



Northern Ireland  
Assembly

Committee for Health

# OFFICIAL REPORT (Hansard)

Severe Fetal Impairment Abortion  
(Amendment) Bill:  
Royal College of Obstetricians  
and Gynaecologists

17 June 2021



live birth and that baby may survive for several weeks following delivery. It is very difficult, and the use of those terms does not really reflect the complexity of the cases that we look after.

At one stage, in 2014, we met Department of Justice representatives, who raised the fact of fatal fetal abnormality and asked the Northern Ireland RCOG to give them a list of fatal fetal conditions. We highlighted to them at that point that there were real problems with using that term and that it would be impossible to compile such a list. The term that we used at that time was "severe life-limiting conditions", which was meant to encompass both terms that are used today.

We have real concerns that, first, if the Bill is passed, for some fatal fetal conditions, clinicians will no longer have the confidence to provide care locally for fear of ending up on the wrong side of the law or the regulations. We know that colleagues in the Republic of Ireland have had such experiences. Secondly, we are really concerned that we will end up in a similar situation to what existed between 2013 and 2019, when clinicians were anxious and unclear about what was meant by the term "an adverse effect on maternal mental health". That arose really because of some of the language that was being used about termination at the time. There were both differing legal interpretations of what was meant by "mental health" and a real lack of clarity. Doctors were fearful of that and no longer had the confidence to look after women locally. Therefore, when women were given the devastating news of a diagnosis in what was a much-wanted and precious pregnancy, doctors felt they could no longer look after those women in Northern Ireland due to the fact that they were distraught and felt that they could not continue the pregnancy to term. If the Bill passes, many women will have to travel to Great Britain in those really difficult and distressing circumstances. They will not be able to be close to family or their local healthcare teams and will, yet again, have difficulty getting post-mortem examinations and will have to suffer the harrowing experience of bringing the remains home for burial or cremation.

It is also important to say that the number of terminations that happen after 24 weeks for severe fetal impairment is really small. Many or most of them are just after 24 weeks, so a case may be 24 weeks plus two or three days. Often, the reason for that is that it can take up to three or four weeks to get results of detailed genetic testing, such as microarray analysis. There are other fetal conditions where there will be a normal 20-week scan but the problems will not become apparent until several weeks after the 24 weeks. Those are not at all common and often involve severe neurological conditions. There are other conditions where a 20-week scan shows a problem, but, as the pregnancy advances, the structural abnormalities become much more pronounced and enlarged. That might result in a really complex surgical delivery for a woman that will confer significant morbidity and might affect her fertility and chances of carrying a further pregnancy.

We have weekly multidisciplinary team (MDT) meetings in the Centre for Fetal Medicine in Belfast and will convene a meeting more urgently than that if there is a time-limited case. A wide range of health professionals is involved in the discussions. Certainly, for pregnancies beyond 24 weeks, there will always be a discussion between two fetal medicine specialists, the consultant's obstetrician, a fetal medicine midwife and a specialist, who is often a geneticist but could be a paediatric surgeon or fetal neuroradiologist. The purpose of the multidisciplinary team meeting is to gather all the evidence, discuss the diagnosis, the complexity of the diagnosis and the likely prognosis and the options that would then be available to the woman and her partner. We then relay that information to the woman and the partner to enable them to make the right decision for them. It is important that those decisions are not rushed and that they have time to think through that really difficult and complex area. Since March, we have been aware of some cases where decisions have been rushed because of concerns that parents have raised due to the media attention that the Bill has gained because of the 24-week limit.

A limited number of women will choose to terminate a pregnancy when they are given the diagnosis of a fatal fetal or severe fetal impairment condition. It is important that all women, whatever choices and decisions they make, are well supported, receive good counselling and have good and adequate antenatal support and access to perinatal clinical psychology services. For the women who continue to term, it is important that there is adequate support for services such as the Children's Hospice and other care providers. Parents should be supported in the longer term with adequate support, including financial support.

**The Chairperson (Mr Gildernew):** OK. Thank you. Jonathan, do you wish to make opening remarks, or do you want to go to members for questions?

**Dr Manderson:** It is John, actually. Sorry.

**The Chairperson (Mr Gildernew):** John, sorry.

**Dr Manderson:** I concur with what Carolyn said. I work in the Ulster Hospital, and Carolyn works in the Royal. We are fetal medicine consultants, and, between our two units, we see the vast majority of fatal or severe life-limiting fetal conditions in Northern Ireland. We work at the coalface of the issue, and we deal with patients who have, obviously, very wanted pregnancies. They are happy to be pregnant, and often they come to a 20-week scan or a scan at another period where they are told some devastating news. It is an incredibly emotive time for them and their families. It is a major life event for them. We see it day in, day out.

