

**Submission by We’re All Equal on the Draft General Comment on Article 6 of the International Covenant on Civil and Political Rights – Right to life (5 October 2017)**

The UN Human Right Committee (UNHRC) has asked for comments on the draft of the latest General Comment on the right to life as expressed in Article 6 of the International Covenant of Civil and Political Rights (ICCPR). What follows is the contribution of the ‘We’re All Equal’ campaign on how the General Comment as currently composed could better establish principles of non-discrimination with regards to disability and abortion law.

In the United Kingdom (the State party in which ‘We’re All Equal’ is based), as in many other jurisdictions, the law currently permits abortion through exemptions from prosecution for doctors who perform terminations on the basis of a series of grounds supplied in the Abortion Act 1967. Also similar to the laws of other countries, there is one ground provided in the Abortion Act which is unlike all the others. That is section 1(1)(d), which grants abortion when there is a “substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped”[[1]](#footnote-1).

Beyond the outdated and ableist language of ‘abnormalities’ and ‘handicap’, another relic of a past age is this provision itself, which is the only provision that allows for a specific type of characteristic to be targeted by the law: physical and mental impairments.

Were there to be a law that allowed abortions to be carried out when the foetus was of a specific race, or sex, there would rightly be an outcry. Yet in many places in the world, that impairments can be grounds for abortion is seen as not remotely surprising or unacceptable. The message this sends is that the lives of people who possess impairments are less valuable, and less worthy of society’s protection or support, simply because of the conditions that may lead to their disability due to the lack of inclusion by society. A lack of inclusion that starts with the State and its laws permitting those with impairments to be destroyed before they are even born.

This is not only a species of invidious legal discrimination, but it has profound and severe implications for the future. The effect of increasing effectiveness of prenatal detection techniques in discovering foetal impairment, is that many communities of people with impairments are being ‘screened out’ before birth. In countries such as Iceland, where article 9(2)(b) of the Icelandic abortion law[[2]](#footnote-2) allows abortion for disability, and article 10 establishes that it is one of the grounds that justifies abortion beyond the general upper limit of 16 weeks right up to birth, 100% of babies detected pre-natally with Down’s syndrome are now aborted.

Similarly to Iceland, in 2015 the Copenhagen Post reported[[3]](#footnote-3) that in 2014, 98% of Danish women with pregnancies in which Down’s syndrome was detected, opted for abortion. This was due to the spread of prenatal ‘nuchal’ testing in Denmark since 2004. The article cites a poll that showed the accompanying significant fall in Down’s syndrome births was seen as a good thing by 60% of Danes, including 70% of men, and 50% of women.

Hitherto, the types of prenatal testing available in countries like Iceland and Denmark have been the ‘combined test’, a set of blood tests that carry an 80-85% success rate in detecting foetal impairment. The situation of ‘screening out’ people with impairments from the population is only set to get worse, however, as new ‘Non-Invasive Prenatal Testing’ (NIPT), which is even more efficient in detection, is implemented in various countries, including the UK.

In 2015, our National Screening Committee (UKNSC) recommended the implementation of the ‘cell-free DNA’ (cfDNA) technique on the basis that it would reduce miscarriages as fewer women would feel the need to opt for confirmation that their baby has an impairment through invasive amniocentesis, which carries a small risk of causing miscarriage. Unfortunately, what was not highlighted was that a National Institute for Health and Research RAPID evaluation study[[4]](#footnote-4) projected that the proposed implementation would result in 102 more babies with Down’s syndrome being identified each year and, based on the current 90% of parents with a diagnosis that terminate a pregnancy in the UK, this was projected to result in 92 more such children being aborted each year. By contrast, the same study projected that it would result in 25 fewer miscarriages per year compared to the current NHS Fetal Anomaly Screening Programme (FASP).

Given there were 717 Down’s syndrome live births in 2013[[5]](#footnote-5), 92 more babies aborted would represent a 13% decrease in these births – therefore likely having a profound effect on future numbers of people with Down’s syndrome in the population. Now that it has been confirmed that the UK will indeed implement cfDNA / NIPT, there will therefore be an overall increase in loss of lives, with the accompanying effect on communities of people with impairments.

This is set to only more firmly establish discriminatory attitudes. In the Netherlands, where NIPT is being introduced for Dutch women this year, members of an opposition party asked the Dutch Minister of Health, Edith Schippers, if she planned to take any measures to prevent the Danish and Icelandic scenario from happening in the Netherlands. Schippers answered: “If freedom of choice results in a situation that nearly no children with Down syndrome are being born, society should accept that”[[6]](#footnote-6).

Such comments illustrate an international reality. A recent report of the International Bioethics Committee (IBC) of the United Nations Educational, Social, and Cultural Organisation (UNESCO) issued a stern warning about the drive to adopt NIPT in national screening programmes, saying that “the potential ethical disadvantages of NIPT can be summarised as routinisation and institutionalisation of the choice of not giving birth to an ill or disabled child”[[7]](#footnote-7).

We believe this is relevant to the UNHRC in deciding how to express ICCPR rights in this General Comment, as well as other human rights standards. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) mandates that States parties ensure that their health policies – including prenatal screening – are informed by and reflective of a ‘social model’ understanding of disability. This requires inclusion and consultation of people with impairments which has often, if not always, failed to take place.

