

DSRF Submission to Northern Ireland Health Committee Scrutinising Severe Fetal Impairment Abortion (Amendment) Bill

Peter Elliott established the research charity, Down syndrome Research Foundation, in 1989 compelled to help improve the outcome for people with Down's syndrome after the full realisation that there was a dearth of research for this vulnerable group. Over the years, it has been a challenge for the charity to fund and establish research projects in the UK, a prenatal screening programme and high termination rates have probably contributed to those challenges.

Today Dr. Elizabeth Corcoran supported by a board of Trustees including other healthcare professionals, parents and research scientists.

In 1989 a paper from the Department of Environmental and Preventive Medicine, Wolfson Institute of Preventive Medicine was clear:

"Antenatal screening and selective termination offer the possibility of preventing the birth of infants with serious congenital abnormalities. Screening is not without costs, both human and financial."

No doubt, if this paper was written today the wording would be different, more sensitive, however, there is no evidence that the intention or the outcome has changed, and the routine offer of screening has not led to any therapeutic benefits. Still today, as then 'about 90% of those found to have a pregnancy with Down's syndrome chose to have a termination.'

Even today, despite being covered by a screening programme for several decades, recent research found that people with Down's syndrome die twenty-eight years before those who do not have the condition highlighting the obvious need for more, high quality research:

https://www.researchgate.net/publication/323993676_Early_death_and_causes_of_death_of_people_with_Down_syndrome_A_systematic_review#:~:text=Results%20People%20with%20Down%20syndrome,age%20and%20poorer%20parental%20education.



This research highlights that survival rates have improved over time; however, we know from a recent Freedom of Information request that £5 is spent on research per year per person living with Down's syndrome whilst £11 is spent on screening. In actual fact, the biggest improvement in life expectancy for this group occurred as they were freed from the institutions which they were often sent to at birth, placed where they did not thrive. Following on from that time, there have been some very public investigations over the years highlighting the ongoing differentiation made for people with Down's syndrome who are, at times, not afforded the healthcare that other people enjoy. They are failed by our institutions:

"failed to provide a balanced view of all treatment options available for children with Down's syndrome and congenital heart disease in the early 1990s"

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1120002/>

Even today In Great Britain women's decisions to continue pregnancy after finding out that their baby has Down's syndrome are often questioned. We were involved with the development and publication of a recent report which confirms that many women are subjected by subtle or not so subtle pressure to terminate pregnancy:

"an expectation by medical professionals for women to terminate when a baby is identified as having Down syndrome"

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

Even as recently as 2015, the Royal College of Obstetricians and Gynaecologists provided a suggestion to the UK Screening Committee regarding the implications of the introduction of a new screening test as a primary test:

"If the decision has been made primarily on cost grounds, then a more rigorous economic analysis has to be made that includes the lifetime costs of caring for children and adults with Down's syndrome"



T: 01892 71 1121 E: DSRF@DSRF-UK.ORG A: PO BOX 576, TUNBRIDGE WELLS, TN2 9WJ

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<https://www.bioedge.org/bioethics/new-downs-syndrome-test-could-save-money-says-rcog/12017>

On the other hand, we now consider ourselves an inclusive and diverse society, with no exclusions, including the disabled. This is reflected in the establishment of a United Nations Convention of the Rights of People with Disabilities.

In the years following the 1990 HFEA clause which allows abortion up to birth in the case of disability there has been notable comment made.

- The Disability Rights Commission (now the Human Rights Commission) wrote in 2001, of the disability section in the 1967 Abortion Act:

"The Section is offensive to many people; it reinforces negative stereotypes of disability and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equally."

- In 2017, a report from the Committee on the Rights of Persons with Disabilities of the United Kingdom of Great Britain and Northern Ireland recommended:

"The Committee recommends that the State party amend its abortion law accordingly. Women 's rights to reproductive and sexual autonomy should be respected without legalizing selective abortion on the ground of fetal deficiency."

- In 2017 Liz Sayce, the CEO of DR UK commented on Lord Shinkwin's Abortion (Disability Equality) Bill which unfortunately ran out of time:

"The Bill is not about the rights and wrongs of abortion, 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".



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We are submitting to the Health Committee that as an organisation we are in full support of Paul Givan's Severe Fetal Impairment Abortion (Amendment) Bill as this is a time in the UK where, as a society, we have come to understand, that a life with disability is a good life and this belief is reflected in our inclusive legislation and policy. Our laws should reflect that.

We believe that Regulation 7 of the Abortion (Northern Ireland) (No. 2) Regulations 2020 (Severe fetal impairment or fatal fetal abnormality) as laid down, will perpetuate disability stereotypes.

Our opinion has been drawn from the contemporary standards on equality we now claim to hold dear and our experience as a charity with over 30 years of experience in this field. We're concerned that there was no proper consultation with disability groups in Northern Ireland before Regulation 7 was laid down, where it may have become clear that the exclusion of a disability clause from the regulations would not be in conflict with women's rights.

As new laws are laid down, we take a grasp of the equality issues and ensure that we can support women who find themselves pregnant with a baby with Down's syndrome without coercing any towards abortion, subtly or otherwise.

A life with Down's syndrome is not a tragedy although it may be true to say that the existence of screening and selective abortion has made life more difficult for people with Down's syndrome. Research tells us that women and their families are happy with their lives, although we know that with the right focus, we can improve their lives further as our NHS is committed to so doing for other groups.

Whilst we understand that there are many, many people of goodwill in our health services in the UK, the presence of a disability clause in our Abortion law has served as the only reason as to why women might undergo prenatal screening for Down's syndrome. This has led to promotion of abortion for disability and it has served to perpetuate disability stereotypes which of course offends equality legislation and the standards which we claim to uphold.

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