

Inquiry into Abortion on the Grounds of Disability Submission from the

Christian Medical Fellowship

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Please describe your interest in the questions raised by this Inquiry:

The Christian Medical Fellowship (CMF) is an interdenominational Christian organisation with more than 4,000 British doctors as members, practising in all branches of the profession. Through the International Christian Medical and Dental Association we are linked with like-minded colleagues in over 100 other countries.

CMF regularly makes submissions on ethical and professional matters to Government committees and official bodies.

One of CMF's aims is 'to promote Christian values, especially in bioethics and healthcare, among doctors and medical students, in the church and in society'. Many of our members are directly involved 'on the front line' in diagnosing, treating and caring for pregnant women, as well as people with disabilities. As a Christian organisation, we encourage our members to be advocates for those who are weak, sick, marginalised and handicapped and seek to love and care for them to the utmost of their abilities.

Some CMF members have written about their personal experiences with caring for children or others with disability.

1. Beyond healing and caring; a Christian approach to disability¹
2. Beit Cure International²
3. Breaking the Shackles of Deformity³
4. The Pearl Effect⁴

Views on the Law, Guidance and Practice

1. What is your view of Ground E of the Abortion Act 1967 (abortion on grounds of disability)?⁵

The current legal position, where late feticide can be performed on grounds of disability until the moment of delivery, is morally and practically unsustainable.

¹ <http://www.cmf.org.uk/publications/content.asp?context=article&id=2355>

² <http://www.cmf.org.uk/international/hsp.asp?o=891>

³ <http://www.cmf.org.uk/publications/content.asp?context=article&id=2499>

⁴ <http://www.cmf.org.uk/publications/content.asp?context=article&id=1085>

⁵ 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.

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.'*⁶

'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: 'Carry each other's burdens and in this way you will fulfil the law of Christ' (Galatians 6:2); 'Do to others what you would have them do to you' (Matthew 7:12); 'Love your neighbor as yourself' (Matthew 22:39); "'Do not murder"...Love does no harm to its neighbour' (Romans 13:9-10); 'Speak up for those who cannot speak for themselves' (Proverbs 31:8); 'Cure sometimes, treat often, comfort always' (Hippocrates); 'I will not give to a woman a pessary to produce abortion.' (Hippocratic Oath); 'I will maintain the utmost respect for human life from the time of conception even against threat...' (The Declaration of Geneva (1948)); 'The spirit of the Hippocratic Oath can be affirmed by the profession. It enjoins... the duty of caring, the greatest crime being destruction in the co-operation of life by murder, suicide and abortion' BMA Statement (1947); The child deserves 'legal protection before as well as after birth'. The UN Declaration of the Rights of the Child (1959).

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. This has now changed as we note below (q3).

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.

It is almost an unquestioned assumption in society that abortion is a matter of personal choice, and that personal choice or autonomy trumps all other ethical considerations.⁷ Thus, 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.'*⁸

However very few people hold that personal autonomy should be unrestrained. We are not entitled to exercise freedoms that violate or endanger the reasonable freedoms of others; nor conversely are we entitled to restrict the freedom of others by pursuing selfish ends or personal gain. We have laws because we believe as a society that autonomy is *not* absolute. We believe that all human lives are equal in value regardless of age, sex, race or any other characteristic.

⁶ <http://news.bbc.co.uk/1/hi/health/1502827.stm>

⁷ Petchesky RP. *Abortion and Women's Choice*. New York: Longman, 1984

⁸ <http://www.prochoiceforum.org.uk/aad4.php>

We also believe that the right to live, or specifically not to have one's life ended, is the most fundamental right on which all other rights are based.

Some argue from a practical perspective that there needs to be legal provision for women to access abortion after 24 weeks for serious fetal abnormalities because sometimes it will not be known until after 24 weeks that there is a serious abnormality, or how serious the disability may be. Also, it is argued, some women do not have a scan until late in their pregnancy, and women will then need information and time to make a decision about how to proceed, which could take them beyond 24 weeks.

However such arguments are based on the perspective of the mother, and still justify and *support* discrimination against all babies with a disability. Many mothers do not have a scan until later in their pregnancy but if their baby were diagnosed without a disability termination would *not* be permitted after 24 weeks. Disabled babies of the same gestation, already born, would be given curative or palliative treatment in a neonatal unit. It is also rare for a serious disability to be diagnosed after 24 weeks, most are diagnosed before that, so keeping a discriminatory law for a few possible cases only cannot be justified practically, let alone ethically. Those presenting more 'practical' arguments such as this rarely recommend or even suggest practical *alternatives* to abortion, such as adoption, and rarely acknowledge the heightened risk of adverse and long-term mental health consequences of very late termination for abnormality (see Q12 below).

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.⁹ Moreover improved methods of prenatal diagnosis means that many more minor abnormalities are now detectable before birth raising the possibility of termination.

