

**REPORT OF THE WORKING GROUP ON FATAL FETAL
ABNORMALITY**

**HEALTHCARE AND THE LAW ON TERMINATION OF
PREGNANCY FOR FATAL FETAL ABNORMALITY**

**PROPOSALS TO THE MINISTER OF HEALTH AND
THE MINISTER OF JUSTICE**

11 October 2016

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EXECUTIVE SUMMARY

Executive summary

1. The focus of the Fatal Fetal Abnormality working group was to consider healthcare and the law in cases of fatal fetal abnormality (FFA). In particular, the group had to reach conclusions on the standard of health and social care provision for those women who have had such a diagnosis and identify any gaps in provision and how they can be closed, including consideration of the need for legislative change to the law on abortion¹.

2. Of particular importance to the group was the requirement that all health professionals involved in these very difficult cases could fully meet their duty of care to the women concerned.

Evidence

3. Evidence presented by health professionals emphasised concerns over a number of issues in relation to healthcare for women with fatal fetal abnormality pregnancies:

- Medical risks of significant obstetric complications which can impact on a woman's health and on future pregnancies. These concerns are set out in detail in section 4.
- Risks associated with travel to access a termination in other jurisdictions, particularly risks associated with the inability to access, on a private basis, the specialist care required for complex late term terminations and the difficulties in obtaining post mortems, genetic testing and repatriation of fetal remains.

4. The group also considered evidence provided to the Public Health Agency (PHA) from women and their families. Common themes were perceptions of:

- Poor communication and information
- Lack of engagement by healthcare staff
- No joined-up care system
- Difficulty having to access care through normal maternity services
- Feelings of abandonment by local health services
- Lack of aftercare and support following termination of pregnancy
- Poor coordination of care

¹ The terms "abortion" and "termination of pregnancy" both appear in this paper and should be read interchangeably.

Findings

5. Health professionals said that, in their professional opinion, retaining the existing legal constraints would continue to place an unacceptable burden on women's health and wellbeing.

6. Health professionals felt that they were unable to fully meet their duty of care to their patients, particularly when a woman asked for a termination in the interests of her health and wellbeing and in circumstances where no viable life could ensue.

7. The FFA working group acknowledges proposals by the PHA for a series of improvements in healthcare arrangements to lessen the impact of the journey to other jurisdictions for women who choose termination for fatal fetal abnormality. However, it was the considered view of the FFA working group that there is still nothing to alleviate the trauma for the woman of travelling away from home and family at such a difficult time, the loss of her dedicated medical team and the associated financial cost.

8. The group also considered that it might be regarded as disproportionate and inequitable for the state to make such efforts to alleviate the burden on women of travelling to another jurisdiction to have an abortion, in effect facilitating what would be the commission of a crime in this jurisdiction, yet not being prepared to adjust the law to provide the procedure here.

9. One of the most compelling cases for change was the overall recognition by those health professionals who spoke to the group that the existing legal framework prevents them from fully meeting their duty of care to all women in this situation and therefore denies those women who wish to terminate the pregnancy, access to proper standards of health care.

10. In summary, health professionals considered the current situation to be professionally untenable.

Terminology and definitions

11. The terms of reference for the group tasked it to determine how clinical practice and medical capability can best be reflected by appropriate terminology and definitions which would offer legislative clarity for any change to the law on abortion. The group agreed that:

- Fatal fetal abnormality is an acceptable description of a diagnosis made, usually around 20 weeks gestation, of a fetal abnormality which will result in death in utero, at birth or shortly after birth.
- The term 'life limiting condition', which has been used by some participants in the wider debate on abortion law, may include fatal fetal abnormalities but also includes other conditions which result in babies born with disabilities

where life expectancy is not confined to the early period but where medical intervention is still confined to palliative care.

- Modern diagnostic resources allow for very accurate information to be provided to women regarding the condition of the fetus and its viability.
- Expert health professionals can, in relation to the conditions listed at paragraph 4.23, diagnose a fatal abnormality with certainty.
- In those additional conditions where there is uncertainty about the diagnosis of fatal fetal abnormality, the option of a termination will not be available within the scope of any future legislative change for fatal fetal abnormality.

Conclusions

12. The working group concluded that:

- some improvements can be made to the care and support of women with a fatal fetal abnormality diagnosis through the proposals to improve the standard of care under the existing legal framework;
- there is a substantial body of evidence to underwrite the need for legislative change in relation to termination of pregnancy for fatal fetal abnormality;
- health professionals have identified a number of scenarios where they consider their duty of care to patients is being compromised;
- there are women 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.

Proposals

13. The group notes that:

(1) the improvements to services for women with fatal fetal abnormalities identified by the PHA and outlined in Chapter 5 should improve the care and support for some women with a diagnosis of fatal fetal abnormality, though not women who choose to end their pregnancy;

And recommends:

(2) that a change is made to abortion law to provide for termination of pregnancy where the abnormality is of such a nature as to be likely to cause death either before birth, during birth or in the early period after birth. 'In the early period after birth' means those circumstances where life might still be present after birth, but there is no medical treatment which would make the condition survivable and the only option is appropriate, specialised end of life care. Where a diagnosis has been made of such an abnormality, it is to be accepted that the continuance

of such a pregnancy poses a substantial risk of serious adverse effect on a women's health and wellbeing.

1. INTRODUCTION AND BACKGROUND

Introduction

1.1 In July 2016 the Minister of Health and Minister of Justice agreed to establish an inter-Departmental working group on fatal fetal abnormality. The group's origins stem from a request by the leader of the DUP in February 2016 to the then Health Minister, Simon Hamilton, to establish a group to make recommendations on how the issue of fatal fetal abnormality could be addressed, including, if necessary, change to legislation. This request was made immediately prior to a debate in the Assembly on an amendment to the Justice Bill to introduce a provision which would allow for termination in cases of fatal fetal abnormality. The press statement issued by the DUP leader set out the party's opposition to the amendments, recognised the sensitive and controversial nature of the issue, and acknowledged that the matter required more careful consideration than would be possible in a debate on an otherwise unrelated bill. The amendments to the Bill were subsequently defeated.

1.2 Following Executive discussion of the DUP's request, it was agreed that the working group would include representatives from the Department of Justice, and that it would report, by September 2016, to both the Health Minister and the Justice Minister in the first instance, who would then present their recommendations to the Executive.

1.3 Following the Assembly election in May 2016, Michelle O'Neill, MLA, and Claire Sugden, MLA, the newly appointed Health and Justice Ministers, agreed to continue to work together on FFA and in July 2016 confirmed the membership and terms of reference for the group. Due to the urgency of reaching an agreed position on a way forward, they also asked the group to report to both Ministers by the end of September, in accordance with the original timescale envisaged.

Terms of Reference

1.4 The terms of reference for the group are as follows:

- To consider issues relating to cases of fatal fetal abnormality, including matters addressed in the previous consultation by the Department of Justice, and provide a report to the Health and Justice Ministers, making recommendations, including on potential legislative change for termination

of pregnancy as necessary. The Health and Justice Ministers will, in turn, submit proposals to the Executive for approval.

Actions will include:

- Identifying how best to engage with, and obtain input from, women who have experienced fatal fetal abnormality and the health and social care professionals who have treated them;
- Scoping the current health and social care provision for women in Northern Ireland who have had to deal or are dealing with a diagnosis of fatal fetal abnormality;
- Identifying any gaps in health and social care provision and how they can be closed;
- Engaging with appropriate Royal Colleges and other relevant organisations that the group considers can contribute to its work; and
- Determining how clinical practice and medical capability can best be reflected by appropriate terminology and definitions which would offer legislative clarity for any change to the law on abortion.

1.5 The group met for the first time on 14 July and four times subsequently.

Members of the group also held meetings with the appropriate medical professional bodies and with women, and their families, who had experience of fatal fetal abnormalities. Details of the engagement process are at chapter 4.

Approaches to the group

1.6 Both Departments were approached by various organisations seeking a seat on, or a meeting with, the group. However, it was generally accepted that the responses to the DOJ consultation the previous year provided comprehensive evidence of the policy views of those organisations which sought a place on the inter-Departmental group. A small number of written submissions were also sent to the group and were acknowledged. In addition, the PHA and the Chief Nursing Officer and Chief Medical Officer met with a number of women and their partners.

Context

1.7 The terms of reference, set out above, explain the precise remit of the group. The focus is strictly confined to consideration of termination of pregnancy in cases where a diagnosis is made of a fatal fetal abnormality. In particular, the group had to reach conclusions on the standard of health and social care provision for those women, identify any gaps in provision and how they can be closed, including consideration of the need for legislative change. The working group was therefore not an instrument of debate on the wider issues surrounding abortion and did not seek to attract such discussion. Of particular importance to the group was the requirement that all medical midwifery and nursing professionals involved in these very difficult cases could fully meet their duty of care to the woman concerned.

