

# Parliamentary Inquiry into Abortion on the Grounds of Disability

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# Summary of Findings

In 2007, the House of Commons Science and Technology Select Committee reviewed scientific developments relating to abortion, including abortion for fetal disability. Nearly 6 years later, this Commission was set up specifically to review one particular aspect of the Abortion Act 1967 – the provision that allows abortion on the grounds of disability up to birth (section 1(1)(d)) - in the light of the Select Committee’s recommendations,<sup>1</sup> the UK Government’s ratification of the UN Convention on the Rights of Persons with Disabilities in 2009 and the passing of a significant piece of legislation, the Equality Act 2010. Current statistics suggest that a small number of abortions are conducted on the grounds of disability each year in England and Wales.

We are grateful to the 299 contributors who gave oral and written evidence.<sup>2</sup> Our findings show that there continues to be strongly held and polarised views on how the law treats abortion for babies with disabilities and whether it affects wider attitudes towards disability. The vast majority of those who gave written evidence believe that allowing abortion **up to birth on the grounds of disability is discriminatory**, contrary to the spirit of the Equality Act, and does affect wider public attitudes towards discrimination.

The majority of those in medical bodies and involved in fetal medicine strongly argued that the **law is right for the small number of difficult cases** where parents face a late

discovery of their child’s disability and that the law has no impact on wider public attitudes.

Many suggestions were put to the Commission for changing the law from outright repeal of section 1(1)(d) to equalising the time limit. Our review highlighted the stark difference in treatment of a fetus beyond the age of viability outside of the womb and one that is in utero. Differing perspectives on the principles upon which these abortions are carried out were put to the Commission. Some argue that the current practice falls foul of international law, while others argue that since the fetus has no legal status until birth there is no discrimination under the law per se so there can be no discrimination under the Equality Act 2010.

However, the Commission notes that Preamble to the UN Convention on the Rights of the Child states that a child “needs special safeguards and care, including appropriate legal protection, before as well as after birth”<sup>3</sup> and **recommends** that Parliament reviews the question of allowing abortion on the grounds of disability and in particular how the law applies to a fetus beyond the age of viability (currently 24 weeks). Parliament should **consider at the very least the two main options** for removing those elements which a majority of witnesses believe are discriminatory – that is either reducing the upper time limit for abortions on the grounds of disability from birth **to make it equal to the upper limit for able bodied babies or repealing Section 1(1)(d) altogether.**

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<sup>1</sup> The House Of Commons Science and Technology Select Committee, Scientific Developments Relating to the Abortion Act 1967, October 2007, HC 1045-I, paragraphs 79-81, pages 29-31 <http://www.publications.parliament.uk/pa/cm200607/cmselect/cmsctech/1045/1045i.pdf>

<sup>2</sup> Note that where respondents are neither organisations nor professionals, individual contributors are referred to by a respondent number.

<sup>3</sup> Preamble to the 1989 UN Convention on the Rights of the Child

The Commission is concerned at the **lack of transparency of decision-making** in cases of fetal disability. While recognising each case is different, the potential for such significant differences between doctors on which disabilities fall within the scope of the law and those that do not is particularly concerning for parents, practitioners, lawmakers and those with disabilities. These concerns contribute to the Commission's recommendation for a review of this provision of the Abortion Act 1967. We support **proposals for increased transparency and accountability**. If abortion to birth is to continue, we would like to see post-mortems for all abortions that take place after 24 weeks. We are concerned about the potential discrepancies in data reporting and **recommend** that the Department of Health should consider the findings of this report as part of its consideration on publication of abortion statistics. We recommend that a national system of registers

for congenital anomalies should be introduced.

Many respondents reported to the Commission about their experiences of facing the discovery of a fetal disability. There was a common message that most parents are steered towards abortion and feel that they do not receive adequate information about other options, including palliative care after birth and adoption, as well as the reality of living with a child with a disability. Evidence from witnesses highlighted the varying and inconsistent approaches towards informing, counselling and supporting parents in different clinical settings when fetal disability is discovered. The Commission **recommends** that there is a need for consistent, balanced information, trained counsellors, increasing awareness of palliative care for newborns and comprehensive support from the medical profession whatever the parents' decision about their pregnancy.

# Full List of Recommendations

1. The Department of Health should consider the findings of this report as part of the consultation on publication of abortion statistics.
2. Funding should be made available to ensure that there are independent congenital anomaly registers that cover the whole of England, as well as Wales, Scotland and Northern Ireland, and all congenital abnormalities.
3. If the time limit for abortions on the grounds of disability remains to birth, there should be additional written justification for abortions on the grounds of disability after 24 weeks, which should be subject to audit.
4. The reporting time for the form HSA4 should be extended in cases of Ground E abortions to include details about the final diagnosis of the fetal disability.
5. The option of palliative care (perinatal hospice) should be offered to all parents as they consider their decisions about continuing their pregnancy after discovery of a fetal disability. There should be increased funding available for palliative care for newborns.
6. Following a prenatal discovery of a fetal disability, parents should be encouraged and supported to consider adoption for their child as one of the options available to them. Literature distributed by patient interest groups to couples should promote adoption as a positive option.
7. The Adoption Register should be developed to ensure swifter matching of disabled babies with adopting families.
8. It should be best practice that parents are provided with practical and balanced information as soon as possible after discovery of a fetal disability and before leaving hospital so that they can make an informed choice. This should include leaflets or other information written by relevant disability groups. Parents should be offered contact with families with a child with a similar diagnosis without delay.
9. There should be best practice guidelines for training and practice for professionals in counselling families facing a diagnosis of fetal disability. Training should encompass expertise on perinatal hospice, disability, bereavement and family counselling.
10. There should be consideration of the expansion of the role and responsibilities of Learning Disability Liaison Nurses (LDLNs) to all disabling conditions so that they can support couples who discover their unborn child has a disability.
11. Guidelines for the medical profession should include training for obstetricians, fetal medicine specialists and midwives on the practical realities of the lives of children living with the different conditions which are screened for through ante-natal tests.
12. There should be counselling and support offered and available for those who choose an abortion on the grounds of disability both before and after abortion.
13. There needs to be improved, positive and consistent care and support for parents who choose to continue with their pregnancy from across the medical profession, in line with current guidelines.
14. There is an imperative need to improve adequate and accessible long-term care and practical support to be in place for children and adults with disabilities and for those caring for them from the moment of diagnosis.

- 15.** A third signatory should sign the abortion form to confirm that the family has had the correct information and support to make an informed decision and can confirm the abortion meets the criteria under section 1(1)(d).
- 16.** If the time limit for abortions on the grounds of disability remains to birth, a post mortem should be held for abortions conducted after 24 weeks to ensure correct operation of the Act and to improve future medical diagnosis.
- 17.** We recommend that Parliament reviews the question of allowing abortion on the grounds of disability and in particular how the law applies to a fetus beyond the age of viability (currently 24 weeks). Parliament should consider at the very least the two main options for removing those elements which a majority of witnesses believe are discriminatory – that is either reducing the upper time limit for abortions on the grounds of disability from birth to make it equal to the upper limit for able bodied babies or repealing Section 1(1)(d) altogether.

# Background and Structure of the Inquiry

A group of cross-party Parliamentarians came together to look at how the law governing abortion on the grounds of disability was operating in light of the Equality Act 2010, which protects disabled people from discrimination, and to review the practical information and support available to parents expecting a child who may be disabled. The Commission is made up of MPs and Peers of differing opinions and views.

The **terms of reference** of the Commission were to:

- Establish and assess the intention behind the law governing abortion on the grounds of disability.
- Establish how the law works in practice and is interpreted by medical practitioners.
- Determine the impact of the current law on disabled people and assess the views of groups representing their interests.
- Assess the effectiveness of the information and guidance provided to families following the diagnosis of a disability and the impact that has on outcomes.
- Examine how the law, guidance and support for practitioners and families can be developed going forward.

The Inquiry sought input from those with experience both professionally and personally on this issue through oral and written evidence and welcomed a wide range of input. The remit of the Commission's Inquiry was highlighted through the national press.

## The Commission

**Chair:** Fiona Bruce MP

**Vice Chair:** Virendra Sharma MP

Stuart Andrew MP

Baroness Benjamin of Beckenham

Robert Buckland MP

Rob Flello MP

Baroness Hollins of Wimbledon

Baroness Knight of Collingtree

Jeremy Lefroy MP

Baroness Masham of Ilton

Paul Maynard MP

Lord McColl of Dulwich

Dr John Pugh MP

David Simpson MP

Our full report follows.

# 1. The Law Governing Abortion on the Grounds of Disability

1. Section 1(1)(d) of the Abortion Act 1967<sup>4</sup> sets no time limit on when an abortion may take place 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*” (known as Ground E). It is currently legal to terminate a pregnancy up to full-term (40 weeks) on the grounds of the child’s disability,<sup>5</sup> while the upper limit is 24 weeks if there is no disability.<sup>6</sup>
2. According to Department of Health statistics, 2,307 abortions (1% of all abortions) were carried out in 2011 under Ground E of the Abortion Act 1967, due to the risk that the child may be born with a fetal disability.<sup>7</sup> 144 of these abortions took place after 24 weeks.<sup>8</sup> During oral evidence, the Commission was told

that pregnancies have been ended up to the 34th week.<sup>9</sup> In 2011, 29 abortions took place after 32 weeks.<sup>10</sup>

## Background to the Abortion Act 1967 and Ground E

3. Dr Sheelagh McGuinness, an academic lawyer, argues that it was the impact of contracting rubella early in pregnancy and the effects of thalidomide on pregnant mothers that was **part of the impetus for the passing of the Abortion Act in 1967**.<sup>11</sup> In doing so abortion was seen as a “medical” response, i.e. abortion on grounds of disability was seen as acceptable to treat disease and stop transmission of hereditary diseases.<sup>12</sup>

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<sup>4</sup> As amended by the Human Fertilisation and Embryology Act 1990, see section 1(1)(d)

<sup>5</sup> This is also possible in a number of other countries. Twenty other countries in Europe were listed as allowing abortion up to birth in the International Planned Parenthood Federation report, *Abortion, Legislation in Europe*, May 2012. [http://www.ippfen.org/NR/rdonlyres/ED17CA78-43A8-4A49-ABE7-64A836C0413E/0/Abortionlegislation\\_May2012corr.pdf](http://www.ippfen.org/NR/rdonlyres/ED17CA78-43A8-4A49-ABE7-64A836C0413E/0/Abortionlegislation_May2012corr.pdf)

<sup>6</sup> Ground A (risk to the life of the mother) and Ground B (prevent grave permanent injury to physical or mental health of mother) are also not limited to 24 weeks. Grounds F and G also allow similar grounds to A and B in an emergency. See form HSA4. In 2011, 195 abortions were carried out under Grounds A and B, Abortion Statistics, England and Wales: 2011, May 2012, Department of Health, para 1.4 and 2.9, pages 5 and 8. Note that 2 reported over 24 weeks in Table 9 were performed under Grounds A, B, F or G. <https://www.wp.dh.gov.uk/transparency/files/2012/05/Commentary1.pdf>

<sup>7</sup> Note that ARC suggested in Written Evidence, Q1, that “It is more accurate to talk about abortion on grounds of fetal anomaly as the disability would not exist until the child were born. ‘Disability’ does not accurately cover situations where lethal anomalies such as anencephaly or bilateral renal agenesis are prenatally diagnosed. In cases such as these the baby cannot survive.”

<sup>8</sup> 0.1% of all abortions. Department of Health Abortion Statistics 2011, *Op Cit*, page 3; paras 2.9, 2.10, 2.11, 2.14, pages 8-9; Table 5, page 19; and Table 9, page 23. Note that 2 of the 146 reported over 24 weeks in Table 9 were performed under Grounds A, B, F or G.

<sup>9</sup> Jane Fisher, Oral Evidence Session 1, page 6; Professor Lyn Chitty, Oral Evidence Session 4, page 18

<sup>10</sup> See Table 5, page 19, Department of Health Abortion Statistics 2011, *Op Cit*

<sup>11</sup> Similar comment made in Written Evidence, Q2, Anscombe Bioethics Centre

<sup>12</sup> Written Evidence Q2, Dr Sheelagh McGuinness; Dr Sheelagh McGuinness ‘Law, Reproduction, and Disability: Fatally “Handicapped”?’ *Medical Law Review* (forthcoming) <http://medlaw.oxfordjournals.org/content/early/2013/01/02/medlaw.fws041.full>



4. Daniel Kinning, a barrister, makes a similar point that section 1(1)(d) is based *“on an exclusively medical model of disability rather than a social, legal and medical model of disability, failing to take account of the social, moral/ethical considerations.”* He lists various court cases that *“have established the principle that damages could be awarded for wrongful births.”*<sup>13 14</sup>
5. Historically, there has been a presumption of greater protection for the fetus later in pregnancy. Dr Sheelagh McGuinness said, *“Although not a legal person, the human fetus (from implantation) is an entity that is legally protected from destruction save in specific circumstances. This protection stems from, amongst other things, a State interest in its protection. It is therefore important to remember that abortion is not a purely private matter between a doctor and patient, but rather something that falls within the scope of the criminal law. Therefore, whilst many commentators frame abortion as a private choice for pregnant women, this is not how the law of England, Scotland and Wales (neither historically nor currently) treats the issue.”*<sup>15</sup>
6. Dr McGuinness reminded the Commission that after the passing of the Abortion Act, there was no defence available under the Infant Life (Preservation) Act 1929 to end the life of a baby in the womb if it was beyond the age of viability. However, due to confusion about this, abortions were occurring post 1967 on the grounds of disability after viability. Only in 1990 was it made **legitimate to abort up to birth** in the case of disability. She says, *“Section 1(1)(d) can be seen as an anomaly in the broader context of legislative measures to prevent abortions, as it affords fetuses with a potential disability a different, lower level of protection than they would otherwise have but for their ‘diagnosis’.”*<sup>16</sup> Dr Paula Boddington reminded the Commission that *“it is common now that ultrasound images are included in baby albums. At a certain stage of development, the person born without disabilities will be looking back at an image of what many people would clearly think of as ‘themselves at an earlier stage’, and after 24 weeks’ gestation, this will be a stage where they were legally protected. The person born with disabilities will be looking back at ‘themselves at an earlier stage’, but at no point of gestation was their life protected by the law concerning termination of pregnancy.”*<sup>17</sup>
7. The Reproductive Health Matters Journal said the provision *“was put in place in recognition that not all women and their partners feel they have the capacity either to care for a child with substantial disabilities, or to cope with the emotional distress that can arise by carrying a pregnancy to term and losing the infant to a fatal anomaly.”*<sup>18</sup>
8. Others said that Ground E was included because of a fear of disability<sup>19</sup> but with discussion focused on conditions which would be incompatible with survival of the child.<sup>20</sup> The Commission was referred to the seminar

<sup>13</sup> Written Evidence, Q3, Daniel Kinning. For instance *R v Mid-Downs Health Authority* and *R v East Dorset Health Authority*

<sup>14</sup> Similar points about the medical model approach were made in Written Evidence, Q6, CARE; Written Evidence, Q3, Christian Concern and Written Evidence (Additional Notes), Q3, Spina Bifida New Zealand

<sup>15</sup> Written Evidence Q4, Dr Sheelagh McGuinness and Medical Law Review, *Op Cit*

<sup>16</sup> Written Evidence Q4 and Q8, Dr Sheelagh McGuinness and Medical Law Review, *Op Cit*

<sup>17</sup> Written Evidence (Additional information), Q6, Dr Paula Boddington

<sup>18</sup> Written Evidence, Q2, Reproductive Health Matters Journal

<sup>19</sup> Written Evidence, Q2, Professor David Paton

<sup>20</sup> Written Evidence, Q2, ProLife Alliance

held by the Institute of Contemporary British History in which one of the witnesses, when asked if there had been any consultation with disabled people said, *"I think the answer to that is we didn't consult anybody and that if you believe in a woman's right to choose, then this must be one of the aspects that it is the woman's right to choose about."*<sup>21</sup>

9. Various theories were put forward as to **justification for section 1(1)(d) and its current operation**. Dr Sheelagh McGuinness put forward three theories and rejected them all.<sup>22</sup>

- **Best interests of fetus** – life outside the womb would lead to overall harm to the fetus and therefore a termination is justified. She argues that this interpretation would greatly narrow the practical scope of section 1(1)(d) and since this is not the way the Act is currently operating, the law is not protecting the interests of the fetus as currently drafted.<sup>23</sup>
- **Best interests of parents** – a parent has expectations about the type of child they will have and it could be suggested that raising a child with disabilities deviates from this expectation in a very specific way that is peculiar to disability. However, it would be hard to show how every instance of fetal variation would amount to a deviation from expectations. If the reasoning is that this section should uphold parental interests after 24 weeks it does so only narrowly and

excludes any other protection of parental interest (e.g. a marriage breakdown late in pregnancy which changes the mother's mind about her pregnancy).<sup>24</sup>

- **Any reason is acceptable** – but this argues against the current structure of the Abortion Act 1967, which so far from allowing full autonomy mandates that there have to be "reasons" for an abortion to take place.

10. Julian Savulescu, in his review of the justification of late term abortions says, *"Admitting a fetal disability ground, as UK legislation and current practice do, introduces discrimination, is a form of passive eugenics and probably cannot be supported by any plausible account of fetal moral status without significant revision of practice."*<sup>25</sup>

## International Law

11. A number of respondents to the Commission argued that Ground E contravenes international law:

- The 1959 UN Declaration of the Rights of the Child whose preamble states *"Whereas the child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth". Principal 5 states "The child who is physically, mentally or socially handicapped shall be given*

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<sup>21</sup> Madeleine Simms, in the 'The Abortion Act 1967', seminar held 10 July 2011, (Institute of Contemporary British History, 2002, <http://www.icbh.ac.uk/icbh/witness/abortion>), page 58

<sup>22</sup> Written Evidence Q1, Q2 and Q4, Dr Sheelagh McGuinness and Medical Law Review, *Op Cit*

<sup>23</sup> The same point is made by Daniel Kinning, a Barrister and Policy Advisor specialising in bioethics and human rights with experience of advising NGOs, Government and Judiciary in the UK and Europe, Written Evidence, Q2. Written Evidence, Q2., Professor Stephen Wilkinson said that the justification on the best interests of the fetus "at best, applies only to a minority of the most severe cases." Similar point made by Professor Rosamund Scott, Written Evidence, Q2.

