Position Paper: Disability Equality and Abortion in the UK

Overview

There has been a recent move by a vocal anti-abortion minority to amend Ground E (Section 1 (1)(d)) of the Abortion Act 1967 to not allow abortion care on the grounds of a diagnosis of what has been referred to by anti-abortion groups as minor physical abnormalities, such as cleft lip, cleft palate and club foot. There are also calls by a young woman with Down's syndrome to not allow abortion care to be an option after 24 weeks gestation following a diagnosis of Down's syndrome.

Calls for amendments such as these are being presented as a disability rights issue, and sadly cause perceived division between the reproductive rights and disability rights movements, two incredibly important human rights allies.

However well intentioned, arguments against giving time to families to understand a diagnosis of a severe fetal impairment and to consider their options is an attack on broader rights to abortion access and prevents medical professionals from providing pregnant people with the best possible care. At Marie Stopes UK we believe that all gestational limits should be removed from abortion legislation so that abortion care can be regulated and managed in the same way as any other form of medical care.[1]

Amendments to restrict access to Ground E abortions are unnecessary. All medical practitioners working within clinical guidelines already assess whether a procedure is medically safe and appropriate to perform, and abortion care is no exception.

Abortion care should remain available without gestation limit for when a pregnancy is diagnosed with a severe fetal impairment. Such diagnoses are often made at the 20-week scan, or at later scans, and represent difficult and complex cases. It would not be appropriate to have a gestation limit for those that wish to consider abortion care in these circumstances, as families should not feel under pressure when considering all information and options while experiencing a difficult and emotional time.

The Abortion Act 1967 – Ground E

Section 1(1)(d) of the Abortion Act 1967, known as a Ground E notification, outlines that abortion at any gestation is lawful provided that two medical practitioners are of the opinion formed in good faith that "there was a substantial risk that, if the child were born it would suffer from physical or mental abnormalities as to be seriously handicapped."

There is no legal definition of "substantial risk" as this is a clinical matter. Whether a risk will be regarded as substantial may vary with the seriousness and future consequences of the likely impairment. Likewise, there is no legal definition of "serious handicap" as this is also a clinical matter and is considered on a case-by-case basis where the clinician reflects on all available information when making a diagnosis. If a diagnosis of cleft palate, cleft lip, club foot, or any other impairment was considered minor then this diagnosis would not lead to the authorisation of a Ground E abortion.

[1] There is no evidence to suggest that increased, or absence of, gestational limits result in more women seeking terminations at a later gestation. For instance, the Australian Capital Territory has no gestational limit and this has not increased the number of terminations at later gestations, in fact they are extremely rare.

Ground E was not included in the Abortion Act to make a judgement on the value of those who have been born with a disability. The Abortion Act 1967 is out of date in a number of ways, one clear sign of this is the use of the word "handicapped", which many disabled people consider an offensive term. However, restricting Ground E post-24 weeks would have serious and far-reaching implications for a small number of women and their partners, forcing them to make a rapid decision at an incredibly difficult time.

Ultrasound scanning and diagnosis of fetal abnormality or severe fetal impairment

During pregnancy, ultrasound scans available at 18 to 21 weeks gestation check that fetal development is as expected and look for signs of what is called fetal anomaly. This scan looks for numerous conditions, not including Down's syndrome.

Non-Invasive Prenatal Testing (NIPT) is currently available from many private healthcare providers, and in 2016 the Department of Health made the decision to implement NIPT throughout the NHS, though this service has yet to be made widely available. NIPT can be used to test for Down's, Edwards' and Patau's syndromes.[2]

Further tests are often needed for more accurate diagnosis and prognosis, and these can take several weeks to complete. Women and their partners will also need time to seek support from a multidisciplinary team, which may include a specialist fetal medicine consultant, a neonatologist or other consultants, specialist nurses and counsellors. They may also wish to seek advice provided by specialist charities such as Antenatal Results and Choices (ARC), Cleft Lip and Palate Association and the Down's Syndrome Association.

