Invitation to Submit Written Evidence

The terms of reference of the Commission are 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 Abortion Act 1967[1] sets no time limit on when an abortion may take place on the grounds of disability (Ground E). Therefore it is currently legal to terminate a pregnancy up to full-term on the grounds of disability while the upper limit is 24 weeks if there is no disability.

The Equality Act 2010 protects disabled people from discrimination. The Act prohibits discrimination arising from a disability by preventing one person from treating another less favourably because of their disability.

According to Department of Health statistics 2,307 abortions were carried out in 2011 under Abortion Act 1967 Ground E, for disability. [2]

Further details about the Inquiry can be found at: www.abortionanddisability.org

The Inquiry requests responses to this call for written evidence as soon as possible. The deadline for submissions is **5pm** on **Wednesday 6 March 2013**.

If you wish to submit written evidence, please send an electronic copy of your submission to: abortionanddisability@gmail.com

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

The Commission would welcome responses to the following questions. Please continue on a separate page if your answer runs over the box and note there is a limit of **500 words maximum per question**.

We look forward to receiving your submission.

The Commission of Inquiry
January 2013

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[1] As amended by the Human Fertilisation and Embryology Act 1990

[2] https://www.wp.dh.gov.uk/transparency/files/2012/05/Commentary1.pdf

Information about Respondent

Name: Stuart Cowie

Contact details: 1 Mill Street, Leamington Spa, Warks CV31 1ES
stuartcowie@lifecharity.org.uk

Are you responding on behalf of an Organisation or as an Individual? Individual/Organisation (please select)

Name of Organisation: LIFE
Position in Organisation: Head of Education

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

LIFE is a pro-life caring and educational charity. An important part of our work is giving school talks on a range of pro-life issues, but particularly abortion. Although we oppose all direct abortion on principle, we believe that permitting abortion of unborn children with disabilities is a particularly egregious example of the injustice of abortion.

If applicable, please answer the following further questions.

If you are part of an organisation please describe your work in relation to abortion for disability and how often, if at all, you deal with fetal disability. Please include any support you provide to parents or others.

Although we don't directly deal with the issue of fetal disability, LIFE's daughter charity the Zoe's Place Trust does provide respite and hospice care for severely disabled children aged under five: http://www.zoes-place.org.uk/

If you are an individual please describe whether you have any personal knowledge or experience of fetal disability, abortion on the grounds of disability, care for those with a disability or if you have a disability yourself.

Views on the Law, Guidance and Practice

1. What is your view of Ground E of the Abortion Act 1967 (abortion on grounds of disability)?[3]

We believe that this ground is fundamentally wrong and discriminatory, for the simple reason that it treats unborn children who carry some form of disability or impairment differently from those unborn children who do not have such disabilities and impairments.

Raising disabled children is of course difficult, exhausting and sometimes demoralising. It can place a strain on relationships and change family dynamics in unsettling ways. Other children can feel neglected as parents devote large amounts of time to caring for disabled siblings. Yet it is still difficult to see abortion as a truly compassionate response in this situation. Is there perhaps a different model for how to care for disabled children, even those who are severely or terminally ill?

The great danger is that abortion – or post-natal infanticide – of a disabled child is allowed to become a treatment option; that we start to decide that it can be in someone's interest to be killed. This debate is to a very large extent a debate about the kind of culture in which we want to live and the kind of medical culture in which we want doctors to operate. However compelling the case for ending the life of a badly disabled child, there is a very important principle at stake; that we may not intentionally kill. Whatever the law, there will always be hard cases – situations where individuals end up suffering. No-one of course would wish to inflict suffering or to perpetuate suffering unnecessarily. But we need to accept that we cannot respond to suffering by killing the sufferer. The medical imperative must always be to heal, to comfort, and to preserve life.

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[3] Abotion Act 1967, Section 1(1) (d) Ground E: 'there is a substantial risk that if the child were born it would suffer rom such physical or mental abnormalities as to be seriously handicapped'. https://w.wp.dh.gov.uk/transparency/files/2012/05/HSA1-form.pdf

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

The rationale behind this part of the law is that unborn children with disabilities are in some sense less worthy of protection and care than those without such disabilities. That may not have been the intent of those who framed the 1967 Abortion Act and its amending legislation the 1990 Human Fertilisation and Embryology Act, but it is the inescapable conclusion of the internal logic of the provision.

The ostensible justification for using 24 weeks as the upper limit for all other kinds of abortion is that after 24 weeks the child can survivee outside the womb. But as an ethical boundary viability is of very limited use. Viability is a measure of medical skill, not human value.

