

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.

## **Antenatal Results and Choices (ARC)**

### **Question 1**

In answer to the former question, appropriate measures in these circumstances would depend on agreement between practitioner and parent on what was going to be in the potential child and family's best interest. Such agreement would be informed by a professional assessment of the implications of the diagnosis and possible interventions on the long term health of the unborn baby and on the mother. Any measures would require full consent from the pregnant woman.

There are no circumstances where it would be right to override the wishes of the woman carrying the fetus if the decisions she wished to make were within the existing legal framework.

### **Question 3**

Perhaps the third question is most pertinent to the working party. Interpretations of what constitutes 'quality of life' are bound to have a subjective element, but it is essential that parents are given information from a variety of sources to help them assess the prospects of their potential child within their individual context.

Perhaps the most useful goal of the working party, rather than tackling thorny, often irresolvable, philosophical questions, is to look at the real situations that parents and practitioners find themselves in. When it comes to diagnoses in pregnancy, these situations will inevitably be sensitive and complex and what best aids the parents involved is that they feel that they can trust their practitioners to be open and honest and to acknowledge the difficulties involved. What would lead to this situation is the creation of a climate in which we trust both parties to act in good faith, and that, in particular, we trust and respect the decisions parents make in these difficult circumstances.

### *Question 4*

We would suggest that only the first question is truly useful to consider as parents will often be actively looking to practitioners to provide information based on their professional experience and refer them to other sources relating to the perceived 'quality of life' for their child. Many parents will also come with their own perceptions of quality of life informed by their own personal experiences – as with many of the questions raised here, there are no clear cut questions or answers.. The weight of spiritual and religious influences will vary between individuals both from and within different faith groups. Mass media refractions of the debate will often be reductionist and will not always address either the complexities or the ultimately private nature of individual circumstances.

### *Question 5*

Parents are the ones who are going to live with the consequences of decisions made in the antenatal period, and so their views should be paramount. They will often need help in assessing quality of life for their potential child as they may have no or limited knowledge of the condition diagnosed.

Ideally, if both parents are present, every effort should be made to involve both equally and to encourage agreement on any intervention. In the event of a couple reaching an impasse during the

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antenatal period, and when help from a trained third party has made no impact, the autonomy of the woman must be respected.

When it comes to others involved in the decision-making, it should be up to parents to decide who they feel should have input from their side.

We would hope that in a climate of open discussion, mutual respect and trust, recourse to the law will not be required. It remains a last resort in exceptional circumstances, perhaps in the case of negligence or when communication between professionals and parents has irreconcilably broken down.

### **Question 6**

We cannot foresee a situation when it would be ethical to suggest to parents that it was 'uneconomical' to prolong the life of their fetus.

### **Question 8**

Rather than prescriptive guidelines, which may not be flexible enough to apply in what are often very individual circumstances, we would advocate multi-disciplinary professional training and structured support to help equip practitioners with the skills necessary to provide appropriate care in this challenging area.

### **Question 9**

This would not be useful as it would represent an attempt to bring rigidity and absolutes into a realm that is often by its very nature uncertain and highly complex. As mentioned before, open and honest collaboration between parents and their practitioners is the best way to enable parents to make the decisions that are right for them.