



Royal College of
Obstetricians &
Gynaecologists

Severe Fetal Impairment (Amendment) Bill

**RESPONSE TO THE NORTHERN IRELAND HEALTH COMMITTEE CALL
FOR EVIDENCE**

MAY 2021

Background

1. The Royal College of Obstetricians and Gynaecologists (RCOG) works to improve the health and wellbeing of women everywhere, by setting standards for clinical practice, providing doctors with training and lifelong learning, and advocating for women's health globally. Founded in 1929, the RCOG now has over 16,000 members worldwide and works with a range of partners both in the UK and globally to improve the standard of care delivered to women, encourage the study of obstetrics and gynaecology (O&G) and advance the science and practice of the specialties.
2. In 2019, the Northern Ireland (Executive Formation etc) Act (the Act) achieved Royal Assent in the UK Parliament. The Act requires the Secretary of State to, by secondary legislation, amend the law in Northern Ireland in order to implement the recommendations listed under paragraphs 85 and 86 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 by the United Nation's Committee on the Elimination of Discrimination Against Women (CEDAW)¹.
3. We supported the aims of section 9 of the Northern Ireland (Executive Formation etc) Act 2019. Prior to this legislation, abortion in Northern Ireland was provided for in very few circumstances. Healthcare professionals were liable for a penalty of life imprisonment for providing abortion care.
4. CEDAW was correct in its assessment of the previous framework in Northern Ireland when it described it as "ambiguous" without "providing a clear pathway for the care of women requiring an abortion."²
5. We understand any future legislation must comply with those recommendations set out in Paragraphs 85 and 86 of CEDAW, if those regulations are to comply with the legal duty created by the Act.
6. We welcome this opportunity to submit our views to the Northern Ireland Health Committee in response to the Severe Fetal Impairment (Amendment) Bill, which seeks to amend the legal framework with respect to abortion in Northern Ireland.
7. We note that despite the new legal framework taking effect from March 2020, the Department of Health and the Health and Social Care Board have neither funded nor commissioned any service, and that abortion, while legal, is inaccessible for many women in Northern Ireland.

¹ [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](#), UN Committee on the Elimination of Discrimination Against Women, 2018

² Ibid.

Key issues to consider

8. The Severe Fetal Impairment (Amendment) Bill (the Bill) seeks to amend Regulation 7 of the Abortion (Northern Ireland) (No. 2) Regulations 2020. The immediate effect of this Bill would be to completely remove the ability to terminate a pregnancy on the grounds of a non-fatal fetal impairment at any gestation.
9. In addition to this immediate effect, which itself denies women a choice in difficult circumstances, does not take into account the nature of antenatal care in Northern Ireland, and denies the clinical complexity of severe fetal impairment and diagnosis, the Bill would have several additional effects which should be considered by the committee.
10. Importantly, the Bill is inconsistent with the Northern Ireland (Executive Formation etc) Act 2019.
11. Firstly, the Act places a duty on the Secretary of State for Northern Ireland to ensure Northern Ireland provides abortion (and other services) in accordance with Paragraphs 85 and 86 of the CEDAW report. Paragraph 85(b)(iii) of CEDAW states that any regulation must provide access to abortion care for women who receive a diagnosis of “severe fetal impairment” as well as “fatal fetal abnormality.”³
12. **This Bill removes the ability to terminate a pregnancy for severe fetal impairment irrespective of gestation. This is in clear breach of the 2019 Act.**
13. In addition, the practical effect will also breach the requirement to provide abortion care in cases of a fatal fetal impairment. It is clear from clinical practice that it is sometimes not possible to clearly determine a severe fetal impairment from a fatal fetal impairment. This is supported by the literature. **This denial of abortion care for cases which are ultimately fatal breaches the 2019 Act.**
14. Finally, the Bill does not observe CEDAW Paragraph 85(d), that “evidence-based protocols should be adopted for healthcare professionals on providing legal abortions.”⁴ **As this Bill ignores many clinical complexities with respect to severe fetal impairment and does not take into account published evidence on the difficulty in distinguishing a severe fetal impairment from a fatal impairment, the Bill is in breach.**
15. Removing these provisions in law will ultimately (i) prevent a patient-centred, individualised approach to care for women who may already be distressed, (ii) ignore the clinical complexity of severe fetal impairment, (iii) result in women travelling to Great Britain to access healthcare and (iv) is inconsistent with the Northern Ireland (Executive Formation etc) Act 2019.