We are saying to the Committee that we are managing those patients. They are real, live patients. They are from Northern Ireland. We want to manage them locally with their local family support, and we want to be able to deal with them compassionately. We do not want to judge them. We also want to manage them safely. We all have a high degree of training. We in Northern Ireland are lucky that we have highly trained individuals in paediatric cardiology, neuroradiology and fetal medicine. We really have a very highly trained group of people in Northern Ireland, the majority of whom trained elsewhere as well. I trained in Canada, Carolyn trained in Texas and other people trained in centres across the UK. We are a highly trained bunch of people who are dealing with these conditions while trying to manage and support patients. We seek the Committee's understanding of that and its support in helping us to manage those patients locally. The few patients who travel will do so regardless of decisions in Northern Ireland, but we do not want to get back to the position of patients having to travel in order to proceed with a termination in what are awful situations for them. We want to support them locally.

We are also concerned that we want to continue to be clear about the rules, the guidelines and the law. All our staff are. For many years, going back decades and more recently, there were grey areas in that. We do not want to go back to that. Carolyn and I are old enough to have gone through that period, so we know what it is like, for us and for patients, to be in that position. When you have a lack of clarity, it is a really difficult place for medical professionals and patients to be.

We want to be supportive and to make sure that we do the best for the patients and give them all the choices. As Carolyn said, we give them lots of information and involve lots of groups that care for children who have severe disabilities or certain conditions. We have patient contacts and parent contacts. We have good links with the Children's Hospice now. I also echo Carolyn's appeal for psychological support. We are incredibly lacking in that in Northern Ireland, and I urge the Health Committee to look at that. We have a population of patients with stillbirths, fetal anomalies and really difficult outcomes in pregnancy, but we do not have clinical psychologists in every trust across Northern Ireland to support those ladies. There is a bit of a postcode lottery involved. There are one or two clinical psychologists in the Belfast Trust, but it is very piecemeal across the other trusts. That support is severely lacking. In my clinical practice, I have found that patients make well-informed decisions when you have the correct supports, information and patient information leaflets for them. A lot of patients continue with pregnancy. The more knowledge you give patients, in some regards, the higher the percentage of them who will feel supported enough to continue with their pregnancies in those really difficult circumstances. It is incumbent not only on us as doctors but on those who make the laws, rules and advice to be really cognisant and to recognise that we can improve it.

That is what I will say at this stage. I am happy, with Carolyn, to take questions. We are trying to give you a really clear picture of what it is like in those clinical circumstances and those really wanted pregnancies with real-life patients, who are in huge distress. They are really difficult situations to manage.

**The Chairperson (Mr Gildernew):** Thank you, John.

Before we go into questions and answers, can I advise everyone to make sure that they are on mute when they are not speaking? If everyone could use a headset, that helps with the sound. There have been little breaks in the sound for both of you, Carolyn and John, but we were able to follow you.

The first question I have is for Carolyn. In your presentation, you said that you had a concern that, if the Bill passes, clinicians would no longer have the confidence to deal with some of those cases locally. Will you elaborate a little for me on what you mean by that and what the impact would be?

**Dr Bailie:** Yes. I will look at fatal fetal abnormality first. I mentioned that it can be difficult to distinguish between fatal and severe fetal impairment and that there is a lot of interplay between the two. We are

all aware of the intimidating language that has been used around termination of pregnancy. In 2013, doctors were fearful of being on the wrong side of the law. Everybody still remembers that, and we know that our colleagues in the South experienced it. With some of the fatal conditions, clinicians will begin to think, "Right, somebody might interpret this differently. Somebody might interpret this as a severe fetal impairment, yet I know that, in a lot of conditions, the baby will die inside the womb. I am worried about being on the wrong side of the law." Therefore, they act differently, as people did after 2013. Similarly, prior to 2013, many of those women were looked after in Northern Ireland, usually under the clause on the severe adverse effect on the mother's mental health. It was acknowledged that women may have had underlying mental health issues or that, when a woman was given devastating news, she was so distraught that she felt she could not continue the pregnancy to term. Some terminations of pregnancy were therefore undertaken on that basis.

If we remove the Severe Fetal Impairment Abortion (Amendment) Bill, it means there is nothing written down to make clinicians feel that they can clearly act and continue with the termination of a pregnancy for a woman in those difficult circumstances under the mental health regulation, which is currently regulation 4 in the new regulations. That goes back to the lack of clarity and the differing legal interpretations that we were given when we asked what was meant by "maternal mental health". The impact of that would be that, in cases of severe fetal impairment, some of which may be considered fatal, those women would then have to travel, yet again, to Great Britain, as they did between 2013 and 2019.

