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

Michael Abrams

a) Parents must be fully involved in the decision – the child may be extremely precious to them even if severely disabled. No examples are given so it is difficult to suggest what might be done. In general any procedure that has a better than even chance of correcting or improving the defect. Stem cell research though promising is in its infancy: much more work needs to be done to ensure that using stem cells cannot induce further abnormalities nor lead to for instance a virus infection.
b) So long as what the pregnant woman is requesting is lawful her wishes should be followed. exceptionally if following her wishes could lead to the death or serious illness of the mother then overriding could be permissible. However medical staff should be working towards agreement not confrontation.

Question 2

When the baby has such severe abnormalities that survival is out of the question. Whilst there may be arguments for having a law which only permits prolongation of life after a certain foetal age, this is certain to lead to hard cases. It may be more welcome to medical staff than to parents, who may be concerned that medical staff are not doing their best for the newborn. Determining foetal age may be imprecise so that creating what might be a criminal offence is surely inadvisable as well as possibly leading to difficult confrontations over the exact foetal age.

Question 3

No mention is made of the mother/parents religious or other beliefs. These must surely be highly relevant to the ethical position. So a fourth ethical question, which I would rate first, along the lines “what part should the religious or moral beliefs of the mother/parents play” needs to be considered in this context as well as in Question 4. I would regard acting and omitting to act as the next most important.

Question 4

An additional question, foreshadowed in the discussion, is whether it is helpful to families and medical staff to involve the courts in decisions unless such involvement is required by law.

Question 5

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The form of the question seems to me to lead down the wrong path: the question should not be who of those mentioned should carry most weight, but rather how can professional staff work through the issues with parents to come to an agreed outcome. The parents may well want to have their religious/spiritual adviser involved – this is not mentioned. Single mothers, which can include the separated/divorced may present special problems which need to be considered. Differences in view should be resolved by discussion not by some ex cathedra ruling that the views of any one person have to be accepted. I regard recourse to the courts to challenge medical advice, or to get the medical advice to be followed, as an indication that the professionals have lost the confidence of those concerned and is therefore to be avoided by the professionals.

Question 6

None

Question 7

QALYS are subjective and their use may imply a degree of objectivity which is not warranted. Is it not more relevant to put the question differently: does the treatment work, if so how are the resources to be found.

Question 8

See answer to Q2 on setting a minimum resuscitation age. (Would this ethically be any different to setting a maximum age for resuscitation in the elderly?) Professional guidance should focus on the need for professionals to act with the parents and not be confrontational. More directive advice may well have the effect of precipitating confrontation even though that may not be the intention,

Question 9

Case law is developing in this area and may be a preferable way to move forward rather than by legislation which is likely to be both difficult and contentious.