

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

The Genetic Interest Group

Question 1

In answer to the first part of the question, the obvious answer is that measures would be appropriate, at the suggestion of the physician and with the consent of the woman, where this can make a difference to the health and wellbeing of the child to be. We do not think there are circumstances when it would be appropriate to override the wishes of the pregnant woman.

Question 2

We do not believe that any of these circumstances should rule out intervention in all cases, which seems to be the implication of the question.

Question 3

Questions 2 and 3 should be considered; question 1 should not be considered. It is raised later, but another important question is 'Who should decide?' and 'Within what limits?'

Question 4

We think that the Working Party should address the first question. Parents and professionals would welcome considered views on this issue. We do not see the other two questions as particularly relevant however.

Question 5

There is a danger of conflating a couple of issues here. The parents or whoever will do the caring should have a key role in any important decisions. They will be the ones who will most directly live with the consequences of any decisions that are made. But this does not necessarily mean that they are the best judges of the quality of life for the child if they have no previous experience. They will want and need advice on these issues, but they may well want to use their own judgment and values when considering what should happen once they have an understanding of the situation.

Ideally the parents and the professionals will be able to come to an agreement on what should be done. Ultimately, if there is disagreement the case may need to go to the courts. If this happens professionals may want to resist pressure from parents to treat a newborn if they judge such treatment to be futile. As a matter of principle we agree that professionals should have the right to refuse to treat, but whether that is correct in particular circumstances may need to be tested.

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Question 6

No weight should be given to economic considerations.

Question 7

We lack the expertise (in QALY) to give a meaningful answer to this question, although our answer to the previous question may be relevant.

Question 8

The answer depends upon what is meant by 'directive'. We would be happy with guidance that supported professionals and patients in having an honest and open discussion about what should be done in the difficult circumstances discussed in the consultation document. In other words 'directive' in the sense of legitimising a space in which decisions could be made would be welcome. We would not be supportive of a prescriptive approach which tried to outline what *should* be done in particular circumstances.

It would seem possible to set a low limit, but how useful would that be? Anything closer to what medical science currently sees as being the boundary would be problematic. On balance we find it hard to support a definite rule in this area: cases should be dealt with individually.

Question 9

It is unclear what would be achieved by new legislation as such.