Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT
(Hansard)

Severe Fetal Impairment Abortion (Amendment) Bill: Mr Christopher Stalford MLA

7 October 2021

NORTHERN IRELAND ASSEMBLY

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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
Mr Christopher Stalford

Witnesses:

Mr Stalford	MLA - South Belfast
Ms Lynn Murray	Don't Screen Us Out

The Chairperson (Mr Gildernew): I welcome in person Christopher Stalford MLA, the sponsor of the Bill; and, on screen, Lynn Murray, director of Don't Screen Us Out. Lynn, can you hear us OK?

Ms Lynn Murray (Don't Screen Us Out): I can hear you OK.

The Chairperson (Mr Gildernew): We can hear you clearly, Lynn, but we cannot see you. I wonder if there is a camera issue at your side. We can operate with that OK, so, if you do not manage to get the camera going, do not worry.

Ms Murray: OK.

The Chairperson (Mr Gildernew): I invite Christopher to brief the Committee.

Mr Christopher Stalford (Northern Ireland Assembly): Thank you very much, Mr Chairman. Before I answer whatever questions you and the Committee may have, I thought that it would be worthwhile to set out some of my views on the Bill and respond to some of the issues that have been raised in oral evidence.

This is the first opportunity that I have had to speak on the Severe Fetal Impairment Abortion (Amendment) Bill since taking over sponsorship on behalf of my party colleague, the now First Minister, Mr Paul Givan. It is important that I commend Paul for his work on the Bill and thank Don't Screen Us Out and, in particular, Heidi Crowter for their work in fighting against disability discrimination and their work on the Bill. I am grateful that Lynn Murray, whom we have heard from already, is also here to assist in answering your questions.

It is only right that we start by reminding members of the words of Heidi in her brave intervention in May last year, when she called on the Assembly to make it clear that it rejected the regulations that Westminster has sought to impose on us, which allow for abortion on the basis of non-fatal disabilities up to birth. The law has been described by Heidi as making her feel worthless. It is worth noting that the Assembly has been consistent in its support for equality and for creating a society free from disability discrimination. It was a source of profound joy to Heidi and her fellow campaigners when, on 2 June 2020, the Northern Ireland Assembly passed two motions on the issue. Through those two votes, it was clear that 75 MLAs opposed abortion on the basis of non-fatal disabilities such as Down's syndrome. We have heard talk in other contexts about indicative votes. It is my sincere hope and belief that that is an indicative vote of where the Assembly stands on the issue.

Over a year later, what has changed? I hope that the Committee agrees that it is plainly unfair to provide an unborn, viable baby no protection in law because it has a non-fatal disability while a viable baby of exactly the same age is protected because it does not have a disability. That is what is at the heart of the Bill: a recognition that that situation is wrong. The Bill is simple and modest in its scope and ambition. It does not engage any other aspect of the law; it simply reinforces that there is no place for such a situation to exist in Northern Ireland in 2021.

As the law stands, under regulation 7 of the Abortion (Northern Ireland) Regulations 2020, access to abortion on the grounds of disability would be available in two circumstances. The first is if

> *"the death of the fetus is likely before, during or shortly after birth".*

The second is, and again I quote the regulations:

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

Under the Bill, there would be no grounds for an abortion on the basis of the second category, where the baby has a non-fatal disability. That is it. This is a single-clause Bill; it is a simple measure to address the issue.

Regulation 7(1)(b) perpetuates stereotypes that exist in our society concerning people with non-fatal disabilities such as Down's syndrome, namely that they are expendable, that they contribute less and that their life has less value than the life of people who are not disabled. The message that the regulations send out is clear, as Heidi has so eloquently voiced: the lives of people with disabilities are less valuable and less worthy of protection than the lives of people without a disability.

Paul Givan has described regulation 7(1)(b) as being years out of date and a regressive step in the campaign against discrimination and for equity for people with disabilities. I wholeheartedly agree with that sentiment. To have that type of law on the statute books in the 21st century is completely abhorrent. It is not representative of the society that I and, I believe, the vast majority of people want to live in. That is why I agreed to take over as sponsor of the Bill when Paul became First Minister. The law is discriminatory. It discounts the past 30 years of campaigning and advocacy for laws that aim to foster fairness and ensure that those with disabilities are treated as equals. The Disability Discrimination Act 1995 protects the rights of a person with disabilities. Section 75 of the Northern Ireland Act 1998 places a statutory duty on public bodies to:

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

for people with a disability. That was further amended in 2006 by the Disability Discrimination (Northern Ireland) Order to include a requirement that public authorities:

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

In 2009, the UK ratified the United Nations Convention on the Rights of Persons with Disabilities. Those laws reflect the fact that every person is of worth and value, that a person's worth is not subjective or dependent on their capacity to do certain things or to contribute to society in a particular way and that that should not be altered by the diagnosis of a disability. Every life has a value. That is the message that the Assembly should promote. The Bill stands in that legislative tradition and is another strong fairness and equality message. I remind the Committee that, in its 2017 report on Great Britain and Northern, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) stated that it had concerns:

> *"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 United Nations Committee recommended that Great Britain amend its abortion laws accordingly.

