



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Severe Fetal Impairment Abortion (Amendment) Bill:
Abortion Rights Campaign;
Doctors for Choice Northern Ireland;
Women's Policy Group Northern Ireland

24 June 2021

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Members present for all or part of the proceedings:

Mr Colm Gildernew (Chairperson)
Mr Gordon Lyons (Deputy Chairperson)
Ms Paula Bradshaw
Mr Jonathan Buckley
Mr Gerry Carroll
Mr Alan Chambers
Ms Órlaithí Flynn
Ms Cara Hunter
Ms Carál Ní Chuilín

Witnesses:

Ms Helen Stonehouse	Abortion Rights Campaign
Dr Alyson Hunter	Doctors for Choice Northern Ireland
Ms Danielle Roberts	Women's Policy Group Northern Ireland

The Chairperson (Mr Gildernew): I welcome Dr Alyson Hunter, who is a consultant obstetrician with Doctors for Choice. Can you hear me, Dr Hunter?

Dr Alyson Hunter (Doctors for Choice Northern Ireland): Yes, thank you, Colm. Can you hear me?

The Chairperson (Mr Gildernew): Yes, we are hearing you. It is a little faint, Alyson, so, if you could increase the volume, it would do no harm, but I can hear you OK. We also have Helen Stonehouse, who is co-convenor with Abortion Rights Campaign. Can you hear me OK, Helen?

Ms Helen Stonehouse (Abortion Rights Campaign): Yes, I can, thank you. Can you hear me?

The Chairperson (Mr Gildernew): Yes, I am hearing you fine, Helen. Thank you. I also welcome Ms Danielle Roberts, who is policy officer with the Women's Policy Group. Are you hearing us OK, Danielle?

Ms Danielle Roberts (Women's Policy Group Northern Ireland): Yes, Chair. Can you hear me?

The Chairperson (Mr Gildernew): Yes, I can hear you, Danielle. Thank you all for attending and for providing the Committee with your evidence this morning. Dr Hunter, I will go back to you in the first instance, and I will ask each of you to give a brief presentation. We will then move to questions from members. Alyson, can you go ahead and start off with your presentation, please?

Dr A Hunter: Yes, I hope that you can hear me. If you need me to talk louder, let me know. Doctors for Choice is, as you will see from your briefing, a group of doctors, not only including obstetricians. I am also a consultant in fetal medicine in the Belfast Trust. The group includes obstetricians, gynaecologists, GPs and anaesthetists. It is a mixed bunch. We all have the opinion that women should have the highest quality of sexual and reproductive healthcare in Northern Ireland and that that should start with good sex education, easily available contraception for all and, if required, high-quality abortion services. Our main word is "choice". We believe that women must have choice and autonomy, as was said before by Alliance for Choice, regarding their own bodies and their health. My personal opinion and the opinions of the doctors in our group is that we are here, as doctors, to help women and families and are not here to judge them. We want to help them.

I am a fetal medicine consultant, and I know that you got a thorough briefing last week from Carolyn Bailie and John Manderson. I will try not to go over any of the points that they went through. This area involves very long training and is an emotive area. As you can imagine, it is not a popular area to go into. There are a lot of ethical issues and a high burnout rate, and we have to train longer. Practising in fetal medicine Northern Ireland has been particularly difficult in the past 10 to 12 years. Abortion is part of our work in fetal medicine but not the main part. We look after people with multiple pregnancies, other abnormalities, growth issues, prematurity issues and other complex maternal illness in pregnancy. Fetal abnormality and abortion and being able to offer women abortion is a very important part of our work, and we want to be able to give women choice because it has been incredibly difficult not to offer women with a diagnosis of a fetal abnormality this option.

I will try to give you an example of what it is like for me seeing a woman who has a severe abnormality. When we see her, we scan her in a room, we go through all of the findings with her and we take her over to what I call the little pink sitting room. Some of the women over the years who will have written to the Health Committee will have had to face me or one of the other consultants in what will be a life-changing moment for them. We are talking, particularly with regard to the Bill, about fatal or extremely serious and severe abnormality after 24 weeks not, for example, the diagnosis of uncomplicated Down's syndrome. That abnormality will massively affect the child, the woman and the woman's relationship with her partner and her family. Women are brought to that room and, as you can imagine, tears flow. Over the years, some women have said to us, "This is so bad that I do not want to carry on with the pregnancy". Even at that early stage, they might say, for whatever reason, "I just cannot see myself going on". Can you imagine how horrendous it is when we tell them, or have told them in the past, that they must carry on with their pregnancy?

The grief that has been added to by that lack of choice over the years has been horrendous, as has the guilt that is put on top of women. Women feel guilty anyway. The first thing that we try to say to women is, "It is not your fault", because women will say, "This fetal abnormality is my fault. It is something to do with me or something that I have done". Very often, it is not their fault, but they feel such guilt. To make that guilt worse by saying, "And, by the way, in Northern Ireland, you cannot access abortion. You must carry on with the pregnancy, or you will have to travel" is horrendously awful. Not only do we have the sadness; we also have the anger. That anger is often felt by their partners, who think about how the poor woman will have to carry on with the pregnancy, and they think about how that will affect their life.

Let me give you some examples from the past couple of years. One woman had two children with really severe autism. She and her husband had to give up work to look after the children. She got pregnant unexpectedly at the age of 41 and was diagnosed with abnormalities at her ultrasound scan at 20 weeks. I saw her about 10 days later and carried out an amniocentesis. The child had Down's syndrome. When I called her with the result, all I could hear was screaming in the background: the constant sound from her daughter with autism, with which the woman had to live, day in and day out. She was, of course, devastated. She and her partner said that, when they had found out about the pregnancy, they had been so excited and so hopeful that this child might be well, because the child might look after their other children when she and her partner passed away. You can imagine how devastated they were to find out that diagnosis. Can you imagine how much more devastated they were when they found out that they were not allowed to have an abortion in Northern Ireland because she did not meet the criteria? That woman could not carry on with her pregnancy, because of the terrible burden that she already had with her children at home. She had to travel to England alone while her husband looked after the children at home. That was extremely difficult for her, and she told me that, when she was there, she thought of taking her life. After she came back, we had to arrange, through her GP, for her to have a lot of counselling. She did not want to have an abortion, but she just could not go ahead with the pregnancy.