**The Chairperson (Mr Gildernew):** Thank you, Carolyn. Your sound was poor on a couple of occasions, but I was able to follow most of that. Clerk, is Carolyn's sound poor with you as well?

**The Committee Clerk:** The sound is OK at this end, Chair.

**The Chairperson (Mr Gildernew):** I was able to follow it, Carolyn, so thank you. Had you finished that answer?

**Dr Bailie:** Yes. Apologies for the sound. Yes, I am finished.

**The Chairperson (Mr Gildernew):** Thank you. The other issue that I want to follow up with you, John, is psychological support and the fact that there are gaps in it. I think hospice support was also mentioned. Will you elaborate a little on the difficulties those gaps cause in supporting people to continue with pregnancy?

**Dr Manderson:** Historically, we have been really poor at that in Northern Ireland. Obviously, we, as doctors, have been asking for funding; it is yet another thing to be funded. We see the need for it in pregnancy situations because a huge number of people are affected negatively in pregnancy emotionally and psychologically, including those who have miscarriages and moving right through to severe fetal anomalies, stillbirths and really difficult, traumatic birth experiences.

Our focus today is on the severe fetal anomaly and fatal fetal group. Certainly, those are wanted pregnancies. Those women come through, and we, as doctors, because we work with them every day, have to remember that, for those patients, it could be their one pregnancy or one of their most major life events. It is an incredibly emotive time. They need to be supported. We try our best. We see them in counselling. We are sympathetic. We have fetal medicine midwives who ring those patients and keep in touch with them. Some trusts offer bereavement support, but, again, it is very piecemeal. Many patients are not seen or there are no facilities for them to be seen, and they may have a review with a consultant after six or eight weeks. What they really need is ongoing psychological support from a professional who is trained in the field. That will make their life better, reduce the numbers who then have a post-traumatic stress problem and help them in any future pregnancy, because they can enter future pregnancies being incredibly nervous and worried.

Adding those supports at an early point for patients will allow them to have the confidence to make good, informed decisions that they are supported on. There is a huge need and a huge gap in our service for those sorts of supports. Maybe Carolyn can update you on that. I know the Royal has someone for that support. However, again, those people are inundated. They work only so many hours a week, and they just cannot see the number of patients who come through. I see it in our service. We really struggle to give those ladies the psychological support that they need. Even when they are referred back to their GP to be referred on to psychologists, the waiting lists are absolutely enormous. The earlier you manage those patients, the better. Leaving it half a year, a year or two or

three years down the line just does not work for those patients. That needs to be looked at. I encourage you all to look at funding for that.

**The Chairperson (Mr Gildernew):** Thank you, John. I have dealt with such situations on several occasions, as, I am sure, have all representatives. Obviously, the women who are impacted are first and foremost in our minds, but stillbirth and loss of pregnancy have a massive impact on fathers as well. We are not even at the stage of supporting the women, never mind the other family members who are affected. It is a huge issue, indeed. Thank you for that answer.

I will go to members now: first, to Paula Bradshaw, then Carál Ní Chuilín, Jonathan Buckley and Gerry Carroll. Those are the members whose names I have at this time. I will go to you, Paula. Please, go ahead.

**Ms Bradshaw:** Thank you for your written and oral presentations. Last week, I asked a question that would have been better directed to you, John. Can you outline how long it takes to train to become a fetal medicine consultant and what steps you have to go through?

**Dr Manderson:** We all train as general obstetrics and gynaecology consultants, and that takes about nine years. On top of that, there is a three-year training programme to become a subspecialist in fetal medicine: one year is research, and two years are subspecialty work in fetal medicine. Often, the research extends out; in my case, I did a doctorate in that area. I was training in that area for four years. In one of those years, I was in a fetal medicine centre in Toronto, Canada. The majority of us have trained to that level. We have all the general training that any general obstetrics and gynaecology consultant has, but we have an additional two to four years' training and we are working in that field.

The UK is a world leader in fetal medicine. However, it is also a very close-knit community. We attend yearly meetings and have close contact with our colleagues across the UK and Ireland. We are connected through the Royal College of Obstetricians and Gynaecology in London. We have trainees who train in London, Dublin and elsewhere in our units. They go to some units for specific training in certain areas. At the minute, in Belfast, we have strong links with St. George's Hospital in London at a personal and work level. In my unit, I send ladies with twin transfusion problems for laser treatment. Some of you may have seen Dr Basky on the television in 'Baby Surgeons: Delivering Miracles' doing fetoscopic surgery, and we link with that consultant in London.