In evidence that has already been given to the Committee, you heard about parents in other parts of the United Kingdom being pressurised into making a decision about abortion when a diagnosis of a disability had been made. Laws shape the culture of the society that we live in. Do we wish to live in a culture that places such pressure on parents? The press have reported on the story of Emma Mellor, a woman who faced a situation in which she was asked by her doctors about termination at 38 weeks. She said:

> *"the doctors made it really, really, really clear that if I changed my mind on the morning of the induction to let them know, because it wasn't too late. I was told that until my baby had started travelling down the birth canal, I could still terminate."*

Is that the culture that we want to see being legislated for?

I turn to evidence presented to the Committee in oral sessions and will deal with some of the issues and concerns, particularly those raised by the Royal College of Obstetricians and Gynaecologists (RCOG). In its written and oral evidence submissions to the Committee, it indicated that it felt that the Bill is irrelevant, as such abortions are not happening in Northern Ireland at present. I argue that it presented that evidence in a disingenuous way. Abortion law is changing in Northern Ireland. We all know that. The discriminatory acts outlawed by the Bill will become a reality, if they are not outlawed in legislation.

The Secretary of State, in a statement dated 22 July 2021, said:

> *"I am issuing a direction to the Department of Health ... [and] the Health and Social Board".*

The direction includes a requirement to commission, provide and fund abortion services and to secure the availability and affordability of safe and modern contraception so that they are available "in all of the circumstances" — in all of the circumstances — in which abortions are lawful. These are his words:

> *"This includes access to services in cases of Fatal Fetal Abnormality and Severe Fetal Impairment in line with the Abortion (Northern Ireland) (No 2) Regulations 2020 in any service commissioned."*

The Secretary of State's position therefore could not be clearer: the law in Northern Ireland will mirror that which is enforced in England and Wales. Abortions for non-fatal disabilities will become a reality. If the Bill is not passed by the Assembly, the concerning situation that exists Great Britain, which I have already talked about this morning, will potentially be created here. Parents will be questioned by doctors as to why they have decided not to abort their child if they receive a diagnosis of a non-fatal disability such as Down's syndrome. They may, indeed, be pressured into changing their mind.

The RCOG also commented in oral and written submissions to the Committee that the Bill, if passed by the Assembly, would fetter the decision-making processes of doctors in Northern Ireland. In many areas of life, we as legislators put limits on actions because we believe in having a safe and fair society. It is within our power and our competence to legislate on the matter, so we should do so in whichever way, we feel, will be in the best interests of our citizens and will shape the type of society that we want to live in.

As noted, the Secretary of State has been clear: our law will mirror that of the rest of the United Kingdom. The recent High Court decision in London in the case taken by Heidi Crowter underscores what that means. The law as it stands in Great Britain allows for disability discrimination by permitting late-term abortions. The Heidi Crowter case, which, I am pleased to say, is being appealed and will, I suspect, be ultimately heard before the Supreme Court, highlights that legislation is needed to ensure fairness for people with a disability. This legislation provides that fairness. People in Northern Ireland do not agree with the regulations made at Westminster by the Secretary of State. That means that it is incumbent on us, as the representatives of the people of Northern Ireland, to reflect the law that the people whom we represent want to see enacted.

It is important to note that not all members of the medical profession speak with one voice. The evidence of the royal college must be read in that context. It is written as though all doctors agree; they do not. There is a wide variety of views. What the RCOG has done in its submission is concentrate on the extremely small number of difficult cases and ignore the vast majority of clear-cut cases in which accurate assessments can be made. It is clearly wrong to concentrate on the small number of difficult cases and use that as an argument for why we should not afford protection to those who need and deserve it.

While doctors may be in disagreement, I think that all members of the medical profession would agree with me on this key point: what is needed is better care for mother and baby. The outworking of the Bill will ultimately result in that better care environment, which the RCOG and many others in our community want to see. I agree with the views of the RCOG when it says that antenatal care is not good enough in Northern Ireland. However, rather than liberalising the law or propagating unfairness, what is required is a raising of standards. Simply saying that standards of care are not good enough to cope with the Bill, so the legislation should not be passed, is completely the wrong way to look at the legislation. What is needed is proper care and respect for the needs of babies with disabilities and their parents. The Bill will raise those standards, and our health service could lead the way in ensuring proper healthcare for everyone.

