

Submission to the Health Committee on The Severe Fetal Impairment Abortion (Amendment) Bill By email to Committee.health_sfiabill@niassembly.gov.uk

CARE in Northern Ireland supports the Severe Fetal Impairment Abortion (Amendment) Bill. We believe that every baby deserves to be born regardless of their perceived ability and that this Bill will uphold the right to life of babies with non-fatal fetal abnormalities, such as Down's syndrome, club foot and cleft lip/palate.

Introduction to CARE in Northern Ireland

1. CARE (Christian Action Research and Education) Northern Ireland is a well-established mainstream Christian charity providing resources and helping to bring Christian insight and experience to matters of public policy and practical caring initiatives. CARE demonstrates Christ's compassion to people all faiths and none believing that individuals are of immense value, not because of the circumstances of their birth, their behaviour or achievements, but because of their intrinsic worth as people.

Overview of the Bill

2. This Bill will amend one element of The Abortion (Northern Ireland) (No.2) Regulations 2020.¹ The Bill would remove Regulation 7(1)(b) which allows for abortion up to term for pregnancies where there is a diagnosis of 'severe fetal impairment' (SFI), those where "*if the child were born it would suffer from such a physical or mental impairment as to be seriously disabled.*"²
3. The Severe Fetal Impairment Abortion (Amendment) Bill, referred to in this submission as the 'SFIA Bill' passed its Second Stage debate on 15th March 2021 by 48 votes to 12 and is now before the Health Committee for scrutiny.³ This vote at the Second Stage reflects the two votes in the Assembly on 2nd June 2020, where there was a total of 76 votes against abortion on the grounds of non-fatal disabilities, including Down's syndrome.⁴ While the motions were non-binding and did not change the 2020 Regulations, it did send a clear message that the NI Assembly was not prepared to accept this form of disability discrimination.
4. This Bill will not affect the law in the tragic cases of so called 'fatal fetal abnormalities' (FFA).

Key Facts about Abortion in Northern Ireland

5. On 22nd October 2019, changes to the law in Northern Ireland were introduced by section 9 of the Northern Ireland (Executive Formation etc) Act 2019.⁵ This repealed sections 58 and 59 of the Offences Against the Person Act 1861, decriminalising abortion and placing a duty on the UK Government to introduce a new legal framework for abortion in Northern Ireland, implementing the recommendations in paragraphs 85 and 86 of the CEDAW report, *Inquiry concerning the United*

¹ [The Abortion \(Northern Ireland\) Regulations 2020 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

² <https://www.legislation.gov.uk/ukSI/2020/345/regulation/7/made>

³ Northern Ireland Assembly, Hansard, [15 March 2021](#), page 15

⁴ [plenary-02-06-2020.pdf \(niassembly.gov.uk\)](#) p 61-81

⁵ [Northern Ireland \(Executive Formation etc\) Act 2019 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

*Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women.*⁶

6. The Abortion (Northern Ireland) (No. 2) Regulations 2020 came into force on 31st March 2020 and allow access to abortions up to 12 weeks' gestation without conditionality. Abortions beyond 12 weeks' gestation are lawful in specified instances, including in **Regulation 7** when severe fetal impairment and fatal fetal abnormalities are detected.⁷
 - 6.1. Regulation 7 provides the only ground which allows for an abortion on the basis of a characteristic of the fetus (all other grounds for abortion beyond 12 weeks are defined in terms of the woman) and allows for abortion up to birth.
 - 6.2. Regulation 7 is similar to the provisions in the Abortion Act 1967 which allow abortions on the grounds of disability up to birth, compared to all the other grounds which apply up to 24 weeks.⁸ This language is also very similar to that in the 1967 Act: the only difference being the use of 'seriously disabled' instead of 'seriously handicapped'. As in the 1967 Act, there is no definition of 'impairment' or what 'seriously disabled' could mean. The Government recognises these definitions are "*subjective*".⁹
 - 6.3. When Lord Shinkwin introduced a Bill to reduce the time limit for abortions on the grounds of disability to 24 weeks, the charity Disability Rights UK said "*fundamentally it is about equality. Wherever Parliament sets the number of weeks after which abortion is not permitted, it should be exactly the same whether the pregnancy is likely to result in a disabled or a non-disabled child. All lives are equal.*"¹⁰
7. Regulation 7 allows abortions on the grounds of a number of conditions which would be classed as an SFI, such as Down's syndrome, club foot and cleft lip/palate.¹¹ These conditions are monitored through congenital anomaly registries in the other GB jurisdictions,¹² but no such register exists in Northern Ireland. Some data is available through the Director of Public Health's core data tables, which were last updated in December 2019. A congenital anomaly report published in Scotland 6 months ago states: "*Termination of pregnancy for fetal anomaly accounted for almost all of the non-live born babies, showing the impact of antenatal screening on the outcome of babies with these specific types of anomalies.*"¹³

Data on Down's syndrome

8. We note that between 2016-18, there was a difference in how often Down's syndrome was diagnosed across Great Britain, ranging from an average of 18.3 to 27.2 in 10,000 births. Of these, there were an average of 10.2 and 11.2 live births per 10,000 births in Scotland and England, respectively. In Northern Ireland, there were an estimated 16.8 live births per 10,000 births.