We are highly trained. We do not just train in fetal maternal medicine but spend time in the pathology labs, the genetic labs and intensive care managing really sick patients. We have a really thorough training programme. I spent time with a psychologist and sat weekly for about three months in clinics while she spoke to patients. We have a really broad spectrum of training, and our practice is very clinical. We deal with patients, and we link our practice with other specialities such as neuroradiology to look at MRIs. Technology keeps advancing, and genetics has advanced. What we can do now and what we can do in the future will continue to advance. Some conditions can be tested for in families, risks can be predicted, and early diagnosis can be offered. With IVF procedures, diagnosis can be offered before implantation. There are a huge variety of treatment options for patients with serious conditions that run in families.

We are quite a tight-knit bunch in the UK. We work in a multidisciplinary team. We regularly work with our paediatric cardiology colleagues, our neuroradiology colleagues in the Royal Victoria Hospital and, massively, with our paediatric colleagues in counselling and management. Patients will be offered counselling with a paediatrician who is an expert in the area the baby is affected in, such as spina bifida. We have introduced a system where, potentially, those babies can even be operated on in the womb and referred to London or Belgium. There have been huge advances, and it is a really highly trained area. That basically goes for all of us who are consultants in fetal. At the minute, about five of us in Northern Ireland are trained to that level. Hopefully, some more will come on board in the next couple of years. We are the people who are often at the coalface. That gives you an idea of the training we go through to get to this point.

**Ms Bradshaw:** Thank you very much. That was a comprehensive answer. What is your reaction, then, to some of the accusations that were made when we first debated the Bill in the Chamber? They were that people like you were coercing women into abortion and that you were performing abortions on such grounds as cleft lip and club foot, as we saw in headlines in the newspapers. What is your response to those accusations?

**Dr Manderson:** I can respond. I know that Carolyn is probably keen to respond as well. That is completely untrue. It is very far from the truth. No baby would have a termination for a cleft lip, a talipes or an isolated single defect like that. The problem may be a misinterpretation of figures. People do not realise that, when you have babies with severe fetal abnormality, they have a mixture and complexity of conditions, possibly involving their brains or hearts and, on top of that, they may have a cleft lip or a talipes of their foot. I suppose that, in those cases, those babies will have multiple abnormalities. One of them may be a cleft lip.

We refute that accusation. We are a caring and compassionate group of people. We are trained to a high level and are trying to manage difficult situations, and we manage our local population to a high degree.

We encourage people to get post-mortems so that there is an audit process, looking at what we have diagnosed in ultrasound and then confirming that by a post-mortem of the baby. That gives valuable information for future pregnancies. We strongly encourage women to have post-mortems. Therefore there is oversight to the system.

We refute a lot of those allegations. They were disingenuous, to be honest. Carolyn might like to have a word on that as well. It was quite something to hear all that.

**Dr Bailie:** I agree with everything that John has said. We practise in Northern Ireland, but we know the units that we liaise with in England, such as St George's, Birmingham Women's Hospital, Glasgow, and that just would not happen in those units. We know that. It emphasises the importance of having good, strong, multidisciplinary teams to discuss cases and ensure good governance in units. That is really important.

Of course, there is bad practice everywhere. I agree with John about the isolated talipes and cleft lip. I imagine that that is just listed as part of a spectrum of abnormalities in one baby, perhaps with severe chromosomal problems. However, the implication that those babies can be terminated up until term is something that will not happen in Northern Ireland. I know that it does not happen in St George's. We have had discussions over the years and things have arisen, so we are well aware of what is acceptable and unacceptable in units in the UK. I imagine that we will always get somebody who does not practise well. That is inevitable in any walk of life. The protection against that is having strong multidisciplinary teams, good care pathways and good governance.

**Ms Bradshaw:** Thank you both.

**The Chairperson (Mr Gildernew):** Thank you. It brings to mind the fact that, here in the North, families who have a bereavement of this nature also need to travel to England for paediatric pathology, since we do not have a service on the island. I have raised that with the Minister. That is another significant gap and hardship for families who have been bereaved.

**Ms Ní Chuilín:** Thank you very much, Carolyn and John. I appreciate your coming to the Committee today. I also appreciate the professionalism and compassion that you show every day when supporting women and families through difficult situations. I trust your decisions. We need to trust our clinicians to help people to make the right decision for them. I trust whatever decision people make.