The view of the royal college that the care system cannot cope with the provisions of the Bill simply stigmatises further people with disabilities and is tantamount to an admission that the care of people with disabilities is so difficult that doctors would rather not provide that care than face up to challenging healthcare situations. That view suggests to people with disabilities that their lives bring such complexity to the medical profession that some in the profession would find it more convenient that they were never born. It is for that reason that I suggest that some of the evidence presented by the RCOG and others has been distressing and upsetting for those with disabilities to read and listen to. Many people have felt devalued and demeaned and that they are simply a problem that should be exported to England, rather than Northern Ireland setting up its own healthcare practice that gives them the fairness of treatment that they deserve.

As Mr Justice Horner observed in his 2015 judgement on the judicial review that was taken by the Northern Ireland Human Rights Commission, there is

> *"an illogicality in calling for no discrimination against those children who are born suffering from disabilities such as Down's Syndrome or spina bifida on the basis that they should be entitled to enjoy a full life but then, permitting selective abortion so as to prevent those children with such disabilities being born in the first place."*

In that regard, I want to deal with an issue directly with the Committee. It has certainly not gone unnoticed that the tone of the proceedings of the Committee has taken a different attitude and approach when hearing from representative bodies of doctors compared with the way in which groups who represent those with disabilities have been treated. The Committee turned out in full to question the royal college. There was extensive interaction from Committee members with the medical profession. It is notable and concerning that, in contrast, there was limited interaction with those who represent people with disabilities when they appeared before the Committee.

At its core, the Bill is an attempt to rectify an issue of disability discrimination. It has been reported to me that people with disabilities who believe passionately in that cause have felt distress and discrimination in the way in which they have been treated. It is important that we hear from those who feel that they have not been heard, people who are too often voiceless and invisible in our community. Heidi Crowter, who has bravely taken legal action on the issue in the High Court in London, said:

> *"I want them to see the real me. I don't want to be treated differently because of my [extra] chromosome."*

Hannah Wilson, a young woman from Northern Ireland, has said about the current status of the law:

> *"I felt very sad when this was explained to me, it feels so wrong, it touches my heart. The law should not treat some people differently from others."*

Given the distress that some people associated with those groups have felt, I suggest that the Committee may wish to consider whether it would be appropriate to invite some groups and affected individuals back to the Committee in order to allow their voices to be heard and given equal respect to that afforded to others. Experts may have their place. However, as Harold Macmillan once observed:

> *"We have not overthrown the divine right of kings to fall down for the divine right of experts."*

The issue needs to be addressed. We cannot allow the law to treat a preborn baby with a disability in a way that is different from a baby who faces no disability after birth. The unfairness is clear. What is needed is better care in the system for both child and parents to ensure that every child and family has the same opportunities in birth and life. The Bill gives us, as public representatives, a chance to raise healthcare standards and, at the same time, tell people with disabilities, "You matter, you are valued, your voice is worth hearing, and the Assembly will not allow you to be screened out of existence".

I am grateful to you for giving me the time before the Committee, Mr Chairman. I want to finish with a quote from William Wilberforce:

> *"Having heard all of this you may choose to look the other way but you can never again say you did not know."*

I am happy now to hand over to Lynn from Don't Screen Us Out.

Ms Murray: Thank you for allowing me to speak here today on behalf of the Don't Screen Us Out campaign. As we have discussed before, almost 90% of babies who are found prenatally to have Down's syndrome are aborted in Great Britain where there is that clause relating to disability in abortion law. The high numbers are hardly surprising when the Royal College of Obstetricians and Gynaecologists reports that women tell them that they are having their decisions challenged and being pressured into changing their minds about decisions that they have made on screening and abortion.

Thankfully, the wider culture is changing, with the presence of people with Down's syndrome on platforms such as the BBC. Twenty-year-old George Webster was recently invited as a guest presenter on CBeebies, which is big news, and it was shared widely and enthusiastically in the media and by the public. A law promoting abortion for disability is outdated and an unhelpful barrier to equality for all, and I am sure that we will all agree that legislation should not perpetuate negative stereotypes when every other piece of legislation reflects the principle that we are all equal.

The United Nations Convention on the Rights of Persons with Disabilities requires legislation to foster good relations between disabled and non-disabled people and to advance equality of opportunity. Unfortunately, the law on fetal impairment as it stands requires quite the opposite. It requires the perpetuation of a negative stereotype of disability and that a person with a disability will lead a negative life to create the illusion that there is a choice when an individual finds that their baby has a disability.

