Northern Ireland
Assembly

## Committee for Health

# OFFICIAL REPORT
# (Hansard)

## Severe Fetal Impairment Abortion (Amendment) Bill: Mr Paul Givan MLA; Don't Screen Us Out

11 March 2021

# NORTHERN IRELAND ASSEMBLY

# Committee for Health

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**Members present for all or part of the proceedings:**
Mr Colm Gildernew (Chairperson)
Mrs Pam Cameron (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 Heidi Crowter | Don't Screen Us Out |
| Ms Lynn Murray | Don't Screen Us Out |
| Mr Paul Givan MLA | Northern Ireland Assembly |

**The Chairperson (Mr Gildernew):** In relation to this item of business, and to read into the record, the Committee voted, under Standing Order 115(8), on the sponsor of the Bill's request for additional witnesses. A total of six votes were received, all content with the proposal. The following members voted in favour of the proposal: myself, Pam Cameron, Alan Chambers, Cara Hunter, Carál Ní Chuilín and Jonathan Buckley.

I welcome Mr Paul Givan MLA, the sponsor of the Severe Fetal Impairment Abortion (Amendment) Bill, who is here to brief the Committee on the principles of the Bill. I also welcome Lynn Murray and Heidi Crowter from Don't Screen Us Out.

Without further ado, I invite Paul Givan to brief us on the principles of the Bill.

**Mr Paul Givan (Northern Ireland Assembly):** Thank you, Colm, or, to give you your proper title, Mr Chairman, and members of the Committee. I want to read this opening statement for the record, and then we will get contributions from Heidi and Lynn. I will then be more than happy to go into a question-and-answer session.

I am very pleased to have the opportunity to come before the Committee to provide an introductory presentation on the general principles of the Severe Fetal Impairment Abortion (Amendment) Bill. The Bill has been inspired by the advocacy work of the Don't Screen Us Out campaign, in particular the testimony of Heidi Crowter, who is challenging the Abortion Act 1967, which allows terminations on the basis of Down's syndrome and other non-fatal disabilities up until birth.

I am delighted that I have been joined today by Heidi, and Lynn Murray, director of the Don't Screen Us Out campaign. I will invite them to speak after I have provided an overview of the Bill.

Heidi's brave intervention in May last year called on the Northern Ireland Assembly to make it clear that it rejected Westminster's regulations that sanctioned abortion for non-fatal disabilities like hers up to birth. That resulted in the tabling of a motion and a vote that took place on 2 June. On that day, during two votes, 75 Members of the Assembly voted to make it clear that they opposed abortion on the basis of non-fatal disabilities, such as Down's syndrome, up to birth.

Mr Chairman, I agree with your colleague Emma Sheerin, who moved your party's amendment to the motion, when she stated:

> *"To serve disabled people properly, we need to build infrastructure that is totally accessible. We need to have inclusivity to properly service section 75 obligations across all public-sector bodies and to raise awareness of the issues that face less-able people in their daily life.*
>
> *Sinn Féin does not believe that a non-fatal ... abnormality is an appropriate criterion for an abortion." — [Official Report (Hansard), 2 June 2020, p65, col 1].*

I hope that the Committee will agree that it is discriminatory to provide a preborn baby with no protection in law because it has a non-fatal disability, when a baby of exactly the same age is protected because he or she does not have a disability.

Legislatively, the Bill is very simple. It does not engage with any other aspect of abortion law. It simply makes it clear that there is no place for disability discrimination in Northern Ireland in 2021. Through the Bill, there will be no grounds for an abortion on the basis that a baby has a non-fatal disability.

Regulation 7(1)(b) perpetuates falsehoods that have existed for too long in our society about people with non-fatal disabilities such as Down's syndrome: that they have less to contribute to society and are expendable. The regulation encourages society to view those individuals as less valued than people whom we describe as "non-disabled". That sends out a message, loud and clear, as Heidi has eloquently demonstrated, that the lives of people with disabilities as seen as less valuable or worthy of protection than the lives of people without disabilities. To have a law that says that in 2021 is completely unacceptable, and, last June, I described the regulation as:

> *"years out of date and ... a regressive and backwards step in the campaign against discrimination and equality for people with disabilities." — [Official Report (Hansard), 2 June 2020, p77, col 2].*

That is why the Bill has been introduced. The law is discriminatory and disregards the last 30 years, during which many have campaigned and advocated for laws that aim to foster equality and ensure those with disabilities are treated equally to everybody else. That includes laws like the Disability Discrimination Act 1995, which protects the rights of persons with disabilities, and the Northern Ireland Act 1998, which places a statutory duty on public authorities to have:

> *"due regard to the need to promote equality of opportunity"*

for persons with disabilities.