⁶ <https://undocs.org/CEDAW/C/OP.8/GBR/1>, March 2018

⁷ <https://www.legislation.gov.uk/ukxi/2020/345/regulation/7/made>

⁸ Abortion Act 1967, [section 1\(1\)\(d\)](#)

⁹ Explanatory Memorandum to 2020 Regulations, para 7.37 page 12

¹⁰ http://www.legislation.gov.uk/ukxi/2020/503/pdfs/ukxiem_20200503_en.pdf

¹¹ <https://www.disabilityrightsuk.org/news/2017/january/dr-uk-welcomes-debate-abortion-and-disability>

¹² Information from the Wales Congenital Anomaly Register and Information Service (CARIS) on [Cleft Lip & Palate](#)

¹³ In England the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS); in Wales the Congenital Anomaly Register and Information Service (CARIS); in Scotland The Congenital Anomalies Register (CARDRISS)

Congenital anomalies in Scotland, (2000 to 2018), 6 October 2020, page 9

<https://beta.isdscotland.org/media/5981/2020-10-06-congenital-anomalies-in-scotland-2018-main-report.pdf>

Table 1: Diagnosis prevalence of Down’s syndrome per 10,000 Births

	2016	2017	2018	Average over 3 years ¹⁴
England ¹⁵	28.8	27.8	25.0	27.2
Wales ¹⁶	24.8	25.4	23.6	24.6
Scotland ¹⁷	21.7	15.8	17.5	18.3
Northern Ireland	No Data			

Table 2: Live Births of babies with Down’s syndrome per 10,000 Births

	2016	2017	2018	Average over 3 years ¹⁸
England ¹⁹	11.2	10.9	11.6	11.2
Wales	No Data			
Scotland ²⁰	12.6	8.7	9.4	10.2
Northern Ireland ²¹	19.9	15.6	14.9	16.8

9. Scotland is perhaps Northern Ireland’s closest cultural analogue within the UK. Comparing trends in births of children with Down’s syndrome between Northern Ireland (where abortion has previously not been legal based on non-fatal fetal disability) and Scotland (where abortion based on suspected or diagnosed fetal disability has been legal for 30 years) provides concerning foresight into the potential impact of a change in abortion law. When the outcomes of pregnancies with a diagnosis of Down’s syndrome are compared between the two jurisdictions, there is a stark contrast. In 2016-18, in Scotland, the number of abortions were 43.7% of the total number of live births and abortions; in Northern Ireland the proportion was five times lower at 8.3% of the total. CARE NI is concerned that there will be more abortions on the basis of that the unborn child has Down’s syndrome - and other congenital conditions that are not fatal - following the introduction of the 2020 Regulations.

¹⁴ Average of the 3 published numbers
¹⁵ Based on data from NCARDRS 2017 Data, Table 17 and NCARDRS 2018 Annual Statistics, page 5
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/821454/NCARDRS_congenital_anomaly_statistics_2017_tables.ods
¹⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/909405/NCARDRS_Congenital_anomaly_statistics_report_2018.pdf
¹⁷ <http://www.caris.wales.nhs.uk/opendoc/354289>. Spreadsheet reporting rates per 10,000 births by year
¹⁸ Congenital anomalies in Scotland 2000 to 2018, 6 October 2020, Data Table 1
<https://beta.isdscotland.org/media/5886/2020-10-06-table-1-prevalence.xlsx>
¹⁹ Average of the 3 published numbers
²⁰ Based on data from NCARDRS 2017 Data, Table 17, *Op Cit* and NCARDRS 2018 Annual Statistics, *Op Cit*, page 32
²¹ Table 1, *Op Cit*
 Core Tables 2018, Supporting the Director of Public Health, Annual Report 2019, Table 14
<https://www.publichealth.hscni.net/sites/default/files/2020-02/Core%20Tables%202018%20-%20final%20-%20Dec%202019.pdf>
 NB: the figures presented in this table are per 1,000 births not 10,000 births. They include live births and still births. Information from the Public Health Agency suggest that less than 5 of the number reported were still births so the numbers on live births are an approximation.

Table 3: Comparing abortion & live births of babies with Down’s syndrome in Scotland and NI

	2016			2017			2018			Average %
	Live Births	Abortions	% abortions of total births & abortions	Live Births	Abortions	% abortions of total births & abortions	Live Births	Abortions	% abortions of total births & abortions	
Scotland ²²	69	48	41.0%	46	38	45.2%	48	39	44.8%	43.7%
Northern Ireland ²³ ²⁴	48	1	2.0%	36	4	10.0%	34	5	12.8%	8.3%

The Need for the Bill

10. The section below outlines the evidence that supports the need for the SFIA Bill.
11. In summary, CARE NI believes that this Bill is needed to meet international obligations, remove discrimination on the basis of disability, reduce stereotypes and ensure appropriate support for women during pregnancy and beyond. We reject a view which demarcates babies with disabilities as different in status from other babies. In our view, all children are of equal value and worth.