You said that a small percentage of women will discover very late in their pregnancy that their baby will not survive and will want to make a decision to terminate. If the Bill or any other Bill of this nature goes through, where it is the case that babies cannot survive outside the womb, those women will still have to travel. The issue — you raised it, John, as did Colm — is that our psychological services are not what they should be to support not only the women but their families. You kind of covered that. It is something that Órlaithí, in particular, has really majored on.

It is disturbing — Paula touched on this, and I have talked to some constituents about it — that there is a suggestion in the Bill that anyone who discovers that their child in the womb has a cleft palate or a club foot will be encouraged to terminate. That has hurt not only families but some clinicians. We received presentations from the Royal College of Midwives (RCM) and the NI Abortion and Contraception Taskgroup (NIACT) last week. They are credible, compelling and compassionate people, as you are. I ask for your commentary on that. If the Bill were to go through, what would the implications be for your ability to practise and advise?

**Dr Bailie:** It is unfortunate that people think that a baby with isolated club foot or cleft lip may be terminated. That is completely untrue, and I think that every fetal medicine unit in the UK would say that that is completely untrue. Data is recorded, but it is recorded as part of a spectrum of abnormalities in one baby that usually reflects an underlying severe chromosomal or genetic condition. The abnormalities are counted differently and separately. It is important to dispel that myth throughout Northern Ireland. That is part of the problem with abortion. It is such an emotive subject, particularly in Northern Ireland. Many discussions are ongoing in separate silos, and there is a lot of secrecy. We are all about transparency and the importance of having good governance in trusts. That can be provided through having good multidisciplinary team meetings, care pathways and support networks for parents in respect of what decision they make. More discussion about that regionally could help to dispel those myths and show what the support is and the pathways are for women who end up having to visit fetal medicine centres.

**The Chairperson (Mr Gildernew):** Thank you, Carolyn.

**Mr Buckley:** Thank you, Carolyn and John, for coming to the Committee this morning. How do you respond to the recent Congenital Anomalies and Rare Diseases Registration Service for Scotland report on congenital anomalies, which said:

*"Termination of pregnancy for fetal anomaly accounted for almost all of the non-live born babies, showing the impact of antenatal screening on the outcome of babies with these specific types of anomalies"?*

Furthermore, in England, in 2018, 85.2% of pregnancies with an antenatal diagnosis of Down's syndrome led to abortion.

**Dr Bailie:** The last part of your comment was about the figures for Down's syndrome. Screening is optional, and I think that about 45% of women choose not to have it, so the figures relate to women who had screening and where a diagnosis was made. A lot of work has been done in the last few years in England. A consensus statement was released by the RCOG, supported by the Royal College of Midwives and the Society of Radiographers, which looked at the terminology around screening and emphasised the importance of proper education and counselling on the implications of the screening process before and after women have that screening. It also emphasised the importance of health professionals giving non-biased and non-judgemental information and the importance of women being aware of the support services that are available for children who have disabilities.

In Northern Ireland, although there is much to improve on, we have good networks and mechanisms in place, which, of course, can be improved, and that can perhaps be discussed with the Health Committee in the future. A lot of education needs to happen on screening. The RCOG worked with the Down's Syndrome Association and other groups and looked at the terminology that has been used in the guidance and the online e-learning platforms, and, together, they have modified that terminology. Changes have been happening in recent years, although I am sure that there is room for improvement.

**Mr Buckley:** Your presentation was cutting out slightly for me — I am not sure if that is on my end or yours, Carolyn — but, from what I heard, I feel that the approach is very much based on the perspective of mothers who want to end their pregnancies as opposed to wanting to consider the options. What would you say to someone with Down's syndrome or other non-fatal disability who says that having a law that says unborn babies with disabilities like theirs can be aborted up to birth precisely because of their disability makes them feel like they should not exist?

**Dr Bailie:** I completely see why they feel like that. That does not, to my knowledge, happen in units in England. I understand that there have been maybe one or two cases, but good, well-renowned units would not consider termination up until term for Down's syndrome. I know that from chatting to colleagues in England. That would certainly not be the case in Northern Ireland. We would all be aghast at something like that happening.

Part of the problem in Northern Ireland is that the law has been unclear. In the past, we had a law that was based on maternal mental health, but that became very unclear and women were having to travel.

Each case is separate, and each woman is a woman with different circumstances. Those may be circumstances at home or other health problems. Until we are in those circumstances, none of us

really knows how we would feel or what support we would feel we have. The law is based on a fetal problem, but all those decisions are made from the maternal perspective, and women make many different decisions. I would see that it comes from the maternal perspective and that those decisions are made on a case-by-case basis, following further consultation and counselling and further information being given to the parents to make them aware of the support that is available that may help them to continue with the pregnancy.

