

Inquiry into Abortion on the Grounds of Disability – Please contribute!

A new Parliamentary group¹ has been set up to review the law on abortion for disability, with a particular focus on whether it is discriminatory or not.

We strongly encourage as many members as possible to contribute to this Inquiry as the experience and expertise of health professionals will be particularly valuable. Some suggestions to help guide responses are set out in this paper.

There is no need to answer every question and answers can be brief (there is a maximum of 500 words). Written responses are needed by **Wednesday 6 March 2013** so time is limited. Details of where to send responses, and the response form can be found at www.abortionanddisability.org

1. What is your view of Ground E of the Abortion Act 1967 (abortion on grounds of disability)?²

- The current legal position, where late feticide can be performed on grounds of disability until the moment of delivery, is morally and practically unsustainable.
- The Act is unfair and discriminatory in two ways. First, it has a different upper limit for disabled babies and babies without disability (40 and 24 weeks respectively). Second, it allows for some disabled babies to be aborted under ground E (those who will be born with a 'serious' handicap) but not others.
- The Disability Rights Commission (DRC) has stated that Ground E: *'...is offensive to many people; it reinforces negative stereotypes of disability; and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equally.'*³
- *'In common with a wide range of disability and other organisations, the DRC believes the context in which parents choose whether to have a child should be one in which disability and non-disability are valued equally.'*
- Killing people with disabilities, rather than striving to treat, support and care for them, is contrary to the high principles of medicine embodied in the Judeo-Christian ethic and historic codes like the Hippocratic Oath and Declaration of Geneva.

2. What do you consider to be the rationale behind Ground E of the Abortion Act 1967?

- In 1967 when the Abortion Act came into force in Britain, scientific understanding of fetal development, physiology, behaviour and treatment was rudimentary.
- Arguments for the continued existence of Ground E generally focus on negative perceptions of the experience of life with disability, rhetoric about the prevention of suffering, arguments about parental choice and the economic and emotional 'burden' of caring for disabled people.

¹ <http://www.abortionanddisability.org>

² The Abortion Act 1967, Section 1(1)(d) Ground E permits an abortion to take place up to birth if: 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. <https://www.wp.dh.gov.uk/transparency/files/2012/05/HSA1-form.pdf> There is a legal limit of 24 weeks for abortions on other grounds.

³ <http://news.bbc.co.uk/1/hi/health/1502827.stm>

- Advocates for Ground E have argued that '*Abortion for fetal abnormality is not eugenic, unethical or immoral. It is simply one form of abortion...Abortion in any instance should be based on a right women have to make decisions about their own lives.*'⁴

3. What is your view of the operation of Ground E of the Abortion Act 1967?

- The law does not define the criteria for abortion under Ground E ('substantial risk' and 'seriously handicapped') and the criteria are broadly interpreted and include many disabilities that most people would not consider serious.⁵
- Improvements in fetal medicine, neonatal intensive care, palliative care, paediatric surgery and changes in attitudes to people with disabilities have led to conditions that previously would have been considered grounds for abortion now being treatable, curable or amenable to palliative care and support. Treatment options before birth have also significantly expanded. The current legal situation is unsustainable ethically and practically. (see also Q9 below).
- As well as general opinions of how Ground E works in practice, any personal experience or knowledge of its operation would be very useful. Is the actual wording of Ground E misused and abused in practice or does it work well?

4. Do you think the current law is discriminatory against disabled people?

- Ground E treats disabled babies differently to babies without disabilities. They have less legal protection under the law, based on a view that the life of a disabled person is of less worth or less worth living. This is discrimination and it devalues the lives of all people living with a disability and stigmatises their families. (see also Q1 above).
- A child diagnosed with a disability can be aborted up to and even during birth, but as soon as the child is born a panoply of rights, medical and social support comes into play for that child. This leads to the ethically indefensible position that babies with disabilities are treated differently on the basis of whether they are located inside or outside the womb. The Disability Discrimination Act 1995 and 2005 rightly commit society to promoting the civil rights of people with disabilities and fighting discrimination against them.
- Many in the disability rights movement regard antenatal testing and termination for abnormality as a form of social discrimination against disabled people. They argue that it is disingenuous for scientists and clinicians to claim that the development of antenatal screening, with the aim of termination, is neutral and value free.⁶

5. Do you think that the existence of Ground E has any impact on attitudes to disability?

- Personal experience or professional expertise would be helpful here.

