

ARC briefings for MPs

ARC briefing papers in response to proposed amendments to the Abortion Law

July 2008

This briefing has been produced by Antenatal Results and Choices (ARC) the UK charity providing specialised non-directive information and support to parents throughout antenatal testing and when an abnormality is diagnosed in their unborn baby. Ongoing help is offered whatever decision is made about the future of the pregnancy.

It is with concern that we note the amendment to the abortion law (NC6) tabled by Nadine Dorries MP which seeks to have written into legislation that ‘seriously handicapped’ should not include club foot, cleft lip, cleft palate and cleft lip and palate. We urge you to vote against this amendment if debated for the following reasons:

- We know from the live birth prevalence of clefts and talipes (currently 1 in 700 and 1 in 1000 respectively)^{1,2} that by far the majority of women continue their pregnancies after a prenatal diagnosis. However, it is important to note that all conditions can vary in severity. For example, children with cleft palate will always require surgery and other treatments for many years. Moreover, there are some cases in which reconstructive surgery is extremely difficult or impossible because the clefting affects so much of the structure of the palate and sometimes the lower jaw.
- These conditions can sometimes be indicators of an underlying serious chromosomal or genetic syndrome. There may be other structures called ‘soft markers’ that are visible when scanning the fetus, which are not considered as structural abnormalities. These would not be listed as a reason for the termination but their presence increases the likelihood of an underlying serious condition. Some syndromes cannot be diagnosed with certainty through amniocentesis or any other prenatal test, so some women may opt to end the pregnancy because of the significant risk of a serious problem.
- The wording of Ground E of the abortion law makes it clear to clinicians and parents that to meet the criterion, the condition diagnosed must pose a ‘substantial risk of serious handicap’ for the child if born. This enables clinicians to assess each case on an individual basis and to collaborate with parents on determining the best way forward. This is crucial as many conditions that are diagnosed in pregnancy have uncertain and variable prognoses. NC6 would set a precedent of ‘listing’ those conditions that might represent a serious disability, thus creating a hierarchy of serious impairment which any disability rights advocate would surely find unacceptable.
- Having considered expert evidence, the twelfth report of the House of Commons Science and Technology Committee concluded in October 2007³: ‘We do not

consider that an exhaustive list of abnormalities is feasible or desirable, although guidance for professionals who are seeking to determine 'serious handicap' may be feasible and of some use to the medical profession.' As a result the RCOG has established a Working Party to review the college guidelines on termination of pregnancy for abnormality. This group consists of clinicians and specialist stakeholders and ARC believes their findings will be vital in ensuring good practice.

- ARC has been supporting parents through antenatal testing and its aftermath for 20 years. We run a National Helpline and receive calls every day from parents who are considering or have had a termination of pregnancy after the diagnosis of a condition in their unborn baby. Although each parent's personal situation is different, a generic feature is how difficult and distressing they find making the decision to end what is most often a much-wanted pregnancy. They are not seeking the perfect child; they simply want a healthy baby. Those who make the painful choice to end the pregnancy do so after careful consideration of what the diagnosis may mean for their baby/child's quality of life and what it might mean for themselves and their family's future. The least helpful development for parents facing these stressful circumstances and their clinicians would be to have further politicisation of this area based on the entirely misplaced notion that many women are making 'flippant' decisions to terminate pregnancies under ground E for minor or purely cosmetic reasons. In order that parents can work together with clinicians to arrive at the decision that they can best live with, it is essential that Ground E remains as written without the proposed NC6.

Since we prepared this briefing, Charles Walker MP has put down NC15 which attempts to rewrite Ground E. Again the tabling of such an amendment is predicated on the erroneous assumption that parents and clinicians are not taking their responsibilities seriously in the context of a diagnosis of fetal abnormality. We would urge you to also vote against this amendment.