In response to the court ruling on the Heidi Crowter case, academic Katrina Scior from University College London, who works on stigma research, recently referred to the extra challenges that families living with disability might face:

> *"To my mind though the solution cannot be to offer exceptions to legal provisions on abortion in cases such as Down’s Syndrome but to improve services and provision for disabled children and their families, to support parents and siblings, and to challenge widely held beliefs that having a child with Down’s Syndrome is nothing but a heavy burden for those 'unfortunate enough' to be the parent or sibling of someone with Down’s Syndrome."*

Women deserve better, and people with Down's syndrome deserve better.

I would like to make one small but important point with regard to the evidence session on 17 June, when two members of the Royal College of Obstetricians and Gynaecologists spoke. At that time, someone in the Health Committee said that there was a

> *"misconception or an inaccuracy in claiming that the majority of diagnoses of Down's syndrome end up in a termination."*

and that they understood that that was not the case. I feel quite concerned, having presented the statistics before, that there is any doubt as to their accuracy. There is accessible data that I can happily share from the Public Health England National Congenital Anomaly and Rare Disease Registration Service report for 2018 showing estimates of prevalence of congenital anomalies in England. Table 10 specifically refers to Down's syndrome diagnoses. In that report, there were 877 antenatal diagnoses made for Down's syndrome. An estimated 747 of those ended in termination, according to the report. I am happy to share that data because it is important that we agree on the basis of the discussions that we are having and are all on the same page as regards the outcomes.

In light of all that we have presented to you up to now, we ask you to consider that the clause on disability abortion is not helping minority groups, including pregnant women and those with a disability. It appears to chiefly serve to perpetuate a view that disability can cause suffering and create extra anxiety for women. We support the Severe Fetal Impairment Abortion (Amendment) Bill, as sponsored by Christopher, and hope that, in the spirit of equality, the Health Committee will too.

The Chairperson (Mr Gildernew): Thank you, Christopher and Lynn. Before we go to questions, I have to say that I do not recognise that a different approach was taken. I disagree with that. I think that we facilitated everyone who wanted to contribute and listened respectfully to everyone. That approach was taken across the Committee.

Mr Stalford: I am happy to address that if you wish, Mr Chairman.

The Chairperson (Mr Gildernew): I will move on to my questions. I disagree with you, Christopher. I believe that the Committee engaged with everyone on a fair and equal basis.

Having heard the evidence and having followed the Committee's proceedings, are you considering any amendments?

Mr Stalford: I have tabled one technical amendment that relates to commencement. Clause 2(2) states:

> *"This Act comes into force on the day on which this Act receives Royal Assent."*

There is some issue around the words "on the day". If the Bill receives Royal Assent at midday, what does that mean? It is therefore a purely technical amendment. I have no intention of tabling any other amendments, nor have I have seen any evidence of further amendments being tabled.

The Chairperson (Mr Gildernew): Sorry, but I do not fully understand what you mean when you talk about the technical amendment. What would the likely impact be if the clause were not amended?

Mr Stalford: The Bill Clerk will be able to give you the full details, but, for a 24-hour period, there would be confusion about when the law had applied. It is therefore a purely technical amendment. The Bill Clerk will be in with you after me, so she will be able to give you chapter and verse. I was advised of the need to do it to make sure that the wording in the Bill is more precise.

The Chairperson (Mr Gildernew): OK. Thank you. Evidence was presented to the Committee that a limited window does not give women and families time to consider everything fully and that it will bring additional pressures. What are your thoughts on that issue, Christopher?

Mr Stalford: The purpose of my Bill, which would amend the 2020 regulations, is to ensure that babies with disabilities are afforded the same care and protection as all other babies, regardless of gestation. Terminating a pregnancy on the basis that the baby would have a disability when born, where that disability is not likely to result in the death of the baby, either before or shortly after birth, communicates a judgement about the value and worth of that person. The screening results should be given in a highly supportive environment, with accurate information provided. The Down's Syndrome Association conducted two surveys — one in 2009, which was repeated in 2014 — to identify the antenatal and neonatal experience of parents of a child with Down's syndrome. Both surveys showed that women did not recall being provided with enough information about Down's during their pregnancy. Although the purpose of the Bill is clearly equity and fairness, it is also to raise the standard of care provided in Northern Ireland, and one way in which the standard of care can be raised is by improving screening services. Lynn, do you wish to speak to that question as well?