You may wish to raise concerns that:

- The option of 'disposal' for disabled fetuses makes it less likely that society will invest in providing services for them.
- Parents face increasing censure and stigmatisation for having 'chosen' to give birth to

⁴ <http://www.prochoiceforum.org.uk/aad4.php>

⁵ Such as cleft palate, club foot and Down's Syndrome.

⁶ Wyatt, J. 2001. 'Medical paternalism and the fetus'. Journal of Medical Ethics. http://jme.bmj.com/content/27/suppl_2/ii15.full

children with a disability.⁷

- Parents face an expectation from health professionals and others that they will chose abortion, after diagnosis.
- Some disability charities have expressed concern about growing intolerance to disabled people.
- The option of abortion up until birth for a range of conditions places a negative value on people living with the condition and implies that it is socially desirable to prevent them being born.⁸

6. Do you think that the existence of Ground E has any impact on

a) People born disabled?

- Personal experience or professional expertise would be helpful here.
- Many disabled people oppose antenatal screening and abortion for disabling conditions and are particularly sensitive to what they believe it says about their value, the way it shapes attitudes towards them and the practical consequences it has of less investment in services to support, treat and care for them.
- Tom Shakespeare, an academic sociologist who is disabled, says: *"it is very difficult to support a practice which would have prevented one's own existence"*.⁹

b) People who acquire their disability later in life?

- The message communicated by permitting abortion for disability up until birth is that society believes disabled people are of less (or no) value and worth, that their lives are less worth living and that they constitute a financial, emotional or care burden to society.
- Please add any experience or knowledge you may have of the existence of Ground E that may make it harder to cope with, or adapt to, an acquired disability.
- Professionals, unrepresentative charities and governments all make decisions and value judgements about disability, without always considering that the best experts on life as a disabled person are disabled people themselves. It is essential that Government listens to their concerns and recommendations on Ground E.

7. Do you think the current law on abortion on the grounds of disability should be amended or developed?

- Parliament should repeal this discriminatory section of the Abortion Act and should promote research and investment into providing better care, treatment and support for people with disabilities.

If only incremental changes in the law are possible, then to eliminate the discrimination on grounds of disability inherent in the Act these might include:

- Removal of Ground E entirely, so that it is no longer permissible to have an abortion for disability at any point in pregnancy;
- Reducing the time limit for abortion for disability to 24 weeks in line with most other Grounds in the Act.

⁷ Ibid.

⁸ Ibid.

⁹ Ibid.

8. a) Are you aware of, or do you have experience of, guidelines on when abortions may be carried out under Ground E? b) If yes, do you think these guidelines work well in practice?

- Neither the Act nor the courts have provided legal guidance on what degree of risk is 'substantial' or what degree of serious handicap is 'serious' This clause leaves the interpretation to the opinion formed in good faith of two doctors. But while doctors have some expertise in evaluating the level of risk, valuing lives is not something that doctors are trained or competent to do. Whilst doctors are qualified to judge whether a given treatment is worth giving they are not qualified to make an assessment of whether a life is worth living.
- The RCOG says: '*Whether a risk will be regarded as substantial may vary with the seriousness and consequences of the likely disability. Likewise, there is no legal definition of serious handicap. An assessment of the seriousness of a fetal abnormality should be considered on a case-by-case basis, taking into account all available clinical information.*'¹⁰
- This clause puts doctors in the unenviable position of deciding what degree of handicap qualifies for legal protection and what doesn't. This places doctors in the position where they have to make decisions which discriminate against and between levels of disability.
- Personal and practical experience will be helpful in answering this question.

9. Are you aware of any differences of opinion between a) Doctors seeking to interpret Ground E? b) Doctors and families seeking to interpret Ground E?