The Committee will know that the Disability Discrimination Order (Northern Ireland) 2006 further amended the Disability Discrimination Act 1995 to include a requirement that public authorities:

> *"promote positive attitudes towards disabled persons".*

Furthermore, in 2009, the United Kingdom ratified the UN Convention on the Rights of Persons with Disabilities. Those laws reflect the fact that every person is of worth and value, a worth and value that should not be changed by the diagnosis of a disability. I use that phrase "diagnosis of a disability" very uncomfortably, because I know that it does not sit well with people who have Down's syndrome to be referred to as having a "diagnosis".

The Committee will also know that, in its report on Great Britain and Northern Ireland, the UN Committee on the Rights of Persons with Disabilities stated:

> *"The Committee is concerned about perceptions in society that stigmatize persons with disabilities ... and about the termination of pregnancy at any stage on the basis of fetal impairment."*

The committee recommended that Great Britain should "amend its abortion law accordingly".

With that recommendation and the disability discrimination legislation in Northern Ireland, how can we justify allowing laws such as regulation 7(1)(b) to exist? Does it support pregnant women who are given the news that their much-wanted child may have a non-fatal disability? There are too many difficult stories of parents feeling unsupported in those situations to continue with their pregnancies. Does that approach promote positive attitudes towards disability and those who are disabled? I want the Committee to consider the message that regulation 7(1)(b) sends to people like Heidi, who has Down's syndrome, and their friends and families. However, Heidi is best placed to share that with the Committee.

The Bill provides the Assembly with the opportunity to amend the current regulation and send a clear message to people with a condition such as Down's syndrome, and to their family, friends and wider society, that Northern Ireland will not tolerate disability discrimination and that they are equally valued.

I would like Heidi and Lynn to say a few words, which will take another five minutes. We will then be more than happy to answer questions. Heidi's mum, Liz, is with her to support her in this session. Thank you, Heidi. If you could say a few words, that would be great.

**Ms Heidi Crowter (Don't Screen Us Out):** Thank you, Paul. Mr Chairman, I thank the Northern Ireland Assembly for voting last June to make it clear that you reject abortion up to birth on the basis of disabilities such as mine: Down's syndrome. I also thank Paul Givan for taking the lead in Northern Ireland by introducing the Bill that Don't Screen Us Out proposes to change the law to fit with that vote. The law in Great Britain and now, sadly, in Northern Ireland tells me and other people with Down's syndrome that we are worth less than those without a disability. Maybe people are even told that living with Down's syndrome is too hard. If you do not believe me, research confirms that people with Down's syndrome and their families are happy with their lives. I am one of them. That is why I want my voice to be heard and the law to be fairer.

My husband also has Down's syndrome. I value him with all my heart; society should, too. The law makes me feel very sad. It is saying that I and people like me may as well have not been born. I was so happy to watch the debate on 2 June last year as 75 Members voted to say that that was not acceptable in 2020.

Mr Chairman, it is special for me to meet you today. I was so excited when I listened to your very kind comments about me during the debate. You said:

> *"Our amendment welcomes the important intervention by disability campaigner Heidi Crowter, who has been referred to today, and rejects the specific legislative provision in the abortion legislation that goes beyond fatal foetal abnormalities to include non-fatal disabilities such as Down's syndrome. I support the amendment." — [Official Report (Hansard), 2 June 2020, p70, col 2].*

Thank you.

It makes me so happy to be here today as you look at the Bill that will make that commitment a reality. Thank you for caring about people with Down's syndrome. Thank you for listening, and stay happy.

**The Chairperson (Mr Gildernew):** Thank you, Heidi. Your voice has absolutely been heard. Thank you for that contribution.

We are going to Lynn.

**Ms Lynn Murray (Don't Screen Us Out):** Thank you for letting me speak here today. In Great Britain, 90% of babies found to have Down's syndrome are aborted. That is a shocking statistic in our inclusive society. In response to that, the Don't Screen Us Out campaign works across the whole of the UK seeking the reform that would afford the appropriate support to pregnant mothers and people with Down's syndrome.

Down's syndrome does not discriminate. People with the condition are to be found all over the world and in every social group. As such, our campaign represents families and people with Down's syndrome from a wide range of backgrounds who hold a wide range of views about issues such as abortion. For our campaign, this is not an abortion issue; it is a discrimination issue. Twenty-one years ago, when my daughter, Rachel, was born with Down's syndrome, society had a very different view of disability. Equality laws were just in their infancy. Even as some people's perceptions are beginning to change, it is still the case that most people do not understand what it is to live with Down's syndrome. In Great Britain, women are often making decisions about their wanted pregnancies without full knowledge of the reality of life with the condition.

Survey work commissioned by Public Health Scotland and published in 2019 reveals that, while Down's syndrome was known, most respondents admitted that specific knowledge of Down's syndrome was limited. That is why we applaud the Assembly for rejecting the Westminster regulations that promote abortion for non-fatal congenital conditions in June last year and why we are delighted that Paul Givan has subsequently introduced the Bill on severe fetal impairment. The Bill is important because it will send a clear message that Northern Ireland promotes equality and consideration for those with Down's syndrome. A move in this direction will make the way for other countries to follow.