References

1. Cleft lip and palate. NHS Direct Health encyclopedia at <http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=103> accessed 08/07/08
2. Talipes NHS Direct Health encyclopedia [at this website](#)
3. Scientific Developments Relating to the Abortion Act 1967, House of Commons Science and Technology Committee Twelfth Report of Session 2006-2007. October 2007 p31

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This briefing paper was prepared by Antenatal Results and Choices in response to amendment 71 to the Human Fertilisation and Embryology Bill tabled by Baroness

Masham of Ilton, which seeks to repeal subsection (1) of the Abortion Act 1967 (c.87) paragraph (d) and subsection (2) of section (5) paragraph (a).

EXECUTIVE SUMMARY

- Abortion on grounds of fetal abnormality is permitted in 25 out of 27 EU member states. The only EU countries which do not permit abortion on these grounds are Malta and Ireland, where all abortions are extremely restricted.

- It is the considered opinion of the Royal College of Obstetricians and Gynaecologists, the Royal College of Midwives, the Royal College of General Practitioners, the British Medical Association, British Paediatric Society and the Clinical Genetics Society that forcing a woman to continue a pregnancy when the fetus was known to be seriously abnormal would be 'inhumane'.

- The 'Miss D' case in Ireland in 2007 caused significant outrage when a pregnant teenager was refused permission to travel for an abortion, even though her child was severely disabled and would have died after birth. This decision was overturned but caused additional suffering for Miss 'D' at an already distressing time.

- Screening for fetal abnormality in the UK is optional. Most pregnant women in the UK choose to be screened; the majority of women are in favour of termination being available if a significant disability is diagnosed.

- In many cases the mid-pregnancy scan which detects abnormality may not be carried out until 22 weeks; earlier scans may be less accurate. Following a diagnosis of a possible abnormality, additional time is often needed for further tests and to allow the parents to decide whether to continue the pregnancy. Reducing the current time limit or preventing abortion on the grounds of fetal abnormality after 24 weeks would be extremely detrimental to those women who discover an abnormality at a late stage.

- Removing fetal abnormality as grounds for abortion at all gestations would particularly affect those parents who know they are carriers of a genetic disorder and risk having a baby with the condition.

- Abortion on grounds of fetal abnormality is not eugenics, nor the quest for the perfect baby. Clinicians are reluctant to recommend abortion on these grounds and allow the parents to make the decision based on their own judgement and their individual family circumstances.

1. The UK National Screening Committee oversees a national programme of antenatal screening which currently includes a fetal anomaly screening programme (encompassing universal screening for Down's syndrome and a mid-pregnancy anomaly scan) and screening for sickle cell and thalassaemia. The UK NSC provides working standards, guidelines and an auditing service for the NHS and advises Ministers on screening policy.¹

All pregnant women in the UK are offered some kind of antenatal screening. It is always presented as optional and designed to enable women to make reproductive choices.

The UK NSC provides a pre-test information leaflet for women to aid discussions with health professionals and promote informed decision-making. Within this booklet there are contact details for the independent voluntary sector groups offering support around the conditions being screened for and these groups were also consulted for comments on the booklet. Thus women are given the opportunity to obtain balanced information about the conditions and the experience of those living with the conditions and their carers.

The majority of women opt into the testing process². Research evidence shows that most women are in favour of antenatal testing and of having the option to end the pregnancy if a significant abnormality is diagnosed.³ In a large scale study undertaken in 2002, only 5% of women thought it was always wrong to have a termination of pregnancy when: ‘if the child is certain to have a serious mental disability and will never live independently’ and just 6% felt it was always wrong: ‘if the child is certain to have a serious physical disability and will never live independently’.⁴

2. Statistics show that the majority of women decide to end their pregnancy after the diagnosis of a condition that is ‘incompatible with life’ or likely to lead to significant disability.⁵

3. The national charity Antenatal Results and Choices has been supporting parents through antenatal testing and its aftermath for almost 20 years. ARC runs a National Helpline and receives calls on a daily basis from parents who are considering or have had a termination of pregnancy after a diagnosis of a condition in their unborn baby.