People say that they are anti-abortion, but every woman is an individual, and all of us have our problems and circumstances. A diagnosis of a life-limiting or fatal abnormality has huge implications for many people, and abortion will probably be their only option. For us, in Northern Ireland, to wash our hands of those people and say, "No, we cannot do that here" is just wrong. From a legal and human rights perspective, we know that it is wrong. As a doctor who looks after those women, I tell you that it is totally and utterly wrong. That woman should have been looked after. I should have looked after her. In hospital, I should have been able to care for her as she went through her abortion and afterwards. It was absolutely devastating for her, and I felt so bad, as a doctor, to have to do that.

I can give other examples. There was another lady, whose first baby died in utero at 26 weeks —.

The Chairperson (Mr Gildernew): Be very brief, please, Alyson. We are pressed for time.

Dr A Hunter: Sorry.

That lady was forced to go to England when her second child had a serious brain abnormality; it would have had no quality of life. After diagnosis from an MRI at 24 weeks and counselling, she went to England.

People change their mind when this happens to them. I have had people come to me saying that they would never consider an abortion, but, when they go home and think about it, they consider that they could not go ahead with the pregnancy, and vice versa. Other people think that they would not have a baby with an abnormality, but, when it happens to them, they cannot go ahead with an abortion.

So let us try to give some empathy and sympathy to these women. People will get an abortion. If we refuse it, they will travel or perform one illegally. Some of these women cannot travel because of restrictions such as COVID. Who knows what is in the future? Others are restricted by children, home issues, illness, their own illness — they may be too unwell to travel during pregnancy — or refugee status. These women will find a way to have an abortion, and that may be through buying pills over the internet and having very unsafe abortions at home. Those pills are safe early in pregnancy, but, later, at 20 or 24 weeks-plus, they can be very serious indeed.

All I ask, on behalf of Doctors for Choice, and for the women I look after and their families, is, please, can you MLAs refuse to pass this Bill and show your sympathy with each woman as she goes through this terrible time in her life? Thank you.

The Chairperson (Mr Gildernew): Thank you, Alyson. Helen, can you go ahead with your presentation please?

Ms Stonehouse: I thank you all for having me here today. I am from the Abortion Rights Campaign. We campaign primarily in the Republic of Ireland, and I want to speak about the experiences in the Republic of Ireland today.

It has been nearly three years since abortion was legalised in certain circumstances in the Republic of Ireland. Under section 11 of our Health (Regulation of Termination of Pregnancy) Act, abortion is permitted for fetal diagnosis:

"that is likely to lead to the death of a foetus either before, or within 28 days of, birth."

This means that our current abortion legislation is, therefore, very similar to what is being proposed under the Severe Fetal Impairment Bill, in that abortion for fetal indication is only permitted where it is considered fatal.

Before this legislation was passed, activists and doctors repeatedly emphasised that this overly-prescriptive legislation, which restricts access in this way, would force discussions of fatal anomalies into this binary situation, which does not reflect the complex reality of risk and probability that are involved in such pregnancies, as Alyson has already said.

That has been reflected in the experiences of those facing complex fetal diagnoses in Ireland. In 2019, 100 people accessed abortion in the Republic of Ireland in the case of fetal abnormalities under section 11. However, according to NHS statistics, in 2019, 63 residents of the Republic travelled to England and Wales to access abortion under ground E of the Abortion Act, and in 2020, a further 64 people travelled to England for abortion under ground E.

That means that, for every three people who are obtaining an abortion for fetal indication in Ireland, two are still forced to travel to England. An unknown number may have gone to other countries. In many cases, there is only a very limited chance of survival of the fetus, yet they are still denied care in their home jurisdiction.

A group called Termination for Medical Reasons (TFMR) supports people who receive complex prenatal diagnoses, and they say that, of those who came to them for support in 2020, 85% had to travel to England, after being informed that their condition was "not fatal enough".

One of the women supported by TFMR explained the severity of this condition, which was considered not fatal enough: "cloacal exstrophy" — I apologise for the pronunciation —

"is what our baby had, which means that all the organs were outside of the body, stomach, liver, spleen, intestines, bladder which in turn is connected to the colon, no anus, no reproductive organs and spine split in two. We were told that there was little hope that he would survive a birth but that, if he did, he might survive longer than 28 days, and therefore we were told that 'You have options in the UK, but our hands are tied here.'"

The inability of medical professionals to provide care due to the restrictive legislation, causes, as I am sure you can imagine, significant distress to patients and providers. Parents talk about being told that they have to travel because their condition is "not fatal enough", or because it does not tick the correct legal boxes. Doctors have stated that there are certain pregnancies that should have the option of termination of pregnancy that our legislation cannot facilitate. There is a whole portion of ostracised anomalies that are not fatal but are still really not OK. Because doctors face criminal penalties for provision outside of the legislation, they are very overly cautious in their interpretation. So, if there is the odd instance of a fetus or baby having survived more than 28 days, then doctors are being told that they should not be doing this, at risk of criminal prosecution.

