

Chapter

Introduction

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- 1.1 To care for a child is to express one of our most fundamental human instincts. We invest our hopes for the future in our children and want them to live healthy and fulfilling lives. In developed countries, medical care over the past 40 years has advanced dramatically so that many more babies are now born in good health, and fewer babies die in their first year of life. Before the 1960s, few problems could be diagnosed in pregnancy and there was a lack of treatments that could be offered to babies born very early or who were seriously ill. Most of these babies would die and consequently, ethical issues in fetal and neonatal¹ care were less common.
- 1.2 The number of babies born extremely prematurely is rising. Modern medical care is increasingly successful both in saving the lives of these babies and in offering more hope of recovery to babies born later who have health problems. Sometimes, however, a baby will have or develop a condition which means he or she will not live longer than a few weeks or months. Others may have major abnormalities, chronic illness or the potential for serious disability. In these situations, parents may be asked to participate in decisions involving complex ethical issues that relate to the care of their child. Part of the complexity of such decision making can arise from medical uncertainty over whether the babies who live will be seriously affected or make good recoveries. This has stimulated follow-up studies to determine outcomes in cases of extreme prematurity.² Having to make critical care decisions during pregnancy or after a baby is born places great demands, both upon the parents and the healthcare professionals who are 'partners in care' and who must decide on a baby's behalf.
- 1.3 Improved neonatal survival can be attributed to a greater understanding of fetal and neonatal development and advances in care for babies as they adapt to life outside the womb or complete their development. These improvements mean that it is sometimes decided to deliver babies early. This may be a response to complications of pregnancy that put the health of the woman or the fetus at risk, or to enable a baby with health problems to be treated. However, the major advances in fetal medicine that have allowed the diagnosis of a wide range of conditions have not been matched by new ways of treating the fetus before birth.
- 1.4 This Report examines ethical, social and legal issues that arise when making critical care decisions in fetal and neonatal medicine. First, we address critical care decision making for fetuses identified as being at risk of conditions likely to have such serious consequences as to compromise the prospect of live birth or to impair the health of a baby once born; secondly, we consider decisions on whether or not a newborn baby should be resuscitated, and admitted to neonatal intensive care; and thirdly, we address the issues of whether further treatment should be instituted after birth, withheld, or subsequently replaced with another form of care. The decisions we discuss will often affect whether a baby lives or dies. In the event of a baby surviving, there may be consequences such as severe disability which will affect a baby and their family for the rest of their lives.
- 1.5 The Working Party found that it was not always possible to offer an unequivocal answer as to what *ought* to be done in particular circumstances. We also found it necessary to address *how* a decision was made, and *who* should make it. So in our discussion of ethical issues, we explore several concepts to develop an ethical framework to help parents and professionals

¹ The neonatal period refers to the first 28 days following birth.

² See Marlow N (2005) Outcome following preterm birth, in *Robertson's Textbook of Neonatology*, Rennie JM (Editor) (London: Churchill Livingstone), Chapter 3. Currently, there is no routine collection of outcome data on a national basis.

make critical care decisions when they are faced with dilemmas created by medical uncertainty. We consider why and how an ethical analysis is helpful in this process. We discuss what is meant by concepts such as the sanctity, quality and moral status of human life before and after birth. We pay particular attention to the difficulties of balancing different interests in the decision-making process and the assessment of best interests. We also consider whether ethical distinctions can be made between withholding and withdrawing treatment, and whether there is ever a case for the deliberate ending of the life of a newborn child.