<sup>24</sup> Parental interests model supported by Professor Rosamund Scott, Written Evidence, Q2

<sup>25</sup> Julian Savulescu, Is Current Practice around Late Termination of Pregnancy Eugenic and Discriminatory? Maternal Interests and Abortion. *Journal of Medical Ethics* 2001; 27; 165-171. Submitted as evidence to the Commission, page 170. Professor Gordon Stirrat says he agrees with this quote in Q1 of his Written Evidence



*the special treatment, education and care required by his particular condition.*<sup>26</sup>

- The preamble of the 1989 UN Convention on the Rights of the Child<sup>27</sup> refers back to the 1959 Declaration and the need for legal protection, before as well as after birth.
- The 2002 Rome Statute of the International Criminal Court prohibits persecution of an identifiable group of the civilian population through birth prevention (Articles 6 and 7).<sup>28 29</sup>
- The 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>30 31</sup>
  - Rachel Hurst, CBE, previously Director of Disability Awareness in Action argued that if the UK is to fulfil its obligations under the Convention on the Rights of Persons with Disabilities, Ground E should be deleted from the Abortion Act.<sup>32</sup>
  - The Commission was informed that the Committee on the Rights of Persons with Disabilities, in one of its first concluding observations on a state report, recommended that Spain “abolish the distinction made in the

*Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability.*<sup>33</sup>

- In the UK Government’s first report to the Convention Committee, there is acknowledgement that “Concerns were expressed around the approach to abortion in the UK, where disabled people have suggested a bias towards termination of pregnancies if a child is likely to be disabled.”<sup>34</sup>

## The Question of Discrimination in England and Wales and the Status of a Fetus

12. The Equality Act 2010 replaced most of the Disability Discrimination Act 1995 “to streamline and strengthen anti-discrimination legislation in Great Britain”.<sup>35</sup> The Equality Act 2010 Act prohibits discrimination arising from a disability by preventing one person from treating another less favourably because of their disability. There is concern about whether

<sup>26</sup> Written Evidence, Q1, Respondent 58 See <http://www.un.org/cyberschoolbus/humanrights/resources/child.asp>

<sup>27</sup> In force in the UK since January 1992

<sup>28</sup> Written Evidence, Q17, Mike Sullivan, Saving Downs <http://untreaty.un.org/cod/icc/statute/romefra.htm>

<sup>29</sup> Saving Downs has lodged a complaint with the International Criminal Court on the basis that the New Zealand government screening programme is persecution of an identifiable group of the civilian population through birth prevention. See Written Evidence (Additional), Saving Downs, pages 2-3. A similar point of view was expressed in Written Evidence, Q17, Spina Bifida Association of New Zealand

<sup>30</sup> Ratified by the UK Government in 2009 <http://odi.dwp.gov.uk/disabled-people-and-legislation/un-convention-on-the-rights-of-disabled-people.php>

<sup>31</sup> Saving Downs are also in discussion with the New Zealand Human Rights Commission about the screening programme in light of the Convention on the Rights of Persons with Disabilities. See Written Evidence (Additional), Saving Downs, pages 2-3

<sup>32</sup> Written Evidence, Q1, Rachel Hurst CBE

<sup>33</sup> See Written Evidence, (Additional Information), page 12, Spina Bifida New Zealand referencing Committee on the Rights of Persons with Disabilities, “Consideration of Reports submitted by States under Article 35, Concluding Observations – Spain” (19 May 2011): <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx>. Act 2/2010 of 3 March 2010 allows that a pregnancy may be terminated beyond the regular 14 week threshold to 22 weeks provided there is a “risk of serious anomalies in the foetus” “if the foetus has a disability” and, beyond week 22 in case of “an extremely serious and incurable illness” detected in the foetus.

<sup>34</sup> UK Initial Report on the UN Convention on the Rights of Persons with Disabilities, May 2011, HM Government, page 112

<sup>35</sup> <http://odi.dwp.gov.uk/docs/disabled-people-and-legislation/uk-initial-report.pdf>  
See <http://odi.dwp.gov.uk/disabled-people-and-legislation/equality-act-2010-and-dda-1995.php>

Ground E of the Abortion Act is contrary to the Equality Act 2010.

13. Evidence was presented to the Commission that in strict legal terms the law does not consider a fetus a legal person until birth, the Equality Act does not apply to a fetus; and similarly because a fetus is not a person there is no legal discrimination in relation to the gestational limit.<sup>36</sup>
14. It was also argued that while the law does treat disabled and non-disabled fetuses differently, for a discrimination claim to be upheld it would need to be established that *“any differential treatment was unfair and unjustified”*. Professor Stephen Wilkinson argued that the different treatment of disabled fetuses is justifiable on the grounds of the potential harm to the mother of carrying a child to let it die.<sup>37</sup>
15. Further views on whether the law is

discriminatory or not are covered in Section 4 of this report.

## Conclusion

Current statistics suggest that a small number of abortions are conducted on the grounds of disability each year in England and Wales. There are differing perspectives on the principles upon which the abortions are carried out. Some argue that the current practice falls foul of international law, while others argue that since the fetus has no legal status until birth there is no discrimination under the law *per se*. The Commission notes that the Preamble to the UN Convention on the Rights of the Child states that a child “needs special safeguards and care, including appropriate legal protection, before as well as after birth”.

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<sup>36</sup> Nicky Priaulx, Oral Evidence Session 4, page 27. Also raised in written Evidence, Q17, Respondent 17 and Written Evidence, Q4, Professor Stephen Wilkinson

<sup>37</sup> Written Evidence, Q4 and Q2, Professor Stephen Wilkinson

## 2. How the Law Works in Practice

### Pre-Natal Screening

17. At present there are two ultrasound scans offered to all women between 11 and 13 weeks and between 18 and 21 weeks.<sup>38</sup> The aim of these scans is to date the pregnancy, diagnose multiple pregnancies, confirm placental location, and to “identify fetal anomalies”.<sup>39 40</sup> One journal article described this screening as “secondary prevention” of Down’s Syndrome<sup>41</sup> and another said, “secondary prevention aims to reduce the number of children born with birth defects.”<sup>42</sup> Saving Downs says, “the national screening programme is mostly being used for the birth prevention of babies with Down syndrome, rather than birth preparation or life affirming care.”<sup>43</sup> Christian Medical Fellowship suggested that the “increasing availability of routine prenatal tests...promotes the idea that it is part of responsible parenthood to avoid the birth of a disabled child.”<sup>44</sup>
18. Professor Lyn Chitty gave evidence on the new non-invasive “blood tests” which are being trialled and the need for parents to understand the implications of the test and **receive good pre-test counselling** so they “are aware of the tests they will undergo”. These new tests are likely to increase access to prenatal information.<sup>45</sup> The RCN called for “improved prenatal diagnosis so that options and choices can be provided earlier in the pregnancy.”<sup>46</sup>
19. Several organisations said that women need to understand the implications of prenatal testing with information presented accurately and honestly.<sup>47</sup> Further tests can be done if there are questions about the baby’s development. Section 3 of this report reviews the experiences of parents who have discovered their child’s disability.
20. An abortion after 24 weeks involves injecting the fetal heart with potassium chloride to stop

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<sup>38</sup> Screening is optional but in Written Evidence, Q14, Respondent 172 suggested it is not in practice. Written Evidence (Additional information), Q14, Dr Paula Boddington reported on the pressure parents feel to have such testing.

<sup>39</sup> Written Evidence, Introduction, Pranav Pandya; Lynn Murray, Oral Evidence Session 1, page 25 referring to NICE Clinical Guideline 62, Antenatal Care, June 2010, page 26  
<http://www.nice.org.uk/nicemedia/live/11947/40115/40115.pdf>

<sup>40</sup> 2-2.5% of all fetuses have a serious physical abnormality and that chromosome and genetic causes are only a small minority of these. Professor Stuart Campbell, Letter, page 1

<sup>41</sup> Ilyasu Z, Gilmour WH, Stone DH, Prevalence of Down Syndrome in Glasgow, 1980-96 – the growing impact of prenatal diagnosis on younger mothers. Health Bulletin, 60(1), January 2002, pages 20-26.

<sup>42</sup> Christianson A, Howson CP, Modell B, March of Dimes, Global Report on Birth Defects, 2006, page 41, [http://www.marchofdimes.com/downloads/Birth\\_Defects\\_Report-PF.pdf](http://www.marchofdimes.com/downloads/Birth_Defects_Report-PF.pdf)

<sup>43</sup> Written Evidence (Additional), Saving Downs, page 9. Note that JK Morris, E Alberman, BMJ 2009 Oct 26;339:b3794. doi: 10.1136/bmj.b3794 reports that between 1989 and 2008, live births of children with Down’s Syndrome dropped by 1% whereas in the absence of screening, the number of live births would have expected to have increased by 48%.

<sup>44</sup> Written Evidence, Q13, Christian Medical Fellowship

<sup>45</sup> Professor Lyn Chitty, Oral Evidence Session 4, pages 15 and 17. Note that Professor Stuart Campbell said this test will also identify the gender of the fetus and likely lead to requests for abortions on the grounds of sex selection, Letter, page 1. See also <http://www.rapid.nhs.uk/>

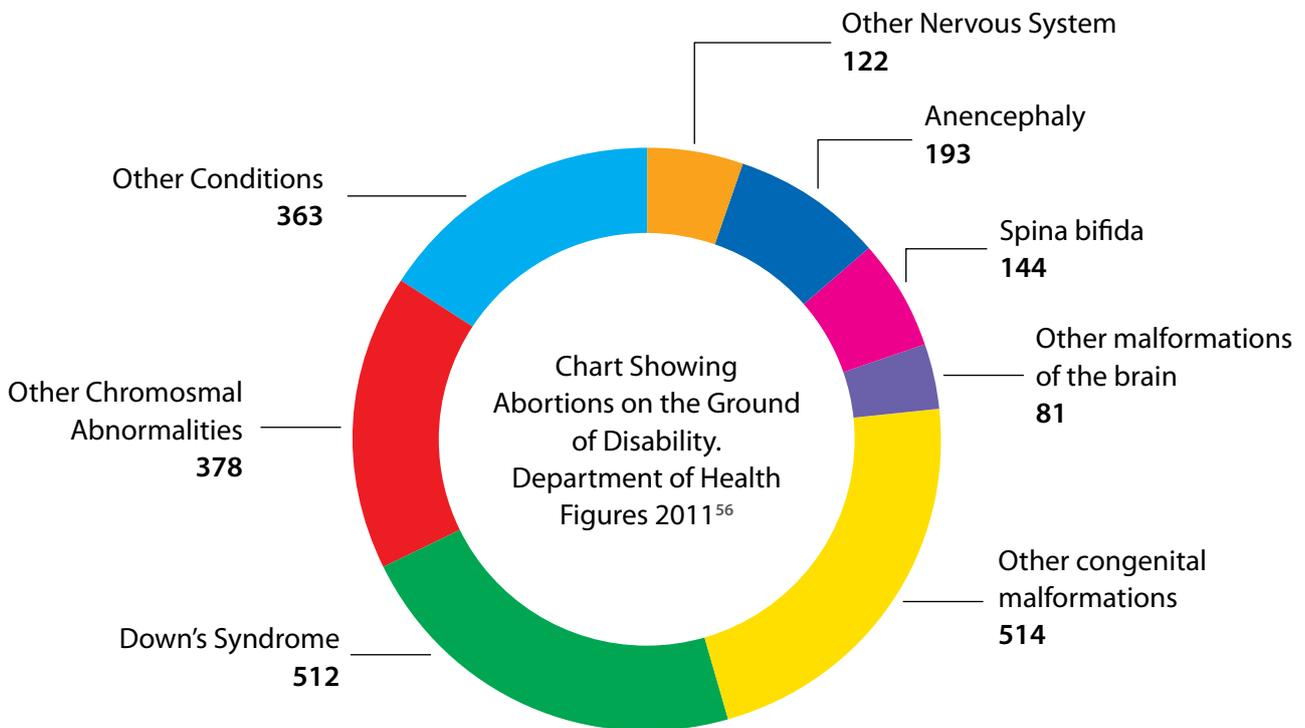
<sup>46</sup> Letter, RCN, responding to Q3

<sup>47</sup> Written Evidence, Q12, Christian Medical Fellowship; Letter, Together for Short Lives, page 3

the heartbeat; then the mother will have a medical induction to deliver the baby after 48 hours.<sup>48</sup> One parent was advised that the baby would experience a certain amount of pain through the procedure: *"I never wanted him to be in pain, and part of the termination was, will he feel it, and they said he's going to feel it."*<sup>49 50</sup> A recently published study noted that live births were reported following 2.2% of late term abortions.<sup>51</sup> Birth registration is required for all abortions after 24 weeks *"creating an additional burden for both parents and staff to overcome, with all the psychological stress associated with the process."*<sup>52</sup>

### The Type of Conditions that Come within the Definition of "Seriously Handicapped"

21. Under Ground E, pregnancies that are beyond 24 weeks can only be ended on the basis of a "substantial risk" of the child being "seriously handicapped". However, the law does not define either "substantial" or "seriously". The chart below illustrates the types of conditions that fall under Ground E from the Department of Health data (see Appendix B for historical data).<sup>53</sup> The evidence from Antenatal Results



<sup>48</sup> Jane Fisher, Oral Evidence Session 1, page 7

<sup>49</sup> Katyia Rowe, Oral Evidence Session 1, page 50-1

<sup>50</sup> Note that Professor KJS Anand said on Channel 4 Despatches in 2008, said, *"Whereas evidence for conscious pain perception is indirect, evidence for the subconscious incorporation of pain into neurological development and plasticity is incontrovertible. Scientific data, not religious or political conviction, should guide the desperately needed research in this field. In the meantime, it seems prudent to avoid pain during gestation"*.

<sup>51</sup> Draper E, Alfrevic Z, Stacey F, Hennessy E, Costeloe K, for the EPICure Study Group. An investigation into the reporting and management of late terminations of pregnancy (between 22+0 and 26+6 weeks of gestation) within NHS Hospitals in England in 2006: the EPICure preterm cohort study. BJOG 2012;119:710–715. See <http://www.epicure.ac.uk/> for information about EPICure, a series of studies of survival and later health among babies and young people who were born at extremely low gestations – from 22 to 26 weeks.

<sup>52</sup> *Ibid*

<sup>53</sup> Dept of Health Abortion Statistics 2011, *Op Cit*, Table 9

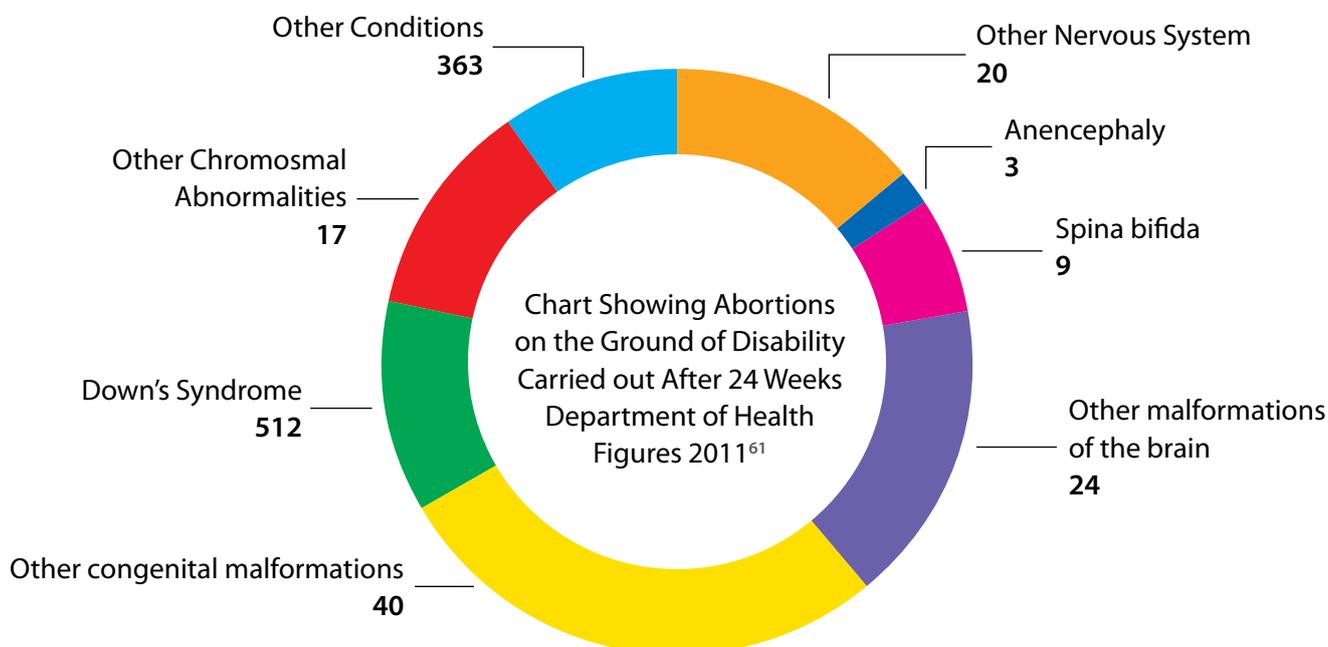
and Choices (ARC) was that in the majority of pregnancies where one of these conditions are identified, parents do abort the child.<sup>54</sup>

A considerable amount of evidence was presented on the experience of expecting a child with Down's Syndrome: **approximately 90% of babies with a definite diagnosis of Down's Syndrome are aborted**; about 30% of births of children with Down's Syndrome have no prenatal diagnosis.<sup>55</sup>

22. Other potential disabilities such as cleft palate and clubfoot are less likely to fall under

Ground E<sup>57</sup> unless other genetic factors are also present.<sup>58 59</sup> Professor Joan Morris reported that a third of babies with a cleft lip have another more severe disability but two thirds of babies with a cleft lip go on to a live birth. She estimated that there have been seven terminations in the last decade for cleft lip only and five for talipes (club foot).<sup>60</sup>

23. The chart below shows the categories of disability for which abortions were carried out after 24 weeks.



<sup>54</sup> Jane Fisher, Oral Evidence Session 1, page 9; Professor Lyn Chitty, Oral Evidence Session 4, pages 17-20

<sup>55</sup> After the prenatal diagnosis of Down's Syndrome 91% of affected pregnancies are terminated and 9% are continued. Some of the continued pregnancies miscarry naturally, some end as still births, and approximately 6% of prenatal diagnosis of Down's Syndrome end in live births. Quoted from page 4 of Morris JK, The National Down Syndrome Cytogenetic Register for England and Wales 2010 Annual Report. Queen Mary University of London, Barts and The London School of Medicine and Dentistry 2011 and Professor Joan Morris, Oral Evidence Session 4, pages 82-3

<sup>56</sup> For full breakdown of data see Table 9, Dept of Health Abortion Statistics 2011, *Op Cit*. Note that discrepancies about the Department of Health data are covered in this section of the Report.