The majority of pregnant women (86%) say they would terminate pregnancy for lethal fetal anomaly and for an anomaly causing mental or physical handicap, even in late pregnancy.¹⁰ 91% of babies with Down's syndrome identified prenatally are currently aborted.¹¹

However, improvements in fetal medicine, neonatal intensive care, palliative care, paediatric surgery, educational care, community support and changes in attitudes to people with disabilities have led to conditions that previously may have been considered grounds for abortion now being treatable, curable or amenable to palliative care and support. Many abnormalities are now far less significant in the degree of handicap they cause. Treatment options before birth have also significantly expanded. The International Fetal Medicine and Surgery Society (IFMSS) was formalized in 1983 and holds its 32nd annual meeting in May this year.¹²

The current legal situation is unsustainable ethically and practically (see also our comments at Q9 below).

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

Yes. Ground E treats disabled babies differently to babies without disabilities. They have less

⁹ Such as cleft palate, club foot and Down's Syndrome.

¹⁰ Souka, AP. et al, 2010. Attitudes of pregnant women regarding termination of pregnancy for fetal abnormality. *Prenatal Diagnosis*, Oct;30(10). pp. 977-80. <http://www.ncbi.nlm.nih.gov/pubmed/20730784>

¹¹ <http://www.wolfson.qmul.ac.uk/ndscr/reports/NDSCRreport11.pdf>

¹² <http://www.ifmss.org/>

legal protection under the law, based on a view that the life of a disabled person is of less worth or less worth living and constitutes a burden to its family and society. This is discrimination and it devalues the lives of all people living with a disability and stigmatises their families (see also our comments at 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.¹³ 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. This means that a disabled baby at 24 weeks gestation in a neonatal unit will be given curative or palliative treatments whereas a baby with the same abnormalities but still in utero at 39 weeks (over 50% older) can be legally aborted. Location is not an ethically significant characteristic for the attribution of rights and the law should not discriminate on the basis of location.

Whilst most people feel very uncomfortable with the suggestion of infanticide for severe disability, its advocates, (eg Harris,¹⁴ Singer,¹⁵ Watson,¹⁶ Crick¹⁷, Savulescu¹⁸), are at least logically consistent. If abortion up to birth is ethical for fetal abnormality then why not infanticide? Conversely, if infanticide is not ethical then why is abortion to the moment of birth?

Moral value under Ground E is applied primarily on the grounds of intellectual or physical capacity, or the burden of care that the individual under consideration would impose on parents, family or society should he or she be born. But doing this discriminates against the intellectually underdeveloped or the physically handicapped. How is this different in nature from racism, sexism or any other form of mistreatment of those who are dependent on, or in some way different from, ourselves?

Parents are more likely to abort a child with Down's syndrome (91%) than with Klinefelters (58%),¹⁹ and politicians and ethicists are more likely to allow abortion on grounds of severe genetic abnormality than on grounds of sex, HLA type, eye, hair or skin colour, or intelligence. The choice of abortion is more likely with more serious abnormalities.²⁰

Yet, who are we to decide whether or not a person with disability has a life that is worth living? Or as ethicists seeking consistency ask, if we can abort for serious genetic abnormalities then to deny it on grounds of 'minor' genetic abnormalities would be 'an unjust infringement of individual liberty' of the parents.²¹

Some argue that the current law is eugenic in its effect.²² Although Government is not directly

¹³ The Disability Discrimination Act 1995 and 2005 rightly commit society to promoting the civil rights of people with disabilities and fighting discrimination against them.

¹⁴ Harris J. Ethical problems in the management of some severely handicapped children. *J Med Ethics* 1981; 7(3):117-24

¹⁵ Singer P. *Practical Ethics*. Cambridge: Cambridge University Press, 1993:181-191

¹⁶ Interview in *Prism* magazine (published by the American Medical Association), May 1973

¹⁷ Quoted by *Pacific News Service*, January 1978

¹⁸ http://www.huffingtonpost.co.uk/2012/02/29/medical-ethicists-propose-after-birth-abortion-law_n_1309985.html?

¹⁹ Mansfield C, Hopfer S, Marteau TM. Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. *Prenat Diagnosis* 1999;19(9):808-12 (September).

²⁰ Schechtman KB et al. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. *Obstet Gynecology* 2002;99(2):216-22 (February)

²¹ Boyle R, Savulescu J. Prenatal diagnosis for 'minor' genetic abnormalities is ethical. *Am J Bioeth* 2003 Winter;3(1):W-IF 3

²² McCabe LL, et al. 2011 Down syndrome: coercion and eugenics. *Genetics in medicine*. Aug;13 (8): pp. 708-10. <http://www.ncbi.nlm.nih.gov/pubmed/21555947>

limiting reproductive choice, the coercion is more subtle in that economic and social coercion can also limit reproductive choice.

