

BRIEFING FOR PEERS

Abortion (Disability Equality) Bill

Committee stage: House of Lords, Friday 27 January 2017

Prepared by Genetic Alliance UK, 23 January 2017

Summary

- Genetic Alliance UK opposes this Bill as we believe this ground for abortion, without a time limit, is necessary and valuable to the patients and families affected by severe genetic conditions.
- The realisation that a wanted pregnancy is affected by a serious genetic condition is difficult and potentially overwhelming. Abortion on grounds of fetal anomaly is an important component of the choices available to a woman in this situation.
- If enacted, the Bill would force a race against time for women and couples, raising the stakes in an already traumatic situation.
- Genetic Alliance UK opposes this Bill to preserve a reproductive choice option. We take no view as to which choice anyone should take in their particular situation, and would support their decision and their right to make it, whatever it is.

About us

Genetic Alliance UK are the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high-quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

The majority of the conditions cared for by our member groups have neither a cure nor an effective treatment available to patients in the UK. The opportunity to avoid the birth of affected children is a key option for families at risk of having children with a genetic condition.

The Abortion (Disability Equality) Bill

This Bill intends to remove the opportunity for abortion on grounds that the unborn child would suffer from physical or mental abnormalities, resulting in a serious handicap. This is a ground for abortion that does not have a time limit.

For the following reasons Genetic Alliance UK urges you to oppose this Bill which will restrict access to abortion in England, Scotland and Wales.

The experience of women and couples with a pregnancy affected by a serious genetic condition

Genetic conditions can often come to a woman or couple with no advance warning. If a couple is at risk of having a child with an autosomal recessive condition (a condition which is passed on by both parents, who are unaffected carriers of the condition) then the couple is most likely to have discovered their risk by having an affected pregnancy. This realisation is shocking and potentially

overwhelming, bringing trauma and tension to what is usually a happy event: pregnancy and the birth of a child. These are usually rare conditions of which the couple would usually have no knowledge in advance of the affected pregnancy.

The couple and ultimately the pregnant woman are put into an urgent situation in which they must assess their options and make a very difficult choice.

A significant subset of genetic conditions are serious enough to cause still-birth or severe, eventually lethal neonatal illness. The quality of life of a child born with one of these conditions is extremely poor. The impact upon the parents of having a child with one of these conditions is enormous. What is usually a happy event, the birth of a child, is turned into a crisis. Parents must witness their newborn struggling with life without any ability to help. This experience can be so devastating to couples that they may choose not to try to have another child. Given the scarcity of cures and treatments for genetic conditions, reproductive choice remains one of the most powerful options for women at risk of having a child affected by a genetic condition.

Abortion on grounds of disability is an important component of the choices available to a woman in this situation.

Making a decision under pressure

This Bill aims to prevent abortion on grounds of disability without a time limit. Termination of a wanted pregnancy is the hardest decision women and couples may have to face. This situation is made significantly more challenging by the short time period in which a decision must be made.

Antenatal care for uncomplicated pregnancies (NICE, last updated March 2016) states:

“1.7.1 Screening for structural anomalies

1.7.1.1 Ultrasound screening for fetal anomalies should be routinely offered, normally between 18 weeks 0 days and 20 weeks 6 days.

1.7.1.4 If an anomaly is detected during the anomaly scan pregnant women should be informed of the findings to enable them to make an informed choice as to whether they wish to continue with the pregnancy or have a termination of pregnancy.”

Women and couples will therefore have ultrasound screening for structural anomalies at between 18 and 21 weeks of pregnancy. At this stage, tests can show many birth defects that are undetectable at earlier stages, such as heart problems, fluid in the brain, or missing limbs. Abnormalities may be of inconclusive severity and require further investigation; fluid in the brain or heart defects may be found to be less serious after further MRI scans. Some investigative measures (such as amniocentesis and chorionic villus sampling), carry their own risk to the pregnancy, and are themselves usually the subject of deliberation. Families may also want to research possible mediation of abnormalities and consider the options which may be open to them, which requires time and knowledge.

3,213 abortions (2% of the total in the UK) were carried out in 2015 according to the ground (set by (1)(1)(d) of the Abortion Act) which this Bill is seeking to abolish. If women and couples are forced to make their decision before a hard 24 week deadline, much of the discussion and thought that women and couples might wish to engage in will become impossible, placing women and couples under an unfair burden to decide quickly in an already appalling and distressing situation. At most, they might have six weeks to make this complex decision, though most will have less time. This could lead to an

increase in termination, as families opt to protect themselves against the possibility of being unable to terminate a pregnancy without the ground that this Bill seeks to remove.

If enacted, the Bill would force a race against time for women and couples, raising the stakes in an already traumatic situation.

Supporting reproductive choice and opposing discrimination against people living with a genetic condition

One of the most important ways in which Genetic Alliance UK supports people living with genetic conditions is by supporting access to reproduction choice. For the majority of genetic conditions there is no cure or ameliorative treatment available. In these cases, reproductive choice is one of very few ways for an individual to take control of how the condition affects them and their family.

It is important to acknowledge the importance of choice for families in these situations. We support access to a range of reproductive choice options, and for women and couples to be empowered to access information to support their choice. We take no view as to which choice anyone should take in any situation, and would support their decision and their right to make it, whatever it is.

Our work to ensure access to reproductive choice is entirely compatible with our work to support patients and families living with a genetic condition which includes campaigning for the implementation of the UK Strategy for Rare Diseases, working to improve diagnostic techniques and pathways, and promoting rare and transparent access to treatments in the NHS.

Genetic Alliance UK opposes this Bill to preserve a reproductive choice option. We take no view as to which choice anyone should take in their particular situation, and would support their decision and their right to make it, whatever it is.

For these reasons Genetic Alliance UK urges you to oppose this Bill which will restrict access to abortion in England, Scotland and Wales.



GENETIC ALLIANCE UK

We are happy to discuss any of the issues raised here. Please contact:

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