The choice-based argument – that parents should be able to make the decision whether or not to raise a child with disabilities – presupposes what it purports to prove, i.e. that unborn children do not have an independent right to life, and so begs the question about the humanity of all unborn children.

This is also true of the argument that it is sometimes kinder to end a life that will be terribly painful rather than allow continued esixtence. We do not extend this argument to born people with disabilities, nor should we.

The issue of children in terrible pain is not an easy one, although the uncertainty factor is a key point. It is a very momentous decision indeed – and, we would argue, unethical – to end a child’s life prematurely on the basis that the child’s life may or may not be short and painful.

There are, of course, many conditions where a short, painful life is for all intents and purposes a certainty. So how do we respond to those cases?

Saying that we must always seek to care and nurture rather than end life may sound glib, but it sums up very neatly a well-developed and venerable tradition in medicine that refuses to consider the intentional ending of life as a treatment option. We do not think that human life must always be sustained in every situation at any cost. What we do argue is that doctors should never intentionally end the life of individual babies. There will sometimes be cases where doctors decide in good faith that it is time to stop a treatment that has become futile and disproportionate and to allow a child to pass away naturally, but there is a crucial difference between this and taking active steps to actually end a child’s life. It is also worth noting that British palliative care is among the best in the world and that only a tiny number of patients will have pain that cannot be effectively managed.

We would also hope for the caring imperative to stimulate the development of new methods of pain relief, new ways of making patients comfortable rather than simply ending lives.

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

In 2011, 2307 abortions were carried out under this ground. Abortions carried out on disabled children represent just over 1% of the total number of abortions carried out in the UK in 2011.

The right to life is quite literally the foundation of all other rights. There is of course another debate to be had about abortion in general, but abortion for disability raises some particularly pressing issues to do with equality, diversity and discrimination. As the Disability Rights Commission noted some years ago, section 1(1)(d) of the Abortion Act

"is offensive to many people…it reinforces negative stereotypes of disability; and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability…is incompatible with valuing disability and non-disability equally."

http://www.bbc.co.uk/ethics/abortion/philosophical/disability.shtml

The principle that people should not be discriminated against unfairly is held dear by many in our society and has been enshrined in law in various ways over the last few decades. The womb is one of the few places where disabled people are yet to achieve equality (one of the others, of course, is the IVF laboratory, where embryos that carry certain medical conditions are routinely discarded or destroyed).

The disabled unborn individuals who are aborted are not merely statistics – they are unique human individuals whose only opportunity to live has been denied. As one academic has written, "each life is not an abstraction, it is a personal reality, one that exists only for one particular unborn human who will no longer be if abortion is chosen".

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

YES

Please give reasons for your answer

As noted above, the law treats human beings with disability differently from those without a disability. That is a prima facie example of unjust discrimination. It would not appear that any attempt has been made to assess the compatibility of the 1967 Act (as amended in 1990) with equality legislation. Despite the uncertain future of the Equality Impact Assessment under the current government, EIAs have been a useful tool for looking at how particular minority groups are affected by the law. The case of abortion for disability would seem to be an obvious example where an EIA ought to be used, given the seriousness of the decision being made.

The great danger is that abortion – or post-natal infanticide – of a disabled child is allowed to become a treatment option; we start to decide that it can be in someone's interest to be killed. This debate is to a very large extent a debate about the kind of culture in which we want to live and the kind of medical culture in which we want doctors to operate. However compelling the case for ending the life of a badly disabled child, there is a very important principle at stake; that we may not intentionally kill. Whatever the law, there will always be hard cases – situations where individuals end up suffering. No-one of course would wish to inflict suffering or to perpetuate suffering unnecessarily. But we need to accept that we cannot respond to suffering by killing the sufferer. The medical imperative must always be to heal, to comfort, and to preserve life.

Taking action against the abortion of disabled unborn children, gives us a chance to proclaim a very important, very profound message about the way we respond to suffering, to imperfection, to illness, to the disabilities of our fellow human beings. It will be a clear and powerful statement to disabled people everywhere that we welcome them as full members of our community and our society. Most importantly, it will preserve the lives of some of the most vulnerable human beings among us.

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

YES

Please give reasons for your answer

There is not a great deal of good research on this issue, not least because of the controversy that surrounds abortion. It seems clear, however, that the message given by the existence of abortion for disability, and in particular by the part of the law allowing abortion of disabled children up to birth, is that children with disabilities are in some sense less important and less deserving of protection than those who do not have such disabilities.