The current eugenic implications of prenatal testing for disability are generally unrecognised, probably because eugenics tends to be associated with non-voluntary state-sponsored sterilisation of mentally disabled people or with outdated pseudo-scientific ideas about human races. Eugenics is not generally associated with voluntary actions.

A broader definition, which captures more of the essence of eugenics in modern societies, is 'the attempt to control human reproduction, in order to 'improve' the genetic characteristics of the next generation'. The key word here is control: the basis of modern technological societies is the control of natural processes, through technology. Thus, eugenics can be seen as an ongoing social process, whereby **social** and **economic** forces and **technological** changes **create results similar** to those that the earlier eugenics movement aimed for. A Nuffield report illustrates this effect:

*At the same time as encouraging a more positive environment for people with severe disabilities, resources are spent **on preventing their births**. Given the option of prenatal diagnosis and abortion of affected fetuses, **some parents may feel that to produce a child with a potentially diagnosable disability is to be blameworthy for that child's birth.**"²³*

Many disabled people see prenatal screening programmes as part of an ongoing history of eugenic attempts to rid society of disabled people. Medical doctors and midwives offer and advise women to have tests because they genuinely think that such tests are in the women's best interest. However, because there is a great pressure on both doctors and parents to make sure that children are born healthy, everyone acts apparently freely and yet is under pressure of an insidious eugenic ideology.

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

Yes. Whatever the motives, even if admirable and compassionate, by contemplating abortion for a malformed fetus an implicit message of rejection is sent.

Wyatt says that parents face increasing censure and stigmatisation for having 'chosen' to give birth to children with a disability. 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.²⁴ Some disability charities similarly have expressed concern about growing intolerance to disabled people.

Negative attitudes towards disabled people are still present in our society, and many disabled people do see prenatal screening programmes (and Ground E) as part of an ongoing history of eugenic attempts to rid society of disabled people (see Q4 above).

Moreover, the needs of patients with disability have been a continued momentum to research and support services, so we are concerned that the option of 'disposal' to birth for fetuses with disability makes it less likely that society will invest in providing services for them in the longer term.

6. Do you think that the existence of Ground E has any impact on: a) People born disabled?

²³ Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues*, London 1993, para 8.11.

²⁴ Wyatt, J. 2001. 'Medical paternalism and the fetus'. *Journal of Medical Ethics*.
http://jme.bmj.com/content/27/suppl_2/ii15.full

Yes. Ground E both reflects and perpetuates distorted social perceptions of disability and it implies that disability, not *discrimination against* the disabled, is the problem to be addressed.

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*". He says that discrimination exists in the mere offer of a prenatal test.²⁵

The number of Down Syndrome pregnancies is actually increasing (with higher average maternal ages)²⁶ but despite this the number of Down Syndrome babies that was *born* each year *fell* from 750 to around 657²⁷ over the same period. In 2010, 1,868 Down's syndrome diagnoses were made, 1,188 (64%) prenatally and 680 (36%) postnatally. Of the 1,188 babies diagnosed prenatally 942 were aborted, 25 miscarried or were stillborn, 52 were born alive and in 167 the outcome was unknown.²⁸ Over 90% of all babies found to have Down's syndrome before birth have their lives ended by abortion.²⁹

A message is implicit within routine testing and abortion that Down Syndrome is a condition which presents such a grave burden, both to families and to society, that it is morally justifiable to embark on expensive testing programs to detect it, and then legal to abort a Down Syndrome child, even up to birth.³⁰ According to the NDSCR there were 90 babies diagnosed with Down's Syndrome who were at 21 or more weeks gestation in 2011.³¹

*'Few women who had given birth to children with genetic diseases or impairments managed the feeling of guilt, of having done something that 'society does not approve of.'*³²

If people with disabilities were fully integrated into society, there would be less impetus for testing and termination because those with disabilities would be seen as full, valuable and equal members of the community. The vast majority of disabled people do not consider their lives to be of such low quality that they are not worth living (indeed, suicide rates in those with Down's Syndrome are substantially lower than those in the general population³³).

b) People who acquire their disability later in life?

Yes. 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.

²⁵ Shakespeare T. Choices and rights: eugenics, genetics and disability equality. *Disability and Society* 1998;13:665-682

²⁶ The National Down Syndrome Cytogenetic Register. 2004 Annual Report. <http://www.wolfson.qmul.ac.uk/ndscr/AP%202004.pdf>

²⁷ This number includes 32 stillbirths

²⁸ The National Down Syndrome Cytogenetic Register for England and Wales: 2010 Annual Report. <http://www.wolfson.qmul.ac.uk/ndscr/reports/NDSCRreport10.pdf>

²⁹ <http://www.cmfblog.org.uk/2011/10/28/abortion-for-downs-syndrome-tragic-story-review-of-trends-and-personal-reflections/>

³⁰ Murray T. *The Worth of a Child*. Berkeley and Los Angeles: University of California Press, 1996, p132

³¹ <http://www.wolfson.qmul.ac.uk/ndscr/reports/NDSCRreport11.pdf>

³² *Reproductive Autonomous Choice – a cherished illusion? Reproductive autonomy examined in the context of preimplantation genetic diagnosis*, Zeiler, *Medicine, Health Care and Philosophy*, 7, 175-183, 2004.

