



# Faculty of Public Health

of the Royal Colleges of Physicians of the United Kingdom

Working to improve the public's health

## **Response from the Faculty of Public Health to the Nuffield Council on Bioethics consultation on *Ethics of Prolonging Life in Fetuses and the Newborn***

The Faculty welcomes the opportunity to comment on the proposals from the Nuffield Council on Bioethics which have been put together by public health colleagues with an interest in, expertise of, ethics. The Faculty's response is provided on a question by question basis.

**Question 1. In cases where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, what measures may it be appropriate to take to sustain the life of the fetus or, where possible, to correct those abnormalities before birth.**

**Do you consider that there are ever circumstances when it would be appropriate to override the wishes of the pregnant woman?**

- 1.1 The Faculty does not envisage circumstances in which it would be appropriate to undertake interventions contrary to the wishes of the pregnant woman. The nature of the relationship between fetus and mother is such that it would not be possible to treat the fetus against the woman's wishes without violating her autonomy. Nor would it be practical to insist that a woman underwent procedures or behaved in a particular way in order to improve the outcome for her fetus. We consider that forcing women to undergo interventions to benefit their fetus is not ethically acceptable. The risk of coercion of women to undergo treatment against their will may deter some from seeking healthcare.
- 1.2 The Faculty can envisage circumstances in which the pregnant woman wishes to have healthcare interventions which she hopes will improve the outcome for her fetus, but which care providers and care commissioners consider inappropriate because they are a) likely to be futile, b) not readily available within UK health services or c) are not a priority for the use of scarce resources. In these circumstances her wishes may be overridden. The Faculty recognises that pregnant women may find such decisions extremely distressing, and notes the importance of robust consideration and documentation of the reasons behind them, and appropriate counselling and support for the women concerned.

**Question 2. In which of these circumstances, if any, would it not be appropriate to use medicine and surgery to prolong the life of the newborn?**

- **When the baby is extremely premature**
- **When the baby has congenital abnormalities**
- **When the baby has poor prospects for survival because of a genetic or other disorder, or because of growth restriction during pregnancy**
- **When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life.**

2.1. The Faculty does not consider that judgements about interventions to prolong life are dependent on the aetiology of the baby's condition, but should take into account the expected outcome, what is thought to be the best interests of the baby, and the wishes of parents.

2.2. It is important to ensure that medical staff – in particular paediatricians – are fully trained, not just in life-prolonging therapies, but in good quality palliative care for those infants where a decision has been made that life-prolonging interventions are not appropriate.

**Question 3. In your view, are these the principal ethical questions that the Working Party should consider?**

- 1. The moral status of the fetus**
- 2. Acting and omitting to act**
- 3. Questions about the quality of life**

**Which of these or other ethical questions would you identify as the most important?**

- 3.1. The Faculty agrees that the moral status of the fetus should be considered.
- 3.2. In addition, the Faculty identifies the following ethical questions as also important:
  - 3.2.1. Questions about the quality of life.
  - 3.2.2. Parental rights. This includes the interests parents have in securing the optimal outcome for their child as well as consideration of the impact of a severely disabled child on parents and other family members.
  - 3.2.3. Utilitarian issues in relation to use of scarce health and social care resources. The Faculty appreciates that rationing of health resources is a difficult topic to address, particularly in such an emotive area. Nevertheless, it would find explicit guidance helpful for its members working to support health service commissioning.
  - 3.2.4. The Faculty recognises that the impact a disability may have on the quality of life of a child and their family is influenced by social environment, such that for some disability is regarded as a social construct. The Faculty would welcome a consideration by the Working Party of the status afforded to people with disabilities and the influence of this on decision-making.
- 3.3 Health professionals should ensure that both actions and omissions to act are based upon the best available evidence, and that decisions on both can be justified accordingly.

**Question 4. The Working Party has identified the following questions for discussion:**

**What might we mean by “quality of life” for a child?**

**How do religious and spiritual influences affect decisions?**

**How do the mass media influence decisions?**

**In your view, are these questions that the Working Party should consider? Should any of these questions be omitted, or are there additional questions that should be included? Which social questions would you identify as the most important?**

- 4.1 The Faculty believe that questions about the social context of decision-making should be considered in order that we can better understand the influences on parents and health and social services. This informs the debate and enables decision makers to respond better and engage positively with the media, religious leaders etc. The Faculty queries why religious and spiritual influences are singled out, whereas other influences, such as political belief, are not.
- 4.2 Further consideration might also be given to the role of faith and community groups, and society, in supporting adults and children with severe disabilities, their families and carers, as well as the social impact on the family and wider society of caring for a severely disabled child, including economic impact.
- 4.3 The Faculty recognises that disability may be regarded as a social construct and that it is also important to consider changing society's view of people with disabilities as well as creating enabling environments for people with severe disabilities.