A. The Bill would ensure NI meets its International Obligations under the UN Convention on the Rights of Persons with Disabilities

12. Regulation 7 is contrary to the non-discrimination provisions in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). In the most recent UNCRPD Committee report on the UK, the Committee reported that it was *“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 recommends that the [UK] amend its abortion law accordingly...without legalizing selective abortion on the ground of fetal deficiency.”*²⁵
13. In December 2019, the Special Rapporteur on the rights of persons with disabilities said about the UN Convention on the Rights of Persons with Disabilities that *“Article 10 recognizes and protects the right to life of persons with disabilities on an equal basis with others, which is critical for contesting legislation, policies and practices whereby the lives of persons with disabilities have been put at risk because of perceived low quality of life...The right to life includes the right to survive and develop on equal basis with others. Disability cannot be a justification for termination of life.”*²⁶ (bold added)
14. We note the comments of Mr Justice Horner who said, *“the Assembly under Section 6(2)(d) of the 1998 [Northern Ireland] Act is not permitted to make laws contrary to [the UNCRPD]. This Convention proceeds on the premise that if abortion is permissible, there should be no*

²² Table 1, *Op Cit*

²³ Core Table 2018, Supporting the Director of Public Health, Annual Report 2019, *Op Cit*, Table 14. See note above <https://www.gov.uk/government/collections/abortion-statistics-for-england-and-wales> Table 12h for the relevant years

²⁴ <https://www.gov.uk/government/collections/abortion-statistics-for-england-and-wales> Table 12h for the relevant years

²⁵ CRPD/C/GBR/CO/1, October 2017, paragraphs 12 and 13 <https://undocs.org/pdf?symbol=en/CRPD/C/GBR/CO/1/ADD.1>

²⁶ Report of the Special Rapporteur on the rights of persons with disabilities, December 2019, A/HRC/43/41, para 48, page 12, <https://undocs.org/pdf?symbol=en/A/HRC/43/41>

discrimination on the basis that the foetus, because of a defect, will result in a child being born with a physical or mental disability”. He also said that if the Assembly sought to legislate in a way that distinguishes between fetuses on the basis of disability “there are good grounds for concluding that any such attempt to legislate by the Assembly would fall foul of Section 6(2)(d) of the 1998 Act”; and “In so far as [a CEDAW recommendation from 2013] was intended to permit abortions on fetuses with imperfections which if allowed to continue to full term would result in children being born with a physical and/or mental disability, then it ignores the UK’s other international law obligations.”²⁷

15. Lord Kerr agreed with Mr Justice Horner and made the same point in the Supreme Court in 2018: *“The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is one of the treaties specified as an EU treaty under the EC (Definition of Treaties) (UNCRPD) Order 2009. Section 6(2)(d) of the NIA forbids the Northern Ireland Assembly from making laws contrary to UNCRPD.... UNCRPD is based on the premise that if abortion is permissible, there should be no discrimination on the basis that the foetus, because of a defect, will result in a child being born with a physical or mental disability”.*²⁸ (Bold added)
16. The Supreme Court has given a non-binding judgment that there is no human right for women to have an abortion on the grounds of the disability of a child who can survive birth.²⁹ CARE NI further notes that statements made in 2019 (i.e. after the CEDAW report that has led to the law change) by other UN Committees suggest that if there is to be access to abortion on the basis of disability it should be strictly limited to cases where clinicians make a good faith judgement that the child will die before, during or very shortly after birth. Where the pregnant woman’s life or health are in serious danger abortion would still be available on those grounds.^{30 31}

B. This Bill would be in line with the past 30 years of disability protection and fighting for equality in Northern Ireland

17. The attitudes towards disability have changed significantly in the past 30 years, as reflected in the legislation in this area: The Disability Discrimination Act 1995,³² the Northern Ireland Act 1998³³ and the Disability Discrimination (Northern Ireland) Order 2006³⁴ all aim to foster equality and introduce legal provisions against disability discrimination in Northern Ireland. These laws reflect the fact that every person, regardless of their disability, is of value and worth. We are concerned that Regulation 7 undermines the disability rights and protections in Northern Ireland as it sends the message that babies with disabilities are not entitled to the same protection under the law.