Historical context

1.8 It is important to note that among health professionals, a diagnosis of conditions such as anencephaly, and the resulting distress for a woman carrying a wanted child, is widely understood. The issue was raised during the DHSSPS 2013 consultation on the draft *Guidance Document - The Limited Circumstances for a Termination of Pregnancy*.

1.9 The point is made to counter any suggestion that the phenomenon of ‘fatal fetal abnormality’ is new; it has long been known to health professionals, but the clarification now set out in the Department of Health, Social Services and Public Safety’s 2016 *Guidance for Health and Social Care Professionals on Termination of Pregnancy in Northern Ireland*, coupled with the very publicly aired experiences of a number of women in the media, has brought the issue to public attention.

1.10 It follows that any investigation into the care and support given to women in this situation, and any improvements that can be made, are not as a result of ‘hard cases making bad law’. While these situations could never have been envisaged by lawmakers in 1861 or 1945, they are a regular feature of professional life for those who deal with pregnant women and their families today. A compassionate, caring and fit for purpose healthcare system should strive to ensure not just that possible serious health risks are averted, but that the evident distress caused by these

diagnoses is minimised as far as possible. This should be accommodated within the legal framework in this jurisdiction.

2. THE CURRENT CRIMINAL LAW ON ABORTION

The law in this jurisdiction

2.1 Abortion in this jurisdiction is governed by sections 58 and 59 of the Offences Against the Person Act 1861 (the 1861 Act), section 25 of the Criminal Justice Act (Northern Ireland) 1945 (the 1945 Act) and judicial case law, which provides the grounds for exemptions from criminal prosecution to allow for termination of pregnancy in certain circumstances, as set out in the following paragraphs.

2.2 Section 58 of the 1861 Act makes it an offence for a woman to have an unlawful abortion or for any other person to carry out an unlawful abortion. It is also unlawful under section 59 to procure any drugs or instruments for use in an abortion. The relevant sections in the Act are as follows:

Offences against the Person Act 1861

58. Administering drugs or using instruments to procure abortion.

Every woman, being with child, who, with intent to procure her own miscarriage, shall unlawfully administer to herself any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, and whosoever, with intent to procure the miscarriage of any woman, whether she be or be not with child, shall unlawfully administer to her or cause to be taken by her any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, shall be guilty of felony, and being convicted thereof shall be liable to be imprisoned for life or to be fined or both.

59. Procuring drugs, &c. to cause abortion.

Whosoever shall unlawfully supply or procure any poison or other noxious thing, or any instrument or thing whatsoever, knowing that the same is intended to be unlawfully used or employed with intent to procure the miscarriage of any woman, whether she be or be not with child, shall be guilty of a misdemeanour, and being convicted thereof shall be liable to be imprisoned for five years or to be fined or both.

2.3 Section 25 of the 1945 Act introduced a law to criminalise child destruction, where a child is capable of being born alive, with an exception only to allow for circumstances when it was necessary to save the life of the mother. The Act provides that a child is deemed to be capable of being born alive after a 28 week gestation period. The 1945 Act is an exact replica of the Infant Life Preservation Act 1929 (the 1929 Act) for England and Wales.

2.4 In 1938, the Bourne judgment determined that the clause contained in the 1929 Act ‘to preserve the life of the mother’ should also apply to abortions carried out under the 1861 Act, so that it covered all abortion procedures, whatever the period of gestation. The judgment introduced into abortion law the concept that the pregnancy could have detrimental effects on a woman’s mental health, such as to pose a significant risk to her life, and that it was lawful to undertake a termination in those circumstances.

2.5 The 1861 and 1945 Acts remain the legislative framework within which abortions may be carried out here, and case law remains as established in the Bourne judgment. This position was again reinforced by Lord Justice Girvan in his judgment in the Matter of an Application by the Society for the Protection of Unborn Children for Judicial Review [2009] NIQB 92, where he accepted the following as a correct statement of the law:

"In summary, it is lawful to perform an operation in Northern Ireland for the termination of a pregnancy, where:

- it is necessary to preserve the life of a woman; or
- there is a risk of real and serious adverse effect on her physical or mental health, which is either long term or permanent.

In other circumstance, it would be unlawful to perform such an operation."

The law elsewhere

2.6 The 1967 Abortion Act, which covers England, Wales and Scotland, introduced exceptions to the 1861 Act, in addition to the existing case law defences. The first of these additional exceptions allowed for abortion if the continuance of the pregnancy involved risk to the life, or injury to the physical or mental health, of the pregnant woman or any existing children, greater than if the pregnancy was terminated. The second decriminalised the procedure in the event of a substantial risk of a child being born ‘seriously handicapped’. Both of these provisions were governed by the upper gestational limit of 28 weeks in the 1929 Act, beyond which it would remain an offence to abort the fetus except for the sole reason of saving the life of the mother. This was reduced to 24 weeks by the Human Fertilisation and Embryology Act 1990.

2.7 In Ireland, the Protection of Life During Pregnancy Act 2013 repealed the old offences contained in the 1861 Act and replaced them with a single offence of the intentional destruction of "unborn human life" with a maximum sentence of 14 years, rather than the life term attached to the 1861 Act offences. The 2013 Act further provides that a pregnancy can be terminated when there is a real and substantial risk to a woman's life (including risk brought about by a threat of suicide), and where the procedures carried out in the 2013 Act are complied with.

2.8 Many countries in the European Union allow abortion on request up to 12 weeks gestation. After this, abortion is allowed only under certain circumstances, which vary from state to state, but which include elements such as risk to the woman's life or health, fetal abnormality or other specific situations that may be related to the circumstances of the conception, or the woman's age. There are 18 European countries in all which, even if abortion is available on request up to 12 weeks, have a specific provision to allow for later terminations, if there is a risk of serious fetal abnormality.

Human rights considerations

2.9 The earlier DOJ consultation paper looked at the current law and its compatibility with the European Convention and other international standards. The paper made clear that the Department's proposal at that time to change the current law was not based on human rights requirements but on public policy grounds.

2.10 Since then, the Northern Ireland Human Rights Commission (NIHRC) has sought a legal ruling that the law as set down in sections 58 and 59 of the 1861 Act is in breach of Articles 3, 8 and 14 of the ECHR in respect of access to termination of pregnancy services for women in cases of serious malformation of the fetus and pregnancy as a result of rape or incest.

2.11 In December 2015, the High Court in Belfast ruled that current abortion law is incompatible with Article 8 rights as it applies to fatal fetal abnormality (FFA) and rape and incest. The Court decided that the law could not be read in a Convention-compliant manner and a Declaration of Incompatibility was issued on 4 January 2016. On 27 January, the Department served notice of appeal. The Attorney General also lodged such notice.

2.12 The Department's decision to appeal related to concerns that the reasoning of the Court may not have provided sufficient legal certainty and that the judgment may not properly reflect existing European jurisprudence on the balance to be struck between the Article 8 rights of a pregnant woman and the margin of appreciation given to individual states on whether Article 2 applies to the fetus.

2.13 The appeal was heard in June 2016 and a ruling is expected before the end of the year.

3. PREVIOUS ENGAGEMENT ON CHANGING THE LAW: THE DOJ CONSULTATION

3.1 The working group also took account of the proposals put forward by the DOJ in its 2014 consultation paper and considered the range of responses, in 2015, to those proposals.

3.2 As a result of those responses, from a range of bodies and organisations, and developments more widely, the Department of Justice believed there was sufficient evidence to suggest that a case had been established for a limited legislative change to the law and that there was substantial support to make such a change.

3.3 In particular, the working group noted that the evidence from health professionals and their professional bodies at the time clearly showed that women in these circumstances needed to have an option to terminate the pregnancy for very valid reasons relating to health and wellbeing. The responses made reference to the risk of injury to physical or mental health that such a pregnancy can have. Many supported the right for women to make a decision on what was best for them and made clear that whatever the decision was, their primary duty as a health professional was to provide the best care, either to support the woman in carrying the pregnancy to term and, where applicable, providing optimum palliative care for any live birth, or in enabling a woman to have a safe termination.

3.4 The concerns expressed by those who opposed change were also considered carefully by the group. The Department of Justice took the view at the time that the health and wellbeing of the woman must take priority, that the law should be clear and offer certainty, and that women here should be permitted to decide, in the context of their overall medical care, on what was in their best interests in the circumstances of fatal fetal abnormality.