³³ Pary RJ: Does suicidal behavior occur in persons with Down's syndrome? *Habilitative Mental Healthcare Newsletter* 15:59-60, 1966

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.

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

Yes. 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 both before and after birth.

If only incremental changes in the law are possible, then to eliminate the discrimination on grounds of disability inherent in the Act could 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. Any subsequent lowering of the upper limit would then need to apply equally to disabled and non-disabled babies.
- Removal of the word 'seriously' so that there is no longer discrimination between the way babies with different disabilities are treated.

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?

a)

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'. Therefore any decision-making is arbitrary, subjective and malleable.

The BMA³⁴ and the Royal College of Obstetricians and Gynaecologists³⁵³⁶ have issued guidance on factors that should influence individual decisions, including the probability of effective treatment, future ability to communicate, the probable degree of dependence on others, and the likely suffering of the child or their carers.

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.'*³⁷

This clause puts doctors in the unenviable position of deciding what degree of handicap qualifies for legal protection and what doesn't. Doctors have to make decisions that discriminate against and between levels of disability.

However the background to the RCOG guidance is of relevance here. In response to the Science

³⁴ British Medical Association Ethics Department. Medical Ethics Today. The BMA's handbook of ethics and law. 2nd ed. BMJ Books. 2004: 242-3

³⁵ *The Care of Women Requesting Induced Abortion: Evidence-based Clinical Guideline Number 7* (2011). Available at www.rcog.org.uk/files/rcog-corp/Abortion%20guideline_web_1.pdf

³⁶ Royal College of Obstetricians and Gynaecologists. Termination of pregnancy for fetal abnormality in England, Wales and Scotland. RCOG. 1996: para 3.3.3 <http://www.rcog.org.uk/termination-pregnancy-fetal-abnormality-england-scotland-and-wales>

³⁷ '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>

and Technology Committee Inquiry in 2007,³⁸ the Government said: 'We note the Committee's recommendation and agree that an exhaustive list of abnormalities is neither feasible nor desirable on the face of the Act, **but we accept that a review of the existing guidance for professionals who are seeking to determine 'serious handicap' may be timely and of use to the medical profession.**' (our emphasis)

The government statement went on to say that:

*'We will therefore be commissioning the RCOG to review its 1996 guidance on the Termination of pregnancy for fetal abnormality. Again, we will work with the College to **ensure that the review committee is made up of a diverse and comprehensive range of specialists** and that all the scientific evidence submitted to the Committee is included in the review.'*³⁹ (our emphasis).

This review was subsequently undertaken by the RCOG and guidelines were issued, but the RCOG is **not** made up of a 'diverse range of specialists'. Of the 18 members, 11 are identifiable as 'pro-choice', most notably the representatives from Marie Stopes International and BPAS; two are members of the Department of Health, four are difficult to categorise, and one is a media doctor. No one has qualifications in mental health, and there is no one from any group working to restrict abortion or providing medical or social support to disabled children and their families.

Moreover, the original 2004 RCOG guidelines were strongly criticised by several members of the Science and Technology Committee in 2007,⁴⁰ as follows, and there is little to suggest that these criticisms about the RCOG do not still apply today:

*'Overall the latest RCOG's written evidence fails to emphasise or in many cases even mention views or studies whose findings do not add weight to a pro-choice agenda....**There have also been questions raised about the bias of the RCOG**...There do not appear to be any groups with an interest in restricting abortion amongst the authors or reviewers. It is not clear where the various RCOG representatives stand on the **issues but it is difficult to avoid the conclusion that this document has been produced by those with an ideological and financial interest in abortion.** The APPPG says that it is 'supported' by the FFP and presumably this involves a financial element. **The impression given is pro-choice organisations and the RCOG are 'in bed together'**.'*⁴¹ (our emphasis).

Thus government recommendation for a review of the guidance on serious handicap by a diverse and comprehensive range of specialists cannot be said to have been fulfilled. This offers the current Inquiry the opportunity to fulfill, or at least contribute to, the Governments recommendation for a review of the guidance.

b)

No. We are concerned with the failure of the medical profession to regulate itself in this area. 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.

³⁸ <http://www.publications.parliament.uk/pa/cm200607/cmselect/cmsctech/1045/1045i.pdf>

³⁹ Government Response to the Report from the House of Commons Science and Technology Committee on the Scientific Developments Relating to the Abortion Act 1967, Cm 7278, page 6. www.official-documents.gov.uk/document/cm72/7278/7278.pdf

⁴⁰ Several members of the committee published a minority report, as part of the STC report.