This chilling effect is really essential, and you cannot underestimate it. In some cases, this lack of clarity over what is legal and what is not means that care can be refused in one hospital but available in another. One woman explained that her experience was extremely traumatic:

"I had a scan in Cork, diagnosed as a possible thanatophoric dysplasia, the consultant said 'No consultant in the country will touch you.' We left thinking that we would have to travel to the UK in a panic. I was already 21 weeks. We made calls, and I had consultations in the UK clinics. No one would take us due to the pandemic. We had to take COVID tests to fly. I made a will to take care of my other daughter in case I died because of the possibility of complications as well as the possibility of getting COVID. One abortion clinic in the UK refused to take me in case of rupture with an anterior placenta."

Thankfully, that woman was referred to a different hospital in Limerick and was able to get the care that she needed because it was legally available. The complication around the clarity of what that meant resulted in her being put through a significant amount of trauma and having to travel halfway through the country and make all of those additional plans. As has been covered by Alliance for Choice, the need to travel for abortion care perpetuates that stigma and harm at an already really difficult time.

The trauma of ending a wanted pregnancy is complicated by difficulties in arranging funerals and the repatriation of remains. One woman said:

"We never got to bring our baby home, not even as ashes. It haunts me to this day and forever will that we had to leave our baby behind."

The Bill would place medical professionals in Northern Ireland in a very similar situation to those in the Republic of Ireland, where diagnosing which anomalies are eligible for abortion is a question of trying to interpret the law rather than the medical science. That means that they have to focus on the interpretation of law rather than focus on providing care and information to the patients. Research from 2017 shows that the legal context in which a diagnosis occurs has a significant impact on the nature of the clinical advice and care that is given, which, in turn, affects the rights and choices available to a pregnant person at a vulnerable time; basically, if doctors are overly focused on whether something is permissible, that will change the advice that they give because they are constrained by the context. That is not because doctors are necessarily trying to pressure people one way or the other; it is because they are concerned about that legal issue.

I am sure that we all agree that it is essential that people receiving a prenatal diagnosis are given evidence-based and unbiased information and support about what continuing or ending a pregnancy might mean for their individual situation.

There is no human rights-compliant way in which to restrict abortion to only fatal fetal diagnoses due to the difficulties in defining what "fatal" means and the impact of that difficulty on diagnostic processes. The Republic of Ireland has been repeatedly criticised by international human rights bodies for failing to provide abortion care, including in cases of prenatal diagnosis. In the cases of Amanda Mellet and Siobhán Whelan, which were taken to the United Nations Human Rights Committee, Ireland was found to have subjected those women to cruel, inhuman and degrading treatment, to discrimination, and to an arbitrary interference with their right to privacy by forcing them to travel overseas for abortion care. Those cases demonstrate that permitting travel to another jurisdiction is not sufficient to meet the human rights obligations that have led to the introduction of abortion legislation in Northern Ireland.

It is also worth noting that there are still cases in the Republic of Ireland of people travelling after a diagnosis of holoprosencephaly, which is the same diagnosis that Ms Whelan received, under our legislation, which permits care for only fatal abnormalities. To give one more example, in December 2020, a young couple from Dublin, despite being told that their baby was unlikely to survive birth and that any short time that he did survive would be spent struggling to breathe, were unable to access a compassionate induction of labour to end the pregnancy. Despite the diagnosis of holoprosencephaly, which was the same as Ms Whelan, they were told, "That isn't something we facilitate here" and had to travel abroad. They organised flights, accommodation, COVID tests, hospital care and a funeral for their baby, all the while worrying that London might go into lockdown before they could bring him home. Their story and far too many others are the legacy of Ireland's restrictive abortion legislation. The Bill would lead to more heartbreaking stories in Northern Ireland for those facing complex pregnancies who are forced to travel in violation of human rights and decency.

Restrictions on reproductive rights do not improve the rights of disabled people. Restrictions on abortion reduce the reproductive rights and freedoms of disabled people, who often face additional barriers in accessing abortion care, particularly if they are forced to travel. In a joint statement, the United Nations Committee on the Elimination of Discrimination against Women (CEDAW) and the Committee on the Rights of Persons with Disabilities (CRPD) said:

"access to safe and legal abortion, as well as related services and information are essential aspects of women's reproductive health ... a prerequisite for safeguarding women's human rights",

They also argue that:

"States must take effective measures to enable women, including women with disabilities, to make autonomous decisions about their sexual and reproductive health".

In order to respect the autonomy of all pregnant people, including disabled people, we argue that it is imperative that the Bill is not brought in to law. No one should have to continue a pregnancy against their will or travel to another jurisdiction for healthcare that should be provided at home.

The Chairperson (Mr Gildernew): Thank you, Helen. We will go to Danielle for the final presentation.

Ms Roberts: Thank you, Chair. I am here today as a representative of the Women's Policy Group. I am one of the co-authors of the collective evidence submission. *[Inaudible owing to poor sound quality]* a group of women who work in health and advocacy roles in different organisations.

The Women's Policy Group wholly disagrees with the Bill in the question. It violates the human rights of women, girls and pregnant people, as was highlighted comprehensively throughout our evidence submission, and I draw the Committee's attention to section 6 in particular, which contains personal testimonies. The Bill would lead to women and pregnant people being rushed to terminate pregnancies before 24 weeks, which removes the time needed for diagnosis, diagnostic tests and specialist advice that is often needed, or being forced to join the 10 a week who already travel to England to access abortion care.

The Women's Policy Group is greatly concerned at how the Bill disregards existing medical evidence on this matter and how it would increase the legal and political scrutiny on abortions for fetal impairments. That would have an extremely negative impact on the ability of medical professionals to

do their jobs, while also limiting the support provided to families facing the diagnosis of severe fetal impairment.