<sup>57</sup> Rosanna Preston, Oral Evidence Session 2, page 31. John Pollard said he would question the legality of aborting a fetus after 24 weeks on the grounds of a cleft lip and cleft palate alone, Oral Evidence Session 4, page 75

<sup>58</sup> Jane Fisher, Oral Evidence Session 1, page 1

<sup>59</sup> The Cleft Lip and Palate Association suggested that it was rare, although possible, to find any other abnormalities. Rosanna Preston, Oral Evidence Session 2, page 26

<sup>60</sup> Professor Joan Morris, Oral Evidence Session 4, pages 87-88

<sup>61</sup> Table 9, Dept of Health Abortion Statistics 2011, *Op Cit*

## Interpretation of Substantial Risk and Seriously Handicapped

24. Given the lack of legal definition of the terms in the Abortion Act, **there were mixed opinions** on the use of the terms “substantial” and “seriously” in the statute.
25. The BMA suggests the “following factors that might be taken into account in assessing the seriousness of a disability:
- the probability of effective treatment, either *in utero* or after birth;
  - the child’s probable potential for self-awareness and potential ability to communicate with others;
  - the suffering that would be experienced by the child when born or by the people caring for the child.”<sup>62</sup>
26. The Royal College of Obstetricians and Gynaecologist (RCOG) Guidelines advise, *“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.”*<sup>63</sup> In their response to the Commission, the RCOG said, *“...Doctors are guided by the view that a serious handicap is a condition that is not trivial and/or readily correctable. This suggests that the*
- level of disability is based on the assessment of whether the child will suffer significant and long-term impairment in such a way that it impacts on their ability to function in society unsupported.”*<sup>64</sup>
27. The majority, but not all, of those professionally involved in fetal medicine believe that the **current wording and accompanying guidance meets the needs of difficult cases** which are treated “conservatively”.<sup>65</sup> There was a strong belief that a list approach to defining disability would not be “workable”, “feasible” or “flexible” enough and would not allow doctors to take into account the views of parents or consider other factors like the parents’ situation and the support available.<sup>66</sup>
28. The Anscombe Bioethics Centre said, *“guidance suggesting criteria for seriousness of disability would not remove the discrimination but would simply shift it onto a more precisely defined group of people. These disabilities would be seen as sufficient to render life of lesser/disposable value – perhaps indeed, as not worth living at all – whereas those with ‘lesser’ disabilities would be granted the status of honorary able-bodied.”*<sup>67</sup>
29. Others were concerned about the **unclear and ill-defined nature of the law**. The terms “seriously” and “substantial” were described as having a “lot of woolliness...no definition at all”<sup>68</sup> and as having “elastic” interpretation<sup>69</sup> and “very vague...I have observed even vague

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<sup>62</sup> Written Evidence, Q7, BMA referring to British Medical Association. Medical Ethics Today. The BMA’s handbook of ethics and law (3rd ed). London: BMJ Books, 2012: page 284.

<sup>63</sup> Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales. RCOG. 2010 <http://www.rcog.org.uk/termination-pregnancy-fetal-abnormality-england-scotland-and-wales>

<sup>64</sup> Written Evidence, Q8, RCOG and BMFMS

<sup>65</sup> Written Evidence, Q9, Dr Lorin Lakasing. A similar point was made by Jane Fisher, Oral Evidence Session 1, page 8, ie if “was a very strong possibility or probability” that a serious condition existed.

<sup>66</sup> See Written Evidence, Q8, RCOG and BMFMS; Letter, RCN, responding to Q1; Written Evidence, Q2, FPA and Brook referring to Science and Technology Committee, Scientific Developments Relating to the Abortion Act 1967, 2007; Written Evidence, Q7, BMA also referring the Science and Technology Select Committee; Written Evidence, Q10, Pranav Pandya; Written Evidence, Q17, Dr Tessa Homfray; Written Evidence, Q8 and Q10, Professor Peter Soothill; Written Evidence, Q7, Respondent 253

<sup>67</sup> Written Evidence, Q10, Anscombe Bioethics Centre. A similar point was made in Written Evidence, Q7, Respondent 192

<sup>68</sup> Jay Jayamohan, Oral Evidence Session 3, page 38

<sup>69</sup> Written Evidence, Q1 and Q3, Church of England. Similar comments were made by Dr Sheelagh McGuinness in her written evidence in Q1, Q4, Q5, Q6 and Q8



*general risks being interpreted as fulfilling Ground E.*<sup>70</sup> One parent informed the Commission “my wife was offered an abortion on the grounds of possible disability, because of our [older] son’s disability”.<sup>71</sup> Another respondent said, “Ground E’s operation, then, seems doubly ambiguous: it fails to recognise places on a spectrum, leading to the legal possibility of abortion in cases which are non-serious, and fails to specify the level of certainty required when assessing certain non-serious disabilities as indicators of more serious ones.”<sup>72</sup>

30. Others were concerned about the **impact of the legal uncertainty on doctors and patients** since it puts doctors in the unenviable position of deciding what degree of handicap qualifies for legal protection and what does not.<sup>73</sup> Even though there is guidance “the responsibility is really pushed entirely on the professional to interpret these words as they feel best.”<sup>74</sup> This means different professionals will carry out an abortion in a situation when another would not,<sup>75</sup> i.e. **there is no consensus around which abnormalities warrant termination.**<sup>76</sup> Professor Gordon Stirrat gave an example of a couple seeking an abortion for a cleft palate at 34 weeks where there was a significant difference between doctors who refused an abortion under Ground E and others who interpreted the law as covering the couple’s situation.<sup>77</sup>

31. Barrister, Daniel Kinning, summed up the main concerns by saying, “The interpretation of Ground E, particularly the meaning of ‘substantial’ and ‘seriously handicapped’ by the courts and medical profession is causing the law to be applied in a haphazard fashion. Evaluating whether a life is worth living is beyond the expertise of the medical profession, but is often conflated with their expertise in assessing treatment options. The current guidelines place the medical profession in the position of discriminating between disabilities and their severity. The medical profession have been advised by the courts to examine disability on a case-by-case basis. The medical profession is being indirectly asked to make decisions that are legal, social, and ethical which are outside of their competence. The case-by-case approach is unhelpful, exposing the medical profession to litigation for ‘wrongful life.’”<sup>78</sup>

## Proposals Put to the Commission on Definitions

32. A number of suggestions for amending the law were put to the Commission:

- There should be list of conditions that on their own do not count as severe or substantial (e.g. cleft palate and club foot). “This way rather than stating what conditions do meet the criteria which would be very hard to encapsulate all, clear exclusions could be stated to remove the ambiguity.”<sup>79</sup>

<sup>70</sup> Written Evidence, Q3, Respondent 58

<sup>71</sup> Written Evidence, Introduction, Respondent 86

<sup>72</sup> Written Evidence (Additional Information), Q3, Respondent 192

<sup>73</sup> Written Evidence, Q8, Christian Medical Fellowship  
Note that in Written Evidence, Q3, Reproductive Health Matters Journal suggests that decisions are being made by ethics committees not doctors.

<sup>74</sup> Professor John Wyatt, Oral Evidence Session 4, page 61; Written Evidence, Q8, Respondent 11

<sup>75</sup> Professor John Wyatt, Oral Evidence Session 4, page 62; Written Evidence, Q3, Respondent 58

<sup>76</sup> Julian Savulescu, Journal of Medical Ethics, *Op Cit* and Written Evidence, Q8, Professor Rosamund Scott

<sup>77</sup> Written Evidence, Q9, and additional evidence Professor Gordon Stirrat

<sup>78</sup> Written Evidence, Q8, Daniel Kinning. Similar comments made in Written Evidence, Q8, Respondent 30

<sup>79</sup> Written Evidence, Q7, Respondent 257

- Attempts should be made to define the terms “substantial risk” and “seriously handicapped”<sup>80</sup> and to be more specific in saying what level of disability should be deemed to be seriously life-limiting in order to warrant such a late termination.<sup>81</sup>
- The law should be amended to exclude Down’s Syndrome as it does “not meet the test of a “serious handicap” since it is a mild to moderate developmental delay” and the decades of experience and research on lives lived with Down’s Syndrome prove beyond a doubt that Down’s Syndrome does not meet that criteria.<sup>82</sup>
- The law should be amended to reflect “quality of life” instead of “seriously handicapped”, since this is what is being considered in practice by doctors. There should also be amendment to section 1(2) to allow the doctor to consider the woman’s actual and reasonably foreseeable environment when making the decision.”<sup>83</sup> However, other respondents said, “The use of ‘quality of life’ in discussions about the future outcome of disabled fetuses is hugely subjective”,<sup>84</sup> nor cannot it be measured in any scientific manner.<sup>85</sup>
- The abortion guidelines could clarify the extent to which healthcare professionals should take into consideration prospective parents’ views when they are interpreting whether a pregnancy falls within Ground E, as it is clear that shared decision-making

does occur. This principle operates in the Human Fertilisation and Embryology Authority (HFEA) guidelines on pre-implantation genetic diagnosis/ screening, which say that both “the views of the people seeking treatment” and “the family circumstances of the people seeking treatment” should be considered when deciding to undertake such screening.<sup>86</sup>

## Conclusion

33. In 2007, the Science and Technology Select Committee recommended that the Department of Health should commission work to produce guidance that would be clinically useful to doctors and patients.<sup>87</sup> In response, the RCOG provided updated guidance in 2010<sup>88</sup> but there still seems to be a considerable difference of views and working practice on what comes within the boundaries of the law and what does not. While recognising each case is different, the potential for such significant differences between doctors on which disabilities fall within the scope of the law and which do not is particularly concerning for parents, practitioners, lawmakers and those who are disabled.
34. The Commission heard from several witnesses who suggested that either RCOG guidance and/or the law needed to be amended so

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<sup>80</sup> Professor Stuart Campbell, Letter, page 3

<sup>81</sup> Written Evidence, Q7, Respondent 11

<sup>82</sup> Written Evidence, Q8 and Q9, Mike Sullivan, Saving Downs; Written Evidence, Q1 and Q7, Respondent 143. Note that Professor Rosamund Scott in Written Evidence, Q2, says that “even an able child with Down’s syndrome has been viewed as seriously disabled in this area of law” referencing *R v East Dorset Health Authority*, [2000] 56 B.M.L.R. 39.

<sup>83</sup> Written Evidence, Q1-4 and Q7, Respondent 225. Similar reference to decisions “based on a comprehensive assessment of the child’s chances of survival and future quality of life” were made in Written Evidence, Q17, RCOG

<sup>84</sup> Written Evidence, Q10, Respondent 173

<sup>85</sup> Dr Kevin Fitzpatrick, Oral Evidence Session 2, page 7

<sup>86</sup> Raised in Written Evidence, Q10, Respondent 253, referring to the HFEA Code of Practice, [http://www.hfea.gov.uk/docs/8th\\_Code\\_of\\_Practice.pdfm](http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdfm), para 10.5 and 10.7 and in Written Evidence, Q6, Professor Rosamund Scott

<sup>87</sup> Science and Technology Select Committee, *Op Cit*, page 32, paragraph 81

<sup>88</sup> Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales. RCOG. 2010

that certain conditions should *not* fall within Ground E. Other witnesses said that trying to categorise a list of conditions in such a way would be subjective, fraught with difficulty and unworkable. The Commission considered the evidence presented and decided against recommending a list approach. The Committee concurred with witnesses who argued that such a list would inevitably discriminate against people with specific disabilities, on arbitrary and subjective grounds.

35. Nevertheless, the Commission believes it is time to review the moral, ethical, legal and practical framework within which this provision of the Abortion Act operates and how the law applies to a fetus beyond the age of viability. We commend the recommendations that follow in this Report to Parliament, the medical profession and the wider public.

## Data Reporting: Discrepancies and Conflicts of Interest

36. Under Regulations, doctors have to submit data on the number and types of abortions (form HSA4). The UN Disability Convention also requires the collection of disability data and statistics to promote the rights of persons with disabilities and to assess the impact of policies on the human rights of persons with disabilities. States must ensure that such

policies do not have the impact of reducing the base population.<sup>89</sup>

37. The Department of Health publishes annual data on terminations<sup>90</sup> and has recently conducted a consultation on how abortion statistics will be presented in the future.<sup>91</sup>
38. EUROCAT (European Surveillance of Congenital Anomalies) publishes data twice a year on congenital abnormalities.<sup>92</sup> EUROCAT is a network of 37 population-based congenital anomaly registries in 21 countries of Europe covering a total of 1.7 million births per year.<sup>93</sup> EUROCAT includes BINOCAR (British Isles Network of Congenital Anomalies), a group of regional congenital anomaly registers which have grown up individually, based on whether funding is available. Wales has full coverage but only about a third of England is covered by these registers; in particular there is no information on London or the south east. Funding for registers is available only on an annual basis.<sup>94</sup>

39. Several witnesses reminded the Commission that part of the **purpose of data recording is to look at trends and see if there are environmental/medical causes of disability** or practical public health information that can be made available to women considering pregnancy.<sup>95</sup> EUROCAT recommended that the Commission, “*keep in mind in the collection of*

<sup>89</sup> Written Evidence (Additional), *Saving Downs*, page 10 referring to Articles 1 and 31 of the UNCRPD

<sup>90</sup> See Department of Health *Abortion Statistics*, *Op Cit*

<sup>91</sup> Consultation on publication of abortion statistics: proposals for changes to the annual abortion statistics publication. [http://consultations.dh.gov.uk/abortion/changes\\_to\\_abortion\\_statistics\\_consultation](http://consultations.dh.gov.uk/abortion/changes_to_abortion_statistics_consultation)

<sup>92</sup> There was some confusion about the EUROCAT data as a particular baby can be counted twice in the EUROCAT data since what is recorded is the specific disability rather than the number of children, Professor Joan Morris, Oral Evidence Session 4, page 87

<sup>93</sup> Letter, EUROCAT and see [www.eurocat-network.eu](http://www.eurocat-network.eu)

<sup>94</sup> Professor Joan Morris, Oral Evidence Session 4, pages 80-1 and pages 84-5. Lack of data coverage was also raised by Patricia Boyd, Oral Evidence Session 3, pages 74 and 76. See also *Researchers call for national funding to monitor all birth defects*, Sophie Wedgwood, *BMJ* 2012;345:e5274

<sup>95</sup> Patricia Boyd, Oral Evidence Session 3, pages 74 and 76 and Professor Joan Morris, Oral Evidence Session 4, page 80, in particular on the link between folic acid and spina bifida.

*data on abortion, that one of its purposes should be to allow us to assess to what extent societal efforts at ensuring a healthy environment for pregnant women is reducing the toll of disability, since primary prevention should obviate the need to consider abortion, and thus lead to lower numbers of abortions.”<sup>96</sup>*

**40. Witnesses raised concerns about disparities and discrepancies in the data reported on the number of abortions on the grounds of disability.**<sup>97</sup> Professor Joan Morris said the Department of Health abortion statistics are “very inaccurate” and have been shown to be underreported not only by the Down's Syndrome National Register but also by other work.<sup>98</sup> A recently published study said that their results showed “that approximately 53% of TOPs recorded by EPICure2 are presented in DH abortion statistics for NHS hospitals” and that “substantial differences in the numbers of reported [abortions] remain unaccounted for.”<sup>99</sup>

Table Showing Differences in Recorded Abortions between the Department of Health and the National Down Syndrome Cytogenetic Register in England and Wales<sup>100</sup>

	2010		2011	
	DH	NDSCR	DH	NDSCR
Down's Syndrome	482	942	512	931
Patau Syndrome	51	151	54	139
Edwards Syndrome	164	344	176	370

**41.** The ProLife Alliance suggested that it is possible to discover a fetal disability, and then obtain a relatively early abortion on the basis of the mental health of the woman rather than under Ground E.<sup>101</sup> It may be that this is the cause of some of the discrepancies. They recommended having “more comprehensive cross-referencing protocols in place and this should be relatively easy to implement”.<sup>102 103</sup>

<sup>96</sup> Letter, Q16, EUROCAT

<sup>97</sup> Beezy Marsh, Oral Evidence Session 2, pages 18-20 and page 23 and Written Evidence, Q15 and Q16, Respondent 58

<sup>98</sup> Professor Joan Morris, Oral Evidence Session 4, page 84

<sup>99</sup> Draper E et al, *Op Cit*, BJOG 2012;119:710–715

<sup>100</sup> Sources of Data: Department of Health Abortion Statistics for England and Wales and the National Down Syndrome Cytogenetic Register for England and Wales

<sup>101</sup> Professor Rosamund Scott in Written Evidence, Q3, argues that this is an acceptable alternative.