There have been numerous reports recently of continuing high levels of hate crimes and harasssment against people with disabilities.
http://www.channel4.com/news/disability-hate-crime-five-years-on-from-fiona-pilkington

Even if we cannot establish any direct causal link between abortion for disability and these kind of offences, it is hard to see how abortion for disability contributes to creating the more positive and welcoming atmosphere for people with disabilities that is surely essential to fighting anti-disability hate crime. If the law is a teacher, what is the lesson that abortion for disability teaches? To us at LIFE it would appear that the abortion law treats people with disabilities merely as burdens and problems, who do not enjoy the same rights as other human beings and are, ultimately, disposable. It should also be noted, though it is not strictly directly relevant to this inquiry, that the growing use of embryo screening to weed out individuals

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

a) People born disabled?

YES

Please give reasons for your answer

As noted above in Q5, it is not fanciful to think that our current abortion law risks imposing a heavy psychological people who are born with a disability. This is especially true when abortion for disability is considered in conjunction with all the other ways in which our society currently disadvantages people with disabilities, as it must be if we are to gain a clear understanding of how exactly it might affect people with disabilities.

There is also the massively important, but often ignored, question of what happens to medical research into, and social and medical support for, disabilities in a society that is gradually screening out carriers of various disabilities. For those parents who do choose to carry a disabled child to term, a society that is being gradually stripped of carriers of chromosomal disorders will appear to be an increasingly harsh and difficult place.

The existence of abortion for disability also increases the pressure on parents who are faced with a diagnosis of disability. Abortion in such cases very easily comes to be seen as the responsible thing to do. It is easy to see how a vicious circle of pressure and expectation might be created, leading to irresistible pressure on parents who do not really want to end a pregnancy but who lack the confidence or the knowledge or the support networks to make another decision.

b) People who acquire their disability later in life?

YES

Please give reasons for your answer

Adapting to acquired disability is a huge challenge for anyone. The way in which society reacts and adapts – or doesn't – can make a significant difference to the ease of this adjustment. A culture that routinely ends the lives of human beings with disabilities at their very start is a culture that is uncomfortable with disability, perhaps even hostile to it. It's hard to see how this can be considered to be creating a supportive and tolerant environment.

As in the debate over assisted suicide, the logic of the position that some people with disabilities are better off dead, and that a life lived in great pain or hardship is in some sense less worth living and less dignified than a "normal" life, represents an existential threat to the wellbeing and security of all people with disabilities, because it risks encouraging them to think of their own lives as in need of justification. As the US philosopher David Vellemann has written in his paper *Against The Right To Die*:

"If others regard you as choosing a state of affairs, they will hold you responsible for it; and if they hold you responsible for a state of affairs, they can ask you to justify it. Hence if people ever come to regard you as existing by choice, they may expect you to justify your continued existence."

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

YES

Please give reasons for your answer

Based on the reasons given above, we believe it is wrong, and incompatible with our social and legal commitment to equality, to allow abortion at any point during pregnancy simply on the grounds of an unborn child's disability. At the very least, the limit for Ground E abortions must be brought down to 24 weeks, the same as for almost all other grounds.

It is of course true that changing the law in this way would not necessarily eliminate eugenic abortion for disability, but rather would mean that abortions carried out for disability risked being "hidden" in the other grounds of the Act. This difficulty could be addressed by having a careful and thorough recording mechanism for recording the disabilities and impairments of all unborn children at the time of abortion.

One huge issue with the law on abortion for disability as it stands is the ambiguity of the phrasing. There seems, for example, to be very little clarity or consensus about the meaning in practice of the concepts "substantial risk" and "serious handicap". We are also highly troubled by the frequency with which the spirit of the 1967 Abortion Act law appears to be violated, when babies are aborted despite not carrying serious disabilities at all. Club foot, cleft lip and palate, and Down's Syndrome are just a few examples of conditions that don't necessarily meet the criteria for serious handicap, but are frequently used as grounds for abortion.

The debate about the abortion of disabled children is to a very large extent a debate about the kind of culture in which we want to live and the kind of medical culture in which we want doctors to operate. However compelling the case for ending the life of a badly disabled child who will never have any sort of life (an anencephalic child for example, with a severely underdeveloped brain stem), there is a very important principle at stake; that we may not intentionally kill. This is not a cost-free policy; some individuals will inevitably suffer. Whatever the law, there will always be hard cases – situations where individuals end up suffering. No-one of course would wish to inflict suffering or to perpetuate suffering unnecessarily. But sometimes we just have to accept that we cannot respond to suffering by killing the sufferer. The medical imperative must always be to heal, to comfort, and to preserve life.