If severe fetal impairment is removed as a submitted reason for abortion, medical professionals in Northern Ireland will be operating in a climate in which they risk criminalisation as they decide whether conditions satisfy the fatal requirement rather than the severe. The Committee has already received presentations on the human rights incompatibility of the Bill, as well as the *[Inaudible owing to poor sound quality]* accompanying the Bill, which outlines the human rights implications.

The Women's Policy Group would particularly highlight the CEDAW recommendations, now incorporated into primary legislation *[Inaudible owing to poor sound quality]* provisions adopted in legislation *[Inaudible owing to poor sound quality]* on the grounds *[Inaudible owing to poor sound quality]* abortion access in two areas for severe fatal impairment, including fatal fetal abnormality, without perpetuating stereotypes towards persons with disabilities and ensuring appropriate and ongoing support, social and financial, for women who decide to carry such pregnancies to term. That is the law that we should have in place now.

It is essential to note that the Committee on the UN Convention on the Rights of People with Disabilities, along with CEDAW, has emphasised that using disability rights as an argument to oppose safe abortion is a misinterpretation of the Convention on the Rights of Persons with Disabilities. Specifically, it stated:

"States parties should fulfill [sic] their obligations under articles 5 and 8 of CEDAW and CRPD ... respectively by addressing the root causes of discrimination against women and persons with disabilities. This includes challenging discriminatory attitudes and fostering respect for the rights and dignity of persons with disabilities, in particular women with disabilities, as well as providing support to parents of children with disabilities in this regard. Health policies and abortion laws that perpetuate deep-rooted stereotypes and stigma undermine women's reproductive autonomy and choice, and they should be repealed because they are discriminatory."

The Women's Policy Group has advocated for many actions to be taken by the Executive to advance the rights of disabled women and disabled people more generally. It would suggest that the Committee should focus instead on the impact of welfare reform and austerity on the health and well-being of disabled people in Northern Ireland, rather than further disrupting the rights of women, which have yet to be implemented *[Inaudible owing to poor sound quality.]* We need to reform how society treats disability in order to support families with disabled children, rather than focusing on *[Inaudible owing to poor sound quality]* medical models and authority that makes it extremely difficult to support disabled children.

Restricting abortions for severe fetal impairment would negatively impact disabled women. Disabled women are also autonomous people, who need access to reproductive healthcare and face greater barriers than non-disabled women face in accessing it.

The Women's Policy Group hopes that the Bill does not proceed for all the reasons outlined in its written submission. Abortion has been decriminalised in Northern Ireland, yet the abortion framework and regulations have still not been commissioned. Despite this, more work has been done publicly in the Northern Ireland Assembly to further restrict abortion access that has not yet been made available.

The Chairperson (Mr Gildernew): OK. Thank you, Danielle. I have just one question, and I will then go to members.

Danielle, in the early part of your presentation, you made the point that the Bill ignores:

"existing medical evidence on this matter".

Could you elaborate a little on what you mean by that?

Ms Roberts: Alyson might be better able to answer that than me, but I think that the point is made in our written submission that there is no clear-cut definition of "severe fetal impairment" or "fatal fetal impairment". If you restrict it to fatal fetal abnormality, the example that Helen gave is exactly what will happen in Northern Ireland. Medical best practice is what we should look at, not words in legislation.

The Chairperson (Mr Gildernew): OK. Thank you. Alyson, do you want to contribute to that answer?

Dr A Hunter: That has been a real issue in the South, and Danielle mentioned it. In the South of Ireland, they make a distinct determination between fatal and severe impairments or abnormalities. It is very difficult. We find that very difficult. For example, there is a condition called trisomy-18, which is an ultimately lethal abnormality. Some fetuses will die in utero. There have been some cases where the child has survived to the age of 2. The majority will die shortly after birth. If you say "fatal", it is very narrowing; we should be thinking of "severe disability" or "limited life".

Gordon asked earlier whether the witnesses agree with termination after 24 weeks in cases of Down's syndrome. In the guidance that we have in the Royal College of Obstetricians and Gynaecologists (RCOG) and our Fetal Medicine Foundation, it is clear that, for a termination after 24 weeks, the fetus has to have a very severe disability or there has to be a life-limiting consequence. Down's syndrome, per se, would not meet the criteria. In a multidisciplinary team (MDT), Down's syndrome with no abnormality would not meet the criteria. However, you can have a baby with Down's syndrome who also has a very severe brain abnormality or a potentially life-limiting cardiac condition. Each case can be very complicated and individual. As health professionals, we want to give as much information to these women as possible. You are absolutely right to say that a Bill that tries to extremely limit women's choices is detrimental. Imposing a strict time limit before you find out as much information as possible is not helpful and extremely unfair.

I want to mention another case. The woman was past 24 weeks. She had an MRI of the brain, which showed that there was going to be a severely life-limiting/fatal abnormality. Again, there was nothing that we could do for that woman. She had to go to England to terminate her pregnancy. Again, she was suicidal in her time there.

We need to have trust. I want to express to MLAs that it upsets me when I hear some of the things that have been said this morning. People like me have put our lives into trying to deliver high-quality care for women who are in a terrible period of their lives. Some MLAs' lack of trust in the medical profession is apparent. It is really quite abhorrent actually, and I find it hard not to take it personally. It is not about me personally; it is about women. However, if you are attacking us, you are attacking the women, their choice and their lives.

The Chairperson (Mr Gildernew): OK. Thank you. I will go to members for questions. I ask all members and the panel to be conscious that we are dealing with very sensitive and very complex issues that people have faced, and continue to face, in their real lives. We should reflect that in how we engage during this evidence session. I also ask members to be conscious of time. I want to be fair to all members and give everyone an equal amount of time within the bounds of the session. In general, all remarks — questions and responses — should be directed through the Chair. I appreciate members' and the panel's adherence to that sensitivity.