C. The Bill would remove the disability discrimination that exists within the current Abortion Regulations

²⁷ Horner J, [2015] NIQB 96, paragraphs 64 and 65

²⁸ [2018] UKSC 27, Lord Kerr at paragraph 331

²⁹ See <https://www.supremecourt.uk/cases/docs/uksc-2017-0131-press-summary.pdf> and [2018] UKSC 27, Lord Mance at paragraph 133 and Lord Kerr at paragraph 331 <https://www.supremecourt.uk/cases/docs/uksc-2017-0131-judgment.pdf>

³⁰ Committee against Torture, Concluding observations on the sixth periodic report of the United Kingdom of Great Britain and Northern Ireland, June 2019, CAT/C/GBR/CO/6, para 47,

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspGeQzFMcltSwMusuUVdUf1fqd uvTgjR%2fsN3VoXuPNbP56JussnRoT32KTfJnOAlqez%2fvRUjyX8nhOMLJygiC7jBHAOMQKp6Cwp7mz4HNCDej>

³¹ International Covenant on Civil and Political Rights, Human Rights Committee, General Comment No 36, Right to Life, September 2019, para 8

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspGeQzFMcltSwMusuUVdUf1fqd uvTgjR%2fsN3VoXuPNbP56JussnRoT32KTfJnOAlqez%2fvRUjyX8nhOMLJygiC7jBHAOMQKp6Cwp7mz4HNCDej>

³² [Disability Discrimination Act 1995 \(legislation.gov.uk\)](http://www.legislation.gov.uk/ukpga/1995/50/enacted)

³³ [Northern Ireland Act 1998 \(legislation.gov.uk\)](http://www.legislation.gov.uk/ukpga/1998/1/enacted)

³⁴ [The Disability Discrimination \(Northern Ireland\) Order 2006 \(legislation.gov.uk\)](http://www.legislation.gov.uk/uksi/2006/1001/enacted)

18. In the 2018 Supreme Court judgment on the Judicial Review brought by the Northern Ireland Human Rights Commission, Lord Mance stated, *“in principle a disabled child should be treated as having exactly the same worth in terms as a non-disabled child... This is also the consistent theme of the United Nations Committee on the Rights of Persons with Disabilities, **expressing concerns about the stigmatising of persons with disabilities as living a life of less value than that of others, and about the termination of pregnancy at any stage on the basis of foetal abnormality, and recommending States to amend their abortion laws accordingly.**”*³⁵

A separate gestational limit for abortion on the grounds of non-fatal disability is discriminatory

- 18.1. The law protects babies without a disability in the womb from the 24th week of pregnancy so that they cannot be aborted; however, it does not provide the same protection for babies of the same gestation who have a suspected or diagnosed non-fatal disability. Separate gestational limits for abortion based on solely on disability promote disability discrimination against babies in the womb.
- 18.2. The SFIA Bill will remove discriminatory gestation limits and ensure that those babies with a non-life limiting disability are protected from this form of disability discrimination.

The current abortion law perpetuates stereotypes towards people with disabilities and will have a profoundly negative impact upon them

- 18.3. Having a ground for abortion on the basis of disability inevitably perpetuates stereotypes towards persons with disabilities, which **goes against** the CEDAW report³⁶ and their recommendation in paragraph 85(b)(iii) that legal effect be given to permit abortion on the basis of disability *“without perpetuating stereotypes towards persons with disabilities”*, a caveat that does not apply in the Abortion Act 1967. The Disability Rights Commission (now the Equality and Human Rights Commission) have said the disability abortion provision in the 1967 Act *“is offensive to many people; it reinforces negative stereotypes of disability... [and] is incompatible with valuing disability and non-disability equally”*.³⁷
- 18.4. For this reason, we are concerned about the message that the current abortion law sends to those with disabilities and the impact that this can have on their sense of self. A person with a disability, on the basis of which an unborn baby could be legally aborted up to birth under Regulation 7, will recognise that their life is valued differently to others.
- Disability Campaigner Heidi Crowter has spoken publicly about the impact of the current law stating, *“the law makes me feel like I should not exist.”*³⁸
 - Hannah Wilson, a young woman with Down’s syndrome from Co. Fermanagh when asked what she thought of the law said, *“I felt very sad when [it] was explained to me, it feels so wrong...”*³⁹
 - Lord Shinkwin, who has osteogenesis imperfecta, has also spoken to the message sent by the Regulations, saying, *“I am a severely disabled parliamentarian who believes that I have as much right to exist as anyone else. The regulations may not apply to me directly, but they still threaten me because they challenge that right by devaluing my existence.*

³⁵ <https://www.supremecourt.uk/cases/docs/uksc-2017-0131-judgment.pdf> at paragraph 133

³⁶ paragraph 62 *“In cases of severe fetal impairment, the Committee aligns itself with the Committee on the Rights of Persons with Disabilities in the condemnation of sex-selective and disability-selective abortions, both stemming from negative stereotypes and prejudices towards women and persons with disabilities.”*
<https://undocs.org/CEDAW/C/OP.8/GBR/1>, March 2018

³⁷ <http://news.bbc.co.uk/1/hi/health/1502827.stm>

³⁸ [Disability rights activist urges MPs to reject NI abortion regulations \(yahoo.com\)](https://www.yahoo.com/news/disability-rights-activist-urges-mps-to-reject-ni-abortion-regulations-123456789.html)

³⁹ <https://care.org.uk/news/2021/03/hannah-wilson-interview>

*The narrative of the regulations is that I should not really exist. Indeed, I would be better off dead. If we pass the regulations today, not only are we endorsing lethal disability discrimination right up to birth but we are in practice saying to anyone who is born with a disability that they somehow escaped the net.*⁴⁰