3.5 Although the case law arising from Bourne may intend to include, or may have in the past had the effect of including, these sorts of circumstances, the proposed statutory change to the law would have put it beyond doubt and provided clarity to both the pregnant woman and her clinical team that, if it is in her own best interest for the sake of her health and wellbeing to terminate the pregnancy, then it should be lawful for such a procedure to be undertaken in her home jurisdiction.

3.6 The response paper clearly stated that where a woman wanted to continue with her pregnancy, the proposed change would have no adverse impact or effect on such a decision.

3.7 In direct response to the consultation, 65 submissions were received from groups representing a major cross section of interested parties. Of these, 47 were in support of changing the law to a greater or lesser extent, including all the relevant medical, nursing and midwifery professional bodies, reproductive healthcare groups, human rights organisations, trades unions, political parties and others. There were also 133 replies from individual members of the public who wished to see change.

3.8 The response paper also referred to two public opinion polls which suggested that a majority of the population were in favour of change. A Belfast Telegraph poll in October 2014 suggested that 58% of people wanted abortion laws liberalised. One commissioned by Amnesty International showed that 60% of people think the law should make access to abortion available where the fetus has a fatal abnormality. The paper also pointed to political support for change in these circumstances from some political parties and individual MLAs.

3.9 Against this, 18 organisations objected to any change. These were churches and faith groups, two political parties and organisations such as Precious Life and the Society for the Protection of the Unborn Child (SPUC). There were also 579 individual replies rejecting change and a postcard petition opposing change with 20,000 signatures. A similar campaign hosted on a website added over 3,000 signatures. There were also 921 letters submitted as a result of seven lobby campaigns.

3.10 The responses to the consultation, along with the lobby campaigns and the petition, showed that 25,140 people, or 1.8% of the adult population, registered their opposition to a change to the law. Against this, 47 out of 65 organisations representing many and varied groups across society were in support of a change. Also noted were the results of the public opinion surveys carried out on behalf of the Belfast Telegraph and Amnesty international.

3.11 The consultation response paper noted that responses in favour of change and responses against were submitted from the perspective of sincere and genuinely

held views, whether professional, political, religious, moral or ethical. The paper noted that all views are to be respected in a democratic society and that for some organisations and individuals any change in the law would be unacceptable from their perspective.

3.12 The Department's response acknowledged the moral and ethical position of those groups and individuals who did not want any change to the law, but concluded that the weight of evidence and the content of the arguments, rather than the number of signatories to a petition or lobby campaign, seemed largely to favour a move to clarify the law so that women would be able to access services for a termination of pregnancy in circumstances of fatal fetal abnormality where continuing with the pregnancy would have a detrimental effect on their health and wellbeing.

3.13 In summary, opinion expressed in submissions by NICRCOG and consultants in the Department of Fetal Medicine at the Royal Jubilee Maternity Service, felt that the existing law, supported by guidelines, needed to allow for termination of pregnancy in cases where fatal fetal abnormality results in a detrimental effect on the health of the woman.

3.14 Others recognised, acknowledged or supported the policy objective to change the law to enable women to make an informed choice as to a termination without the requirement that continuing with the pregnancy would result in a risk to her mental or physical health which is serious and either long term or permanent.

3.15 Some argued that the objective of providing choice in those circumstances should extend to serious but not immediately fatal abnormalities where, for example, a serious genetic disorder would adversely affect the woman, her family or existing children.

3.16 The response paper argued that the existing case law provides for termination of pregnancy only to protect the woman against the risk of physical or mental health issues which are real and serious and long term or permanent. However, there may be cases when there is a risk of damage to a woman's health through carrying a pregnancy in these circumstances which is assessed not to meet this high threshold and which may therefore be outside of the current legal parameters for a termination.

Conclusion

3.17 From evidence provided to the DOJ consultation, and further evidence now submitted to this group and detailed in the next section, it is clear that women faced with these circumstances can experience a variety of reactions. Those who decide it is best for them to continue with the pregnancy are accommodated and supported in this decision. Those who may face a risk to their life or of serious long term or permanent harm to their health can be protected under the existing law. Others do not fall within either of these groups but face risks to their physical and mental health including acute trauma and distress, and possible financial hardship, because they cannot access the health service they require in this jurisdiction. As a result, the group concludes that there is a substantial body of evidence to underwrite the need for legislative change in relation to fatal fetal abnormality.

4. EVIDENCE TO THE WORKING GROUP

4.1 In October 2015, the Chief Medical Officer asked the Public Health Agency (PHA) to consider the information available to professionals across Health and Social Care Trusts who may have to provide care and support to pregnant women carrying a baby with a fatal abnormality. The PHA assembled a working group of health professionals with experience of working with pregnant women to consider current practice and how the experience of women with a diagnosis of fatal fetal abnormality could be improved.

4.2 The FFA working group took the PHA work as its primary source of information in its consideration of whether care and support could be improved and whether a change to the law could support improvements in practice. The group also considered responses by professional health bodies to the DOJ consultation in 2014/15.

Evidence from medical bodies

4.3 The FFA working group discussed the proposals outlined in this paper with representatives of the PHA, the Royal College of Midwives, the Royal College of Obstetricians and Gynaecologists and the Royal College of Psychiatrists on 25 August 2016. It held discussions with the Royal College of General Practitioners at a later date. Further discussions with representatives of these professional bodies were held on 3 October 2016.

4.4 The main theme arising from discussion with health professionals was that the current law on termination of pregnancy here has a direct, negative, impact on the duty of care required of those professionals in relation to their patients.

Medical risks

4.5 Some of the conditions that cause fatal fetal abnormality can result in significant obstetric complications and a higher rate of complex caesarean delivery, which carries an additional risk to the woman's health and may have a potential impact on future pregnancies, including risk to the health of the woman and any future fetus.

4.6 The group was told by the Royal College of Obstetricians and Gynaecologists that severe polyhydramnios (excessive accumulation of amniotic fluid surrounding

the fetus in utero) can complicate some pregnancies where the fetus has a fatal fetal abnormality (polyhydramnios is almost always present when the fetus has anencephaly and is also prevalent in a number of other fatal fetal conditions). In these situations the polyhydramnios becomes more severe as the pregnancy advances and it often results in other complications such as malpresentations of the fetus and difficult surgical deliveries. Such polyhydramnios may also necessitate bedrest due to the considerable discomfort and breathing problems associated with the condition, increasing the background risk for maternal thromboembolism.

4.7 Delivery by Caesarean section may sometimes be required with an increased risk for the woman. Difficult and more extensive surgical incisions are sometimes required in order to deliver a fetus at an advanced gestation with an abnormally enlarged body part, such as hydranencephaly or a very enlarged abdomen. These types of uterine incisions increase the risk of haemorrhage at the time of the delivery and also increase the risk of uterine rupture and placenta praevia in future pregnancies. The former (uterine rupture) poses a potential threat to the life of both the woman and the fetus in any subsequent pregnancy and placenta praevia is a well recognized cause of life threatening haemorrhage in the woman.

4.8 Caesarean sections are not infrequent in women with a diagnosis of fatal fetal abnormality due to the problems highlighted above and the higher incidence of labour commencing prematurely.

4.9 An increasing number of pregnant women now have other health problems or comorbidities, most of which have a tendency to worsen as the pregnancy advances (e.g. gestational diabetes/diabetes/hypertension). The incidence of obesity is increasing and this confers additional risks at any gestation, but more so if a surgical delivery is required at an advanced gestation. Demographics have changed considerably and the prevalence of the older pregnant woman is also increasing, when other comorbidities are more likely to be present and when some fatal fetal abnormalities are also more common.

4.10 The group was advised that such complex deliveries do currently take place here due to women being unable to access termination of pregnancy in this jurisdiction when carrying a fetus with a fatal abnormality. For a variety of reasons – lack of funding, parental responsibilities, ill health, or anxiety about the journey -

many of these women will choose not to, or be unable to, travel to other jurisdictions. This subjects them to further mental distress, as they perceive that they are being compelled against their will to face potential additional physical health risks.

Risks associated with travel

4.11 A major concern raised by health professionals related to their duty of care for women who did not feel that they could continue the pregnancy. General Medical Council (GMC) guidelines state that doctors are duty bound to make the care of the patient their first concern, and to take action if they think that patient safety is being compromised. Serious concerns were expressed about the increased risk of harmful physical and mental health outcomes for women who travelled to other jurisdictions, with some health professionals having experience of women returning from other jurisdictions with adverse health outcomes and significant clinical complications.

4.12 Health professionals were clear that their uncertainty about how much information can be provided to women who have chosen to have a termination is currently compromising their duty of care as expressed in GMC guidance. There is an overriding professional duty to provide care that is compassionate and humane. Health professionals advised that they had significant professional concerns that women are being placed in a situation where, with no alternative available within the health service here, they feel forced to leave home, a partner, other children or close family for an ill-identified pathway of care. In their view, this is not compassionate treatment and care.

