

## **Anscombe Bioethics Centre Submission on Severe Fetal Impairment Abortion (Amendment) Bill**

On behalf of the Anscombe Bioethics Centre, we wish to offer our support for the Severe Fetal Impairment Abortion (Amendment) Bill. The Anscombe Centre is a research centre based in Oxford, serving the whole of the United Kingdom, including Northern Ireland, in addition to the Republic of Ireland. As a Catholic research centre, we have a particular interest in supporting Catholic healthcare professionals and healthcare users. However, those using our services and resources include those of other faiths and denominations, and those of no religious faith.

### **Arbitrary targeting of some human individuals**

Respect for living human individuals, including those who are disabled and/or still in utero, is not the sole province of religious believers. Just as it is arbitrary to recognise rights and interests only at birth (birth is not when the individual with his/her stake in the future comes into existence) it is arbitrary to recognise rights, claims or interests in some, but only in some, unborn human beings. Such a stance is egregious: it not only allows a particular group – disabled babies – to be deprived deliberately of life simply because they are disabled but communicates a message to born disabled people, their families, and society, that they are less valued and respected than other human beings. Discriminatory targeting of some human beings on the basis of location, age, dependency or level of ability is unworthy of a civilised society.

In supporting the Severe Fetal Impairment Abortion (Amendment) Bill we are aware that the Bill, while not itself depriving anyone of protection, leaves intact the current legality of abortion for life-limiting foetal conditions. However, insofar as the Bill itself, as opposed to prior legislation, deprives no-one of their rights but rather seeks to protect the rights of at least those with non-terminal disabilities it is in our view worthy of support. If the Bill is passed, children, perhaps some already in existence, with Down Syndrome, spina bifida and other conditions may enjoy a life for years to come which would otherwise have been deliberately ended on grounds of their condition. These children deserve to be protected, even if sadly, other children are not.

### **Impact of abortion on women and couples**

Nor is it only the rights of children that the Bill would protect, but the rights and interests of women too. Abortion for disability is routinely offered to women in Britain, and in various other countries, as if it were health care, or in some way beneficial to the woman. Yet there is much evidence that abortion for foetal anomaly is not only an anti-medical act in its immediate physical effects on mother and child but a particularly distressing experience for the woman that can cause significant trauma and mental suffering. For example, one study found that “overall rates of psychological morbidity in women having termination for ultrasound-detected fetal anomaly are significant, persisting throughout the 12-month follow-up.”<sup>1</sup> Women and men are both significantly affected, although with some differences, and a meta-study<sup>2</sup> looking at various studies in this area found that “Couples experienced selective termination as

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<sup>1</sup> Davies V, Gledhill J, McFadyen A, Whitlow B & Economides D (2005) Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study. *Ultrasound in Obstetrics & Gynecology* 25:389-392.

<sup>2</sup>Sandelowski M & Barroso J (2005) The travesty of choosing after positive prenatal diagnosis. *J Obstet Gynecol Neonatal Nurs* 34: 307-18.

traumatic, regardless of the prenatal test revealing the fetal impairment or stage in pregnancy in which the termination occurred.” The same meta-study found that “Couples, health care providers, family, and friends underestimated the intensity and duration of feelings of loss following selective termination.”

### **Lack of information on life with the child’s condition**

Women offered abortions, often at the time the prenatal test results are communicated, are often very unprepared for the choice they are asked to make. A Swedish study found that 25.6% of women who nonetheless opted for abortion for foetal anomaly said that the “information provided was not adequate to enable a decision.”<sup>3</sup> Often, women and couples are not put in touch with parents of disabled children with the relevant condition, or with adult disabled people with that condition, though this can be extremely helpful in giving parents confidence in going ahead with the pregnancy. It is noteworthy that factors contributing to the choice to continue pregnancy include experience with those with disabilities.<sup>4</sup>

Many women will have accepted prenatal tests only because this seemed expected of them, not because this was something they clearly wanted: in situations of stress during pregnancy, many women will respond by complying with what they think is the recommendation of the healthcare professional.<sup>5</sup> After an adverse result, even if the offer of abortion is refused, the offer may be repeated, sometimes numerous times. While an assertive, articulate woman may continue to refuse abortion (or prior unwanted tests), a less assertive and articulate woman may well comply. It is also worth noting the lack of support so often experienced, in an abortion-prone culture, by those who do choose to take the pregnancy to term.<sup>6</sup>

### **Conclusion**

We hope that this brief contribution may be of some assistance to the Committee in your deliberations on the Severe Fetal Impairment Abortion (Amendment) Bill. We hope above all that Northern Ireland will be preserved from the experience of Britain and many other countries regarding abortion for foetal anomaly. In Britain, such abortions, profoundly harmful as they are to the child and to his or her mother and father, follow closely upon prenatal diagnosis as very much an expected event. Parents should not be given mixed messages concerning the need and right of their children, including their disabled children, to be accepted unconditionally. Such acceptance is no less appropriate before than after the child is born, since it is the same child who is involved. To say this is in no way to abandon parents who receive an adverse diagnosis; rather, the efforts of society should be strongly, proactively focused, before and after birth, on positive support for them and their children. In offering such support, organisations run for – and ideally by – born individuals with the relevant condition should play a key role.

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<sup>3</sup> Asplin N, Wessel H, Marions L & Öhman SG (2013) Pregnant women’s perspectives on decision-making when a fetal malformation is detected by ultrasound examination. *Sex Reprod Healthcare* 4:79-84.

<sup>4</sup> Sandelowski M & Barroso J (2005) *Op. Cit.*

<sup>5</sup> Aune I & Moller A (2012) ‘I want a choice, but I don’t want to decide’ - a qualitative study of pregnant women’s experiences regarding early ultrasound risk assessment for chromosomal anomalies. *Midwifery* 28:14-23.

<sup>6</sup> See e.g. Redlinger-Grosse K, Bernhardt BA, Berg K, Muenke M, and Biesecker BB (2002) The decision to continue: The experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *Am. J. Med. Genet* 112: 369–378.