⁴¹ *Scientific Developments Relating to the Abortion Act 1967*. House of Commons Science and Technology Committee. 2006-7.

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmsctech/1045/1045i.pdf>

In 2001 a 28 week fetus was aborted for bilateral cleft lip and palate. There was public outrage, yet the Crown Prosecution Service declined to prosecute the two doctors involved, satisfied they had decided in good faith that the child, if born, would be seriously handicapped.⁴² Other minor abnormalities that have also resulted in termination under Ground E include webbed fingers, extra digits and club foot.

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?

a)

Ground E leaves the interpretation of 'substantial' and 'serious' to the subjective opinion formed in good faith of two doctors. While 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, 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.⁴³ 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.⁴⁴

Importantly, the results of diagnostic tests do not provide reliable information about the future 'quality of life' or subjective well-being of individual babies. So, while doctors have some expertise in evaluating the level of risk, valuing lives is not something that doctors are trained or competent to do. Doctors are qualified to judge whether a given treatment is worth giving but they are not qualified to make an assessment of whether a **life is worth living**. Yet this Ground encourages them to do so all the time.

b)

Yes. Attitudes towards termination for a range of genetic conditions were studied in health professionals and lay people in three European countries: Germany, Portugal and the UK, interviewing more than 1,700 study participants. Overall, it was found that health professionals were **more likely** than lay persons to report that they would opt for termination following diagnosis of a fetal abnormality.⁴⁵

The same study recommends that further research is needed to determine first the extent to which differences between health professionals and lay people (families) reflect a difference in **perception of disability**, including tolerance of having a child with a disability; and second,

⁴² Dyer C. Doctors who performed late abortion will not be prosecuted. *BMJ* 2005; 330:688

⁴³ '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.

⁴⁴ Wyatt, J. 2001. 'Medical paternalism and the fetus'. *Journal of Medical Ethics*.
http://jme.bmj.com/content/27/suppl_2/ii15.full

⁴⁵ Drake H, et al. 1996. Attitudes towards termination for fetal abnormality: comparisons in three European countries. *Clinical Genetics*. Mar;49(3):134-40. <http://www.ncbi.nlm.nih.gov/pubmed/8737978>

whether such differences result in health professionals **presenting termination** of pregnancy in a way that is not concordant with patients' value systems.⁴⁶

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 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*'.⁴⁷

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

The use of the terms 'substantial risk', 'seriously handicapped' and 'quality of life' in discussions about the future outcome of disabled fetuses are clearly beset with philosophical, moral, logical and practical difficulties. The use of 'quality of life' measures 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 also recommend 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?

Anecdotal evidence suggests that there is little support or information available for families who want to keep their babies or have them adopted, as opposed to having them aborted.

There also seems to be a presumption from doctors that parents with disabled children would choose to have them aborted. Most healthcare professionals working in obstetrics or neonatal medicine have little first-hand experience of the lives of children and adults with disability. Their understanding of the lives of disabled people is mainly drawn from standard medical texts. Therefore there is a marked 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.

At the same time, there is often more subtle or direct coercive pressure placed on parents who decide **not** to abort.⁴⁸ For example, doctors (and abortion clinics) repeatedly asking 'Are you sure?' or relating stories of others who have chosen abortion.⁴⁹

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*

⁴⁶ Drake H, et al. 1996. Attitudes towards termination for fetal abnormality: comparisons in three European countries. *Clinical Genetics*. Mar;49(3):134-40. <http://www.ncbi.nlm.nih.gov/pubmed/8737978>

⁴⁷ <http://amzn.to/ULiFz6>

⁴⁸ <http://www.cmfblog.org.uk/2013/02/19/women-who-keep-their-disabled-babies-face-coercion-discrimination-and-disdain/>

⁴⁹ <http://righttoknow.org.uk/comment-and-coverage/press-release-marketing-tactics-used-to-increase-abortion-pressure>

Eugenics'.⁵⁰ She relates personal stories of nine women who '*confronted the stigma of disability and in the face of silent disapproval and even open hostility, had their babies anyway, in the belief that all life is valuable and that some are not more worthy of it than others*'.

Health professionals are concerned to promote patient *autonomy* by helping patients make an independent decision that is most in line with their values and personal situation, and they try to be *non-directive* (providing neutral information and allowing patients to make their decisions without feeling judged).⁵¹ But we cannot underestimate the coercive power present in a system where a conveyor belt of expectation moves in the direction of choosing not to give birth to children with special needs who are either regarded as a burden, or in some sense not fully human. '*We need to become a lot more honest about the way choice is limited by the 'technological imperative', by institutionalised medical practice and by the disability phobic culture in which we live.*'⁵²

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

There needs to be more accuracy and honesty in the language used. The 'A' word (abortion) is rarely mentioned in the screening literature but instead is '*glossed over with an extraordinary amount of euphemism*'.⁵³ Likewise, doctors talk about 'screening and its sequelae' and of pregnancies being 'terminated', 'selectively terminated' or 'interrupted'. The 'baby' becomes the 'uterine contents', 'products of conception' or simply 'products'. Parents, when a fetal disorder is diagnosed are required 'choose a reproductive option' or 'intervene' and fetal death is referred to 'permanent asystole' or 'mechanical disruption of the fetus'.

