

***UK NSC's consultation on cfDNA
screening***

Response by:

Christian Concern

Christian Legal Centre

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About Us

Christian Concern is a policy and legal resource centre that identifies changes in policy and law that will affect the Christian heritage of our nation. The team of lawyers and advisers at Christian Concern conduct research into, and campaign on, legislation and policy changes that may affect Christian freedoms or the moral values of the UK. Christian Concern reaches a mailing list of over 80,000 supporters. www.christianconcern.com
Christian Concern is linked to a sister and separate organisation, the Christian Legal Centre, which takes up cases affecting Christian freedoms. www.christianlegalcentre.com

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Christian Concern submission to UK NSC consultation on cfDNA screening

- We do not agree that cfDNA testing should be made available to women who identify as having a 1 in 150 or greater risk of trisomy.
- It is claimed that the proposed technology will help reduce the number of miscarriages caused by invasive testing procedures such as amniocentesis or chorionic villous sampling. However, according to the RAPID study referred to by the UKNSC, cfDNA testing will lead to 102 more T21 pregnancies being detected every year. Statistics from the National Down Syndrome Cytogenetic Register (NDSCR) demonstrate that 90% of all babies diagnosed with Down's syndrome are aborted; based on these figures, the proposed practice will result in 92 more annual abortions on the basis of Down's syndrome. This is compared to 25 fewer miscarriages as a result of IDP. Furthermore, due to the accuracy of cfDNA, there is likely to be increased pressure for the test to be made available as part of initial antenatal screening. The NSC Review has acknowledged that, were the test to be used as part of *primary* screening, it would lead to the detection of an additional 289 more babies with trisomies.
- Abortion on the grounds of disability operates against a presumption towards valuing the lives of disabled and non-disabled people equally and is contrary to Article 14 ('prohibition against discrimination') of the European Convention on Human Rights and Convention of the Rights of Persons with Disabilities (CRPD). The CRPD, which was adopted by the United Nations (UN) General Assembly, is a legally binding human rights convention which was signed by the UK in 2007 (and ratified in 2009). It outlines the rights of people with disabilities, enshrining the principles of dignity, non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of person with disabilities as part of human diversity. A recent report of the International Bioethics Committee (IBC) of the United Nations Educational, Social, and Cultural Organisation (UNESCO) said: "Prevention as a social objective, focused, for example, on reducing care costs for people with congenital conditions or disabilities... would imply a discriminatory practice that sends the message that these people are unwelcome in society...A widespread use of NIPT, namely as general screening in order to detect abnormalities, followed by an abortion, is perceived by some people as an evidence of the will to avoid permanent pain in a lifetime, by others as a sign of a situation of the exclusion society gives to people affected by this illness, meaning indirectly that certain lives are worth living, and others less."¹
- Justifying terminations on the grounds of disability also devalues the lives of those already living with a disability. In relation to Ground E of the Abortion Act 1967, which permits abortion up to birth where there is a risk that the baby will be born with a 'serious handicap', the Disability Rights Commission said: "*Ground E 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.*" Furthermore, financial investment in in vitro neonatal research and therapies in England, Wales and Scotland is at an all-time low due to the availability of abortion

¹ 'Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights', October 02nd 2015, : <http://unesdoc.unesco.org/images/0023/002332/233258e.pdf>

as a 'quick' and inexpensive option. A mother's decision to continue with her pregnancy should be based upon valuing non-disability and disability equally.

- The Abortion Act does not define the terms 'substantial risk' or 'serious handicap', and offers no guidance as to the criteria to be applied in practice. In the absence of any coherent and uniform guidance from the courts, the interpretation of these terms is left to the discretion of doctors, who continue to sanction abortions under Ground E for Down's syndrome. This is despite the fact that Down's syndrome does not meet the 'serious handicap' criteria.² On this basis, screening for Down's syndrome should only be provided with the intention of preparing and assisting families to properly care for a child with special needs.
- There is a notable discrepancy between the figures cited by the UKNSC, leading to serious concern over the credibility of the claims made in its consultation document. Findings from the Systematic Review indicate that the proposals would lead to 20 more T21 pregnancies being detected every year, whilst RAPID has suggested an increase of 102 pregnancies. This means that according to the systematic review, there would be 18 more annual abortions on the basis of Down's syndrome, whilst figures from RAPID indicate an increase of 92 abortions.³ Furthermore, the **RAPID review has indicated half the reduction in miscarriages compared to the systematic review.**
- There is additional concern that permitting the use of cfDNA will result in the normalisation of the procedure and increased pressure on regulators to expand the categories of defects eligible for screening. This in turn would lead to more abortions on the basis of disability. The IBC's report warned that "[t]he 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."⁴
- Since the proposed technology would allow a baby's gender to be identified, there is an additional risk of an increase in the practice of illegal gender-selective abortion. The IBC report said: "Another risk lies in the cultural prejudices of preferring a child of the male sex, the sex of the baby being one of the characteristics that can obviously be discovered by NIPT. As this test can be carried out at a very early stage of the pregnancy it would be difficult, even impossible for doctors to forbid the communicating of sex to the parents, and especially at a time when many countries have liberalised abortion. This could lead to a selection based on sex, which is against ethical values of equality and non-discrimination."⁵
- The presumption that mothers with a disability diagnosis will always opt for an abortion has resulted in many women making choices they have later regretted. The IBC report has noted: "Ironically, the introduction of a test that may bring informed choice to more pregnant women may undermine this goal in practice, if NIPT is used without thinking enough about the impact. Furthermore, there is the risk that pregnant

