delivery occurs close to or at Term.

Cases highlighted in the Hansard report where women were repeatedly offered termination of pregnancy at late gestations in other parts of the UK suggests practice which our colleagues in Fetal Medicine Units there would not recognise. It emphasises the importance of good governance embedded within multidisciplinary team work.

Consequence of removing Regulation 7(1)(b)

We think it is important to consider what influenced the reduction in the number of abortions in NI in recent years and how the Givan Bill may similarly influence future abortion care provision in NI.

The number of abortions recorded in Northern Ireland decreased significantly in the years following 2013 (51 abortions in 2012/2013, 8 abortions in 2018 /2019) (1). These abortions were performed on the grounds of the risk of a longterm or permanent adverse effect on the maternal mental or physical health. The majority of those abortions performed on the grounds of an adverse effect on maternal mental health occurred where there was a severe / 'fatal' fetal abnormality and where the woman had pre-existing mental health problems and felt she couldn't cope, or where she was so distressed that she felt that she could not

continue the pregnancy to term. (early medical abortions are not included in these numbers as at that time women and girls either travelled to Great Britain or purchased pills online). In late 2012 / 2013 the then Attorney General sent a letter to all consultant obstetricians and gynaecologists in Northern Ireland, advising them to be careful to practice within the law or they could spend 10 years in prison. Given the intimidating language used, clarity was sought as to what constituted an adverse effect on maternal mental health. Legal interpretation differed and no clarity was given. As a direct consequence of this obstetricians and gynaecologists changed their practice for fear of being on the wrong side of the law. Consequently women had to travel to Great Britain, without the support of family and the care of local teams. They were unable to get a post mortem and some had to return home with the fetal remains wrapped in clingfilm, in shoe boxes, being X rayed at the airport and suffering other harrowing experiences.

It is therefore misleading when stated by Mr Givan in the Hansard Report of 11th March 2021, that – ‘The physical and mental welfare of a mother are grounds for permitting a termination, and that has been the case in Northern Ireland for many years’. The implication is, that if regulation 7(1)(b) is removed, women will still be able to have a termination of pregnancy before 24 weeks (where there is severe fetal impairment and where the woman is distraught) under mental health grounds (regulation 4). Our previous experience clearly shows otherwise, with the consequence that many women will have to travel to GB, as happened between 2013 and 2019.

Post mortem examination of the baby following delivery is a vital step in understanding the underlying cause of significant fetal impairment which may carry a significant risk of recurrence. With modern techniques e.g. preimplantation diagnosis there are opportunities to mitigate this risk in future pregnancies should a genetic cause be identified at post mortem. Having to travel for termination will preclude women from this opportunity.

Women with complex medical problems can also be at increased risk if they have to seek care elsewhere and we know of cases in recent years where women have suffered significant morbidity in such instances, in some cases precluding them from having any further pregnancies.

Fatal Fetal Abnormality / Severe Fetal Impairment

‘Fatal’ fetal abnormality is not a clinical term. In previous discussions with the Department of Justice in 2013 / 2014, the NI Royal College of Obstetricians and Gynaecologists (RCOG) Committee and fetal medicine specialists had highlighted that it is impossible to create a list of ‘fatal’ conditions. The same fetal condition may cause death in utero, during labour, immediately after birth or within a few days / weeks of birth or later. There is much interplay between ‘fatal’ fetal conditions and severe fetal impairment. Because of this significant interplay, obstetricians in Northern Ireland had previously used the term ‘severe life limiting’ rather than ‘fatal’. Eventually, the NI RCOG Committee reluctantly accepted the term ‘fatal’, as it was the term used internationally.

A recent study in the Republic of Ireland has demonstrated how difficult it can be to distinguish if an anomaly is severe or fatal. They looked at coronial inquests into stillbirths

and neonatal deaths and concluded that “less than half of the anomalies could be classified as fatal fetal abnormalities, and yet all were fatal” (2). This emphasises the complexity of these cases and the importance of having a multidisciplinary team to assess each on a case by case basis, with as much information as possible available to aid decision making.

The consequence of removing Regulation 7(1)(b) is likely to adversely impact on women who wish to proceed to have a termination of pregnancy for some ‘fatal’ fetal conditions after 24 weeks gestation, as clinicians will err on the side of caution due to the interplay mentioned above. We have already highlighted how the same is likely to occur at less than 24 weeks due to clinicians being fearful to proceed on the grounds of maternal mental health.