³ [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](#), UN Committee on the Elimination of Discrimination Against Women, 2018

⁴ Ibid

Misleading claims

16. This Bill has been associated with several misleading claims which seek to trivialize very complex clinical care.
17. It is not always possible to clearly distinguish between a “severe fetal impairment” and a “fatal fetal disability.” The Republic of Ireland determines that a fatal fetal disability is one which leads to death prenatally or within 28 days of birth. A recent study 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, yet all were fatal.”
18. Some severe fetal impairments are not detected until later in the pregnancy. This is especially true in Northern Ireland where the screening programme differs from the rest of Great Britain. Diagnoses of severe fetal impairments are consequently picked up later in pregnancy.
19. Claims around abortion for cleft lip after 24 weeks are untrue. This claim comes from data published by the UK Department of Health and Social Care which only counts which anomalies are *mentioned* in the data collected – it does not detail other impairments mentioned alongside cleft lip. Clefting itself is associated with 300 different syndromes, some of which are severe or fatal.
20. In England and Wales in 2019, there were a total of 12 abortions after 24 weeks carried out where Down’s Syndrome was mentioned. While the data cannot be further interrogated, these cases likely had other significant severe impairments. This data is aggregated because, given there are so few cases, they may be identifiable.

Guidance on termination of pregnancy for fetal impairment

21. In May 2010, the RCOG published ‘Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales’ (the “**RCOG Guidance**”). This guidance refers to the Abortion Act 1967 under which termination of pregnancy for “severe handicap” is possible under Ground E.
22. The RCOG Guidance makes various recommendations as to the information and support that should be available to women. It states, at page ix, that:
 - “2. A robust management pathway must be in place to ensure that appropriate information and support are available. For most major fetal abnormalities, referral to a doctor with expertise in fetal medicine is recommended (section 6).
 3. All practitioners performing fetal anomaly ultrasound screening should be trained to impart information about abnormal findings to women and a health professional should be available to provide immediate support to the woman and her partner (section 6).
 - ...
 5. All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a non-directive, non-judgemental and supportive approach (section 6).
 6. It should not be assumed that, even in the presence of an obviously fatal fetal condition such as anencephaly, a woman will choose to have a termination. A decision to decline the offer of termination must be fully supported (section 6).”

23. The RCOG Guidance, at pp8-10, then defines “serious handicap”. It concludes that providing termination of pregnancy after 24 weeks for life limiting anomalies should remain.

Serious handicap

The law does not define serious handicap. The view has been expressed that ‘provided the condition is not trivial, or readily correctable, or will merely lead to the child being disadvantaged, the law will allow doctors scope for determining the seriousness of a condition. At a minimum it is suggested a “serious handicap” would require the child to have physical or mental disability which would cause significant suffering or long-term impairment of their ability to function in society. The most serious genetic or other conditions which manifest themselves at birth or almost immediately thereafter are by and large likely to fall within the scope of Section 1(1)(d)’.

The Working Party sees little reason to change the current law regarding the definition of serious abnormality and concludes that it would be unrealistic to produce a definitive list of conditions that constitute serious handicap. Precise definition is impractical for two reasons. Firstly, sufficiently advanced diagnostic techniques capable of accurately defining abnormalities or of predicting the seriousness of outcomes are not currently available. Secondly, consequences of an abnormality are difficult to predict, not only for the fetus in terms of viability or residual disability but also in relation to the impact in childhood as well as on the family into which the child would be born.” (Emphasis added)

24. The RCOG Guidance acknowledges that there are occasions when an abnormality is diagnosed, and the clinician does not consider that termination meets the criteria set out in the 1967 Act after the woman requests it. In these circumstances the RCOG Guidance states, at p25, that:

“There may be a situation when an abnormality is diagnosed and the clinician does not consider that termination would meet the criteria of the law but the woman requests it [...]If the diagnosis is made after 24 weeks, the woman should be given access to a second opinion and if she is still not offered a termination, she should be offered counselling”.

