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VIEWPOINT

Advocating for Reproductive Rights in Northern Ireland: Access to First-Trimester Screening

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Authoritarian populist governments around the globe are attacking reproductive rights as part of political strategies to reinforce traditional gender roles and gain legitimacy among certain electorates. However, various coalitions of academics, nongovernmental organizations, and medical professionals have helped protect reproductive rights in challenging political contexts, giving hope to those wishing to follow suit. In this viewpoint, we outline our efforts to advocate for universal access to first-trimester antenatal screening in Northern Ireland, a country where religion and politics have long weighed on women's ability to make decisions over their reproductive health.

Northern Ireland, a part of the United Kingdom (UK) where abortion used to be unlawful in all circumstances unless the life of the pregnant woman was at risk, decriminalized abortion in 2019 and authorized it under several circumstances, including in cases of "severe fetal impairment or fatal fetal abnormality."[1] However, region-wide access to abortion services was not achieved until 2022.[2] As outlined by Fiona Bloomer and Emma Campbell, the use of human rights law was instrumental in the push for legislative reform, with international and national human rights bodies playing active roles throughout this process.[3] Despite the furthering of reproductive rights in this context, some aspects of pregnancy care in Northern Ireland remain subpar and dissociated from any human rights language, resulting in discrimination against women (and pregnant persons). This is the case for first-trimester antenatal screening, a service routinely offered to all pregnant women across the UK but (un)surprisingly, not in Northern Ireland.

Starting on these premises, our interdisciplinary research team met in 2023 to discuss how to best advocate for the availability of this service in Northern Ireland. We agreed to draft a policy brief outlining the impact of this situation on pregnant women, its human rights ramifications, and the need for a more co-

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herent social policy. It was published in June 2024.[4]

First-trimester screening allows the detection of three of the most common chromosomal abnormalities: trisomy 13 (Patau syndrome), trisomy 18 (Edwards syndrome), and trisomy 21 (Down syndrome). All three trisomies lead to higher incidences of miscarriages, stillbirth, and neonatal and infant mortality. Such incidences are particularly high for trisomies 13 and 18, both considered "fatal fetal abnormalities," whereas trisomy 21 is considered a "serious fetal abnormality" given the significant lifelong health issues it results in. First-trimester screening policies are recommended by the World Health Organization and, in the UK, by the National Institute for Health and Care Excellence and by the Royal College of Obstetricians and Gynaecologists.[5]

In the UK (excluding Northern Ireland), pregnant women are routinely offered a screening test called "the combined test," consisting of an ultrasound scan and blood test at 11–14 weeks' gestation, with 90%–95% accuracy. Another test is available: a blood test analyzing cell-free DNA. This test, called noninvasive prenatal testing (NIPT), is carried out from 10 weeks' gestation, with >99% accuracy, although it is often accessed privately. In Northern Ireland, however, the reality is very different: some hospitals offer screening via a blood test (the "quadruple test"), but practice is inconsistent and the test is performed later (14–20 weeks' gestation) and is of lesser quality. NIPT can be accessed privately, but knowledge about its availability is low, and the financial cost is high (average £400). As a result, in Northern Ireland, most fetal abnormalities are diagnosed following the anomaly scan, which typically occurs at around 19–21 weeks' gestation.

During the writing of our policy brief, we conducted two roundtables: one with bereaved families who had received a diagnosis of fatal or severe fetal abnormalities, and one with medical professionals involved in fetal medicine and maternity care. The harrowing stories shared by families and medical professionals all pointed toward the same conclusion: early diagnosis is crucial to minimize trauma for everyone involved. These discussions prompted us to stress in our policy brief that the absence of first-trimester antenatal screening results in later diagnoses, causing significant distress for pregnant women (and for health professionals), who are obliged to make (or support) decisions on whether to terminate or continue a pregnancy during the second half of gestation.[6]

Our research suggests that the absence of first-trimester antenatal screening breaches several human rights for women living in Northern Ireland: their human right to health, their right to privacy, and their right to be free from cruel and inhuman treatment, all of which are protected by various treaties ratified by the UK.[7] It also suggests that since this service is primarily targeted at pregnant women, its absence results in gender discrimination for five reasons. First, this situation exposes women to preventable mental and physical harm related to late diagnoses of fetal abnormalities (such as increased risk of trauma, limited choices around abortion methods, and having to make decisions—often hurried—around feticide and palliative care). Second, women deciding to terminate their pregnancies due to fatal or severe fetal abnormalities must do so at a later stage, forcing them to disclose personal details to persons aware of the pregnancy by then. Third, women deciding to continue their pregnancies in such circumstances are unable to prepare themselves and their family for the possibility of pregnancy loss, infant death, or becoming a carer for a disabled child until week 20+ of gestation. Fourth, the anomaly scan is not as accurate as first-trimester screening for certain conditions, resulting in some women receiving a diagnosis only at birth or through an investigation following a stillbirth or late miscarriage. Fifth, because trisomies 13, 18, and 21 result in disabilities likely to require regular care, a task most often performed by mothers, women are unable to access what is likely to represent life-changing information.[8]

To raise awareness among the public and politicians, we shared our policy brief with the BBC's Northern Ireland health correspondent in mid-2024 and suggested that they could speak confidentially with families who had expressed an interest in doing so. A few months later, the BBC published a story exploring how the absence of early pregnancy screening services was affecting women in Northern Ireland.[9] Using our policy brief and the BBC news story, we then contacted the Northern Ireland Assembly Committee for Health to discuss our research findings. After this meeting, the committee asked Northern Ireland's minister for health to explain why there had been a delay in the provision of screening services. The outcome of this was a commitment to expedite action, but no time frame was confirmed.

We are currently writing a second policy brief to continue raising awareness of the issue to ensure that pregnant women in Northern Ireland have access to better care. To conclude with the words of a parent we spoke with:

> I trusted the [physicians] and hospitals to do the right thing because I wasn't aware of any reason why I shouldn't. I was 36 and I was not offered any test. Much to my distress, I was led blindly to a scan at 21 weeks, where you have more limited options and risk complications to your physical and mental health. It is also incredibly distressing to have to act quickly in those emotionally charged circumstances.

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