Ms Murray: Yes. I very much agree with that. We are trying to push our health services to provide care pathways for women, sometimes to baffled looks, because there is no understanding of what that might mean. When a woman is given news about Down's syndrome, she may have in her mind a stereotype of what Down's syndrome is. More lived experience needs to be presented to women. Ideally, screening would have led to some improved medical outcomes as well, but, sadly, that has not been the case, possibly because of the high levels of abortion. We tend to find that there is not much research done on Down's syndrome. Outcomes for women in pregnancy have not improved, nor have outcomes for people with Down's syndrome improved. We would like to see research improved, and, as I said, we would also like to see a care pathway established. One or two hospitals in England have tried to do that in a very limited way, but we would like to expand on that and provide much better support for women, because there is a consensus — I do not think that anyone disagrees — that there is not enough care and support available for women who find themselves in an unexpected situation.

Mr Stalford: With your permission, Chair, may I go back to the question about amendments?

The Chairperson (Mr Gildernew): Yes.

Mr Stalford: This is an important point for people to note. As you know, this is a two-clause Bill, and it is extremely focused on one issue. Having been in the Speaker's Office for a while and familiarised myself with some of the criteria for amendments, I am of the view that — again, all these things rest entirely in the hands of Mr Speaker — the scope for amending this Bill is much more constrained than the scope for amending other, much bigger Bills.

It is important that members understand that this is singularly focused legislation. It is aimed at addressing one specific issue. I hope that that addresses members' concerns. I have already stated that it is not my intention to table further amendments to the Bill beyond the technical one that I detailed to the Committee. It is important in the context of the legislative process that members understand that. We are all legislators here, and it is my personal view that the scope for amending the Bill is very narrow. It is therefore important that members consider that. You will have the Bill Clerk in after me, and she can give you further advice on that, but, as I said, it is important that members understand that point.

The Chairperson (Mr Gildernew): Thank you both.

I draw your attention to the letter that the Committee received from the Human Rights Commission. One of its concluding paragraphs states:

> *"The effect of the Bill in Northern Ireland, if passed, will be to compel women in those circumstances to travel to Great Britain. Women in Northern Ireland will be disadvantaged."*

What is your opinion on that?

Mr Stalford: I disagree with the Human Rights Commission. The effect of the Bill will be to raise the standard of care provided to women. It must be about that. It must have a dual effect. It must be about sending out a message that we, as a society, value people with disability and do not believe that they are in any way less worthy of existence than the rest of us. Accompanying that, it must be about raising the standard of care provided in the health service for people who find themselves dealing with this very difficult situation. Lynn, do you want to touch on that?

Ms Murray: Yes. That is what all the publicity around, and awareness raising of, Heidi Crowter's case is about. It is about saying to women, "Having a child with a disability is not what you might think it is". It is a good life: evidence shows us that, and I can verify that that is the case. There are, however, definitely improvements that can be made, which are, as I said, being thwarted by high rates of abortion. For example, there are no specialised services for people with Down's syndrome. We live in an age in which we can improve outcomes medically etc, and we want to change the legislation to say that all lives are equal, which is what we say in every other piece of legislation. The difficulty here is that a different message is enshrined in abortion law.

We will support women. I mentioned people before, and I am glad that we are seeing role models in the media to show women that, contrary to what they saw in a leaflet or what was said to them by someone who has no experience of Down's syndrome, life can be good, and, in fact, their child might become famous and do exceptionally well. The idea that abortion is the answer to disability is out of step with whom we believe ourselves to be today.

Mr Stalford: In addition, Chair, I bring you back to the indicative votes that were held in the Assembly on the issue. On that occasion, 75 out of 90 Assembly Members voted in accordance with the principles of the Bill. Seventy-five out of 90 Members put their hand to a provision that we will not abort children on the basis of non-fatal fetal abnormality. My Bill gives effect to the will of the Assembly in that regard.

The Chairperson (Mr Gildernew): OK. Thank you. I will now move to questions from members.

Mrs Cameron: Thank you, Christopher, for your attendance at the Committee this morning. I put on record my thanks to the Bill's previous sponsor, Paul Givan, for his work on it, and to Lynn, who is with us as well this morning. Heartfelt thanks to Heidi Crowter and her team for the incredible fight that they are putting up to ensure that discrimination does not continue to exist against people like her and that they are given their place in this world along with the rest of us, which is right and proper. I wish them all the best with the appeal.

There has been an overriding focus in recent years on the rights of women and the importance of bodily autonomy but little emphasis on the evolving rights of the unborn child. Researchers have recently rolled back on claims that the fetus cannot feel pain at certain stages of gestation. Does the Bill seek to restore partially the balance and protect the unborn child who is disabled in the same way as those who are not disabled?