As well as being accurate and truthful, the language employed by health professionals must be in **lay terms, neutral, compassionate and person-centred**.

Many families facing complex and frightening problems seek wise counsel, **advice and support** from professionals, not just the communication of percentages and clinical facts.

Health professionals should **signpost** families receiving a diagnosis of disability to a wide range of sources of information, including information leaflets covering **all** their options, and telephone and online helplines manned by trained professional counsellors.

Families are likely to have unrealistic and negative views of disability (see our comments at Q4 above) and many (most?) are not provided with information that presents disability from the perspective of those with disabilities.⁵⁴ We therefore recommend that every patient who receives a prenatal diagnosis should be given **information written by individuals who have the same disability and their families**.

Even better would be for those receiving a diagnosis of disability to **meet, without delay, a person with that diagnosis or a similar condition, a family who has a child with that diagnosis or a similar condition**,⁵⁵ and a healthcare professional caring for babies, children and

⁵⁰ Reist MT. *Defiant Birth : Women Who Resist Medical Eugenics*. Australia: Spinifex Press, 2006.

<http://amzn.to/XNMVW3>

⁵¹ Susswain L. Difficult Choices: Prenatal Testing for Disability. *Leadership Perspectives in Developmental Disability* 2002; 2(1): Winter

⁵² Bridle L. *Prenatal Diagnosis, Choice and the Moral Character of Parenthood*. Seminar, Wesley Hospital Auditorium, September 2001

⁵³ Kristol E. Picture Perfect: The politics of prenatal testing. *First Things* 1993 (April);32:17-24.

⁵⁴ Dunne C and Warren C. Lethal Autonomy: The Malfunction of the Informed Consent Mechanism within the Context of Prenatal Diagnosis of Genetic Variants. *Issues in Law & Medicine* 1998;14(2): 165-202.

⁵⁵ Parens E and Asch A. The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations. *Hastings Center Report* 1999; 29(5): S1-S22

adults with the relevant condition.

Also, all parents should also be given, as standard, immediate contact with disability specific **support groups** for those with specific conditions, and health professionals who are experienced in caring for affected children and adults and their families.

It is important that all advice and counselling from the support groups and information providers is be provided by **qualified and trained counsellors** who are able to spot and support vulnerable individuals, those with specific risk factors, or those with particular underpinning values, such as religious beliefs, which may well influence the maternal decision on pregnancy termination.⁵⁶

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 wider consultation, with the time set out in guidelines so that it is not a rushed decision.

Abortion cannot wind back the clock. Rather than leading to psychological well-being, abortion for fetal abnormality is an emotionally traumatic major life event which leads to severe posttraumatic stress response and intense grief reactions that are still detectable some years later.

Instead of facing the problems of bringing up a disabled child, women may face long-term psychological ill health. Disabled babies are often very much wanted. Conflicting maternal desires can make the decision very traumatic. These factors mean that abortions for disability are often 'high risk' for developing subsequent mental health problems. As abortions for congenital abnormality usually occur in pregnancies that are both late and wanted, it is not surprising that psychological morbidity following termination of pregnancy for fetal anomaly is prevalent and persistent,^{57 58 59 60} and associated with long-lasting consequences for a substantial number of women.^{61 62} People do not easily 'get over it' although proper support during the loss can lessen psychological morbidity.⁶³ Families are also not immune with even very young children and those sheltered from knowledge of the event showing reactions to their parents' distress and maternal absence.⁶⁴

Clearly this information should be provided as an important part of the decision making process for women.

13. Please make any recommendations for how a) prenatal and b) postnatal counselling,

⁵⁶ Souka, AP. et al, 2010. Attitudes of pregnant women regarding termination of pregnancy for fetal abnormality. *Prenatal Diagnosis*, Oct;30(10). pp. 977-80. <http://www.ncbi.nlm.nih.gov/pubmed/20730784>

⁵⁷ Davies V et al. Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study. *Ultrasound Obstet Gynaecol* 2005;25(4):389-92 (April)

⁵⁸ Kersting A et al. Grief after termination of pregnancy due to fetal malformation. *J Psychosom Obstet Gynaecol* 2004;25(2):163-9 (June)

⁵⁹ Lloyd, "Sequelae and Support After Termination of Pregnancy for Fetal Malformation," *British Medical Journal*, 290:907-909 (1985).