Clearly, screening and abortion for disability has had a profound negative impact on those found to have congenital anomalies. Despite these impacts, people with the screened-for conditions are rarely consulted. Meaningful consultation in those matters has to include people like Heidi Crowter, and I applaud the Committee for having her speak today. Add to her perspective the conclusions of a small study of people with Down's syndrome published in 2017 for the Nuffield Council on Bioethics non-invasive prenatal testing (NIPT) report, which, according to the study's author:

> *"highlighted a negative societal view of disability which"*

people with Down's syndrome:

> *"described in terms of lack of understanding and fear; standing in stark contrast to their own more positive life experiences."*

Northern Ireland is required to have an abortion law that does not perpetuate stereotypes. The way to do that is to support Paul Givan's Bill, because singling out a minority group on the basis of potential disability perpetuates a stereotype. That much is clear from the picture that we have seen developing in Great Britain over the years where life with disability is conveyed in a medicalised manner.

Moreover, obligations under the Convention on the Rights of Persons with Disabilities entail that disabled people and their families should be accommodated, included and supported by society. Yet the evidence suggests that parents of children diagnosed with congenital disability are not given the information and help that they need to choose to bear and raise a disabled child.

Evidence also suggests that an unconscious bias exists in many areas of life, and particularly in antenatal situations where women are offered an abortion as soon as it is found out that their baby has Down's syndrome, and women's decisions to continue with these wanted pregnancies are questioned time and again. In a survey published in 2019, of 208 women who found out that their baby had Down's syndrome, 69% were offered a termination in the same conversation.

We agree with the sentiments expressed in the Assembly earlier this week that we:

> *"need to stop the perpetuation of stigma around such conditions as Down's syndrome." — [Official Report (Hansard), 8 March 2021, p11, col 1].*

The move to change a regulation that is clearly discriminatory is a good place to start.

**The Chairperson (Mr Gildernew):** Thank you very much, Lynn. I will go straight to members' questions.

**Ms Hunter:** I thank the panel for being here today. My question is to Paul, the proposer of the Bill. Thank you for being here and for your opening statement. What level of engagement have you had with the Human Rights Commission, doctors, clinical groups, the Equality Commission and women's groups? If you could detail any responses that you have had, that would be great.

**Mr Givan:** The Bill has been introduced to the Assembly, and I hope that it comes through on Monday to Second Stage. That would allow the Committee to call for evidence and get all the stakeholders to provide responses.

The most significant consultation exercise that was carried out on this area was the Northern Ireland Office's consultation on its regulations on the entirety of abortion law. This Bill relates to a very narrow area, but, of those thousands of people who responded, 79% said that they were opposed to what Westminster was doing. This Bill focuses in on the one area of the Act that relates to and interfaces with discrimination legislation. I have an open-door policy on engagement, and I have already engaged in correspondence with the Human Rights Commission. Members will be familiar with how laws are enacted. A Bill is introduced, and that automatically goes to the Human Rights Commission. The Committee that will scrutinise a Bill will put out a call for evidence, and everybody can carry out the scrutiny process. My door is open, and I will engage with anybody on the issue because it is important that we have this debate, and, hopefully, we can take things forward to address this legislation.

**Ms Hunter:** Statistically, on average, how many abortions under those criteria currently happen in the UK? How many women from Northern Ireland have to travel to get abortions on those grounds?

**Mr Givan:** Statistics are available on the number of abortions that are provided in Great Britain. On our new legal framework in that regard, I have asked to be provided with a detailed breakdown of the grounds on which a termination of pregnancy had taken place. As we know, in our laws, it is up to 12 weeks for any reason, so specific identification as to the purpose of the termination of that pregnancy is not needed. However, since the laws have come into place in Northern Ireland, approximately 1,100 terminations have now taken place.

I have figures for Great Britain that relate to 2018 statistics. I would rather be precise, so if you give me one second, I should be able to get that at my fingertips. Sorry, I just do not have the precise details at my fingertips. Lynn may be able to assist me on that question.

**Ms Murray:** I was about to say that I have the stat here. I meant to have this in front of me, but I just did not have time. For Down's syndrome, you are talking about roughly 700 abortions a year. There were 656 in 2019, and I think that we had a stat that maybe one person travelled from Northern Ireland in one of the years. I might be wrong on that. We can check that and submit it.

**Ms Hunter:** Thank you, Lynn and Paul. If you get any further information, I would be really keen to see it.

My last question refers to pathways. I am curious about what happens if a woman receives a diagnosis of a non-fatal fetal abnormality and decides to carry to term. Can you outline what financial or counselling support are available? On the other side of the argument, what happens with women who do not wish to carry to term? What do the days after diagnosis look like for them if they wish to seek an abortion? Do you have any information on that?