<sup>102</sup> Written Evidence, Q15, ProLife Alliance

<sup>103</sup> Similar points about the differences in numbers were made in Written Evidence, Q2, BMA and Written Evidence, Q8 and Q10, Professor Peter Soothill



42. There were also concerns raised by Savings Down's and the Down Syndrome Research Foundation UK that the Down's Syndrome National Register falls under the Wolfson Institute of Preventive Medicine, which has antenatal screening as one of its activities. Both organisations recommended that the Register should be independent of the Wolfson Institute.<sup>104</sup>

43. The Commission notes that in a Parliamentary debate on changing the time limit to birth for fetal disability, the Minister for Health at the time told Parliament that the Government would "*introduce regulations to make it necessary for the nature of the handicap to be specified on the notification for a late abortion after 24 weeks*".<sup>105</sup> The Abortion Regulations 1991 introduced a new version of the notification form which required the recording of the fetal diagnosis and further information for a pregnancy over 24 weeks.<sup>106</sup> However, the need for additional data on late terminations is no longer required on the current version of the notification form, HSA4, which was revised in 2006.<sup>107</sup>

## Proposals Put to the Commission on Data Collection

44. There were a number of proposals put forward:

### *Practical*

- Regulations for reporting need to be strengthened with regular audits being conducted.<sup>108</sup>
- Regulations should be drafted requiring doctors to strictly document the presence of disability at the screening stage in order to distinguish abortions on the grounds of disability from other grounds,<sup>109</sup> and there should be written justification over and above the data collected on abortions carried out after 24 weeks, which should be subject to audit.<sup>110</sup>
- The reporting time for the HSA4 form could be extended to include details about the final diagnosis of the fetal disability. Such information is only picked up at a later stage and is not often included. The Office for National Statistics (ONS) would be the appropriate agency to collate such data.<sup>111</sup>

<sup>104</sup> Written Evidence (Additional), Saving Down's, page 10 and Written Evidence, Q15 and Q16, Down Syndrome Research Foundation UK

<sup>105</sup> The Rt Hon Mr Kenneth Clarke, Hansard, HC, 21 June 1990, vol. 174, col 1201

<sup>106</sup> See Schedule 2. Information recorded in sections 13 and 14 of the form.

<sup>107</sup> The information required on form HSA4 is set out in the Schedule of the Abortion (Amendment)(England) Regulations 2002 and the Abortion (Amendment)(Wales) Regulations 2002

<sup>108</sup> Written Evidence, Q16, Daniel Kinning

<sup>109</sup> Written Evidence, Q7, Christian Concern

<sup>110</sup> Written Evidence, Q10, Professor Gordon Stirrat

<sup>111</sup> Written Evidence, Q4, RCOG and BMFMS

- Consideration needs to be given to handing over the statutory obligation for the collation and publication of data to an independent body overseen by Parliament.<sup>112</sup>

#### *New Data*

- Data should be collected on how many abortions are offered to women under Clause E versus how many are taken up.<sup>113</sup>
- The outcome for those babies diagnosed with a fetal disability should be documented as future evidence for parents in a similar position.<sup>114</sup>
- There should be a national register for all congenital anomalies, not just for Down's Syndrome.<sup>115</sup>

## Conclusion

45. In 2007, the Science and Technology Select Committee recommended that consideration of the issues around fetal disability “*would be enhanced by better collection of data relating to the reasons for abortion beyond 24 weeks for foetal abnormality, and appropriate analysis of such data*”.<sup>116</sup> However, there still seems to be considerable weaknesses, gaps and limitations

in the data on fetal disability which needs to be resolved.

#### **Recommendation 1**

**The Department of Health should consider the findings of this report as part of the consultation on publication of abortion statistics.**

#### **Recommendation 2**

**Funding should be made available to ensure that there are independent congenital anomaly registers that cover the whole of England, as well as Wales, Scotland and Northern Ireland, and all congenital abnormalities.**

#### **Recommendation 3**

**If the time limit for abortions on the grounds of disability remains to birth, there should be additional written justification for abortions on the grounds of disability after 24 weeks, which should be subject to audit.**

#### **Recommendation 4**

**The reporting time for the form HSA4 should be extended in cases of Ground E abortions to include details about the final diagnosis of the fetal disability.**

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<sup>112</sup> Written Evidence, Q16, Daniel Kinning

<sup>113</sup> Written Evidence, Q15, Dr Lorin Lakasing

<sup>114</sup> Written Evidence, Q16, Respondent 173

<sup>115</sup> Written Evidence, Q16, Pranav Pandya

<sup>116</sup> Science and Technology Select Committee, *Op Cit*, page 32, paragraph 82

# 3. The Experience of Information and Guidance Provided to Families Following the Discovery of a Disability

46. The Commission heard from families who have had experience with a pregnancy where a fetal disability was discovered and from those who support them. We are extremely grateful for the testimonies we have received.

## Understanding the Diagnosis

47. The **importance of accurate communication of the diagnosis** was stressed in an area where there are often many uncertainties.<sup>117</sup> One respondent suggested that a diagnosis in writing should be given to parents.<sup>118</sup> Concerns were expressed as to whether parents really understand the certainty, or lack of certainty, of test results since there is not always clarity about the implications for a particular child after pre-natal testing.<sup>119</sup> Doctors talk to patients in terms of degrees of risk for particular outcomes.<sup>120</sup> Professor John

Wyatt said that women can be “confronted by ambiguous results which cause a huge amount of anxiety and uncertainty”.<sup>121</sup> For instance, since the outcome of Down’s Syndrome represents a spectrum it is “almost impossible to predict” the implications for the child.<sup>122</sup>

48. Others told the Commission about **diagnoses that had proved incorrect**.<sup>123</sup> One parent said, “We were advised that my daughter could be aborted up to birth due to the results of antenatal tests. The most serious result indicated a Dandy Walker malformation of the brain. In fact when scanned after birth there was no such malformation. Our daughter is now 6 years old and a happy normal child.”<sup>124</sup>

49. Mr Jayamohan told the Commission that of thirty-two post-mortems that he knew had been done on late stage terminations there had been “two where the diagnosis has been

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<sup>117</sup> Hannah Battye, Oral Evidence Session 2, page 37

<sup>118</sup> Written Evidence, Q12, Respondent 169

<sup>119</sup> The National Society for Genetics Counsellors (NSGC) published guidelines in 2011 for delivering a Down’s syndrome diagnosis. The guidelines include helpful bullet point lists for counselling patients, a list of approved written and on-line resources, and recommends providing the patients the opportunity to contact a national or local parent support organisation. These guidelines are available at: <http://www.ncbi.nlm.nih.gov/pubmed/21618060>. Many of the resources are available at [www.downsyndromediagnosis.org](http://www.downsyndromediagnosis.org). See Written Evidence, Q11, Respondent 143

<sup>120</sup> Jay Jayamohan, Oral Evidence Session 3, pages 28 and 35; Lynda Brook, Oral Evidence Session 3, page 55; Professor Lyn Chitty, Oral Evidence Session 4, page 23; Nicky Priaulx, Oral Evidence Session 4, page 45; Written Evidence, Q9, Stephen Browne; Written Evidence, Q9, Christian Medical Fellowship

<sup>121</sup> Professor John Wyatt, Oral Evidence Session 4, page 59

<sup>122</sup> Professor John Wyatt, Oral Evidence Session 4, page 60

<sup>123</sup> Professor Sue Buckley, Oral Evidence Session 2, page 50. Lack of accuracy was also raised in Written Evidence, Q4, Respondent 13. Sarah Mullen who gave evidence in Oral Session 3 is a case in point, pages 12-14

<sup>124</sup> Written Evidence, Introduction, Respondent 185 (wished to remain anonymous)

profoundly wrong.”<sup>125</sup> However, Professor Stuart Campbell said, “The risks of terminating a normal fetus by mistake are extremely low.”<sup>126</sup>

## Considering the Options

50. A considerable number of witnesses reported from their experience that after the discovery of a fetal disability, the **presumption of the medical profession was that parents would opt for abortion.**<sup>127</sup>

- “My son (who is now 8 years old) has Down Syndrome, he was diagnosed in the womb at 35 weeks and I was actively encouraged to seek a termination by the doctor who gave me the diagnosis. I was given no support by my local hospital in my decision to keep my baby, I had to actively seek support elsewhere and I’m sure you will appreciate how difficult this was as I was heavily pregnant and in a vulnerable state.”<sup>128</sup>
- “We came under huge pressure to have an abortion and the strongest argument given was that a disabled child “would affect our lifestyle”, in other words be a burden on us.”<sup>129</sup>
- “I have encountered individuals who feel that they have to resort to abortion because

*this is the expectation of the health care professionals they have encountered, or because they have not been given support when making this decision or because they feel fearful that they will not be able to cope in the future due to limited resources, finances or community support in their locality.*<sup>130</sup>

- “From my perspective as a GP there is a clear feeling/understanding in parents carrying a baby that may be disabled that they “should” have an abortion, that this is what is anticipated by the medical profession and by society more generally.”<sup>131</sup>
- “When we were trying to make a decision in our own personal case we were told in no uncertain terms by a leading international obstetric team that our daughter would choke to death and suffer an unpleasant death and therefore we should consider a termination that evening.”<sup>132</sup>

51. Parents can find themselves given **only** a leaflet on abortion and plenty of support or advice on having an abortion<sup>133</sup> rather than a support package and/or information specific to the condition diagnosed.<sup>134</sup><sup>135</sup> Two parents in the oral sessions said they had not been given any extra support, leaving women to

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<sup>125</sup> Jay Jayamohan, Oral Evidence Session 3, page 36. Similar comment in Written Evidence, Q17, Respondent 58

<sup>126</sup> Professor Stuart Campbell, Letter, page 1

<sup>127</sup> For instance, Written evidence, Q8, Respondent 8, parent; Written Evidence, Q11, Respondent 21; Written Evidence, Q5, Respondent 30

<sup>128</sup> Written Evidence, Introduction, Respondent 11

<sup>129</sup> Written Evidence, Q8, Respondent 185 (wished to remain anonymous)

<sup>130</sup> Written Evidence, Q14, Respondent 30

<sup>131</sup> Written Evidence, Q5, Respondent 56

<sup>132</sup> Written Evidence, Q9, Respondent 146

<sup>133</sup> Hannah Battye, Oral Evidence Session 2, page 33; Hayley Goleniowska, Oral Evidence Session 2, page 52; Lucy McLynn, Oral Evidence Session 2, page 55-7; Email Respondent 11; Written Evidence, Q12, Respondent 139; a Paediatric Registrar, reported on her experience of parents who felt they were being pressured to have an abortion in Written Evidence, Introduction, Q5, Q11, Respondent 202

<sup>134</sup> Dr Kevin Fitzpatrick, Oral Evidence Session 2, page 15; Hayley Goleniowska, Oral Evidence Session 2, page 53; Email, Respondent 262; See also Sunday Times, 7 April 2013, Heart Unit ‘Pressured Mothers to Abort’

<sup>135</sup> The Genetic Alliance UK said they were aware anecdotally that some face difficulties in accessing a termination on Ground E. Written Evidence, Q12, Genetic Alliance UK



find information proactively at a time of great distress.<sup>136</sup>

- *"The only thing I was ever offered was this leaflet.<sup>137</sup> ... Nothing else was ever provided, either by NHS or privately, to offer any support. There was good information online, of course. We looked at the Down's Syndrome Association website... I think that comes back to the fact that the assumption is, if you get that diagnosis, you're going to terminate your pregnancy, and that's where everything is being pushed, in terms of information, in terms of support. You get plenty of support around a termination... I also think there's actually quite a systemic discrimination against the mothers of disabled foetuses, babies at that stage. That, to my mind, is discrimination by association... women who are having disabled children are subtly, or not so subtly, pushed down the road of termination. I consider that to be discriminatory. Why should you be treated differently and not be given the same approach to your pregnancy? The presumption for another mother would be that you're going to go ahead and have this much longed for and wanted baby."<sup>138</sup>*
- *"...the pressure was to end life not to support and inform parents. Every time we received a diagnosis of another potential problem we had to find out what we could on the internet and then ask questions. Information and support was minimal. Indeed we were made to feel as if we were doing something wrong by continuing with a pregnancy where the child might have been disabled."<sup>139</sup>*

- *"The genetic midwife I was introduced to (even though I had not asked to see her) did not offer me anything in the way of support for keeping my baby. All she said was that it was my decision. However, it was clear that should I have chosen termination then there would be lots of support but choosing to keep the baby effectively meant I was on my own."<sup>140</sup>*

## Palliative Care for Newborns

52. Professor John Wyatt and Together for Short Lives raised the need for parents to be aware of palliative care as an option when considering continuing with a pregnancy. Two respondents referred to studies that indicated that more parents chose to continue with their pregnancy when access to hospice care for their child was available.<sup>141</sup>
53. Amy Kuebelbeck of the US organisation, PerinatalHospice.org, described perinatal hospice as an approach that *"walks with these families on their journey through pregnancy, birth, and death, honouring the baby as well as the baby's family. The concept builds upon the pioneering work of Britain's own Dame Cicely Saunders, founder of the modern hospice movement. Perinatal hospice is not a place; it is more a frame of mind. It is a way of caring for the pregnant mother, the baby, the father, and all involved with dignity and love."*<sup>142</sup>
54. Dr Hilary Cass said that in the UK more paediatric palliative care consultants are

<sup>136</sup> Lynn Murray, Oral Evidence Session 1, page 27; Sarah Mullen, Oral Session 3, page 14-15

<sup>137</sup> Referring to ARC leaflet, A Handbook to be given to parents when a disability is diagnosed in their unborn child

<sup>138</sup> Lucy McLynn, Oral Evidence Session 2, pages 57 and 58

<sup>139</sup> Written Evidence, Q11, Respondent 185 (wished to remain anonymous)

<sup>140</sup> Written Evidence, Q3, Respondent 152

<sup>141</sup> Professor Patricia Casey, Oral Evidence Session 4, page 50 and Written Evidence, Q17, Amy Kuebelbeck

<sup>142</sup> Written Evidence, Introduction, Amy Kuebelbeck

needed as there are only 10 specialists at the moment, and there should be more awareness of the possibility of a referral for this type of service.<sup>143</sup>

55. The Commission notes that in 1967 there were few children's hospices and no baby hospices. The recent fast growth of both these resources is something we should be proud of (for instance Zoe's Places). Bringing up a disabled child is rarely easy, but the respite (as well as terminal) care which these hospices provide can make a major difference to parents and siblings of special needs children. One couple informed the Commission of the "immeasurable support" they had received from a children's hospice.<sup>144</sup>

#### **Recommendation 5**

**The option of palliative care (perinatal hospice) should be offered to all parents as they consider their decisions about continuing their pregnancy after discovery of a fetal disability. There should be increased funding available for palliative care for newborns.**

### **Considering Adoption**

56. Ann Furedi from BPAS said that she thought parents expecting a disabled child would rarely consider **adoption**: "*I would imagine it's a pretty uncommon phenomenon*".<sup>145</sup> Professor John Wyatt said it should be discussed as an option but thinks it generally is not.<sup>146</sup>

57. The Commission received evidence from three parents who had adopted a disabled child. One described their child as having a "*wonderful quality of life*" and making an "*amazing contribution*" to their family<sup>147</sup> and another said they were "*very grateful for our son... He has a loving and cheerful personality and his joy is infectious!*"<sup>148</sup>

58. The third parent said, "*Expectant mothers should receive full information about placing their child for adoption and be supported in allowing the child to be relinquished so they can still have a happy childhood being loved by a family who can accept them as they are with their disabilities. A concurrent foster placement from birth would give parents time to change their mind but many people would be willing to parent a baby with disabilities if they could care for it from birth including people who would not usually adopt ie parents who have already had children with a disability or people with professional experience of disabled children if the child was placed with them as a newborn. If the birth parents do not change their mind then they should be supported to relinquish their babies and other people with experience of disability should care for them from birth.*"<sup>149</sup>

#### **Recommendation 6**

**Following a prenatal discovery of a fetal disability, parents should be encouraged and supported to consider adoption for their child as one of the options available to them. Literature distributed by patient interest groups to couples should promote adoption as a positive option.**

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<sup>143</sup> Dr Richard Hain, Oral Evidence Session 3, page 52; Dr Hilary Cass, Oral Evidence Session 3, page 22; Lynda Brooks, Oral Evidence Session 3, pages 54 and 55; Written Evidence, Q14, Anscombe Bioethics Centre supported a hospice approach.

<sup>144</sup> Written Evidence, Q13, Respondent 146

<sup>145</sup> Ann Furedi, Oral Evidence Session 4, pages 6-7

<sup>146</sup> Professor John Wyatt, Oral Evidence Session 4, page 61. Similar comment made in Letter, Respondent 221

<sup>147</sup> Written Evidence, Introduction, Respondent 145

<sup>148</sup> Written Evidence, Q14, Respondent 193

<sup>149</sup> Written Evidence, Q11, Respondent 94



59. However, some respondents expressed concern that a child put up for adoption could spend the rest of their life in the foster care system.<sup>150</sup> There have been concerns about the delays for disabled children,<sup>151</sup> but the Commission notes the Government current initiatives to speed up the adoption process<sup>152</sup> and **urges there that there should be swift processes for all children but especially where parents have voluntarily relinquished babies for care by other families.** While it is beyond the remit of the Inquiry, it is essential that disabled children are treated equally within the care system.