25. On “Chromosomal abnormalities” such as Down’s syndrome it states, at p14, that:

“Chromosomal abnormalities detected at amniocentesis or chorionic villus sampling are usually diagnosed and decisions made by 24 weeks. However, late diagnosis may arise following either late booking or late manifestation of clinical features arising from an underlying abnormality such as hydramnios in duodenal atresia (associated with trisomy 21) or fetal growth restriction (associated with trisomy 18). A fetus with a structural abnormality associated with a chromosome abnormality is likely to have a poorer prognosis.”

26. On counselling and support, the RCOG Guidance states, at pp22-24, that:

“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.

...

The decision by the woman to continue her pregnancy must be fully supported and it should not be assumed that, even in the presence of an obviously fatal fetal condition, a woman will choose to have a termination. If she wishes to continue with the pregnancy, she should be managed either at the fetal medicine unit (depending on the abnormality) or in conjunction with her referring obstetrician. Some women will choose to continue the pregnancy with the option of palliative care after delivery and this decision must be respected, supported and an individualised care plan agreed. Other women will decline termination for non-lethal conditions and will need referral to specialists such as paediatricians, paediatric surgeons or neonatologists. The baby may need to be born in a centre with immediate access to a range of paediatric specialists, such as cardiologist or paediatric surgeons. In either instance, a coordinated care pathway needs to be established and women should have easy access to a designated health professional throughout the pregnancy. It will be helpful to provide her with details of any relevant parent support organisations. Regardless of the nature of the abnormality, it will also be necessary to ensure that the woman's needs as an expectant mother are not overlooked. Antenatal care should be arranged so that she does not have to wait with others where pregnancies are straightforward. She should also be offered one-to-one antenatal sessions tailored to her specific needs."

27. The RCOG Guidance therefore recognises that an assessment of the seriousness of a fetal anomaly should be considered on a case-by-case basis and that healthcare professionals involved in caring for women and their families should adopt a non-directive, non-judgemental and supportive approach. It also refers to the importance of healthcare professionals providing a robust management pathway to ensure support and information is available.
28. Following publication of the report, 'Non-invasive prenatal testing: ethical issues' (2017) by the Nuffield Council on Bioethics (the "Nuffield Report"), the landing page on the RCOG website was updated to make clear that the RCOG Guidance provides advice for clinicians supporting women who choose to continue their pregnancy as well. In addition, in 2017/2018 the RCOG eLearning team worked closely with the Down's Syndrome Association and Down's Syndrome Scotland to implement their suggested changes to wording in the following core knowledge eTutorials:
 - Principles of antenatal care
 - Genetic disorders
 - Ultrasound scanning of fetal anomaly
29. In 2018/2019, the RCOG worked with the authors of these tutorials to add in some text about the evaluative roll-out of Non-invasive Prenatal Testing being launched (dealt with further below). In the longer term, the RCOG will review the videos on our eLearning platform relating to screening for Down's syndrome. In addition, a number of pieces of guidance are currently being developed, including an RCOG Green-Top Guideline on Care After Non-invasive Testing.

30. The term “serious handicap” is not one which tends to be used in ordinary or medical language anymore and it is not defined in legislation. The RCOG Guidance, at p8, echoes the view found in *Principles of Medical Law* (2nd ed.), a widely cited and authoritative text on the law as it relates to healthcare, that:⁵

“...provided the condition is not trivial, or readily correctable, or will merely lead to the child being disadvantaged, the law will allow doctors scope for determining the seriousness of a condition. At a minimum it is suggested a “serious handicap” would require the child to have physical or mental disability which would cause significant suffering or long-term impairment of their ability to function in society.”

31. The RCOG guidance provides some further information for clinicians to weigh when deciding what constitutes a fetal anomaly. These factors are not restricted to criteria relating to fetal viability and include, at p9:

- The potential for effective treatment, either *in utero* or after birth;
- On the part of the child, the probable degree of self-awareness and of ability to communicate with others;
- The suffering that would be experienced; and,
- The probability of being able to live alone and to be self-supportive as an adult.