**Mr Givan:** The question about financial support for people is a really good one. Lynn can talk to that, but that came through. Many families felt that there was a lack of support, and they would have liked support. The Committee on the Elimination of Discrimination against Women (CEDAW) recommendation states:

> *"ensuring appropriate and ongoing support, social and financial, for women who decide to carry such pregnancies to term."*

However, Westminster did not regulate for that. Westminster implemented all the other aspects but did not put into law the provision of support for people who want to go through. That speaks to the very issue that I am highlighting about inequality and the way in which people with disabilities are treated. You raise an important point, and that support needs to be made. There is research around that, and I refer you to the 2018 survey carried out in Great Britain of 1,410 women who gave birth to babies with Down's syndrome. It goes back to 2000, so that is over 21 years ago. The research stated that 69% of those women were offered a termination in the very same sentence in which they were told that the condition had been identified. Almost 70% of those women were asked about a termination when the news had just been broken to them. We know that that news will come as a shock to people. We are under no illusions that it will come as a shock. After the women advised that they wanted to continue with the pregnancy, 46% of them were asked again if they wished to terminate. That begs a question about the pathways of care and support so that people feel that they have support. Based on that survey, the evidence indicates that that support is not there.

Sara McNeill, who is married to Peter and lives in Ahoghill, just outside Ballymena, has a lovely little Down's syndrome boy called Tom. She has spoken about why she supports the Bill, and I want to put her words on the record. She said that people should:

> *"Not to be blinded by poor, outdated preconceptions of what Down's syndrome is. I thought our outlook seemed bleak when our doctor first shared her suspicions about our brand new baby … but now I know better and, because I do, I am going to shout about how amazing our boy is".*

There is a real challenge for us as legislators in looking at the kind of environment in which that news is provided to people and what kind of support is given. We need to challenge that, and the Bill speaks to it. Lynn, do you want to pick up on that point as well to provide some of your experiences?

**Ms Murray:** In 2017, the Nuffield Council on Bioethics called for new guidance. There is guidance on the termination of a pregnancy, and the Royal College of Obstetricians and Gynaecologists (RCOG) was asked to rename those guidelines and to expand them to include references and guidelines for people to continue with pregnancy, but that has not come forward yet. We are still, sadly, lacking that sort of thing in the rest of the UK. We definitely need that. Emotional support is definitely the greater issue. When my child was born, someone said to me, "This might come as a shock". We all understand that it is a shock for some people, and we have to help them to understand what it means.

**Ms Hunter:** Thank you, Lynn, for your contribution, and thank you, Paul. I will touch on my last point, Paul, but I know that we are stuck for time. If a woman is told of the diagnosis and does not wish to carry to term, are you saying that, if the Bill were to pass, she would have to travel to receive that kind of healthcare?

**Mr Givan:** The Bill is in no way about condemning women. It is very much intended to send out, as a society, a clear message that living with a congenital disability is living with a good life, and that is what the Bill speaks to. We need to provide that support. The Bill speaks to the basis on which the termination of a pregnancy can be permissible in our law. This is purely on that condition of non-fatal disability after 12 weeks and right up to birth. It does not change the abortion law in any other area. That can be a debate for another day. The Bill sticks to a single ground upon which a termination can be granted, and it would remove the right to terminate solely on the basis of a non-fatal disability. The other aspects of abortion law would remain intact. The physical and mental welfare of a mother are grounds for permitting a termination, and that has been the case in Northern Ireland for many years. Does the Bill remove the grounds that an abortion can be granted purely because somebody at that preborn stage has a disability? Yes, it does. I am clear on that. I believe that that is very much in line with international best practice and international law.

The United Nations has spoken on that, and people have invoked the United Nations convention on the issue. The UN Convention on the Rights of the Child makes it clear. It says that there needs to be:

> *"special safeguards and care, including appropriate legal protection, before as well as after birth".*

The Bill is therefore very much in line with the United Nations Convention on the Rights of the Child. I want the best law that supports and protects the pre-birth stage of life, and I also want to have the best laws in place that support and protect mothers and families who are going through pregnancies.

**Ms Hunter:** Thank you, Paul. Again, I thank the panel for their time today.

**Mrs Cameron:** Thank you, Paul, Lynn and Heidi. Heidi, I wanted to speak to you first, briefly, if that is OK. It is lovely to see you today, Heidi, looking so well. I wanted to congratulate you on your marriage. I am sure that it was a wonderful day for you and your husband and, indeed, for your family. Thank you for being here at the Committee today, and thank you for all your efforts, Heidi, and for your bravery in campaigning to end discrimination against those with Down's syndrome. Heidi, can you tell us what supporting this Bill means to you personally?

**Ms Crowter:** I support this Bill because I am someone who has Down's syndrome, and I think that it is a fantastic Bill. I think that we should have the same protection as any other baby. My nephew is 10 years old, and I am 25, but we are still humans and we still have the right to life.

**Mrs Cameron:** That is great. Thank you, Heidi.

**Ms Crowter:** I am someone who has Down's syndrome, and my nephew does not.

**Mrs Cameron:** Thank you so much. Heidi, I was looking at your Twitter, and I love your quote about seeing my ability and not my disability. You can certainly see your ability. That is wonderful. I think that you are truly inspirational, and I want to thank you again. Thank you very much.