- Alan, a man from Northern Ireland living with cerebral palsy has spoken out against the abortion regulations and the impact that they will have on society and its perceptions of people with disabilities stating *“I believe that prenatal diagnosis can be a very positive thing, in that it can prepare parents for any eventuality that may occur. The problem I have is when the diagnosis is turned into a death sentence, and a life is terminated because of a deformity, disability or disease. ...a society that tries to eradicate conditions like Down’s Syndrome, Spina Bifida or any other malady through abortion is a society that has lost its way. It is a society that has lost its capacity for acceptance, tolerance and compassion.*⁴¹
- David Smyth, a Lawyer and Charity Boss who lives near Hillsborough, Northern Ireland, who was born with a cleft lip and palate, says, *“it is unthinkable that babies are being aborted due to cleft lip or palate.”* Further stating, *‘I don’t consider myself as disabled and receive no Government disability benefit, and yet the condition I have - cleft lip and palate - is serious enough in the Government’s eyes to allow people like me to be aborted up to birth. This outdated law is a throwback to when people with conditions like mine were not treated as equals... Society has moved on. It’s time that our law was updated to reflect this. This law change is well overdue.*⁴²

D. This Bill would recognise the positive impact those with a disability have on our society

19. Accounts from parents and families of those with disabilities such as Down’s syndrome, provide personal examples of how much people with disabilities contribute to their family, friends and society. Karen and Edwin Wilson, whose daughter Hannah has Down’s syndrome, note, *“As a family, we are adamant that we would not change anything about Hannah. God has entrusted us with a unique young lady, who has so much to give society.*⁴³
20. In 2011, the American Journal of Medical Genetics published a series of articles about Down’s syndrome. One of these covered a study of people with Down’s syndrome who were older than 12 on information that could be shared with new and expectant parents of children with Down’s syndrome. *“Among those surveyed, nearly 99% of people with DS indicated that they were happy with their lives, 97% liked who they are, and 96% liked how they look. Nearly 99% people with DS expressed love for their families, and 97% liked their brothers and sisters.”*⁴⁴ Another article surveyed the views of siblings: *“96% of brothers/sisters that responded to the survey indicated that they had affection toward their sibling with Down’s Syndrome; and 94% of older siblings expressed*

⁴⁰ House of Lords, Hansard, 28 April 2021, vol 811, col 2271.

⁴¹ <https://archbishopcranmer.com/abortion-northern-ireland-disabled-speak-out/>

⁴² NI man David Smyth, born with a cleft lip and palate, urges support for campaign to close abortion law loophole, [Belfast Telegraph](#), 30 May 2020

⁴³ Exclusive interview: 'We just want to be treated like everyone else' | CARE

⁴⁴ Skotko BG et al, Self-perceptions From People With Down Syndrome, *Am J Med Genet A*, 2011 Oct;155A(10):2360-9. doi: 10.1002/ajmg.a.34235. Epub 2011 Sep 9. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3740159/>

feelings of pride.”⁴⁵ 79% of parents said “their outlook on life was more positive” because of their child.⁴⁶

E. This Bill would protect women who are pregnant with a disabled child from the negative & stereotyping impact of the 2020 Regulations

21. The parents of children with conditions such as Down’s syndrome in other parts of the UK have spoken out about the stigma and stereotypes that the equivalent law in GB perpetuates, particularly in relation to the differential treatment that they have received accessing healthcare while pregnant and beyond. We are concerned this will become prevalent in Northern Ireland unless the current law is changed.
22. As one mother of a girl with Down’s syndrome put it: “*This is not an argument about choice but of equality. My three girls are equally loved and equally valued. My middle daughter has Down Syndrome. She should enjoy the same rights before and after birth as any other human being.*”⁴⁷ Another mother said: “*I was horrified when I learned that as Drs were fighting to save my son’s life when he was born in Bristol with Down’s Syndrome at 35 weeks, another similar baby could be being terminated just down the corridor.*”⁴⁸
23. The experiences of individuals and their families in other parts of the UK, where disability selective abortions have been in place for thirty years, demonstrate that such stereotypes and inadequacies in support are inevitable when laws are in place which make a distinction between unborn babies with a disability, and those without.
- 23.1. A report by national Down’s syndrome charities found that **69% of pregnant women who were given diagnostic test result indicating their baby had Down’s syndrome were offered a termination in the same conversation**, and of 210 women who received a positive result [in a test for Down’s syndrome] but who advised that they wanted to continue the pregnancy, 46% had termination mentioned subsequently, and of 271 who had a ‘high chance’ result and said they wished to continue the pregnancy, 50% were offered at termination.⁴⁹ One woman reported she was told, “*Sorry, it’s bad news, baby does have Down syndrome; I’ve booked you in for a termination on Thursday at 10*”; **another woman says her doctor felt she was selfish not to terminate**.⁵⁰ The same report found that where parents had received the news that their unborn child has Down’s syndrome and stated that they wished to continue with the pregnancy, 46% had termination mentioned more than once.⁵¹ One mother, Emma Mellor, relays in a news article that **she was offered a termination 15 times during her pregnancy despite making it clear she did not want one**.⁵² We want to ensure that this does not become