32. The Nuffield Report states at paragraph 1.53, in relation to anomalies, that:

“what constitutes a significant medical condition or impairment is a judgement that depends on several factors, including the likely level of impairment, the available treatment options, and the views of and potential impact on the family and the individual themselves.”

33. Inevitably, the circumstances and impact of a diagnosis of fetal abnormality on individual women will vary enormously. It is essential that clinicians are permitted, under the law, to support women and their families to consider what effect the diagnosis has on their individual circumstances, and allow them to reach a decision which is right for them. Women and their families may decide that they cannot offer the support required, for instance if they already have significant caring responsibilities (including for existing children, and children with disabilities), suffer from a disability themselves or for other reasons.

34. Most terminations of pregnancy after 24 weeks are managed medically, and the regimen is outlined in the guideline produced by the National Institute for Health and Care Excellence and the RCOG, titled ‘Abortion care’ (2019).

Guidance from the British Medical Association

35. The British Medical Association issued guidance (updated in September 2020), titled ‘The law and ethics of abortion’.

36. On fetal abnormality, at pp7-8, it states that:

“The Abortion Act is silent on the definition of “serious handicap”. It is therefore a matter of clinical judgment and accepted practice. The RCOG (Royal College of Obstetricians and

⁵ A Grubb, *Principles of Medical Law* (2nd ed, OUP) (2004), p760. Now in its 4th iteration (2017).

Gynaecologists) has detailed guidance for health professionals involved in late abortions for fetal abnormalities. 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.”

Consensus statement from RCOG, Royal College of Midwives and the Society of Radiographers

37. A consensus statement has been produced by the RCOG, with support from the Royal College of Midwives and the Society of Radiographers. This consensus statement, entitled ‘Supporting women and their partners through prenatal screening for Down’s syndrome, Edwards’ syndrome and Patau’s syndrome’, provides more information for healthcare professionals and women about the screening pathway.⁶ This was published on 2 December 2020. It includes a section which describes how counselling both before and after screening is recommended, as well the importance of presenting information and support in a non-directive way. The consensus statement has received stakeholder comment and feedback from a number of organisations, including the Nuffield Council on Bioethics, Antenatal Results and Choices, the Down’s Syndrome Association, Support Organisation for Trisomy 13/18 (SOFT), Positive About Down Syndrome, British Maternal and Fetal Medicine Society, NHS Fetal Anomaly Screening Programme and the Down’s Syndrome Research Foundation.

38. Following publication of the consensus statement, Hugh Whittall, Director of the Nuffield Council on Bioethics, said in a statement that:⁷

“We have been pleased to see significant shifts in approaches to prenatal screening and the language that surrounds it since we published our inquiry on the ethics of NIPT in 2017. This important statement from three professional bodies is a signifier of that shift. We welcome the messages it sends to all healthcare professionals involved in the delivery of prenatal screening across the UK.

⁶ It can be accessed here: <https://www.rcog.org.uk/en/guidelines-research-services/guidelines/consensus-statement-prenatal-screening/>

⁷ Accessible at <https://www.rcog.org.uk/en/news/advice-for-health-professionals-providing-pregnancy-screening-tests-published/>

The statement couldn't be clearer: women and couples should be provided with accurate, balanced and non-directive information and support to enable them to make choices at each stage of prenatal screening. Critically, their choices must be fully respected. Whilst this should always have been the case, the introduction of NIPT to the NHS pathway has created an opportunity to ensure a high-quality service is being offered consistently."