Consequently women will have to travel for cases of severe fetal impairment and also for some cases of ‘fatal’ fetal abnormality.

Late Abortion

Most fetal anomalies are detected following the 19 / 20 week anomaly scan and are referred to the Centre for Fetal Medicine. Delays in referral can occur due to suboptimal anomaly scan views, late identification of a pregnancy and other social factors. Therefore some women may not have their first appointment in Fetal Medicine until 21 or 22 weeks gestation, or sometimes later, for unavoidable reasons. Referrals in Great Britain generally occur earlier, due to national screening programmes and detailed early ultrasound being available in many units.

At Fetal Medicine a detailed history will be taken to ascertain any underlying genetic or familial conditions, an ultrasound scan will be performed using a high resolution ultrasound machine and appropriate investigations offered. The couple may need a period of time to come to terms with the significance of the provisional diagnosis they have been told, before launching into further investigations.

Investigations may include chromosomal analysis, microarray, exome sequencing, analysis of complex metabolic panels, fetal MRI and advanced fetal echocardiography. Samples are often forwarded to laboratories in England for the detection of rare diseases. Fetal MRI imaging may be required for brain abnormalities, which is best performed from 22/23 weeks onwards to achieve the necessary image resolution for accurate diagnosis. Polymerase chain reaction (following amniocentesis) to assess initial chromosomal analysis may take up to 1 week to be returned. More detailed chromosomal arrays and exome sequencing may take up to one month to complete and where there is a positive diagnosis the results will require a consultation with specialists in medical genetics. These genetic investigations can yield valuable diagnostic and prognostic information but currently it takes time to get the results.

Inevitably for some women a diagnosis will not be made until close to or beyond 24 weeks.

The circumstances of, and impact of a diagnosis of fetal abnormality on individual women will vary enormously. After receiving all the available information it is important that

women and their partners receive appropriate counselling and support and have sufficient time to reflect on the important decision which is theirs to make, within the constraints of the law. Women and their families may decide that they cannot offer the support required, for instance if they already have significant caring responsibilities (including children with disabilities), if there is a risk of recurrence of an inherited condition, if they suffer from a disability themselves, to prevent suffering or for other reasons.

Restricting access to abortion by removing Regulation 7(1)(b) will inevitably result in some women feeling pressurised and rushed into making a decision, possibly terminating a much wanted pregnancy prior to 24 weeks, a decision which they may not necessarily have made had they had the necessary information available, the opportunity to discuss with the relevant specialists and the support, time and space to come to the right decision.

We have already seen evidence of rushed decisions in recent weeks following the media attention generated by this Bill, with parents concerned about a potential 24 week time limit and making a decision without all of the necessary information being available.

Late Diagnosis (after 24 weeks gestation)

Several fetal abnormalities may not present on scan until the late third trimester e.g. brain or evolving heart abnormalities. In some cases it is not possible to diagnose or predict the severity of a fetal anomaly prior to 24 weeks as some develop into more complex fetal conditions as gestation advances and some women present late for antenatal care.

We estimate that in NI approximately 5 women each year would meet the criteria for a termination of pregnancy after 24 +0 weeks under regulation 7(1)(b). Some of these will be straddling 24 weeks gestation and some may in fact be 'fatal', although deemed as severe fetal impairment.

Abortion figures in NI (2020/2021) for cases of severe fetal impairment / 'fatal' fetal abnormality have not increased compared to those recorded in 2012 / 2013 (recorded under risk of adverse effect on maternal (mental) health), which was the year prior to women having to travel to Great Britain for care (3).

Multidisciplinary Team & Complexity of Decision Making

After 24 weeks gestation the multidisciplinary team (MDT) will always be involved, including as a minimum, two fetal medicine specialists, the woman's obstetrician, senior midwife and a specialist from the relevant area, for example, medical & clinical genetics or paediatric surgery. Other members of the multidisciplinary team include fetal neuroradiologists, neonatologists, neurosurgeons, paediatric cardiologists, neurologists, nephrologists and virologists.