Ms C Hunter: Thank you very much, Chair. I am mindful of time, so I will try to be brief. I thank the panel for being here. Alyson, Helen and Danielle, thank you for your contributions. My question is for Alyson. Hypothetically, if the Bill were to pass, how would that change the advice and support that you can give to a woman who presents after the 24-week mark and the fetus has a severe impairment? What would that look like? I am trying to grasp that, so your answer will be helpful.

Dr A Hunter: Thank you, Cara. If it becomes impossible to offer women termination after 24 weeks, we can still try to find out as much as we can for a woman in Northern Ireland at that time. We can still try to convene our MDT and get information for her. That is what we do with these complex abnormalities. We have MDTs where we discuss with fetal cardiologists, paediatricians, neonatologists, geneticists and a whole range of people how to get as much information for those women as possible.

If abortion is not possible for the woman in Northern Ireland and she wishes to proceed with that — again, many women will decide to carry on with the pregnancy, and we can look after those women — the only option for her is to travel to mainland Great Britain and seek a termination there, which, for the all reasons that I have said, is wrong. I know that you have heard a lot of reasons from other fetal medicine consultants and others about why that would be particularly difficult for women. A woman may find travel very difficult. Some women may not be able to travel because, for example, they are unwell. A woman may develop obstetric complications from some of the severe fetal abnormalities. Severe early onset pre-eclampsia, for example, could mean that they have a seizure and die. We could not send those women away. Such things are rare — a later termination is, in itself, rare — but they are a reality.

What will we do with a woman in that situation? What will we be able to do to help her? She will probably have to carry on until the pre-eclampsia becomes so severe that she needs to be delivered. At that stage, the child may survive for a while, and the woman and her family will have to go through that. She may have severe problems coping with that, when her choice would have been to have a termination. That is what we are looking at. Either she will be forced to travel if she wishes to go ahead with an abortion, or, if she cannot travel, she will be forced to carry on with a pregnancy that she does not want to go on with. Either way, it is not a good situation for the woman to be in.

Ms C Hunter: Thank you, Alyson. That was a very detailed answer.

Mr Carroll: Thanks, panel. I have two questions, which might both be for Alyson, so apologies to the other panellists. Alyson, you touched on — how would you say it? — the opposition to the work that you and others carry out and the fact that it is hard not to take that personally. I do not doubt that that is a reality for you. What would you say to the presumption and misinformation that abortion is, essentially, forced and that women are pressured into making a decision about a termination, generally speaking and specifically under the regulations that exist at the minute? On the disinformation and untruth that women are pressured to have a termination solely because of a cleft palate or a club foot diagnosis, how does that make you feel?

My final question is more general, but it is connected to the Bill. As doctors and people in the medical field, how does it make you feel that women cannot get access to services, such as telemedicine and others, in their hospitals and from GPs here, and that abortion, which is essentially a form of healthcare across the world, is treated very differently? As medical practitioners and people who are invested in medical practice, how does that make you feel? Those are my questions. Thanks for presenting this morning.

Dr A Hunter: Thank you, Gerry. I think that MLAs and politicians will know better than anybody that, when you say something, there are many ways in which people may misconstrue that. On the earlier point, women may report in a conversation with counselling that they were forced. That is their perception, and it is their right to have that perception. If the woman is concerned enough that she wants to launch an investigation, she should have the right to be able to launch that investigation against the health professional, and we should be able to find evidence. If there is evidence that a clinician forced their opinion or was trying to force an abortion, they will be in very serious trouble, because we have standards that we have to adhere to, one of which is not to put our personal preferences on to the healthcare that we provide to people. That is unfortunate, but I understand that it happens. It has happened to all of us: people have taken things that we have said the wrong way. There is protection for the public, from that point of view. Abortion should not be forced on anybody. Even though I believe in them, it is absolutely a woman's right to say that that is not what she wants.

When you go into practice as an obstetrician, it is about babies and delivery. My experiences over the years and some of the things that I saw led me into fetal medicine. That has probably changed my views on abortion over the years. I appreciate that many people have very fixed views on abortion. It is their right to have that view, and I can understand why it is a very ethically difficult area for some people. However, given what I have seen over the years, not just fetal abnormalities but unwanted pregnancies or pregnancies that women feel that they cannot continue with, I totally believe in the right to abortion at earlier gestations as well. I was wary about it in the past, but medical evidence has come through to show that telemedicine in early pregnancy, before 10 to 12 weeks, and the delivery of abortion pills at home, is safe. That should be available to women.

It is never an easy decision but the more private and respectful it is for a woman the better, as long as it is safe. In Doctors for Choice, our key words are choice and safety. Safety is what we want to provide. It has been very difficult for an awful lot of healthcare professionals, not just doctors but people who work across the Province. It is a postcode lottery and there are some places where it has been impossible to provide abortion. It is extremely hard for women. We talk about travelling to the mainland but, if you are from Derry and are travelling to Belfast and are away from your family, that is hard too. Women should be given the choice.

To go back to one of your points, we ask our politicians to trust the medical profession. We have to adhere to very strict guidance in the way that we act. It has become much stricter as the years have gone by. While we respect other people's views, we ask you to respect what we do in trying to help women at these very difficult times. I hope that that has answered your questions.

Mr Carroll: Yes, thank you.

Ms Bradshaw: Thank you, ladies, for your presentation this morning. I want to address Helen's comments at the start. Thank you very much for taking an interest and showing up today. You have provided us with the reality of, and a sense of clarity on, what it is like for women to bounce between hospitals in a state of emotional stress. I have to say that I was very choked up when you said that it haunts you to this day that you had to leave your baby behind. Thank you for sharing that.

I just want to pick a point up with Alyson. You talked about not being able to help a lady or a couple when they leave your consultancy room. What happens to them next? Do they, then, have to do what Helen indicated? Do they have to phone round hospitals in England and make their own travel arrangements? How do they navigate the system when you cannot provide the support that you want to provide for them?