#### **Recommendation 7**

**The Adoption Register should be developed to ensure swifter matching of disabled babies with adopting families.**

### **The Need for Information**

60. The common message from parents and some professionals **was that there is a lack of information about the child's potential**

**disability after its discovery.** What actually happens to parents seems to be "highly variable" across the country.<sup>153</sup>

61. Parents said **they needed practical and balanced information available as soon as possible after the discovery of a fetal disability and before leaving hospital so that they can make an informed choice.**<sup>154 155</sup>

<sup>156</sup>The Down Syndrome Research Foundation UK recommended that nationally funded information should be given to all parents but that this would require government funding and the support of relevant medical bodies.<sup>157</sup> Petals (Pregnancy Expectations Trauma And Loss Society) is piloting a specialist counselling service in the Cambridge area for parents who are faced with decisions following discovery of fetal disability in pregnancy.<sup>158</sup>

62. Dr Richard Hain said parents need to see specialists as soon as possible so they have plenty of time to consider their decision.<sup>159</sup> Mr Jayamohan told the Commission that parents frequently make their choice before

<sup>150</sup> Letter, Respondent 6; figures on disabled children in care were quoted by Respondent 142 in Q6 of her Written Evidence

<sup>151</sup> For instance see <http://www.baaf.org.uk/info/disability> and Dr Claire Baker, Permanence and Stability For Disabled Looked After Children, Institute for Research and Innovation in Social Sciences, 2011, page 2

<sup>152</sup> See New 'Passport to support' for adopters, 3 May 2013 <https://www.gov.uk/government/news/new-passport-to-support-for-adopters>

<sup>153</sup> See Dr Hilary Cass, Oral Evidence Session 3, page 20; Hannah Battye, Oral Evidence Session 2, page 32; Lynn Murray, Oral Evidence Session 1, page 23 and 31; Katyia Rowe Session 1, page 49-5

<sup>154</sup> Hannah Battye, Oral Evidence Session 2, page 34; Hayley Goleniowska, Oral Evidence Session 2, page 53

<sup>155</sup> Families who receive a diagnosis of a cleft palate receive specialist help from one of nine units around the country, usually within 24 hours. The Cleft Lip and Palate Association (CLAPA) provide support via parents as well as a website with information

<sup>156</sup> The charity, Antenatal Results and Choices (ARC), supports parents through booklets, a telephone helpline with four people on the team, a website, emails and direct counselling in London. ARC supplied three booklets to the Commission: A Handbook to be given to parents when an anomaly is diagnosed in their unborn baby; Supporting you Throughout Your Pregnancy: A Handbook for Parents after a Prenatal Diagnosis and Helping parents and professionals through antenatal testing and its consequences

<sup>157</sup> Written Evidence, Q13, Down Syndrome Research Foundation UK referring to a US booklet *Understanding a Down Syndrome Diagnosis*, which was supplied to the Commission. The Foundation provides a booklet to new parents called *Bright Beginnings* and signposts to relevant parental support groups. It also provides a booklet for professionals called *Delivering a Down Syndrome Diagnosis* and an online tutorial called *Brighter Tomorrows*.

<sup>158</sup> See Written Evidence from Petals and [www.petalscharity.org](http://www.petalscharity.org)

<sup>159</sup> Dr Richard Hain, Oral Evidence Session 3, page 57

they are able to see a consultant.<sup>160</sup> Another respondent said offering a consultation with a specialist in the area of the disability would be very helpful since they would have a more in-depth knowledge of the prognosis, would have closer links with support groups than a general obstetrician.<sup>161</sup>

63. Lorin Lakasing, a specialist in fetal medicine, said, *“it is critical that this [information] is done well and this often requires time and multiple visits / consultations. This is the main reason for not imposing a gestational limit. Bad or regrettable decisions are far more likely to be made if they are made in haste.”*<sup>162</sup> Pranav Pandya, Chair of the Fetal Anomaly Screening Programme of the National Screening Programme, said information and guidance will improve by implementation of Fetal Medicine Specialist Commissioning. *“This will result in a smaller number of Fetal Medicine Units (possibly 14) in the country with greater experience and expertise providing a high standard of care. The disadvantage is that woman may need to travel further for their consultations but this would hopefully be a small price to pay to get the best care.”*<sup>163</sup> However, there is a risk that this will discriminate against those who cannot travel any distance to get this specialist help.

64. One parent summarised what many others reported, *“Guidelines and standards need to be set in place which all hospitals need to meet, to*

*ensure families are given support and education on disabilities when faced with such a situation. To give a family a diagnosis of a disability and then to immediately follow that up with the advice that they can have a termination without any other information is simply not acceptable in a civilized society.”*<sup>164</sup>

## Proposals Put to the Commission on Improving Information and Guidance

65. A number of those who gave evidence strongly recommended that, before making a decision, parents should be offered the opportunity to meet or **be in contact with other parents to understand the implications of the child’s disability** – *“the real lives of children living with disabilities should be represented rather than horror stories and worst-case scenarios”*<sup>165</sup> – so they can understand what might be possible and not possible and by doing so give them **an informed choice**.<sup>166</sup> Saving Downs said such a referral “must” be made<sup>167</sup> and Jay Jayamohan said it was his practice to offer parents the opportunity “to speak to a family who have a child with a similar condition.”<sup>168</sup> Another respondent said it would be helpful for charities to proactively contact parents.<sup>169</sup> The Cleft Lip and Palate Association (CLAPA) provide support via their Parent Contact Scheme.<sup>170</sup>

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<sup>160</sup> Jay Jayamohan, Oral Evidence Session 3, page 32

<sup>161</sup> Written Evidence, Q13, Respondent 225

<sup>162</sup> Written Evidence, Q12, Dr Lorin Lakasing

<sup>163</sup> Written Evidence, Q12, Pranav Pandya

<sup>164</sup> Written Evidence, Q10, Respondent 11

<sup>165</sup> Written Evidence, Q12, Respondent 12

<sup>166</sup> For instance Dr Kevin Fitzpatrick, Oral Evidence Session 2, page 13; Hayley Goleniowska, Oral Evidence Session 2, page 62; Written Evidence, Q13, Respondent 21; Written Evidence, Q12, Dr Sheelagh McGuinness

<sup>167</sup> Written Evidence (Additional), Saving Downs, page 9

<sup>168</sup> Mr Jay Jayamohan, Oral Evidence Session 3, page 29

<sup>169</sup> Written Evidence, Q13, Respondent 139

<sup>170</sup> Rosanna Preston, Oral Evidence Session 2, page 29



### Recommendation 8

Parents should be provided with practical and balanced information as soon as possible after discovery of a fetal disability and before leaving hospital so that they can make an informed choice. This should include leaflets or other information provided by relevant disability groups. Parents should be offered contact with families with a child with a similar diagnosis without delay.

66. It was suggested that each hospital should have a specific person, who is **qualified and trained**<sup>171</sup> in how to support families and offer non-directional support,<sup>172</sup> although counselling should not be compulsory.<sup>173</sup> **The need for specific training was stressed.**<sup>174</sup> Dr Hilary Cass said there needs to be **much clearer guidelines** about how counselling takes place.<sup>175</sup>

### Recommendation 9

There should be best practice guidelines for training and practice for professionals in counselling families facing a diagnosis of fetal disability. Training should encompass expertise on perinatal hospice, disability, bereavement and family counselling.

67. Another suggestion was a *“named health care professional who can act as a co-ordinator for their care pre- and post-natally would be ideal.”*<sup>176</sup> One parent suggested a mentor to guide a parent through the whole process as *“it’s like*

*being dumped in the middle of a desert with no road map.”*<sup>177</sup> The Commission learnt of the role of Learning Disability Liaison Nurses (LDLNs) who act as a liaison point for healthcare for people with learning disabilities (see Appendix A). The RCN said they were *“aware of instances where learning disability nurses are involved in the support of parents who have a pre-term fetus diagnosed with a disability, yet these structures are not formally in place.”*<sup>178</sup> This sort of liaison and knowledge support would be invaluable for parents. In 2012, a major report on LDLNs suggested there was *“potential for learning disabilities nurses to undertake, new, advanced and extended roles should be developed in line with advances in other fields of nursing.”*<sup>179</sup> In hospitals where LDLNs are in post their advice and support to counsellors/ therapists has been invaluable or very helpful.

### Recommendation 10

There should be consideration of the expansion of the role and responsibilities of Learning Disability Liaison Nurses (LDLNs) to all disabling conditions so that they can support couples who discover their unborn child has a disability.

68. The **level of awareness of different conditions** by medical professionals and the general public was raised frequently before the Commission. There are examples of charities working with healthcare professionals to raise awareness.<sup>180</sup>

<sup>171</sup> Jane Fisher in Oral Evidence Session 1, page 18 said, “Well, we’re not, and we don’t pretend to be, trained counsellors. We don’t have counselling qualifications, because I don’t feel that’s ever really been our job. We have a stiff initiation training to go onto the helpline.”

<sup>172</sup> Written Evidence, Q13, Respondent 11; Written Evidence, Q11, Respondent 142

<sup>173</sup> Written Evidence, Q11, Genetic Alliance UK; this point was also made in Written Evidence, Q13, FPA and Brook

<sup>174</sup> Written Evidence, Q13, Dr Lorin Lakasing; Written Evidence, Q12, Christian Medical Fellowship

<sup>175</sup> Dr Hilary Cass, Oral Evidence Session 3, page 26

<sup>176</sup> Written Evidence, Q13, Jane Fisher, ARC

<sup>177</sup> Written Evidence, Q13, Respondent 132

<sup>178</sup> Letter, RCN, Responding to Q11 and Q13

<sup>179</sup> *Strengthening the Commitment. The report of the UK Modernising Learning Disabilities Nursing Review.* Department of Health, Department of Health, Social Services and Public Safety, Welsh Government, The Scottish Government, 2012, page 17.

69. There was particular concern about whether practitioners and counsellors had ever met individuals with disabilities so that they could reflect a true picture of what life would be like for families, since the views of medical professionals can strongly influence patients.<sup>181</sup> In September 2011, a journal article reported that more than three-quarters of parents with a Down's 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's syndrome. Moreover, it found that nearly 99% of people with Down's syndrome are happy with their lives. Overwhelmingly, parents and siblings reported loving, and having pride in, their family member with Down's syndrome.<sup>182</sup> Various witnesses cited that these change in the improved life expectancy, medical treatment and situation of Down's Syndrome children, and the achievements of individuals with learning difficulties, **are not reflected in the attitudes of the medical profession towards parents and their child.**<sup>183</sup> One parent said, "*It appears that only the negative aspects of caring for a child with a disability are discussed with the*

*parents by professionals. Mention is rarely made of the joy that bringing up a child with Down Syndrome (for example) can bring.*"<sup>184</sup> Kate Powell, who has Down's Syndrome said, in her oral evidence, "*I feel in my opinion that I don't have a handicap... If a mother is afraid of having a baby with Down Syndrome, people with Down Syndrome can achieve. They can do things. They can work. They can work in things. They can achieve in lots of things.*"<sup>185</sup>

70. However, Jay Jayamohan reminded the Commission that life for some children and their families can be "miserable".<sup>186</sup> A consultant in genetics also said, "*Of course there are many families whose handicapped child has enriched the family but we are not all blessed with unending patience and tolerance. Many children are very, very challenging indeed.*"<sup>187</sup>

**Recommendation 11**  
**Guidelines for the medical profession should include training for obstetricians, fetal medicine specialists and midwives on the practical realities of the lives of children living with the different conditions which are screened for through ante-natal tests**

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<sup>180</sup> For example, Rosanna Preston, Oral Evidence Session 2, page 30 said CLAPA and ARC are jointly doing some training for sonographers on how to deal with diagnosing a cleft lip and breaking that news to families. The Down's Syndrome Association has produced a programme called Tell It Right, Start It Right, see Professor Sue Buckley, Oral Evidence Session 2, page 43. Jane Fisher, ARC, Oral Evidence Session 1, page 6, said they "run a well-evaluated training programme" for healthcare professionals.

<sup>181</sup> Professor John Wyatt, Oral Evidence Session 4, page 66. Similar point made by paediatrician, in Written Evidence, Q1 and Q8, Respondent 224

<sup>182</sup> Skotko BG, Levine SP, Goldstein R, Having a son or daughter with Down syndrome: Perspectives from mothers and fathers, *American Journal of Medical Genetics Part A*, Vol 155, Issue 10, pages 2335-2347, October 2011

<sup>183</sup> Professor Sue Buckley, Oral Evidence Session 2, page 47; Janet Carr, Oral Evidence Session 1, page 39-40; Dr Ian Hall, Oral Evidence Session 3, page 64; Lynn Murray, Oral Evidence Session 1, page 27. But increased life expectancy leading to parents having to plan for care for their child after their death and for coping with dementia in children with Down's Syndrome. Janet Carr, Oral Evidence Session 1, page 40

<sup>184</sup> Written Evidence, Q3, Respondent 152. The joy of her grandson and how he brings it to other people was reported in Written Evidence, Q14, Respondent 106. Written Evidence, Q14, Respondent 134 reported "the happiness, joy and love" that that his disabled cousin has brought us his family. See also <http://youtu.be/dsLoFP5LbnU> Video for World Down's Syndrome Day 2013, 21st March

<sup>185</sup> Kate Powell, Oral Evidence Session 3, pages 44 and 47

<sup>186</sup> Jay Jayamohan, Oral Evidence Session 3, page 28

<sup>187</sup> Written Evidence, Q14, Dr Tessa Homfrey



71. Some of the other proposals put to the Commission were as follows:
- The RCN suggested it would be very useful to have a means to assess the effectiveness of the information and guidance provided to parents since this is often provided by nurses and midwives. This could prove to be a valuable tool to developing better counselling and future provision.<sup>188</sup>
  - The Genetic Alliance UK said that balance of information currently available did not need to be altered.<sup>189</sup>

## Practical Support for Parents Who Decide to Have an Abortion

72. Parents who choose an abortion should be offered support and on-going longer term counselling<sup>190</sup> as they deal with the grief of their loss. They are suffering from *“bereavement like any other person who has lost a relative.”*<sup>191</sup> As this child is often wanted an abortion can be traumatic.<sup>192</sup>
73. Counselling of women after termination of pregnancy should be linked to high quality

perinatal pathology services and clinical genetics,<sup>193</sup> with support for the **mental health impact** of having a termination on the grounds of fetal disability, where needed.<sup>194</sup> Professor Patricia Casey reported that there is a relatively limited amount of research on the effects of abortion for fetal disability. She told the Commission that at the time of the abortion, 40% of women will be experiencing extreme mental health symptoms and *“the studies have all found that around 20 per cent of women, between one and two years after an abortion for fetal anomaly, have a psychiatric condition, usually a complicated grief reaction, a depressive disorder or post-traumatic stress disorder.”*<sup>195</sup> <sup>196</sup> Professor Gordon Stirrat suggested that *“Abortion (particularly in the 3rd trimester) is likely to engender feelings of guilt. Appropriate post abortion care and counselling must have, as one of its aims, reduction of these feelings.”*<sup>197</sup>

### Recommendation 12

**There should be counselling and support offered and available for those who choose an abortion on the grounds of disability both before and after abortion.**

<sup>188</sup> Letter, RCN, Responding to Q12 and Q13

<sup>189</sup> Written Evidence, Q12, Genetic Alliance UK

<sup>190</sup> Written Evidence, Q11, Respondent 169

<sup>191</sup> Written Evidence, Q2, Dr Tessa Homfray

<sup>192</sup> Written Evidence, Q12 and Q14, Respondent 142; Written Evidence, Q12, Christian Medical Fellowship

<sup>193</sup> Written Evidence, Q13, Professor Peter Soothill

<sup>194</sup> Ann Furedi, Oral Evidence Session 4, page 12

<sup>195</sup> Professor Patricia Casey, Oral Evidence Session 4, pages 47, 48 and 50. Similar point made in Written Evidence, Q12, Christian Medical Fellowship

<sup>196</sup> Note that the Human Genetics Commission, *Making Babies: Reproductive Decisions and Genetic Technologies* (2006) para 3.31 says, “that support would be available afterwards to help them cope with the unhappiness and distress that can persist for months or years after a termination of pregnancy for fetal abnormality.” Quoted by Professor Rosamund Scott, Written Evidence, Q12

<sup>197</sup> Written Evidence, Q13 Professor Gordon Stirrat

## Practical Support for Parents Who Chose to Keep their Baby

74. The RCOG Guidelines specify that a woman who decides to continue with her pregnancy *“must be fully supported... a coordinated care pathway needs to be established and women should have easy access to a designated health professional throughout the pregnancy... Regardless of the nature of the abnormality, it will also be necessary to ensure that the woman’s needs as an expectant mother are not overlooked.”*<sup>198</sup>

75. Katyia Rowe reported that during her pregnancy and during the birth of her baby who died within hours from his disabilities the *“support was fantastic... brilliant”*. She told the Commission that she had the support of her doctors, weekly treatment through the last weeks of her pregnancy, a special theatre team for the labour, a family room after her son’s birth so that she and her partner could spend time with the baby, an offer of a chaplain and support after the birth from a bereavement midwife and other midwives.<sup>199</sup>

76. One doctor told of a patient who found more comfort going through a pregnancy than having an abortion. *“A patient of mine was found to be carrying a fetus with an almost certainly fatal anomaly. After extensive counselling she elected*

*to have an induced abortion at 20 weeks. Despite support she was traumatized by this event and required treatment for depression for some time after it. Genetic and autopsy evidence suggested that there was about a 1/100 chance of recurrence. Two years later she became pregnant again and once more came under my care. Tragically, the fetus was similarly affected. On this occasion she elected to continue with the pregnancy. The baby was born at term and died in her arms aged 2 hours. “If only I had done this the first time” she said to me with tears streaming down her face.”*<sup>200</sup>

77. However, some mothers felt they were **treated differently** because they were carrying a disabled baby.<sup>201</sup> Dr Fitzpatrick said that he had heard of patients who had been refused treatment when they decided to keep their baby.<sup>202</sup> Others reported some disdain from medical professionals if they decided to continue with their pregnancy.<sup>203</sup> One parent said her doctor *“became short-tempered and abrupt with me because he clearly didn’t agree with my decision.”*<sup>204</sup> Another mother felt pressured into an abortion and reported that her doctor threatened that all medical help would be denied.<sup>205</sup>