⁴⁵ Skotko BG et al, Having a Brother or Sister With Down Syndrome: Perspectives From Siblings, Am J Med Genet A, 2011 Oct;155A(10):2348-59. doi: 10.1002/ajmg.a.34228.Epub 2011 Sep 9

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3348944/>

⁴⁶ Skotko BG et al, Having a Brother or Sister With Down Syndrome: Perspectives From Mothers and Fathers, Am J Med Genet A, 2011 Oct;155A(10):2335-47. doi: 10.1002/ajmg.a.34293.Epub 2011 Sep 9.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3353148/>

⁴⁷ <https://twitter.com/CostertonSarah/status/1264495364876513280>

⁴⁸ <https://twitter.com/annabellall/status/1231894044613259264>

⁴⁹ PADS: Sharing the news, The maternity experience of parents of a baby with Down syndrome, Down syndrome UK, October 2019, page 21

<https://www.downsyndromeuk.co.uk/flipbook.html>

⁵⁰ *Ibid*

⁵¹ PADS: Sharing the news, *Op Cit* page 21

⁵² ‘At 38 weeks, I was told I could still terminate’ [Down’s syndrome: ‘In all honesty we were offered 15 terminations’ - BBC News](#)

the experience of parents in Northern Ireland if they are to learn that their child has Down's syndrome.

- 23.2. **There is also evidence which shows these impacts do not end at birth:** Following a postnatal diagnosis, in those early moments where parents should be surrounded by support and encouragement, one couple describe being given a leaflet which included “*What to do if you don't want your baby*”.⁵³ Another woman describes being asked at a hospital appointment **why she had not terminated her daughter who, by this stage, was three years old.**⁵⁴ This Bill will mean that parents will not have to continually justify their child's very existence.
24. CARE NI are also concerned about the wider impact of the current regulations on community views of disability, the use of economic arguments associated with non-invasive prenatal screening.
- 24.1. This issue was raised in a 2015 report from the International Bioethics Committee which stated that “[e]ffects of discrimination and stigmatization can also occur with regard to prenatal and preimplantation genetic testing. The consequence of detecting a genetic abnormality is very often not a therapeutic intervention for the unborn child,” further stating, “[the] widespread use of genetic screening and in particular of NIPT may foster a culture of ‘perfectionism’ or ‘zero defect’ and even renew some ‘eugenic trends,’ with the consequence that it could become more and more difficult to accept imperfect and disability as part of normal human life and a component of the diversity we were all called to acknowledge and respect.”⁵⁵
- 24.2. This may also exacerbate a phenomenon known as ‘diagnostic overshadowing’: a number of parents of children with Down's syndrome have described how the fact that their child has Down's syndrome has impacted their ability to access therapeutic care — they recount being told in response to particular health concerns (e.g. delays in learning to walk) “*that's just Down's syndrome,*” rather than being offered supportive interventions.⁵⁶ Addressing congenital conditions through the lens of antenatal screening risks fostering an understanding that the optimum intervention is to ensure such conditions no longer exist, rather than to ask how those living with such conditions can be supported to live full lives. If the population impacted by such conditions is reduced via antenatal screening, this will undoubtedly have implications for future research, a concern noted in the Nuffield report on Non-Invasive Prenatal Testing.⁵⁷
- 24.3. In a response to a consultation into the introduction of non-invasive prenatal screening for conditions such as Down's Syndrome “[the RCOG] called for a ‘rigorous economic analysis’, including the lifetime costs of caring for those with the condition,” the Association of Genetic Nurses and Counsellors (who would be involved in the care of women with pregnancies with a fetal diagnosis of Down's syndrome also commented that, “[b]enefits to this may include...reducing the healthcare/social care costs of treating/looking after patients with such conditions,” as a result of an increase in termination of pregnancies where such conditions were diagnosed.⁵⁸ This is a deeply concerning utilitarian attitude towards the so-called ‘benefits’ of screening for chromosomal conditions, and, in the case of the RCOG,

⁵³ PADS: Sharing the news, *Op Cit* page 21

⁵⁴ <https://twitter.com/rachelmewes1982/status/1367052135418986497>
<https://twitter.com/rachelmewes1982/status/1359837978680578048>

⁵⁵ [Report of the IBC](#) on Updating Its Reflection on the Human Genome and Human Rights, October 2015, paragraphs 22 & 125

⁵⁶ [Diagnostic Overshadowing #HoldsMeBack | Down's Syndrome Research Foundation \(dsrf-uk.org\)](#)

⁵⁷ Non-invasive Prenatal Testing: Ethical Issues, Nuffield Council on Bioethics, [published 1 March 2017](#), see 5.14.