I will move on to the Bill and a very quick question to Paul. Thank you for bringing the Bill to the Assembly. My office has been inundated with calls for me personally to support the Bill, and, obviously, I will be doing that. There are many supporters of the Bill, even at this early stage, from my point of view in my constituency of South Antrim. Paul, what wider political support, if any, have you received to date?

**Mr Givan:** Thank you, Pam. Like yours has, my office has been inundated with correspondence supporting the Bill. Obviously, as I indicated in my opening statement, this was to introduce a piece of legislation based on a motion that the Assembly passed. There was the amendment as well, and this was the area where there was the greatest consensus amongst Assembly Members in their opposition to what had been imposed on us by Westminster. Therefore, I hope that widespread support will be expressed on Monday, particularly to allow the Health Committee to get into the detailed scrutiny work on it. It is important that the Bill be tested — every piece of legislation should be properly tested, scrutinised and interrogated. I hope that the Assembly will allow the Bill to proceed to its next stage.

The Bill is in my name. I accept that because the rules of the Assembly allow only a single MLA to sponsor legislation. I wish that it allowed other Members to do so, but the Bill has been taken forward with a wider political consensus on it. The Don't Screen Us Out campaign issued a press release today, and I am really pleased that it got political support from Members such as Trevor Lunn, who has indicated that he will be voting in favour at Second Stage because of the discriminatory aspect of this law when it comes to disability. I am pleased that Dolores Kelly has put her support for the Bill on public record. She said:

> *"I hope that this Bill gets the support it needs and that people with disabilities here in Northern Ireland will be reassured of society's protection and support."*

That is very welcome. Robbie Butler has also expressed his support publicly. He says:

> *"Currently abortion law in Northern Ireland does not value the lives of those with disabilities. It is damaging and it is wrong."*

That is welcome. Councillor Doyle from Aontú has gone on the record that Aontú supports what the Bill is about because of how it discriminates on non-fatal disability. That is really welcome.

I have made the point before that these issues cross political boundaries. It should never be viewed in the political-identity politics that we have in Northern Ireland because we all have shared ambitions and objectives to tackle discrimination. I am really pleased with the public political support that has been expressed by a range of MLAs and political parties. What has been most impactive, from this Bill went public, with respect to the political class that we are all part of, has been voices like Heidi's and people like Sarah from Ahoghill. I have listened to Laura and Lyndsey who have spoken about how they have children with this condition and they support the Bill. They are not viewing it through the debate on pro-life or pro-choice; they are viewing it as discriminatory legislation. What does that message say to their child who will grow up in this society? Here is a law that, pre-birth, would have been grounds for their life to be ended. They do not think that that is appropriate. Their voices have had the most impact, and they are raising awareness. I am humbled, to be honest, that this is providing a platform for those people to have a voice and be heard.

**Mr Carroll:** Thanks for your comments and contribution, Heidi. I have a couple of questions for you, Paul. You did not have the figures for Cara, but do you have any figures on the late termination of pregnancies in the North? For example, what gestation period they happened in and the reasons for them. Do you have any evidence that those decisions were solely or primarily based on disability diagnosis? Are you aware of how many people from the North went to Britain before the legislation changed to seek a termination after 24 weeks? How many cases were specifically related to a cleft-palate diagnosis?

I have a few other questions, but I will let you respond to those first.

**Mr Givan:** Thank you, Gerry. For some of those questions, I cannot provide detail. Apologies to Cara, but I now have the figures; I have found them amongst my papers. These figures are from 2018. They are the latest that we have and relate to those that took place in England and Wales. There were 3,269 abortions undertaken because of what is termed fetal abnormality. O those, 618 abortions were recorded as Down's syndrome being the principal reason. Eighteen of those were after 24 weeks, which we know that even in our law in the 1945 Act, is the point of viability. Those are the figures for 2018.

I have been seeking precise figures for Northern Ireland. I have questions for which responses are outstanding for weeks. They are some of the best figures on the general principle that the Bill seeks to address, specifically on the number of abortions for Down's syndrome. In total, 3,269 were for fetal abnormality. That is the point that I go to, Gerry, in the Bill. The severe fetal impairment is undefined on what it covers, but it is deliberately mirrored on the 1967 Act, which speaks about "seriously handicapped". The interpretation of seriously handicapped includes Down's syndrome, cleft lip and club foot. That is what this law is mirrored on in Northern Ireland, and that is why I am seeking to have it changed. I appreciate that there are some specifics that I have not been able to answer, but that is something that we want to get more specifics on.

If I can make a wider point, I accept that the numbers that we are talking about are small. However, that is exactly why, as a society, we should seek to protect minorities and make sure that there is no discrimination against minorities. It is all the more reason why we need to act. This has an impact upon those such as Heidi, who are very much alive, and yet they see a piece of legislation that they regard as discriminatory. This speaks to where society is for those who are alive, their family and friends and how that impacts on how wider society views people with this condition.