Mr Stalford: Yes is the short answer. The debate is obviously very emotive. It is important that we deal with these issues in a sensitive way. I understand and fully accept that there are strongly held pro-life and pro-choice views on the issues at a general principle level. At this level, there is much less division in society. Regardless of what label one attaches to oneself, the majority of people, whether they would classify themselves as "pro-life" or "pro-choice", recognise that there is something inherently unfair — the campaign is called "Don't Screen Us Out" — in screening out of existence people who will be born with a disability. That sends a powerful message as to the sort of society that we wish to become.

Not so long ago, I read an article about Iceland. Iceland is not free of Down's syndrome: they simply abort every child diagnosed with it. It is right neither at a human level nor at a societal level that we should consider one person less worthy of an existence than another. At the macro level, people take strong views on abortion, but, when we drill down into an issue such as this, there is much more common ground.

Mrs Cameron: I have a few more questions. Is it not accurate to say that the Bill does not seek to prevent someone travelling to another jurisdiction to access an abortion?

Mr Stalford: The scope of the Bill is closely defined. It is a two-clause Bill that addresses a single issue. That is important for people to note. This legislation, if passed, will not be subject to mission creep. The scope for amending a single-issue Bill is very tight anyway. This deals with a specific issue: screening out people with non-fatal disabilities. That is the focus and the sole objective of the Bill. It is important that we remain focused on that as what is at its heart. That is it, simple as. There are no back doors. There will be no hidden clauses at a later date. This is what the Bill aims to do.

Mrs Cameron: How can concerns raised around clarity and certainty for clinicians be squared with the Bill's content? Can those issues be addressed by a new protocol for the profession, for example?

Mr Stalford: Yes, I think that they can. The position adopted by the royal college is strange. On the one hand, the argument was being made that the cases that the Bill would seek to legislate for are so infinitesimally small as a percentage of abortions that would be carried out as not to merit legislative provision, while, on the other hand, the argument was being made that, if this legislative provision were passed, it would place an undue burden on the health service. You cannot have it both ways. You cannot argue that the legislation is irrelevant because the number of cases is so small, while, at the same time, be arguing that, if that number of cases were legislated for, it would place an undue burden on the health service. Frankly, that is doublespeak. We have it within us, as a devolved region of the United Kingdom, to raise the standard of care provided to families who find themselves facing this difficult situation and to send a powerful message to people with disabilities that we value them, that we feel that they are equal to us and that we, as a society, do not believe that people should be screened out. Lynn, do you want to come in on that?

Ms Murray: Yes. As I said, Heidi made that public gesture to show that she feels that there is discrimination. That has been well-received by the media. Lots of people in the media told us that they did not realise that the law extended to pregnancies involving children with disabilities. That was quite a revelation to a lot of people, and there was a lot of shock among people with very different opinions on abortion. They see it clearly as a discrimination issue, and that is very important.

When the RCOG spoke about abortion, it said that, if it is found before birth that there is another medical condition as well as Down's syndrome, it means that the child will be more seriously impacted on. Again, that is not the case. For example, Heidi was born with heart problems. It was thought that she also had leukaemia, but it never came to anything. She has gone on to lead a very fulfilled life. Again, we need to look more closely at those sorts of issues and understand what having Down's syndrome and possibly another medical condition means after birth. One women was told, "The baby has Down's syndrome. We don't know what that means. The baby also has a heart condition so will be at the more severe end of the condition". What we see in reality, however, is that that is not the case.

The Chairperson (Mr Gildernew): Thank you, Lynn. May I have a brief question, Pam, and as brief a response as possible, because I want to get to other members?

Mrs Cameron: Yes. Thanks, Chair.

Finally from me, in GB, research has shown that 69% of pregnant women who receive a positive diagnostic test result for Down's syndrome were offered a termination in the same conversation. Moving forward, is there therefore a need to address concerns about stereotyping disabilities in prenatal screening?

Mr Stalford: Yes, there is. I am glad that you raised that issue. I was looking for this reference. In 2017, the UN Committee on the Rights of Persons with Disabilities stated in its report on Great Britain and Northern Ireland:

> *"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."*

It continued:

> *"The Committee recommends that [GB] amend its abortion law accordingly."*

The law that pertains in GB may be the law. We now recognise, however, that things in our history that were the law were bad things. It is our job as legislators to legislate for that.

Ms Bradshaw: Thank you, Christopher, for coming to the Committee today. I will start on a positive note by saying that I fully agree that we should raise the standard of support and care for mothers during the screening process and for those living with disabilities later in life. We are very much on the same page about that. I fail to notice anything in the Bill that goes any way towards addressing those issues, however. You said today, for example, that the Bill will send out a message. I do not think that that message is strong enough to compel the Department of Health or any partner bodies to address those concerns. We as a Committee possibly need to come back to that.