Dr A Hunter: Thank you, Paula. Until the last couple of years — there was so much fear following the Attorney General's 2013 letter — that is exactly what we were told to do. We were advised to not even give women advice. If they asked about abortion, we were saying that we could not provide it: end of story. In that original letter, we were advised that if we procured or gave advice about how to achieve an abortion, we could be prosecuted. That was extremely difficult. It was just horrendous. In the last couple of years, since the Government brought in a measure that means that we can give women money to seek a termination across the water, we can direct them towards the British Pregnancy Advisory Service (BPAS). If a woman has a difficult case — for example, if abortion might rupture her uterus or she may have a severe haemorrhage or a very difficult delivery — we can phone some of the mainland NHS units. It is a very difficult time for the women. There will be a lot left for them to do. We try to help as much as we can, but they will have to make a lot of the arrangements for travel and where they stay. You will not want to have to do that when you have this type of diagnosis.

We are scared to go back to those days of 2013. I do not know whether I could go back to those days. It was so difficult to work at that time. There was a lot of fear, and I found it extremely difficult to do my job in an empathetic and kind way. We have real trouble getting people. We have just lost a doctor who we trained in fetal medicine. We have to spend part of our training on the mainland, and she just decided to go to the mainland because she will be able to give more holistic care there. We have just appointed a doctor who worked in England and has come back here to work in fetal medicine. However, she is looking at what is going on here and saying, "Will I stay in this job if I have to work within these confines?".

As I mentioned, fetal medicine is not just about abortion and abnormalities; it is about multiple pregnancies, difficult pregnancies, growth problems, prematurity, correct time of delivery and where to deliver babies with specific problems. There is a lot to fetal medicine. We look after people with severe medical conditions who then become pregnant. If we do not get this right in Northern Ireland, we will lose fetal-maternal care. It is a big issue. We do not want to go back. Last week, Carolyn Bailie and John Manderson mentioned that the lack of clarity is very difficult for us in helping women. It will be very difficult for us if it becomes very confined. If we feel fear, we will not do our job properly.

Ms Bradshaw: Thank you, Alyson. I thank Danielle for her submission on behalf of the Women's Policy Group. My second and last very general question is for her: what message would be sent out by the Northern Ireland Assembly's passing this Bill? What would the people who you represent feel that that says to them, as women, about being able to make choices about their own reproductive healthcare?

Ms Roberts: It removes choice. Quite often, we are talking about people who are a good way through a very much wanted pregnancy. The majority of abortions, 95% plus, happen before 10 weeks. We are not talking about big numbers, but we are talking about big impacts. Termination for medical reasons has been mentioned. There have been some very high-profile cases in Northern Ireland of women who have been forced to travel. Sarah Ewart, Ashleigh Topley and Denise Phelan have all been kind of obliged to share their deeply personal and traumatic experiences in order to try to bring about change. There are the testimonies of the Women's Policy Group as well as Alliance for Choice, which briefed the Committee earlier. People have gone through horrendous things. As Alyson highlighted, they have been forced to travel because they cannot get care here. That means that they are away from their support systems, family and medical teams.

It sends a message that we will just adopt NIMBYism: "It is fine to pack you off to England, but we do not want you doing it here". That is the reality: people will continue to travel to England. There is funded care in England and it is legal, so people will continue to travel. It is basically just saying, "Out

of sight, out of mind. Your trauma is not something that we want to bother ourselves with", instead of providing support for people who need access to a termination for medical reasons.

There is also the way that some of the debate around this Bill has happened. There has been quite a lot of playing people who are disabled against those who need abortions. Those are not separate groups. Disabled people need access to abortion care as well. There is quite a lot of paternalism towards disabled people, who can also make autonomous choices. Coercion by doctors has been mentioned. BPAS had a report out recently that stated that disabled women and women of colour were more likely to report that they had been coerced into taking long-acting reversible contraception such as IUDs. There are attitudes about disabled people that need to be challenged. It is not a zero-sum game. We need to provide, for everybody, good reproductive health care that is appropriate to their needs.

I am not sure if I have answered your question but hopefully that was helpful.

Ms Bradshaw: You did. Thanks very much, Danielle. Thank you, ladies.

Mr Buckley: Thank you, Alyson, Helen and Danielle, for your presentations. Danielle, you spoke about people with disabilities who had been played, and about how the contents of the Bill are playing people who are vulnerable. I will say, first and foremost, that I do not believe that for one second. I believe that the Bill is actually giving a voice to people with disabilities, who have asked us to speak up on their behalf as they feel that they have been denied and excluded from the conversation. I will just put that as a prelude.

Danielle, your approach, and that of the Women's Policy Group, in your presentation is very much focused on the perspective of mothers who want to end their pregnancies. What would you say to someone with Down's syndrome or another non-fatal disability who says that having a law that states that unborn babies with disabilities like theirs can be aborted up to birth, precisely because of their disability, makes them feel that they should not exist?

Ms Roberts: Well, you already heard from Alyson that that is not the case. Down's syndrome is not a permitted reason for an abortion after 24 weeks. I also draw your attention to groups such as Disabled Women Ireland, which advocates for a pro-choice position, and Sisters of Frida, which is also a pro-choice organisation and advocates for the rights of disabled women on many issues, including abortion access.

I do not see where this imaginary question that you pose will be asked. I have been asked, "What if your mother had aborted you?". That would have been her choice. It is not for me to criticise any other person for a decision that they made in an informed way with the input of their partner and medical practitioner, as appropriate. It is not for me to criticise somebody else's choice. Everybody should be able to make an informed choice. At the minute, women in Northern Ireland are not offered the same screening as people elsewhere, so, quite often, that informed choice is not actually fully facilitated. That needs to be addressed as well.

