

**SUBMISSION TO THE
UNITED NATIONS COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES**

Draft general comment on art. 5

29th November 2017

*Don’t Screen Us Out* is a United Kingdom (UK) Down’s syndrome campaign group. We are an umbrella advocacy group. Our principles are based around ensuring that antenatal screening programmes are not in conflict with established national and international human rights principles on disability.

The group was established on 15th January 2016 following recommendations made by the UK National Screening Committee (UK NSC) that Non-Invasive Prenatal Testing (NIPT), a genetic blood test, is introduced into the UK National Health Service (NHS) antenatal screening pathway. NIPT has now been authorised and is to be implemented in an ‘evaluative’ way from 2018.

The Don’t Screen Us Out mission is to ensure that the basic human rights of people living with Down’s syndrome in the UK are understood and upheld in public health screening programmes. We aspire to ensure that the UK Department of Health adhere to the spirit of article 13B of the United Nations Human Rights Charter (UNHRC) on human rights and fundamental freedom for all, that they will ensure that this is freedom is applicable to everyone, regardless of their genetic makeup.

This draft on Article 5 of the UNCRPD has highlighted the stigmatization and discrimination that disability-selective antenatal screening policies bring (Page 16, section 44). We applaud and welcome these statements.

For decades, since people with disability were no longer incarcerated in institutions, there has been a corresponding move towards identification of babies with difference in the womb. Such a move has rarely led to therapeutic intervention, and has not carried public health benefit. In fact, the sole health benefit is now seen in the introduction of more efficient screening technologies which reduce the miscarriage harm caused by the screening programmes themselves.

1. There is now a wealth of evidence in the UK about the issues and harms which have arisen from existing screening programmes, here are some examples.
* 2009 Alison Hall of the PHG foundation discussed ethical issues around screening where she tells us ‘Consideration of these ethical, legal and social issues should play an important role during the introduction of cffDNA [NIPT] technology’ <http://www.phgfoundation.org/download/ffdna/ffDNA_appendix.pdf>
* 2016 PM David Cameron, stated in Parliament at Prime Minister’s Question Time, with regard to the introduction of new NIPT, that ‘there are moral and ethical issues that need to be considered in these cases.’
* 2016 Dr Gareth Thomas article published in AMA Journal of Ethics ‘We argue that prenatal screening (and specifically NIPT) for Down syndrome can be considered a form of contemporary eugenics, in that it effaces, devalues, and possibly prevents the births of people with the condition.’
* 2016 In his book *Down’s Syndrome Screening and Reproductive Politics*

Dr. Gareth Thomas explores how and why we are so invested in this practice and what effects this has on those involved. This research “captures how this routinisation is deepened by a systematic, but subtle, framing of Down’s syndrome as a negative pregnancy outcome.”

* 2017 Answer to a recent Parliamentary Question, the Scottish Government replied “Non-invasive Prenatal Testing (NIPT) in the national screening programme will not be used to reveal non-medical features of the fetus, such as sex.”
* Down’s syndrome Scotland (DSS) produced a 2017 Health Report, one of the standout statements was “With regard to ante/post-natal care, findings from our questionnaire illustrate appalling behaviours from professionals who are supposed to support expectant/ new parents. DSS therefore asks for the review of pregnancy screening practice as a matter of urgency, as well as a review of the support given to parents whose baby is diagnosed with Ds at birth.” No such review has yet taken place.
* 2017 Nuffield Bioethics Committee published a 149-page report on NIPT with recommendations, much of these issues already exist in current screening programmes. They make the point therein “Although we recognise the gains made in securing greater rights for disabled people over the last 50 years, there should be broader efforts made by the Government and others to confront any institutional and societal biases and prejudices against disabled people and to tackle discrimination, stigma and exclusion. This includes responsibilities to shape societal attitudes and has implications for public awareness as well as medical education and training. It is our view that women and couples would be better able to make genuine choices about their pregnancies if all disabled children were actively welcomed when they are born into the world and valued as equal to those without disabilities.”
* 2016 As part of Nuffield’s work around NIPT, a small study was carried out “on gaining the views of individuals with genetic variations and a learning disability.” <http://nuffieldbioethics.org/wp-content/uploads/Barter-report-on-NIPT-summary-plain-English.pdf>

“Participants spoke of negative discourses about disability and a lack of understanding and fear of Down syndrome.

This stood in stark contrast to their life experience and the life possibilities for anyone born with Down syndrome or disability.

Participants agreed with testing as a means of preparation and as an opportunity for prospective parents to gain information.

Participants’ views of termination varied from disagreeing to feeling unsure. Overall participants were saddened and expressed disappointment with termination following testing.

At the same time, most agreed with a woman's decision to choose.

There was a consistent and strong call for balanced information, including the possibility to meet people with Down syndrome, as a means of supporting educated or informed choice for women and families.

Decisions to test and decisions taken following testing may have a direct or indirect impact on individuals on an emotional and practical level.”

1. Government-sponsored antenatal screening programmes should only exist to furnish an individual with genetic information about her wanted, unborn baby, however,
* Much antenatal screening training and development has been informed by an organisation who don’t employ any front-line resources portraying the lived experience; those people who have children with the screened-for conditions or who have the condition themselves.
* Language employed in UK screening programmes and literature doesn’t comply with the Public Health equality duty and often implies negativity around Down’s syndrome e.g. ‘problem’ ‘risk’.
* There is no protocol for individuals continuing with a pregnancy after a genetic condition has been detected.
* Despite the UK ratifying the UNCRPD, no mention is made of these Articles in screening literature for professionals or in any guidance.
* A recent UK Government document referred to “those antenatal screening programmes aiming to enable reproductive choice.”

The scientific ability to identify conditions prenatally should be a means to an end, a way to lead to therapeutic intervention. Instead, it could be hypothesized, that the technology is not serving public interest but has, instead, created institutionalized stigmatization of targeted groups in order to justify public spending on mass screening programmes. Due to a lack of ethical intervention, those ‘Harmful stereotypes’, referred to in the UNCRPD’s draft document on Article 5, persist in screening programmes and perhaps affect care at birth too.

The UK National Screening Committee makes a distinction between recommended screening programmes (health benefit) and other types of programmes; therefore, it must be made clear in the offer of screening when there is no possibility of therapeutic interventions during pregnancy, i.e. the only result of participating in screening is confirmation that the screened-for condition is present.

The existence of a pre-existing genetic condition should not assume a purely medical perspective in a screening situation, this affronts a state’s treaty obligations to the UN Convention on the Rights of Persons with Disabilities (CRPD) to make sure that its health policies – including antenatal screening – are informed by and reflective of a ‘social model’ understanding of disability.

**To address stigmatization and discrimination caused by Disability Selective Screening Programmes Don’t Screen Us Out therefore makes the following recommendations:**

UN Countries which provide population antenatal screening programmes should, specifically:

1. Carry out a full ethical review of state funded Fetal Anomaly Screening Programmes.
2. Improve training and guidance requirements for medical professionals.
3. Provide ready and accessible provision of every needed support for parents continuing their pregnancy.
4. Provide information about adoption services and short-term concurrent foster placement from birth.
5. Provide information about and provision of palliative care for babies with life limiting conditions.