- Personal experience will be particularly useful in answering this question.
- There are a small number of lethal abnormalities – such as anencephaly or Tay Sachs disease - where outcome can be predicted with a high degree of certainty, but in clinical experience the majority of cases involve high levels of uncertainty about detailed neurological, cognitive and behavioural outcomes. There is still limited scientific understanding of the developing central nervous system and the relationship between fetal abnormalities and long-term function. In fact, there is evidence now of the ability of the fetus' central nervous system to adapt, repair, regrow and 'rewire' its neural tissue in response to injury.¹¹
- Improvements in fetal medicine, neonatal care and paediatric surgery have led to many structural abnormalities that previously would have been fatal now being considered treatable or curable. Blood transfusions may be given through the umbilical vessels. Drugs designed to cross the placenta may be given to the mother. Tubes can be inserted under ultrasound guidance to drain fluid from kidneys, chest or brain. Fetal surgery to treat major malformations, including lung abnormalities and spina bifida, is possible in more centres worldwide.¹²
- It should not be presumed that parents will choose abortion even for babies with disabilities that are incompatible with life outside the womb. Babies who are terminally ill

¹⁰ 'Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales'. RCOG. 25/06/2010
<http://www.rcog.org.uk/termination-pregnancy-fetal-abnormality-england-scotland-and-wales>

¹¹ "Submission from Christian Medical Fellowship to the Nuffield Council on Bioethics' Working Party on The Ethics of Prolonging Life in Fetuses and the Newborn", CMF, 2005.

¹² Wyatt, J. 2001. 'Medical paternalism and the fetus'. Journal of Medical Ethics.
http://jme.bmj.com/content/27/suppl_2/ii15.full

should be treated like adults who are terminally ill, with appropriate palliative care. Amy Kuebelbeck has catalogued testimonies of women who chose to keep their babies in just this situation in: '*A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief*'.¹³ More research is needed in this area.

- The results of diagnostic tests do not provide reliable information about the future 'quality of life' or subjective well-being of individual babies.

10. Please suggest any ways in which guidance on Ground E abortions could be amended or developed.

- The use of 'Quality of Life' in discussions about the future outcome of disabled fetuses is beset with philosophical, moral, logical and practical difficulties. Its use can perpetuate and enhance negative stereotypes, prejudices and discriminatory behaviour against disabled children and adults and can lead to stigmatisation of disabled people and their families.
- We suggest that guidelines should not be 'directive' but rather 'advisory', and flexible enough to recognise that each situation is different. Directive protocols tend to assume that 'one size fits all' and in this respect are unhelpful.
- We suggest setting guidance to ensure that women and their families are offered sufficient time for advice, support and reflection before making a decision.

Views on Information, Counselling, Care and Support.

11. Are you aware of information, guidance and support that is given to families who receive news that their child may be born disabled?

- Any personal experience will be helpful here. You may wish to raise concerns that there seems to be:
- Little support or information available for families who want to keep their babies or have them adopted, as opposed to having them aborted;
- A strong presumption from doctors that parents with disabled children would choose to have them aborted;
- Subtle or direct coercive pressure placed on parents who decide not to abort.¹⁴ (eg. Doctors repeatedly asking 'Are you sure?' or relating stories of others who have chosen abortion). Testimonies of women with experience of facing coercive pressure from doctors have been collected by Melinda Tankard Reist in her book: '*Defiant Birth: Women Who Resist Medical Eugenics*'.¹⁵ More research is needed in this area.
- Most healthcare professionals working in obstetrics or neonatal medicine have little first-hand experience of the lives of children and adults with disability. Hence their understanding of the lives of disabled people is mainly drawn from standard medical texts. There is a strong tendency for health professionals to emphasise the medical and functional impairments associated with a particular diagnosis, without a counterbalancing emphasis on the abilities and positive features of the lives of people with the condition.

¹³ <http://amzn.to/ULiFz6>

¹⁴ <http://www.cmfblog.org.uk/2013/02/19/women-who-keep-their-disabled-babies-face-coercion-discrimination-and-disdain/>

¹⁵ <http://amzn.to/XNMVW3>

- It is far better to provide parents with access to families with children with similar conditions, support groups for those with specific conditions and health professionals who are experienced in caring for affected children and adults and their families.

12. Do you think current information and guidance provided to families following a diagnosis of disability could be improved?