⁶⁰ Zeanah CH et al. Do women grieve after terminating pregnancies because of fetal anomalies? A controlled investigation. *Obstet Gynaecol* 1993;82(2):270-5 (August)

⁶¹ Korenromp MJ et al. Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenat Diagn* 2005 Mar;25(3):253-60

⁶² Kersting A et al. Trauma and grief 2-7 years after termination of pregnancy because of fetal anomalies--a pilot study. *J Psychosom Obstet Gynaecol* 2005;26(1):9-14 (March)

⁶³ Geerinck-Vercammen CR, Kanhai HH. Coping with termination of pregnancy for fetal abnormality in a supportive environment. *Prenat Diagn* 2003;23(7):543-8 (July)

⁶⁴ Furlong RM, Black RB. Pregnancy termination for genetic indications: the impact on families. *Soc Work Health Care* 1984;10(1):17-34 (Autumn)

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.

a)

As we have noted earlier (Q4), the increasing availability of routine prenatal tests and more pressure to 'improve' and make this technology more widely accessible promotes the idea that it is part of responsible parenthood to avoid the birth of a disabled child. This influences parental decision-making. There is a vicious circle of pressure at play today. Nobody is literally forced to have tests, but the pressure is there for doctors to offer them and for mothers to have them. Everyone acts freely and yet under pressure.

Many women report that they have felt as if they have been placed on a prenatal testing conveyor belt without being fully aware that it may lead them to having to make difficult decisions or lead to anxieties that they would not otherwise have faced. As some prefer not to know the sex of their child before birth, some also prefer not to know if their baby carries any genetic abnormalities, especially if there is nothing than can be offered other than abortion.

Therefore, in order to make fully informed decisions, parents need answers to questions such as: what the test actually measures and its accuracy; the difference between a screening test and a diagnostic test; what a non-reassuring screening test result means; what their choices would be if they had a non-reassuring screening test result; what further testing might be available; what treatments are available if a condition did exist and what support is available for them.

We have also noted earlier (Q11 and Q12) that the attitudes of parents towards their children may be strongly influenced by the language and covert attitudes and values communicated by health professionals (Most have little first-hand experience of the lives of children and adults with disability so their understanding of the lives of disabled people is mainly drawn from standard medical texts and there is a tendency 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. At the same time, doctors (and abortion clinics) repeatedly ask 'Are you sure?' or relate stories of others who have chosen abortion).

Studies have shown that different ways of presenting risks of genetic disease result in different choices by parents.⁶⁵

In an era of evidence-based medicine, it's important to note that there is no research to support the presumption that terminating the pregnancy is easier on the mother psychologically. In fact, research to date suggests the opposite (see Q12).

Therefore, as we have recommended at Q12 above:

- 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.
- 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

⁶⁵ Wyatt, J. 2001. 'Medical paternalism and the fetus'. Journal of Medical Ethics. http://jme.bmj.com/content/27/suppl_2/ii15.full

above) may also be helpful.

- Information provided on the risks of abortion for fetal disability.

b)

Bringing up a child with special needs often involves substantial emotional and financial cost. Practical support for the longer term must be 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 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 and organisations for those with disabilities.

Perinatal palliative care is an appropriate option for patients whose babies are diagnosed prenatally with a severe or terminal disability. It is also appropriate for families who are faced with decisions about aggressive medical intervention. Palliative care can include palliative measures that may extend life or make life more comfortable for the baby. Some families are looking for another option besides termination or massive intervention. Perinatal hospice offers a third way.

One early report, written before the spread of perinatal hospice and palliative care, estimated that about 20% of parents chose to continue their pregnancies—even in the absence of support. But the percentages increase dramatically when parents are offered perinatal hospice support and reassured that they will not be abandoned by their caregivers. In one British study, when parents were offered perinatal hospice as an option, 40% chose to continue.⁶⁶

Parents need and deserve best-practices care. Britain has a unique programme of children and baby hospices. These offer a positive, civilised response to the challenge of disability. Examples of hospices providing **perinatal hospice/palliative care programs and support** include The Maypole Project⁶⁷ which offers emotional psychosocial support, including **prenatal support**, integrated with children's hospices and children's hospitals in southeast London and Kent to ensure a holistic package of care. They support children diagnosed with a complex life-threatening or life-shortening illness and/or disability between birth and 18 years of age. Also Zoe's Place baby hospices which offers palliative, respite and terminal care for babies/infants aged from birth to five years old.⁶⁸

More generally, it is important to note that disability does not preclude a satisfying life. Many problems attributed to the existence of a disability actually stem from inadequate community and social arrangements that public health professionals should work to change.⁶⁹

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

From his experience in Uganda, one CMF member challenges attitudes to disability. He explains how disabled people can make distinctive contributions to society: '*A distraught mother of a boy with severe learning difficulties was surprised when her doctor chided her 'You think this child is all your own responsibility, don't you? He isn't. He is society's responsibility. Society needs*

⁶⁶ Breeze AC et al. Palliative care for prenatally diagnosed lethal fetal abnormality. *Arch Dis Child Fetal Neonatal Ed.* 2007 Jan;92(1):F56-8.