4.13 Most concerning, however, is the fact that many women with a fatal fetal abnormality require specialist care that is only available in NHS facilities. While some agencies are known to advise women of where they can receive the most appropriate care, health professionals in this jurisdiction are unclear whether they are able to offer such advice. Many women, even those fortunate enough to be properly and fully advised, are unable to afford private healthcare in NHS facilities.

4.14 Termination of pregnancy in the later stages carries with it significantly higher clinical risk to women than early termination managed through the prescription of medication. The vast majority of procedures carried out in private clinics in other UK jurisdictions are under twelve weeks gestation, and many are medical procedures,

where drugs are prescribed by a clinic for the woman to take in her own home. This cannot be equated with a termination at over 20 weeks for a fatal fetal abnormality. Many private facilities do not regularly facilitate more complex terminations, and are not in a position to provide the aftercare needed by women with complex presentations. Specialist care can be vitally important for women who wish to plan future pregnancies. There may be a requirement for genetic testing or post mortem information about the cause of the fatality to plan for future pregnancies.

4.15 Health professionals have advised that women who travel to other jurisdictions face significant barriers to securing the additional services they require, including bereavement services and genetic testing.

4.16 Many health professionals in this field consider that there are circumstances where a termination in this jurisdiction should be one of the options that a health professional can discuss and, following non directive counselling and consent, offer a termination of pregnancy if a woman so chooses. The current law prohibits this.

4.17 Termination of pregnancy, at a late stage and in these particularly distressing circumstances, is not an inconsequential procedure and can impact on women's physical and mental health. For women who decide this is the only option open to them and who have to travel to another jurisdiction because of the law here, this is further complicated by the stress of travel, the clinical risk associated with some procedures, the problems associated with aspects of aftercare such as availability of post-mortems, the need for bereavement care, problems with repatriation of remains and the distress at being away from their family and clinical teams who have supported them in their pregnancy to date.

4.18 In summary, the view of the health professionals who work most closely with women with an FFA diagnosis is that there are many circumstances where a termination is an entirely appropriate healthcare option for a woman, but one that cannot currently be performed here. The current law clearly has the potential to have a negative impact on these women's physical and mental health.

Terminology and definitions

4.19 The terms of reference for the group tasked it to determine how clinical practice and medical capability can best be reflected by appropriate terminology and definitions which would offer legislative clarity for any change to the law on abortion.

4.20 It recognised that while the conditions grouped under the collective term of fatal fetal abnormalities are rare, they are sufficiently common that health professionals working in this field will encounter them in the routine course of their work. It was remarkable that while it has proved difficult to provide a legal definition of fatal fetal abnormality that will negate the fear held by some that any change to the law will inevitably lead to 'abortion on demand', health professionals were able to consistently identify a range of conditions that are, in their experience, fatal.

4.21 In its work on this subject, the PHA sought to answer the question 'What is a fatal fetal abnormality?' in a proposed, but not yet finalised, information leaflet for parents. Their answer was as follows:

'A fatal fetal abnormality is a term used to describe a number of conditions one of which has been diagnosed by your obstetrician. This condition may cause your baby to die in the womb, or survive for a short period following birth. If your baby is born alive, as no meaningful medical intervention will change the outcome for the baby, he/she is likely to only live for a short time.'

4.22 The group discussed this subject in some detail with representatives of the relevant professional bodies. A number of points were agreed:

- Fatal fetal abnormality is a widely acceptable description of a diagnosis made, usually around 20 weeks gestation, of a fetal abnormality which will result in death in utero, at birth or shortly after birth.
- The term 'life limiting conditions', which has been used by some participants in the wider debate on abortion law, may include fatal fetal abnormalities but also includes other conditions which result in babies born with disabilities where life expectancy is not confined to the early period but where medical intervention is still confined to palliative care.

- Modern diagnostic resources allow for very accurate information regarding the condition of the fetus and its viability to be provided to the woman.

4.23 The health professionals also discussed with the group the terminology and definitions that might best meet the objective of a law to provide for termination solely within the terms of reference of the working group, in other words to provide for termination strictly for cases of fatal fetal abnormality, as defined above. The following definitions were considered:

- A fetus with a life-threatening physical condition that, in reasonable medical judgment, regardless of the provision of life saving medical treatment, is incompatible with life outside the womb.
- A fetus suffering from a condition that, in reasonable medical judgment, will cause death either before birth, or during birth, or, should a live birth occur, is incompatible with life outside the womb.
- Incompatible with life outside the womb meaning that the child will not be expected to survive and there is no medical intervention which can be performed to treat the condition to improve the chances of survival.
- The fetal condition is of such a nature as to be likely to cause death before birth, during birth or, in the event of a live birth, no medical treatment could be offered, other than appropriate palliative and nursing care which would make the condition survivable.

Difficulties were noted in all these definitions. Following discussion, the term considered best to allow clinicians to work with legal certainty to provide optimum care for women in these circumstances, was:

The fetal abnormality is of such a nature as to be likely to cause death either before birth, during birth or in the early period after birth. 'In the early period after birth' means those circumstances where life might still be present after birth, but there is no medical treatment which would make the condition survivable and the only option is appropriate, specialised end of life care.

4.24 In order to address questions about the general nature of the term FFA, the working group considered evidence from health professionals about the main conditions that may be covered by the term. The following four broad areas were highlighted, although it must be recognised that the list is not exhaustive:

- **Major chromosomal trisomy**, which are usually lethal. Examples include complete Trisomy 18 (Edwards's syndrome) and complete Trisomy 13 (Patau syndrome). Both cause multiple congenital abnormalities. An exception, and outside the scope of FFA is Trisomy 21 (Down syndrome).
- **Lethal autosomal recessive genetic disorders** – there are a series of these disorders that are incompatible with life. Most are rare but well characterised including biochemical disorders e.g.: some Neu-Laxova syndrome (abnormal skin and blood serine enzymes), and lethal skeletal dysplasias e.g.: Thanatophoric dysplasia (abnormal bone structure).
- **Rare midline developmental disorders** where the midline organs don't develop appropriately e.g. Potter syndrome/Potter sequence where the kidneys are absent, resulting in further abnormal fetal development. The baby cannot survive without kidneys.
- **Lethal neural tube defects involving the skull**. Examples include anencephaly (absence of the cranium), hydranencephaly (fluid filled head with no brain development), certain forms of holoprosencephaly (abnormal development of the frontal lobes and brainstem).

4.25 Health professionals told the group that in their professional view, these diagnoses can be made with certainty prenatally (either by invasive testing such as amniocentesis or chorionic villous biopsy to confirm chromosomal abnormalities and a spectrum of other rarer genetic conditions or by ultrasound (eg anencephaly and Potter syndrome)). Other rare abnormalities may also be detected by ultrasound where the anatomical disruption to major organs is so severe that it would be impossible for the fetus to survive. Recent medical advances now mean that some fatal fetal conditions can be diagnosed by a maternal blood sample antenatally (e.g. thanatophoric dysplasia). This is called non invasive prenatal diagnosis.

4.26 The group was also informed that there is a different group of abnormalities detected by ultrasound where, antenatally, it is difficult to predict the outcome. In

these cases, even with joint discussion by health professionals in fetal medicine , medical genetics and neonatology, it can be difficult to accurately counsel parents and sometimes they are given a prognosis which covers a spectrum from mild to severe disability. In some of these situations, the baby may die at birth or in the early neonatal period, however, the diagnosis antenatally is not sufficiently sound to categorise these fetuses as falling into the fatal fetal abnormality group.

4.27 It was the unanimous view of all health professionals that such abnormalities were sufficiently distinct as to be viewed as separate to those with a diagnosed fatal fetal abnormality. In those cases where there is uncertainty about the diagnosis of fatal fetal abnormality, the group stressed that *there should be no option for a termination of pregnancy under any proposal for legislative change arising from this review.*

Women, their partners and families

4.28 The working group was keen to hear the views of women with personal experience of an FFA diagnosis, including women who continued their pregnancies and those who chose otherwise. The working group took account of written testimony provided by individuals to the Departments of Health and Justice and again, the group relied on the work being carried out by the PHA, who were in contact with 12 women and, in some cases, their partners.

4.29 The women were also asked whether they wished to engage directly with the Chief Medical Officer and Chief Nursing Officer (representing the working group) and three women and one partner took the opportunity to meet.

4.30 Following the publicity around the formation of the working group, a number of women approached the Departments of Health or Justice seeking to be involved. They were put in contact with a named person within the PHA.

4.31 The PHA provided a report to the working group describing the women's experiences and outlining the many difficulties some of them had faced. The women and their partners who shared their experiences told the PHA that these pregnancies were much wanted babies and when advised of the diagnosis they and their whole

family circles were devastated. A small number of women continued their pregnancies. The majority did not.