⁵⁸ Non-invasive prenatal testing, Summary of consultation responses, Nuffield Council on Bioethics, published June 2017
[Evidence gathering - The Nuffield Council on Bioethics \(nuffieldbioethics.org\)](#), page 24.

one which more than 100 doctors and nurses signed a letter to condemn, alongside parents of children with Down's syndrome.⁵⁹

- 24.4. A recent survey by Disability Action NI highlights significant concerns amongst disabled people and their families regarding their ability to access support during the pandemic and in the longer term.⁶⁰ Those with disabilities such as Down's syndrome who have a higher risk of severe outcomes from Covid-19,⁶¹ have been pressured elsewhere in the UK into accepting a Do Not Resuscitate (DNR) simply because they have a congenital condition.⁶²
- 24.5. The point about wider impacts is also illustrated by Dr Elizabeth Corcoran of the Down's Syndrome Research Foundation UK, who highlights that *"[r]esearch into the health issues affecting people with Down syndrome has been hampered and blocked by the ingrained belief that the only way to help the Down syndrome community is to reduce their numbers. Millions [of pounds] in funding has been poured into running and refining the screening [process] whilst only £5.33 per person per year is spent on research that could improve the lives of people with Down syndrome."*⁶³

F. This Bill would ensure that as pre-natal testing becomes more prevalent, parents do not feel they ought to have an abortion if their baby is found to have a so-called serious fetal impairment.

Background to Screening

25. Unlike elsewhere in the UK, Northern Ireland does not have a national antenatal screening program, with a standardised screening pathway for so-called 'congenital anomalies'. Some women may be offered screening tests, followed by further testing if initial tests provide a 'high chance' result, but this does not appear to be standardised across maternity services in NI.⁶⁴ Screening is, however, available privately,⁶⁵ meaning it is possible to determine the likelihood a child may have certain genetic conditions, such as Down's syndrome, after **10 weeks' gestation**.⁶⁶ This result must be confirmed by diagnostic testing.
26. All pregnant women in Northern Ireland are currently offered a detailed ultrasound scan (often known as an 'anomaly scan') at around 20 weeks which looks for certain structural abnormalities which can indicate a range of congenital conditions, such as Down's syndrome, Spina Bifida, and skeletal dysplasia.⁶⁷

Concerns Relating to Screening

⁵⁹ [Doctors' anger over medical body's call to 'abort Down's babies' because it costs too much to care for them | Daily Mail Online](#)

⁶⁰ [The Impact of Covid-19 on disabled people in Northern Ireland](#), Executive Summary, Disability Action Northern Ireland, pages 3-4

⁶¹ [Covid-19 and Down Syndrome - DSMIG](#)

⁶² [Fury at 'do not resuscitate' notices given to Covid patients with learning disabilities | World news | The Guardian](#) Whilst this has been a significant concern regarding DNRs amongst people with disabilities in NI, there does not appear to be evidence of widespread imposition of DNRs as there have been elsewhere in the UK [The Impact of Covid-19 on disabled people in Northern Ireland](#), Executive Summary, Disability Action Northern Ireland, pages 5

⁶³ Down's Syndrome Research Foundation [Press Release](#) 27 October 2019, *New report calls for cultural changes to end systemic discrimination towards parents expecting a baby with Down syndrome*

⁶⁴ [Testing for abnormalities | nidirect](#)

⁶⁵ See <https://www.belfastfertility.co.uk/treatments/harmony-prenatal-test/>

⁶⁶ See pages 2, 4 and para 1.12 on pages 7-8 of *Non-invasive Prenatal Testing: Ethical Issues*, Nuffield Council on Bioethics, [published 1 March 2017](#).

⁶⁷ [Subsequent appointments - Northern Health and Social Care Trust \(hscni.net\) Maternity | South Eastern HSC Trust \(hscni.net\) Maternity Services | Western Health & Social Care Trust \(hscni.net\)](#) (see the *Maternity Services Booklet*) [Maternity Services | Southern Health & Social Care Trust \(hscni.net\)](#) [Belfast - Northern Ireland Maternity and Parenting \(ni-maternity.com\)](#)