Counselling, good quality information and support for those who receive a diagnosis of a severe fetal impairment is essential. The Royal College of Obstetricians and Gynaecologists report, *Termination of Pregnancy for Fetal Abnormality*, was created to assist doctors and other health professionals to support women and their families when a fetal impairment is diagnosed and to help women to decide, within the constraints of the law, whether or not to continue their pregnancy.[3] This report outlines 13 recommendations, recommendation 5 and 6, respectively, state that,

"5. All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a non-directive, non-judgemental and supportive approach (section 6).

6. It should not be assumed that, even in the presence of an obviously fatal fetal condition such as anencephaly, a woman will choose to have a termination. A decision to decline the offer of termination must be fully supported (section 6)."

It is concerning that those raising their voices to not permit a Ground E abortion authorisation in the case of a Down's syndrome diagnosis felt that their doctors assumed that they would consider an abortion when this was not a decision that aligned with their personal circumstance. No one should feel pressured or stigmatised when making a very personal decision about their pregnancy following this diagnosis. This is an issue of the process of diagnosis and the need to improve training to provide non-judgemental care – this is not an issue with abortion law.

[2] Marie Stopes UK does not offer ultrasound services for the purpose of identifying any kind of fetal anomaly or fatal fetal abnormality.

[3] RCOG, (2010), Termination of Pregnancy for Fetal Abnormality in England Scotland and Wales: Report of a working party. Available at: https://www.rcog.org.uk/globalassets/documents/guidelines/terminationpregnancyreport18may2010.pdf

The impact of restricting Ground E

Restricting Ground E post-24 weeks would not allow women, couples or families the opportunity to engage with their doctor and third sector specialist organisations for further tests and enhanced evaluation in order to fully understand the implications of a diagnosis.

In addition, such restrictions could have the effect of more pregnancies being ended at 23 weeks because women feel unable to cope mentally or physically with continuing the pregnancy following a diagnosis of a severe fetal impairment, and would have no other option available to them at a later gestation. It would create a situation which would not allow women and their families to wait for further tests, forcing them to base their decision on incomplete information.

The Department of Health's annual abortion statistics for England and Wales provide data about how many abortions are performed under Ground E, at what gestation and for what underlying reason. [4] When looking at the number of abortions where Down's syndrome was listed as the principal medical condition within the Ground E notification, a very small number of women chose to access abortion care after 24 weeks gestation – 25 in 2016, 21 in 2017, and 23 in 2018.

Fetal abnormalities often occur in combination or syndromes – for example Down's syndrome is commonly associated with serious heart abnormalities. These can be impossible to diagnose until after 24 weeks gestation. Furthermore, some of the abortion certifications listing Down's syndrome in the statistics as the principal condition may have had other, more serious, abnormalities but the reporting clinician chose to list Down's syndrome as the overall summary diagnosis.

Similarly, for abortions where cleft lip or palate were referenced within the form which legally authorises an abortion after 24 weeks gestation represents a small number of women – 4 in 2016, 4 in 2017, and 2 in 2018. It should be noted that this is from a data set showing where these conditions are mentioned, and may not be the principal reason for the abortion.

Club foot is not a condition that is specifically reported in the Department of Health abortion statistics and so we do not know if any abortions authorised under Ground E have been due to a diagnosis of club foot, although it would seem unlikely that a clinician would consider isolated club foot to fall under Ground E. Club foot is found in combination with other serious conditions, including lethal chromosomal anomalies. Congenital malformations of the musculoskeletal system are recorded in the abortion statistics, with data showing that in 2018 there were 24 abortions for this reason after 24 weeks gestation. This category also includes conditions that are fatal.

In 2018, a total of 3,269 abortions were authorised under Ground E in England and Wales. This represents 2% of the total number of 205,295 abortions. Only 283 abortions were performed after 23 weeks, 0.1% of the total number. This is a similar level to 2017 when there were 3,314 (2%) abortions under Ground E at any gestation.

The Department of Health and Social Care's 2018 abortion statistics outline the following:

"Congenital malformations were reported as the principal medical condition in nearly half (49%; 1,591) of the 3,269 cases undertaken under Ground E. The most commonly reported malformations were of the nervous system (21% of all ground E cases; 696) and the cardiovascular system (10%; 323). Chromosomal abnormalities were reported as the principal medical condition for approximately a third (33%; 1,079) of Ground E cases. Down's syndrome was the most commonly reported chromosomal abnormality (19%; 618). Other conditions account for 18% of Ground E abortions, this includes cases

[4] Department of Health, (2019) Abortion Statistics for England and Wales: 2018. Available at: https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2018

where the fetus was affected by maternal factors, hydrops fetalis, Cystic Hygroma and family history of heritable disorders."