**Dr Manderson:** I concur with Carolyn. Northern Ireland is slightly different from England. We do not have the same screening as England. Down's syndrome is used as an example because it is the most common chromosome disorder. In England, all units offer screening for that condition in the first trimester, which is the first 12 to 14 weeks. We do not do that in Northern Ireland. Introducing a new screening programme for that would require money and training and all that goes with that, so we do not currently offer that. It is done on a piecemeal basis for patients who ask for it, and it is often done through a blood test at 15 to 16 weeks. We do not, however, have a screening process across Northern Ireland to pick up Down's syndrome per se. With those wanted pregnancies, things are found through the ultrasound at the 20-week scan or people go privately to have a genetic scan at an earlier point and come back with a diagnosis of certain conditions. It is not in any way a targeted search programme. The 20-week scan is carried out to pick up conditions so that we can manage patients properly and refer them to the right units so that babies with cardiac conditions, gut conditions and brain conditions can be managed in the womb, if possible, and delivered and supported and so that they can be delivered in the right place to manage them immediately after birth.

Through fetal medicine, we manage patients very much on a patient-by-patient basis. We respect the decisions that patients make; we are totally supportive of whatever decision they make. We want to be supportive of whatever decision a patient makes on the basis of the information that they have been given about their case. Not every pregnancy is the same. We support people. We support them to continue pregnancies as well, and we give them options in cases of life-limiting conditions in which babies may not be expected to survive very long by linking with the Children's Hospice. That is invaluable. A number of my patients have spent two to three weeks in the Children's Hospice with their little babies and have found that invaluable for making memories. We are very much involved with that.

I suppose that we are asking for more help in that regard. I believe that the more support we give those women — it is important to have that support and management locally — the more women will feel confident to continue with a pregnancy. There will still be patients, however, who make the really difficult decision that they do not want to continue with the pregnancy. In all situations, including Down's syndrome, that is a really difficult place for patients to be. We need to be able to support patients, whatever their decision, because this hits everybody across all social and religious divides. They need support with it, and, as local clinicians, we would like to be able to offer that support.

**Mr Buckley:** I go back to Carolyn's point about —.

**The Chairperson (Mr Gildernew):** Please be very brief, Jonathan.

**Mr Buckley:** The law sends a signal that —

**The Chairperson (Mr Gildernew):** A very brief question, please, Jonathan.

**Mr Buckley:** — you can abort up until birth for Down's. Do you not think that it is odd that doctors are asked to fight to keep premature babies alive, while they are intervening to end the life of babies of exactly the same gestation because they have a disability? How do you think the double standard makes people with disabilities feel? That gets to the nub of the Bill's purpose.

**Dr Bailie:** I do not think that the law states that you can abort a baby with Down's syndrome up until term. What happens is that, for any conditions beyond 24 weeks, there is a multidisciplinary team meeting in fetal medicine units, where all the information is available, including that on the complexity of the diagnosis and the likely prognosis. From chatting to colleagues, I suggest that, after 24 weeks, in most cases of isolated Down's, where there are not any other complex associated abnormalities, most units would not agree to that. I do not think that the law says that you can abort a pregnancy with Down's up until term. That is —.

**Dr Manderson:** That is not what is being practised. It needs to be made clear that we are not doing that. That is being used a little bit. That is not what is happening, nor is it what we would want to do. I

agree entirely with Carolyn: each case is taken as an individual case, and we would certainly not promote that in any shape or form.

**Mr Carroll:** Thanks, Carolyn and John, for your presentation and for the briefing paper that we got beforehand. There is some information in your written evidence that is quite important and useful, and I want to tease out some of it. You comment that, if it is progressed, the Bill will ultimately:

*"prevent a patient-centred, individualised approach to care for women who may already be distressed"*

and

*"ignore the clinical complexity of severe fetal impairment".*

On the Health Committee, we constantly talk about having a patient-centred approach to care and a patient-centred health focus. That is true for everything, and it should be the same when it comes to pregnancy and terminations. It is important to challenge the idea that women are deciding willy-nilly, without consulting their MDT or whomever, that they need or have to get a termination.

There is a paragraph in your presentation about terminations in England and Wales in 2019 in which Down's syndrome was mentioned. It states that there was a total of 12 abortions. I am not sure whether those were solely for a diagnosis of Down's syndrome, so I want to tease that out. There is what appears to be either a misconception or an inaccuracy in claiming that the majority of diagnoses of Down's syndrome end up in a termination. My understanding is that that is not the case. Are you able to speak to that figure or perhaps challenge the misconception, which, unfortunately, is being repeated?

