

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.

Foundation for People with Learning Disabilities

Question 2

- *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 in pregnancy*
- *when the baby has acquired brain damage and is considered likely to have severe disabilities later in life.*

As a charity working to improve the opportunities and rights of people with learning disabilities and their families, the Foundation in this response is emphasising the value of the life of a disabled person. The Foundation would therefore wish to urge that measures are taken to sustain the life of the fetus, where it may have serious impairments, or where possible to correct abnormalities, and also to prolong the life of the newborn.

Clearly these situations are very distressing for parents and particularly the mother. Legally where severe problems are identified she can seek a termination after 24 weeks. The Foundation believes along with the Disability Rights Commission¹ that late terminations on the grounds of disability are discriminatory. The exception would be when there is a late diagnosis of anencephaly or other fatal conditions where the baby would die within hours, when the mother should have the choice of whether to carry the baby to full term.

It notes that it is beyond the remit of the working party to consider the legal limits of abortion, but the Foundation would suggest the moral status of the fetus with severe disabilities as it approaches full term should not differ from that of the non-disabled fetus.

The Foundation believes that it is important that parents are presented with a balanced view of disability. Too often the birth of a disabled child is presented as a tragedy, whereas the reality is that disabled people often lead full lives, greatly loved by their families.²

Parents with learning disabilities should receive sensitive and accessible information.

¹ news.bbc.co.uk/1/hi/health/150827

² See the newsletters of the Down's Syndrome Association and Down's Heart Association, for example.

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Question 3

- *The moral status of the fetus*
- *Acting or omitting to act*
- *Questions about the quality of life.*

As stated above the Foundation thinks it is very important to address the question of the moral status of the fetus, believing that there should be no difference in the status of the fetus approaching full term and the newly born baby.

Omitting to act is also a moral issue. The Foundation would only consider taking no action if the baby would only survive for a short time and would be in severe pain.

It believes that questions about quality of life are not appropriate. This is firstly because it is difficult to have a clear prognosis about the quality of life at this stage. Secondly views about the quality of life are always subjective. Mencap argues that treatments should be judged on their outcomes and not on issues of quality of life³.

Question 5.

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?

When parents are involved, whose views should take precedence?

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?

As stated above, the Foundation has serious misgivings about using arguments about quality of life. It appears that this consultation views it as a key question as it is repeated, but as stated above it is usually not possible to predict the future

³ Mencap 2001 Considerations of Quality of Life: Medical decision-making for people with severe learning disabilities www.mencap.org.uk

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for many newborn babies with disabilities. In addition judgements are being made on another's behalf and may be prejudiced by negative views of disability. It is also not possible fully to predict what treatments may become available.

As a father, John Picton has written,

'Who is to judge the value of another's life? Who has the right to say that life is not worth living, that it should be squashed out? We exist for one another and, as a result, none of us has the freedom to do as we wish; we delude ourselves if we think otherwise. Rather, we have a duty to care for each other. That is the society I wish to be part of.'⁴

As stated in a recent report from the Valuing People Support Team: 'It is difficult to say we value differences in people and at the same time say it would be a good thing if fewer disabled people were born.'⁵

Religious and spiritual influences will influence decision making but this does not necessarily mean that there will be unanimity: other influences are also powerful. In the Foundation's recent study only two respondents discussed screening. One mother discussed how she had refused screening because of her religious beliefs.

The media is a powerful force for moulding public opinion. Developments such as universal screening for Down's syndrome have generally been represented as desirable in the media. This in its turn is likely to encourage negative views of disability.

Where decisions have to be made about treatments, it is important that families are given balanced and comprehensive information in a way that is accessible to them; that they are given time and not rushed. It would be hoped that agreement could be reached through discussion. Sometimes it might be useful to have other individuals trusted by the families involved.

It would be hoped that recourse to the law would be rare. Such situations as those of Baby Charlotte Wyatt⁶ where there is a substantial difference between clinicians and parents should go to the courts.

⁴Picton, S. and J. What it means for us: Two parents' perspectives in Ward, L. Ed. (2000) Considered Choices: The new genetics, prenatal testing and people with learning disabilities Kidderminster: British Institute of Learning Disabilities

⁵ Valuing People Support Team (2005) The Story So Far... Valuing People A new strategy for the 21st century London: The Department of Health

⁶ See news.bbc.co.uk/1/hi/health/3724780.stm

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Question 7

The Foundation believes that for these complex decisions, economic considerations should be secondary. They should be based on a clear policy and not influenced by local resource issues. There should not be postcode lottery.

Question 8

Would drawing up new legislation in this area be helpful to parents and professionals?

The Foundation believes that these questions are best answered by parents and clinicians directly involved in these decisions. It has reservations about setting a minimum age below which resuscitation would not be permitted.