- 1.6 We have sought to make the social context for critical care decisions an integral part of the Report, even though there has been little systematic research on the issues that we address. We found social issues to be inextricably linked to ethical issues, especially in decision making where so much depends on the relationships between the different parties. When professionals and families cannot agree about what should be done, a case may need to be resolved in the courts. At a broader level, social changes have transformed attitudes to children, such that in the past decade new public policies have been put in place to assert or protect their rights.³ Similarly, the concept of 'disability' has been redefined to try to offer greater protection and social inclusion for this group.⁴ The social consequences of decisions made about the critical care of fetuses and newborn babies extend beyond the family. When children develop chronic illness or disability, the quality of their lives depends not only on the commitment of their own families, but also upon the level of community support they will receive as they grow up. A report from the Prime Minister's Strategy Unit notes that, "Since 1975, the fastest growth in numbers [of disabled people] has been for children—from 476,000 disabled children under the age of 16 in 1975 to 772,000 in 2002", an increase of 62%.⁵ Over the same period, the number of adults reporting disabilities has risen by only 22%. Although there will be other reasons,⁶ some of the incidence will be associated with critical care decisions, either for babies born prematurely or babies who have been diagnosed with a disabling condition around the normal time of birth.
- 1.7 Media attention has focused recently on the financial cost of the care both for the newborn and for children who survive with major disability.⁷ Most policy makers work on the principle that no healthcare system can provide unlimited healthcare resources and, regardless of their financing and organisation, all employ mechanisms at different levels to set priorities for spending.⁸ An important question for the Working Party was how finite healthcare resources should be allocated for the potential lifelong healthcare needs of a newborn baby starting life in intensive care.
- 1.8 We have examined the legal framework for decision making in fetal and neonatal medicine. In the UK, many of the relevant legal principles governing decision making in the context of this Report are to be found in the judgements of the courts deciding individual cases.⁹ There

³ For example, Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*; United Nations (1989) *UN Convention on the Rights of the Child*. See also paragraphs 3.44 and 7.24.

⁴ We used the definition of disability in the Disability Discrimination Act 1995, that "a person has a disability if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities".

⁵ Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People* (London: Strategy Unit).

⁶ Some of this increase (62%) in the number of disabled children can be attributed in part to higher rates of diagnosis and reporting of disability, as well as success in treating specific health problems such as head injuries or childhood cancer, which would previously have caused death.

⁷ See, for example, BBC Online (2006) *Early babies dubbed bed blockers*, 27 March, available at: <http://news.bbc.co.uk/1/hi/health/4848698.stm>; accessed on: 25 Aug 2006.

⁸ Frankel S (1991) Health needs, health-care requirements, and the myth of infinite demand *Lancet* **337**: 1588–90.

⁹ Within the United Kingdom there are in fact *three* legal systems: in (1) England and Wales; (2) Scotland; and (3) Northern Ireland. See Chapter 8, footnote 1.

is little legislation that has direct relevance, and judgements have tended to take account of the particular circumstances of each case to concentrate on the best interests of the individual baby when there are differences of opinion on care. This approach has led to a degree of flexibility and pragmatism which comes at the cost of some unpredictability. We have explored how far this flexibility is a strength, or whether new, more specific legislation should be introduced. We also examined alternative methods for resolving disputes.

- 1.9 We thought it important to elicit a wide range of views from individuals, families, patient groups and organisations engaged in medicine, nursing, law, religion and policy. Through targeted fact-finding meetings and wider consultation (see Appendices 1 and 2), we tried to capture the 'voices' of as many different individuals and organisations as possible. The contributions and perspectives of these participants emerge at different stages of the Report.
- 1.10 We have written this Report with a broad audience in mind. Our recommendations are directed primarily towards policy makers. Nevertheless, we hope that those with an involvement in critical care decision making, including families, doctors, midwives, nurses and others will find it relevant and helpful. We begin in Chapter 2 by considering a number of philosophical concepts to help outline an ethical framework for decision making in fetal and neonatal medicine. In Chapter 3 we set out the context in which such decisions are made. This allows us in Chapters 4–6 to examine, in turn, issues related to fetal medicine, extremely premature babies at the borderline of viability, and other babies requiring critical care, using examples. In Chapter 7 we discuss issues arising for children and families living with disability. Chapter 8 offers a discussion on regulation and the resolution of disagreements relating to critical care decision making. The main conclusions and recommendations of the Working Party are summarised in Chapter 9.