27. The International Bioethics Committee have raised a number of concerns relating to antenatal screening. They say “[t]he potential ethical disadvantages of NIPT can be summarized as routinization and institutionalization of the choice of not giving birth to an ill or disabled child.”⁶⁸
28. The experiences of parents both in Northern Ireland and elsewhere in the UK are set out in section E (above) witness to precisely this concern. The fact that it has become common practice to offer women a termination following a diagnosis or ‘high chance’ screening result for Down’s syndrome demonstrates a culture where termination has become a ‘routine’ response to congenital abnormality. Termination should no more be a routine discussion following diagnoses of a non-fatal fetal abnormality than it should be following the determination of the child’s sex, which frequently is made at the same ‘anomaly scan’.
29. In England, where NIPT is available privately and offered by some NHS Trusts, an article published by the Sunday Times in 2019 suggests that there has been a decrease in live births of children diagnosed with Down’s syndrome linked with the increased detection of Down’s syndrome and the interest in NIPT as a screening test.⁶⁹ This suggests fears that screening leads only to increases in termination of pregnancies where certain conditions are suspected or diagnosed rather than to improvements in care are not without foundation (see our comments above).
30. The International Bioethics Committee have also warned that increased prevalence of screening may lead to adverse impacts for those who ‘opt-out’, either of testing itself or of termination following a positive result. They say, “women may feel pressured to submit to such screening. They might be stigmatized if they refuse to take the test.”⁷⁰ They also say “[t]his could have a major impact... on the perception of disability and on societal solidarity with disabled people and women who give birth to them.”⁷¹ Experiences of parents who choose to screen but not to terminate in GB suggests such stigmatisation has occurred in that jurisdiction (see our comments above).
31. Significant concerns are also raised amongst individuals with Down’s syndrome and their families (often based on lived experience) that parents receiving an antenatal diagnosis of Down’s syndrome are not fully informed of the rich lives that individuals with Down’s syndrome and their families can go on to lead. A report into the impact of screening reports that, “[a] recurring finding from the survey was how often a woman’s decision is being disregarded, her choice undermined throughout her pregnancy experience.”⁷² It goes on, “[t]his report corroborates concerns held by many within the Down syndrome community that parents expecting a baby with Down syndrome are being pressured into screening and encouraged to terminate,” It also highlights that many parents are met with “outdated negative views of Down’s syndrome.”⁷³
32. The attitudes enshrined by screening can be seen in the language used by highly qualified medical professionals and services: as recently as 2019, women in England have received information about antenatal screening from an NHS service which discusses the ‘risk’ the baby will have a ‘handicap’ as opposed to being ‘normal’. The language of ‘risk’ relating to certain congenital conditions is also used by the website nidirect.gov.uk.

⁶⁸ [Report of the IBC](#) on Updating Its Reflection on the Human Genome and Human Rights, October 2015, paragraphs 89
⁶⁹ [Times Article Down's Syndrome](#), 8 December 2019. See e.g. [Non-Invasive Prenatal Testing \(NIPT\) - The SAFE Test - St George's University Hospitals NHS Foundation Trust](#). [Don't Screen Us Out - Press Release](#), 30 January 2021.

⁷⁰ [Report of the IBC](#) on Updating Its Reflection on the Human Genome and Human Rights, October 2015, paragraph 89
⁷¹ *Ibid*, paragraph 22

⁷² [Press release - England announce roll-out of new Down's syndrome test that will likely see rise in abortions - Don't Screen Us Out New report calls for cultural changes to end systemic discrimination towards parents expecting a baby with Down syndrome | Down's Syndrome Research Foundation \(dsrf-uk.org\)](#) “Sharing the News – The maternity experience of parents of a baby with Down syndrome”, [DSUK: Down syndrome UK](#), page 19.

⁷³ [DSUK: Down syndrome UK](#), page 24.

33. In England and Wales, until this year, the only formal pathway for women carrying a child diagnosed with Down's syndrome (one of the conditions commonly screened for during pregnancy) has been termination of pregnancy.⁷⁴ This suggests that screening has primarily been occurring with a view to preventing the birth of children with such conditions rather than to ensure they receive specialised care.
34. The changes to abortion law set out in the SFIA Bill should ensure that healthcare interventions related to non-fatal conditions are focused on improving the quality of life of unborn children, and improving the support given to prospective parents, rather than on detection with a view to termination. Interventions should include specialised care pathways for women who receive a diagnosis of 'fetal impairment', such as the newly published pathway for women expecting a child with Down's syndrome, produced jointly with disability charities, Down's Syndrome Research Foundation and Positive About Down's Syndrome, and St. George's University Hospitals.⁷⁵

Conclusion

35. This Bill removes the grounds for terminating a pregnancy on the basis of a 'fetal impairment' that is not fatal from our law entirely. It is not limited to cases above 24 weeks of pregnancy. This is about ensuring the laws in Northern Ireland foster a culture where people with disabilities are equally valued. **The SFIA Bill will create equality by upholding the rights of the unborn with disabilities and reinforcing that all lives in Northern Ireland are equal.**

⁷⁴ [NEW Pathway for Personalised Antenatal Care of Pregnancies Suspected or Diagnosed with Down's Syndrome | Down's Syndrome Research Foundation \(dsrf-uk.org\)](https://www.dsrf-uk.org/new-pathway-for-personalised-antenatal-care-of-pregnancies-suspected-or-diagnosed-with-downs-syndrome)

⁷⁵ [NEW Pathway for Personalised Antenatal Care of Pregnancies Suspected or Diagnosed with Down's Syndrome | Down's Syndrome Research Foundation \(dsrf-uk.org\)](https://www.dsrf-uk.org/new-pathway-for-personalised-antenatal-care-of-pregnancies-suspected-or-diagnosed-with-downs-syndrome)

For more detailed information contact: CARE Northern Ireland
East Belfast Network Centre | 55 Templemore Avenue | Belfast | BT5 4FT | t: 07805 813929
Rebecca Stevenson | email: rebecca.stevenson@care.org.uk