4.32 In general, communication and information was described as poor. A common theme was that health professionals appeared not to know what to say or what advice they were able to give. At worst, care was described as inhumane, lacking any compassion, disjointed and failing.

4.33 The impression the women who wanted a termination were left with was that some staff did not want to engage because of their own personal beliefs or because they feared sanction if they provided information.

4.34 The experience of care provided was variable. Many felt that, from the point of diagnosis, they had to find information for themselves and, as a result, they did not feel part of a joined up care system. Once a diagnosis was made many of the women felt they became a problem. Some felt the diagnosis 'wrote off' their baby too quickly and that they weren't given full information about all the options available to them.

4.35 Women described how they didn't fit into the normal maternity service, though that was all that was available. Others described the efforts made by individual consultants and midwives who tried to help but were constrained in what information they could provide. As a result many women got their advice from the internet or from outside the Health Service here.

4.36 A small number of women, including some who continued their pregnancy, felt services were good, often related to the efforts individual health professionals made on their behalf, though there were times when being part of a normal maternity service was distressing. There was particular praise from those who used the Children's Hospice service as a mechanism of support and the Department of Health is aware of plans by a charity to further develop additional perinatal care facilities.

4.37 Those who accessed a termination of pregnancy elsewhere felt abandoned by the health service here. Some women were able to access private treatment in NHS facilities, and the care received was described as compassionate and kind. Those who were not signposted to the NHS by agencies, or could not afford to be treated

privately by the NHS, had no option but to access the services of independent clinics. Many women found that service distressing.

4.38 The lack of information and support following the procedure was found to be particularly distressing. Women didn't know who to talk to when they came home or what to do next. Many were not fully aware of what happened to them or their baby. Some women were able to access support when they returned home but felt at times that people judged them. Most were unaware of how to bring their baby's remains home or, in one instance, that this was an option.

4.39 As one would expect, the women who met the Chief Medical Officer and Chief Nursing Officer reflected the same themes, inconsistency of communication, lack of compassion and poor coordination of care. The women felt they were left to navigate their own way at a time of great distress with inconsistency in advice and support provided.

4.40 Many articulated the need for more information on the range of congenital conditions, outlining the full spectrum of potential consequences for the pregnancy from death being almost inevitable immediately after birth through to a life limiting condition. This information was crucial in order that fully informed decisions could be made.

5. PROPOSALS FOR CHANGE

Current healthcare arrangements

Department of Health's Maternity Strategy

5.1 The Department of Health's Maternity Strategy (2012-2018) sets out the strategic direction for maternity care in this jurisdiction. At the heart of the strategy is the need to place women in control of their own pregnancy and support women and their partners to make proactive and informed choices about their lifestyle, self-care, and type of health and social care (HSC) maternity service which will be appropriate to their needs.

5.2 The Strategy aims to improve the quality of services for women with straightforward pregnancies, or those with more complex conditions, during the entire pregnancy. This contrasts adversely with the current approach to services provided for women who receive a diagnosis of fatal fetal abnormality. In particular, the Strategy adopts an outcomes approach to maternity care under six key standards of care including:

- effective communication and high-quality maternity care;
- effective, locally accessible, antenatal care and a positive experience for prospective parents; and,
- appropriate advice, and support for parents and baby after birth.

5.3 The aim of the Public Health Agency work commissioned by the Chief Medical Officer in October 2015 is to ensure that appropriate and regionally consistent care and support is provided for women carrying a fetus with a fatal abnormality, within the law as it currently stands. The PHA has made a number of suggestions to improve the services and information provided to women with a diagnosis of fatal fetal abnormality. They had no mandate to make suggestions that go further than the existing law. The PHA made a number of service proposals that should make improvements to the care and support of women in these circumstances as soon as they are implemented.

Gaps in provision of healthcare

5.4 It is clear that the health service standards set out in the Department of Health's Maternity Strategy are not being applied to women who receive a diagnosis of fatal fetal abnormality. These women therefore experience a particularly stark inequality, compared to other expectant women, in relation to communication, locally accessible care, appropriate advice and support at a time when they are at their most vulnerable.

5.5 Health professionals working with the PHA have identified a number of scenarios where they consider that their duty of care to patients is being compromised and the existing law and guidance is insufficiently clear. Their concerns are focused on the quality of care received by women from here who have travelled to other jurisdictions for a termination of their pregnancy that would not be lawful here. Health professionals here have experience of women returning from other jurisdictions with adverse health outcomes resulting from, in their view, poor care in some private facilities.

5.6 Furthermore, some women with complex presentations require very specialist care available only in certain NHS facilities. Health professionals are concerned, bearing in mind their existing duty of care to a woman before she travels and after her return, that they may risk prosecution if they advise a woman of NHS facilities, or a specific NHS facility, where the health professional is aware that the standard of care and services available will meet the specific clinical needs of the women. Such needs may include additional information about the condition that caused the fatal fetal abnormality in order to plan for future pregnancies. Such information may require a post mortem and/or genetic tests to be carried out following a termination.

Improved provision of information

5.7 Information leaflets for a fatal fetal abnormality diagnosis have been drafted to cover scenarios where the woman has chosen to continue the pregnancy, where she can lawfully terminate the pregnancy in this jurisdiction and where she needs to access termination services in another jurisdiction. All of the information sets have core elements including general information on fatal fetal abnormalities, non-

judgemental information on options, care before, during and after pregnancy and information on funeral arrangements and organ donation.

Improved consistency of care

5.8 The PHA has proposed to the Department of Health the establishment of a regional team to help women and their families deal with a diagnosis of fatal fetal abnormality. Obstetric and midwifery care will be provided by the local Trust team, as with any pregnant woman. The new team will aim to provide direct advice and support, signpost and co-ordinate the woman's journey through the various Health and Social Care services, complementing the local obstetric and midwifery care team, and if the woman avails of termination services outside the jurisdiction, aim to re-establish her care with local systems when she returns.

5.9 The proposed model is based on a small team of health professionals located in a geographically central hospital reporting to a midwife consultant. The approach should provide regionally consistent care, support and information. Each woman will be assigned a named care co-ordinator, and the creation of these roles will enable a degree of specialism to be developed, resulting in increased awareness of best practice in the care and support of women where a diagnosis of a fatal fetal abnormality has been made.

5.10 A further proposal was for health professionals to signpost women to certain NHS facilities, not as a formally commissioned HSC service or under any contractual arrangement, but where the NHS facility is aware of, and able to meet, the particularly complex needs of private patients with a fatal fetal abnormality.

5.11 Health professionals envisaged a situation where they did not advocate or promote that a woman should have a termination, but provided advice that, if she ultimately chose to have the procedure privately, that she approach a named hospital in England or Scotland, where the HSC has been advised that that hospital will treat such patients privately.

5.12 Legal advice received by the group has stated that such signposting may not be lawful, and there is uncertainty whether health professionals would risk prosecution. The group will recommend to the PHA that they should not pursue this initiative.

5.13 The transfer of patients for treatment by the Health and Social Care Board (HSCB) is known as an Extra Contractual Referral (ECR) and occurs when the HSCB approves a consultant's request to transfer a patient to a provider in another jurisdiction for assessment or treatment. An ECR is used to secure treatment which the consultant considers necessary but which is not available through the HSC locally. In these circumstances the Board will pay approved treatment costs and fund the cost of travel, accommodation, meals, etc for the patient.

5.14 In the event of the death of a paediatric patient, arrangements will be made to transfer the patient's remains home via the nearest seaport. Additional social work or other support for the families involved will be provided, where this is deemed appropriate, by the HSC Trust. When a parent wishes to travel by commercial scheduled airline either separately or with remains this will also be accommodated.

5.15 The Department has received legal advice that it would be unlawful to procure in another jurisdiction, a service that would not be lawful in this jurisdiction. The denial of the ECR facility, including the repatriation of fetal remains, provides evidence of a further inequality experienced by women who receive a diagnosis of fatal fetal abnormality, who have to travel outside the North for a termination of pregnancy, compared to the services provided to other patients and parents who are referred for treatment under the ECR arrangements.

Providing the best possible care

5.16 Unlike the PHA, the Fatal fetal abnormality Working Group was given a specific mandate to include in its consideration whether legislative change was necessary to ensure the best quality care and support to women with a diagnosis of fatal fetal abnormality.

5.17 As explained in the introductory section, the group was not asked to consider the moral arguments relating to termination of pregnancy. Its remit was to consider the provision of health and social care in cases of fatal fetal abnormality. To that end, it drew upon the work of the PHA, which identified a number of areas where both health and social care professionals and women and their families considered that the care and support available did not meet a standard which could reasonably be expected.