78. Other parents reported **negative attitudes after birth**, especially where the disability is first apparent at birth.<sup>206</sup> These parents need as much information and support as those where the diagnosis is prenatal.<sup>207</sup>

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<sup>198</sup> RCOG, Termination of Pregnancy for Fetal Abnormality, *Op Cit*, pages 23-4

<sup>199</sup> Katyia Rowe, Oral Evidence Session 1, pages 48-52

<sup>200</sup> Written Evidence, Q14, Professor Gordon Stirrat

<sup>201</sup> Lucy McLynn, Oral Evidence Session 2, pages 58 and 60

<sup>202</sup> Dr Kevin Fitzpatrick, Oral Evidence Session 2, page 8

<sup>203</sup> Hayley Goleniowska, Oral Evidence Session 2, page 59

<sup>204</sup> Written Evidence, Q9, Respondent 11

<sup>205</sup> Email, Respondent 23

<sup>206</sup> For instance, Written Evidence, Q4 and Q5, Respondent 143

<sup>207</sup> Written Evidence, Q14, Respondent 143



- *“Parents I have spoken to have said that Doctors treating their children with Down’s Syndrome for example (for heart and other conditions post natal) criticised them for not having abortions, saying their children will not have a good life. And parent carers at this time will not be in a strong position – imagine how that feels?”*<sup>208</sup>
- *“Parents who learn of their baby’s disability after birth are sometimes told that it’s too bad they didn’t find out earlier so they could have “taken care of it.”*<sup>209</sup>
- *“I have already come across people who view my choice to have my child as detrimental to the rest of society. I have heard views expressed that suggest my child is seen as a drain on resources. A common view is that it was not fair on my other child to bring a disabled child into the world.”*<sup>210</sup>

**79.** One paediatrician recommended that parents who have babies with disabilities should be offered plenty of psychological support and early introduction to people experienced in caring for children with such conditions (parents as well as doctors, nurses and therapists).<sup>211</sup> Others said there should be particular support available for fathers.<sup>212</sup> One parent said, *“It would be helpful if agencies who deal with specific disabilities or even local*

*community support groups could be involved at birth. They could immediately offer advice and support at an extremely difficult time for parents of a new baby with a disability.”*<sup>213</sup>

### **Recommendation 13**

**There needs to be improved, positive and consistent care and comprehensive support for parents who choose to continue with their pregnancy from across the medical profession, in line with current guidelines.**

**80.** Other parents spoke about the **longer term difficulties of bringing up a disabled child** as the child can be excluded from mainstream activities and feel ostracised,<sup>214</sup> as well as bullied.<sup>215</sup> There are also fewer resources/ support networks for parents as fewer disabled children are born, which can lead to an even a greater feeling of isolation.<sup>216</sup> One parent said current attitudes have made *“raising [my] son and obtaining support tougher.”*<sup>217</sup> One parent reported difficulties in getting their baby’s heart condition successfully diagnosed and treated.<sup>218</sup> Another respondent said, there are fewer *“resources for [disabled] children (and parents) after birth and consequently in their lives (nursery, school and a place to work)...people with disability not only are discriminated in the womb but for life.”*<sup>219</sup>

<sup>208</sup> Letter, British Academy of Childhood Disability

<sup>209</sup> Written Evidence, Q6, Amy Kuebelbeck. Similar comment in Written Evidence, Q5, Down Syndrome Research Foundation UK

<sup>210</sup> Written Evidence, Q5, Respondent 152

<sup>211</sup> Written Evidence, Q13, Respondent 202; Sarah Mullen, Oral Evidence Session 3, page 13

<sup>212</sup> Katyia Rowe, Oral Evidence Session 1, page 56-7 and Professor Patricia Casey, Oral Evidence Session 4, page 55

<sup>213</sup> Written Evidence, Q13, Respondent 152

<sup>214</sup> Written Evidence, Q6, Respondent 12

<sup>215</sup> Written Evidence, Q6, Respondent 25

<sup>216</sup> Dr Kevin Fitzpatrick, Oral Evidence Session 2, pages 16-17

<sup>217</sup> Letter, Respondent 12

<sup>218</sup> Written Evidence, Q14, Respondent 103

<sup>219</sup> Written Evidence, Q1, Respondent 93

81. A number of witnesses expressed concern that more money is being spent on screening for disabilities (i.e. prevention by abortion) than research into true prevention/cures/support.<sup>220</sup> Data suggests that the cost of screening for Down's Syndrome is between £29m and £31m per year<sup>221</sup> whereas Government investment into research into Down's Syndrome in 2012-13 was £1.8m.<sup>222</sup>

82. Others said that wider attitudes within society towards **disabled children can affect parents:**

- *"Permission to eliminate the disabled before they are born is becoming an obligation, in the minds of some. Parents who choose not to abort a disabled child are sometimes treated as selfish and irresponsible pariahs who foisted a disabled child upon society, a child who could have—should have—been eliminated before birth."*<sup>223</sup>
- *"The parents, almost without exception, felt hugely guilty for allowing their disabled children to be born, not because they didn't love and accept them for who they were but for society's attitude to disability and the negative views surrounding it. They almost felt guilty for accessing the services their families required, due to the limited nature of these facilities and the necessity of fighting for resources."*<sup>224</sup>
- *"Mothers who choose NOT to undergo screening for fetal disability and those who choose NOT to abort their babies, on account*

*of disability, face pressure or a feeling of disapproval (whether openly expressed or tacitly held by obstetricians or midwives) as if they are doing wrong by bringing into the world a child who will require extra NHS resources."*<sup>225</sup>

## Conclusion

83. There is considerable variation in support available to parents at a time of great uncertainty. The Commission has made various recommendations which would improve the situation for parents. We also consider it essential that there is a wider support network for disabled children and adults so that parents can have the assurance that long-term practical support and knowledge will be available for them and their child should they continue with their pregnancy or place their child for adoption. Whilst this is beyond the remit of this Inquiry, it is nevertheless an important factor influencing the choices facing parents who have a baby diagnosed with a disability.

### Recommendation 14

**There is an imperative need to improve adequate and accessible long-term care and practical support to be in place for children and adults with disabilities and for those caring for them from the moment of diagnosis.**

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<sup>220</sup> Lynn Murray, Oral Evidence Session 1, page 32; Written Evidence, Q5, Respondent 18; Written Evidence, Q4, Respondent 21; Written Evidence, Q7, Respondent 58; Written Evidence, Q7; Respondent 173; Written Evidence, Q4, Down Research Foundation UK. Written Evidence, Q6, Respondent 143

<sup>221</sup> Hansard, House of Commons, 3 June 2013, Column 834W

<sup>222</sup> Hansard, House of Commons, 3 June 2013, Column 836W

<sup>223</sup> Written Evidence, Q6, Amy Kuebelbeck

<sup>224</sup> Written Evidence, Q14, Respondent 25

<sup>225</sup> Written Evidence, Q5, Respondent 58

# 4. Views on Whether There is a Need for a Change in the Law

84. The Commission heard from many different points of view on whether the law should be changed for abortion on the grounds of disability.

## Changes in Knowledge and Understanding since the Abortion Act

85. In the context of reviewing section 1(1)(d), some respondents pointed out there have been **significant changes** in “the conception of disability, rights and human dignity” and the care of people with disabilities.<sup>226</sup> Others noted that medical knowledge has changed since 1967 which raises questions about some of the presumptions that might have been informative at the time:

- Christian Medical Fellowship (CMF) said, *“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.”*<sup>227</sup>

- *“Medical therapies are being focused on unborn fetuses. Unborn fetuses are therefore increasingly becoming our patients and we therefore have the duty to act in their best interests.”*<sup>228 229</sup> Furthermore it is not clear that if a condition was treatable whether Parliament ever intended it to come within the scope of Ground E.<sup>230</sup>
- Professor John Wyatt said that he thought that in the 1967 Abortion Act Parliament had set out to distinguish between the gestational age at which abortion could be carried out and the gestational age at which premature babies were likely to survive. With the practice of late feticide and the survival of increasingly premature babies there is now a “strange ambiguity that the same hospital can be intensively supporting premature babies and performing late abortions at the same time.”<sup>231</sup> CMF described this situation as “ethically indefensible.”<sup>232</sup>
- Amy Kuebelbeck suggested that part of the rationale in 1967 was to ease the suffering of parents, especially parents whose baby has a condition so serious that the baby is expected to die. However, she points out that “knowledge about caring for parents experiencing miscarriage/stillbirth/infant

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<sup>226</sup> For instance, Written Evidence, Introduction, Daniel Kinning

<sup>227</sup> Written Evidence, Q3, Christian Medical Fellowship

<sup>228</sup> Written Evidence, Introduction, Respondent 214

<sup>229</sup> See the story of Samuel Armas who was treated in the womb for spina bifida in 1999, <http://www.foxnews.com/story/0,2933,519181,00.html> and the story of Gonzalo Pardo Sánchez reported in The Times, 11 May 2013, Happy and healthy, the child saved by surgery that stopped him dying in the womb at 21 weeks <http://www.thetimes.co.uk/tto/news/world/europe/article3761541.ece>

<sup>230</sup> Professor John Wyatt, Oral Evidence Session 4, page 63

<sup>231</sup> Professor John Wyatt, Oral Evidence Session 4, page 71

<sup>232</sup> Written Evidence, Q4, Christian Medical Fellowship

*death has increased exponentially since 1967. It is now known that there is no shortcut through grief, and termination does not cause parents to grieve any less.*<sup>233</sup>

86. However, FPA and Brook pointed out that in 2007 the Science and Technology Select Committee did not recommend any changes to section 1(1)(d); and that *“nothing has changed in either fetal survival or neo-natal care to make this conclusion any different”*.<sup>234</sup>

## Views on Ground E

87. Strong feelings about the so-called “Ground E”, the ability to have an abortion on the grounds of disability, were expressed to the Commission. A large number of those who responded to the Inquiry said Ground E is **discriminatory and should be repealed**.

View	Representative comments
Many felt that it enshrines discrimination within the law <sup>235</sup> and is in complete conflict with the Equality Act 2010 <sup>236</sup>	<p>“The fact that such an option is available implies somehow that disabled children do not have value and worth and should be got rid of.”<sup>237</sup></p> <p>“I defend the right of a newly-pregnant woman to seek an abortion for personal reasons, but I do not accept that a disabled baby should be aborted purely because of the existence of the disability because lives of disabled people are in general of great value and quality and medical advances are such that it seems unnecessary.”<sup>238</sup></p> <p>“Any continuing assumption that disability indicates that an abortion would have been in a child’s best interests represents outmoded and unsupportable attitudes to disability. Rightly, disability groups argue that disability ought to be seen as giving individuals a different, not a lesser, experience of life. The belief that individuals with disability will be automatically disadvantaged or that their quality of life will be unacceptable, might have had some, limited validity in 1967, but not today.”<sup>239</sup></p> <p>“...our culture is heavily centred around the rights of children and their protection – it is shameful this does not extend to unborn disabled children.”<sup>240</sup></p>

<sup>233</sup> Written Evidence, Q2, Amy Kuebelbeck

<sup>234</sup> Written Evidence, Q1, FPA and Brook referring to Science and Technology Committee, Scientific Developments Relating to the Abortion Act 1967, 2007

<sup>235</sup> Joanna Jepson and Sarah Mullen, Oral Evidence Session 3, pages 5, 9 and 16; Julian Savulescu, Journal of Medical Ethics, Op Cit; Written Evidence, Q5, Amy Kuebelbeck; Written Evidence, Q1, Mike Sullivan, Saving Downs

<sup>236</sup> Written Evidence, Q1, Respondent 2 and Written Evidence, Q1, Respondent 139

<sup>237</sup> Letter, British Academy of Childhood Disability

<sup>238</sup> Written Evidence, Q4, Respondent 12

<sup>239</sup> Written Evidence, Q2, Church of England

<sup>240</sup> Written Evidence, Q1, Respondent 104



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View

Representative comments

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“What we have struggled with is that our daughter who lived 22 months could legally been terminated just a few hours before she was born, yet a non-disabled child can only be terminated up to 24 weeks. This point is independent of one’s overarching view of the rights and wrongs of the abortion law, but pertains to the rights of a disabled child. Once our daughter was born her rights were no different to that of child without disability, however just hours previously her rights were non-existent compared to that of a child without disability.”<sup>241</sup>

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Affects wider society attitudes towards disability negatively

It is hard to see how Ground E contributes to a “positive and welcoming atmosphere” for people with disabilities.<sup>242</sup>

Views were expressed to the Commission such as:

- “why were you born?”<sup>243</sup>
  - a “disabled life is not worth living” whether at birth or if a disability develops later;<sup>244</sup>
  - does not value individuals with disabilities.<sup>245</sup>
  - death is preferable to life with a disability;<sup>246</sup>
  - disabled people are inferior and less worthy;<sup>247</sup>
  - disabled children do not have the right to be born;<sup>248</sup>
  - treats them as second class citizens;<sup>249</sup>
  - lives that could have been “avoided.”<sup>250</sup>
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<sup>241</sup> Written Evidence, Q1, Respondent 146

<sup>242</sup> Written Evidence, Q5, LIFE

<sup>243</sup> Lucy McLynn, Oral Evidence Session 2, page 59

<sup>244</sup> Dr Kevin Fitzpatrick, Oral Evidence Session 2, page 2; Written Evidence Q3, Respondent 2,

<sup>245</sup> Written Evidence, Q3, Respondent 2

<sup>246</sup> Written Evidence, Q5, Alison Davis, No Less Human

<sup>247</sup> Written Evidence, Q1, Respondent 12

<sup>248</sup> Written Evidence, Q2, Respondent 18

<sup>249</sup> Written Evidence, Q1, Respondent 9

<sup>250</sup> Written Evidence, Q6, Respondent 143

View	Representative comments
At odds with the spirit of the Paralympics <sup>251</sup>	The Act as it stands assumes a disabled life will be less worthy than an able life and yet we saw in the 2012 Paralympics disabled people competing to high standard showing with care disabilities can be substantially overcome. <sup>252</sup>  We should not value a life simply for its function and ability. The Paralympics of 2012 served as a reminder that those with disability and often unvalued can achieve amazing things. <sup>253</sup>
In conflict with traditional medical practice	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. <sup>254</sup>  Termination should not be seen as a treatment option. <sup>255</sup>  It overlooks the fact that the unborn child is a much the doctor's patient as is the mother. <sup>256</sup>
Could be considered a cost-cutting exercise <sup>257</sup>	"...of even greater concern is the possibility that Ground E might be used by some to support arguments for viewing children born with disability as representing an avoidable financial drain on resources." <sup>258</sup>  "Ground E is especially dangerous in an age of squeezed healthcare budgets. Good care for disabled infants is expensive; we must be extremely careful not to allow abortion to become a cost-cutting measure, or an excuse for running down or neglecting essential services for those with disabilities." <sup>259</sup>  "As use of health care resources is under increasing scrutiny [pressure to have an abortion] is likely to increase and places a negative societal value on people living with a disability and implies that it is preferable to prevent them being born." <sup>260</sup>

<sup>251</sup> Written Evidence, Q1, Respondent 18. Similar comment made in Written Evidence, Q5, Respondent 145

<sup>252</sup> Written Evidence, Q1, Respondent 36

<sup>253</sup> Written Evidence, Q10, Respondent 173

<sup>254</sup> Written Evidence, Q1, Christian Medical Fellowship and Written Evidence, Q1, Dr John Etherton

<sup>255</sup> Written Evidence, Q1, LIFE. Similar comment made by Down Research Foundation UK

<sup>256</sup> A point made by LIFE and Written Evidence, Introduction, Respondent 214

<sup>257</sup> See also Ukip candidate suspended over 'compulsory abortion' manifesto, 18 December 2012 <http://www.itv.com/news/2012-12-18/ukip-candidate-suspended-over-compulsory-abortion-manifesto/>  
Councillor considers resignation over disabled comment, 27 February 2013 <http://www.bbc.co.uk/news/uk-england-cornwall-21594109>

<sup>258</sup> Written Evidence, Q5, Church of England

<sup>259</sup> Written Evidence, Q1, LIFE

<sup>260</sup> Written Evidence, Q5, Respondent 30



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View	Representative comments
Harms parental choice as much as it facilitates it	The lack of social assistance provided for the disabled makes it increasingly difficult to make a free choice when a fetal disability is diagnosed. <sup>261</sup>
Element of eugenics <sup>262</sup>	Ground E reflects to me the spectre of eugenics and the worrying trend in society to only value the perfect and beautiful, the 'useful' and productive. <sup>263</sup>  "It has been hypothesised that when the State (and therefore by extension the NHS) funds a screening programme that selects for fetal anomalies there is a risk that this may be viewed as eugenics, or that the social acceptance of people with disabilities is diminished leading to substandard health care of affected children." <sup>264</sup>  Has implications beyond abortion and informs the policy and practice of pre-implantation genetic diagnosis (PGD). <sup>265</sup>

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**88. Others argued that Ground E is not discriminatory but is needed for parents and should be retained as it is.**<sup>266</sup>

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<sup>261</sup> Dr Sheelagh McGuinness, Q5. A similar point was made in Written Evidence, Q4, Christian Medical Fellowship

<sup>262</sup> Written evidence, Q17, Respondent 7; Julian Savulescu, *Journal of Medical Ethics*, Op Cit; Written Evidence, Q2, Alison Davis, No Less Human

<sup>263</sup> Written Evidence, Q17, Respondent 18

<sup>264</sup> Ritchie K, Boynton J, Bradbury I, Foster L, Iqbal K, Kohli H, Love C, Penney G, Quinn S, Reid M, Slattery J, Wright D, 2004, *Routine ultrasound scanning before 24 weeks of pregnancy*. Health Technology Assessment Report 5. Glasgow: NHS Quality Improvement Scotland

<sup>265</sup> Written Evidence, Q5, Dr Sheelagh McGuinness and Written Evidence, Q4, Christian Medical Fellowship

<sup>266</sup> Including RCN, The Society and College of Radiographers, Reproductive Health Matters Journal, Genetic Alliance UK, FPA and Brook, The Royal College of Obstetricians and Gynaecologists (RCOG) and the British Maternal and Fetal Medicine Society (BMFMS), the BMA

View	Representative comments
Right and not discriminatory	<p>Clause E is not about discrimination against disability...when applied properly, it is robust and fair...which reflects a considerable amount of thought, ethical debate and compassion".<sup>267</sup></p> <p>It works well in exceptional circumstances and as intended. <sup>268</sup></p> <p>In our view, Ground E is always invoked with great care and concern. It is not a light or easy option for women or healthcare professionals.<sup>269</sup></p> <p>"it would be indefensibly cruel to compel a woman, knowingly and unwillingly, to carry a severely impaired fetus to term and to give birth, only for her to then have to watch her child suffer and perhaps die prematurely."  <sup>270 271</sup></p>
Does not affect wider society attitudes towards disability	<p>The decision of parents to terminate a pregnancy is so personal<sup>272</sup> and some parents do choose to continue with their pregnancy.<sup>273</sup></p> <p>Offering termination of pregnancy for fetal disability is not "any reflection on the disabled". <sup>274</sup></p> <p>"I do not believe that a woman who may have terminated a pregnancy for spina bifida, let's say, will go on to discriminate against a person in a wheelchair as a result of a similar condition. It is childish to suggest that the choices we make as individuals about our own lives, are reflected in society as a whole."<sup>275</sup></p> <p>"The majority of people are not aware of the existence of Ground E. Societal attitudes towards disability are influenced by other factors, lack of facilities, support and cost."<sup>276</sup></p>

<sup>267</sup> Written Evidence, Q1 and Q4, Dr Lorin Lakasing. Similar comment made by Ann Furedi, Oral Evidence Session 4, page 9

<sup>268</sup> Written Evidence, Q3, Professor Peter Soothill

<sup>269</sup> Written Evidence, Q3, The Society and College of Radiographers

<sup>270</sup> Written Evidence, Q2, Professor Stephen Wilkinson. Written Evidence, Q1 and Q4, FPA and Brook said such a scenario would be "inhumane". "Inhumane" also used in a paper produced by the BMA and others in 1987, referred to in Written Evidence, Q2, BMA. Similar point made in Written Evidence, Q2, Respondent 267

<sup>271</sup> Note that the opposite experience is reported in Section 4 of this report.