**Ms Murray:** I have a stat from one of our press releases in 2016: in Northern Ireland 52 children were born with Down's syndrome, and one was aborted. If you look at that stat compared to Great Britain, where 90% of women who find out that their baby has Down's syndrome who go on to abort.

**Mr Carroll:** Thank you. I would take issue, Paul, with this conversation about standing up for minorities and your party's record on supporting welfare reform and other regressive measures, but we will maybe get into that in another discussion and debate.

Paul, have you spoken to any fetal medical consultants? Are you aware of the scale of the waiting lists for people who are trying to get access to speech and language therapy in your constituency, as well as other areas across the North?

**Mr Givan:** I have a meeting lined up with the General Medical Council (GMC) tomorrow in advance of the debate. In previous capacities when this issue was discussed at length, in the wider debate on laws in Northern Ireland, I met the Royal College of Obstetricians and Gynaecologists (RCOG) and have had many discussions about this subject. This is where the Committee has an important role in calling for evidence and hearing directly from people who will be able to give their views, and I welcome that engagement.

One of the medical practitioners whom I have spoken to and who has gone on the record on this is Dr Sarah Harris. She is a general practitioner but also works in other spheres in the medical field. She says:

> *"As a medical professional, I am involved in supporting individuals throughout their life’s journey, from birth to death. I know first-hand how they provide joy and happiness to everyone around them. I have seen how many of them lead full, vibrant and fulfilling lives with numerous opportunities available to them".*

In that context she goes on to say about the current law:

> *"Its existence implies that those living with disabilities are in some way inferior and not entitled to the same chance in life as those of us who merely had the privilege of living with good health. Being born with a disability does not make you any less likely to lead a fulfilling life than anyone else. To make this assumption is contrary to everything I stand for as a medical professional."*

There may well be differing views on this in the medical profession, but that is one medical professional who is very much in favour of what the Bill is seeking to do.

**Ms Bradshaw:** Thank you, Paul and to the panel for being here today. This is a really important conversation. Since you are here to talk about the general principles of the Bill, Paul, I want to put on record that I have been engaging with a wide range of opinions on this. That included an online pro-life event that I attended on Monday night. It was interesting to hear you say that your door is open. The group indicated that it had tried to secure a meeting with you and that, to date, you have refused. The group feels disenfranchised, as you have worked with Care UK in London but have not worked with local pro-life groups on the Bill. The group is disappointed, as your party's pledge was to make the repeal of all abortion regulations the first item on the agenda when the Assembly was restored. What do you say to that group? The group is disappointed that this Bill does not outlaw abortion in its entirety.

**Mr Givan:** Thank you, Paula. I am sure the Center for Bio-Ethical Reform (CBR) will be delighted that you are advocating on its behalf. On the wider debate, I am going to stick to the principles of the Bill. I appreciate that some members may want to stray into a much bigger debate on abortion law. Whether you are pro-life or pro-choice, this Bill is about abortion law and disability discrimination. On that point, I have met any organisation that has sought to meet me on this issue, including that group. Factually, what you say is inaccurate.

The general principles of the Bill relate to disability discrimination legislation. That is what it is about.

**Ms Bradshaw:** Thank you, Paul. I thank Heidi and Lynn. It is great to have you here today. I have spoken about how much we loved my aunt who had Down's syndrome. You are absolutely right to challenge societal attitudes towards people with Down's syndrome. Thank you for your contribution this morning.

Last night, I read the Don't Screen Us Out paperwork, and I will focus on that if you do not mind. The screening process for Down's syndrome also looks for Edwards' syndrome and Patau's syndrome. Is the Bill suggesting that the screening process should be removed as part of antenatal services? In the Republic of Ireland, there is a list of severe fetal impairments that cannot be the basis for a termination diagnosis. As you know, Paul, there are about 40 severe fetal impairments that our fetal medical consultants know a lot more about. It takes about 18 to 20 years for medical consultants to get to the point where they understand fetal medicine. Is it better to isolate Down's syndrome and some of the severe fetal impairments as not being grounds for abortion as opposed to all the 40-plus conditions that medical professionals are screening for?

**Mr Givan:** Paula, that speaks to the weakness of the legislation that Westminster imposed on us: it did not define severe fetal impairment in the regulations. That is one of the problems. Therefore, it is about the interpretation and mirroring of how the legislation, based on the 1967 Act in Great Britain, has been implemented. I am fully aware of the non-invasive prenatal testing that takes place. My answer is, no, if that is to be a pathway to provide the support that needs to be available for people. Lynn can speak about the terminology of screening, and that is why Don't Screen Us Out is the name of the organisation. In other countries, we see the language of "screening out" or "eradicating a diagnosis", as though, somehow, there has been a cure. We need to be very careful with that kind of pejorative language and what the screening exercise is about. Lynn, maybe you want to pick up on the impact of screening?