Mr Stalford: May I come in on that?

The Chairperson (Mr Gildernew): No. I will let Paula finish her question.

Mr Stalford: Is there a question?

Ms Bradshaw: I will not address the straw man arguments that Christopher has put up not only in his oral evidence to the Committee but in the written briefing that we have received today. We can come back to those at a later stage. Any concerns that he has that, I feel, are legitimate have been addressed in the oral and written evidence that we have received from healthcare professionals, from women who have been affected and from many others. To say that we have received evidence of pressure, or that local clinicians and other healthcare professionals have questioned the decisions of women locally, is untrue. We have not received any of that. To say that we have is an absolute affront to the professionalism and integrity of the healthcare professionals from whom the Committee has heard evidence. I am not expecting a response. Those are my thoughts, and I am putting them on the record.

Mr Stalford: Am I allowed to respond?

The Chairperson (Mr Gildernew): Yes. Go ahead.

Mr Stalford: If Ms Bradshaw has concerns about the failure of the Department of Health or partner bodies to raise the standard of care, I suggest that there are probably few people in Northern Ireland in a better position to raise those concerns than a member of Stormont's Health Committee.

The Chairperson (Mr Gildernew): Paula, have you another question, or will I go to Gerry?

Ms Bradshaw: Go to Gerry, Chair.

Mr Carroll: I have a few questions.

The Chairperson (Mr Gildernew): In that case, I ask you to be brief. Likewise, panel, will one of you deal with the substantive issue? If required, the other panel member can provide additional information. I am trying to avoid repetition. That is in keeping with other sessions. Gerry, be as brief as you can. I would like questions and answers to be succinct.

Mr Carroll: The written paper is in Paul Givan's name, but you have taken over the Bill, Christopher. You have spoken today about upholding the rights of people with disabilities and about the idea that they are less valuable than people without disabilities. Do you accept that the political and societal approach to people with disabilities shapes the discrimination and that that discrimination was, unfortunately, at large prior to the 2020 legislation that you are trying to amend?

Mr Stalford: Society evolves, of course. Things that were acceptable 50 or 60 years ago in how people interacted with and treated one another are clearly unacceptable now. The same applies to provisions that were acceptable in 1968, after the Abortion Act. Society has moved on, particularly in scientific advances. When that legislation was passed, society's attitude was very much that people born with a disability were second-class citizens. I do not think that that is the attitude any more. The prevailing social mores of a few years ago have changed over time, and the legislation reflects where, I think, the broad majority of people are in their attitude towards disabled people.

Mr Carroll: Many people view the way in which the state treats people with disabilities as evidence of disabled people being treated disgracefully. For instance, they have minimal access to benefits and are treated disgracefully when it comes to care.

Mr Stalford: I absolutely agree with you.

Mr Carroll: There is a concern that the Bill focuses on one aspect, which relates to a small number of pregnancies.

I need to move on, because I have a few questions. Do you believe that women are coerced or pressured into having a termination when they receive a diagnosis of a severe fetal disability?

Mr Stalford: I have never lived that experience. In my opening address, what I did was to give you direct quotations from people who have.

Mr Carroll: Many people would dispute that idea.

Mr Stalford: Gerry, to be fair —.

The Chairperson (Mr Gildernew): Through the Chair.

Mr Stalford: Mr Chairman, what I quoted in my opening address was the lived experience of real people.

Mr Carroll: OK. Pam referred to the research that shows that 69% of pregnant women who receive a positive diagnostic test for Down's syndrome were offered a termination in the same conversation. It does not mention any offer of support for those women to continue the pregnancy. I do not know whether that was offered, but it would be an interesting area to look at.

Have you engaged with midwives, or their various representatives, on the Bill?

Mr Stalford: I have all the submissions. I took over responsibility for the Bill during the summer. I am happy to meet any group that wants to meet me to talk about its provisions. There are a lot of submissions for a two-clause Bill — it got a significant amount of public interest — but I have read through most of them. If anyone wishes to meet me — that includes members of your Committee, Mr Chairman, or you — I will be happy to make myself available to talk through the issues.

Mr Carroll: Thank you. From memory, as one of the representatives who were quite offended by the aims of the Bill, I think it might have been the royal college, but I stand to be corrected on that.

I have two final quick questions. If the law changes in those cases, you will be seeking to prevent women from accessing terminations. Pam said that the Bill does not prevent people from travelling, so presumably those women will still be able to access terminations elsewhere.

Mr Stalford: Our job, as representatives of the people of Northern Ireland, is to legislate for what we think should be the prevailing situation in Northern Ireland, and 75 out of 90 Assembly Members put their hand to one or two motions on this issue, indicating that they did not believe that people with non-fatal disabilities should be screened out in the way in which things pertain in GB. Therefore, I am seeking, through this legislation, to enact the will of the Assembly in that regard.