8.

a) Are you aware of, or do you have experience of, guidelines on when abortions may be carried out under Ground E?

NO

b) If yes, do you think these guidelines work well in practice?

N/A

Please give reasons for your answer

9. Are you aware of any differences of opinion between

a) Doctors seeking to interpret Ground E?

NO

b) Doctors and families seeking to interpret Ground E?

NO

Please give reasons for your answer

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

Views on Information, Counselling, Care and Support

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

YES

If YES, please specify

We are aware of various organisations that offer support to such families – e.g. CLAPA, the Down's Syndrome Association, Ante-Natal Results and Choices. This comes in the form of leaflets, websites, individual representatives in hospitals, medical personnel who have received special training

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

YES

Please give reasons for your answer

There is considerable evidence to suggest that parents are being given poor, incomplete or partial information at the time of diagnosis of fetal disability and impairment, and that such information is presented insensitively by medical staff. For example, the leaflet produced by the organization Ante-Natal Results and Choices, which is among the most commonly distributed such material, is perceived by many parents as having a strong bias towards abortion.
http://www.arc-uk.org/need-help/publications/help-for-parents

There is very little provision for simple measures such as enabling parents to spend some time with families who already have a child with a disability, or speaking to people with experience of living with disability. There is inadequate provision of materials provided by specialists support groups, and even – shockingly – reports of medical staff being reluctant to signpost to such groups because the medical staff believe, wrongly, that such groups seek to impose a particular choice on couples.

There are numerous individual reports from parents of insensitive or manipulative behavior from clinicians who had clearly made up their minds about what they thought should be done and forgotten that they were dealing with individuals with their own views and hopes. This is inappropriate and must end.

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

The key needs here, in both categories, are for good information, sensitively presented, and contact with experienced and knowledgeable people who can not only give parents support, but can help them to a realistic understanding of what it is like to bring up a child with disabilities and impairments. This is a long-standing ambition for and recommendation from organisations like the Down's Syndrome Association. If the abortion debate is to be framed in terms of choice, then the inconsistency and unevenness of information and support for parents faced with disability is a huge problem, because parents will not be making informed choices.

Concrete ideas in this area might include:

- Straightforward unbiased information about the condition, including data on health consequences, social aspects, the extent to which it is life-limiting, the likelihood of cures and treatments becoming available, the availability of support services.
- No undue pressure to be placed on families to opt for or against particular treatments
- Sensitive and unbiased treatment of families by all medical staff.
- Contact with those who live with the condition or disability in question, whether patients, family members and friends, so that it is possible to see how and whether the disability or impairment affects everyday life.
- A "cooling off" period between diagnosis and possible abortion, to allow a considered and informed decision to be made.

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

Views on data collection

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

YES

If yes please specify

LIFE is aware of the annual abortion statistics issued by the Department of Health in co-operation with the Office of National Statistics. We also know of the specific data related to disability and impairment collected by various other organisations and projects, such as EPICure and Eurocat.

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

YES

Data collection and statistical analysis is not an area in which LIFE has specialist expertise. However, recent studies and reports have given reason to think that the Department of Health statistics concerning abortion for disability may not be providing an accurate picture.

In 2012, an article in the British Journal of Obstetrics and Gynaecology by Draper et al. compared DoH figures with those indicated by the Epicure Preterm Cohort Study and found "substantial under-reporting" of late abortion in the official statistics.
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 Volume 119, Issue 6, pages 710–715, May 2012

This possibility seems to be supported by data from Eurocat: http://www.telegraph.co.uk/health/healthnews/9845780/Cleft-lip-abortions-10-times-as-common-as-reported.html. While it is true that Eurocat themselves rebutted the idea of a discrepancy (http://www.thejournal.ie/reports-on-abortions-over-minor-foetal-abnormalities-incorrect-says-eurocat-784069-Feb2013/), their response did not resolve many of the lingering questions.

Other analyses, e.g. by Dr Peter Saunders, have found similar problems.
http://pjsaunders.blogspot.co.uk/2013/01/the-department-of-health-is-grossly.html

All of these concerns must be seen in the context of continuing doubts about the rigour and integrity of the abortion certification process. A report in summer 2012 by the Care Quality Commission revealed serious problems with the completion of HSA1 forms: http://www.cqc.org.uk/media/findings-termination-pregnancy-inspections-published

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

NO