⁶⁷ <http://www.themaypoleproject.co.uk/>

⁶⁸ <http://www.zoes-place.org.uk>

⁶⁹ Asch A. Prenatal diagnosis and selective abortion: a challenge to practice and policy. *Am J Public Health* 1999;89(11):1649-57 (November)

handicap.”⁷⁰

Another paediatrician, with a long experience of caring for children with disabilities writes: *‘In a culture that views success and failure in materialistic terms, many perceive disabled children as an extra burden. But paradoxically, divorce rates and unhappiness are no more common in the families of disabled children than in those with healthy children. Like the grit in the oyster that causes a pearl to form, caring for a child with special needs often strengthens relational bonds and encourages spiritual growth.’*⁷¹

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 Cytogenetic Register (NDSCR).⁷² It also appears that abortions for clubfoot, 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.⁷³

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?

The House of Commons Science and Technology Committee recommended in 2007 that:

*We believe that consideration of these matters and the production of guidance would be enhanced by better collection of data relating to the reasons for abortion beyond 24 weeks for fetal abnormality, and appropriate analysis of such data, with due regard to the need to protect the confidentiality of patients.*⁷⁴

If the NDSCR statistics are accurate (and there is no reason to doubt their accuracy), then the Department of Health is only being notified of 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.

Moreover, 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?

⁷⁰ <http://www.cmf.org.uk/publications/content.asp?context=article&id=2355>

⁷¹ <http://www.cmf.org.uk/publications/content.asp?context=article&id=1085>

⁷² <http://www.cmfblog.org.uk/2013/01/11/the-department-of-health-is-grossly-under-reporting-the-true-number-of-abortions-for-downs-syndrome/>

⁷³ http://www.thesundaytimes.co.uk/sto/news/uk_news/Health/article1206769.ece

⁷⁴ *Scientific Developments Relating to the Abortion Act 1967*. House of Commons Science and Technology Committee. 2006-7. Para 80.

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmsctech/1045/1045i.pdf>

In a culture that views success and failure in materialistic terms, many perceive disabled children as an extra burden.

But paradoxically, research on Down Syndrome children published in the American Journal of Medical Genetics⁷⁵ found that more than three-quarters of parents with a Down Syndrome child had a *more positive outlook on life* and almost 90% of siblings said they considered themselves *better people* because of their family member with Down Syndrome. Moreover, it found that nearly 99% of people with Down Syndrome are happy with their lives. Overwhelmingly, parents and siblings reported loving, and having pride in, their family member with Down Syndrome:

'Life is all about attitude and perspective. Sometimes the people we think need the most help are actually the ones providing...help to the rest of us.'

'I've redefined the way I measure success in my life. It's not based on material things, money, or power. It is based on family happiness, taking care of each other...'

'My definition of normal has changed.'

'I look at people with less prejudice, but see the potential in everyone.'

'I've learned that a person's worth is not measured by an IQ score.'

In a retrospective study of infants with inoperable spina bifida, parents encouraged to care for their child at home reported stronger family ties than those confined to hospital based care.⁷⁶ Involved parents appeared significantly more serene and saw themselves as wiser and better people. In these poignantly painful circumstances, agape love was given a growth spurt. Still, is this enough to keep parents of disabled children united? The marital strain they face could be said to justify early infanticide. Yet healthy children also bring problems and many childless marriages break up. A study comparing healthy school children with their mentally or physically disabled peers showed no difference in parental divorce rates, unless social deprivation had contributed both to developmental delay and family stress.⁷⁷

Society often thinks of disabled lives as being unhappy. A study compared the mental states of both healthy and variously disabled school children. It was the older, healthy children who most significantly expressed frustration, worry or alienation. The disabled group favoured activities shared with companions; this tallies with the closer relational bonds described by the interactive parents of spina bifida babies. Whilst our culture promotes autonomy, it seems that the interdependence of these families acts as their cement.⁷⁸

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⁷⁵ Skotko, B. et al. 2011. 'Having a son or daughter with Down syndrome: Perspectives from mothers and fathers.' *American Journal of Medical Genetics Part A*. Volume 155, Issue 10, pp 2335–2347. <http://onlinelibrary.wiley.com/doi/10.1002/ajmg.a.34293/full>

⁷⁶ Delight E et al. Babies with spina bifida treated without surgery; parents' views on home versus hospital care. *BMJ* 1988; 297:1230- 1233

⁷⁷ Goodall J et al. Do disabled schoolchildren disable a marriage? *Maternal and Child Health* 1993; May:151- 159

⁷⁸ Goodall J. The value of disabled lives in a cost conscious society. MA thesis: Keele University, 1991