5.18 Extensive consideration was also made of the consultation exercise carried out by the Department of Justice in 2014/15, which gave access to the views of interested parties across the spectrum of opinion.

5.19 It is clear that, through the PHA's proposals, some improvements can be made to the care and support of women with a diagnosis of fatal fetal abnormality. However, the working group concluded that a change to the law is necessary to enable health and social care professionals to best meet the clinical needs of women facing such a diagnosis who do not wish to continue with their pregnancy. This is particularly the case where there are reasons that women cannot continue with the pregnancy to full term due to the adverse effects on their own health and concerns about future pregnancies.

5.20 Although termination of pregnancy in this jurisdiction can be made available under current law in a particular, limited, set of circumstances, the conditions require that it must be necessary to preserve the life of a woman, or there must be a risk of real and serious adverse effect on her physical or mental health, which is either long term or permanent. The current definition of the level and seriousness of risk builds on the words of the judge in the Bourne case, who decreed that if the consequence of the pregnancy was to make the woman a "...physical or mental wreck..." a doctor was entitled to perform a termination.

5.21 The group understands that no-one could contend that the mental distress felt by women in this situation is other than real and serious. However, no matter how traumatic the circumstances and no matter how distraught the woman is, no acute reaction will fall within the current legal framework unless it also has "...long term or permanent..." serious consequences on either physical or mental health.

5.22 The group has therefore concluded that:

- the Department of Health has a general duty, under the Health and Personal Social Services (Northern Ireland) Order 1972, to secure improvement in the physical and mental health of people here and to develop policies to secure that improvement. This is subject to the criminal law as set out earlier which leads to an inability for health professionals to provide appropriate healthcare in all cases to a woman with a diagnosis of fatal fetal abnormality. However,

other patients in population groups for whom Health and Social Care is unable to provide treatment for locally are referred to hospitals outside the jurisdiction are provided with clinical and financial support,

- the evidence from health professionals, and the experiences of women themselves, suggests that the care provided under the current legal framework does not allow the health needs of women to be adequately met. Medical risks arise to the health of the woman for a number of reasons, as set out in the previous chapter;
- the current practice results in inequality of outcomes for women in this particular patient population group when compared to the standards for treatment and care afforded to other pregnant women by Health and Social Care as required by the Department of Health's Maternity Strategy,
- the current situation here for women with a diagnosis of fatal fetal abnormality does not sit easily with the GMC's comments on the recent Montgomery judgement (2015)², where the GMC notes that in good medical practice, the principle that the relationship between a doctor and a patient should be a partnership based on openness, trust and communication is central. Discussing risk with a patient should be part of a dialogue. The key is to understand what matters – or is likely to matter – to the individual patient. In the Montgomery judgment, the Court concluded that a doctor is under a duty not only to make a patient aware of risks involved in any recommended treatment but also of any reasonable alternative or variant treatments. In certain fatal fetal abnormality cases a termination of pregnancy in another jurisdiction might be a reasonable alternative, but our present criminal law constrains the discussion that a doctor may have with a patient about that option and therefore arguably prevents a doctor here from discharging their duty to their patient under the current law.
- compared to the treatment and care afforded to patients under the Extra Contractual Referral process, women with a diagnosis of fatal fetal abnormality who travel outside of this jurisdiction for a termination have to

² <https://www.supremecourt.uk/cases/uksc-2013-0136.html>

navigate their own way to make an informed decision with no regard to their financial circumstances, receive an inequitable service.

- that the Executive should reflect on the view of women affected by the current law who have asked the group if it is reasonable for a compassionate and caring society to continue to uphold a situation where women are either compelled, against their will, to endure a situation not of their making, that risks real and serious adverse effect on their physical or mental health, on the grounds that the serious effects may not be long term or permanent, or alternatively, have to travel, in these distressing circumstances, with no healthcare support, to another jurisdiction to access a termination often in unsuitable environments and with the risk of detrimental outcomes to physical and mental health.

Changing the law

5.23 Current case law interprets the statutory provisions in the 1861 Act to make it lawful to perform a termination of pregnancy in this jurisdiction where:

- it is necessary to preserve the life of a woman; or
- there is a risk of real and serious adverse effect on her physical or mental health, which is either long term or permanent.

5.24 The law therefore does not allow for a termination of pregnancy specifically for cases of fatal fetal abnormality. The Department of Health guidelines on termination of pregnancy, Guidance for Health and Social Care Professionals on Termination of Pregnancy in Northern Ireland, published in March 2016, reflect this fact. The recommendation from the previous Department of Justice consultation proposed that the law would have to provide for a statutory exception, in addition to the existing case law exceptions.

5.25 During the Assembly debate in February 2016, on the Consideration Stage of the Justice Bill, individual MLAs proposed a change to abortion law along the following lines:

A person shall not be guilty of an offence under sections 58 and 59 of the Offences against the Person Act 1861 and sections 25 and 26 of the Criminal

Justice Act (Northern Ireland) 1945 when

- (a) a pregnancy is terminated by a registered medical practitioner where a diagnosis has been made of a foetal abnormality which is likely to prove fatal, and
- (b) the diagnosis was made by two suitably qualified registered medical practitioners who are of the opinion, formed in good faith, that—
 - (i) the condition of the fetus is likely to cause death either before birth, or during birth, or,
 - (ii) if a live birth should occur, there is no medical treatment which could be offered to alter the fatal nature of the condition or improve the chances of survival.

5.26 During the debate, concerns were raised about various aspects of the proposed amendment. It was fully acknowledged by the then Minister of Justice that aspects of the Private Member's draft were in need of further work, and an undertaking was made to bring a revised Departmental sponsored version to the Assembly for further debate at Further Consideration Stage should the amendment be passed. In the event the amendment was defeated on a count of 59 to 40.

5.27 The major issues which were identified as concerns by Assembly members were as follows:

- The test and balance of proof needs to be clearly articulated
- The proposed amendment places the mother's choice as the central and deciding factor, rather than the mental or physical well-being of the mother
- Legislation should be drafted to ensure there is no drift toward the 67 Abortion Act
- There is no such term as fatal fetal abnormality
- Legislation should not allow pregnancies to be terminated solely on the basis of the condition of the fetus.

- There should be a maximum time limit prescribing when a fetus with a fatal abnormality can be legally terminated
- It is wrong that because a child is severely, or likely to be severely, disabled and only have a very short life, it can be aborted. That is saying that a child likely to be severely disabled has fewer rights
- Legislation should stipulate that women must have access to relevant support

5.28 Since then, the working group, as outlined in its terms of reference, and as part of its consideration of cases of fatal fetal abnormality, has revisited the proposed legislative framework for the law on abortion and has considered the concerns raised by MLAs:

The test and balance of proof

The working group considered carefully the terms of a proposed legislative provision. It engaged on the detail of this with the relevant medical professional bodies. The resulting terminology of the proposed legislative provision reflects the opinion of the representatives of the professionals in the appropriate Royal Colleges.

The proposed amendment places the mother's choice as the central and deciding factor, rather than the mental or physical well-being of the mother

The group agreed that it should recommend a provision which, as well as carefully defining the assessment of the fetal abnormality, also made it clear that in these circumstances the health and wellbeing of the woman was also an appropriate factor to be included in the legal framework for termination of pregnancy. This is reflected in the proposals.

Legislation should be drafted to ensure there is no drift toward the 1967 Abortion Act

The group's remit was to look at cases of fatal fetal abnormality and to propose a way to ensure that any legislative change would be confined to providing for termination of pregnancy as an option only for women in these circumstances, and only to meet the objective of providing the best possible

healthcare for women who have received devastating news in their pregnancy that there is a fetal abnormality which will prove fatal. The proposed change will only allow for a termination in these very specific circumstances.

There is no such term as fatal fetal abnormality

There has been much criticism of the use of this term by many bodies and individuals, some with a particular ethical and moral stance on abortion. Many 'pro-life' campaign groups, and others, have chosen to use a different term – babies with 'life limiting conditions' and have argued that there is no medical diagnosis of a fatal fetal abnormality.

In reply, the working group acknowledges the views expressed and the basis of these concerns, but is content, on the strength of the expert professional evidence provided, that the term is sufficiently widely used, both in medical discussion and otherwise, to describe a set of circumstances where a fetal abnormality is assessed as likely to cause death in the womb, during birth or in the early period following birth. It would be totally wrong to equate the term with that of 'babies with life-limiting conditions' which includes a much wider group of medical conditions which would not necessarily result in pre-natal or early post-natal death. The proposed legislative change is restricted to fatal fetal abnormality only and does not extend to circumstances involving wider life-limiting conditions.