² ¹³In 2013, 590 abortions were performed for Down's syndrome:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/319460/Abortion_Statistics__England_and_Wales_2013.pdf

³ Based on Statistics from the **National Down Syndrome Cytogenetic Register (NDSCR)** which demonstrate that 90% of all babies diagnosed with Down's syndrome are aborted;

⁴ Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights', October 02nd 2015,; <http://unesdoc.unesco.org/images/0023/002332/233258e.pdf>

⁵ 'Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights', October 02nd 2015,; <http://unesdoc.unesco.org/images/0023/002332/233258e.pdf>

women with a positive result don't await the validation of the result through invasive diagnostics, but immediately choose to abort the embryo or foetus, without adequate counselling about the relevance of the detected abnormality. Also women may feel pressured to submit to such screening. They might be stigmatised if they refuse to take the test". A British Parliamentary Inquiry into abortion on the grounds of disability concluded that: "...the studies have all found that around 20% of women, between one and two years after an abortion for fetal abnormality, have a psychiatric condition, usually a complicated grief reaction, a depressive disorder or post-traumatic stress disorder."⁶

- Other research has suggested that mothers who terminate a pregnancy on the grounds of disability experience the same degree of pain and emotional suffering as parents who lose a baby unexpectedly⁷ and that abortion for disability can be a "traumatic event...which entails the risk of severe and complicated grieving."⁸ A recent study found that 17% of women who aborted their babies on the grounds of disability were diagnosed with psychiatric conditions, including post-traumatic stress, anxiety or depression, 14 months after the procedure.⁹
- An increasing body of research demonstrates that abortion itself – whether or not on the grounds of disability - increases the risk of mental health problems in women, even in cases where the pregnancy was unwanted from the outset.¹⁰
- We affirm the value of the life and well-being of **both** mothers and unborn children. We advocate for better specialist counselling, care and support for women and families facing a disability diagnosis. Unborn babies, whether healthy or disabled, are human beings with intrinsic worth and value. We support measures that would value and protect the life, health and well-being of **both** the mother and the unborn child.
- In this instance, the proposals would place the mental health of women at significant risk and fail to adequately protect the lives of babies diagnosed with disability, being primarily concerned with preventing the miscarriage of children *without* chromosomal abnormalities. We reiterate therefore that the plans contravene Article 2 ECHR ('right to life'), Article 14 ECHR ('prohibition against discrimination') as well as the CRPD – and should be dropped.

⁶ <http://www.abortionanddisability.org/resources/Abortion-and-Disability-Report-17-7-13.pdf>

⁷ Zeanah, 1993

⁸ Korenromp et al, 2005,

⁹ Korenromp et al, 2005,

¹⁰ Following adjustments for confounding variables, a major longitudinal survey published in 2008 by the British Journal of Psychiatry found that women who have abortions are 30% more likely to experience suicidal thoughts, substance abuse, anxiety disorders and clinical depression, compared to women with other pregnancy outcomes (DM Fergusson et.al., "Abortion and mental health disorders: evidence from a 30-year longitudinal study", The British Journal of Psychiatry, 193:444-451,2008). Research conducted by Finland's National Research and Development Centre for Welfare found that suicide rates in abortive women was three times higher than for the general population, and six times higher than for women carrying their pregnancy to term (M. Gissler et.al, "Injury deaths, suicides and homicides associated with pregnancy). In a 2009 paper, Fergusson stated: 'The mental health risks associated with abortion may be larger, and certainly are not smaller, than the mental health risks associated with unwanted pregnancies that come to term (Fergusson DM et al. Abortion and mental health (correspondence). British Journal of Psychiatry 2009;195:83-84). His research found that women reporting distress at having an abortion were 40-80% more likely to experience mental ill health than those not having an abortion (Fergusson DM et al. Reactions to abortion and subsequent mental health. British Journal of Psychiatry 2009;195:420-426)