<sup>272</sup> Jane Fisher, Oral Evidence Session 1, page 6; Written Evidence, Q6, Respondent 25; Written Evidence, Q5, Respondent 225

<sup>273</sup> Written Evidence, Q6, Dr Lorin Lakasing; Written Evidence, Q6, Respondent 225

<sup>274</sup> Professor Lyn Chitty, Oral Evidence Session 4, page 22

<sup>275</sup> Written Evidence, Q6, Dr Lorin Lakasing

<sup>276</sup> Written Evidence, Q5, Respondent 257. Similar comment made in Written Evidence, Q5, Petals



View	Representative comments
	<p>"The woman's choice does not discriminate against disabled people. In addition the fetus has different rights by law before birth compared with after birth."<sup>277</sup></p> <p>"It is scurrilous to imply that women choosing to end a pregnancy in these circumstances are in any way discriminatory in their attitudes or that their very personal decision in any way causes, or exacerbates, discrimination against disabled people... There is no evidence that removing the rights of one section of the community (pregnant women) would increase the rights of another (disabled people)."<sup>278</sup></p> <p>"...given the very small number of abortions which take place after 24 weeks, this is not a relevant consideration here"<sup>279</sup></p>
Solely a decision for parents <sup>280</sup> and supports patient autonomy <sup>281</sup>	<p>The decision should rest with the mother as she tends to be the principal carer.<sup>282</sup></p> <p>What may not be "serious" to one family may be to another.<sup>283</sup></p> <p>"...a woman's choice to have an abortion is made with regard to personal circumstance. It is not a blanket rejection of a particular fetal abnormality or genetic condition..."<sup>284</sup></p>
Some abnormalities are not detected until late in pregnancy <sup>285</sup>	<p>"until we have a system where we can give families diagnoses earlier, that ground E is helpful in a very, very small number of patients."<sup>286</sup></p> <p>Abnormalities present late in pregnancy and particularly some of the serious ones, eg. brain anomaly.<sup>287</sup></p> <p>Some parents do not come forward for screening until after 24 weeks. These are generally more disadvantaged women.<sup>288</sup></p>

<sup>277</sup> Written Evidence, Q4, Pranav Pandya. A similar point was made in Written Evidence, Q4, The Society and College of Radiographers

<sup>278</sup> Written Evidence, Q4 and Q7, Reproductive Matters Journal. Similar comment made by Respondent 213 in Letter, page 1

<sup>279</sup> Written Evidence, Q4, Professor Stephen Wilkinson

<sup>280</sup> Jane Fisher, Oral Evidence Session 1, pages 5 and 8-9

<sup>281</sup> Written Evidence, Q2, Reproductive Health Matters Journal

<sup>282</sup> Janet Carr, Oral Evidence Session 1, page 38

<sup>283</sup> Written Evidence, Q2, Professor Stephen Wilkinson

<sup>284</sup> Written Evidence, Q3, Genetic Alliance UK

<sup>285</sup> Two parents reported to the Commission their experiences of receiving a diagnosis at 32 weeks and 35 weeks. A family support practitioner working at a children's hospice in England, reports a diagnosis at 36 weeks, Letter, Respondent 221

<sup>286</sup> Jay Jayamohan, Oral Evidence Session 3, page 28

<sup>287</sup> Professor Lyn Chitty, Oral Evidence Session 4, page 21. Written Evidence, Q2, BMA

<sup>288</sup> Written Evidence, Q1, Pranav Pandya. Written Evidence, Q2, BMA

View	Representative comments
Gives parents time and choices <sup>289</sup>	<p data-bbox="509 367 1442 546">“...It is about choices relating to ability to provide care and the pain and suffering of individuals, including the unborn child...allows time for parents to adjust to a diagnosis and prognosis and affords them the opportunity to do research, visit support groups, see specialist in other areas etc. all of which are essential prior to a decision of such gravity.”<sup>290</sup></p> <p data-bbox="509 568 1422 712">Lowering the limit to 24 weeks might push some people into making a decision before they have got all the facts.<sup>291</sup> “...The current law is much better in that it allows desperately difficult decisions to have suitably deep consideration and be taken without a rush.”<sup>292</sup></p> <p data-bbox="509 734 1398 837">“Please understand that finding out that your unborn baby has a serious disability is one of the hardest things that a parent can hear. Please don’t make it any harder by taking away our right to choose.”<sup>293</sup></p> <p data-bbox="509 860 1422 1039">Allows couples with genetic conditions to try for a healthy pregnancy in the knowledge that Ground E provides them with a safety net in the event of an adverse diagnosis. Many couples in this situation would not feel they could try for a healthy pregnancy at all if they did not have the option of abortion.<sup>294</sup></p>

Medicine cannot fix every disability

The law recognises that some parents think it is kinder to let their baby go early rather than suffer and see this option as “a last resort”<sup>295</sup>

There should not be naivety about the conditions that babies can have which would lead them to suffer greatly.<sup>296</sup>

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<sup>289</sup> The point was made that this argument focuses on the mother’s perspective and still justifies and supports discrimination against disabled babies. Written Evidence, Q2, Christian Medical Fellowship and Written Evidence, Q2, Daniel Kinning

<sup>290</sup> Written Evidence, Q4, Q1 and Q4, Dr Lorin Lakasing. Similar comments made by Ann Furedi, Oral Evidence Session 4, pages 9-10 and Professor Lyn Chitty, Oral Evidence Session 4, page 21, Written Evidence, Q1, Respondent 257

<sup>291</sup> Patricia Boyd, Oral Evidence Session 3, page 74; Written Evidence, Q4, Respondent 257; Written Evidence, Q1, Pranav Pandya; Written Evidence, Q7, Dr Tessa Homfray; Letter, Together for Short Lives, pages 1 and 3

<sup>292</sup> Written Evidence, Q3, Professor Peter Soothill

<sup>293</sup> Respondent 41, anonymous letter from mother who had an abortion at 34 weeks. Forwarded by Jane Fisher, CEO, ARC. Similar point made in Written Evidence, Q14, Respondent 267

<sup>294</sup> Written Evidence, Q2, Reproductive Health Matters Journal. Also supported by FPA and Brook in Written Evidence, Q2

<sup>295</sup> Written Evidence, Q2 and Q17, Respondent 142

<sup>296</sup> Written Evidence, Q4, Respondent 142



View	Representative comments
Can be in the best interest of the child or children already in the family	<p>A child may be placed for adoption and spend the rest of his or her life in the care system.<sup>297</sup></p> <p>There may be lack of care for child after their parents die; and it prevents suffering of children after they are born. Siblings may also suffer because they do not get as much attention as their sick sibling.<sup>298</sup></p> <p>If Ground E were removed, it could be challenged under the Human Rights Act on the grounds of a right to family life.<sup>299</sup></p>
Saves resources	<p>For families: Homes will need to be adjusted to care for children.<sup>300</sup></p> <p>For taxpayers: Parents will be full-time carers and not be able to work, therefore will be claiming benefits; Schools for children with special needs are already stretched; Resources for equipment like wheelchairs are over-subscribed; Significant costs on limited NHS budget.<sup>301</sup></p>

## Proposals Put to the Commission on Amending the Law

89. Some argued that the law around Ground E **should be amended**. The following section sets out the proposals put to the Commission.

### *Completely New Models*

90. There were **some new legal models** proposed to the Commission on the grounds of:

#### *Fetal interests:*

- frame the wording of section 1(1)(d) to permit abortion only when the presence of a 'severe abnormality incompatible

with any significant period of survival' or any quality of life is identified, with a test based around if parents would withdraw treatment at birth drawn from guidance of the Royal College of Paediatrics and Child Health.<sup>302</sup> Guidance could provide more specific examples of criteria which count in favour and against providing an abortion in certain circumstances.<sup>303</sup>

- allow ground E for lethal or severe abnormalities but questions of how to treat a viable fetus arise and could logically lead to changes in practice around abortion more generally or treatment of disabled new-borns.<sup>304</sup>
- consider the ethical concept of the fetus as

<sup>297</sup> Letter, Respondent 6. Figures on disabled children in care were quoted by Respondent 142 in Q6 of her Written Evidence.

<sup>298</sup> Letter, Respondent 6

<sup>299</sup> Written Evidence, Q14, Respondent 257

<sup>300</sup> Letter, Respondent 6

<sup>301</sup> Letter, Respondent 6

<sup>302</sup> McGuinness argues that this test would be no more problematic than the current wording but would allow for a more specific assessment of each child

<sup>303</sup> Written Evidence, Q1, Q7 and Q10, Dr Sheelagh McGuinness and *Medical Law Review*, *Op Cit*

<sup>304</sup> Julian Savulescu, *Journal of Medical Ethics*, *Op Cit*

a patient when 'there exist forms of clinical management that are reliably expected to result in a greater balance of good over clinical harms for that human being'. It would confer a duty of care without necessarily needing to confer personhood on the unborn child.<sup>305</sup>

*Parental Interests:*

- amend the Abortion Act to remove the time limit in section 1(1)(a); or allow women to make the decision for themselves without external scrutiny which would mean amending the Abortion Act to an 'any reason' based model of regulation.<sup>306</sup>
- Have a maternal/family interest's model as the standard by which to judge if an abortion should take place. Adopting such a framework would liberalise the approach to late terminations.<sup>307</sup>

*Recognising the Viability of a Fetus*

91. Professor Paton and the Anscombe Bioethics Centre proposed that the link between the Abortion Act and the Infant Life (Preservation) Act should be re-established. This would have the effect of not allowing doctors to deliberately kill any baby after viability.<sup>308</sup>

92. Rachel Hurst, CBE, previously Director of Disability Awareness in Action, recommended that the law should recognise that a viable fetus is a human being since if a child was born at that gestational age the birth would be registered and the child would obtain all the rights of a person. She argues that if the UK is to fulfil its obligations under the Convention on the Rights of Persons with Disabilities, Ground E should be deleted from the Abortion Act.<sup>309</sup>

*Change in Time Limits*

93. There were strong views on the legality of performing abortions up to birth. It was described as:

- "particularly scandalous"<sup>310</sup> and abhorrent".<sup>311</sup>
- equivalent to infanticide in late pregnancy.<sup>312</sup>
- One respondent said, "That abortions can be performed up to term under ground E is extraordinary. In the case of twins where one has a disability and the other not, abortion by lethal injection would be carried out just prior to delivery of the well twin. The difference between this and infanticide – seconds – from an ethical perspective we would suggest there is no difference."<sup>313</sup>

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<sup>305</sup> Written Evidence, Q7, Professor Gordon Stirrat referencing Chervenak & McCullough, *J. Med Ethics* (2012). Doi.1136/medethics-2012-100491

<sup>306</sup> Written Evidence, Q1, Q7 and Q10, Dr Sheelagh McGuinness and *Medical Law Review*, *Op Cit*

<sup>307</sup> Julian Savulescu, *Journal of Medical Ethics*, *Op Cit*. A similar argument was put forward in Written Evidence, Q4, Professor Stephen Wilkinson who also says that if this is the assumption behind Ground E then it is hard to argue that it sends out an unacceptably negative message about people with disabilities.

<sup>308</sup> Written Evidence, Q10, Professor David Paton, Written Evidence, Q7, Anscombe Bioethics Centre

<sup>309</sup> Rachel Hurst, CBE, Oral Evidence Session 4, pages 25 and 41 and Written Evidence, Q1

<sup>310</sup> Written Evidence, Q1, Professor David Paton

<sup>311</sup> Written Evidence, Q1, Respondent 21

<sup>312</sup> Written Evidence, Q3, Respondent 16

<sup>313</sup> Written Evidence, Q1, Respondent 173



94. Some argued that if Ground E were to be maintained, the limit for abortions on the ground for disability **should be the same as any other gestational time limit so that there is equal treatment for babies with a disability and those without.**<sup>314</sup> Ann Furedi said if there is concern about *“inequity, by far the best thing to do would be to remove the time limit altogether and to allow all abortions to be taking place at the time that is appropriate for the woman... [there is] no evidence to suggest that a greater number of abortions would be taking place later in pregnancy if the time limit were removed.”*<sup>315</sup> However even if the time limit were equal, it *“would still be discriminatory by singling out the disabled fetus for termination.”*<sup>316</sup> Another said there may need to be a transition towards 24 weeks as expertise and resources become more available.<sup>317</sup> Together for Short Lives said that if the law were changed from the current gestational limit of birth, there would be a larger number of babies born with disabilities and *“that the considerable financial impact of this needs to be acknowledged from the outset.”*<sup>318</sup>

#### *Differentials between disabilities*

95. There were some proposals for differentiating between disabilities within the law:

- An equal gestation limit for terminations under Ground E but allow later terminations for fetal abnormalities only if it were beyond reasonable doubt that the child would have extremely severe developmental problems. A committee structure should be instituted to examine such requests.<sup>319</sup>
- Recognition within the time limits that some disabilities are treatable and others are not but even with a differential, the upper limit should not be birth.<sup>320</sup>
- *“Third trimester abortions should be restricted to pregnancies complicated by fetal anomalies in which either death or absence of cognitive developmental capacity is certain or near certain. Only in these cases should compassion for the pregnant woman be decisive. In all other cases, integrity requires that doctors refuse requests for third trimester abortion.”*<sup>321</sup>
- 'Disability' should mean that a condition is diagnosed which is incompatible with life e.g. anencephalic infant.<sup>322</sup>
- it should be certain that the fetus would, if born, have a severe handicap. The certainty should relate to a handicap so severe that it would put intolerable strain on the family or society.<sup>323</sup>

<sup>314</sup> Written evidence, Q7 and Q10, Respondent 12; Joanna Jepson, Oral Evidence Session 3, page 5; Professor John Wyatt, Oral Evidence Session 4, page 70; John Pollard, Oral Evidence Session 4, page 79; Written Evidence, Q7, Respondent 145; Written Evidence, Q1 & Q7, Respondent 13

<sup>315</sup> Ann Furedi, Oral Evidence Session 4, page 10

<sup>316</sup> Written Evidence, Q7, Daniel Kinning

<sup>317</sup> Lynda Brook, Oral Evidence Session 3, page 60

<sup>318</sup> Letter, Together for Short Lives, page 3

<sup>319</sup> Professor Stuart Campbell, Letter, page 3

<sup>320</sup> Dr Hilary Cass, Oral Evidence Session 3, page 24

<sup>321</sup> Written Evidence, Q7, Professor Gordon Stirrat referencing Chervenak, McCullough & Campbell BJOG(1999) 106; 293-296

<sup>322</sup> Letter, Respondent 65

<sup>323</sup> Written Evidence, Q7, Respondent 90

*Information and Reflection Period within the Law*

96. Dr Byron C. Calhoun suggested that there should be an addition to the law to offer families either adoption for a child with non-lethal anomalies and/or perinatal hospice with palliative care for a child with lethal anomalies.<sup>324</sup> Recommendation 5 proposes that parents should be given information about hospice care for newborns.
97. The Commission was advised on several occasions that there should be a mandatory “thinking time” of at least a week for parents to consider all the options presented to them.<sup>325</sup> The Christian Medical Fellowship said, “*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.*”<sup>326</sup>

*Screening and Abortion for Disability*

98. There were several proposals for amending the law on pre-natal screening:
- the Abortion Act should be amended to create an offence for any person to offer or promote a screening test for the purpose of detecting disability with a view to aborting

a child that is found to be disabled, or to suggest or encourage an abortion of a child thought to be disabled.<sup>327 328</sup>