The term 'fatal fetal abnormality' has been used throughout this paper to describe a set of circumstances, but, as it is a general term requiring further definition, it will not form part of any legislative proposal.

Legislation should not allow pregnancies to be terminated solely on the basis of the condition of the fetus

The proposal also includes the impact on the health and wellbeing of the woman.

There should be a maximum time limit prescribing when a fetus with a fatal abnormality can be legally terminated

An assessment of the fetal condition is normally carried out at or shortly after 20 weeks gestation. It would be contradictory to insert a viability clause in

relation to a particular gestation period whenever the objective is to allow for a termination once the fetus is assessed as *not being viable*.

It is wrong that because a child is severely, or likely to be severely, disabled and only have a very short life, it can be aborted. That is saying that a child likely to be severely disabled has fewer rights

The working group agrees and fully supports this argument and has no intention of proposing or promoting a change to the law which will affect disabled children. The provision will only offer termination of pregnancy where a clinical assessment of the fetus finds the condition is not survivable following birth.

Legislation should stipulate that women must have access to relevant support

The proposal offers this either in legislation or by guidance.

Options for a legal framework

5.29 Although it must be stated that any legislative provision will be the subject of further detailed instructions to Legislative Counsel, and the way any provision is drafted is a matter for those legal experts, health professionals from the professional bodies all agreed that the following definition would provide a clear and unequivocal legal framework within which they felt that they could work to ensure that terminations were only available where the fetus was destined not to survive:

- that a diagnosis had been made of a fetal abnormality and;
- in relation to such a diagnosis, an assessment must be made by two suitably qualified medical professionals that the abnormality is of such a nature as to be likely to cause death either before birth, during birth or in the early period after birth.
- ‘In the early period after birth’ means those circumstances where life might still be present after birth, but there is no medical treatment which would make the condition survivable and the only option is appropriate, specialised end of life care.

5.30 The group then looked at how this terminology could be used in a number of options for changing the law. These are:

- (a) *retaining the case law based on Bourne and using an abortion bill to make a statutory exception to the existing offences at s.58 and s.59 of the 1861 Offences Against the Person Act for fatal fetal abnormality.*
- (b) *an abortion bill to put on a statutory footing existing case law exceptions to the offences at s.58 and s.59 of the 1861 Offences Against the Person Act, and adding a further exception for fatal fetal abnormality.*
- (c) *an abortion bill to put on a statutory footing a recalibrated interpretation of the threshold used in the Bourne ruling.*

Option (a) retain case law and make statutory exception for fatal fetal abnormality

5.31 This option builds on the recommendation from the earlier consultation by the Department of Justice. The existing case law would continue to provide a defence to the offences in the 1861 Act. The test to be applied would therefore continue to be set by the courts, currently defined by Nicholson LJ in the Court of Appeal judgment in *FPANI* [2004]:

- it is necessary to preserve the life of a woman; or
- there is a risk of real and serious adverse effect on her physical or mental health, which is either long term or permanent.

5.32 This case law clearly does not provide for the option of an abortion solely on the grounds of a diagnosis of a fatal fetal abnormality. There have to be serious, long term or permanent, physical or mental health issues affecting the woman. It is accepted that a change to the law is necessary if a termination is to be legal in circumstances of fatal fetal abnormality where a woman does *not* present with physical or mental health issues which are likely to be long term or permanent, as described above.

5.33 The previous consultation heard evidence of physical problems attached to, for example, anencephalic pregnancies, that, if carried to term, can cause problems for women in future pregnancies. As evidenced earlier, it also recognised that such a

diagnosis and the loss of a wanted pregnancy can be acutely traumatic. However, none of these elements falls within the present Bourne interpretation.

5.34 The DOJ consultation and evidence to the working group also heard that the added difficulties imposed by the lack of termination provision here just serve to heighten the levels of trauma for women who do not wish to carry the pregnancy to term. We have also heard how women in these circumstances resent entirely the implication that they must have severe and long term mental health problems in order to avail of a termination. They have made clear that they fear the stigma that might attach to this 'label', and the possible effect on many other aspects of their lives.

5.35 The proposed legislative framework would therefore add a description of the circumstances involving fetal abnormality under which a medical professional could agree, without fear of criminal sanction, to a woman's request to have a termination. The framework builds on the recommendation in the previous Department of Justice consultation. The core issues would need to include provision for the following circumstances:

- that a diagnosis had been made of a fetal abnormality and;
- in relation to such a diagnosis, an assessment must be made by two suitably qualified medical professionals that the abnormality is of such a nature as to be likely to cause death either before birth, during birth or in the early period after birth.
- 'In the early period after birth' means those circumstances where life might still be present after birth, but there is no medical treatment which would make the condition survivable and the only option is appropriate, specialised end of life care.

5.36 It is also possible to connect the fetal abnormality diagnosis with the impact on the health of the woman, as indeed was the case with the previous proposals from the Department of Justice. However, this should not require the threshold of the current Bourne case law to be met, but instead should recognise that there is an inherent and obvious risk of damage to a woman's health and wellbeing by being expected by law, against her wishes, to carry a pregnancy to term with no prospect of viable life at its conclusion. The provision could therefore contain a proviso that

where a diagnosis has been made of a fetal abnormality, as set out above, it is to be accepted that the continuance of such a pregnancy poses a substantial risk of serious adverse effect on a women's health or wellbeing.

5.37 The provision could also include other statutory safeguards relating to the delivery of health care. For example:

- every woman should be given an opportunity to decide freely whether to terminate the pregnancy or continue to the point of natural delivery;
- where a woman decides to continue with the pregnancy or to terminate the pregnancy she should receive suitable medical care to enable her to do so;
- she should be offered a clinical assessment of the potential impact on her health of either continuing or terminating the pregnancy;
- information should be given on the provision of neonatal and postnatal palliative care in such circumstances;
- the provision could define what is meant by a 'suitably qualified' medical professional.

Alternatively, these issues could be left to guidance.

Option (b) replace case law by statute, including a provision for fatal fetal abnormality

5.38 This option would incorporate into statutory law the current case law exceptions to the offences in the 1861 Act as well as providing grounds for the option of a termination in cases of fetal abnormality. There would be no appreciable difference in the practical outworking of this option compared to the framework at option (a). The benefit would be that the law regarding abortion would be contained in statutory form, rather than governed by both case law and statute, which could lead to unnecessary confusion. It would also place the decision-making power on the law on abortion more directly in the hands of the legislature than as at present with the courts, although doubtless there will always remain scope for challenge on definitions arising from such a controversial subject. It would provide better certainty

for clinicians who have to make difficult decisions under the current case law. It might also address concerns about wider application of the law to cases outside of fatal fetal abnormality by ensuring that appropriate definitions and terminology have all been agreed by the legislature and set in statute.

5.39 The proposed legal framework under this option would offer that:

- A person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical professional if two registered medical professionals are of the opinion, that:
 - (i) it is necessary to preserve the life of a woman or there is a risk of real and serious adverse effect on her physical or mental health, which is either long term or permanent; or
 - (ii) a diagnosis had been made of a fetal abnormality and the abnormality is of such a nature as to be likely to cause death either before birth, during birth or, in the event of life at birth, no medical treatment which would make the condition survivable could be offered, other than appropriate specialised end of life care.

Where such a diagnosis has been made it is to be accepted that the continuance of such a pregnancy poses a substantial risk of serious adverse effect on a women's health or wellbeing.

Option (c) replace case law by statute, revisiting the Bourne interpretation

5.40 There is probably some merit in taking the opportunity to examine the current case law interpretation and its history with a view to considering whether, if option (b) was the preferred route, it might be worth seeking to revisit the current interpretation of the original Bourne ruling.

5.41 To make a change to the Bourne case law and put it in statute would be acceptable within the construct of the 1861 offences. The important word in this regard in both s.58 and s.59 is '*unlawfully*': to '*unlawfully*' administer or '*unlawfully*' use any instrument to cause a miscarriage. This word provides the scope to retain

these offences as the basis for abortion law and for case law to interpret, or indeed allow for a statutory defence, as to when it is 'lawful' to terminate a pregnancy. In the Bourne case, the judge used the provision in the 1929 Infant Life Preservation Act to define when abortion would be lawful under the 1861 Act. So it became lawful, through this court ruling, to terminate a pregnancy where it was done to 'preserve the life of the mother' and 'preserving the life of the mother' was also determined to incorporate where the pregnancy was liable to make the woman 'a physical or mental wreck'.

5.42 This definition dictated policy and law on abortion in the UK until the 1967 Act changed things for England, Wales and Scotland. In this jurisdiction, the case law continued to define the framework for termination of pregnancy. This meant that medical professionals were themselves tasked with interpreting what a 'physical or mental wreck' might mean.

