

Dementia and Disabilities Unit,
1N14, Department of Health and Social Care,
Quarry House, Quarry Hill
Leeds
LS2 7UE

25 April 2019

Dear Sir / Madam

I am writing in response to the DHSC consultation '*Learning disability and autism training for health and care staff*'. The Nuffield Council on Bioethics strongly welcomes the proposals for training on learning disability and autism that aim to help improve healthcare experiences for people with disabilities.

Following a 12-month inquiry, the Nuffield Council published the report [*Non-invasive prenatal testing: ethical issues*](#) in 2017. Non-invasive prenatal testing (NIPT) is a technique that can be used to test a fetus for a range of genetic conditions and features. NIPT is used most commonly to test for Down's syndrome. People with Down's syndrome have a learning disability that can vary from mild to severe in different people.

In our report, we conclude that women and couples should be able to access NIPT to enable them to find out at an early stage of pregnancy, if they wish, whether their fetus has a significant medical condition or impairment that manifests in childhood. This can help women and couples prepare psychologically and practically for the birth of a disabled child, and can also help them make decisions about whether to terminate a pregnancy. NIPT became available to women in Wales through the NHS fetal anomaly screening programme in 2018, and will soon be available to women in England and Scotland.

In our report, we discuss how NIPT could change the way we view pregnancy, disability and difference. We consider the possibility that increasing uptake of NIPT by women and couples could lead to a decrease in the number of people born and living with genetic conditions and impairments. This might lead to fewer resources being invested in research and health and social care relating to people with genetic conditions. It might also give rise to perceptions that people are 'to blame' for having a baby with a disability, might change views about what is considered to be a healthy pregnancy or child, and might make disabled people and their families more vulnerable to stigma, discrimination and abuse.

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The report recommends that NIPT should only be available within an environment that enables, as far as possible, women and couples to make autonomous, informed choices. However, concerns about the challenges faced by disabled children and adults in accessing adequate healthcare and social support, as well as educational and employment opportunities, might influence the choices of women and couples who have received a diagnosis of fetal anomaly.

For all these reasons, our report recommends that the Government should ensure it is meeting its duties to provide disabled people with high quality specialist health and social care, and to tackle the discrimination, exclusion and negative societal attitudes experienced by disabled people. We believe women and couples will be better able to make genuine choices about their pregnancies if all disabled children are actively welcomed into the world. A collective effort should be made to better acknowledge the lived experience of disability and to challenge the view that caring for a disabled child is necessarily burdensome or undesirable. We believe organisations and individuals that are subject to the Public Sector Equality Duty, such as health and social care providers, the BBC, providers of medical education and training, and schools and other education providers, have a particular duty to tackle the discrimination and exclusion experienced by disabled people. Training of the kind described in this consultation could play a significant role in helping deliver that.

Should you require any further information about our report on NIPT, please contact Catherine Joynson, Assistant Director (cjoynson@nuffieldbioethics.org).

Yours sincerely,

A handwritten signature in black ink that reads "Hugh Whittall". The signature is written in a cursive, flowing style.

Hugh Whittall
Director, Nuffield Council on Bioethics