Screening

- 39.** Screening is the process to assess risk or detect early disease and provide further tests or treatment at an earlier stage with the objective of improving outcomes. Individuals can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition. Fetal anomaly screening is offered as an option and is not a mandatory part of routine antenatal care. The key objective of the screening programme is to enable parents to make informed choices, at each step along the screening pathway.
- 40.** First trimester screening covers issues such as iron-deficiency anaemia, sickle cell, thalassaemia, HIV, hepatitis B and congenital syphilis. It also covers fetal trisomy – including Down's syndrome – with test between 11-14 weeks gestation as part of the NHS Fetal Anomaly Screening Programme. In the first trimester, screening objectives are targeted, there are well-defined diagnostic pathways, good access to centres capable of providing comprehensive care as well as patient support and information.
- 41.** Second trimester or mid-gestational ultrasound screening for fetal structural abnormalities is very different from first trimester screening. By contrast, second trimester ultrasound screening is undertaken at 18-20+6 weeks and covers a wide range of potential concerns including anatomy of fetal organs (brain, heart, bowel etc.), functioning of different fetal organ systems (hydrops, anaemia, neuromuscular etc.) as well as fetal growth. These conditions encompass a very wide range of disease severity and typically require specialist care in tertiary centres. In 2019, only 10% of Ground E abortions occurred prior to 13 weeks' gestation – reflecting the stage at which most fetal abnormalities are detected.

Further testing

- 42.** When a fetal condition is suspected or diagnosed, women are typically referred to a specialist tertiary centre to have further investigations as required to enable provision of personalised information and support.
- 43.** The range of fetal health conditions includes, but is not limited to, anatomical, nutritional, cardiovascular, immune, viral, chromosomal and genetic. The investigations required to formulate an accurate diagnosis and evaluate prognosis are complex in terms of the type, timing and interpretation of results. For example, specialist fetal MRI imaging may be required for suspected fetal brain abnormalities. This investigation is only available in a few centres in this country and is typically performed after 23 weeks gestation in order to achieve the necessary image resolution for accurate diagnosis.
- 44.** Women would usually be offered invasive prenatal diagnosis (such as amniocentesis) which carries a risk of miscarriage and therefore women should be given time to consider whether they want this

investigation. Even when such a procedure is undertaken, the initial genetic results – preliminary polymerase chain reaction – will take up to one week to be returned. Furthermore, the chromosomal arrays and exome sequencing genetic analysis may take 2 to 3 weeks to complete and has resulted in several ‘tiers’ of interpretation of results ranging from possible clinical significance, probable clinical significance to a pathological clinical result. Typically, such results require a consultation with specialist clinical geneticists for the parents to understand and process this information – and then consider the options of expectant management versus termination of the pregnancy.

45. A diagnosis of major fetal problems and the clinical consequences of the diagnosis are always reviewed in weekly fetal medicine multidisciplinary team meetings which typically include paediatricians, paediatric surgeons, geneticists, clinical geneticists, neurologists, virologists, obstetricians and midwives. Such meetings are a focus for ensuring that the woman receives as complete a picture as possible of the nature of the diagnosis and its consequences so as to inform her decision-making regarding the pregnancy.
46. Testing, and the interpretation of the results of those tests, which can be extremely complex, therefore requires a period beyond 24 weeks in some cases. In addition to further diagnostic tests, women and their partners must have an appropriate period of time to reflect on the important decision which is theirs to make within the constraints of the law. A consequence of restricting the term limits in these cases would be two-fold. First, it is unlikely the necessary testing, interpretation and diagnosis could be achieved within this period. This would essentially force women and their partners to decide to continue or terminate their pregnancy without the full information required. Secondly, it would leave very little time to properly reflect on the results and the information that is available. A likely consequence would be that in otherwise wanted pregnancies women would terminate before 24 weeks under a different ground, where the anomaly may not be severe, due to a lack of information and the pressure they are would be placed under.
47. Although women are likely to be provided with an earlier indication of a chromosomal anomaly such as Down’s syndrome, they are recommended to undergo an invasive test before they decide to terminate an otherwise wanted pregnancy, which can increase the time that it takes to get a more definitive diagnosis. In addition, it will always be the case that some women will present late for antenatal care. This may be due to a number of reasons, including late identification of a pregnancy, coming to terms with the pregnancy, potentially seeking to keep the pregnancy a secret, not engaging with health services due to a lack of experience, social and economic reasons and systemic barriers to access or referral. It is therefore important that healthcare professionals are able to care for individual women in different and sometimes complex circumstances which can lead to a late prenatal diagnosis. A late, prenatal diagnosis should not result in a woman being forced to quickly or hurriedly decide either to continue or to terminate her pregnancy, given that she may not have all the information she requires, and that such decisions are significant.