Mr Buckley: I am listening to the views of many people with disabilities who have presented to the Committee in support of the Bill and who feel discriminated against. Maybe Alyson could clarify the particulars of the example that she gave of an abortion involving Down's syndrome. The language that she used was that the parents had been:

"so hopeful that this child might be well, because the child might look after their other children".

They talked about the terrible burden on their other children and how that impacted their choice about their unborn child at that time. That relates to the comments that I mentioned earlier from people such as Tommy Jessop, an actor in the BBC crime drama 'Line of Duty'. He said:

"We are the only people in the UK where people try to end our lives before we are born just because we have Down's syndrome."

That is the language that has been used and, in reality, what has happened across England and Wales, where we have seen people with Down's syndrome seemingly being targeted because of their disabilities.

Dr A Hunter: Jonathan, first of all, after 24 weeks, Down's syndrome on its own, without another, very severe or fatal, related abnormality, is not possible. Before 24 weeks, it is possible. If you had met the couple in the case that I alluded to and had seen what they were going through and if you had phoned and listened to the constant wailing of that poor woman and her husband, who had to give up their jobs, who lost their income and who were under huge economic stress, you would understand. Yes, they did want a child who was well and could go out and live independently and get a job and live a normal life — if there is such a thing as "normal" — if only they could get somebody who would support and look after their other two children when they died. With all due respect, somebody with Down's syndrome would not be able to provide for or independently look after those other children.

I agree that it is the right of people with Down's syndrome to say, "Why are we being picked on?". Are they being picked on more than people with other disabilities? I do not think so. I have friends who have children with Down's syndrome. One of them did not know; she was not given the option of termination. One was given the option; she says that she would never have gone for it. She knows what I do, and she says that she is pro-choice. She says that, for her to look after her child, it is a dramatic change in life and needs a special type of person. She says that her heart breaks at the thought of somebody who is forced to carry on a pregnancy, with a child with a disability like her child's, when they feel that they could not cope with that child. Every case is an individual.

I get the impression that you are not supportive of abortion for women. I was not either, until I went into obstetrics and gynaecology and actually saw the kind of things that people go through in this life — the kind of problems that I have listened to in that little pink room. People have got all kinds of problems — you have them; I have them — that we do not know about. For some, to have a child with a severe or fatal abnormality is going to be the final straw. We know from times in the past that, when people were not given the option of abortion, relationships broke down and people had severe mental health issues for the rest of their life. Children were not adopted into happy families. They were rejected, and they lived in institutions.

This is a woman's choice; that is what we are asking for. We are asking for women's choice. We are asking for compassion. There are many people in this life who do amazing jobs, are wonderful parents and look after people who have severe disabilities or who are going to have life-limiting conditions. There are other people who, for many reasons, cannot do that. They should be given the opportunity that the Bill tries to deny them by stopping them ending a pregnancy when they feel that they cannot look after their child.

Mr Buckley: I will finish on this, Chair, because I know that you are pushed for time.

I respectfully disagree with Alyson. I can only go by the story that you told and the language that you used in the first instance. I happen to disagree, and I believe that people should be given a chance in life. The families who have been in contact with me about the Bill are supportive of it. They have children with Down's syndrome and feel that the law discriminates against them. I believe that to be true of the current laws, and I am supportive of those families. I thank you for taking the time to present to the Committee today.

Ms Ní Chuilín: Thank you all for your presentation today and for your perseverance. You have clarified that, after 24 weeks, with the diagnosis of Down's syndrome in an uncomplicated pregnancy, an abortion is not allowed. We need to deal in facts.

I want to get your views on the Stanton Healthcare clinic. To me, there is coercion and control in that, and I want your views on that.

I respect what you have all done for families, and particularly for women. Notwithstanding your personal experiences, I feel that what has not been extracted from this is the other example of health and social care workers. In the past, women who wanted to end a pregnancy because they just could not continue were not given support at all. In fact, they were told that it was not only illegal but immoral. That has changed slightly. Can you give me your views on the coercion and control that appears to happen at that healthcare clinic?

I put on record my appreciation and thanks for your coming here today and for your ongoing work.

Dr A Hunter: I have heard stories of women going to Stanton. What we find, in Doctors for Choice and in the Northern Ireland Abortion and Contraception Taskgroup (NIACT), of which I am also a member, is that women are brought there under the false pretences of, "Are you looking for an abortion?". It

looks like it is offering women an abortion, but, when they get there, it seems to be the opposite. I do not know a lot about this area, but there is now also a discussion about reversal of abortion pills being given out. When you do something that takes people in under a false pretext, that is really wrong. We are surprised that that clinic seems to still be operating. I do not know the legalities of what that entails, but it is very wrong for women who go there. Women should be given a balanced opinion. They should know that they can carry on with the pregnancy or have an abortion. If they go in and are given a very one-sided view, that is wrong. From a medical point of view, if we were accused of doing that, we would be investigated. If we were found to be coercing or forcing somebody's hand, which should not be done, we would face being struck off from the GMC as a doctor. I am not sure how that clinic gets away with seemingly doing the opposite, which is what we have heard that it does.

The Chairperson (Mr Gildernew): Thank you, Alyson. Danielle has indicated that she wants to speak.

Ms Roberts: Thanks, Chair. There are options for non-directive counselling. Informing Choices Northern Ireland (ICNI) gives everybody all the options. However, because abortion services have not been commissioned, and it is a charity, it is at risk. It is on a knife edge as to whether it can continue. It has announced that it will have to withdraw the central access point provision in October because of a lack of commissioning and a lack of funding.