**Dr Bailie:** Thank you, Gerry. Those figures relate to after 24 weeks' gestation, where it is most likely that there has been a late diagnosis because of some other complex problem in a baby with Down's syndrome. Babies with Down's syndrome can have complex cardiac abnormalities and sometimes quite severe structural neurological problems. That is what that paragraph refers to: later detection, after 24 weeks. A lot of the discussion about late termination up until term is just not accurate. Sometimes, people will also refer to late termination after 24 weeks, so there is a little bit of confusion as to whether it is 24 weeks plus one week, whether it is 24 plus two weeks or whether we are talking about term. The figures relate to Down's syndrome after 24 weeks where another complex abnormality was detected. Sometimes, that goes undetected until after 24 weeks.

**Mr Carroll:** Your submission states, in the event of a fatal fetal diagnosis:

*"Some women will choose to continue the pregnancy with the option of palliative care after delivery and this decision must be respected, supported and an individualised care plan agreed."*

That is crucial and speaks to something that Jonathan said. From my point of view and that of most of the Committee, you need to have a situation in which people are not forced to make decisions. We teased this out a bit last week, but the Bill might force women to make decisions before 24 weeks. Women should have access to palliative care and support and to a psychologist.

If the Bill is passed and the law changed, I think that it will prevent five women a year from accessing termination after 24-plus weeks. Not only is that a tiny number of people but the amount of distress that it would cause those women seems to be quite large. It would also cause a lot of stress to people who perhaps have a stillbirth or some other difficult or traumatic pregnancy.

**Dr Bailie:** I mentioned five patients in the report, but, in fact, there were fewer. Most of them were just after 24 weeks, in the twenty-fourth to twenty-fifth week of pregnancy. Most were because results had not come through in time. With data protection and privacy laws, we cannot say what those conditions were, but they were complex conditions. Unfortunately, we cannot discuss them, as we could then demonstrate the complexity of the problems.

You made a comment about supporting women who continue with the pregnancy. That is very much how we start conversations. In the fetal medicine unit in Belfast we have relatively good support, but it could be better. We provide good antenatal and bereavement midwife support and clinical psychology. Most of the fetal medicine consultants have been to the Children's Hospice to see the hospice and the care that it provides. We have had meetings, including regional meetings, with the Children's Hospice.

We are about to pilot care pathways with them for antenatal care, care during labour and care after delivery to ensure that the care is as comprehensive and supportive as possible.

We have a link nurse/midwife who works between us and the Children's Hospice. She has come to the fetal medicine unit and fetal medicine clinics. She has come to some of our large monthly multidisciplinary perinatal surgical meetings with all the other specialists. We have neonatal input into our medicine clinics several times a week, at which the neonatologist will talk to parents about the implications of the problem and what it is likely to be like for the baby following delivery and what the parents should expect.

There is a huge amount of support available. I am sorry if that did not come across in my presentation, but that is very much what we are about in fetal medicine.

**Mr Carroll:** Thanks for that information.

**Ms Flynn:** John and Carolyn, I would like to express my thanks to you in your role as clinicians who are dealing with the most complex and difficult of situations yet are clearly providing support and treatment for many women and families who are going through something that does not bear thinking about unless you have experienced it. Thanks to you both for that and for your comments today.

John, you mentioned the lack of clinical psychologists. That is not a new issue for the Committee, and it is certainly not a new issue for me. We are aware of it and have been trying to open up a conversation with the Minister of Health about appointing a lead psychologist to the Department's management board so that there is continuous input on the level of need or on gaps in services, in order to make sure that those gaps are not widening. We are aware that it is a problem, and I am happy to continue to lobby the Minister and the Department to try to enhance those services. It has been brought up repeatedly that the situation that we are talking about has an impact, not just on the mental health of the woman but on the wider family. In recent months and over the past year, a good bit of progress has been made on perinatal mental health overall, with some additional investment having gone into it. It would be unfortunate, however, if we were to take almost a backward step. Although, as Carolyn outlined, the Bill would have an impact on very small numbers of people, its mental health impact would be more profound. I just want to say that.

John, I wrote down all your feedback about gaps in services. As I said, I am more than happy to follow up on some of that, and I intend to do so.