**Ms Murray:** We are not against screening per se, but it has to be done in a way that reflects how we think in the 21st century. We will be screening for a much wider range of conditions; that is why this is important. While we are looking at small numbers today, there are a lot of other conditions that may be brought into screening. The introduction of NIPT has been at a good time for our campaign to stop the discrimination against Down's syndrome and ask about screening. Are we doing it the best way that we can or are we creating more stigma around congenital conditions? Does that make sense?

**Ms Bradshaw:** Absolutely. I appreciate that. That cuts to the heart of the fact that we got the regulations last year when none of us was in the Assembly. Paul and I were on TV about three years ago, and I said then that I wanted this debate and that I wanted any decision on abortion legislation or regulations to take place through this sort of process and not through Westminster. However, we are where we are, so I fully agree.

This is more of a wider statement than a question, but the Regulation and Quality Improvement Authority (RQIA,) which is our local regulatory body, might have a role in looking at the full range of issues that you have raised today about the language used by our healthcare professionals when a diagnosis is made, the type of screening, the timing of screening, and support services. Some trusts have a psychologist or a social worker on board if there is a diagnosis; others do not. Therefore, we need to do a lot of work to support families. People say that I am pro-abortion. I want to put on the record that I am not; I am pro-choice, but I want to make sure that women are absolutely supported in this issue.

The third question, Paul, is about the potential if the Bill passes into law that women will seek an abortion before 24 weeks on grounds of mental or physical impairment. When I met fetal medicine consultants on Friday evening, they said that, when you get a diagnosis at 20 weeks, regardless of the condition or impairment, it takes a couple of weeks for further tests, scans or other investigatory work to take place that may take women over the 24 weeks, which then means that there is the potential that women will use those grounds in law to have an abortion at 23 weeks plus six days, rather than give themselves the opportunity to find out the full facts so that they can make a fully informed decision as to whether they would carry the fetus to term. Can you speak to the potential for unintended consequences of this sort of amendment?

**Mr Givan:** Thank you, Paula. That argument can be applied equally to every other form of pregnancy. We are all familiar now with the law: it is up to 12 weeks for any reason. The issue that I and others have is that, after 12 weeks, there are three grounds under which a termination is permissible under the law: the mother's physical or mental health; what is termed "fatal fetal abnormality" or life-limiting conditions; and severe fetal impairment. All other pregnancies are protected in law after 12 weeks, but here we have a category that is singled out as not being protected. The argument that it will lead to mothers giving their physical and mental health as a reason why they cannot proceed with a pregnancy can be applied  equally to every form of pregnancy that is no longer permissible under the law after 12 weeks. So, I do not think that it is unique in the context of this law that discriminates on the grounds of disability.

**Ms Bradshaw:** Chair, I have one very small question.

**The Chairperson (Mr Gildernew):** Be very brief, Paula, please.

**Ms Bradshaw:** You will be aware that the IONA test can be purchased for £320 from private healthcare providers at 10 weeks, and it can identify Patau's syndrome, Edwards' syndrome and Down’s syndrome. Based on what you just said, if a woman got a scan at 10 weeks, she could terminate the pregnancy. So, what you are doing is almost creating a situation in which women who have the means could get a termination while those who do not have the money could not. What is your response to the socio-economic consequences of what you propose?

**Mr Givan:** I do not believe that this should be viewed through the economic advantages or disadvantages when it comes to classes in our society, and I would not want to view the protection of people with disabilities on that basis. I do not accept the narrative about having the means to pay. We need to look at what has happened. Lynn can speak to this better than I can, but what have the consequences been where non-invasive prenatal testing has taken place in Great Britain? It has led to an increase in terminations for people who have Down's syndrome. How does it help, when we have a duty to promote and defend people with disabilities, that that process has led to greater disadvantage for that minority in our society? Lynn will be able to give better examples of that than I can.

**Ms Murray:** Just to be clear, IONA and the other tests are still screening tests. They will provide a screening result, but they are not very reliable for younger women. Although they are quite reliable for women in older age groups, they are just another screening test. Although people may get results at that time, I do not see that that would be a major issue. As I say, you still have to go in and have all the different tests.

A report in 'The Sunday Times' about NHS hospitals in England that are using NIPT said that births in those hospitals have reduced by 30% compared with hospitals not using NIPT. That is the issue that we have to keep coming back to: we can introduce new tests, but we do not seem to be hitting the issue here, which is that women are still seen to be afraid of the outcome. It is such a speculative thing to say how your life is going to be. As Heidi said, we know that people who have children with Down's syndrome are happy, and the research is telling us that. That is where it is all very different from it being about abortion; it is about women being reassured that their life is not going to be bad — it is still going to be good.