There are options. It is not a prescription. It is not that you have received a diagnosis and therefore must have an abortion. That is an option. We need to work towards a society where people are supported, whether they choose to continue with that pregnancy or not. That includes having accessible childcare for disabled children. We currently have a great lack of that, which is illustrated by the Employers For Childcare survey. The report that came out today about the personal independence payments (PIPs), which was mentioned in the previous briefing session, shows that there are very low levels of support for disabled people. We need to ensure that people are supported, whatever path they choose.

With regard to Stanton and abortion pill reversal, I draw the Committee's attention to the series of reports by openDemocracy, which have revealed what is said in so-called crisis-pregnancy centres. It also did some undercover investigative journalism that resulted in action being taken against doctors who were providing abortion pill reversal, which is not medically sound.

Jonathan Buckley made the point that you are hearing from disabled people who disagree with that law. Disabled people are not a homogenous group. There are disabled people who support that law. There are disabled women who are members of the Women's Policy Group and support that law. There are as many different views among people who are disabled as there are among the population as a whole.

If you google "abortion Belfast", Stanton will come up. That is because there is no information from the Department of Health on how to access an abortion. If people are lucky enough to find Informing Choices Northern Ireland, they will get all the information. If they are lucky enough to find the Alliance for Choice website, they will get all the information. However, if you google "abortion Belfast", *[Inaudible owing to poor sound quality]* you will be directed to Stanton Healthcare, rather than to NHS-provided care, which is just wrong.

The Chairperson (Mr Gildernew): Thank you, Danielle. I see that Helen has her hand up. Helen, could you be brief if it is on the same issue, please?

Ms Stonehouse: I will just say briefly that some of those clinics operate in the Republic of Ireland as well. Quite often, they will target people who are already vulnerable, such as migrant groups and people who are already socially and economically vulnerable, because, quite often, the goal is not to provide any *[Inaudible owing to poor sound quality]* but just to delay them past the point where they can legally access abortion. We have seen that happen quite frequently here. It emphasises the need for evidence-based information to be given and available to people at all stages throughout pregnancy, whether they receive a prenatal diagnosis or not, so that they can make an informed choice about what is best for them in their circumstances.

The Chairperson (Mr Gildernew): Thank you, and thank you, Carál. The final indication that I have at this time is from Gordon Lyons. Go ahead, Gordon, please.

Mr Lyons: Thanks very much. Alyson, in particular, I want to thank you and your team for the work that you have been doing to support families who receive difficult diagnoses. I have some experience of that and of the shock, trauma and uncertainty that there can be for expectant families. I know that you have fantastic staff throughout the health service. I want to thank them publicly for the support that they have given.

I have a couple of questions. The first relates to the current regulations, which state that an abortion can take place at any time where:

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

It is for two registered medical professionals to assess that. To a degree, that is, obviously, subjective based on what they consider to be "seriously disabled". We have heard very clearly from you that you do not believe that Down's syndrome, on its own, is a reason for termination. Are you, or are doctors, finding it difficult to come to agreement on what that actually means? Can there be wide variations on that?

My second question was along similar lines to Jonathan's question about the message that it sends to disabled people. I have had much correspondence. I accept Danielle's point that disabled people are not a homogenous group by any means. However, much of the correspondence that I have received is from people who tell me that, essentially, the law, as it stands, is saying that there is a difference in value between disabled people and people who are not disabled.

Mr Chairman, I am aware that that question has already been asked. I assume that others do not want to add too much to that. In the interests of time, I am happy to let that go. Perhaps Alyson could give a little feedback on how that judgement on serious disability takes place. Do you take into consideration other factors outside of the child's disability, such as family circumstances? Is that what you were trying to say with regard to the other two children in the example that you gave?

Dr A Hunter: Thanks, Gordon. In the first case that I gave, that did not apply because it was less than 21 weeks. You can have abortion under 21 weeks for a range of reasons; in Northern Ireland, it would always be for a severe disability. After 24 weeks, there is strict guidance about what we as *[Inaudible owing to poor sound quality]* have to go through it all. For example, you could have a child who has what appears to be a genetic abnormality, but there could also be structural abnormalities shown in scans, such as serious cardiac or brain abnormalities. We would then discuss the kind of life that that child could expect. Would it die in utero or shortly after birth? If it lived, how long would it live for? Would its life be very restricted? We are talking about severe life-limiting disabilities, where, if a child is born, it is going to die and not live to have a healthy adulthood. For example, a child with Down's syndrome and no other abnormalities can live to have a healthy adulthood, but a child who is born with severe and unfixable cardiac or brain abnormalities may have a very limited quality of life. It may never be able to even have eye contact with its parents, or it may be in a wheelchair and die in infancy or before the age of five. We are talking about really serious conditions.

Each case is dealt with individually. So far, in Northern Ireland, we have not had many cases that have gone over the 24 weeks. It has been with things where, really, we are talking about very, very poor quality of life. I do not know whether I can help you much more, because, again, each case is individual. I understand what you say, and it is only right that people from disabled groups have the right to say that they feel that they are being discriminated against or picked on. However, as Danielle said, we are talking about the woman's choice. It is the woman herself who must make that choice about her pregnancy.

Mr Lyons: I dropped out there for a second due to connection problems. I got most of the answer. I understand what you said about life-limiting disabilities. The regulations say that being "seriously disabled" is still a reason. Fundamentally, the current regulations treat children differently on the basis of whether they are disabled or not. That is the real challenge with the current regulations. The Bill is trying to rectify that. A lot of us will take different views on it, but I appreciate your time and the answers that you have given.

The Chairperson (Mr Gildernew): I thank the panel for attending, giving the Committee your evidence and engaging with Committee members during the question and answer session and for the written evidence that you provided. Dr Hunter, Helen and Danielle, thank you very much. I wish you all the very best in the time ahead, and please take care.