Indeed, based on the stern warning issued by UNESCO’s International Bioethics Committee’s warning on the use of NIPT to detect abnormalities and sex early in pregnancy[[8]](#footnote-8), and the reports of NGOs for persons with disabilities, that the level of technology made possible by the latest prenatal screening tests, it is becoming increasing clear that these technologies are being used, if only in an informal manner due to the ableist culture in the medical system, to screen persons with disabilities out of the population before they are born. Thus, the availability of abortion without effective restrictions brings about the enforced disappearance of persons with disabilities.

What enables these deleterious policies however, are laws that permit the discriminatory targeting of children with impairments in the womb, and it is precisely the existence of such laws that has led to the UK’s recent censure by the U.N. Committee on the Rights of Persons with Disabilities (UNCRPD). In August of this year, the UNCRPD gave its concluding observations[[9]](#footnote-9) on how the UK is respecting its Convention obligations. In this context, it identified and faulted as contraventions of the UNCRPD’s article 5 on equality and non-discrimination, “perceptions in society stigmatising persons with disabilities as living a life of less value and the termination of pregnancy at any stage on the basis of foetal impairment”, and recommended that the UK “changes abortion law accordingly. Women’s rights to reproductive and sexual autonomy should be respected without legalising selective abortions on ground of foetus deficiency”.

This follows on from ICCPR rights to non-discrimination (articles 2 and 26), including for children (article 24). It also follows on from the excellent language in paragraph 64 of the General Comment which we see as directly relevant to abortion laws that contain, enable, and worsen disability discrimination:

*The right to life must be respected and ensured without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or any other status, including caste, sexual orientation and gender identity, disability, albinism, and age. Legal protections for the right to life must apply equally to all individuals and provide them with effective guarantees against all forms of discrimination. Any deprivation of life based on discrimination in law or fact is ipso facto arbitrary in nature*.

Laws which directly target people with impairments in the womb surely contravene all these standards. We call on the UNHRC to therefore include in its remarks about the scope and nature of States parties regulation of abortion in paragraph 9 of the draft of the General Comment under consultation, that they repeal any provision of their laws that explicitly allows for abortion based on the characteristic of physical and mental impairments. Additionally, we call for mention to be made in that same section of a positive obligation of States parties to provide support for children with impairments and their families, so as to help overturn an international culture of discrimination, in which such children are valued less than their fully-abled counterparts.

Finally, it also concerns us that one of the remarks made by the UNHRC in paragraph 9 of the draft of the new General Comment sees the lack of access to abortion for a woman who has a child with a ‘fatal impairment’ as being a violation of the article 7 right to freedom from torture, on the basis that this “would cause the woman substantial pain or suffering”. This suggests that the existence of a child with a severe impairment is somehow intrinsically burdensome (at least more than any help can alleviate), assumes that every prognosis or diagnosis of life-limiting impairment will necessarily lead to the short-term death of the child (this is not necessarily the case), and also seems to open the door for disability discrimination, by implying that we may judge the existence of children with impairments by the mental burden this may place on her parents.

We recommend the removal of this as a specific example from the text of paragraph 9, due to the discriminatory implications it creates, and the fact that abortion on the grounds of distress to the mother can be legal without explicit and discriminatory grounding of that distress in the characteristics of her child.

1. Section 1(1)(d), Abortion Act 1967: https://www.legislation.gov.uk/ukpga/1967/87/section/1 [↑](#footnote-ref-1)
2. Law on counseling and education regarding sex and childbirth and on abortion and sterilisation (1975):

   http://www.althingi.is/lagas/nuna/1975025.html [↑](#footnote-ref-2)
3. Down’s Syndrome heading for extinction in Denmark, Copenhagen Post, October 20th 2015: http://cphpost.dk/news/down-syndrome-heading-for-extinction-in-denmark.html [↑](#footnote-ref-3)
4. RAPID non-invasive prenatal testing (NIPT) evaluation study: a report for the UK National

   Screening Committee (Executive Summary): http://legacy.screening.nhs.uk/policydb\_download.php?doc=551 [↑](#footnote-ref-4)
5. The National Down Syndrome Cytogenetic Register for England and Wales: 2013 Annual Report, by Morris and Springett, December 2014: http://www.binocar.org/content/annrep2013\_FINAL\_nologo.pdf [↑](#footnote-ref-5)
6. Dutch Minister of Health: if National screening program leads to disappearance of people with Down syndrome, society has to accept that, Huffington Post, March 29th 2017: http://www.huffingtonpost.com/entry/dutch-minister-of-health-if-national-screening-program\_us\_58739680e4b0eb9e49bfbd4f? [↑](#footnote-ref-6)
7. Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights (2015):

   http://unesdoc.unesco.org/images/0023/002332/233258e.pdf [↑](#footnote-ref-7)
8. Paragraphs 22, 90 and 91 in the report issue concerns that in contexts where there is a widespread use of NIPT and other prenatal screening and testing technologies and increasing liberalisation of abortion, discrimination and stigmatisation of persons with disabilities or of persons of a particular sex would take place in utero. Of particular concern for persons with disabilities is that “erroneous or misinterpreted results could lead to the destruction of healthy and normal embryos and foetuses”. “Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights”, UNESCO, SHS/YES/IBC-22/15/2 REV.2, 2015 <http://unesdoc.unesco.org/images/0023/002332/233258e.pdf> [↑](#footnote-ref-8)
9. ​​Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, UNCRPD, August 2017: http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/GBR/CRPD\_C\_GBR\_CO\_1\_28817\_E.docx [↑](#footnote-ref-9)