I have two points to make on which I would like to hear your views. Carolyn mentioned the briefings that the Committee got last week from the RCM and NIACT. NIACT talked about some of the feedback that it had got from clinicians and doctors, who were saying that some of the arguments made at Second Stage were not based in reality and that they had almost found them insulting. They are fearful about the really important relationship between clinician and patient being damaged. That relationship is based on trust. It needs to be there, and we all have a responsibility to try to maintain and support that relationship, for the clinician and the patient.

One of the other issues that were raised is the fact that this legislation is really complex medical legislation. Doctors have not been consulted on it or been spoken to about it. If you have any, I would like your feedback on the Bill as it goes through its different legislative stages and on any correspondence or conversations that you have had with the Minister about some of your concerns.

**Dr Manderson:** Thanks for that. I am glad that psychological support is being actively looked at and championed. Hopefully, that will bear fruit.

As Carolyn said, it was disappointing to hear some of the language that was used. We need the trust of our patients, and we would see it as a very backward step if the Bill were passed. We would go back to having a very grey area in which we would be trying to make decisions that were based on maternal mental health and well-being. Our trust challenged that, because we felt that the mental health bar in the older legislation was set at a very high level; in fact, we felt that what was happening was not legal. That led to the period of six years in which doctors did not know what they could or could not do. Ultimately, that impacted on us as physicians, but it also impacted on patients. We do not want to go back there, because it was incredibly unsettling for the staff in our units. Some people are not happy with what is happening, while others are really uncertain. To be honest, it is debilitating. If the Bill passes, we fear that doctors and patients will be back in a very difficult situation.

The small numbers would definitely be very affected, and there would be a ripple effect on their wider family and on the other decisions that we currently make with certainty. We might then think, "Is it OK to make that decision or not?". Carolyn was clear earlier about how that could affect all of us. We know where we are with the guidelines at the minute. We need to be trusted and supported. We have multidisciplinary teams, good governance, post-mortem backups and regular meetings with our pathology colleagues over in Alder Hey Children's Hospital. Although Alder Hey is in Liverpool, it offers a really good service to patients from Northern Ireland. It is a much better service than we had when our service was collapsing here for years. Our reports have a much quicker turnaround. It is not ideal, because we would love to have the same quality of service based here at home, but that is a discussion for another day. We have good supportive links with Alder Hey. Alder Hey staff have been in all our hospitals discussing issues, so we have that backup. We therefore urge people not to change things, to continue to be supportive and not to use the inaccurate language that has been used. Carolyn may want to say something about that, although she may have dealt with it earlier in the conversation.

**Dr Bailie:** Thanks. To my knowledge, there was no correspondence with any fetal medicine consultants or with my colleagues in wider obstetrics and gynaecology prior to the Bill's introduction.

**Ms Flynn:** Thank you very much, Carolyn and John.

**Ms Hunter:** I thank John and Carolyn for being here this morning. Your contributions have been very helpful. It is helpful to get a medical insight into aspects of this. I appreciate the point that you made about prenatal screening here. Over the past number of weeks, I have said to other panels that, in comparison with other parts of these islands, prenatal screening is poor. I therefore note your point. Can you give clarity on the point of gestation at which most fatal fetal abnormalities and severe fetal impairments are found? I recognise that every case is unique, but any information will be helpful.

**Dr Bailie:** Most structural abnormalities or suspicions of a severe underlying chromosomal abnormality will be picked up at the 19-20 week scan. Some will be picked up a little sooner. Very occasionally, major fatal fetal abnormalities will be picked up at the booking scan, but most will be picked up at the 19-20 week scan.

**Dr Manderson:** Some come through to us because a number of patients choose to have genetic testing in the private sector. There are tests that can be done on the fetal chromosomes in the maternal blood sample from 10 weeks. There are also patients who come to us at around the 12- to 14-week stage with a diagnosis of a severe chromosomal condition that we know to be fatal or to cause a severe impairment.

You are quite right, however. There is not a wholesale screening programme across all our trusts at an earlier point in the first trimester. We rely on the scan to pick up abnormality.

The other thing to say about that is that not all babies with severe chromosomal conditions have a scan abnormality. When you see a structural abnormality on top of a chromosomal abnormality, it will often be at the more severe end of the spectrum for that chromosomal abnormality.

**Ms Hunter:** Thank you both. That is great.

**The Chairperson (Mr Gildernew):** *[Inaudible owing to poor sound quality.]*

**The Committee Clerk:** Sorry, Chair, but you are on mute.

**The Chairperson (Mr Gildernew):** Thank you, Clerk.

Thank you, Carolyn and John, for your written presentation and for your evidence to the Committee. It has been very useful. I wish you all the very best in your important work. I thank you for attending today.

**Dr Bailie:** Thank you

**Dr Manderson:** Thank you.