- Many people facing complex and frightening problems seek wise counsel, advice and support from professionals, not just the communication of percentages and clinical facts.
- The language employed by health professionals must be in lay terms, neutral and person-centred.
- Women and their families should be offered a wide range of sources of information, including information leaflets covering all options, telephone and online helplines manned by trained professional counsellors and the option of speaking (without delay) to other families with children affected by similar conditions.
- Advice and counselling should be provided by qualified and trained counsellors.
- Patients are extremely vulnerable when presented with devastating news and may be subject to sudden impulsive reactions, emotional denial, depressive ideation and the effects of illness, fatigue, or medication. Thus there should be sufficient **time** for information giving, reflection and wide consultation

13. Please make any recommendations for how a) prenatal and b) postnatal counselling, care and support could be developed for families following a diagnosis of fetal disability, and what you think the likely impact will be in each case.

- The attitudes of parents towards their children may be strongly influenced by the language and covert attitudes and values communicated by health professionals. Studies have shown that different ways of presenting risks of genetic disease result in different choices by parents.¹⁶
- Diagnostic and prognostic information must be conveyed in a way that is genuinely neutral, balanced, compassionate and well-informed.
- Advice and counselling should be provided by qualified and trained counsellors.
- As noted at Q12 above, parents should be offered the option to meet others who have first-hand experience of the condition or disability in question. This includes affected patients and their families, disability specific support groups, healthcare professionals caring for babies, children and adults with the relevant condition. Reading testimonies of women who have chosen to continue with their pregnancies such as those collected by Reist and Kuebelbeck (see above) may also be helpful.
- Bringing up a child with special needs often involves substantial emotional and financial cost. Practical support for the longer term needs to be put in place for families and access routes to financial and emotional support as well as treatment need to be clearly signposted. This includes routes for exploring adoption for those families who feel

¹⁶ Wyatt, J. 2001. 'Medical paternalism and the fetus'. Journal of Medical Ethics. http://jme.bmj.com/content/27/suppl_2/ii15.full

personally ill-equipped but who wish to offer their child 'the gift of life'.

- More statutory funding should be provided for information, care and support groups for those with disabilities.
- More research into the care, support and treatment of specific disabilities.

14. Do you have examples or experiences that you would like to communicate to this Inquiry?

- Experiences do not have to be personal experiences, they could (with appropriate permission) be those of family and friends.
- Any information on the support and care available (or not) for people with disabilities and their families will be useful.
- Also information on the influence of social factors, finances and societal attitudes in the decisions that parents make following diagnosis of disability.

Views on data collection

15. Are you aware of any data that is currently collected on abortion on the grounds of disability?

- Department of Health statistics appear to be under-reporting the true number of abortions for some of the most common congenital abnormalities. Figures recorded by the DoH are significantly lower than those recorded by the National Down's Syndrome Cytogenic Register (NDSCR).¹⁷ It also appears that abortions for club foot, cleft palate and cleft lip are being substantially underreported and this raises the question about whether they are being deliberately authorised on mental health grounds rather than under ground E.¹⁸ It also raises the possibility that DoH figures for other ground E conditions may also be inaccurate.

16. Do you think data could be better collated and reported?

- If the NDSCR statistics are accurate (and there is no reason to doubt their accuracy), then the DoH is only being notified about under half of abortions carried out for some of the most common congenital abnormalities (The 'trisomy' conditions Down's syndrome, Patau's Syndrome and Edwards' syndrome). These disparities need investigating. Either doctors are falsifying certification forms, or miss-classifying them as abortions on mental health grounds, or not recording them at all.
- Accurate and reliable data is essential to inform a proper public and political debate.
- It is important to know about any unexpected fluctuations in the number of babies aborted for an abnormality in order to determine whether there is a specific cause for this.

17. Is there any other information you are able to provide which is relevant to this Inquiry?

- Evidence, experience and information is needed on all aspects of this issue, from law,

¹⁷ <http://www.cmfblog.org.uk/2013/01/11/the-department-of-health-is-grossly-under-reporting-the-true-number-of-abortion-for-downs-syndrome/>

¹⁸ http://www.thesundaytimes.co.uk/sto/news/uk_news/Health/article1206769.ece

guidance and data collection to information, care and support for families with disabled children or adults, or those who have had an abortion under Ground E, so please contribute!

The form and guidance can be downloaded from www.abortionanddisability.org If you wish to submit written evidence, please send an electronic copy of your submission to: abortionanddisability@gmail.com.

Alternatively, you can write to: Fiona Bruce MP, House of Commons, London. SW1A 0AA

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