Mr Carroll: Many people, me included, take the view that it is exporting a health situation, which has happened for many decades.

Finally, the situation about Iceland was referenced, and it is often quoted in general conversations. It is actually inaccurate to say that there are no people with Down's syndrome. That is my interpretation of what you said. If that is not directly what you said, that is my bad. The numbers of people being born with Down's syndrome vary from year to year in Iceland. The WHO reports on cases where, in some years, out of 100,000 live births, there are a handful of people being born with Down's syndrome, and some years there are not. Apart from 1989 and 2009, there were people born with Down's syndrome in Iceland, so I think that myth needs to be challenged.

Mr Stalford: If we are talking about percentages per 100,000 births, and there are years where zero children were born with Down's syndrome, that sends a very powerful message.

The Chairperson (Mr Gildernew): Thank you, Gerry and Christopher. We have a final question from Jonathan Buckley.

Mr Buckley: Can you hear me, Chair?

The Chairperson (Mr Gildernew): Yes. I am not seeing you, but we are hearing you.

Mr Buckley: Apologies. My Wi-Fi signal has not been good, so I have had to disable the camera. Christopher, thank you very much for your presentation. The Northern Ireland Human Rights Commission and others rely heavily on the Committee on the Elimination of Discrimination Against Women (CEDAW) report to reject the Bill. Do you agree that only that which is contained in the Convention on the Elimination of All Forms of Discrimination against Women itself, not the CEDAW report, is legally binding?

Mr Stalford: Yes, that is correct. CEDAW has no legal enforceable recognition, as far as I understand it.

Mr Buckley: That is an important clarification, and it certainly informs the debate here. In your opening comments, you alluded to the scrutiny of the Bill. Do you agree that some of the language thrown about describing carrying a child with a fetal anomaly is degrading and inhuman and ignores the many positive experiences of many women in Northern Ireland in those situations?

Mr Stalford: Yes, I agree. Some of the language used by people is insensitive. That places an obligation on those of us who stand on the other side of that debate to be equally sensitive. As I said, this is a very emotive issue. People at a very macro level adopt labels and dig themselves into trenches, but I happen to think that, at a micro level, when it comes to the content of the Bill, regardless of what label you attach to yourself, it is perfectly possible to support this legislation. It is important that all voices in the debate, particularly the voices of those whose lived experience has been raising a child with Down's syndrome or raising a child with a disability, or of disability campaigning groups, have their voices heard, and, in that context, it is important that the Committee considers hearing from them more fully.

Mr Buckley: I would also be interested to hear Lynn's opinion on that, given her representation with Don't Screen Us Out.

Mr Stalford: I am happy to hand over to her.

Ms Murray: What we are saying here is — and I think maybe it addresses what Jonathan was saying — the Royal College of Obstetricians and Gynaecologists itself is telling us that women are reporting coercion around screening and abortion. It goes back to this idea of perpetuating stereotypes. There is a very positive lived experience of people who have given birth to a child with disability, and we are now hearing the voices of people with disability. Heidi and, as I said, lots of other people now commenting in the media are completely understanding what this situation is. These voices are important. We cannot just say that we disagree that this does not cause negative stereotypes.

Mr Buckley: Finally, regardless of where people stand on this Bill, it has given legitimate rise to the conversations surrounding the wholly inadequate services that there are for disabled people in relation to healthcare. Does the Bill sponsor believe that the Bill should be accompanied by a greater focus on children's palliative end-of-life care, specialised pathways for women who have received a diagnosis of serious fetal impairment, and post-pregnancy support? How can this be achieved?

Mr Stalford: Yes, I absolutely do believe that it is not enough that the Bill should stand in isolation, and I agree with everything that you have said. That is where I think it is an important part of the role of not only your Committee but all of us as Assembly Members to hold the Department and the Minister to account on improving the service given to people in the situations that have been discussed today.

Mr Chairman, did you say that Mr Buckley was the final questioner?

The Chairperson (Mr Gildernew): Yes.

Mr Stalford: In that case, I am happy to make the offer to the Committee that I make myself available to any member who wants to speak to me about the content of the Bill at any time. Mr Carroll, you mentioned groups: if any group has been in touch with you that has not been in touch with me, if you put them in contact with me, I will be happy to speak with them.

The Chairperson (Mr Gildernew): Thank you, members. I thank Lynn for appearing at the Committee again and Christopher for coming along today and taking members' questions. I wish you all the best, and take care.

Mr Stalford: Thank you, Mr Chairman.