Effect on women

48. Women who terminate a pregnancy for a life limiting fetal anomaly are often making this decision for an otherwise wanted pregnancy, and therefore the termination can be considered a unique form of bereavement, which can be misunderstood and stigma-bearing. Levels of grief can be high, and for some individuals distress persists long after the diagnosis and termination – not least because of the potential for similar complications in future pregnancies. Social and cultural factors can play a role in how this form of bereavement may be understood and approached.

49. The legal framework contributes to the factors that weigh on a woman's experiences which can result in social judgment, self-judgment, and a need for secrecy. In addition, removing this provision in law, or imposing a gestational time limit, risks substantially affecting the mental and physical health and wellbeing of women; many would find themselves with the choice of either carrying a pregnancy to term or being rushed towards deciding that they should terminate their pregnancy. In this context, increasing legal and societal constraints will only serve to worsen the process and long-term outcomes for women. Changing the law in this way would also place healthcare professionals in a worrying situation, effectively relegating the job of properly caring for women in difficult circumstances and allowing them time to decide what is right for them, to preventing them from making a choice which is specific to their circumstances, and likely exporting the problem to Great Britain.

Complexity of decision-making

- 50.** We must also recognise the limitations of existing diagnostic tools. The truth, which clinicians have to share with pregnant women, is that it is not possible to know for certain what the outcome of a particular pregnancy will be – they simply interpret the evidence so as to provide a likelihood of certain events. This includes intrauterine fetal demise, further worsening of the fetus's condition prior to birth, impacts on the woman's physical and mental health, and undetected sequelae presenting subsequent to birth.
- 51.** As a result, there are relatively few examples of diagnosed anomalies where clinicians can tell a woman definitively that there is absolutely no chance of her fetus surviving. The current law recognises this difficulty and provides registered medical practitioners with the ethically necessary ability to certify abortions where the ultimate outcome may be either fetal demise or a serious, irreparable disorder that results not in death but an unknown period of suffering. Women and families often report making the decision to end a pregnancy not because fetal demise is certain, but because they do not want their much-loved unborn child to live with pain or suffering. This might include the need for postnatal surgery to correct any other physical congenital anomalies.
- 52.** With regard to Down's syndrome specifically, common congenital defects diagnosed in babies with Down's syndrome include heart, brain or bowel defects as well as issues such as hydrops fetalis, which is a very serious condition causing fluid to accumulate around the baby's organs, and which can cause perinatal death and serious maternal health issues. These are factors which play into the complexity of decision-making in this context specifically.
- 53.** At the same time, underpinned by a woman's ability to consent or opt out of aspects of antenatal care, clinicians treat many women who know they wish to continue their pregnancy to term and thus opt out of screening or diagnostic testing. Further, there are patients who continue with their pregnancies subsequent to the diagnosis of a fetal abnormality. According to the National Congenital Anomaly and Rare Disease Registration Service, which collects information from every region in England, in 2018 (the latest year for which figures are available), 73.5% of congenital abnormalities were diagnosed antenatally, and a total of 73.4% of all fetuses and babies diagnosed with a congenital abnormality (both antenatally and postnatally) resulted in a live birth.
- 54.** Again, in relation to Down's syndrome specifically, in 2018, 56% of Down's syndrome diagnoses were made antenatally, with 44% of women opting out of screening and/or diagnosis. Of the 1,570 Down's syndrome diagnoses, there were 722 live births compared to 799 terminations of pregnancy. As a testament to the complexity of diagnosing likely outcomes, 41 of the 1,570 Down's syndrome diagnoses ended in post-20-week miscarriage or stillbirth. For those women who continue with their

pregnancy following a diagnosis of Down's syndrome, the risk of stillbirth or late miscarriage is 57 per 1000 live births – ten times higher than the population as a whole.⁸

55. All of this shows that decisions about antenatal care are complex and driven by a woman's personal choices about her health and wellbeing – whether or not she wishes to continue a pregnancy, but also whether or not she wishes to engage with national screening programmes or diagnostic tests. As a result, simply considering the outcomes for pregnancies diagnosed antenatally does not adequately reflect the choices made by women during their pregnancies.