- 4.4 Consideration should also be given to media portrayals of people with disabilities. Neonatal cases which also come before the courts can be difficult for the media to encapsulate, and there is a risk of focussing on or generating emotive issues which are either an over-simplification of the issues involved, or just part of the case.

#### **Question 5. Who is best placed to judge the quality of life for a child?**

**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 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.**

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

**Who else should be involved?**

**How should such decisions be made, and how should any differences in view between the parties involved be resolved?**

**When, if at all, do you think that people should use the law to challenge medical advice?**

- 5.1. The Faculty recognises the inherent difficulties in judging quality of life for a child who may not yet have reached its full potential and who cannot express for themselves the value that they place on their life.
- 5.2. The largest burden of responsibility for long term care falls on the parents. Parents need assistance in making decisions with provision of realistic prognoses from practitioners who have experience of managing children with severe disabilities and who can counsel parents about the likely impact of treatments on the child, the parents and other family members.
- 5.3. Wherever possible decisions should be made in partnership between parents and healthcare staff. Nevertheless, the Faculty recognises that there have been circumstances in which the views of parents and healthcare staff have not been reconciled and the courts have been asked to make decisions in the best interests of the child. These have included cases where parents wish to withhold treatment and those where parents require that their child is treated. The Faculty accepts that in a few cases there may be the need for a final arbiter to resolve disputes but would welcome consideration of how this can be done outside the court system, and in an environment which helps to strengthen the relationship between parents and health and social care providers.
- 5.4. The Faculty notes that the courts are unlikely to require doctors to undertake interventions which their professional judgment deems inappropriate.
- 5.5. The Faculty would not welcome interference by the courts in commissioning decisions based on the most appropriate use of health resources for the community. It accepts that health commissioners are required to ensure that their decision-making processes are reasonable, but considers that the review of these are a subject for performance management within the NHS and should not lie within the remit of the courts.

#### **Question 6. How much weight (if any) should be given to economic considerations in determining whether to prolong the life of fetuses or the newborn?**

- 6.1. The Faculty appreciates the aversion that many people have to considering the economics of care when determining life and death issues. Nevertheless, it recognises that health and social care resources are limited. The Faculty would welcome an explicit review of economic considerations, including costs to the health service, to parents, to social services and to society in general, in order that interventions and support services are properly and adequately funded. The Faculty believes, however, that whilst economic considerations are important, they should not be the main driving force behind decision-making on whether or not to institute medical treatment.

**Question 7. Should a quality-adjusted life (QALY) (or another measure of health gain) for a newborn child be given the same weight as a QALY for a middle aged or elderly person?**

- 7.1 The Faculty notes the inherent difficulties in attempting to use QALYs to compare health gain from different interventions for different conditions or populations.
- 7.2 QALYs imply value judgements and the opinions of marginalised people, such as people with disabilities, are not usually included in forming these judgements.

**Question 8. Would drawing up more directive professional guidance be helpful to parents and professionals? If so, should the UK follow practice in other countries and set a minimum age below which resuscitation normally would not be permitted?**

- 8.1. The Faculty believes that more directive professional guidance which sets out the reasoning behind decisions would help parents and professionals working in partnership to reach decisions.
- 8.2. The Faculty considers that having a minimum age below which resuscitation normally would not be permitted may not be as helpful as having comprehensive general guidance which assists decision-making.

**Question 9. Would drawing up new legislation in this area be helpful to parents and professionals?**

- 9.1. The Faculty would not welcome further legislation into decisions around prolonging life of fetuses and newborn at present. The Faculty notes the great advances in medical practice which may lead to better survival and quality of life for very preterm babies, and is concerned that the legislative process may not be able to keep up with improvements in healthcare.
- 9.2. While the Faculty accepts that legislation can assist with decision-making (by making the decisions in a generality at the point of agreeing the legislation), it believes that these very difficult decisions about life and death in the newborn are deserving of individual consideration, taking into account the impact on the child, their family and society as a whole.

**About the Faculty of Public Health**

The Faculty of Public Health (FPH) sets and maintains professional standards for public health specialists. The Faculty works to improve the public's health through its three key areas of activity: professional affairs, education and standards, and advocacy and policy contribution. For further information visit our website [www.fph.org.uk](http://www.fph.org.uk).