While it is clear that only a very small number of women would be affected by the proposed restrictions, this should only serve to prove that Ground E is not a discriminatory instrument, but a necessary authorisation in the most acute, complex and sensitive cases.

Addressing Disability and Reproductive Rights

The UN Committee on the Elimination of Discrimination against Women (CEDAW) has made it clear that the UK was violating the rights of women in Northern Ireland if provision does not exist for those who have had a diagnosis of severe fetal impairment or fatal fetal abnormality.[5] The Committee's report, published in February 2018, found that should care not be provided for in these circumstances, the UK is responsible for,

> *'…grave violations of rights under the Convention [on the Elimination of All Forms of Discrimination against Women] considering that the State party's criminal law compels women in cases of severe fetal impairment, including FFA [fatal fetal abnormality], and victims of rape or incest to carry pregnancies to full term, thereby subjecting them to severe physical and mental anguish, constituting gender-based violence against women.'*

The inclusion of severe fetal impairment and fatal fetal abnormality in the CEDAW requirements is incredibly important for when patients and their healthcare providers have very difficult conversations about prognosis and the odds of survival when an impairment or fatal abnormality is detected.

It is often very difficult to determine if a diagnosed fetal abnormality is "fatal". As we have seen in the Republic of Ireland, where the law only provides for fatal fetal abnormality, women seeking abortion care after such a devastating diagnosis often have no choice but to travel to England as the obstetricians cannot risk breaking the law if their predictions on survival or likelihood of intrauterine death are unclear.

It is essential that provision in these circumstances continue to be supported across the UK.

Reproductive Rights for Disabled Women

It is also important to address that disabled women face significant obstacles in accessing the full range of sexual and reproductive healthcare services. Individuals with disabilities are often denied crucial education and information about sex and contraception, as assumptions may be made about their sex lives. Disabled women also frequently face limitations on reproductive choices through failures to make necessary services and contraception options most suited to their needs and conditions accessible to them. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that disabled people should be provided with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health.

[5] Committee on the Elimination of Discrimination Against Women, Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, U.N Doc. CEDAW C/OP.8/GBR/1 (23 February 2018) https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/GBR/INT_CEDAW_ITB_GBR_8637_E.pdf

Disability stigma and the discrimination of disabled people must be challenged, and this requires policies to support disabled people and their carers to access the services and information they need. Such recent attempts to restrict abortion care have little to do with protecting disabled people. Indeed, they will be restricting abortion rights for all women, including disabled women.

Marie Stopes UK's Statement:

"We support the right of women to opt for an abortion following a diagnosis of severe fetal impairment for the same reason we support reproductive rights for disabled people and the right to choose in general. Women are the best judge of their own circumstances and capacity and should be trusted to make the decision that is right for them and their families.

"When women and their partners make the choice to access abortion after a diagnosis of fetal impairment, they are not devaluing disabled people. It is an individual decision made on the basis of a number of complex personal factors. This decision can often be a difficult and emotional one and they deserve our compassion and support, not our judgement."

About Marie Stopes UK

Marie Stopes UK is an independent provider of abortion services throughout England, where we provide care to more than 62,000 women every year in 50 locations across the country. Our services are commissioned by Clinical Commissioning Groups (CCGs) to provide NHS abortion care, and we also provide abortion care privately.

Abortion is the most common medical or surgical gynaecological procedure performed in the UK, and one in three women in Britain will have an abortion by the time they are 45.[6] Our clinics support and care for those who choose to access their legal right to an abortion as outlined in the 1967 Abortion Act.

[6] Royal College of Obstetricians and Gynaecologists, (2017) "Abortion Care: Our Responsibility". Available at: https://www.rcog.org.uk/globalassets/documents/members/membership-news/og-magazine/spring-2017/abortion-care-services.pdf