- there should be legislation on the prohibition on the termination of disabled fetuses with regulations drafted requiring doctors to strictly document the presence of disability at the screening stage in order to distinguish abortions under section 1(1)(a). Disciplinary sanctions should be strengthened for doctors who fail to comply with such regulations.<sup>329</sup>

*To Increase Accountability and Transparency*

99. There were several proposals on increasing accountability and transparency of data collection:

*Changes in Procedure for Form HSA4*

- a third signatory should be required for section 1(1)(d), e.g. a counsellor who can ensure that the family have had the correct information and support to make an informed decision and can confirm the abortion meets the criteria. This would meet one of the arguments of the disabled rights groups that the medical profession is biased and would make this section fairer.<sup>330</sup>
- a third party separate from the two doctors who signed the abortion forms should be available to ensure that the correct reason for the abortion was recorded, especially for

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<sup>324</sup> Written Evidence, Q10, Dr Byron C. Calhoun

<sup>325</sup> Professor Sue Buckley, Oral Evidence Session 2, page 49 and Professor Patricia Casey, Oral Evidence Session 4, pages 54-5. A two week time period was suggested in Written Evidence, Q12, Eileen Maher

<sup>326</sup> Written Evidence, Q12, Christian Medical Fellowship

<sup>327</sup> Letter, SPUC, page 2

<sup>328</sup> Written Evidence, Q17, LIFE

<sup>329</sup> Written Evidence, Q7, Daniel Kinning

<sup>330</sup> Written Evidence, Q7 and Q10, Respondent 257



- abortions after 24 weeks of pregnancy.<sup>331</sup>
- the certifying professional would need to certify that accurate, medically-reviewed information about the diagnosed condition was provided to the parents along with the contact information of a local or national support organisation for the diagnosed condition as well as referral to a genetic counsellor.<sup>332</sup>

#### *Inquests and Post-Mortems*

- there should be a report to the Coroner for all late term abortions to confirm the reasons for such an abortion, which would be *“put in place in order to ensure that things are being done according to the law as they ought to be done.”* This would require some changes in the coroner’s legislation as the coroner’s remit does not currently cover still births.<sup>333</sup>
- there should be post mortems for all abortions after 24 weeks. Professor Stuart Campbell said, *“I am strongly of the opinion that it should be performed in all cases. It is necessary to satisfy the parents that a correct diagnosis was made and for audit by the fetal medicine team who have to ensure that they maintain standards.”*<sup>334</sup> Jay Jayamohan said post-mortems would improve future diagnosis. He told the Committee that he asks women who have a late abortion if there can be *“a postmortem on your baby, because, until we get that information, we have no idea of the accuracy of what we’re telling you? We look at the scan and we think*

*your baby will have this, this and this. We have to make a decision based on what we’ve got at the moment. But, in 20 years’ time, if I want to improve the information I’m giving to a woman, I need your help now.*<sup>335</sup>

## Conclusion

100. It is clear that very strong and polarised views on the operation of section 1(1)(d) remain. The passing of the Equality Act 2010 and the recent Paralympics highlight the inconsistency with which society as a whole approaches fetal disability. These cases, although small in number, are extremely difficult for all concerned. Given the inconsistencies in practice and data collection that our report has highlighted, we recommend increasing accountability and transparency.

### Recommendation 15

**A third signatory should sign the abortion form to confirm that the family has had the correct information and support to make an informed decision and can confirm the abortion meets the criteria under section 1(1)(d).**

### Recommendation 16

**If the time limit for abortions on the grounds of disability remains to birth, a post mortem should be held for abortions conducted after 24 weeks to ensure correct operation of the Act and to improve future medical diagnosis**

<sup>331</sup> Beezy Marsh, Oral Evidence Session 2, page 24

<sup>332</sup> Written Evidence, Q10, Respondent 143. This would comport with professional guidelines by RCOG, SOGC, and ACOG on how to deliver a diagnosis of Down syndrome, but would apply equally to any diagnosis.

<sup>333</sup> John Pollard, Oral Evidence Session 4, pages 73-4, 76, 78-9. Mr Pollard has held about twelve inquests where the baby has been born and shown signs of life and has confirmed they all met the requirements of the law. Note that Mr Pollard said that he thought not every case would need a post mortem.

<sup>334</sup> Professor Stuart Campbell, Letter, page 2. Similar comment Written Evidence, Q9, ProLife Alliance.

<sup>335</sup> Jay Jayamohan, Oral Evidence Session 3, page 33. Similar comment from Patricia Boyd, Oral Evidence Session 3, page 73

## 5. The Conclusion of the Commission

101. This Report gives a summary of the evidence we have heard from individuals who have experienced pregnancies with disabled babies, from individuals who are disabled, professionals working with parents before and after birth, and from the general public. A wide range of views and experiences has been put to the Commission.
102. We are very concerned to hear that so many parents feel they are pushed towards an abortion without due consideration of the other options and that those parents who do decide to keep their child face discrimination. **All parents expecting a child with a fetal disability need balanced information about what life would be like with a disabled child, time to consider their decision and comprehensive support from the medical profession whatever their decision should be.**
103. The Commission has considered the proposals for changes in the law put to us and the case for not making any changes at all. The vast majority of those who gave evidence felt strongly that the current provision of the Abortion Act 1967 that allows abortion up to birth on the grounds of the child's disability, while not allowing a similar limit for babies without disability is **discrimination and that this needs reviewing in light of the changes to societal attitudes to disability, and the passing of the Equality Act 2010.**
104. There were particularly strong feelings about the **treatment of babies beyond the age of viability of 24 weeks** who would be intensively cared for if they were born prematurely, but who are subject to feticide at the same gestational limit because they have an identified fetal disability. Given the historical perspective that a fetus is increasingly protected as it gets closer to birth, the ability to have an abortion after viability seems contrary to the protections that were put in place in the **Infant Life (Preservation) Act 1929** "... *with intent to destroy the life of a child capable of being born alive, by any wilful act causes a child to die before it has an existence independent of its mother...*".
105. The Commission has noted that since the last review of the Abortion Act 1967 by the Science and Technology Select Committee in 2007<sup>336</sup> the Equality Act 2010 has passed into domestic law and the UK Government has ratified the 2006 UN Convention on the Rights of Persons with Disabilities (UNCPRD). Both of these have given the Commission cause to reflect on current practice. We have noted that the Committee on the Rights of Persons with Disabilities, in one of its first concluding observations on a state report, recommended that Spain "**abolish the distinction made in the Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability.**"<sup>337</sup>
106. Given the changes in domestic and international law and societal attitudes in recent years which are influencing views on disability, **we recommend that Parliament reviews the question of allowing abortion on the grounds of disability and considers at the very least the two main options** for removing those elements which a majority of witnesses believe are discriminatory – that is either reducing the upper time limit for abortions on

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<sup>336</sup> Science and Technology Select Committee, *Op Cit*

<sup>337</sup> See footnote 33



the grounds of disability from birth to make it equal to the upper limit for able bodied babies or repealing Section 1(1)(d) altogether.

107. We recognise that there will be strong views about any change, especially from the medical bodies. The main concerns about any change are as follows:

- Allowing parents time to make their decision. We recognise this is a practical pressure. Most mothers have a scan at 20 weeks. The Commission has recommended improved practices for provision of information and support for parents which should ensure parents are given balanced information to weigh all the options.
- The possibility of an increased number of abortions before 24 weeks because parents feel they do not have time or certainty. The Commission has addressed the need for information and support in its recommendations after the discovery of a fetal disability and this should ensure parents feel more supported which could lead to a decrease in abortions. We are also aware that new pre-natal testing will be providing information to parents earlier than has been the case.
- In the few cases where abnormalities are diagnosed after 24 weeks, and parents

would need to carry a child to term. The Commission recognises that there will be a few cases every year where this happens – some of the evidence submitted to us came from parents in this situation. We do not detract from the difficulties parents face if they hear this news late in their pregnancy. The Commission has recommended that there should be increased support for families who are expecting a child with a fetal disability both before and after birth and that skilled palliative care after birth should be made available where needed.

108. The Commission recommends this Report to Parliament.

#### **Recommendation 17**

**We recommend that Parliament reviews the question of allowing abortion on the grounds of disability and in particular how the law applies to a fetus beyond the age of viability (currently 24 weeks). Parliament should consider at the very least the two main options for removing those elements which a majority of witnesses believe are discriminatory – that is either reducing the upper time limit for abortions on the grounds of disability from birth to make it equal to the upper limit for able bodied babies or repealing Section 1(1)(d) altogether.**

# Appendix A:

## Care for Adults with Disabilities

1. There is also concern that Ground E supports an **attitude that older disabled people are less worthy of care** and there is less tolerance of disability for those who become disabled later in life.<sup>338</sup> *“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.”*<sup>339</sup> Saving Downs said Ground E *“impacts on the lives of all disabled people, because it reinforces negative stereotypes about the worth and value of a disabled person... Ground E reinforces a societal view that a disability is something to be avoided, rather than something to be recognised, accepted and supported as a natural part of human diversity.”*<sup>340</sup>
2. The Commission was told that quite a few disabled people have reported that they have felt they have been put under real compulsion to have fetal testing or even an abortion – on the grounds that they are not fit to have children; particularly people with learning difficulties.<sup>341</sup> One respondent said, *“At a regular clinic appointment that I attended with my adult disabled daughter, the consultant explained to her that as the genetic basis of her disability is known, she would be able to have an abortion of any fetus who were affected by her disability, or take part in pre-implantation diagnosis, and dispose of any embryos, who carried her faulty gene. He did not seem aware of how tactless he was and did not consider that she may find it upsetting that the doctor who should be treating her disability and researching for a cure, was more excited by the fact that in the future there would be no reason for people like her to exist.”*<sup>342</sup>
3. The Commission notes that a recent Inquiry into the premature deaths of people born with learning disabilities highlighted some serious shortcomings in the provision of equal healthcare for people living with a disability.<sup>343</sup><sup>344</sup> This is not a new concern. Fifteen years ago Sheila Hollins and colleagues reported that the risk of people with learning disabilities dying before the age of 50 was 58 times higher than in England and Wales generally.<sup>345</sup> Over the following years, the Disability Rights Commission and Mencap have produced reports highlighting the unequal healthcare

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<sup>338</sup> Written Evidence, Q6, Dr Respondent 13; Written Evidence, Q6, Respondent 18

<sup>339</sup> Written Evidence, Q6, Christian Medical Fellowship

<sup>340</sup> Written Evidence, Q6, Mike Sullivan, Saving Downs

<sup>341</sup> Written Evidence, Q13, Rachel Hurst CBE

<sup>342</sup> Written Evidence, Q6, Respondent 164

<sup>343</sup> Confidential Inquiry into Premature Deaths of People With Learning Disabilities (CIPOLD), 2013, Pauline Heslop, Peter Blair, Peter Fleming, Matt Hoghton, Anna Marriott, Lesley Russ

<sup>344</sup> A similar point was made in Dr Ian Hall's evidence in Oral Evidence Session 3, page 66 and in Written Evidence, Q14, Respondent 86 who cited examples of discrimination against his disabled son.

<sup>345</sup> Hollins S, Attard MT, von Fraunhofer N, McGuigan S and Sedgwick P (1998) Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental medicine and child neurology*, 40(1): 50–56. Referenced on page 10 of CIPOLD report.



that people with learning disabilities often received. In 2007, Mencap brought to wide public attention what was considered to be 'institutional discrimination' by healthcare services towards people with learning disabilities and their families and carers.<sup>346</sup>

4. In 2009 a report by the Parliamentary and Health Service Ombudsman reinforced the urgent need for systemic change within the NHS for people with learning disabilities and considered that the outcomes of its investigation were a "shocking indictment of services which profess to value individuals and to personalise services according to individual need".<sup>347</sup>
5. The 2013 Confidential Inquiry into Premature Deaths of People With Learning Disabilities (CIPOLD) report<sup>348</sup> suggests that part of the cause of the unequal treatment of people with disability lies in:
  - the lack for advocacy for disabled people;
  - a lack of coordination of care across and between the different disease pathways and service providers;
  - poor or non-existent learning disability awareness training for hospital staff; and
  - a lack of awareness of the roles and responsibilities of different professionals and agencies and how they might offer support to people with learning disabilities.
6. The 2013 CIPOLD review of deaths noted the crucial role that hospital based Learning Disability Liaison Nurses (LDLNs) take in facilitating access to healthcare for people with learning disabilities. The Commission has made a recommendation on the role of LDLNs earlier in this report.<sup>349</sup>

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<sup>346</sup> Mencap, *Death by Indifference*, 2007. Referenced on pages 10 and 11 of CIPOLD report.

<sup>347</sup> Parliamentary and Health Service Ombudsman, *Six Lives: The Provision of Public Services to People with Learning Disabilities*. 2009, London: The Stationery Office.

<sup>348</sup> CIPOLD, 2013, *Op Cit*

<sup>349</sup> *Ibid*

# Appendix B: Historical Data on Abortions on Ground E

Department of Health Figures, Table 9, Abortion Statistics England and Wales

All Weeks	2007	2008	2009	2010	2011
Other Nervous System	134	112	130	122	122
Anencephaly	144	172	159	189	193
Spina bifida	117	118	114	123	144
Other malformations of the brain	78	75	93	88	81
Other Congenital Malformations	412	479	519	572	514
Down's Syndrome	437	436	468	482	512
Other Chromosomal Abnormalities	310	303	307	349	378
Other Conditions	307	293	295	365	363
<b>Total</b>	<b>1,939</b>	<b>1,988</b>	<b>2,085</b>	<b>2,290</b>	<b>2,307</b>

After 24 weeks	2007	2008	2009	2010	2011
Other Nervous System	40	21	43	26	20
Anencephaly					3
Spina bifida				12	9
Other malformations of the brain	19	21	24	28	24
Other Congenital Malformations	34	43	43	40	40
Down's Syndrome				10	17
Other Chromosomal Abnormalities*	31	27	18	19	17
Other Conditions	11	12	8	12	14
<b>Total</b>	<b>135</b>	<b>124</b>	<b>136</b>	<b>147</b>	<b>144</b>

\* includes Down's Syndrome for 2007-2009

# Appendix C: List of Witnesses and Written Submissions

## The Inquiry took oral evidence from the following witnesses:

- Hannah Battye, parent
- Dr Patricia A Boyd, Clinical Director of the Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire
- Dr Lynda Brook, Paediatric Palliative Care Consultant, Alder Hey Children's Hospital, Liverpool
- Professor Sue Buckley, Director of Research at the Down Syndrome Education International Organisation and Emeritus Professor of Developmental Disability at the University of Portsmouth
- Janet Carr, clinical psychologist and researcher
- Professor Patricia Casey, Professor of Psychiatry at the Department of Psychiatry, University College Dublin and the Mater Misericordiae University Hospital.
- Dr Hilary Cass, President of the Royal College of Paediatrics and Child Health
- Professor Lyn Chitty, fetal medicine and genetic specialist
- Jane Fisher, CEO, Antenatal Results and Choices (ARC)
- Dr Kevin Fitzpatrick OBE
- Ann Furedi, CEO of the British Pregnancy Advisory Service
- Hayley Goleniowska, parent
- Dr Richard Hain, Consultant and Lead Clinician in Paediatric Palliative Care at the Children's Hospital in Cardiff.
- Dr Ian Hall, Chair of the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists.
- John Horan, Barrister at Cloisters Chambers
- Rachel Hurst CBE, former Director of Disability Awareness in Action
- Mr Jay Jayahoman, Consultant Paediatric Neurosurgeon at the John Radcliffe Hospital, Oxfordshire
- Reverend Joanna Jepson
- Beezy Marsh, journalist
- Lucy McLynn, parent
- Professor Joan Morris, Professor of Medical Statistics at Barts and the London School of Medicine and Dentistry, Queen Mary University of London and Director of the National Down Syndrome Cytogenetic Register
- Sarah Mullen, parent
- Lynn Murray, parent
- John Pollard, Coroner for Greater Manchester South District
- Katy Powell, adult with Down's Syndrome
- Rosanna Preston, CEO Cleft Lip and Palate Association (CLAPA)
- Dr Nicky Prialx, Reader in Law at Cardiff University
- Katyia Rowe, parent
- John Wyatt, Emeritus Professor of Neonatal Paediatrics at University College London and previously Consultant Neonatologist at University College London Hospitals NHS Foundation Trust

## Written Submissions

### The following organisations submitted written evidence to the Inquiry:

Affinity - Gospel Churches in Partnership  
Anscombe Bioethics Centre  
ARC  
BMA  
Bristol Students for Life  
British Academy of Childhood Disability  
CARE  
Catholic Parliamentary Office Scotland  
Christian Concern  
Christian Medical Fellowship  
Church of England  
Down Syndrome Research Foundation UK  
Edinburgh University Life Society  
EUROCAT  
Evangelical Alliance  
Foundation for Life (Salisbury)  
FPA and Brook  
Genetic Alliance UK  
Image & Pregnancy Helpline  
Labour Life Group  
LIFE  
No Less Human  
Oxford Students for Life

Petals (Pregnancy Expectations Trauma And Loss Society)

ProLife Alliance

RCN

RCOG

Reproductive Health Matters Journal

Saving Downs

Scottish Council on Human Bioethics

Society & College of Radiographers

Spina Bifida Association of New Zealand

SPUC

Together for Short Lives

## Summary of Written Evidence

273 individual written responses were submitted to the Commission.

Three individuals/organisations made written and oral submissions.

34 organisations provided written submissions.

239 individuals made written submissions.

213 of the 273 were submitted on the response form. 60 were submitted as letters or emails, some with accompanying articles.

231 of the 273 written submissions said that Ground E was discriminatory.

18 said Ground E was not discriminatory.

24 responses did not specifically answer this question or make a position clear.



**Parliamentary Inquiry into Abortion  
on the Grounds of Disability**

**July 2013**