5.43 However, in 1994, in Northern Health and Social Services Board v A & Ors [1994] NIJB 1, MacDermott LJ considered the meaning of the phrase "for the purpose only of preserving the life of the mother" in s 25(1) of the 1945 Act and commented that:

"... 'for the purpose only of preserving the life of the mother' does not relate only to some life-threatening situation. Life in this context means the physical and mental health or well-being of the mother and the doctor's act is lawful where the continuance of the pregnancy would adversely affect the mental or physical health of the mother. The adverse effect must however be a real and serious one and it will always be a question of fact and degree whether the perceived effect of non-termination is sufficiently grave to warrant terminating the unborn child" (para 5).

5.44 This interpretation went on to be further refined in 2004 when Nicholson LJ ruled that being a 'physical or mental wreck' equated to there being a risk of real and serious adverse effect on a woman's physical or mental health which is either '**long term or permanent**'. This was upheld by Girvan LJ in his judgment in SPUC [2009].

5.45 Given the historical emphasis on the woman's health as the primary indicator for a termination, it may be that there is scope to consider whether the current threshold, as outlined in the previous paragraph, is pitched at too high a level to ensure that women do not suffer very negative consequences, illustrated by circumstances such as a diagnosis of a serious fetal abnormality leading to fatality.

5.46 For example, is it possible for anyone to say with any degree of certainty how long a woman will undergo mental suffering as a result of, say, having to carry a pregnancy to term with no prospect of life at the end? Is the fact that a woman decides that to do so is 'too much for her to bear' (RCOG response to DOJ consultation) and seeks an abortion elsewhere not an indication that in those cases the degree of suffering is too great for her to contemplate and therefore should be within the scope of the law to alleviate that suffering?

5.47 During the hearing of the appeal against the ruling in the NIHRC case, the Lord Chief Justice made reference, in relation to Article 3 of the Convention, to the possibility of 'revisiting' the Bourne interpretation and 'recalibrating' the Bourne test. This was in the context of discussion on the likelihood of the threshold emanating from Bourne (by virtue of the Nicholson LJ ruling in the CA judgment in FPANI [2004]), which requires the effect on the woman's health to be 'long term or permanent', breaching the Article 3 threshold by ignoring shorter 'acute' periods of trauma which might amount to inhuman treatment within the meaning of Article 3.

5.48 Although this discussion gives no indication of how the Court of Appeal might ultimately rule on this issue (which it may not address at all), it nevertheless illustrates that there is scope for a further interpretation of the Bourne test given the high threshold set by the Nicholson formulation and the need to consider these matters through the lens of Article 3 ECHR.

5.49 As a result, this option would seek to alter the legislative framework along the following lines:

- A person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical professional if two registered medical professionals are of the opinion that:

- (i) it is necessary to preserve the life of a woman; or
- (ii) there is a risk of real and serious adverse effect on her physical or mental health or wellbeing.

5.50 If this option were followed, it is then much less clear whether a separate provision would be needed specifically to address cases of fatal fetal abnormality. In options (a) and (b) above, the proposal suggests that it is to be accepted that the continuance of such a pregnancy poses a substantial risk of serious adverse effect on a women's health or wellbeing, or that the continuance of the pregnancy would be likely to have a serious detrimental effect on the health and wellbeing of the woman. If the statute were to incorporate, for all circumstances, a revised interpretation of the Bourne definition, then the law would allow for abortion in all cases (including sexual crime) where a woman's health and wellbeing were affected in a real and serious adverse way, including cases of fatal fetal abnormality.

Conclusions on changing the law

5.51 The working group concluded that possible improvements to health care provision under the existing legal framework for cases of fatal fetal abnormality were to be welcomed, but that evidence, both to the previous DOJ consultation and directly to either the PHA or the FFA working group, as set out earlier in this paper, from women affected by fatal fetal abnormality and from health professionals, strongly suggested that there was a fundamental need to adjust abortion law. In summary, health professionals said that retaining the status quo would continue to place an unacceptable burden on women's health and wellbeing. Health professionals felt that they were unable to fully meet the duty of care to their patients when an individual asked for their pregnancy to be terminated in circumstances where no viable life could ensue.

5.52 Although improvements can be made to lessen the impact of the journey to England and attempts made to ensure that a termination can be accessed in an NHS hospital, rather than a private clinic, there is still nothing to alleviate the trauma for the woman of travelling away from home and family at such a difficult time, the loss of her dedicated medical team and the financial cost. There are also professional

issues of concern in relation to the after care of women who have undergone a termination elsewhere.

5.53 In looking at the proposals to improve the care of women who wish to access a termination elsewhere, the FFA working group also considered whether it might be regarded as disproportionate and inequitable for the state to make such efforts to alleviate the burden on women of travelling to another jurisdiction to have an abortion, in effect facilitating what would be the commission of a crime in this jurisdiction, yet not being prepared to adjust the law to provide the procedure here.

5.54 However, one of the most compelling cases for change was the overall recognition by those health professionals and representatives of professional bodies who spoke to the group that to continue to operate under the existing legal framework prevents them from fully meeting their duty of care to women in this situation and therefore denies those women access to proper standards of health care. In summary, they considered the current situation as untenable.

5.55 Three proposals for changing the law have been considered by the working group, as outlined earlier. The first, option (a), makes a statutory exception to the criminal law on abortion (i.e. to sections 58 and 59 of the Offences Against the Person Act 1861) for cases of fatal fetal abnormality. The second, option (b), would do the same, but would also include provision in the statute to except cases currently covered by case law – where the woman's life is at risk, including where there is risk of serious adverse effect on her health which is either long term or permanent. The third, option (c), looks at the current court-based interpretation of what is deemed 'lawful' under the Bourne ruling and suggests that there might be merit in considering reducing the threshold put in place under previous court decisions by removing the 'long-term and permanent' aspect of risk to the woman's health. This would mean that the legal threshold for termination of pregnancy in all cases would be either where it is necessary to preserve the life of a woman; or where there is a risk of real and serious adverse effect on her physical or mental health or wellbeing.

5.56 If this adjustment to the current Bourne threshold was the preferred option, it might possibly remove the need for any specific mention of fatal fetal abnormality, as there is no doubt that women facing such a diagnosis would suffer real and serious consequences on their health and wellbeing. Or, for the avoidance of doubt, the

provision could include a similar rider to that in the other options, namely that it is to be accepted that the continuance of such a pregnancy poses a substantial risk of serious adverse effect on a women's health or wellbeing.

5.57 Having considered the above options and its remit and terms of reference, the working group concludes that option (a) would meet the requirement to allow for health professionals to fully meet their duty of care to women who have been diagnosed with a fatal fetal abnormality and where to continue with the pregnancy would have a serious effect on their health or wellbeing.

5.58 However, the group also recognises that there may be merit in choosing option (b) which would bring all exceptions to current abortion law within the one statutory instrument.

5.59 Option (c), whilst offering a full explanation and useful itinerary of how current case law came about, might possibly remove any need to legislate specifically for fatal fetal abnormality, and may be seen as exceeding the group's terms of reference.

ANNEXES

TERMS OF REFERENCE

The group's objective will be:

- To consider issues relating to cases of fatal fetal abnormality, including matters addressed in the previous consultation by the Department of Justice, and provide a report to the DOH and DOJ Ministers, making recommendations, including on potential legislative change for termination of pregnancy as necessary. The DOH and DOJ Ministers will, in turn, submit proposals to the Executive for approval.

Actions will include:

- Identifying how best to engage with, and obtain input from, women who have experienced fatal fetal abnormality and the health and social care professionals who have treated them;
- Scoping the current health and social care provision for women in Northern Ireland who have had to deal or are dealing with a diagnosis of fatal fetal abnormality;
- Identifying any gaps in provision and how they can be closed;
- Engaging with appropriate Royal Colleges and other relevant organisations that the Group considers can contribute to its work; and
- Determining how clinical practice and medical capability can best be reflected by appropriate terminology and definitions which would offer legislative clarity for any change to the law on abortion.

MEMBERSHIP

The membership of the group is as follows:

- **Chief Medical Officer, Michael McBride (Chair);**
- **Chief Nursing Officer, Charlotte McArdle;**
- **Chief Social Services Officer, Seán Holland;**
- **DOH Secondary Care Directorate, Jackie Johnston;**
- **Departmental Solicitor's Office, Hugh Widdis;**
- **Department of Justice, Brian Grzymek and Amanda Patterson.**

ENGAGEMENT

The group met with:

**Northern Ireland Committee of the Royal College of Obstetricians
and Gynaecologists**

Royal College of Midwives

Royal College of Psychiatrists

Royal College of General Practitioners

Public Health Agency

Three women who had experience of fatal fetal abnormality