**Ms Bradshaw:** Thank you; I fully understand that. I was just trying to get to the technicalities of the Bill.

**Mr Buckley:** I thank Paul for briefing us on the general principles of the Bill. I look forward to further debate and scrutiny at the stages of the Bill's progress. I will be supporting the Bill on Monday: I support its intentions, as I believe that the current law is discriminatory and wrong. I do so on behalf of the thousands of constituents in Upper Bann who have been in touch with me who equally believe that the law is discriminatory and wrong.

I am excited to see that Heidi is with us today. Heidi, you are very welcome, and thank you very much for your briefing to the Committee. You have been an inspirational young lady for disability rights. There are many people who now know you as a household name in Northern Ireland because of everything that you have done, so thank you very much. You have given a voice to those who have otherwise felt voiceless for far too long in this process, so we really thank you for that. I want to hear about your life: I want you to tell us what led you to be involved in this campaign and how, day to day, you view the discriminatory legislation in relation to your life.

**Ms Crowter:** I got married in July 2020. *[Inaudible.]*

**Ms Murray:** Do you remember, Heidi, in 2016, the first time that we met outside Parliament?

**Ms Crowter:** I first got involved when my mum and I met an amazing lady called Lynn Murray. *[Laughter.]* That was outside the Houses of Parliament. I got involved because, in 2018, the Government were going to bring in NIPT without consultation. Don't Screen Us Out is a fantastic campaign, which is led by an amazing lady.

**Mr Buckley:** OK, thank you. How does it make you feel when you hear people talk about crisis pregnancies and devastating diagnoses because a baby has Down's syndrome? How does that make you feel as an individual?

**Ms Crowter:** It makes me feel that I want to go back to my mummy's womb.

**Mr Buckley:** OK. We really appreciate you appearing before the Committee today, and we look forward to further engagement with you as this process continues.

Lynn, what impact has the law had in Great Britain in influencing how the medical profession responds to pregnancies that *[Inaudible.]*

**Ms Murray:** Is it me, Chair?

**The Chairperson (Mr Gildernew):** Yes, go ahead, Lynn.

**Ms Murray:** I have lost —. It is exactly what we said. Everything has become quite medicalised, and people are trying to convey a life based on a list of medical issues, and you simply cannot do that. That is precisely why we have to come to realise that a life of disability should not be assessed on a list of medical issues.

You do not meet someone and they immediately tell you all about their medical issues because you will begin to judge their life. It is something that you might start to talk about later. I would not meet you, and say, "I've got a heart condition", but that is very much how this issue is introduced. It is introduced as a medical list of things, and people then say, "Well, how can we deal with that?". That is very much only a little part of life and not the fuller part of life.

That list is so speculative. Nobody is going to have everything that is on the list. There are also things that people with Down's syndrome, for instance, are less likely to get than the rest of society, such as cancer tumours, but, again, we do not present that positive view. So, it probably becomes a very negative way to focus and *[Inaudible]* consulting people with Down's syndrome, we do not understand that this is not how a life is.

**Mr Buckley:** Have women and fathers felt supported to continue with pregnancy? Has that been an experience?

**Ms Murray:** No. People who were given the news, at best just under 50% were told in a negative manner. Some were told in a neutral manner, and one or two in a positive manner, but almost half of those told were told in a negative manner.

My daughter was born 21 years ago, when my experience, as I now know, was actually fine. However, the stories that I hear, right up until this year, are that people, even when they have made a decision based on an earlier scan, at the next scan they went to, they were taken into a room, and told, "Oh, there's a region here in the brain and it's OK now, but if it's not OK the next time, you can then think about your decision". They were saying to me, "We have already made our decision. Why are they questioning us?". We just cannot seem to get away from that because there is always the idea, "Well, you can abort up to birth, so we'll have to keep *[Inaudible]* the way you're sure about what you want". That is the gaslighting that women are exposed to.

**Mr Buckley:** I thank Lynn, Heidi and Paul, and I look forward to further engagement as we go through the Bill.

**The Chairperson (Mr Gildernew):** I remind members that we are here to discuss the principles of the Bill. I do not want those who have come along to be put on the spot with personal-type questions. We respect the fact that they are here to assist with the principles of the Bill.

**Mr Chambers:** I thank Heidi, Lynn and Paul for their very useful presentation.

Over the past three weeks, I have received a huge postbag of emails and letters about this Bill. If any of those who contacted me and did not receive a response are listening, I apologise but I am working my way through them, and everyone will receive an acknowledgement.

I find this an emotive and sensitive subject. I welcome the forthcoming debate on this focused piece of legislation, which is designed to protect against disability discrimination. I will be supporting it as it makes its way through the Assembly process.

**The Chairperson (Mr Gildernew):** I thank the sponsor of the Bill, Mr Paul Givan MLA; Lynn Murray; and you, Heidi, for coming along today and assisting the Committee in its consideration of the principles of the Bill. Thank you very much. Good luck to you all. Please take care and stay safe in the time ahead.

**Ms Murray:** Thank you.

**Mr Givan:** Thank you.

**Ms Crowter:** Thank you. Have a good day.

**The Chairperson (Mr Gildernew):** You, too, Heidi.