Consequences of restricting termination of pregnancy for a severe impairment

56. This Bill removes any termination of pregnancy for a severe impairment, which is clearly inconsistent with the Northern Ireland (Executive Formation etc) Act 2019. We consider that this would be an extremely dangerous restriction which will have untold ramifications for both women and healthcare professionals.
57. First, there are timing issues, where it is not always possible to diagnose or understand the severity of a fetal anomaly prior to 24 weeks. This is an extremely complex area of medicine, which demands pathways and medical care which are appropriate for women in a variety of clinical and personal circumstances. In addition, there will always be cases where women will present late for antenatal care, as described in paragraph 47.
58. Second, there is substantial difficulty in diagnosing whether a fetal anomaly is "severe" or "fatal". A good example of this is in the Republic of Ireland, which recently passed the Health (Regulation of Termination of Pregnancy) Act 2018. In the Act, it considers a '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.*" A recent paper titled 'The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland' (2020) examined the findings of coronial inquests into stillbirths and neonatal deaths for foetuses and neonates which had died following diagnosis of a congenital abnormality (Exhibit BT11). The study concludes that "*less than half of the congenital anomalies could be classified as an FFA [Fatal Fetal Anomaly]; however, all were fatal. This acknowledges the complexity of these cases. In isolation, the congenital anomaly may not be fatal, but combined as multiorgan system anomalies, it is. Knowledge is required to inform clinical practice and counselling of parents who receive such a diagnosis.*" In these cases, as a direct result of the restrictive legal provision which does not provide for true medical assessment of the impact of severe fetal anomaly, women are forced to continue with a pregnancy that ultimately results in stillbirth or fatality within 28 days, or must travel to Great Britain in order to have a termination, if they can afford to do this.
59. Third, in addition to the complex nature of diagnosing conditions, there is also good reason why we consider that it would be unworkable to provide a list of anomalies which might meet a 'fatal abnormality' threshold. Medicine is constantly innovating and improving and we are today able to remedy conditions which would have been considered severe or fatal in the past. Any list committed to law would not be exhaustive and would have limited value for healthcare professionals, given the interplay of conditions which can arise, but it would also be quickly outdated. The value of judging,

⁸ These statistics relate to both antenatal diagnosis of Down's syndrome and postnatal diagnosis (i.e. for those women who choose not to undergo prenatal testing). They are different from the abortion statistics which only cover antenatal diagnosis: <https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs>.

on a case-by-case basis, with a multidisciplinary team, is that clinicians can use their knowledge of the latest techniques and developments. An outdated list in law which determines which impairments are covered by the regulations could have the opposite effect of what is intended.

60. Termination of pregnancy for a severe impairment is never a decision arrived at lightly. Certification for the abortion is dependent upon the good faith opinion of two registered medical practitioners who must arrive at the same conclusion. The idea that clinicians, or women, approach this situation with anything other than the gravity it deserves is mistaken. This is partly shown by the very few cases of termination after 24 weeks where Down's syndrome is mentioned, but also by the published experiences of the specialists involved.
61. A recent qualitative study to explore fetal medicine specialists' experiences of caring for parents in the Republic of Ireland shows how this restriction can affect the care that they are able to provide. Fetal medicine specialists said:

"I think that my biggest challenge is the understanding of what is covered under the legislation. I think that it is more what is covered and I think people thought that if we had termination of pregnancy introduced in Ireland that nobody would ever have to travel to the UK for termination of pregnancy again. And that is not the case."

"... the litigious environment that we work in and the medical legal aspects of working in this area have been shown... difficult cases last year and cases that have made it into the media and the cases that will go to court. And so we are not protected in our practicing in any way."

62. It is clear from the experiences of clinicians in the Republic of Ireland that women who do not meet the requirements for a fatal anomaly are forced to travel to England. We can expect that a change in the law in Northern Ireland will continue to result in women travelling to Great Britain, where their termination may be permitted, or consider an unregulated method of termination, exposing themselves to harm and prosecution under the law.

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