



Don't Screen Us Out submission to Northern Ireland Health Committee Consultation on Severe Fetal Impairment Abortion (Amendment) Bill

About 90% of babies who are prenatally diagnosed with Down's syndrome are aborted in Great Britain where there is a clause relating to disability in the Abortion Law and abortion up to birth in such cases. A recent Scottish CARDRISS report on Congenital Anomalies highlighted:

*"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."*¹

The long-term consequences of this have a profound effect on the population of the Down's syndrome community, and enable a kind of informal eugenics in which selected group of disabled people are effectively 'screened out' of the population before they are even born. The UK's obligations under the Convention on the Rights of Persons with Disabilities (CRPD), entail that disabled people and their families should be accommodated, included, and supported by society.

Selective elimination of children with Down's Syndrome due to a lack of proper inclusion, accommodation, and support, violates disabled rights and our ethical obligations to disabled people and communities.

Many parents whose children have been given a diagnosis or prognosis of fetal disability have experienced a lack of clarity in how this has been communicated to them. Additionally, many have experienced a presumption of the medical profession that they would opt for abortion, and a lack of information and support for the option of bearing and raising their disabled baby

All of this causes a culture in which parents feel pressure to abort their babies if they have Down's Syndrome or other disabilities.

The outcome is high rates of termination after mothers are told that their baby has Down's syndrome during pregnancy. Evidence from women who have found that their baby has Down's syndrome highlights:

- Assumption that women will favour terminating the pregnancy,
- Expressions of sadness from NHS staff delivering news.
- Continued questioning of the decisions made by women to continue with their pregnancy.

These are all issues highlighted in the results of a survey published in 2019 in the 'Sharing the News' report².

¹ <https://beta.isdscotland.org/find-publications-and-data/population-health/births-and-maternity/congenital-anomalies-in-scotland/>

² <https://downsyndromeuk.co.uk/flipbook.html>



This is the situation which babies with Down's syndrome are born into in Great Britain, and as they mature, they are becomingly increasingly aware of this inequality. The activism of Heidi Crowter and others to challenge abortion for disability is testimony to this³.

Notwithstanding, the ongoing development of equality legislation at a national and international level has confirmed a change in our culture, the human rights aspect of these laws formalises a tolerant contemporary culture, placing minority groups on an equal basis with others, with the expectation that our legislation and organisations incorporate and embrace this change, and that there is consideration and consultation with minority groups. There have been some important developments that the Health Committee should consider when scrutinising this Bill:

- The UN Committee on the Rights of Persons with Disabilities has consistently criticised countries that provide for abortion on the basis of disability.
- The Committee on the Rights of Persons with Disabilities' concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland made a key recommendation that the UK change its abortion law so that it does not single out babies with disabilities. UK Government has decided to ignore this recommendation.
- The Disability Rights Commission (now the Equality and Human Rights Commission) has said that this aspect of the Abortion Act "is offensive to many people; it reinforces negative stereotypes of disability...[and] is incompatible with valuing disability and non-disability equally".
- The 2013 Parliamentary Inquiry into Abortion for Disability found the vast majority of those who gave evidence believed allowing abortion up to birth on the grounds of disability is discriminatory, contrary to the spirit of the Equality Act 2010 and that it affects wider public attitudes towards discrimination. The Inquiry recommended Parliament reviews the question of allowing abortion on the grounds of disability and should consider repealing section 1(1)(d) of the Abortion Act which allows for it.
- Disabled peer Lord Shinkwin proposed a Bill in the House of Lords that would have repealed section 1(1)(d) of the Abortion Act - the Bill was defeated but unfortunately ran out of time. The Bill was supported by Disability Rights UK.
- When Boris Johnson's Government introduced the new abortion regulations to Northern Ireland last March. The regulations that the Northern Ireland Office introduced allow abortion up to birth for disabilities including Down's syndrome, cleft lip and club foot. 1,875 people with Down's syndrome and their families signed a letter to Boris Johnson urging him to ensure that selective abortion for Down's syndrome was not introduced to Northern Ireland.
- A landmark case against the UK Government over the current discriminatory abortion law that allows abortion up to birth for Down's syndrome is to be heard at the High Court.

Disability should no longer viewed through the lens of uninformed perceptions of quality of life, on the contrary, all of our public services should now be informed by our equality standards. The case to be heard soon in the High Court in London challenges the current abortion law in Great Britain in

³ https://dimensions-uk.org/get-involved/campaign/leaders_list/heidi-crowter/



this respect⁴. Legislation should be informed by an equality perspective on an equal basis with all other perspectives. That is not to say that the disability perspective clashes with other rights, proper consideration of the disability perspective is transformative, informing people and processes that a life with disability is a good life. Our institutions should not be promoting ideas at variance with this. We've moved away from a hierarchical social system, whereby non-disabled people are considered superior to those who are disabled, towards a flat structure where we are all equal.

To hold dear to the idea of disability abortion is to perpetuate disability stereotypes. Having a clause in abortion law which singles out on the basis of a characteristic and accompanying stereotype (resulting in very high rates of termination), strongly suggests that we have simply moved the goalposts in terms of discrimination. Yet, officially, we're no longer an ableist society, we're a society which seeks to foster good relations and promote non-discrimination. Consider, any proposal to add a clause to abortion law for any other minority group would be treated with the disdain it deserves.

The law in Northern Ireland and in the rest of the UK which promotes disability abortion is perpetuating disability stereotypes and stigmatising people living with Down's syndrome and many of our supporters have experienced discrimination based purely on the basis of Down's syndrome in education, work and in health where 'diagnostic overshadowing' is common. Down's syndrome is not a reason to exclude and neither is it a reason to offer abortion, this is clear stereotyping.

Some of the videos on our YouTube channel illustrates the pervasive attitudes around Down syndrome which we should all be battling against:

- Aljazeera We can screen them out <https://www.youtube.com/watch?v=fCEKXY52X1U>
- BBC Radio Down syndrome could be eradicated <https://www.youtube.com/watch?v=ukQmj4xlQK8>
- BBC Radio Down's syndrome is treated as a tragedy <https://www.youtube.com/watch?v=ukQmj4xlQK8>

For all of the reasons given, Don't Screen us Out, an organisation representing people with Down's syndrome and their families, fully supports Bill Givan's bill to amend the Abortion (Northern Ireland) (No. 2) Regulations 2020 to remove the ground for an abortion in cases of severe fetal impairment. This Bill is known as the Severe Fetal Impairment Abortion (Amendment) Bill.

⁴ <https://www.bbc.co.uk/news/uk-england-56982646>