An MDT meeting allows an evidence based discussion regarding all available options and ensures that the woman receives as complete a picture of the nature of the diagnosis and its consequences as possible to inform her decision making. The role of the MDT is also to determine if the grounds for termination of pregnancy are met under regulation 7(1)(a) or

7(1)(b). MDT meetings occur weekly and are also assembled urgently if close to or beyond 24 weeks gestation.

Severe Fetal Impairment / Antenatal Support

The debate prior to the passing of the Second stage of the Bill mentions cleft palate, club foot and uncomplicated Down syndrome as reasons for late termination occurring. This is inaccurate and misleading. Privacy laws based on the very small number of terminations preclude listing the severe fetal conditions which have resulted in termination beyond 24 weeks (and indeed before), which would otherwise have demonstrated the complex nature and severity of these fetal conditions. Club foot (talipes) can be seen in association with severe structural abnormalities in severe / 'fatal' chromosomal abnormalities which can be diagnosed antenatally (by amniocentesis), likewise for cleft palate. Other cases of bilateral talipes are associated with severe neurological disease which is often diagnosed after 24 weeks gestation. Some cases of Down syndrome can be complicated by structural abnormalities of the nervous and cardiovascular system, with differing severity, requiring complex postnatal surgery.

A limited number of women in Northern Ireland when given the news of a severe or 'fatal' fetal diagnosis will opt for a termination of pregnancy. Antenatal midwifery support services and clinical psychology are available and a link nurse provides support and liaises with the Northern Ireland Children's Hospice. Most fetal medicine consultants have visited the Children's Hospice and antenatal, intranatal and postnatal care pathways (written by the Children's Hospice in conjunction with clinicians) are about to be piloted within the Fetal Medicine Unit.

We have a network of parents (who have previously attended Fetal Medicine) who offer to talk to parents who are given the diagnosis of a similar severe fetal condition and parents are offered the support of charities such as SHINE and Joy 21.

We strongly agree that there needs to be more investment in supporting women, partners and their families, including better access to formal counselling services, antenatal support, appropriate financial support for the Children's Hospice and longer term financial support for families.

Emerging Technologies / Advances in Fetal Medicine

Given the substantial experience in Belfast of caring for babies born with spina bifida, two years ago the Belfast Trust submitted a bid to become the second centre in the UK to offer prenatal surgery for spina bifida. Sadly we were not successful and Leuven, Belgium became the second centre (in addition to University College Hospital, London). We refer those cases who can be considered for prenatal surgery to Leuven, funded by NHS England. Those not eligible have postnatal surgery undertaken by the very experienced neurosurgical team in Belfast.

We also have excellent and long standing links with the world famous Fetal Medicine Unit at St Georges, London, referring patients there regularly for complex prenatal procedures,

trying to ensure that the women we provide care for have access to the latest technologies to offer better outcomes and some hope in those very difficult and complex cases. Fetal neuroradiology networks with the team at Great Ormond Street to refine diagnoses from very complex fetal brain MRI's, to aid prognosis and decision making. Genomic testing is a rapidly expanding field which yields valuable information to help provide a more detailed diagnosis and prognosis.

We feel that the tone in parts of the Hansard Report undermines the dedicated work of those teams caring for women in NI, to provide the best possible care for women and to support them in the very difficult decisions which they and their families have to make.

Conclusion

We are concerned that in removing regulation 7(1)(b), women will yet again have to travel to GB for care in cases of severe fetal impairment and in some cases of 'fatal' fetal abnormality.

Clinicians are likely to face a similar situation as to that which occurred in 2013, concerned about the interpretation of regulation 4 and what is meant by maternal mental health, uncertain as to whether they can provide care for a woman who has been given devastating news and who feels that she cannot continue with the pregnancy to term.

We have seen evidence in recent weeks of women making rushed decisions, due to concern around the 24 week limit generated by the Bill.

We believe that women need to be supported in these most difficult of circumstances, with decision making on a case by case basis, underpinned by robust pathways, cared for by their local teams and with family support close by. Adequate financial support needs to be available for counselling, care providers and for families.

References

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- 2.Power S, Meaney S, O'Donoghue K. The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland. *Prenatal Diag.* 2020 Apr; 40(5):549-556.doi: 10.1002/pd.5642. Epub 2020 Feb 7. PMID:31913532
- 3.Changes in Abortion Law in NI. Reilly K, Bailie C. Ulster Obstetrical & Gynaecological Society Virtual Meeting, February 2021.

