

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.

## **Carine de Beaufort**

### **Question 1**

One has to consider the kind/severity and the impact of the disabilities on the future human being as well as on his/her direct environment.

Will he/she be able to communicate or relate to other human beings? What will be his/her quality of life –well being, possibility to enjoy life? At what cost /burden? If there are possibilities to communicate and to express 'well being', it seems important to evaluate the possibilities to intervene prenatally in order to correct existing abnormalities. New approaches, new surgery techniques (prenatal, intra uterine procedures) need carefully designed protocols (with IRB agreement) and long term follow up to evaluate the quality of life as mentioned above. Through those well described projects, information will become available about successful and unsuccessful long term intervention techniques. It will only be a realistic possibility in those countries where high- tech intensive care is available and research is accepted with internationally acceptable conditions.

Different publications end last century describe situations in which a heroic action is undertaken to save a VLBW ( very low birth weight baby)– against the wish of the parents, without success and with a lot of suffering for the child and the parents. A very careful explanation by competent professionals to future parents is needed to explain the risks and the possibilities for their child in future. After this information it should be checked whether any question/unclarity remains. If a fundamental difference in opinion/approach between health care professionals and parents remains , I would propose to respect as well the doctor as the wish of the parents. Another health professional /team should be invited to take over. If such a person would not be available, one should not exclude to rediscuss with the parents the risks for their child.

### **Question 2**

Actually different countries within Europe have different criteria to  
For the moment several countries have clearly discussed the gestational date before which one should not intervene aggressively. Two problems may arise : in how far is the date exact and sometimes children of 24- 25 weeks may present spontaneous breathing. Then the child should – of course - get a chance but with a very careful evaluation of every medical step taken. The risks for severe disabilities long-term are very high in the population born with a GA of 26 weeks or less.  
Congenital abnormalities can be very different in severity and in intervention possibilities. Once again, a careful evaluation should be made about the quality of life of the child, the possibilities to relate to other humans etc. The place where this discussion evaluation takes place and the availability of intervention possibilities will play a major role ( recent discussion in a EU country between a visiting surgeon from an African country and a local surgeon on the viability post surgery of the child with an oesophagus atresia. In EU countries the survival rate will be extremely high and the disabilities long term will be negligible in most cases, where as in Africa this child would not be operated and die.

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Long term disabilities due to growth restriction in utero can be very variable and thus the prognosis remains to be seen and discussed. What is included? SGA of immature lungs or underdeveloped intestines etc. Growth restriction can be linked to severe complications in the neonatal phase and to small complications later on in life ( as well as possibly increased risk in late adulthood for the metabolic syndrome).

. Genetic disorders represent an enormous variety of pathologies with a sliding scale of severity. Those who are associated any way with severe suffering at an early age for the child and its family ( f ex Werdnig hoffmann ) and those which may lead in mid adulthood to severe disease will need a different approach. Again a careful evaluation of a competent team on the quality of life of the child the burden for him/her and his/her family should be discussed.

A child with Acquired brain damage and enormous chance to present severe disabilities later in life requests again a discussion between team and parents. The prognosis needs to be discussed in detail. Is the child able to communicate, is he/she able to become independent in simple things (eating, getting dressed) and/or in more complicated things (living on her own). The considerations / opinion of the parents are extremely important.

Furthermore, one should take into consideration the possibilities-if the prognosis is extremely negative- to intervene. Is the child suffering at that time point, is he on artificial ventilation, how is his/her EEG etc. Would he/she be able to breathe self? Does he depend on artificial feeding and medication to survive?

### **Question3**

3,

### **Question 4**

Possibility to communicate, to relate to other people. Absence of continuous life struggle (muscle disease with continuous difficulty to breathe), absence of continuous pain. Possibility to express emotions be happy/sad. Thereafter the possibility to become independent with – food intake-miction/defecation—to become independent (maybe by living in a protected environment but independently of the parents).

It will influence the decisions/ views of parents and teams working in different countries. Whether one considers handicap as a punishment or death as non existent (heaven whether a girl is seen as a lower human being, this will have an impact on the views of the parents of the child.

Whether one has the right to receive blood /blood products (the culture which forbids this might exclude the person who did not respect its (un)written law. A child may be completely excluded and even need adoption because of this).

It seems difficult not to consider the cultural environment in which a child will grow up. On the other hand, every child has a right to live and to receive the best treatment, adjusted to his/her needs. A medical team should look at medical arguments to

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intervene or to omit action, but the future environment of the child should not be excluded, but should not prevail at any price.

Probably a lot. Through soaps, through repetitive messages over radio/TV a lot of ideas have been presented to the Public (vaccinations program UK, constitution arguments in Holland etc). Mediation hypes can't be avoided and therefore should be used?!

NO

With respect to the newborns with problems (SGA/VLBW/extremely premature babies) several long term follow up studies show the importance of the role of the parents. The more intensive their involvement, frequently the better the result/functioning of the child.( POPS) I do not know how to include it in this set of questions, but in the discussion with the parents of a high risk child, one should try to get some information on the parents wishes convictions, but also capabilities to accompany, knowing that the road will be long and difficult.

### **Question 5**

Parents together with an experienced team of health care professionals working in the field of children with various degrees of disabilities. Later on, hopefully the child himself.

When families as well as professionals are involved, whose decision should carry the most weight on whether or not to intervene to prolong the life of a fetus or a newborn baby?

Examples of people likely to be involved: the mother, the father, other family members, doctors or other healthcare professionals, healthcare managers, the courts, the social services.

Parents, thereafter the health care team taking care of the child.

When parents are involved, whose views should take precedence? For example: mother, father, parents together. Parents together.

Parents, health care team, those invited by the parents and the team.

Exchange of information, exchange of ideas is the first step towards better understanding of the different people involved . If a profound disagreement persists, other healthcare professionals should be invited to take over. Sometimes privileged contact may exist between parents and a third party. That party should be invited in the discussion if the parents wish so.. if a disagreement in the approach remains, one do should respect the opinion of both groups and invite another health professional team.

I do not think that law, in the situation of careful evaluation of the risks/benefit should be involved. If severe medical negligence, bad practice, mistakes are involved, a medical expert group should be involved with people competent in the field , able to judge whether the complaints are real or not ( different reasons – frustration, guilt, anger, sadness, money etc- can all lead to use the law) ( example: Dutch tucht college) and to propose a punishment where indicated.

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### **Question 6**

This will depend on the country/continent one lives, the accessibility to care the severity of the problem and the consequences. Inevitably some countries will prioritise the use of antibiotics to high tech intervention in a child with a hernia diafragmatica. If there is no money ...  
A careful evaluation should be made in order to money as useful as possible.

### **Question 8**

I think clarity improves and facilitates the discussion. One can hide less easily behind difficult words; say a lot and nothing in the same time.

I think one should define guidance with evidence based information. If the children born before 26 weeks of gestation develop major severe disabilities in long term, and the chance to have a healthy survivor is very limited, the medical team taking care of this child should keep this in mind. Of course the wish of the parents needs to be taking into account, but careful explanation of these major risks for future need to be explained carefully. In the mean time, if a child born at 25 weeks is able to breath, move and scream, he's entitled to get a chance.

### **Question 9**

On one hand a law is something black on white, written, inflexible. On the other hand, a lot of things nowadays are done ( see recent publications on euthanasia and approaches in neonatal care units) without previous discussion with the parents , without consent and differently depending on the health care team present that specific day in that placer. Guidelines and/or a legislation respecting child (life worthy living) , parents and health care professionals , in these difficult situations, may be easier for parents and health care professionals.