Although each parent’s personal situation is different, a generic feature is how painful and distressing they find making the decision to end what is most often a much-wanted pregnancy.⁶ We can safely say that in ARC’s experience parents who undertake antenatal screening and testing and have to cope with its consequences are not seeking the perfect child, or looking to in any way denigrate those living with impairments. They simply want a healthy baby. Decisions women make in the abstract before they embark on the screening process often fall away when they confront the complex reality that accompanies a confirmed diagnosis. Those who make the painful choice to end the pregnancy do so after careful consideration of what the diagnosis may mean for their baby/child’s quality of life and what it might mean for themselves and their family’s future.

4. Removing fetal abnormality as grounds for abortion would particularly affect the reproductive choices of those parents who know they are carriers of a genetic disorder and risk having a baby with the condition. Often they have children living with the condition so are well-placed to know exactly what the reality is. There is evidence that once testing and termination became an option parents who were, or believed themselves to be, at increased risk of an abnormal pregnancy were more likely to choose to become pregnant in an attempt to have the healthy child they wanted.⁷ The Genetic Interest

Group (GIG) the national alliance of patient organisations which support children, families and individuals affected by genetic disorders shares ARC's view that termination on the grounds of fetal abnormality should continue to be available.

5. Baroness Masham's amendments would force a woman to carry a pregnancy to term when a lethal abnormality had been confirmed. A diagnosis of a condition that is 'incompatible with life' can happen early in pregnancy. For example a scan at 12 weeks can diagnose anencephaly, a condition which means the baby's skull has not formed properly, affecting development of the brain. The 'Miss D' case in Ireland earlier this year highlighted the distress that can be caused when such a diagnosis is made and a woman is offered no choice but to continue for two thirds of her pregnancy with knowledge of the bleak prognosis. (A 17-year old in the care of the Irish Republic's health service, was initially prevented from going to Britain for an abortion. The teenager had to endure 10 days of high court proceedings before being given leave to travel). Ireland has always had one of the world's most restrictive abortion laws, but in June 2007 a TNS/MRBI poll found that 75% supported legal abortion when the fetus cannot survive outside the womb.⁸

When considering reducing abortion time limits in 1987, the RCOG, RCM, RCGP, BMA, British Paediatric Society and the Clinical Genetics Society made the following comment in their report : 'It would be inhumane to those mothers, their babies and families to insist on the continuation of a pregnancy when the fetus was known to be seriously abnormal.'⁹

6. 25 out of the 27 members of the European Union enable women to end a pregnancy legally after a diagnosis of fetal impairment.¹⁰ The only exceptions are Ireland and Malta where abortion remains illegal. In the UK polls have regularly shown that the majority of the public support the availability of legal abortion in such circumstances.¹¹

7. Some who advocate banning termination on the grounds of fetal abnormality do so on the grounds that it is underpinned by eugenic principles. However, a eugenic policy demands public coercion. In ARC's experience women are offered a termination after the diagnosis of a significant anomaly, but clinicians are extremely wary of being directive and it is left to the woman to decide how she wants to proceed. She will then make her decision about the future of her pregnancy based on her individual family circumstances and the knowledge she will live with the consequences of her decision.

8. With reference to the table in the appendix, despite the improvements that have been made in providing earlier diagnoses in pregnancy using first trimester screening tests, it is important not to assume that this means that most parents can opt for earlier terminations of pregnancy and thus would not be affected by a reduction in time limits or will never need a termination after 24 weeks. It is still true that a large proportion of problems in an unborn baby first become apparent at the mid-pregnancy scan which in some settings is not offered until 22 weeks gestation¹². It is not possible to offer this scan significantly earlier without compromising its effectiveness. It is also the case that first trimester screening tests are not available in all units across the country. We take calls every day

on our National Helpline from parents who are reeling from the shock of being told of something wrong with their baby at the mid-pregnancy scan, struggling to take in the news and to know how to proceed. Any encroachment on the current time limits will result in added pressure on these parents at a time when they can least withstand it.